



Hot off the press!
Results from studies in our Division
Patient Satisfaction Survey

For the past 4 months, patients and parents in the Rheumatology clinic filled out anonymous surveys about their satisfaction with the clinic and services provided, the information provided by the Rheumatology team and the impact of disease on their child's quality of life.

Overall, parents (92%) and patients (85%) are satisfied with the care received in clinic, and 95% of parents and 87% of patients feel that most of their questions are answered in clinic. While 80% of parents find written information provided in clinic helpful, 40% of patients do not find the written information helpful. When asked about the things they most like about clinic, parents and patients said they appreciated the Rheumatology team's helpfulness and friendliness. Wait times, parking and the need to travel to get to clinic were listed as aspects of the clinic parents/patients want to change. Common disease-associated difficulties mentioned by parents and patients are: physical difficulties, pain and the need for medications/procedures.

In conclusion, the majority of patients and parents are satisfied with their care in clinic - particularly with their interactions with the Rheumatology team. Results of the survey reveal that patients do not particularly find the written information about their disease/medication helpful, which suggests that more work is needed to find ways of engaging children and teens in learning about their disease. Ultimately, the feedback resulting from the survey has been helpful in making sure that our Pediatric Rheumatology clinic continues to improve and provide the best care possible to all of our parents and patients.

Thank you to everyone who completed the survey!

Announcements



This year, we are seeing familiar faces rejoin the Rheumatology Team. **Dr. Kristin Houghton**, who some of you may have already seen in clinic, is now back from maternity leave.

Dr. Tommy Gerschman, who completed his Pediatric Rheumatology training with us a few years ago, will also return to clinic this month. Welcome back Kristin and Tommy!



Rheumatology
Research Report

For Patients & their Families

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Editor's Space



Research assistants at the Rheumatology Winter Celebration, Dec. 2013

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Happy 2014 and welcome to another issue of our research newsletter! We hope you had a wonderful and relaxing holiday season. The Rheumatology team is looking forward to the coming year as we continue to lead two multi-centre studies on juvenile arthritis and childhood vasculitis.

In this edition of the newsletter, we will tell you about the results of the patient satisfaction survey that over 600 of you participated in, and announce the launch of our family resource page on the Rheumatology website.

As always, you can read about new studies and studies that are currently recruiting patients in this newsletter. Happy New Year!

Wishing you all the best in health and happiness for 2014!

The New Kids on the Block: Our Division's Newest Projects



The Abatacept Registry



The Rheumatology clinic is participating in an observational study to evaluate the long-term safety of a new drug used to treat juvenile arthritis (JIA) called Abatacept (Orencia). Abatacept is approved for use in both adults and children with arthritis. This study will involve collecting clinical data over the course of 10 years about patients who are currently taking Abatacept for their JIA. Information will be collected even after the patient stops taking the medication. The intent is to gather information about the long term effects and safety of this medication.

Help us Improve How We Do Research: Clinical Research Participant Online Survey



The BC Clinical Research Infrastructure Network (BCCRIN) is conducting an on-line, anonymous survey about parent/patient experiences with **clinical trials** – which are studies that test the safety and effectiveness of **new drugs and medical interventions**. If you have ever been asked to participate in a clinical trial or are the parent of a child who has been asked, you are now invited to complete the online survey at the link below.

Fill out the survey at: www.bccrin.ca/survey

Check this out! Rheumatology Online Resources

We have recently launched a Family Resources section on our Rheumatology website. The resources page features short information pamphlets written by our rheumatology nurses about the different rheumatic diseases, medications and more!

Visit the website at:

<http://www.bcchildrens.ca/Services/SpecializedPediatrics/Rheumatology/resources.htm>

We want to hear from you!

If you are a parent/patient in the Rheumatology clinic and would like to contribute to the Rheumatology Research Newsletter, please contact our research coordinator at rheumresearch@phsa.ca

Studies Currently Recruiting Patients

Systemic Lupus Erythematosus (SLE)

PedANAM as a Screening Tool for children with SLE

Research Question: Is the Pediatric ANAM computer test a useful tool for monitoring the cognitive status (how well your brain works) of patients with lupus?

Eligibility? 10-18 years old with SLE.

What do participants do? Take a 30-minute computer test every 6 months at the same time as your Rheumatology clinic visits, for 3 years.

Childhood Vasculitis

Pediatric Vasculitis Study

Research Question: What is the best way to diagnose, monitor and treat children and teens with vasculitis?

Eligibility? Newly diagnosed with vasculitis or previously enrolled in ARCHiVE/Brainworks

What do participants do?

Provide blood and urine samples at 0, 3-6 and 12 months (new patients), or only when flaring (ARCHiVE/Brainworks patients), and a one-time saliva sample.

Juvenile Idiopathic Arthritis (JIA)

I have inactive disease.

I'm newly diagnosed.

PREVENT-JIA Study

Research Question: Can a new blood test that measures a protein called S100 help predict if a patient whose arthritis is under control will have disease flare after medications are stopped?

Eligibility? Any subtype of JIA, except oligoarthritis persistent who has inactive disease on medications for 6 to 12 months.

What do participants do? Maintain a stable dose of medication, occasionally provide blood samples for testing in Germany and return for clinic visits every 3 months.

LEAP Study (Linking Exercise, Activity, and Pathophysiology in JIA) www.leapjia.com

Research Question: Does physical activity improve or worsen disease activity in kids with arthritis, does it help or worsen bone and muscle development, and how does it overall affect their outcome?

Eligibility? Children 8-16 years old
What do participants do? Fill out questionnaires, complete specialized bone scans, perform jumping tests, and provide blood samples every 6 months for 2 years (5 times) at time of routine testing.