



# RHEUMATOLOGY RESEARCH REPORT

*For Patients & their Families*

## EDITOR'S SPACE

Welcome to the newly redesigned Summer 2021 Research Report! The past eighteen months has been challenging for everyone. Many of our research studies were put on hold at the start of the pandemic, but our team worked hard to adapt our studies so that our patients and their families can continue to contribute to Rheumatology research. **A special thank you to everyone who has participated in one (or more) of our projects- whether it's by giving a blood sample, completing an online survey, or participating in a zoom interview! All your contributions are valuable and very much appreciated.**

In this edition of the newsletter, you will read about new studies going on in our clinic as well as some updates on ongoing studies. We also have some results from the CAPRI JIA Registry and Biologically-Based Outcome Predictors in JIA (The BBOP Study). Happy reading!

**INTERESTED IN JOINING OUR RESEARCH STUDIES?**

Contact us at [RheumResearch@phsa.ca](mailto:RheumResearch@phsa.ca)

## THE PARTICIPATORS



Click the image to learn how YOU can help do research!



**What does it mean to participate in research?**

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THE UNIVERSITY  
OF BRITISH COLUMBIA

## New Kids on the Block:

Our Division's Newest Projects



### UCAN CAN-DU: A collaboration between Canada and the Netherlands to better understand childhood arthritis

One of the biggest challenges of treating juvenile idiopathic arthritis (JIA) is providing the best treatment, at just the right time. Biologic therapies are common and highly effective but may come with undesired side effects. Additionally, biologics are prescribed to one in three patients without an end date. It can be challenging, both to know when to start and stop treatment, and to determine which biologic is best for an individual patient, and these are questions the international UCAN CAN-DU study is focusing on. The Rheumatology team at BC Children's is a study site in the UCAN CAN-DU research network across Canada and the Netherlands, working to improve personalized medicine care for children with JIA. Researchers and pediatric rheumatologists are working to develop a system to predict a child's arthritis disease course, a clinical tool to predict response to therapy and to identify the risk of relapse after discontinuing therapy.

We are now inviting eligible patients and their families to participate in this study. The study team will lead interested patients through an informed consent process prior to collecting medical history, a blood sample and questionnaires that ask about how having JIA affects a child and family. Participating families will gain access to their child's study information through a unique electronic portal, and questionnaires can be done online as well. We hope many BC families can become a part of this study.



## Updates on ongoing studies



### CAPRI JIA Registry Newsletter

The Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI) national registry was implemented in 2017 and was funded by the Arthritis Society. It collects information provided by Canadian children and teens with Juvenile Idiopathic Arthritis (JIA), from 17 centres in Canada. Using the information, pediatric rheumatologists can examine many aspects of JIA care in Canada, including quality of life, different treatment approaches, side effects, and the results of treatment.



Our most recent results show that over 400 patients have enrolled in the registry and that about 70% of them reached full control of JIA within one year, compared to 45% a decade ago. For more information on our recent findings, scan the QR code or [click here!](#)

### Rheumatology Research Studies during COVID-19

This past year, to practice better social distancing, the Pediatric Rheumatology Research team has been working hard to move some of our ongoing research studies online. For virtual visits, children and families who are currently participating in the CAPRI or CAN-Fever Registry have been contacted by the research team to complete their usual questionnaires by email. These questionnaires can even be completed on your phone! Those having in-person visits will continue to be approached by research team members who will present a QR code that can be scanned via phone to access questionnaires.

For more information on COVID-19 and participating in research please visit:

- [COVID-19: Information for Research Participants](#)
- [Cassie+Friends COVID-19 Centre](#)

**Hot off the Press!**  
Results from Studies in our Division



## Clinical and psychosocial stress factors are associated with less physical activity over time in children with JIA

Link to full article: <https://ped-rheum.biomedcentral.com/articles/10.1186/s12969-021-00584-4>

This study, conducted in part by Drs. Houghton, Cabral, Guzman, Morishita, and Tucker, examined changes in physical activity levels in children with within the first 2-years of being newly diagnosed JIA and the relationships of this physical activity with behavioural, social, and clinical factors. This research used questionnaire data collected from 82 children and teenagers, clinical findings of the doctors, and social and economic factors such as household income.

The study found that Canadian children with newly diagnosed JIA had lower physical activity than healthy Canadian children. Physical activity decreased over the first two years, even while treatments were reducing the level of arthritis disease activity. Lower physical activity was associated with active arthritis and lower scores on the JIA-related quality-of-life questionnaires (indicating higher levels of stress related to JIA). Socioeconomic status did not influence physical activity in this study.

The findings of the study highlight the need for future research to better understand how health related quality of life and patient reported outcomes (pain, fatigue, stress, attitudes, barriers, motivation, social support) relate to physical activity. Presently, encouraging age appropriate physical activity and safe sport participation remains an important part of JIA management.



## Medication side effects and their impact on quality of life

Link to full article: <https://pubmed.ncbi.nlm.nih.gov/33787074/>

Using information provide by patients with arthritis in the CAPRI Juvenile Arthritis Registry, Drs. Cabral, Tucker and Guzman, together with researchers across Canada, explored the severity and frequency of side effects from reported by kids and their parents to the arthritis medications they take. Parents reported side effects at about 42% of visits to the pediatric rheumatology clinic. Most commonly reported side effects were tummy aches, nausea, headaches and concentration problems, of mild to moderate severity. There were very few serious side effects that required hospitalization or urgent medical attention.

They calculated that within one year of diagnosis, 2/3 parents or guardians reported that their child had at least one medication side effect. Quality of life was reported as lower when there were side effects, even if arthritis was controlled. This study shows us the need to ask patients and families about medication side effects, as an important part of JIA care.





## Meet Sofia, a Cassie + Friends Youth Research Advisor



Click the image to read about how Sofia has been involved in research!

## We want to hear from you! - The COVID Rheumatology Survey Study

The COVID-19 pandemic has had widespread impact on usual medical care, including the care of children seen here at BCCH Rheumatology clinics. You may have experienced changes such as an increase in virtual medical visits, limitations in accessing allied health providers (e.g social work, occupational and physical therapy), difficulty getting test done for routine lab screening, and changes in how routine infused medications are provided. Additionally, many patients and families may have had anxiety about whether they are at increased risk of COVID-19 because they might be immunosuppressed because of their disease or its treatments.

The rheumatologists and research staff have developed a survey to get feedback from the patients and families of BCCH Rheumatology. We invite any patient/parent being seen in our clinic to participate in this anonymous survey and share their experience on how COVID-19 has affected their care. Click the link or scan the QR code to complete the survey!



<https://redcap.link/COVIDRheumSurvey>

## Hello and Goodbyes from the Rheumatology Team!

Congratulations to **Dr. Tristan Kerr** and **Dr. Jonathan Park**! Our senior fellows have completed their Rheumatology training this summer and will be joining the Rheumatology teams in Saskatchewan and Ontario respectively. We are also bidding farewell to our research co-op student, **Rafid Haq**, who will be completing his work term at the end of August and returning to UBC to complete his undergraduate degree. We wish you all the best!

We are very excited to welcome **Dr. Dalal Mohammad** who will be joining our team as our new Rheumatology fellow. **Gladys Salindong** is also joining us as our new administrative assistant! We have recently welcomed **Dorothy (Dot) Chow**, who is working with us as a nurse while **Laura Musyj** is home with her new baby girl. Our research team is also growing - **Steffanie Fisher** joined us in June as our new research coordinator and **Erica Won** will be our new co-op student in September. Welcome to the team everyone!

