Important Dates/Upcoming Events:

**July 13-16, 2017**: Juvenile Arthritis Conference
Houston, TX

**August 21-26, 2017**: Camp Cambria organized by
The Arthritis Society

**October 15, 2017**: Art in Motion 10K Kleinberg, ON


Announcements:

**New Rheumatology Fellows starting July 2017**
- Dr. Dilan Dissanayake
- Dr. Elizaveta Limenis
- Dr. Watchareewan (Taylor) Sontichai
- Dr. Alhanouf (Hanouf) Al-Saleem

**Celebrations in the Division of Rheumatology**
- Dr. Yeung and collaborator Dr. Wulffraat from
University Medical Center Utrecht (Netherlands)
were awarded $8 million pediatric rheumatology
research grant
- Dr. Schneider received the 2017 Medical Staff
Association Citizenship Award

Research Update: **Biobank 101**
By Ingrid Goh

You may have been asked during your visits to SickKids to participate in a biobank. There are several biobanks that you may be able to contribute to either at SickKids or in other institutions such as the National Institutes of Health or other research organizations. Here’s a quick tutorial about biobanks.

**What is a biobank?**
A biobank is a place that stores biological specimens (blood, tissue, saliva, etc.). These items are stored for future use.

See Biobank 101 on page 2

Feature Article: **Teens Taking Charge Self-Management Program Now Available by Roshan Dewani**

Juvenile idiopathic arthritis (JIA) affects about 1 in 1,000 Canadian children. JIA causes inflammation in the joints and impacts physical, emotional and social well-being.

A team of researchers led by Dr. Jennifer Stinson at SickKids developed an online program based on feedback from teens and their families that they could not find reliable information in one central place.

Funded by The Arthritis Society and Canadian Institutes of Health Research (CIHR) program, Teens Taking Charge: Managing JIA Online Program is now publically available online in English and French ([http://bit.ly/2meLk2u](http://bit.ly/2meLk2u)).

This interactive internet-based program was designed for teens with JIA and their parents as a reliable, easily accessible resource to be used throughout the course of their illness. The content, delivered in 12 modules, includes information about JIA, its treatments, and self-management strategies (for example, how to deal with physical and emotional symptoms). It also facilitates peer support through discussion boards, and videos offering instruction and inspiration.

See Taking Charge on page 2
Biobank (continued from page 1)

Why is a biobank needed?
When people have rare diseases, it is difficult for researchers to get enough specimens on specific conditions and they are difficult to get it when they need it to do research. By storing samples, we can have samples when it is needed and collect enough samples to do experiments on.

How long are the samples kept in the biobank?
The samples are usually kept in the biobank forever. You may decide to request that your specimens are removed from the biobank. If you decide this, you can contact the biobank or the research group who are collecting these samples for the biobank.

Who gets access to samples in the biobank?
When you decide to donate biological specimens to a biobank you have the choice of deciding whether to allow only researchers at SickKids to use your specimens or if you will let researchers around the world use your specimens. Samples stored in a biobank are not given to just anyone. Researchers who want to obtain samples from the biobank need to first get approval from their research ethics board. They then need to apply to the biobank governance committee to access the samples. The biobank governance committee is a group of members who is responsible for deciding whether the samples should be released to the researchers.

What happens to the samples in research?
The researchers will receive de-identified specimens and do experiments. Some of these findings may be published in scientific journals. We may or may not know about the results of these findings. If there are findings which are clinically significant then it will be communicated to the biobank. The biobank will contact your doctor and let them know. Your doctor will contact you and ask you if you want to know about these results.

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
- 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

Taking Charge (continued from page 1)

“Going through the modules in the Teens Taking Charge program helped me better understand arthritis, which gave me the self-confidence to manage what I was going through,” says Madeleine Dempster, 19, former SickKids patient and research participant on this project.

The website was tested for effectiveness using a randomized controlled trial of 333 adolescents from 11 paediatric centres across Canada. “The results so far have shown that teens who used this online resource tended to experience less overall pain, and less pain interference with sleep and enjoyment of daily life as well as self-efficacy, compared to teens who did not use the site,” says Stinson.

