

JAK Inhibitor Clinical Trial

Children with JIA are often recommended to get so-called “biologic” medications (e.g. adalimumab/Amgevita) if earlier treatments are not successful. A new class of medicines not produced “biologically”, but by synthetic construction are referred to as “small molecule drugs”. Both types of drug work similarly by interrupting varied points in the chemical/protein immune pathways that produce inflammation and/or damage. Either treatment may be recommended if initial medication strategies are unsuccessful. ‘Small molecule’ drugs can be given as pills, which is more practical than ‘biologics’ that are given by injection. A group of ‘small molecule drugs’ known as JAK inhibitors have been used very successfully in adult arthritis and other medical conditions, and one type is already being used in children.

One type of JAK inhibitor has been successful in adults but has not yet been approved for use in children. We will be participating in a clinical trial of the JAK inhibitor called Upadacitinib (RINVOQ) to determine how effective it is in children with poly-JIA. Being part of a clinical trial allows free access to a medication that is otherwise expensive and/or difficult to access through pharmacare, and measures of success rate compared to other treatments will help decision making for both doctors and patients.

Ask about this trial coming soon!



Hellos and Goodbyes



A sad farewell to **Jenny Tekano**, our nurse for 33 years, and **Iris Davidson**, our physiotherapist for 44 years. We would like to thank you both for all your dedication and contributions you’ve made over your remarkable careers. We wish you both the best for your retirement! We would also like to say goodbyes to **Steffanie Fisher**, our research coordinator, and **Janis Bui**, one of our secretaries. Good luck with your future endeavors!

We are excited to welcome **Kristine Si** and **Megan Mcallister** who have recently joined our team as our new nurse and physiotherapist, respectively. **Nadia Alattas** has also joined our team as a new research coordinator. Welcome to the team everyone!



Editor's Space

Welcome to the 2023 Summer Rheumatology Research Newsletter! In this edition, we will be sharing some updates from the CAPRI Registry, and results from the LEAP Study. We will also be introducing our new study coming this fall called PERSON-JIA. In addition, patients with poly-JIA will soon have the opportunity to test in a clinical trial, a new medicine called a JAK inhibitor. A special thank you to our patients and families for participating in our studies; whether it's completing a questionnaire or giving a blood sample. We appreciate your time and contribution. Hope you enjoy reading our newsletter!

Scotiabank Vancouver Run for Cassie + Friends

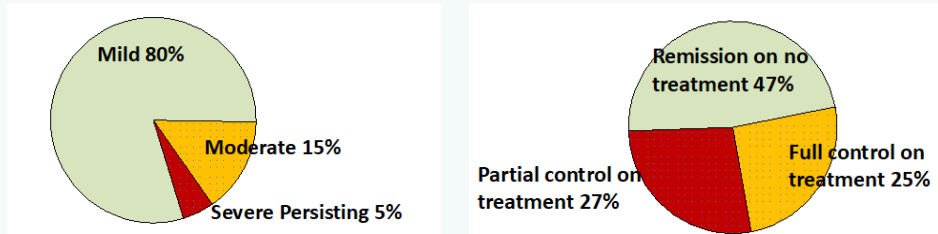
Come join us at the annual Vancouver Half-Marathon & 5K event on **Sunday, June 25th**. Run or walk to bring awareness to JIA, meet others and have fun! Go to <https://cassieandfriends.ca/vancouverrun/> or scan the QR code to register with the Cassie + Friends team. We hope to see you there!



PERSON-JIA

When a child or teenager is diagnosed with juvenile idiopathic arthritis (JIA), families are faced with the decision of what treatment to start. To help families with this decision, the Rheumatology Team at BCCH will be starting the PERSON-JIA study this fall. With the use of the data from hundreds of volunteer families participating in the CAPRI Registry, our Canada-wide research team has developed a way to produce a report for families that provides personalized information about what to expect from their child's disease and the chances of response to treatment or risk of side effects. This study tests whether discussing the report in clinic at the time of diagnosis will improve disease control and patient/family satisfaction.

We will be recruiting for participants soon, so stay tuned!



These are examples of how the Report may look for a patient. The percent chances and the look of the charts (proportion of green, yellow, or red sections) change from patient to patient depending on their disease.

CAPRI Registry Updates



The CAPRI JIA Registry is a national study that collects information on disease course in Canadian children and adolescents with JIA to improve care and outcomes. The registry is led by Dr. Jaime Guzman and is funded by the Arthritis Society and the Canadian Institutes of Health Research. In BC alone, we have **238** patients participating. With 20 sites participating across Canada, we now have a total of **1182** patients involved in the registry!

Results from the 2022 Canadian CAPRI Registry Report showed that 73% of participants reached fully controlled disease within one year after being diagnosed with JIA.

LEAP Findings



Children with JIA may have difficulty keeping up with physical activity due to joint stiffness, pain, or fatigue. The LEAP Study is examining physical activity in Canadian kids and teens with JIA, to assess their level of activity and learn what factors tend to increase or decrease it. A total of 573 kids with JIA (age 8-16) and their parents participated in the study for 2 years, and completed questionnaires about activity, pain, fatigue and quality of life. Information about the severity and activity of their arthritis was also collected.

“LEAP” found that kids with JIA are less physically active than peers of the same age and sex. Similarly, kids with more active arthritis are less physically active than kids with inactive arthritis. When parents were more physically active, their kids tended to be more physically active. Fatigue in children with JIA tended to limit their activity more than pain.

In summary, the level of arthritis activity and fatigue in children with JIA interfere with a child's ability to be physically active; further research on how to limit fatigue in JIA may be important. Also, parents have an important role in encouraging kids with JIA to stay active. We are now looking at how physical activity changes over the study period of 2 years, and if this is associated with inflammation seen in blood tests and also bone and muscle strength. So, stay tuned for more LEAP knowledge coming your way!



Are you interested in learning more?

- Vasculitis Foundation - <https://www.vasculitisfoundation.org>
- Arthritis Society - <https://arthritis.ca/>
- CASSIE + FRIENDS – <https://cassieandfriends.ca>
- BCCH Rheumatology - <https://www.bcchr.ca/rheumatology>

If you have any questions or are interested in participating in our research studies, you can contact us at rheumresearch@phsa.ca.