



News Rheum

Your Rheumatology Newsletter

Issue: Fall 2021

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COVID-19 Hub

Coming to SickKids?

Learn what to expect ahead of your appointment or stay

Quick Links:

Family and Visitors: <https://www.sickkids.ca/en/news/covid19/#visitors>

Screening: <https://www.sickkids.ca/en/news/covid19/#screening>

Masking: <https://www.sickkids.ca/en/news/covid19/#masking>

Vaccines: <https://www.sickkids.ca/en/news/covid19/#vaccines>

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 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 rheumatology.fac@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

Cassie + Friends

Is a Canadian charity dedicated to the pediatric rheumatic disease community. They provide research, information, connection and support to children and their families.

Cassie + Friends: Educational Webinars

Taking the Reins: Transitioning from Pediatric to Adult Rheumatology Care:

Thursday October 28th at 4 p.m. PST/ 7 p.m. EST

Presented by:

- Dr. Natasha Gakhal, Dr. Evelyn Rozenblyum, and Danielle McCormack, Physiotherapist from the JIA clinic team at Women's College Hospital
- Emma Linsley, JIA patient and third year Psychology student at McGill University

Registration Link: <https://bit.ly/3acnuwl>

Other Events: Toronto Run/Walk (Virtual):

Friday October 1st to Sunday October 31st, 2021
Join us from anywhere in Canada in the Toronto Waterfront VIRTUAL run/walk and Scotiabank Charity Challenge in support of kids and families affected by juvenile arthritis and other rheumatic diseases. Our team will consist of kids, families, friends, corporate partners and healthcare professionals who are all showing their support to kids in Ontario affected by pediatric rheumatic disease.

Select your distance and sign up for the VIRTUAL event here - <https://raceroster.com/events/2021/48139/2021-scotiabank-toronto-waterfront-marathon?aff=X453C>

Distances include a 1 km kids run (\$25) or 5km, 10km, 21.1 km, and 42.2km (\$40)



ART IN MOTION – RUN/WALK 2021

Beautiful fall colors are the canvas to this art themed extravaganza. Join Art in Motion virtually and in-person for the Art in Motion 10K/5K/2K.

- **When:** Sunday October 17, 2021
- The race is a family friendly run or walk of 10K/5K/2K
- **Where:** Boyd Conservation Area in Kleinburg, near Canada's Wonderland
- **Why:** To raise money and awareness for kids with arthritis at SickKids and for the Dr. Bonnie Cameron Post-Secondary Scholarship
- Chip-timed and fully supported, each participant will receive tech shirt or hat, finisher's medal, digital download of all race photos, and a fabulous finish line feast!
- Participation is free for fundraisers raising \$150 or more
- Those raising over \$1,000 will be treated to a Champagne toast at the finish and a VIP Swag Bag to take home
- Those who can't make it to Boyd Conservation Area on race day can participate virtually and Art in Motion will do their best to ship shirts and medals to larger groups ahead of race day
- Promo code for those that just want to participate is **SICKKIDS** – which will save the participant \$5. The registration link is: <https://raceroster.com/events/2021/47394/art-in-motion-10k5k2k> - There are both in person and virtual options to participate
- For those interested in volunteering they can inquire at volunteer@artinmotion10K.com
- For those interested in sponsoring the event, more info is available at <https://artinmotion10k.com/sponsors/> or by emailing sponsor@artinmotion10k.com
- The website for general information is <https://artinmotion10k.com/>

Support the [Dr. Bonnie Cameron Post-Secondary Scholarship](#) by making a tax deductible donation.



CASSIE + FRIENDS

SCHOOL TOOLKIT

Cassie and Friends has prepared a toolkit for youth affected by juvenile arthritis who are attending school. As this can be an intimidating time for children, teens, and their families this resource provides additional support for navigating questions and communication for a successful school year.

