

For Immediate Release

EPILEPSY SURVEY GIVES VOICE TO PATIENTS IN SETTING THEIR RESEARCH PRIORITIES

Toronto, ON – October 16, 2019 - [Eplink](#) – the Epilepsy Research Program of the [Ontario Brain Institute](#) (OBI), in collaboration with the James Lind Alliance and the Ontario Brain Institute, announced the launch of an online survey to work directly with patients, caregivers and clinicians to better identify research priorities around epilepsy and seizures.

This project, also known as a Priority Setting Partnership (PSP), is the first such initiative for epilepsy in Canada. The PSP is being led by Eplink, and funded by OBI, in a partnership with the James Lind Alliance, a U.K.-based non-profit that sets health research priorities. The outcome of this PSP will be a “Top 10” list of research questions that will serve to guide researchers and funding agencies. Patients, caregivers and clinicians will use the survey results to compile this list and prioritise which questions are the most important for research to address.

“There are still many aspects of epilepsy and seizures that we don’t fully understand, which can pull research in many different directions,” said Dr. Jorge Burneo, Chair of the Epilepsy PSP Steering Committee and Epileptologist at Western University. “By collecting the questions of people in the epilepsy community, we can focus our work on answering the questions that are the most meaningful to the people who benefit from our research, which as a result will serve to help clinicians provide better care, and improve the lives of patients and their caregivers.”

Epilepsy is a brain disease where individuals experience multiple seizures during their lifetime. It is estimated that 1 in 100 people have epilepsy, approximately 300,000 Canadians. About one-third of people with epilepsy continue to experience seizures despite taking medication, and are in need of community support and the development of new, more effective therapies. Seizures can range from full-body convulsions to blank stares, and in some cases can be life-threatening.

Despite its prevalence, epilepsy is an under-researched disease, with many questions still unanswered about its cause, diagnosis and treatment. Survey results will be shared with research organizations and funding agencies across Canada, bringing the needs of patients and caregivers to the forefront and giving them the power to shape the national epilepsy research agenda.

“In 1989, we were devastated when our daughter Kayleigh was diagnosed with Rett syndrome. What we didn’t know was that seizures would be the greatest challenge for our child”, said Terry Boyd, Epilepsy PSP Steering Committee member. “There is so much still unknown about seizures and epilepsy. I am encouraged and hopeful with the PSP’s work in collecting priority questions from Canadians who live with epilepsy, their caregivers and the health professionals who support them. It is our collective voice that will guide tomorrow’s research so those we love and care for can live a better quality of life.”

To learn more about this initiative or to participate in this survey, please visit: braininstitute.ca/epilepsy-ppsp. Survey participants may include: 1) anyone living with epilepsy, 2) anyone who has seizures as a result of a co-existing condition (e.g. Rett syndrome), 3) caregivers or

family members of someone living with epilepsy or seizures, 4) health care providers, or 5) community epilepsy agency representatives. The survey will be open until January 2020, and the results will be released in October 2020.

About EpLink

EpLink – The Epilepsy Research Program of the Ontario Brain Institute is dedicated to reducing seizures and improving quality of life for people with epilepsy through research. We have over 25 researchers and over 30 collaborators from eight universities and hospitals across Ontario working to improve drug, diet and genetic therapies, surgical outcomes, brain monitoring and modulation, and quality of life for people with epilepsy. We work with industry partners, patients, caregivers, and community epilepsy agency representatives to bring our research to the community. We also host research talks and public education events to raise epilepsy awareness. For more information about our program, please visit eplink.ca.

About the Ontario Brain Institute

The Ontario Brain Institute is a provincially funded, not-for-profit organization that accelerates discovery and innovation, benefiting both patients and the economy. Our collaborative ‘team science’ approach promotes brain research, commercialization and care by connecting researchers, clinicians, industry, patients, and their advocates to improve the lives of those living with brain disorders. Welcome to Brain Central. Visit www.braininstitute.ca for more information. Follow us on Twitter (@OntarioBrain). *Funding provided, in part by, the Government of Ontario.*

About the James Lind Alliance

The James Lind Alliance (JLA) infrastructure is hosted by the National Institute for Health Research (NIHR) to provide the support and processes for Priority Setting Partnerships (PSPs). PSPs aim to help patients, caregivers and clinicians work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. For further information, visit the JLA website (www.jla.nihr.ac.uk).

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