



## Hot off the Press! Results from Studies in our Division

### A recurring rollercoaster ride: a qualitative study of the emotional experiences of parents of children with Juvenile Idiopathic Arthritis

This recently published study reports findings of focus groups and interviews held with parents of kids with JIA. The study took place in Ottawa and Vancouver. Our local investigators were Dr. Guzman, Dr. Tucker, and Jayne Green (RN). Participants' children varied in terms of the duration of the disease, their type of JIA, and their age. Parents described strong complex emotional experiences that felt like a rollercoaster ride with its ups, downs and turns; instead of simple ordered emotions with a resolution or end point.

Some emotions predominated at certain times:

- Before diagnosis: mounting anxiety, fear and confusion.
- Shortly after diagnosis: shock, disbelief, and fear, with a sense of having being blindsided by the disease.
- In periods with less disease symptoms: hope and gratitude, as well as fatigue and frustration.
- In times of disease flare: sorrow and frustration, but also admiration and sympathy for the courageous way their kids coped with JIA.

The results of this study will help health care providers better understand the emotional experiences of parents of kids with JIA — so that they can give better support and more effective care.

### Announcements

This spring and summer marks many goodbyes and hellos to staff on the Rheumatology team. **Chris Carriere**, a clinical secretary with us for 3 years retired in April. We wish her all the best for her retirement! In June, we will also say goodbye to our wonderful fellow **Dr. Anita Dhanrajani**. We wish her success in all her future endeavors.



New Rheumatology research students

Our research assistants **Jayson Tan** and **Sophia Knowles** have returned to finish their studies at SFU. **Emerson Gaglardi**, **Mary Jo Lozano**, **Abigail Moraes**, **Jordan Chiu**, and **Mike Guron** will be joining the Rheumatology team as new research assistants this summer. You will likely meet them in clinic soon! We also welcome back **Angelyne Sarmiento**, who has recently returned from maternity leave as a research coordinator.

**Cassie & Friends Family Day 2016** is coming up! This fun day of learning and activities for both patients and their families will be held on October 22, 2016. Keep your eyes open for posters in clinic!



# Rheumatology Research Report

For Patients &  
their Families  
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Some of the Pediatric Rheumatology team in early spring 2016

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### Editor's Space

Welcome to the Spring/Summer 2016 Research Report! In this edition, you will find introductions to three studies that will soon be open to enrollment, as well as our new Autoinflammatory Diseases clinic. You will also read about results from a recently published study on JIA, and some announcements from our team. Happy reading!

### JOIN US AT THE 2016 SCOTIABANK RUN



This year's half-marathon & 5k runs will be held on **June 26th**. You can run or walk, or come to cheer others on! Cassie and Friends is a non-profit organization run by parents of kids with arthritis. This year, Cassie & Friends has teamed up with Ivivva (kid's Lululemon) with prizes for kids who join their charity team! Register with the Cassie & Friends team at <http://www.canadarunningseries.com/svhm/charity/cassie.htm>



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

### **Tear Biomarkers of Inflammation**

Recruitment for this study has started! This study involves the collection of tear samples, eye crust, and blood samples to analyze biological substances in these samples to help improve screening and management of uveitis.

We will be recruiting patients with JIA and/or uveitis. We will also be recruiting healthy adults and children to join the study. Having these two groups means that researchers will be able to compare the immune systems between healthy people and people with Uveitis and/or JIA.

If you are interested in being a study participant, please feel free to ask any member of the rheumatology team.

### **CAPRI National JIA Registry**

A registry is a collection of information about all individuals with a specific disease or condition to provide doctors and scientist with valuable information about the disease.

The **Canadian Alliance of Pediatric Rheumatology Investigators National Juvenile Idiopathic Arthritis Registry** (CAPRI JIA Registry) will collect information on all children with Juvenile Idiopathic Arthritis (JIA) in Canada, looking at disease course, outcomes and medication adverse events. This registry will help us answer important questions like:

- What are the expected outcomes for a child with JIA?
- What are the risks of medication adverse events?
- How does JIA affect the lives of children with JIA over time?

All newly diagnosed JIA patients or patients who have previously participated in the ReACCh-Out study can participate in this registry. We hope to start enrolling patients into the registry in Fall 2016!



#### **What is uveitis?**

Uveitis is inflammation of a part of the eye called the uvea. Kids with juvenile idiopathic arthritis (JIA) are at a greater risk for developing uveitis, but kids without JIA can get it too. Early diagnosis and treatment can help prevent severity of the disease.

### **Jointly Managing JIA Online: An Internet-based Psycho-educational Game for Children with Juvenile Idiopathic Arthritis (JIA) and their parents**

While there are lots of people involved in a child's medical care, it is important for kids to understand their own disease and be involved in how their disease is treated and managed. We are working with researchers in Toronto who have created a computer game to help kids with JIA and their parents to jointly manage their arthritis.

JIA kids aged 8 – 11 years will be asked to participate in this study to test this new game. Participants will be randomly assigned to be part of one of two groups, one group who will be asked to play an online game designed to teach kids about JIA, and another who have usual care for JIA. Researchers will then compare the differences between the participants who played the game, and those who did not. Recruitment for this study has started!

### **Introducing**

#### **Autoinflammatory Diseases Clinic at BC Children's Hospital!**

Our first clinic was held in January 2016, and we will continue to hold them on a monthly basis. Autoinflammatory diseases are a group of rare diseases with a frequent common feature of recurrent fevers episodes. Awareness of these diseases is generally low. Because of this, it often takes a long time for a patient with an autoinflammatory condition to receive a diagnosis and get best treatment. At this clinic, the rheumatology team will be able to collaborate with other experts in immunology, genetics, and infectious diseases in order to better diagnose and treat patients.

Many patients and their families have already been approached about the **CAN-Fever registry** —our new study on autoinflammatory diseases. Recruitment for this study continues to be open, and we welcome you to ask us about it in clinic if you are interested!

#### **Autoinflammatory Clinic Parent Meetup**

If you are scheduled for this clinic there is the chance to meet other parents over coffee while you are waiting to be seen. Keep your eyes open in clinic for signs!



**Are you interested in joining our research studies?**

Please visit our website to see a complete list of our research studies:

<http://tinyurl.com/rheumresearch>