

# **Developing Tools to Improve Parent Health Literacy in Nephrotic Syndrome.**

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## **1 - Purpose/Rationale**

### ***1.1 - Target Audience Refinement and Personal Connections***

The goal of this summer studentship was to produce an education science-based lesson promoting my scientific communication skills as well as teaching a concept to a group of individuals remotely. Given my history of STEAM outreach through video ([youtube.com/scifiles](https://youtube.com/scifiles)), I was eager to push my knowledge of science communication strategies and educational tools to a new medium; Zoom.

In order to develop a lesson plan, I first had to identify the audience that I wanted to present to. Initial ideas included presenting to the elderly, school-age children, and parents. Ultimately, I decided to pursue a communication project focused on parent and patient scientific literacy in the field of immunology. This decision was guided by my personal connection to the parent-patient-doctor relationship through my younger brother's diagnosis with nephrotic syndrome. Watching my brother grow up dealing with this chronic kidney disease and the way my parents had to learn biology, physiology and medicine to deal with his condition, I was inspired to help parents and patients affected by the disease learn more about nephrotic syndrome. As both of my parents came from non-science backgrounds, there was a lot to learn when my brother was diagnosed with this condition. I strongly believe that a tool that helps bridge this knowledge gap will be incredibly useful in helping parents adapt to their child's new diagnosis.

### ***1.2 - Nephrotic Syndrome Patient Care***

Nephrotic syndrome is characterized as a group of symptoms including proteinuria (protein leakage into the urine) and edema (swelling). These symptoms can re-occur in flare ups, known as relapses, multiple times after diagnosis. Both edema and proteinuria are indicative of improper kidney functioning, and without proper treatment, can lead to kidney failure. Nephrotic syndrome is more common in men than in women, and most frequently occurs between ages 2 and 6. There are many different conditions that present with nephrotic syndrome, including focal segmental glomerulosclerosis (FSGS), minimal change disease (MCD) and lupus -- all of which require different treatment regimes (1).

After diagnosis with nephrotic syndrome, patients are typically prescribed an induction dose of prednisone. This dose is given for four to six weeks, with tapered doses given thereafter. Recent research has suggested that doses given within a precise range, 2000-2500 mg/m<sup>2</sup>, result in the best long-term outcomes for these patients. However, ensuring that patients consistently and continuously take their medications requires an understanding of the severity of the condition, the importance of consistent dosing and the impact of missed doses by the parents (2).

Outside of medications, daily management and care for patients with nephrotic syndrome can be complex. Parents are advised to test their child's urine daily through urinalysis test strips, monitoring for increases in protein leakage. Second line medications, such as cyclophosphamide, may also be prescribed in attempts to prevent relapse (3). With complex treatment plans and rigorous monitoring,

some parents of patients with nephrotic syndrome may find it difficult to navigate the many facets of the disease, especially without prior experience in the healthcare sector (4).

Previous research has demonstrated that parents tend to overestimate the amount they know about nephrotic syndrome, despite feeling confident in their knowledge base (4). Cao et al. analyzed knowledge gaps in three domains: disease understanding, management and access to information. They found that while 90% of parents self-identified as knowledgeable, only 29% were able to answer disease specific questions. Goals outlined in this lesson address some aspects of disease understanding examined by Cao et al. while also providing an access point to information (4).

### ***1.3 - Previous Research***

The treatment of childhood nephrotic syndrome is a complex issue and requires collaboration between patients, caretakers and medical personnel. Patients and parents have reported difficulty understanding the diagnosis among concerns of learning their child's individual patterns of disease (5). Recent studies have demonstrated a correlation between parent health literacy and incidence of relapse in pediatric nephrotic syndrome patients, finding that higher literacy skills in parents correlated with a significantly lower relapse rate and higher odds of complete remission after initial treatment (6).

Both adult patients and parents have expressed interest in increased communication of information on nephrotic syndrome to patients, stressing the lack of accessible information on the condition, which makes it more challenging to manage. Beanlands et. al surveyed patients and parents with nephrotic syndrome finding that novel communication methods between patients and healthcare personnel are important future steps in increasing understanding of the condition (7).

### ***1.4 - Project Goals and Intentions***

This study aimed to find an effective way to facilitate improved parental health literacy through a virtual lesson on the immune system and its connection to nephrotic syndrome. In the hopes of increasing parental comprehension of the discussed topics, the lesson was focused on discussing pathways involved in the development of nephrotic syndrome as well as the actions of treatment measures. The goal of these pathway-oriented conversations was to expose parents to the concept of pathways in the physiology of the condition.

In the hopes of assessing changes in parent health literacy, a pre- and post-lesson survey was provided to gauge parent's understanding of the lesson-specific concepts and general health literacy skills using the All Aspects of Health Literacy Scale (AAHLS).

## **2 - Methods**

### ***2.1 - Lesson Plan Development***

The scope of the project was first defined as a single lesson provided to parents and patients virtually, with evaluation via a pre- and post-lesson survey. Due to timing of this project during the COVID-19 Pandemic, the interventions were set to be in an online format. The first stage of the project involved designing the lesson, which consisted of three distinct sub-sections.

