Parents Helping Parents – iPARENT TO PARENT

By Sara Aholha Kohut

Parenting is hard and can get complicated in the best of circumstances. When you have a child diagnosed with a chronic condition, parenting becomes even more complicated. It can be difficult to navigate the roles of everyday parenting while also helping to manage your child’s symptoms, medications, appointments, procedures, etc… Often it can be difficult to find other parents who understand. Although there are several ways to get involved and meet other parents at the hospital, it can be challenging for some parents to come in-person outside of clinic appointments.

See Parent Peer Mentor on page 2

Kids Helping Kids – iPeer2Peer

By Celia Cassani

Juvenile Idiopathic Arthritis (JIA) is a common long-term condition that results in challenges to many aspects of both physical and mental health. In youth, JIA can result in physical and emotional obstacles, school and work problems (e.g., absenteeism, productivity), and challenges in social interactions (e.g., peer and friend restrictions). Peer mentoring is a form of social support that patients can participate in to help lessen these challenges. Peer mentoring helps to increase the likelihood of adolescent involvement in managing their disease, decrease feelings of social isolation, and help patients develop positive self-identity.

iPeer2Peer is an innovative program that patients can access through the internet. The program encourages self-management while also providing access to different tools. The program can improve the quality of life of patients by providing supportive opportunities for social interaction between youth who understand.

If you are 12-18 years with JIA and are interested in being matched with a mentor, please email celia.cassiani@sickkids.ca for more information.

Learn more at…

https://lab.research.sickkids.ca/iouch/ipeer2peer/
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](https://pr-coin.org/families) for more information
- Members for the SickKids Rheumatology Family Advisory Council and its subcommittees

Contact: [rheumatology.clinic@sickkids.ca](mailto:rheumatology.clinic@sickkids.ca)

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Announcements

*Congratulations to…*

**Dr. Linda Hiraki** who won the 2018 Arthritis Society Stars Career Development Award.

**Dr. Shirley Tse** who won the 2018 Canadian Rheumatology Association Teacher Educator Award.

**Dr. Rayfel Schneider** who won the 2019 CPSO Award, as a model of the “ideal physician”.

**Saunya Dover** who received the 2019 Clinical Research Excellence Award.

**Kamela Ramlackhan** who received the 2019 Administrative Excellence Award.

*And a warm welcome to…*

New staff **Dr. Andrea Knight** and **Dr. Dilan Dissanayake**

New fellows **Dr. Chelsea DeCoste, Dr. Lester Liao, Dr. Tala El Tal**, and **Dr. Raffaella Carlomagno**

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Parent Peer Mentor

Peer mentoring programs have been shown to be accessible if done online and helpful for teens living with JIA by supporting improved disease and pain management. We are offering a chance for parents to get connected as well. Connecting with other parents who share similar experiences not only offers social and emotional support, but also practical tips and tricks for day to day life with a child with JIA. We encourage all parents to take care of themselves, since research has shown that when a parent takes care of their own stress it improves their child’s health outcomes!

If you are interested in being a mentor to other parents with children with JIA OR are a parent who would like to get connected to another parent, please contact [natalie.weiser@sickkids.ca](mailto:natalie.weiser@sickkids.ca) for more information.

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SickKids Rheumatology Family Advisory Council Facebook Group

The Rheumatology Family Advisory Council has recently created a Facebook Group. If you are interested in learning about the Family Advisory Council, joining or helping out on any of the workgroups, make a request to be added to the group. This group will also allow you to network caregivers.

The QR code will send you to the Facebook Group page.

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To subscribe to News Rheum please visit: [www.eepurl.com/c49p5X](http://www.eepurl.com/c49p5X)
New JIA Transition Clinic Opens at Womens College Hospital

By Lynn Spiegel, Evelyn Rozenblyum, and Ingrid Goh

Rheumatology patients are followed by the SickKids healthcare team until they reach 18 years of age. Once they turn 18, their care will be transferred to an adult rheumatologist. Switching from a pediatric to an adult rheumatologist comes at a critical time when young adults are going through many different transitions or changes in their lives. Some of these changes may include graduating from high school, taking a gap year, starting a new program in college or university, beginning a new job, and/ or moving away from home. All of these changes can be overwhelming.

It can be challenging for patients and their caregivers to move from the pediatric to the adult healthcare system. Adults are expected to take charge of their own health. This includes knowing about their medical condition, knowing which treatments they are taking, being responsible for filling their prescriptions, and speaking to their healthcare team about their treatment plan.

The SickKids team has recently developed a SickKids Rheumatology Transition Policy to help patients and their families understand how things will work as they are preparing to move over to adult care. This document outlines what patients and caregivers can expect from the SickKids healthcare team and what patients and caregivers are expected to do during this learning process.

To help support patients and families during this period of transition, the SickKids rheumatology team has paired up with the adult rheumatology team at Women's College Hospital to establish a Juvenile Idiopathic Arthritis (JIA) Transition Clinic. This clinic is based at Women's College Hospital and will see young adults with JIA from 18-25 years. This program will help young adults to develop the skills they need to confidently navigate the adult healthcare system. In addition to providing medical care, young adults will also be provided with advice and support around lifestyle, education and vocation.

The Women’s College Hospital JIA transition team consists of Dr. Natasha Gahkal, an adult rheumatologist, Dr. Evelyn Rozenblyum, a pediatric rheumatologist, and Ms. Danielle McCormack, a physiotherapist. They will support you during this journey. Teens and caregivers who would like more information about the JIA Transition Clinic should speak to their healthcare team.

New JIA Education Clinic

By Ingrid Goh

The SickKids rheumatology clinic will be hosting a new JIA patient education clinic on September 23, 2019. This event is co-produced by our Rheumatology Family Advisory Council. We understand that there you receive a lot of information on your first visit to our clinic and you may have many questions and want to look at different strategies that may help you adapt to the changes.

This clinic was created to help support patients and families with their new diagnosis. The day will be filled with opportunities for patients and families recently diagnosed with JIA to meet the different members of the rheumatology team, learn, ask questions, and meet other families.

This is the team’s first attempt at hosting an education clinic. If this clinic is successful we will continue to host similar clinics and also host similar clinics for other rheumatic conditions.

To subscribe to News Rheum please visit: www.eepurl.com/c49p5X
KidsKorner
#SupportEachOther!

Come share your positive messages and pictures with us in Clinic 9! You can then #share using #hashtags on #socialmedia.

More information on self-management of JIA
https://bit.ly/2W7hEDP

A magazine and social network for young adults with arthritis
https://arthursplace.co.uk/

Support links, opportunities, and events for JIA