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Date Dec. 21/1999
Abstract

In this dissertation I provide an ethnographic account of the testimony of four expert witnesses who appeared before the Commission of Inquiry on the Blood System in Canada (the Krever Inquiry) as they described the production of scientific knowledge and the role that knowledge played in the struggle to protect the blood supply from being contaminated by AIDS during the early 1980's. In doing so, I bring together the experts' testimony with contemporary documents gathered by the Commission and interviews I conducted with participants in the proceedings. Using insights drawn from the disciplines of anthropology, sociology, and history, I explore what the witnesses' accounts reveal about their understandings of their professional world and its relationships with other worlds, especially that of public health policy making.

The Krever Inquiry offered a valuable opportunity for carrying out such an investigation. It provided a site where science was not only used, it was talked about. The Inquiry invited those involved in the blood system in the early 1980's to reflect upon and explain the beliefs and actions which surrounded one of the worst public health disasters in Canadian history and it asked the witnesses how similar catastrophes could be avoided in the future.

As a result, many of the issues addressed at the hearings reflect matters of current concern in public health and medicine. The Inquiry addressed difficult issues surrounding the nature of scientific knowledge and its application in health decision-making and policy formulation. This study, therefore, may be of interest to those dealing with the problems surrounding uncertainty and the management of public health crises. It may also be of interest to those dealing with conflicts rising out of the intersection of different worlds of experience and practice, as well as to those involved in the current initiatives to both make medical and public health institutions more proactive, and inclusive, and public health decision-making more transparent.
## Table of Contents

Abstract ................................................................................................................................. ii
Table of Contents ................................................................................................................ iii
Acknowledgment .................................................................................................................. x

## SECTION ONE: SETTING THE STAGE

**PREFACE** .......................................................................................................................... 1
First Inklings: The Emergence of AIDS .................................................................................. 1
Research Background and Subject Matter of this Dissertation ............................................. 4

**INTRODUCTION** ............................................................................................................... 11
Un fulfilled Expectations, Growing Outrage ........................................................................... 11
An Investigation Into the Disaster is Called ........................................................................... 14
The Role of Public Inquiries .................................................................................................... 17
Turner's Social Drama ............................................................................................................ 19
The Tainted Blood Tragedy as Social Drama ......................................................................... 22
Science Studies, Constructivism, Actor Network Theory ....................................................... 24
Science as Narrative: Understanding the World Through Stories ......................................... 30
Accounting for the Stories Told at the Hearings .................................................................. 31
Chapter Outline ...................................................................................................................... 34

**CHAPTER ONE: CONTEXTUALIZING THE ACCOUNTS** .................................................... 36
The Physical Setting ............................................................................................................... 36
The Participants ....................................................................................................................... 37
The Rules of Procedure .......................................................................................................... 40
The Hearing Room: A Day in the Life .................................................................................... 43

*The opening act* ................................................................................................................... 43
*Curriculum vitae* ................................................................................................................ 45
*Examination in-chief* ......................................................................................................... 46
*Cross-examination* ............................................................................................................. 49
January 4th 1983, Meeting ................................................................. 116

3.2 Taking Action .................................................................................. 118
January 13th Joint Statement ............................................................... 118
Assessing the Evidence: Individual Judgement and its Determinants .......... 124
  Situated perspectives ................................................................. 125
  Distinguishing between paid and volunteer donors ......................... 126
  Constructing the public ............................................................. 128
Playing the Odds: Decision-Making and Risk ..................................... 129
The Lessons of History ................................................................. 134
Summary ....................................................................................... 136

PART TWO: AIDS AND THE CANADIAN BLOOD SUPPLY

CHAPTER FOUR: DR. ROGER PERRAULT AND DR. MARTIN DAVEY: SETTING THE
CONTEXT OF THE DISASTER IN CANADA ........................................... 139

4.1 Outline of the Examination of Dr. Perrault and Dr. Davey ............... 139
Introduction ................................................................................... 139
A Difference of Styles ................................................................. 141
  Lawyers .................................................................................. 141
  Witnesses .............................................................................. 142
Denying Responsibility ............................................................... 144

4.2 Establishing the Witnesses' Expertise ........................................... 145
Curriculum Vitae ........................................................................... 145

4.3 The Canadian Blood System: The 1940's to the 1970's ................... 147
Origins and Financing of the System ................................................ 147
Regulating the System .................................................................. 151
Structure and Organization of the Canadian Red Cross ....................... 152
The Revolution in Transfusion Medicine .......................................... 153
The Growth of an Industry ........................................................... 155
Keeping Pace: Transforming Canada's Blood System in the 1970's .......... 157
The Problem of Self Sufficiency ..................................................... 158

4.4 Into the 1980's and Disaster ........................................................... 160
Could Things Have Been Done Better? .......................................... 160
Accounting for the Red Cross's Early Response ................................ 165
  Supply issues ........................................................................ 165
  Expertise within the Red Cross ................................................ 166
  Access to information ............................................................. 167
  Institutional alliances ............................................................... 168
Safeguarding the System: Donor Screening and Blood Testing ............. 169
SECTION THREE: ANALYSIS

CHAPTER SEVEN : TRACING THE CONFLICTS IN THE TAINTED BLOOD TRAGEDY

Introduction ....................................................... 245

7.1 Confronting AIDS ........................................... 246
Early Warning Signs ......................................... 246
Early Investigations ......................................... 247
Conflicting Interpretations ................................. 249
Communicating the Information ......................... 252
Education and Practical Experience and their Influence on Thought and Action ............................ 253
Standards and Methods and the Demand for Certainty ......................................................... 257
Models and Analogies ......................................... 260
The hepatitis analogy ......................................... 261
Sick blood: healthy blood ..................................... 263

7.2 Institutional Priorities and Conflicting Perspectives ......................................................... 264
Introduction ....................................................... 264
Internal Conflicts and the Role of Institutional Memory .......................................................... 265
The Struggle for Institutional Power and Influence in the United States ................................. 267
Canadian Institutional Responses to AIDS and the Blood Supply ......................................... 271

7.3 Science and Society: Constructing Difference ................................................................. 273
Introduction ....................................................... 273
The Lay Public ..................................................... 274
The Haitian Community ...................................... 276
The Gay Community ............................................ 277
Blood Donors ...................................................... 279
Dangerous Reifications ........................................ 282

7.4 The Politics of Making Difference ................................................................. 284
Introduction ....................................................... 284
Distinguishing Science from Politics ....................... 285
Science as Politics ................................................ 287

7.5 Constructing A Fact: the "One In A Million" Calculation ................................................ 289
Introduction ....................................................... 289
Risk and Cost-Benefit Analysis .............................. 290
Characterizing the Calculation ............................... 291
A Deadly Silence ................................................ 296
Effects of the Calculation ....................................... 300
## CHAPTER EIGHT: ECHOS OF THE PAST: BLOOD SYMBOLISM AND THE TAINTED BLOOD TRAGEDY

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>303</td>
</tr>
<tr>
<td>Blood Symbolism in the West</td>
<td>304</td>
</tr>
<tr>
<td>The Greeks: Blood, the Tie that Unites</td>
<td>306</td>
</tr>
<tr>
<td>The Judeo-Christian Legacy</td>
<td>309</td>
</tr>
<tr>
<td>Blood and Modern Science</td>
<td>312</td>
</tr>
<tr>
<td>Traditional Beliefs and the Problem of AIDS in the Blood supply</td>
<td>314</td>
</tr>
<tr>
<td>Blood, Disease and Morality</td>
<td>314</td>
</tr>
<tr>
<td>The Gift of Life</td>
<td>317</td>
</tr>
<tr>
<td>Nourishing Blood</td>
<td>318</td>
</tr>
<tr>
<td>Blood and the Social Body</td>
<td>319</td>
</tr>
<tr>
<td>Distinguishing Good Donors from Bad and its Impact on Policy</td>
<td>320</td>
</tr>
<tr>
<td>Purifying the Blood</td>
<td>322</td>
</tr>
<tr>
<td>Exclusion</td>
<td>322</td>
</tr>
<tr>
<td>Observation</td>
<td>323</td>
</tr>
<tr>
<td>Summary</td>
<td>324</td>
</tr>
</tbody>
</table>

## CHAPTER NINE: CONCLUSION

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>327</td>
</tr>
<tr>
<td>The Tainted Blood Tragedy as &quot;Social Drama&quot;</td>
<td>328</td>
</tr>
<tr>
<td>Conflicting Views of Science and its Role In Public Health Decision-Making</td>
<td>331</td>
</tr>
<tr>
<td>Conflicting hierarchies of methods and evidence</td>
<td>333</td>
</tr>
<tr>
<td>Conflicting hierarchies of styles</td>
<td>334</td>
</tr>
<tr>
<td>Situated perspectives</td>
<td>335</td>
</tr>
<tr>
<td>Shifting interests: shifting perspectives</td>
<td>337</td>
</tr>
<tr>
<td>The diversity of perspectives within institutions</td>
<td>338</td>
</tr>
<tr>
<td>The Struggle for Institutional Power and Control</td>
<td>338</td>
</tr>
<tr>
<td>Science, Society and Politics</td>
<td>341</td>
</tr>
<tr>
<td>Tainted Science?</td>
<td>345</td>
</tr>
<tr>
<td>Heros and Villains</td>
<td>348</td>
</tr>
<tr>
<td>Towards a Resolution of the Problems Embodied in the Tainted Blood Tragedy</td>
<td>350</td>
</tr>
</tbody>
</table>

## EPILOGUE

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abbreviations</td>
<td>361</td>
</tr>
<tr>
<td>Glossary</td>
<td>363</td>
</tr>
<tr>
<td>Technical Bibliography</td>
<td>367</td>
</tr>
<tr>
<td>Bibliography</td>
<td>369</td>
</tr>
</tbody>
</table>
Appendix 1: Chronology of Important Events, November 1980 to May 1984 383
Appendix 2: List of Names of Scientific Experts Cited 387
Appendix 3  List of Names of Legal Counsel Cited 389
Appendix 4: Index of Transcript Volumes Cited 390
Acknowledgment

I would not have been able to carry out my research without the assistance and support of a wide range of individuals and groups. I owe a special debt of gratitude to the Commissioner, Mr. Justice Horace Krever, who made me welcome at the Commission of Inquiry on the Blood System in Canada and who expended considerable time and effort helping me understand the public inquiry process in Canada as well as the specific structures and goals of his commission. I also owe a special thanks to the staff at the commission, particularly to Dr. Penny Chan, the Executive Coordinator and Scientific Advisor and Gregory Hamara, the Director of Communications, both of whom spent many hours helping me in my work.

Likewise, I owe a debt to many of the participants at the inquiry, especially Kenneth Arenson, who was extremely generous in the time he devoted to helping me. Among the others who went out of their way to help me during my research at the inquiry were, Dr. Barbara Blake, Rebecca Bragg, Maureen Currie, R. Douglas Elliott, Jerry Friese, Dr. Roslyn Herst, Gabe and Lynn Kampf, the late Edward Kubin, Andre Picard, Kathryn Podrebarac, David Pollock, Dr. Alan Powell, Donna Ring, Alan West and Durhane Wong-Reiger. In addition to these individuals I extend my thanks to the many others at the hearings who shared their time, experiences, and understandings with me.

I owe a number of debts to individuals outside of the commission, especially to my Research Supervisor, Dr. Martin Silverman and to the other members of my Research Committee, Prof. Brian Elliott, and Dr. Stephen Straker. I am fortunate, indeed, to have been the beneficiary of their insights, encouragement and guidance. I thank my colleagues in the Department of Anthropology at the University of British Columbia for their advice and support during my research. I also want to thank Murray Braithwaite and Harry Andrew, who, over the years, helped me develop a greater appreciation of the complexities of the legal process and legal reasoning.

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Finally, I thank the Social Sciences and Humanities Research Council for the Doctoral Fellowship which helped finance the early years of my research, and I thank the University of British Columbia for the University Graduate Fellowship I received.

In acknowledging the contribution of these individuals and institutions I do not intend to suggest that they are responsible for or endorse the views expressed in this document. Similarly, while those I have mentioned, along with many others, contributed greatly to my dissertation, I alone must take responsibility for its weaknesses and errors.
SECTION ONE: SETTING THE STAGE

PREFACE

First Inklings: The Emergence of AIDS

By the spring of 1981 rumors were beginning to circulate in New York City that a number of gay men were in intensive care units at local hospitals being treated for a rare form of pneumonia. Following up on the rumors Dr. Lawrence Mass, a physician and part-time reporter with the fledgling gay tabloid, New York Native, contacted a doctor from the Centers for Disease Control (CDC) on loan to the New York City Health Department.¹ The expert from the CDC assured Dr. Mass there was no strange new epidemic affecting the gay community. Accepting the assurance, Mass wrote an article for the New York Native discounting the rumors. The article, which appeared in the May 18th edition of the tabloid, was the first published reference to the disease which would later become known as Acquired Immunodeficiency Syndrome, AIDS (Kinsella 1989:25-28).²

¹ Headquartered in Atlanta, Georgia, the Centers for Disease Control is the key federal agency responsible for disease surveillance in the United States (Grmek 1990:13).

² Throughout this text I refer to AIDS as infecting, or contaminating the blood supply. Based on current understandings this usage is technically wrong. AIDS is the disease caused by the Human Immunodeficiency Virus, HIV. While first isolated in early 1983 the virus was not formally identified until the spring of 1984, the time my account of the early history of the contamination of the blood supply ends. I have, therefore, adopted the terminology most common during the period July 1982 to April 1984 which refers to AIDS in the blood supply.

The term AIDS, initially an acronym for Acquired Immune Deficiency Syndrome (today generally interpreted as Acquired Immunodeficiency Syndrome), was developed at a CDC meeting in Atlanta and first officially used at a July 27 1982, Public Health Service Committee meeting on opportunistic infections. Its use thereafter in CDC reports led to its popularization. Prior to the introduction of the term AIDS, names such as Gay Related Immune Deficiency (GRID), the Gay Plague or Gay Cancer were commonly used to refer to the syndrome (Grmek...
Meanwhile, infectious disease experts at CDC headquarters in Atlanta, Georgia were beginning to fear a strange new malady was indeed affecting young gay men in the major seaboard cities of the United States. In April "a technician responsible for non-routine drug orders" noted an ominous increase in requests for pentamidine, a drug distributed solely by the CDC, used to treat Pneumocystis carinii pneumonia (PCP), a rare opportunistic infection almost exclusively associated with individuals suffering from immune system impairment. Concerns at the CDC were further heightened by a report submitted by Dr. Michael Gottlieb, an immunology fellow at the University of California at Los Angeles Hospital. In late 1980 Gottlieb treated a previously healthy young man suffering from immune abnormalities and PCP. Two months later, he saw another male patient with similar symptoms. Believing the occurrences unusual enough to warrant further investigation, he began contacting colleagues and local health authorities. By May he had uncovered 3 more cases of the disease, at which point he informed CDC Atlanta, that since October of 1980, at least 5 young, gay men had been treated for PCP in Los Angeles area hospitals (Grmek 1990:4-6).

On June 5th 1981, the *Morbidity and Mortality Weekly Reports (MMWR)*, the CDC's weekly bulletin distributed to physicians and public health officials throughout the country, described the 5 Los Angeles cases. A month later, a second report of this strange outbreak appeared in the *MMWR*, under the title of "Kaposi’s sarcoma and Pneumocystis carinii pneumonia among homosexual men -- New York City and California." By early summer teams of CDC 1990:32). Several of the witnesses at the hearings stressed the fact that the name Acquired Immune Deficiency Syndrome underlined the confusion surrounding the nature of the malady and that initially it was not considered "a disease in itself but was marked by the presence of some other, relatively uncommon disease or infection..."(Epstein 1996:55).

3 Between 1967 and 1979 the CDC received only two requests for the drug where the patients were not receiving treatments known to suppress the immune response (Grmek 1990:6).
investigators were in the field gathering information on the disease and individuals it was affecting. The age of AIDS had arrived.

I first became aware of the outbreak in the late fall of 1981. At the time I was working as a Clinic Assistant for the Canadian Red Cross Blood Transfusion Service, in Toronto. We had just set up a blood donor clinic in an auditorium of a church in the city’s west-side. Thumbing through a newspaper as I waited for the clinic to open I happen upon a brief report of a mysterious and apparently deadly new illness affecting homosexuals in the United States. The report caught my attention. Perhaps it was because you did not hear about new diseases appearing everyday, perhaps it was the question of why it was affecting one particular segment of society, but something made that report stick in my mind.

While it caught my attention, I certainly had no inkling that fourteen years later I would be sitting in a stuffy hearing room on the 20th floor of an office tower in downtown Toronto listening to legal and medical experts argue over how over 1,000 Canadians came to be infected with this deadly disease through the blood supply. As I sat in the hearing room it seemed hard to believe that strange new disease I had first read about so may years ago had led to one of the greatest public health disasters in Canadian history.

---

4 I joined the Canadian Red Cross Blood Transfusion Service in the late summer of 1981, about two months after the MMWR first reported that a mysterious illness was affecting gay men in the United States. By the time I left the in the late summer of 1986 the ELISA and Western Blot tests for AIDS had been in place almost a year. During those 5 years I worked on the mobile clinics, screening donors, asking if they had read the health questionnaire and pamphlets carefully, making sure they had not had a cold or flu recently, they were not taking any medications, and had not suffered from any serious health problems in the past. I checked their iron level and did an ABO grouping. I assisted the nurses during the venipuncture, chatted with and looked after the donors while they were bleeding, and provided them with general information about blood and the blood program.
Research Background and Subject Matter of this Dissertation

It was March 7, 1995, I was a Ph.D candidate in the Department of Anthropology at the University of British Columbia and for my field work I had returned to my old hometown of Toronto to attend the national hearings of the Commission of Inquiry on the Blood System in Canada (The Krever Inquiry). This was the second of 4 visits I made to the inquiry over a three year period. I had spent two weeks at the commission while it was in Vancouver in April of 1994 during the provincial phase of the hearings. I travelled to Toronto in March 1995 for the opening of the national phase of the inquiry. Between March and July I attended the hearings on a daily basis, taking notes, and making audio recordings of the testimony. Following the day's hearings I retired to the media room to read and take notes on the Exhibits and transcripts. On the days the commission was not sitting I would either work in the media room or interview some of the participants involved in the proceedings.

---

5 During the provincial phase of the proceedings, February to December 1994, the commission travelled across Canada hearing evidence from local officials, those who had been affected by the contamination of the blood supply, and others who had information to contribute. After a short break, during which time the commission issued its Interim Report, the national phase of the hearings were opened and the authorities in charge of the blood system were asked to explain how the disaster came about.

6 While I was only able to attend the provincial hearings while they were in Vancouver I was able to video tape the proceedings as most were broadcast nationally on the Cable Parliamentary Access Channel (CPAC).

7 The commission received 175,000 separate documents totally between 800,000 and 1,000,000 pages (Commission of Inquiry on the Blood System in Canada, "Facts", December 1996). Of those approximately 100,000 pages of documentary evidence were selected and filed in the form of 1184 separate Exhibits.


9 During the course of my interviews I spoke with the Commissioner, commission staff, witnesses, lawyers, and members of the intervenor groups.
I followed a similar pattern on my return in October of that year. After the close of the hearings in December 1995 I continued to work in the media room and interview those involved in the inquiry. I returned in November 1996 to hear the final submissions, again staying on several months after the close of the public proceedings in late December 1996.

While I followed the inquiry from its opening to its closing days, I restrict my attention in this dissertation to a small but critical set of issues pertaining to the early years of the crisis in the blood system. A detailed accounting of the early history of the contamination of the blood supply was presented during the public hearings. While I draw on that material and explore many of the events of the early 1980's in some detail, I do not intend to provide a history of the tainted blood tragedy.¹⁰

I limit my attention to issues surrounding AIDS and the blood supply during the period between June 1981, when the disease was first officially reported, and April 1984, when the discovery of the virus responsible for causing AIDS was officially announced.¹¹ Even then, my primary concern is not in reconstructing the history of the period. Rather my intention is to provide an ethnographic account of the ways in which the experts who appeared at the hearings reflected upon and represented science and its role in the events and decisions surrounding the

¹⁰ I do not, for example, engage the complex and difficult issues surrounding the contamination of the blood supply with hepatitis C, a topic of considerable importance to the history of the disaster and a matter of much attention at the hearings. During the course of the inquiry it was revealed that at least 12,000 Canadians were infected with hepatitis C through the use of blood in the 1980's and that many of those will eventually succumb to complications arising from the disease. The contamination of the blood supply with hepatitis C has caused enormous personal suffering and has imposed staggering social and economic costs and has become matter of ongoing public controversy and debate.

¹¹ While focusing on a limited time period and on only a small part of the story of the tainted blood tragedy, I believe that the issues I address represent fundamental patterns in the way information was generated, assessed, and applied in meeting the problems facing the blood supply in the 1980's.
contamination of the blood supply. I pay close attention to the experts' accounts in order to gain insight both into their understandings of their world and its interactions with other worlds. In doing so, I pay particular attention to the various ways in which the experts see outside social and political influences as impinging upon and, indeed, contaminating scientific practice and understanding.

I focus on the testimony of just four of the almost 300 expert witnesses who appeared at the commission: Dr. Donald Francis, an infectious diseases expert at the Centers for Disease Control, Atlanta, during the early years of the epidemic; Dr. Thomas Zuck, blood banker, industry representative and former Director of the Blood Products Division of the Federal Drug Administration in the United States; Dr. Roger Perrault, former Director of the Canadian Red Cross Blood Transfusion Service (CRC BTS); and Dr. Martin Davey, former Assistant Director of the CRC BTS.

I single out the testimony of these witnesses, because of the positions they occupied and the roles they played in the early struggle against the disease, because of the breadth of expertise and experience they represented as a group, because collectively their accounts reflected and embodied the range of perspectives presented by the expert witnesses at the inquiry, and because of the highly articulate accounts they offered both of science and its relationship to public policy decision-making.

During the early years of the AIDS epidemic the international community looked to the United States for information on AIDS and guidance on how to respond to it. The Centers for Disease Control (CDC) in the United States became the dominant authority on AIDS both nationally and internationally, while the standards and recommendations of its parent organization, the United States Public Health Service, became models for action throughout the
The contamination of the Canadian blood supply, the experts’ understandings of the problem, the decisions they took, and the measures they instituted to protect the blood supply can not be adequately addressed without an understanding of the situation in the United States at the time. The importance of understanding the situation in the U. S. was underlined by the commission’s inviting two American experts, Francis and Zuck, to be the first witnesses to appear at the national phase of the hearings. Through their testimony the commission was able to explore the state of knowledge concerning AIDS in the early 1980's while at the same time it was able to examine how that knowledge came to affect and be incorporated into policy decision-making both in the United States and elsewhere.

In terms of their professional backgrounds, practical experiences, and differing perspectives Francis and Zuck were ideal witnesses to lead-off the national hearings. Francis was among the first researchers at the CDC involved in investigating AIDS. He was also among the first to address the problem of AIDS and the blood supply. During the early years of the epidemic he advocated a proactive response to AIDS, especially the institution of what some thought were radical interventions to protect the blood supply from contamination. While Francis’s recommendations were criticized or ignored at the time, many now believe that had they been followed, the lives of a significant number of blood recipients could have been saved.

Zuck’s role in the early history of the disaster was less direct than that of Francis. He was,

12 In addition to being noted experts in their respective fields Zuck and Francis were both seasoned witnesses, each having appeared in numerous court cases, governmental investigations and institutional inquiries into the blood disaster. Both were also used to operating in the political sphere. Such experiences can be critical in determining the effectiveness of the expert witnesses’ testimony. Those experts unfamiliar with acting in legal and political settings frequently prove to be poor representatives of science (Salter 1988:190).
nevertheless, an active and influential member of the blood banking community in the early 1980's and was soon to become Director of the Blood and Blood Products Division of the Federal Drug Administration (FDA). Zuck, therefore, provided the commission with important insights into the American blood banking system as well as the FDA, the agency responsible for regulating blood and blood products in the U.S.

The occasionally provocative and often conflicting accounts offered by Zuck and Francis provided points of departure for the examination of the witnesses which were to follow. Of those witnesses, none received more attention than Perrault and Davey. There was good reason for this. Perrault and Davey were in charge of the Canadian Red Cross Blood Transfusion Service, the sole supplier of blood and blood products in Canada, and by default, the agency which was responsible for the regulation and safety of the Canadian blood supply in the early and mid 1980's. A wide range of institutions, agencies and individuals looked to the Canadian Red Cross for advice concerning AIDS and the blood supply during the early years of the epidemic. Perrault and Davey, therefore, had an enormous influence both on the ways in which the problem was understood and on the ways in which individuals and institutions throughout the country responded to the threat.

Francis, Zuck, Perrault and Davey could be considered to be the key witnesses in the commission’s investigation of the tainted blood tragedy. Not only did they provide a broad mapping of the understandings and decisions surrounding the contamination of the blood supply, they also presented an insightful and diverse series of perspectives on science and its relation to public policy making. They offered conflicting interpretations of the nature of scientific inquiry and disagreed widely over the role of science in the decision-making process. They debated what constitutes an adequate method, what constitutes proof and what sort of evidence provides
sufficient warrant for action. They offered conflicting assessments of the quality and meaning of
the information available during the early years of the outbreak, they differed over the
significance of the uncertainty which existed at the time, and they offered divergent
interpretations of the role of science in the formulation of the early strategies to deal with the
problem of AIDS in the blood supply. Unsurprisingly, they also disagreed over the value of those
formulations.

I recount some of that testimony as the witnesses describe their experiences and
understandings of the events which led to the contamination of the blood system with AIDS. I
look at the ways they depict science and explain its role in the management of public health
problems such as the contamination of the blood system. I explore what these representations
reveal about their understandings of science and its relation to society, and I examine what their
accounts of doing science can tell us about the manufacture and application of scientific
knowledge in situations such as the contaminated blood crisis.

I pay close attention to their claims and counter claims and address some of the sources of
their differences. I also look at the points of narrative overlap in their accounts and try to locate
the sources of those shared beliefs. These points of consensus highlight the often unexamined
shared assumptions -- the matters of ‘common sense’ -- which were woven into the witnesses’
accounts and understandings. I conclude my examination by showing how insights drawn from
the events and decisions surrounding the tragedy can serve as important lessons for those
currently in charge of the blood system and can assist in understanding and reformulating the role
of science in the broader sphere of public health policy and decision-making.

The setting of the *Krever Inquiry* was particularly well suited to exploring these sorts of
questions. The public inquiry form, as Liora Salter, Brian Wynne, and a number of others, have
pointed out, helps reveal the often undisclosed commitments and assumptions of the contesting parties involved. The Krever Inquiry was all the better suited to making such revelations because unlike many commissions of inquiry, science was not simply used as an instrument of investigation and evaluation, it was a central focus of the investigations. The hearings brought together a wide range of experts, representing a variety of disciplines, expertise and understandings and asked them, in a highly public forum, to discuss the role science played in the blood disaster and explain the place of science in public policy making.

---

13 According to Salter inquiries accomplish this by questioning the significance of the information under consideration while at the same time fostering public debate over it (Salter 1981:30). Wynne observes that the study of scientific controversy can be a fruitful site from which to study "science in the making." An adversarial setting pressures the contenders to make their conventions and premises explicit (Wynne 1989:33). Similarly Thomas Brante argues that during a controversy the contending experts scrutinize each others arguments and assumptions, and often violate taboos, to discuss connections between knowledge claims and interests. The observer in such situations, Brante suggests, is better able to explore the hidden norms and values within the scientific community (Brante 1993:186-187).
INTRODUCTION

Unfulfilled Expectations, Growing Outrage

The periodic ‘visitation’ of infectious diseases has been an important part of human history, inflicting enormous suffering and precipitating large scale social transformations. During the last century however, the development of sophisticated surveillance and reporting techniques, the increasing availability and use of vaccines, as well as advances in diagnosis and treatment, damped the frequency and scope of the outbreaks and lessened the severity of their effects.

It became possible to think of a day when the greatest killers of humankind would be defeated. This optimism gained substance with the World Health Organization’s announcement in the late 1970’s of the eradication of smallpox from the natural environment.

We seemed, and indeed we were, poised to enter a new world -- but not the one envisioned in the hopeful conjectures of the research scientists and public health officials. We were about to enter a world where modern medicines and techniques for managing disease not only appeared ineffective, they seemed to contribute to the dangers surrounding us.¹ We were about to encounter what the historian of medicine Mirko Grmek refers to as the first of “post modern plagues,” AIDS.

¹ Keith Wailoo, for example, has pointed out that the spread of AIDS through the blood supply is a problem made possible by 20th century science and technology. AIDS could not have manifested itself in the same way in the 19th century prior to the existence of a blood transfusion network and the wide-spread use of the syringe (Wailoo 1997:14-5). Similarly the technological advances in the late 1960's and early 1970's which allowed for the large-scale production of anti-hemolytic clotting concentrates exposed hemophiliacs to a much greater risk of being infected by AIDS, and many other disease, than did earlier treatment practices based on the use of cryoprecipitate. Where the earlier product was manufactured from plasma collected from as few as 3 individuals clotting concentrates were manufactured in lots using plasma collected from 5,000 to 20,000 donors.
AIDS brought with it a set of challenges which changed our relationships with nature and with one another. Its effects were felt throughout society. The buoyant optimism of the 1970's, which saw the possible end to the scourge of infectious disease, gradually gave way to the sense that despite our sophisticated science and technology we remained vulnerable. Science was unable to protect us from this new and deadly threat, a threat which had been carried into our midst by groups of individuals accused of flouting the values and norms of society and the laws of nature. Homosexuals and drug addicts -- those already marginalised because of their ‘aberrant’ behaviour -- were identified as the carriers of the contagion. Their transgressions presented a tangible threat to the entire society. The AIDS epidemic revealed the “stresses and vulnerabilities” of our society and exposed its “fault lines” (Treichler 1992:87). Fear, suspicion and intolerance marked the emergence of AIDS as they had marked so many other diseases in the past.

The blood banking sphere was among the first areas where the transformations became apparent. The threat of AIDS was first generalized through the blood supply. The “gift of life” for decades a powerful symbolic expression of the bonds uniting individuals and communities -- a powerful expression of social concern, belonging and sharing -- suddenly became a focus of conflict and dissension. A conflict over blood signalled that a serious social disruption was under way: the world as we knew it was about to change but few heard the warning.

Some of the effects of the contamination of the blood supply were almost immediately apparent -- donors began to stay away from clinics, patients deferred treatment, demands for the exclusion of dangerous groups and individuals began to be voiced. Other effects, however, became apparent only with the passage of time. Not until the late 1980's and into the early 1990's, when those infected through the use of tainted blood products began to speak out and be heard,
did the extent of the devastation begin to be realized.

In speaking out, those who were directly affected offered scathing criticisms of governmental agencies, social institutions and private corporations for their failure to ensure the safety of the blood supply. Experts and administrators who worked in the field during the time offered their own criticisms and explanations of the disaster.

Public awareness of the criticisms grew, in part, because both the national and international media took up and championed the story. The French media in particular helped bring the story to the attention of the world. By late 1992 the story had become front page news as journalists chronicled the failure of the blood system and its officials to protect the blood supply or inform the broader public of the risk posed by the use of blood and blood products. Reports began to appear recounting the devastation experienced by the individuals and the families of those infected with HIV/AIDS through the blood supply.²

² The story of the Canadian media’s involvement in the tragedy is complex. While recognized as a central force in helping bring the disaster to light, the media has been criticized for being slow off the mark. Only after French reporters ‘broke the story’ did a serious interest within Canadian media emerge. As the journalist Andre Picard has noted, it was not until late 1992 that “tainted blood” became front page news in Canada. “[F]or almost a decade after the first victims started dying” the story went unnoticed (Picard 1995:1).

The media’s involvement in the story, however, did not begin in 1992. The media was an key instrument of communication from the early days of the outbreak and was thus an important actor in the tragedy. Blood banking officials have suggested the sensationalism surrounding early media reports of the disease contributed to the problems they faced in trying to manage the crisis. Others have accused it of playing the role of patsy, passing on whatever information blood officials provided, without questioning what was being said. The truth likely lies somewhere between. In many instances what blood bankers saw as sensationalism, now appear to have been more accurate than the reassurances they were issuing, while in other instances the extravagances of the media reports helped fan deeply held fears and biases.
An Investigation Into the Disaster Is Called

With this coverage came growing outrage and increasing pressure for a public accounting of the events and decisions which had led to the contamination of the blood supply. A threat to the blood system represented a potential threat to all; anyone might require blood to save their lives. If public confidence in the system collapsed, the ability to ensure the availability of this essential life-giving liquor would be seriously compromised. In late 1992 and early 1993 The Standing Committee on Health and Welfare, Social Affairs, Seniors and the Status of Women, carried out an investigation of the tainted blood tragedy. In its report, *Tragedy and Challenge: Canada’s Blood System and HIV*, May 1993, the Sub-Committee recommended that: “...a public inquiry be carried out into the Canadian Blood System, with the efficiency and safety of the system as the primary focus. The inquiry should include, but not be limited to, a full examination of the events of the 1980's when the Canadian blood supply became contaminated by the human immunodeficiency virus, the pathogen associated with AIDS.”

In its report the Sub-Committee noted that while it was mindful of the changes which had been made and were currently under way to make the blood system safer -- and in no way wanted to interfere with these initiatives -- it none-the-less felt a comprehensive review of the Canadian Blood System was necessary. It was necessary “in part to clarify the tragic events of the 1980’s, in part to reaffirm confidence in the system, and in part to ensure that the Canadian Blood System will be able to deal with future challenges as well as the myriad [of] requirements of day-to-day operations” (Wilbee 1993:25).

While the federal Minister of Health at the time, Lucien Bouchard, initially balked at the idea of such an investigation, by September he gave into mounting pressure, and announced that a joint federal and provincial commission of inquiry would go ahead. *The Royal Commission on...*
the Blood System in Canada (the Krever Inquiry) was established by Order-in Council 1993-1879 the following month. Mr. Justice Horace Krever – an eminent judge of the Ontario Court of Appeals with wide experience in the legal/medical field -- was appointed to head the commission. He was to investigate the events surrounding the contamination of the blood system in the early 1980's, report on the current state and safety of the system, and to make recommendations for its future operation.

In fulfilling its mandate the commission carried out an exacting examination of the current blood system, appointing expert committees and individuals to investigate and report on its current state and to offer advice on its future operations and goals. The commission also investigated the state of the relevant scientific knowledge and its role in the decisions taken to protect the Canadian blood supply from contamination by AIDS in the early 1980's. In carrying out this investigation the commission conducted a series of public hearings at which more than 400 expert and lay witnesses testified.

3 The appointment of Justice Krever to head the commission was widely applauded. He was seen to bring considerable experience and expertise to his task. Justice Krever was appointed Justice of the Court of Appeal of Ontario in 1986 -- for the previous 11 years having served as a Justice of the Supreme Court of Ontario. During his career he had been a member of several "medical and scientific panels and boards of investigation" including: "chair of a special committee on the Human Tissue Gift Act 1971 to 1975", "co-chair of the Royal Society of Canada Study on AIDS in 1988," and "Commissioner of the Royal Commission on the Confidentiality of Health Records in Ontario between 1977 and 1980 (Commission information package). In theory and practice Justice Krever personified what Martin Bulmer describes as the requirements of chair of a royal commission. He was "a person known to be effective in the conduct of committee business..." a person of "...drive, tact, patience, good temper, conciliatory skill, and the ability to provide leadership without dominance" (Bulmer 1983:441).

4 The hearings were divided into two main phases. The first, the provincial hearings, began in March 1994 and continued until late October. During the provincial phase the commission travelled across the country, hearing both from those affected by the contamination of the blood supply as well as local public health and blood officials. The second phase, the national hearings, were held in Toronto between March and December 1995. During this time the commission heard from national and international experts as they tried to explain the disaster and made
During the hearings the commission explored what was known, how it came to be known, who knew it, and how that knowledge was applied. It explored the communication networks which existed between research scientists, public health institutions, drug manufacturers, policy makers, hospitals, clinicians, the media and the public. It examined how, and to what extent, available information was made accessible to all of these levels of decision makers, and it examined the factors which restricted information sharing. Among the most difficult and controversial issues it grappled with was the extent to which the demand that action be based on scientifically valid knowledge, conflicted with and impeded the institution of prudent public health measures.

The public hearings provided both those who had been injured by the system, and the experts who administered it, a chance to give voice to their own understandings, experiences and concerns, while providing the wider public audience an opportunity to gain insight into the enormous complexity of the issues, beliefs and practices which led to one of the greatest public health tragedies in Canadian history. The inquiry, therefore, served multiple purposes. It not only presented an instrument of investigation and reform, it provided those involved with the tragedy a vehicle to express their concerns and experiences, while at the same time it furnished a means of public education.

The educative functions of the proceedings were particularly important. The inquiry gave many Canadians insight into the operation of the blood system while exposing the enormity of the tragedy which resulted from the contamination of the blood supply. It served to publicly acknowledge the failings of the system and the sufferings of individuals and groups by showing recommendations to avoid such a tragedy in the future. A series of unprecedented legal actions launched in early 1996, challenging the authority of the commission, delayed the hearing of final submissions for almost a year. As a result of the challenges Commissioner Krever's Final Report was not released until September 1997.
they had been taken into account. It also served to reassure the audience that the suffering would not be in vain and that the failings would not be repeated. Through this public accounting the commission sought to reestablish confidence in the system and put to rest the social dissension surrounding the disaster.

In this sense the commission followed a familiar pattern. The persistence of the public inquiry process and its current popularity rests, in part, in its widely recognized value in dealing with controversial issues and the rehabilitation of institutions which have fallen into disrepute.

The Role of Public Inquiries

Commissions of inquiry have become popular instruments of investigation and policy making and are widely used by governments to respond to matters of public controversy (Salter 1981:221 Wynne 1982:52-3). The more explosive the issue, the more likely it will be dealt with by a commission of inquiry (Salter 1981:204). Their popularity is due, in part, to their perceived ability to depoliticize the problem and get government officials out of the political hot-seat, in part, to their fluid form and wide applicability, and in part to their capacity to diffuse social conflict. In order to be effective, therefore, they must not only appear as objective, giving an equal voice to all parties concerned, they must do so in a timely manner. Speed is often a central issue in such investigations (Wraith and Lamb 1973; Salter 1981; Wynne 1982; Wynne & Smith 1989; Ashforth 1990).

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5 Commissions of inquiry can be broadly divided into two types. They can be defined as either "investigatory commissions which look into allegations of wrong-doing by government officials" or "advisory commissions which advise governments on controversial policy matters". Both types may hold hearings, carry out research, gather information and present recommendations (Robbins 1982:3). The degree to which any inquiry fits into these analytic categories of course varies. The Krever Inquiry, for example, functioned both as an investigatory and advisory instrument.
While frequently employed, public inquiries have not been without their detractors and criticisms. Historically they have a strong association with despotism (Burton and Carlen 1979:4). As a number of studies have shown, the suspicion and dissatisfaction which often surrounds their use has not been out of place (Webb 1932; Wraith and Lamb 1973; Burton and Carlen 1979; Bulmer 1981; Wynne 1982; Ashforth 1990).

In his influential study of the Windscale Inquiry and nuclear decision-making in Great Britain, for instance, Brian Wynne draws on the work of Mary Douglas, Edmund Leach, Steven Lukes, Max Gluckman and Victor Turner, to suggest that inquiries are elaborate rituals staged to distract attention away from contradictions between belief and experience (Wynne 1982:9, 181-2). Wynne joins many critics of the process, who have noted that while appearing collective and consensual, public inquiries are instruments of the state. They are governed by practices, conventions and ways of thinking determined by the authorities and used to promote the idea and the practice of expert control. While being powerful instruments of investigation their scope and methods are oftentimes strictly delimited. The scope of an inquiry, set out in its mandate, serves to establish and limit the focus of its investigations. The often limited mandate of an inquiry can serve to restrict investigations to a defined range of appropriate questions -- questions which themselves are formulated with a predilection toward prevailing authoritative modes of fact gathering based on models provided by science and the law. It is not surprising, therefore, to find the inquiry process criticized for its tendency to reduce complex social problems to singular rational causes amenable to ‘reasonable’, engineering style, solutions.

The inquiry provides a format in which both the public (albeit a public represented largely in the form of interest groups) and professional experts are invited to participate and often exchange ideas. One of the strengths of the public inquiry is it capacity to bring together a wide range of
groups and individuals representing of a variety of goals, viewpoints, and expertise and invite them to discuss the problem and offer possible solutions. While the range of participants and expertise varies widely between inquiries, its inclusiveness has led to some concern over its tendency to co-opt public dissent, drawing it “into a narrowly controlled process at the expense of political opposition on a broader front.” Adding insult to the injury, the public’s willing participation in the process can be, and often is used to legitimate predetermined decisions (Wynne 1982).

While many critics of the public inquiry system draw attention to their shortcomings as instruments of ‘rational’ policy making, they are quick to acknowledge the significance of inquiries as social phenomena in themselves. Wynne, for example, describes public inquiries as important sites from which to explore value conflicts within a society: sites from which it is possible to get beyond crude stereotypes which explain conflict as the clash of specific social interests, and ask, “what, beneath public expression and institutional manipulation this conflict means”. Alluding to Turner’s notion of “social drama”, he suggests that it is possible “to understand the ‘deep structures’ of power and social order by analyzing the implicit classification and metaphor transmitted in such rituals. The public inquiry, exposes, at least temporarily, the lasting but hidden structures and processes of social life” (Wynne 1982:9-11).

Turner’s Social Drama

Wynne’s use of Victor Turner’s idea of “social drama” helps provide valuable insight into public inquiries and helps cast light on their functions in situations of social conflict (Wynne 1982:9-10).

In *Dramas Fields and Metaphors* (1974) Turner describes how he developed the idea of
"social drama" as a means of accounting for particular types of social conflict and change while working among the Ndembu of Zambia. He recounts how one of the things which struck him most about Ndembu social life "was its propensity toward conflict" and that in watching their day-to-day interactions he began to perceive a form to the process, a form which he saw as being essentially dramatic. Turner called these "public episodes of tensional eruption... social dramas." These dramas seemed to constitute "isolable and minutely describable units of social process". They were "units of aharmonic or disharmonic process, arising in conflict situations" (Turner 1974:31-3).

Turner came to see the pattern in a variety of settings and societies. He described the "social drama" as typically consisting of four main phases, the first of which arises with a breach or deliberate nonfulfillment of some crucial norm regulating relations between persons or groups within the same "perjuring system or set or field of social relations." The breach is a "symbolic trigger of confrontation or encounter." While it may be committed by an individual, he notes, it is always done with the belief that they are acting as a representative of others. Following the breach a period of "mounting crisis ensues" (Turner 1974:37-8).

Unless quick action is taken and the breach is sealed off in an area of limited social interaction the 'crisis' will likely escalate. Eventually it will become "... coextensive with some dominant cleavage in the widest set of relevant social relations to which the conflicting... parties belong."

The crisis phase exposes patterns of conflict and intrigue which hitherto had been covert. It represents a turning point, a moment of danger and suspense when "a true state of affairs is revealed" and it is no longer possible to pretend there is nothing "rotten" in the relations within...

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6 See also, Victor Turner, *Schism and Continuity In an African Society* (1957) in which he initially develops his idea of the "social drama".
the larger group or to ignore or wish the conflict away. It “dares the representatives of order to grapple with it” (Turner 1974:38-9).

In the third phase of the drama, redressive action is undertaken. To limit the further spread of the crisis adjutative and redressive mechanisms are put into action. These are enacted by “leading or structurally representative members of the system in crisis.” The mechanisms adopted will vary in type and complexity depending on the perceived significance of the breach, the extent of the crisis, the nature of the social group where the breach occurred, and the degree of the group’s autonomy in terms of wider or external systems of social relations. These mechanisms range from informal mediation or arbitration to formal juridical and legal initiatives. In some circumstances the performance of public ritual may be called upon in an attempt to resolve the crisis (Turner 1974:39).

During the redressive phase pragmatic techniques and symbolic action are most fully expressed. It is also during this phase that “a distanced replication and critique of the events leading up to and composing the ‘crisis’” is carried out. This recapitulation, Turner suggests, may be presented in the rational idiom of a judicial process or it may find expression in the metaphors and symbols of a ritual process. A failure of the redressive measures usually precipitates a regression to crisis and the possible use of direct force. Generally, however, regression becomes a matter of smouldering factionalism without overt confrontations (Turner 1974:41).

The final phase involves either the ‘reintegration’ of the “disturbed social group” or the “social recognition and legitimization or irreparable schism between the contesting parties.” From the perspective of the observer the fourth phase presents “an opportunity for taking stock.” Having already taken careful account of the temporal character of the drama the moment has arrived to address the situation synchronically. The political power relations which proceeded the
drama can be compared with the ‘political field’ that followed the redressive phase. “As likely as not... the scope and range of the field will have altered” but more importantly “the nature and intensity of the relation between parts and the structure of the total field will have changed (Turner 1974:42). Yet through all the change certain norms and relationships will be maintained. The explanation of both change and persistence Turner insists, “can only be found by systematic analysis of processual units and temporal structures, by looking at the phases as well as atemporal systems” (Turner 1974:43).

The Tainted Blood Tragedy as Social Drama.

Using Turner’s model, public inquiries can be seen as an aspect of the third phase of a social drama. Following Turner, the Krever Inquiry might be described as a sophisticated instrument of social reflexivity aimed at reproducing, as exactly as possible, the chains of social events which led to social disruption and individual suffering. The stories presented at the hearings attempted to establish the facts and contextualize the events which led to and constituted the crisis. In doing so they revealed some of the hidden motives which impelled the actors to behave in the way they did. The stories, “frequently saturated with moral implications” allowed the earlier events and actions to be measured against the “ethical yardsticks of the group” (Turner 1988:39). The Commission’s task was to provide a measure of what was done in the past as well as to offer advice on what ought to done in the future.

Turner’s model helps reveal that the tainted blood tragedy involved two separate, though related breaches. The first involved a breach of norms and values by ‘miscreant’ groups and individuals whose behaviour was not only seen as putting them at risk for the disease, it was actually believed in some way associated with the emergence of the contagion. A crisis erupted
when the errant few spread their impurity to the blood supply, thus generalizing the risk of the disease to the innocent citizenry. The crisis, which represented deep routed social-political conflicts over social values and norms, was effectively sealed off through the use of a technological fix in the form of a test to detect the virus believed to cause AIDS. The test, developed in the United States in the fall of 1984, and in general use at Canadian Red Cross blood centres by late 1985, served to minimize the threat the disease posed to the general population. The conflicts which lay behind the crisis, therefore, could once again be pushed out of sight or at least into the background.

A second breach, however, occurred simultaneously with the first. It involved the failure of the experts and administrators in charge of the blood system to prevent the disaster or to adequately warn other health care workers and the lay public of the potential significance of the disease for the blood supply and its users. The crisis surrounding this breach, however, did not emerge until the early 1990's, when the media and those affected by the contamination of the blood supply began to publicly question the actions of the experts and administrators involved in disaster. Widely held expectations came to be undone. Those in charge of the system, it appeared, neither could be trusted nor could they be depended upon -- realizations which were made all the more unsettling by the fact that these failures involved a cherished institution, the Red Cross and a potent symbol of community belonging and caring, volunteer blood donation.

The second crisis brought with it many of the issues and problems which had been sealed off in 1985. The second crisis embodied a complex and interrelated network of scientific and social conflicts which threatened the blood system, public health and government agencies as well as the credibility of science and the scientific expert.
Science Studies, Constructivism, Actor Network Theory

The question of the relationship between science and society and the existence of the boundaries between the two was a matter of considerable concern at the hearings; a concern shared by many theorists and researchers working in a programme broadly referred to as the social studies of science, a programme in which this dissertation might be said to be located.

Researchers in the field of science studies have begun to investigate how communities of scientists, engineers, and physicians, as well as non-scientists, go about creating knowledge and the ways in which this knowledge is applied in the social world. These studies have done much to dispel the stereotypic distinction between science and society, the view that science somehow exists autonomously, free from the social and cultural worlds in which it is created and used.

In the last twenty years, in particular, the field of science studies has expanded enormously and has become crowded with a diversity of theoretical and methodological orientations. Amidst all of this diversity, however, a couple of trends have become apparent. Attention has moved away from the products of science, turning instead towards its practices. In the late 1970's and early 1980's the laboratory bench became a site of ethnographic interest as concerns began to focus on what scientists actually do and say as they go about making science. "The field of resources" that scientists operate in and on became a matter of particular interest (Pickering 1992:2-3) as ethnographers followed science-in-the-making and found that much of it occurred outside of the laboratory and involved individuals, groups, and institutions not normally considered to be within the realm of science. In the late 1980's and into the 1990's these ethnographers of science have found themselves in boardrooms, courtrooms, hearing rooms and

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7 In a recent essay Sharon Traweek catalogues some twenty academic disciplines which have been part of the "avalanche of research" in the field of science studies since World War II (Traweek 1993:4-6).
a variety of other venues as they traced the networks of things and people tied together in the production of scientific knowledge. This has led to an expanded view of science and its place in decision-making as well as a reevaluation of the boundaries traditionally maintained between scientific knowledge, politics and so called popular belief.

While the questions raised by these investigations and the perspectives brought to them have been diverse, many of those working in the field of the social studies of science have adopted a constructivist interpretation of the production of scientific knowledge. Constructivism is not so much a theory as it is a collection of related perspectives based on the premises that scientific knowledge is constructed rather than discovered and that the processes involved in that construction are socially and historically situated.

The claim that scientific and medical knowledge is socially constructed is not intended to demean or belittle science. Rather, it aims at drawing attention to scientific knowledge as a product of creative social actors (Rapp 1991). The constructivist framework allows for an exploration of how humans give meaning to their experience through what they do and what they say -- discourse and practice (Feldman 1995:13).

The constructivists do not see the production of scientific and medical knowledge as something separate from other human activities. Science and medicine are treated as domains “of social practice and discourse, the limits and the contents of which are... set up by wider -- but not separate -- social practices.” Science and medicine, however, are not seen as mere products and reflections of the social and cultural contexts in which they are produced. Science and medicine both express and contribute to the dominant social and cultural beliefs and practices of the time while maintaining their own identities (Wright & Treacher 1982:11).

The constructivist frame offers an antidote to essentialist accounts of science and the
production of scientific knowledge while trying to avoid both idealist and social determinist interpretations. Its influences come from a variety of sources including the works of Dilthey, Mannheim, Ricouer, Fleck, Berger and Luckman, Kuhn, Foucault, and Geertz. Its roots are in the sociology of knowledge, interaction theory and interpretive anthropology (Treichler 1992:70-71).

A major step in the development of the constructivist perspective, at least in terms of science studies, came with the publication of T.S. Kuhn’s *Structure of Scientific Revolutions* (1962/1970). Kuhn’s anthropologically sensitive approach, with its emphasis on the social situatedness of scientific theories and the centrality of communities of shared meaning and practice in the production of scientific knowledge, emboldened sociologists and others to claim the content of science to be a rightful subject of the social analyst. It was no longer simply mistaken scientific beliefs which required social explanation, all scientific theories needed to be understood in terms of their social and cultural underpinnings.

While the impetus for an anthropologically oriented analysis of science was derived through the work of Kuhn, anthropology’s influence in the field was most directly felt through the work of Clifford Geertz. Paula Treichler notes, for example, that it was Geertz who insisted the cultural be “inserted into the study of the sociology of knowledge” (Treichler 1992:72).

Byron Good, argues that the greatest contribution anthropology has made to the sociology of knowledge, is its “insistence that human knowledge is culturally shaped and constituted in relation to distinctive forms of life and social organization” – a view, he notes, which has run

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8 Geertz’s interpretative approach assumes that: rather than being “…an experimental science in search of law…” anthropology is an interpretive science in search of meaning; that all interpretations whether they be the anthropologists’ or the informants’ are constructed not discovered; the whole truth of a matter is never attainable, cultural analysis is inherently incomplete; culture can be understood as “an assemblage of texts”... “as imaginative works built out of social materials” that need to be understood as meaningful within a specified context (Geertz 1973 in Feldman 1995:11-12).
headlong into “the realist claims of modern biology” (Good 1994:21). Good suggests that the confidence that shines through in the work of Evans-Pritchard and Levi-Strauss is no longer available to the ethnographer and that this lack of confidence has affected our view of the natural sciences’ ability to simply represent the empirical world (Good 1994:21).

The constructivist frame has figured in the recent work of a wide range of anthropologists, historians, sociologists and others involved in the social studies of science (eg. Haraway, Latour, Law, Callon, Porter, Woolgar, Wailoo, Traweek, Feldman, Downey, Heath, Hess, Martin, Rabinow, Rapp, Lock, Treichler).

While sharing a broad constructivist orientation the theoretical frameworks these scholars have adopted are far from uniform. Traweek, for example, pursues a Geertzian inspired interpretive approach which she describes as concerned with the “patterned interactions, such as oral and written discourse, or any other social ‘text’... in which the form and the content reverberate to evoke significant strategic meaning to those who know the local patterns.” In examining the world of high energy physics she explores how relations of power are created and enacted both locally and globally through discursive practice and through representations and other evocations (Traweek 1988; 1992; 1993).

Like Traweek, Latour, the French anthropologist turned sociologist, and leading exponent of “actor-network theory” (ANT), draws attention to the social and political factors involved in the construction and presentation of scientific knowledge. However, unlike Traweek and many of her colleagues, Latour and the actor-network theorists also insist that viruses and bacteria, as well as scientific instruments, be considered as actors in the construction of scientific knowledge. They insist on a symmetrical treatment of people and things. Rats, fleas, bacilli, viruses, scallops, flourescent dyes, electron microscopes, are all seen to be actants, all have to be negotiated with
and enlisted in the making of science.

Latour and his colleagues draw attention to the discursive strategies scientists use to enlist and control allies and to the ways instruments function to convert local phenomenon into inscriptions, immutable mobiles; portable representations of the world which can be gathered together in "centres of calculation" and strategically deployed to promote particular points of view (Latour 1987:22-26; Woolgar 1988:69-71).

For actor-network theorists the construction of a scientific fact is much like a military operation. It involves tying people and things together into networks of alliance while at the same time trying to break apart competing alliances. Science, like culture or society, is never contacted directly. Instead what is seen is "a gamut of weaker and stronger associations" (Latour 1987:258). Part of the job of the anthropologist of science is to trace out these associations and enumerate the strategies employed in the building, stabilizing and deconstructing the networks of relationship whereby statements are made into facts or fiction (Latour 1987:25).

Actor-network theorists (ANT) are critical of sociologists of scientific knowledge such as Barry Barnes, David Bloor, Harry Collins, and Steven Yearly. They take exception to sociologists' adoption of an ontology given to them by scientists, which divides the world into the poles of 'Nature' and 'Society'. For the actor-network theorists, 'Nature' and 'Society' are inextricably linked in scientific and technical practices: Nature and Society are the twin results of another activity, network building (Law 1986; Pickering 1992; Callon and Latour 1992). "Instead of providing the explanation, Nature and Society ... [must be] accounted for as the historical consequences of the movement of collective things" (Latour 1990:170).9

9 Latour argues that, "the major advantage for anthropology of this displacement is that it dissolves the great divide which Levi-Strauss, Horton, Goody and science students have struggled with for so long ... all collectives have to co-produce at once their societies and their
While arguing that science is social, perhaps the most social of all human activities, Latour boasts that the ‘social’ elements which populate his writing may not conform to the idea of the ‘social’ found in many of his colleagues work (Latour 1987:63). He is right. The influences of capitalism, the proletarian classes, and male dominance are all absent from his accounts, as are explanations of science based on the interests of multinational corporations, the military establishment, or those of professional elites. Latour warns that social interests cannot be used as explanatory devices because they are themselves reformulated in the process of making science. An important aspect in enlisting allies is the job of translating their interests into your interests, he points out.

Latour insists that in order to study “science in the making” it is necessary to be as undecided about what society is as we are about the nature of nature. The danger of not doing so, he warns, lies in ending up like the sociologists of scientific knowledge, being a social determinist when it comes to science and a realist when it comes to society (Latour 1987:143-4; 1992:345-8).

Haraway, a primatologist and a leading exponent of the field of science studies, agrees with Latour that it is necessary to resist ‘social’ explanations of scientific practice, that by exploding the binary opposition between science and society we can gain insight into the ways scientific practice creates its own contexts. However, she, like many others, is critical of Latour and his actor-network colleagues for their impoverished view of the ‘collective’. Haraway argues that while they correctly resist the opposition of science and society, actor-network theorists “draw a suspicious line around what gets to count as practice.” Questions about how “the practices of masculine supremacy or many other systems of structured inequality” get built never get gods -- Us as much as Them” (Latour 1990:170). In a recent series of lectures at the University of British Columbia (November 1998) Latour argued that what is needed is an approach which acknowledges a “multi-naturalism” as well as a “multi-culturalism”.


addressed. This blind spot, she suggests, has led to a failure on the part of many of those working within ANT to take account of the last twenty years of feminist research (Haraway 1992:332-3).

Neglecting to account for systems of structured inequality in the production and application of scientific knowledge is a serious omission. Anthropologists, especially those working in the field of medical anthropology, have drawn attention to the critical importance of understanding the power relationships involved in the production and use of scientific knowledge. Margaret Lock, Emily Martin, and Rayna Rapp, for instance, have built upon such ideas as Foucault’s, “biopolitics”, to explore the ways in which biomedicine has extracted patients from society to individualize and objectify their experiences and create docile bodies. Lock, Martin, and Rapp, have provided valuable insight into the ways scientific narrative naturalizes social hierarchical relationships and how, through these narratives, structures of domination are learned and internalized.

Science as Narrative: Understanding the World Through Stories.

Despite their many differences most constructivists acknowledge the importance of discursive practices in creating meaning in science and medicine. As in Foucault’s system, entities are seen to be the “products of the discourse which embodies them” (Treichler 1992:73). Science might be described as an activity involving “the construction and sustenance of fictional accounts which are sometimes transformed into stabilized objects” (Latour & Woolgar 1979 quoted in Feldman 1995:15-16).

In recent years Jamie Feldman, Emily Martin, Rayna Rapp, Sharon Traweek and others studying the production of science and medicine have come to treat scientific discourse as narrative, “as story telling within... contested narrative fields” (Haraway 1989:6). Like all stories
scientific stories can be temporarily stabilized, but they are never static. They rise out of social interaction and change over time. They are always capable of being challenged, reinterpreted and conflated with other stories, given new meanings and used for different purposes in different situations. This was something which became evidently clear at the Krever Inquiry hearings.

Emphasizing that the stories are manufactured within contested fields draws attention to the constructed nature of science while avoiding the idea of sole authorship. It leaves open the possibility of multiple authors, both human and nonhuman. A scientific story must not only accommodate and represent the often changing goals, interests, beliefs, and practices of social actors it must also meet and express the demands of the nonhuman world. “The lens of storytelling defines a thin line between realism and nominalism” (Haraway 1989:8)

Accounting for the Stories Told at the Inquiry

The stories told in the course of a “social drama” are never self contained, independent inventions, while drawing on earlier stories they become incorporated into those which follow. The stories told at the Krever Inquiry were no exception. The accounts the witnesses provided were linked to a variety of earlier narratives, some specifically about the tragedy, others about the social and historical setting in which the disaster was enacted. The witnesses’ accounts also became part of an enormous number of narratives which followed. Thousands of newspaper articles and media reports represented and commented on the testimony heard before the commission. At least three Canadian journalists have published books on the tainted blood tragedy in which they drew on stories of institutional failure, individual shortsightedness, political indifference and corporate greed which had been recounted before the commission. In the Gift of Death (1995), for example, Andre Picard, brings together a damning critique of the
Canadian Blood System during the 1980's with the personal stories of those whose lives were profoundly affected by the contamination of the blood supply.¹⁰

The most influential of the narratives to incorporate and comment on the stories told at the hearings, Justice Krever's *Final Report on the Blood System in Canada*, has been taken up in a wide range of settings by a variety of story tellers. Elements from the *Report* have become part of the personal commentaries of those affected by the contamination of the blood supply. They have become part of a myriad of media reports, embedded in the rhetoric of politicians, and incorporated into the stories told by scientists. They have appeared in other investigations into public health policy making and embodied in the policies of the newly formed Canadian Blood Services.

The perspectives expressed and the issues addressed in the various accounts of the disaster have varied widely. Where many journalists explored the personal suffering of those affected, providing poignant reminders of the human costs involved, others, such as Justice Krever, provided a legal accounting of what was known, what was done and what should be done in the future.

Despite their differences these accounts share a number of similarities. They have sought to uncover the conditions and failings which impeded the pursuit of scientific knowledge and thwarted its appropriate application. They have endeavoured to reveal what was truly known by the scientists at the time and enumerated the mistakes made. They have sought to disclose the social, political, institutional and economic interests and goals which led to those aberrations and offered a range of technical and social engineering-style solutions to those shortcomings. In

¹⁰ Picard, like many of the journalists I spoke to at the hearings, said he felt one of the most important things he could do in reporting on the tragedy is give a human face to the story.
doing so, they have accepted the ontology provided by the experts which divides the world into science and the rest. Outside of the sufferings of the individuals affected by the contamination of the blood supply, the social-cultural face of the story has appeared mainly as a means of accounting for the mistakes made.

My approach is somewhat different. While sharing the underlying goal of most of the stories, that of helping insure the tragedy is not repeated in the future, I do not search for what was truly known or should have been known, nor do I suggest socio-technical solutions to the failings which plagued the blood system in the 1980's. Rather, I try to understand the beliefs and practices which made the understandings and actions of the experts possible at the time. I explore what the experts knew and what they needed to know as they carried out their various roles during the early years of the contaminated blood crisis. I try to understand what made those thoughts possible and reasonable to the people who held them and acted on them. I show that the disaster was the outcome of complex, historically and culturally located ways of knowing and behaving that are not readily remediable through social engineering-style solutions.

In the chapters which follow, I present a close examination of the testimony of four of the almost three hundred expert witnesses who appeared at the Krever Inquiry. I analyze the witnesses’ often divergent descriptions of science and its place in public health policy making and explore what their testimony reveals about the complex network of beliefs, practices, people and things involved in the construction and application of the scientific knowledge during the early years of the contaminated blood crisis.

To accomplish this I draw on a variety of sources including the interviews I conducted, the Exhibits filed at the hearings and the transcripts of the proceedings. I bring together insights gathered from these sources with recent research in the fields of cultural, symbolic and medical
anthropology, as well as from the sociology, history, and philosophy of science. Drawing on those insights I show that the boundaries the witnesses described as existing between science and society not only misconstrued the relationship between the spheres, they contributed to the crisis in the early 1980's.

Chapter Outline

In Chapter 1, I explore the context in which the testimony was presented. I begin with a brief description of the physical and social environment of the hearings and outline some of the rules of procedures and patterns of interaction which helped shape the inquiry as well as the witnesses’ testimony.

In Chapters 2 through 6, I turn my attention to the testimony of my four main witnesses and use that testimony to provide a brief history of the tragedy.

In Chapter 7, I reconsider the testimony of the four witnesses and explore what their various accounts reveal about their understandings of the production and application of scientific knowledge.

In Chapter 8, I turn my attention to a notable silence in the witnesses accounts -- the absence of any meaningful recognition or discussion of the symbols and beliefs surrounding blood in Western culture.

In Chapter 9, the concluding chapter I review the insights derived from earlier chapters to show that the opposition between science and society depicted in the witnesses’ testimony presents an inadequate account of the relationship between the spheres and that the related reliance on technical, engineering-style solutions is an insufficient strategy to avoid similar disasters in the blood system in the future. I suggest that a more profitable approach to
understanding science and its role in public policy making is to be found in promoting a dialogue between the dynamic and often contradictory systems of meanings, values and practices involved in and expressed in the witnesses’ accounts at the hearings.
CHAPTER ONE: CONTEXTUALIZING THE ACCOUNTS

In the following chapter I briefly review the history of my research at the commission and situate the day to day activities at the hearings within the context of the structures and procedures associated with the public inquiry process in Canada.

The Physical Setting

The national hearings were held on the 20th floor of the MacLean Hunter tower in downtown Toronto. The hearing room was a large, rectangular space, some 40 feet across. The windows which ran along the 85 foot length of the west wall lent a sense of openness to the room. At its north end, toward the window-side, sitting on a slight angle, was Justice Krever's desk. Located on a platform, about a foot in height, it stood above the rest of the room. Fifteen feet to its left, again sitting at an angle, was the witness stand. It too was perched on a platform, although not quite as high as the Commissioner's. (The angles of the desks provided a more direct line of sight between the witnesses and the Commissioner.) Slightly forward of the Commissioner's desk and a little closer to the window was the registrar's desk. Running down the centre of the room were five rows of heavy wooden tables. Each row was divided in the middle creating 10 seating sections with a corridor down the centre. Each section had four seats where the legal representatives and their invited guests sat.¹

Behind the lawyers' desks was a small open space and behind that was the public seating area which could accommodate about another 40 people. To the window-side of the public area stood

¹ About 5 minutes before the proceedings began a folding table was set-up immediately behind the other desks, thus providing two additional seats. The Hepatitis C Survivors Society was assigned to these seats but not without some protest on their part.
a television camera. Immediately behind it sat the sound engineer with his mixing board which
controlled the rows of microphones perched on the desks. Beside him was the translation booth.

The room had three entrances. One, on the eastern side of the north wall, lead to the
commission offices; the Commissioner entered and exited the room through this door.
Commission counsel and other staff members also frequently used this door. The remaining two
sets of doors were located on the east wall, one toward the north end and one towards the south.
The north door was most often used by the witnesses, the southerly door functioned as the public
entrance, used by commission staff, witnesses and the public spectators.

The Participants

Finding a good vantage point near one of the speaker cabinets in the public seating area, I
settled in. It was about 9:30 A.M., the proceedings were set to begin in 30 minutes.\(^2\) I arrived
early because I wanted to be sure I got a seat. As it turned out, I need not have worried. By the
time the proceedings began, 16 of us were sitting the public area. While far from a capacity
crowd this turned out to be one of the largest turn-outs at the national hearings. A typical
morning would find perhaps two or three of us sitting in the public ‘gallery’ and two or three
stalwart reporters in the media room.

Having unpacked my tape recorder and set-up my microphone I began to sketch the lay-out of
the room and make notes on the comings and goings. Things were relatively quiet for the first
few minutes. A handful of people were in the room. A couple of lawyers had settled in at their
desks, commission staff moved in and out of the room while the sound-engineer was busy

\(^2\) While in Toronto the commission generally sat Monday to Thursday between the hours of 10
A.M. to 1 P.M. and from 2:30 P.M. to 4:30 P.M.
thumping microphones making sure they were working. The pace picked up as ten o’clock drew closer. Legal counsel began to trundle in, dragging cartfuls of documents. Reporters, some with camera-persons in tow, scanned the area looking for likely candidates to interview, while others, who I could not identify, drifted in -- sometimes by themselves, sometimes in groups -- and found seats in the public area. Several of the commission staff hurriedly distributed documents to the participants, while the lawyers began to form small groups chatting, joking, and welcoming colleagues as they arrived.

I recognized a number of the faces in the room, having become familiar with them over the previous year, but I still had a lot of sorting out to do. It was a difficult task just trying to keep track of the participants at the inquiry. Sixteen groups and individuals were granted standing during the organizational hearings held on November 22 and 23 1993.\(^{3}\) By the time the national hearings started the number had increased to 19.\(^{4}\) This included representatives of the federal and

\(^{3}\) The purpose of the introductory hearings was “to determine who should be granted standing and who should benefit from a recommendation to the government ...to obtain funding assistance” (Krever 1993:17). In most cases the two questions were linked. The cost of legal representation, made it virtually impossible for many of the organizations and individuals seeking standing to participate in a meaningful way without funding. The funding guidelines, as set by the federal government, therefore, played an important role in determining who would be granted standing. The guidelines stipulated that, to qualify for funding, the group or individual must have an identifiable and historically demonstrated interest in the issues that both requires representation and promised to contribute to the inquiry. Those requesting assistance were required to show that they did not have the resources to represent those interests. They were also required to have a funding proposal and an ability to account for the monies, if received.

\(^{4}\) Those with standing at the inquiry included: The Canadian Blood Agency (CBC); Canadian Red Cross Society (CRCS); Canadian Hemophilia Society (CHS); Canadian AIDS Society (CAS); Hemophilia Ontario, Toronto and Central Region Chapter; Miles Canada; Connaught Laboratories Ltd.; HIV-T Group, Blood Transfused; Hepatitis C Group; Gignac, Sutts Group; Jean-Daniel Couture and Jean-Henry Godin; Canadian Hemophiliacs Infected with HIV and Janet Conners; Canadian Hemophiliacs Infected with HIV; Hepatitis C Survivors Society; Committee of HIV Infected and Transmitted; Association of Hemophilic Clinic Directors of Canada; the Provinces of British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, New Brunswick, Newfoundland and Labrador, Prince Edward Island, Nova Scotia, the Northwest
provincial governments, the Red Cross, treating physicians, pharmaceutical manufacturers, as well as individuals and groups affected by the tainted blood tragedy. Together they embodied a wide variety of interests, goals, experiences and expectations.

With the exception of the Hepatitis C Survivors Society all of the groups and individuals with standing at the commission were represented by legal counsel. Some had a single lawyer present at the hearings, others had as many as four legal representatives in attendance at any one time.

Participation in the inquiry was not restricted to those granted standing. Justice Krever welcomed submissions from interested parties, and made it clear that anyone who was either directly or indirectly affected by the contamination of the blood supply was welcome to testify before the commission. Many of the individuals and groups affected, took the opportunity to tell their stories and share their experiences during the provincial phase of the inquiry. The day-to-day activities of the hearings, however, remained in the hands of the lawyers. If a question was to be asked, a clarification sought, a request made, it had to be posed through legal counsel.

Territories and the Yukon; and the Government of Canada. The Province of Quebec did not seek standing at the inquiry although it participated in and was represented by counsel at the Quebec hearings and the national hearings (Krever 1995:1106-7).

The Hepatitis C Survivors Society was granted standing but not intervenor funding and thus could not afford legal representation, although on occasion, 'volunteer' legal counsel appeared on their behalf. For the most part, however, members of the Society sat at the hearings and conducted cross-examinations. Two other groups with standing lacked the financial means to adequately represent themselves and did not receive funding. They did, however, have legal representation. Mr. Kenneth Arenson acted without fee on the behalf of the Committee of HIV Infected and Transmitted (CHAT) and Mr. David Harvey acted similarly for Hemophilia Ontario, Toronto and Central Ontario Region.

Until December 1994 both Mr. Arenson and Mr. Harvey represented the HIV-T Group, Blood Transfused. In early December 1994, the Group issued a press release suggesting that as co-chair of the Royal Society of Canada Study on AIDS (1988) Justice Krever had remained silent about the dangers posed by HIV in the blood supply. They argued, therefore, that his position as Commissioner of the current inquiry represented a conflict of interest. Mr. Harvey and Mr. Arenson made it clear they did not support the group's actions and immediately resigned.
Submissions from the floor were not entertained.⁶

The Rules of Procedure

The form and power of a Federal inquiry is broadly defined in the Inquiries Act.⁷ The Act gives a commission the power to take evidence under oath, to subpoena witness and documentary evidence, and to make findings of wrong-doing or innocence. (These findings, however, are not considered legal determinations and in fact, may be contrary to what a law court might find.) The Act also grants the commission the right to engage legal counsel as well as accountants, engineers, or other experts (Robbins 1982:11).

The specific nature of the problem and the information being sought play an important role in determining the form an inquiry will take. The “terms of reference”, set out in the order-in-council establishing the commission, therefore, play a significant role in shaping the proceedings as does the choice of Commissioner (Wraith and Lamb 1971; Salter 1981; Bulmer 1983; Smith...

