

# Rheumatology Research Report

For Patients &  
their Families

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The New Teck Acute Care Centre

## Editor's Space

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Welcome to the Winter 2018 Research Report! In this edition, we will introduce you to 3 studies that are open or will soon be open for recruitment, as well as an update on the CAPRI-JIA registry. You will also read about results from the CAN-Fever study, and some announcements from our team. Happy reading! *We wish you and your loved ones a joyful and prosperous 2018!*

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*Congratulations*



**Dr. Lori Tucker** received the **2017 Dr. Parminder Singh Award of Distinction** from the BC Paediatric Society. She was nominated by community-based physicians for this prestigious award, which is very well-deserved. **Dr. Kristin Houghton** was also awarded the **2017 UBC Clinical Faculty Award for Excellence in Clinical Teaching**, which recognizes her exceptional work in training and educating future pediatric Rheumatologists. Congratulations Drs. Tucker & Houghton!



## ***THE NEW KIDS ON THE BLOCK: Our Division's Newest Projects***

### **iPeer2Peer Program: A Way for Young Adults to Connect!**

Juvenile Idiopathic Arthritis (JIA) often impacts the emotional and physical health of affected teens and their relationships with their friends and family. A new study, **iPeer2Peer**, aims to help teens with JIA connect to other teens with JIA to see if a peer support program conducted over the internet can help the teen to cope with these problems. This Canada-wide study is led by Dr. Jennifer Stinson from the Hospital for Sick Children in Toronto, and in BC it is being led by **Dr. Lori Tucker**.



Teens with JIA between the ages of 12-18 who agree to participate in this study will be paired with mentors (young adults with JIA 18-26 years old) who have learnt to function well with JIA. The JIA mentors will have an intensive training program before being connected with the teens. Mentors will connect with their paired patients using Skype to ask how they are managing their JIA, and to offer advice and support. The patients will also complete a set of online questionnaires regularly as they progress through the study. Please contact our team if you wish to learn more about this exciting new study.

### **Help Build the Pediatric Rheumatology Biobank!**



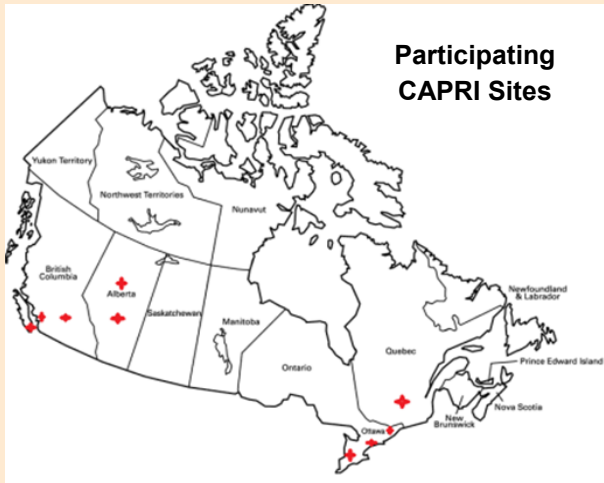
Like a bank that keeps your money safe, a BioBank can safely store almost any kind of samples (blood, urine, saliva) from patients. When enough samples have been collected from patients with a specific disease, scientists may be able to use them in experiments to answer a research question about that disease. Sometimes these samples are collected as part of a planned and current research study/question, and sometimes the samples are simply saved 'leftovers' from your routine tests that could to be used to answer future research questions.

We have worked with the BC Children's Hospital to create a Rheumatology Biobank, and as part of an international study based in Vancouver, we already have the world's largest collection of samples from children with chronic vasculitis collected from around the world. We recently screened some of these 'banked' samples and diagnosed 5 children with a new cause of vasculitis! We also used the samples to set up a diagnostic test that can determine within a few hours if a child has this kind of vasculitis. Your contribution of samples to the biobank will help increase our chances of discovering and diagnosing different types of rheumatic diseases, some of which we may not know about yet!

## CAPRI-JIA National Registry:

### Study Update

We are now recruiting patients for the cross-Canada **CAPRI JIA Registry** study. We have sites in Victoria, Vancouver, Burnaby, Penticton, Edmonton, Calgary, London, Ottawa and Montreal. From the BC Children's Hospital alone, we have over 80 participants.



### Update from the Brown Lab- Our BCCH Pediatric Rheumatology Research Lab

In 2016, Dr. Kelly Brown was awarded the **Michael Smith Foundation for Health Research/Cassie & Friends Scholar award**. In a few months, a new post-doctoral fellow will join her lab to support the mission of improving care for children with rheumatologic conditions through research in the laboratory.

*“The MSFHR Scholar award has given me time and stability to bring in someone who can help me accelerate the work whilst also learning more about pediatric rheumatology. The post-doc will be bridging the lab and the clinic, using clinical information to inform the basic science so that the basic science can in turn have a meaningful impact on clinical practice.”*

- Dr. Kelly Brown

You can read the article on Dr. Brown here:

<https://tinyurl.com/kbrown-scholar>

Are you interested in joining our research studies? Contact us at [RheumResearch@phsa.ca](mailto:RheumResearch@phsa.ca)

You can also visit our website to see a complete list of our studies: <http://tinyurl.com/rheumresearch>



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

### **How Long Does it Take for Children with Autoinflammatory Diseases to be Diagnosed?**

*By Dr. Lori Tucker and Dr. Kelly Brown*



Auto-inflammatory diseases (AIInD, also called periodic fever syndromes) are uncommon diseases that develop during childhood, but many of the symptoms such as fever, rash and achiness are similar to other common childhood illness. This means that doctors must consider and exclude the more common diseases first and it may take a long time for the diagnosis of AIInD to be made. CAN-Fever is a registry collecting information about children with AIInD who are seen in the AIInD Clinic at BC Children's Hospital. We looked at how long it took for patients to be diagnosed after parents first started seeing symptoms in their children.

48 patients joined the CAN-Fever registry in 2016. The average time to correctly diagnose a periodic fever syndrome in these patients was 1.9 years (the range was from 1 to 16 months) and this was similar to the 1.8 years it took to diagnose children with chronic recurrent multifocal osteomyelitis (CRMO), a form of auto-inflammatory bone disease.

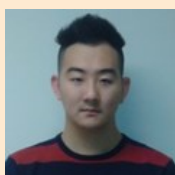
In conclusion, the CAN-Fever team identified many children in BC with AIInD who did not receive a diagnosis for years. We believe that part of the reason is that AIInD are still not widely known in the medical community. We hope the Pediatric Rheumatology AID Clinic can help with this problem.

### ***Announcements***



As the year comes to a close, we bid farewell to a few of our team members. **Dr. Georgina Tiller**, Rheumatology fellow, will be returning to Melbourne, Australia to practice pediatric rheumatology there. **Ritu Ratan** is also moving on to another department in the hospital. It has been a pleasure to have them on our team. We wish you both the best of luck!

We would like to extend a warm welcome back to **Felice Mizan** who is returning from maternity leave in January. **Joey Fu**, 4<sup>th</sup> year UBC student, will also be joining our team as a new research co-op student helping out with our Autoinflammation stud-



Joey



Felice