Important Dates & Upcoming Events:

2019 Camp Cambria – August 19 to 25, 2019
Registration Opens January 26, 2019
http://campcambria.org/camps/ontario/

2019 Art in Motion 10K – October 20, 2019
http://artinmotion10k.com/

Cassie+Friends/Scotiabank Marathon – October 20, 2019
http://cassieandfriends.ca/support/scotiabank-charity-challenge/

Young Minds Matter – A series of workshops for parents and children ages 8 to 12.
Increasing motivation: March 2, 2019
Increasing self-esteem: April 13, 2019

Scholarships

Dr. Bonnie Cameron Post-Secondary Scholarship
2019 Scholarship Application will be available soon!
http://artinmotion10k.com/dr-bonnie-cameron-post-secondary-scholarship/

UCBeyond Scholarship
2019 Scholarship Application will be available soon!
http://www.ucbeyond.ca/apply.html

Lupus Canada Scholarship
2019 Scholarship Application will be available soon!
https://www.lupuscanada.org/lupus-canada-scholarship-program/

What is MyChart?

SickKids is transforming the delivery of care by providing patients and authorized parents/legal guardians with online access to parts of their SickKids electronic health record with MyChart. We are proud to offer an easy-to-use, free tool for our patients and their families to access their health record wherever they are.

Our very own nurse, Holly Convery, is a MyChart champion and has signed up many of her patients for MyChart, particularly her adolescent patients. Holly says, "MyChart is a positive tool that promotes growth in both teens and their parents. Teens, who are using MyChart, are becoming more knowledgeable about their health conditions and more independent in managing their own health. Parents are recognizing that teens must take ownership of their health. The parent’s role is moving from total control to support and guidance. In my opinion, MyChart use is promoting the skills necessary for successful transitions from SickKids to adult health care."

One of Holly’s patients, 15-year-old Kayla, signed up for MyChart shortly after we launched the patient portal. Both her and her mother have accounts and use the mobile application frequently. Kayla shared with us her positive experience with MyChart so far: “The new app (MyChart) has been nothing but beneficial ever since I started utilizing the app in June. I have been going to SickKids for around seven years, and this app has really helped me when it comes to managing and staying up to date with my health…I feel more involved with what is happening…which deepens my knowledge and understanding about what is happening to me allowing me to play a more active role in my health care…It is about time that we start using technology in ways that will benefit us…MyChart has definitely had a positive influence on my healthcare management.”

To learn more or sign up to MyChart, visit www.sickkids.ca/mychart or speak to your healthcare provider.
Announcements:

Celebrations

Dr. Rayfel Schneider is the recipient of the 2019 College of Physicians & Surgeons of Ontario Award which recognizes 8 roles that reflect an “ideal physician”. Congratulations Rayfel!

Congratulations to our nursing staff; Karen, Holly and Michelle who celebrated 20 and 25 years of service at SickKids!

Art in Motion 10k – the unique and creative run took place on October 14th, 2018 and raised over $10,000 for SickKids Rheumatology. See Our Patient Inspiration Article Below!

Cassie + Friends – a team organized by Cassie + Friends participated in the Scotiabank Waterfront Marathon on October 21st, 2018 and raised just under $20,000 for SickKids Rheumatology. See Our Patient Inspiration Article Below!

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://pr-coin.org/families 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

Research – UCAN Update

On behalf of UCAN (Understanding Childhood Arthritis Network) project team here at SickKids, we are excited to share the latest news on UCAN, a research study that aims to improve the lives of kids with arthritis!

In this unique Canadian-Dutch Research Network, we will develop tests that enable us to learn about the biology of each child’s arthritis and be able to predict when and which biologic therapy to start and when to stop. We will improve the health of each child by selecting the right, effective treatment and prevent medication side effects. This approach will result in a dramatic reduction in health care burden for patients, families and society. A better understanding of the biology of disease will also lead to better therapies and ultimately a cure for arthritis. Lessons learned in childhood arthritis will be shared with physicians worldwide through strategic partnerships with decision makers throughout the world and also by building a state-of-the-art electronic health platform to share information with physicians, patients and their families in real-time. We expect the results will rapidly lead to improved care for children with arthritis as it will help ensure that biologic therapies are used in the safest and most beneficial and cost-effective way, directly improving the health and quality of life of affected children and their families.