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⁶ This was a source of considerable frustration for some of those affected by the contamination of the blood supply, as I learned during my interviews and conversations with them. Many expressed resentment over having others speak for them while several told me they felt frustrated by their lawyers’ unwillingness to pursue the issues and questions they wanted addressed. Some of the lawyers I spoke with also noted the tension, explaining to me that occasionally they found themselves faced with demands from their clients, which in their professional judgement were not in the best interests of those clients.

⁷ The modern form of the royal commission in Canada was set out in 1846 in An Act to Empower Commissioners Inquiring into Matters Concerned with the Public Business, to take Evidence on Oath. Later Parts were added in 1880, 1912 and 1934. There are another 40 federal statutes which confer powers to hold inquiries in addition to the Inquiries Act and another forty seven which refer to the Act. A number of the provinces also have their own Acts governing inquiries (Robbins 1982:11). Part I of the current federal Inquiries Act is very similar to the original 1846 Act (Robbins 1982:7).
Historically, Commissioners have enjoyed a wide degree of discretion in establishing the specific rules of procedure which will be followed. They have, however, generally done so with an eye to previous undertakings. This sensitivity to precedents has led to some significant changes over the years, including the way in which the rules of procedure are themselves determined. In the late 1960's the Le Dain Inquiry opened the door to an increased public participation in the process while the Mackenzie Valley Pipeline Inquiry in the early 1970's set a precedent by providing funding for the participation of the lay public (Salter 1981a:343-4). A few years later The Thompson West Coast Oil Ports Inquiry gave participants a major role in developing the rules of procedure. Since that time, those with standing have assumed a greater role in determining the day to day structure and practice of a commission (Robbins 1982:18.)

Justice Krever followed precedent at the organizational hearings, inviting the legal representatives of those granted standing to attend a meeting “to discuss both the issues and procedures that should be adopted that would make it possible to canvas all the important issues adequately and in a fair way” (Krever 1993:20). Out of that meeting a set of 39 Rules of Procedure and Practice were established. The Rules of Procedure set-out the general rules for examination and the process for requesting the appearance of particular witnesses. It outlined the forms of evidence which would be accepted; established the protocol to be followed to protect witness confidentiality; defined the times the commission would sit; and stipulated the witnesses’ right to counsel.

One of the most significant procedural determinations in any inquiry is the degree to which

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8 The Cabinet, as a rule, is responsible for selecting and appointing a Commissioner to carry out the inquiry.
the hearing process will follow a formal legal model or will adopt a more relaxed informal practice. This choice can have a significant effect on the inclusiveness of the hearings and the degree of satisfaction the participants experience with the proceedings (Robbins 1982:14).

The *Krever Inquiry* adopted a relatively formal set of practices and procedures modeled on those of the courtroom. This lent an adversarial character to the proceedings. While cross-examination occasionally livened things up and helped draw out and clarify the information presented (Salter 1981:187, 199) it also led to unhelpful confrontations between lawyers, between lawyers and witnesses and between the Commissioner and the lawyers.

With some notable exceptions, those who had been affected by the disease were treated rather gently. In general the lawyers reserved their more aggressive tactics for the expert witnesses. Throughout the hearings the Commissioner had to remind lawyers for the intervenor groups that the inquiry was not a court of law, the process of examination was to be inquisitorial not adversarial, and the witnesses were to be treated with respect.10

While the adoption of court-like procedures, may have contributed to the polarization of individuals and issues (Salter 1981) it can hardly be seen as the sole source of the adversarial interactions. Several of the lawyers identified very strongly with the groups they represented and

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9 While the commission followed a relatively formal legal model, the hearing room was far more relaxed than an actual courtroom. The registrar, for instance, did not call the hearing to order when the Commissioner entered the room, participants were allowed to bring coffee and other beverages with them, cellular telephones were constantly ringing, lawyers and spectators alike came and went as they pleased. On one occasion one of the witnesses on the National Advisory Committee on AIDS panel got up from the stand, left the room, and return, without any comment being made.

The Commissioner explained to me that it was his intention to make the proceedings as comfortable as possible for those not familiar with the courtroom while at the same time making sure the significance of the process and the decorum of the hearings was maintained.

10 All inquiries in theory, at least, are inquisitorial. The Commissioner is generally expected to intervene when things become too adversarial (Gee 1990:44).
that occasionally spilled over into the proceedings. For the most part, the lawyers at the inquiry were skilled courtroom litigators. They were in the habit of conducting adversarial examinations and were well experienced in the art. Some skilful performances were rendered at the hearings.

At times it was hard to tell a genuine emotive outburst from what was being played out for the benefit of the media. Everyone was conscious of the media's presence; witnesses, lawyers, Justice Krever, and the members of the intervenor groups all used the press to get their messages out. The reporters, however, were fickle, their attention was hard to hold, they needed the promise of a good story to coax them out.

The Hearing Room: A Day in the Life

The opening act

The promise of a good story had lured the press out this March morning. A new phase in the inquiry was beginning. The stories of the injured and the local functionaries had been told; it was time for those who were in charge of the system to provide a public accounting for the disaster.

The show was about to get under-way, and the opening act was a headliner. Reporters from as far away as San Francisco had come to hear him testify. Dr. Donald Pinkston Francis, internationally respected infectious diseases expert and outspoken public health advocate, was about to take the stand.

Francis was a popular and controversial figure. He had been on the front-line in the Sudan when Ebola first stuck and he was part of the WHO team that claimed victory over small-pox. His vociferous stand against the apathy of public officials and the inaction of the blood bankers when AIDS first emerged into public consciousness in the early 1980's made him a hero of books, movies and television.
Despite the anticipation there was nothing exceptional about his time on the stand. He levelled some stinging criticisms at the blood officials in both Canada and the United States and there were some heated exchanges between himself and Earl Cherniak, counsel for the Canadian Red Cross Society but for the most part, opening day at the national hearings followed a pattern which had become familiar in the provincial phase. As Justice Krever entered the hearing room, everyone rose. He seated himself, gave a nod of acknowledgement, and we all sat down again. The Commissioner wished the participants a good morning. (Most days, it was Commission Counsel who wished the Commissioner good morning.) As usual the next step in the procedure was to take care of any business; the filing of exhibits, follow-ups to previous issues, addressing other matters which may have arisen.

Mr. Cherniak, rose and presented an extended submission on the behalf of his clients. He outlined a number of concerns including the belief that the tentative hearing schedule, which had been distributed to counsel, devoted too much time to the events of the 1980's and not enough time to the present structure of the system, the changes which had been implemented and the Red Cross’s vision for the future.

After listening to the submission Justice Krever said that he had noted their concerns, but “...The inquiry cannot go on for ever” and ultimately he, as Commissioner, would decide what issues would be addressed, not the Canadian Red Cross Society or its representatives (21470).

Following a couple of other matters of business, Ms. Marlys Edwardh, Senior Commission Counsel, introduced Francis who was then sworn-in and informed of his right to object to answer

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11 Information cited from the commission transcripts appear in this text as page numbers eg. (21470). In instances where it is not self evident who made the comment the citation includes a reference to the speaker eg. (Krever 21470). For an index of the transcript volumes cited in this text see Appendix 3.
any questions under Section 5 of the *Canada Evidence Act*. (All witnesses were sworn in -- although occasionally the procedure was overlooked until after the testimony was already underway.) Francis did not avail himself of the protection of Section 5 of the *Canada Evidence Act* although many witnesses who appeared before the commission did. That many sought protection was not surprising given the plethora of outstanding and potential lawsuits arising from the contamination of the blood system. (The legal implications no doubt contributed to the circumspection displayed in the answers provided by a number of the witnesses.)

One final piece of business, which had been overlooked, the filing of Exhibits -- including 11 volumes of documents relating to the early history of HIV and the American institutional response to the disease -- was dealt with before Edwardh turned her attention to Francis’ Curriculum Vitae.

Curriculum vitae

A review of the expert witness’s Curriculum Vitae generally followed their swearing-in. This ensured that the highlights of the C.V. were entered into the record while providing the audience -- especially those watching the hearings at home on television -- with an outline of the witness’ education, practical experience, employment history, professional affiliations and memberships, publication record, etc.¹²

The review helped focus attention on those areas of the witness’ training, experience and expertise which bore most directly on the issues of interest to the commission.

¹² Copies of the witness’s C.V. were distributed to the legal representatives of each of the intervenor groups and extra copies were frequently made available for the media and other observers in the hearing room.
The C.V. was an important element in negotiating the public identity of the witnesses. It was employed both by them and counsel to establish or challenge their expertise and authority to speak on particular matters.

Examination in-chief

The first part of the morning was taken up examining Francis’s C.V. and exploring the history, structure, and functions of the Centers for Disease Control in the United States. At 11:30 A.M. the commission took its customary morning break, resuming about twenty minutes later. After the break Edwardh turned to the early history of the disease. Her examination ranged from a general review of institutional structures of the blood system in the United States in the early 1980's to the specific events and activities surrounding the emergence of AIDS and the efforts taken to protect the blood supply. She examined the evidence available at the time, the methods used to generate it and the meanings attached to it by the experts. In the process Francis was called on to enumerate facts as well as offer opinions on a range of technical and social issues. Among the areas addressed were clinical medicine, public health and public health education, epidemiology, virology, serology, transfusion medicine, and blood product manufacturing.

The interaction between Edwardh and Francis was relaxed, assuming the form of a dialogue for the most part. She asked many open ended questions: his answers frequently took a narrative style, sometimes running two or three minutes in length. A typical exchange, however, included a

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question of one or two sentences and an answer of three or four. From time to time the Commissioner would interject, sometimes to clarify a point about the documents that were being referred to, sometimes to seek clarification, and other times to pursue an issue which had been overlooked or not fully addressed.

The documentary evidence played an important role in Francis's testimony as it did with all the expert witnesses. The documents were used by the witnesses and examiners to affirm particular points of view as well as to challenge them. They were interpreted and reinterpreted; and at times, their meanings became a matter of considerable debate and controversy.

Previous evidence also entered the dialogue through the questions of the examiners. It helped shape their examinations, providing a source of questions as well as a resource drawn upon to challenge the testimony of a witness. Witnesses too, drew upon and commented on previous testimony.

Witnesses became familiar with previous testimony through a variety of sources. The expert witnesses were interviewed by Commission Counsel prior to their appearance and might become aware of the previous evidence in this manner. They might also be briefed by other counsel at the commission as to particular matters that required further comment or clarification. A number of the organizations represented at the inquiry sent 'observers' -- scientific experts, communications specialists, bureaucrats -- to the hearings. A witness associated with one of these groups, therefore, might be made aware, either formally or informally, of previous testimony or documentary evidence. Media reports and the live and taped broadcasts of the proceedings provided yet other sources, as did press releases issued by a variety of the organizations

14 It was not uncommon for Francis to use sentences containing as many as 35 to 50 words. Ms. Edwardh's sentences were somewhat more modest, extending on occasion to 25 or 30 words.
represented at the inquiry.

Copies of the previous day's transcripts could be purchased on floppy disk from the transcription company contracted by the commission. A 'hard' copy of the transcripts also was available, to the witnesses, the media as well as the public, in the media room. Finally, it was not uncommon to see witnesses who had appeared at the commission or were scheduled to appear, watching the proceedings in the public area.

As was custom, the proceedings adjourned at 1:00 P.M for lunch. The reporters converged on the hearing room, forming a scrum around Dr. Francis. Within a few minutes, however, virtually everyone had drifted from the room.

Around 2:15 people began to drift back into the hearing room, with a final rush at 2:30, just as the proceedings got under-way. Far fewer of the seats in the public area were occupied in the afternoon session.

Perhaps the greatest struggle at the hearings that afternoon took place amongst the members of the audience -- the struggle to stay awake. It was a battle waged most afternoons -- the heads of audience members gently tipping forward, jerking up suddenly only to sink slowly forward again. The recycled air in the office tower, the warmth of the afternoon sun coming through the window, and the relative inactivity of the observers, when combined with what at times could be a staggeringly dull exchange of questions and answers, acted as a potent soporific on many of the spectators. By the time 4:30 arrived, the usual time the proceedings adjourned for the day, everyone appeared ready for a change.
Cross-examination

Francis was on the stand for about 18 hours over a 4 day period. Edwardh’s examination in-chief took about 10 1/2 hours, the cross examination lasted approximately 7 1/2 hours. During that 7 1/2 hours he was examined by 12 lawyers.\textsuperscript{15}

On average 30 to 50 percent of an expert witness’s time on the stand was dedicated to cross-examination. As most witnesses appeared for a pre-determined period -- generally 2 to 4 days -- there were real time constraints when it came to cross-examination. Those wishing to question the witness were asked to let the commission know how much time they would require. Commission Counsel then determined the amount of time each would be given to carry out their cross-examination.

The time restrictions helped shape the style of examination and the interactions between the witnesses and the lawyers, and this affected the quality of the evidence presented. Cross-examination was much faster paced, something which became apparent to me as I tried to keep up taking notes. Less time was spend pondering the minutiae in the documentary evidence. Strategies were also employed to limit the witness’s answers, especially the use of restrictive yes/no style questions. More open-ended why questions, inviting narrative exposition, were generally avoided. This depended, in part, on whether the examiner considered the witness an ally or not. The lawyer was more likely to relinquish some control and give ‘freer rein’ to those they perceived as having allied interests. This pattern appeared to be typical of that found in

\textsuperscript{15} Most of the intervenor groups were allotted thirty minutes for their cross examination. Some -- such as counsel for the federal government -- took less than 10 minutes others such as Cherniak questioned Francis on the behalf of the CRCS for 3 1/2 hours.
During cross-examination the lawyers often tried to keep the witnesses focused on a very narrow range of issues. As one lawyer at the inquiry explained to me, the object is to convince the witnesses that you know the material better than they do. You do this by keeping them locked into a very narrow channel which you have researched thoroughly. You try not to let them out of it. You make them think that your knowledge of the field is "a mile wide and a mile deep, when in fact it is a mile deep but only an inch wide".

This sort of strategy led to some interesting interactions, as the witnesses in many cases were equally well-skilled in handling themselves in difficult public situations. Struggles between the witnesses and counsel would occasionally break out, especially when overly restrictive tactics were employed by the lawyers or evasive answers were proffered by the experts. Justice Krever would intervene on occasion to ensure that the witnesses had an adequate opportunity to answer fully the questions posed. Ensuring that the witnesses had an adequate opportunity to present their views was a critical issue not only in terms of gathering information but also in terms of the concern over natural justice. This was particularly pertinent to the Krever Inquiry given the

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16 For a discussion and analysis of examination techniques employed in the courtroom see William M. O’Barr Linguistic Evidence: Language Power and Strategy in the Courtroom (1982), and Susan Urmston Philips, The Social Organization of Questions and Answers in Courtroom Discourse (1987). For a discussion of issues the expert medical witnesses may face in the courtroom and the public inquiry see D.J. Gee The Courts and the Doctor (1990). Gee suggests that among the various venues to which a doctor may be called to testify the public inquiry is perhaps the most stressful. Even veteran witnesses can find themselves shaken by the experience (Gee 1990).

17 These sorts of struggles were not restricted to the cross-examination, but they were far more common during this phase than during the examination-in-chief.

legal challenges which were launched following the commission's issuance of Section 13 notices in late December 1995. Section 13 of the Canada Inquiries Act stipulates that: "no report shall be made against any person until reasonable notice has been given to the person of the charge of misconduct alleged against him and the person has been allowed full opportunity to be heard in person or by counsel." 19

The specific and often divergent interests and concerns represented by the various intervenor groups, helped limit the duplication of the areas covered in their cross-examinations, enabling the

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19 A central responsibility in investigatory inquiries is the protection of individual rights, including the right to be heard. The question of whether some of the witnesses had been given an adequate chance to present their views became an important issue in the legal challenges which were launched against the Krever Inquiry following the commission's issuing of Section 13 notices to 95 persons, corporations and governments. The notices informed the recipients of the possibility the commission might make findings of 'misconduct' against them. The Canadian Red Cross and five pharmaceutical companies, together with the federal government, a half dozen provincial governments and various ex-officials of the Canadian Blood System immediately launched a series of unprecedented court challenges over the scope of the inquiry and its ability to make specific findings of misconduct. Several of the litigants fell out after the Federal Court ruled in Justice Krever's favour but a number of them including the Red Cross, 13 of its ex or current officials, several pharmaceutical companies as well as a number of ex-bureaucrats and government ministers appealed the ruling.

Justice Richard of the Federal Court of Appeal ruled in Justice Krever's favour upholding his right to make findings of individual misconduct. Justice Richard stated that the Blood inquiry "does not carry the same weight as a trial," Justice Krever's findings of wrong-doing only reflect his own "opinions." The Court did, however, restrict the number of individuals Justice Krever could name.

Following this decision the Red Cross, 2 of the drug companies and 12 individuals applied for and were granted leave to appeal the case to the Supreme Court of Canada. The matter came to an end in the late Summer of 1997 when the Supreme Court unanimously upheld the lower court ruling that Justice Krever had the authority to make findings of fault.

The legal challenges, which delayed the release of the Final Report by more than a year, were considered by many to be extremely significant for the future of public inquiries in Canada. In pursuing the matter to the Supreme Court the Red Cross argued that given the current widespread use of commissions of inquiry, establishing what powers they were to have and what legal "safeguards" the "targets" of such proceedings were to enjoy, was a matter of "national importance" and a matter "urgently" requiring the guidance of the Supreme Court.

Concern was expressed in many quarters that if the Supreme Court found in favour of the litigants it would spell the end of the ability of public inquiries to carry out thorough-going investigations.
individual lawyers to focus their expertise and energy on the particular areas of concern to them and the groups they represented. Some of the legal representatives carried the strategy further, forming alliances with one lawyer taking responsibility for issues surrounding risk estimates, for example, another perhaps focusing on educational efforts, and another dealing with the acquisition and distribution of manufactured plasma products.

While there appeared to be no strict adherence to this strategy it occasionally provided intervenor counsel with the opportunity to pursue key issues in greater depth than would have been possible had they not worked co-operatively. The co-operative interaction amongst the various groups also extended their sharing of information and informants.20

Access to information and expert advice was an issue of considerable concern. A number of representatives from the intervenor groups complained to me about not having adequate access to experts. They felt at a disadvantage compared to some of the groups represented at the inquiry who had their own scientists on staff.21

While the strategies employed by the intervenor counsel helped reduce overlap among themselves, their examinations often travelled the same path already covered by the Commission Counsel. As a result there were many repetitious moments in the cross-examination, although on occasion it drew out some important issues.

20 Liora Salter (1981) and Brian Wynne (1982) have drawn attention to ways in which public inquiries can stimulate and facilitate the formation of information gathering networks amongst intervenor groups.

21 Counsel for some of the groups also spoke about the difficulties they had experienced in finding scientists who were willing to go on the record with their criticisms of the Blood System and the decisions which were made surrounding AIDS and the blood supply in the early 1980's.
2.1 Confronting AIDS

Curriculum Vitae

Ms. Edwardh, senior counsel for the commission, began her examination in-chief with a brief overview of Dr. Francis’s Curriculum Vitae (CV). She pointed out that from 1975 to 1977, he held a Fellowship in infectious diseases in Channing Laboratory, Harvard University Medical School in Boston and in 1979, he received his Doctor of Science in Microbiology and Virology at Harvard School of Public Health (21482-3).

Francis pointed out that he had combined clinical work in infectious disease with laboratory research while at the School of Public Health. He recalled that it was during this period he first learned that a viral infection, years after its acute phase, could lead to a variety of chronic manifestations, including cancer. This insight, he suggested, gave him an abiding interest in the late manifestations of viral infections (21487-8).¹

Turning to his practical experience Edwardh noted that he joined the CDC in 1971 and for the next 20 years remained with the organization. After retiring from the service, she said, Francis

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¹ One of the most interesting models of this phenomenon at the time was feline leukaemia virus, a disease which initially produced only a mild clinical state in the animal but could later cause marked immunosuppression, the occurrence of opportunistic infections, immunocomplex diseases and cancer (Francis 21488).
joined a private pharmaceutical company, where he was involved in research on the development of an AIDS vaccine (21484).

She pointed out that in 1978 he assumed the position of Assistant Director for Medical Science, Hepatitis and Viral Enteritis Division, Centers for Disease Control, Phoenix Arizona (21488).²

Francis told the commission that he was initially in charge of the epidemiology side of the activities at Arizona, monitoring hepatitis, studying its occurrences, designing and implementing programs for its control. An important part of his work there involved the investigation of the newly developed hepatitis vaccine (21489-90).³ This research necessitated carrying out in-depth interviews, which, he suggested, led him to develop some “very close relationships” with a several of the participants in the study (21490-1).

Edwardh noted that in May 1983 he became coordinator, AIDS Laboratory Activities, Division of Viral Diseases at the CDC Atlanta serving also as Assistant Director, Division of Viral Diseases Centers for Disease Control, Atlanta.

Discussing his involvement with research on the emerging epidemic Francis explained that given his “background in a disease of cats that looked very similar to the disease we were seeing in humans at that time” and his “experience working with the gay community where this new disease, AIDS, was prevalent,” it was impossible for him to stay out of the “melee” (21491-2).

² This section of the CDC was primarily assigned to monitor and control hepatitis in the United States but it was also a World Health Organization collaborating centre for hepatitis which involved a considerable amount of international work (Francis 21488-9).

³ This was one of the two studies which led to the licensure of the hepatitis B vaccine. The study centred on five cities in the United States and involved 2,000 gay men, all of whom were considered to be free of hepatitis at the time of their enrolment. Half of the group was given the vaccine and half received a placebo. Both sub-groups were tracked for almost 24 months to compare their respective rates of infection (21490-1).
Francis related how, toward the end of his assignment in Atlanta, the Director of the Centers for Infectious Diseases at the CDC, asked him to bring together existing laboratory and epidemiological field studies in the form of a Prevention Program. He drafted a national program for the prevention of AIDS in the United States which was then sent on to Washington for approval and funding. The problem, according to Francis, was the Administration “was not interested in aggressively pursuing the prevention of AIDS”. The proposal was summarily rejected (21493).

Francis recalled that his dismay at the attitude of the federal government caused him to contact officials in California who had earlier expressed interest in setting-up a prevention program. Finding his ideas well received, he requested a transfer which was granted. He became a CDC consultant to the State of California, a position which he held until 1992 when he retired from the Public Health Service (PHS) (21494).

After establishing Francis' educational, practical and research experience Edward briefly touched on his publication record recounting that he had written on feline leukaemia virus and on infectious disease outbreaks; particularly on methods or strategies for their prevention and control. She also noted that in 1979 he had written an article for the *Lancet* on Hepatitis B infections in commercially prepared plasma products in India and that since the early 1980's he had written extensively on the epidemiology of AIDS, its spread and its control (21494-7).

The Centers for Disease Control and Its Role in Public Health

The review of Francis’s C.V. provided Commission Counsel an opportunity to explore the history of the CDC. Francis explained that while originally established to deal with malaria, the CDC went through a number of changes over the years, eventually becoming the key Public
Health Service agency involved in disease surveillance (21527-8).  

Francis took this opportunity to point out one of the strengths of the CDC; its ability to bring young people into the Public Health Service. He recounted, how, in the early 1970's he had planned to move to Canada to avoid serving in Vietnam but changed his mind after learning that the CDC was a “uniformed agency” and he could fulfil his military service with them. He downplayed the militaristic aspects of the CDC, however, saying that little emphasis was placed on hierarchy within the agency. Instead, he stressed the nonconformist ethos of the agency, its ability to attract youthful people willing “to question the system”. This, he suggested, was one of the reasons why the CDC was so successful. Francis felt it essential that an activist spirit permeate the sphere of public health; the status quo was antithetical to good public health (21525).

*Morbidity and Mortality Weekly Reports*

Noting that everyone at the inquiry had occasion to read the *Morbidity and Mortality Weekly Reports (MMRW)*, the CDC’s official instrument of communication, Edwardh asked Francis if he

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4 Originally the acronym CDC stood for Communicable Disease Center. It was later renamed the NCDC, the National Communicable Disease Center. In 1980 the acronym CDC was again adopted, this time, however, it stood for the Centers for Disease Control and Prevention, a change prompted by “the victory thought to have been won over infectious diseases.” The new name reflected an enlargement of the organization’s original mandate to include a commitment to “the institution of research surveillance, and prevention of all causes of morbidity and mortality (Grmek 1990:14). Francis explained that the CDC originally focused on infectious diseases but over the years came “to include both occupational and chronic non-infectious disease situations” within its purview. He also pointed out that at the same time it was expanding its scope in the early 1980’s funding for the institution was beginning to dwindle; annual budget cuts of 10 to 12 percent were common (21509).

5 Francis returned to this point later arguing that “on the whole we are too conservative in public health”, that despite the costs, “overreaction is probably a wise thing...” (21727). He was adamant, however, that his view of the public health expert’s role as advocate was not a moral, ethical stance, it was simply a matter of doing the job (22015-6).
might describe how it is created and say a bit about its history (21518).

Francis confessed to being unfamiliar with its founding history but he suspected it dated back to the earliest days of the CDC. Basiclly, he said, the MMWR provides an epidemiological accounting -- a “reporting of the given occurrence of diseases by geographical area” and that this is frequently broken down on an annual basis by age and sex (21518). He explained that “the simplest way to understand epidemiology is it is the who, what, when and why of disease occurrence and much of that can be described statistically” (21518).

He estimated the weekly circulation of the MMWR in the early 1980's to have been somewhere between 100,000 and 200,000 copies. While distributed internationally, he said, it was designed primarily to keep public health practitioners and physicians in the United States apprised of current public health problems and trends. He described it as a particularly effective instrument in this respect because of its rapid reporting ability: Where it might take six months to publish an article in a journal, the MMWR can get the information out within a week (21519-20).

Francis related how the MMWR’s review process changed as the AIDS problem began to grow and how the publication became subject to political interference. In the past, he said, the MMWR was “extremely independent”, today all the articles are reviewed in Washington at the Center Director’s level; the Center Director ultimately decides what is going to appear in the publication. He also noted, the MMWR has changed from being an exclusively internal publication to one which includes a number of jointly authored articles (21520-2).

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6 According to the medical historian Mirko Grmek the MMWR first appeared in 1961 (Grmek 1990:14).

7 According to Francis it is generally the person carrying out the particular investigation who gets “stuck” with the job of writing the article, although in the past, it was hard to tell who the author was because the items were anonymous. These days you tend to see more attribution, he said (21520).
Early Steps

Turning her attention to the early history of the outbreak Edwardh asked Francis how he had “become involved with the AIDS issue” (21537).

Francis said that, as far as memory served, his involvement began with a phone call just prior to the publication of the report of Pneumocystis carinii pneumonia (PCP) amongst young gay men in Los Angeles, June 1981. He recalled that Jim Curran, a associate at the CDC, had phoned him as one colleague to another to see if he could “lure” him into joining the effort to uncover “the epidemiology, the transmission and the cause of this new disease”. According to Francis the call was a typical attempt to interest and recruit people to investigate a new disease (21537-40).9

The Commissioner interjected, asking Francis whether Pneumocystis carinii pneumonia was indeed a new disease?

Francis said that neither PCP nor Kaposi’s sarcoma (KS) were new diseases, “but they were certainly new diseases in healthy and young people.” These were not the typical sort of individuals affected by the diseases. PCP, for instance, was a disease generally seen amongst cancer patients and those suffering from immunosuppressive disorders “so it was a very unusual phenomenon” (21540).10

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8 Curran was head of the Venereal Disease Branch of the CDC and had wide experience working with the transmission of infectious diseases within the gay community. Curran headed the CDC effort to track the new outbreak.

9 Francis, in fact, had already pointed-out that the CDC “will tap into any person who will cooperate with them to search out the cause of a new disease” and that in the case of AIDS, laboratories around the world were working with the agency (21492).

10 Kaposi’s sarcoma generally affected older men, usually of Mediterranean or Jewish ancestry (Grmek 1990:113).
Edwardh drew his attention to the first two reports of the diseases in the *MMWR* in June and July of 1981 and asked him to discuss the CDC’s initial response, especially its formation of a Task Force in July of 1981 to investigate the reports of PCP and Kaposi’s coming out of New York and Los Angeles (21541).

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The June 5 1981, *MMWR*, outlined the 5 cases of PCP in California. All had been treated in Los Angeles between October 1980 and May 1981. In addition to the rare pneumonia all 5 had a current or previous history of cytomegalovirus (CMV) infection as well as candidal mucosal infection. Four of the men had serologic evidence of past hepatitis B infection although none appeared to be currently infected. “The patients did not know each other and had no known contacts or knowledge of sexual partners who had similar illnesses.” Two of them “reported having frequent homosexual contacts with various partners.” All 5 used inhalant drugs such as amyl nitrite and one reported “parenteral drug abuse” (*MMWR* 1981:250-1).

The Editorial Note following the report stated that “the fact that these patients were all homosexual suggests an association between some aspect of a homosexual lifestyle or disease acquired through sexual contact and Pneumocystis pneumonia in this population.” It was speculated that the PCP and candidiasis infections might be related to a common exposure that predisposes individuals to opportunistic infections. Cytomegalovirus (CMV), it was pointed out, had been known “to induce transient abnormalities of in-vitro cellular-immune function...” The authors of the Note, however, cautioned that it was not possible to establish the role of CMV in the recent series of illnesses given the “lack of published data on cellular-immunity among healthy homosexual males...” (*MMWR* 1981:251-2).

A month later the first scientific report of a rare cancer affecting gay men appeared. The July 3 1981, *MMWR*, reported that in past the 30 months Kaposi’s sarcoma (KS), had been diagnosed in 26 homosexual men (20 in New York City and 6 in California.) Like the PCP outbreak in Los Angeles the rare form of sarcoma seemed to be affecting relatively young, previously healthy, homosexual men. A number of the KS patients also suffered from opportunistic infections including PCP, CMV, candidiasis, and herpes simplex. Past infections with hepatitis were also common. It was also noted that since that previous report of the 5 PCP cases in Los Angeles an additional 10 cases (4 in Los Angeles and 6 in the San Francisco Bay area) had been identified in homosexual men. Two of the 10 new cases also had KS (*MMWR* 1981:305-6).

The Editorial Note following this report indicated that it was “not clear if or how the clustering of KS, Pneumocystis, and other serious diseases in homosexual men is related.” It also observed, earlier studies of patients with KS demonstrated a specific serologic association between KS and CMV and researchers had previously hypothesized “that the activation of oncogenic virus during periods of immunosuppression may result in the development of KS.” The author cautioned, however, that while immunosuppression often results in CMV, “it is not yet clear whether CMV infection precedes or follows the above-mentioned disorders” (*MMWR* 1981:306-7).
Francis described it as “a common response to an unusual event”. It was a serious situation. “This was not just a disease that made you feel sick and the whites of your eyes turned yellow like hepatitis; this was a disease that when that happened you went on to die.” It was typical in such situations, for the CDC to establish a group to look into and evaluate reported occurrences, he said (21542-3).

Francis suggested that the first thing you do when investigating a new disease is find some way of reporting it. This, requires several things including a clear definition of the disease, the cooperation of medical personnel in the field who are in contact with infected patients and the development of a network of investigators to follow up reports when they are received.

In the case of this mysterious new outbreak, one of the first problems that had to be dealt with was that both PCP and Kaposi’s sarcoma existed previous to the outbreak; a means had to be devised to separate the new disease from the older ones. Francis recalled that while the definition changed over time it was initially decided that because Kaposi’s sarcoma was a disease of older individuals, only biopsy-confirmed cases, reported in those under sixty years of age, were to be considered as an occurrence of the new disease. Similarly, only those cases of PCP where the individual was free of the underlying conditions traditionally associated with the infection, would be considered as an instance of the new disease (21543-5).

With a working definition established reporting forms were drawn-up and distributed to those in the field. Francis explained that the success of the approach depended on gaining the cooperation of local health officials and practitioners for whom the form represented extra work and few rewards. They were certainly not compelled to help: At the time the disease was not reportable under law. Nonetheless, he said, in the case of this new disease, as with other diseases, when the CDC asked for assistance there was high compliance on the part of those in the field.
Reports began to flow in. Once received an investigator was dispatched to follow them up. Initially these follow-ups were carried out by CDC representatives but as the number of cases increased they came to depend on local individuals to carry out the investigations (21544-5).

Francis recounted how in tracking the outbreak, the CDC also drew on existing resources. One of the most valuable of these turned out to be the dispensing records for pentamidine, an unlicensed drug distributed by the CDC and used almost exclusively for the treatment of PCP. The CDC had been the sole distributor of the drug in the United States since 1967. Dispensing records provided an overview of the historical incidence of PCP infections while in-coming requests for the drug helped identify new cases as they emerged. Cancer registries throughout the United States were also examined in an attempt to establish the incidence of Kaposi's sarcoma prior to 1980 and to track current incidence rates (21549-50).

With an information gathering and research network in place, the CDC rapidly began to compile an enormous amount of information. By November 10, as Edwardh pointed-out, they had documented 159 cases of the disease in the United States.

Francis added that in 40 percent of those cases, the individuals had already died (21552).

Conflicting Hypotheses

Francis told the inquiry that the early information emerging from epidemiological, clinical and laboratory research reinforced the belief, at least amongst CDC experts, that they were looking at a new disease, caused by a viral agent with a pattern of transmission similar to hepatitis B. He also noted that almost from the beginning a link was made between the behaviours of those
affected and the disease. He did allow, however, that a number of competing hypothesis were entertained during the early months and years, especially by those outside of the CDC (21574). Some, for example, felt that amyl or butyl nitrite might cause the illnesses by altering the immune systems of its users while others speculated a toxic contaminant in the nitrites might be causing the outbreak (21576).

Francis told the commission that personally, he did not see support for the nitrite hypotheses in the epidemiological data. First, the outbreak seemed to be concentrated in a few major cities, whereas “poppers” (a term commonly used to refer to the nitrites), were used across the country. If nitrites, or some contaminant in them, was causing the immune suppression, why was the disease not being seen throughout the United States? Second, not all the gay men with AIDS used poppers. The involvement of nitrites became even more problematic, with the identification of the syndrome amongst I.V. drug users in December 1981.

Intravenous drug users were not known to take poppers. The nitrite hypotheses did not provide a link between the groups. With the reports of Haitian and hemophiliac cases in July 1982, the nitrite hypothesis grew even less plausible (21593-94). Laboratory tests also revealed

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12 A short while later Francis pointed to a June 18 1982, edition of the *MMWR* saying it provided important support for the early suppositions. The *MMWR* reported on a cluster of KS and PCP infections amongst male homosexuals in Los Angeles and Orange Counties California. He explained that investigators established a pattern of sexual contact amongst various members of the group and some time later linked them with another group of patients in New York. Ultimately, he said, all of them were linked to the Canadian airline steward, referred to as “patient zero” (21590-3).


14 The disease was first reported amongst Haitians in the United States in the July 9 1982, *MMWR* (Exhibit 549:tab 28.) The following week the *MMWR* announced that PCP had been reported in the cases of three hemophiliacs (Exhibit 549:tab 29). The emergence of a variety of groups at risk for the disease had important implications for research both the terms of the
no causal link between nitrites and the new syndrome. Francis described how they had exposed “some poor rats to nitrites for several months and probably gave them terrible headaches, but nothing else”. Other than the association between the gay “lifestyle” and the use of poppers, the nitrite hypothesis lacked any strong supporting evidence. Despite this, he said, the hypothesis persisted until it was finally laid to rest in a September 9 1983, article in the *MMWR* (21589).

Another popular explanation at the time was the “immunologic overload” hypothesis, based on the notion that repeated exposures to foreign proteins in clotting factors, the “garbage” in street drugs or the introduction of semen into the blood stream during anal intercourse, might eventually cause the immune system to “burn-out”.

The major problem with this theory, according to Francis, was the apparently recent appearance of the disease. Homosexual behaviour has existed for thousands of years yet this devastating form of immune suppression appeared to have arisen only recently. Similarly, he said, the intravenous injection of contaminated street drugs has gone on for decades yet there was no indication in the historical and medical literature of the previous existence of the disease among drug users. Another problem, he pointed out, was the theory’s inability to explain why the transmission of the disease and its incidence. Where gay and IV drug using populations were diverse, and in many instances anonymous, hemophiliacs presented a relatively circumscribed and easily observed group. With the hemophiliacs “you have an entire group to study.” Within months of the disease being reported in the hemophiliac population studies were beginning to report the extent of the disease markers within the population (Francis:21649). Hemophiliacs, however, were frequent users of blood products. It was not until the emergence of transfusion associated cases, which were more likely to be one time treatments, that the moment of infection could be identified and specific suspect donors identified and traced.

When the early hypotheses began fall apart some researchers speculated that nitrites were acting in conjunction with a genetic predisposition to produce the new disease. Most of the investigators at the CDC, however, felt that nitrites use “was really a secondary phenomenon due to sexual contact. That... individuals who had lots of sexual activity would be more likely to use stimulants” (Francis 21589).
outbreak among gay men and intravenous drug users was restricted to specific geographic locales when the behaviours were evident throughout the country. He characterized the theory as "...a new and yet to be described phenomenon..." one which remains undocumented "to this day" (21575).

Some explanations enjoyed wider support than others. When Edward asked about Cytomegalovirus (CMV), for example, Francis acknowledged that many, both inside and outside of the CDC, initially thought CMV was involved in the outbreak. He pointed out that from the first published report of the disease in June 1981, CMV was "mentioned as a possible etiology" (21576). (Early studies indicated that close to 90 percent of those affected by the syndrome were either currently infected with, or had a history of, CMV.)

Francis, however, made it clear that the CMV hypothesis had its sticking points. It had been known for some time -- in fact long before AIDS appeared -- that CMV infection was widespread amongst sexually active individuals, both gay and heterosexual. It remained to be explained, then, why only some of those infected with CMV developed immune suppression. There was also the puzzle of why -- given the history of CMV -- this new disease was appearing only now. Francis suggested that some of those working in the field speculated that either the cytomegalovirus had changed or that it was working in combination with some other agent (21575-6). Even if this was true, he said, it still did not explain why approximately 10 per cent of those with AIDS showed no indication of CMV infection at all (21579). By the summer of 1982, as he recalled, the CMV hypothesis had lost much of its force (21586).

As information continued to accumulate throughout 1982 and 1983 many of the early conjectures grew less plausible. The ever increasing number of medical and scientific experts working in the field of AIDS research, however, were far from agreeing as to what was causing
the disease or what methods might be effective in its prevention. This uncertainty helped fuel resistance within the blood banking sector to the imposition of any new protocols aimed at protecting the blood supply.

A Clash of Opinions: The January 4th 1983, Joint Meeting

This resistance became particularly apparent at the January 4th 1983, meeting in Atlanta. The meeting represented a critical juncture in the early history of AIDS and the blood supply. The meeting had been called by United States Assistant Health Secretary, Edward Brandt with the purpose of formulating recommendations for the prevention of AIDS; the emphasis was on the possible transmission of the disease through blood and blood products (Francis 21783-4). Invitees included representatives from the volunteer and commercial blood banking sectors, pharmaceutical manufactures, the hemophilia and gay communities, hemophilia treaters, the CDC, the FDA and the media.

Francis told the commission that he and his colleagues at the CDC had been somewhat naive going into the meeting; they expected that the information would be presented, a series of preventative methods would be proffered and that the various groups would simply fall in line behind the CDC recommendations. In practice, he said, they found things to be quite different.

Francis recalled there being a big square table at the meeting, with about 40 invitees located around it. At its head sat the CDC representatives. Behind them stood a large screen onto which various slides were projected depicting the history of AIDS, the epidemiology of transfusion and hemophilia associated AIDS, and the benefits of surrogate testing (21823-4). Following the Surrogate testing involved the use of indirect laboratory tests as an indicator of possible risk. For example, the early association between Hepatitis B and AIDS suggested that tests which detected individuals with a history of hepatitis B might be effective in identifying those at risk of
various presentations, a series of what Francis described as “relatively obvious” methodologies for dealing for the problem of AIDS in the blood supply, were tabled. As he explained, the methodologies, “were out on the table for discussion and the meeting was supposed to come to some recommendations. It was quite obvious what the CDC recommendations were going to be, but it’s typical that you want to bring the parties at hand along with you before you make the final recommendations of the group. And... after the meeting, we naively presumed that we would have a summary of what the group recommended along these avenues” (21824).

According to Francis, what followed, was “an absolutely horrible” discussion in which the blood bankers from the volunteer sector resisted the CDC’s proposals. The blood bankers simply claimed that “they did not believe that transfusion associated AIDS from blood itself -- from non-plasma containing material -- had been documented well enough to make such radical recommendations” (21825).

The CDC, in fact, found itself stymied almost at every turn. Francis described the gay community representatives as being resistant to the institution of any measures which would further stigmatize “a group who had already been, in many segments of the population, despised in the first place.” They were against the use of any sort of questioning regarding sexual preference although they did support the use of surrogate tests, a strategy which also had some support within the commercial plasma collection sector. The volunteer blood bankers, however, were steadfast in their opposition to the use of surrogate testing (21824-5).

Francis said that he became so frustrated at the “remarkable resistance to action”, that towards the end of the meeting he began to pound the table asking “‘How many deaths will it take? If you don’t believe five cases, will you believe 10; will you believe 20; will you believe 30?’” carrying the new disease.
The Search for Meaning

Initially, at least, the disagreements amongst the various players in the blood system could be explained as due to the lack of information. With the increasing amount of data which came available in 1982 and 1983, debate began to centre on the significance and meaning of what was being revealed.

At the commission hearings, Mr. Sandy Graham, counsel for the Government of Canada, drew attention to the uncertainty surrounding the meaning of the information emerging in 1982 and 1983. Graham was attempting to deflect Francis' criticism of governmental inaction during the early years of the epidemic. In doing so, he contrasted the views presented in two prestigious medical journals in early 1983 (22076). He pointed to an “Editorial” in the January 13th edition of the *New England Journal of Medicine* which noted the current hemophilia treatment program had been very successful and would be abandoned only with the “greatest reluctance” on the part of physicians and patients alike. The author nevertheless goes on to say that even if the evidence to demand such a radical action is lacking, the time has arrived to consider such a move (22077-8).

Graham then pointed to an article in the April 2, 1983, *Lancet* which argued the inverse. While advocating the maintenance of current surveillance levels it stressed that the link between clotting concentrate and AIDS “must be regarded as not proven” and that the available data did “not constitute a strong argument for a change in treatment policy” (22078-9).

17 While this helped insure his place in the history of the struggle to protect the blood supply it effectively marked the end of Francis’ official involvement in the blood problem. He had become “persona non grata” with the blood bankers.
Francis agreed, there was considerable discussion and debate over the meaning and significance of the rapidly accumulating information and there were a variety of approaches employed in trying to establish what the evidence was saying.

**Conflicting standards**

Some, like the volunteer blood bankers, met the uncertainty by refusing to accept any hypothesis which had not been generated through the appropriate application of scientific methods and which had not satisfied the standards of scientific proof. Until those demands had been met any significant change to standard practice was simply unwarranted on scientific grounds.

They argued there was simply no proof that AIDS was caused by an infectious agent, let alone a virus, never mind it being transmitted through the blood supply. Early research had failed to fulfil Koch's postulates.¹⁸ No specific causal agent had been isolated and identified, nor had any researchers successfully transferred the disease from one host to another.

During his testimony Francis acknowledged that efforts to isolate the virus from infected individuals and transfer it into chimpanzees had been unsuccessful (21723). He denied, however, that this failure was sufficient to warrant inaction on the part of those in charge of the blood system. According to Francis it was common within public health to take action without having

¹⁸ Great advances in bacteriology were made in the latter decades of the 19th century but there were also numerous failures for which there were no shortage of fanciful explanations. To stem the tide of this uncritical work, physician/bacteriologist, Robert Koch (1843-1910), set out his now famous postulates which maintained “that to prove that an infectious agent is the cause of an illness, it is necessary to establish that: 1) The parasite is present in every case of the disease under appropriate circumstances; 2) The parasite should occur in no other disease as a fortuitous and non-pathogenic parasite; 3) The parasite must be isolated from those infected subjects, cultivated in vitro (in pure culture), and induce the disease when introduced into health subjects” (Fujimura and Chou 1994).
satisfied Koch’s postulates. He illustrated his point noting that preventative action had been initiated in the cases of legionaries disease and toxic shock syndrome long before any causal agent had been identified (21730-31).

Besides, Francis felt that the California baby case, reported in the December 1982 MMWR, had satisfied the postulates, “… [H]ere you had a clear case of an at-risk individual, a gay male donating blood, or in this case a portion of the blood, platelets, to a baby who then developed AIDS…” The laboratory experiments may have been unsuccessful but here you had the terms of Koch’s postulates satisfied “in a real life setting” (21762). 19

Many, however, did not accept the California baby case as being a case of AIDS. As Francis pointed out, sceptics argued that an infant’s immune system was immature and this made it difficult to tell whether the observed immune suppression was the result of an infectious disease or the result of congenital defects (21711). 20 Critics of the imputed link between blood, blood products and AIDS could simply ignore the implications of AIDS in children.

Practical experience and its role in understanding

There was a general refusal within the volunteer blood banking sector to accept the interpretations and recommendations of the CDC experts. As far as they were concerned they simply lacked adequate scientific warrant. Many of the insights, however, were later verified and the recommended strategies shown to be effective. The question arose as to how it was that the CDC experts got things right when so many others did not.

19 The California baby case, also known as the Allman case (after the physician treating the infant) became the first published report of transfusion associated AIDS.

20 The problems surrounding the immature immune systems of infants, in fact, led the CDC to exclude such cases from the official definition of AIDS.
According to Francis, experience was key to his and his colleagues early insights. For example, when the Commissioner asked him about his early belief that AIDS was caused by a virus Francis explained that it was not a matter of brilliance that brought him and his associates at the CDC to fix upon a virus as the cause, to deduce its patterns of transmission and to develop a series of effective preventative strategies. Rather, he explained, it was their past experience working with infectious diseases amongst gay men which provided them with a uniquely placed "light pole". Other investigators with different backgrounds were looking for the "keys" under different light poles. As a result there were "multiple hypotheses working in parallel." It just happened to turn out the "keys" were under the CDC's light pole, he said (21559-61).

The following day the Commissioner returned to the question of the divergent points of view which existed at the time. He asked Francis whether it was "... unreasonable for other people to have a different view -- was it not possible that you were far-sighted and they were normal, if I can put it that way, as opposed to your being right and them being backwards" (21728)?

Francis again emphasized the importance of experience saying, "...it is true that we were far-sighted and they were not, and I would not put good and evil, or even right or wrong on this in any way. The difference is, we were experienced and they were not" (21728). He said that the senior level of the CDC group working on AIDS, "had probably seen 200 outbreaks of a variety of different diseases in different countries and different agents, that sort of expertise is what you need to apply to a new disease syndrome, and there should be a great deal of weight given to the expertise" (21729).

Thinking through models and analogies

Throughout his testimony Francis explained that this sort of experience is central to the
investigation of any new disease; “you are always trying to look at [the] occurrence of the disease and fit it into some pattern so at least you get some idea of where to search. And you take all the older diseases and say ‘Is there a pattern of this epidemiology that looks the same?’” (21559-60).

He argued that it was experience which first brought the CDC experts to view the outbreak as significant and serious and that this led them, almost immediately, to see the disease as being caused by a virus. Experience was also central to developing an understanding of the transmission patterns and therefore the identification of those at risk, and it was fundamental to the development of preventive strategies. The key to all of this, according to Francis was the CDC experts’ experience with hepatitis in the gay community.

Francis suggested that those working in the field of infectious diseases, saw gay men as a “bellwether” of new epidemics to come. Experience had taught them that “once diseases got into the gay community they spread very, very effectively, usually from coastal cities into the interior of the United States, and then out. Therefore, the occurrence of any new disease in the gay population was something that we all considered something to watch very carefully” (21551-52).21

The hepatitis analogy

Those at the CDC with experience in the epidemiology of hepatitis B in the homosexual community had been struck by the similarities between it and the new outbreak. Like hepatitis B those at greatest risk of contracting the disease appeared to be homosexuals, “blood sharers”,

21 It had been widely known from the mid 1970’s onward that hepatitis was widespread within the gay community, that up to 90 per cent of gay men tested positive for hepatitis B antibodies. Unlike antigen tests which indicated whether a patient was currently infected with the disease antibody tests also recognized people who had recovered from the disease (Francis:21801).
individuals from developing countries, and the sexual partners of those at risk. And like hepatitis B the new disease appeared to be transmitted through contact with bodily fluids. According to Francis, by July 1982, it was clear that the new outbreak almost mimicked hepatitis B to a ‘T’ (21609). It was not just that the patterns of transmission and the populations at risk were similar, “...they were identical... they were mirror images of each other” (Francis 21751).

The analogy drawn between hepatitis B and AIDS helped give form to and directed much of the early research at the CDC. It also provided the foundation for many of the recommendations and guidelines which were developed in the coming months and years.22

Building Institutional Networks

One of the things that became clear during Francis’s testimony was the enormous number of different realms and areas of expertise involved in the early response to AIDS. The scientists at the CDC knew they had to gain the support and assistance of a wide variety of individuals and institutions if they were going to be able to carry out their research programme and get their recommendations enacted.

Francis recalled how the CDC struggled to enlist the support of a variety of agencies, institutions, groups and individuals world wide while at the same time maintain its scientific integrity and control. He stressed that despite its efforts to enlist a wide range of allies, the CDC tried to remain primarily scientific and for the most part stayed out of politics -- at least formal politics (21523).

He explained that as a result, the CDC had sometimes been relatively weak politically (21523)  

22 The Guidelines for Health Care Workers which appeared in the November 5, 1982 MMWR (Exhibit 549, tab 41) for example, were virtually identical to those recommended for health workers dealing with hepatitis B patients and their specimens.
and that this led to difficulty gaining adequate funding. While Francis expressed the view that a "clear insulation" between science and politics was appropriate and necessary, he was unable to answer how you get the required public health funding without having political support (21529).

During cross-examination, counsel for the Gignac Sutts Group, asked Francis' about the problem of elected officials interfering in the scientific independence of the Public Health Service. He wanted to know how to ensure that when public health recommendations are made by scientific agencies such as the CDC they are followed (21961).

Francis began by making it clear that prior to AIDS, he had not really felt any conflict with elected officials. In the pre-AIDS era “we would make recommendations on a scientific basis and it caused very little ire from the politicians.” The situation was very different with AIDS, he said, particularly after 1985, when the CDC “ended up with clear political conflicts on what messages needed to come out”. He suggested that perhaps what was needed was a body like a “National Board of Health” which could serve as both a director of recommendations and an “insulator from the politicians above.” He acknowledged, however, that this would not overcome the problems involved in budget setting which requires political support (21961-63).

The problems the CDC faced trying to maintain support and control were not restricted to its relations with funding agencies and elected officials. They extended to the CDC’s interactions with the other agencies and institutions involved in the investigation, as well as with social and consumer groups. On occasion these relations were far from collegial.

For example, during cross-examination by Earl Cherniak, counsel for the Red Cross, Francis recalled that there had been “... active resistance to CDC; there was actually efforts to move responsibilities away from CDC to NIH and FDA in order to defuse the spark that CDC was trying to put to this” (22259-60).
Social Alliances

Francis suggested, however, that a more positive relationship existed between the CDC and the gay community. He agreed with Mr. Elliott, counsel for the Canadian AIDS Society (CAS), that during the early days of the outbreak it was important to have input from gays, as well as the trust and support of the gay community leadership (21924). He said that those, like himself, who were familiar with the gay community, knew that there would be political statements and public objections to the exclusion of gay donors, but they remained confident about gaining the cooperation of the gay leadership (21924-25).

He recalled that while the gay community representatives at the January 4th 1983 meeting had voiced strong opposition to the use of screening by direct questioning of donors, he remained convinced that their concerns could be met. He explained that while it was the job of the representatives “to express their political views” they were also “very reasonable” individuals. They were, after all, scientists, he pointed out; one a M.D., the other a Ph.D biologist. (21825-26).

The answer to the dilemma, Francis suggested, rested in avoiding a blanket exclusion of all gay donors and thus not raising a civil rights issue. He believed that allowing gay men who did not have sex with other men to donate would “... get rid of any feeling that you're discriminating against a specific group. But if they’ve had sex, that takes them out of the -- out of the system” (21826).

Francis, also agreed with counsel for the HIV-T group about the importance of involving lay actors in the development of public health policies and initiatives (21976). He pointed out that the CDC had in fact tried to shift some of the responsibility for safeguarding the blood system to consumer groups as well as to the fractionators and blood bankers. The handful of experts at the
CDC, he explained, were already “overwhelmed” by all the different sides of the “mammoth epidemic”. It was felt that these groups had more resources and were thus better able to deal with the problems (21978).

Francis cautioned, however, that the inclusion of lay representatives sometimes impeded CDC attempts to gain broad support for its recommendations. He recalled the CDC representatives having “the wind taken out of their sails” at the July 1982 meeting of the FDA’s Blood Products Advisory Committee when, Mr. Carman, a hemophiliac and representative of the National Hemophilia Foundation (NHF), pleaded with the assembled scientists, “‘Don’t take this [factor concentrate] away from us.’” Francis also expressed concern about involving individuals like Carman, who were in the employ of organizations such as the NHF. The NHF, he said, no doubt “received some money from manufactures” which left “all sorts of potentials for conflict of interest” (21978).

Francis maintained that while it is important to bring lay representatives into the decision-making process it is essential that they not be allowed to “undermine proper public health practices”(21977). The experts have to be very clear in asserting their expertise and be willing to go against the wishes of the consumer groups when necessary. In terms of “statistics and words”, it is essential “to stay at a scientific level and bring the consumer groups to that level…” (21979).

The participation of consumer groups, manufactures and blood bankers was welcome, even necessary, but they had to ‘toe-the-line’ and not hinder the work of the experts. Francis saw them as being there in an educative and enabling capacity: they were to assist and inform CDC scientists. They were welcome to make their concerns known in scientific terms but -- as in the case of the politicians and the blood bankers -- they should have no ability to exert pressure on public health experts (21972). The decisions had to be left to the qualified experts.
Measuring Risk: The ‘One in a Million’ Calculation

In his testimony Francis argued that having to make decisions in the face of limited data and uncertainty was not a new phenomenon. Decision-making in public health is never straightforward. It was common in public health and medicine to take action without having all the information at hand. “We are always taking cutting edge data and making recommendations using that cutting edge information knowing that there are huge pieces of the puzzle that are missing” (21699). Even in cases where there is a fair degree of certainty in terms of the data and a consensus as to its meaning, decision-making is far from straightforward. There are always potentially negative consequences to any action, there are always the costs as well as the benefits to be considered. Francis explained that public health specialists are always “balancing the costs”, comparing the cost of taking action with that of doing nothing -- all the while keeping in mind that “the earlier you get water on the fire the easier it is down the road” (21724-25).

During cross-examination, Cherniak attempted to show that the blood bankers and others, who refused to be goaded into what they believed were precipitous actions behaved reasonably given what was known at the time. They were doing exactly what Francis described as essential; they were trying to balance the costs and benefits. They were trying to balance the theoretical risk of contracting AIDS against “the risk of not using blood products which were necessary for their [patients’] survival or their treatment”. Like many at the time, he said, the blood bankers were relying on the current risk estimations of contracting AIDS through the use of blood and blood products and this was driving their strategies (22241).

Francis agreed. The problem, he said, was that the risk estimates were faulty: in fact they were downright misleading. In early 1983 estimates began to circulate suggesting that the risk of contracting AIDS from a blood transfusion was in the order of “one in a million.” Francis
suggested to the commission that while the “information, per se, was always correct” the supposed risk calculations represented the rate of infection not the risk of being infected. There were 10 million transfusions and 10 cases of AIDS. That was correct, but the denominator did not represent the number of recipients, it represented the number of transfusions. It, therefore, represented the incidence not the risk of contracting the disease. (Transfusion recipients receive an average of three to 4 units of blood). He also pointed out that the calculation took no account of the incubation period which was known to extend for a long period, although how long was unclear. Only those cases which had appeared were measured; the many which were suspected to lie “underneath the surface” were ignored (22241-2).

Cherniak retorted that “it was the best information available at the time and it was widely accepted” (22242).

Francis snapped back, “Wrong. It was the worst information at the time and it was widely accepted.” Those using the figure, “had to know it was wrong... unless they were idiots.” Francis did not believe they were idiots. As far as he was concerned, they knew the figure was wrong, yet they persisted in using it. They intentionally misled the public (22242-44).

Cherniak challenged Francis’ characterization, asking him to show the commission one publication from 1983, 1984 or 1985 suggesting the “one in a million” calculation was wrong (22243). The figure, he argued, had been presented at conferences by eminent scientists, and had appeared in industry newsletters and prestigious peer reviewed journals. It even appeared in Public Health Service publications (22243-4).23

Francis reiterated that while the figures were accurate they represented the incidence, not the

23 A PHS public information document dated April 1984, for example, stated that “...The chance of contracting AIDS through a blood transfusion has been estimated at less than one in a million” (22245).
risk, and using them as a risk estimate was misleading. The figure was intended to reassure people that everything was fine and not to worry about it. As far as the Public Health Service’s role in spreading the misinformation, that too was the fault of the blood bankers. The estimate referred to in the April 1984, PHS document, he explained, had been provided by the American Red Cross. (The offices of the ARC were conveniently located just across the street from the PHS office which produced the pamphlet) (22246).

The blood bankers’ estimates which minimized the risks became part of the cost/benefit analyses and helped fuel resistance to the imposition of what many saw as “costly” and “unproven” safeguards (Francis 21827). Francis suggested, for instance, that Carman was “balancing the benefits without necessarily understanding the risks” when he pleaded that the clotting concentrates not be taken away (21645).

2.2 Taking Action

January 13th Joint Statement and the Matter of Public Education

On January 13, 1983 the American Association of Blood Banks, the American Red Cross, and the Council of Community Blood Centers released its “Joint Statement on Acquired Immune Deficiency Syndrome Related To Transfusion.”24 The statement noted that the possibility of the

24 The Statement presented 7 recommendations for reducing the risk of AIDS transmission through the blood supply including the need for blood banks to: further extend educational campaigns to physicians to reduce the use of blood; prepare for increased cryoprecipitate use; give greater consideration to autologous transfusion; include specific questions to detect possible AIDS or exposure to patients with AIDS in their donor screening; avoid targeting individuals from high risk groups when recruiting donors; increase efforts to limit voluntary blood donation by individuals from groups with a high prevalence of AIDS; evaluate the use of surrogate tests for detecting donations at risk for carrying AIDS.

The communique made it clear that direct or indirect questions regarding donor’s sexual preference were inappropriate, that such an invasion of privacy could not be justified without evidence of clear cut benefits. It also made clear that no recommendation was being made for the
transmission of AIDS through blood, while unproven, has been raised and that this "impression" is reinforced by the 8 confirmed cases of hemophiliacs treated with factor concentrate, by a case of an infant, "and by the fewer than 10 unconfirmed case reports of other transfusion recipients" (Exhibit 554:tab 18).

While acknowledging the possibility of transfusion associated AIDS the January 13th Joint Statement made clear the volunteer sector's reluctance to put forward aggressive and costly safeguards and its intention to rely on more passive strategies. Rather than trying to apply a blanket exclusion of all high risk donors, or asking invasive personal questions or instituting "unproven" laboratory tests, the volunteer blood sector opted for a program of communication and public education.

Francis described the initiative as operating on two levels. The first was largely a public health undertaking involving community outreach programs and mass communication in the media. It was designed to inform the public about the disease, particularly the behaviours associated with its transmission, as well as to provide them with strategies to avoid infection. One of its central aims was to keep high risk donors away from the blood clinics (Francis 21835).

The second level of the program was to take place within the blood clinics themselves. Here pamphlets and questions were to be used to inform donors of the risk groups and behaviours associated with AIDS. The hope was that any individuals at risk for the disease who made it through the clinic door would voluntarily exclude themselves (Francis 21835).

routine implementation of any laboratory screening program for AIDS, although it indicated that various laboratory tests were being evaluated in areas of the country where AIDS was prevalent. It was felt, however, that the implementation of a laboratory screening program for AIDS by the voluntary sector would be inappropriate at this time. In closing, the authors noted: "...that the cause of AIDS is unknown and that evidence for its transmission by blood is still inconclusive... Until more information is available, we believe the measures outlined ... are prudent and appropriate" (Exhibit 554:tab 18).
Francis suggested that from a public health standpoint, these strategies -- the provision of basic information on what the disease was and how to prevent it -- were quite appropriate (21932). When you have “...an epidemic that is transmitted by behaviours such as intravenous drug use and sexual activity, education becomes paramount” (21972). He also noted the importance of educating physicians to reduce the unnecessary use of blood (21862).

The specifics of the January 13th Joint Statement, however, were another matter. While reviewing the document with Edward, Francis referred to it as “incredibly confusing, a nightmarish form of public health education...” (21871). He took particular umbrage with a statement in item 6(b), which claimed that direct questions about their sexual behaviour “no matter how well intentioned, are ineffective in eliminating those [high risk] donors!” (21871). He pointed out that direct questioning had been adopted by some collectors within the commercial sector and that their experience had shown it to be a very effective strategy for reducing the number of at risk donors. He also pointed to his own experience using such questions while working on hepatitis within the gay community. He said that as long as the interviews were conducted in private and carried out in a non-judgmental manner he encountered few problems with their use. In fact, he told the commission, the use of such questions, “was standard practice in public health ... not to mention medicine, where that information was necessary” (21772).

Francis allowed that the practice of questioning donors about their general state of health was important. He argued, however, that such procedures were insufficient to safeguard the blood supply: they were “frosting compared to the ultimate questions which are dealing with risk

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25 For example, Alpha Therapeutics, one of the more aggressive members of the commercial sector, announced at the January 4th, meeting that it had initiated a program (mid-December 1982) to educate its donors and ask them directly if they fell into any of the high risk groups. Francis noted information quickly came forward indicating that during the first few weeks of the program 305 donors had identified themselves and been deferred (21782).
behaviour" (21869). General health questions, he suggested, were of no value in picking up asymptomatic individuals and were extremely difficult to apply effectively in the fast moving and highly public setting of a blood donor clinic (21870).

A few minutes later Edwardh asked about the value of the pamphlets used within the blood clinics. He again agreed with the idea in principle, but added that while pamphlets might be useful as a reference, he "would not rely on such a passive approach" (21892).

Ms. Currie, counsel for the CRC, interrupted at this point saying she would like it noted for the record that while Francis is an expert in infectious diseases and epidemiology he has no expertise in blood banking. She argued that in litigation cases, both in Canada and the United States, his qualifications in blood banking had not been accepted (21892-93).

The Commissioner replied that he was not sure why Currie wanted this noted and that he "would like to hear [Francis] on anything he has an opinion on." He then reminded her and the other participants, "for the fifteenth time," that this was not litigation. Francis's qualifications, he said, did not restrict the kind of evidence the commission would like to hear from him (21893).

Currie responded that she was not objecting to the questioning but that she "wanted it noted that we will be hearing from people who are indeed experts in blood banking" (21893).

Following the exchange both Edwardh and Francis worked together to reinforce his authority to speak on the matter at hand. Edwardh rephrased her question asking whether, based on his "public health background," he believed that the donor education program should have rested solely on the provision of an information pamphlet distributed within the blood donor clinics (21894). Francis replied that "from my experience in public health education, which is part of the process here regardless of whether it is a blood bank or not, this is -- these kinds of documents are useful but they are passive--pamphlets to read are not the finest form of health education"
Comment on the educational effort in Canada

Several times during his appearance Francis was asked to comment specifically on Canadian efforts to inform and educate both blood donors and the wider public of the risks associated with AIDS. After drawing attention to a March 10, 1983 Canadian Red Cross press release and its April 1983 and 1984 donor questionnaires, Edward, for example, asked him to comment on the CRC’s education efforts (21914).

Francis replied that he saw no evidence the CRC was making an effort to adjust to the epidemic, despite the claim in its press release that “it was doing everything possible to protect the health of blood recipients” (21918). He questioned the value of the CRC donor questionnaire introduced in April 1983 noting it provided no indication gay men and IV drug users should not donate and was critical of CRC’s failure to provide their donors with any information about who was at risk until April 1984 (21919).

During cross examination, Mr. Elliott, Counsel for the Canadian AIDS Society (CAS) asked Francis how Canadian officials should have reacted given the information coming from the United States in 1982 and 1983 (21932). Francis pointed out that at the time there really were no therapies available so the focus should mainly have been on providing information and education. He believed that it would have been important to get the information out that the disease was serious, that it was presumably caused by a transmissible agent, and that increased

26 The March 10 1983, Press Release, announced that “although there is no conclusive evidence that AIDS is transmitted through blood or blood products” the CRC was advising “...sexually active homosexual or bisexual men with multiple partners, recent Haitian immigrants, current or past drug abusers and sexual partners of individuals at high risk for AIDS” to refrain from donating for the present time.
Communication Breakdown: The Problem of Contradictory Advice

Among the factors undermining the education efforts both in Canada and the United States was the often contradictory nature of the available educational material. The various actors and institutions involved in the effort not only presented information packages which contradicted each other, they occasionally contradicted their own material -- sometimes within the same article or release.

Edwardh drew Francis' attention to the July 14, 1982 National Hemophilia Association ALERT. The ALERT was written in response to the forthcoming publication of the first report of AIDS in the hemophiliac community (21630). She pointed out that in addition to announcing the possibility that AIDS represents a threat to users of clotting factor the ALERT also contained the reassuring statement that "It is important to note at this time the risk of contracting this immunosuppressive disease is minimal and the CDC is not recommending any change in blood product use" (21632). She asked Francis whether there was sufficient information, at that time, for an epidemiologist to form a "meaningful conclusion" as to "the nature or the level" of the risk AIDS posed to hemophiliacs and whether the characterization of the risk as being "minimal" was appropriate? (21630).

Francis replied that there was sufficient information available and that the past history of hepatitis transmission in factor concentrates "would give one great anxiety about another transmissible agent in this material." He suggested that despite what was being said in the ALERT he would assume "that the risk would be substantial -- unknown but substantial" (21630-
Justice Krever drew attention to another, more troubling aspect of the document -- its odd incongruity -- when he remarked "[b]ut I would have thought an ALERT would be something other than a statement---'Don't worry about it', wouldn't it?" (21631).

Francis agreed there was indeed a “very strange discordance” within the document. This pattern of behaviour, he said, would be common in the coming months with various individuals, institutions and organizations announcing the concerns of the CDC and “then constantly minimizing the potential message” (21631-32).

Francis pointed out that not only was the information in the ALERT confusing, it misrepresented the situation. He said that at the time, the CDC had taken no position on the use of blood products nor was the CDC in the habit of making recommendations to individual treaters of a specific disease unless it was something sexually transmitted or antibiotic resistance or “something very narrow” (21634). He referred to Carman's plea at the July 27th 1982 BPAC meeting as “a somewhat sad example that shows some of the reasons behind the dichotomy of, there is an alert but don't do anything about it” (21633-4).

Withholding information

While Francis' strongest criticisms were aimed at the blood banking industry he acknowledged that the Public Health Service was also responsible for some of the confusion and for perhaps dragging its feet. The Public Health Service's initial use of the term “multiple partners” clearly could not be considered one of its greatest triumphs. On the whole, however, he seemed willing to forgive the PHS its failures.

During her examination Edwardh explored what information was available on transfusion
associated AIDS (TAA) in 1982 and 1983 and who had access to it. In doing so she demonstrated that information about the emergence of TAA cases had circulated informally amongst members of Public Health Service and the blood banking community for many months prior to any formal public announcements of the investigations. In commenting on the situation she observed “one gets the sense in reading these documents that there was a real concern about publishing that information widely…”(21745).27

Francis agreed, there was a hesitancy to publish information about suspected TAA cases, a situation which he noted existed throughout 1983.28 He argued, however, that this reluctance was not without reason; the information was held back, because investigations were on-going. The researchers were trying to assemble a “full picture” of the donors to see if they could identify a high risk donor in each of the cases (21745).

The hesitancy, according to Francis, was not so much about getting the information out to the public as it was about needing to have a high degree of confidence in it. He suggested it was, “clearly something that you would want a lot of confidence in before you put it in the lay press and cause... a potential panic. If you are going to cause a widespread panic you want it to be well-founded” (21745-46). Francis did acknowledge, however, that there was another significant

27 In illustrating the situation Edwardh drew attention to an October 25th, 1982, Memo to File, written by Dr. Katz of the ARC reporting his recent conversation with Dr. Curran of the CDC. Dr. Curran had told him that “Christine Russell, a Washington Post reporter, knows about the two cases being studied (although he said she did not get the information from the CDC)...and that Russell has concluded that the disease is transmissible by blood and further has concluded from interviews that blood bankers have blinkers on.” Katz also noted in the memo that Curran had told him that he attempted to dissuade Russell from writing the story in that way (21693; Exhibit 553:tab 28).

28 A full report of transfusion associated AIDS cases was not published until January 12, 1984 when the New England Journal of Medicine carried a review of the then 18 cases investigated in the previous year and-a-half (21907-8; Exhibit 552:tab 10).
reason for the hesitancy to make the information public. The news of transfusion associated AIDS was somewhat different than the previous information which had emerged concerning the disease itself. TAA, for the first time, generalized the risk of AIDS and it became a “front story in *Time, Newsweek* and the like” (21764).

When asked by Edwardh whether he felt that an appropriate degree of caution had been exercised in providing the public with information on TAA, Francis said that he believed so, but allowed that with all the evidence available at the time indicating the disease was blood transmissible, it could be argued that they held back too long (21747).

It was evident from Francis's testimony that the communication and education program was a complex undertaking, involving a vast array of actors and institutions each with its own priorities and concerns and each engaged in multiple networks of formal and informal communications. It was also clear that the information that circulated through these channels was often confusing, misleading, unequally distributed, and open to a variety of possible interpretations.

Clinical and Laboratory Response

*Clinic: the debate of donor screening*

The blood sector's response to AIDS, did not end with its education and communication initiative. Collection agencies pursued a number of strategies at the clinical and laboratory levels. At the clinic level, for example, commercial plasma collectors conducted physical examinations and questioned donors about risk behaviours. Most volunteer operations, however, confined themselves to providing an information brochure and asking general health questions. Nonetheless, some within the volunteer sector took innovative approaches to donor screening. The New York Blood Center, for example, developed the Confidential Unit Exclusion program
(CUE) which allowed donors who suspected they might be at risk to confidentially designate their blood to be used for research only (Francis 21881).  

Laboratory: the debate over surrogate testing

Similarly, a variety of approaches co-existed at the laboratory level. While many within the commercial sector were receptive to the idea of surrogate testing, most on the volunteer side shunned its use, questioning the need for and the value of such interventions, in the not-for-profit setting. Some within the volunteer sector, however, did adopt these “unproven” and “costly” measures. The Stanford Medical Center introduced a sophisticated and expensive test to measure T-cell ratios in the summer of 1983 (21899; Volume 555:Tab 45) while the following spring San Francisco's Irwin Memorial Blood Bank began using the hepatitis B-core test (22149).

The use of surrogate testing had been an issue of debate within the blood collection and manufacturing sectors for some time. Investigations such as the TTV study which began in the late 1970's suggested that surrogate tests could significantly reduce the incidence of non-A/non-B (NANB) hepatitis transmission in blood and blood products. The mandatory use of such tests, however, met with strong opposition and it was not until 1986 that an industry wide program of surrogate testing for NANB hepatitis was established in the United States.  

The Confidential Unit Exclusion programme (CUE), one of the more innovative approaches to the problem of screening out at risk donors, was initiated Dr. Pyndyck at the New York Blood Center in February 1983. The CUE programme provided donors with a form in which they checked off a box indicating whether their blood was to be used for transfusion or research. This allowed donors who might be at risk to confidentially exclude their blood from the donor pool without drawing attention to themselves.

