

Rheumatology Research Report

For Patients & their
Families:
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Photo: Pediatric Rheumatology Team 2014



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Support children with arthritis and rheumatic diseases! **RUN** or **Sponsor** a runner!

The Division of Pediatric Rheumatology partners with **Cassie and Friends** (A Society for Children with Arthritis and Rheumatic Diseases) in the upcoming ScotiaBank Half Marathon/5K race, taking place on **Sunday, June 22nd**.

Cassie and Friends, a nonprofit organization run by parents of children with arthritis, is one of three featured charities at the race this year. In the past 3 years, this small charity has actually been one of the top fundraisers! All funds raised directly benefit children and families in BC affected by arthritis, lupus and other rheumatic diseases who are cared for here at BC Children's Hospital.

Join the rheumatology team, our patients, their parents, families and friends to raise awareness of juvenile arthritis and/or fundraise. We are aiming for over 100 runners this year!

To register: <http://tinyurl.com/ScotiabankRun>
To donate or join the team:
<http://tinyurl.com/DonateToRheumatology>

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



The Treg Study: The Role of T Regulatory Cells in Control and Remission of Juvenile Idiopathic Arthritis (JIA)

The unregulated immune response seen in JIA patients causes swollen, inflamed joints. Studies show that this may be due to the abnormal functioning of a certain type of white blood cell, the T regulatory cell (Treg). Tregs produce chemokines (protein signals) which attract immune cells towards them, leading to suppression of the immune response.



Through analysis of blood and inflamed joint fluid, we will study how Treg cells in JIA patients work, and whether measuring how these cells respond is a way to help predict if the disease will go into remission versus flare.

LEAP Exercise Intervention



The LEAP study recently presented a poster at the Pediatric Rheumatology Symposium Meetings (PRSYM) analysing physical activity (PA) in LEAP participants. The results of the analysis showed that children with JIA report much lower levels of PA compared to their healthy peers. This is

problematic however as having a good level of PA is important for all kids to develop strong bones and muscles.

The LEAP team is excited to introduce a new part of this program aimed at studying a four month exercise program specially designed for kids with JIA. Children in the study will do weekly home based sessions that include jumping and resistance band exercises. The results from this study will help with the creation of evidence-base guidelines for PA programs for children with JIA.

Announcements

In June we say goodbye to **Dr. Hend Al-Kwai**, one of our amazing rheumatology fellows. She will be returning to Saudi Arabia to practice rheumatology. This summer, we will be welcoming two medical summer students, **Tristan Kerr** and **Clara Westwell-Roper**; a UBC co-op student, **Kiana Yau**; and a new rheumatology fellow, **Dr. Anita Dhanrajani** to the team.



Kiana Yau

Open invitation: Studies Currently Recruiting Patients

PedANAM as a Screening Tool for children with SLE

Research Question:

Is the Pediatric ANAM computer test a useful tool for monitoring brain function of children and teens with lupus?

Current Status:

The study is open for enrollment. 21 patients are enrolled here at BCCH, with over 220 enrolled across North America.

Pediatric Vasculitis Study

Research Question:

What is the best way to diagnose, monitor and treat children and teens with chronic vasculitis?

Current Status:

18 patients enrolled in BC, with over 500 patients participating worldwide.

LEAP Study (Linking Exercise, Activity, and Pathophysiology in JIA)

www.leapjia.com

Research Question: How does physical activity affect disease activity, bone and muscle development and outcome in kids with JIA?

Current Participants: Over 300 enrolled patients across Canada, with 67 located here in Vancouver.

PREVENT-JIA Study

Research Question: Can a new blood test help predict if a patient whose arthritis is under control will have disease flare after stopping medications?

Current Participants: 7 patients are currently enrolled, and 1 patient has completed the study.

Teens Taking Charge

Research Question: Does a new website designed to teach teens about JIA help them become more independent in their disease management?

Current Participants: 87 patients enrolled in BC and 272 patients enrolled across Canada. 27 of our patients have completed the study.

For more details on our studies, visit <http://tinyurl.com/RheumResearch>

We want to hear from you!

If you are a parent/patient in the Rheumatology clinic and would like to contribute to the Rheumatology Research Newsletter, please contact our research coordinator at rheumresearch@phsa.ca



Hot off the press!
Results from studies in our Division
Recent presentations at the Canadian Rheumatology
Association and Pediatric Rheumatology Symposium
Meetings:

The Rollercoaster of Juvenile Idiopathic Arthritis: A Qualitative Examination of Parents' Emotional Responses to the Disease and its Management

Parents of children with JIA participated in focus groups to discuss their experiences throughout their child's illness. They described their experience as an intensely emotional rollercoaster. The time before diagnosis was described as a time of increasing anxiety, followed by shock, disbelief and fear once a diagnosis was reached. Later on, during times of increased symptoms, parents often felt admiration for their child's ability to cope. This study may help doctors develop or provide resources that will help support parents through this journey.

Younger age and severity of renal presentation distinguishes MPA from GPA in children. An ARCHiVE study.

ARCHiVE, an online pediatric vasculitis database, aims to collect data from vasculitis patients worldwide in order to develop "tools" to help doctors distinguish different types of Vasculitis. GPA (granulomatosis with polyangiitis) and MPA (microscopic polyangiitis) are similar and may initially be difficult to tell apart. Understanding the differences ultimately may help find different causes and treatments, but also helps us better advise on potential outcomes. Analysis of ARCHiVE data showed that MPA patients tend to experience symptoms at a younger age and –usually had more severe kidney problems than GPA patients.

Greater trochanter enthesitis and sacroiliitis with hip arthritis presenting as gait abnormality in young children: Report of 3 cases

3 patients presented with abnormal gait and pain in the leg & buttock area – uncommon symptoms that delayed making an accurate diagnosis. An MRI on each of the 3 patients demonstrated sacroiliitis (inflammation where the lower spine & pelvis connect), which helped doctors confirm a final diagnosis of ERA (enthesitis related arthritis), a subtype of juvenile idiopathic arthritis. This study may help doctors who see patients with similar symptoms in the future reach a firm diagnosis more quickly.

****Contact us at rheumresearch@phsa.ca if you would like more details on any of the presentations****