



News Rheum

Your Rheumatology Newsletter

Issue: Spring 2021

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Scholarships to Apply for University & College:

April 30th, 2021 Lupus Canada Scholarship
<https://lupuscanada.org/news/lupus-canada-scholarship/>

May 14th, 2021 Dr. Bonnie Cameron Post-Secondary Scholarship
<https://artinmotion10k.com/dr-bonnie-cameron-post-secondary-scholarship/>

May 31st, 2021 UCBeyond 2021 Scholarship Program
<https://www.ucbeyond.ca/en/apply-now>

Want to Get Involved?

The Division of Rheumatology is seeking parents and patients to help in several areas. We are looking for:

- A member to sit on the SickKids Rheumatology Research Council
- Members to represent SickKids on the PR-COIN parent and patient working groups. Please see <https://www.pr-coin.org/families-overview> for more information
- Members for the SickKids Rheumatology Family Advisory Council and its subcommittees

Please contact us if you're interested in joining or would like to contribute content to the next newsletter:

rheumatology.newsletter@sickkids.ca

Cassie + Friends: Educational Webinars

Rare Rheumatic Disease Talks:

Saturday April 24th at 2:30 p.m. PST/5:30 P.M. EST

Presented by: Talks on JDM, SLE, Vasculitis and Auto-inflammatory diseases.

<https://us02web.zoom.us/meeting/register/tZcucequpzopG9dnLoDTZcA3NHL9FdMZAYZO>

Putting on Your Life Jacket: Self-care for Caregivers:

Saturday May 29th at 4:30 p.m. PST/7:30 p.m. EST

Presented by: Lisa Greene, Family Life Educator

https://us02web.zoom.us/meeting/register/tZUpcOGspz0vHdAZ_ePBotFn0u-1AnXLfKo9

Teen Talks, Let's Get Digital: User Centered Design for Web and Mobile Health

Applications:

Saturday April 15th at 5 p.m. PST/8 p.m. EST
Presented by: Dr. Jennifer Stinson and the iOUCH team

https://us02web.zoom.us/meeting/register/tZYpdO-gpzoqH9clRZ1bM8nkTv3hsix_pM5F

Recordings of previous webinars:

<https://cassieandfriends.ca/virtualeducation/>



If you would like to join the mailing list please email: rheumatology.newsletter@sickkids.ca

CRA Recommendation on Covid-19 Vaccination in Persons with Autoimmune Rheumatic Disease (ARD) <https://rheum.ca/decision-aid/>

Clinical trial results show that COVID-19 vaccines are safe and effective. However, people with autoimmune rheumatic diseases were not part of those clinical trials, so we don't know how well these vaccines work in people with autoimmune rheumatic diseases. We do know with other vaccines, like the flu shot, people whose immune system activity is lowered by medications may have somewhat less protection from vaccination, although most people are usually still protected. Side effects are also usually not different from everyone else.

What are the benefits of the COVID-19 vaccine?

Preventing COVID-19 infection. These vaccines prevent 70% to 95% of COVID-19 infections in people who get the vaccines. This is even better than the annual flu vaccine, which prevents the flu around 40% to 60% of the time.

Reducing severity of COVID-19. COVID-19 is less severe in people who get the vaccine.

Protecting others. Getting vaccinated yourself may also protect people around you. As more people get vaccinated, we will see less COVID-19 spread.

These vaccines do not contain live COVID-19 virus, so there is no chance of getting COVID-19 from them.

For more information on the decision aid for the COVID-19 vaccine please visit - <https://rheum.ca/decision-aid/>

Subgroup Considerations

- People taking rituximab: Based on serological studies from other vaccines, rituximab is expected to decrease immunogenicity
- People taking other DMARDs: Some other DMARDs may reduce protection from the vaccine. Given the large magnitude of benefit of the COVID-19 vaccines, it is likely that the benefits of the vaccine will still be large for most ARD patients. Continuing medications will often be the safest option to prevent disease flares until more evidence is available
- Additional considerations apply for pregnant and breastfeeding women. These were not covered in the scope of this guideline

Implementation Considerations

- As vaccine access is determined by provincial health authorities, it will be essential to ensure people with ARDs do not face unnecessary additional barriers to vaccine access. For instance, people with ARDs should not be required to obtain a physician letter as proof of an informed decision discussion. Please see decision aid at <https://rheum.ca/decision-aid/>

Research Priorities The following research areas were considered a high priority:

- Observational evidence on the frequency of harms (in particular serious adverse events/serious disease flares) in people with ARDs: If very infrequent, may lower the importance of these outcomes
- Evidence comparing the frequency of serious adverse events and autoimmune adverse events in people with ARDs: if not different with sufficient certainty, the panel may decide not to rate the quality of evidence for harms down for indirectness
- Evidence on the benefits (both clinical outcomes and serological studies) in people with ARDs on different medications: may help identify subpopulations of patients with lower benefits and inform decisions regarding whether to hold medications around the time of vaccination
- Evidence on patient values preferences for the benefits and harms across different patient populations
- Understanding vaccine hesitancy and barriers to vaccine access faced by persons with ARDs
- Understanding vaccine benefits and harms in populations at risk for inequities. We additionally encourage the collection of data that documents vaccine access difficulties for patients facing barriers to accessing vaccination, to support advocacy for improved prioritization protocols and vaccine delivery



Juvenile Arthritis (JIA) – Research in Action with Dr. Herman Tam

Did you know it can take up to 17 years for research to trickle from journals and publications into your child's clinic appointment? When we heard the recent American College of Rheumatology (ACR) Meeting was a "big one for Pediatric Rheumatologists," we wanted to know why. So, we asked Dr. Herman Tam, a specialist at BC Children's Hospital (and former SickKids fellow), to share some of the highlights – in a way we can all understand.