## ***2.2 - Creation of the Evaluation Tools***

In order to evaluate the effectiveness of the intervention, the All Aspects of Health Literacy Scale (AAHLS) was implemented (8). The AAHLS evaluates health literacy in three categories: functional health literacy, communicative health literacy, and critical health literacy. These broad categories allowed us to get a wide sense of the breadth of the patient's health literacy skills (8).

A pre- and post-lesson survey was developed in Qualtrics to assess patient demographics, lesson specific questions, AAHLS, and a post-lesson review. Parent demographics collected include age, ethnicity, gender, profession, education level and duration of child's nephrotic syndrome diagnosis. The lesson specific questions asked parents to rank their understanding of concepts related to the lesson. The post-lesson review provided feedback on the lesson itself as well as a repeated measure of the lesson specific questions.

## ***2.3 - Participant Recruitment***

In order to recruit patients and parents for the lessons, I contacted Kelly Helm from NephCure Kidney International (NephCure). As part of their organization's outreach efforts, they host regularly scheduled meetings with patients and parents online. Working with NephCure, I was able to host meetings with participants of their existing networks. These participants were located worldwide and had varying levels of experience with nephrotic syndrome and scientific literacy. Patients registered for the lessons through the NephCure website and Kelly Helm acted as a co-facilitator during the Zoom lessons.

## ***2.4 - Online Requirement***

This project was undertaken from May through August 2020, in the midst of the COVID-19 global pandemic. As a result, it was necessary that all lessons and communications were virtual. Furthermore, with access to science education being most challenging in remote communities, development of online-curricula may allow for future distance-education lessons to occur. This would help reduce some of the burden that rural patients face when dealing with an unfamiliar condition. The lesson also utilized at-home materials, providing patients with the ability to facilitate the demonstrations themselves while watching the lesson online.

# **3 - Developing the Lesson Plans**

## ***3.1 - Online Facilitation Tools***

In order to address the online constraints into the lesson plan development, I aimed to incorporate features of the Zoom platform in the development of the lessons. These tools included the split screen feature, the ability to use multiple camera angles in conducting the lessons, the annotate tool, and the reaction tool. In order to facilitate the use of these tools, my lesson began with an introduction of these features in Zoom to familiarize the participants with them. Throughout my lesson, the tools were used repeatedly. For example, students demonstrated that they were ready to proceed with the activity by raising their ‘hand’ or by annotating the screen as a team during a group activity.

Furthermore, two devices were set up to facilitate the lesson. A phone was placed on a tripod that was angled above the workstation for an overhead view of the experiment, and a laptop was used to show a view of me as I presented as well as to present the accompanying presentation slides.

### **3.2 - Key Learning Objectives and Rationale**

The topic of the lesson was first defined as teaching pathways of the innate and adaptive immune systems. The immune system was chosen as a topic due to its association with childhood nephrotic syndrome in both patients with MCD and FSGS. T lymphocyte and B cell dysfunction have both been implicated in possible MCD and FSGS pathways, so an introduction into the basis of these immune systems was an ideal target for the introductory lesson (9). The physical features of the innate immune system were included in the lesson plan to provide a more general knowledge of human physiology and to increase parent and child exposure to medical language. In order to help parents, associate the lessons with their child’s conditions, a final segment on the implications of improperly functioning immune systems in nephrotic syndrome was also developed.

The specific learning objectives for the project are outlined below in **Table 1**.

**Table 1.** Learning objectives, associated activities and rationales.

<b>Learning Objective</b>	<b>Associated Activity</b>	<b>Rationale</b>
1) Describe the difference between the adaptive and innate immune system	1. Layers of the Innate Immune System 2. Operation Activation	Provides insight into different components of the immune system, their structure and function.
2) List at least one component of the innate immune system	Layers of the Innate Immune System	Provides a specific understanding of the innate immune system to promote general literacy.
3) List the cell types involved in the adaptive immune system	Operation Activation	Provides a specific understanding of the adaptive immune system to be linked to their condition.

4) Understand how the function of the immune system is connected to their condition	Nephrotic Syndrome Demonstration	Building off of the adaptive immune system lesson, this teaches them of the biological basis of their condition.
5) Describe one negative impact of a damaged immune system	Nephrotic Syndrome Demonstration	Encourage critical thinking of the adaptive immune system pathways to promote increased critical scientific literacy.

### **3.3 - Activity Specific Lesson Plans and Development**

Three distinct activities were created to ensure that all elements of the learning objectives were addressed. The lesson plan development is outlined below and lesson plans in their entirety are attached in the **Appendix**. Images and procedures for these demonstrations were produced in a cartoon style to appeal to the patients as well as the parents in the demonstration.

#### *Activity 1: Layers of the Innate Immune System<sup>1</sup>*

In order to teach participants about the innate immune system, I wanted to make sure that there was a tangible element to the activity. Being the first activity in an online-facilitated lesson, I believed it was important to ensure that the first activity was very interactive and engaging so I set a goal of developing a mini experiment that participants could conduct from kitchen materials. A layered liquid tower experiment was selected as an accessible and effective option (10).

The layers of the innate immune system taught through this demo were the physical barriers: skin, sweat, mucus, stomach acid, enzymes, blood, toxic proteins. The lesson was introduced through an analogy of a castle, where the distinction between adaptive and innate immune system were drawn through the comparison of guards and the walls of the castle. The participants then participated in a brainstorm of the parts of the innate immune system.