On January 14th we launched UCAN study recruitment in all of our Rheumatology clinics. We will soon be expanding UCAN at hospitals across Canada and the Netherlands.

If you’re a candidate for UCAN, you may meet our UCAN research coordinators in clinic. They’ll explain the study in more detail to you. Our implementation team includes Dr. Shirley Tse (site lead at SickKids), Dr. Deborah Levy (site co-lead), Aniba Khan, Maryam Masood, Stephanie Lappan-Gracon, Christine O’Brien, Kristi Whitney, and Holly Convery. We are excited to share this project with everyone.

Many exciting times ahead!
Hi my name is Kinlagh, I’m 13 years old and I’m in grade 8. I have polyarticular juvenile idiopathic arthritis, rheumatoid factor positive. In April of 2016, I had a sprained ankle that wasn’t getting better. It took over 6 months to finally diagnose my arthritis after noticing yet another sore joint. Once I was diagnosed, my rheumatologist at SickKids found 5 other active joints that are now in remission. But my ankle has been pretty stubborn. I’ve been through several joint injection procedures and 4 medication changes to try and help it.

Because of the ongoing arthritis in my ankle, I’m not able to participate in as many activities as I would like. I sometimes have to sit out during gym class at school, but I still play softball in the summer and take swimming lessons in the winter. I am often limited in my softball playing; I’ll sometimes miss a practice to be able to play in a game, and when I get on base during a game, I’ll usually get a pinch runner.

Although I’m not able to play on any sports teams at school, I participate in various clubs instead. I am the co-captain of my Improv Team, I’m in the Children-Sponsoring Club, and I co-lead the Community Club. I’m also very active in promoting arthritis awareness by sharing my story with my classmates and fundraising throughout my school and in my community.

I keep working through these challenges by keeping a positive outlook. And I’m really proud to say that the year I was diagnosed, I won the award for the highest grades in my graduating class.

Unlike most kids with arthritis, I was diagnosed at age 11, so I can remember what my life was without arthritis; that has been the hardest part for me, knowing both lives. I’m hoping that we can find a cure for JIA so that the kids who were diagnosed at a young age can also experience life without JIA and so that I can go back to that life as well.

Dr. Bonnie Cameron and Kinlagh at the Art in Motion 10k
Reese’s Story

All my life, I didn’t understand the disease or why I had lots of pain or why I had to take so many medications, needles, IVs or why I had to see my doctors at SickKids Hospital so much. Now that I’m older, I have just accepted my situation as normal and I’ve done my best to just do what is necessary.

So far, I have put my disease out of my mind and just pushed through playing every sport I could, at the highest levels! I love competing, I love sports and I love being active so I don’t let it stop me – EVER. I’ve hit plenty of roadblocks that required regular injections or IV infusions, changing medications all the time, constant blood work, new procedures or new ways to manage pain. I have used every kind of leg brace, ankle brace, wrist brace and orthotics and now there are some signs of long term damage. At one point, one of the medications did too much damage to my liver and I had to stop meds to let it heal. However, I never once thought about changing anything about my crazy active life!

I liked to keep my situation private. I don’t like people to know I manage this disease because I want to be strong and fit and not have any excuses. With all my trips to SickKids appointments or for IV Infusions or blood work, I’ve missed school or practices but I usually say its for another reason because I’m a fully committed athlete and student. I’m slowly learning that it’s not about being weak and maybe I could support other kids, especially girls, who might think they can’t do something when I know they can with the right support. I’m learning that I can’t just ignore it and have to take charge of my health so I can achieve all the things I want while still being a good example for other kids who are learning how to manage.

Lots of girls stop playing sports at my age and even more stop if they deal with any kind of chronic pain. I want girls to know that NOTHING should stop you from what you want even if it’s sports, music, art or anything you love. I train hard and I have big athletic goals that I intend to reach. I may be learning how to be more open about my condition but I will never, ever let it get in my way.