Canada chose not to follow the American lead. Canadian officials opted instead to study the situation further thus forestalling the use of surrogate testing until they became unnecessary with the introduction of the hepatitis C antibody test in the early 1990's. Researchers in the United States occasionally referred to the study as “Canada's gift” because once surrogate testing had

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29 The Confidential Unit Exclusion programme (CUE), one of the more innovative approaches to the problem of screening out at risk donors, was initiated Dr. Pyndyck at the New York Blood Center in February 1983. The CUE programme provided donors with a form in which they checked off a box indicating whether their blood was to be used for transfusion or research. This allowed donors who might be at risk to confidentially exclude their blood from the donor pool without drawing attention to themselves.

30 Canada chose not to follow the American lead. Canadian officials opted instead to study the situation further thus forestalling the use of surrogate testing until they became unnecessary with the introduction of the hepatitis C antibody test in the early 1990's. Researchers in the United States occasionally referred to the study as “Canada's gift” because once surrogate testing had
The suggestion that surrogate testing could reduce the risk of AIDS transmission met similar opposition. Francis recalled the blood bankers' giving a cool reception to the evidence presented by Dr. Tom Spira at the January 4th meeting, suggesting that the use of surrogate tests could reduce the transmission of AIDS in blood by as much as 80 percent or more (21799-800).

Francis said they refused to endorse the use of such tests in the volunteer sector, arguing that the blood transmissibility of AIDS had not been proven nor had the effectiveness of the proposed tests. The costs -- especially in terms of lost donors -- were simply too great, the benefits too uncertain, to support such radical interventions. The blood bankers wanted scientific proof of their value before they would endorse the tests.

Francis, on the other hand, believed that there was sufficient evidence to warrant the use of at least two broad groups of tests -- those which focused on lymphocytes (absolute lymphocyte counts, T-cell ratios, and immune complex tests) and those which indicated a donor's history of hepatitis B infection (hepatitis B core (HBC) and hepatitis B surface (HBS) antibody tests.) All of these tests appeared to be sensitive enough to pick-up a significant proportion of the “at risk donors” while at the same time specific enough to be practicable, that is to say -- from the CDC's perspective, at least -- they did not generate a prohibitive number of “false positives” (Francis 21803).

Francis told the commission that he would have liked to have seen a combination of tests employed, perhaps an absolute lymphocyte count and the HBC antibody test although he would have been happy to see any one of them instituted. He admitted that some of tests -- the measurement of T-cell ratios, for example -- were complicated, expensive and for most part had been introduced in the U.S. it was considered unethical to give recipients untested blood. It was therefore impossible for American researchers to carry out a double blind, prospective study to determine the actual value of the surrogate tests (22001).
impractical in the context of large scale blood collection. A few of the tests, however -- the absolute lymphocyte counts as well as both hepatitis surface and core antibody tests -- were easy to do and relatively inexpensive (21804-5).31

Besides, he said, the hepatitis test fit with already existing blood banking policy which stipulated that if you had hepatitis in the past you could not donate blood. The difference was that rather than relying on the donor's memory or knowledge of past infection “... you were actually asking the blood to answer the question of whether you have a history of hepatitis...” (21808).32

Francis told the inquiry that the blood bankers remained unconvinced. As far as they were concerned, the transmission of AIDS by blood remained unproven and the value of surrogate testing was yet to be established. They argued that more study was required before any action could be taken although, as he pointed out, in the January 13th Joint Statement the blood bankers agreed to study the effectiveness and feasibility of the proposed tests.33

In his cross-examination Cherniak noted it was not just blood bankers who resisted the wide-scale imposition of surrogate testing. The FDA had serious reservations about the use of such tests, believing, that in some cases, they might result in a more dangerous, rather than a safer

31 Francis estimated that a combination of hepatitis B-core and an absolute lymphocyte count would increase the cost of a unit of blood by less than $10.00 and result in the elimination of between 5 to 10 per cent of donors (21817).

32 The hepatitis antibody tests had the additional advantage, Francis suggested, of reducing the number of NANB infections by around 30 per cent. Given that somewhere around 7 percent of recipients contracted post transfusion NANB hepatitis this would represent a huge decrease in the number of infections (21808).

33 According to Francis, the studies, which were to be conducted by the blood bankers at clinics in the three 'hot spots' in the United States, in reality amounted to nothing more than a few “feeble” attempts to “scientifically evaluate” the tests. The months which followed saw no peer reviewed research published on the matter. In fact, when Irwin Memorial Blood Bank instituted hepatitis B-core testing more than a year later they used Spira's data to support the initiative (21874-5).
Cherniak also argued that there were great differences between what PHS branches such as the CDC were recommending and what its sister organizations within the Service were actually doing. He showed that in the period 1983 to 1985, for example, the blood bank at the NIH Medical Center in Bethesda Maryland neither conducted surrogate testing nor did it question donors about their sexual orientation (22167-69). Not only that, he suggested, opinion within the CDC was in fact divided. He drew Francis' attention to a transcript of Curran's testimony at a Congressional hearing in December 1990. Cherniak noted that in his testimony Curran stated that he felt a "uniform national policy" on the implementation of surrogate testing would have been unmanageable and unwise at the time.

Francis replied that this was totally at odds with what he believed Curran's position was at the time and as Cherniak had provided only one page of the transcript, it was impossible to determine exactly what Curran had indeed said in his testimony (22146-7).

A short while later Cherniak asked Francis to turn to the transcript of an August 1983 Congressional hearing which both Dr. William Foege, Director of the CDC, and Dr. William Brandt, Assistant Secretary of Health attended. At the hearing Brandt testified that he thought the current measures, recommending that members of groups at risk not donate, would reduce the risk of AIDS. Cherniak went on to point out Brandt assured the Hearing that, "At present the risk of acquiring AIDS through a blood transfusion appears to be extremely small" (22171-2).

Francis agreed with Brandt's assessment: it was assumed that the measures adopted would

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He pointed out, for example, that in 1983, FDA representatives concerned over a number of hepatitis transmissions associated coagulating concentrates manufactured from plasma screened for hepatitis B-core, had tried to dissuade manufacturers from using such tests. It was believed that in screening out donors with a history of hepatitis B they also removed antibodies which could neutralize the HBV (22164-5).
reduce the risk which, at the time was seen to be relatively small (22172-3).

Cherniak directed him to a statement which Dr. Quiddan, of the FDA, made during Brandt's presentation. Quiddan suggested that while various possible surrogate tests had been identified and were under study, none were without their "shortcomings." Cherniak suggested that if Foege or anyone else at the hearing had thought there should have been a surrogate test put in place, this would have been the time for them to speak out (22176-7).

Francis replied that the CDC had recommended that surrogate testing be put in place, but the compromise had been to study the effectiveness of the tests instead (22177).

Again Cherniak directed him to the transcript, this time to Brandt's closing remarks, in which he said that of the six proposed surrogate tests that had been evaluated to date, all were non-specific; none of the proposed tests were useful. Surely with Foege sitting right there, if the CDC supported a recommendation for surrogate testing he would have spoken up and said Brandt is wrong, suggested Cherniak (22178-80).

Francis responded with a question. If Cherniak was in that position, would he have spoken up in front of a Congressional Hearing and said his boss was wrong (22181)?

Recommendation Not Regulation.

While Francis was critical of many of the early initiatives to reduce the risk of AIDS he did not see them all as failures. One of the most successful endeavours came in the form of the widely distributed guidelines for Health Care Workers published in the November 5th 1982, *MMWR*. 35

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35 Entitled "Acquired Immune Deficiency Syndrome (AIDS): Precautions for Clinical and Laboratory Staffs" the November 5th guidelines suggested that while "the etiology of the underlying immune deficiencies seen in AIDS cases is unknown..." it is possible "that a
Francis described the guidelines as “proactive public health at its best”. He pointed out that at the time no transmission had occurred in a setting such as a hospital, yet an aggressive and expensive set of recommendations were made and a collaborative effort was launched to minimize the risk of infection amongst health care workers (21700).

Interestingly, where these precautions had often been neglected by health care workers when dealing with hepatitis risks they were closely adhered to when dealing with AIDS patients and their specimens. Francis explained, that those involved in the treatment of AIDS patients had been provided with “a certain direct visual educational stimulus” and were acutely aware of the devastating effects of the disease. They thus needed little encouragement to adopt the recommended precautionary measures. “This disease scared all of us who were involved in it” (21701). Francis stressed the importance of seeing the effects of the disease again when he lamented over the failure of the CDC experts to adequately communicate the seriousness of the problem. He suggested that perhaps if they had taken their sceptical colleagues to the clinics and let them see the devastating effects of the disease it might have got the message across (21729).

Overall, Francis believed that the recommendation route was a reasonable path to follow. Recommendations such as the guidelines for health-care workers served as important instruments of communication and education: they also became powerful devices for stimulating action and gaining compliance. In many ways the recommendation route was actually preferable to ruling by regulation, particularly when, as Francis indicated, the FDA, the agency responsible for establishing and enforcing regulations in the blood banking realm, seemed strangely unwilling to

transmissible agent may be involved.” It suggested that because the distribution of AIDS and its modes of transmission resembled that of hepatitis B it was “prudent for hospital personnel to use the same precautions when caring for patients with AIDS as those used for patients with hepatitis infection, in which blood and body fluids likely to have been contaminated with blood are considered infective” (Exhibit 549:tab 43).
The issue of the relative dearth of regulatory action arose when Edwardh asked Francis to clarify a statement reputedly made by Dr. Donahue, head of the Blood and Blood Products division of the FDA at a December 3rd & 4th 1982 Blood Products Advisory Committee meeting. Donahue was quoted in the December 10 1982, *Council of Community Blood Banks Newsletter*, as having said at the meeting that the matter of donor screening “...is not subject to responsible regulatory action. I think the blood banks must look at the question remembering their responsibility for the blood supply and their basic social responsibility” (21756).

When asked by Edwardh whether he could help the commission understand the thinking behind this statement, Francis said he could not. He knew of nothing which would prevent the FDA from regulating donor screening. It was their role to do so and they had done so in the past - hepatitis being a case in point (21757). He speculated that being a blood banker and having only recently moved over to the regulatory side Donahue had perhaps not “shifted his hat” from the responsibilities of a blood banker to those of a regulator (21758).

Francis related how the regulator's intention not to interfere with the operation of the volunteer side of the blood industry was made clear at the next BPAC meeting when the discussion turned to surrogate testing. At the meeting Donahue made a sharp distinction between blood and plasma; a distinction which “made no sense” to Francis (21759). The volunteer blood bankers believed strongly in the need to distinguish the volunteer from the paid sector. Francis for example, recalled encountering little resistance to the idea that AIDS was transmitted through commercial plasma at the January 4th 1983 meeting. The opposition came from the blood

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36 The Blood and Blood Products Division, part of the Office of Biologics which was in turn part of the FDA, was the agency directly responsible for regulating blood and blood products in the United States.
bankers in the volunteer sector, who said, "...well, that's the commercial. They can transmit
disease but certainly our whole blood does not" (21819).

Francis recounted how the blood bankers simply would not acknowledge, at least not publicly,
that "their" donors could carry the disease. Their attitude, he said, was that the commercial
plasma donors carried the disease, they were "dirty". Volunteer donors were different, they were
"clean" (21828).

The FDA's reluctance to regulate the volunteer sector came into question again the following
day when counsel for the HIV-T group, asked why the FDA did not support the CDC
recommendations to institute surrogate testing in early 1983. "Was it just a question of who was
in the government, or might there have been other pressures on the government in terms of the
industry" (219754-5)?

Francis responded by pointing to a 20/20 interview in which Donahue himself had suggested
that too "clubby" a relationship existed between the blood bankers and regulators (21975).

Exploring the issue further counsel asked whether, from a public health standpoint, the
movement of personnel between regulatory agencies and industry, which he had described
earlier, was appropriate.

He said he thought it was, explaining, that you need regulators who have some expertise in
blood banking. He clarified his point saying that while he felt it appropriate to have movement
between the realms, he believed it is necessary to ensure the individual has clearly changed hats
once he or she has moved to a different desk (21975).

While critical of Donahue's reluctance to take more forceful action, Francis believed it
reasonable to try to get compliance from the volunteer sector without resorting to regulation.
When you are in midst of an epidemic, he suggested, the best way to get immediate action is
through “voluntary intervention”. That way, he explained, you avoid “going through all of the officialdom” (21778-79).

The Demand for Prudence: The Demand for Proof

Many within the blood system were reluctant to take potentially costly steps, when it had not been proven, scientifically, that AIDS was blood-borne, or that the proposed safeguards would effectively reduce the risk of transmission. At the same time there were those, like Francis, who were convinced there was sufficient evidence that a serious disease was “coming down the track”. Even if the final proof was not available, prudence demanded immediate action. “the fire was in the basement and was going in ... the gas mains” (Francis: 21725). Immediate action was essential if disaster was to be averted.

These two radically different orientations toward the appropriate way to proceed -- expressed in struggle between those advocating prudence and those demanding proof -- marked the early history of the response to AIDS in the blood supply. It was not surprising therefore, that in investigating that history the witnesses should find themselves faced with the question of how to balance the need to act prudently against the demand for scientific proof and rigour.

Francis argued that while a lack of scientific proof is frequently cited in defense of inaction, it is not an acceptable response to the threats which emerge in the public health sphere; inaction kills (21699). He used the efforts of the 19th century physician Dr. Snow as an example of the type of action required in public health.

During the 1854 cholera epidemic in London, Snow identified a water pump in Broad Street as a source of contamination and removed its handle, disabling it. Francis described how Snow carried out an investigation which led him to identify the pump as the source of the infection.
While Snow did not have proof the water contained bacteria, nor proof that cholera was even caused by bacteria, he took the handle off the pump. This action greatly inconvenienced local residents who used the pump -- but, as Francis explained, it brought about an end to the outbreak (21699-700).37

Francis likened the situation which confronted Snow as "absolutely typical" of the state of affairs in the public health field today; you often have to react in the face of imperfect information and uncertainty.38 That, he suggested, is exactly what the CDC had done in its early response to AIDS. Taking the case of the November 1982 Guidelines for Health Care Workers, he explained that you have the presumption that an infectious agent is responsible for the disease and that it is transmissible through blood. You also assume -- based on observations of hemophiliacs and IV drug users -- that it is transmissible through accidental needle punctures. You bring this together with your experience and see that the pattern is very similar to that of hepatitis B and from there you make the next leap forward, you make recommendations for prevention without having all the information (21700).

37 Francis's interpretation of the importance of the removal of the handle is open to debate. Even Snow admitted that his actions likely had little direct practical benefit as the disease was already in abeyance by the time he shut down the Broad Street pump. The symbolic importance of Snow's actions and the publicity which his investigations drew should not be underestimated, however; they led to the passage of a series of bills forcing the overhauling of London's fetid water supply and sewage systems (Wills 1996:113-115). Snow's reaction, has become an exemplar in the field of public health, a model to guide behaviour. (For a discussion of the role of exemplars in scientific practice see T.S Kuhn 1962/1970.)

38 During cross-examination Cherniak suggested that the analogy Francis was making between the Broad Street pump and the situation blood bankers were facing was inappropriate. When Snow removed the handle for the pump he inconvenienced people, but they could go down the road to another pump. There was no comparable substitute if you took factor concentrates off the market. "It would mean a drastic change in lifestyle...". Francis responded, that on balancing the risks and benefits, he believed the risks warranted going to the more inconvenient (and less effective) cryoprecipitate (22200-1).
A short while later the Commissioner asked Francis; “From the point of view of public health policy and epidemiology, at what stage when you see an impending epidemic, an impending disaster occurring, and you don't yet know how to stop it, because you don't know its cause, at what stage does one -- should one take action? Only after you have 99 per cent proof of the cause or earlier, and if so, if earlier how much earlier” (21724)?

Francis answered that you need to balance the level of confidence you have in your knowledge, with the seriousness of the situation, the potential impact of your recommendations and the costs involved (21724). He also said that you never forget that it is easier to intervene in an outbreak and make “a false positive reaction” than to wait and try to put the fire out once the situation has “exploded” (21725).

Francis admitted that there was always the possibility of getting burned -- at least politically -- by acting early, as had happened with the swine flu inoculation program in the mid 1970's.\(^{39}\) In public health, he said, it is better to move ahead aggressively and have a few “false positives” (21726). He stressed the need in public health to overreact, rather than under-react noting that: “Looking back at it we were far too-- far too conservative on our reaction to AIDS” given the information at the time (21727).

The Commissioner replied that “it is easy to say that looking back on it: “The question is what is occurring? At what stage would it be reasonable -- unreasonable not to take action” (21728).

This was not the first time that question had been broached at the inquiry nor would it be the last. Time and time again the witnesses were asked, at what point does the need to act prudently

\(^{39}\) In 1976 a potentially deadly outbreak of swine flu appeared to be on the horizon. CDC officials, mindful of the great 1918-19 influenza pandemic, recommended a massive public inoculation program. The outbreak never materialized but tragically a number of individuals were injured by the vaccine. The CDC was criticized for its overreaction, criticism which Francis felt was unjustified and inappropriate (21726).
outweigh the demand for scientific proof? When is the confidence level in one's knowledge sufficient to warrant action, at 95 per cent? at 99 per cent? At what point is it no longer possible to justify inaction?

Summary

During his appearance Francis offered a provocative view of science and the relationship of science and public health policy. A number of the witnesses who followed took particular umbrage with his interpretation of the history of the blood tragedy, and his prescription of act first, seek proof later, when dealing with potentially significant problems in the realm of public health.

Francis presented an almost mythic portrait of the scientist, a heroic character battling the forces of darkness and ignorance, locked in a desperate struggle to reveal the true state of nature. His use of the metaphor of the light poles was revealing. Nature is out there waiting to be discovered. So long as the light of inquiry is directed to the right spot, nature will be revealed.

According to Francis the primary source and orientation of this light comes from the practical and educational experience of the investigator. In the case of AIDS, for example, only those -- such as himself and his colleagues at the CDC -- with very particular experiences and education in the areas of public health, infectious diseases, and epidemiology were truly capable of understanding and speaking to the problem of AIDS in the blood supply. Only they had the education and experience necessary.

Francis recounted how he and his colleagues found themselves not only facing the problem of discovering the pathology and etiology of the disease, they had to get their voices heard above the cacophony of ill-informed and often misleading prognostications and recommendations made by
the pretenders to expertise such as the blood bankers. If the plans for action of those who were
truly capable of understanding and dealing with the problem were to prevail, allies would have to
be enlisted -- scientists and scientific institutions from around the world recruited and controlled,
standards of reporting, case definitions, and practice guidelines created, jurisdictional boundaries
-- spheres of authority and influence -- fought for and won, and channels of communication
established and maintained.

There was also the problem of finding the necessary resources to manage all of this. Pleas for
funding met with indifference from the United States Federal administration. At the same time
the nature of the disease, the way it was transmitted, the groups it affected, and its high fatality
rate prompted politicians and interest groups to interfere in matters which in Francis's view
should have been left in the hands of those with the necessary experience and skills. All the
while Francis and his associates had to keep in mind the possibility of unleashing a public panic.

Francis described the overall response to the contamination of the blood supply as woefully
inadequate. He argued that it was not, as many wish to claim, the lack of scientific certainty
which thwarted attempts to respond to the disease; it was short-sightedness, denial, complacency,
ignorance, conservatism, political indifference, personal and institutional interests, and public
fear. He explained, that the scientific uncertainty which existed at time was not unusual; if
anything, it was commonplace. Whenever it comes to applying science, especially in the public
health sphere, there will be gaps in the structure of knowledge and points of uncertainty. He
pointed to cholera, legionnaires disease and toxic shock syndrome as examples of the way newly
emerging and potentially deadly situations should be dealt with by public health officers. The
authorities did not wait for a causal agent to be identified, they acted immediately, removing
pump handles, closing hotels and taking products off the market. You shoot first and look for
proof later: you take the cutting edge information and apply it, knowing that while there are gaps in your knowledge, a fire is easier to put out while it is still in the "basement"; hesitation equals death.

He argued that if such tragedies are to be avoided in the future one of the most important things is to ensure that the management of such problems be left in the hands of qualified experts; all others, non experts, scientist and lay-person alike, have to be kept from interfering with the expert formulation of public health policy.

While arguing that science, both in its generation and application, must be insulated from the corrupting influences of outside non-expert forces, Francis did see a role for outsiders in the process. The lay public, for example, had an important role to play as informants. They must not, however, be allowed to get in the way of the experts as they carry out their work. The public must be elevated to the level of science; science must never be brought down to the level of the public.

While describing the lay-public as a potential threat to good public health practice, experience had taught him this was a manageable threat. Gaining compliance was essential. Communication, empathy and understanding were key to successful interactions between the scientific and public spheres.

Likewise, interference from the political realm must be minimized if similar tragedies are to be avoided. This, as Francis admitted, is not an easy problem to resolve. Scientific research is expensive, it requires significant funding and that, inevitably, brings science and scientific experts into contact with the contaminating influence of politics. While unhappy with the situation, he appeared to recognize that the fortunes of science were bound together with politics. The only solution he had for coordinating interaction between the two spheres rested in the
establishment of some hypothetical agency which might act as a buffer between politics and science.

In the end, Francis' greatest hope for the future lay in ensuring the presence of more heroic figures like Snow (and himself), scientists with the foresight to see or at least dimly perceive the truth hiding in the shadows and the courage to act upon their vision.
3.1 Confronting AIDS

Introduction

The next witness to appear before the commission was Dr. Thomas Zuck. Zuck's involvement with AIDS was less direct than Francis's, at least in the early years of the epidemic. As a result his authority to speak on some of the early issues was questioned during cross-examination. While less directly involved during the critical early phase of the outbreak, he was, nonetheless, an active member of the volunteer blood banking community, and in 1985 became Director of the Blood and Blood Products Division of the FDA, the agency responsible for regulating the blood industry in the United States. Therefore he brought a different perspective to many of the issues addressed in Francis's testimony.

Where Francis presented himself as an activist, willing to challenge the status-quo, Zuck adopted a persona of reasonableness; 'a man of infinite reason'. He was on the stand for three days. The first day and part of the following morning was devoted to Stephenson's examination in-chief. The interaction between Stephenson, senior counsel for the commission, and Zuck was cordial, frequently assuming a conversational character. As in the case of Francis, the examination was inquisitorial rather than adversarial in form. Stephenson's questions were

1 Before beginning her cross-examination, for example, Ms. Podrebarac, counsel for the Canadian Hemophilia Society, observed: Zuck was not involved on an operational level in the blood banking community; his name is neither prominent in the scientific literature of the time nor the popular literature dealing with the period; and he had not attended a number of the key meetings and conferences addressed in Francis's testimony (22728).

Zuck accepted Podrebarac's synopsis but added that while he was not operationally active within a blood centre during the early years of the epidemic, he was involved in the governance of Irwin Memorial Blood Bank in San Francisco and the Editor in Chief of the journal Transfusion (22729).
relatively open and included many how and why queries. Zuck's answers on a number of occasions extended to a minute or more in length. Throughout the examination Zuck enjoyed a certain degree of control, on many occasions directing the discussion and suggesting issues which needed to be addressed.

An experienced and skilful witness, Zuck had appeared in a number of litigation cases over 'tainted blood' in the United States. He described, himself, as a “lapsed lawyer” having earned a law degree from Yale in 1958 (22269).2

Stephenson completed his questioning by mid-morning of the second day. The remaining time was given over to cross-examination. Interactions during cross-examination took on a more adversarial character. The questions asked were more restrictive, the answers somewhat shorter.

Curriculum Vitae

Stephenson, began with a review of the witness's Curriculum Vitae. He noted that after receiving a medical degree from Hahnemann Medical College in 1963, Zuck interned for a year at the Tripler United States Army Hospital in Honolulu3 and then did a residency at Fitzsimmons Army Medical Centre in Denver, Colorado from 1964 to 1968. (22269-70).

Continuing, Stephenson noted that in 1968 Zuck assumed the role of Medical Director of the Blood Bank and Coagulation Laboratory and Staff Pathologist at Fitzsimmons;4 in 1972 he

2 While officially “inactive” in terms of legal practice Zuck identified himself as a lawyer as well as a scientist in his testimony.

3 Zuck was a member of the United States Army from 1963 to 1987; he retired with the rank of full colonel.

4 Zuck explained the link between blood banking and pathology. Pathology, he said, included the subdisplines of immunohematology (blood banking and haematology) chemistry, microbiology, surgical pathology “and the like” (22270).
became the Assistant Chief of the Department of Pathology; and in 1974 became Chief of the Department of Surgery at the Letterman Army Institute of Research at the Presidio in San Francisco.

While at Letterman, he said, Zuck was involved in research on the treatment of combat casualties, focusing on resuscitation through the use of transfusions and blood substitutes. He told the commission that Zuck held that position until 1977 when he became Chief of the Department of Pathology at Walter Reed Army Medical Centre in Washington DC. He remained there till 1980 when he assumed the roles of Deputy Director of the Army Institute of Pathology and Consultant in Pathology to the Surgeon General of the United States Army.

Stephenson said, he returned to the Letterman Institute of Research in 1982 to become its Commander, remaining there until 1985 when he was loaned to the FDA where he served as Director of Blood and Blood Products. After retiring from military service in 1987 he assumed positions as Director of the Hoxworth Blood Centre at the University of Cincinnati Medical Centre and Professor of Transfusion Medicine at the University of Cincinnati. At that time of his appearance he continued to hold both positions (22271-74).  

Stephenson then highlighted a few of Zuck's affiliations pointing out his long association with the learned journal, *Transfusion*, where, among other things, he had been Editor in Chief from 1982 to 1987. He also indicated that Zuck served as referee for a number of journals including

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5 When Mr. Selnes, counsel for Canadian Hemophiliacs Infected with HIV, later asked him how he became a blood banker Zuck replied; “By accident. And I think most my age got into it by accident. The transfusion service was usually in the laboratory and was overseen by pathologists and during my training, I ended up at a blood bank and developed some interest in it because it was clinically a little more close to the patient than average pathology. And somehow it just --- that is the way my career went, really by accident. There were no fellowships, no training, no conscious decisions back in 1963/1964. Subsequently, there were formal training programs, fellowships. People made a conscious effort to enter the field” (28845).
Science, the New England Journal of Medicine, the Annals of Internal Medicine, Vox Sanguinis and the Journal of Acquired Immune Deficiency Syndrome (22275-76).

In addressing Zuck's associations with blood banking organizations, Stephenson noted that: from 1971 to 1982 he had been an Inspection and Accreditation Inspector with the American Association of Blood Banks (AABB); from 1978 to 1979 he was President Elect of the AABB; between 1979 and 1980 he served as President of the AABB; and from 1987 to present, he had been a member of the Executive Committee of the Council of Community Blood Centres (CCBC) (22276-77).

The American Volunteer Blood System

Having reviewed Zuck's credentials, experience, and affiliations, Stephenson turned his attention to the structure and organization of the volunteer blood system in the United States.²

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² The American Association of Blood Banks (AABB) is a not-for-profit trade association consisting of approximately 8,000 individual members and 2,500 institutional members (22289). It functions as an inspection, accreditation and standard setting organization. Zuck explained that in order to train laboratory technologists a blood centre must be accredited by the AABB. The AABB's "death grip" on accreditation was the "hook", the means of getting the volunteer blood banks to comply with the AABB inspections. "In order for you to have a blood bank training program, a specialist in blood banking -- in order for you to engage in certain activities which the technologist(s) find rewarding, such as reference laboratories" you need accreditation from the agency. The AABB controls the gateway into the profession. There is no other avenue of accreditation into the profession (Zuck 22758). "Member facilities of the AABB collect virtually all of the nation's blood supply and transfuse more than 80 percent" (Leveton 1995:36).

³ The CCBC is a trade organization representing that vast majority of non-American Red Cross (ARC), not for profit community blood centres. The focus of the Council is on financial management, donor recruitment, supply issues, outdating, bulk purchasing and in ensuring a "captive insurance company for liability insurance for victims of transfusions" (Zuck 22328).

⁴ A popular misconception in the 1980's amongst medical experts and the lay public -- one that still persists today -- was that the Canadian system was based on volunteers while the American system relied on paid donors. Based on the understanding that donated blood was less likely to carry infection, the Canadian blood supply was considered to be safer than that south of
Zuck described the volunteer sub-system as being "rather like Gaul," in that "it has been divided into three parts." The first part, the blood centre element is dominated by the American Red Cross which collects approximately 50 per cent of the blood in the United States. The second part, consists of free standing, non-Red Cross Blood centres, referred to as community blood centres. They are responsible for collecting about 40 percent of the America blood supply. The third part of "Gaul", is made up of hospitals which collect at least a portion of the blood they use; they account for the final 10 percent of the collections. Zuck was careful to stipulate that while some hospitals, like some Community Centres, operate on a for-profit basis, that does not necessarily mean they pay their donors (22289-90).

Stephenson returned to the question of renumerated donation a short while later, asking whether there were still pockets in the United States where blood donors were paid (22308-309).

Zuck replied that there may be a few, private, for-profit blood banks in the "backwoods" which pay their donors, but that as far as he knew, paid donors were restricted to a second sub-system, the commercial plasma sector (22309). The commercial sector, he said, is made up of a

the border. Canadian blood was better. The actual situation was somewhat more complicated. In the United States whole blood collection, in the 1980's as today, was almost entirely volunteer based. Much of the plasma used in the manufacture of 'blood products' in the United States, however, was derived through commercial collections: Canadian plasma collections were strictly volunteer. Canada, however, was not self sufficient in plasma; only about half of Canadian needs for plasma products such as clotting factors were derived from Canadian source material. The remainder was purchased, by and large, from U.S. commercial sources. These issues are of some importance as the witnesses' accounts demonstrate. The distinction between paid and volunteer donors became a critical factor in decision-making in the early 1980's. Their accounts also show the degree to which this distinction was warranted, continues to be a matter of debate and that views remain divided in terms of the propriety of its current use.

9 The community blood centres collect approximately 40 per cent of the whole blood supply in the United States and operate under a variety of corporate organizations, most being not-for-profit establishments. These include organizations which collect as little as 10 to 15 thousand units of blood a year to those which collect up to 750 thousand units.
variety of organizations. These range from large scale corporate multilocal centres owned by one of the fractionators to small-scale operations consisting of a single free-standing collection centre which sells its plasma (referred to as “source” plasma in the industry) either to one of the fractionators or to a broker.

Brokers, Zuck explained, buy up plasma from the free standing centres and broker it “the same way you would... broker strawberries or bananas for something else” (22312). Zuck pointed out that plasma “recovered” from volunteer whole blood donations was also often shipped to brokers and that this provided an important source of income for the volunteer collectors. The brokers pass the plasma on to a fractionator or another customer for a fee (22316). Whether the product it is sold on the spot market or through a contractual agreement, its price is set through negotiation and varies depending on how tough the market is at the time. As Zuck explained, “... this sounds a lot like you are selling ‘pork bellies’ and I don’t mean it to be that way, but...that’s the way it is” (22324-25).

The Commissioner drew attention to Zuck’s use of the term fee rather than price. Did the use of the term have anything to do with the question of avoiding product liability, he inquired? “What is being sold I take it in your interpretation is not a product ...but is more like a service” (22318)?

Zuck agreed, the term is used as part of a legal fiction known as the Blood Shield Statutes. The Statutes, he explained, are in effect in 48 of the 50 States and help protect those who are involved in providing blood and blood components from strict liability by defining them as

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10 During. In doing so he quipped; “People don’t like that analogy with blood. There is something cross-examination Zuck again referred to the trade in blood and blood products using the example of ‘pork bellies’ being unpleasant about relating it ‘to pork bellies’. But the market [in blood] works the same way. Although, I don’t know of any futures in blood” (22708).
services rather than products. By defining them as services "... one can avoid strict liability doctrines" (22319).  

AIDS and Institutional Relationships

After exploring the structure and organization of the blood system in the United States, Stephenson turned his attention to the effect AIDS had on institutional relationships in the United States. He was particularly interested in developing an understanding of the relationship between the CDC and the blood banking community (22333-34).

Zuck explained that "like many things in our lives, AIDS has changed so much of what we do." He said that prior to the emergence of the disease the working relationships amongst the various members of the blood system were far less close than they are today. The CDC, in fact, only really became involved in the System in 1981. He described how in the face of the emerging epidemic the Public Health Service developed a Task Force bringing together FDA, CDC and NIH representatives with those of the blood banking industry. In the process he said, people at the FDA became very close to the people at the CDC who were tracking the epidemic. Likewise, through collaborative efforts to understand and combat the disease organizations such as the Red Cross developed strong relationships with members of the Public Health Service. Zuck recalled that by the time he joined the FDA, in 1985, close working relationships existed between the various members of the system (22334-35).

11 Zuck explained that the Statutes, grew out of an incident at Darlington Hospital in the 1950's when a large number of people were infected with hepatitis through the use of blood products. Following the incident blood and blood products were deemed "unavoidably unsafe." From there the ARC and the AABB began to lobby, state by state, for the "shield statutes." Without this protection, Zuck suggested, the blood industry could not survive. He pointed out that similar situation exists in the vaccine industry in the United States (22709-11).
AIDS brought about a number of changes including improving communications between the various participants in the blood system. Zuck told the commission, for example, that prior to the outbreak he only read the *MMWR* occasionally; beyond its reports on hepatitis and a few infectious diseases, there was little in it which was of interest or concern to blood bankers.

He contrasted this with the current situation, saying, that like most blood bankers, he now “reads every issue”. He went on to explain that the *MMWR* came to have considerable influence within the FDA, sometimes having a significant affect on policy (22336-37). He also noted that the CDC was equally concerned about getting the FDA's feedback on the proposed content of *MMWR* articles. He described how members of FDA would often receive drafts of articles that were about to appear in the *MMWR* and would be asked to provide comments. As a result, he said, representatives from the CDC and FDA would frequently carry on telephone conversations discussing things such as the possible impact of particular recommendations being contemplated by the CDC (22337).

Early Understandings of the Disease

Stephenson turned his attention to the state of knowledge surrounding AIDS during the early years of the outbreak. He was particularly interested in what sources of information were available and utilized and who was able to access and use them. He asked, for example, whether, as a blood banker, Zuck, would have read the June 18th 1982 MMWR report outlining the pattern of personal contacts within a cluster of KS and PCP cases in California (22342).¹²

Zuck replied that it was difficult for him to speak as a typical blood banker because he was

¹² This was the article Francis pointed to as providing critical support for hypothesis the disease was caused by a blood-born agent, likely a virus.
about to go to San Francisco, one of the epicentres for the disease. The things happening in that city were, therefore, of particular interest to him. Despite his professed interest in the situation, however, he had trouble reconstructing "exactly what he thought" at the time. He had no recollection of reading the report on the clusters of Kaposi's sarcoma and PCP in California, nor did he think it likely that the July 9th 1982, *MMWR* report of 34 Haitians with the disease would have caught his attention. As far as he could recall, "it took the jolt of the hemophiliacs before we really started to say this is a problem and we need to attend to it" (22342-43).

It was the demography of the hemophilia cases which scared the blood bankers the most, he said. Not only were they geographically dispersed, they were occurring in relatively affluent areas that were not associated with "rampant drug use and the like." He said that these occurrences did not fit the patterns seen in the previous cases amongst homosexuals and drug users and this gave the blood bankers a sense there "was something going on that we did not understand".

The well-known association of clotting fraction concentrates and the transmission of diseases gave the blood bankers further cause for concern. Zuck explained that given "the multiplier effect of the fraction," whenever anything crops up amongst hemophiliacs it gives real pause for concern (22343-4).

While the blood bankers were growing concerned, they still tended to confine their reading to the mainstream peer reviewed medical journals. Articles appearing in the more popular journals remained outside of their regular field of perusal. Even an article by eminent researchers could easily be overlooked if it appeared outside of the mainstream, peer reviewed medical journals.

Stephenson, for instance, asked whether Zuck had read the article by Gottlieb and Groopman
which appeared in the September 9, 1982 edition of *Nature*. Zuck replied that he could not recall having read it but that he was certainly aware of the authors. He described Gottlieb as was one of the doctors involved in the investigation of the initial cases in Los Angeles and Groopman as an immunologist and hematologist of "some note."

He explained, that an article such as this could be easily overlooked if it appeared in *Nature*. *Nature*, he said, was a valuable journal, but not one blood bankers read routinely. "It is a British journal. And it is a kind of journal in the old style of 100 years ago. Doctors wrote letters to one another and that is how communications took place...Letters are written, news and views" (22345-6).

Zuck suggested that articles which appeared in the *Journal of the American Medical Association* (JAMA), the *New England Journal of Medicine* (NEJM), and the *Lancet* were much more widely read in the medical profession at the time. He also observed that the material which appeared in these journals tended to take a more cautious approach to the situation.

Stephenson directed Zuck to an article which appeared in the September 24th 1982 JAMA. The article presented an overview of the current epidemiological, clinical and laboratory understandings of the disease. While addressing some of the concerns raised by the three hemophilia cases, the article stressed the many uncertainties surrounding the cause and transmission of the disease. Among its more provocative statements, was the claim that "...it seems unlikely that a virus alone is inducing AIDS...". Stephenson wondered what Zuck had taken from the article (22347).

13 Entitled, "Kaposi's sarcoma: an oncologic looking glass" (a purposeful reference to the Alice in Wonderland like situation they were facing where things were becoming "curiouser and curiouser"). The article noted that: "The increasing incidence of the epidemic and its apparent transmission by sexual contact, drug apparatus and blood products strongly suggest a viral agent" (Exhibit 549:tab 34).
Zuck said that the questions raised in the article regarding the etiology of the disease show that “[w]e were at sea here. We didn't understand what we were looking at”. The article, he suggested, reflected the confusion existing at that moment. He pointed out, for example, that it was known that the disease mimicked hepatitis ‘B’, and that a high percentage of the homosexuals with AIDS also had ‘B’ and ‘C’, and that Hepatitis ‘B’ and ‘C’ were therefore among the candidates in the search for a cause. Based on that, he said, the suggestion that a virus alone was unlikely to be the cause of the disease was “curious;” it illustrates, that “we really don't understand what is going on (22347-48).”

According to Zuck the blood bankers really didn't have a lot to go on at that point. The Allman case (the San Francisco Baby Case) was widely known, he said, but it had not been published. He suggested that all they really had by the early winter of 1982, was a few hemophilia cases and a platelet case. This was not enough to stir the blood banking community to action (22348).

Even the publication of the November 5th MMWR, outlining the steps health care workers should take to protect themselves from exposure to the bodily fluids of AIDS patients failed to communicate a need for action. Zuck told the commission he was uncertain whether he had read the November 5th guidelines, but being a laboratician, and involved with clinical laboratories at

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14 Later, during cross-examination by Mr. Harvey, counsel for Hemophilia Ontario, Toronto and Central Region, asked Zuck if he agreed, while it may not have been known in 1982 whether everyone exposed to the virus would go on to get the disease, it was generally felt that exposure was not a good thing. Dr. Zuck corrected Mr. Harvey. “In 1982 there was no virus. There was something. We putting contracts out from the NIH to study inhalants and nitrates. We were looking at all kinds of strange things. Articles were being written that this is CMV plus something else. We had learned writers saying this can't be a virus alone...We didn't even know it was infectious at that time” 22702-3).

15 A short while later he suggested that his closeness to the situation makes it hard for him to say how widely the Allman case was known 22349).
the time, he was sure he had been aware of their publication (22349).

When Stephenson asked what he took from the guidelines Zuck replied, that they said to him, the CDC was sufficiently concerned the disease was blood-borne and that it was transmitted in a fashion similar to hepatitis B (22350-51).16

Stephenson wondered whether the article, which treated blood as a potentially contaminated product, prompted him to extrapolate those risks to blood recipients? Did it cause him to think that precautions should be put in place for blood recipients, he asked?

Zuck described the connection of the risks confronting health care workers with those facing blood recipients as a “hindsight stretch”. “We were dealing with one whole blood donation at this point -- one in a background of millions” (22351).

According to Zuck, the watershed, at least for the blood bankers, came with the December 3rd and 4th 1982 FDA Blood Products Advisory Committee meeting.17 He told the commission that the message had gone out that Dr. Evatt's presentation was going to be important. The “wake-up call for everybody”, came when Evatt expressed the concern that transfusion associated AIDS (TAA) may follow the same increasing pattern seen with hemophilia patients. At that point,

16 Dr. Zuck later suggested that the analogy between hepatitis B and the new disease was of particular value in terms of developing interdiction strategies for AIDS (22393). He also suggested that in some ways the outbreak was reminiscent of the prototypic modern disaster, the flu epidemic of 1919. However, he said, AIDS is historically different than either the flu or hepatitis in that it seemed to have a starting point. It was not, simply a newly discovered virus, it was a new entity (22907).

17 The Blood Products Advisory Committee meeting had been called to address the mounting concerns that AIDS was transmitted through blood products and to discuss possible strategies for reducing the risk. It was announced at the meeting that there were five cases of TAA currently under investigation and that the first of these was about to be published in the MMWR. Up until that point there had been no published reports of transfusion associated AIDS although information about the existence of such cases had been circulating informally amongst experts for months.
suggested Zuck, it was hard to deny something was going on. The CDC were the ones with all
the information "... and they were the ones that expressed the concern, and so they concerned
other people" (22357).

He agreed with Stephenson that while the use of words like 'suggest' 'possible' and
'probable' may have reflected the lack of conclusive evidence at the time there was certainly
sufficient warning that everyone had to take the situation seriously. By January 1983, he
suggested, the controversy had turned from whether disease could be transmitted through blood
and blood products to "What do you do about it" (22357).

He clarified this point later, during cross-examination by Ms. Stoltz, counsel for the HIV-T
group, who suggested that Zuck claimed that following the January 4th meeting "there was
basically a clear consensus on the part of blood bankers that it was likely that there was such a
thing as transfusion associated AIDS."

Zuck corrected her; he had not said the uncertainty and debate surrounding the existence of
TAA had been resolved -- what he said was there had been a clear consensus that some kind of
action had to be taken because of the possibility it was transmitted in blood. He explained that
there was still a "whole continuum of how people accepted a relatively small amount of scientific
data There was no broad agreement that the disease was either caused by a virus or that it was
transmitted through blood. Some remained unconvinced of the reality of TAA for a long time,
while others "'said it was a clear as the nose on your face'" (22689-90).18

In the course of Stephenson's examination, Zuck had in fact made it clear that TAA continued
to be a matter of debate throughout 1983 and into the early months of 1984. He did, however,

18 Zuck reminded the commission, that the specific safety measures which were adopted, were
put in place on an interim basis, pending the emergence of further data (22689).
agree with Stephenson that a couple of seminal articles published during that period helped shift people's opinion towards accepting its existence.

The first of these came in the spring of 1983. In an article which appeared in the May 20th 1983 edition of the journal Science, Dr. Luc Montagnier and his colleagues announced they had isolated a retrovirus, dubbed LAV (lymphadenopathy-associated virus), from an AIDS patient in France and had managed to reproduce it in vivo. Zuck explained that despite there being little fanfare around its publication, the article put blood bankers, virologists, and AIDS workers on notice that they were likely dealing with a virus, probably a retrovirus (22417).19

The second seminal event, according to Zuck, came with the publication of the January 12, 1984 article in the New England Journal of Medicine (NEJM) in which Curran and his colleagues at the CDC reported on their investigation of 18 transfusion associated AIDS cases. Zuck explained that this article was important, in part, because of where it appeared. The NEJM was one of the most respected and widely read medical journals in the world. The journal had a circulation of approximately 280,000 and was regularly reviewed by the popular press. He suggested that the article's appearance in this prestigious journal, helped bring home the reality of TAA to the broader medical and scientific community as well as to the lay public (22418).

19 The November 20th edition carried 5 different reports of the breakthrough which came as the result of the work at researchers at the Harvard University School of Public Health, the National Cancer Institute and the Pasteur institute. In an item entitled Research News the author reviews the information noting that it is too soon to tell if HTLV is indeed responsible for AIDS but it is a much needed lead given the now 1350 reported cases and a mortality rate estimated to be 70 per cent or more. The author goes on to outline the arguments Robert Gallo at the NIH put forward in support of further investigating the link between HTLV and AIDS (Exhibit 550:tab 50). Gallo was one of the leading exponents of the retrovirus hypothesis in the United States. He lobbied extensively trying to gain support for the view that AIDS was caused by HTLV (Zuck 22341). HTLV, the first human retrovirus to be identified, was discovered by Poise and Gallo in 1980 (Zuck 22889). Although incorrectly identified as HTLV this represents the first time the virus responsible for AIDS was isolated.
He went on to explain that "everyone knew about this paper months before it showed up" and that there had been concern within the blood banking community that when it did come out it would get "press play" which would "likely frighten patients". He told the commission that there was always the worry with the AIDS epidemic that "people would not take blood [they] really need because they were afraid of being infected" and that deaths would result. "So you were always balancing this kind of concern against news" (22418-9).

January 4th 1983, Meeting

While acknowledging that "reasonable men may differ about this," Zuck said he believed the response to have been "amazingly fast" (22395). He pointed to the period between the January 4th meeting and the end of January 1983, noting that "...to build a consensus in 30 days on topics this controversial.. is remarkable." He told the commission that never had such a mobilization within the blood system taken place, at least not in peacetime (22395-96).

The enormity of this accomplishment should not be overlooked, as Zuck made clear in

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Despite his claim that the mobilization within the blood industry was unprecedented, Zuck acknowledged that what was actually done was no more than the minimum. When Stephenson asked him whether the response which followed the January consensus had been adequate, he replied that "based on the magnitude of the problem in the United States and the concerns of the public it would have been unacceptable to do less." In retrospect, he said, we have learned that a more rigorous approach might have been more appropriate (22509-10). He insisted, however, that the short-comings of the approach could only be appreciated after the fact. The scientific data available at the time did not support doing more. There was no conclusive evidence that AIDS was transmitted by blood nor was there any proof that the methods proposed would protect the blood supply: some even felt they would exacerbate the situation by bringing more at-risk individuals into the clinics seeking tests and by removing protective antibodies from the blood supply (22510).

The blood bankers were driven to take a conservative approach because of the uncertainty of the situation, their own disbelief that the disease presented a real threat to the system and a fear of doing or saying anything that might evoke fear amongst the public or reduce the supply of that vital substance, blood.
discussing the January 4th meeting. He described the meeting as a critical juncture in the American Blood System's confrontation with the disease, bringing together most of the major institutional participants and putting the latest information at their disposal. Yet, as he acknowledged, little agreement was reached as to the meaning of the data, let alone how to react to it. The situation was one of “countervailing interests trying to solve a problem.... The gay groups did not want to have their lifestyle become a subject of inquiry... there were people who were worried about costs... there were people who didn't care about costs... there were people who wanted a purer scientific approach... and there were other people who said ‘look, we have got enough data. We had better do something and if we are wrong, we can always back off and say ok it isn't transmitted by blood’” (22370-1).

The meeting was fraught with disagreement. As Zuck explained, there was no consensus on the proper course to be taken, even amongst the CDC representatives. The “younger investigators,” people like Francis, Evatt and Spira, believed strongly that the data spoke of an immediate need to institute precautions such as surrogate testing. The senior people at the CDC “who handled everything on balance of the public health issues”, were less convinced. They did not see the evidence as being strong enough, or the situation urgent enough to warrant such

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21 Zuck did not attend the January 4th meeting. He told the inquiry that he was depending on reports of the meeting which had been carried in house organs such as the AABB and CCBC newsletters as well as accounts of the meeting relayed to him by colleagues who had been there (22360).

22 Zuck later emphasized this point. Mr Stephenson had suggested to him that those who attended the meeting composed a broadly representative and qualified group and that “although they had different perspectives, different ideas as to how to do it, their intention was to do what was appropriate... to maintain a proper blood supply and a safe blood system” (22539). Zuck said he was reluctant to accept the view that everyone was concerned with doing the best thing for the blood supply. He reminded the commission “that there were clear perspectives and agendas that people wanted to achieve.” The representatives at the meeting were concerned with doing the right thing, “but from their perspective” (22540).
interventions (22371-72). In the end, he said, the senior people carried the day: The CDC never did recommend the institution of surrogate testing for AIDS (22372).

3.2 Taking Action

January 13th Joint Statement

While the countervailing perspectives, interests and agendas of the various participants in the blood system collided at the January 4th meeting, a series of commitments and recommendations did flow out of it. Zuck, for example, had considerable praise for the recommendations contained in the blood banker's January 13th Joint Statement which followed a little over a week later.

Stephenson led Zuck through a detailed discussion of those recommendations. He began by drawing Zuck's attention to the first recommendation that “blood banks and transfusion services should further extend educational campaigns to physicians to balance the decision to use each [blood] component against the risks of transfusion, be they well-established (e.g. hepatitis, cytomegalovirus, malaria) or under investigation (e.g. AIDS)” (22374-5; Exhibit 554:tab 18).

Zuck noted that it was fascinating, that 12 years after the Joint Statement was written, its first recommendation -- aimed at the reduction of the use of blood -- remains a fundamental risk reduction strategy. He also pointed out that educating physicians to reduce the use of blood and blood products was among the primary recommendations of the commission's own Management

23 The first of these came with the January 13 Joint Statement from the blood bankers followed the next day by the recommendations of the National Hemophilia Foundation Medical and Scientific Advisory Council. On January 28th, the plasma industry representative, the American Blood Resources Association (ABRA) issued its recommendations. The PHS published its recommendations in the March 4th MMWR, and on March 24th, Dr. Petricciani, Director of the FDA's Office of Biologics, sent a series of recommendations to blood bankers, commercial plasma collectors and manufacturers.
When Stephenson asked whether such education programs were actually initiated following the January 13th Joint Statement Zuck conceded that it "...varied widely...[i]t varied in intensity and it varied in whether it was done at all.... Some thought that this really wasn't a problem yet. We are still dealing with a small group of hemophiliacs and one child. So a lot of people wanted more data. That is the group that said, 'Let's not jump ahead here. Let's not get patients upset.... That may do a lot more damage than all this stuff we are talking about.'" (22375-6).

Zuck thought the second recommendation of the Joint Statement -- that the use of "‘autologous blood transfusions ...should be considered more frequently...’" -- was a sound recommendation. Blood bankers needed to educate the physicians that autologous donation was available. He was uncertain, however, whether the recommendation had any significant effect on practice at the time (22375-76).

Zuck suggested recommendation 3 -- "‘Blood banks should plan to deal with increased requests for cryoprecipitate ...’" -- was an important step in the attempt to reduce the transmission of AIDS in blood and blood products. He said that studies carried out at the time were "showing that there were some T-cell abnormalities in patients [hemophiliacs] that got concentrate.... Cyroprecipitate was considered to be a safer product because it was manufactured from single units of plasma. Treatment for a typical “bleed” might mean exposure to only 3 or 4 donors thus minimizing the potential exposure to infections. Nevertheless, as far as Zuck knew, there appeared to have been no significant increase in the demand for cryoprecipitate in the

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24 Zuck was Vice-Chair of the Management Committee which was formed in the spring of 1994 to assist Commissioner Krever in preparing his Interim Report. "The objective of the Committee was to assess safety of the present blood supply and make recommendations on ways to minimize risks and continuously improve the safety of the blood supply" (Interim Report Annexes 1994:8).
coming months (22377-9).

Zuck felt that recommendation 4 -- advocating that blood donors be questioned about their health history -- presented a somewhat more complicated scenario. Two basic approaches could be taken to the strategies contained in this paragraph. The first, he said, entailed asking a donor “Do you feel well today.” If they answered in the affirmative they passed into the system, but if they said they did not feel well, or had any concerns at all, they were referred to a series of detailed questions about night sweats, and so on. This was the approach the Red Cross and many other blood centres adopted initially. It fit well with existing practice, it had been standard practice since the 1940's to ask donors whether they felt well (Zuck:22380).

The second approach involved a program of more intensive questioning, but as Zuck indicated, “...precious few blood banks really asked the questions ‘right off the bat’, although some did.” He explained that among the things holding the blood bankers back, was their concern over the repercussions which might flow from the use of such questions. They were afraid that if they asked direct questions about sexual behaviour they might offend their donors. They were also concerned that such questions would be interpreted by gay organizations as an attempt “to get at them” (22381) and it was feared this might precipitate a backlash from the homosexual community (22391).

Zuck suggested that “on the whole” the gay community was cooperative, “they wanted to do good”, but there was strong opposition within the group to the institution of questioning of this sort. They felt that such questions unfairly targeted them and amounted to little more than an

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25 Recommendation 4 of the Joint Statement noted that “Donor screening should include specific questions to detect possible AIDS or exposure to patients with AIDS. In particular all donors should be asked questions designed to elicit a history of night sweats, unexplained fevers, unexpected weight loss, lymphadenopathy or Kaposi's sarcoma. All positive or suggestive answers should be evaluated before anyone donates” (Exhibit 554:tab 18).
attempt to place a blanket exclusion on gay men. According to Zuck, the blood bankers were afraid that the use of direct questions could drive a small but highly militant minority within the gay community to act vindictively. The blood bankers were concerned, that individuals who might not otherwise give blood, would present at clinics and lie in order to donate if they felt their lifestyle was being challenged (22389-91, 22541). He recounted hearing stories coming out of the focus groups, commissioned by the blood bankers, suggesting that some gays “would lie if directly challenged.” It was not only the blood bankers who were concerned about this, he pointed out. The gay groups shared the same concerns about this militant minority (22391;22541).

While discussing recommendation 5 -- that donor recruitment should avoid targeting groups “‘that may have a high incidence of AIDS’” -- Zuck offered that in pursuing this goal the blood banking community went far beyond the simple strategy of passive avoidance implied in the recommendation (22381). They took an aggressive approach, one which involved getting out into the community and working with gay groups. At the time, he said, it was perceived as “a relatively successful education program” (22383).

Then there was recommendation 6a, addressing the question of whether blood bankers should make “‘positive attempts to limit voluntary donations from the high risk groups’”. According to Zuck there was not sufficient evidence at the time to take a proactive stance here. First, he said, there was the data outlined in 6a suggesting that the risk appeared to be less than 1 in a million of contracting transfusion associated AIDS (22386-7). Second, as 6b indicates, he said, there was no evidence available to suggest that direct questioning would be effective in removing those at risk. In fact, according to Zuck, there was reason to believe its use might unintentionally increase the risks especially given the strong opposition which had been voiced by some members of the gay
community (22391).

The representatives of the gay community at the January 4th meeting had made it clear they opposed the use of direct questioning. They did, however, support the use of surrogate tests which they felt to be both less invasive and less discriminatory, as Zuck acknowledged (22392). The blood banking community, however, was less enamoured with the prospect of using surrogate testing -- something which recommendation 7 of the Joint Statement made clear.26

Zuck explained that the issues surrounding the use of surrogate testing were complex. He illustrated his point by outlining some of the costs and benefits associated with the implementation of surrogate testing. On the plus side, he said, it was known that surrogate testing would reduce the transmission of TAA and it was also believed the institution of surrogate testing would increase public confidence in the blood supply (22452).27

On the down side, he said, the efficacy of the proposed safeguards was unknown. Dr. Tom Spira's data -- suggesting a very high association between those with a history of hepatitis B infection and those at risk for AIDS -- faced serious questions for example. According to Zuck one of the problems with Spira's data, was that it was derived from a study of male homosexuals attending a sexually transmitted disease clinic. These, individuals, were living in the “fast lane”;

26 While suggesting that a number of “laboratory and clinical findings” were “…present in nearly all AIDS patients” Recommendation 7 went on to state, that strategies to detect these manifestations were currently being evaluated and that blood banks were not being advised to implement any routine laboratory screening program at this time (Exhibit 554:tab 18).

27 Maintaining confidence in the system was an important issue according to Zuck and he illustrated his point with one of his “favourite examples”. The blood bankers, he said, were concerned that “a little old lady in tennis shoes” needing a hip replacement would not seek appropriate treatment out of fear over having a blood transfusion. The scenario included “the elderly woman” taking a fall as a result of her putting off the surgery, contracting pneumonia, and dying (22452). Zuck, later explained that he used the story of “the elderly woman in tennis shoes requiring hip replacement” frequently -- it being a particular favourite of his (22764).
many researchers questioned whether the information was applicable to blood donors in the setting of a volunteer blood clinic (22446). He noted that where Spira's data suggested that as many as 80 percent or more of homosexual men tested positive for hepatitis B core, other studies such as that of Dr. Pert of the New York State Health Department indicated as few as 20 percent had a history of hepatitis B infection (22447).

The undetermined value of the tests had to be weighed against the very real costs of their institution. These included not only increased financial burdens but also the cost in lost donors (22453). Zuck pointed out that for every donor removed through screening another one had to be found. A new, first time donor, he suggested, was approximately 33 times more likely to carry a transmissible disease than someone who had been giving for years (22454).

There was also the concern that such tests would act as a magnet drawing individuals into the blood donation centres to get tested. Zuck drew the commission's attention to the issue of test-seeking on several occasions (22422, 22450, 22510, 22561, 22662). He explained that studies carried out in a number of different settings have shown that test-seeking is a reality. It was therefore unclear, he said, whether surrogate testing would increase or decrease the risk of AIDS (22450-51).

During cross-examination, Mr. Arenson challenged Zuck, suggesting that the concerns about test seeking behaviour never existed, or at least, not at the time. He took Zuck to several key documents relating to surrogate testing; none of which listed test seeking as an issue (22636-8).

Zuck replied that “it was a real concern”, that its absence in these documents was perhaps an oversight on the part of the authors. Arenson then invited him to point to one piece of documentary evidence to support his claims. Zuck acknowledged he could not, at least not off the top of his head (22638).
Arenson also suggested that if there had been any concerns that the test would bring high risk donors into the clinics they could have been easily overcome by educating people that it was not a test for AIDS, but merely a test indicating someone was associated with possible risk behaviours. High risk individuals would thus have no reason to come in. The test would tell them nothing they did not already know (22641).

Zuck admitted there was nothing preventing blood bankers from putting this message out; it simply had not been considered (22641).

Arenson then invited him to agree “that test seeking behaviour is a rationalization after the fact that...while it may have been one of the things that was discussed...at coffee... and in corridor conversations, it never made it to the official lists of reasons why anti-core should not be used at the time.”

Zuck grudgingly agreed that it appeared to be the case, at least as far as the documentary evidence would suggest (22641).

Assessing the Evidence: Individual Judgement and Its Determinants

In the course of his examination Stephenson carried out a detailed exploration of the factors affecting the blood bankers response to the emerging epidemic.

In discussing that response, Zuck described blood bankers as being “....pretty conservative folk... as far as jumping into new things”(22475). He suggested that in the case of AIDS, however, this conservatism has to be understood within the context of the information they were working with. He described how they faced a situation fraught with uncertainty. While the evidence was strong enough to say the outbreak needed to be taken seriously, there were no clear answers as to what was causing of the disease and no clear indication of the appropriate course of
action. With the paucity of definitive data, he said, decisions had to be based on individual judgement calls (22358).

Situated perspectives

Zuck discussed the issue of individual judgement while responding to a question from Stephenson about the controversy over the use of hepatitis B-core screening. Zuck recounted that some experts argued that the test was valuable, in part, because of its high specificity. Others -- himself included -- felt that it should not be used because its specificity was relatively low. He maintained that despite claims to the contrary, hepatitis B-core was not highly specific and there was “documentation to show the lack of specificity” (22438).

The Commissioner expressed puzzlement. How was it possible that one person would see the test as being highly specific, while another would see it as having a low specificity?

Zuck replied; “Specificity is in the eyes of the beholder.” In some contexts 60 percent specificity may be good but not “in terms of the context of blood banking because you are going to throw away one whole heck of a lot of donors that are not infected”. These lost donors all had to be replaced with higher risk, first time donors (22438-39).

Zuck made a similar point about the situated nature of judgement a short while later, this time suggesting that the decision of whether or not to institute the test rested on political

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28 Sensitivity... is the probability that a test result will be positive when the test is administered to people who actually have the disease or condition in question.... Specificity... is the probability that a test will be negative when administered to people who are free of the disease or condition in question” Gertsman (1998:59-60). Specificity often decreases as sensitivity increases -- the more sensitive the alarm, the more likely it will be to give false alarms (Krever 1995:19).

29 When the Commissioner asked him what the author of the document, Spira, intended to convey in terms of the specificity of the test Zuck replied that had no idea how Spira defined it; in fact he did not think Spira had in fact defined it (22439).
considerations rather than scientific ones. He was discussing the Confidential Unit Exclusion program (CUE), developed by the New York Blood Bank in 1983. Stephenson asked about the program, pointing-out that Zuck had written somewhere that it turned out to be less effective than originally thought, that the donors really did not understand the program (22546).

Zuck replied that for whatever reason it did not work. He pointed to a recent study, (REDS) suggesting it to be only 9 percent effective. That is only one in 11 infected donors, he said.

"Which in your view means that it is good, or not good? queried Stephenson" (22546-7).

"Well it depends on your perspective", replied Zuck. If you think one infected HIV donor in the United States a year is too many, then it is partially effective. If you think it is not effective as a cost benefit endeavour, then it is probably not very effective. So, it is kind of a political decision not a science decision" (22547).

*Distinguishing between paid and volunteer donors*

The concerns about the effectiveness and costs involved were not the only factors affecting the blood bankers' evaluations of the proposed screening measures. Zuck revealed that their decisions were also shaped both by the type of relationship they believed existed between them and their donors as well as their understandings and assumptions about the character and motivations of the donor population.

He explained to the commission that despite their concerns about the militant minority within the gay community, blood bankers in the volunteer sector generally conceived their relationship with their donors as based on trust and an understanding of their mutual obligations (22878).

They held a very different view of the relationship between paid donors and the commercial
Blood bankers believe “that a paid donor can be challenged a bit more aggressively than a volunteer donor. You are not relying on their good will. You are relying on a contractual relationship, a donation for which they are paid” (22398). If you subjected the volunteer donor to the same “abuse” that you subject paid donors to, they might get angry and withdraw, thus creating serious shortages in the blood supply.31

The motivations and character of the volunteer donor were felt to be different from those of their commercial counterpart. Zuck spelled out some of the perceived differences when Stephenson asked him about the commercial sector’s more aggressive approach to donor screening. The volunteer blood bankers believed their donors were motivated by altruism; that they were motivated to do good. This led the blood bankers to assume that so long as the donors knew the ‘good’ they would do the ‘good’. Those who knew they were at risk would refrain from donating (22408). The use of stringent screening measures for volunteers, therefore, was seen as unnecessary. “…[T]hese were altruistic people.” All that was required was to educate them about the risks; from there on “they will do the right thing” (22693-4).32

30 While the blood bankers believed in a fundamental distinction between paid and volunteer donors, in practice, it was not always clear what constituted payment. During cross-examination, for example, Zuck acknowledged the FDA had great difficulty actually defining what constituted payment of a donor, saying “…[i]t has been generally left up to the discretion of the inspectors about whether something is paid. Dollars are clear. The most common definition, and it has been more or less accepted by the FDA administration, is any form of renumeration that is readily convertible into cash.” When it comes right down to it, he said, blood bankers and regulators remain uncertain as to what effect incentives such as T-shirts or theatre tickets have on a donor’s honesty about their health history (22727).

31 He admitted, however, that the “volunteer sector may have overreacted”, that they may have underestimated how far they could push the volunteer donors, particularly given that direct questioning was accepted by the volunteers when it was eventually put in place (22399).

32 The initial results of the ELISA test showed that this assumption had been completely erroneous. However, even in the face of this evidence the blood bankers maintained their basic assumptions about the altruistic motivations of their donors. The high incidence of HIV infected
Zuck told the commission that he continued to believe the two groups of donors represent significantly different risks and limitations. He pointed out, for example, that a first-time paid plasma pharesis donor, has an approximately tenfold higher rate of infectious diseases across the board compared to a volunteer whole blood donor. It does not matter whether you are talking of HIV or HTLV, the first time paid donor has a much higher tested rate of infection. This sort of data, he suggested, supports the view that a more stringent screening protocol within the commercial sector is necessary and justified (22630).

*Constructing the public*

The relatively positive light in which the blood bankers viewed “their” donors did not extend to their perception of the general public or the users of blood and blood products, a group often collectively referred to as the “consumers”. The matter came up when Mr. Lavigne, counsel for the Hepatitis C Group, asked Zuck about the problems physicians faced in communicating issues of risk to their patients.

Zuck explained that “we have learned a very serious lesson that the public does not relate to generalized risk... [W]hat the public relates to is a child in a hospital with a disease that somebody knows, and then that risk becomes real. But the abstraction of risk to the public in, whether it is nuclear power, whether it is HIV transmission in blood transfusion, whether it is airline safety, it doesn't make any difference. Statistical probabilities of one in a million, two in a million, one in 500,000 are meaningless to the American public” (22796).

Zuck described the “consumers” not only as incapable of thinking about risk in concrete units was the result of denial on the part of the small percentage of donors engaged in risk behaviours (22544).
terms, they are unreasonable in their demands and expectations. "[T]he curious thing about a
blood transfusion recipient," he said, "is the public is unwilling to accept the risk" (22797).

While they may have felt the demands of the "consumers" to be unreasonable, the blood
bankers found themselves unable to resist the pressure placed on them to take a more proactive
approach to the safety of the blood supply. In the spring of 1984, the Irwin Memorial Blood Bank
in San Francisco put anti-B core testing in place.

Zuck described the situation leading up to the decision to put the test in place, noting that the
public grew more fearful throughout 1983 and by 1984 they had become "very, very frightened"
(22673). "People were terrified", he said, and as a result, operating rooms in San Francisco
hospitals were being "under utilized." Irwin Memorial Blood Bank responded by instituting anti-
B core testing. The decision, according to Zuck, was more a matter of politics than a matter of
science. "It was principally done as... a public confidence issue" to reassure a public who were
either seeking surgery outside of the city or deferring it altogether (22458).

Playing the Odds: Decision-Making and Risk

According to Zuck, the blood bankers found it hard to understand the public reaction. As far
as they were concerned the risk was so low as to be almost inconsequential. As Zuck explained,
the risk of contracting TAA was believed to "one in a million, or less". On this basis, any
precautions the authorities initiated were for the most part, motivated by social/political concerns
rather than scientific ones.

The commission cast particular attention on the origin of the "one in a million calculation"

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33 It seems, however, that there were risks and then there were risks. Zuck later pointed out,
for example, that the only risk associated with transfusion that a recipient "seems to care about"
is HIV (22872).
during Zuck's appearance, especially given that he was one of the experts responsible for calculating and publishing the figure at the time.

In exploring the origin of the calculation Stephenson drew Zuck's attention to paragraph 6a of the January 13th 1983 *Joint Statement* which noted that “fewer than 10 cases of AIDS with possible linkage to transfusion have been seen despite approximately 10 million transfusions per year. “Is this “where the famous one in a million terminology comes from”, Stephenson asked (22386)?

Zuck allowed that it was one of the places where the figure appeared. He continued, saying that while the arithmetic has been highly criticized, and it has even been suggested that “any idiot should have known this was wrong”, things in fact are not that straightforward (22386). One of the things the estimation has been criticized for, he suggested, is its failure to account for the lag period between the time of infection and the appearance of the disease. He pointed out that by 1983, when the estimate was made, they were already 5 or more years into the epidemic.

“...[S]o we are talking about an appearance of ten cases over a five or six year period in which not ten million but closer to fifty million transfusions had been given.” He also pointed out that while no one was sure at the time, the lag period was believed to be somewhere between 6 months and 2 years. Contrary to what Francis suggested yesterday, he argued, the calculation more than allowed for the lag period (22386-7).

In cross-examination, Mr. Cherniak pointed to an editorial in the November/December 1983 edition of *Transfusion* in which Zuck characterized the risk of contracting AIDS through a blood transfusion as being “probably less than one in a million.” He wondered what Zuck based his
Zuck replied that, in part, it was a reflection of the Public Health Service statements and, in part, it reflected the limited understanding of the latency period at the time. A third element in the calculation, he suggested, was the actual limited numbers involved (22515-6). He defended the use of the “one in a million” calculation arguing that it was not only “idiots” who believed the estimation to be true. Many reasonable individuals -- himself included -- felt there was good reason to accept the “one in a million” estimate. He protested, that to claim, as Francis had, that those who believed the figure should have known otherwise, was not quite fair. The only data available suggesting they were dealing with a virus of a lengthy incubation period, he argued, was the March 1983 paper describing LAV. He further defended the figure noting that over a year later, the Public Health Service itself was still using the “one in a million calculation”. There was a great deal of scepticism about the seriousness of the situation, he said (22516-20).

During cross-examination, Arenson, counsel for the CHAT Group, asked Zuck to describe how the figure had been arrived at originally. Among other things, he wanted to know if it was based on the apparently “simple minded” calculation implied in paragraph 6a of the *Joint Statement*? Did “...people put 10 over the denominator 10 million donations and come up with one in a million ....?” (22581).

Zuck replied that you could calculate it that way, but he doubted many did (22581).

Arenson pursued the issue further, asking what numerator and what denominator had been

34 In that “Editorial” Zuck stated, “...if it is transmitted by blood transfusion the risk of acquiring AIDS from components that blood banks routinely make from units donated by volunteers is very small indeed, probably less than one in a million”.

35 Zuck indicated that he was aware of what Francis had said about the source of the Public Health Service estimate but that he was not sure the information had come from the Red Cross or not (22516).
used to arrive at the “one in a million” figure (22582)?

Zuck explained that “... different people had figured it out in different ways.” It could be figured out in the way suggested by Arenson or it might be figured out on the basis of recipients; the number of recipients infected verses the number of people transfused annually. If you are figuring it this way, he explained, you would take the approximately 3 million blood recipients per year and multiply that by 6 (the number of years the disease was assumed to have been around). You thus had 18 million recipients and 10 cases. If you round that down to allow for the latency period you arrive at the “one in a million” estimation. “It was an approximation. A great deal has been made of this. It was an approximation” (22583).

Asking Zuck to correct him if he was wrong, Arenson suggested that the problem with these calculations was they failed to take into account almost half of the blood recipients, who died as a result of the disorder(s) for which they received blood transfusion. (22583).

Zuck agreed, presumably this was the case (22584).

Arenson turned his attention to the fall of 1984, the period surrounding the initial evaluation of the ELISA test kits. He asked Zuck whether he recalled what these early evaluations revealed concerning the actual incidence of AIDS in the donor population. When Zuck was unable to recall the specific figures Arenson assisted him, suggesting that studies carried out in late 1984 and early 1985 revealed the risk to be somewhere around a thousand times greater than that represented by the one in a million figure (22588).36

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36 Arenson referred him to an extract from a Canadian study entitled “Clinical Evaluation of Abbott HTLV III E.I.A. for the Detection of Antibody to Human T-Cell Lymphotrophic Retrovirus Type III” (22586-87). The study, carried out in Toronto in January and March of 1985, concluded that: “The overall incidence of repeatable reactive specimens in a normal health donor population was 0.37% and it did not appear to be substantially different from that seen in the U.S (range of 0.05 to 0.5% with a mean of 0.24%)” (22587).
Zuck replied; “No one believes the one in a million figure was correct, sir. We know it was wrong.”

Arenson pointed out that while studies began to reveal that the real figure might be several orders of magnitude higher than originally estimated, there was no public announcement of this in the United States until the fall of 1985.

Zuck failed to see the significance of Arenson's point: whatever the risk may have been was irrelevant once the ELISA and Western blot confirmatory tests were in place. Only the ‘window period’— the time between when a person is initially infected and when they develop sufficient antibodies to be detectable by the test -- remained a concern (Zuck:22589-92).

Arenson suggested that Zuck was overlooking an important point, the blood bankers should also have been concerned about, and felt a responsibility toward, past recipients. Arenson argued that given the enormously higher prevalence of the disease than had been originally estimated, recipients should have been advised to see their doctors and get tested. Instead the blood bankers dissuaded them from doing that (22592-3).

Zuck explained that as soon as the blood bankers became aware of the problem they began tracing past recipients through infected donors (22593).