Moving into the activity itself, each layer of the innate immune system that was identified was correlated with a layer in a liquid density tower. Participants then poured layers on top of each other to create a density tower, representative of the innate immune system. All components used were household materials, including: cork, rubbing alcohol, oil, vinegar, soap, honey, beads.

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<sup>1</sup> Learning Objectives Addressed: 1) and 2)

### *Activity 2: Operation Activation<sup>2</sup>*

Transitioning from the innate immune system activity to the adaptive immune system began by returning to the castle analogy and allowing participants to brainstorm what the ‘guards’ of our body could be.

For the adaptive immune system activity, I wanted to have the participants act as a team in order to demonstrate the pathway nature of the adaptive immune system. Drafts of the activity included a tag game that participants could play between parent and child on each call, as well as a game that involved turning on and off participant cameras to demonstrate activation. Ultimately, I decided on an activity that utilized built-in zoom features such as annotations, reactions and cameras that allowed participants to work as a team to activate the immune system and destroy a viral infection.

The activity started with participants annotating a screen as viruses, infecting healthy cells that they saw by circling them. They then acted as dendritic cells, by grabbing household items as ‘viruses’ to be ingested. As a team, we then chose how we wanted to call in the Helper T-Cells, Killer T-Cells and B-Cells, respectively. We then utilized the annotate tool again to destroy infected cells and produce antibodies.

The lesson allowed the participants to learn the concepts and interact with the materials at the same time in a unique way that integrated the features of zoom.

### *Activity 3: Nephrotic Syndrome Demonstration<sup>3</sup>*

This activity was adapted from NephCure’s library of “Just-for-kids” materials (11) to include elements of immune system interaction. Using cups, coffee filters, beads and water, the activity was intended to demonstrate the difference between healthy and nephrotic syndrome affected kidneys. A link to the previous activities was established by associating the damage in the nephrotic syndrome kidney to misbehaving components of the immune system. The link also allowed for facilitation of a discussion regarding the issues with malfunctioning immune systems more generally.

### **3.4 - Extension Activities and Additional Learning Objectives**

After facilitating the first three activities, time permitted for the creation of a few more lesson plans. As the previous activities focused on the immunological foundations of nephrotic syndrome, the extension activities aimed to expand the scope of the lesson plans beyond nephrotic syndrome, as well as building off of the previous content. The following learning objective were selected as priorities:

**Table 2.** Additional Learning objectives, associated activities and rationales.

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<sup>2</sup> Learning Objectives Addressed: 1) and 3)

<sup>3</sup> Learning Objectives: 4) and 5)

Learning Objective	Associated Activity	Rationale
1) Understand a diagnostic technique used for autoimmune diseases.	1) ELISA Demonstration 2) What your pee says about you	Diagnostic techniques require an understanding of the fundamentals of each disease -- building off of the earlier activities. Diagnostic techniques are also applicable to conditions outside of nephrotic syndrome, broadening the activity's reach.
2) Understand what the ELISA technique is used for in laboratories.	1) ELISA Demonstration	The ELISA technique uses the concept of antibodies discussed in the previous lesson (Operation Activation) and can integrate discussion of nephrotic syndrome.
3) Perform an ELISA-like procedure.	1) ELISA Demonstration	Using basic ingredients, being able to replicate an ELISA will provide students with a hands-on experience performing a realistic scientific technique -- increasing engagement with the topic.
4) Discuss the historical context of urinalysis.	2) What your pee says about you	Discussion of the historical context of urinalysis will allow for discussion of nephrotic syndrome diagnosis through urinalysis and then link to other conditions diagnosed similarly (i.e. diabetes).
5) Understand the basic principles of pH testing.	1) ELISA Demonstration 2) What your pee says about you	As red cabbage pH indicator will be used to perform both activities, the urinalysis activity will be able to further explore these principles through understanding of urine pH.

Both experiments used red cabbage pH indicator as their primary ingredient, allowing colour change to occur.

The primary principle of ELISA taught in the demonstration was the idea of multiple reactions; each reaction layering on top of the previous. This logic of layered reactions describes how in immunological testing, technicians must first add antibodies to a plate, then add samples, and finally add markers that indicate whether a molecule is present. In the case of this demonstration, it involved setting up three

“patient samples” for detection of disease. The participants then added liquids in a specific sequence to finally identify the patients who have a given disease.

The urinalysis experiment began with a discussion of how historical urine testing may have occurred. This then led into the idea of the modern colour change reactions used in urinalysis, finally focusing on pH as one of the readings on a typical urinalysis strip.

## **4 - Debrief**

### ***4.1 - Description of the Lessons***

Throughout this project, a number of different presentations of the first three lessons were conducted.

The first lesson was conducted on July 1, 2020 with the help of NephCure. It consisted of 5 families that simultaneously participated in a Zoom-call session. All families were able to participate in the activities at home, and the use of co-facilitation by Kelly Helm worked well to switch between camera angles.

The second lesson was conducted on July 13, 2020 with a single family (4 children). This had more interaction directly as the family was able to respond to my questions without interruption. Due to a lack of annotation feature on their Zoom device, the operation activation activity was changed to include hand gestures instead of the use of the annotation tool.

