



CAPRI JIA Registry Update



The **Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI) Juvenile Idiopathic Arthritis (JIA) Registry** collects data to help us better learn how JIA affects the lives of Canadian children and adolescents, the effectiveness and side effects of medications, and long-term disease outcomes. The registry is led by Dr. Jaime Guzman and is supported by the Arthritis Society and the Canadian Institutes of Health Research. In BC alone we have **379** patients participating and **1400** patients participating across Canada at 20 pediatric rheumatology clinics.

BC research assistant Clare Cunningham recently completed a study of the *Trajectories of Physical Function in Children with JIA*. Clare's study included data provided by 940 children and youth newly diagnosed with JIA, and physical function was reported by parents answering two questions: "Is it hard for your child to run and play because of arthritis?" and "Does your child usually need help from you or another person because of arthritis?"

The study found that functional impact was greater at the time the disease was diagnosed and greatly improved during the first year of treatment. The initial functional impact was different across the seven JIA subtypes, where function was less affected by oligoarthritis, systemic and psoriatic arthritis, and more affected by RF-positive polyarthritis. Over seven years of follow-up, function became normal for most patients but about 1 in 3 had mild persisting impairments.

We hope this research reassures Canadian families that with modern treatments very few children with JIA experience long-lasting functional impairments – if they do, these impairments are mild.



THANK YOU to the children and families involved in our study!



Want to learn more?

- CAPRI JIA Registry <https://www.capricanada.org/>
- Cassie + Friends <https://cassieandfriends.ca/>
- BCCH Rheumatology <https://www.bcchr.ca/rheumatology>
- Newsletters <https://www.bcchr.ca/rheumatology/newsletters>

If you have any questions or have interest in participating in research, please contact us at rheumresearch@phsa.ca



Rheumatology Research Newsletter

For Patients and their Families
Volume 21, Issue 1
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EDITOR'S SPACE

Welcome to the Spring 2025 Rheumatology Research Newsletter! We are excited to share updates on the many new and ongoing research projects operated by our team in BC and beyond. We touch on JIA and other rheumatic conditions, mental health, genetics, and clinical trials. Our research is united by the common goal of improving the quality of life in children with rheumatic diseases and would not be possible without the time and dedication families put into participating in research. We truly thank you for this and hope you enjoy this newsletter!



Cassie + Friends Run

Come join us for the annual 5K Vancouver Half-Marathon on **Sunday, June 22nd**, taking place at **UBC on Marine Drive, Vancouver, BC**. Run or walk to support a major fundraiser that makes Cassie + Friends activities possible, bring awareness to JIA and other rheumatic diseases, and meet others in the community!

Scan the QR code to register now with the Cassie + Friends team. We hope to see you there!



Editors: Dr. David Cabral, Timothy Cheng, Dr. Jaime Guzman, Kristina Kurvits, Ali Hussein, Nick Mcphate
Contributors: Nadia Alattas, Clare Cunningham, Sarah James, Dr. Lori Tucker

Mental Health Screening in Rheumatology

Sarah James, our occupational therapist, recently led a mental health screening project as part of the inaugural C&W Practice-based research challenge! Her project invited 40 children aged 8-17 years old with Juvenile Idiopathic Arthritis (JIA) and their parents to participate in a mental health screening during their usual clinic visit. This update will share the project's findings and the team's next steps.

FINDING #1: How acceptable was it for children and parents to do the screening? Most of the kids and parents (over 90%) found doing the questionnaire acceptable. More parents (87.5%) compared to kids (57%) thought that our team should check in about mental health during appointments.

FINDING #2: How common are feelings of anxiety and depression among kids with JIA in our clinic? It was found that scores related to anxiety and depression reported by the kids who participated were similar to kids in the general population.

What's next? The Rheumatology team plans to include regular mental health screening in our clinic for kids with JIA and other rheumatic conditions. The frequency of those screenings is yet to be confirmed.

THANK YOU to the kids and parents who participated in the study!

Studies that are taking off

Clinical Trials: Our rheumatology team is involved in a number of international clinical trials looking at new and pending treatments. This includes biologic drugs for conditions like psoriatic arthritis, systemic lupus erythematosus, and vasculitis. We hope to support the search for treatments of such rare diseases and to determine the safety and effectiveness of new drugs for the pediatric population. In the upcoming year, we will be working to enroll kids into these studies at BC Children's Hospital. If you are interested in learning more, please reach out to our team at: rheumresearch@phsa.ca

BC-GEN Study: The Rheumatology team is launching a survey project called BC-Gen that asks families who visit our clinic about their thoughts on genetic testing. Participants will be recruited in-clinic or via email from **May to July of 2025**. If you're interested in participating, please reach out to study staff at: kristina.kurvits@cw.bc.ca



Northern Health Project



Our team has been working with Cassie + Friends to learn about the challenges/ barriers and facilitators families of children with arthritis and rheumatic disease face who live in Northern BC.

Working together, we interviewed families attending either of our Prince George or Terrace clinics, asking about their needs and gaps in accessing care

Challenges/ Barriers: families described long travel times to appointments, increased financial costs, and limited knowledge.

Potential Facilitators: existing community services, educational resources, and connections with other families navigating CRDs.



We presented this work at the Canadian Rheumatology Association meeting, and have started to work on the study's action items.



Hello and Goodbyes



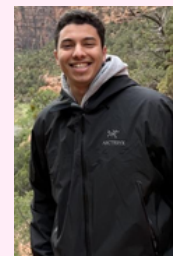
Meghan Jones

We were sad to say goodbye to nurse **Kaija Gnazzowsky** and clerk **Gladys Salindong** this past year. We have greatly appreciated your hard work and wish you the best on your future endeavours. We would also like to say a sad farewell to research coordinator **Arnima Singh** who was filling in for **Nadia Alattas** while she was on maternity leave. Arnima will be completing her Master's at UBC. Welcome back Nadia!

Our team would like to extend a warm welcome to nurse **Meghan Jones** and research coordinator **Ali Hussein**, and a warm welcome back to nurse **Indy Toor**.

We would also like to welcome back **Dr. Stephanie Wong** who will be joining the team in May. Dr. Wong did her fellowship training in our Division before leaving to get further training in pediatric lupus. We are delighted to welcome her back as a staff pediatric rheumatologist.

We are beyond excited to work with all of you!



Ali Hussein