Post-Secondary Scholarship Deadlines:

May 29, 2020 Lupus Canada Scholarship  
https://www.lupuscanada.org/lupus-canada-scholarship-program/

May 31, 2020 UCBeyond 2020 Scholarship  
https://www.ucbeyond.ca/about.html

July 10, 2020 Dr. Bonnie Cameron Post-Secondary Scholarship  
https://artinmotion10k.com/dr-bonnie-cameron-post-secondary-scholarship/

MyChart Registration is Now Online!

What is MyChart?

MyChart is a secure, online patient portal that provides patients and authorized family members and caregivers access to parts of their SickKids’ electronic health record, anywhere, at any time.

MyChart can be accessed online, via your favorite web browser, or you can download the app on iPhone or Android from their respective app stores.

What can you see or do through MyChart?

- View your lab & imaging results
- Upload photos for your care team
- Update your medications/allergies
- View your upcoming appointments
- Review your after visit summaries
- Send messages to your care team
- Access other relevant health resources

You can now register for MyChart online by visiting: https://bit.ly/2zQzyEO

Announcements:

Due to COVID-19 the following events have been cancelled or postponed:

April 7, 2020 Rheumatology Research Retreat  
Postponed, new date TBD

May 9, 2020 Family Day presented by Cassie + Friends  
Postponed, new date TBD
Virtual Care & Ontario Telemedicine Network (OTN)

Virtual care is a powerful tool in Ontario’s efforts to contain the spread of COVID-19. The OTN platform is part of Ontario’s publicly funded health care system that streamlines virtual care to ensure that everyone has easy access to the best possible care when and where they need it. They do so by simplifying phone consultations, emails, text messaging, remote monitoring and video visits to work with care providers and patients to connect safely at a distance, minimizing the risk of community infection.

Virtual visits can help:
- Screen patients
- Gather patient history, including travel and exposure detail
- Assess symptoms, severity and treatment options
- Monitor progress and check in on patients in isolation
- Communicate with multiple people at once, including family members and/or caregivers
- Connect with colleagues to share information and seek additional clinical input/advice

For more information regarding OTN please visit their website: [https://bit.ly/3cW8m5A](https://bit.ly/3cW8m5A)

Research News: How Does Pain Change Over Time for Children with JIA

Juvenile Idiopathic Arthritis or JIA is a type of arthritis that happens in kids and teens. That’s why it is also called childhood arthritis. Arthritis is the inflammation of joints, the places in the body where bones come together. When joints get inflamed, they can become red, swollen, warm to the touch, stiff and painful. The pain caused by JIA can be a real problem for kids and teens because it can affect their quality of life including their mood, stress levels and how active they are. JIA is the most common type of arthritis in kids under 16 years old and about 10,000 children and teens in Canada have it. That’s why it’s important to learn as much as we can about it, so kids and teens with JIA can get the best treatment possible.

A group of researchers from across Canada come together to study Canadian kids with JIA. They wanted to understand how JIA affects children and teens, including how painful the disease can be. They called this study Research in Arthritis in Canadian Children Emphasizing Outcomes Study (ReACCh-Out). Researchers looked at kids who were just diagnosed with JIA and followed them for five years. At the end of study they found some pretty interesting results. For many children, pain can be mild to moderate in the beginning of the disease. The good news is that for 9 out of 10 children, with time the pain decreases or remains low.

Only 1 out of 10 children with JIA have problematic pain. For some, the pain can start off as mild but become stronger with time. For others, the pain is moderate and does not change. Researchers also found that girls who are older and have a higher number of swollen joints seem to be more likely to have this problematic type of pain.

Researchers will need to do more work to understand exactly why children with JIA have different types of pain. The good news is that doctors can help either way. If you or your child has JIA, tell your doctors about your pain so they can help you deal with it.

The research study described in this article is: Shiff et al., 2018. Trajectories of pain severity in juvenile idiopathic arthritis: results from the Research in Arthritis in Canadian Children Emphasizing Outcomes cohort. Pain. 159(10): 57-66.

To learn more about JIA and how it affects children and teens, you can visit the JIA Learning Hub on the AboutKidsHealth website: [https://bit.ly/2YoEFGj](https://bit.ly/2YoEFGj) or visit the Arthritis Society’s Childhood arthritis webpages: [https://bit.ly/2z1av12](https://bit.ly/2z1av12)

If you would like to join the mailing list please email: rheumatology.newsletter@sickkids.ca
YOUR CHILD and NOVEL CORONAVIRUS, COVID-19

Q&A for Parents of Immunocompromised Children

What is novel coronavirus (COVID-19)?

A new strain of coronavirus (SARS-CoV-2) was identified in Wuhan, China, and has now spread across the globe. The World Health Organization has named this novel coronavirus outbreak COVID-19 and has declared the outbreak a pandemic.

