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https://www.cheoresearch.ca/for-patients-family/partner-in-research/

Collage of Family Leaders in Photo

Thanks doesn’t even begin to share how much we value you all! Please watch your email inbox for an Everything Gift Card that will be coming your way at the end of April. It can be a little slow to load, but just follow the prompts. Just our small way of letting you know we feel lucky to have you!

\*\* Call to Actions

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\*\* Carrier Screening Feasibility Study – Call for Partners

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Ontario Health has suggested publicly funded universal carrier screening, conditional upon a pilot study to determine feasibility. Carrier screening determines if an individual carries a gene variant associated with a genetic condition, helping assess the likelihood of passing it on to their children.

Members of Newborn Screening Ontario (NSO), Prenatal Screening Ontario (PSO), and Better Outcomes Registry and Network (BORN) will work together to propose this pilot study. We want to ensure that preferences of the population we serve will be accounted for as we develop the plans.

We are looking to do informational interviews with:

· People who are planning to have children in the future

· Young Adults

· People who are currently pregnant

· People who are carriers of genetic conditions

· People who have or are parents of people who have Cystic Fibrosis, Spinal Muscular Atrophy, Sickle Cell Anemia, Alpha Thalassemia, or Beta Thalassemia

We will only request about 1 hour of time for a virtual meeting. All calls will take place in April. Following the call, participants will receive a $35 gift card. Please reach out to Emma Bedoukian (mailto:ebedoukian@cheo.on.ca?subject=Newborn%20Screening%20Call&body=Hi%20Emma%2C%20%0AI%20am%20interested%20in%20participating%20in%20the%20informational%20interview%20for%20the%20newborn%20screening.%20) (ebedoukian@cheo.on.ca) by April 11th if interested. Not everyone that reaches out will be contacted.

\*\* Canadian Cancer Society

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Time: April 9th, 2025 12:00 PM-1:30 PM EST

Language: English

Register here (https://us02web.zoom.us/meeting/register/-MkQBRsRQzWxxDzn2myQvw)

Meaningful engagement of people with lived and living experience of cancer in research is increasingly being recognized and valued and is an important component of CCS funding. We are pleased to host a virtual learning and knowledge exchange event (over Zoom) to share relevant learnings and success stories from a panel including researchers and patient partners.

Researchers, trainees, people with lived and living experiences of cancer and others interested in learning about patient engagement in research are invited to attend this session.

After registering, you will receive a confirmation email containing information about joining the meeting. Learn more about patient engagement in research here (https://cancer.ca/en/research/for-researchers/patient-and-community-engagement-for-researchers)

\*\* Our visit to the RI Lab

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Picture of people around a table with a presentation board showing Zebra fish

We had a large group of family leaders join us for the visit to Isabella Pena’s Lab.

Together, we explored the lab, tried out the equipment and discussed the amazing work and discoveries using Zebrafish!

\*\* Robin Gaines Research Award Update: Evaluating Virtual Feeding Programs

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Picture of women with should length blond hair beside a science poster

Last year, Lisa Aquilino became the first recipient of the Robin Gaines Research Award, marking our inaugural review of projects for this Research and Development competition. Now, Lisa is sharing her findings through a new research poster.

Her study evaluates the transition of CHEO’s Interprofessional Feeding Team from in-person to virtual sessions in 2021. By comparing data from both formats, the research examines wait times, patient attendance, and parent feedback on accessibility, usefulness, and satisfaction.

Findings show that while the virtual format led to longer wait times due to a COVID-19 backlog, it also allowed more patients to attend consistently. Parents generally preferred the virtual format, citing greater convenience and effectiveness in meeting their children's healthcare needs.

The Interprofessional Feeding Team’s work highlights how virtual care can enhance accessibility while maintaining quality support for families—an important insight for future program development.

\*\* Closing the Loop

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SPOR Strategy Refresh – Report Now Available!

Some time ago, I encouraged you to share your feedback during the Canadian Institute of Health Research’s (CIHR) refresh of the Strategy for Patient-Oriented Research (SPOR). The report is now in!

You can check it out here: SPOR Report (https://cihr-irsc.gc.ca/e/54236.html) .

https://cihr-irsc.gc.ca/e/54236.html

\*\* Grand Rounds Recording Ready

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https://youtu.be/OZRCAcWwJLM?si=o4wLVJhkEdXp9L0c

Special thanks to Sofia, Leanne and Nat for their help with preparing our presentation for Grand Rounds.

\*\* Did you know?

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CanChild Centre for Childhood Disability Research offers the F-words Foundation Course. It’s a free, five module, self-paced online training (https://www.canchild.ca/en/research-in-practice/f-words-in-childhood-disability/f-words-training) course designed for families, health care providers, managers, community service providers, and educators who support children and youth of all abilities.

Did you know RI family leader Samantha Bellefeuille is featured in module 5?

\*\* Winning QITI Applications

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Picutre of a trophy

Warm thanks for your reviews with the fall QITI internal grant contest. The projects that have been selected and funded are:

-Leveraging Community Connectedness to Address Follow-Up Needs of Febrile Neonates Visiting the Pediatric Emergency Department: A Feasibility Study

&

-Reducing Missed Opportunities for Vaccination: Improving pneumococcal vaccination (Pneu-C-20) rate among immunocompromised pediatric patients with autoimmune/inflammatory rheumatic diseases at Children's Hospital of Eastern Ontario

Do you have something you would like to share in our newsletter? Articles, professional learning, an update on your engagement work, you name it,

- We want to share it!

Plain Text Version (https://www.cheoresearch.ca/for-patients-family/partner-in-research/)

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