This bilingual, interactive, internet-based program was funded by The Arthritis Society and the Canadian Institutes of Health Research (CIHR). “We’re proud to partner with Dr. Stinson and her fellow investigators on this collaborative effort that will benefit thousands of young people across Canada,” says Arthritis Society president and CEO, Janet Yale.

To learn more, check out http://bit.ly/2meLk2u
To read the entire article visit http://bit.ly/2na5mIM

If you would like to join the mailing list please email: rheumatology.newsletter@sickkids.ca
Transitioning from Canadian to American Healthcare
By Gia Caci

Life transitions are never easy. Moving is an emotional and stressful event for families. Changing healthcare for a chronically ill child adds an additional level of complexity. Prioritizing your child’s healthcare transition is mandatory.

My child was a patient in the rheumatology and ophthalmology clinics at SickKids for 8 years. In June, we started our first ever biologic taper to “test the waters” of remission. In July, my husband accepted a new position, and we relocated from Ontario to California.

Health care system differences between two countries at the beginning of a medicine taper sounded like the “perfect storm” to me.

The main difference between health insurance in Canada versus the United States centers around who and how much coverage is paid. In Ontario, OHIP is funded by taxes, and care is managed and paid for by the government. Patients pay no premiums and there are seldom any fees to see a doctor or stay in a hospital.

In the US, healthcare insurance is typically offered by your employer who has a blanket plan for all employees from an insurance company. You pay monthly premiums and co-pays to use the insurance. Unlike OHIP, employer sponsored plans typically cover medical, pharmacy, para medical, hospital and dental benefits within policy limits. Employers often offer different levels of insurance that dictate the premiums and coverage benefits. If your child is on DMARDS, or a biologic, you will most likely default into the highest level (most expensive) plan just to have some pharmaceutical coverage.

The relocation forced me to deal with the healthcare transition head-on and not procrastinate. The intricacies of insurance, pharmacy and doctor visit differences are overwhelming at best.

Picking an Insurance Plan

The two most important items to research prior to choosing a US health care plan are the pharmacy coverage (have the DIN# for your child’s medications) and whether the doctors you are being referred to are “in-network”. Out of network doctors mean less financial coverage for you if you choose to use their services.

Work with your human resources department at work to understand the specialist and drug coverage prior to picking your level of insurance. Most plans can only be changed annually, so you need to make the best-informed choice up front.

Here is a list of “to-dos” to make a medical transition as seamless as possible. This list is not all encompassing, and some points may not apply to every situation.

Before You Relocate

- Start to look for your new doctor as soon as possible
- Make appointment(s) with your new doctor(s) as soon as possible
- Request a summary of your child’s treatment records
- Request your child’s immunization records
- Request and fill ALL prescriptions for ALL family members before you move

After You Relocate

- Choose the best insurance for your family
- Enroll in DMARD/biologic financial assistance drug programs
- Set up on-line pharmacy account so there are no delays in filling prescription.
- Tell your new doctor everything that your child uses for treatment
- Use transition tools
- Meet with your child’s Special Education team at school if you need to continue an IEP
- Be prepared for differences in methodology and treatment

A successful healthcare migration is a team effort. It involves your child’s primary doctors at the old and new hospitals. Parents must be the project manager between the systems. Navigating any healthcare journey is a quest. Transitions will take time, continuous communication, follow-up, patience, and some good luck along the way. The effort and challenges will be worth the result: the optimal health care results for your child.

To read the entire article visit http://bit.ly/2uDgiTa
This issue we feature some of our real rheumatology superheroes as drawn by you!

Kristi
By: Aida, 8

Dr. Spiegel
By: Makayla, 7

Audrey
By: Emma, 7

Dr. Tse
By: Addison, 10

Dr. Feldman
By: Aaliya, 8

Kids Korner:

Art Rheum

Join us in the Art Rheum while you wait for your doctor.

Come make crafts and have a fun time with our volunteers!

Games!

We have board games that you can borrow to play with while you are in clinic.

Ask one of your clinic friends to help you find them.

If you would like to join the mailing list please email: rheumatology.newsletter@sickkids.ca