The following day Zuck again found himself defending the use of the “one in a million” calculation. This time it was the counsel for Canadian Hemophiliacs Infected with HIV, who

37 During Stephenson's examination Zuck had suggested that as the test was implemented and results began to accumulate it appeared that approximately 1 in 2,500 donations tested positive for HIV, the virus associated with AIDS (22421).

38 This, unfortunately, was only effective in cases where: infected donors were identified; records existed of their past donations and the individuals who received them; and the blood bankers were able to locate the recipients once they were identified as having been exposed to a potentially contaminated transfusion.
sought clarification. He wanted to know how it was that figure remained the same for almost two years while the number of transfusion related AIDS cases increased considerably over that time. He wondered if, as a blood banker, Zuck had any experience dealing with the curve of an epidemic and factoring that into an equation for doing a risk analysis (22852).

Zuck replied, “No I am not an epidemiologist, if that's what you mean” (22852). When pressed further about the blood bankers' abilities to deal with complex epidemiological computations Zuck pointed out that they “were not isolated from the rest of the world. The CDC was making calculations. These data were published....” Contrary to what Francis may claim, he said, the blood bankers were relying on the knowledge and experience of infectious disease specialists and epidemiologists. He allowed that the blood bankers may not have been listening to Francis, but his was only one of the perspectives being offered by the PHS (22853-4).

The Lessons of History

During the course of Zuck's appearance, assurances were sought that such a tragedy could not/would not be repeated. Stephenson broached the issue, asking Zuck whether the United States blood industry and the public health sector had “learned anything from the AIDS epidemic and the way it was handled and if they have instituted any improvements...” (22466)?

Zuck replied that if Stephenson was asking -- “could it happen today”? -- it might be helpful to think of the story of ICL because it illustrates the lessons learned in the United States. The ICL story, he said, provides a very instructive “excursion into fantasy land”.

Zuck recounted how ICL -- an idiopathic (unexplained) form of CD-4 lymphocytopenia

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39 The persistence of the “one in a million” calculation was remarkable given that the number of TAA cases reported in the U.S. tripled during the period of its use.
(reduced CD-4 counts) -- first emerged as an issue at an AIDS meeting in Amsterdam in 1993 when Jeffery Lawrence, a young scientist from Cornell University, announced that he had discovered patients suffering from low CD-4 counts with reverse transcriptase enzyme in their blood and who did not have any sign of being infected with HIV.\(^{40}\)

According to Zuck, the announcement immediately set off a shock wave: It suddenly looked like they were dealing with a new virus. He described, how in one day the ARC, the CCBC and the AABB had organized a meeting of relevant scientists to look at the data surrounding ICL but that the CDC stepped in and asked the blood bankers to hold off, and they would organize a meeting. Less than three weeks later, the CDC hosted a meeting out of which a working group was struck. This working group, he suggested, was composed of some of the leading AIDS and public health figures at the time (22469-70).

In the end the panic turned out to be over nothing, he said. He recalled that within two or three months, it became evident that ICL was just the tail of a normal CD-4 count distribution. He contrasted this with the situation which had surrounded the San Francisco baby case, which had literally taken years to untangle (22470).

The question of whether such a disaster could be repeated came up again when Harvey, counsel for Hemophilia Ontario, Toronto and Central Ontario Region, asked how it could be insured that a society such as our own -- which relies so heavily on technology -- does not become complacent once tests are in place? How can you ensure that “diligence” is maintained,  

\(^{40}\) Reverse transcriptase is an enzyme associated with all retroviruses. It converts the RNA of the virus into DNA. The retrovirus then inserts its own DNA “into the genetical material of your cell...and so now the cell reproduces...it reproduces virus. And this is running the genetic machinery backward. So it is retro and so it is called retrovirus because of this characteristic” (Zuck 22468).
he asked (22720)?

Zuck replied that the ICL case provides a good example of the current state of vigilance.

Harvey said that he was aware of many of the names associated with the ICL investigation; they were well known AIDS researchers. Suggesting that “‘Once bitten twice shy’”, he wondered how the sense of urgency, the sense of caution, could be maintained once the generation who lived through the problems “is replaced by a generation that wasn’t there when AIDS happened?” How do you ensure “that this becomes part of this system and it isn’t just part of the personal memory of the people within the system?” (22721-2).

Zuck said that he could claim no knowledge in that area but that he could opine on the subject. “…I think as we train the younger physicians, we have fellows, and I think they walk through this with us, and they watch what we have gone through. We are passing on to them a legacy, I think, that maybe things should have been done differently. Then reasonable men can differ -- and women -- reasonable people differ” (22722).

Summary

Zuck had relatively little to say about the activities involved in the generation of scientific evidence. For Zuck the critical part of science lies in the assessing of information as it becomes available. Consensus lies at the heart of evaluating evidence and decision-making in science. A whole lot of “reasonable” scientists consider the merits of the available evidence and come to some agreement to what it means and how it should be acted upon.

Zuck acknowledged that there are a number of hiccups which can get in the way. Often, at least initially, there is little information to go on. What evidence exists may be far from definitive. In the face of such uncertainty, scientists may find themselves unable to reach
agreement. Even in cases where there is a body of established evidence, reasonable men and women can differ as to its meaning because each assesses the information from their own perspective and with their own priorities in mind. These problems are further compounded when it comes to translating that information into action. This, as Zuck pointed out, invariably involves some form of cost/benefit or risk/benefit calculation which again is subject to limited and inadequate data, personal judgements, and institutional goals and priorities.

According to Zuck, scientists, especially blood bankers, are a conservative lot when it comes to responding to new information. This, he suggested, is not necessarily a bad thing, nor is it unreasonable, particularly in situations where the costs of taking action can be high and the information available is wanting in quality and/or quantity. Nevertheless, he acknowledged that there are situations where it is both prudent and justified to act before the final definitive evidence is available. Shooting from the hip is not the answer, but neither is waiting till the enemy is on top of your lines. You wait until enough “reasonable” men and women agree that it is time to act.

The problem of AIDS in the blood supply is a case in point where action was taken before all the information was in. Zuck explained, the epidemiological evidence available suggesting that AIDS was the result of a blood-borne transmissible agent, while far from conclusive, appeared significant enough to warrant concern. He also stressed that those with the most information and the greatest experience -- the experts at the CDC -- were alarmed, added a further rationale for accepting something was up. Finally, when prestigious mainstream peer reviewed medical journals started publishing on the subject -- even if the articles tended to take a non-alarmist stand -- it was hard to deny the significance of the situation.

According to Zuck the blood bankers did indeed take notice; they did not wait for conclusive
proof before reacting. True, as he admitted, the steps they took amounted to nothing more than the acceptable minimum but given the slimness of the evidence and the possible costs involved in overreacting, the speed with which they mobilized was remarkable, even "unprecedented".

He took pains to point out that while in retrospect it may be possible to say not enough was done, this was far from clear at the time. Knowledge is cumulative. We simply did not know then what we know now. We cannot judge the past from our privileged position in the present. Zuck was hopeful, however, that the errors of the past will not be repeated. The infection of the blood supply with HIV provided an important learning experience. It provided a legacy that, hopefully, those who were there and experienced it first hand will pass on to future generations of physicians and researchers.
CHAPTER FOUR: DR. ROGER PERRAULT AND DR. MARTIN DAVEY: SETTING THE CONTEXT OF THE DISASTER IN CANADA

4.1 Outline of the Examination of Dr. Roger Perrault and Dr. Martin Davey

Introduction

On the 8th of May 1995, two months into the National hearings and more than a year and a half after the public hearings phase of the inquiry began, Dr. Roger Perrault and Dr. Martin Davey took the witness stand. These men were at the helm of the Canadian Red Cross Blood Transfusion Service during the early, critical years of the AIDS epidemic. Perrault had been the National Director of Transfusion Service from 1974 to 1986. Davey, the Deputy Director of the Service from 1981 to 1986, was his right hand man.¹

Their testimony was expected to yield important insights into the development of the early understandings of AIDS in Canada and help explain many of the decisions made and actions taken to safeguard the national blood supply. Perrault’s and Davey’s appearance, therefore, constituted perhaps the most anticipated and important event of the hearings. Its significance was reflected, in the length and extensiveness of their examination. Appearing a total of 22 days in the period from May 8 to June 14 1995, they were questioned by 24 different lawyers representing 21 groups and institutions.²

¹ A third individual, Dr. John Derrick (deceased) also played a prominent role in the Red Cross BTS National Office. Derrick was Director of Blood Product Services during the early years of the epidemic (Davey 26017). He played a critical role in formulating National Office policy on AIDS. While Derrick passed away in the intervening years his thoughts and actions, occupied considerable attention during Perrault’s and Davey’s appearance.

² Perrault’s and Davey’s testimony is contained in 22 volumes, totalling almost 5,000 pages.
The significance the commission attached to their evidence and the gruelling nature of their time on the stand was underlined by Justice Krever, when at the close of their testimony, he observed, "...this is the end of the longest ordeal I think any witness can probably have experienced, not just in an inquiry, but anywhere that I am aware of. And I am sorry it had to be 22 days, gentleman, but your evidence was vital as I am sure you appreciate and I thank you very much for it" (31028).

Perrault's and Davey's evidence was presented in three phases. For the first five days, Mr. Stephenson conducted the examination in-chief. During that time he established an overview of post World War II transfusion medicine, addressed the growth of the international trade in blood and blood products and outlined the history of the Canadian Blood System.\(^3\) Paying particular attention to the funding and regulatory structures of the System, Stephenson traced out the various organizations involved in its operation while examining their changing roles and often rancorous interrelationships. His central concern, however, was with developing an understanding of the technical, political and economic issues which surrounded blood fractionation in Canada in the 1970's and early 1980's.

Stephenson's examination provided critical insight into the structure, organization and politics of the blood system in the era prior to the emergence of AIDS. By and large, he left the investigation of the disease and its repercussions to his colleague Edwardh who began her examination in-chief on May 16th, six days into Perrault's and Davey's appearance. Building on

\(^3\) In his *Interim Report*, Commissioner Krever identified three major institutional participants in the Blood System: The Canadian Red Cross Society; the Canadian Blood Agency (formerly the Canadian Blood Committee,) and the Health Protection Branch of Health Canada. He also noted that while not formally institutionalized, the "700,000 voluntary blood donors," "...the consumers of blood and blood products, their physicians and the hospitals in which patients are treated and in which physicians practice" are equally "significant" participants in the system (Krever 1995:5).
Stephenson’s examination she “set out the background,” the institutional context, in which the mysterious syndrome emerged. She then turned her attention to the state of knowledge surrounding the disease in Canada and undertook a close examination of the Canadian efforts to protect the blood supply.

Comparing the actions of the Canadian blood authorities with those of their American and European counterparts she revealed some sharp contrasts between the way Canada dealt with the threat and the way it was dealt with elsewhere. In exploring these issues Edwardh constructed a detailed map of the interrelationships between science, society, politics and economics in the Canadian Blood System in the early 1980’s.

The cross-examination phase, began on the 15th day of their appearance. Much of the information addressed during this period, covered ground already traversed during the examination in-chief.4

A Difference of Styles.

Lawyers

The style of questioning adopted by the individual lawyers varied widely, and these differences affected both the form and the content of the witnesses’ answers. Stephenson, for example, invited either witness to comment whenever they had insight into the issues at hand. The doctors thus enjoyed considerable control over the examination process. Their performance at times resembled that of a wrestling tag-team; when one of them ended up on the ropes, the other one jumped into the ring. As a result, Stephenson occasionally found himself outflanked

4 When asked by Mr. Cherniak, whether this sort of duplication was helpful the Commissioner replied, it was not but he was permitting it “so that people can feel that they have participated in the way they want to participate” (29547).
and outnumbered.

This situation changed considerably when Edwardh took the reins. Beginning her examination with the comment, “This is round two, gentlemen,” she informed Perrault and Davey that she intended to ask each of them different questions and that she would specify who was to provide the answer. She explained that while the commission had intentionally put them together as a panel, there were some matters on which she would like to have their “specific recollections”, rather than their “joint recollections” (27040-42).

Counsel for the Red Cross, protested, saying that while the request seemed fair, there were many issues which both men dealt with and they each should be given the opportunity to share their insights.

Justice Krever replied that at the moment the discussion was one of “generalities”: they would “have to wait to see what the questions are and what the answers are” (27043-44).

Witnesses

Davey expressed his dissatisfaction with the arrangement throughout Edwardh’s examination, interrupting her questions, interjecting during Perrault’s answers, refusing to stop talking, and on one occasion challenging the legal status of a document she was using to conduct her examination. His relative disregard of Edwardh’s instructions and his occasionally aggressive behaviour contributed to the palpable tension which existed between the two of them. Edwardh was equally unyielding and confrontational. When Davey refused to stop speaking she simply raised her voice and carried on. She made no secret of her frustration with Davey’s behaviour, more than once saying she was tired of having to argue with him over every point.

Davey’s discomfort with the situation was apparent in his physical disposition, fidgeting in his
chair. His habit of drawing the palms of his hands across his face lent an aura of strain and exasperation to his presence.

Perrault bore the tribulation in a more stoic manner. Sitting upright in his chair, he tended to either look directly at the person conducting the examination or thumb through the documents which lay before him on the stand. His physical bearing was matched by a business-like approach to the examination. He generally refrained from speaking unless spoken to and avoided any direct challenge to the counsel's authority. He did, however, practice his own forms of resistance: constantly asking counsel to repeat questions; demanding that all the documents relating to specific questions be put before him; denying, what, in many cases seemed to be obvious conclusions. He thus forced the counsel to spend an enormous amount of time visiting and revisiting the issues and the documentary evidence, frustrating the progress of the examination while providing himself with time to consider his responses to individual questions.

Perrault's interpersonal skills and his ability to operate under pressure were apparent. He had many years of experience in which to master his skills. As head of the Transfusion Service, Perrault's duties were largely bureaucratic in nature. By his own account, he spent much of his time as Director of the Red Cross cajoling, making presentations to and arguing with, representatives of governments, agencies and industries.

Where Perrault was a skilled bureaucrat, well practised in the art of testifying before panels, boards, and committees, Davey's expertise rested more in the scientific realm. As Deputy Director of the Canadian Red Cross Blood Transfusion Service, he had been largely involved in and responsible for the scientific and technical side of the operation.

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5 A back problem which plagued him during his appearance at the inquiry no doubt contributed to his rigid bearing.
Denying Responsibility

While their physical appearance and behaviour may have been a study in contrasts, Perrault and Davey shared a single message: neither they nor the Red Cross should be held responsible for the tragedy which devastated the lives of thousands of individuals and ultimately undermined the foundations of the Canadian Blood System. The Red Cross had taken the appropriate steps based on the available information. If there were failures, they rested on the shoulders of governments and their representatives, manufacturers, the Hemophilia Society, treating physicians and hemophiliacs, the media, interest groups, and the public at large.

Perrault's and Davey's unwillingness to place any responsibility for the tragedy on the blood collection side set their evidence apart from that of Francis and Zuck. These differences can be attributed, at least in part, to the very different positions occupied by the CRC officials at the inquiry. Unlike the case of the two American witnesses, the specific decisions made by Perrault and Davey and the actions they took in the early 1980's, were matters of intense concern and scrutiny at the inquiry. In addition, the institution which they ran during the early 1980's had been, and continued to be, a lightning rod for law-suits emerging out of the tainted blood tragedy.

It was no surprise, therefore, when Perrault and Davey sought the protection of Section 5 of the Canada Evidence Act -- but even this could do little to immunize them in the court of public opinion, fed on a daily succession of "startling revelations" in the media.6

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6 Their caution was not without reason. Shortly after the release of Justice Krever's Final Report the Canadian Hemophilia society formally requested a criminal investigation into the events surrounding the contamination of Canadian blood supply. On December 21 1997, in a nationally televised press conference the RCMP announced it would begin a primary investigation to determine if there was sufficient evidence to warrant a full scale criminal investigation into the blood tragedy. Less than two months later, in a second nationally televised press conference, the RCMP announced it had come into possession of sufficient information to warrant a full scale criminal investigation into the contamination of the blood supply.
4.2 Establishing the Witnesses’ Expertise

Curriculum Vitae

Following the established pattern, once the witnesses were sworn, Stephenson began a brief review of their Curricula Vitae. Starting with Perrault he noted that after graduating in 1963 from the Faculty of Medicine at the University of Ottawa he pursued a series of post graduate training experiences. Serving in the Royal Canadian Navy from 1964 to 1968, he trained in Pathology and Internal Medicine at the National Defence Centre, Ottawa where he carried-out “extensive research on various elements of blood and the preservation of blood”. From 1968 to 1969 Perrault did a residency in internal medicine at the Ottawa General Hospital and from 1969 to 1972 he took up a Medical Research Council Fellowship to Sweden in Immunohematology at the University of Uppsala. In 1981, he was made a Fellow in Internal Medicine by the Royal College of Physicians and Surgeons (Stephenson 25955-6).

Highlighting his work experience, Stephenson pointed out that on returning from Sweden in 1972 Perrault became the Medical Director of the Canadian Red Cross Blood Transfusion Service for Ottawa Centre, at the same time holding an appointment as assistant Professor of Medicine at the University of Ottawa. Two years later he assumed the role of National Director of the Blood Transfusion Service, a position he held until 1986 when he became Deputy Secretary General of Operations. He served in this capacity until 1989 when he took over as Deputy Secretary General of Blood Services. In 1991 he left the Red Cross to become President and Chief Executive Officer of IAF BioVac Inc., a Quebec based vaccine manufacturer (25956-7). In 1993 Perrault assumed the Presidency of the Industrial Biotechnology Association of

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Perrault explained that the field of Immunohematology included issues related to the “immunology of blood” as well as the biochemistry of blood preservation and “other areas of routine blood banking” (25955).
Canada, a position he continued to hold at the time of his appearance at the inquiry (25957).

Turning his attention to Davey’s Curriculum Vitae, Stephenson pointed out that he received his Bachelor of Medicine/Bachelor of Surgery from the University of Sydney in 1960, his M.D. from the University of Adelaide in 1965, and was named Fellow of the Royal College of Pathologists of Australasia in Hematology (25958). Outlining Davey’s professional experience and training, Stephenson noted that in 1960 he became Resident Medical Officer at the Royal Prince Albert Hospital in Sydney, Australia and the following year assumed the role of Senior Resident and Medical Officer, at the Royal Adelaide Hospital. Between 1962 and 1966, he was Research Fellow at the National Heart Foundation of Australia conducting research at the Department of Medicine at the University of Adelaide, 1962 to 1964, and the Theodore Kocher Institute in Bern, Switzerland, 1964 to 1966 (25961).

Stephenson, continued, pointing out that on his return to Australia in 1967, Davey became the Director of the Red Cross Blood Transfusion Service of Western Australia, where he remained until 1980. In 1981, he joined the Canadian Red Cross BTS as Deputy Director, a position he held until 1986, when he became Acting National Director of the Service. Davey left full time employment with the Red Cross in 1987 but continued to work with them as a consultant; assisting with the preparation of budgets and managing the Research Program which he had previously established. He left the Red Cross in mid-1988 (25963). 9

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8 When asked to explain his specialization Davey said the Australian degree requirements were somewhat different from those in Canada. Canadian hematologists specialize either in clinical or laboratory hematology, while in Australia hematology is a combined discipline involving training in both the laboratory and the clinic (22959).

9 In 1989 Davey joined a Canadian volunteer development agency, working briefly as a District Medical Officer in the Province of Nampula, Mozambique, his stay cut short by a serious illness. After working as a Clinic Assistant in Hematology and Oncology at the Hospital for Sick Children in 1991 he undertook a Master’s Degree in Community Health and Epidemiology at the
4.3 The Canadian Blood System: The 1940's to the 1970's

Origins and Financing of the System

After leading Davey through a brief overview of the Australian Blood System in the 1970's (25964-84) Stephenson turned to Perrault, asking him if he could provide a “snapshot” of the Blood Transfusion Service as it looked when he took over as its National Director in 1974 (25984-85).

Perrault suggested that to appreciate the situation in 1974 it is necessary to understand some of the early history of the blood system especially its funding history.¹⁰

He described how, following the Second World War, the federal government and the Canadian Medical Association asked the Red Cross to establish a national blood system (25987).¹¹ The first CRC blood centre opened in Vancouver in 1947. Others soon followed

University of Toronto. He was nearing completion of these studies when he appeared at the inquiry (25964).

¹⁰ Perrault’s point is an important one, in order to understand the contamination of the Canadian blood supply with AIDS it is necessary to have some grasp of the history of the Canadian Blood System. In order to provide a adequate account of that history I supplement Davey’s and Perrault’s accounts with evidence presented by other witnesses who appeared before the commission. For the sake of clarity I have, in a few instances, included reference to material from outside of the inquiry.

¹¹ The Society found the prospect appealing. Not only was it looking for a new post-war role, it had an expertise in blood banking as a result of its experience supplying blood to Canadian and allied forces during the Second World War. Plasma, in particular, was used extensively on the battlefields during World War II. The widespread use of this lifesaving product became possible because of newly developed processing techniques allowing liquid plasma to be dried to a powder. The powder was relatively easy to store and transport, had a long shelf life and was easily reconstituted by adding sterile water. Impressed by the miraculous resuscitative, the Canadian military requested the Red Cross make available the equivalent of two thousand donations a week. The Red Cross fell far short of this goal during 1940, its first year of operations, collecting slightly over 5,000 units. By 1943, however, annual donations had increased by 100 fold and by 1944 collections exceeded a million units (Porter 1960:140-6; Guiou 1985:105-20; Picard 1995:22-3; Starr 1998:102-3). Perrault underlined the scale of the accomplishment, noting the Canadian population at the time was only 12 million (25987).
Perrault said that while during the first decade of its operation the technical and recruiting costs of the blood system had been born entirely by the Red Cross by the closing years of the 1950's it was clear they could no longer carry on in this manner. An agreement was arrived at where federal and provincial governments would jointly assume responsibility for 30 percent of the technical and operating costs of the collection and distribution system in 1959. The Red Cross would continue to pay all costs associated with the blood donor recruitment (BDR) arm of the operation (25987-88).12

The CRC continued to pay all of recruitment costs until 1973 when the governments assumed financial responsibility for 30 percent of that operation. By then the governments' financial support of the technical side had increased to 90 percent. In 1973 an agreement was reached, whereby, all of the technical costs and 40 percent of the recruitment costs would be met by the governments involved. It was also agreed that support of BDR functions would increase to a maximum of 80 percent by 1976 (Perrault 25988-90).

Along with the changes came a number of problems. The structures and mechanisms in place for negotiating and managing the Red Cross annual budget in the early 1970's were a product of an earlier era. They were cumbersome, not well suited to the new fiscal environment. In an attempt to overcome this situation the Federal/Provincial Budget and Program Review Committee was established in 1974. As Davey explained, the Review Committee was seen as a means to better monitor and manage Blood Program spending and to facilitate negotiation and

12 It was not until the late 1985 that the two arms of the Red Cross Blood Program, BTS and BDR, were unified into a single entity (Lindores:401). The often fractious relationship between the two arms at times impeded communication. There were occasions during AIDS crisis where conflicting messages came from the different jurisdictions, complicating attempts to mount action.
communication between the provinces and the Red Cross (Davey 26088-89).\textsuperscript{13}

Among other things, the Committee was responsible for reviewing and approving the annual Red Cross budget proposal, a practice which contributed to the tense and acerbic relationship which existed between the Red Cross and the funding agencies during the 1970's and into the 1980's.

Perrault spoke of the strategizing and trepidation which preceded encounters with the funders and the need to regroup and redeploy his staff to prepare to meet with the often hostile bureaucrats. At a time when Red Cross officials had determined the blood system needed to radically transform itself, the new funding structure seemed to impede the realization of its goals (30597). Constantly having to go hat-in-hand to the Budget Review committee to get approval for every expenditure frustrated the Red Cross officials.

The late 1970's and early 1980's was a time of fiscal restraint and, as Stephenson suggested, the funders were growing uncomfortable with the spiralling demands of the Transfusion Service. They had seen the annual budget of the Service increase enormously during the decade of the 1970's, rising from 12 million dollars in 1970 to around 50 million by 1980 (Perrault 26274).

In late 1980, the Chapin Key Committee, a provincial body appointed to look into the problems surrounding the organization and functioning of the blood system, especially the area of blood fractionation, concluded that "it would be advisable to develop some public body to oversee, if necessary, [to] control and certainly monitor the blood collection processing and distribution system" (26285).

\textsuperscript{13} A more thorough history of the funding system was presented August 8 to 11, 1995, when a panel of four, former Canadian Blood Committee (CBC) members, Mr. Fred Anderson, Mr. Ambrose Hearn, Mr. Stephen Dreezer and Dr. Peter Glynn appeared before the commission. The CBC was the successor to the Budget Review Committee.
While demanding a few revisions to the Committee's Report, the provincial Health Ministers endorsed its plan to establish an inter-provincial authority which would set out and maintain a Canadian blood policy. The new agency was the Canadian Blood Committee (CBC).

The CBC was a national organization made up of representatives from each of the provinces as well as the federal government. It was to be a consensus building organization which would act on the behalf of the governments to set broad policy guidelines and allocate funding. Intended to establish policies regarding the collection, processing, distribution and utilization of blood and blood products, it was also responsible for maintaining the four guiding principles of the Canadian Blood Program: that the Program be based on volunteer blood donations; that Canada be self-sufficient in blood and blood products; that blood and blood products be distributed free of charge; and that the program itself be non-profit (26081, 26157).

Unfortunately, relations between the provinces and the Red Cross became even more strained. According to both Davey and Perrault, the increasingly acrimonious relationship, was due, in part, to the zeal with which the CBC Secretariat pursued a painstaking line by line analysis of the Red Cross Annual Budget.

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14 Quebec, the only hold-out, joined as an observer the following year and became a full member in 1983 (Hearn 35431). Perrault noted that Quebec's joining lessened the burden on the Red Cross because it meant that only one budget had to be prepared and presented rather than two (30680).

15 The first three of these principles emerged out the 1973 Charlottetown Conference (Perrault 26081), while the fourth appears to have emerged out the Chatfield Committee Report submitted to the Federal/Provincial Conference of Health Ministers in 1979 (Stephenson 26157).
Regulating the System

While the provinces were responsible for funding the system, the regulation of blood and blood products fell within federal purview. The federal government, however, lacked both the resources and the will to exert any significant degree of control over the Blood Service. While there was talk, both within the Health Protection Branch and the Red Cross, of the need to establish a regulatory structure for the System, it was not seen as a priority. The Red Cross after all, had established and operated the Program for over three decades. They were the experts in the field and they enjoyed wide public support.

The few regulations which did exist, fell within the jurisdiction of several agencies within the Health Protection Branch (HPB) of Health and Welfare Canada (HWC). The agency most directly involved was the Bureau of Biologies (BoB). The Bureau was part of the Drugs Directorate which had been formed in 1974. During its first two years the BoB was composed of the Bacterial Products Division and the Viral Products Division (Furesz:42502-2). In 1978, a third body, the Blood Products Division was created. This new division assumed responsibility for inspecting and licensing plasma collection and manufacturing centres as well as for reviewing and licensing new blood products (Furesz:42508-9).  

The latter of these responsibilities assumed precedence. This was in part a pragmatic decision (Pope 42575). A revolution was under way in the blood manufacturing industry in the late 1970's. This led to a backlog of new products awaiting regulatory approval. Understaffed and underfunded, the Bureau of Drugs focussed its efforts in the area of approving and licensing these new biological drugs. In the process the Canadian licensing system became a model of

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16 Plasmapheresis operations became subject to inspection and licensing in 1978 (Pope:42527); whole blood collections remained unregulated until 1989 (Pope:42491).
Structure and Organization of the Canadian Red Cross

Amidst all the change, two things remained constant: the internal structure of the Red Cross and the organization’s control over the day to day operations of the Blood Sub-System.

In the 1970’s, the Canadian Red Cross Society was made up of three branches: Domestic Programs (or Field Services); International Programs; the Blood Services Program. The actual operation of the blood system involved both the Blood Program Branch, which was responsible for the technical operations and the Domestic Programs Branch, which was responsible for blood donor recruitment.

All three branches were centrally administered by a Board of Governors made up of volunteers who generally served a two year term (Lindores:239). Within the Board was a sub-committee known as the National Advisory Committee. Composed of medical and scientific experts, the Advisory Committee provided technical advice on matters relating to the blood system (26021-22).

While the Board retained ultimate decision-making authority within the Society its primary functions, in terms of the Blood Program, were in the areas of establishing National Policy and reviewing the annual budget. The Board generally refrained from any direct interference in the technical operations of the Blood Program (Perrault 26010). On those occasions where the technical matters were of concern to the Board, they depended on their expert National Advisory Committee for advice. The Committee also provided advice to the CRC BTS (26021).

Next in the line of command was the National Commissioner, the highest paid position in the
Society. The Commissioner was responsible for all three Red Cross Program areas and reported to the Board of Governors (Perrault:26002-3).¹⁷

The Blood Program was headed by the National Director of Blood Services. He reported to the National Commissioner. In 1978 the position of Deputy National Director was established in order to provide assistance to the National Director. The Deputy Director assumed responsibility for the technical operations of the system, allowing the Director to concentrate on the ever increasing administrative responsibilities (Perrault:26017).

By 1979 the CRC BTS was made up of 17 regional centres, each headed by a Medical Director; most Medical Directors worked part-time and were rarely present on site, maintaining contact with the centre via telephone (Perrault:2600).¹⁸ At most clinics one or more Deputy Directors assisted the Medical Director (Davey:27102).

The Revolution in Transfusion Medicine

While the structure and organization of the Red Cross Blood Transfusion Service remained relatively constant throughout the 1970's a revolution was under way in the production and use of blood products. The enormous growth in the manufacture and use of blood products in the 1970's came out of two, almost simultaneous, developments in the field of transfusion medicine which had occurred in the previous decade. The first of these, the introduction of plastic bag

¹⁷ The title of National Commissioner was changed to Secretary General in the early 1980's (26002).

¹⁸ The Medical Director was responsible for the day to day operations of the centre. This included everything from coordinating the activities of the Nursing, Laboratory, Transportation and Administration departments to overseeing the core functions of the operation, including the collection and testing of blood, its separation into components as well as the shipping of raw and processed products (Lindores:403-4).
technology, helped protect the collected blood from contamination and facilitated the relatively safe and effective separation of blood into a wide range of components. It opened the door to the mass production of highly specific biological drugs, particularly those manufactured from plasma. These highly specific products enabled “better targeting of therapeutic modalities to particular groups of patients” (Perrault:25590-1).

The second major development came with Dr. Judith Poole’s discovery of cryoprecipitate. Poole found that the “bit of a blob” that always formed at the bottom of a bottle of fresh frozen plasma contained most of the clotting factors in the bottle. A few units of fresh frozen plasma could supply sufficient clotting factors to staunch most bleeds. In the years which followed, cryoprecipitate transformed the treatment of hemophilia. To many, it represented a first step towards freeing hemophiliacs from a life centred around the hospital (Perrault:26023).

The impact of Poole’s discovery, however, was not immediately felt within the industry. The production of cryoprecipitate was a relatively simple matter. While it required some additional resources it could be carried out within the regional blood centres, using existing equipment and blood supplies. The production of factor concentrates was a vastly more complicated matter requiring dedicated facilities.

In 1970, a new process was introduced allowing for the large scale production of concentrated and purified forms of the clotting factors (Perrault 26024). It was only following this that the full impact of the earlier discovery was realized. The popularity of the new clotting concentrates soared in the 1970’s. The rapid increase in the production and use of factor VIII and IX concentrates revolutionized the blood industry throughout the world, transformed treatment
practices and virtually “normalized” the lives of many hemophiliacs. The major down-side to all of this appeared to be a greatly increased risk of viral transmission, especially hepatitis. This was due, in part, to the pooling of up to 20,000 units of plasma in the production of a single lot concentrate. Infection with hepatitis became an accepted cost of partaking in the benefits of the revolution.

Perrault was well aware of the benefits associated with the new products. He recalled, during his training in the 1960’s, having to rely on the infusion of plasma to stem bleeding episodes. Not only were large quantities of the product required, the results were often unpredictable. He described how prior to the introduction of cryoprecipitate hemophiliacs lives revolved around the hospital; many spent up to nine months of the year institutionalized. With its introduction they were no longer hospitalized for months on end. The development of factor concentrates further freed hemophiliacs from the hospital setting (Perrault:25992, 26023).

The Growth of an Industry

The development of concentrates and their growing popularity created an increased demand for plasma. This led to unprecedented changes in the collection of and trade in blood and blood products around the world. Collections had to be stepped-up, especially plasma, which was the raw resource of this expanding industry. The international trade in blood components and

19 Concentrates became so popular, in fact, that by the early 1980's they were being promoted not only as a treatment for bleeding episodes but also as a prophylactic against future ones.

20 Where cryoprecipitate had to be stored at minus 40 degrees Celsius, the new concentrates could be stored at home in the refrigerator and administered by the patients themselves. For the first time in history hemophiliacs could lead a relatively ‘normal’ lifestyle carrying on careers, even those requiring travel. If a bleed occurred, the hemophiliac could treat themselves almost immediately, minimizing the potential for life threatening episodes while reducing the crippling effects caused by bleeding into joints.
products soared. Trans-national blood brokerage firms began to proliferate; populations in “developing nations” began to be ‘milked’ for their plasma.

When the Commissioner asked whether international brokers were indeed part of the plasma trade in the mid 1970's Davey replied that they certainly were and they presented a source of some concern at the time. He explained that brokers would assemble plasma from independent collection centres in the United States and elsewhere. This would then be sold to European or American fractionators who would process it into clotting concentrates and other products (26047-8).

Davey recalled that one of the concerns at the time was that at least some of the plasma entering the U.S. market originated from collection centres which were neither reputable nor well regulated. There was also a concern, he said, that populations in Africa as well as Central and South America were being exploited. According to Davey, however, there was little to be done about it, because it was impossible to trace the sources of the plasma. Plasma he suggested “is about as easy to trace to its source as it would be to trace milk to a particular dairy” (26048).

No one, either in Canada or the United States, appeared willing to raise an alarm about the situation. Concentrates were seen as a miraculous boon by patients and treating physicians alike; the blood industry, both the volunteer and commercial sectors, were preoccupied with trying to keep pace with the increasing demanded for the raw and manufactured products; government regulators had their hands full reviewing and licensing the wave of new blood products entering the market place.
Keeping Pace: Transforming Canada's Blood System in the 1970's

When Perrault took over as Director of the Transfusion Service in 1974 he found Canada had not kept pace with the rapidly changing collection, manufacturing and distribution environments. Rather than finding himself at the helm of a modern biologicals manufacturing and distribution organization, he found himself in charge of a "cottage industry," as much as 20 years out of date (Perrault: 25985, 26708). He quickly determined that if Canada was going to enjoy the benefits of the bio-pharmaceutical revolution under way, the system would have to be reorganized.

Perrault identified a number of deficiencies including the fact that too few doctors and researchers were involved in the blood program. He recalled, that at the time only 2 or 3 Medical Directors at the 17 Red Cross regional blood centres were employed on a full time basis. He began hiring full-time Medical Directors. In doing so, he sought to foster alliances with other researchers and institutions by encouraging cross appointments with the universities and practical communities (Perrault: 26000-1; Davey: 27103). The Red Cross officials believed these cross appointments would both increase the research and funding potential of the Red Cross while raising awareness about transfusion medicine within academic circles (26001).  

What Perrault needed were young people who had a eye to entrepreneurial endeavours: these were the kind of staff he required if he was going to drag the Canadian Red Cross out of the 1950's. In order to attract this sort of scientist he had to make the role of the Medical Director more meaningful and interesting. Towards that end he began working on patent sharing

21 Davey explained to the commission, "[y]ou got better value with cross-appointed staff because they provided a liaison with academic and practical communities" (27101).

22 It was 1983 when the CBC first provided the Red Cross with a research budget. Until that time the CRC was totally dependent on others for its research needs (Edwardh 26281-2).
protocols, drawing on models developed by the universities (Rock 23957-8).\textsuperscript{23}

Another thing to catch Perrault’s attention during his early tenure was the lack of a unified acquisition and distribution system for the new blood products coming onto the market. He described how he began lobbing the provinces, arguing, that if the Red Cross assumed responsibility for the purchase and supply of the new products, costs could be reduced and usage could be more effectively monitored. In 1978 the Red Cross was given control of the importation and distribution of clotting factors (Perrault 26026).

The CRC’s control over the collection and distribution of blood and blood products in Canada was complete but there was a new fly in the ointment. The enormous popularity of clotting concentrates had led to a shortage of plasma. Perrault recalled, how, in the late 1970's, for the first time since its inception, the Canadian Blood Program began to face critical shortages of plasma (26240).\textsuperscript{24}

The Problem of Self Sufficiency

Perrault was convinced the most pressing issue facing the System was that of self-sufficiency and it was clear from his testimony that this remained a major source of concern and frustration to him throughout his time as Director of the Transfusion Service. He told the commission that at the time he believed the conventional sources of plasma -- whole blood collections from which the plasma portion was then removed -- had reached their limits. He set about to expand the

\textsuperscript{23} Dr. Gail Rock, was Medical Director of the Ottawa Red Cross Blood Centre from 1974 to October 1988. She testified before the commission April 10 to 12 1995.

\textsuperscript{24} A sufficient supply of red cells had never been a significant problem, nor did it turn into one in the 1970's. The shortages which emerged in the later years of the 1970's and plagued the system through 1980's were for the most part the result of the increasing demand for plasma which accompanied the wide-scale production and use of factor concentrates.
CRC's plasmapheresis collections (26312).

He saw self-sufficiency as not only including the collection of enough whole blood and plasma to meet Canadian requirements, but also having the capability of processing that into fractionated products. He told the commission that from the time he took over -- to the present day -- there were no Canadian manufacturers capable of processing sufficient product to satisfy domestic requirements. He described Connaught Laboratories in Ontario -- the major Canadian blood fractionator -- as ill suited to the task, being lumbered with equipment and technologies belonging more to the 1950's than the 1970's (26053-7).

Canada was forced to depend on the U.S. manufacturers to meet its needs. Perrault said he was concerned about this reliance, because if an emergency arose, the Americans might well supply themselves first, leaving Canada to fend for itself (Perrault 26220). He devised a plan by which the Red Cross would open its own fractionation facilities. When he first presented it to the provincial funding authorities in 1976, they turned a deaf ear (26071).

Perrault was undeterred; there was no question in his mind of the need for a Canadian -- a Red Cross operated -- fractionation plant. He had a vision of a totally integrated system from the point of donor recruitment to the point of distribution. He struggled for years to get the funders to listen to him, but even with the support of organizations such as the Canadian Hematology Society, he was unable to gain the approval from the funding authorities (26080-3).

One of the problems, as Stephenson pointed out, was not everyone saw the principle of self sufficiency as encompassing the production side. Some provincial representatives were unwilling

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25 Apheresis technologies allowed for targeted collection of specific blood components. The donor is connected to a apheresis machine through plastic tubing and a needle in each arm. Whole blood is removed through one arm, this enters the apheresis machine where the 'target' component is separated. The remaining components are returned via the other arm.
to make any additional financial commitments to the Red Cross, especially if it meant further extending the Red Cross’ control over the blood system. They argued that Canada should focus on collecting sufficient blood and blood components to meet the needs of the country and leave the processing to the pharmaceutical manufacturers in the United States.

Perrault described it as a situation where many of the provincial representatives were more intent on insuring the interests of their constituents than they were in meeting the needs of the Blood Program. Manitoba, Quebec and Ontario, for example, all wanted pharmaceutical companies located within their own jurisdictions to be assisted in establishing domestic fractionation operations (26134-5). Stephenson pointed out that Ontario even went as far as to threaten to pull out of the National Blood Program if Connaught was not awarded a contract for the production of at least a portion of the clotting concentrates used in Canada (26163). While saying that he thought it was more a matter of posturing than it was a real threat, Perrault noted, with some chagrin, that the Red Cross was eventually forced by the Budget Review Committee to supply Connaught and two other Canadian fractionators with plasma, despite the fact that much of the precious fluid was being wasted due to production failures (26059, 26294).

4.4 Into the 1980's and Disaster

Could Things Have Been Done Better?

After outlining the general ground-rules for the second phase of their appearance Edwardh began her examination. Referring to Perrault as an obviously “intelligent and thoughtful person”, she invited him to share with the commission, any views he might have as to “to what, if anything had gone wrong, that led to so many hundreds of people becoming infected as a result of their use of blood products” during the early years of 1980's (27044).
Perrault’s immediate response was “that given the context of the time... people did their best with the knowledge they had” and that he would leave it to the commission to make any judgements in hindsight as to what was correct or incorrect. Nevertheless, he did allow that in retrospect a few things “were of some significance in this context”. The most critical of these -- the lack of national self-sufficiency in plasma -- was a problem, he suggested, shared by many countries. While acknowledging that self-sufficiency would not have eradicated the problem in Canada, he said it certainly would have lessened the impact of the disease on hemophiliacs (27045-46). Beyond that, Perrault found it “very difficult to judge, on individual specific measures, which one would have been truly more effective.” He felt that overall, if one looks at the transmission of AIDS through blood and blood products on a prevalence basis, adjusting for population differences, Canada had a lower rate than many countries (27047-48).

Lower rate or not, Edwardh was interesting in discussing some of the specific measures which might have lessened the impact of the disease on the Canadian blood supply and its users. Was the timing of the introduction of “specific information for prospective donors” a significant factor in this respect, she asked?

Perrault replied that he did not think so and that he expected his reasons for this would be elaborated on during the course of the coming days (27050).

Edwardh then asked Perrault whether there was anything else he felt had not been done as quickly as it could have?

Perrault offered that on a more general level, and further down the scale, there was the problem of “the lack of a national blood policy.” The lack of a national policy, he said, created difficulties for the Red Cross as well as the provincial and federal health authorities involved with AIDS. The failure to set out any clear definition of responsibility made it difficult to act.
The ability to mount an effective response to the disease, he said, was further hampered by the structure of the Canadian Health System. "[R]emember the context we are dealing with... We are trying to deal with a national issue in an area of provincial responsibility. And that is difficult at the best of times" (27051-52).

In charting out some of the other factors which may have affected the early response to AIDS, Edwardh explored the Red Cross's reliance on consensus decision-making. She asked Perrault whether he agreed that the Red Cross was committed to a consensus decision-making process; that this applied both to its internal functioning and to its external interactions; and that in consequence the entire process was "tedious", "slow", and "time consuming" (27054).

Perrault agreed. The Red Cross relied on consensus decision-making, both in its internal and external dealings. He maintained, however, that the question of whether this sort of decision-making impedes response speed has to be examined "on a case-by-case basis". Acting without consensus, he argued, may take even longer, especially if you have to reverse yourself later (27055-57).

The Commissioner wanted to know what effect the commitment to consensus had in the context of the fragmentary structure of the blood system. He asked Perrault, whether in retrospect it could be said that requiring the Blood Services arm of the CRC to get the "agreement or approval" of the non Blood Services arm, contributed to "the problems that arose out of decision-making" (27057).

Perrault replied that it was an issue in terms of "administrative matters" but not as far as "technical matters." On technical matters, Blood Services dealt with the National Advisory Committee and this was usually preceded by consultation with the Medical Directors. He told the commission that he could not recall one occasion where the Board contradicted the National
Advisory Committee (27057).

When pressed further by the Commissioner, Perrault acknowledged that while the Board may not have contradicted the Advisory Committee it did have to be consulted on some issues and this had the potential to slow things down (27058). He also acknowledged that had the Red Cross authority structure been unified, the operation of the Service would likely have been more efficient (27061).

Edwardh turned to Davey asking him whether, “having had an opportunity ...to review the records and think about the organization and the decisions made,” he had any views on what went wrong and what could have been done differently (27062-63).

Davey explained that to adequately address the question, two aspects of the problem must be distinguished one, the transmission of AIDS by clotting factors; the other, the transmission of AIDS by blood and blood components. Each required different control measures, he said (27063). He suggested, for example, that the infection of many Canadian hemophiliacs could have been avoided had there been “one, co-operative competent plasma fractionator”. This simple solution to the problem, he lamented, had been prevented by some “provinces and organizations” pursuing their own interests “to the detriment of the safety and efficiency of the system” (27064-65).

The existence of a single component manufacturer would not have solved all the problems, of course. There was the problem of transfusion-associated AIDS and that could not be resolved at the manufacturing level. But here, as elsewhere, Davey described the Red Cross as handicapped by “divided and ill defined systems of control” (27066).

Part of this problem, he admitted, rested in the Red Cross structure; the separation of authority within the organization had led to delays in the production of printed donor information. He
insisted, however, that these delays had no great significance in terms of the spread of the disease through the blood supply (27067-68).

The real problem, according to Davey, was not so much in the structure and organization of the Society, as it was in the lack of support it received from the provincial and federal authorities when they tried to put decisions into action. The Red Cross, he said, would have been more successful in accomplishing what had to be done to control AIDS, if the health authorities had given more attention to the disease. He explained that they did get some support, both from the Laboratory Centre for Disease Control (LCDC), and the National Advisory Committee on AIDS (NACAIDS). Far too often, however, they were left to stand on their own, especially when it came to unpopular decisions such as excluding groups considered at high risk for the disease. Rather than government authorities coming forward and saying “look, they are doing what they have to do,” the Red Cross found itself alone, facing accusations of discrimination (27043-44).

Yet, despite all these problems, Davey was satisfied that the Red Cross’ overall effort to control the disease had been effective. This is born out, he maintained, when the outcome in

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26 The LCDC’s mandate was to provide “epidemiological, laboratory surveillance and diagnostic systems for disease control”, as well as the “[p]revision of national programs, microbiological reference services, quality assurance systems and laboratory medicine” (Clayton 41366). The LCDC was the Canadian version of the CDC, although it was much smaller than its American counterpart and far less able to carry out the sort of work the CDC engaged in. Where the CDC had a staff of approximately 2,000 in the early 1980’s the LCDC made do with about 150. The CDC’s budget was about three hundred times that of the LCDC. Like the CDC, the LCDC publishes a weekly report, the Canadian Diseases Weekly Report (CDWR) (Clayton 41379-80).

27 NACAIDS, established by the Minister of Health in September 1983, was made-up of 16 physicians from across the country. It had a mandate “to make recommendations to the Minister with respect to federal government leadership in the control, prevention, and management of Acquired Immunodeficiency Syndrome” (Exhibit 684:tab 26).
Canada is measured against what is observed elsewhere (27075).

Accounting for the Red Cross's Early Response to AIDS

Supply Issues

Moving from the structure and organization of the blood system Edwardh explored "some other aspects of the context" which might have affected decision-making during the early days of the epidemic. Drawing attention to issues surrounding the supply of blood and blood products, she asked if the witnesses agreed that the blood shortages which reoccurred consistently after 1981 placed additional pressures on the Blood Service? She also wondered whether "...the drive to produce fresh frozen plasma" as well as the goal of self-sufficiency contributed to the pressures on the System (27083)?

Perrault agreed; the shortages placed a continual and growing pressure on the System throughout the early 1980's. He also allowed that the drive to produce fresh frozen plasma for fractionation further increased that pressure but he saw the goal of self-sufficiency as being a somewhat different case. While it may have further increased the stress, "...we [the Red Cross] were creating that pressure" (27085).

Edwardh said that her concern was not whether the pressure was internal or external in origin; she simply wanted to know whether Perrault would identify the "operating principle" of self sufficiency, as one of the pressures at the time.

Perrault replied that it was, in terms of getting sufficient funding to achieve that goal (27085). Edwardh pointed out that the documents indicate the issue extended beyond the fiscal domain. The commitment to self sufficiency created "a real need to keep and maintain the donor base". Perrault conceded that it placed an added emphasis on maintaining the donor base (27085-86).
Expertise within the Red Cross

Another important part of the context in which the decisions were being made rested in the expertise of the decision makers. Edwardh began to explore this issue by asking the witnesses whether anyone at the National Office -- aside from the laboratory staff -- had special expertise in the areas of infectious diseases and/or public health.

Perrault replied that he had none himself, and was unaware of anyone at National Office -- other than Davey -- who did have any expertise in those areas (27097).

Davey began by making it clear that he had no specific training or qualifications in either area, beyond that acquired during his “undergraduate training in clinical work”. He quickly added, however, that he had developed an interest in hepatitis as a result of his practical experience as a blood banker. He said that while working in Australia he had studied or supervised research on the serological epidemiology of “hepatitis, tetanus, diphtheria, varicella and other herpes viruses.” He also recalled having lectured in the areas of microbiology and viral hepatitis (27097).

Davey went on to describe how he built on this experience in the course of his work in Canada. From that “point of view,” he suggested, he “had training in laboratory management and the evaluation of laboratory methods which included training in general epidemiological concepts of screening for disease.” His interest in this area, he said, led him to both conduct studies and publish articles on the subject. These publications, he explained, were mainly in abstracts and so were not included in his Curriculum Vitae (27099).

Edwardh returned to Davey’s claims a few days later noting that the only peer reviewed

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28 Serological epidemiology, he explained, involved the use of serological tests to measure the incidence and prevalence of particular diseases (27097).
article on hepatitis mentioned in Davey's C.V. was published in 1964 and dealt with the neurological complications observed in two individuals with chronic liver disease. She then went on to clarify with Davey that when he was saying that he had a special interest in hepatitis, he was not claiming the expertise of a specialist working in the field.

Davey agreed, he was "by no means" making such a suggestion. "...[I]t is not my principle professional interest" (28877).

Access to information

Regardless of how skilled and knowledgeable they were in the areas of infectious diseases and public health, their decisions could only be as good as the information they had to work with. Edwardh was interested in determining the extent to which Perrault and Davey had been able to keep up with the information appearing in the scientific, medical and public health journals during the early years of 1980's.

Perrault began by saying "[L]et's define the term 'keeping up'. A lot of this was at the scanning level". He went on to explain that before Davey arrived at the National Office, a system had been set up whereby a senior technologist "would scan the journals and make a synopsis." Perrault would read the synopsis. As he recalled the synopsis would also be circulated to the regional blood centres. He said that while he would peruse the journals every week or two, he was more likely to read specific articles when someone brought them to his attention. Overall, he considered himself to have kept "fairly well" abreast of the information appearing in the speciality journals during the early 1980's (27117-18).

Davey, like Perrault, believed that he had "kept up" with available information. He described how he would scan journal indices looking for relevant information and had "...depended, to
some extent, on abstracting and reprinting services...”. He paid particular attention to “the American Blood Services newsletters because they reprinted ...much of the relevant information”. He also read the *Canadian Diseases Weekly Report (CDWR)* in order to track information in the field of epidemiology. The *CDWR*, he explained, tended to reprint relevant *MMWR* items; it “was our standing resource” in that area (27119).

**Institutional alliances**

As well as exploring their access to published information Edwardh traced out Perrault’s and Davey’s associations and interactions with other blood bankers and blood banking agencies.

Perrault told the commission that he had not been a member of the American Association of Blood Bankers. He explained that the CRC BTS budget presentation coincided with the annual AABB meetings making it impossible for him to attend them. The commission learned that Perrault’s commitments at the CRC had kept him from the AABB annual meetings and that he felt there was no real need for him to join; enough of his staff were members to ensure he was kept well informed of happenings within the AABB (27119). Davey had become a member of the American Association of Blood Banks (AABB) in about 1974. He recalled the CRC regularly receiving and reviewing information from the AABB, as well as the American Red Cross, and the Council of Community Blood Centres (27120-1).

Davey agreed with Edwardh’s suggestion that the relationship between the Canadian and American Red Cross had been good, and that the ARC consistently gave its sister organization “the benefit of their views, their advice and their experience over this entire period from 1981 to ‘85.” He illustrated the closeness of the relationship, pointing out that Dr. Dodd, the senior physician in the Red Cross Blood Services in America, had been a member of the Canadian
Blood Transfusion Service Advisory Committee and that for a period of time, Perrault played a reciprocal role as a member of their Advisory Committee (27123-5).

Safeguarding the System: Donor Screening and Blood Testing

Exploring some of the other elements affecting Red Cross decision-making in the early 1980's Edwardh sought Perrault’s and Davey’s views on blood donor screening and blood testing. She began by asking, whether, given his experience dealing with hepatitis, Davey would agree, “the primary vehicle for preserving the safety of the blood supply, arose from the careful selection of blood donors?” Was this why the volunteer system was considered so important, she asked (27132-3)?

Davey agreed: the selection of donors was of critical importance. There was no question that blood collected from volunteer donors had a lower likelihood of transmitting diseases such as hepatitis.

Edwardh wondered whether he would also agree that donor screening was of primary importance in the selecting of donors, that it presented the first line of defence when it came to protecting the blood system from contamination (27133)?

Davey replied that screening was intended to protect both donor and recipient, and that while it was an important part of the program to safeguard the blood supply, it was not the primary element. Experience had shown that individuals who appeared quite normal from the perspective of their medical history and their physical health could be carriers of hepatitis. Only laboratory testing could detect these carriers (27133-4).

He also refused to accept Edwardh’s assertion that screening was the first line of defence. Screening had to go hand in hand with testing. He was even reluctant to accept the primacy of
screening in situations where no specific tests to detect the disease existed. In those cases, he argued, there was always the possibility of using surrogate tests. He qualified this, however, noting, in the case of hepatitis, none of the surrogate tests “proved particularly effective and donor screening appeared to be the most effective measure.” In bringing the matter to a close, he returned to his earlier point, “the absolutely most effective measure in reducing hepatitis transmission by transfusion, was not paying donors” (27134-35).29

Edwardh ended the opening phase of her examination by drawing attention to the strict order of command within the Red Cross. She pointed, for example, to the donor questionnaire employed at the clinics, noting that it was designed by National Office through its committee structures (27141) as was the donor criteria manual (27142). She then suggested that: “When it came to the application of the appropriate questions to be addressed to donors, and when it came to the health questionnaire...and the kind of deferral that any specific response would generate...that was a matter of national standards. They weren’t minimum standards, they were national standards” (27145).

Perrault agreed, Medical Directors were not expected to deviate from the standards prescribed by National Office (27146).

29 Edwardh returned to the issue of surrogate testing the following day, suggesting, when it came to the dealing with problem of AIDS in the blood supply, surrogate testing was never seriously evaluated by the CRC. Davey explained that it had been addressed in internal discussions amongst members of National Office and the CRC’s National Reference Laboratory but the evidence was felt insufficient to warrant any formal consideration. Instead of evaluating the tests themselves, Red Cross National Office chose to rely on reports provided by their point man on AIDS Dr. Derrick; reports based on information gleaned at U.S. meetings (27347).
Summary

Into the 1970's

During the opening days of their appearance, Stephenson led Perrault and Davey through a history of the Canadian Blood System from its early roots in the World War II effort to supply blood for the wounded, to the emergence of the first national volunteer system in 1945, through the turbulent years of the late 1970's and early 1980's. The commission learned that the CRC had set-up the National Blood Service at the request of the federal government and the Canadian Medical Association and that following its establishment, the blood system had been largely neglected by the federal and provincial authorities. Only in the 1970's, after the provinces had assumed financial responsibility for almost its entire operation, did attention begin to fall on the blood system. This attention, however, tended to be restricted to controlling spending rather than providing any meaningful direction or regulation.

The witnesses described the 1970's as a period of rapid transformation, which not only saw enormous changes in the fiscal structure and management of the system, but also in the collection and processing of blood and blood products. It was also a period in which new products and new treatment modalities were developed and introduced. The new techniques provided enormous benefits to patients, virtually normalizing the lives of thousands of hemophiliacs.

The commission also learned, however, that by the time Perrault took command of the Transfusion Service in 1974, its technology and organization was sadly out of date. If Canada was going to participate in the revolution which was under way in the blood industry the System would have to be modernized, and rapidly. According to Perrault and Davey, this was not an easy task. The System was plagued by a myriad of problems: new practices and technologies were creating ever increasing demands on already limited resources; administrators struggled with out-
dated facilities and equipment; governments and regulators showed no leadership; the roles and responsibilities of the various participants remained undefined; and an air of hostility permeated the relationships between the various institutions involved. The situation was exacerbated by the rigid, hierarchical structure of the Red Cross which further impeded its ability to respond to the changes going on around it. By the late 1970's officials at the Red Cross National Office faced a System which was chronically underfunded, poorly organized, beginning to face blood shortages and subject to increasing political interference.

Into the 1980's

Edwardh built upon Stephenson's examination to establish an overview of the blood system on the eve of the disaster. She began by inviting the witnesses for their evaluation of the success of the early strategies employed to safeguard the blood supply from the threat of AIDS and sought their insights into the structural and practical impediments they encountered in attempt to mount action.

The witnesses defended the Red Cross's initial response to the disease arguing that given the circumstances, at the time, it is difficult to see how things could have been done better. When pressed, however, they pointed to a number of structural and practical factors which mitigated against taking a more proactive stance. In doing so they acknowledged that a few of the impediments and pressures originated within the Red Cross itself.

They agreed with the Commissioner and Edwardh that the fragmented structure of the Red Cross may have slowed efforts to educate and inform the public of the risks of AIDS as well as impeding the speed with which decisions were made within the organization. They argued, however, that these factors really had little effect on the overall outcome. The proof of this, they
maintained, is reflected in the infection rate seen amongst blood recipients. In this respect, they insisted, the Canadian record is a good as or better than most countries.

They also agreed with Edwardh that while the officials at National Office were highly skilled and experienced in transfusion medicine and blood collection they had limited expertise in the areas of public health and infectious disease. The witnesses pointed out, however, that they were not alone, they had a range of resources to draw on, including colleagues and institutions involved in blood collection in the U.S., Europe and elsewhere as well as industry publications and scientific journals.

They agreed that the increasing demands for blood and blood components which accompanied the rapid growth of the plasma processing industry in the 1970's and early 1980's along with the accompanying blood shortages and the strict goal of gaining Canadian self sufficiency -- both in terms of supply and processing -- had placed extra pressures on the System during the early days of the epidemic. They allowed that these supply issues coupled with the perceived need to appease volunteer donors, so as to not loose their support, had affected the decisions regarding appropriate safeguards -- especially in the area of donor screening.

Both Perrault and Davey argued, however, that the main problems they had to cope with lay outside of the Red Cross in the unwieldy structure of the blood system itself, especially in the ill defined roles and responsibilities of the participants. There was no leadership; the federal government abrogated its responsibility to regulate. The provincial governments, responsible for financing the system, insisted on putting their economic interests above what was best for the blood supply and its users. When the Red Cross officials attempted on their own to implement the unpopular but necessary safeguards they received no support from the government agency and authorities.
Throughout their testimony Perrault and Davey, maintained that if there were failures in Canada’s initial response to AIDS in the blood supply, they could not be blamed on the Red Cross or its staff.
CHAPTER FIVE: DR. PERRAULT AND DR. DAVEY: THE RED CROSS RESPONSE, JULY 1982 TO MAY 1983

Introduction

I have divided my account of Dr. Perrault's and Dr. Davey's testimony into two sections. These sections reflect what can be seen in the witnesses' testimony as two distinct although interconnected phases in the Canadian Blood System's initial confrontation with and reaction to AIDS. During the first phase, July 1982 to April of 1983, Canadian Red Cross officials established research priorities, gathered information, accessed the American response to the disease, outlined a broad plan of action and enlisted support for their strategies from within the Red Cross. It culminated with the revision of the blood donor questionnaire in the spring of 1983.

The second phase, which I address in the next chapter, covers the period May 1983 until May 1984. During this time Red Cross officials continued to monitor and access emerging information, elaborated and formalized the organization's response to the disease and enlisted further support for their plans from both within and outside of the organization. The second phase culminated with the production of the first Canadian donor information pamphlet in the spring of 1984.

Tentative First Steps

Having established a contextual frame, Ms. Edwardh turned to the early understandings of AIDS in Canada and the initial development of a strategy to protect the Canadian Blood System. She began by reminding Perrault and Davey that the first report of a new illness in the gay community appeared in the MMWR in July 1981 and that by the time the first report of hemophiliacs with unexplained immune abnormalities was published in July 1982 "AIDS was
already recognized as a serious public health problem in the United States” (27145-6).

Edwardh suggested that despite the increasing awareness and growing concern surrounding
the disease during this period, the Red Cross neither contacted other public health and blood
collection agencies, nor did they take any discernable actions to deal with the problem (27147).

Perrault and Davey agreed with her general outline of the situation although they cautioned
that just because they had taken no direct action it did not mean they had not discussed the
problem with other agencies.

While unable to recall specific instances when such discussions took place, Perrault would not
rule out the possibility they had occurred. Davey remembered receiving a call from Dr. Aronson
of the FDA sometime in mid-to-late July 1982. During the call Aronson mentioned that the
MMWR was about to make a report -- or it had just appeared -- of two cases of immune
deficiency in hemophiliacs.¹ According to Davey the question he was left with after talking to
Aronson, “was whether this was AIDS, or whether --or what exactly it was” (27148-9).

The MMWR report marked a turning point for the Canadian Red Cross. In the following
months the CRC became involved in an unprecedented series of meetings, committees, working
groups, discussions and press releases, all of which were focussed on the issue of AIDS and the
blood supply. During this period the CRC, for the first time in its history, found itself the object
of concerted and sustained criticism.

¹ The July 16 MMWR, actually mentioned three cases of unexplained immune deficiency
among hemophilia A patients. Two had already died, while the third remained critically ill
(Exhibit 549:tab 29).
Early Research and Education Programs

Drawing attention to the period immediately following the publication of the July 16 *MMWR*, Edwardh began to explore two key elements in the Red Cross's initial responses to the news: its program to inform physicians of the risk of contracting AIDS through the use of blood and blood products; its attempts to establish a research and surveillance program.

*Informing the medical community*

Edwardh pointed out that following the report's publication the Red Cross received two phone calls from Dr. Furesz, head of the Bureau of Biologics. The first of these, she said, came on August 3rd, when Furesz made an informal phone call to the CRC National Office to inquire if they had established a position in light of the recent *MMWR* report. He learned the CRC had taken no position. The following day, Furesz called back. Making it clear he was wearing his "official hat" he requested the Red Cross notify all physicians who might be administering blood products of the possible risk of AIDS transmission. He also asked for assistance in establishing a surveillance program amongst hemophiliacs (27155).²

Davey explained to the commission that the Red Cross had been eager to comply with the requests but there were limitations to what they could do. They could not be expected to notify all physicians in the country who might be transfusing blood or blood products to their patients. This was simply beyond their capabilities and was not what Furesz was expecting anyway. It was agreed, he explained, that the Red Cross -- through its regional blood centres -- would immediately notify its regular users, the hospitals, of the potential risks associated with the use of

² In an August 13 1982, memo to file, Derrick presents a slightly different account, reporting that the first phone call came from Jessamine of the LCDC, Ottawa. The next day Furesz called to officially request the assistance of the Red Cross (Exhibit 614:tab 46).
blood and blood products. From there, he said, it was believed the normal pattern of communication would take over, and the information would "trickle down" to individual physicians and their patients (27156).

Edwardh suggested that there was no evidence at all that the Red Cross issued an Alert to the hospitals during August of 1982. Davey agreed, no formal Alert was sent out at the time. He insisted, however, that a good deal was done by way of personal contact at venues such as the Royal College meetings (27187-8).³

_Surveillance_

Edwardh was also critical of the Red Cross's early attempts to initiate a surveillance program. She suggested not only its efforts to comply with the request, but its entire involvement in the initiative, left much to be desired. Questioning the decision to ask the Red Cross to initiate a program of surveillance in the first place, she wondered if Davey had found Furesz's request at all unusual?

Davey said, he felt there was nothing odd about asking the Red Cross to participate. He explained that "there was a defined role for the Red Cross within what comprises surveillance.... [S]urveillance is not just watching. It is watching, analyzing and drawing conclusions and then propagating those." One of the things the Red Cross could do, he said, would be to provide details about the product and the prominence of its constituents (27169).

³ Davey later explained that the National Office felt no responsibility to directly inform hospitals of the risk so long as there were "no solid facts", so long as the information was "tentative and incomplete". He went on to suggest that while the hospitals may not have been contacted directly by National Office, the Hemophilia treatment centres had been notified. He felt certain the information would "trickle down" from the treatment centres to the physicians (27253-4).
Outlining the Red Cross’s efforts to establish a surveillance program, Edwardh drew on an August 13th Trip Report by Dr. Derrick. The report detailed a meeting he attended between the CRC and the Ontario Public Health Central Laboratory. According to the report, the two agencies met on August 10 1982 and agreed to carry out a “...mutual pilot study...to assess the antibody profile of some 100 hemophilia A patients in order to determine whether these individuals were indeed at risk of contracting infections because of AIDS” (27164).

Edwardh also pointed to a letter Furesz wrote after being informed of the proposed study, noting Furesz was “obviously enthusiastic” about the planned antibody study. She wondered whether that enthusiasm had been misplaced? Was the CRC actually capable of conducting such a study even with the assistance of the Ontario Laboratory and the CHS (27170)?

Before Davey could respond, Commissioner Krever asked; “What antibody could you have discovered?” (27171).

Davey replied: the idea was “that you could measure a variety of antibodies. On the one hand, for example, the blood group antibodies which are natural constituents, which occur naturally, the level of which may be depressed in immune deficiency. On the other hand, antibodies to common infectious agents, such a the herpes group of viruses --“ (27171).

The Commissioner interrupted, asking how the discovery of such antibodies would lead to the conclusion that a transmissible agent was causing the loss of immunity (27171).

“It couldn’t lead you to that conclusion,” replied Davey. It was essentially a study of immune function. The levels of antibodies to naturally occurring or known agents were the tools of the study. “If, for example, ...you measured blood group isogluttins and you found significantly depressed levels in a group of hemophiliacs, that would suggest some sort of alteration or suppression of immune function, systematically.” What was being proposed was “a sort of
marker study of overall humoral immune function in individuals... it wasn't a search for a specific immune agent" (27171-2).

Edwardh pursued the issue. Noting that it was clear in the MMWR's of the time, that AIDS was associated with the reversal of T-cell ratios, she asked whether the proposed research would have looked at T-cells?

Davey said, that the Red Cross recognised the focus of their study, humoral immunity (which involved B-cells), was not the only thing involved in the disease, but neither they, nor the Ontario Laboratories, had the equipment to pursue the type of cellular immunity studies which were becoming the standard in AIDS research. The Red Cross, like many others at the time, he explained, became subject to "very quickly changing concepts" and limited resources (27173-4).

Edwardh left the question of the surveillance initiative for the moment but returned to it a short time later drawing attention to a joint meeting between the CRC, the LCDC, the BoB and the CHS MSAC (Medical Scientific Advisory Committee). Pointing to another of Derrick's trip reports, she noted the meeting, held in Ottawa on September 27 1982, had been convened to discuss the current situation in Canada in terms of the occurrence, reporting, and identification of AIDS amongst recipients of blood and blood products (27199).4

Edwardh suggested that at the meeting, Derrick announced the CRC was "... not able to initiate a reporting system, verification of reported cases and possible coordination of specimen testing." Had it not been evident from the time the BoB had come knocking at the door, the Red Cross could not carry out these functions, she asked (27200)?

Perrault pointed to the opening paragraph of Derrick's statement which alluded to the

4 Among those present at the meeting were the Director of the LCDC, Jessamine, the Director of the BoB, Furesz, the Chair of the CHS MSAC, Dr. Strawczinski, and Derrick, the Red Cross' "main point-man on AIDS" (Edwardh 27200).
problems encountered trying to fulfil the BoB request. The position being expressed at the meeting, he suggested, reflected Derrick's experience trying to initiate a surveillance program (27201).

Davey offered a different interpretation of the statement, arguing that it should be read with an emphasis on the term "initiate". The Red Cross was 'willing and able' to be in "the surveillance loop" but the appropriate centre for the initiative was the public health system. It goes back to a point Edwardh was "trying to make earlier," he said. "...[P]erhaps we are being asked to do one or two inappropriate things. There are things we can offer to do. But this is a primary function" (27201-2). The Red Cross, he explained, did not have the capability of carrying out such an undertaking. It did not have access to the necessary information. Cases might be diagnosed anywhere in the health system and there was no reason to believe the information would get back to the Red Cross (27203).

Davey used the example of hepatitis to illustrate his point. Hepatitis was a reportable disease yet the Red Cross was not always notified of transfusion associated hepatitis cases (27203). AIDS, by implication, would present an even more difficult problem. It was not a reportable disease at the time. If the Red Cross couldn't rely on being informed of cases of hepatitis, how was it going to track a disease that was not even reportable?

Edwardh remained unconvinced. The Red Cross, she suggested, appeared unwilling to be involved in any research aimed at detecting AIDS in the blood supply. She pointed to Derrick's reaction to a suggestion Jessamine made at the meeting, that perhaps blood products themselves should be looked at (27208). Derrick, she said, left no doubt about what he thought of the idea. He was "firmly against any such step." He told the group that such a study would be futile because they had no idea what to look for. He also made it clear that he was concerned about
such an undertaking because “...if a suspicion arose about blood products currently distributed by
the Canadian Red Cross, it could seriously harm our capability to provide a number of products”
(27209).

Davey denied Derrick's statements reflected a general reluctance to become involved in
research. It was a specific response to the proposal put forward by Jessamine; there simply was
no constructive plan behind the proposal, he said. Experience, Davey said, had shown that it was
“very unrewarding to look at blood products in terms of viral contaminants” unless there was
some specific target in mind; blindly looking for a contaminant was a waste of time (27210).

Edwardh said she found it strange Derrick would suggest that to inquire is to risk suspicion,
“...is to risk people turning away from the product...” (27211).

Davey said that it must be remembered that Derrick stood at the far end of the spectrum. He
was expressing a concern, in his own “typically cautious way”, that any suspicion cast on the
product would cause patients to stop using it. Derrick, he surmised, was likely trying to avoid
putting hemophilia treaters “in the difficult position of having patients refusing treatment, which
they thought was essential” (27212-3).

When asked by Edwardh whether he would have undertaken such a study, Davey replied he
would, but only if it was properly targeted and within the technical means of the Red Cross.
Jessamine's proposal met neither requirement (27213). Davey felt Derrick's reservations well
founded; there was nothing to be gained in “raising a fear by undertaking something that was
predictably fruitless” (27214).

Edwardh returned to the Red Cross's commitment to carry a surveillance program the
following day. This time she questioned whether the joint research project had progressed at an
adequate pace. While the initial meeting between the Red Cross and the Ontario Provincial
laboratory had taken place in August 1982 it was April 1983 before any proposal was submitted for funding, she noted. Was this not an inordinate length of time for a matter of such urgency, she asked (27263)?

Davey did not think so: “I would have to say one was working to really quite a tight time schedule”. You have to keep in mind, he said, that following the August meeting, Derrick first had to go out and enlist the support of a group of experts to develop the protocol for the proposed research. Davey described it as an achievement “… on Derrick’s part to have got together a group so qualified… He had really gone out pushing… Provoking people’s interest, identifying appropriate people and pushing them to do something that wasn't necessarily in their direct line of interest” (27263-4).

Whether or not the time frame was reasonable, the research project came to nothing in the end. By the time it reached the funders it had become clear research on humoral immunity would yield little insight into either the transmission of the disease or its treatment. Funding was denied, the project was abandoned (Davey 27165).

Several years passed before the Red Cross would again make an effort to carry out any research into AIDS, an unfortunate state of affairs. One of the consistent problems facing the CRCS during the early years of the epidemic was the relative dearth of reliable Canadian data on which to base its decisions.

Edwardh was puzzled why the Red Cross had undertaken so little research into the disease during the early critical days. She pointed out that in 1983, for the first time in its history, the Red Cross established a formal research program. The program, directed by Davey, had

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5 The program was established following the CBC’s approval of the setting aside of up to 1 percent of the total annual CRC BTS budget (about $500,000) for research and development purposes (Edwardh 25596).
approximately 990,000 dollars in funding for the years 1983 to 1985. Yet, during that period, Edwardh noted, not one study relating to AIDS or donor screening was carried out by the Society. Despite this, the Red Cross claimed that moving research forward into the question of whether AIDS was transmitted by blood and blood products was a priority (27596-8).

