

Rheumatology Research Report

For Patients &
their Families
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Photo: The Rheumatology Team supporting Cassie & Friends at the Scotiabank Vancouver Half-Marathon in June 2014

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Editor's Space

This past summer, the Rheumatology staff stayed active by running with the Cassie and Friends team at the Scotiabank Marathon and 5K Run. We raised a total of \$95,000! Great job to all those who participated.

In this edition you can read about three new studies on arthritis and periodic fever syndromes. You can also read about our new logo contest and about ongoing studies that are open for recruitment. On page 2, we share results from a recent study that looked at data from the ReACCh-Out database, to which some of you have contributed data. Happy reading!



Join us for **Family Day** on **Saturday, October 18th 2014**
at Science World! There will be workshops, sessions, and lots of
activities for kids and teens.

NEW!

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



Cardiopulmonary Comorbidities in Systemic Juvenile Idiopathic Arthritis (CP in SJIA)

This is a joint study between Cardiology, Respiriology and Rheumatology in which we will look at the heart and lung health of children with systemic juvenile idiopathic arthritis (sJIA). Children with sJIA are often affected by symptoms involving other organs in addition to their joints. This study will help us determine the frequency of heart/lung symptoms in children, and if abnormalities are present, we will also investigate whether the current medications that we use play a role in contributing to these problems. Results from this study will help determine whether we need to routinely screen children with sJIA for heart and lung abnormalities.

A randomized, double-blind, placebo controlled study of Canakinumab in patients with Hereditary Periodic Fevers

The purpose of this clinical trial is to find out whether Canakinumab (ILARIS) is effective and safe for treating children with periodic fevers such as Tumor Necrosis Factor Receptor Associated Period Syndrome (TRAPS), Hyperimmunoglobulinemia D with periodic fever syndrome (HIDS), or colchicine-resistant Familial Mediterranean fever (crFMF). For more information, visit <http://clinicaltrials.gov/show/NCT02059291>.

Predicting disease course in children with Juvenile Idiopathic Arthritis (JIA)

What is the best way to estimate the risk of a severe disease course in a child with juvenile idiopathic arthritis using information known at diagnosis?

Thanks to funding from the Canadian Initiative for Outcomes in Rheumatology cAre (CIORA), **Dr. Jaime Guzman**, **Dr. Lori Tucker** and other researchers across Canada will try to answer this question by developing a "tool" using data collected on hundreds of children with JIA across Canada. This "tool" will assist parents and doctors in choosing treatments, by pinpointing children who may be at a greater risk of a severe JIA course. We will be inviting parents and adolescents to participate in a one-time focus group to ask for input for the development of this tool. We encourage you to participate in this worthwhile project!

LEAP Exercise Intervention Study

A good level of physical activity (PA) is important for all kids to develop strong bones and muscles.



The **LEAP** team is excited to have begun recruitment for the second arm of the LEAP study that's focused on evaluating the feasibility of establishing a 6-month home exercise program for children with JIA and determining if it is effective in improving muscle, bone and joint health. Participants will meet with an exercise specialist or personal trainer to create a personalised weekly home exercise program that will include jumping, handgrip and resistance band exercises. There will also be monthly group exercise sessions led by the exercise specialist. These sessions will allow participants to meet other children with JIA and exercise together. Results from the questionnaires and the bone and muscle tests that participants complete will help with the creation of evidence-based guidelines for physical activity programs used for children with JIA.

Are you interested in joining one of our research studies?

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

<http://tinyurl.com/rheumresearch>

WE NEED YOUR HELP IN DESIGNING A LOGO FOR OUR LATEST RESEARCH INITIATIVE— PARC!



PARC stands for Pediatric Autoinflammatory Research Consortium. PARC is a group of people (families, patients, healthcare professionals) interested in learning more about pediatric auto-inflammatory diseases through collaboration across disciplines and specialties. In these diseases, the body acts like it's fighting an infection when there isn't one, and this causes symptoms like fever or aches. Since autoinflammatory diseases are so rare, doctors want to collect as much information /data as possible on as many children as possible to better understand the disease and learn how to best take care of affected children.

If you would like to submit a drawing, ask our research staff for an application or email rheumresearch@phsa.ca.



Hot off the press! Results from studies in our Division

The outcomes of JIA in children managed with contemporary treatments: results from the ReACCh-Out Cohort by Dr. Jaime Guzman & CAPRI Investigators

Featured recently on [Arthritis UK](#) and the [CFRI](#) website, Dr. Guzman's article on outcomes in 1,104 children with juvenile idiopathic arthritis (JIA) across Canada examines the progression disease in the different types of JIA. This data was collected as part of the ReACCH Out study. Large outcome studies on JIA are rare, and it is therefore difficult to inform families about prospects for outcome, ongoing severity and the needs for differing treatments depending on their child's subtype of JIA. The goal of this study is to estimate the probability of reaching remission (quiet disease) in the first 5 years after diagnosis, and to describe treatments used achieve remission.

The analysis shows that the probability of having inactive disease 2 years after diagnosis is high (>70%) in almost all JIA subtypes, except for RF positive polyarthritis (48%). Similarly, about 50% of patients achieved remission within 5 years of diagnosis across all JIA subtypes except for polyarthritis (positive and negative).

In terms of initial treatment, patients with oligoarthritis can expect to receive joint injections with non-steroidal anti-inflammatory drugs (NSAIDs) while those with polyarthritis would most likely be treated with disease modifying antirheumatic drugs (DMARDs).

In conclusion, Canadian children with JIA have a high probability of achieving inactive disease or having no active joints within 2 years after diagnosis while receiving current recommended treatment. However, certain subtypes of JIA have a higher probability of reaching remission within 5 years than others.

Announcements

This summer, the Rheumatology team said goodbye to 3 of our team members. **Dr. Mercedes Chan** who has been with us for 4 years will be moving to Edmonton to hold a position at the University of Alberta as an Assistant Professor. Also, our research assistants **Audrea Chen** and **Megan Bruschetta** have both returned to university to complete their studies. We wish them all the best!

We are happy to welcome **Stephanie Duncombe** to the team! Stephanie is a 3rd year Physiology and Kinesiology student from UBC who will be joining us as a research assistant. Welcome!



Stephanie