In each School Toolkit, you will find:

- A breakdown of some of the most common challenges for students with JA
- Customizable template letters and other resources to help you communicate with your school
- Ideas for how parents, healthcare teams, teachers and even other classmates can help support your child at school
- Fun and engaging tools to help you and/or your child raise awareness of JA at school or in their class
- Stories from other youth who have shared their school experience with rheumatic disease

Listed below are the elementary, secondary, and post secondary school resource toolkit (links):

Elementary – Support your young child from their primary to intermediate elementary school years

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

Secondary – Helps teens face new challenges and learn to advocate for themselves at high school

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

Post Secondary – Take your independence to the next level as you further your education as a young adult

<https://cassieandfriends.ca/post-secondary/>

Does your child need extra support? Here are other helpful resources

Dealing with bullying (written by SickKids staff) - <https://bit.ly/3oJ296p>

Mental Health – Resource Page - <https://bit.ly/3AgcV6c>

Talking to your teacher about JIA - <https://bit.ly/3AmAsCd>

Fitting and packing your child's backpack - <https://bit.ly/2WQY1FQ>





Patient Inspiration Story – Sunika Dyall-Richards

January 5, 1990 was the start of a great life for my mom, siblings and myself. It was the day that we came to this beautiful country we now call home, Canada. My mom, the eldest of the 15 children, was sponsored by my late grandparents to join her 13 siblings, cousins and other extended family. I went from having 30 people back home to call family to having an undisclosed number of aunts, uncles, first, second, and third cousins..... friends that have now become family!

Fast forward to 2001 when the chapter of my life as wife and mom began. We brought our son Daimar into the world. When Daimar was 3 years old we brought home our beautiful baby girl, Sunika. We introduced Daimar to Sunika and explained that it would be his job to love and protect his little sister. Their bond as siblings grew and flourished each and every day. Their love, kindness, and compassion for each other is unmatched and one that many people don't get to experience. Daimar is a very gifted basketball player with a full scholarship to Eckhard College in Florida. Daimar's biggest motivation aside from the love of the game is to make something amazing of himself and hopes he can move himself and his family (especially Sunika) to a warmer climate. Having Daimar leave for Florida in August 2020 was hard for us as a family but especially difficult for Sunika.

Fast forward to my baby girl....When Sunika was about 5 years old we noticed that her fingers would change colour unexpectedly. Shortly after an assessment, she was diagnosed Raynaud's syndrome. Sunika also had some other health issues such as reflux, trouble swallowing food, arthritis, and dizziness. At 9 years old we were told Sunika had scleroderma. At that very young age Sunika started attending appointments with her rheumatologist, Dr. Brian Feldman at The Hospital for Sick Children. From that point the list of departments involved with Sunika's care grew to eight. Sunika was hospitalized in January of 2021 with a scleroderma-related issue and for four days, we were paralyzed by fear for our child. It seemed the tests were never ending, the list of doctors grew, new departments were introduced, and was information overload to us as her parents. During Sunika's hospitalization at SickKids we decided as a group to open up to our family and friends about Sunika's condition. I realized that I needed help with better understanding scleroderma so I joined a scleroderma support group through Instagram. Although, it was informative, I became even more fearful for the future of my 16 year old. My husband and I decided it was time to have some hard conversations with our children about the reality of scleroderma.

We learned that June is scleroderma month and a great time to raise awareness and money for this great cause. Sunika showed me just how strong she is when she made a video which we posted on every social media venue we could. I thought by posting her story it would help other patients like Sunika. We as a family were blown away not only by the physical support but financial support from this fundraiser. Our goal of \$500 was raised within 20 minutes and Sunika raised close to \$7,700 in total. Her video was shared by so many that even some of her teachers saw and donated. Her friends reached out to tell her how much they supported her! After the amazing success of the video we decided it was time to do one more thing. As a family we decided to do a physical walk on June 22nd calling it exactly what this disease has given my daughter, a fight!! We named the walk "Sunika's Fight" and what a success it was! We had 60 participants show up and ready to walk for our beautiful girl. My mom's family came and prepared some delicious snacks to go along with our "thank you" BBQ. We had a DJ volunteer his services during the walk and Dan Crawford and friends from 33 Division saw Sunika's video and came out to support and walk with us.

We as a family were extremely thankful for everyone that not only donated financially (especially during COVID times) but that came out for our walk. We are thankful for all the wonderful people on the Instagram Scleroderma group that reached out to Sunika. Offering support by phone calls, texts, sending encouraging gifts, and most of all giving Sunika their insight of their personal fights. Making her see that she is "normal" like all these wonderful people. We know we have a long way to go with this disease but, when you have a great team behind you, you don't stop fighting. Sunika's fight will go on for as long as we have blood, sweat and tears running through our body.

Sending love, strength and appreciation to the entire Scleroderma community for supporting my baby and my entire family!
Dyall-Richards Family