

Rheumatology Research Report

For Patients &
their Families

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Rheumatology team members at the 2016 Scotiabank Run

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Editor's Space

Welcome to the Spring 2017 Research Report! In this edition, you will find introductions to three studies that are open or will soon be open for recruitment, as well as an update on Teens Taking Charge website. You will also read about results from a recently published study on JIA, and some announcements from our team. Happy reading!

JOIN US AT THE 2017 SCOTIABANK RUN!



CASSIE + FRIENDS
Society for Children with Juvenile Arthritis
and Other Rheumatic Diseases

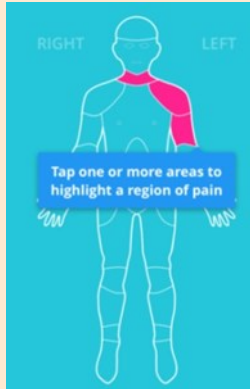
This year's half-marathon & 5k runs will be held on **Sunday June 25th**. You can run or walk, or come to cheer others on! Cassie and Friends is a non-profit organization run by parents of kids with arthritis. **Register with the Cassie & Friends team at <http://www.cassieandfriendsrun.ca/>**

NEW!

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

iCanCope with Pain Study

Musculoskeletal pain or joint inflammation is a common symptom associated with juvenile idiopathic arthritis (JIA) and it affects a number of patients. iCanCope, a newly developed app, wants to help patients with this pain and teach them how to manage it.



The aim of the iCanCope study is to help test the app to see if it is helpful for kids with musculoskeletal pain. Participants would spend around 15 minutes using the app every day and navigate through the app with the help of Copey the friendly monster. The study is targeted towards patients with JIA between the ages of 12-18 who are having active episodes of pain linked to their JIA.

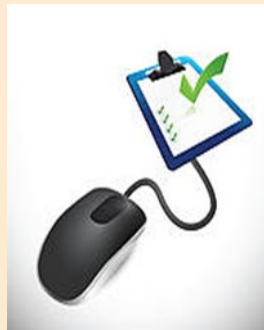
Recruitment for this study has not started yet, but we hope to start enrollment in May 2017. Keep a look out for the study next time you're in clinic!

RACER: A Questionnaire for Teens Moving on To Adult Rheumatology Care

JIA often continues into adulthood, so most patients who are seen in the rheumatology clinic at BC Children's may be transitioning into the adult rheumatology healthcare system in the future. As an adult, patients are expected to become more responsible and independent with regards managing their health. Patients have to be knowledgeable about their disease, and have disease self-management skills so that they can successfully transition

We are looking to recruit JIA patients between the ages of 16-18 to help test an online questionnaire called "Readiness for Adult Care in Rheumatology (RACER)". This questionnaire is designed for adolescents with arthritis and aims to assess how ready a patient is to take care of themselves in the adult healthcare system.

If you are interested in helping us test this questionnaire, please contact us!



60 Days of iThermonitoring: A Study for Children with Periodic Fever Syndromes

Recruitment for the iThermonitor study has started! Children who are diagnosed with PFAPA (a fever syndrome with mouth sores, sore throat, and swollen glands) may be eligible to participate in this study. Drs. Lori Tucker and Kelly Brown are looking to learn more about PFAPA, one of the most common fever disorders.



For 60 days, participants will carry out daily urine and saliva collection so that Dr. Brown's lab can analyze the samples for certain proteins that may help predict when episodes will happen. Participants will use a new wearable thermometer called the iThermonitor. This device continuously measures and records the child's body temperature and sends it to the parent's smartphone. Combining the exact information of when fevers start to markers in the urine and saliva will give incredible new information about this disease.



If you are interested in participating in this study, feel free to talk to any member of the rheumatology team!

Teens Taking Charge

In 2012, the Hospital for Sick Children (Sick Kids) in Toronto together with pediatric rheumatology groups across Canada, including our group, started a project to test an online website for teens with JIA, called **Teens Taking Charge: Managing JIA Online**. The website was designed to provide teens with JIA with a place they could learn more about their disease from a reliable and trustworthy source, with information about disease, medications, exercise, and coping with JIA. The website has videos of teens and lots of great information.

The Teens Taking Charge website tested so well among the research participants that it is now available for everyone to use! Kids who did the study increased their knowledge about JIA, and had better coping skills.

Try out the website at: <http://teens.aboutkidshealth.ca/JIA>

Are you interested in joining our research studies?

Contact us at RheumResearch@phsa.ca

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

<http://tinyurl.com/rheumresearch>



Hot off the Press!

Results from Studies in our Division

Predicting Which Children with Juvenile Idiopathic Arthritis Will Have a Severe Disease Course

by Dr. Jaime Guzman, Lori Tucker and the ReACCh-Out team

In this paper, researchers were able to identify four JIA disease courses, and develop a tool that can estimate the probability that a newly diagnosed patient might have a severe disease course based on symptoms at diagnosis.

These findings were based on data from 609 patients who participated in the ReACCh-Out study between the years 2005-2010, which may include some of you! Using questionnaires, information on pain, medication, number of joints with active arthritis and patient-reported side effects investigators identified four distinct JIA disease courses. These were: **mild, moderate, severe controlled and severe persisting**. The four disease courses were identified based on research data collected over 5 years with 5 different variables, which patients, parents, & clinicians deemed important. The different disease courses differed from one another in terms of many variables, notably of patient reported quality of life and the probability of achieving inactive disease.

The findings of this paper will help patients and their families in clinic through shared decision making with their care providers. When counselling newly diagnosed families, a physician may describe the four disease courses and give an estimate of the chance that the child might follow a severe disease course.

Announcements

In the first few months of 2017, we welcomed new staff but also said goodbye to some. Our research coordinator **Felice Mizan** has left on maternity leave and recently welcomed a baby boy into the world! We wish her all the best and happiness in motherhood. We welcome **Ritu Ratan** who will be filling in for Felice while she is away.

We would also like to extend a warm welcome to a few new faces joining our team:

- **Dr. Andrea Human**, Rheumatologist
- **Dr. Georgina Tiller**, Rheumatology fellow
- **Iwona Niemietz**, Master's student in Dr. Kelly Brown's lab.
- **Shikha Kumar**, Research assistant
- **Yuliya Badayeva**, Research assistant



L-R: Shikha Kumar, Yuliya Badayeva, Ritu Ratan