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

RI Family Leader Program Newsletter March 2024 Issue 103

\*\* Calls to Action (6)

Picture of an old telephone

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\*\* 1. LLSC Survey

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The Leukemia & Lymphoma Society of Canada (LLSC) is conducting a survey for individuals and their families who have been personally affected by pediatric cancer:

LLSC PEDIATRIC MARKET RESEARCH-Change is needed to improve the childhood cancer experience in Canada, and we need YOUR help to make that happen.

Please help us enrich our pediatric support service offer by sharing this survey to anyone you know who is ...

· a sibling of a pediatric cancer survivor

· a pediatric cancer survivor currently between 18 and 24 years of age

· a parent, or other type of caregiver, of a pediatric cancer survivor

· a parent who lost a child to pediatric cancer within the last 5 years

Only someone who’s been through what they have can make a real difference in changing the pediatric cancer experience in Canada. Share the survey! (https://bit.ly/4gmUQs2)

\*\* 2. See Hazel’s Research Story & Consider sharing yours!

Picture of young girl and her mother

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https://www.cheo.on.ca/en/news/new-cheo-program-gives-all-families-a-stronger-connection-to-research-opportunities.aspx

The CHEO Research Institute is looking for a family passionate about research to help promote the Research Connection Program!

If you have a story to share and a passion for research at CHEO, we’d love to hear from you. Help us highlight the importance of family engagement in research by sharing your experience. Interested? Please reach out! (mailto:kcourtney@cheo.on.ca?subject=research%20connection&body=Hi%20Kim%2C%20I%20am%20interested%20in%20sharing%20our%20story%20with%20the%20Ottawa%20community%20to%20highlight%20the%20new%20research%20connection%20program%20at%20CHEO%20)

\*\* 3. Talking Circle Participants

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https://docs.google.com/forms/d/e/1FAIpQLSehgXFrQoKpIs6A08ias6HYgbD-w30FAp--xxJj-2pAj5X7ow/viewform

Poster highlighting the need for more indigenous voices in a child maltreatment study.

Please share this within your networks and groups. We aim to have an array of Indigenous youth voices as we shape future research areas.

\*\* 4. CHEO Grand Rounds

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I’ve been invited to present at the CHEO Grand Rounds on Wednesday, March 18, at 8:30 AM onsite at CHEO. I’d love to share some reflections on our Family Leader Program, but I’m wondering if anyone would be interested in co-presenting with me?

Let me know if you're interested—I’d love to collaborate! Please reach out! (mailto:kcourtney@cheo.on.ca?subject=Grand%20Rounds%20&body=Co-presenting%20at%20CHEO%20Grand%20Rounds%20)

\*\* 5. EDP Advisory Group

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Nicole Obeid shares -We are excited to announce the development of a Patient and Family Engagement/ Advisory Group for young people and family members with lived experience of eating disorders. This group will provide valuable expertise as we work to advance our understanding and treatment of eating disorders through innovative research.

Our team of researchers and clinical members are dedicated to research focused on advancing personalized care for eating disorders, connecting insights about the brain, body, mind, and life experiences to uncover the best ways to treat and overcome eating disorders. Current research projects explore areas such as genetics, brain health, blood, and gut bacteria to better understand how these factors influence treatment outcomes. By learning about characteristics ranging from postal code to genetic code, we aim to develop personalized approaches to care that address the unique needs of each young person who receives treatment at CHEO.

If you are interested in learning more about this opportunity and what it entails, we would love tohear from you! (mailto:kcourtney@cheo.on.ca?subject=EDP%20Advisory&body=Hi%20Kim%2C%20I%20am%20interested%20in%20the%20EDP%20advisory%20role.)

\*\* 6. Health Learning Systems Input

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https://can01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fforms.office.com%2Fpages%2Fresponsepage.aspx%3Fid%3D12NHk\_QP2EKRDz3py2JwCYta\_frfXodMhx2CyAUtWGxUNEsyNFFQUTVaNlZIUUhFWFFSSElRRkFEWS4u%26route%3Dshorturl&data=05%7C02%7CKCourtney%40cheo.on.ca%7Cf37785e7714941a5aabc08dd5c1a3f99%7C219bf6057ee74841ae574e4147b8d97a%7C0%7C0%7C638767989994346268%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=wFdEs4qBVDVolk7mzmdHBVjbW31yJNbEEtmHEdniTUA%3D&reserved=0

Shelley, a longtime friend of the RI Family Leader Program, will be hosting these Health Learning Systems workshops with her team. I encourage you to consider participating to ensure that the patient and family voice is reflected in the guidelines. There is compensation for your time.

\*\* Our visit to the Simulation Lab

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2 pictures of youth and leader visiting the Simulation lab, Leader is holding electronic infant while youth practice chest compressions

We had a great turnout at the Family Leader Simulation Lab event. Together, we learned about the benefits of using simulations for teaching, learning and refining practices here at CHEO. Special thank you to our Family Leader, Kate, who helped organize this event!

\*\* And the winners are…

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Picture of a trophy

I am pleased to announce the recipients of the 2025-2026 Robin Gaines Research Grant:

Karrie-Lynn Burnett is a Communicative Disorders Assistant. Her research entitled ‘An innovative quality improvement initiative in pediatric audiology: assessing the

efficacy of awake auditory brainstem response (aABR) testing as part of an audiological test

battery for children who are considered ‘hard-to-test’’is evaluating the effectiveness of an innovation in assessment in CHEO’s audiology clinic – the recently implemented awake Auditory Brainstem Response (aABR) procedure for the diagnostic hearing assessment of children who are considered difficult to test using standard behavioral audiometry measures.

Marie-Josée Arpin is a Speech-Language Pathologist who works with in- and out-patients who present with brain injuries. Her research entitled ‘Consultations to Speech-Language Pathology in Pediatric Brain Injury: Identifying Referral Patterns and Barriers during the Acute Recovery Period’ is examining the patterns of referral to SLP for patients admitted to CHEO after a brain injury, including the barriers that exist in ensuring timely and appropriate referrals during the acute recovery period.

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/)

Picture of small purple tulips growing just above the snow.

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