View this email in your browser (\*|ARCHIVE|\*)

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

\*\* Calls to Action (2)

------------------------------------------------------------

1. Leslie is looking for a family leader to review her project, Transitioning to Adult Oncology Care: Examining Successes and Failures Experienced by Bone Marrow Transplant Patients at the Children's Hospital of Eastern Ontario (CHEO) Please reach out if you would like to provide a written review. (mailto:kcourtney@cheo.on.ca?subject=Review&body=Re%3A%20Transitioning%20to%20Adult%20Oncology%20Care%3A%20Examining%20Successes%20and%20Failures%20Experienced%20by%20Bone%20Marrow%20Transplant%20Patients%20at%20the%20Children's%20Hospital%20of%20Eastern%20Ontario%20(CHEO)%0A%0AI%20am%20interested%20in%20providing%20a%20review.%20)

2.The Care4Rare team is looking for a rare disease family leader to collaborate on a national project called “From knowledge to action for rare disease (K2A-RD): Developing a Canadian roadmap and toolkit for integrating genomic medicine into clinical care for the diagnosis of rare disease”. We know that genomic sequencing - which decodes a person’s DNA looking for rare differences that cause disease - is an excellent test for diagnosing rare diseases. However, this test is expensive and complex, and we don’t know exactly which patients need this testing done first. Many provinces and territories lack specialized knowledge, skills, tools, and resources needed to perform genomic sequencing. Together with the family leader and a diverse group of researchers, genetics experts, policymakers, and decision-makers, we will produce the guidance and tools needed for provincial health systems to integrate this test in a way that benefits Canadians with rare disease while using healthcare dollars

wisely.

The family leader will be an integrated member of our leadership team and will contribute to the direction of our project as well as the development, planning, and interpretation and sharing of findings from various pieces of this project. Activities may include:

• Joining team meetings to provide feedback on study progress and direction;

• Reviewing interview guides and findings from interviews with genetics healthcare professionals;

• Helping to develop a workshop for implementing genomic sequencing in Canadian provinces;

• Reviewing drafts of manuscripts and key guidance documents to define Canadian standards for genomic sequencing.

This project is projected to take about 3 years. Family leader involvement can be negotiated, but we estimate the commitment to be about 2 hours per month, on average, and time will be compensated ($50/hour). If you are interested or would like more details about this project, please contact Caitlin Slomp (cslomp@cheo.on.ca) or Taila Hartley (thartley@cheo.on.ca). (mailto:thartley@cheo.on.ca?subject=Partnering%20with%20Care4Rare&body=)

\*\* Registration Open for 2 more days!

------------------------------------------------------------

This is sure to be an amazing course. Open to youth and free!

https://lnkd.in/g8mdBYRu

\*\* CHEO RI Open House

------------------------------------------------------------

Special Thanks to Leanne and Mairead for representing the RI Family Leader Program at the CHEO RI Open House. Thank you Family Leaders for your help in shaping our directions in the years to come.

\*\* Where Discovery takes Root

------------------------------------------------------------

Shaping a healthier tomorrow at CHEO and beyond

Read more about the CHEO Research Strategy 2025-2029 (https://www.cheoresearch.ca/strategy/)

\*\* Child Bright Engagement Role

------------------------------------------------------------

Accepting applications: T&CB Program Co-Lead

Are you passionate about building capacity and driving innovation in patient-oriented research? Join the CHILD-BRIGHT Network as Co-Lead of the Training & Capacity Building (T&CB) Program, which is responsible for establishing the training and mentoring agenda of the network.

This is a part-time position. If you are a person with a brain-based development disability or a parent or other family member who has been much involved in the care of a child/youth with such a disability, you will be compensated at 5 hours/week for up to 2 years. For academics, this is a non-compensated role. Applications (https://www.child-bright.ca/training-colead-application) will be accepted until January 17, 2025.

Visit our website for more information. If you have any questions, don't hesitate to contact the T&CB Program coordinator, Pierre Zwiegers, at pierrezwiegers@child-bright.ca (mailto:pierrezwiegers@child-bright.ca) .

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/)

Copyright (C) \*|2023|\* \*|LIST:CHEO RI|\*. All rights reserved.

\*|IFNOT:ARCHIVE\_PAGE|\*\*|kcourtney@cheo.on.ca|\*\*|END:IF|\*

Want to change how you receive these emails?

You can update your preferences (\*|UPDATE\_PROFILE|\*) or unsubscribe (\*|UNSUB|\*)

http://eepurl.com/ivm7s2

CHEO RI Logo