The third lesson was conducted on July 16, 2020, with two participants. This again, was more interactive than the first lesson due to a smaller number of participants. Both participants, however, were not doing the activities themselves during the demonstration, instead, opting to watch my screen. This allowed the lesson to move forward more quickly, but may have impacted their retention of the information due to a lack of hands on learning.

### ***4.2 - Survey Results***

Surveys performed on Qualtrics were analyzed internally for enjoyment of lessons, understanding of learning outcomes, AAHLS results and in post-lesson surveys thoughts on the lesson. Positive feedback was received from parents on their lesson enjoyment, and results suggested an improvement in learning outcome understanding from parents.

## **5 - Conclusion**

### ***5.1 - Implications of Survey Feedback***

The survey results, though limited, suggest that there was an improvement in outlined learning objectives in the post-survey when compared to the pre-survey (survey data not shown). Furthermore, survey feedback and feedback during the lessons themselves suggested that both parents and children

were enjoying the lessons and were actively engaged. Despite generally positive feedback in the post-surveys compared to the pre-surveys, there is a need to ensure that children retain the ability to define the importance of the innate and adaptive immune system. Overall, it appears as though the lesson was able to increase health literacy in parents of patients with nephrotic syndrome.

## ***5.2 - Future Directions and Implications***

To increase the validity of the conclusions, more lessons could be run in a research-oriented format to determine the efficacy of the lesson plan on increasing parent health literacy. This would increase the number of survey responses, helping clarify the impact that the lesson had on parents. Furthermore, future experiments may include re-testing the AAHLS on parents to see how the lesson impacts overall health literacy, not just parent specific outcomes. Furthermore, the activities could be expanded beyond nephrotic syndrome patients, teaching more parents and children about the importance of the immune system. One specific group of interest are parents of children with other autoimmune conditions, including Type 1 Diabetes and Celiac Disease.

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## 7.1 - APPENDIX A: Lesson Plans

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### 7.1a - Layered Liquid Innate Immunity Demo/Experiment

*Time Required:* ~ 30 minutes

*Learning Outcomes Addressed:*

1. Describe the difference between the adaptive and innate immune system
2. List at least one component of the innate immune system

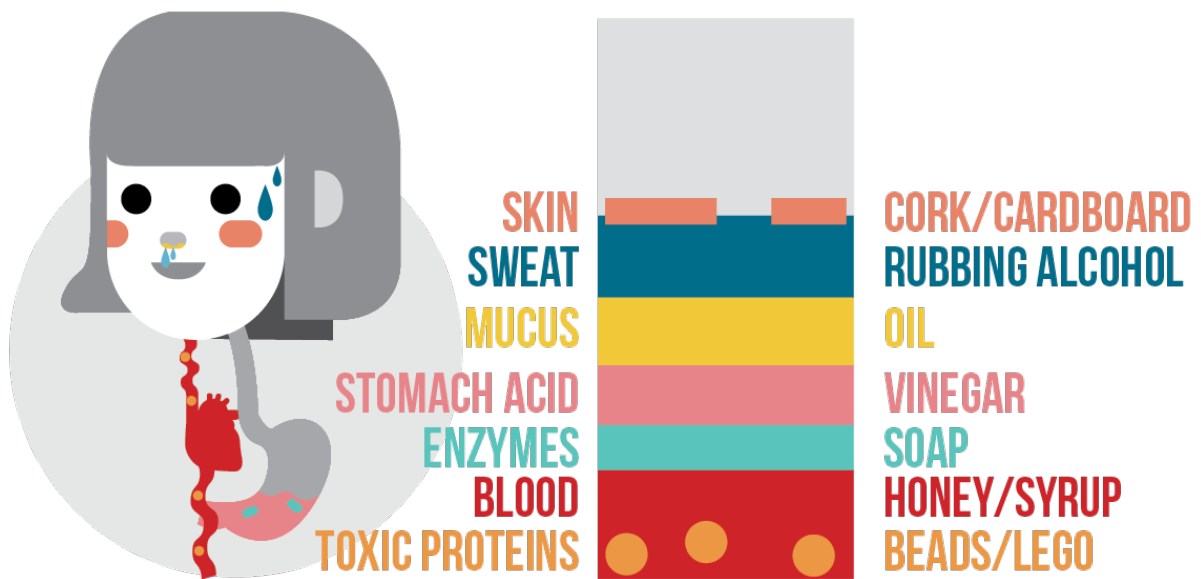
*Introduction to participants/Lesson flow:*

1. Get students and parents to list things that cause disease -> ex. Viruses, bacteria
2. Brainstorm ways that the body can fight infections --> see if we can categorise their suggestions (use zoom group chat)
3. Introduce the two layers of the immune system by grouping their brainstorm into innate and adaptive --> use **analogy** of a castle: walls are your innate immune system, guards are your adaptive
  - a. Emphasize non-selective innate immune system
  - b. Selective adaptive immune system
4. Confirm that their brainstorm has all elements of the innate immune system mentioned in the experiment:
  - a. Blood
  - b. Complement Proteins -> describe them as mines that invaders step on and set off a chain reaction
  - c. Skin
  - d. Stomach Acid
  - e. Mucus
  - f. Enzymes
5. Explain the layered liquid experiment and ensure all students have correct materials
6. Begin demo!

