

Drs. Cabral, Tucker, Mohammad, and Guzman, and at the Cassie and Friends Marathon Fundraiser on June 24th, 2022

Welcome to the 2022 Summer Rheumatology research report! We are excited to be sharing some updates to our CAPRI Registry, ReACCH, and PedVas studies, as well as introducing a new study for the summer that you can participate in called the "BC CREW study"! As always, we greatly appreciate the time and energy families put into participating in these studies. It is your engagement that makes research possible, whether it be filling out a questionnaire or donating blood for a study, so thank you. We hope you enjoy this issue of our newsletter!

We have a website! Check us out at <https://www.bcchr.ca/rheumatology>. Visit to learn more about the pediatric rheumatology team researchers and our current projects! Ask us questions anytime at rheumresearch@phsa.ca

Editors: Erica Won, Maddy Hutchinson

Contributors: Dr. Bosman, Dr. Cabral, Dr. Guzman, Dr. Tucker

PedVas

Childhood chronic vasculitis is a group of rare diseases in which your body's immune system, which is meant to protect you, gets confused and attacks its own blood vessels. The affected blood vessels can cause serious dysfunction of important body organs such as the kidneys, lungs and brain. It occurs in 1% of children, making it difficult to study.

To help us improve treatment and outcomes of childhood chronic vasculitis, the Rheumatology team at BCCH started the Pediatric Vasculitis Initiative, or PedVas, in 2012. With collaborators from over 40 hospitals around the world, the PedVas team has set up a registry to collect medical information and blood samples from patients with vasculitis. We have analyzed different measures of inflammation in the blood to better understand when to stop and start medicines, as well as studied specific genes that have recently been identified as causing new vasculitis syndromes, called DADA2 and COPA.

So what are we working on now?

Laboratory "predictors" from urine or blood are called "biomarkers". If a biomarker helps detect the inflammation early, or if the inflammation is very severe, it may help guide treatment and reduce long-term damage. In PedVas, we are examining such biomarkers in the urine samples of children with vasculitis to see how severely their kidneys may be affected. Drs. Brown, Cabral, and Morishita received a grant from the Canadian Institutes of Health Research last fall to take a deep dive into these "biomarkers" over the next few years.



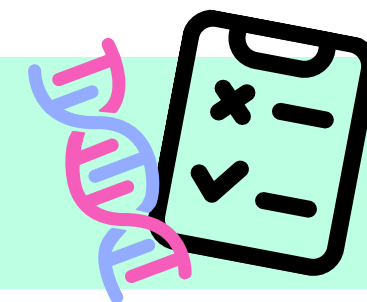


ReACCH study updates!

Results from our REACCH-OUT and CAPRI Registry studies have recently been used to compare how treatments and outcomes have changed for children and teens with JIA over the last decade. By comparing the results from REACCH-OUT (1128 participants from 2005-2010) and the CAPRI Registry (721 participants from 2017-2021), we noted an increased use of biologic medications, such as adalimumab, and DMARDs, such as methotrexate, alongside an increase of full disease control, otherwise known as "inactive disease". Within 70 weeks after their diagnosis, 6% of patients between 2005-2010 had started a biologic medication compared to the 26% of patients who started a biologic medication between 2017-2021. Along with this increase in the use of biologics and DMARDs, we saw that achieving inactive disease increased from 63% to 84%. Collected in real clinical settings across Canada, these results suggest that more aggressive treatment is associated with improved outcomes for children and teens with JIA.



BC CREW Survey



Pediatric rheumatic diseases are complex and may be influenced by several factors, including a person's genetics. For some patients, genetic testing may help determine if their disease was passed down through their family or may be passed down in the future. As part of a project to expand advanced genetic testing for rheumatology patients, we want to learn about patients and families understanding and opinions of genetic testing. We have created a brief, anonymous survey for patients and families to fill out. If you are the parent of a child with a rheumatic condition or are a patient between 12 and 25 years old that was diagnosed with a rheumatic condition before you turned 18, you are eligible to participate.

We will be reaching out soon to ask for participates, so stay tuned!



CAPRI Registry updates!

The CAPRI Registry is a national study collecting long term information on children and teens with JIA, which many of our patients are involved in. In an article published this year, written by our very own Dr. Kristin Houghton, data from the CAPRI Registry was used to develop and validate a 2-question disability screen that can be applied at every clinic visit for children with JIA. The Kids Disability Screen (KDS) may serve as a more efficient tool to assess disability than standard, lengthier questionnaires, such as the CHAQ. This great news will provide a quick and convenient way to assess if disability decreases with treatment.

Hellos and Goodbyes

Dr. Stephanie Wong finished her fellowship with us and will be pursuing a pediatric lupus fellowship at The Hospital for Sick Kids in Toronto. She also has welcomed a baby girl into the world! Congratulations on your new adventures, Dr. Wong! We are also wishing our co-op research students, **Erica Won** and **Maddy Hutchinson**, well as they return to continue their undergraduate degrees at UBC and SFU, respectively. Good luck, we wish you all the best!

A warm welcome to our new fellow arriving in July, **Dr. Shamma Alzaabi**, and our new co-op students, **Naomi Choong** and **Jessica Moh**. We hope you have a wonderful experience!