Davey reminded Edwardh that there were a variety of means for moving research along, some of which they had already discussed.

Edwardh said she took it that those means all proceeded outside of the organization.

Perrault replied, as far as he knew, that was the case (27598). He suggested the lack of a research initiative within the CRC BTS perhaps reflected a reticence, on the part of the Medical Directors, to spend the entirety of their new research budget on AIDS. The type of research necessary “was of a very large nature”, he explained. It was a costly undertaking and it could quickly swallow up the entire research budget for the year. “...[W]e felt that we were better advised to support a major request to have this done outside of the Red Cross” (27598-9). (And without a commitment of Red Cross funds, as Edwardh was careful to point out (27599).)

Gathering and Evaluating Information

Like many public health organizations throughout the world the Red Cross relied on the data emerging from the U.S. This was especially true in the months following the report in the July 1982 *MMWR*, when Canadian blood officials were struggling to formulate a policy on AIDS.6

Edwardh reviewed the quality and availability of the information coming out of the U.S., looking at the information available as well as the mechanisms and processes through which it

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6 Paradoxically, while making themselves dependent on the U.S. data, the Red Cross officials argued that the information and measures coming from their American counterparts could not be directly applied to the Canadian situation.
was gathered and interpreted in Canada. She pointed to a meeting of the Immunology/Virology Blood Transfusion Service Working Group held in early September 1982, asking if she would be correct in suggesting this would be the group within the Red Cross with the most expertise in the area of virology (27174-5). Davey described the working group as representing the greatest concentration of expertise in the CRC, both in terms of infectious diseases and virology (27175).  

Edwardh said that the meeting had been convened to consider the emerging information concerning the risk AIDS posed to hemophiliacs. She noted that after some consideration the Working Group reached the opinion the evidence suggesting hemophiliacs were at risk was “still inconclusive” and had been given far too much attention in the press. While acknowledging that Davey had not attended the meeting, she wondered if he could explain, in scientific terms, what his colleagues meant when they used the language “still inconclusive” (27176)?

Davey replied that he understood them to be saying a couple of things: first, they were “...uncertain as to whether the immune deficiency observed in hemophiliacs was AIDS in the same sense as that reported...in the homosexual community;” second, “...they did not consider there was conclusive evidence, whatever this was, that it was an infectious agent” (27177).

Edwardh asked what the basis was for these conclusions? What information was available to the group at this time? Were they, for example, in touch with the CDC?  

There was little information beyond that published in the MMWR, he said. There was of course a great deal of background material available about AIDS or GRID. That information, he suggested, had been accumulating for some time, but it did not specifically address the problem

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7 He explained that it had initially been formed to deal with issues surrounding the production of immune globulin and was made up of experts from the Canadian Red Cross, the federal and provincial health services, as well as the American Red Cross. It brought together experts in the fields of biology, immunology and public health (27175).
of transfusion associated AIDS.

Neither he, nor Perrault, could recall having any formal contact with the CDC, although Perrault speculated that Derrick may have spoken informally to colleagues at the meetings he attended in the United States. Davey said he expected the BoB and the LCDC would be in touch with the CDC and they would pass on any relevant information (27179-80).

The first major information to emerge concerning the transmission of AIDS in blood products in Canada came in late December 1982, with the publication of an article in the *Medical Post* entitled “Blood Banks Hidden Time Bomb.” The article reported on a study of 33 hemophiliacs in Montreal. The work, carried out by Tsoukas and Shuster, suggested 70 percent of the asymptomatic hemophiliacs studied had “decreased cell-mediated immunity characteristic of AIDS.” Davey and Derrick were also interviewed in the report (Edwardh 27296).

Edwardh suggested that the findings of the study presented three possibilities: 1) the observed decrease in cell-mediated immunity in these asymptomatic hemophiliacs is a result of something totally unrelated to AIDS; 2) these asymptomatic hemophiliacs with decreased cell-mediated immunity may be at the beginning stages of AIDS; 3) some portion of those individuals displaying the decrease may eventually go on to AIDS (27297).

She concluded with two final observations concerning the study. First, Tsoukas and Shuster had determined on the basis of laboratory tests that both asymptomatic homosexual and hemophiliac populations were displaying similar signs. Second, Shuster, a clinical immunologist, concluded that the immune dysfunction they were observing “...appears to be the thing... that occurs before you actually get the frank clinical disease (27297-8).

Davey described Shuster’s claim as nothing more than speculation; it was still unclear whether the disease being observed in hemophiliacs was the same one affecting homosexuals (27297).
Edwardh asked how such doubts could persist when Tsoukas's and Shuster's laboratory studies had shown that both groups were suffering from cell-mediated immunity problems.

Davey replied, the similarities proved nothing. It would be false reasoning to assume that because all AIDS patients had cell-mediated immunity problems, all otherwise healthy individuals with cell mediated immunity problems would come down with AIDS (27298-9). He explained that there were several possibilities why hemophiliacs were exhibiting signs of immune abnormalities. Some studies, for example, suggested that constant exposure to foreign proteins in clotting concentrates might lead to the collapse of the immune system. He recounted having been involved in a program of intensive immunization of individuals with red cells which yielded some evidence that “... immune exhaustion could be induced by systematic exposure to varieties of foreign antigens” (27302-4).

Edwardh replied that while she appreciated he “found this alternative view to be a very interesting one,” would he not agree, by December of 1982, at least that the preponderance of scientific opinion was that this was likely a transmissible infectious agent?

Davey replied; “It was a very common view that this could involve one or more infectious agents. And that among that view was one view that this might be a unique agent, and other views that if it were infectious agents it might involve the interaction of a large number of common and well known infectious agents” (27304-5).

When pressed as to the preponderance of scientific opinion, Davey replied that he “didn't poll people at the time” and “certainly wasn't at all their meetings in the U.S.” He described feeling “that the possibility was high enough that on a precautionary basis, one should act in certain areas as if this were so” (27305).

These feelings did not necessarily get translated into action. Davey did not find the evidence
sufficient to justify removing gays from the donor pool. His thinking at the time, he said, was reflected in his comments in the *Medical Post* article. "If an agent is identified, if a test can be developed for carriers, as has happened for hepatitis B, then we would have a reliable, feasible way of (saying we will exclude) excluding blood from [these] people because (we could) have identified them positively as having an injurious agent in their blood. We're nowhere near that stage" (27310).

Davey told the commission he had been unconvinced by the available epidemiological evidence. Before taking any step to remove gay men from the donor pool he needed to see an infectious agent clearly identified (27310).

Perrault agreed; most of the evidence at the time was descriptive in nature. It lacked the necessary scientific rigour to justify "pressing a panic button and saying, 'Ok, we're going to move now, we're going to tear the whole shop apart'" (27311-2). The problem, Perrault explained, was not simply the lack of conclusive scientific proof. The Red Cross officials were deeply concerned that the social and political ramifications of taking any precipitous action could pose a greater threat to the system and its users than that presented by the disease. They felt the system was already under siege -- blood shortages were becoming chronic. Increasing the safeguards, they believed, would push up costs and exacerbate the shortages while creating unfounded fears amongst those who relied on blood and blood products. Perrault explained that before they were willing to institute screening measures and reduce the blood supply by five or ten percent, they needed to be sure they were "doing the right thing" (27313).
The Hepatitis Analogy

The National Office preferred a ‘wait and see’ approach, but in the coming months they encountered increasing pressure to take action. Along with a growing agreement within the scientific community that the disease was likely caused by an infectious agent and that it was transmissible through blood and blood products came mounting demands for reform from user groups such as the CHS. Perhaps the most difficult problem they met, however, was justifying the relative inaction of the Canadian System in the face of the more proactive response mounted by their counterparts south of the border (27336).

Edwardh was interested in the manner and extent to which the information and the actions being taken in the United States affected the way CRC officials perceived the problem and formulated their response.

In addressing these questions she drew the witnesses’ attention to the November 5 1982, *MMWR* which carried the PHS recommendations for health care workers dealing with AIDS patients and their specimens. Edwardh began by asking whether Davey agreed that the recommendations were premised on the belief that a transmissible agent may be involved and that the vectors of transmission appeared to be the same as hepatitis B (27219-20).

Davey agreed, the precautions were premised on the belief that a transmissible agent could be involved, but noted, while the vectors appeared similar to those associated with hepatitis B, they were not the same (27220).

Edwardh then asked whether the recommended precautions went beyond what could be considered usual protocol. “Certainly in most circumstances, she suggested, “gloves would not be worn when patients are having their beds cleaned or anything like that…” (27221)?

Davey replied that it might go beyond routine practice but it is a protocol commonly used for
patients who are known to be infectious. Perrault added that it is "hepatitis B inoculate infection protocol... it is not unusual in that sense."

Davey then turned to the Commissioner saying; "I mean, Sir, we could perhaps cut through the detailed examination --- "

Edwardh continued her questioning paying no attention to Davey's plea. She wanted to clarify Perrault's previous comment. When he said there was nothing unusual in the protocol, he was speaking in terms of hepatitis B, was he not, she asked (27221-2).

Before Perrault had a chance to answer Davey jumped in, saying, "it was ... essentially infectious disease precautions equivalent to those observed for hepatitis B". The precautions, he said, were standard practice within the transfusion service; all blood samples were treated as if they were infectious. He also suggested that hospitals which found themselves unable to apply these procedures immediately had not been adequately dealing with infectious patients and materials previously (27222-3).

Edwardh disagreed, while such procedures might be manageable for the big teaching hospitals and large scale laboratories, they did create inconvenience and increased costs. Recommendations for the use of such things as biological safety cabinets, she pointed out, presented a considerable burden for smaller scale facilities (27223-27). She wondered to what extent the Red Cross was actually following the so-called standard protocol? Were Red Cross phlebotomists, for example, wearing gloves in 1982?

Perrault could not "recall exactly".

Davey acknowledged that it was not a matter of routine. The nurses, he explained, found it difficult to perform "large calibre vena puncture" wearing gloves. Besides, Davey did not believe a blood clinic setting could be compared to a hospital setting; in a hospital "they are taking blood
from sick people” (27228-31).

While the witnesses were unwilling to attach any particular significance to the November 5 PHS recommendations, they did eventually agree with two of Edwardh's points: By November 1982, the United States Public Health Service issued a directive which would both inconvenience hospitals and increase their costs; the PHS did this because of their concern that the new disease being observed “was transmissible by blood and other bodily substances” (27227).

While acknowledging these points, Davey attempted to undercut their significance. He told the commission that something about AIDS always puzzled him, why is it “so infrequently transmitted in a hospital setting.” Unlike hepatitis, there have been no AIDS epidemics among hospital workers. “This, is where the hepatitis model fell down for us.” It did not predict the behaviour of the disease (27228).

The discussion ended with Edwardh pointing out that no one, at the time, was suggesting “hepatitis B as anything but a model for vectors of transmission” (27229).8

Donor Screening

In exploring the more proactive measures instituted to safeguard the blood supply in the U.S., Edwardh pointed to the program of direct questioning adopted by Alpha Pharmaceutical in December 1982. She wondered whether the early success of the screening program -- the deferral of over 300 donors in the first few weeks of operation -- had not suggested to CRC decision

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8 Throughout their testimony Dr. Perrault and Dr. Davey maintained they had found the hepatitis B analogy inadequate in a number of respects. They were, however, “fishing around for models”. As Dr. Davey suggested, this quest brought them to consider HTLV, lentiviruses and even Kuru, in an attempt to understand the behaviour of the new disease. One of the problems in using these models, he explained, was that they tended to mislead researchers, in some cases even causing them to misclassify the virus (29322-24).
makers that direct questioning could be successfully employed? She also wondered whether this should not have provided a very persuasive argument for the use of such questioning, especially given that Alpha was a commercial collector and it was assumed that paid donors were less prone to acknowledge impediments to their donating than were volunteer donors?

Davey replied that there was not enough information to make a judgement about the success of the program, "it says that there are 308 affirmations; it doesn't say how many denials they had." He also noted that Alpha was a commercial operation; there was nothing to indicate that the direct questioning would be successful in a volunteer setting. Paid donors, he said, "can be pressed and told eventually to go away and don't come back" (27370-71).

Edwardh was puzzled. Was there not a "fundamental assumption" that volunteers are more candid in their answers than paid donors?

Davey agreed. It was assumed volunteer donors would answer questions more truthfully, but that was not the issue here. The primary concern about using direct questioning was, "the people...will be offended by the questions and will either go away or not come back and then spread the message" (27372).

A Lack of Conclusive Evidence

Just what was to be done to protect the blood supply became a matter of debate at a meeting of the Immunology/Virology BTS Working Group in late January 1983. Both Davey and Derrick attended the meeting. Dr. Dodd from the ARC was also there. According to Edwardh the Minutes of the Meeting showed that Derrick expressed disappointment with the recommendations recently put forward by the National Hemophilia Foundation (NHF) in the U.S. The NHF had called for sweeping changes to the blood donor system. Derrick felt the
recommendations unwarranted; that they had been put forward “despite the lack of conclusive evidence with reference to the direct transmission via blood products...” (27379).

Not everyone at the meeting accepted Derrick's position. Edwardh pointed out, for example, that Dodd had taken umbrage at his comments. Dodd maintained that conclusive evidence or not, “... the view that AIDS could be transmitted in blood transfusion was quite widely held (27382).

Perrault replied that regardless of what Dodd may have said, the lack of conclusive evidence at the time was a valid scientific concern.

The Importance of Standards: Koch's Postulates

Edwardh asked Perrault about the standard of evidence Derrick was using when he suggested the evidence was inconclusive. Was he measuring the evidence against the standard of Koch's classic infectious disease model?

Perrault said he believed so.

Davey interrupted, saying, there had been a reworking of Koch's postulates, called Sackett's postulates. He described the reworked standard as a valuable approach in situations were public health problems have to be solved on epidemiological, rather than experimental, evidence. With this model it is possible to “...epidemiologically go through the evidence to the point where one was convinced of [the] etiology without going through the full experimental rigour of Koch's postulates.”

Pressed on the point, Davey acknowledged that the reworked criteria likely did not apply to Derrick's analysis of data. He nevertheless maintained that it did apply to his own thinking at the time, and even taking the modified postulates into account, the evidence was insufficient to convince him that a blood-borne pathogen was involved (27384).
When asked by Edwardh at what point was he finally convinced, Davey replied, not until “around '85 when serological evidence became available”. The tool that was required to understand AIDS was the serology, he explained (27386).

Davey suggested that two arguments were actually going on at the meeting: one focussed on what was known, what was proven; the other centred on what was prudent. This second discussion, he maintained, was going on well ahead of any scientific conviction. To understand the situation he said, it is necessary to appreciate the disagreement between the scientist who is saying, “‘proof is not absolutely conclusive’” and the manager of a health facility, who is saying “‘but this is what we should do now’” (27387).

Safeguarding the Canadian System

*Communicating risk and the notion of self-exclusion*

Edwardh returned to Dodd's presentation at the meeting. She noted that while the U.S volunteer sector had not adopted the use of direct questioning, Dodd suggested the Canadian system lent itself quite well to the inclusion of specific questions, “which could be at least partially effective in excluding high risk donors without alienation effects” (27389). The group, Edwardh pointed out, was reluctant to take up Dodd's recommendation. They concluded instead that “...should evidence accumulate indicating that collection from certain groups of donors is indeed putting blood recipients at risk of developing AIDS... then the most acceptable approach ... would be to contact group representatives and place the problem before them rather than approaching them individually” (27391-2).

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9 Davey added that to this day he does not believe HIV to be the sole determining agent in AIDS.
Edwardh wondered whether Davey could explain the rationale which lay behind the decision to deal with group leaders rather than approaching individual donors directly?

Davey began by making it clear that the group of central concern was the gay community. He described gays in Toronto as having "... a recognizable social community acknowledged by themselves as such and represented by community organizations and community publications which had fairly wide circulation to interested people in Toronto." Red Cross officials assumed that a similar organization existed in other Canadian cities.

The goal, Davey explained, was to avoid having individuals at high risk donating blood. The most effective way of achieving this was to ensure they did not present at clinics in the first place. National Office staff believed this would be best accomplished by gaining the cooperation of the leadership. Through them, individual members of the community could be educated to recognize themselves as being at high risk. Once this was accomplished, they would not come to the clinics; there would be no need for additional screening measures. This was the basis of the concept of self-exclusion (27398-9).

While the Red Cross officials relied on "at risk" donors to exclude themselves, they did little to either promote the key component of the program, donor education, or to test its effectiveness. The lack of emphasis on donor education became a matter of concern for some within the Red Cross. For example, sometime later in her examination, Edwardh indicated that at a September 1983 BTS Working Group meeting, apprehension had been expressed over the effectiveness of the education measures so far undertaken, especially in terms of the information being provided to the gay community regarding self exclusion.10 These concerns, she suggested, failed to prompt

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10 The minutes of the March 24/25 Medical Directors meeting indicate that a few centres in the major urban areas were noticing an increase in donors from high risk groups attending clinics (Exhibit 617:tab 16).
Perrault or Davey to canvas the Medical Directors or request an official report from them “about their successes or failures with the gay community…”.

Perrault agreed. No evaluation of the effectiveness of the program was undertaken at the time (28080-2).

Edwardh asked whether, in fact, any attempt outside of the print and broadcast media had been made to inform and educate donors about self deferral prior to April 1984 (28089)?

Perrault acknowledged the Red Cross was not actively distributing donor information at this time (28090).

Edwardh wondered to what degree the lack of effort put towards public education could be attributed to the concern over frightening away donors?

Perrault replied, it “was certainly part of our concern... 1983 was probably our worst -- donor recruitment year, and we were dealing with a number of issues simultaneously. We were dealing with the concentrate issues. We were dealing with the contractual issues. We were dealing with the new relationship with the Canadian Blood Committee. There were a number of issues on the table at that time” (28091).

January 13th 1983 Joint Statement

Self exclusion was only one among a range of possible strategies for reducing the risk of AIDS associated with the use of blood and blood products. A number of these had been outlined in the January 13th Joint Statement issued by the volunteer blood bankers in the United States following the January 4th meeting in Atlanta.

Davey pointed out that Dodd had brought a copy of the recommendations to the Meeting of the Working Group and that the meeting provided him with his first opportunity to examine the
recommendations. He told the commission he had been relatively impressed with the document “especially as this was the first coherent statement of the overall American, U.S. voluntary blood services approach to this problem” (27402-403).

He agreed with Edward, the recommendations were based on a consensus within the American volunteer sector that the evidence was sufficient to warrant taking certain steps. However, he was careful to add, that the authors left no doubt the recommendations were based on inconclusive data. He acknowledged the Immunology/Virology BTS Working Group believed the evidence sufficient to justify adopting the recommendations as an interim guide to policy in Canada. He also noted the Group did not advocate a blanket acceptance of the document and that they recognized the conditions in Canada were somewhat different. For example, while autologous donation might be appropriate in the context of the American system, neither the Red Cross nor the Canadian Health System, was practically prepared to deal with the practice. While holding some reservations overall, he said, he had felt the recommendations reasonable and prudent (27405).

Edward pointed out that within days of the Working Group meeting Davey sent a copy of the American Joint Statement recommendations to all Medical Directors. In an accompanying memo he instructed them to examine the recommendations with an eye to their application and to notify him by February 4th of any ideas or concerns they might have in those regards (27409-10).

Davey clarified the situation. He did send copies of the Joint Statement with an accompanying memo instructing the Medical Directors to take-up the recommendations as a working policy but in no way had he implied that considerations of the Statement would be concluded by February 4th. He informed the Directors the matter would be addressed further at the March 24th meeting and any definitive work on it would not be done until that time. He also pointed out to the
commission, that before sending out the recommendations, some alterations, in the form of priorities and reservations, had been added to them (27411, 27436).

The Canadian Hemophilia Society recommendations

Two weeks after the Immunology/Virology BTS Working Group met to consider strategies to safeguard the blood supply, the Canadian Hemophilia Society released its recommendations calling for sweeping changes to the current practices.

On February 7th Derrick travelled to London, Ontario to attend a meeting which focussed on those recommendations. Edwardh pointed to a memo to file Derrick had written following the meeting. In that memo he indicated that the CHS wanted “‘serious efforts to be made to exclude blood donors who might be at high risk of transmitting AIDS’” (27432). The CHS felt these efforts should include the use of specific health questioning to detect the symptoms surrounding AIDS.

Edwardh suggested that Derrick left the CHS membership with the sense that modifying the donor questionnaire to reflect their concerns was a real possibility.

Davey agreed, the CHS proposals were “felt feasible, at least.” Perrault added that the Medical Directors at that point were still being canvassed for their opinions on the Joint Statement recommendations and “we would do as resolved by the Medical Directors” (27432). He insisted this had been made abundantly clear at the meeting. Both witnesses disagreed with Edwardh's suggestion that members of the CHS could have come away with the impression the Red Cross had agreed to implement the proposed reforms. National Office staff were not in a position to make any decisions until they heard from the Medical Directors (27441-2).
The March 4th United States Public Health Service recommendations

The National Office's commitment to consultation did not survive the events of the following month. On March 4th, the MMWR published the U.S. Public Health Services recommendations for reducing the risk of transmitting AIDS through the blood supply. That same day, the American Red Cross issued a press release indicating that it was immediately moving to provide information to its donors and that it would urge members of high risk groups to refrain from donating for the present (27485). This, Edwardh observed, presented a marked change of position for the ARC; up until then the ARC had been reluctant to initiate a public education program, particularly one which encouraged donors not to donate (27486).

The Canadian Red Cross Responds: March 10th Press Release

Edwardh suggested that the PHS publication, along with the ARC announcement, attracted the attention of the media, prompting the Canadian Red Cross to immediately adopt a policy on donor screening (27492).

Davey agreed. The Red Cross, feeling itself under intense pressure, called an emergency meeting of BTS and BDR representatives. The purpose was to establish a strategy for informing the public of what steps the CRC was taking in regard to AIDS.

Edwardh noted that the meeting, held on March 10th, culminated in a press release which “parroted” the PHS recommendations. The CRC announced it was going to provide its donors with information about the risks associated with AIDS and that it would institute health questioning at its clinics. The CRC also called on those at high risk for the disease to temporarily
refrain from giving blood.\textsuperscript{11} In the end, she said, the National Office acted on the matter of donor screening without the assistance of the Medical Directors (27496-7).

She went on to suggest that while the Red Cross publicly announced it would be asking “specific AIDS related symptoms questions”, a decision had been made earlier that morning not to use such instruments. They were considered too general to be of value: too many healthy donors would be excluded (27507).

Perrault replied that he could not recall whether such a decision had actually been made at that point. While accepting Edwardh’s general characterization of the situation, he emphasized the pressure they were under; “What we are dealing with here is a situation we could not control.” The Red Cross officials, he explained, felt they had to make a preemptive decision; that they had no choice but to follow the U.S. lead despite the situation being quite different here in Canada (27496, 27511).

Edwardh wondered whether Perrault agreed that the measures laid out in the March 10th press release were prudent and appropriate, even given the differences in the American and Canadian situations (27510)?

Perrault was reluctant to concede the point. He felt the information they had at the time was almost secondary: it really did not matter what the science of the matter was. The PHS publication and the concerns it stirred up could not be ignored. Perrault did allow, however, that prudence required some action be taken by this point (27511).

Edwardh reformulated her question, would he “... agree that despite any differences in the

\textsuperscript{11} The CRC, for example, adopted the problematic language of the \textit{MMWR}, defining those at risk as including, “sexually-active homosexual or bisexual men with multiple partners” (Exhibit 617:tab 3). (One of the problems, was no one was quite sure what multiple meant. In San Francisco it might mean 200 or more while in Hamilton, Ontario it might mean two (Francis 22127).
Canadian situation, you personally felt these to be appropriate and prudent measures to prevent or reduce the risk of transfusion-transmitted AIDS" (27512)?

Perrault said that he felt there “was a good supposition” for excluding high risk donors, but the matter of “symptom specific” questioning was still being looked at.

Reactions to the March 10th Press Release

The suggestion that certain groups exclude themselves from donating brought an immediate reaction from representatives of the Haitian and gay communities who were concerned the Red Cross move would fuel further discrimination against members of both communities (Edwardh 27601-3). What followed was an ugly series of accusations and counter claims, which, according to Perrault damaged everyone involved.

Response of the gay community

In describing the problems they faced with the gay community Perrault told how Derrick was constantly hearing “frightening” comments to the effect that some gay men were going to ignore the recommendation. Perrault made it clear, he was not suggesting the entire community was uncooperative. On the whole “the gay community had taken a very responsible approach to this” but there were people within the group who did not pay attention. According to Perrault the one bright point in it all was that “we felt that the message was getting through loud and clear” (27555).

Edwardh wanted to clarify a point. Was he suggesting that a message of resistance or perhaps even anger was coming from the gay community?

Perrault said he felt it was, “[i]n a broad sweeping way” (27556).
Davey spoke up: the homosexual community was saying that a blanket exclusion would be met with passive as well as aggressive forms of resistance. Members of the community would surreptitiously donate, pickets would be established at clinic sites and charges of discrimination would be pursued. Davey explained that these concerns were part of the reason why the Red Cross was so careful in avoiding calling for the total exclusion of the gay community (22557).

Edwardh responded that the real reason the Red Cross didn't apply a blanket exclusion at the time was the CDC in Atlanta had not accepted that all gay men were at risk. Only those with multiple sexual partners were defined as being at risk. The CRC was simply following the guidelines set out in the March 4th *MMWR*.

Davey agreed that the CDC definition was the central reason the Red Cross did not call for a blanket exclusion (27557).\footnote{He later explained that avoiding a blanket exclusion had allowed for a resolution of the difficulties with the gay community. He described how the problems with the gay community abated considerably once they got a better understanding of CRC position and realized there would be no blanket exclusion (27670).}

Rather than relying on a blanket exclusion the Red Cross put its faith in the strategy of self-deferral. While confident high risk donors would not attend the clinics, they did have a back-up strategy. Davey explained that should high risk donors present themselves at the clinic site they would be identified by the nursing staff. He believed their appearance would give them away, that like their counter-parts in San Francisco, they were “flamboyant in dress and behaviour” (27765).
Response of the Haitian community

Relations between the Red Cross and the Haitian community proved even more difficult. The Haitian community representatives, deeply concerned about the effect such a ban would have on the community, accused the Red Cross of racism and discrimination. Letters of protest were sent to the CRC and the Minister of Health. Protests were also launched by the Haitian Consulates General in Toronto and Montreal as well as the Haitian Embassy in Ottawa (27659). The Haitian Red Cross and the Canadian Human Rights Commission even became involved (27651).

Edwardh suggested these difficult relations continued over many months, deeply concerning all levels of the Red Cross Society.

Perrault agreed; discrimination was against the fundamental principles of the Society (27653). The idea that the CRC would be accused of such a thing shook the organization. Perrault described the situation as extremely damaging. The Red Cross officials, he explained, saw it as eroding crucial public support and were concerned with what appeared to be a significant decline in support for their clinics in Montreal.

The Haitian community was suffering enormously as well, he noted. "...[Y]ou have to understand the anxiety in the Haitian community. It was very easy to recognize a French-speaking Black person in any part of -- there is very few places in North America where Blacks speak French. And that is Haiti, or if you are in Montreal. But it was really a very difficult situation for them. And I really had a lot of sympathy for their community” (27653-4).

During cross-examination Mr. Elliott broached the question of whether the lack of expertise within the Red Cross, with respect to the Haitian community, had contributed to the problems.

13 The principles of the International Red Cross/ Red Crescent movement as set out in 1965 include, “humanity, impartiality, neutrality, independence, voluntary service, unity and universality.” (Krever 1995:5; Moorehead 1998:561).
Was there anyone in authority at National Office who had expertise in Haitian culture, he wondered.

Perrault replied that “it depends on what you mean by ‘Haitian culture.’” He told the inquiry that he had “read extensively on Haitian history;” like the well educated Haitians he met and associated with, his “classical” education was in French literature; and he had even played soccer against a Haitian team in college (29480-2).

According to Perrault the Red Cross was under considerable pressure over the Haitian situation. He described hearing pleas from both the Haitian and medical communities to keep the issue quiet and to accept Haitian donors because of the suffering it was causing to the group (27654). He also pointed out that these sorts of concerns were being played out against the memory of 1977. In the summer of 1977, he explained, the Red Cross had a strike in Montreal. It lasted 12 weeks. He told the commission that the experience taught everyone involved what blood shortages could do. Everyone, National Office staff, the Montreal staff, and the medical community was frightened by the spectre of further shortages (27663).

Eventually the Red Cross backed down, choosing to rely on already established screening protocols. Anyone having been in a malarial area in the last 3 years was automatically deferred. Haiti was a malarial area, thus anyone who had recently arrived from Haiti would be removed from the system. While not perfect, the Red Cross considered it a reasonable alternative (27660). The Red Cross also engineered a proclamation of reconciliation with community. Negotiations went on for months, but the Haitian representatives never did sign the document. As

14 Most of the data from the United States at the time indicated that AIDS was a problem primarily amongst recent immigrants from Haiti. The malarial screening, therefore, at least in theory, would pick out those most at risk while avoiding any suggestion of racism or discrimination (27660).
Elliott, suggested “it started out as a disaster and it remained a disaster.” Members of the Haitian community, continued to express bitterness over the situation at the commission hearings in Montreal in 1994 (28479-80).

There was no doubt, as Perrault suggested that “it was a very difficult period” for the Red Cross. Edwardh, however, pointed out that Red Cross may have been, at least in part, the author of its own misery in that it had engaged in no consultation with the communities involved before issuing the March 10 press release.

Perrault explained that there simply was no time for consultation, the story was already out in the U.S. media (27607).\(^\text{15}\)

The public criticisms and confrontations made an indelible impression on the Red Cross officials. Their announced intentions to make changes to the system put them in a position they were both unfamiliar with and unprepared to meet. They had neither the resources or the experience for the job. In their hour of darkness no one came forward with support. At times it seemed almost as though the entire blood system was in jeopardy and no one was there to hold it together except a handful of individuals in the Red Cross National Office who were already taxed to the limit.

\(^\text{15}\) As far as Red Cross officials were concerned, the media was to blame for a large part of their woes. Ms. Edwardh pointed to a May 17th 1983 memorandum by Derrick in which he referred to the “‘unfortunate’” situation following the March 10 press release. In the memo Derrick observed that “‘...our resources at the CRC have since been strained to the utmost in attempting to cope with the distortions, misinformation and misinterpretation by some of the press in its reporting of the Canadian Red Cross position in dealing with the possible risk of AIDS transmission through blood. The inroads of these activities on one's time and resources are excessive.... Yet this is a job that must be done in a situation such as this when the confidence of the blood donors, blood recipients and the general public is at stake. I sincerely believe a great deal of harm can come from 'created scares' such as occurred in the case where individuals needing therapeutic blood components and products have been very frightened in using them and conscientious blood donors and other groups have been offended’” (27841-2).
Formulating Policy

Davey and Derrick were digesting these matters when they arrived at the March 24th Medical Directors meeting. What they encountered there did little to bolster their spirits.

According to Edwardh, the Medical Directors wanted a clear policy established in regards to AIDS. Some felt the PHS recommendations, particularly the recommendation that donors be asked specific questions about their health, offered a viable approach. There was a general consensus amongst the Medical Directors that a question such as “[h]ave you had any unexplained night sweats, swollen glands, etc’…” would be acceptable. Their support for such question could not have been a surprise, she said; the Joint Statement they received from Davey in January recommended exactly that approach (27576).

Edwardh wondered if Davey felt the Medical Directors to be “offside” in their support of the use of questions to detect fairly non-specific symptoms (27577).

To the contrary, said Davey; they presented an alternate approach which was at least worth considering.16

Edwardh pointed to the minutes of the meeting suggesting they seemed to contradict what he was claiming. The minutes report Davey telling the Medical Directors, “that no Centre should be asking any questions other than the basic ‘Are you well?’” (27577-8).

Perrault replied that Davey's comment did not rule out the possibility of asking of more detailed questions: It was just that “you don't ask questions until you've asked that one” (27578).

Edwardh suggested that the discussion ended with the Directors supporting the use of specific health questions and Davey opposing their use.

16 Davey maintained throughout his testimony that the scientist had to remain open to all possible theories until the final proof was in.
Davey agreed, but insisted that his reasons for not supporting their use were not minuted and need to be examined further (27582-4). First, he said, we did not expect individuals with AIDS to be in our clinics and that if they did present, they would be immediately disqualified by reason of their health; second, the Red Cross was not in the business of providing a diagnostic service. Then there was the problem that the questions were so non-specific, and the prevalence of the disease so low, that most of those screened-out would be false positives. Davey also pointed to the concern about unnecessarily alarming donors "having [them] leave our clinics believing they had AIDS or had a significant risk of developing AIDS" when in fact they did not (27586-7).

He told the inquiry he wanted questioning to be limited to "'are you feeling well'" believing it to be as effective in excluding "symptomatic carriers of AIDS as any other measure" (27594). Edwardh wondered whether in adopting this stance Davey was aware that he was not only rejecting the position of the American Red Cross but also turning a blind eye to the clinical experience of his Medical Directors, a clinical experience which, collectively, far outweighed his own.

Davey said that he had not been aware of the ARC position, but that even if he was, he still would have chosen to do things differently. The weight he gave to the Medical Directors' experience, was another matter. He respected their opinions; that is why the issue was left open for further consideration (27595-6).

Edwardh suggested that despite the apparent disagreements at the meeting, one point of accord was reached. It was agreed a working group would be formed to develop a Red Cross policy on AIDS in the areas of donor recruitment, donor screening, donor deferral and the utilization and disposal of blood considered to be at risk (27610-11).

On March 29th Perrault, along with other members of the National Office, the BDR, and a
handful of invited guests -- including several Medical Directors and officials from the Canadian Blood Committee -- met to fulfil that commitment.

Edwardh pointed out that in the end, the Working Group recommended an even more cautious path than the one earlier promulgated by Davey. Instead of asking the specific question "Are you well" donors would only confront a preamble stressing the importance of being in 'good health' (27626).

Perrault replied that he could see no difference between having a preamble at the beginning of the donor questionnaire stressing the importance of wellness and a direct question inquiring "Are you well" (27627-7).

Edwardh responded that he could not possibly know because the Red Cross never investigated whether there was any difference between the two approaches. Instead, they relied on the "anecdotal impressions" brought to the table by the members of the Working Group. She noted that in doing so, the CRCS departed from the proposals being put forward by the largest public health agency in the world (27628).

Davey immediately took exception, arguing that the decision had been based on clinical experience and that he did not agree that the Medical Directors had rejected his proposal. "...[T]he ultimate validation of the procedure adopted by the Canadian Red Cross," he said, "is the consequences in terms of...(the) comparative incidence of [transfusion associated] AIDS in different countries..." (27628-9).

Edwardh suggested that in the end, the decisions reached at the meeting appeared to be strategic and tactical moves aimed at avoiding further inflaming the situation which emerged following the March 10 press release.

Perrault replied that while the decision was not exclusively based on avoiding inflaming the
situation further, it was a consideration. He suggested that one of the things at the root of it all, was the concern over blood shortages. This, he explained, was why the charge of discrimination had been so disturbing. "It was a blow that came at a time of shortage and, keeping in mind that when there is approximately 330,000 people a year who receive blood and blood products in one form or another... and we had to worry about that everyday" (27658-9).

With a working policy in hand the next logical step was gaining the approval of the Blood Transfusion Advisory Committee. Perrault, Davey, and Derrick met with the group on April 15th 1983.

Edwardh was puzzled; according to the minutes of the meeting, Davey presented a review of the Red Cross's response to AIDS in which he described the disease as a real, but limited, public health issue in Canada. She wondered how he could reconcile that view with the opinion that had been expressed by other experts working in the field, that an epidemic wave was beginning to be seen in this country.

Davey confirmed he had described AIDS as being of a limited dimension in terms of public health. If one defines "limited dimension" by the number of cases reported, he explained, then it certainly was of limited dimension. There were no reported cases of transfusion associated AIDS. Like many diseases Public Health authorities deal with, he explained, it was a very serious problem, but one of limited dimension (27674-5).

Perrault spoke up saying that he did not want to leave the impression they had thought the matter trivial. "We spent a great deal of time on this and the technical language contained in the

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17 This was the expert committee which provided advice to Red Cross Board of Governors. Perrault had already testified that if the Advisory Committee gave its approval it was generally a matter of formality getting approval from the BOG -- at least in terms of technical scientific matters.
Advisory Committee minutes certainly is not reflective of the day to day situation” (27675).

Edwardh pointed out, that at the meeting Davey asked the committee to endorse the approach “specifically with reference to the change in the preamble” in the donor questionnaire. She wondered why this committee had been asked to consider the preamble? What mandate did they have to say whether it was appropriate or inappropriate (27676)?

Davey explained that he “was essentially asking whether, in the judgement of the committee members, this was an appropriate response to the problem, having given them all the information then available.”

Perrault added that it had been presented to the committee as a “double check.” They were an advisory group, a lot of issues were brought before them for information and discussion and to give them a chance to comment.

Edwardh disagreed. The minutes make it clear, she said, that Davey was not simply presenting the proposal as a matter of information, he was seeking “their express approval for the steps taken.” If the Committee had not approved the move, she noted, the National Office would have had to have gone back to the ‘drawing board’.

Perrault agreed; Davey was seeking the Committee's approval. Both he and Davey also agreed that had approval been withheld they would have had to draft another proposal.

Edwardh reminded them that several members of the Committee drew attention to the differences between what was promised in the March 10th press release and what was now being proposed; they wondered why the BTS was no longer proposing to follow the approach outlined in the March 4th FDA release.\footnote{The release, which appeared in the March 4th \textit{MMWR}, noted that while “the cause of AIDS remains unknown the Public Health Service recommends...: As a temporary measure, members of groups at increased risk for AIDS should refrain from donating plasma and/or blood... Studies}
to the commitment to ask specific questions. She also pointed out that Derrick told the group
"the situation with respect to AIDS in Canada warranted a different approach from that in the
U.S." She wondered what Derrick meant by this, given that it was widely accepted that AIDS
epidemic was approximately a year and a half behind what was being seen in the United States?
What could cause him to think that the disease would assume a different dimension in Canada
(27684)?

Davey ventured that Derrick may have felt that the time lag had given us an opportunity to
"watch and measure" the situation "and not go categorically and immediately to the U.S.
questionnaire approach" (27685).

Was Derrick saying a different approach was justified on the basis of the year and a half lag
period, Edwardh asked?

"No, No...," replied Perrault. The blood banking systems were totally different in the two
countries. Canada was a national system. A national approach had to be taken. The Americans
did not follow our lead in 1947, he explained. We built a unified volunteer system. They built a
fractured system based on both volunteer and commercial operations. "So the two systems were
fundamentally different, with fundamentally different histories" (27685).

Edwardh said that she could not see how the minor procedural distinctions between the
American Red Cross and the Canadian Red Cross could justify taking a different approach to
donor screening (27686).

Perrault replied that he was not trying to justify what Derrick was saying, he was merely

should be conducted to evaluate their effectiveness... Physicians should adhere strictly to medical
indications for transfusion... autologous blood transfusion are encouraged... Work should
continue toward development of safer blood products for use by patients with hemophilia”
(Exhibit 550:tab 27).
“stating what he might have meant by the differences” (27687).

Returning to April 15th meeting of BTS Advisory Committee Edwardh noted that the adoption of the preamble was put to a vote. The arguments of the National Office staff prevailed. The motion passed with two abstentions and one vote against (26693). The last hurdle had been met; the BTS Advisory Committee had given their assent. The rest was a matter of formality. The new questionnaire with its ‘good health’ preamble appeared at the clinics within weeks.
CHAPTER SIX: DR. PERRAULT AND DR. DAVEY: THE QUEST FOR SUPPORT, MAY 1983 TO MAY 1984

Introduction

The second phase of the Red Cross initiative commenced. With a working policy in hand and a new Questionnaire in place at the clinics, attention turned to garnering support from outside of the Red Cross. The March fiasco, which had seen the Red Cross left alone to face a barrage of criticism, was indelibly etched in the minds of the BTS officials. They were not about to let it happen again. They knew, however, that in order to gain the necessary support, their policy would have to be developed further. During the next year, attaining these objectives would become a driving force within the National Office.

Seeking Support

The first opportunity to pursue these goals presented itself within weeks of getting the new Questionnaire in place. In the spring of 1983 the Assistant Deputy Minister of Health invited a group of experts to sit on an Ad Hoc Task Force on AIDS being convened by the federal government. The Task Force brought together leading researchers from universities, hospitals and public health agencies across Canada. Among those invited to join was Dr. Perrault.¹

Ms. Edwardh told the commission that Perrault was unable to attend the first meeting in Ottawa on May 5 1983 and sent Dr. Derrick in his place. Derrick, she suggested, had been given explicit instructions to inform the group about what the Red Cross was doing and to gain their endorsement for the course of action set out in the March 10th press release. She noted that in

¹ In its mandate the Ad Hoc Task Force was to “review the status of AIDS in Canada and other countries, and to make recommendations to the Minister of Health and Welfare and other appropriate agencies... with regard to the diagnosis, treatment control, and prevention of AIDS in Canada.” Ad Hoc Task Force, Mandate (Exhibit 683:tab 3).
doing this the Red Cross was seeking support for measures which were not actually being taken (27718).²

Perrault was unable recall whether he had given Derrick specific instructions to gain the group's support. He described Derrick's failure to make it clear the Red Cross no longer intended to follow the announced strategies as an oversight. He conceded however, that the presentation could have led the group to endorse a program that was not being pursued (27720-1).

The Red Cross found the Task Force was not going to cater to its needs and wants. Many of the issues Derrick brought with him were never addressed.³ Reading from the minutes of the meeting, Edwardh indicated that the Red Cross requested the formation of a special sub-committee to deal specifically with blood and blood products. As she pointed out, the group decided instead “that a representative on each of 3 existing sub-committees could be identified who would carry on this role.”⁴ She wondered why the Red Cross let the matter drop without pursuing it further (27732)?

Perrault said that he never found out why the group decided not to institute a blood sub-committee but learned very quickly it was futile to push for one. There were simply too many competing interests within the group, and this, he explained, created a particularly difficult

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² In the March 10 Press release the CRCS said that it was going to provide donors with information about the risks associated with AIDS and it would institute health questioning at its clinics. It also called on those groups at high risk for the disease to temporarily refrain from giving blood (Exhibit 617:tab 3). By the time of the May 5th meeting the Society no longer maintained any of these positions.

³ The central focus of the meeting was organizational issues. Clinical, laboratory and epidemiological sub-committees were formed, strategies were developed to avoid duplication of efforts and protocols were discussed for the gathering, collation and coordination of information (Minutes of the Ad Hoc National Task Force On AIDS May 5 1983 (Exhibit 683:tab 3).

⁴ See note above.
situation when it came to setting priorities. Everyone was struggling with shortages: the LCDC was looking for additional staffing; the BoB was under-resourced; another group was looking for a viral culture lab. All of these things were enormously expensive (27733-5).

Edwardh noted a further problem with the Committee. Beyond the representatives from the Red Cross, no one had any expertise in blood banking.

Perrault replied that you first need to define blood banking. He noted that the main concern of everyone at the time was the epidemiology of the situation and that he had been looking forward to gaining support in this area. He acknowledged nevertheless that when it came to specific strategies to protect the blood supply, the members of the Committee had no practical or technical knowledge of blood banking (27735-6).

The major accomplishment of the meeting was its recommendation to establish a national advisory body. The recommendation was adopted by the Minister of Health; the Ad Hoc Task Force became The National Advisory Committee on AIDS (NACAIDS).  

Name change aside, the Red Cross remained committed to gaining the group's endorsement of their program at its next meeting. In the interim, the CRC officials began to address the growing concern being expressed in a number of quarters that AIDS could be transmitted through blood transfusions.

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5 The newly formed National Advisory Committee on AIDS, held its first meeting September 30th 1983. NACAIDS was composed of essentially the same membership as the Ad Hoc Advisory Committee. It would be October 1984 before anyone with even limited experience in blood banking joined the Committee.
Edwardh turned the witnesses' attention to an *AIDS Update* written by Derrick in early June 1983. The *Update*, circulated within National Office and sent to regional blood centres, noted the formation of two independent committees in the United States to reinvestigate the approximately 12 cases of transfusion associated AIDS reported by the CDC. According to Derrick the reinvestigation was being carried out because "...there are a number of experts who feel the evidence on... which the CDC and the National U.S. Public Health Service base their new requirements for blood donor acceptance by blood collection agencies, was inconclusive...". Derrick further emphasized the over-reaction of the authorities in the United States, saying that "...at most, the risk of developing the syndrome from these sources would appear to be 1 in about $1.5 \times 10^6$" (27884-5; Exhibit 617:tab 9).

Edwardh pointed out that the risk estimation presented in the *Update* was based on a calculation Davey set out in a May 30th memo-to-file which he copied to both Perrault and Derrick. She wanted to know whether it would be fair to say that Davey had carried out the calculation without the assistance of an epidemiologist (27885-6).

Davey acknowledged he carried out the calculation by himself, based on information provided to him by Dr. Dowdle of the American Red Cross. He explained he had to rely on U.S. data, there being "... no relevant Canadian information at the time" (27886).

Edwardh noted, that even with the American data, and the much higher incidence of AIDS in that country, Davey arrived at the conclusion that "... the risk of AIDS associated with transfusion is very low, and may not even be significant" (27886-7).

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The risk estimate of 1 in 1.5 million applied strictly to recipients of whole blood and its components. In his memo Davey estimated the risk to hemophiliacs using clotting concentrates to be approximately 1 in 1,080 (Exhibit 617:tab 9).
Davey recalled speaking really in terms of the Canadian situation, but suggested that even in the context of the U.S. data, the risk appeared very small at the time -- especially when compared to the established risks associated with blood transfusion (27888-9).\(^7\)

Edwardh remarked on the capacity of the figures to mislead, in that they only represented those with the end state of the disease and failed to take into account anyone who fell below the threshold of the official definition of AIDS. She said that while it was known at the time that at least some of those displaying prodromal symptoms would go on to develop AIDS, no attempt was made to factor it into the calculations. “These figures”, she said, “are designed to give the impression of the least serious impact” (27888-9).

Davey pointed out that his analysis states its assumptions.\(^8\) He told the commission that you could redo the calculation, substituting other factors, and you might “come out with somewhat different figures”, but the differences would be insignificant. The information available, he maintained, inevitably led to a figure of about the same order of magnitude. According to Davey the only thing the figures were designed to do, was provide an estimate of the risk; he did not dream up the calculation. “Other individuals at about the same time and for some time afterwards, made similar estimates from the same data” (27889-90).

Edwardh retorted that to the extent those figures were provided to people who may have been

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\(^7\) Later, during cross-examination Mr. Cherniak asked Davey to compare the risk of contracting transfusion AIDS to other risks in transfusion medicine at the time. Davey recalled that between 1977 and 1980 the overall death rate due to transfusion complications in the United States was estimated at about 1 in 200,000, while about 1 in 4,000 experienced serious infectious complications (hepatitis infection was not considered serious), 1 in 6,000 had blood group incompatibilities (30893-4).

\(^8\) In the memo Davey suggested that based on the official CDC definition there were 6 confirmed cases of transfusion associated AIDS; that these had occurred over a three year period; that \(3 \times 10^6\) patients received \(10^7\) units of red blood cells annually (Exhibit 619:tab 9).
unaware of the number of individuals potentially implicated, "...they [were] designed to be entirely dismissive of risk." She pointed out that in his memo Davey, himself, concluded the risk was insignificant (27891).  

Davey reiterated that he laid out his assumptions and while different factors could have been, and in fact were, substituted by various experts in the field, they all ended up putting the risk in the same order of magnitude (27892).

Edwardh turned to the question of how Davey arrived at his figures. She wondered whether the fact that most blood recipients received multiple units of blood had been factored into his calculation (27892)?

Davey acknowledged it had not, explaining that using the number of patients transfused admittedly gave a different denominator but the numerator remained the same. "And what you would be calculating then is something like the carrier rate, based on cases that had actually occurred. And that would in fact be a rate figure of say 1 in 5,000,000 or 10,000,000" (27893).

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9 Davey concluded his May 30 memo: “[w]hile these [calculations] are very imprecise and may be affected by many variables not recognized as risk factors, they illustrate that the risk of AIDS associated with transfusion is very low and may not even be significant” (Exhibit 619:tab 9).

10 During cross-examination Mr. Arenson again took up the issue of the numerators and denominators employed, pointing out that one of the flaws in the calculation was that it took three years of transfusions as the denominator yet used only one year of the disease's appearance as numerator. This was one way in which it failed to account for the latency period of the disease. Davey acknowledged Arenson’s point; there may have been some problem with the numerator and denominator, in this sense (29341).

Another problem with the calculation according to Arenson was that it took no account of the approximately 50 percent of blood recipients who die within months of receiving a transfusion. The reported cases therefore, underestimated, by half, the actual number of individuals who contracted the disease through transfusion (29341).

Davey disagreed. You might end up with “a bias in ascertaining the rate of infection...but if you are calculating, as I am here, the risk of actually developing the disease, then it is valid to simply look at reported cases of it” (29342).
Edwardh asked Davey if he did not see the figure misleading to the extent that it was “promulgated and maintained for almost a couple of years by the Canadian Red Cross.” Would it not mislead people who were unfamiliar with the history of the disease (27893)?

“Not if one understands the assumptions on which it is based,” replied Davey (27893).

Edwardh noted that Davey was saying he clearly set out his assumptions, yet when these figures were presented publicly the assumptions were not always included. She said that when Perrault, for example, presented the calculations to NAC AIDS he did so without making Davey’s assumptions explicit (27893-4).

Further Conflicts with the Gay Community

There were reasons why the Red Cross might be interested in presenting the risk of transmitting AIDS through blood and blood products in the most favourable light possible. A bad spring, set-off by the March 10th press release, turned into a terrible summer for the Red Cross. It was the worst year to date in terms of donor recruitment. The problems with the Haitian community continued to simmer, informal reports coming out of the CDC seemed to confirm the reality of transfusion associated AIDS, and then, in July, relations with the gay community deteriorated once again.

Edwardh provided a brief outline of the events leading up to the confrontation. Derrick, she said, had been invited to a July 19th press conference celebrating the formation of the AIDS

11 Mr. Seines made a similar point about the risk estimates surrounding the use of clotting concentrates. He asked Davey whether these estimates had been revised as more cases of AIDS amongst hemophiliacs started to appear between 1983 to early 1984. Davey suggested that there had been no real increase in the officially reported cases involving hemophiliacs in Canada during that time. When Seines pointed out that he had already acknowledged his calculations were based on American data, Davey explained that he thought Canada might be a little different because half of the factor concentrates used were made from Canadian plasma (29679).
Committee of Toronto (ACT).\textsuperscript{12} Unable to attend the meeting, he asked Dr. Herst, Deputy Director of the Toronto Centre, to go in his place. Derrick equipped Herst with a question and answer sheet outlining the current policies of the National Office. Drawing on the information in that sheet Herst announced at the meeting that the unofficial policy of the Red Cross was now to ask all gay men to refrain from donating: The question of multiple partners was no longer an issue.

Edwardh wondered whether Perrault could recall the “kerfuffle” that ensued following Herst’s comments (27978-80). Perrault recalled the situation “sufficiently to verify” that a “kerfuffle” ensued. Davey added that Herst’s comments led Professor Lynch, a prominent gay activist, to read a statement on the steps of the Ontario legislature, “the gist of [which] was that the homosexual community took great exception to the statement that had been made because it took -- it stigmatized them...” (27981).

On July 22, after a hastily convened meeting, the Red Cross issued a press release aimed at calming the gay community in Toronto. The release, Edwardh suggested, in effect reinstated the earlier March 10 position, asking those within the gay community with “multiple partners” to refrain from donating for the time being (27982). The problem of labelling the entire community was once again skirted.

Davey agreed, the CRC press release was aimed at quelling concerns within the community. He clarified the situation, however, noting that the March 10 criteria had never been disowned; it

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\textsuperscript{12} ACT was gay community initiative formed in the spring of 1983 (Edwardh 23515). The Committee aimed at providing education about AIDS both within the community and the broader society as well as assisting those affected by the disease. It acted as a liaison between the gay community and other institutions and was particularly concerned with medical issues in the media. Approximately 100 to 200 individuals attended its first meeting in April 1983 (Alloway 23515).
could hardly be said the Red Cross was “going back” to something it had never abandoned (27983).

Edwardh suggested that internal policy within the Red Cross, as expressed in such things as the question and answer sheet given to Herst, appeared to be at odds with the position being publicly represented (28005).

Davey explained the discrepancy as arising out of a concern over the threats being made that if a total ban were applied, some gay donors would come in and give blood without telling anyone about what they were doing (28006).

Perrault added that while they were concerned about individuals coming in and donating in anger, it also had to be remembered this was taking place during the summer. The summer was always a difficult time to maintain an adequate blood supply and Red Cross officials did not want to jeopardise the donor base further (28006).

Edwardh expressed her uneasiness over what the witnesses were saying; “...[To suggest that there was any serious concern about members of the community coming forward and deliberately donating in order to sabotage and contaminate the blood supply ... is a horrendous allegation].” The claim that members of the community would do such a thing, she said, is completely outside the evidence already heard by the commission. She wanted to know if there was any evidence coming from Canada that such actions were being contemplated (28007).

Perrault replied that while he had no personal knowledge of the threats, he would not necessarily expect to; it was highly unlikely that the individuals involved would make that kind of threat publicly. He said he depended on Derrick for this information and Derrick, no doubt, was getting much of it from U.S. sources (28008-10).

The decision not to levy a blanket exclusion, of course, was motivated by a number of factors
beyond the alleged threats coming from militant gays. Perrault recalled that they had chosen not
to exclude all sexually active homosexual males, in part, because the "gay community had been
extremely co-operative and we did not want to lose [their] co-operation" (28010-1).

Later, during cross-examination, Mr. Elliott, counsel for the Canadian AIDS Society,
emphasized the co-operative attitude of the community. He pointed out, that at the conclusion of
the AIDS Committee of Toronto (ACT) press conference in July, Professor Lynch, on the behalf
of the Committee, said that the group was "eager to work together with the Red Cross" in order
to: "counter the fear of AIDS" arising out of recent reports; make people aware of "the important
role gay men and women have long played in the Canadian Blood System"; and "assure a safe
blood supply." According to Mr. Elliott there was virtually no opposition to the Red Cross's
actions coming from the gay community (29493).

Perrault agreed: there was an offer of collaboration and Derrick had reported the general good
will of the community to him (29493).

Continued Concerns Over Donor Education

There were a number of sources of pressure on the National Office that summer. Edwardh
noted, for example, that some Medical Directors had begun to push for the development of a
uniform national policy regarding donor information about the risks associated with AIDS and
they wanted that information available at the clinic sites as soon as possible (28022-6).

Up until this point the Red Cross relied almost entirely on the mechanism of self deferral.
Edwardh observed that the strategy was premised on the existence of an informed donor who had
been educated about risk factors. She also noted that in order for the program to be successful the
donors not only had to be informed, they required a means of excluding themselves without
embarrassment. Edwardh pointed out it was recognized at the time that some at-risk donors would inevitably be caught up in settings such as workplace drives and would find it impossible to avoid donating without drawing attention to themselves (28026-8). She wondered whether the inclusion of "a privacy component" had not struck him as an important addition to the system?

Davey said he shared the belief that information must be provided at the clinic site. He noted, however, that the primary focus of the program was to ensure high risk individuals did not attend the clinics in the first place. While he admitted that it was possible that some individuals might be caught-up in office drives he explained that the clinics were designed to move large numbers of people through and were not suited to providing privacy (28028-9).

Donor Screening: Navigating Turbulent Social Waters

The issues surrounding donor screening became a matter of increasing concern in the ensuing months. By August, Derrick had begun to lobby for a meeting of the BTS AIDS Working Group to consider the matters surrounding donor screening and to prepare for the upcoming meeting of NACAIDS. A meeting of the Working Group was called for early September (Edwardh 28035).

Reviewing the minutes of that meeting Edwardh drew attention to Derrick's presentation to the Group. She said that after considering the presentation, the Working Group decided "...that a more definitive CRC BTS policy on AIDS was needed" and that it should be developed with an eye to its presentation by Perrault at the upcoming NACAIDS meeting. They also recommended Derrick be given responsibility for developing the position, and that he be assisted by the Chair

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13 The AIDS Working Group had been formed in the spring of 1983 to deal with issues such as donor screening and the revision of donor questionnaire. There was an unresolved debate between the witnesses and Edwardh whether this was really the Immunology and Virology Working Group wearing a different hat or whether it was separate entity (28051).
of the Group, Perrault, and the Alternate Chair, Davey. (28055).

Edwardh further pointed out that it was decided that a donor information pamphlet be
developed as soon an appropriate survey was conducted to determine the types of questions and
concerns being expressed at the clinics. An Ad Hoc Working Group was formed to produce the
pamphlet.

Edwardh turned to a curious comment recorded in the minutes, in which Perrault is reported
to have said “... the scientific issues were easy to identify. However, it is the navigation of the
political waters which pose the greatest danger.” She wondered what Perrault meant by his
comment (28056-58).

Perrault explained that in saying the scientific issues were easy to identify he was simply
suggesting that on scientific side you were dealing with published information; it is not coming
from a “sensational press”. It may not always be perfectly clear because “sometimes you still
don't have definitive data, but you have something to work from” (28059-60).

He went on to explain that his comment regarding the dangers of the political waters has to be
understood in context. They had just been “sailing through the press” and the coverage of the
events of March and July when he spoke of the dangers posed by the political waters. On top of
that, he said, the Haitian community and the Human Rights Commission were putting enormous
pressure on the organization. Perrault pointed out that the impact of the human rights issues, in
terms of negative public relations, represented a significant political risk for the CRC and that he
felt this needed to be kept in mind when considering the options (28060-1).

Edwardh summarized the conclusions reached by the Working Group: the Red Cross needed a
more definitive policy regarding AIDS; information must be provided to blood donors; the whole
approach they had taken to AIDS must be evaluated; this could lead to a further re-evaluation of
Enlisting NACAIDS

One of the primary reasons for establishing a definitive policy regarding AIDS was, of course, to get the approval of NACAIDS. Something, puzzled Edward: what made National Office staff think it was within the “bailiwick” of NACAIDS to endorse the Red Cross’s position regarding donor screening when they had no expertise in blood banking (28078)?

Perrault explained, as he had earlier, that the Red Cross was not necessarily looking for support in the area of blood banking. NACAIDS represented a large body of expertise and could provide valuable support on the epidemiological side of the disease, an area where they were admittedly weak (28077-8). Perrault also pointed out that NACAIDS included representatives from the LCDC and the BOB. The Red Cross thus gained federal input on matters concerning donor screening through NACAIDS, the only federal input they received on the matter.

Edward asked Perrault if he thought the input of the Bureau of Biologics so important, why had he not phoned the agency? Perrault replied that National Office staff contacted the BoB in regards to “a number of other issues” but they had not called to discuss donor screening because the agency had never expressed an interest in the issue (28079).

Later testimony made it clear that there were other reasons for wanting the support of NACAIDS. During cross-examination, for example, Mr. Rennie pointed out that the Red Cross had made it a priority to gain NACAIDS endorsement for its proposed HTLV-III testing plan in 1985. Was the support of NACAIDS intended to give “a measure of credibility and independence to the recommendations?” he asked (30426).

Perrault replied that their endorsement had no authoritative power, but that “it certainly had
moral suasion.” He went on to say that is why he and Dr. Gilmore, the Chair of NACAIDS, had gone together to the June 1985 meeting with the Canadian Blood Committee concerning funding for the proposed plan to institute HIV testing (30426-7). Perrault later explained that he was concerned that his “repeated trips to the CBC for money were getting monotonous to them” and that he felt Gilmore's presence would underline the urgency of the situation (30468).

National Office staff headed into the September NACAIDS meeting feeling pressure on all sides. The meeting did little to assuage their concerns. Edwardh pointed out that once again many of the major issues brought to the table by the CRC were never addressed although a number of matters with direct bearing on the Transfusion Service were taken up (28092-3). The Clinical Sub-Committee, for example, met over lunch to consider the March 4th U.S. Public Health Service recommendations. They returned recommending that the American PHS guidelines be adopted.

14 Perrault had already described NACAIDS as the only formal committee whose assistance could be depend on in dealing with organizations such as the CBC at the time (30421-2).

15 The commission was already aware of Gilmore's support of the Red Cross. During Gilmore's appearance at the hearings, April 17 to 21 1995, Arenson pointed to a February 1985 article in the Montreal Gazette in which, Gilmore, as Chair of NACAIDS, was quoted saying: “Canada's blood banks appear to be free of AIDS, which has infected at least 102 adults in the U.S.... We have a clean healthy blood system in Canada... Anyone who might have AIDS has not been donating blood... It's a marvellous thing”.

Gilmore apologized for that mis-statement saying he found it difficult to explain given that at the time there was “genuine concern” over the contamination of the Canadian blood supply. However, he reminded the commission that there had been concern over individuals refusing to receive transfusions as well as the danger that there would be insufficient donations because of the fear of contracting AIDS from donating blood (25090-1).

Mr. Arenson suggested that Gilmore appeared to have been proud of “disseminating this falsely reassuring information”. He pointed to a letter Gilmore sent to Perrault following the appearance of the article in which he says, “I thought you might enjoy receiving this...We are not perfect, but it certainly begins nicely.”

Gilmore reacted angrily when Arenson went on to suggest he had been enlisted by Perrault to reassure the public...” He replied indignantly that Perrault had not enlisted him; his statements had been entirely voluntarily (25092-3).
Edwardh pointed out that the only concern Perrault voiced at the time was over autologous donations (28093-5).

Perrault explained that he was concerned over autologous donations in part because many of the individuals making such donations were not well in the first place. CRC clinics were not equipped to deal with this situation; they did not have the necessary resuscitation capabilities (28097).

Edwardh suggested that Perrault had accepted the idea that donors should be informed about AIDS and the associated risks and that high risk donors should be encouraged to refrain from donating for the time being. That is what the U.S. blood bankers construed this to mean, she said. They believed they were required to give this information to donors at the clinic site (28099-100).

Perrault did not read the recommendation this way. While it said donors must be informed, it did not stipulate how this was to be accomplished. There was no requirement that information be provided at the clinic site. Perrault said that he saw the PHS recommendations more as a working document (28100-1).

Edwardh pressed the matter further; “Why did you let this go through and approve it in circumstances where you know the Red Cross was, in fact, weeks if not months away from having a process to put [out] a single piece of paper that clearly deals with the issues that the MMWR was talking about: What is AIDS? Who is at risk?” (28104).

Perrault explained that they had not gone into details at the meeting; there had been no full discussion of the issues. “I agreed in principle; I did not agree with all the mechanisms” (28105).

Edwardh asked why he would agree that studies should be carried out to evaluate screening procedures for their effectiveness in excluding plasma and blood with a high probability of
transmitting AIDS, when the CRC had no plan to do so (28105).

Perrault replied that he was “saying in principle I agree with the philosophy. I am not agreeing with all the details, because I don't know what they discussed at lunch” (28106).

Edwardh retorted that the minutes indicate that he supported the adoption of these recommendations (28106).

Insisting that he had agreed only in principle, Perrault explained that he was “...not trying to shoehorn this into a Canadian policy” (28107).

Edwardh shot back that his colleagues on NACAIDS believed that was exactly what they were doing (28107).

After further discussion of the specifics of the recommendations Edwardh asked Perrault whether he would agree that by adopting or agreeing to approve the PHS recommendations, he caused his “...colleagues at NACAIDS to believe the Red Cross was doing things or thinking about doing things that in fact they had no intention of considering?” (28107-10).

Perrault acknowledged that, in retrospect, he understood his actions to have had this effect. He then went on to explain that there was a shared sense of frustration both within NACAIDS and the Red Cross over the lack of leadership at the time; “...we all felt rudderless.” Perrault reminded the commission that the situation in Canada was very different from that in the United States: unlike their American counterparts, the LCDC and the BoB were critically under-resourced (28110-4).

Edwardh pointed out that Perrault went into the meeting armed with a “bunch of information” including material on the Confidential Unit Exclusion (CUE) program in New York City, the Alpha Therapeutics program of direct questioning, as well as examples of other intervention strategies, such as a donor questionnaire from the Irish blood service. Noting that earlier
witnesses had not recalled this information coming to the attention of the Committee members, she wondered if Perrault had any recollection of whether it had been provided to the group (28119-23).

Perrault explained that “the first meeting was partly an organizational meeting, and there was a lot of information floating back and forth... One of the difficulties that I had was the secretarial support for that meeting. On a number of meetings we arrived and material was shuffled around the table... it may have been distributed around the table, it may have been copied. I don't know. But there were times I know I was missing material, or it was provided at the last second. We hardly had time to consider it, on a number of occasions” (28126-7).

Edwardh concluded her exploration of the September NACAIDS meeting by asking whether the language of the title of the information package, “Catalogue of Reference Material According to Item Number in AIDS Background Memorandum for Use at the National Advisory Committee on AIDS” might not suggest that the material was never intended to be distributed (28128)?

Perrault replied that he “wouldn't draw that conclusion” (28129).

Further Attempts to Discount the Risks

Following the meeting Derrick drew up a memorandum to Dr. Perrault stating the Red Cross was in the process of designing an information pamphlet which was to be available mid December to early January. Edwardh pointed to the tension in the language of the memo. She said she found it puzzling, on the one hand, Derrick appeared to be “acknowledging the existence of transfusion associated AIDS as a scientific fact” while, on the other hand, he was saying that even if it was true “the whole issue has been consistently overemphasized in the Canadian press.” She wondered whether Perrault shared this view? (28131-6).
Perrault explained that his view changed over time.

When asked specifically about the period of November 1983, he replied that he was in relative agreement with Derrick on the matter. While saying that the term “overemphasized” might be a little strong, he was quick to point out that “the media loved the story” and “a very senior [Canadian Broadcasting Corporation] reporter” had said to him; “This was the perfect thing for me, sex, blood and such issues” (28136).

Was this attention perhaps due to it being a new illness and a clearly fatal one, Edwardh asked.

That was part of it, said Perrault; “but also the mode of transmission was of some interest or was the topic of sensational reporting” (28136).

Edwardh turned to the November NACAIDS meeting. She pointed to a position paper Derrick had prepared for presentation to the Committee. The paper stated that transfusion associated AIDS was no longer simply a theoretical possibility; as of August 1983 there were proven cases. Edwardh asked Perrault if he agreed with that viewpoint at the time (28137)?

Saying that they had already addressed this issue, Perrault explained that the epidemiological evidence was there but “the final evidence could not be arrived at until much later.” If one is speaking in terms of “scientific precision”, he said, then the final answer was not in. He went on to say, however, that most individuals in the National Office believed the evidence strong enough to warrant the conclusion that transfusion associated AIDS was a reality (28138).

Edwardh described the Red Cross as taking the position at the meeting that while TAA may be a reality, there were very few established cases. She pointed out, for example, that Derrick’s position paper suggested that there were no paediatric cases at the time.

Perrault replied that some definitions were still being worked on, and that based on the
existing criteria, there were no paediatric cases at the time (28138).

Edwardh said that she found it to be a curious approach to say that because a clear definition was lacking, there were no cases, especially when those treating the children had the clear intuition they were suffering from AIDS.

Perrault replied that he was "...just referring to the official reporting of the LCDC" (28139).^{16}

Edwardh remarked that the Red Cross presentation included “nothing more than the official statistics.” She also indicated that this had not eluded some members of the Committee. A couple of them voiced concern over the possibility the number of cases associated with blood and blood

^{16} The problems surrounding the reporting of transfusion associated AIDS in children arose again during Ms. Stoltz's cross-examination. She pointed out that the minutes of the previous NACAIDS meeting in September indicate that the Clinical sub-Committee considered and endorsed the position that children should be included in the case definition of AIDS although they should be “categorized and tabulated separately.”

Perrault reiterated that they were not included in the Red Cross presentations because of some real doubts which existed at the time. Besides, he said “...[w]e were not going to differ from the CDC and federal authorities on those issues.” NACAIDS was only an advisory group, he explained; they did not have the responsibility of making reports in the CDWR (29974).

Stoltz directed him to a July 1 1984 issue of the *Canadian Medical Association Journal* in which an article prepared by Dr. Derrick reported there were no cases of transfusion associated AIDS in Canada. She then reminded the witnesses that throughout their testimony they referred to the Red Cross's reliance on treating physicians, especially in terms of communicating the risks and benefits of blood therapy to their patients. Here is a case, she said, where “the Red Cross is communicating what I perceive to be false information and clearly conveying to physicians the perception that there is no AIDS in Canadian blood and this is something they do not have to worry about...” (29976-7).

Perrault repeated his earlier argument. The Red Cross was not going to disagree with the federal authorities and certainly not in the *CMAJ*. He did acknowledge, however, that it would have been more accurate to have adopted the approach taken in the *CDWR* and the *MMWR* and say that a paediatric case had been identified but because of the confusing situation surrounding paediatric AIDS it could not be said, categorically, that it is transfusion associated AIDS (29977-8).

Davey spoke up, noting he shared the scepticism over the existence of paediatric AIDS and that it was impossible at the time to distinguish congenital immune deficiencies from those associated with AIDS at the time. Only with the advent of a serologic test could anything definitive be said about neonatal cases (29978-9).
products was being under-reported.  

Edwardh wondered whether any of the information being presented at the meeting was new to Perrault (28141)?  

He replied that he had been familiar with most of the data and was aware of the possibility the official statistics published in the *CDWR* represented only a small portion of the actual cases, especially given that in many of the provinces, AIDS was not a reportable disease (28143-4).  

Edwardh pointed out that despite the concerns expressed, Perrault told the Committee the Red Cross was ""...unwilling to change the present screening procedures unless more cases related to blood transfusion become apparent’’ (28145). The Red Cross presentation, she argued, consistently underplayed the threat AIDS posed to the blood system. Perrault, for example, had told the Committee that few gays donated blood, while Derrick’s position paper suggested that the more proactive stance of U.S. regulators, blood bankers and commercial collectors came ““in response to pressures exerted by the media, user groups and other special interest groups...””.  

Perrault could not recall exactly what he told the Committee about the number of gays donating while acknowledging that he certainly did not have “good numbers” on which to base such an assertion “because we didn't ask” about sexual orientation at the time (28146-7).  

Whether the measures being initiated in the United States were being propelled by *bona fida* public health concerns, or were a response to external pressures, was a hard question to answer, he said. “I think it is difficult to separate the two, during that period of time, as the pressures

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17 Dr. Joncas, Professor of Microbiology and Immunology at the University of Montreal, for example, advised the Committee that 29 suspected cases of paediatric AIDS had been identified in the United States, 22 of which had an association with blood transfusion. Another Committee member drew attention to Tsoukas' most recent work in Montreal, indicating approximately one-third of the hemophilia patients examined were suffering from the syndrome (Minutes of the November 5th 1983 NACAIDS meeting, Exhibit 683:tab 16).
were certainly there. Allowing that to assign all causative relationships to the pressures alone, was perhaps an over-statement”; you might describe it as a case where external pressures “nudged” good public health measures into place (28149-50).

Davey added that the measures taken in the United States “…should best be described as ‘discretionary measures.’ Meaning they were undertaken in the lack of definitive knowledge…the things that prudent people might reasonably do” (28150-51).

Edwardh thanked Davey for his insight while reminding him that included in Derrick’s presentation to NACAIDS were his early risk calculations. She noted, that after presenting these calculations Derrick made the “strange comment” that “‘[g]iven those odds, the Canadian Red Cross has chosen not to expand its medical screening of blood donors...’” Edwardh suggested that reading the statement in context, Derrick was saying “we accept it is blood-borne, but given the odds of transmission, it is worth it to us not to expand medical screening, because of the risk to the donor base.” Edwardh wanted to know if Perrault shared a similar position (28151).