*Materials:*

1. Rubbing alcohol
2. Oil
3. Food colouring (optional)
4. Maple Syrup/Honey
5. Beads/lego brick
6. Vinegar
7. Clear Jar

*Diagram:*



*Procedure:*

1. Start by adding honey/syrup represents blood -> full of proteins, sugars and nutrients that help sustain our bodies
2. Add heavy beads -> they represent complement proteins in our blood that help us fight off bacterial infections
3. Add soap -> represents our enzymes -> kill bacteria
4. Add vinegar -> represents HCl that exists in our stomachs that kills bacterial/viral pathogens
5. Add oil -> represents mucus = traps our invaders
6. Add Rubbing alcohol -> represents components of our sweat that kill bacteria
7. Add Cork -> represents our skin, layer that stops the invaders physically
8. Extension = mix it to see what happens

## 7.1b - Operation Activation

*Time Required:* ~ 30 minutes

### *Learning Outcomes Addressed:*

1. Describe the difference between the adaptive and innate immune system
2. List the cell types involved in the adaptive immune system

### *Introduction to participants/Lesson flow:*

1. Using the list generated before, remind the students about the differences between adaptive and innate immune systems
2. Explain the term pathogen: anything that can cause harm in our body
3. Confirm that the adaptive immune system list has all the cells listed in this experiment: Dendritic Cell, Helper T-Cell, Killer T-Cell, B-Cell
4. Follow the PowerPoint below, describing each behaviour

Activity 2: Operation Activation

### VIRUS

The **VIRUS**' goal is to infect all the cells in our body!

Circle the healthy cells to infect them!



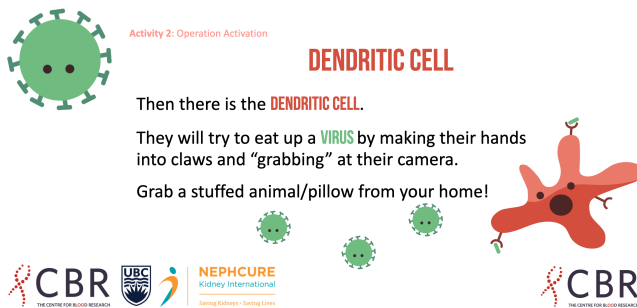
Activity 2: Operation Activation

### DENDRITIC CELL

Then there is the **DENDRITIC CELL**.

They will try to eat up a **VIRUS** by making their hands into claws and "grabbing" at their camera.

Grab a stuffed animal/pillow from your home!



Activity 2: Operation Activation

### HELPER T-CELL

Then **DENDRITIC CELL** will then call out for a **HELPER T-CELLS**.

Can you think of a special way to call them?

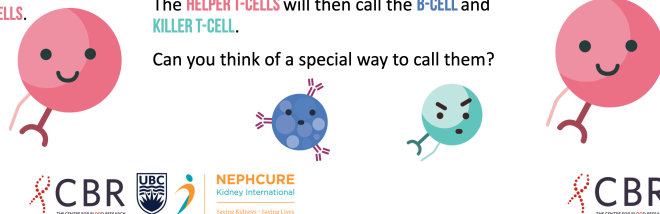


Activity 2: Operation Activation

### HELPER T-CELL

The **HELPER T-CELLS** will then call the **B-CELL** and **KILLER T-CELL**.

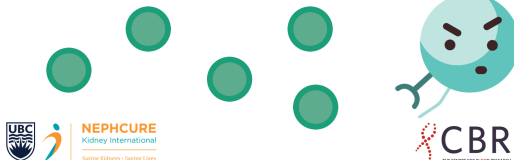
Can you think of a special way to call them?



Activity 2: Operation Activation

### KILLER T-CELL

The **KILLER T-CELLS** have arrived and will destroy the infected cells by striking through them!

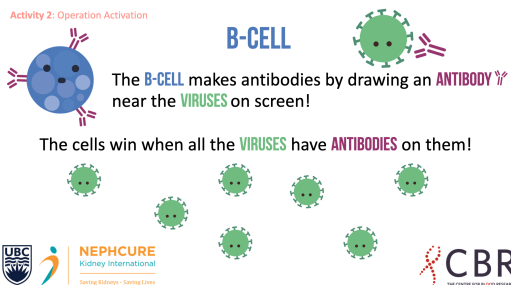


Activity 2: Operation Activation

### B-CELL

The **B-CELL** makes antibodies by drawing an **ANTIBODY** near the **VIRUSES** on screen!

The cells win when all the **VIRUSES** have **ANTIBODIES** on them!



## 7.1c - Nephrotic Syndrome Demonstration

*Time Required:* ~ 30 minutes

*Learning Outcomes Addressed:*

1. Link the function of the immune system to Nephrotic Syndrome.
2. Describe one negative impact of a damaged immune system.