Is my child at high risk of getting COVID-19?

Healthy children are at normal risk of acquiring COVID-19 and at normal risk of complications. Children who are immunocompromised and children with chronic medical conditions may be at higher risk of complications if they do get it.

Is my child immunocompromised?

Immunocompromised children have weak immune systems. Examples of children with weakened immune systems include, but are not limited to, the following medical conditions or medical histories:

- solid organ transplant (for example: heart, kidney, lung, liver, intestinal)
- bone marrow transplant
- cancer
- congenital immunodeficiency
- HIV/AIDS
- rheumatic disease
- gastro-intestinal disease
- is taking selective immunomodulators (for example: anti-TNF agents, azathioprine, MMF and all immunosuppressive agents)
- is taking long-term steroid therapy
- is in a severe malnourished state
- has severe burns

Is my child at high risk of complications because of a medical condition?

We are still learning a lot about this virus and why some people seem to be getting sicker. At the moment serious illness in children seems to be much less common than in adults. Whether some children with underlying or chronic medical conditions are at greater risk of worse illness if they catch COVID-19 is not yet clear. Based on our experience with influenza illness we believe certain children with underlying disease might be at increased risk of complications for COVID-19 infection, for example children with chronic lung disease.
How do I know if my child has COVID-19?

Your child may have COVID-19 if he/she has some or all of these symptoms:

- fever
- cough or sneezing
- sore throat
- difficulty breathing or fast breathing
- runny or stuffy nose
- body aches
- headache
- chills
- fatigue
- sometimes diarrhea and vomiting

While fever might be the most prominent symptom in immunocompromised children, it’s important to note that not all children with COVID-19 will have a fever. For children with runny or stuffy nose you should be most concerned regarding COVID-19 if other symptoms develop. For an immunocompromised child with COVID-19 infection we do not yet know whether or not they have different symptoms.

Should I come to the hospital if I think my child has COVID-19?

If your child has symptoms of COVID-19, we recommend that you contact your primary care team at SickKids before coming to the hospital. They will help you determine if your child needs to be seen and where to go.

You should come to the hospital right away if your child has the following symptoms:

- Fast breathing or trouble breathing
- Bluish skin color
- Not drinking enough fluids
- Not waking up or not interacting
- Being so irritable that the child does not want to be held
- Fever with a rash

Should my child continue on their immunosuppressive medications?

Your child should continue to take their regular medications as prescribed, unless directed differently by your treating team.

For more information regarding COVID-19, treatment of immunocompromised patients and additional resources, Cassie + Friends has some nice information on their website: https://bit.ly/2SoO253 or visit the About Kids Health website: https://bit.ly/2SmbTCq
Living with JRA by Shane Patterson

Growing up with Juvenile Rheumatoid Arthritis from a young age was not easy. There was a lot of difficulties to overcome. With the right help and patience that I received from my doctors, nurses and parents, I was able to do the things I had a lot of passion for. My name is Shane I was diagnosed with JRA in my left ankle when I was 18 months old and now I am 26. I live out in the Canadian Rockies doing what I enjoy most which is white water rafting in the summer and snowboarding in the winter. To get to this point when I was in my early teens I had to right off my Sunday mornings due to feeling ill from my methotrexate. However, that didn’t stop me from trying my best to go outside and still hang out with my friends. Remembering back, it was pretty tough not being able to run as fast or as far, not being able to wake up and not feel sore … but what I was taught to look for the positives, look back and see what I have accomplished already and what I was able to overcome with my draw backs. I fought through the pain mentally and physically and didn’t let anyone tell me I couldn’t do it. I learned to have a sense of humour about it. Learn to live with it and enjoy the challenges. I still find things that I can’t do, for instance ski. Since my ankle isn’t straight I can’t ski straight but I didn’t let that stop me from enjoying winter and now I snowboard every day for the winter at work in the Terrain Park. I keep close watch on my arthritis. I make sure that if I feel sore I do something about it. I do a lot of physical activity which makes me happier and I’m not going to let my JRA stop that. It wasn’t all just me, it was also the help and all the support I have had from my doctor, nurses and parents. The nurses made me feel comfortable at the hospital and for all my appointments. I really enjoyed going there and they made it so I wanted to go back. Dr. Laxer had patience for me when I was acting up and made both my parents and I feel we had the best knowledge and support team. I know it wasn’t easy for my parents but they both were there for me the entire time and wholeheartedly supported me through all my tough times and decisions. I feel like I am a lot stronger now than ever. I work hard to keep my joints feeling good so I can still do the things I enjoy most in life. If you want to talk more about it come find me at Jasper Rafting Adventures and we will talk on the raft!