Perrault replied, it was part of the considerations at the time. Edwardh wondered if what Derrick was saying did not sound “a little bit like playing the odds” (28151).

“I wouldn't read too much into that language,” replied Perrault.

“Was it simply a matter of risk/benefit then?” asked Edwardh (28152).

Perrault felt risk/benefit was a better description. He explained they were weighing what was believed an almost negligible risk against the loss of perhaps 5 per cent of collections. He underlined the significance of the loss, noting, that over a year, this represented almost 50,000 donations, the equivalent of an entire year’s collections at a medium sized blood centre (28152).

Turning her attention to the screening methods under consideration, Edwardh pointed out that
the Red Cross's presentation of the various strategies to NACAIDS tended to focus on the costs rather than the benefits. She noted, for example, that Derrick's position paper provided a negative presentation of the CUE program; the only thing discussed was the potential loss of 12 per cent of male donors between the ages of 24 and 36 (28163).

Perrault did not see anything negative about it. It is "just a statement of some numbers..." outlining the problem. "He is giving a very succinct fact" (28164).

Edwardh argued that the CRC's presentation to NACAIDS had provided the Committee with an inadequate understanding of what the Red Cross was doing to protect the blood supply. The Committee, she said, was never told that information about AIDS was not available at the clinic sites. At best, she suggested, Committee members came away from the meeting with a "superficial" understanding of what the Red Cross was doing (28156-7).

Perrault said that he would not dispute the point. He then went on to explain the problem as resting, in part, on the diversity of specializations represented within the Committee. "...I am sure that the epidemiologist had a superficial understanding of the clinical part... each one dealing with his own specialty may have been more superficially informed about the others" (28157).

Edwardh wondered whether Perrault had benefited from the range of expertise represented by the Committee. Had the concerns they raised caused him to rethink his own position in any way, or had he simply come in the hope of gaining approval for the Red Cross strategy and left when he did not get it (28157)?

Perrault replied that he certainly did not reassess the whole situation; he had already been aware of many of the points raised at the meeting. "...[T]hings were not changing substantially in the course of that year, and that is all I am saying there, at that point. The situation had not changed" (28158).
Besides, he was not ready to agree with Edwardh's assertion that the CRCS had failed to gain the approval of NACAIDS. He pointed out that when he received the minutes of the meeting and they did not reflect the Committee's endorsement, he wrote the Secretary complaining about the omission, requesting that they be amended. The commission was unable to find any indication the request was acted on beyond the Secretary bringing it to the attention of the Chair of the Committee (28158-62).

Growing Concern Over Transfusion Associated AIDS

The apparent lack of a formal endorsement did not stop the Red Cross from going forward with its plans. The position paper presented to NACAIDS was tabled again two weeks later at the BTS Advisory Committee meeting (28169). At that meeting, a new and pressing problem emerged: the CDC was about to publish the results of its ongoing investigation into transfusion associated AIDS cases in the U.S. (28171).

Davey explained that while the National Office was not given an advance copy of the publication, nor did they have any particular information concerning its conclusions, they were aware of the gist of the content. They knew the article, which was to appear in the January 12th edition of the *New England Journal of Medicine*, would “increase suspicion very significantly” in regard to the existence of transfusion associated AIDS (28171-2).

Edwardh asked if the witnesses would agree that the *NEJM* article was a “watershed publication”. Did it bring an end to any reasonable questions concerning the existence of the phenomenon (28174)?

Davey described it as an important publication which “increased the odds considerably” but that it did not bring an end to the doubts. Perrault agreed with Davey, pointing out, that “...when
you say 'reasonable' you have to go back to the distinction that is made when it comes to the final scientific proof. But that is -- it is a good document. It is taken seriously" (28174-5).

Edwardh wondered whether Davey had been concerned that another wave of public alarm might be set off in Canada when the article was published.

Davey agreed. There was a concern that it would trigger further alarm, especially given that the NEJM frequently followed up its publications with a press conference. He was also "concerned that the findings might be misrepresented, which can always happen in public...it was something we had to be prepared to deal with..." (28173; 28176).

Perrault explained that while they were worried the article would create further anxiety within the public sphere the CRC staff had been concerned about the possibility of transfusion associated AIDS all year: They were concerned from the point of view of the recipient, the donor base, and the overall confidence in the system. "These were concerns we lived with virtually on a daily basis" (28177).

Edwardh described how, with these concerns in mind and a sense of what was "coming down the tubes", the BTS Advisory Committee began its deliberations on what was to be done about donor screening. In the end, she pointed out, the conclusions the Committee came to exactly paralleled the course of action proposed in Derrick's position paper (28179). 18

What the CRC was saying, suggested Edwardh, was that it was declining to expand its medical screening beyond voluntary self exclusion.

18 Among other things the Committee decided, "... based on the current evidence and knowledge with reference to the extremely small risk of acquiring AIDS through blood transfusion, or other therapy utilizing blood component or plasma derivatives, as compared to the beneficial effects therefrom, the Canadian Red Cross will continue its present course of appealing to well informed, and by virtue of the fact that they are voluntary, well motivated donors to self-exclude from donating blood where there is any possibility that their donation might harm rather than help [a recipient]" (28179-80).
Perrault agreed, but made it clear he did not feel this precluded the possibility of change. They could change, he argued -- they just chose not to do so at that moment (28181-2).

Steady Sailing: Holding True to Course

Shortly before Christmas 1983 Derrick sent a memorandum updating all Medical Directors as to what had been happening about AIDS. In the memo Derrick said that as far as he was concerned, the chance of developing AIDS as an outcome of infusing blood or blood components, was minuscule and that "...[t]here are many now who consider that the importance of AIDS as a public health threat in this country has been overrated" (Edwardh 28228). Surely this view was at odds with the one held by his colleagues on NACAIDS, suggested Edwardh.

Perrault agreed. It would be unlikely they shared his view.

Derrick's memo, Edwardh pointed out, suggests "'[t]he CRC position, was, with the exception of a minor wording change, accepted in totality by the NACA....'" Certainly, she said, there had been no endorsement of the CRC position on screening at the November NACAIDS meeting (28230).

Perrault replied that while the Committee may not have formally endorsed the proposal, he had no recollection of them rejecting it either.

Edwardh was puzzled: surely looking at something is different than accepting it in totality. Is there not "a difference between receiving something as information and endorsing a position of someone?" she inquired (28231).

"Well they had a chance to look at it," said Perrault. "That was what I recall" (28232).

Returning to the memo, Edwardh noted that attached to it was "‘a mock up of the completed information package’" and accompanying this was a request from National Office asking the
Medical Directors to examine the new donor screening pamphlet and send along their comments by January 9th 1984. This time frame, she said, obviously left no room for the Medical Directors to interview donors or carry out focus groups to determine the types of questions which should be included. What was being sought were the insights of the Directors and their staff, not those of the donors (28255).

The vetting of the pamphlet, in fact, speeded up considerably at this point, as its progress had fallen behind schedule. Comments on the draft were hurriedly sought from the Executive Committee of the Medical Directors (an administrative group) as well as from the Chair of Donor Selection Criteria Group (28258-9). By early March the pamphlet was ready to send to the printers and by early May -- shortly after the press conference announcing the discovery of the HTLV-III virus and forecasting the imminent development of a test for the disease -- it was in Red Cross blood donor clinics across the country. Phase two of the Red Cross's response to the AIDS threat was complete. The third phase would begin shortly as the Red Cross officials began to consider, in earnest, the benefits and drawbacks of heating plasma products to kill the viruses they carried.

Summary

Perrault and Davey offered perspectives on the generation and application of scientific knowledge and its role in public policy decision-making which differed in significant ways from those presented by Francis and Zuck. Yet, in some ways, the stories they told, echoed those of the U.S. officials who had testified before them.

19 Perrault had made a commitment to both the BTS Advisory Committee and NACAIDS in the fall that the information pamphlet would be in place by April 1984.
Davey -- the person responsible for the technical side of the Canadian Blood Transfusion Service during the early years of the epidemic -- described science as rigorous to a fault, extremely conservative, hierarchical, and highly structured in practice and organization; but it is also open. Every theory put forward must be considered until it is either proven wrong, or shown to be insufficient on methodological grounds. No theory can be accepted, however, until proven. Proof in the case of AIDS required the identification of a specific agent or agents and the demonstration of its or their causal role in the illness. The epidemiologists' natural histories, demographic patterns, case studies, behaviour profiles, and individual observations and experiences, were insufficient to warrant acceptance of the hypothesis that AIDS was caused by a blood-borne infectious agent. The accumulating evidence of the link between blood products and the disease failed to change his opinion. In late 1982, when cellular abnormalities consistent with those observed in AIDS patients were reported amongst hemophiliacs, Davey discounted it, saying that there were other possible explanations for what was being seen and each required investigation.

For Davey the contamination of the blood supply with AIDS remained a problem of limited public health concern. In early 1983, using epidemiological information provided by a colleague in the United States, he calculated the risk of contracting AIDS through a blood transfusion to be in the order of "a million to one". The risk in other words was "insignificant". The minimal risk associated with contracting transfusion associated AIDS did not justify taking precautionary measures that might well jeopardise the quality and the availability of the nation's blood supply: the risks did not justify the potential costs of acting precipitously.

While considering a wide variety of possible explanations the Red Cross conducted no original research into this or any other matter related to AIDS during the early years of the
outbreak. According to Perrault and Davey, a restrictive research budget, coupled with a limited technological base, precluded the possibility. Canadian Red Cross officials relied, instead, on information coming from a variety of U.S. sources. This information, however, could not be applied directly. The information, as well as the responses it inspired in the U.S, had to be interpreted and reshaped to fit the Canadian context. Perrault explained that they were not about to “shoehorn” American policy into a setting that was epidemiologically, institutionally and socially distinct.

Like Zuck, Perrault and Davey stressed the importance of consensus decision-making in the assessment, validation and application of the available information. The development of a policy appropriate to the Canadian context required consideration and input from a broad range of actors and institutions. During their appearance they reviewed in detail the pains-taking process National Office staff went through to gain agreement for their interpretations of the information and their proposed plan of action.

Despite their avowed commitment to consultation, Perrault and Davey proffered a view of science and decision-making which minimized the role of individual judgement as much as possible. They emphasized the importance of a hierarchy of methods. Those methods which were seen to assure the greatest degree of objectivity, those methods most suited to limiting human intervention and the introduction of bias, those most capable of standardized application, were characterized as residing at the pinnacle of the hierarchy.

The methods of the laboratory -- an area in which both doctors claimed qualification -- provided the model to which all other fields must aspire. Little time was given for the consideration of evidence or insight based on an appeal to practical experience. Likewise uncontrolled studies were treated as being of limited value.
Perrault and Davey described the hierarchy of method as being uniform and invariant across scientific fields. The methods, objects, and standards of verification of the laboratory, along with its products, were described as more reliable, more certain, less likely to be affected by the biases of the researcher.

The emphasis on hierarchy was also reflected in Davey's and Perrault's characterization of the institutional organization of the Red Cross. While information gathering was encouraged at all levels, its assessment and application was rigidly controlled by the centralized administration. Operating procedures and protocols were established exclusively by National Office. Once issued, directives were expected to be followed without deviation.

The hierarchical relations within the organization carried over to its interactions with other institutions, agencies and groups. For example, Perrault was asked, why, in late 1983, the Red Cross officials would accept and promote information suggesting there were no paediatric cases of transfusion associated AIDS when they knew those involved in the treatment of AIDS felt differently. Perrault described the Red Cross stance as reflecting the position of the LCDC and the CDC at the time. He explained that problems surrounding the diagnosis of immune diseases in infants led to the exclusion of paediatric AIDS as a category. Besides, he did not feel it appropriate for the Red Cross to disagree, at least not publicly, with the definitions and statistics coming from the LCDC. It was the agency in Canada charged with tracking and reporting diseases in Canada.

In some ways, Red Cross officials had little choice but to accept the data coming from such institutions. Carrying out none of their own research into AIDS, they were forced to depend on the information gleaned from others. In areas where no reliable or officially sanctioned information was available the Red Cross authorities found themselves in a bind. For example,
when it came to dealing with various communities and individuals affected by the outbreak, Red Cross officials were seriously hampered by their lack of understanding and information.

In order to fill the gaps in their knowledge, the officials seem to have deviated from the rigorous standards and methods required of science and science based policy decision-making. During her examination, Edwardh led the witnesses to acknowledge that the question of carrying out any expert investigation into the social groups involved, their structure and organization, their patterns of communication, their beliefs, practices, concerns, and goals, never seemed to arise. Instead, totalizing views, based on common-sense understandings and anecdotal information provided the basis for both characterizing the groups and individuals involved and developing.

The Red Cross officials compounded the problem by maintaining a policy of only meeting with the leaders of the communities affected by the crisis, and then very infrequently. It was assumed that as long as the leaders of the communities were enlisted the compliance of the general membership could be counted on. Direct contact with the broader community membership could therefore be ignored while contact with the leadership was kept to a minimum.

When matters became truly pressing, communications were released through the media generally without prior consultation with the groups involved or any follow-up to assess its effectiveness. Not surprisingly, the responses these communications elicited, gave Perrault and Davey pause for concern. They recounted the ‘litany of woes’ which resulted from their asking those believed “at-risk” -- recent Haitian emigres, sexually active gay males, hemophiliacs, and IV drug users -- to temporarily refrain from donating. They described how on the one hand they were facing charges of discrimination and racism and on the other were receiving demands for stricter screening protocols from user groups such as the Canadian Hemophilia Society. To top
things off, there was the constant worry over how the wider public would react to reports appearing in the media linking AIDS to the blood supply. They were concerned that the fear of contracting AIDS would cause donors to stop giving blood and patients to refuse necessary life saving transfusions.

The Red Cross authorities felt unable to control or deal effectively with the social-political realm. These outsiders neither recognized nor conformed to the authority structure within the blood system, nor did they respect the cherished standards and methods of science. The Red Cross officials felt overwhelmed. There was no regulatory structure to guide or to legitimate their decisions and actions. Despite their efforts to enlist political and scientific support few were willing to defend them against the very worrisome charges being levied.

Rudderless and powerless, they found it difficult to navigate the “dangerous political waters” into which they had sailed. The need to preserve the blood supply, coupled with the pressures coming from outside interest groups, politicians, human rights groups, radicals, and the sensationalistic media, proved to be too much. The Red Cross officials found themselves compromising their scientific principles and beliefs.

Perrault and Davey found it difficult to advise the commission on how disasters such as the contamination of the blood supply with AIDS might be avoided in the future. While both agreed that it was a terrible situation, neither was willing to acknowledge that there had been any significant failures in terms in the scientific management of the problem of AIDS and the blood supply -- at least as far as it was understood at the time. Throughout their testimony Perrault and Davey maintained there was nothing to suggest that the measures taken were inappropriate, given the situation and what was known. The overall effectiveness of the response, they argued, is borne out when the transmission rate of AIDS amongst Canadian users of blood and blood
products is compared to that of other countries; Canada did as well or better than other countries in protecting its blood recipients.

If there were failings in the response to AIDS in the Blood Supply, they originated in the organization and structure of the System and were outside of the specific purview and control of the Red Cross. They suggested a number of improvements that could be made to the System itself which might help avoid future disasters: adequate funding needs to be provided so that emerging problems can be effectively met; a clearly defined system of responsibilities and regulations must be established and adhered to; and finally, interest groups, politicians and the general public, must be prevented from interfering with the application of scientifically determined courses of action. On this point, at least, they agreed with Francis; some means must be found to control the influence of outsiders so that those who have the expertise to be making decisions can get on with their business. Just who the outsider was, of course, depended on who was speaking and what they were speaking about.
CHAPTER SEVEN: TRACING THE CONFLICTS IN THE TAINTED BLOOD TRAGEDY

Introduction

In the following section I bring together some key issues in the witnesses' accounts with the insights of anthropologists, sociologists, historians and others to examine how scientific knowledge was generated, processed and used during the early years of the AIDS epidemic. I explore why it was that some like Dr. Francis and his colleagues almost immediately saw the outbreak as a serious threat while other experts did not recognize its significance. I examine why some scientists quickly arrived at the conclusion that AIDS was caused by a transmissible agent, like a virus, transmitted through blood and blood products, while others took years to arrive at these understandings. Finally, I explore how a group of experts at the CDC, with little experience in blood banking, developed a set of effective strategies for reducing the risk of AIDS in the blood supply while the majority of blood banker's were unable to recognize their value.

The section is divided in 5 Parts. In Part 1, I discuss the experts' initial confrontation with AIDS and the strategies employed to understand and contain its spread through the blood supply. I explore the importance of experience and methodology, look at the use of analogy, and discuss the influence of preexisting categories in the construction and application of early understandings of the disease. In Part 2, I examine the role institutions played in the generation, assessment and use of scientific knowledge about AIDS. I discuss the relationship between individual perception and institutional location and explore how institutional goals and responsibilities affected the way information was evaluated and reacted to during the emerging crisis. I also look at the
struggles being carried on behind the scenes over what institutions were going to have authority
to speak on matters relating to AIDS and blood and show how these affected early
understandings and reactions.

In Part 3, I examine the witnesses' understandings of the social world and the various groups
involved in the tainted blood tragedy. I show that these understandings affected the way they
constructed the disease and responded to it. In Part 4, I discuss the 'political' problems the
witnesses describe encountering in trying to apply their understandings. I show that the political
struggles which surrounded the contamination of the blood supply did not simply emerge at the
point where the worlds of science and society intersected -- or collided -- as the experts would
have it: politics was an essential, although unacknowledged, element in the manufacture of
scientific understanding. In Part 5, I bring a number of these issues together to explore the
manufacture and use of the "one in a million" risk calculation. I examine the information and
methods employed in its construction, trace the transformations it underwent as it moved from
artifact to fact, explore the apparent lack of contemporary criticism and enumerate some of the
individual and institutional consequences of the wide-spread dissemination and use of the
erroneous estimate.

7.1 Confronting AIDS

Early Warning Signs

In the early days of the outbreak, a few clinicians working in the major cities of the American
seaboard began to confront unexpected opportunistic infections and rare cancers amongst young
gay males. The occurrences were diffuse enough to avoid sparking any national alarm. While
rumours began to circulate about a new and deadly disease affecting members of the gay
community there was little information available publicly.

Behind the scenes, another story was brewing. Concerns were beginning to mount as the first traces of the disease came to the attention of the infectious disease experts at the CDC. In April 1981, a staff member responsible for non-routine drug orders at the CDC informed her superior that since February, nine requests had been received from New York City for pentamidine, an infrequently prescribed drug, used to treat Pneumocystis cariini pneumonia (PCP). She also informed him of the rumours circulating in New York about the appearance of certain rare cancers (Shilts 1987 in Grmek 1990:6). The following month the CDC learned of five recent cases of PCP among previously healthy young homosexual males in Los Angeles.

The outbreak appeared to be affecting homosexuals exclusively. This caught the attention of the CDC experts. The experts at the CDC were sensitive to the problem of infectious diseases within the gay community since many had been involved in research on hepatitis B in the gay male population. These CDC researchers knew that communicable diseases could spread rapidly through the community and could quickly spread beyond it. The gay community was a bellwether for new epidemics.

Early Investigations

Within a month, efforts were under way to enlist a group of researchers to look into the outbreak. Among the first people contacted was Francis, who was working on the hepatitis B vaccine at the CDC in Phoenix, Arizona. Francis was enlisted to head up the laboratory

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1 Because pentamidine was rarely prescribed it was distributed outside of regular commercial channels. The CDC took control of the drug in 1967. In the following thirteen years they dispensed the drug only twice to adult patients who were not suffering from cancer or some recent immunosuppressive treatment (Shilts 1987 in Grmek 1990:6).
investigations. He was a logical choice for the job since he was very familiar with the spread and control of infectious diseases especially in gay populations\(^2\) and had been involved in research on the feline leukaemia virus, the first virus recognized to cause cancer.\(^3\)

In July 1981, the CDC established a Task Force to carry out surveillance and conduct epidemiologic and laboratory investigations on the outbreak. In order to get the program going, a means of reporting the new syndrome had to be devised. A definition distinguishing the phenomena from the previously existing diseases of KS and PCP was devised.\(^4\) The success of the reporting system depended on gaining the cooperation of treating physicians and local hospitals, as well as local public health officials and nurse epidemiologists.\(^5\)

To track the current outbreak and establish its history, the CDC drew on dispensing records for pentamindine as well as tumour registries. These recording systems served as important instruments for CDC researchers as they reconstructed the history of the disease and traced out

\(^2\) At the time Francis was working in the gay community carrying-out research on the new hepatitis B vaccine. He recounted having developing close working relationships with a number of individuals in the study.

\(^3\) Francis recalled that immediately after Dr. Curran contacted him from Atlanta he, phoned his mentor, at Harvard to discuss the new outbreak. He told the commission how both of them had been struck by the similarities they saw between the feline leukaemia virus and the new disease.

\(^4\) A reporting form was developed for all “...biopsy proved cases of Kaposi’s sarcoma in persons under 60 years of age without underlying immunosuppressive disease or therapy” and all cases “...of life threatening or fatal opportunistic infections documented by biopsy or culture from patients with no known underlying illness or history of immunosuppressive treatment” (Curran et al. 1982:248, Exhibit 549:tab 11).

\(^5\) Francis recalled that by early August 1981, the CDC had requested all state health departments to notify them “of illnesses suspected of fitting the case definition.” He told the commission that he was pleased with the cooperation of the local level professionals, particularly as it meant they had to take on extra work with no direct rewards. AIDS was not a reportable disease at the time; there was nothing to compel their assistance (21544).
current outbreaks and patterns of transmission.

By early November the CDC had documented 159 cases of KS, PCP, and other serious opportunistic infections among previously healthy individuals (Curran et al. 1982, Exhibit 549:tab 11). By December it was apparent the disease was not restricted to homosexuals; it was also being seen amongst I.V drug users (Masur et al. 1981, Exhibit 549:tab 6).

Conflicting Interpretations

Despite the early success of their information gathering efforts the CDC experts found themselves facing a number of serious stumbling blocks, not the least of which was the amorphous character of the affected communities. Many individuals in both groups were unwilling even to identify themselves, let alone cooperate with official government agencies like the CDC. It was, therefore, impossible to get an accurate idea of the prevalence of the infection within the suspect groups. As Francis explained, the fear that they were only seeing “the tip of the iceberg” nagged CDC researchers. The situation was further complicated by the fact that the disease appeared restricted to small sub-populations or sub-cultures of individuals who did not fit into the broader society. Those who lacked the experience of the CDC experts, who did not see the gay community as a bellwether, were unable to grasp the significance of the disease and its public health implications. It remained a curious disease of the marginalized, one which did not pose a significant threat to public health.

The link that was made between social behaviour and the disease did not help. Something in their behaviour, something ‘they’ were doing, was causing the disease.\(^6\) This sort of thinking not

\(^6\) Nina Glick-Schiller (1994) suggests that the use of ‘culture’ as a criterion for “defining membership in high risk groups” contributed greatly to the perception of AIDS as a disease of the “other”. The wide-scale use of a reified notion of culture as an explanatory term served to
only served to distance the threat of the disease it also helped place the onus on those affected; they were somehow responsible for their own misery.

Two new pieces of information emerged which both challenged and reinforced the notion of AIDS as a disease of the marginal: the July 9th report of Haitians; and the July 16th report of three previously healthy hemophiliacs suffering from unexplained immune deficiency.

It was not clear why the disease was appearing amongst Haitians. It was recognized, however, that most of those affected were recent immigrants from Haiti. It was known that hepatitis B was a common infection in ‘developing’ nations and that the disease's pattern of transmission appeared to be similar to that of hepatitis B. Beyond that, just why this group was being affected remained a mystery. Mystery or not, the fact that it seemed to be affecting mainly recent immigrants from Haiti was important; it further reinforced the idea that it was a disease of the other. AIDS continued to be seen as a disease confined to small groups of outsiders.

The hemophiliacs represented a departure from this pattern. Unlike those affected in the other groups the hemophilic cases were not clustered in the major urban centres. They were geographically dispersed. As Zuck explained, they came from relatively affluent areas not associated with “rampant” drug use. The group itself was also different in some significant ways.

distance and subordinate those affected by the disease, ultimately impeding efforts to educate the public and prevent the spread of the disease (Glick-Schiller et al. 1994:1337). Glick-Schiller, however, points to a more recent turn towards a ‘critical’ medical anthropology, which, rather than treating culture as a primary explanatory variable *sui generis*, treats it as “an inventive creative process that unfolds within particular historical, political-economic, and social contexts” (Merrill Singer 1988 in Glick Schiller et al. 1994:1344). This shift, she suggests, may contribute to better informed policy decisions (Schiller et al. 1994:1344). (For an overview of ‘critical’ medical anthropology see Merrill Singer, 1990).

Francis explained that it was later learned that Haiti was a favourite vacation destination for American gays and that they would pay Haitian men for sex -- many of whom were heterosexuals. The disease thus quickly spread through Haitian society (Francis 21609).
Unlike the homosexuals and I.V. drug users at least, the hemophiliacs seemingly, had done nothing to bring the disease upon themselves; they were 'innocent victims'. Hemophiliacs were also a highly circumscribed, controlled and dependent group, and thus were ideal subjects for epidemiological investigation. For the first time it was possible to get a sense of how much of the "iceberg" lay below the surface. Within months of the first report of hemophiliacs being affected, studies began to emerge suggesting that as many as 70 percent of the group were showing immune abnormalities associated with AIDS.

The hemophiliacs, nevertheless, shared two important characteristics with the 'others' associated with the disease: they were at risk for hepatitis B and they were a sub-population standing outside of mainstream society. Factor concentrates were widely heralded as 'normalizing' the lives of hemophiliacs, as Dr. Perrault noted in his testimony. However, hemophiliacs were not considered to be quite the same as the rest of society. It was accepted that these miraculous drugs came with a price. The multiplier effect associated with pooling thousands of units of plasma in the manufacture of concentrates almost guaranteed users would be exposed to a wide variety of foreign proteins and blood-borne infections, especially hepatitis.

So again the blood bankers could distance the affected group; what was happening to 'them' was not the same as what would be expected amongst the rest of 'us'. The fact of contaminants in the concentrates could also be used to argue that what was being seen in hemophiliacs was not the same as what was occurring with other AIDS suffers. It was not AIDS that was being seen amongst hemophiliacs. Dr. Davey told the commission, for example, that some of his research suggested that foreign proteins in the concentrates could cause a form of immune suppression. While the laboratory studies of the immune abnormalities being experienced by the two groups might look identical, that was far from proof they were caused by the same thing, he said.
As far as he and the other blood bankers were concerned, the available information simply did not warrant creating a panic, especially among those who depended on the drugs, nor did it provide sufficient reason to change standard operating practices. Zuck suggested that the real wake-up for the medical community did not come until later in 1982, when it was reported in the MMWR, the CDC's official organ of communication, that the disease appeared to be affecting blood transfusion recipients. For the first time, the threat of AIDS became generalized. With that emerged a new impetus to understand and deal with the disease.

This new group, transfusion recipients, could add another piece to the puzzle. Unlike hemophiliacs, most transfusion recipients were not regular users of blood products. Investigators could, at least in theory, determine the exact date of infection, and thus establish the latency period of the disease.

Communicating the Information

The emerging information was only of use as far as people were aware of it, and that depended, in part, on whether and where it was published. There was a great deal of reticence towards reporting information that might be unsettling to the public. Instead much of the information circulated within informal communications networks. Rumours of the existence of a significant number of transfusion associated AIDS cases circulated within public health and blood banking sectors for more than a year and a half before finally being published in the January 1984 NEJM. Blood banking officials showed little inclination to communicate information about the disease to those outside of their network. Those outside of the loop, such as treating physicians and the users of blood and blood products, remained unaware of the increasing evidence of the link between blood transfusion and AIDS.
This is not to suggest that the blood bankers had complete access to all the emerging information. Even when published, articles and reports could easily be overlooked if they appeared outside of the mainstream medical journals. As Zuck pointed out, the blood bankers were "pretty conservative folk", tending to restrict their attention to journals which reflected a like-minded editorial policy. Articles which appeared in publications outside of the mainstream, those more inclined to present a radical interpretation, were passed over. Even studies conducted by leading researchers in the field could be neglected if they did not appear in the right place. Zuck, for example, explained that important information appearing in the *MMWR* or in journals such as *Nature* went unnoticed by the blood bankers. They simply did not read them, at least not on a regular basis.

**Education and Practical Experience and Their Influence on Thought and Action**

Availability and access to information was one thing; how that information was understood and acted upon was another. It was apparent from the testimony that it depended, in part, on the educational background and practical experience of the individual scientists. Just how great an influence it had or should have had remained a matter of debate at the hearings.

For Francis, practical experience was not only central to recognizing the significance of the outbreak, it played a fundamental role in the development of the hypotheses which guided the initial research at the CDC. As he explained, it was not brilliance which provided him and his colleagues with their early insights into the disease; it was their backgrounds. The "keys" to the "puzzle" just happened to be under their "light pole".

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Francis' use of the term puzzle may lend insight into both his understanding of science and the early investigations of AIDS. Thomas Kuhn (1962/1970) points out that scientific puzzles are very different than problems. Puzzles have an assured solution, a problem may have no answer.
According to Francis their practical experience led CDC experts to assume almost immediately that they were seeing a disease, that a transmissible agent was involved, probably a virus, and that it was likely spread in a manner similar to hepatitis B. Those who lacked the experience working with infectious diseases amongst the gay community, were less inclined to accept this interpretation.9

Many of the blood bankers at the January 4 1983 joint meeting at the CDC in Atlanta were highly resistant to the idea the disease was caused by a blood-borne agent. As a group, the blood bankers tended to have a background in pathology and were more comfortable with the entities and procedures associated with the laboratory. They lacked experience with epidemiological evidence and found it unconvincing. Historical trends and demographic patterns may be interesting, but what they required was the identification of an infectious agent which could be shown to cause the disease. Perrault explained that without such evidence they were not about“

For the most part a scientific community admits only research problems which are puzzles. To qualify as a genuine research project, a puzzle must not only be seen to have an assured solution, “there must also be rules that both limit the nature of acceptable solutions and the steps by which they are obtained.” A study of the “rules of the game” which guide the selection and solving of puzzles, Kuhn suggests, can reveal a great deal “about the commitments that scientists derive from their paradigms.” A strong network of such commitments, “... provides rules that tell the practitioner of a mature speciality what both the world and his science are like...” and allow the specialist “...to concentrate with assurance upon the esoteric problems that these rules and existing knowledge define for him” (Kuhn 1970:35-42).

9 The CDC experts found it difficult to convey their sense of the seriousness of the situation to their colleagues, few of whom read the CDC's main instrument of communication, the MMRW. While CDC experts ran themselves ragged making personal presentations they were unable to get their word out. At the commission Francis lamented over their failure to convince their colleagues of the significance of the situation. He wondered, if perhaps, they had taken the time to bring their colleagues to the clinic sites and let them see the devastating effects of the disease for themselves, whether things might have been different (21729).
to tear the whole shop apart.\textsuperscript{10}

The different groups of experts focused on different objects to reach their conclusions. Although they did engage in laboratory work the public health specialists at the CDC focused on the social and historical patterns of the disease. From those they quickly reached the conclusion it was caused by an infectious entity. The blood bankers, however, demanded the standards of the laboratory be met. They needed to see a causal agent identified and its role in the infection demonstrated before they could accept its existence.

Even if an infectious agent was involved, the blood bankers found it hard to conceive of it posing a significant threat to the blood supply and its users. Unlike the infectious disease experts at the CDC, whose experience brought them to associate blood with disease, the blood bankers' experiences emphasized the therapeutic benefits of blood. Donated blood was "the gift of life". They recognized, of course, that blood transfusions did transmit diseases, but for the most part these infections were assumed not to have serious consequences.\textsuperscript{11}

\textsuperscript{10} In an article entitled 'Style' for Historians and Philosophers (1992), Ian Hacking draws on the work of Alistair Crombie (1988) to develop a view of scientific inquiry as composed of a small number of historically based styles of reasoning -- including the epidemiological and laboratory styles -- which have become autonomous over time. Each style is associated with a unique set of techniques, laws and objects; each provides its own standards of objectivity. In this sense there can be no independently true or false statements, theories or facts in science. They are always true or false within the context of the "self stabilizing techniques" associated with a particular "style of reasoning". In Dissent in science: Styles of scientific practice and the controversy over the cause of AIDS (1994) Joan Fujimura and Danny Chou, expand on Hacking's ideas to suggest that the debate over whether HIV causes AIDS can be seen to rest in the clash between epidemiological and laboratory styles of practice. These two styles of practice, the author's argue, are associated with different objects, methods, and verification standards. Fujimura and Chou's discussion of the contemporary controversy over the cause of AIDS, parallels the conflict in the early years of the blood disaster between those who saw the epidemiological data as convincing and those who demanded to see a viral agent.

\textsuperscript{11} Davey suggested to the commission that at the time it was believed that approximately 1 in 4,000 blood recipients developed a serious infection as a result of a blood transfusion.
The blood bankers were not the only ones reluctant to accept the viral hypothesis, or the potential danger. The CDC received little support from the hemophiliac community. Some pleaded with blood bankers and public health officials not to take the products away from them. Hemophiliacs and their families had direct experience of the benefits factor concentrates brought to their lives.\(^{12}\) Like the blood bankers, they had grown to accept that viruses could be transmitted through the products they used. Experience suggested they could live with it. Besides, the experts in the hemophilia treatment community, many of whom maintained strong associations with blood banks and pharmaceutical companies, were telling them that the products were safe and not to stop taking their treatments.\(^{13}\) The hemophiliacs depended on and trusted these sources.

Similarly the gay community was unwilling to accept the CDC's dire prognostications. Gays had long been a target of discrimination. The 1970's and early 1980's was a particularly turbulent time: they met considerable hostility and resistance as they tried to organize themselves and express a political presence. They were thus inclined to view reports of the new disease with great suspicion, seeing it as yet another attempt to "medicalize" and control their behaviour.\(^{14}\)

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\(^{12}\) At the July 1982 meeting of the FDA's Blood Products Advisory Committee, for example, Mr. Carman, the representative of the National Hemophilia Foundation, begged manufactures and regulators not to take the concentrates away.

\(^{13}\) Association and trade newsletters, for example, noted the CDC's concerns, but warned their readers that the risks associated with a serious 'bleed' far outweighed the dangers posed by AIDS.

\(^{14}\) In discussing the early attitudes of the gay community towards the outbreak Mr. Ed Jackson, a member of the Toronto AIDS Activist Panel which appeared before the commission March 29 to 31 1995, noted that concern had been expressed by some that AIDS was not as serious as was being made out; that it represented another attempt by authorities to medicalize the community. A parallel was drawn, he said, between the past, where authorities had treated homosexuality as a medical condition and the current situation where they were once again being pathologized (23422-3). The community was also deeply concerned about the association being made between the gay community as a whole and the disease. At the January 4th meeting, representatives of the homosexual community voiced strong opposition to the use of any screening measures which
Standards and Methods and the Demand for Certainty

Where for some experience was key to understanding the phenomenon, for others the critical element in developing scientific understanding rested in the quality of the available information. Its certainty and reliability, its imputed objectivity and generalizability, are what matters and these depended on the adherence to a rigorous method.

The importance attached to method became evident as the commission counsel and the lawyers for the intervenor groups attempted to determine the point at which the experts believed they had sufficient information to conclude that AIDS was caused by a blood-borne transmissible agent. Francis maintained that almost from the start the available information was highly indicative of a transmissible viral agent; by the time the first transfusion related cases began to appear in late 1982 there could be little doubt. Personal opinion based on experience and observation were sufficient to satisfy him.

Zuck was more cautious. He felt that by January 1983 there was enough evidence that the hypothesis had to be taken seriously and acted upon. He stressed, however, that this is a 'far cry' from saying that the hypothesis had been proven. Proof did not come until Gallo and his team at the NIH identified the virus in the spring of 1984.

At the other end of the spectrum, Davey professed having never been satisfied with the epidemiological evidence. The observational studies and the opinions of colleagues, while interesting, did not provide sufficient warrant to accept or act upon the hypothesis. There were simply too many unknowns, too many potential costs involved, to act without reliable evidence. What was required were rigorous, controlled studies, which could demonstrate a definitive link between an imputed agent and the manifestation of the disease in a subject.

would further stigmatize the group.
Davey wanted to see Koch's postulates or their equivalent satisfied before he could accept that a viral agent was involved. Koch's postulates became the focus of discussion on several occasions during the proceedings. These discussions helped highlight some of the problems associated with following scientific standards and methods. Decisions as to whether a particular standard had been met, for example, were far from uniform among the witnesses and appeared to rest, in part, on the judgement of the individual scientists making the assessment. Testimony suggested that different versions of the postulates were available and that the experts could be working from different standards and expectations. The issue came up when Ms. Edwardh, counsel for the commission asked about Derrick's presentation at the January 1983 meeting of the Immunology/Virology BTS Working Group at which he stated that there was still no proof that AIDS was transmitted through blood. She wondered if his opinion was based on the failure of the evidence to satisfy Koch's postulates?

Perrault suggested that was likely the case. Davey immediately interjected noting that at the time there was a modified version of those postulates which could be satisfied without meeting the full rigour of Koch's classic formulation. In the end, Davey admitted, Derrick was not likely relying on the modified version of the postulates; the standards of proof he demanded could never be met by epidemiological data alone. Davey went on to insist, however, that he, at least, had been working from the modified version, and had not been convinced by the evidence.

Francis appeared to be working from a very different standard. He did not feel the full rigour of Koch's postulates needed to be satisfied before action was taken, although he agreed that things were more straightforward in situations where they had been met. Besides, he believed a relaxed form of Koch's postulates had been satisfied by the time Derrick was making his statement. He argued that the San Francisco baby case reported in the December 1982 MMWR
provided a real life setting in which Koch's postulates had been met. Here you had a clear case of an at risk individual donating blood, and a recipient of that blood who developed AIDS. There were several examples like this, he said. While they may have been inconclusive in the sense that no agent had been identified, a clear link had been established between individuals with AIDS and the transmission of the disease through their blood.

The version of Koch's postulates Francis was referring to appeared to be antithetical to the position taken by Davey at the inquiry and Derrick at the meeting. What they were looking for was a set of criteria which could be employed to overcome the subjective perceptions and judgements of the individual scientist. For Davey, Koch's postulates offered a standard by which all could agree, regardless of their own personal experiences, expectations and interests. The matter was simple -- the evidence either satisfied Koch's postulates or it did not. The evidence would speak for itself.

A similar situation existed around the debate over the use of surrogate testing. Francis pointed out that Spira's study, the main research used to support the use of surrogate testing, was widely questioned by the blood banking and regulatory communities. It was suggested that the data was skewed by the choice of subjects -- gay male patients attending a sexually transmitted disease clinic. The people in Spira's study were living in the “fast lane”, explained Zuck. They were not seen to represent the type of people who attend volunteer blood clinics. The data could not be generalized. Blood bankers chose to put their faith in studies such as those of Pert which showed as few as 21 percent of gay males attending blood clinics tested positive to hepatitis B core.

According to Francis the public health officials at the CDC had little difficulty with Spira's sample. For them the study provided strong evidence of the value of instituting surrogate testing. It fit perfectly well with existing information that the gay male population was at risk for
hepatitis B. Rather than the sample being skewed, he said, the individuals represented in Spira's study "had less sexual activity than the AIDS patients." In the end, he noted, the value of the study was recognized. Over a year after it was rejected by the blood bankers at Atlanta the Irwin Memorial Blood Bank used it to support the introduction of surrogate testing in 1984.

Models and Analogies

Francis argued that in the public health sphere, where you are often faced by potentially fast moving diseases, it is neither reasonable nor possible to wait until nature has spoken unequivocally. It may take years before definitive proof is available, and in the sphere of public health, delay means death. Action has to be initiated despite gaps in the knowledge structure. Some means must be found to temporarily fill in the gaps and assist the scientists in understanding what they were seeing. A guide for research was needed and a prescription for action was sought.

According to Davey, this was exactly what the officials at the Red Cross did. He described how, on finding themselves confronted by a new and uncertain situation, they began to "fish about" for models to think about the disease and to guide donor screening and blood testing protocols. They considered various candidates including human T-cell leukaemia virus

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15 Francis pointed to Dr. Snow's removing the Broad Street pump handle in the 1854 cholera epidemic in London and the handling of toxic shock syndrome and legionaries disease in United States in the 1970's as models of the way to handle potentially serious disease outbreaks. In none of the cases did the authorities wait for the identification of a causal agent before initiating a significant response, he argued.

16 Models, metaphors and analogies function in science in a variety of ways. They help define research programs by providing questions, insights and agendas. They serve to enlarge conceptual resources while allowing the accommodation of novel types of data. Models and metaphors are what connect theory and the material world and they provide the tools through which to extend theory. "Theories concretized in models and metaphors ... can provide guidelines
The hepatitis analogy

CDC researchers almost immediately drew an analogy between the new disease and hepatitis B. The same groups seemed to be affected and the patterns of transmission appeared almost identical. It seemed reasonable to the CDC officials that prevention strategies similar to those employed for hepatitis B would be effective in forestalling the spread of the new disease. The Public Health Service's November 1982 guidelines for the prevention of the spread of AIDS amongst health care workers, were premised on the analogy between the spread of hepatitis and AIDS.

Francis described the November guidelines as "proactive public health at its best". Although no cases of the disease had been reported amongst health care workers, a costly prevention program had been recommended and widely adopted. There were, however, some puzzling limitations associated with the initiative. In his examination of Zuck, for example, Mr. Stephenson broached the question why it was that the hepatitis analogy -- which suggested that bodily fluids including blood possessed a significant enough risk to health care workers to warrant the inconvenience and expense associated with following the MMWR guidelines -- was

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for new experiments and new theoretical innovations; the metaphors or analogies on which they are based provide strategies for dealing with anomalies in ways that formal systems cannot.” They also function as maps of structures, drawing attention to specific features of things and relationships -- they provide a map of the new rendered in terms of the familiar (Sismondo 1996:127-129). (For a discussion of the role of models, metaphors and analogies in science see Mary Hesse, Models and Analogies in Science (1966) and Dedre Gentner, “Are Scientific Models Analogies?” in David S. Miall (ed.), Metaphor: Problems and Perspectives (1982).
According to Zuck it was unfair to suggest that blood bankers should have made the connection between health care workers and blood recipients. Such a link, he suggested, requires a "hindsight stretch". He reminded the commission that, at the time, only one whole blood donation had been associated with AIDS; this was in the background of millions.

The focus on empirically verifiable data may have helped to diminish what appears in "hindsight" as obvious logical connections. There were, however, other factors at play which impeded extending the risk to blood recipients. Blood bankers and others may have failed to extend the analogy from health care workers to blood recipients because they did not accept the parallels being drawn between the AIDS and hepatitis.

In their testimony both Davey and Perrault down-played the significance of the hepatitis B model, suggesting that the precautions recommended in the MMWR guidelines were nothing more than a restatement of standard operating procedures within the health care industry. Davey went on to describe the hepatitis model as inadequate. It let them down by failing to predict the behaviour of the disease. Unlike hepatitis, he argued, AIDS is not readily transmitted in hospital or clinical settings. Davey demanded more than the model could deliver and its failure to meet his demands allowed him to dismiss it.

While the hepatitis B analogy played an important role, it had its limitations. By associating AIDS with hepatitis B, researchers and physicians could be led to underestimate the significance of the disease. During cross-examination, for example, Perrault agreed that drawing an analogy

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17 The failure to extend the risk seemed particularly odd given that it was recognized that the groups identified to be at risk for AIDS were also at risk for hepatitis and that it had been known for decades that blood recipients were at increased risk for hepatitis.

Studies in the United States in the late 1970's and early 1980's revealed that between 7 and 8 percent of blood recipients developed post-transfusion hepatitis (Exhibit 577:tab 12).
between the two diseases may have led some physicians to believe, that, like hepatitis, many
hemophiliacs might catch AIDS, but only a small percentage would actually die from it.

Hepatitis was an accepted cost associated with the use of blood and blood products, why not
AIDS?\(^\text{18}\)

**Sick Blood: healthy Blood**

I suggest there may have been another and more important reason why the blood bankers
failed to extend the analogy. When pressed as to the significance of the guidelines Perrault and
Davey had to acknowledge that the precautions were not quite as standard as they wanted to
maintain. Many of the guidelines, in fact, were anything but standard practice at the Red Cross.
Davey defended following a less stringent protocol, noting that hospitals and laboratories were
dealing with specimens of individuals who were sick while the Red Cross was dealing with the
blood of healthy individuals, that of volunteer donors.

This distinction between healthy blood and sick blood should help answer the question of why
the protocols associated with hepatitis were not extended to blood recipients. On the one hand,
blood bankers associated donated blood with life, it was “the gift of life”. On the other hand,
blood specimens from patients, by definition were seen as dangerous: they were vehicles of
disease and death. Blood was perceived differently, depending on how it was classified,

\(^\text{18}\) In the case of clotting concentrates the inclusion of antibody positive material was
considered an important prophylactic measure. This was one of the arguments against using the
hepatitis B core test as a surrogate test. There was a concern that in screening out all plasma
which tested positive for hepatitis B core you removed all the protective antibodies in the pool.
Invariably some hepatitis B virus will get by the antigen tests in place and slip into the supply,
but now there would no longer be any antibodies to counteract its effect. In attempting to resolve
one problem another would be created. Thus, while the hepatitis analogy provided a guide for
understanding and responding to the disease it also provided a rationale for doing nothing -- or at
least an excuse for not doing what was being recommended.
depending on who it came from and the context in which it was encountered.

This is the thinking behind Davey's explanation of why the Red Cross did not need to follow the same rigid protocol as hospitals when handling blood specimens. The blood of a volunteer donor was pure and life restoring, the blood of a patient, contaminated and polluting. The distinction helped minimize the dangers posed by donated blood and obscure the shared risks of health care worker and blood recipient.

For the public health and infectious disease experts used to seeing blood as a major route of infection, there was no distinction between the blood of a donor and the blood of a patient. Blood was blood; all of it represented a potential threat.

7.2 Institutional Priorities and Conflicting Perspectives

Introduction

It was clear from the testimony that if the evidence was speaking, it was saying different things to different people. The ways in which the evidence was assessed, and the meaning and significance it was given varied from scientist to scientist, and this, according to Zuck, depended, in part, on the goals, interests and responsibilities of the scientists and the institutions in which they were located. Where CDC experts such as Francis saw their primary responsibilities resting in the eradication, or at least the control, of the infectious diseases, the blood bankers saw themselves as primarily responsible for ensuring the availability of an adequate supply of blood and blood products. One of the problems -- in Canada especially -- was that blood bankers were not only responsible for maintaining the supply of blood and blood products (collection, manufacturing, and distribution), they were also responsible for ensuring its safety. They were not about to do anything which would jeopardize the blood supply, nor were they about to step
back into the darkness of the past, on the basis of some hypothetical virus, particularly one the likes of which no one had seen before. They accepted that clotting factors transmitted disease; it was an unpleasant but unavoidable and tolerable cost of participating in a modern medical and commercial miracle.

Zuck described how institutional concerns affected the way individual scientists evaluated the strategies proposed to protect the blood supply. He explained, for example, that in terms of the debate over surrogate testing, a specificity of 60 percent might seem good to a public health specialist who is looking at the number of infections it will reduce. That same figure, will be very unappealing to the blood banker who sees the 40 percent false positives as perfectly healthy donors being falsely excluded. Each person excluded by the test, will have to be replaced by another donor, and as Zuck pointed out, a new donor is “approximately 33 times more likely to carry a transmissible disease than a someone who had been giving for years”.

Internal Conflicts and the Role of Institutional Memory

The witnesses agreed that institutional goals, interests, and responsibilities affected early investigations, understandings and responses to the disease. The extent and nature of those influences, however, remained a matter of debate. For example, there was a question whether a consensus of opinion even existed within the CDC as to the value of the hepatitis B core test in screening out at risk individuals. Red Cross counsel pointed out that the records of Congressional hearings, held in 1983, imply CDC officials were not inclined to support the institution of surrogate testing. This lack of unanimity was further evidenced, he argued, in the agency's failure to issue any firm recommendations regarding the use of surrogate tests.

Francis said that as far as he knew there was unanimous support for the use of the test within
the agency; the apparent lack of support from CDC officials at the hearings proves nothing.

There were obvious political reasons why CDC representatives might be hesitant to engage in a public debate over the issue in the setting of a Congressional hearing. Similarly, he said, the fact that no formal CDC recommendations for surrogate testing were forthcoming means nothing. The CDC wanted the tests put in place, the blood bankers did not. A compromise was agreed to; the tests would be evaluated by the blood bankers. 19 Besides, as Francis argued, the CDC was not in the practice of making such recommendations -- the blood system was the FDA's responsibility.

Zuck added further support for the supposition that there had been a lack of consensus within the CDC when he suggested there had been a split between the "junior" members of the CDC, who wanted immediate action and the senior managers of the agency, who wanted to take a more circumspect approach. Francis denied any such differences, yet he provided a clue as to why the senior staff might have been reluctant to take any action which might be construed as premature. During the early days of outbreak some saw the situation as similar to the swine flu scare of the previous decade.

In 1976, faced with what it believed was an imminent outbreak of the swine flu, the CDC successfully lobbied the federal government to initiate a nation-wide inoculation program. Millions of people were inoculated, but the outbreak never materialized. Unfortunately, several individuals who received the vaccine died, many others were injured. 20 Federal administrators

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19 The problem, as Francis pointed out, was the blood bankers never undertook a serious evaluation of the tests.

20 Fifty million individuals were inoculated at a cost of approximately 100 million dollars. The program left more than 500 people with Guillain Barre syndrome, "a serious iatrogenic disorder of the nervous system." (Beveridge 1978:23; Grmek 1990:14).
took a very dim view of the Agency's overreaction and severely criticized the CDC. Francis described the criticisms as unjust. Whether or not they were unjust, the head of the agency eventually resigned over the matter leaving the incident to serve as a potent warning of the costs of acting precipitously (Grmek 1990:14-15).²¹

The Struggle for Institutional Power and Influence In the United States

The swine flu debacle points to another important factor helping shape early understandings and response: the tension which existed between the various institutions and agency involved. In some cases, clear battle lines were drawn. Francis recounted that during the early days of the struggle to protect the blood system from AIDS a concerted effort had been made on the part of blood bankers and the FDA to wrest control of the situation from the CDC. It was argued that CDC lacked the experience to understand the complexities of the situation and that it had no business meddling in the regulatory affairs of the blood industry.

The FDA had been responsible for regulating the volunteer blood system for many years and during that time had demonstrated no particular interest in making radical changes in the system, a pattern they continued to pursue. Where FDA could be relied on to take the concerns of the

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²¹ In its investigation of the decision-making surrounding the contamination of the American blood supply the Institute of Medicine (IOM) concluded that the extent to which “the lessons of the swine flu experience” may have positively influenced CDC behaviour, causing it to assess its scientific evidence with more care “before issuing a warning of a new or threatening epidemic, may never be known.” However, the IOM went on to note that one thing is clear, the concerns over “jeopardising the CDC’s remaining credibility” and the potential destruction of “its ability to see its warnings lead to public policy” caused the agency to take a disastrously less forceful stand than it should have over AIDS and the blood supply (Leveton 1995:127).

Interestingly, where the CDC's over-reaction in 1976 led to the resignation of the head of the agency, its under-reaction in the case of AIDS -- a far more serious misjudgment in terms of its public health outcomes -- led to no such act of public contrition.
blood bankers into account\textsuperscript{22} the upstarts at the CDC displayed no sensitivity to the concerns of the volunteer blood sector representatives. To a large extent the blood bankers were used to regulating themselves through such organizations as the AABB and the CCBC. They resented the CDC's intrusion into what they considered their area of expertise and control; they did not want to see the imposition of potentially costly, and unnecessary, safety measures.

The FDA also had good reason to oppose the CDC. The CDC was in a process of redefinition and its recent name change reflected its newly developing and expanding identity. It was no longer the National Center for Disease Control. It was now the Centers for Disease Control and Prevention. It was a plural entity concerned with the control and prevention of chronic as well as infectious diseases. AIDS provided it with an opportunity to extend its borders into regulator's traditional territory. The FDA, aware of the apparently expansionist intentions of its sister organization, may well have found its interests better served by joining the blood bankers in opposing the CDC.\textsuperscript{23}

\textsuperscript{22} It was apparent in the testimony of Francis and Zuck that FDA staff and the blood banking sector representatives shared a number of common interests. For years personnel had been moving back and forth between the two sectors. Moving between sectors was not only condoned, it was approved practice. Dr. Zuck had in fact served in the positions of blood banker, industry representative and FDA regulator. As Francis explained, so long as the individuals involved remembered which "hat" they were wearing at the time he saw no problem with the practice; you ended up with better informed, more capable staff in both spheres. (Francis's argument is consistent with his view of practical experience as being key to understanding.)

\textsuperscript{23} In its analysis of crisis decision-making in the American Blood System, the Institute of Medicine noted, not only did participants at the January 4th meeting express reservations about the CDC's data, they questioned its credibility as an information source. Some questioned the CDC's motives in pressing the urgency of the AIDS situation. They saw it as a self-serving strategy aimed at ensuring the survival of the Agency. In a January 26 1983 inter-office memo, for example, an American Red Cross official suggests, "CDC is likely to continue to play up AIDS -- it has long been noted that CDC increasingly needs a major epidemic to justify its existence...especially in light of Federal funding cuts....AIDS probably played some positive role in CDC's successful battle with OMB to fund a new $15,000,000 virology lab. This CDC perspective is also obvious from the general 'marketing nature' of the January 4, 1983...
While the blood bankers and the FDA may have harboured many concerns over the CDC, in the end they could not ignore the institution's experts; they were the ones, as Zuck pointed out, with all the information. If you were working in the field of AIDS research or if you wanted to know what was going on, one way or another, you had to go through the CDC.

This state of affairs was not a matter of serendipity; it was not simply a matter of the "keys" being under the CDC's "light post." Francis told the commission how, from the very beginning of the outbreak, the CDC sought to enlist the assistance of researchers and institutions around the world. The CDC was in an ideal position to accomplish this. They had developed an extensive international network of formal and informal relationships which included non-scientists as well as scientists. In trying to gain an understanding of the disease and combat its spread the experts at the CDC drew on and extended this network. They brought together people, things and resources from around the globe and then tried to keep them all in order. Sometimes they were more successful, sometimes less so. They were able to keep the network in place and exert enough control to turn themselves into a "centre of calculation" when it came to AIDS.\textsuperscript{24}

Assembling and managing an enormous amount of information allowed the CDC to

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meeting.... We can not depend on CDC to provide scientific, objective, unbiased leadership on the topic....” (Leveton 1995:115).
\end{quote}

\textsuperscript{24} The CDC's position illustrates Bruno Latour's notion of "centres of calculation". "Centres of calculation" organize and direct research networks, collecting and centralizing the information thus generated. The staple of these "centres" are bits of paper or anything else which is easily moved back and forth and on which the instruments of science can inscribe the traces of the nature. As more and more resources and bits of information (or "immutable mobiles" as Latour calls them) are accumulated, translated into higher order abstractions and inscribed on further bits of paper, the scales of power slowly tip; everyone is forced "to come to the centres" (Latour 1987:232-3).
consolidate its power and become an international authority on AIDS. If you wanted to disagree with the theories and practices it was espousing, you quickly found yourself having to disagree with a wide range of people and things which, the CDC had bound into its network of alliances.

The CDC's power and influence grew. The MMWR, the CDC's official instrument of communication, was transformed from a publication of only peripheral interest in the blood banking and regulatory communities in the early 1980's to one which was almost mandatory reading by the middle of the decade.

Prior to the emergence of AIDS the agency had limited interaction and poor relations within the regulatory sphere. During the early years of the outbreak, as I have discussed, the relationship between the two was, at best, oppositional. By the mid 1980's the situation had changed considerably. Zuck told the commission that by 1985, when he joined the FDA, a cordial and mutually beneficial dialogue had developed between the agencies. By the mid-eighties the CDC had begun to play a role in policy decisions. CDC staff would regularly ask FDA representatives for comments on articles they was about to publish. The FDA staff would make an effort to provide almost immediate feedback and would take the information received into account when

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25 During the first year following the report of the 3 hemophiliacs, there was little information available on the disease outside of what appeared in the MMWR. Even after the rapid expansion of the AIDS research industry the MMWR was the publication people looked to for the latest, breaking news on the disease.

26 This was one of the things the Canadian officials were trying to account for at the Krever Inquiry. In choosing not to follow the advice of the CDC they had failed to follow the majority of countries in the Western world. They were asked to explain why they felt it appropriate to take a different path.

27 Historically, the CDC experts had been outsiders in the formulation of regulatory policy. The CDC staff were the field workers. They monitored disease outbreaks and traced their spread. The business of turning information into regulation belonged to the FDA. The CDC's brief intrusions into the regulatory domain, as in the case of swine flu, provided a warning of what happens when the 'labour' starts to influence policy.
making policy decisions. The CDC had moved from being an outsider to being a consulting partner. By the mid 1980's the FDA had come to see its goals and interests being better served as an ally of the CDC than an adversary.

By activating and extending its networks of relationships and by centralizing control of, and access to, the products of those associations, the CDC was able to exert a significant influence on the production of scientific knowledge and its application. In the process the CDC redefined itself, increasing its power, authority and boundaries of influence.

Canadian Institutional Responses to AIDS and the Blood Supply

The early patterns of response to AIDS in Canada, like in many other countries, included reliance on the United States for its research. Canadian public health institutions were not capable of such research undertakings. While the LCDC might loosely be characterized as the Canadian counterpart of the CDC, in reality they were very different institutions. The LCDC was underfunded and understaffed and lacked the extensive network of national and international relationships enjoyed by its American counter-part.

Canadian health authorities undertook limited investigation of the outbreak in the year following the *MMWR*'s first announcement of 5 cases of unexplained PCP infections among homosexual men in Los Angeles. Following the initial report of hemophiliacs with AIDS in July of 1982, the Bureau of Biologics and the LCDC began to rouse themselves. Among the first things Canadian authorities did was to try to enlist the Red Cross in a surveillance and research program. The initiative failed for several reasons. The Red Cross did not feel capable of meeting the demands being placed on it by Health Canada; it did not feel well served by the proposed research programs; and it was not comfortable following others -- especially not in matters in
which they considered themselves the experts.

National Office staff were already locked in a battle with the provinces over funding. Up until this point at least they had maintained virtual control over the technical side of the operation. They were reluctant to see that power eroded especially at a time when they were facing chronic shortages in plasma and other blood components. They saw these outside intrusions as having the potential to further disrupt their ability to maintain an adequate blood supply. As far as they were concerned taking shelter in 'tried and true' methods of the past was the safest approach in the face of the growing storm.

After formulating a basic 'wait-and-see response' to the problem of AIDS in the blood supply, officials in the National Office set about to enlist support for their position. This was a torturous process as Davey and Perrault revealed in their testimony. A variety of position papers were generated, information packages assembled, and consensus meetings held within the organization, as the proposal moved through the various levels of the CRC decision-making hierarchy. Each successive level was duly informed of the previous level's endorsement; even where the endorsements were less than wholehearted or were based on apparent misunderstandings of what National Office was actually doing or intending to do.

The real prize in the process was not in gaining the endorsement of their colleagues -- that was almost a forgone conclusion given the organizational and power structure of the CRC. The goal lay in gaining the endorsement of the newly formed National Advisory Committee on AIDS (NACAIDS). Obtaining the support of NACAIDS was deemed necessary for a number of reasons. The only group functioning in a national advisory capacity, NACAIDS was charged with making recommendations to the Minister of Health for the control, prevention and management of AIDS. NACAIDS, therefore, was in a position to influence policy decisions regarding the
issue of AIDS and the blood supply.

NACAIDS was made up of 16 respected physicians and scientists. Enlisted from across the country, they represented a number of disciplines including immunology, microbiology, epidemiology and infectious diseases. The support of such a group would lend scientific legitimacy to the Red Cross's proposals, especially when it came to dealing with regulatory and funding agencies. It also made good public relations sense. When the Red Cross faced public criticism it would be able to point to this national body of learned scientists and say “they support our position.” They did not want to find themselves standing alone. Like the CDC they were trying to put themselves in a position where they could say, “if you disagree with us, you disagree with all our learned friends.”

7.3 Science and Society: Constructing Difference

Introduction

Both the American and Canadian experts felt they had good reason for seeking support. They felt as though they were constantly on the verge of loosing control of the situation. The witnesses consistently portrayed the ‘social’ realm as standing in opposition to and threatening good science at almost every turn. They described how political greed, self concerned interest groups, and a public driven by emotion threatened to engulf the experts and thwart their efforts. As Francis explained, more than once the experts “had the wind taken out of their sails” by people who had no business meddling in technical matters. There seemed to be no question, as far as the

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When meeting with the Canadian Blood Committee (the provincial funding agency) in the summer of 1984, for example, the Red Cross brought Dr. Gilmore with them to plead their case for funding for HIV testing. Perrault told the commission that he felt Gilmore as Chair of NACAIDS would be taken more seriously than the Red Cross staff which would be seen as making yet another plea for more money.
witnesses were concerned there is science and then there is the rest.\(^{29}\)

The Lay Public

Lay actors were seen to function at a lower level than scientists. Francis made this clear when discussing the appropriate place of the public in public health decision-making. He believed the lay public had an important role to play as informants. He also recognized that “the involvement of consumer groups can be very good and very useful”. While seeing a place in the decision-making process for the consideration of the perspectives of various groups, he was adamant in his belief that debate can only take place at the level of science. The consumer groups have to be brought up to that level, he warned; science must never be brought down to the level of the public.

Zuck was more explicit: The public does not relate to generalized knowledge. They can not think in terms of abstract representations of risk. Instead they relate to concrete things such as a child in a hospital bed. As a result they can almost be counted on to act in ways detrimental to their own and the public good. That is why the experts feel it necessary to take control and make the necessary decisions.\(^{30}\)

\(^{29}\) This view also appears to be have been shared by the lawyers at the commission as they sought to uncover the social/political factors which had contaminated science and the decision-making in the blood system in the early 1980's. Science itself was rarely suspect, rather the failings were of institutional structures and individual scientists or the illicit intrusion of the social and political into the domain of a-social science and technology.

\(^{30}\) For a criticism of the view that the lay public does not deal with risk and risk assessments in a rational manner see Kristen S. Shrader-Frechette, “Probabilistic Uncertainty and Technological Risks” in *Science, Politics and Morality* (1993), Rene Von Schomberg (Editor). Shrader-Frechette argues that the public's unwillingness to accept expert risk estimates has more to do with the failure of risk assessors to comprehend the complex manner in which lay actors evaluate risk. For further discussion of the claim that the public is incapable of understanding complex technical issues, see, *Misunderstanding science? The public reconstruction of science and*
All agreed; the important thing was that the public not be upset. One way of maintaining calm is to ensure that the public not be given information that was unsettling. Even Francis, who advocated a 'shoot first, look later' policy when dealing with potential serious public health issues, felt the CDC had been reasonable holding back publication of information on the TAA cases under investigation for over a year. He believed that given its disturbing implications the information should not be made public until the experts were certain of their evidence.  

The blood bankers did not have to be convinced of this; they knew that when information about TAA reached the public trouble invariably followed. Perrault described how the U.S Public Health Service recommendations of March 1983, and the attendant publicity, forced the Red Cross officials to act precipitously to avert public panic. Perrault was also well aware that they could not count on the lay public reacting reasonably to the recommendations made by the experts. Both he and Davey recounted, in graphic detail, the public relations nightmare which ensued following the March 10 Canadian Red Cross press release asking members of at-risk technology (1996), Alan Irwin & Brian Wynne, Editors, in which Wynne suggests the lay public's failure to accept expert risk estimates may have more to do with their distrust of the experts and the validity of their evaluations than an inability to understand the information.

Francis's position is particularly interesting in view of both the CDC's 1976 warnings about an imminent epidemic of swine flu as well as its reputation to 'go off half cocked'. Here, at least, when it came to the safety of the blood supply the CDC was far more circumspect in its statements. Why was it that an deadly infection in the blood was deemed to be far more frightening and potentially disruptive than a deadly flu outbreak? The institutionalized memory of the flu debacle contributed to the senior staff's unwillingness to make premature pronouncements, but Francis was one of the brash "junior" staff pushing for immediate action. Yet in the case of making the public aware of the looming disaster he seems uncharacteristically insistent on the need for certainty before making any public announcements. The problem of AIDS and the blood supply seemed to represent a special case -- something almost too terrible to share with the public.
groups to temporarily refrain from donating.\(^{32}\)

The Haitian Community

Haitian community leaders, for example made it abundantly clear that they were unhappy with the press release. Deeply concerned about the association being made between AIDS and their community -- which was already facing significant social discrimination -- they accused the Red Cross of racism. Perrault explained that it was almost unthinkable that the humanitarian Red Cross could be accused of racism. It was an untenable situation for an organization which depended on the good will, trust and support of the public.

With its public support in peril, and no one willing to come to its defence, the Red Cross stood alone in the conflict with the Haitian community and its allies. The Haitian Consulates in Montreal and Toronto, the Haitian Embassy in Ottawa and even the Quebec Human Rights Commission and the Haitian Red Cross entered the fray. The situation was quickly beginning to spin out of control. The future of the blood system itself seemed in peril\(^{33}\).

From the perspective of the Red Cross officials the confrontation with the Haitian community was disastrous for everyone involved. In horror and panic Red Cross officials beat a hasty retreat. Rather than pursuing their request that recent Haitian immigrants refrain from donating, the Red

\(^{32}\) The Canadian press release mimicked the earlier American statement asking all those at risk of AIDS not to give blood. The groups outlined in the release included: "Patients diagnosed with AIDS, sexual partners of AIDS patients, persons with AIDS symptoms, sexually active homosexual or bisexual men with multiple partners, recent Haitian immigrants, current or past drug abusers, and the sexual partners of individuals at high risk for AIDS" (Exhibit 617:tab 3).

\(^{33}\) Perrault recalled that they were concerned by the apparent drop in donor support in areas such as Montreal. The memory of the Red Cross workers strike of 1977, which had led to crippling blood shortages, set off alarm bells in the minds of the Red Cross officials and others throughout the medical community.
Cross reverted to the methods already in place to protect the blood supply. Despite the backtracking, the damage had been done. The commission heard that the rift which emerged between the community and the Red Cross has never been completely resolved.

The problems were partly of the Red Cross's own making. Perrault told the inquiry how he was sympathetic to the situation of the Haitians as a visible minority. Nevertheless, it was apparent from the testimony that the Red Cross was unprepared to meet the concerns expressed by the Haitian community and its allies. They were unprepared because they had little knowledge of, and virtually no contact with, the people they had just defined as dangerous.

Perrault appeared unwilling to accept this suggestion. When asked if anyone at National Office had expertise on Haitian culture, Perrault responded that while it depended on what was meant by culture, he considered himself to have some expertise. He explained that he was well read in Haitian history and like many Haitians he had a classical education in French literature. He also recalled having played soccer against a Haitian team while at college. His dealings with Haitian colleagues and other well educated individuals from the community further bolstered his confidence in his expertise when it came to Haitian culture.

The Gay Community

The Red Cross's interactions with gay community followed a similar pattern. Despite Red Cross National Headquarters being located in the heart of Toronto's gay district, National Office officials had almost no contact with the community members prior to the March 10 press release. The only contact had been a single overture made by Derrick, and this had been restricted to a

34 It was hoped that existing screening criteria which excluded anyone recently in a malaria area would catch Haitian immigrants at risk for AIDS.
telephone conversation. Davey and Perrault had a naïve understanding of the community's social organization -- their concept of gay culture was guided largely by popular stereotypes. At one point during his testimony Davey went as far as to suggest that it was possible to identify a gay donor by his appearance. When challenged on the point he defended his claim noting that gays were flamboyant in dress and behaviour.

Their limited understanding of the social structure and organization of the gay community, to say, nothing about its membership, had significant consequences when it came to devising intervention strategies. They assumed the community to be similar in structure to the one they were familiar with in their day to day activities: the centralized, hierarchical structures of the Red Cross and of professional science. The Red Cross education program, for example, was premised on the existence of a relatively unified gay community with a recognized and centralized leadership. They assumed that information appearing in the mainstream media would be sufficient both to communicate the risk behaviours associated with AIDS and the need for those at risk to exclude themselves voluntarily from donation. They believed that, if necessary, they could always co-opt the leadership of the community to spread the word.

They were so secure in their assumptions that when criticisms of the organization's public association of AIDS with the gay community as a whole emerged, Red Cross officials interpreted it as evidence their communication strategies were effective.

The Canadian officials were not the only ones contending with pressures which they saw as coming from the gay community. All four experts noted that the blood bankers in the United States at the time were concerned, that if offended, members of the community would donate surreptitiously. Rumours were circulating that some gays threatened to donate out of spite if a blanket exclusion of the community was imposed. Zuck, as well as Perrault and Davey,
suggested these threats were taken seriously enough that they became a factor in the decision not to institute more rigid screening procedures. The blood bankers were concerned that in trying to increase safety they might inadvertently precipitate a backlash which would further endanger the blood supply. Doing nothing seemed the safest thing to do.\(^{35}\)

That concern over a gay backlash was a factor in decision-making suggests a very different criteria for the sufficiency of evidence at work when it came to the matters in the social realm. There was no demand for proof. Instead informal conversations with colleagues, rumours, anecdotes and common sense understandings were considered sufficient evidence on which to propagate information and base decisions. Despite the lack of any reliable evidence they seemed prepared to make sweeping generalizations about the community, levelling, what Edwardh described as “horrendous allegations” against its members. It was a pattern that would be repeated in the coming months and years.

Blood donors

Blood bankers, both in Canada and the United States, drew on a similar hodge-podge of stereotypes and impressions in their representations of blood donors. They started from the assumption that volunteer donors were altruistic and had no motivation to donate other than to help others. Volunteer donors were uniformly seen as responsible members of the community.

The blood bankers saw their relationship with the volunteer donors as based on trust and an

\(^{35}\) A wide range of opinion was expressed at the hearings as to the reality of the threat that if angered gay donors would surreptitiously donate. Mr. Arenson, for example, challenged Zuck on the matter, asking him to indicate even one piece of contemporaneous scientific literature where the issue was mentioned. Zuck admitted he was not able to do so, at least not off the top of his head. He agreed that the issue may have been something which was discussed informally over the lunch table. When Perrault and Davey were questioned about the threats, they admitted to relying on information coming from Derrick who in turn was likely relying on American sources.
understanding of their mutual obligations. Paid donors were another matter. Relationships in the commercial sector were seen to be based on a cash nexus rather than on trust and obligation. Paid donors donated out of economic self interest and could not be depended on to remove themselves from the donor pool. The only good they were aiming to do was for themselves. The proof of this was evident; their blood was many times more likely to carry disease.\(^\text{36}\)

The supposed distinctions between paid and volunteer donors meant different strategies were required in each of the sectors. Paid donors could not be trusted to tell the truth or act appropriately. They required close scrutiny and would tolerate the intrusion because of the economic incentive involved. You could push a paid donor, you could inconvenience them and invade their privacy.\(^\text{37}\)

The volunteer donor required special care and handling. Altruistic motivations ensured they presented little risk in the first place. Their only aim was to do good. So long as they knew the risks they would do the right thing and exclude themselves when appropriate. All that what was needed was to educate them. There was no need to go to the trouble and expense of

\(^{36}\) The high incidence of disease in paid-for blood is not so much proof of the self interest of commercial donors as it is evidence of what happens when you collect in prisons, operate skidrow clinics and pay relatively modest fees. The belief that volunteer blood is safer because of the altruistic motivations of its donors was championed in Richard Titmuss's *The Gift Relationship (1971)*, an influential analysis of the link between blood donation practices and the political ideology and cultural ethos of the society. (For a criticism of Titmuss's work see Harvey Sapolsky 1989; Thomas Murray 1990; Sapolsky and Boswell 1992:175; Hartwig von Schubert 1994; Alvin Drake 1996). A number of studies have since suggested there is no necessary link between bought blood and high infection rates. Sweden, for example, pays all of its donors yet has a low rate of hepatitis transmission while Japan switched from a paid to a volunteer system in the 1960's without any significant reduction in the high rate of hepatitis transmission (Sapolsky 1989:149-150, Sapolsky and Boswell 1992:175).