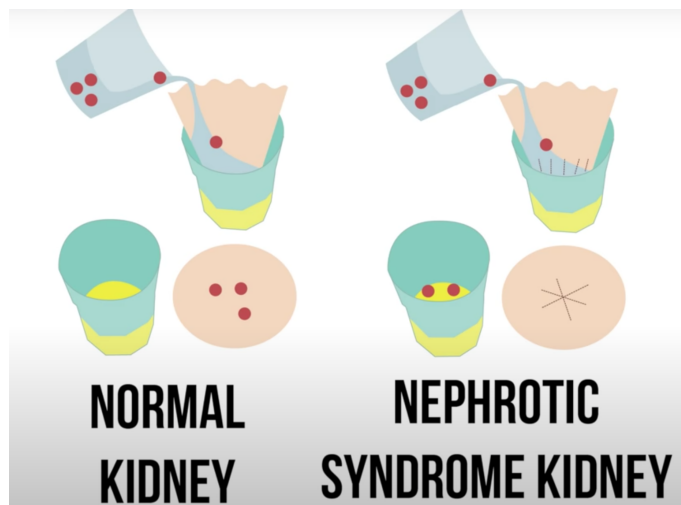
*Introduction to participants/Lesson flow:*

1. Link to the cells of the immune system discussed in the active activity -- brainstorm, what are some ways that these cells could stop working?
  - a. Discuss the idea of the immune cells attacking yourself --> **analogy**: your castle's guards swap sides and start attacking from inside!
  - b. Introduce the term **autoimmune** --> get them to repeat it and then define the word with reference to the analogy
2. Talk about Nephrotic Syndrome's autoimmune cause: immune system attacks your kidneys!
  - a. Ask them what they know about kidneys: refine our focus to filtration, like a coffee filter!
3. Introduce the demonstration as a way to see how our body might be hurting our kidney's filters

*Materials:*

1. 2 Coffee Filters
2. 2 Cups
3. Jug of Water
4. Beads
5. Scissors/hole punch
6. Tape
7. Label/papers: Nephrotic Syndrome Kidney vs Normal Kidney

*Diagram:* (Taken from my video: <https://www.youtube.com/watch?v=PciD3CjHWcQ>)



*Procedure:*

1. Attach coffee filters to the top of two jars using tape, label one jar with the Nephrotic Syndrome Kidney Label and the other with the Normal Kidney label
  - a. Explain how the cup of water represents pee, as our kidney gets rid of stuff, we do not want in our bodies
2. Discuss how the filters look emphasize the following:
  - a. No big holes
  - b. Smooth surface
3. Take a pair of scissors/hole punch and poke holes in the nephrotic syndrome kidney --> this represents the immune system attacking the kidney cells!
4. Add beads to the jar of water --> the beads represent important proteins that we want to keep in our bodies
  - a. Hypothesize with the participants: where will the beads end up in both kidneys?
5. Pour the bead/water jug overtop of a cup, observe what happens
6. Discuss how the beads got through in the Nephrotic Syndrome kidney but not in the normal kidney
7. Extension discussion: Possible questions/discussion points
  - a. Daily urine tests: Test to see how much of the 'beads' escaped into the urine, helping us know how many 'holes' there are in our filters
  - b. Medications: help stop our immune system from attacking our kidneys!
    - i. What are issues with stopping our immune system? What else would it stop them from doing? --> link to immunosuppression in kids with nephrotic syndrome

## 7.1d - Diagnosis: ELISA Demonstration

*Time Required:* ~ 30 minutes

*Learning Outcomes Addressed:*

1. Understand a diagnostic technique used for autoimmune diseases.
2. Understand what the ELISA technique is used for in laboratories.
3. Perform an ELISA-like procedure

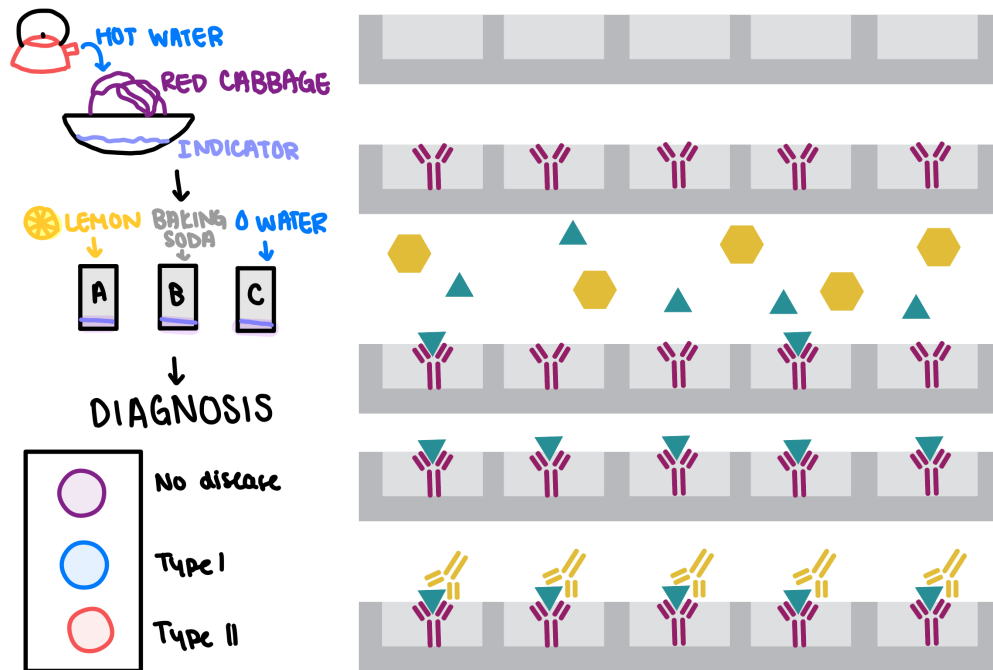
*Introduction to participants/Lesson flow:*

