

Rheumatology Research Report

For Patients & their Families
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Welcome to the Spring / Summer 2018 Research Report! In this edition, we will introduce you to 2 new studies and provide you an update on the CAN-Fever Registry and the LEAP Study. Many members of the BC Children's Rheumatology team also presented research results at a recent conference in February, which you can read about towards the end of the newsletter along with some announcements from our team. We hope you have a great summer!

JOIN US AT THE 2018 SCOTIABANK RUN

This year's half-marathon & 5k runs will be held on **Sunday June 24th**. 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 and rheumatic diseases. **Register with the Cassie & Friends team** at <http://cassieandfriends.ca/support/scotiabank-charity-challenge>



"For me, it's one of the most inspiring times of my year. When I run beside one of our 10 year old patients with JIA, it makes me proud to be a part of a community of kids, parents and health care providers together."

– Dr. Lori Tucker, Pediatric Rheumatologist



New Kids on the Block:

Our Division's Newest Projects

Improving Workplace Support for Millennial Young Adults with Rheumatic Disease

Young adults with rheumatic diseases such as juvenile idiopathic arthritis (JIA) and lupus report having difficulties finding a job, keeping it, or staying productive at work. With support from the Arthritis Society, Dr. Arif Jetha and Dr. Lori Tucker are working together to conduct a survey of youth across



Canada with JIA and lupus to better understand their work experiences and workplace needs. It is hoped that results of this study will help inform clinicians, policymakers and employers on how to better support young adults with rheumatic disease in the workplace.

Immunotyping Autoinflammatory Disease

Pediatric autoinflammatory diseases are a group of rare diseases that usually start in childhood and result in repeating episodes of inflammation, with regular episodes of fevers, rashes or inflammation in different body organs. Autoinflammatory disease is often difficult to identify as symptoms can look like viral infections that are commonly seen in children. Some children suffer for several years before they are diagnosed.



In this project, we are inviting children with autoinflammatory disease to donate biological samples, blood, urine and saliva, to be studied together

with information collected in another study called the CAN-Fever Research Registry. Some of the information from the registry is needed to properly understand the results obtained from the biological sample testing, and in turn help us better understand and treat autoinflammatory disease.



Are you interested in joining our research studies?

Contact us at RheumResearch@phsa.ca

For more information, visit our website: <http://tinyurl.com/rheumatologyresearch>

Updates on Ongoing Studies



**CAN-Fever Registry Update:
116 patients in the registry!**

The **CAN-Fever Registry** is a secure online database based here in BC to Collect information on children with various types of autoinflammatory disease. This information will be studied to help us better understand and treat autoinflammatory disease. Since it opened over 2 years ago, we now have data on 116 children with an autoinflammatory condition. This includes 27 patients with chronic recurrent osteomyelitis (CRMO), 24 patients with Periodic Fever, Aphthous Stomatitis, Pharyngitis, Adenitis Syndrome (PFAPA), and 32 with an unclassified periodic fever or inflammatory syndrome. **Dr. Lori Tucker**, CAN-Fever principal investigator, recently presented some data at the 2018 Canadian Rheumatology Association meeting in February.

The LEAP Study is Wrapping Up! Results are on the way!!



Linking Exercise, Activity, and Pathophysiology in Childhood Arthritis (LEAP) is a national study that began in January 2012. The overall aim was to we can gain a better understanding of how physical activity affects arthritis, and its effect on developing bones and

muscles. Over the last 6 years, **713 children** from 12 different hospitals across Canada contributed their time and effort to completing questionnaires, and bone and muscle tests for the LEAP Study! The last patient in the study is expected to complete all their visits this summer. The focus of the LEAP Study team will now shift to analyzing data and presenting results at various conferences and meetings.

Thank You

Hellos & Goodbyes from the Rheumatology Team

Dara Mairiang and **Muhammed Dhalla**, two of our fellows, will be completing their Rheumatology training this summer. We also bid farewell to our research co-op students **Jenna Jessa** and **Joey Fu**, who will be completing their work terms in August and returning to UBC to finish their undergraduate degrees. We will miss you all!

In July, we will be welcoming two new fellows who will be joining us for the next two years: **Tara McGrath** and **Hon Ng**. Welcome to the team!



Hot off the Press!
Results from Studies in our Division

In February of this year, the **Canadian Rheumatology Association** held their Annual Scientific Meeting in downtown Vancouver. The meeting brought together Rheumatologists, medical students and trainees, allied health professionals, and other care providers from all across Canada to learn about the latest research in rheumatic diseases. At this meeting, individuals have the chance to share and present their research results to other members of the rheumatology community. Our team at BC Children's Hospital presented a total of **12 abstracts/posters** at the meeting! Here are the projects our team presented:

1. Providing Patient and Family Education and Support for Children with Rheumatic Diseases and Their Families: Cassie and Friends Annual Family Day in BC
2. Perspectives on Uptake of and Adherence to a 6-month Home- and Group-based Exercise Intervention for Children with Juvenile Idiopathic Arthritis (LEAP Study)
3. Muscle and bone strength in Children with Juvenile Idiopathic Arthritis: Results of a 6-month Home- and Group-based Exercise Intervention (LEAP Study)
4. Knowledge Translation in Juvenile Idiopathic Research in Canada: Comparing and contrasting parent and adolescent perceptions
5. Children with Auto-inflammatory Diseases in British Columbia, Canada: Years of Delay Before Diagnosis
6. Ethnicity in Children with Auto-Inflammatory Disease in British Columbia
7. The Relationship of Serum Amyloid A, C-Reactive Protein, and Disease Activity in Periodic Fever Syndrome
8. Pediatric Variations in Treatment of ANCA-associated Vasculitis (AAV) – a Pediatric Vasculitis Initiative (PedVas) Study
9. Role for S100A12 in Mediating Vascular Inflammation
10. Prednisone Tapering Consensus Treatment Plans (CTP) for Pediatric Rheumatic Diseases: A Quality Improvement Initiative
11. Echocardiographic Screening in Childhood Onset Systemic Lupus Erythematosus
12. Pediatric Coronary Artery Ectasia – Rheumatic Disease Associations

If you could like a copy of any of the above abstracts, please ask one of our research staff!