\(^{37}\) For an ethnographic account of the experience of paid donors see Martin J. Kretzmann, *Bad blood: The Moral stigmatization of paid plasma donors* (1992). Among other things Kretzmann notes that staff interactions with "paid donors were marked by an absence of trust and a social-moral devaluation..." (Kretzmann 1992:417).
expanding the screening program. Besides, the volunteers would not tolerate the inconvenience and intrusiveness of tighter screening procedures. Questions about sexual practices would offend them and they would stop donating. Increased screening would lead to blood shortages.

The great divide between volunteer and paid donors, rooted in the seemingly ‘natural’ opposition between altruistic and self interested behaviour, was treated as beyond question.\textsuperscript{38} It provided a bedrock on which to establish policy. Yet the witnesses did reveal some awareness that matters were not that straightforward. They knew that social pressures and other factors played a role in causing people to ‘volunteer’.\textsuperscript{39} They realized, for example, that at risk donors caught up in company blood drives could not easily refuse without leaving themselves open to discrimination in the workplace. This is one of the reasons why the Confidential Unit Program (CUE), developed by the New York Blood Bank, garnered so much attention; it allowed donors to discreetly direct their blood to ‘research’ rather than transfusion. The blood bankers also knew the recognition and awards given to repeat donors could act as incentives to donate.

Awareness of these factors was not sufficient to shake the blood bankers’ faith in the opposition between volunteer and paid donors. However, the blood bankers were deft at repairing apparent contradictions in their position. For example, in suggesting that gays were threatening to donate surreptitiously, they faced a conundrum. If their donors were good people who donated only out

\textsuperscript{38} Literature available at the time, however, suggested that the motivations of volunteer donors were complex and varied, and included everything from low self esteem to social competition between groups. See, for example, Oswalt 1977; Piliavin, Callero & Evans 1982.

\textsuperscript{39} The term volunteer is misleading. Paid donors are equally volunteers; they just receive monetary compensation for volunteering. A less confusing means of distinguishing the two might be in terms of compensated and uncompensated donors, but this too is problematic. As Zuck noted, it is hard to pin down what constitutes compensation. Matters become particularly murky when such rewards as emotional gratification and the enhancement of self-esteem and public identity are factored in. (For a discussion of the various factors involved in donor motivation, see Piliavan 1991).
of altruism, how could it be that gay donors would suddenly act maliciously? The solution required some creative theorizing. The answer, according to Davey, was that it was not their regular gay donors who posed the threat; it was a militant minority within the gay community who were to blame. These were not, 'good' donors, these were 'bad' people who were motivated out of maliciousness and spite. Davey, of course, had no evidence to base this on other than the third hand reports of threats supposedly made at American focus groups.

Others outside of the volunteer blood banking sector were less inclined to rely on such distinctions. Neither Francis nor his colleagues appeared sympathetic to the opposition between donor groups envisioned by the blood bankers. At the January 4th 1983 meeting the CDC experts advocated the institution of the same safeguards in both sectors. To do otherwise, Francis explained to the inquiry, did not make any sense. The public health experts, who specialized in infectious diseases, could no more see the rationale for distinguishing between the blood of paid and volunteer donors than they could see the distinction between the blood of patients and donors. All of it was potentially dangerous. To the volunteer blood sector, the CDC's failure to recognize the differences was evidence they did not understand their needs or concerns.

Dangerous Reifications

The experts involved during the early years of the outbreak appear to have been willing -- on the basis of relatively weak and unsubstantiated information -- to make broad generalizations about the public and pointed claims about specific social groups and cultures. These generalizations came to affect early understandings and strategies.

The evidence presented at the commission showed a clear and immediate association of the disease with particular social groups and behaviours. From the beginning, AIDS was recognized
as a social disease -- a disease which affected particular groups of individuals and 'cultures'. The scientists' understandings of the social world, therefore, had a critical impact on how the disease was understood and acted upon. The social world did not simply provide a context in which science was carried out. It was an important element in the construction of the natural history of the disease and the theoretical models which described it.

This is one of the reasons why the disease and its treatment were perceived so differently by different experts and different groups of experts. The witnesses left little doubt that they were working from disparate and often inconsistent understandings of the communities and individuals with whom they were interacting and publicly defining.

For example, Francis, familiar with the gay community and its associated patterns of disease transmission, immediately recognized the seriousness of the situation. He understood the rapidity with which infectious diseases spread in the community and knew that the disease would not remain confined to it. He had a long and positive working relationship with the gay community and saw it as composed of generally responsible and cooperative individuals. He was particularly critical of public education efforts which failed to account for the community's diversity.

He had not taken the rumoured threats of the gay community very seriously. He recognized there was resistance to the ways it was being represented and treated by the scientists, but he also believed solutions could be found to resolve the difficulties, solutions which would satisfy both scientists and the gay community. The trick, he said, lay in getting the issues out of the political arena.

The Canadian blood officials, on the other hand, envisioned the community as a unified whole, at least in the major urban centres. In speaking of the gay community in Toronto, for instance, Davey suggested that “this was a recognizable social community acknowledged by
themselves as such and represented by community organizations, community publications which had fairly wide circulation to interested people...\textsuperscript{40}

For Perrault and Davey the gay community represented a seemingly intractable problem. The Red Cross experts took the rumours coming out of the U.S. seriously and were deeply concerned over the putative threats. The gay community's reactions to Red Cross safety initiatives in Canada further convinced the Red Cross officials they were dealing with what could be a hostile and dangerous group.

The officials did little to improve the situation. Rather than launching any studies into the organization, practices and beliefs of gay Canadians, Haitians, and blood donors in general, they relied on information and rumours coming from their U.S. counterparts as well as their own commonsense understandings. Unfamiliar with the community and unwilling to pursue any significant dialogue with its membership, the Canadian Red Cross officials felt stymied. Of one thing was certain; the potential cost to the blood supply was too high to risk further offense.

7.4: The Politics of Making Difference

Introduction

The very different understandings and representations of the social world and its inhabitants put the two groups of experts at odds and contributed to their different approaches to the disease. In constructing the disease they not only defined 'nature', they defined 'society'. The groups and individuals affected by the disease were scrutinized, catalogued, and subjected to analysis. Gaps

\textsuperscript{40} During testimony before the commission, members of the AIDS Activist Panel were critical of the Red Cross's naive assumption of the existence of a cohesive community with a uniform and recognized leadership. (See, for example Mr. Ed Jackson's and Mr. George Hislop's testimony on the subject especially pp. 23297-23300).
in the data were filled through the use of analogies and commonsense understandings. All of this was represented in bite-sized caricatures and recommendations in the *MMWR* and other scientific publications.

The experts were not doing this without resistance from those they were defining and representing. The interference and opposition of the so called 'interest groups' was identified by the witnesses as one of the greatest problems they faced in dealing with the disease. For some, such as Perrault and Davey, the intrusion of politics into science seemed an intractable problem. Others such as Francis maintained the hope that the political issues could be made to disappear -- or at least be circumvented -- and the business of science could be gotten on with.

Distinguishing Science From Politics

The distinction which was made between science and politics is important.\(^1\) It provides insight into the witnesses' understandings of science and its relation to the world, while at the same time, it draws attention to some of the important issues and concerns they believed important in shaping early responses to the disease. The distinction is also noteworthy because throughout their testimony the witnesses seemed to contradict or at least problematize the opposition. While they argued that science and politics are opposed, their testimony demonstrated many ways in which they are bound together.

There was a general interest at the commission in establishing whether the various initiatives

\(^1\) The term politics was used in a variety of ways and never clearly defined during the witnesses' testimony. At times it was used in a restricted sense to refer to the formal realm of politics and politicians. At others times it was used to refer to a wide range of social, political and economic power relations between individuals, groups and institutions. While its use varied, one point remained consistent, to suggest that an action was based on politics was to suggest that it was in some way flawed or lacking justification.
taken to protect blood supply both in Canada and the United States were founded on scientific knowledge or prompted by political pressures. Sorting out science from politics, however, was not always an easy matter. The witnesses frequently disagreed as to whether particular actions were rooted in science or politics. There was also little agreement over the role politics actually played in decision-making, a problem exacerbated by the loose usage of the term.

For Perrault and Davey -- who maintained scientific knowledge during the early years of the outbreak was fraught with uncertainty -- most, if not all, of the recommendations, as well as the measures adopted to protect the blood supply, were the result of political considerations and pressures. The scientific evidence to warrant such undertakings simply did not exist.

Francis described the situation somewhat differently. Politics was not driving action, it was impeding it. AIDS, like no other disease before it, invited politicians and others to meddle in public health affairs. The science of the matter was clear enough. The problem was politics and politicians kept getting in the way of the proper application of scientific understanding.

Zuck offered a compromise between the two positions: both politics and science had guided action during the early years of the epidemic. He used the institution of surrogate testing at the Irwin Memorial Blood Bank in San Francisco in early 1984 to illustrate his point. There were good scientific reasons for putting the test in place.\(^42\) There were also powerful political motivations at work. San Francisco was a city in crisis. The operating rooms in the area were deserted and patients were shunning treatment. Something had to be done to reestablish public confidence in the blood supply; one way of accomplishing this was through the use of surrogate tests. Whether the tests actually identified those at risk, was, in some ways, beside the point. As

\(^{42}\) Zuck recalled that available evidence suggested surrogate tests would reduce the incidence of the transmission of AIDS through the blood supply, even if by how much, and at what costs, remained a question.
long as the public believed they worked they would be effective in saving lives; the "little old lady in tennis shoes," Zuck referred to, would have the hip surgery necessary to save her life.

Science as Politics

While extremely sensitive to the political opposition they encountered, the witnesses seemed unaware or at least unwilling to acknowledge that in creating and presenting their definitions of the various groups, they too were engaged in political actions. They understood that their definitions and recommendations had brought them into political conflict with the various groups, but described this conflict as emerging from the social consequences of the definitions, rather than the political act of creating the categories of 'others'. The failure to recognize the political significance of the categories established by the scientific community contributed to the conflicts between experts and the communities under their gaze and ultimately impacted on the way all of them reacted to the disease.43

Each witness described how the early investigations into AIDS required enlisting a wide range of actors (scientists and others), institutions, resources and things in the world. It was also clear from what the witnesses said that these networks of allies were carefully managed and their

43 That the exercise of power involved in defining others escaped the notice of the experts is perhaps understandable. As Foucault notes, modern power is only tolerable "on condition that it mask a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms" (Foucault 1980:86 quoted in Dreyfus & Rabinow 1983:134). Foucault describes modern power, "bio-power," as having emerged in the Classical Age, coalescing around two poles: 1) concern with the human species, where scientific categories rather than juridical ones became the object of sustained political attention -- the goal, gaining regulative control of the vitality of life; 2) concern with the body as an object to be manipulated through the exercise of disciplinary power -- the goal, the creation of docile, productive bodies (Dreyfus and Rabinow 1983:134). "Bio-power brought life and its mechanisms into the realm of explicit calculations and made knowledge/power an agent of transformation of life...." (Foucault 1980:143 quoted in Dreyfus and Rabinow).
products, data, were centralized and controlled. These were essential elements in the struggle to ensure that particular favoured interpretations, definitions and recommendations prevailed. Whose interpretations would be heard, which advice would be followed, depended, in significant part, on who could build and maintain control of the strongest and most extensive networks of relationships between people, things and resources.

The witnesses did not appear to recognize making science as a political activity, that, in constructing scientific knowledge, they were engaged not only in building networks of resources but networks of power and domination as well. They had no difficulty, however, in recognizing and enumerating the ways in which external political considerations affected and impinged upon the generation and application of that knowledge.

They nevertheless acknowledged that the situation might be difficult if not impossible to change. Francis described how despite enlisting a range of allies the CDC tried to avoid politics and stay at the level of science. He lamented over what he saw as the intrusion of formal politics into science, but also recognized that it appeared unavoidable. Research required funding, which required financial support which inevitably brought politics and politicians into picture. Perrault and Davey made it clear that in some cases they were unable to pursue the proper scientific course of action because they lacked adequate political support.

If politics was an intrusion, it appeared to be a necessary one. The witnesses may have envisioned an ideal world where science could be carried out free of political interference but they accepted in practice, at least, the two may not be separable. There was even a question of whether they could be distinguished, as Perrault candidly acknowledged when asked whether the more proactive response of the American blood bankers was based on science or politics. So long as the controversy over the cause and transmission of the disease remained open, he said, it was
hard to say where science ended and politics began.

Such determinations, it appeared, could only be made once conclusions or outcomes were settled. Even then, as the witnesses demonstrated, what one expert calls politics another calls science.

While there were a number of problems surrounding the witnesses’ characterizations of the opposition between science and politics there is little doubt that their belief in that opposition shaped their accounts at the inquiry as it shaped their understandings and actions when they first confronted AIDS. Their belief in the fundamental opposition between science and the social world, like other sedimented beliefs and habits, whether specific to individuals, institutions, disciplines or more generally shared, would require more than a few simple counter examples if it were to be unseated. It would require far more significant evidence than that because it is far more than a mere assumption; it expresses a complex system of belief and practice. It can not easily be given up without reorganizing of the system it expresses.

7.5 Constructing a Fact: The “One In A Million” Calculation

Introduction

I have discussed a number of the issues the witnesses identified as significant to the production and application of the scientific knowledge surrounding AIDS during the early years of the epidemic. Drawing on the witnesses accounts I also presented a number of my own interpretations of the issues surrounding AIDS, science and public health decision-making in the early 1980’s. I now provide a brief study showing how these issues were reflected in the production and use of the “one in a million” risk estimate, an estimate which had considerable impact on the institutional and individual responses to the problem of AIDS in the blood supply.
Risk and Cost-Benefit Analysis

Throughout their testimony the witnesses emphasized the need to consider both the costs and benefits when deciding what course of action to take. Whether the decisions pertain to a single patient or involve larger public health issues, carrying out a cost-benefit analysis is an integral part of decision-making. The witnesses described how in dealing with the emerging problem of AIDS and the blood supply, available information was assembled, selected and translated into numeric representations of the benefits and costs of the proposed safety strategies. These were then compared to the costs and benefits of taking no action. In the process, complex social and technical problems were translated into accounting problems capable of providing answers amenable to policy formulation. The numerical abstractions not only provided a guide for policy decisions, they were used to legitimate decisions and elicit support for them.

While maintaining the importance of the cost-benefit calculations the witnesses revealed that the process of translation is seldom straightforward or objective. They revealed their awareness that the determination and weighing of the benefits and the costs, like all assessments, varies from scientist to scientist and depends on a wide variety of elements including the experience, goals, interests and values of those making the determinations, their institutional location and the wider social political and historical environment. These elements affect the way information is accessed, helping shape perceptions of its reliability and its significance.

A fundamental element in any cost-benefit analysis rests in determining the seriousness of the situation and the likelihood of its occurrence. As Francis explained, cost-benefit decisions depend on the determination of the risks involved. The measure of risk, in turn, depends, in part, on the imputed seriousness of the consequences and, in part, on the likelihood of the occurrence of those consequences. Even in situations where a particular problem may have extremely serious
consequences, available remedies may not be employed if their associated costs are considered high and their likelihood of occurring is considered small.

During the testimony it became apparent that many of the decisions concerning the safeguards to be employed in the Canadian Blood System hinged on the risk AIDS was seen to pose to users of blood and blood products. It was equally clear that the blood bankers refused to accept the risk as being significant. They dismissed it, in fact, suggesting there was less than a "one in a million" chance of contracting AIDS through a blood transfusion. The risk was virtually non existent: it simply did not warrant or require any radical undertakings.

Characterizing the Calculation

The "one in a million" calculation was among the most controversial and rigorously scrutinized facts at the inquiry. Emerging shortly after the first published report of transfusion associated AIDS in December 1982, the figure was widely disseminated and used for more than a year in the United States and for almost two years in Canada. Even when the early test results started to come in late in 1984 and early 1985 indicating that the calculation had grossly underestimated the risks, no attempt was initiated to inform physicians or 'consumers' of the matter.44

During their testimony the witnesses characterized the calculation as being everything from an

44 The American blood bankers saw no need to correct the erroneous calculation because it was no longer an issue. Once the ELISA and Western Blot tests for HIV were in place the old calculation had no significance -- infected units would be identified and removed from the blood supply. The Canadian situation was somewhat different. Testing was not fully in place in Canada until late in 1985. Canadian officials were aware for many months prior to its initiation that the risks appeared to be significantly higher than publicly stated. Yet no public mention was made of the new information -- it was considered too earlier in the investigation of the test to accept the data as reliable.
outright deception, maniacally crafted to suit the interests of the blood banking community, to the most objective and reliable representation of the situation available at the time.

Francis described it as accurate but totally misleading. It was used “to reassure that everything is fine; don't worry about it.” He told the inquiry that at the time there was no reliable basis on which to make such calculations: too many unknowns existed. As far as he was concerned, those using the figures must have realized they were wrong; either that or they were “idiots”. He did not believe they were idiots.

The calculations, he suggested, were not only based on inadequate evidence, the methods employed were incapable of providing an epidemiologically sound representation of the risk blood recipients were facing. The “one in a million” calculation may have been widely accepted at the time, but according to Francis, it was also the worst information available.

Zuck professed that he could not understand the “to-do” Francis made over the calculation; it was nothing more than an approximation. He acknowledged a variety of approaches could have been taken in working out the calculation and that some blood bankers may have used simplistic methodologies to arrive at the figure. He argued, however, that the blood bankers were not working in isolation. They were relying on experts in the fields of infectious diseases and epidemiology. The Public Health Service, he pointed out, used the calculation well into 1984. In retrospect the calculation may be criticized but only in retrospect; at the time it seemed more than reasonable.

While admitting he was no expert in the field of risk calculation, Davey, too defended both the use of the figure as well as his own methods of calculating it. He took exception to the suggestion that the estimate was somehow designed to dismiss the risk associated with transfusion associated AIDS. There was nothing misleading about his calculation. It was just a
set of numbers which reflected the facts as they were known. He repeatedly told the commission that he had stated his assumptions clearly for all to see. Anyone who wanted to repeat his work could. In fact, he suggested, many experts in the field did carry out the calculation, and while not all of them used the same method as he, they all arrived at an estimate in the same order of magnitude.

There appeared to be little that could shake the blood bankers' faith in the calculations at the time, or their confidence in the reasonableness of that belief in retrospect. Yet for all their faith, the actual processes involved in its generation seemed far from the ideal methods of scientific investigation they had described to the commission. The methods employed to arrive at it were various. A central inspiration for the idea appears to have been item 6a in the blood bankers' January 13th 1983 Joint Statement which noted that despite the approximately 10 million transfusions annually, fewer than 10 cases of transfusion associated AIDS cases had been reported.

These figures and others like them seem to have inspired a few individuals in the U.S blood banking sector to carry out what amounted to little more than 'back of an envelop' calculations. These calculations then spread through informal and formal networks of communication to other blood bankers, to the wider public health sphere, to hospitals, physicians and the public, appearing in peer reviewed scientific journals and at professional conferences as well as in industry newsletters, government publications and popular press.

Zuck, Perrault and Davey argued that given the knowledge of the time, the estimate, as well as the evidence and methods employed in deriving it, were perfectly reasonable. Others at the

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45 A conversation with an American Red Cross official, for example, seems to have been the inspiration for Davey's calculation while Francis pointed to a telephone call to Red Cross National Headquarters in Washington as the source of the U.S. Public Health Service figures.
proceedings were less convinced.

In the face of probing questions even Zuck and Davey were forced to admit that a few things might not have been factored into the estimate. When considering the data on which the calculations were based, they acknowledged there had been a general concern at the time that only the “tip of the iceberg” was visible, that the vast majority of AIDS cases may have been going unreported and that the real rate of transfusion associated infections was not reflected in the official figures. The fact that the calculations were based solely on officially reported cases of transfusion related AIDS, they admitted, may have led to some underestimation of the actual risk. They agreed that many cases of what appeared to be AIDS simply did not meet the criteria of the official definition of the disease and therefore were not counted.

There were other questions concerning the way the data was handled. Measuring the total number of transfusions against the number of reported cases of transfusion associated AIDS yielded a per unit rather than a per recipient estimation. The witnesses thus agreed that the “one in a million” calculation did not refer to the risk faced by a typical blood recipient at all. Recipients at the time received an average of between three and four units of blood. If the per unit risk was one in a million, the actual risk per patient would be almost 4 times that. This was never made clear in the presentations of the estimate. The witnesses also agreed that the rough

46 The reasons for under-reporting TAA were many and varied: the official definitions excluded many cases; AIDS was not a reportable disease, so no legal compulsion to report cases existed; reporting meant extra work for the physicians involved; AIDS was a stigmatizing disease, so both patients and physicians were understandably reluctant to make the diagnosis known; AIDS was a widely misconceived and unrecognized disease.

47 Infants and young children who developed immune deficiency -- a significant group -- were among those excluded, as was anyone in the incubation phase of the disease. Even those who were displaying prodromal symptoms were excluded. An individual might be seriously ill from the effects of the disease, but if he or she had not developed one of the defining infections or Kaposi's sarcoma they were not represented in the calculations.
mathematical formulas employed in arriving at the calculation were incapable of accounting for an epidemic curve.  

While admitting some shortcomings, the blood bankers at the inquiry did not accept all the criticisms levelled against the calculation. When it was suggested it failed to account for the latency period of the disease Zuck explained that the calculations had been made 5 years into the epidemic, so they were actually looking at 50 million transfusions, not ten million. There was plenty of allowance for things such as the latency period, which, in 1983, was thought to be between six months and two years.

Similarly, Davey refused to accept that by failing to account for the 50 per cent of recipients who died as a result of the reasons associated with their need for blood in the first place, the calculation underestimated the risk by half. The calculation, he argued, represented the risk of developing AIDS, not the rate of infection. The 50 percent of the patients who died post transfusion were of no significance to the issue. They would never develop AIDS. The calculation did not purport to be a measurement of the risk of being infected, it expressed the risk of developing the disease.

Davey also maintained that while the calculation remained unchanged for almost two years it was still an accurate representation of the situation: there were no officially reported cases of transfusion associated AIDS in Canada until 1985.  

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48 At that time, the number of reported AIDS cases were doubling every six months. There was concern among public health officials that TAA would follow that same pattern exponential growth. The simplistic mathematical formulas the blood bankers were using to calculate the risk of TAA were incapable of representing or predicting such patterns.

49 It was suggested to him that the fact the Canadian situation had not changed was beside the point. He was supposedly basing his calculation on American data and the number of cases in the U.S. changed radically between 1983 and 1985 -- something he would have been aware of at the time, having received regular updates on the American situation from Derrick.
United States, the situation in Canada was seen to be different.\footnote{50}

A Deadly Silence

Many of the problems which surrounded the generation and application of the estimate are understandable given that those doing the computations had no qualifications to be carrying them out and depended on extremely limited and unreliable data. A coterie of blood bankers and their associates who had a decided interest in reassuring themselves and others that AIDS posed no problem to the blood supply got busy. Following an ‘anything goes’ methodology, these amateur epidemiologists came up with the wonderfully dismissive metaphor of “one in a million”.

The estimate was widely embraced. This is particularly puzzling given the scepticism displayed by the blood bankers and others about any information coming forward concerning AIDS during the early years of the outbreak. How could the experts not notice the now readily apparent shortcomings of the estimation? Relative to the standards of scientific theory and practice the witnesses described as being in place at the time, the methodological weaknesses were glaring. The uncertainty of the evidence today seems unmistakable, yet the computations based on it seem to have passed without criticism when presented at meetings and in scientific papers, peer reviewed journals, government publications and the popular press.

The apparent lack of contemporary criticism lends support to the argument that concerns over the calculation are the product of retrospective analysis and fail to adequately represent past

\footnote{50} Canada’s blood system was entirely volunteer based; the epidemic lagged well behind that seen in the United States; and Canadian society was seen to be different. The Red Cross officials argued that there was no reason to believe that situation occurring in the U.S. would be repeated in Canada.
understandings.\textsuperscript{51} While there may be some merit to the claim, it overlooks a number of other possible explanations presented at the hearings as to why no criticism were forthcoming. It also begs the question of how the weaknesses were overlooked in the first place.

It neglects, for example, the important observation that the sources distributing the information seemed beyond question. These were not a bunch of commercial corporations making self-serving claim about their products. Rather, these were institutions like the Public Health Service and the Red Cross. What institution was more trusted than the Red Cross at the time? They had the trust of other scientists, regulators, politicians and the public.

Many simply took the information at face value, and why not? The individuals involved were not only affiliated with trusted institutions, they were the experts in the area of blood, infectious diseases and public health. The authorities in the field were the ones providing the estimates. Who was more likely to know the risks?\textsuperscript{52}

For the doubters there were few incentives to challenge the calculations openly. The

\textsuperscript{51} The problem of retrospective understandings and their affect on the interpretation of the past was a constant theme at the hearings. Witnesses and lawyers regularly accused each other of using a "retropectrascope" in their analyses. While often amounting to little more that name calling, these accusations helped focus attention on the contemporary record. For lawyers and witnesses alike, the record became an important resource in establishing or challenging claims. This reliance on the record inculcated an attitude amongst many at the hearings that if it is not inscribed on a piece of paper, it did not happen, or at least it was not a significant issue. This is unfortunate indeed as there can be little question that informal communications and interactions played a central role in developing an understanding of the disease and devising protocols to respond to it.

\textsuperscript{52} When Perrault argued that the Red Cross estimate must have been reasonable because no one challenged it, the Commissioner reminded him Red Cross officials had not challenged LCDC figures on the number of reported AIDS cases in Canada even when they knew they were underrepresenting the actual numbers by excluding paediatric cases. LCDC staff were considered the experts in matter and as Perrault had already explained, he did not feel it appropriate to challenge the authorities in the field. Why would the situation be expected to be any different when pronouncements were made by the Red Cross experts?
institutions involved enjoyed considerable power and authority. They had extensive support within the scientific, political and social spheres. It was necessary to think very carefully before disagreeing with and potentially antagonizing such institutions.\textsuperscript{53}

There were other reasons for the silence. Those with doubts were reluctant to engage in a public debate which could inflame an already volatile situation. If concerns were expressed, it was done behind closed doors. Two experts at the November 1983 NACAIDS meeting, for example, expressed concern over the under-reporting of cases, especially the omission of the growing number of infants and young children affected by AIDS. They were assured that the Red Cross would look into the matter immediately. The Red Cross, however, was already aware of the situation. They had decided to follow the official definitions of the disease proffered by the CDC and the LCDC which excluded such cases. Perrault was not about to disagree with authorities such as the LCDC, especially not in public venues.

For those who were sceptical, it was difficult to begin to criticize the calculation. One of the problems was that as the calculation spread it began to shed all the conditions, limitations and assumptions surrounding its creation. As it moved from scribblings on the 'back of an envelop' to a statement of scientific fact, many of the initial conditions of its production disappeared. The messiness of the methods and the limitations of evidence simply vanished. In the case of Davey's calculations what remained was a memo to file containing a series of neat mathematical formula

\textsuperscript{53} In Canada the Red Cross had such an extensive involvement in most areas related to blood that it was difficult to find independent experts able to evaluate Red Cross proposals, or to give advice on matters related to the Blood System. If you had an expertise in blood you likely had some association with the Red Cross. The Red Cross's influence in Canada also meant that if you were looking for a job in Canada in the field of transfusion medicine and you were on bad terms with the Society, your employment options could be seriously limited. See, for example the testimony of Dr. Richard Huntsman who appeared before the commission in Newfoundland August 15 to 17, 1994.
and a selective list of assumptions. By the time it was presented to the members of NACAIDS even these assumptions had disappeared; by the time it was published and widely circulated within industry and government documents all that was visible was a neat and tidy fact: “the risk of contracting AIDS from a blood transfusion is estimated to be less than “one in a million”. By the time it reached the popular press even the “one in a million” had disappeared; the Chair of NACAIDS was happy to be quoted saying “there is no AIDS in the Canadian Blood supply... its a marvellous thing”. The humble origins and conditions of the initial computations were no longer there to criticize, at least not without going to a lot of work trying to recover them. Davey had disappeared as well, in his place stood the disembodied authority of organizations such as NACAIDS and Health Canada.54

There were, of course, other factors working in the calculation's favour. The volunteer blood bankers were already receptive to the notion that the risk was very low. Their preconceptions about the link between good blood and good blood donors made it hard for them to associate AIDS with volunteer blood. The “one in a million calculation” confirmed their beliefs and expectations. Rather than raising suspicion, the long term stability of the estimate was interpreted as a sign the education and self exclusion program was working.

The blood bankers told the inquiry that they were shocked when they first became aware of

54 The process illustrates Latour's notion of the role of modalities in the production of scientific facts. Modalities are sentences which either modify or qualify a particular statement. There are two types of modalities, positive or negative. Positive modalities are “those sentences that lead a statement away from its conditions of production, making it solid enough to render some other consequences necessary.” Negative modalities are “those sentences that lead a statement in the other direction towards its conditions of production and that explain in detail why it is solid or weak instead of using it to render some other consequences more necessary.” Modalities can be used to push the audience in different directions; the status of the claim will change depending on the direction. It will become either an item of certainty requiring no further examination (a “black box” as Latour calls it) or an item of continued debate and controversy (Latour 1987:22-24).
the actual number of infected donations that appeared to be entering the system. Investigations were immediately launched and to their further surprise it was discovered that most of the infected units were coming from gay donors. Even this, however, was not enough to cause them to rethink their assumptions in any significant way. According to the blood bankers, the problem was one of denial. Those at risk simply could not accept the fact that they were at risk.\(^5^5\)

Effects of the Calculation

Faced with 'a million to one' risk, patients were more likely to consent to procedures or treatments involving the infusion of blood and blood products and physicians were more likely to the order the use of such products in some cases the unnecessary use of those products. At a time when the actual patient risk was closer to one in a thousand than to one in a million, this had a real effect on the spread of the disease through the blood supply.\(^5^6\)

\(^5^5\) Interestingly, the ones who seemed to be in the greatest denial were the blood bankers themselves. In *The AIDS Disaster* (1990), Charles Perrow and Mauro Guillen argue that it is difficult to find a reason why the blood industry representatives resisted the imposition of screening measures such as hepatitis B core. Perrow and Guillen found explanations based on economic interest inadequate, given the relatively minimal cost of such tests which could easily be recovered due to the "inelastic demand" for blood (Perrow and Guillen 1990:44). Perrow and Guillen conclude that the major factor affecting the failure to ensure a safe supply of blood rested in the blood bankers' inability "to confront the danger -- the association of life giving blood and 'diseased homosexual men' was simply too much for the blood industry" (Perrow & Guillen 1990:138).

\(^5^6\) It is ironic that the origins of the "one in a million calculation" can be traced to the set of recommendations suggesting physicians need be educated about the risks associated with blood and blood products so as to encourage their more *appropriate* use. A risk of "one in a million" did little to dissuade physicians from engaging in the then not uncommon practice of 'topping-up' a patient up with a pint or two after surgery. A transfusion would frequently be given as a matter of course. It reduced post-operative pallor, providing a visual indication of health and vigour which had important psychological benefits for patient, family and physician. There was also the possibility the recipient might move through the system a little quicker as a result of the restorative effects of the transfusion, thus freeing up the hospital bed. It made good business sense as well as seeming like good medicine.
The calculation further affected patient care by virtually removing AIDS as a consideration in diagnosis. A physician treating a sixty year old man who had undergone coronary bypass surgery the year before could hardly be expected to be looking for, or even considering, AIDS, in her patient -- not with odds of 'a million to one' against it. Patients suffering from the disease went unidentified. Opportunities for critical, early intervention and treatment were lost. Many died of AIDS without ever knowing they had been infected or perhaps even more tragically without ever knowing they had passed the disease on to their families. By down-playing the risk of contracting AIDS from a transfusion, blood bankers and other authorities contributed to an under-reporting of the disease while abetting its spread.

The wide availability and acceptance of the figure also had serious repercussions in terms of policy decisions and the choice of strategies to the protect the blood system. As I have indicated, the commission was told repeatedly that in medicine in particular, and science in general, cost-benefit analysis plays a central role in considering the course of action to be followed. The benefits of a particular action or intervention are carefully weighed against its costs. When strategies for protecting the blood supply were being formulated, their costs were weighed against what appeared to be a relatively minimal threat. A risk of "one in a million" was not a strong argument in support of change, particularly when change was seen as bringing its own costs in terms of blood shortages, increased risks from a variety of sources, and a further erosion of public confidence.

The problems were compounded by the fact that the effectiveness of the proposed strategies, as well as the benefits of implementing them, were in question. Blood bankers were arguing that the introduction of hepatitis B-core testing as a surrogate might be effective only in removing as little as 20 or 30 percent of those at risk of carrying the disease, and this would come at a cost of
perhaps 5 percent of the blood supply. The misery inflicted upon those who were falsely labelled by the test also had to be considered.

The costs of instituting protocols such as surrogate testing seemed clear; but what would be gained through their use? The Canadian blood bankers reasoned that if the risk was "one in a million" and the test was 30 percent effective, and one million units were transfused annually in Canada, then you would be looking at removing one unit of infected blood every three years. The "one in a million" estimate thus fostered a sense of complacency while providing a strong argument for taking a 'wait- and-see-approach' to the problem.

The failure to correct the estimate expeditiously and publicly when the data became available in early 1985 and the failure to recommend that patients who received a transfusion get tested, meant transfusion related AIDS cases continued to be under-recognized and under-reported. It meant that treating physicians remained relatively insensitive to the possibility their patients who had received blood transfusions could be infected, and it meant that neither the individuals who received blood nor their families realized the magnitude of the risk they had encountered.

Yet, from the perspective of the blood bankers and public health officials the "one in a million figure" was a good number to think. It helped reduce some of the pressures they were facing, especially in terms of quelling what was seen to be an increasingly fearful public. It affirmed the basic premises and expectations on which the blood bankers were operating while gently easing the public into the recognition that AIDS was no longer just a disease of the 'outsider'. The bad news was that AIDS was in the blood supply, everyone was potentially at risk. The good news was the risk was small, very small indeed. There was no need for panic; 'life' could continue to be distributed in convenient, easy to use, plastic bags.
CHAPTER EIGHT: ECHOS OF THE PAST: BLOOD SYMBOLISM AND THE TAINTED BLOOD TRAGEDY

What are we to make of the red symbolism which, in its archetypal form in the initiation rites is represented by the intersection of two ‘rivers of blood’? This duality, this ambivalence, this simultaneous possession of two contrary values or qualities, is quite characteristic of redness in the Ndembu view. As they say, ‘redness acts both for good and ill’ (Victor Turner 1967, *The Forest of Symbols* quoted in Buckley and Gottlieb 1988).

Introduction

Understandably, blood was a topic of considerable interest during the witnesses’ testimony. The commission heard of its capacity to restore and normalize life as well as its propensity to carry and transmit infectious diseases. The witnesses surveyed the modern history of transfusion medicine and recounted the recent advances in the collection, manufacture, and regulation of blood and blood products.

Beyond its recent medical, technical, commercial and regulatory history, however, blood remained an element of limited interest. The symbolic was overlooked in favour of the scientific and technical; recent history was privileged over that of the more distant past. Yet the stories the witnesses told reflected patterns of symbolic belief and behaviour which have surrounded blood in Western cultural and medical traditions for centuries. The significance of these patterns appeared to go unrecognized by the witnesses or their examiners.¹

¹ In fact the only time the issue of the symbolism was addressed in any significant manner at the national phase of the hearings was during the Ethics Panel - Round Table discussion. Dr.
In the following chapter I briefly outline the history of blood symbolism in the West. I then turn to the witnesses’ accounts to show that while often appearing so ‘natural’ or commonplace as to go unnoticed, the habits of thought and practice which surround blood in Western culture appear to have deeply affected early understandings and responses to AIDS.

During the early years of the outbreak blood continued to be seen as it had for centuries, a magical substance, imbued with miraculous healing virtues and dangerous and destructive powers. Linked to the health and moral character of individuals, blood was used to determine who posed a threat and who did not, who belonged and who did not. It was an important site where those issues were both publically confronted and contested.

AIDS may have been a new disease, but the ways in which it was understood and acted upon reflected systems of thought and practice entrenched in Western medicine and culture over many centuries.

Blood Symbolism in the West

Blood symbolism in the West was built out of a shifting and diverse amalgam of Greek philosophy and medicine, Judaeo-Christian doctrine, occult knowledge, and practical and supernatural indigenous beliefs. Blood tied together and gave meaning and expression to diverse experiences and diverse realms of experience. It was at once the symbol of life, capable of miraculous feats of healing, and the ultimate source of death and decay, possessing the power to

Fred Lowy described blood -- “the substance of life” -- as being an “emotionally charged subject” for everyone. It was Dr. Margaret Somerville, however, who drew attention to the symbolic significance of the contamination of the blood supply, especially the symbolic impact of patients being injured through institutions that were supposed to care for them. Other members of the Round Table included Professor Bernard Dickens and Dr. Michael Burgess (Ethics Round Table, December 21, 1995).
sicken and corrupt. It played as central a role in the kitchen as it did on the alter. A prime ingredient in medicine and magic, it provided the glue holding families and societies together.

Blood’s regenerative and salvic powers made it a very special liquid, one linked to the power of the divine spirit and the life force. A metaphor of “the unifying force of the divine, blood came to be interpreted literally, associated with purifying, regenerating fire, with the fecundating sun, with the heavenly saviour.” Blood helped transform profane practice into sacred experience (Camporesi 1995 31-32). Blood ‘spouting’ from the deft application of the physicians lance not only acted as a purge, ridding the body of foul humours, it stood as reminder of the blood which ‘spouted’ from the Lamb of God and provided a vehicle through which to gain divine union. For those who could afford it a personal ‘bloodletting lancet’ became a prized possession and status marker (Hale 1992:542-3).

Blood the giver of life, was also its destroyer. The menstruating woman was particularly dangerous: her gaze alone was considered capable of destroying crops, killing children and befouling mirrors. Menstrual blood was not unique in its destructive capacity. The lot and destiny of all blood was degeneration and corruption (Camporesi 1995:111). With the passage of years the life-bestowing liquor begins to decay, growing dark and gloomy it blackens, corruption begins to engulf the body (Camporesi 1995:107): the ‘river of life’ ultimately extinguishes the

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2 In what Piero Camporesi describes as “the recycling of ‘pagan’ physiology by Christian theology,” Innocent III, a contemporary of St. Francis, wrote of menstruation saying: “Nothing is more monstrous than women’s menstruation. On its occasion the must goes sour. Gardens wither, oats go sterile. Grafts fail. The leaves and fruit of trees shrivel on the spot. Mirrors cloud over, ivory darkens in its lustre. Sword blades dull. Beehives die out. Iron rusts, copper tarnishes. The air has an unpleasant smell. And dogs that taste it go mad.... Ants smell it and drop what they are carrying, never to take it up again” (Innocent III quoted in Camporesi 1995:115).
The Greeks: Blood, the Tie that Unites

The history of blood symbolism in the West can be traced at least as far back as Homer. The Greeks believed the heart and blood to be both the seat of the soul and the carrier of heredity (Lonie 1981:293). Close family were represented as being of “one blood”. Children inherited “the blood and with it the characteristics (represented by the image of blood) of their parents.” Through the blood they also inherited the duty to protect the family honour, the well being of the social group, and the social order itself (Visser 1984:194).

By the fifth century B.C. the Greeks had devised elaborate laws and punishments to deal with crimes involving the spilling of blood. The unlawful spilling of blood was believed to have serious consequences. It not only polluted the individual who had the “blood on his hands”; it put the entire community at risk. Blood on the hands of a murderer could never be completely washed away. Even if the visible traces were removed, invisible blood remained; anyone who came in contact with it was in danger of being infected by the *miasma* (pollution). The family of the slain was especially susceptible to the pollution if they failed to avenge the family honour by initiating proper legal proceedings against the perpetrator. The pollution associated with the unlawful spilling of blood thus contributed to the persistence of the honour system, strengthened

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3 The opposition of blood as life and blood as its destroyer seem to have been reconciled in Medieval theological physiology. Innocent III writes: “But notice with what food the conceptus is nourished in the womb: precisely with menstrual blood, which ceases to flow from a woman after conception.... It is said to be detestable and impure, that contact therewith, fruits and grains are blighted, ... and if dogs chance to eat it they go mad. The fetuses conceived contract the vice of the seed, so the leprosy and elephantitis afflicts those born of such corruption” (Innocent III in Camoresi 1995:112-3).
the legal system and tied the two together (Visser 1984:193-196).

At the same time the laws concerning the shedding of blood were being codified, Greek medicine was being reformulated. This was the age of Hippocrates of Cos (460-379 B.C.), the so-called ‘father’ of Western medicine.

The essential and unifying element in Hippocratic medicine was the notion of the four humours: blood, phlegm, yellow bile, black bile. Of the four humours, blood was seen as paramount. Based on Empedocles’ theory of the four elements, (air, fire, water and earth), the idea of the humours became one of the most enduring aspects of the Hippocratic legacy, influencing Western medical practice into modern times. The theory reflected an underlying cognitive and symbolic association between disorder and disease. For the Greeks the humours mirrored the universal order, the order of nature; disease reflected a disruption of that order (Starr 1998:144).

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4 It also served to maintain a link between justice and truth. A jury which caused an innocent man or woman to be convicted would have his blood on their hands and would, themselves, become polluted. If they acquitted the guilty and set him or her free, they and everyone else would be at risk from the contagion carried by the murderer (Visser 1984:201). The impurity associated with the shedding of human blood thus maintained a “quasi-physical” nature reflecting an attitude where physical and ethical realities were entwined (Visser 1984:198).

5 The four fundamental elements were believed to come into being through a combination of the four fundamental qualities hot, dry, wet and cold. The elements were further identified with the four constituent humours of the body: 1) blood, originating in the heart, identified with air (hot, wet); 2) phlegm, originating in the brain, identified with water (cold, wet); 3) yellow bile originating in the liver, identified with fire (hot, dry); 4) black bile originating in the spleen identified with earth (cold, dry) (Ackerknecht 1982:52). Each humour was also associated with a colour, a taste, an age, a season, and a temperament. Blood for instance, “has a ruddy colour, is bitter, rules in maturity, abounds in spring and causes wildness of spirit” (Brody 1974:36).

6 Health depended on a harmonic mixture of the humours (eucrasia). Illness arose from an improper balance of the humours (dyscrasia). In Genesis and Development of a Scientific Fact (1935) Ludwig Fleck describes dyscrasia as a depraved condition of the system involving the blood especially. Dyscrasia was believed to arise from noxious foul mixtures of humours which resulted in a “change in the blood” (Fleck 1979:11).
It was believed that an imbalance in the humours would be reflected in the appearance and habits of the patient. Careful note was taken of the general disposition, countenance, energy levels, complexion, skin texture, bowel function and diet (Hackett 1973:83-4; Ackerknecht 1982:58-9; Hale 1994:543). A patient’s humours were linked to personal character. A sanguine person -- someone in whom there is an overabundance of blood -- might be jolly, simple or fat and likely to display “an alienation of the mind” being prone to laughter and singing (Brody 1974:36).

The Hippocratic physician believed in nature’s innate healing force. Diet was the favoured means of treatment, although bleeding and other sorts of purges would be employed. In the hands of later physicians, such as the Roman, Claudius Galen (129-210 A.D.) bloodletting.

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8 Diet and blood were directly linked in Greek physiology. Nutritional fluids, a compound of the four humour producing substances, were believed to concoct food in the stomach and digestive tract transforming it into blood. (A number of Hippocratic writers also saw the liver as being involved in the process). The link between food and blood was evident in the ideas surrounding the nutrition of the embryo. While opinions were divided over the exact mechanisms involved, it was widely agreed the fetus derived its nutrition from the mother’s blood (Lonie 1981:293-4). Milk, was seen to be a form of blood; its richest and fattiest, form (Lonie 1981:204-6; Buckley and Gottlieb 1988:38). Observation of pregnant and lactating women convinced many that the source of nutrition for the fetus and the infant was menstrual blood. Menstruation was believed to involve the expulsion of excess, unconcocted blood. While pregnant or nursing, a woman had no excess blood, and hence no menses --the excess being concocted into either food for the embryo or into milk (Laqueur 1990:35-6). Aristotle followed the Hippocratics in linking blood and nutrition. Like the Hippocratics, Aristotle assumed the fetus to be nourished by menstrual blood. Once the fetus is fully articulated, he notes, its growth slows down and it requires less nutriment. Excess menstrual blood begins to flow from the womb to the breasts through a system of vessels connecting the two. Once in the breast, the blood “... is concocted and sweetened into milk” (Aristotle in Lonie 1981:204).

9 For a brief discussion of Galen’s bloodletting and the debates it sparked, both in his time and later, see Peter H. Niebyl (1972), “Galen, Van Helmont and Blood Letting” in Allen G. Debus, (Editor) *Science, Medicine and Society in the Renaissance*. Niebyl, for example, points out that

Through the work of Galen and his followers the idea of the humours, with blood as the principle humour, was carried into European culture and medicine (Ackerknecht 1982:76; Starr 1998:18). His most famous theory, explaining the flow of blood, dominated Western medicine until the time of Harvey (Cartwright 1972:27; Hackett 1973:87; Starr 1998:18)\(^{10}\).

The Judaeo-Christian Legacy

Like the Greeks, the Judaeo-Christian tradition also saw blood as containing the qualities of

while extremely popular in the 17th century, bloodletting was opposed by ‘fanatics’ such as the physician J.B. Van Helmont. Van Helmont associated blood with vital spirit; he saw its bleeding away as injurious to the patient. He claimed that unlike menstruation, the natural model on which the practice was based, bloodletting did not distinguish “good blood” from “bad blood”. The practice should be abandoned, argued Van Helmont, because it failed to accurately imitate nature.

Niebyl describes Van Helmont’s argument as resting on the mistaken notion that Galen saw menses as evacuating “bad blood”. Rather, Galen saw menses as evacuating excess blood and this was consistent with his use of bloodletting to rid the body of excess blood, “the plethora”, which he believed to be a cause of disease. Van Helmont’s problem, Niebyl suggests, is that in associating blood with vital strength he could not accept that an excess could cause harm (Niebyl 1972:14).

\(^{10}\) Galen believed food concocted in the stomach was transported to the liver, converted to blood and charged with “natural spirit”, a nourishing essence and necessity of life. The nourishment of the “natural spirit” was then carried to the body by the blood coursing through the veins. Along the way impurities were collected by the venous blood. After this the blood was transported again through the veins to the right side of the heart and from there a small portion was sent to the lungs where the impurities were expelled. The rest of the blood was believed to pass from the right side of the heart to the left side, through invisible pores. There, the “heat” of that organ imbued the blood with vital spirit, the source of intelligence. This vitalized blood was then distributed to the body. A third essence, “animal spirit” was formed when the “vital spirit” carried by the arterial blood reached the brain. This spirit was distributed to the body through the nerves, which Galen believed were hollow. “Animal spirit” was responsible for movement and sensation. The flow of blood itself, was seen to be analogous to an irrigation system. Blood flowed along the runnel’s eventually being absorbed by the hungry body (Hackett 1973:85-6; Boer 1980:xv).
being as well as life itself. The Christians emphasized the link between good character and good blood (Seeman 1961:32). By the late middle ages these ideas had become embodied in the Christian conception of stigma. Stigmata could be a sign of grace, as in the case of St. Francis, or they could be a bodily sign of physical disorder (Goldin 1994:1359-60). These metaphors, coupled with the Christian notion of sin, helped shape thinking about illness. Disease could be seen as a divine punishment for sin, the ravaged body, the outward sign or mark of inner moral corruption; a corruption carried and transmitted through the blood.

Like the Greeks, European Christians saw the miasma associated with disease as a threat to the innocent as well as the guilty. The corrupt few endangered the well being of the group. Long standing strategies, such as exclusion -- the traditional solution to leprosy -- were employed to separate those of impure blood. The tactics of confinement and observation -- expressed in the

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11 The relationship between blood and vital and spiritual essences was made clear in Biblical passages such as Leviticus (17:11): “For the life of the flesh is in the blood; and I have given it to you upon the alter to make an atonement for your souls; for it is the blood that maketh an atonement for the soul.”

12 The Greeks had originally developed the notion of “stigma to refer to bodily signs designed to expose something unusual and bad about the moral status of the signifier.” Unlike the Christians, the Greeks saw stigmata as socially imposed markers, not “natural” eruptions: they were brands intended to identify their bearers as slaves, criminals, or traitors (Goffman 1963:1).

13 Disease and immorality were linked to “a change in the blood”. For example, at its peak in thirteenth century Europe, leprosy was seen as rooted in an imbalance of the blood, brought about by wanton sexuality (Brody 1974:36-37). Similarly in the 16th century syphilis was linked to corrupt blood. Like leprosy it was associated with the rampant moral and social decay of society. These depictions functioned as allegories of the soul placed in danger by the wretched flesh (Brody 1974:144-6), helped stigmatize the victims and reinforced the popular view, that disease, like crop failures and other natural disasters, was the wage of sin (Hale 1993:552-4).

14 The inspiration and legitimization for the practice of exclusion, came at least in part from Biblical passages such as Leviticus (13:46), which states of the leper: “All the days wherein the plague shall be in him he shall be defiled, he is unclean: he shall dwell alone; without the camp shall his habitation be.”
practice of quarantine, and in the newly emerging hospitals -- were also called-upon to detect and control the dangerous others.\(^\text{15}\)

While the blood of the ‘corrupt’ presented a danger to be assiduously avoided, the blood of the ‘pure’ was a much sought after medicament and restorative. Marsilio Ficino, an influential writer and thinker of the Florentine Renaissance illustrates the European ‘taste’ for blood. In *The Book of Life* (1489/1980) he recommends doctors try “...with human blood distilled in fire, to restore those whom old age has eaten away. What is wrong with our giving them a drink of blood if it will restore people who are almost half-dead with age? It is a common and an ancient opinion that certain old women who were fortune-tellers (which we call witches) used to suck the blood of infants and become rejuvenated from it” (Ficino 1980:57).

Ficino’s prescription was not exceptional. Blood was a popular medicine, tonic, restorative, and potable. The blood of infants was a recommended treatment for a number of afflictions.

\(^{15}\) In *Discipline and Punish* (1979) Foucault draws attention to differences between the techniques of exclusion and those of confinement and observation, pointing out that they represent two different, but not exclusive, projects. The leper, the excluded “was caught up in the practice of rejection... left to his own doom in a mass among which it was useless to differentiate: those sick of the plague were caught up in a meticulous tactical partitioning in which individual differentiations were the constricting effects of a power that multiplied, articulated, and subdivided itself; the great confinement on the one hand the correct training on the other.” The goal of the first project, exclusion, is a pure society while that of the second, confinement and observation, is a disciplined society (Foucault 1979:198-199). For Foucault the second project, provides the means through which the medicalization of society and the subjectification of the individual is accomplished.

\(^{16}\) For those whose digestion will tolerate it, Ficino recommends a bolder step; blood might be sucked directly from a vein of the left arm of a willing adolescent. He advises that care should be taken that the youth has excellent blood; that they be “clean, happy, temperate,” and that the “sucking”, be done “while hungry and thirsty and with the Moon rising.” Ficino goes on to suggest that in situations where an agreeable young person is not available, the blood of a pig could substitute (Ficino 1980:57).
including leprosy. A prime ingredient in the alchemists’ elixirs and salves, blood fortified the stews and puddings which graced the European table.

Blood and Modern Science

Blood occupied an important place in the practical and symbolic life of many pre-modern Europeans but did that change with the triumphs of medicine and science, with the dominance of rationality and reason over magic and superstition? “Are we, really strangers to blood? Are we really so far removed from those centuries when ...blood was a daily reality...?”, asks Umberto Eco in his forward to Camporesi’s evocative study of blood in Western thought and life (Eco in Camporesi 1995:10).

Perhaps not as much as we would like to think. At the turn of the 20th century blood continued to be seen as more that just another bodily fluid, it remained “the law upon which ...physical integrity depends’” (McCann 1918 in Wailoo 1997:6). “For the modern hematologist blood was a microcosm” which could be scrutinized to discover the “true reasons for lethargy, debility, pallor and death.” The precious fluid contained “a wealth of vital yet hidden information about disease, the body, and society” (Wailoo 1997:6). The hematologist was a spy “reading and interpreting” the whole body by “‘counting’ ‘monocytes’ and ‘analyzing leucocytes’” (Cabot 1903 in Wailoo 1997:6).

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17 The use of the blood of infants served symbolically to oppose the pure blood of the innocent with the corrupt blood of the leper (Brody 1972:72).

18 The 16th century poet, physician and philosopher, Levinus Lennius, wrote: ‘Blood is the human beings finest juice...family remedy, household drug, aliment of life’” wrote,” (Lennius 1564 fol.70r in Camporesi 1995:51). It was “the prime ‘sauce,’ and the most prestigious, coveted stock”; it was “the ultimate cauldron -- the last dip’ as Mauss authoritatively reveals -- and ‘the sorcerer’s alter’...” (Camporesi 1995:18).
The apparent correspondence between traditional beliefs surrounding blood and those expressed in the emerging science of the time moved the Polish bacteriologist/historian, Ludwig Fleck, to claim that “modern ‘scientific’ medicine is as dependent on social and cultural factors as medicine of the past”.

In *Genesis and Development of a Scientific Fact* (1935) Fleck argues that the development and interpretation of the Wassermann reaction grew out of a chaotic mixture of traditional ideas of syphilitic changes in blood. These ideas existed long before modern scientific proof was available and they did not vanish with the development of the Wassermann reaction. Rather, they became embodied in it. They were expressed in the modern scientific view to which they contributed (Fleck 1979:24). These long standing cultural beliefs provided powerful support for contemporary views about the problems of syphilis and its relationship to blood (Fleck 1979:77).

What Fleck saw at the beginning of the century seems as true in its closing years. The stories the witnesses told of their early confrontations with AIDS and the struggle to protect the blood system embodied themes, beliefs and practices which have been played out many times before.

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19 Fleck suggests that modern scientific understandings of syphilis were shaped by the traditional view of the infection as a carnal scourge which was linked both with the traditional moralistic connotations surrounding disease and with the persistent idea of “change in syphilitic blood”, an idea rooted in the humoral theory (Fleck 1979:77).

The idea that syphilis could be detected in the blood was established and given support by the traditional associations between foul blood and syphilis (Fleck 1979:11). The association of syphilis and foul blood not only persisted, it gained popularity within the modern scientific community, despite the fact that careful examination of syphilitic blood with chemical and microscopical aids yielded little to nothing in the way of practical results (Fleck 1979:13). Wassermann’s ‘test’ would never have enjoyed the social and professional support essential to the development of the reaction and its “technical perfection” had it not been for the deep held belief that a test could be developed that would reveal the corruption in the blood. It provided the necessary impetus and support for the collective experience essential to turning belief into scientific fact (Fleck 1979:77).
As the hematologist and historian of medicine Max Wintrobe observed on the eve of the AIDS epidemic, “even hematologists in their daily talk confuse and assign genetic, racial and other features to the blood. We are creatures of habit, and habits have a way of lasting” (Wintrobe 1978 in Wailoo 1997:6)

Traditional Beliefs and the Problem of AIDS in the Blood Supply

In times of crisis our first inclinations are often to draw upon time tested understandings and practices. This is what the witnesses claim to have done. When confronted by the frightening and deadly disease they immediately began “fishing around for models” to think about and respond to it.

The mysterious outbreak was almost immediately linked with blood. While debate continued for years whether the disease could actually be spread by blood -- a situation almost impossible to imagine for some -- there was never any question that it affected ‘a change in the blood’. Just as illness was reflected in an imbalance of the humours for the Greeks, AIDS was manifest in a cellular imbalance in the blood. The inversion of the ratio of particular types of ‘blood’ cells was immediately associated with the disease. A ‘change in the blood’, an inner ‘invisible corruption’ foreshadowed the ravages which would later beset the body.

Blood, Disease and Morality

It was also apparent in the witnesses’ accounts that from the beginning the disease was connected to behaviour. Promiscuity, ‘deviant’ sexual behaviour, prostitution, ‘rampant drug use’, marked the time; it was amongst the groups associated with these behaviours that the disease was first manifest. In a familiar pattern, blood, disease, behaviour and moral culpability
came to be linked.

The imputation of moral responsibility was a key ingredient in the early conceptualizations of the disease. AIDS was not treated like the mumps, measles or for that matter pneumonia -- even though many of those affected by AIDS were actually succumbing to pneumonia. The victims of these diseases carried no personal responsibility for their plight, they did not have a moral taint about them. Those afflicted with AIDS, however, were seen in some way to have brought their sufferings upon themselves. ‘They’ were doing something bad which was making ‘them’ sick: that the disease was associated with a personal, moral failing, was never in doubt. Consequently those without moral deficiencies had nothing to fear from its presence.

Initially at least, the sickening could be seen to be confined to individuals and social groups who transgressed the norms of the social order. So long as it remained the “Gay Plague”, “Gay Cancer” or “GRID,” it could be looked upon with curiosity rather than concern. These names themselves reflected and reinforced the idea it was a disease confined to morally identifiable groups and individuals.

For those who constructed the strongest boundaries between the outsiders and the rest of society, for those who operated with stereotypic models of the ‘other’, the disease was a significant public health concern, but one of limited scope. The disease posed little threat to the majority of society, who did not engage in suspect behaviours.

The actual degree of threat the guilty ‘others’ posed, was a matter of considerable debate. The public health experts at the CDC, who had experience with infectious diseases and the social groups most prone to them, were less likely to view the boundaries as impermeable. As it turned out their initial inclinations were correct: AIDS was not disposed to remain confined to a circumscribed group. AIDS was in the blood and blood breached the boundaries constructed by
many of the experts. The threat of AIDS was first extended to general public through the blood supply. Figuratively and literally, blood tied insider and outsider together.

There was great reluctance on the part of many to accept that the disease was in the blood supply, that the boundaries between the ‘pure’ and ‘impure’ had been breached. When the initial evidence emerged suggesting that hemophiliacs were displaying signs of the disease, explanations were generated to discount the possibility and maintain the hypothetical distinctions as well as the imputed integrity of the blood system. Some argued that the ‘change in the blood’ seen in the hemophiliac population was not the same as the one affecting homosexuals and drug abusers: hemophiliacs were reacting to the foreign proteins in the blood products. Others proffered the possibility that the affected hemophiliacs had engaged in risk behaviours they were not disclosing.

Even when it finally had to be acknowledged that this was indeed AIDS, the threat could still be distanced; hemophiliacs, after all, were not really the same as the rest of us. The physical disabilities which made them dependent on the blood of others, exposed them to risks ‘normal’, ‘untainted’ people would not face.

Things began to change with the emergence of cases involving transfusion recipients, especially young children. Typically transfusion recipients were not regular users of blood. As a result, the date they received the tainted blood could be pinpointed; the infected recipient could be directly linked to the infected donor. Nevertheless, it was still possible to argue that the

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If the disease was transmitted through blood it not only potentially threatened all the users of blood and blood products, it challenged the fundamental assumptions of the experts in charge of the system and jeopardized the existence of the institutions involved in collecting and processing blood. Deeply embedded ways of knowing and acting, cherished structures and practices, were not going to be abandoned, not, at least, without considerable struggle.
transfusion recipients were guilty of some moral transgression which had led to their being infected.

The situation surrounding children with AIDS was more difficult. While suspicions could still be harboured about their adult counterparts, it was hard to argue that infants were somehow the authors of their own misery. The innocence of the young child presented a seemingly intractable problem and a powerful symbol, one which could only be resolved by removing children from the list of those affected. That is exactly what was done. Young children were not included in the official AIDS statistics. It was argued that their immune systems were too immature to allow a definitive diagnosis: it was possible that they were suffering from an inherited immune defect rather than an acquired immune deficiency.

As the number of hemophiliacs and transfusion associated AIDS cases grew, even the most conservative and unreflective had to acknowledge the disease was affecting individuals who had done nothing to bring the infection upon themselves; the contagion was indeed circulating in the blood. Blood recipients, hemophiliacs and children quickly became the "innocent victims". Their innocence set them apart from the guilty, who were now doubly guilty, not only responsible for making themselves sick, they were passing the contagion to innocent others. As in the past the moral transgressions of the few were seen to jeopardize the health and stability of the entire community.

The Gift of Life

Not everyone -- at least, not in the early years of the epidemic -- was willing or able to accept

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21 As time passed, the spouses of blood recipients and hemophiliacs too were cast as innocent victims, as they became subject to secondary infection through their partners.
the connection made between blood and AIDS. While some emphasized the traditional symbolic relationships between blood and corruption, others relied upon and gave expression to equally long standing associations between blood, health and life. For many, blood remained “the gift of life.” A much sought after medicine, it not only saved the lives of thousands every year, it dramatically reduced the sufferings and sped the healing of tens of thousands more. Blood not only gave life, it nourished and sustained it. The belief in blood’s power to invigorate was so deeply ingrained that surgery patients continued to be ‘topped-up’ as matter of course to help restore their vitality. To be full of blood was to be full of life. A patient whose flesh was well ‘basted’ in the vital juice provided a sign of well being and attested to the doctor’s skill; it gave comfort to all.

Nourishing Blood

The positive associations the blood bankers made and continue to make, extended beyond blood’s power as a resuscitative. The underlying but often unrecognized symbolic association between blood and nourishment expressed in Western medicine and popular culture was echoed in the food metaphors employed in the testimony of the witnesses. More than once Dr. Zuck illustrated the marketing principles involved in the blood trade using the metaphor of pork bellies. Dr. Zuck’s metaphor, aimed at demystifying blood by presenting it as just another commodity to be traded on the market, retained another powerful, though perhaps unrecognized, link with the past. When human blood was not available to our health-conscious Renaissance forbearers, the blood of the pig was considered the most suitable substitute. (A firm blood sausage, a tasty bit of blood pudding made from the vital ‘juice’ of the pig is still a staple in many European cultures.)
Similarly, Dr. Davey's use of the metaphor of milk (when discussing the international trade in blood) is evocative. Milk has enjoyed a powerful symbolic association with the blood since at least the time of the Hippocratic physicians. To the Greeks milk was but a variant of blood as was male and female sperm. Blood, the source of life, was also the fundamental source of nourishment.

Blood and the Social Body

Blood was truly a miraculous substance, capable of restoring and nourishing the social as well as the physical body. Dr. Perrault explained how the development of clotting factors 'normalized' the lives of hemophiliacs. With the discovery of clotting factors in the 1960's and the subsequent development of cryoprecipitate, hemophiliacs were finally freed from a life of constant institutionalization. The wide-scale introduction of factor concentrates in the 1970's meant they were able to work and to travel like 'normal' people. The technological advances of the 1960's and 1970's meant that those who had previously been excluded due to a difference in their blood could be reintegrated into the social body.

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22 The associations between blood, life, sperm and vitality became part of Western thought. In early part of the 18th century, for example, Giambattista Vico looked back approvingly at the wisdom of the ancients noting: “[All of the ancients] reduced the liquids [of the body] to blood alone. They called the spermal substance “blood” (as is demonstrated by the poetical expression ‘sanguine cretus’ sprung from blood, for ‘generated’), and correctly, since that substance is the flower and cream of blood. And, once more with reason, they deemed the blood the juice of the fibres of which the flesh is composed: whence the Latins used succiplenus ‘full of juice,’ to denote ‘plump fleshy’ or ‘basted with good blood.’... And the poet theologians, again correctly, posited the flow of life in the flow of blood, in whose correct motion our life consists” (Vico 1977:491-2, quoted in Camporesi 1995:84).

23 The link between blood and milk persisted in medical thought and practice until relatively recent times. For example, in the 19th century, during the great cholera epidemic, some Canadian physicians transfused milk into their patients “in the belief that ‘the white corpuscles of milk were capable of being transformed into red blood corpuscles’”(Jennings 1888 in Starr 1998:38).
Donating blood provided an opportunity to express social belonging, contribute to the group and improve social identity. It also had an especially important role to play in the redemption of the outcast. The practice of collecting blood in prisons, for example, was promoted as an important rehabilitative practice, allowing otherwise peripheralized individuals to participate in society and contribute to the social good.24

Distinguishing Between Good Donors and Bad Donors and Its Policy Implications

While blood bankers emphasized blood's positive powers, they were not unaware of blood's dangerous side; their thinking reflected the deep rooted opposition between the pure and the corrupt. Zuck, Perrault and Davey emphasized the symbolic opposition between good and bad people, and good and bad blood. In the process they associated themselves and the products they handled with the 'good'.

The ways in which blood bankers conceptualized donors followed an ancient pattern linking blood, disease and personal character. Donors of good character had pure blood, donors of bad character had polluted blood.

The blood of good donors did not transmit disease, at least not serious diseases. Good donors were socially minded, altruistic, individuals who gave their blood voluntarily. Neither they nor their blood required additional scrutiny. The blood bankers' belief in the purity of their blood was so strong in fact, that, as Dr. Davey explained, normal clinical safety protocols need not apply to its handling.

Bad donors sold their blood. Selling "the gift of life" immediately put them under suspicion.

24 Concerns over the quality of "prison blood" brought a virtual end to the practice by the early 1980's.
This suspicion was born out -- tests 'proved' their blood was far more dangerous than that given by volunteers. Nor could they be trusted to tell the truth when it came to disclosing health risks. They had to be forced to confess their moral and physical weaknesses. Their blood, like their social selves, was tainted.

It was clear to the blood bankers at least that the good blood of volunteer donors allows for a different set of regulations than those which governed bad blood, the blood of paid donors.

To the public health officials on the front lines of the epidemic -- those who emphasized the link between blood and disease -- the distinction between paid and volunteer donors made no sense; all blood was potentially threatening. Since all blood was suspect and needed to be put to the test, all blood donors needed to be treated with suspicion.

It was not that these experts failed to recognize the opposition between good blood and bad or that they questioned the assumption that bad blood was associated with bad or 'dangerous' behaviour. It was just that experience had taught them the signs of corruption had to be looked for everywhere.

For the CDC officials such as Dr. Francis, the situation had the earmarks of a public health crisis: the link they made between blood, disease and behaviour called for immediate and decisive intervention. They almost immediately began pressing for action including laboratory testing, clinical examinations and direct questioning.

The volunteer blood bankers, on the other hand, associated the blood of volunteer donors with life, health, and purity and so could sustain a view that such costly interventions were unnecessary. An education program aimed at making sure that people were aware of the disease and its associated risks might be appropriate but no further intrusions into established practice were necessary.
Purifying the Blood

Exclusion

There came a point, however, where it was no longer possible to simply wish away or deny the terrible reality, blood was in the blood supply. The contamination of the blood supply signalled a serious breach of the social-moral and natural orders and marked the beginning of a major social drama. Suddenly everyone stood at risk of being contaminated by the miasma which had been unleashed by the errant few. The blood system, the institutions associated with it, blood donors and blood recipients, were all put at jeopardy by their misdeeds.

It seemed necessary, therefore, to find some means to identify and remove the dangerous groups and individuals. The fatal bond uniting them with the rest of society had to be severed. A range of strategies were proposed. Time-tested methods for dealing with contagion were called upon. A zealous few recommended the imposition of quarantine and the reactivation of leper colonies. Others advocated less draconian forms of social banishment. The suspect groups and individuals did not have to be removed from society at large, they simply had be excluded from donating blood.

While less draconian than some proposals, exclusion from donating represented a severe sanction. As I have suggested, blood donation and personal and social identity are closely linked. Donating blood provides a powerful symbol of group membership and can play an important role in defining social and personal worth. It provides individuals and groups with the ability both to participate in and meaningfully affect the world in which they inhabit. To be defined as having unfit blood is to be labelled as defiled, impure, and a threat to society.

The problem was compounded by the fact that the label could not be easily dismissed or ignored. It did not come with the taint of religious bias or political interest, it was being proffered
by trusted sources such the Red Cross.

It was a sanction that some of those so defined and labelled were unwilling to accept and unable to tolerate. The social stigma attached to the disease was too great to bear for those already historically marginalized and discriminated against. Some, such as I.V. drug users, could do little to resist further marginalization and social degradation. Others, such as gays, were less willing to accept the pronouncements and more able to resist being labelled as a threat to the populace -- they had seen how science and medicine were used in the past to control their behaviour. They felt they had penetrated the veil and were not about to be fooled again.  

Observation

What was to be done with those who refused or were unable to comply with their exclusion? Some, such as the experts at the CDC, suggested that science and technology should be employed to ‘observe’ and interrogate potential donors, to detect and exclude the errant few. The problem of public labelling and the associated stigma, it was argued, could thus be avoided, as could the attendant ‘political’ struggle. Surrogate tests such as hepatitis B core could be used to reveal an individual’s association with dangerous groups and practices. The blood could be asked to witness for the character of the individual. Clinical examinations could also be used to determine if the individual was pure of body or defiled. Finally, the donor could be interrogated

25 While members of the affected communities may have harboured deep suspicions as to the motivations for their being labelled as dangerous, they still had to deal with the force of those pronouncements in the broader society. The lay public had little reason to doubt what the experts were telling them about the threat posed by those dangerous others. It fit perfectly well with what they already knew. Like the scientists, they understood that blood, disease and moral character were intimately linked. Long standing fears surfaced and not only amongst the lay-public. The commission heard stories of physicians who refused to treat patients once they found out they were infected with AIDS.
and forced to confess to their dangerous behaviours and made to comply with their banishment.

Others felt these costly and invasive methods unnecessary; the mark of guilt would be clearly visible in the body and behaviour of the guilty few who might persist in donating. The I.V. drug user, the homosexual, the AIDS patient, would bear the marks of their corruption. They would be identifiable in the crowd and easily excluded.²⁶

Eventually the dream was realized, the sign of the corruption was found, but not in the behaviour or on the body of the infected -- it was there in the blood itself. The long standing belief that the blood would reveal the moral and physical taint of the individual had been justified once again.

Summary

Since at least the time of the early Greeks, blood has occupied a pre-eminent position in Western thought and practice. Possessing the powers of life and death, it was the source of individual character and identity and a thread binding society together. An important element connecting individuals and groups it helped define social responsibility both to others and to the state. For the Hippocratics blood was the “paramount humour”, determining the patient’s state of health and shaping their personal character. In the centuries that followed, blood remained a focal point in Western culture and medicine. New meanings and practices came to be attached to the

²⁶ Interestingly, when the blood bankers and public health officials prepared their early lists of groups at risk, those who should not donate blood, hemophiliacs and their sexual partners were conspicuously absent. The experts at the inquiry were quick to explain that given their physical problems, hemophiliacs would not be normally expected to donate. The witnesses were hard pressed, however, to explain how the spouses of hemophiliacs had been overlooked. One might conclude that they simply did not fit the image of the deviant ‘other’ associated with the infected. They certainly bore none of the signs -- the “needle tracks” of the I.V drug user, the “flamboyant” speech and behaviour patterns of the gays, the distinctive skin colour and language of the Haitians -- which were seen to mark the carriers of the disease.
miraculous fluid but blood continued to provide a central means of understanding and manipulating the individual’s physical, moral, and social being.

So ‘natural’ seeming were such beliefs and practices that even in the rarefied world of the research scientist, blood worked its magic. Ludwig Fleck (1935) demonstrated that the development of the Wassermann reaction for the detection of syphilis during the early years of the century both depended on and reinforced centuries old beliefs and practices associated with blood in the West.