- In order to diagnose autoimmune diseases, a number of lab tests are often required.
- For autoimmune conditions, such as Nephrotic Syndrome, researchers are able to look for select proteins in blood samples using the ELISA technique.
  - ELISA stands for: enzyme-linked immunosorbent assay
  - The idea behind ELISA is that you follow these steps:
    1. Coat a well plate in antibodies against a specific protein
    2. Add your sample to the wells
    3. Rinse away the sample -- only the specific protein should remain in the well plates
    4. Check for colour changes

*Materials:*

1. Spoons
2. 3 cups
3. 1 cup of chopped red cabbage
4. Boiling water
5. Lemon juice (other citrus fruits/vinegar work as well)
6. Baking soda (soap also works)

*Diagram:*



*Procedure:*

1. Pre-experiment prep: Add boiling water to 1 cup of chopped red cabbage. Strain the mixture and let cool.
2. Label 3 cups: Patient A, Patient B, Patient C
3. Add 2 tablespoons of the cabbage juice to each cup
4. Add 1 tsp lemon juice to Patient A, one 1 tsp water to Patient B, 1 tsp baking soda to Patient C
5. Watch for a colour change -- observe your results

## 7.1e - Diagnosis: Urinalysis

*Time Required:* ~ 30 minutes

*Learning Outcomes Addressed:*

1. Understand a diagnostic technique used for autoimmune diseases.
2. Discuss the historical context of urinalysis.
3. Understand the basic principles of pH testing.

*Introduction to participants/Lesson flow:*

- Urine contains many different hints to our health: How did we test urine before urine test strips were created?
  - Glucose testing: taste
  - Acidity
- What can we detect in urine?
  - pH (i.e. acidity)
  - Protein (i.e. kidney function)
  - Blood
  - Glucose (i.e. diabetes)
  - Concentration (i.e. a measure of hydration)
  - Leukocytes (i.e. cells of the adaptive immune system)
  - Nitrite
  - Bilirubin (i.e. liver function)
  - Ketones
  - Microalbumin
  - Creatinine (i.e. kidney functions)
- How do pH strips work?
  - Chemical reactions that result in colour change
  - In this demonstration we will look into the measure of pH

*Materials:*

1. 1 cup of chopped red cabbage
2. Boiling water
3. Plate/Paper
4. Spoon
5. Samples: lemon juice, vinegar, soap, baking soda, water (anything acidic or basic)

*Diagram:*



*Procedure:*

1. Pre-experiment prep: Add boiling water to 1 cup of chopped red cabbage. Strain the mixture and let cool.
2. Place 5 spoonfuls of cabbage indicator onto a plate, spaced ~1 cm apart.
3. Place one drop of each sample onto the plate in the following order: lemon juice, vinegar, water, soap, baking soda.
4. Observe what happens to the colours!

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## 7.2 - APPENDIX B: Videos of Lesson Plans

**Lesson Plan Video:** [https://www.youtube.com/playlist?list=PLd\\_HDWmfDWna874bBxjYKjy30B7ue0e0a](https://www.youtube.com/playlist?list=PLd_HDWmfDWna874bBxjYKjy30B7ue0e0a)

## 7.3 - APPENDIX C: Parent Surveys

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### 7.3a - Parent Pre-Survey

#### Start of Block: Presurvey Consent

Our intention with this survey is to evaluate the efficacy and value of our programming. However, in the future if we desire to use this data in a research study, would you consent to your data being used? Your data will be kept anonymous and confidential. Please select yes or no.

If you'd like more information now or in the future about this, you can contact us here: [jenna.usprech@ubc.ca](mailto:jenna.usprech@ubc.ca)

☐ Yes (1)

☐ No (2)

#### End of Block: Presurvey Consent

#### Start of Block: Demographics and Patient Condition Information

Q2 How old are you?

---

Q2 What is your ethnicity?

---

Q3 What is your gender?

☐ Male (1)

☐ Female (2)

☐ Other (3)

Q4 What is your profession?

---

Q5 What was your highest level of school completed?

---

Q6 How old is your child?

---

Q7 When was your child diagnosed with Nephrotic Syndrome?

---

Q8 What diagnosis does your child have as the cause of their Nephrotic Syndrome?

o Minimal Change Disease (1)

o FSGS (2)

o Other (3) \_\_\_\_\_

**End of Block: Demographics and Patient Condition Information**

**Start of Block: Lesson Specific Questions**

Q9 Rank your response to the statements below:

1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree nor Disagree, 4 = Agree, 5 = Strongly Agree

1                      2                      3                      3                      4                      5

I can define what the adaptive immune system is and know why it is important. ()	
I can define what the innate immune system is and know why it is important. ()	
My child can define what the adaptive immune system is and knows why it is important. ()	
My child can define what the innate immune system is and knows why it is important. ()	
I can list one component of the adaptive immune system. ()	
I can list one component of the innate immune system. ()	
My child can list one component of the innate immune system. ()	
My child can list one component of the adaptive immune system. ()	
I know how the immune system is related to Nephrotic Syndrome. ()	
My child knows how the immune system is related to Nephrotic Syndrome ()	
I know why having a working immune system is important. ()	

My child knows why having a working immune system is important. ( )	
I know the consequences of a malfunctioning immune system. ( )	
My child knows the consequences of a malfunctioning immune system. ( )	
I trust the opinions of scientists. ( )	
I trust the opinions of doctors. ( )	

### End of Block: Lesson Specific Questions

### Start of Block: AAHLS

These questions were adapted from the All Aspects of Health Literacy Scale test.

