

Rheumatology Research Report

For Patients & their Families

Volume 16, Issue 1

Spring/Summer 2019



Cassie and Friends team at ScotiaBank 5k and Half Marathon

Editor
Khaye Rufin

Senior Editors
Dr. Lori Tucker
Dr. David Cabral

*Division of
Pediatric
Rheumatology,
BC Children's
Hospital*

Editor's Space

Welcome to the Spring/Summer 2019 Research Report! In this edition, we will tell you about three new studies on JIA. We will also provide you with the study results from the CAPRI Registry and a CRMO Chart Review. You will also read about genetic testing and some other announcements from our team. Happy reading!

Are you interested in joining our research studies?

Contact us at RheumResearch@phsa.ca

For more information, visit our website:

<http://tinyurl.com/rheumatologyresearch>

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

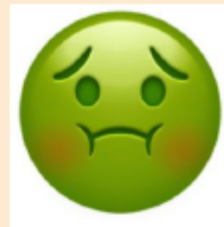


The PRINTO evidence-based revision of the International League Against Rheumatism (ILAR) Classification criteria for juvenile idiopathic arthritis

There is a need to revise the current classification criteria for JIA to enable us to more readily study this disease across the world, so we can understand and treat it better, and also so we can better emphasise the differences (or similarities) between this childhood form of arthritis and adult forms. In order to do so, a large international study led by the pediatric rheumatology research network, PRINTO, will be analyzing various laboratory measurements in the blood, along with clinical information from JIA patients around the world. We are a key participating centre in the study, and will be asking consent from our patients and families to participate and anonymously use their clinical and laboratory information.

Addressing nausea caused by Methotrexate

Methotrexate (MTX) is a first line of treatment for JIA that is both inexpensive and frequently effective. However, some patients suffer from side-effects including nausea, stomach pain and vomiting that are so severe that MTX must be stopped even when it is effective. The following two studies are looking at different aspects of this problem:



The Ondansetron Premedication Trial in Juvenile Idiopathic Arthritis (OPT-JIA)

Dr. Jaime Guzman, with support from the Arthritis Society, will be conducting a study to test the effectiveness of routine treatment with ondansetron (an anti-nausea drug) just prior to receiving MTX. We think that taking this medication BEFORE the child ever experiences nausea from MTX (rather than after they get nausea) may reduce the occurrence or severity of nausea so that more children can tolerate this otherwise relatively safe effective treatment.

Juvenile Idiopathic Arthritis: Predictors of Methotrexate Intolerance

Drs. Kelly Brown, Jaime Guzman, Kim Morishita and David Cabral will collect saliva from JIA patients that have received MTX to extract DNA and examine if genetic markers can predict which patients are likely to develop intolerable nausea from taking methotrexate and which ones are not. This is a pilot study with the ultimate goal to establish a prediction-test that will allow physicians to identify which patients can tolerate MTX and which patients should be started on another treatment option.

Hot off the Press!

Results from Studies in our Division



JIA CAPRI Registry

Juvenile Idiopathic Arthritis (JIA) is the most common childhood rheumatic disease. The CAPRI JIA Registry is a Canadian project that is collecting information from many children with JIA across the country to learn about how new treatment approaches work, and the types of side effects children with JIA face. The registry is funded by the Arthritis Society and led by Dr. Jaime Guzman. The most recent Registry results show that parents report frequent side effects in their children; mostly stomach upset, nausea and mood changes. Although the side-effects are on the average mild, they have an impact on the child's quality of life. Serious adverse events requiring hospitalization or major treatments are very uncommon.



Outcomes of patients with 'chronic recurrent multifocal osteomyelitis' (CRMO) treated with pamidronate, a retrospective chart review

CRMO is an inflammatory disease in bones resulting in pain and swelling (resembling infection) of one or more bones. (This is similar to JIA that resembles an infection in the joints between bones). Children with CRMO who don't respond to treatment with naproxen may have dramatic improvement when treated with pamidronate, an IV bone strengthening drug. We would like to predict how frequently patients are likely to respond to this treatment, either partially or completely and if they will routinely need continuing treatments every 3 months. Dr. Tamara McMillan led investigation of the efficacy of pamidronate treatment for CNO/CRMO patients in BCCH. We reviewed our clinic's experience from 2012-2017 and studied 17 children with CRMO treated with pamidronate - 47% had a complete response, 35% a partial response and only 3 patients had no response. We also found that routine 3 monthly treatments with pamidronate may not be necessary for patients with a sustained good response 3 months following initial treatment; i.e. the need for routine 3-monthly may be evaluated based on the 3 month response following the first dose.





Clinical Updates: Genetic Testing Why and How?

Genetic testing aims to identify any abnormalities in a handful of our genes (approximately 1% of all our genes) called **mutations** that are known to cause various diseases. For the majority of children we see in the Autoinflammatory Disease clinics, and some children with arthritis or other rheumatic diseases, undergoing genetic testing is part of getting a diagnosis for your child.

Getting a positive result from genetic testing, or finding a mutation, may direct us towards a specific diagnosis for your child; sometimes however, the results are not clear, and we may need the help of a genetic doctor, and we may want to do further testing to look for new mutations not previously described to cause illness. Sometimes, the genetic results will help us to decide what course of treatment might be best for your child. If your child's initial genetic screening test results are negative, or there is a mutation with an unknown effect, further investigation may be necessary. Although this may be a long process, we hope to provide more answers for children we see who have unexplained auto-inflammatory diseases.

Hellos and Goodbyes from the Rheumatology team!

Our senior fellow, **Tara McMillan**, will be completing her Rheumatology training this summer. We will also be bidding farewell to our research co-op students, **Maria Belen** and **Neall Struwig**, who will be completing their work terms in August and returning to SFU and UBC, respectively, to complete their undergraduate degrees. We wish you all the best!

We would like to welcome our new fellows: **Tristan Kerr** and **Jon Park**! We are pleased to have them as new fellows on our team. Joining our research team from UBC as a new co-op student is **Kelly Nguyen**.