

# Rheumatology

## Research Report

For Patients & their Families  
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**a place of mind**



### Editor's Space

Welcome to the fall edition of the Rheumatology Research Report! I hope you enjoyed the somewhat chilly summer in Vancouver. The Rheumatology team has kept themselves busy this summer with our ever-growing research program. In this report, we will tell you about a new study on arthritis (page 2), as well as answer some questions you might have about participating in research studies (page 3). We will also introduce you to some new faces you might see around the Rheumatology clinic in the coming months. Happy reading!

*Good luck in the coming school year!*



## **Our Division's Newest Projects: The New Kids on the Block**

### **The scope of childhood arthritis in BC, Canada: Are children with juvenile idiopathic arthritis (JIA) being seen by a pediatric rheumatologist?**

The "Scope of JIA" study is funded by the Arthritis Society and Ministry of Health to find out what type of doctors children with JIA in BC see for their arthritis care. The accepted best standard of care is that they be seen by a pediatric rheumatology team. We will determine if some kids with JIA are only looked after by their family doctor, pediatrician or other specialists such as orthopedic surgeons or adult rheumatologists. We will use anonymous data from the BC Ministry of Health to find children in the province diagnosed with JIA and see what types of doctors they have seen. We will determine if all children with JIA in BC are receiving the best standard of care and treatment. This study may also highlight regions in the province where we should either focus more pediatric rheumatology outreach, or need to develop training programs for family doctors to increase their awareness of JIA.



#### **Research FAQs: Questions about research you've always wanted to ask!**

### **#1. Why do we have to do research on children? Isn't it enough to study adults?**

*Children's bodies are very different from adults and as they grow up, their brain and bodies are constantly changing. As kids grow go from being infants to toddlers to children to teenagers, the effect of medication and treatments on the body may be different to the effects on adults. Sometimes the treatment and care that is given to children are the same as those for adults. These treatments work and are useful in adults but they may not work as well in children. Doing research in kids will help us develop treatments and care for children that is right for their age, allowing us to provide the best possible care for our children.*

### **#2. Do I have to participate in research studies? What happens if I change my mind and I don't want to continue in the study?**

*All research studies done at BC Children's Hospital are completely voluntary. Your decision to join a study or not will not affect your medical care in any way. If you decide to join a study, you are free to change your mind anytime! If you and your child are participating in a research study and do not want to continue, you can just let your doctor or the Rheumatology research staff know.*

### **#3. What is informed consent? Why is it so long? Why do I have to sign a new form for each study I join?**

*The informed consent form is your guide to learning all the key facts about a research study. It makes sure that you have the opportunity to learn about all the details of a research study to help you decide if you should join a study. The consent form is specific to each study so you may be asked to read a new one each time you join a new study.*



#### **Good News!**

### **LEAP Study Update: 80 subjects and counting!**

**Linking Exercise, Activity and Pathophysiology in Juvenile Idiopathic Arthritis, or LEAP**, is a study that is looking at how physical activity affects the disease progression and bone and muscle development of children with arthritis. We are happy to share that Vancouver is currently leading the way with 39 "LEAPers"; other Canadian cities like Winnipeg (19), Ottawa (10), Halifax (9), Edmonton (2), and Sherbrooke (1) are also up and running. Please visit the LEAP website at [www.leapija.com](http://www.leapija.com) for more updates!



## Open invitation: Rheumatology Studies Currently Recruiting Patients

### Studying the Pediatric ANAM in childhood SLE

*The PedANAM is a short computerized test developed to assess brain functioning in children. The brain can be affected in by lupus and currently we do not have any simple and effective tool for monitoring the cognitive status children with lupus. We need to do this study to test if the PedANAM test fulfills this need. If it proves to be effective we hope to use it in the clinic in the future as a routine test.*

#### Who is eligible?

Children with lupus  
who are 10 to 18 years  
old

#### What do participants do?

You will be asked to take a 30-minute computer  
test every 6 months at the same time as your  
Rheumatology clinic visit.

### Teens Taking Charge: Managing Arthritis Online

*Teens with JIA increasingly need to learn about their disease and how to manage it more independently from their parents; this new web program aims to provide information and teach coping skills.*

#### Who is eligible?

Teens with JIA  
between 12 to 18 years  
old

#### What do participants do?

Teens will be asked to visit a special website for  
the 12-week study period and work through the  
web modules. They will also receive a monthly  
phone call from a health coach.

### Announcements

We would like to welcome and introduce our new fellow **Dr. Hend Al-Kwai** who received her MD training in Saudi Arabia. She will be training in Pediatric Rheumatology with us starting this October.

We would also like to say thank you and bid farewell to our co-op students **Omar Sadek** and **Shandel Riedlinger**, who will both be returning to UBC this Fall to complete their studies. They have been invaluable members of our team and we wish them all the best!



**Emma Hitchcock** and **Kevin Huang**  
will join our team as new research  
assistants supporting our  
Rheumatology studies in the coming  
year. Welcome to the team!