Chinn, D., & McCarthy, C. (2013). All Aspects of Health Literacy Scale (AAHLS): developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings. *Patient education and counseling*, 90(2), 247–253. <https://doi.org/10.1016/j.pec.2012.10.019>

Q10 How often do you need someone to help you when you are given information to read by your doctor, nurse, or pharmacist?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q11 When you need help, can you easily get hold of someone to assist you?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)
- ☐ Not Applicable (4)

Q12 Do you need help to fill in official documents?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q13 When you talk to a doctor or nurse, do you give them all the information they need to help you?

- ☐ Often (1)

- ☐ Sometimes (2)
- ☐ Rarely (3)

Q14 When you talk to a doctor or nurse, do you ask the questions you need to ask?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q15 When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q16 Are you someone who likes to find out lots of different information about your health?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q17 How often do you think carefully about whether health information makes sense in your particular situation?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q18 How often do you try to work out whether information about your health can be trusted?

- ☐ Often (1)
- ☐ Sometimes (2)
- ☐ Rarely (3)

Q19 Are you the sort of person who might question your doctor or nurse's advice based on your own research?

- ☐ Yes, Definitely (1)
- ☐ Maybe/Sometimes (2)
- ☐ Not Really (3)

Q20 Do you think that there plenty of ways to have a say in what the government does about health?

- ☐ Yes, Definitely (1)
- ☐ Maybe/Sometimes (2)
- ☐ Not Really (3)

Q21 Within the last 12 months have you taken action to do something about a health issue that affects your family or community?

- ☐ Yes (1)
- ☐ No (2)

Q22 What do you think matters most for everyone's health?

- ☐ Information and encouragement to lead healthy lifestyles (1)
- ☐ Good housing, education, decent jobs and good local facilities (2)

**End of Block: AAHLS**

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### ***7.3b - Parent Post-Survey***

#### **Start of Block: Presurvey Consent**

Our intention with this survey is to evaluate the efficacy and value of our programming. However, in the future if we desire to use this data in a research study, would you consent to your data being used? Your data will be kept anonymous and confidential. Please select yes or no.

If you'd like more information now or in the future about this, you can contact us here: [jenna.usprech@ubc.ca](mailto:jenna.usprech@ubc.ca)

- ☐ Yes (1)
- ☐ No (2)

**End of Block: Presurvey Consent**

#### **Start of Block: Demographics and Patient Condition Information**

Q1 How old are you?

---

Q2 What is your ethnicity?

---

Q3 What is your gender?

- ☐ Male (1)
- ☐ Female (2)
- ☐ Other (3)

Q4 What is your profession?

---

Q5 What was your highest level of school completed?

---

Q6 How old is your child?

---

Q7 When was your child diagnosed with Nephrotic Syndrome?

---

Q8 What diagnosis does your child have as the cause of their Nephrotic Syndrome?

☐ Minimal Change Disease (1)

☐ FSGS (2)

☐ Other (3) \_\_\_\_\_

**End of Block: Demographics and Patient Condition Information**

**Start of Block: Lesson Specific Questions**

Q9 Rank your response to the statements below:

1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree nor Disagree, 4 = Agree, 5 = Strongly Agree

1                      2                      3                      3                      4                      5

I can define what the adaptive immune system is and know why it is important. ()	
I can define what the innate immune system is and know why it is important. ()	
My child can define what the adaptive immune system is and knows why it is important. ()	
My child can define what the innate immune system is and knows why it is important. ()	
I can list one component of the adaptive immune system. ()	

I can list one component of the innate immune system. ()	
My child can list one component of the innate immune system. ()	
My child can list one component of the adaptive immune system. ()	
I know how the immune system is related to Nephrotic Syndrome. ()	
My child knows how the immune system is related to Nephrotic Syndrome ()	
I know why having a working immune system is important. ()	
My child knows why having a working immune system is important. ()	
I know the consequences of a malfunctioning immune system. ()	
My child knows the consequences of a malfunctioning immune system. ()	
I trust the opinions of scientists. ()	
I trust the opinions of doctors. ()	

#### End of Block: Lesson Specific Questions

#### Start of Block: Post-Lesson Review

Q10 Rank your response to the statements below:

1 = Strongly Disagree, 2 = Disagree, 3 = Neither Agree nor Disagree, 4 = Agree, 5 = Strongly Agree

1            2            3            3            4            5

This lesson helped me understand the immune system. ()	
This lesson helped my child understand the immune system. ()	
I would enjoy participating in another lesson like this. ()	

Q11 Please describe your favourite part of the lesson.

---

Q12 Please describe your something that could be improved from this lesson.

---

Q13 On a scale from 0-10, how likely are you to recommend this workshop to a friend or fellow parent?

o 0-10

**End of Block: Post-Lesson Review**