Here's what Dr. Tam told us he learned at ACR – the largest meeting of rheumatology experts in the world:

New data might change the way we treat kids with pJIA.

Dr. Tam heard about a new North American study called CARRA STOP-JIA, a study that SickKids is a part of. In the study, Dr. Kimura, Chief of Pediatric Rheumatology, and the other investigators at the Joseph Sanzari Children's Hospital in New Jersey, looked at three ways to start treatment plans for children with polyarticular JIA (pJIA):

- **Step Up:** Patients started treatment with a non-biologic DMARD medicine only (e.g. methotrexate)
- **Early Combination:** Patients started treatment with both a non-biologic DMARD and a biologic medicine.
- **Biologic First:** Patients started treatment with a biologic medicine only.

So, what did the study show? In all three groups, results were similar in terms of limiting inflammation and helping children become symptom free. But, less than half of the patients became symptom free using any of the options (and not too many parents chose the biologic first option).

How can you use the results? For one, you can be reassured that the treatments available for your child today, for the most part, work! For all three options, kids had less pain and were better able to move after one year. Second, when considering ways to treat your child with pJIA, you can ask about and review the results of this study with your doctor.

Doctors are looking at new targets to help your child have the best life possible.

A Canadian study (ReACCh-Out) that **SickKids patients** are also participating in, presented by Dr. Jaime Guzman, Pediatric Rheumatologist at BC Children's Hospital, looked at all the ways JIA can negatively impact a child's quality of life.

So, what did the study show? The study found that pain, restrictions on participating in activities and treatment intensity were the most important factors affecting a child's quality of life.

How can you use the results? Hopefully by working with your medical team to talk about and focus on these specific targets – i.e. making sure your child can continue doing the things they love, even with modifications; working with your kids to make their treatments as manageable as possible and using strategies to reduce your child's pain – we can all help give kids the highest quality life possible.

Sometimes medication is a real struggle. Here's what to watch for.

Dr. Alessandra Alongi did a study called -1494: Patient-Reported Adverse Events, Quality of Life and Treatment Adherence in Juvenile Idiopathic Arthritis: Analysis of Two Large International Cohorts. This study was a big one! In her study, Dr. Alessandra Alongi looked at 8400+ kids over 13,000+ clinic visits in multiple countries to figure out how medication adverse effects (a fancy way of saying nausea, injection pain, missed school days, etc.) really affected kids and if it made them less likely to take their medications.

So, what did the study show? Nausea was the most common adverse effect with a high impact on taking medications but not too much impact on a child's overall quality of life. On the other hand, mood swings, sleep problems and weight gain can have really big impacts on a child's mental, emotional and social health. All adverse effects can affect a child being able to participate in their school activities and how likely they are to stick with their treatments.

How can you use the results? With nearly 30% of kids and families reporting they experienced adverse effects, it's important to know that you and your child are not alone in the challenges you may be facing. Most importantly, help is available. Discuss with your rheumatology care team on strategies to mitigate adverse effects, and how you may participate and benefit from research, including this study from Dr. Alongi who cares for kids with arthritis in Italy.

These research findings, along with many others presented, continues to improve our – and your – understanding of JIA. Huge thanks to Dr. Herman Tam (@DrPedsRheum), Pediatric Rheumatologist at BC Children's Hospital, for helping bring that research into action for you.

Source: <https://cassieandfriends.ca/news/research-into-action-with-herman-tam/>

Patient Inspiration Story – Jake Da Luz

Greetings!

My name is Jake Da Luz. I am currently 17 years of age and I was diagnosed with Systemic Juvenile Idiopathic Arthritis at the age of 3 and a half. My memory of being diagnosed is pretty much a blur, but my parents remember it like it was yesterday.

I was at my cottage with my grandparents when my mother got a call saying I wasn't feeling well. By the time they drove me home, my condition deteriorated and by Monday I was taken to St. Joseph's Hospital. After spending a few days there doing many tests they concluded it was a form of arthritis and quickly connected me with SickKids. This was the start of my journey, not knowing where it would lead me in years to come.

Over the next several years things went from bad to worse until I was able to qualify for a new drug study on Tocilizumab (Actemra). Once I was steady on the drug, I was finally able to try out my favorite sport, HOCKEY. Once I got on the ice I fell in love with the game. After about a year of skating and getting my body back, my dad signed me up with Faustina Hockey Club for my first ever year of sports. This was at the age of 8. By my second year of hockey I won leading scorer in the league. Since then I haven't lost that title. If it wasn't for my team at SickKids I wouldn't have been able to live my dream of playing hockey. So, a Big Thank You to all my medical staff!!

To give back my mom and I started a charity ball hockey tournament in support of SickKids with proceeds going to arthritis and diabetes priorities. (Bar Down by the Lake – GIVING BACK HOPE). I felt it was my duty to give back, raise awareness and spread HOPE since SickKids made me who I am today. Over the course of 7 years we raised well over \$50,000.

None of this would have been possible without the tremendous support from my mom, dad, brother, Faustina Hockey Club, MLSE, the community of south Etobicoke, and so many friends and family that have been there for me along the way. Although my journey has had its up and downs I wouldn't change a thing. What I have gone through has made me who I am today.

So, just remember -- If you feel like quitting, don't. Never Give Up!!!

