

MEDIA RELEASE

ONTARIO EPILEPSY COMMUNITY URGES ONTARIO GOVERNMENT TO IMPROVE STANDARDS OF CARE, ACCESS TO TREATMENT, AND DISABILITY AND EMPLOYMENT SUPPORTS

Government commended by community for Ontario Brain Institute epilepsy research grant

TORONTO, ON (March 6, 2012) – Today at Queen’s Park, 40 members of Ontario’s epilepsy community, led by [Epilepsy Ontario](#) and the [Epilepsy Cure Initiative](#), gathered to meet with MPPs and policy advisors to increase awareness of epilepsy within government and advocate for the implementation of an Ontario Epilepsy Strategy. The key topics of discussion included the impact of epilepsy on Ontarians, consistent standards of patient care, improved access to treatment and disability and employment supports.

“Recently, the Ontario Health Technology Advisory Committee released recommendations to improve access to and standardize epilepsy care in Ontario which we strongly support as the foundation for a provincial epilepsy strategy,” said Rozalyn Werner-Arcé, Executive Director, Epilepsy Ontario. “On behalf of Ontarians living with epilepsy, their families and employers, we ask the government to ensure it incorporates the key role of community epilepsy organizations in the implementation of this strategy.”

Better access to medication to improve seizure control

Epilepsy, the second most common neurological condition after headache, is a seizure disorder caused by sudden bursts of electrical energy in a person's brain. Up to one-third of people living with epilepsy do not have adequate seizure control, severely impacting their independence, productivity and overall quality of life. The disorder can cause significant challenges, including difficulty finding employment, loss of driving privileges, cognitive decline, memory impairment and higher mortality rates.

“Far too many Ontarians still endure seizures, along with the damage each one leaves in its wake. Today, we call upon the Ontario government to ensure its citizens have swift access to new treatments for epilepsy as soon as they become available in Canada, in order to better their control seizures and improve their health and quality of life,” Werner-Arcé added.

Support needed for workplace discrimination and disability

Epilepsy Action Day at Queen’s Park, an initiative founded by Margaret Maye of the Epilepsy Cure Initiative, provides individuals living with epilepsy the opportunity to speak directly to government representatives about the most pressing issues facing their community. In addition to consistent standards of care and better access to treatment, community advocates from across Ontario addressed the need for improved access to disability and employment supports.

“Many people with uncontrolled seizures experience significant difficulties in many aspects of life, including disability and discrimination issues in the workplace,” said Melanie Jeffrey, a member of the epilepsy community from Simcoe County. “A deeper understanding of these issues is greatly needed

among our MPPs, as is improved access to programs that recognize and support the needs of Ontarians with epilepsy in the workforce.”

Community commends government for epilepsy research funding

On March 5, the Minister of Economic Development and Innovation, Brad Duguid, and the Ontario Brain Institute (OBI) announced their support of The Epilepsy Discovery Project – New Approaches to Intractable Epilepsy. Led by Dr. McIntyre Burnham and Dr. Jorge Burneo, the project is described as “an unprecedented collaboration between Ontario's premier academic researchers and doctors, not-for-profit epilepsy organizations and the private sector,” and is aimed at discovering new therapies and technologies to improve the lives of those persons affected by epilepsy who do not respond to any available pharmaceutical treatments.

Dr. Burnham, a pharmacologist and director of the Epilepsy Research Program at the University of Toronto, as well as an Epilepsy Ontario board member, called the research funding announcement “a step in the right direction for Ontarians living with epilepsy.”

“Our community commends the Ontario government for its significant investment through the Ontario Brain Institute in leading-edge brain research being conducted here in Toronto and across the province,” Dr. Burnham added. “But we are here today to remind the government that much more needs to be done to respond to the serious unmet medical and social needs within our community.”

About Epilepsy Ontario

Epilepsy Ontario (EO) is a non-profit non-governmental health organization and registered charity dedicated to promoting independence and optimal quality of life for children and adults living with seizure disorders, by promoting information, awareness, support services, advocacy, education and research. Through a network of local agencies, contacts and associates, Epilepsy Ontario provides client services, counselling, information and referral services, education and advocacy services for children and adults living with seizure disorders, and for their families, friends, co-workers and caregivers. EO offers long-term programs to raise standards of care and support medical research into seizure disorders. EO hopes to improve public awareness and education through publications, the EO web site, conferences, and outreach programs. Epilepsy Ontario will soon launch a new information and referral program to be led by an Epilepsy Information Specialist.

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