



INSIGHT Newsletter

Vol. 3 Issue 1 – Spring 2017 

Dear INSIGHT Participants and Families,

We have officially recruited 500 participants to the INSIGHT study! What a milestone! Currently we are the largest prospective paediatric study on nephrotic syndrome in North America and we would like to thank all of our participants for donating your time to join this study! Together we will help answer important questions that will help children and families with nephrotic syndrome in the future.

Thank you! ☺

The INSIGHT Team



Family Appreciation Night 2017

Please join us as we thank you for your continued support in our effort to better understand childhood nephrotic syndrome. There will be activities for children at the event.

Tuesday June 27th, 2017

5:30 – 8:00pm

2nd Floor Gallery, Peter Gilgan Centre
686 Bay Street, Toronto



INSIGHT on CBC News!

INSIGHT was in the news highlighting one of our studies!

CBC News link:

<http://www.cbc.ca/news/health/health-literacy-parents-1.3987678>

Also check out the interview with Dr. Rulan Parekh, Principal Investigator of the INSIGHT study:

<http://www.sickkids.ca/AboutSickKids/Newsroom/Past-News/2017/science-show-and-tell-health-literacy-children-chronic-kidney-disease.html>

Appetizers will be provided. Parking available upon request. **Please RSVP by June 1, 2017** to: insight.study@sickkids.ca or 416-813-7654 x309362
In RSVP please provide: Number of children attending, number of adults attending, whether you will require parking and any dietary restrictions

Focus Groups - We want your opinion

We would like to invite parents and families to a focus group meeting. Our goal at the focus group will be to determine key patient centred outcomes and research priorities for families. These focus groups will be held for 1 hour on a weekday evening, light appetizers will be provided. We are hoping to host 2 separate meetings. If you are available April 18-21 in the evening and would like to participate, please email insight.study@sickkids.ca with preferred dates and times.



❖ Join the SickKids Family Advisory Network! More info at <http://www.sickkids.ca/patient-family-resources/child-family-centred-care/Children-and-Families-as-Partners-in-Care/index.html>

Principal Investigator:

Dr. Rulan Parekh

Co-investigators:

Dr. Diane Hebert
Dr. Rachel Pearl
Dr. Valerie Langlois
Dr. Seetha Radhakrishnan
Dr. Christoph Licht
Dr. Damien Noone
Dr. Leo Levin
Dr. Lisa Strug

Nurses:

Josie Brooke
Monica Piekut
Michele Reddon
Kim Aitken-Menezes
Ashley McNaughton

Nephrology Fellows:

Simon Carter

Study Team:

Jovanka Vasilevska-Ristovska
416-813-7654 ext. 304819
jovanka.vasilevska-ristovska@sickkids.ca
Tonny Banh
416-813-7654 ext. 309362
tonny.banh@sickkids.ca
Karlota Borges
416-813-7654 ext. 301868
karlota.borges@sickkids.ca
Mikaeel Ghany
416-813-7654 ext. 309361
mikaeel.ghany@sickkids.ca
Tasha Jawa
natasha.jawa@sickkids.ca

And a big thank you goes to our students for all their hard work!

Aliya Szpindel, Bianca Bondi,
Shawn Khullar, Alex Gaglione,
Christine Byrd, Harry Lo, Natalia
Konstantelos, Maryam Khan, Zaid
Al Azzawi



To the left: Dr. Simon Carter and Dr. Rahul Chanchlani at INSIGHT Family Appreciation Day, July 2016
To the right: Nephrology physicians and support staff outside the TORONTO sign at City Hall lit orange in honour of World Kidney Day, March 9 2017

INSIGHT published articles

The rationale and design of Insight into Nephrotic Syndrome: Investigating Genes, Health and Therapeutics (INSIGHT): a prospective cohort study of childhood nephrotic syndrome. BMC Nephrology. (2013).

- This paper discusses the goals of INSIGHT and what we hope to achieve over the course of the study
- We demonstrate what information we collect and why it is important

Parental attitudes to genetic testing differ by ethnicity and immigration in childhood nephrotic syndrome: a cross-sectional study. Canadian Journal of Kidney Health & Disease. (2016).

- This paper investigates whether ethnicity and immigration status influences parental interest in genetic testing
- 85% of parents were interested in genetic testing for their child with lower rates of interest among those of South Asian descent or those born outside of Canada

Ethnic Differences in Incidence and Outcomes of Childhood Nephrotic Syndrome. Clinical Journal of the American Society of Nephrology. (2016).

- This paper investigates ethnic differences among incidence rates and outcomes of children with nephrotic syndrome
- Despite the higher incidence of nephrotic syndrome among South Asian children, South and East/Southeast Asian children have significantly less complicated clinical outcomes compared to European children

Newly Published!

Parental Health Literacy and Outcomes of Childhood Nephrotic Syndrome. Pediatrics. (2017)

- This paper investigates the effects of parental health literacy on treatment response among children with nephrotic syndrome
- Lower health literacy, specifically reading comprehension, is associated with higher relapse rates and fewer achieving complete remission

Visit our website at <http://lab.research.sickkids.ca/parekh/research/insight/>