

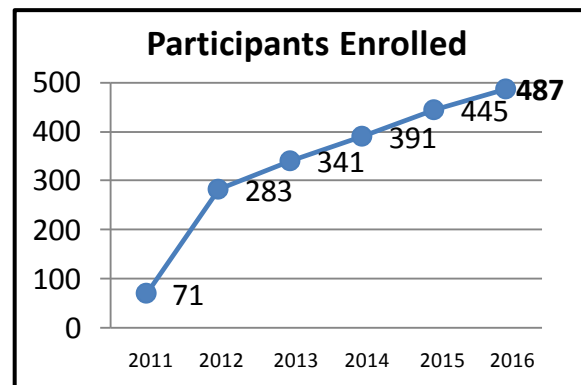
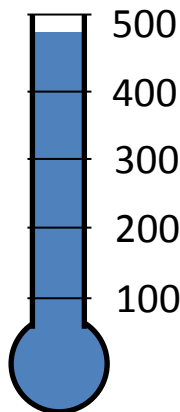


INSIGHT Newsletter

Vol. 2 Issue 1 – Winter 2016

Dear INSIGHT Participants and Families,
 Season's Greetings! We are now coming to the end of our 6th year of recruitment for the INSIGHT study with 487 participants. So close to 500! We would like to thank all of our participants for another great year. You are all helping answer important questions that will help families and children with nephrotic syndrome in the future.

From all of the INSIGHT team, we wish you a very Happy Holidays!



Family Appreciation Night

Family Appreciation Night was a success!

In June 2016 we had our first INSIGHT Family Appreciation Night. We would like to thank all the families that came and made it a success! Food was eaten, prizes were won, and parents had a lot of great suggestions and feedback for what we should study next in INSIGHT. If you weren't there – we would still love your feedback! Email insight.study@sickkids.ca with any questions or suggestions you have for INSIGHT or for our next Family Appreciation Night.



Upcoming Events!

INSIGHT Focus Groups

- In the New Year, our goal is to design different strategies (infographics, apps) to provide up-to-date information for families new to nephrotic syndrome
- The first step will be a brief questionnaire to explore parents' experience when their child was diagnosed
- We will then hold focus groups to get feedback on what YOU think is important information to provide and the best way to deliver information

If you are interested in attending focus groups please email insight.study@sickkids.ca. We will send more info about exact dates in the New Year!

Blood and Urine Collection

What are we doing with blood & urine we collect?

- We are collecting blood and urine to examine genetic factors associated with nephrotic syndrome.
- For blood, we will be extracting and testing DNA. We will then compare to the general population to see whether there are particular genes that are different that may have to do with nephrotic syndrome.
- For urine, we will be extracting and testing protein and other substances in the sample. We are looking to see whether these things in the urine can tell us about genes in the DNA.

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

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Christine Byrd, Luana Santos,
Rachel Wine, Shawn Hudes,
Nahid Iseyas

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

To be published soon:

Parental Health Literacy and Outcomes of Childhood Nephrotic Syndrome. Pediatrics: accepted Dec 2016.

- 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/>