Dear INSIGHT Participants and Families,

Season's Greetings! We are coming up to our 5th year of recruitment for the INSIGHT study with a total of 447 participants enrolled! Thank you to all our wonderful families for participating in INSIGHT. You are

helping to answer important questions that will help many other children and families affected by nephrotic syndrome. We look forward to working together in the New Year. From all of the INSIGHT team, we wish you a very Happy Holidays! Sincerely,

## The INSIGHT Team:

Dr. Rulan Parekh, Jovanka Vasilevska-Ristovska, Tonny Banh, Karlota Borges & Mikaeel Ghany

# Goals of INSIGHT

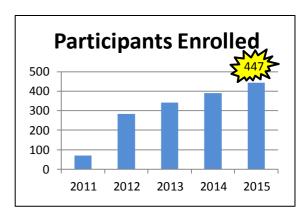
- Understand what causes nephrotic syndrome and how children respond to treatment
- Understand the impact nephrotic syndrome has on children and families at home or at school
- Help doctors better treat nephrotic syndrome to prevent kidney disease progression

# Science Update

#### What have we learned from INSIGHT so far?

- In the Greater Toronto Area, there is approximately a 6 times higher incidence of nephrotic syndrome among South Asian children compared to European children
- South Asian and East/Southeast Asian children have higher rates of complete remission after

initial therapy, 35% fewer subsequent relapses after initial treatment and 25% longer relapse free periods compared to European children in our study



# **Upcoming Events!**

### **INSIGHT Family Appreciation Night**

 We are planning to have an Appreciation Night at SickKids in the Spring - please let us know if you're interested! All families are welcome! We will present some of the findings from the study so far, and there will be opportunities to ask us questions and tell us what you think is important to study! Light refreshments will be provided.

### **INSIGHT Focus Group**

 We are going to hold a meeting with INSIGHT parents to help us better understand how families would like to learn about nephrotic syndrome and what would be valuable in a nephrotic syndrome teaching app.

If you are interested in attending one or both of the upcoming events or would like more information, please email us at <a href="mailto:insight.study@sickkids.ca">insight.study@sickkids.ca</a> or give us a call at 416-813-7654 ext. 301868!