Interview with 2017 UCBeyond Scholarship Winner: Sarah

Tell us a bit about your story:
I was diagnosed around the age of 2 with oligoarticular extended juvenile idiopathic arthritis. It predominately affected my knees, making it difficult to walk. At the age of 2 I received a corticosteroid shot to my knee, which resulted in my arthritis going mostly into remission until I was 11 years old. At that age, it flared up again in both my knees, as well as one elbow and several fingers. I was put on several medications to manage the inflammation. After several months, I had a severe allergic reaction to one of the medications, so all medications were stopped. I was then given another corticosteroid shot. After this, I did physiotherapy everyday until the age of 14 to minimize any lasting damage. I have mostly been in remission ever since.

Which university are you going to and what are you studying?
I am going to the University of Toronto, and I am taking engineering.

How did you manage school, appointments, and all the other things you did?
It was hard at first to keep on track of everything, and I often relied on my parents to keep track of it all. As I got older, however, I had to learn how to deal with it all on my own. My go-to strategy is to make lists of everything that I need to do and when, so that I can ensure I am not forgetting anything and that everything gets done.

Did your school/teachers know about your condition? How did they help you?
Yes, my teachers and school knew about my condition. They were very accommodating and understanding of my condition. My teachers would help me catch up on any work that I missed, and were very understanding of the various physical accommodations that I required.

See School on page 2
Research Results: Characteristics of Patients with Arthritis of the Jaw

SickKids rheumatology recently collaborated on an international study with three other hospitals to look at JIA patients with arthritis that only involves the temporomandibular or jaw joints (“isolated TMJ arthritis”). Patients with TMJ arthritis often have no symptoms, especially early on. Many patients are often seen initially by dental or medical non-rheumatology specialists who may be unfamiliar with this condition.

Medical records of patients followed in pediatric rheumatology clinics for jaw arthritis were reviewed to look for patterns. 55 patients were included in this study (89% were female). The physician referring to rheumatology was the dentist or orthodontist in 33 (60%) of cases, the pediatrician or family doctor in 16 (29%), and physicians of other specialties in 6 (11%) of cases. Interestingly, 4 (7%) of patients were referred to rheumatology by their ophthalmologist because they had uveitis (eye inflammation), and their TMJ arthritis was diagnosed after detection of uveitis.

The average age of diagnosis of TMJ arthritis was 13 years. 6 (11%) patients eventually developed arthritis in other joints.

Increased awareness of isolated TMJ arthritis by non-rheumatology health providers will hopefully lead to earlier diagnosis and management which will help reduce long term complications of this condition.

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: rheumatology.newsletter@sickkids.ca

If you would like to contribute to the next newsletter or have suggestions for content, let us know:

rheumatology.newsletter@sickkids.ca

Epic is coming! SickKids Launches New Electronic Medical Records System June 2018

By Ingrid Goh and Dr. Deborah Levy

On June 2, 2018 The Hospital for Sick Children will be launching a new electronic medical record system called Epic.

What will this mean for you?

- We will be decreasing our appointment bookings in June and through the summer while adjusting to the new system
- Your appointment may be longer as we adjust to the new system
- We may be changing the setup of some of the examination rooms
- Patients will need to wear their wristband as it must be scanned at multiple points in the hospital
- Multiple existing computer system will be integrated into one system, allowing for improved communication and ultimate this will be a tool to provide better care for you
- You will have the option of signing up for the patient portal “MyChart”

What is the patient portal?

- The patient portal allows you to access some of your medical records
- You can also use the patient portal as another way of communicating with your healthcare team
- You will receive printed prescriptions and a visit summary sheet at the end of your appointment that will highlight important information that was discussed
- You can see which research studies that you are participating in
- You may receive information about upcoming research studies that you may be interested in joining
How did your parents help with school?
My parents had a vital role in my education. They made sure that I didn’t miss any material due to absences resulting from my condition. They gave me extra work to do in the summer to make up for anything I may have missed, to ensure that I did not fall behind.

What was your biggest obstacle in school?
My biggest obstacle in school was balancing all of my extracurricular activities with my condition and education. I was very involved with band and basketball, and my grades were also very important to me. Striking the right balance between them was very difficult, and took lots of trial and error to determine the right combination.

How would you handle a good arthritis day?
I would handle a good arthritis day by making the most out of it. Without the distraction of pain, I would really try and focus on the things that otherwise were harder to concentrate on. Taking advantage of good days was very important, because you never knew when another one would occur.

How would you handle a bad arthritis day?
The way in which I would handle a bad arthritis day was to distract myself, while also allowing time for rest. Doing small, simple tasks helped keep my focus away from the pain, while also feeling productive. By doing this I could allow myself the necessary time to recover, while also doing the things I needed to do.

What do you want to do when you finish school?
I would like to work in the biomedical engineering field to improve healthcare. I have always had an interest in biology, as well as a passion for helping other patients. I would love to work at SickKids Hospital one day and be able to help patients like the staff at SickKids once helped me.

What advice do you have for others to succeed in school?
Advice that I have for others for succeeding in school is to find how each subject you are taking can be applied to something you are passionate about. The individual subject itself may not be directly related to your interest, but by finding ways to connect what you are learning to your passions, it will make it much more enjoyable. By finding a passion for the subject you will find yourself more invested and able to succeed.

Here are some websites that have more information about balancing school and arthritis:

Information about school:
Cassie and Friends  

Arthritis Research UK  
https://bit.ly/2HvY1A9

Information about higher education:
Teens Taking Charge  

Information for Teachers:
Kids Get Arthritis Too  
https://bit.ly/2qHe7hX
Story on a String: Bravery Beads are now in Rheumatology Clinic

Bravery Beads tell the story of patients’ journey. They serve as a reminder of patients’ bravery in facing each procedure or event in their treatment. Each bead stands for a different procedure or event.

Patients receive a coloured cord and bead to spell out their first name and a Child Life bead. Patients can pick up the the Bravery Beads they need every time they come to the hospital.

The Bravery Bead program is entirely funded and supported by the hospital’s Women’s Auxiliary Volunteers.