



News Rheum

Your Rheumatology Newsletter

Issue: Summer 2022

Inside This Issue – Summer 2022

Upcoming Events	pg. 1
Take a Pain Check	pg. 1
In the News	pg. 1
Research 4 Kids	pg. 2
Get Involved	pg. 2
Patient Story	pg. 3
Summer Safety	pg. 4

Upcoming Events

October 16, 2022

Art in Motion 10K

<https://artinmotion10k.com/>

Toronto Run/Walk for Juvenile Arthritis

<https://cassieandfriends.ca/event/torontorun/>

November 12, 2022

Arthritis Fire Ball

<https://arthritis.ca/site/fireball/fireball.html>

In the News

Welcome back Neely from maternity leave!
Welcome to Noreen, who will be sharing the social worker coverage with Neely.

Congratulations to Dr. Rozenblyum, Dr. Shehab, Dr. Al Bijadi, and Dr. Mwizerwa, who welcomed new additions to their family!

Congratulations to SPARRK volunteer, Vanessa Carbone, who won the 2022 CARRA Patient/Caregiver Award!

Congratulations to Dr. Rae Yeung for winning the 2022 Department of Paediatrics Sustained Excellence in Research Award!

Welcome to the new fellows joining the rheumatology team: Dr. Molly Dushnicky, Dr. Edan Itzkovitz, Dr. Greta Mastrangelo, and Dr. Steve Balgobin.

Farewell to outgoing fellows, Dr. Jeanine McColl and Dr. Abdulaziz Al Mutairi.

Take a Pain Check

By Natasha Trehan

Take a Pain Check is a non-profit organization founded by Natasha Trehan, a university student who lives with Juvenile Idiopathic Arthritis. Take a Pain Check's mission aims to empower youth and young adults impacted by rheumatic diseases to advocate for themselves and create a supportive, safe, and inclusive community where individuals feel understood. Through several youth-led initiatives such as podcast episodes, blog posts and ambassador programs, their vision is that all youth and young adults feel supported in their journey with rheumatic diseases.

Their latest launch, [Joint Chat Rheum](#), is a program, aimed at building a community and making connections at a deeper level. It is led by ambassadors and executive members who are young leaders living with rheumatic diseases. Through a virtual space - Zoom - there will be monthly one-hour-long sessions which include team building exercises, discussing relevant topics, activities, Q&A and much more!

Continued on page 2...



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

Continued from page 1

Members will get access to their Discord community platform to continue conversations with the TAPC community and their new arthritis friends! It is open to anyone ages 13-25 living with a rheumatic disease. Note: this platform is a social hangout for people living with chronic conditions (not medical advice).

Check out their website:

<https://www.takeapaincheck.com/>

Watch their Podcast at:

<https://www.youtube.com/channel/UCRF07SYaN-9fbatNCKhL08g>

Listen on:

<https://open.spotify.com/show/7i3rG9obaaiRQLiqFMcpiH>

Or follow on:

Twitter: @takeapaincheck

Instagram: @takeapaincheck_

If you have any questions, feel free to email us at takeapaincheck@gmail.com

Research 4 Kids

There are many ways to contribute to clinical research at SickKids to help improve knowledge and develop treatments to improve patient care.

Here are some of the ways you can get involved in clinical research at SickKids:

You can be a research participant. This is where you participate in research study. Some of the opportunities are available in the [Research4Kids study database](#).

You can be a research family advisor. This is where you use your perspective to provide input and participate in decision-making during the research process—from planning to execution and interpretation.

You can be a member of the Research Family Advisory Committee. This is a committee made up of patients, family members, researchers and clinicians who volunteer their time to enhance patient-oriented research at SickKids.

