



Rheumatology Research Newsletter

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For patients
& families!



Welcome to the Spring 2026 Rheumatology Research Newsletter! In this edition, we will be sharing new research projects that we have been working on and updates on studies that are already underway. We would like to thank all the families that are already participating in research with us and look forward to advancing knowledge and care for the rheumatology team.

If any questions come up as you read, or if you are interested in participating in research, you can reach out to the research team at [rheumresearch@phsa.ca!](mailto:rheumresearch@phsa.ca)



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Patient Experience at the YARD Transition Clinic

The transition from pediatric to adult care is an important milestone, which is why the **Young Adult Rheumatic Disease (YARD) clinic** exists to support youth through this process. Recently, a survey was conducted to better understand their needs, readiness for adult care, and overall experience with the clinic.

Of 59 active YARD patients, 26 completed the survey. Overall satisfaction with care was high, with over **80%** of respondents reporting positive experiences. Patients noted strengths such as improved confidence discussing their condition, easier communication with the care team, and better understanding of their disease and future health. Areas for improvement included increased access to multidisciplinary providers, clearer communication around scheduling, and additional information on topics such as reproductive health, substance use, and insurance.

Ongoing Recruitment Updates

- **VISTA-JIA:** This national pilot study supports teens with juvenile idiopathic arthritis (JIA) as they transition into adult care through a virtual self-management program. Participants aged 12–17 join one-hour sessions with a healthcare professional and a small group of peers to discuss medication management, lifestyle, exercise, and coping strategies. The first round of sessions for the BCCH site is currently underway!
- **CAN-Fever:** This year marks an exciting milestone as CAN-Fever completes its 10th year! The study focuses on understanding autoinflammatory conditions in children by gathering important information from patients and families, using short questionnaires.
- **PCV-20:** This study explores a new vaccine called Prevnar 20 (PCV20), which protects against 20 strains of the *Streptococcus pneumoniae* bacteria. Researchers are looking at how children with weaker immune systems respond, helping to demonstrate that this important vaccine is effective for our patients on immunosuppressive medications.



Pharmaceutical Trials

The rheumatology team is involved in a number of clinical trials exploring new treatments for pediatric rheumatology patients. Below is a quick summary of all our ongoing trials!

- **POLY-JIA:** Testing the tolerability and safety of Upadacitinib in patients aged 5-17 years old diagnosed with polyarticular JIA
- **BLOSSOM:** Evaluating IV Anifrolumab in patients aged 5-18 years old diagnosed with moderate to severe SLE
- **KNAPSACK:** Evaluating safety and efficacy of Risankizumab in patients diagnosed with JIA aged 5-18 years old
- **AAV:** Evaluating Avacopan in combination with Rituximab or Cyclophosphamide in patients aged 5-18 years & diagnosed with ANCA-associated vasculitis



Paint Me a Picture: CAPRI-JIA Registry Results

The **Canadian Alliance of Pediatric Rheumatology Investigators (CAPRI) Juvenile Idiopathic Arthritis (JIA) Registry** collects data from children and adolescents across Canada to better understand how JIA affects daily life, how well treatments work, and long-term disease outcomes. About **1,400 patients** are participating across **20** pediatric rheumatology clinics nationwide.

Over the past year, research assistant Timothy Cheng completed a study examining how JIA affects the emotional and social well-being of children shortly after diagnosis and one year later.

The study found that the psychosocial impact of JIA, including emotional distress, behavioural challenges, and school-related difficulties, was highest soon after diagnosis. Results also showed that pain, fatigue, and reduced physical function were strongly linked to psychosocial difficulties.

These findings highlight the importance of monitoring emotional well-being early and throughout care, and suggest that pain and fatigue should be addressed directly to improve overall quality of life.