Little has changed today. Blood symbols and metaphors continue to flow through our daily lives and our science, reflecting and expressing the deeply sedimented beliefs and practices of our ancestors. Both in our day-to-day lives and at the ‘cutting edge’ of science, we continue to look to the symbol systems surrounding blood for answers and guidance to some of our most important questions and concerns: we continue to understand ourselves in terms of blood and structure social boundaries in terms of blood.

Without an appreciation of the cultural history of blood in the West it is impossible to adequately understand the early associations made between blood and AIDS, the significance of the early risk categories, the reactions of the individuals and social groups involved in the tragedy, the distinctions made between “good” donors and “bad” donors, the categorization of safe and dangerous blood, and the decisions made not to institute proactive donor screening.

This is not to suggest that the symbols and beliefs surrounding blood determined the experts’ understandings and behaviour -- not, at least, in any simple sense. Blood presented a multivocal symbol, one which spoke of and to a range of concerns and experiences. While part of a web of signification tying together diverse realms and diverse experiences, its multi-vocality allowed for difference and contradiction.
The meanings and symbols surrounding blood provided a field of possibilities, a ground of beliefs, a set of expectations and resources which were differentially understood, taken-up, transformed and applied as the experts went about trying to construct an understanding of, and a way of reacting to, the strange and frightening new disease confronting them.

If we fail to appreciate and understand the cultural symbols and practices which deeply influence and continue to shape our understandings of and our relationships with the social, natural, and moral, and spiritual worlds during the early years of the AIDS epidemic we will likely revisit similar disasters in the blood system in the future.
CHAPTER NINE: CONCLUSION

Introduction

In the preceding chapters I looked at the testimony of four expert witnesses who appeared before the *Commission of Inquiry on the Blood System In Canada* as they tried to explain science and its role in the tainted blood tragedy. I traced their accounts as they described the disease and its effects, the efforts to understand it and the attempts to deal with its spread in the blood supply.

Not all of the stories the witnesses told were neat and tidy. They were often fragmentary, their meanings multiple and equivocal. They were complex social products incorporating, commenting on, and explaining other stories. The stories they told about AIDS and the blood supply were not simply about a disease: they were also about the world and the people who inhabit it.

They were stories about science, society, politics and nature and the relationships and boundaries which exist between them. They were about: the strategies and methods employed to investigate the outbreak; who was at risk of being infected; who threatened to infect others; what social groups were involved; what behaviours were associated with the disease; and who has the authority to define, represent and control those affected. The stories were about science and its battle with a deadly disease but they were also about values and morals and the struggle for power, authority, and prestige.

In their accounts the witnesses revealed that the controversy surrounding the "tainted blood tragedy" encompassed two distinct although not separate sets of conflicts. The first of these embodied and expressed a range of concerns which existed in the early 1980's over what many saw as the degeneration of society. Rampant drug use, promiscuity, deviant sexual practices, and
the increasing political power of subpopulations, were perceived as threatening social order. AIDS embodied and reflected these threats; its presence in the blood supply symbolized that a serious social crisis was under way.

The contamination of the blood supply precipitated a social crisis in which the structure of society, its values and norms, who was to be considered a member of the group and who was to be excluded, were questioned and fought over. In the process, simmering conflicts and clandestine oppositions erupted into clear sight, spreading quickly along existing cleavages.

The controversy surrounding the blood disaster also embodied and expressed a second set of conflicts over the nature, use and control of scientific knowledge. It expressed disagreements over the place of practical experience, the methods to be employed, and the standards to be followed in the production of scientific knowledge. It involved differing views of the limits of that knowledge, what science could and could not be expected to contribute to policy making, and the role the public was to play in the technical decisions affecting them. It was about the relationship between society and knowledge and who was to have power in that association.

The two sets of controversies were linked in the contamination of the blood supply and in the stories the witnesses told of that disaster; so closely linked that they were difficult to disentangle.

The Tainted Blood Tragedy as Social Drama

In the opening pages of this text I suggested that the “tainted blood tragedy” might be thought of as a “social drama”. Victor Turner developed the idea of “social drama” as a means of accounting for particular types of social conflict and change arising out of a breach or deliberate nonfulfillment of some crucial norm regulating relations between persons or groups within the same “perjuring system or set or field of social relations.” This breach acts as a “symbolic
trigger” for confrontation (Turner 1974:31-3, 37-8). It represents the first of four phases in a social process: breach, crisis, redress and resolution or return to conflict.

In recounting the events surrounding the contamination of the blood supply the witnesses revealed that the “social drama” was triggered by two distinct but related breaches of norms values and expectations.

The first breach involved the transgression of social norms by small groups of marginalised individuals. These transgressions were seen to have brought about AIDS and hence the threat to the blood supply and its users. A period of “mounting crisis” followed. Conflicts spread along existing lines of opposition, the exclusion or further stigmatization of already marginalised groups increased; relations between groups and between institutions and groups deteriorated, bringing deep and enduring social oppositions into sharp focus (Turner 1974:38-9).

The need to undertake redressive measures to stem the crisis was avoided, however, by the timely development of a test to detect AIDS in the blood supply. The test did not resolve the underlying conflicts, rather it sealed-off the breach. The threat was contained, the problem of AIDS was again confined largely to minority groups. The crisis abated and the social conflicts expressed in the conflicts over the contamination of the blood supply were pushed out of the spotlight to simmer in the fissures of society.

The second breach occurred with the perceived failure of the scientists and other respected authorities to prevent the contamination of the blood supply. The authorities were seen not only to have failed in their promise and responsibility to protect the blood supply and its users but also in their having misled the public and other health experts as to the extent of their failings and the significance of the threat.

Unlike the first breach the second did not immediately trigger a crisis. Conflicts smouldered
almost unnoticed for a decade before emerging into a crisis. When the crisis did emerge it was all the more potent because it contained the unresolved conflicts of the first breach. The authority of the state, the credibility of science and scientific experts, and the existence of revered public institutions were all threatened. The public trust had been betrayed: the beliefs, practices, values and order of society were all put in jeopardy.

Redressive action was swift. A coalition of state and private interests offered compensation to the “innocent victims” of the tragedy. In an further attempt to resolve the mounting crisis, leading citizens and community representatives were called on by the federal and several provincial governments to form a commission of inquiry into the blood system. The inquiry constituted an element in the third, or redressive phase of an extended and extensive, social drama, the tainted blood tragedy.

The Commission, a powerful investigatory and advisory instrument of the state, was established to give meaning to the disaster, rearticulate relations within the group, and assert an overarching system of norms, values and meanings which could guide future action. The inquiry represented an tool for converting the particular values and ends of the actors involved in the controversy into a system of shared meaning. It sought to create a ground of fundamental agreement amidst disagreement.

In attempting to accomplish this, an extensive series of public hearings were held in which the events leading to and composing the crisis were recounted and criticized. This recapitulation allowed the conflicting groups to give voice to their concerns, understandings, and criticisms. It also gave them and the rest of society a chance to confront and evaluate their collective representations (Turner 1974:39-41).

The hearings provided a sophisticated instrument of social reflexivity aimed at reproducing,
as exactly as possible, the chains of events and actions which led to the social disruption and individual suffering associated with the contamination of the blood supply. Meaning was apprehended by looking back over a temporal process: it was generated in the narratives constructed in the examination of the witnesses. Through those narratives the participants attempted to establish the facts and contextualize the events which led to and constituted the crisis. They explored the ideas and the acts which led to the tragedy. The use of reflexive narrative allowed the group to scrutinize itself, to portray its acts as well as its understandings to itself (Turner 1982).

The narratives exposed the conscious and unconscious purposes of the actors in the tainted blood tragedy revealing sometimes selfish and partisan interests. They revealed the hidden motives -- the struggles for power, authority, and control -- the personal and institutional values and goals which impelled the actors to behave in particular ways; and they challenged the participants in the inquiry to measure those actions against the “ethical yardsticks of the group” (Turner 1988:39).

The presentation of the witnesses’ accounts at the hearings thus offered real dangers. While enacted to reassert and reinforce existing orders, the process offered the potential for transformation. There was always the possibility that in deconstructing and reconstructing the relationships, meanings, values, and purposes of the group they might be rebound in a different manner (Turner 1982:84).

Conflicting Views of Science and its Role in Public Health Decision-Making

In probing the understandings and actions of the early 1980's the commission revealed a series of unresolved conflicts. Among the most difficult and divisive of these was the issue of
uncertainty and its place in science and public policy making. Here as elsewhere, the witnesses presented some very different understandings of the manufacture and use of scientific knowledge.

Dr. Davey and Dr. Perrault, who were at the helm of the Red Cross Transfusion Service during the early 1980's, presented a model based on a notion of ideal science -- science in the service of no master -- where judgement and advice are withheld until a sufficient degree of certainty has been achieved. Throughout their testimony they tried to show they had been justified in their insistence that the standards of ideal science were met before any significant revision of the blood system be undertaken.

In his account of the disaster, Francis, a well known and popular public health advocate with the CDC, represented the situation of science in the service of policy makers; pressed to give advice on matters of immediate concern, experts find themselves having to act in the face of uncertainty. For Francis the blood bankers' hesitancy spelt death. The situation they faced in the early 1980's demanded an immediate and expedient response. As far as he was concerned the

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1 Uncertainty has become a matter of increasing concern as scientists become more and more involved in what Salter (1988) has referred to as "mandated science" -- science in the service of policy making and standard setting.

Often compelled to make recommendations based on imperfect or incomplete information, these scientists have found themselves facing a number of dilemmas. If they -- having repeatedly assured the public of their ability to solve all technical problems -- acknowledge the uncertainties and limitations of scientific understanding they run the risk of losing credibility and breeding "embittered cynicism" and "disillusionment" in place of "naive trust". If they fail to include mention of the uncertainties they run the risk of being accused of "conveying a certainty that is not warranted by the facts".

Experts in the service of the state walk a perilous tightrope. They can easily find themselves charged with over-reacting if they issue warnings which in the short term are not realized and yet severely criticized for maintaining the status quo if they fail to raise concern over matters which later turn out badly. If they simply refuse to offer an opinion, science may be seen as shirking its public role as provider of advice when needed.

Uncertainty is thus at once a technical and a political issue, putting both the credibility and the legitimacy of science at risk (Funtowicz and Ravetz 1990:11-2).
blood bankers' actions were disastrously inadequate, based on the worst information available at the time, and driven by a vision of science ill suited to the demands.

For their part the blood bankers suggested that whatever model of proactive public health Francis was advocating, it was not based on science.

Conflicting hierarchies of methods and evidence

In their testimony the witnesses provided an extensive discussion of the quality of information available during the early years of the epidemic while also addressing related issues of method and the place of experience and practical expertise in the production of evidence. In doing so they again revealed some very different understandings.

According to Francis, by early 1983 officials at the CDC felt the evidence was strong enough to accept that AIDS was caused by a blood-borne infectious agent. While admitting it was not perfect, Francis described the evidence derived from his own and his associates' observations and opinions as sufficient -- given the potential significance of the situation -- to justify a response that would be expensive and inconvenient for those involved.

The evidence which spoke so clearly to the CDC researchers failed to move the blood bankers. For Davey and his colleagues, arguments from experience were of little significance; the observations, personal opinions and clinical experience of individual scientists did not provide a credible foundation for either understanding or action.

Davey believed in a hierarchy of evidence based on method. Only the highest level evidence, that derived from randomized, controlled studies, could provide adequate justification for the radical change in practice advocated by the CDC experts. As Perrault explained, the blood bankers needed to see proof that an infectious agent was involved before they were going to "tear
the shop apart”.

Conflicting hierarchies of styles

In part, the conflict reflected a clash between different styles of practice. The blood bankers, many of them with a background in pathology, were more familiar with the laboratory, its objects, methods of investigation and standards of verification, than they were with those of epidemiology. The objects, practices and evidence of the epidemiologist, in fact, could never satisfy them that AIDS was caused by a blood-borne infectious agent as Davey made clear. They needed to see a physical entity isolated and duplicated in the laboratory, not historical and demographic trends out there in the world. The blood bankers insisted that when it came proving the existence of a pathogenic entity, only physical evidence that could be abstracted from the world and made to conform to the standards of the laboratory would satisfy them.  

The blood bankers' attitude reflected a hierarchal ordering of the world and the modes of scientific investigation. The laboratory, its methods and objects stood at the pinnacle of the hierarchy. Clinical research, with its prospective, double blind studies, which emulated as much as possible the controlled conditions of the laboratory, stood somewhat lower on the scale. Epidemiological research ranked too low in the hierarchy to be given much consideration. Further down the scale was the research of the social scientist; so far down the scale, in fact, that it was rarely even recognized let alone considered as a possible source of information and

2 In Inventing AIDS (1990) Cindy Patton suggests that the epidemiological data challenged “established modes of constructing scientific knowledge.” HIV affected individuals “became something like the voice of the virus, speaking the inchoate desires believed to drive them to the risky behaviours which ‘cause AIDS’”. The insights of the affected, pressed into the service of science, were converted into “summary representations” of the experiences of those “living under the sign of HIV” (Patton 1990:52).
guidance.

This hierarchical vision and the belief in the superiority of their practices and products instilled the blood bankers with a sense they were masters of all they surveyed. Both Davey and Zuck, for example, admitted that despite having no training or expertise in epidemiology they felt qualified to calculate the risks of contracting transfusion associated AIDS. An education in French literature and history, experience playing soccer against Haitian teams, and his interactions with Haitian colleagues were sufficient grounds for Perrault to claim expertise in Haitian culture.

Yet when they left the confines of their own specialities they left behind the demands for professional accreditation, methodological rigour and the certainty, which supposedly gave authority to their views in the first place. No controlled double blind studies were required to support their claims that volunteer donors were motivated by altruism or that, if offended, gays would donate out of spite. In fact, no formal studies were required when it came to making determinations about the social world.

The self reliant, pioneering spirit was not unique to the blood bankers. The infectious diseases experts at the CDC displayed a similar proclivity towards traversing professional boundaries. Personal and practical experience provided the CDC experts with sufficient ground to claim expertise in a wide variety of areas including that of blood banking.

**Situated perspectives**

While some of the conflicts occurring over the quality, meaning and significance of the early evidence can be attributed to differences of practice and professional chauvinism the witnesses made it clear that a number of other factors were also informing the experts' judgements and
responses during the early years of the tragedy.

During their testimony the witnesses suggested that in many cases understanding and action depended on the context in which the expert was located. Zuck, for example, discussed how institutional priorities and responsibilities helped shape the way information was accessed and used.

Pointing to the debates surrounding surrogate testing he explained how, when faced with the same information, a blood banker and a public health expert could easily arrive at different conclusions as to the right path to follow. For the public health specialist such as Francis, who was responsible for monitoring and controlling the spread of infectious diseases, a technique which promised to reduce the transmission of AIDS through the blood supply was worth pursuing, despite the information being less than certain and the technology less than perfect. At a cost of 5 to 10 dollars per donor and a reduction of only 5 per cent of the donor base, even if it only reduced the infection rate by a small amount, surrogate testing appeared the prudent thing to do.

The blood bankers saw things from a different perspective. The potential loss of 5 per cent of their regular donors was a significant matter, especially when many healthy individuals would be falsely excluded due to the lack of specificity of the tests. Each of these donors would have to be replaced with riskier first time donors. Then there was the potential of attracting individuals seeking a test for the disease and the concern that protective antibodies which normally find their way into the blood supply would be excluded.

When coupled with the weakness of the evidence supporting the use of the tests and the apparently low incidence of the disease amongst blood recipients, the value of the proposed intervention seemed limited indeed.
The blood bankers saw what the CDC officials were advocating as anything but prudent and they had the figures to support their position. Based on an extremely limited collection of official data the blood bankers had calculated the risk of contracting AIDS from a blood transfusion to be less than “one in a million”. Given the negligible risk of contacting AIDS through the blood supply and the significant costs involved, the value of surrogate testing seemed extremely dubious indeed. By arriving at an estimate which virtually dismissed the problem of Transfusion Associated AIDS, they constructed a context in which the prudent thing to do was to maintain the status quo until they saw good reason to change.

_Shifting interests: shifting perspectives_

While pointing to the importance of institutional concerns the witnesses made it clear that these were by no means static and that as they changed so too did understandings and practices.

Zuck testified, for example, that by the spring of 1984 public fears surrounding the contamination of the blood supply had left the San Francisco area facing a critical under-utilization of operating rooms. Patients were either postponing surgery or going elsewhere to have it done. In an attempt to bolster public confidence, Irwin Memorial Blood Bank, along with several other blood banks in the area, instituted surrogate testing. In a remarkable about-face, the blood bankers justified the introduction of the test on the basis of a CDC study of hepatitis rates amongst gay men attending a STD clinic. The blood bankers had earlier dismissed the same study arguing the sample was skewed. They claimed that it did not represent the type of people who attended donor clinics and therefore no generalizations could be derived from its findings.
The Diversity of Perspectives within Institutions

While pointing to influence of institutional bias the witnesses challenged the simplistic notion that a uniform set of shared views could be identified with individual agencies and organizations.

During their testimony Perrault and Davey acknowledged that a significant difference of opinion existed within the Canadian Red Cross. They disclosed, for example, that in many cases the Medical Directors, who were dealing with the practical problems at donor clinics, called for, and expected to see, a much more proactive program of donor screening than the one proposed by National Office representatives. Judgement varied depending on the individual expert's location within the structure of the organization.

Similarly Zuck revealed that the bravado of the junior CDC staff, who advocated a radical revision of donor screening practices, stood in sharp contrast to the circumspect attitude of the senior members. The perceptions of the senior staff were tempered by the lessons they had learned about reacting 'prematurely' in the Swine Flu incident. They were not about to risk their own jobs or further jeopardize the credibility of the agency by being accused of 'overreacting' to this new disease. Like the blood bankers and their allies at the FDA, they required stronger evidence before they would endorse any significant interventions. Inaction, even in an institution known for its radical ethos, was less likely to bring criticism than over-reaction. Doing nothing seemed a more prudent alternative, at least from the perspective of individual and institutional well-being.

The Struggle for Institutional Power and Control

The Canadian Red Cross officials shared a similar perspective when it came to the matter of disrupting the status quo. Throughout the early years of the disaster they remained dedicated to
following a wait-and-see approach to the problem of AIDS and the blood supply. Convinced that
the evidence available did not warrant a radical revision of standard operating procedures they
did their best to thwart any step that might jeopardize their determined course.

Testimony revealed, for example, that in the summer 1982, shortly after the first published
reports of AIDS amongst hemophiliacs appeared in the MMWR, the Bureau of Biologics
requested the Red Cross to join the effort to investigate the problem of AIDS and the
hemophiliac population. National Office officials initially appeared receptive to the proposal.
Their cooperative attitude, however, changed considerably in the coming weeks.

At a September 1982 meeting of Public Health representatives and others involved in the
Canadian Blood System, John Derrick, the Red Cross 'point man' on AIDS, made it clear that
the Society had neither the interest nor the ability to participate in the proposed investigation into
AIDS among Canadian hemophiliacs. As Davey explained to the commission, the National
Office representatives believed that the studies being proposed showed little promise of
providing useful information and in fact could do harm to the system and its users by
undermining confidence in the safety of the supply.

The Red Cross officials were the acknowledged experts in the area of blood and blood
banking in Canada. They were not about to become part of a research effort controlled by others,
especially not one they felt could create unfounded fears about the blood supply, one which could
potentially lead to the imposition of what they believed to be unnecessary interventions.

National Office staff were steadfast in their refusal to acknowledge the potential threat AIDS
posed to the consumers of blood and blood products and they refused to accept any Canadian
data to the contrary. The findings of a study released in late 1982 indicating that as many as 70
percent of hemophiliacs in Montreal using clotting concentrates showed signs of immune
abnormalities were dismissed by the Red Cross authorities as lacking credible foundation.

The Red Cross authorities chose instead to rely on information coming from the United States. They would not, however, allow themselves to be bound by the recommendations being issued by American blood bankers and public health officials. Perrault and Davey explained to the commission that the structure and organization of the Canadian Blood System was radically different from that of the U.S., as was the situation surrounding AIDS. There was no reason to assume the disease would follow the same pattern of exponential growth seen in the U.S or that measures designed for that setting would be effective in Canada; the two societies were simply too different. The Red Cross officials were not about to 'shoe-horn' American policy into the Canadian setting.

With no reliable Canadian data, there were no grounds for saying that their wait-and-see approach was wrong. Equally, there was no evidence to prove that it was right. They knew that in order to carry the day they would have to enlist support for their position. The commission heard of the National Office staff's carefully orchestrated campaign to consolidate support within the organization. It also heard of their single minded pursuit of external bodies such as the National Advisory Committee on AIDS, whose public endorsement, they believed, would lend credibility to the Red Cross's plans.

Meanwhile in the United States a similar set of political struggles was taking place. The CDC was in the process of redefining itself and extending its grasp. It was also trying to rehabilitate its credibility which had been seriously tarnished by their perceived over reaction to Swine Flu in the mid-1970's. All of this was taking place in a context of increasing fiscal constraint. Competition for scarce resources was escalating.

Francis and Zuck testified that both the blood bankers and FDA officials saw their authority
threatened by the CDC's intrusion. A concerted effort was made to wrest control of the situation away from the upstart agency. The expertise of the CDC staff was challenged; they were charged with failing to understand the complexities involved in the blood banking sphere. Their dire warnings were dismissed as political posturings while their recommendations were described as dangerous over-reactions which would make the blood supply more, not less, dangerous.

Despite these challenges the CDC managed to assert and maintain control. Francis described to the commission how, from the earliest days of the AIDS epidemic, the agency busied itself bringing together an extensive network of allies from around the world, coordinating research and collecting an enormous amount of data. In the process they turned themselves into a necessary passage point for those seeking information on the disease and came to influence understandings and practices worldwide.

The commission heard that by mid-1985 the CDC had become a close ally and advisor to the FDA while the MMWR, the agency's central instrument of communication, had been transformed from a publication of only peripheral interest to blood bankers to one which was part of their regular reading.

Science, Society and Politics

While their testimony revealed many differences of opinion the witnesses did agree on one point: the need to insulate science from political interference. The intrusion of politics into the realms of science and public health policy decision-making became a matter of particular focus as the witnesses described the political problems they encountered in trying to respond to the crisis.

While rarely defined, “politics” was generally used to refer to the other-than-scientific factors
affecting the production and use of knowledge. It was most often employed as a slur -- a foreign, illegitimate intrusion of outside power into the territory staked-out by a particular group or groups of experts. Such intrusions were a regular occurrence, as was evident in the witnesses' accounts of the inter-institutional conflicts which marked the early days of the tainted blood tragedy.

Nowhere, however, were the battle lines more clearly drawn than in the war the experts waged against the social world, a world which they described as impinging upon and threatening to disrupt their work and advice at every turn. For the witnesses the worlds of science and society stood sharply divided.\(^3\)

They counterpoised the politically motivated viewpoints and agendas of the social "interest groups" involved in the crisis to the scientific understandings and advice of the expert. The intrusion of external interests -- whether those of local politicians trying to gain economic benefits for their constituency or the acts of those resisting the stigmatizing labels being placed upon them -- were seen to threaten the well-being of all involved.

Individual social actors fared little better in the witnesses' appraisals. Described as operating

\(^3\) Their unanimity in this represented a tradition which extends back at least to the 17th century. For many, the 17th century marks the rise of modern science, a time when the representatives of science and those of society struggled to hammer out the modern "constitution". Robert Boyle, as representative of science, was granted authority over all matters natural while Thomas Hobbes, as representative of society, was granted domain over the social-political field. The world henceforth -- at least in theory -- would be cleaved in two, and divided upon itself (Latour 1990:155).

For an account of the creation of the distinct spheres of authority see Steven Shapin & Simon Shaffer, *Leviathan and the Air Pump* (1985). For a critical discussion of the cleavage represented in the modern "constitution" see Bruno Latour's *Postmodern? No, Simply AModern! Steps Towards An Anthropology of Science* (1990). Latour maintains, as the title suggests, that we have never been truly modern. "It is not that Boyle invents scientific discourse and Hobbes, political discourse; it is that Boyle invents a political discourse where politics should not count and Hobbes devises a scientific politics were experimental science should not count" (Latour 1990:155-6). (See also Latour (1993), *We Have Never Been Modern*).
on a lower level than the scientist, they were emotional — to be read irrational — unable to generalize, selfish in their goals and unreasonable in their demands and expectations.

Little wonder then that they felt the paternalism of the early 1980's had been justified. According to the witnesses, their withholding disconcerting information from the public — which in their judgement included just about any information regarding Transfusion Associated AIDS — and taking responsibility for making difficult decisions, was appropriate given the extraordinary situation. 4

AIDS in the blood supply represented a different sort of threat than that posed by contaminated blood products. Blood products were generally used only by a small sub-population, a population already at risk for infections from their dependence on these drugs. The contamination of the whole blood supply, however, had the potential to threaten the entire society. Expressing an uncharacteristically conservative frame of mind, Francis explained that in a situation such as this you want to be very “confident” in your information before making it public; there is too great “a potential for panic”. The public was not trusted to act well in the face of bad news, or, as it seemed from the testimony, in just about any other situation.

As far as the Canadian blood bankers were concerned, they had good reason to distrust social actors and groups. Every time they had anything to do with them it seemed to turn into a disaster. Perrault and Davey explained how the few interactions the Red Cross had with the gay and Haitian communities in the early years of the crisis turned into major confrontations.

4 The experts were especially cautious when it came to the question of the transmission of AIDS through the blood supply. Other than a report of an infant that developed AIDS following a transfusion, which appeared in the MMWR of December 1982, little mention was made of the problem until the publication of an ongoing study in the NEJM, January 1984. That study recounted what many experts in the blood banking and public health spheres were already aware of — in the previous year and a half 18 cases of AIDS had been directly linked to blood transfusions in the United States while many other cases remained under investigation.
It was apparent from their testimony, however, that one of the reasons they encountered so many problems in their dealings with the social world was that they lacked any informed insight into the groups and individuals they were characterizing and whose behaviour they were trying to control. The Canadian officials acknowledged that they made no attempt to establish a dialogue with the groups involved until relations with them already had degenerated. Prior to their fracases with the gay and Haitian communities, communication was a one way street, restricted to a brief statement carried in the media.

Even after conflict erupted, the policy was to limit interaction to the community leaders. National Office staff assumed that the communities they were dealing with were hierarchical organizations -- just like the Red Cross and the other institutions and agencies they interacted with. Following a time-honoured model they believed that once the compliance of the leadership was gained, 'normal' patterns of communication would ensure the information 'trickle down' to individual community members.

These presumptions not only reflected a failure to recognize the diversity of the communities involved and the complexity of their cultures, they expressed an attitude that the blood bankers had little to learn from the groups and individuals whose compliance they were seeking to gain. The Red Cross experts were not about to be told how to conduct their business by outsiders. The degree to which these authoritarian and totalizing viewpoints were reflected in the witnesses' accounts, of course, varied. Francis, for example, was critical of the communication strategies of the Canadian and American blood officials, especially their failure to recognize the diversity of the gay community. He described taking a more consultative approach, pointing out that during the early years of the epidemic he maintained both personal and professional relationships with individuals in the gay community. He told the commission that he was aware the community
representatives had political agendas to fulfil, but that he believed scientific fixes could be found to get around the problems.

Francis’s testimony reflected a less contemptuous and exclusionary attitude but there was never any doubt that he shared the view that science and society stand opposed and that the scientific expert must be recognized as the authority when it comes to managing technical problems in the social realm. He did see the public as having a role to play in the manufacture and application of knowledge. They were important as informants and there was even room for debate between the various interest groups and experts -- but he also saw it as essential that the lay participants be strictly controlled. Francis was forceful in his warnings that the experts had to be vigilant in ensuring that public participation remain at the level of science.

Tainted Science?

While adamant in maintaining the distinction between the ‘pure’ knowledge of science and the ‘tainted’ politics of social life, the witnesses revealed that their understandings of the disease were no more free of social and cultural content than were the actors in the social-political world they were trying to protect themselves against. Their accounts revealed the struggles for power and territory and the strivings for legitimacy and credibility which arose out of the collision of the competing systems of meanings, practices, values, and goals, represented in the early investigations of AIDS and the blood supply. These struggles embodied a range of conflicts over who was going to have authority in matters involving the blood system, public health, and science in general. They were about whose version of truth, whose system of beliefs, practices, and practices, and values.

5 For a revealing examination of the role of interest groups and social interests in the production of knowledge surrounding AIDS, see Steven Epstein, 1996, *Impure Science: AIDS, Activism and the Politics of Knowledge.*
values, and goals, was going to prevail as well as who was going to lead and who was going to follow.

The stories the experts told also revealed that their understandings of the disease and the people it was affecting embodied deeply embedded cultural values and norms, habits of thought and practice, the significance of which went unnoticed and unexamined. The notion of ‘innocent victims’ and with it the implication that there are others who are ‘guilty perpetrators’ reflected a persistent and deeply moralistic but unquestioned understanding of the disease and those it affected.

The moralism which permeated the understandings of the experts came to be expressed in a variety of ways in the experts testimony. Perrault, Davey and Zuck, for example, told the commission that the blood bankers believe that paid and volunteer donors represent morally distinct groups. They explained that volunteer donors are altruistic individuals whose only motivation in donating is to do good. They give pure blood, “the gift of life”. Paid donors, however, are different. Rather than being communally minded, socially concerned citizens, they are morally suspect individuals who seek personal gain from “the gift”. Their blood, like their social-moral being, is suspect, considered capable of contaminating those who come into contact with it.

They believed this in the early 1980's -- when it helped lead them to conclude that a program of limited intervention was sufficient to met the problem of AIDS and the volunteer blood system and they continued to believe this in 1995 when they tried to explain how the disaster happened.

The linking of AIDS with moral behaviour reflected an association of disease, social disorder and the breakdown of public morality that has been part of Western culture and medicine for centuries. More often than not the moral-physical corruption associated with disease has been
represented as being carried in the blood of the affected.\(^6\)

This was one of the reasons why the blood bankers were unable to accept that AIDS was transmitted through the volunteer blood supply. AIDS was not simply a disease of the body; it symbolized the corruption of the moral self and a poisoning of social relationships. Such associations made it difficult for the blood bankers to see how AIDS could be a threat to the volunteer blood supply. They could not bring themselves to connect such a stigmatizing disease with the physiologically and morally pure blood of their volunteer donors. The symbols were too deeply rooted in the culture of blood banking as well as in medicine and popular culture to be overcome completely.\(^7\)

The CDC representatives were no less influenced by entrenched cultural belief systems. Francis told the commission that he and his colleagues saw no justification for the distinction between paid and volunteer donors, nor did they accept the policy implications of the divide. His testimony revealed, however, that they did not deny the disease was associated with moral behaviour -- in fact, the CDC experts were the first to make the link between "risky" behaviour and the illness. Nor did they deny the existence of pure and impure, safe and dangerous donors; they just refused to accept the distinction as co-extensive with the categories of volunteer and paid donors.

Following an ancient tradition linking corrupt blood and disease -- the same one which Fleck

\(^6\) Not all diseases, of course, carry a moral taint. That is reserved for special threats and special individuals and groups; those who have transgressed the bounds of 'acceptable' behaviour. Measles, a disease of childhood, carries no such moral taint nor is it associated with the blood.

\(^7\) For example, as I have suggested, even after the disastrous lesson of the early 1980's, when thousands in Canada and the United States were infected with AIDS through the blood of volunteer donors, the blood bankers persisted in maintaining a moral divide between the 'healthy' blood of volunteers and the 'tainted' blood of unscrupulous, paid donors.
identified as providing the impetus for the development of the Wassermann reaction -- the CDC experts saw all blood as capable of carrying and spreading the corruption associated with AIDS. Dangerous others had to be sought everywhere. Every feasible technical means had be to employed to identify and remove those whose moral behaviour threatened the rest of society.

Heroes and Villains

The nature of the disaster and the setting in which the experts' accounts were presented, a public inquiry, made it tempting to cast the characters in the story of the tainted blood tragedy in the roles of heroes and villains; heroes who pursued the truth and practised ‘pure’ science and villains who pursued self interested goals, allowing social, political, or institutional concerns to ‘taint’ their understandings. The refusal of those in charge of the blood system to accept any responsibility for the devastation and suffering brought about by the contamination of the blood supply made seeking out and publicly identifying their supposed departures from the norms and standards of scientific practice, all the more appealing.  

Those hoping the hearings would uncover such deviations, however, were largely disappointed. Trying to sort out the heroes and villains in the tragedy on the basis of whose knowledge was ‘pure’ and whose knowledge was ‘tainted’ by the intrusion of non-scientific elements proved to be unrewarding. Such an approach was neither capable of providing a satisfactory explanation of the causes of the situation nor could it offer a guide for developing

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8 Brian Wynne observes that in the public discourse about technology and accidents “human error” is usually cited as the source of the problem, as if to exonerate the technical part of the system and place the burden on social actors who have in some way deviated from “normal rule bound operating procedures”. He suggests that this contributes to a “double bias” in which: a) experts are being held responsible for events that they cannot control, or can not be directly blamed for; and b) their defence is to blame “human error” in some other part of the system (Wynne 1988:157).
strategies to avoid similar disasters in the future. As the testimony at the hearings suggested, distinguishing the heroes and villains on the basis of ‘pure’ or ‘tainted’ science is possible only when an unnecessarily limited and unsupported view of the distinction between science and society is employed. The supposed heroes of the story, Francis and the other “junior” staff at the CDC -- whose early insights and advice have generally been validated with the passage of time -- were no less influenced by personal and professional dispositions, institutional interests, and cultural patterns of thought than were the supposed villains of the piece, the blood bankers. In fact, the social values, interests, and goals embedded in the understandings and advice of the CDC experts appear to have been not so much foreign intrusions as they were essential elements in the construction of their understandings and recommendations.

Similarly, the testimony presented at the hearings revealed that the tainted blood tragedy can not simply be explained in terms of the failure of individual scientists to follow proper standards and protocols. No clear disregard of the available information was revealed, no explicit failure to follow the standards of scientific practice were disclosed. Rather, it became evident that there was neither an unambiguous state of knowledge to refer to during the early outbreak nor was there a uniformly relevant and universally applicable set of standards available upon which existing information could be unequivocally evaluated and actions formulated.⁹

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⁹ This is a common experience in inquiries into civil accidents. In attempting to assess blame and determine compensation one of the central questions that must be asked is whether such an outcome was foreseeable. This involves not only determining the mechanisms responsible for the accident but also the state of knowledge in the relevant disciplines prior to the incident. The problem is that even when referring to the present moment it is difficult to define the state of knowledge of any particular discipline, at least in an objective manner. What is to count as prior knowledge is not simply discovered ‘out there’ in the course of the inquiry. For example, just what cases are to be classified as similar enough that the knowledge and experience of the risks involved in them can be said to constitute a state of knowledge pertinent to the situation under investigation depends on such things as the institutional and legal framework in which the investigation is taking place (Wynne 1989:39-40,43).
While it was clear from the testimony that given the potential seriousness of the situation, blood bankers, both in Canada and the United States, did nothing more than the bare minimum, no undeniable evidence of corruption or villainy was forthcoming.\(^{10}\)

Towards a Resolution of the Conflicts Embodied in the Tainted Blood Tragedy

Instead of showing the disaster to be the result of corruption or malfeasance the witnesses revealed that the disaster was fuelled by a series of confrontations and conflicts between different worlds of meaning and practice, and that these involved clashes and struggles occurring both between and within the worlds of science and society. These problems cannot be adequately explained in terms of human failings nor can they be resolved solely through the application of technical, engineering-style solutions. If solutions are to found it will require building a broader understanding of the nature and sources of the conflicts.

That such understandings and insights be developed is of critical importance. The confrontations, debates, and conflicts revealed in the witnesses' accounts are not unique to the tainted blood tragedy nor to the commission established to investigate the disaster. They reflect pressing problems and ongoing concerns in the worlds of public health, medicine, and science as the actors within these various fields try to cope with their rapidly changing social, technical and

\(^{10}\) It is important to be clear about what I mean by the term corruption. For the experts and many others at the hearings, corruption referred to the intrusion of outside political forces and social interests into the world of science. This is not the sense in which I use the term. Rather, I follow Liora Salter in distinguishing between those situations in which the science under examination can be said to express or embody social, political, and institutional, interests and values and those instances of genuine fraud and bias involving the breach of professional conduct and the violation of public trust. As Salter warns, we need to be careful in acknowledging what is trivially true -- that science embodies values and interests -- that we do not allow this to mask the far more significant situations where genuine bias and corruption are at play (Salter 1988:193-94).
political environments; environments which include an increasingly organized and in some cases hostile public.

More and more, scientists, public health experts, and government authorities find themselves having to acknowledge and address publicly the limits of scientific knowledge, the problems surrounding uncertainty, and the existence of conflicting understandings and practices within science. Likewise, they find themselves faced with the challenge of designing a public health system which is proactive yet driven by science, one which can provide a more inclusive and transparent policy making process yet can lay claim to the authority lent by its adherence to the methods and practices of science and thus can be seen as trustworthy.

The overlap between these conundrums and the issues addressed at the commission is obvious. Those involved in the current debates surrounding the restructuring and reorganization of the policy decision-making process, may, therefore, find what the experts had to say at the Krever Inquiry to be of interest and assistance. For example, one of the key questions raised at the hearings concerned the point at which the potential risks associated with the contamination of the blood supply justified action. This is a question of enormous concern within the public health sphere, and it is one which many have hoped would be resolved by following the “precautionary principle”.

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12 The “precautionary principle” is intended to help cut through uncertainty and ensure the proactive pursuit of the ‘public good’. While stipulating the need to “act on facts, and on the most accurate interpretation of them, using the best scientific information” the “precautionary principle” stresses, that “where the health of the people is at stake” we must not wait until 100% of the evidence is in before taking action; that even when the scientific knowledge is inconclusive we should be prepared to act “if the balance of likely costs and benefits justifies it” (Horton 1998:252).
The testimony presented at the hearings, however, gives reason to question the principle's ability to ensure a proactive public health system. The witnesses' accounts revealed that while guidelines such as the “precautionary principle” can be used to promote a proactive attitude in public health, they can just as easily be used to argue that the evidence is insufficient to justify action, that the ‘public good’ is best served by not acting. This was an argument the blood bankers used in the early 1980's when they denied that the benefits of anti B-core testing had been sufficiently demonstrated to justify its use as a surrogate test for AIDS. They maintained that given the uncertain benefits, the enormous costs, and the potential risks associated with instituting such a measure, the ‘public good’ was best served by taking a wait-and-see approach.

As the witnesses revealed, the practice of cost-benefit accounting on which the “precautionary principle” is premised can be as fraught with controversy and disagreement as the problems it is designed to overcome. Far from being a transparent accounting process, cost-benefit analysis embodies and expresses a range of assumptions, biases, values and interests. The problems and conflicts which serve to impede agreement and dissuade action do not evaporate in the face of the “precautionary principle”, they simply appear in a new and more problematic guise, the supposedly ‘pure’ numbers used in cost-benefit accounting.

The testimony presented at the hearings left little doubt that strictly technical solutions which maintain an opposition between science and society, those which rely on the use of overarching principles and standards, those which reduce complex social behaviours to “summary representations” and exclude all but the issues deemed amenable to scientific solution, are incapable of resolving the current problems surrounding science and its use in public health policy. The witnesses showed very clearly why these sorts of approaches are inadequate. They traced out the complex network of actors, institutions, and resources linked together in the
production and use of scientific knowledge, and they helped reveal the interactions between the supposedly separate worlds of the scientist and the social actor. Their testimony helped educate both the audience and those who participated more directly in the hearings to the often unnoticed meanings, values, and goals embodied in scientific understanding and practice while making present the often multiple and contradictory demands that science and scientists must face in realms such as public health and public policy decision-making.

The hearings provided a highly public venue for the identification and discussion of those issues while inviting the participants, witnesses and audience alike, to judge their systems of thought and practice, to reevaluate their expectations of what science can accomplish and to reexamine what role scientists, physicians, and public health experts should play in ensuring and protecting the well-being of the public.

These are enormously important and topical issues and in addressing them we might do well to take advantage of the groundwork established by the commission. To do this will need to identify and develop the means to further foster and expand upon the exchange of ideas and understandings pursued at the hearings. This will require gaining the cooperation and collaboration of a wide variety of individuals, groups, and institutions. It will require reflection and self reflection on the part of scientists and non-scientists alike and it will require asking difficult questions: if no overarching system of standards, methods and practices is available within science to be called upon as guide and arbitrator, whose interpretations will prevail; if science, like all social understanding and behaviour, embodies and expresses conflicting values, goals and interests, whose values and concerns are to be represented, whose are to be expunged; how is power to be distributed between the various actors and institutions involved in the production and use of scientific knowledge; how are the inevitable conflicts which will arise over
these issues to be managed?"

These questions will not be resolved over night nor will they yield to a single set of procedures or answers. They will likely have to be revisited and reanswered again and again at different times and at the same time in different places. One thing is certain, however -- if we are to answer these questions communication must be made a priority\textsuperscript{13}. Here again a lesson can be learned from the testimony presented at the hearings. It was clear from the witnesses' accounts that the crisis in the blood system arose, in part, because the experts in the realms of blood banking and public health, those on the frontline of the emerging disaster, failed to effectively communicate their understandings, concerns, and practices to one another. It was also clear that the crisis was exacerbated by the failure of the experts to communicate the significance of the situation to other health agencies, health care specialists, government officials and the public.

The witnesses' accounts revealed that the experts talked past one another, failing to understand the meaning and significance of what their colleagues were saying and experiencing. The deficient state of communications left the broader health community with dangerously inadequate information on which to base decisions. It contributed to the unnecessary spread of the disease through the blood supply,\textsuperscript{14} promoted the under-diagnosis and under-reporting of transfusion associated AIDS, and led to a gross underestimation of potential seriousness of the

\textsuperscript{13}Richard Mathias, one of the original members of the National Advisory Committee on AIDS, for example, notes that, "The effectiveness of any public health program [blood banking included] depends largely on effective communication with other public health agencies, with physicians and other health care workers, and with the residents of the community"(Mathias 1998:6).

\textsuperscript{14}The unnecessary use of blood and blood products-- the common practice of "topping-up" the patient, for example -- could have been reduced had surgeons and other physicians been better appraised of the situation. The reduction of the use of blood, as Zuck pointed out in his testimony, and as was made clear in the commission's \textit{Interim Report}, remains one of the primary means of limiting the spread of infectious diseases through the blood system.
public health threat. The failure to communicate with the public, especially the groups most directly involved -- blood donors, gays, I.V. drug users, Haitians and blood and blood product users -- significantly impaired the understandings of everyone involved, and in many cases served to thwart effective interventions.

To some degree these failings can be explained as rising out of the constraints the experts and authorities were operating under. These included a poorly organized system in which roles and responsibilities were inadequately defined. For example, it was unclear who should be responsible for notifying other health care specialists of the threat AIDS posed to the blood supply and its users. In an ill-fated decision Canadian health officials chose to call upon and rely on the Red Cross to communicate this information to other health care specialists. That the public health authorities abrogated their responsibilities is not surprising given their chronic under-resourcing and under-staffing. Yet in dumping the responsibility on the Red Cross they transferred the problem to an institution which was equally incapable of meeting the demands. In both cases the inadequacy of resources underlines the lack of political will on the part of governments and elected officials to do anything about the problem.

These shortcomings, however, do not adequately explain nor do they excuse the inadequate state of communications. Rather, as the witnesses revealed in their accounts, the roots of the problem rested in the ignorance, fear, arrogance and self interest of those charged with the responsibility for ensuring the safety of the blood system and the well-being of its users. The problems rose out of the willingness of the experts to accept and rely on 'common sense' assumptions and stereotypes, especially when it came to critical matters involving the character, abilities, and motivations of the public. The experts maintained an unreasonable fear of, and aversion to, the public, in many cases displaying an unjustifiable refusal to engage in any sort of
interaction with those outside of the world of science. As a result the experts unnecessarily limited their understandings of the groups and individuals involved, ensuring that from the outset their strategies to combat the disease would fail and their dismal appraisals of the public would be borne-out.

The experts' ignorance of the groups involved, and their belief in the superiority of scientific methods and practices were not the only causes of the communications failure. The struggles for power and authority going on between the various health and government agencies involved, and their unwillingness to do anything which might undermine or diminish their claimed dominion over the situation, contributed in important ways to the communications nightmare. The Canadian Red Cross officials, for example, were unwilling to acknowledge the extent of the potential problem to agencies charged with formulating recommendations for dealing with the disease for the fear that outside authorities might begin to dictate what must be done in the realm that the Red Cross had so long reigned over. Similarly those in charge of the CDC in the United States were reluctant to speak out publicly about the disease and the threat it posed to the blood supply for fear that they might find themselves accused of imprudent behaviour. They were not about to see either their own or the agency's credibility undermined in the way it had been a few years earlier with the Swine flu debacle.

These struggles for power and authority, when combined with the experts' limited understandings of the social world and its inhabitants, provided a formula for disaster. Yet as the testimony at the hearings revealed, the experts in charge actually felt justified in their silence. After all, the experts believed the public to be emotional and prone to irrational behaviour when confronted with disturbing news. As far as the experts were concerned, it was better for everyone involved that they keep the truly troubling items -- like the growing evidence of the reality of
transfusion associated AIDS -- to themselves. If they did not remain silent there was always the risk that an unreasonable and unruly public would force them to follow a path of political expediency rather than the course prescribed by scientific method and understanding, and that was an almost unthinkable outcome. Perhaps that is why the experts failed to speak out when their colleagues proffered information which was at best dubious and at worst completely misleading. No one challenged the “one in a million” risk calculation, no one spoke out publically about the widely held concerns that the majority of transfusion associated AIDS cases, such as those being seen in young children, were going unreported.

When the duplicity and silence, and the sufferings which these wrought, finally became apparent they almost destroyed the blood system and grievously undermined public trust in the experts, officials and institutions responsible for managing public health. There will be a long and difficult road to travel if that trust is to be regained. Perhaps one step on that road would be for all of those involved in the disaster to admit that despite their best intentions, ignorance and fear won the day, that ignorance and fear know no boundaries, that they can flourish as easily within science as outside of it.
EPILOGUE

Some reason for hope has emerged since the time the witnesses testified at the hearings. The glaring communications problems which bedevilled the blood system in the 1980's have been noticed and their remedy has become a topic of particular concern for those involved in the reevaluation and reorganization currently underway within the blood system and the wider spheres of medicine and public health.¹ For example, the first Annual General Meeting of the newly formed Canadian Blood Services (CBS) (Ottawa, January 19/20 1999) -- the independent national agency which took over from the Red Cross in 1998 following the revelations at the Krever Inquiry, was open to the public and televised nationally on the Canadian Parliamentary Access Channel (CPAC). The meeting included presentations from a broad range of “stakeholders” as well as a series of public question and answer sessions in which CBS Board Members fielded queries from the audience. Openness, or at least the appearance of openness, was also a concern at the recent CMA conference on the Future of Health Care in Canada (February 25/26 1999). While the CMA conference did not reflect the presence and participation of the public in the way the earlier CBS meeting had, it too was broadcast nationally on CPAC. While the public may have been notable in its absence, the need to improve public education and communication as well as the need for an expanded role for the public in health decision-making were among the central topics addressed at the conference. Particular emphasis was placed on the

¹ For a discussion of the importance of the rapid and effective communication of research findings in public health and the current strategies aimed at achieving this, see, for example, David R. MacLean (1996) "Positioning Dissemination in Public Health Policy." In Canadian Journal of Public Health 87:S40-43. MacLean argues that "...the dissemination of knowledge and practice is being recognized more and more as a legitimate and important component of the health policy agenda."
new information technology (IT) and its potential to overcome many of the current problems surrounding communication and participation.

The belief that the new information technologies will somehow transcend the barriers which up until this point have limited communicative interaction and understanding is a common element in the discourse surrounding public health these days. The Internet and the realm of electronic communications are being looked to as a means to bring about an improved state of information gathering and sharing, and a more open, democratic, system of decision-making.

The IT revolution does, indeed, hold many promises, some of which might well be greeted with circumspection. While the Internet can assist in bringing about some of the necessary changes, the story of the tainted blood tragedy should create some apprehension about looking to yet another technological fix for solutions to complex social problems. Technological fixes will not resolve the difficult human and social issues that need to be addressed if the necessary

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2 Rear Admiral William Rowley, Fleet Surgeon, U.S. Navy, for example, pointed out that the new information technology not only makes it possible to centralize information it also makes it possible to make that information widely and rapidly available. Rowley pointed to the role of IT in the current U.S. Military project aimed at planning health care for the future; a project involving 250 military and non military personnel from a variety of backgrounds and geographic locations. Rowley described the work of these individuals involving trendspotting, identifying emerging forces, outlining possible scenarios and visions, establishing goals and values. Rowley explained, that communicating through the Internet rather than having to attend meetings was less disruptive to the lives of these busy people and they were thus more willing to participate in such projects. Rowley did acknowledge, however, that while communicating through the Internet is important, it is not sufficient, that on occasion the individuals involved need to be brought together to interact face-to-face.

3 For a discussion of the importance of information technology see for example Joy L. Johnson et al. (1996) "A Dissemination Research Agenda to Strengthen Health Promotion and Disease Prevention." In Canadian Journal of Public Health 87:S5-S10. Johnson suggests that the new information technology offers a range of promises, that it can "help meet the increasing need for information dissemination, exchange and management... provide rapid access to research results, interconnections between researchers, collaboration across a large number of state holders, and can foster efforts in education and administration."
reorganization of the distribution of power and knowledge is to be accomplished. That will require an expanded view of science, including its uses, and its limitations. It will necessitate a deeper appreciation of how experts as socially and historically situated actors, go about making and applying knowledge. It will require us to educate ourselves about the character of scientific knowledge, and to educate ourselves to the ways in which that knowledge intersects, affects, and is affected by other forms of knowledge and practice. It will require us to develop an understanding of the ways in which power, authority and legitimacy are negotiated, distributed, and contested in the process of making science, and it will demand a better understanding of the ways in which inequities in the access to, and distribution of, power are enacted and expressed in the process of making and using scientific knowledge.

Ultimately, as the testimony presented at the *Krever Inquiry* suggests, it will require reorganizing our social relationships as well as rethinking our relationships with our technologies.
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AABB</td>
<td>American Association of Blood Banks</td>
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<tr>
<td>ABC</td>
<td>American Blood Commission</td>
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<tr>
<td>ACT</td>
<td>AIDS Committee of Toronto, a gay community initiative providing support and acting as a lobby group</td>
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<tr>
<td>AJM</td>
<td>American Journal of Medicine</td>
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<tr>
<td>ARC</td>
<td>American Red Cross</td>
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<tr>
<td>BDR</td>
<td>Blood Donor Recruitment (Canadian Red Cross Society)</td>
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<tr>
<td>BTS</td>
<td>Blood Transfusion Service (Canadian Red Cross Society)</td>
</tr>
<tr>
<td>CBC</td>
<td>Canadian Blood Committee, responsible for funding the Blood System</td>
</tr>
<tr>
<td>CCBC</td>
<td>Council of Community Blood Centres (U.S. Volunteer Blood Banking Sector)</td>
</tr>
<tr>
<td>CDC</td>
<td>Centres for Disease Control, Atlanta. (U.S. Public Health Service)</td>
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<tr>
<td>CDWR</td>
<td><em>Canadian Diseases Weekly Report</em>; published by LCDC</td>
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<tr>
<td>CHS</td>
<td>Canadian Hemophilia Society</td>
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<tr>
<td>CMA</td>
<td>Canadian Medical Association</td>
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<tr>
<td>CMAJ</td>
<td><em>Canadian Medical Association Journal</em></td>
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<tr>
<td>CRCS</td>
<td>Canadian Red Cross Society</td>
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<tr>
<td>FDA</td>
<td>Food and Drug Administration, regulator, U.S.</td>
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<tr>
<td>HPB</td>
<td>Federal Health Protection Branch</td>
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<tr>
<td>HIV</td>
<td>human immunodeficiency virus,</td>
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<tr>
<td>HTLV</td>
<td>Human T-cell lymphotrophic virus; first identified human retrovirus</td>
</tr>
<tr>
<td>JAMA</td>
<td><em>Journal of the American Medical Association</em></td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Description</td>
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<tr>
<td>LCDC</td>
<td>Laboratory Centre for Disease Control; branch of the federal Ministry of Health and Welfare</td>
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<tr>
<td>MMWR</td>
<td><em>Morbidity and Mortality Weekly Report</em> published by CDC</td>
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<tr>
<td>MSAC</td>
<td>Medical Science Advisory Committee</td>
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<tr>
<td>NANB</td>
<td>Non A Non B hepatitis</td>
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<tr>
<td>NAC-AIDS</td>
<td>National Advisory Committee on AIDS, established by the Canadian federal government in 1983 to study and advise on AIDS; originally the National Task Force on AIDS</td>
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<tr>
<td>NEJM</td>
<td><em>New England Journal of Medicine</em></td>
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<tr>
<td>NHF</td>
<td>National Haemophilia Foundation (U.S.)</td>
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<tr>
<td>NIH</td>
<td>National Institute of Health, (U.S.)</td>
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<tr>
<td>PHS</td>
<td>Public Health Service (U.S.)</td>
</tr>
<tr>
<td>STD</td>
<td>sexually transmitted disease</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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Glossary

**ABO blood group**: major human blood types; determined by presence or absence of A and B antigenic structures on red blood cells.

**AIDS**: acquired immunodeficiency syndrome, a clinical disease characterized by opportunistic infections such as Kaposi's sarcoma and pneumocystis carinii pneumonia in an individual infected with HIV. According to the 1993 CDC classification, any HIV infected person with a T4 count of less than 200 has AIDS, even if they have not suffered from opportunistic infections.

**Antibody**: protective protein of the immune system, either existing naturally or in response to an antigen. The presence of an antibody will often indicate the presence of the antigen.

**Antigen**: molecule or a part of a molecule; stimulates production of humoral antibodies, e.g., toxins, foreign proteins, and bacteria.

**Anti-HBc test**: anti-Hepatitis B-core test; one of several tests able to identify persons who have a history of Hepatitis B infection; suggested as a surrogate test for persons at high risk for AIDS before the discovery of a test for the HIV antibody.

**Apheresis**: blood is withdrawn from a donor, a portion is mechanically separated and collected (e.g., plasma or platelets), the remainder is returned to the donor.

**Autologous transfusions**: recipient is transfused with own's own blood or blood products which had been collected earlier.

**Blood products**: products produced from blood or plasma by fractionation, such as Factor VIII.

**Blood components**: red cells, plasma, and cryoprecipitate; blood components are produced by less complex processes than fractionation.

**CD4 cell**: receptor on the surface of T4 cells; play's an important role in the cell mediated immune system. A normal CD4 count is between 500 and 1500 per microlitre.

**Cell mediated immune system**: one of the three major systems making up the body's immunological defence.

**Clinically latent phase**: period after primary infection when the infected person feels perfectly well; may extend 6 months to 15 years in case of HIV infection.

**Cryoprecipitate**: blood component used to promote coagulation; produced by freezing plasma obtained then thawing it; cryoprecipitate from a pool of several donors are pooled and administered intravenously to treat a bleeding episode.
CUE Confidential Unit Exclusion: a procedure allowing donors to confidentially designate their blood be used for research, rather than for transfusion.

Cytomegalovirus: viruses related to herpes family; attacks persons who are immunosuppressed.

Direct questioning: screening process for prospective blood donors that relies on asking direct questions about belonging to groups that were at high risk of contracting and transmitting AIDS.

ELISA test: enzyme linked immunosorbent assay test; screening test for detecting HIV antibody; not particularly accurate, reactive samples must be retested; repeatedly reactive, samples are subjected to a more sensitive test, such as Western blot.

Epidemiology: study of the incidence and distribution of diseases with the goal of their prevention.

Etiology: study of the causes of diseases.

Factor concentrates: products obtained through precipitation and concentration of proteins contained in plasma which are necessary for blood coagulation.

Factor VIII: a blood protein, which aids in coagulation. Individuals with hemophilia A have a deficiency of this factor. Produced from plasma by fractionation.

Factor IX: human blood protein, involved in blood coagulation; a deficiency of this factor results in Hemophilia B.

Fractionation: biochemical process used to separate blood components from plasma eg. factor VIII and factor IX, immune globulins, albumins.

GRID: gay related immune deficiency; early name used for the syndrome which became known as AIDS.

Hematology: the medical specialty that deals with blood and blood forming tissues.

Hepatitis B: viral infection of the liver; can be acute chronic or life-threatening; transmitted through blood, including blood transfusions, as well as through sexual contact.

Hepatitis C: viral infection of the liver believed transmitted in manner similar to hepatitis B; can be acute, chronic or life-threatening; prior to 1989 was classified as Non A Non B hepatitis NANB.

High risk groups: groups whose members are recognized to participate in behaviours which are at high risk of transmitting HIV.
Human Immunodeficiency Virus (HIV): etiological agent responsible for the clinical disease AIDS; may take up to a year before person infected with HIV tests positive to the presence of the HIV antibody.

HTLV-III: human T cell lymphotropic virus, type III; early name for HIV.

Humoral system: one of three major systems making-up the immunological defence of the human body; controlled by antibody producing B cells.

Immune deficiency: breakdown or inability of parts of the immune system to function which leaves the individual susceptible to diseases they would not normally get.

Immunosuppressed: significant or complete suppression of immune response.

Incidence: number of people in the entire population or some subset of the population at any given time affected by a particular disease; expressed as a percentage.

Kaposi's sarcoma: cancer of the blood cells; produces tumours in the skin and in the linings of internal organs.

Kuru: disease of the central nervous system causing decrease in brain cells; initially causing disruption of coordination then paralysis, dementia and death.

LAV: lymphocyte associated virus; early name for HIV used by researchers at the Pasteur Institute.

Lentivirus: family of retroviruses affecting primates and domestic animals; belonging to the same family as HIV they cause diseases in animals similar to AIDS in humans.

Lymphadenopathy: disease of the lymph nodes, associated with fever, night sweats, weight loss and swollen lymph glands; onset can be an indicator of HIV infection.

Lymphocyte: white blood cell; divided into two types, B and T lymphocytes, responsible for humoral and cellular immunity respectively.

Opportunistic infection (OI): infection that occurs because the immune system has been suppressed or compromised.

Plasma: straw colour fluid making up about 55% of blood volume; contains a variety of cellular components.

Pneumocystis carinii pneumonia (PCP): rare pneumonia common in persons with AIDS and those suffering from other forms of immunosuppression.
Prodromal: disease state prior to the onset of symptoms associated with the fully developed infection eg. the swollen lymph glands, night sweats or fever which frequently precedes 'full blown' AIDS infection.

Recovered plasma: plasma removed from unfrozen whole blood.

Retrovirus: family of viruses containing genetic information consisting of RNA; share common strategy for replicating using the enzyme reverse transcriptase; integrates self into host cell to reproduce.

Seroprevalence: proportion of blood donors testing HIV positive at a given time; expressed as a percentage.

Source plasma: plasma collected by plasmapheresis; used for fractionation.

Surrogate test: indirect test to indicate possible infection; eg. testing for the presence of antibodies to hepatitis B core used an indirect test for those at risk of AIDS.

Symptom specific questioning: questions designed to gain a specific insights into a donors state of health as a way of screening out prospective blood donors who might be infected with HIV.

T4 cells /T4 lymphocytes: white blood cells that play a critical role in the immunological defence system, activating and/or organizing other parts of the immune defence; T4 lymphocytes are also called helper T cells.

TAA: transfusion associated AIDS

Western blot: laboratory testing method used to confirm presence of HIV; like the Wassermann reaction the results must be interpreted rather than simply read.

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Wynne, Brian


Appendix 1: Chronology of Important Events, November 1980 to May 1984

1980

November  Dr. Michael Gottlieb sees his first case of Pneumocystis carinii pneumonia (PCP) in a young gay male in Los Angeles.

1981

May  First published report of "an exotic new disease" affecting members of the gay community in New York appears in New York Native.

Dr. Gottlieb notifies the Los Angeles County Department of Public Health and The Centers for Disease Control of 5 cases of Pneumocystis carinii pneumonia among young men in Los Angeles.


July  Report of ten new cases of Pneumocystis carinii pneumonia and twenty-six cases of Kaposi's sarcoma diagnosed in homosexual men; published in Morbidity and Mortality Weekly Report.


1982


June  Report on a cluster of cases of Kaposi's sarcoma and Pneumocystis carinii pneumonia among American homosexual men; provides support to the theory that the disease is caused by an infectious agent; published in Morbidity and Mortality Weekly Report.

July  Cases of three hemophiliacs diagnosed with Pneumocystis carinii pneumonia in the United States who had been treated with factor VIII concentrate; published in Morbidity and Mortality Weekly Report.

The U.S. Public Health Service creates Task Force on Opportunistic Infections in Hemophilia Patients to determine whether the use of blood products is a risk factor for AIDS.

August  Canadian Red Cross and the Canadian Hemophilia Society are requested by officials in the Bureau of Biologies to monitor the disease among hemophiliacs.

Eight cases of AIDS are reported to the Health Protection Branch in Canada.
September  The Canadian Red Cross announces at a joint meeting with the Laboratory Centre for Disease Control, the Canadian Hemophilia Society, and the Bureau of Biologies that it can not fulfill early commitment it made to monitor hemophiliacs.

Meeting of Immunology/Virology Blood Transfusion Service Working Group (the group within the Red Cross with the most expertise in the area of virology) concludes evidence suggesting hemophiliacs are at risk is still inconclusive and far too much attention has been given to the issue in the press.

November  U.S. Public Health Service publishes guidelines for clinical and laboratory staff in contact with AIDS patients or their specimens and or bodily fluids; published in Morbidity and Mortality Weekly Report.

December  Four new cases of AIDS in hemophiliacs and one case of Transfusion Associated AIDS in an infant in the United States Morbidity and Mortality Weekly Report.

Dr. Evatt of the CDC announces at December 3rd and 4th FDA Blood Products Advisory Committee meeting that transfusion associated AIDS may follow same increasing pattern seen with hemophiliacs

Canada Diseases Weekly Report announces that a Montreal study has concluded that hemophiliacs who had been treated with factor VIII concentrate have immune deficiencies similar to those of non-hemophiliac patients infected with AIDS.

Alpha Therapeutic Corporation, a U. S. fractionator, introduces a donor screening program to exclude plasma donors at high risk of contracting AIDS.

The U. S. National Hemophilia Foundation recommends in its medical bulletin that mild hemophiliacs, newly diagnosed hemophiliacs, and hemophiliacs under the age of five years not be treated with factor concentrates.

1983

January  U. S. Public Health Service holds a public meeting, attended by organizations involved in the blood supply, to discuss ways to prevent transmission of AIDS through blood components and blood products; agreement reached that measures should be taken to exclude persons at high risk of contracting AIDS from making blood donations.

The American Association of Blood Banks, the American Red Cross, and the Council of Community Blood Centres issue a Joint Statement recommending that specific measures, including the use of autologous blood, education of physicians regarding blood use, and questioning of donors to detect symptoms of AIDS or exposure to patients with AIDS be taken to reduce the risk of AIDS to the blood supply.

The medical and scientific advisory council of the U. S. National Hemophilia Foundation
recommends, manufacturers of factor VIII concentrate, blood centres, and physicians treating
hemophiliacs take measures to reduce the risk of AIDS to the blood supply.

**March** The U.S. Federal Drug Administration recommends all facilities involved in the
collection of whole blood and plasma instruct donors at high risk of contracting AIDS not to
make donations; all prospective donors are to be asked specific questions to detect AIDS
symptoms and exposure to persons infected with AIDS.

Distribution of pamphlets on AIDS to donors at blood and plasma centres begins in the U.S.

Medical and Scientific Advisory Committee of the Canadian Hemophilia Society distributes
recommendations aimed at reducing the risk of exposure to AIDS for hemophiliacs.

Canadian Red Cross issues press release asking persons at high risk of contracting AIDS not to
donate blood.

**May** Canadian Red Cross introduces new donor questionnaire stressing the importance of good
health but avoiding the direct question: "Are you well"?

Luc Montagnier and colleagues at the Pasteur Institute in Paris isolate a new retrovirus,
Lymphadenopathy-associated virus (LAV), believed to cause AIDS.

Formation of National Task Force on AIDS (later the National Advisory Committee on AIDS), a
group of 16 scientific and medical experts appointed by the Canadian Minister of National
Health and Welfare to provide advice to the Minister on issues relating to AIDS, meets for the
first time.

**June** *Canada Diseases Weekly Report* publishes first report of AIDS in a Canadian hemophiliac.

**July** Canadian Red Cross issues second press release asking individuals at high risk of
contracting AIDS not to donate blood.

**September** First meeting of the National Advisory Committee on AIDS (NACAIDS).

**November** Second meeting of NACAIDS where the Red Cross presents and seeks endorsement
of its proposed plan of action to deal with AIDS in the blood supply; Canadian Red Cross
position is noted but it is neither endorsed or rejected by the Committee.

**1984**

**January** Report on eighteen cases of AIDS in U.S. believed caused by the transfusion of blood
components published in *New England Journal of Medicine*.

First report of a spouse of a hemophiliac with AIDS published in the *Annals of Internal
Medicine*. 
April  Robert Gallo announces that he and his colleagues at the U. S. National Cancer Institute have isolated, human T-cell lymphotropic virus III (HTLV-III), the retrovirus that causes AIDS.

The U. S. Assistant Secretary of Health announces the etiological agent which causes AIDS has been identified and that a test will be available within six months.

April - July  The Cutter Biological Division of Miles Laboratories Inc. (Cutter) and five blood banks in the San Francisco area introduce a test for the antibody to the core of the hepatitis B virus as a surrogate test for AIDS.

May  The first Canadian Red Cross pamphlet on AIDS is distributed to donors at blood centres; pamphlet identifies persons at high risk of contracting AIDS and asks those persons to refrain from donating blood.

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Krever, Horace
Appendix 2: List of Names of Scientific Experts Cited

Bove, Dr. Joseph, Director AABB, Blood Banker, Yale University

Brant, Dr. Edward, Assistant Secretary of Health.

Clayton, Dr. Alastair, Director General, LCDC, Ottawa.

Curran, James W., Director of AIDS program, CDC, Atlanta; author of seminal January, 1984 article associating certain AIDS cases with blood transfusions.

Davey, Dr. Martin G., Assistant Director, BTS, CRCS (National); along with Perrault and Derrick one of people at National Office, CRCS, responsible for making AIDS policy.

Derrick, John, PH.D (deceased), held various positions in CRCS (National Office). Director, Blood Product Services during the early years of the AIDS epidemic; with Dr. Perrault and Dr. Davey he was primarily responsible for developing National CRCS policy on AIDS; coordinated and distributed information on AIDS.

Dodd, Dr. Roger, Assistant Director Blood Services ARC; Head, Transmissible Diseases, Immunology Laboratory, ARC; information source to CRCS regarding AIDS in the U.S.

Donahue, Dr. Dennis, Director Division of Blood and Blood Products, FDA.

Evatt, Dr. Bruce, epidemiologist at CDC, early advocate of view AIDS was caused by a viral agent.

Foege, Dr. William, Director, CDC Atlanta.

Francis, Dr. Donald, American infectious diseases expert at CDC; involved in early research in epidemiology and etiology of AIDS.

Furesz, Dr. John, Director Bureau of Biologies Health Protection Branch, Canada.

Gilmore, Dr. Norbert, Chair of NACAIDS during the early years of the Committee's existence.

Herst, Dr. Roslyn, Deputy Medical Director, BTS, CRCS (Toronto).

Jessamine, Dr. Alexander Gordon, Chief, Field Epidemiology Division, Bureau of Epidemiology, LCDC, Ottawa (1979-1987); first person in Canada to collect epidemiological information on AIDS.

Katz, Dr. Alfred, Senior official, ARC.
Perrault, Dr. Roger, National Director, CRCS BTS (1974-1986): CRCS representative on NACAIDS.

Perkins, Dr. Herb, Medical Director Irwin Memorial Blood Bank.

Petricciani, Dr. John, Director, Bureau of Biologics, FDA.

Pindyck, Dr. Joanna, Director, Greater New York Blood Program; responsible for developing confidential unit exclusion (CUE) program.

Rock, Dr. Gail, Medical Director, Ottawa Centre, CRCS (1974-1988).

Spira, Dr. Thomas, (CDC) conducted early study suggesting value of Hepatitis B as a surrogate test for identifying persons at high risk of contracting or transmitting AIDS.

Zuck, Dr. Thomas, Blood banker, representative of the volunteer blood sector and former FDA blood and blood products regulator.

Source:
Lang, Susan E.
Appendix 3: List of Names of Legal Counsel Cited

Arenson, Mr. Ken, Committee of HIV Infected and Transfused

Blue, Mr. Ian, Hepatitis C Survivors Society

Cherniak, Mr. Earl, Canadian Red Cross

Currie, Ms. Maureen, Canadian Red Cross

Edwardh, Ms. Marlys, Senior Commission Counsel

Elliott, Mr. R. Douglas, Canadian AIDS Society

Harvey, Mr. David, Hemophilia Ontario, Toronto and Central Region

Krever, Mr. Justice Horace, Commissioner

Lavigne, Mr. Pierre, The Hepatitis Group of Transfusion Recipients and Hemophiliacs

Nesseth, Mr. Paul, Gignac, Sutts Group

Podrebarac, Ms. Katheryn, Canadian Hemophilia Society

Rennie, Mr. Donald, Government of Canada

Selnes, Mr. William, Canadian Hemophiliacs Infected with HIV

Simand, Ms. Harriett, HIV-T Group (Blood Transfused)

Stephenson, Mr. Roy, Senior Commission Counsel

Stoltz, Ms. Lori, HIV-T Groups (Blood Transfused)

Tough, Ms. Bonnie, Canadian Hemophilia Society

West, Mr. Allen N., Connaught Laboratories Limited

Source:
Krever, Horace
### Appendix 4: Index of Transcript Volumes Cited

<table>
<thead>
<tr>
<th>Volume</th>
<th>Date</th>
<th>Page Start</th>
<th>Page End</th>
<th>Witnesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Feb. 15/94</td>
<td>223</td>
<td>413</td>
<td>Douglas Lindores, Dr. Roslyn Herst (CRC BTS)</td>
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<td>March 8/95</td>
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<td>March 9/95</td>
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<td>George Hislop, Ed Jackson, Prof. Tom Alloway, Dr. Dale McCarthy</td>
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<tr>
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<td>March 30/95</td>
<td>23493</td>
<td>23718</td>
<td>(AIDS Activist Panel)</td>
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<td>March 31/95</td>
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<td>April 11/95</td>
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<td>Dr. Norbert Gilmore, Dr. Richard Mathias, Dr. Frances Shepard, Dr. Colin Soskolne</td>
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<td>April 19/95</td>
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<td>24876</td>
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<td>April 20/95</td>
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<td>April 21/95</td>
<td>25147</td>
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<td>Date</td>
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<td>June 13/95</td>
<td>30814</td>
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<td></td>
</tr>
</tbody>
</table>
Volume | Date       | Page Start | Page End | Witnesses
-------|------------|------------|----------|------------------------
166    | Aug. 8/95  | 35282      | 35506    | Ambrose Hearn, Fred Anderson, Stephen Dreezer, Dr..Peter Glynn (CBC)
167    | Aug. 9/95  | 35507      | 35748    | *                       
168    | Aug.10/95  | 35749      | 35998    | *                       
169    | Aug.11/95  | 35999      | 36278    | *                       
235    | Dec. 21/95 | 48662      | 48842    | Dr. Fred Lowy, Prof. Bernard Dickens. Dr. Margaret Sommerville, Dr. Michael Burgess (Ethics Panel-Round Table)