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 (for more information please contact crystal.grasby@sickkids.ca)
- 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 (for more information please contact crystal.grasby@sickkids.ca)
- A parent representation to join our JIA New Patient Education group (for more information please contact crystal.grasby@sickkids.ca)

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

rheumatology.newsletter@sickkids.ca

Patient Inspiration Story

By: Maya Crespi



Hi, my name is Maya, and I am 18 years old. I was diagnosed with juvenile idiopathic arthritis when I was just over a year and a half. I began walking at an early age, but my parents noticed that I walked with a limp and was in constant pain. My parents were sent to the rheumatology clinic at SickKids Hospital where they received the diagnosis. At first, my mom couldn't believe that I had been diagnosed with arthritis! She didn't want to accept that I may be unable to enjoy everyday activities due to my pain. However, she was determined to help me live the best life possible, and she signed me up for gymnastics and dance. Despite my arthritis, I excelled in both activities and developed a love for gymnastics.

I began competitive gymnastics in 2012 when I was 9 years old. However, during the first few years of my training I experienced constant arthritic pain and swelling in my knees. I remember it was hard to walk, let alone jump and tumble. I received a couple cortisone injections in my knee that helped relieve the pain. I was able to continue training because of my support system and sheer passion for gymnastics.

As I grew up, I not only learned to manage the pain of my arthritis, but also the pain of gymnastics related injuries. Yet, managing a constant cycle of physical pain is only possible with a strong mindset. As I moved up levels in gymnastics my most prominent fear was injury. I became fearful of getting injured and having to deal with that pain on top of arthritis. This mindset started to hinder my progress in gymnastics, and I lost all confidence in my abilities. Yet, in 2018 I had a breakthrough when a new coach arrived at my gym and exposed me to a new mindset. My coach helped me understand that fear does not define your abilities, nor should it stop you from reaching your goals. I learned that my fear was the only thing limiting me from achieving greatness.

I am currently training as a level 8/9 artistic gymnast, and I hope to continue training and competing throughout university. In September 2021 I joined the neuroscience psychology program at York University. Although my future in neuroscience is far away, I know that I would like to work as a psychiatrist with athletes struggling to cope with arthritis, and other physical or psychological challenges. When I am not training for competition or studying for school, I coach a lovely group of competitive gymnasts.

Many people ask me how I've managed to stay in gymnastics for so long despite my arthritis, gymnastics related injuries, and pain. Honestly, living in chronic pain is mentally and physically draining. Although my love for gymnastics is strong, sometimes it is tough to keep going. However, the mindset that keeps me going is to treat each setback as a lesson to learn from. The more setbacks you experience, the more lessons you learn, and the stronger person you become. It is also important not to compare yourself to others. Remember, your journey is unique to you!

Summer Safety

By: Jessica Guo

Summer's here! It's important to be mindful of summer habits to stay safe and healthy while enjoying the weather. This can include everything from staying active, bringing a water bottle so you can stay hydrated, and ensuring proper protection from the sun.

With the weather improving, we have more opportunities to go outside or find other ways to stay moving. Activities like going on walks, swimming at the pool or at the beach, and playing with friends can be great ways to get your bodies moving this summer. Having a buddy in case of flare ups or other symptoms is often helpful for many people with rheumatic conditions. This way somebody is always there to provide support if it's needed.

Hydration is essential to a making sure you are having a safe summer. Drinking water throughout the day and especially when spending time in the heat and sun is important to avoid overheating or heat exhaustion. Always bring a water bottle when going out for the day and try to make sure there are places where you can refill it when you need to.

For many children with rheumatic conditions, the sun can easily irritate the skin and potentially aggravate other symptoms. This makes proper sun protection essential! A high number SPF sunscreen should be applied regularly, and it is also recommended to wear hats, long sleeves, and other coverings to minimize skin exposure to sunlight. Other ways to stay safe include finding shade outdoors or bringing an umbrella to create your own shade. Be mindful of getting too much direct sunlight between 11 am and 3 pm as that is when the sun's rays are strongest.

We hope you can use some of these tips to make your summer a safe and fun one! You can always ask your doctor questions that you have about your condition in the warm weather.

