



VOLUME 5. SUMMER 2020

INSIGHT Newsletter

A Message from
the INSIGHT
Team

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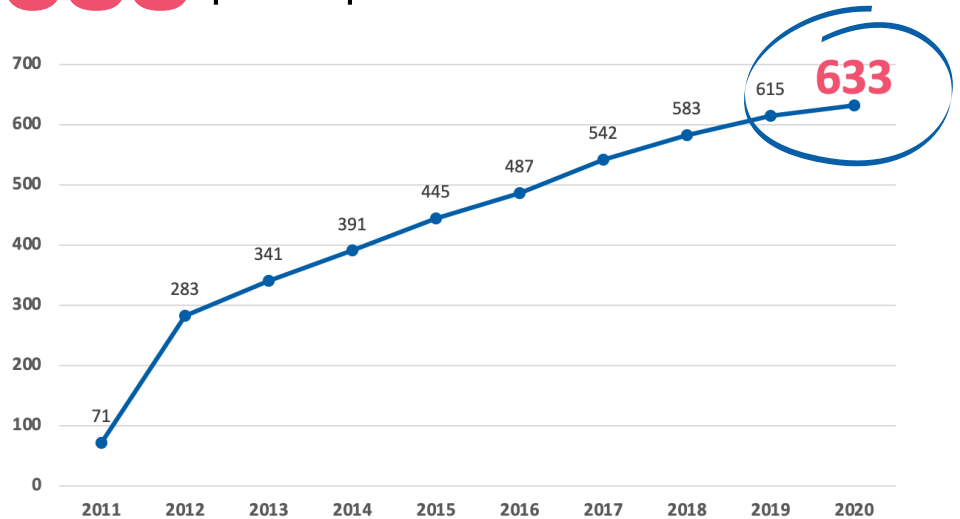
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NephCure Canada

633 participants have been recruited!



Dear INSIGHT Participants and Families,

We hope you and your loved ones are staying safe and healthy during these uncertain times. We wanted to reach out and fill you all in on our study progress this past year.

Since the beginning of 2019, we have **published four new papers** - information on which can be found below! Through social media, our papers have been shared across the world. As a result, we have had international researchers reach out to collaborate. This has allowed us to **translate our infographics into three different languages**, with more to come! Thank you all for your comments and feedback on the infographics, which made them possible!

We are very grateful for the time you have taken to be a part of our study. As the beginning of the school year approaches, if you have any concerns about returning to school, please reach out to us. We are developing a tool for families with children returning to school and would love your input.

We hope you had a wonderful summer. Stay safe,
The INSIGHT Team



FAMILY APPRECIATION NIGHT UPDATE

Our annual Family Appreciation Night is cancelled this year, in light of current circumstances. We are already looking forward to hosting the event next year, if and when it is safe to do so. When the time comes, we will send out information surrounding the details of the event!



COVID-19 WELL-BEING SURVEY

We have sent out a short survey to your emails to collect information that will help us understand the impact of the COVID-19 pandemic on your families.

When you have a moment, please fill out the survey!



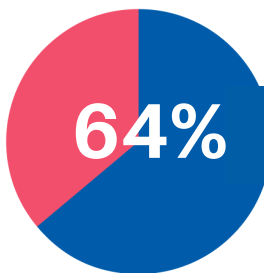
GENETIC TESTING UPDATE

We have **completed the first round of genetic testing** and analysis is underway! We hope to share some informative news from this data in the coming year.



4 THINGS WE'VE LEARNED THIS YEAR

1



64%

of individuals with nephrotic syndrome reported having **allergies or asthma** at presentation

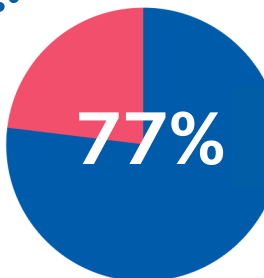
Surprisingly, allergies and asthma were not associated with increased frequency of relapse. [Click to learn more!](#)

2

Children born **prematurely** or with a **low birth weight** were more likely to have steroid resistant nephrotic syndrome. Birth weight and prematurity did not influence time to first relapse. [Click to learn more!](#)



3



77%

of individuals with childhood nephrotic syndrome are **disease free** at 18 years of age!

It is difficult, however, to predict an individual child's disease course. [Click to learn more!](#)

4

In a study conducted based on concerns from INSIGHT parents, **children's quality of life**, including sleep, and social and emotional functioning **is affected** when on medication for nephrotic syndrome and **improves once medications are discontinued**. Thank you for helping to guide our research! [Click to learn more!](#)



Study Team

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

Aleksandra Stojanova, Nandita Manoj, Divya Balendra, Annie Li, Bianca Bondi, Sabreena Moosa, Shawn Khullar, Natalia Konstantelos



INFOGRAPHICS

Our infographics are available in clinic and online! Now, some are available in three different languages: **Spanish,**

Portuguese, French.

These infographics wouldn't be possible without all of your feedback and guidance - thank you!

CLICK HERE TO SEE MORE



O QUE É SÍNDROME NEFRÓTICA DA INFÂNCIA?

Os rins filtram as impurezas do sangue. No síndrome nefrótica, as células que fazem a barreira de filtração do rim ficam com um "vazamento". Isso faz com que a urina tenha muita proteína e muita gordura. Por causa disso, a urina pode ficar com uma aparência de leite e espuma.



A perda aumentada de proteína na urina pode causar:



Ainda não é conhecido o que exatamente causa a síndrome nefrótica. Estudos sugerem que alguns fatores podem estar envolvidos, principalmente no sistema imunológico.

Sua criança não está sozinha! 100.000 crianças vivem com síndrome nefrótica.

COMO GERALMENTE É A EVOLUÇÃO?

93% respondem ao corticoide. 85% das crianças ficam sem a doença com o passar dos anos, próximo da adolescência. Recidivas são comuns. 75% das crianças que respondem ao tratamento não desenvolvem doença crônica. 5 MESES.



PARENT CONNECTIONS

A SickKids Nephrology Parent has been sharing her positive experiences on her FaceBook page "**Nephrology Parents at Sick Kids**".

CLICK HERE TO LEARN MORE ABOUT THEIR EXPERIENCE



Thank you all for your continued support of our study! All publications, infographics and study information can be found on our lab website:

<https://lab.research.sickkids.ca/parekh/>



A NOTE FROM NEPHCURE CANADA

NephCure Kidney International is happy to introduce **NephCure Canada**. NephCure



NEPHCURE[®]
Kidney International
Saving Kidneys • Saving Lives

Canada's Regional Volunteer, Ms. Nadya Hrycak, is based in Toronto and is working to create a page for Canadian patients and their families. In the meantime, feel free to visit the main website at **<https://nephcure.org/>** or contact Ms. Hrycak at **nadyahrycak@gmail.com** to find out how to get involved.