

Voices OF EPILEPSY

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Left to right, Epilepsy Ontario executive director Rozalyn Werner-Arcé, Health and Long-Term Care Minister Deb Matthews, Opposition health critic Christine Elliot and Epilepsy Ontario treasurer Gino Piazza are seen here during Epilepsy Action Day at Queen's Park.

2013 Epilepsy Action Day was 'Amazing'

By Deron Hamel

During the 2012 Epilepsy Action Day at Queen's Park, Ontario's epilepsy support agencies, along with people living with seizure disorders and their families, asked MPPs for a provincial epilepsy strategy to address their needs. At the 2013 Action Day on Sept. 24, the same people were thanking government officials for launching the Epilepsy Strategy Implementation Task Force in spring.

This demonstrates what's possible through engagement with government decision-makers, and it was one of the

many ingredients that made the event an "amazing day," says Epilepsy Ontario executive director Rozalyn Werner-Arcé.

"It's quite amazing when you think that one year ago we were at Queen's Park and we were asking for a strategy and here we are one year later, thanking them for the strategy," she says.

This year's Epilepsy Action Day focused on discussing the social burden of epilepsy as well as what needs to be done to improve epilepsy awareness through education.

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Documentary Aimed at Erasing Epilepsy Stigma

TORONTO – Epilepsy is a reminder that none of us has complete control over our bodies. That's one of the powerful messages driven home during the Canadian premiere of *On the Edge: Living with Epilepsy*, a documentary

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Why Hiring People with Epilepsy Makes Good Business Sense

Employers who make a point of hiring people with epilepsy are not just doing the right thing; they're making a smart business decision, says employment consultant Tim Nourse, who's involved with Epilepsy Toronto's employment program.

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Petition Launched to Begin CBD Trials in Canada

Ten-month-old Kaitlyn Pogson is living with Dravet syndrome, a rare catastrophic form of intractable epilepsy that causes her to go into hour-long seizures every few days. When this happens, Kaitlyn must be rushed to hospital where she's administered anti-seizure medication that has little impact and often produces side effects, such as reduced appetite.

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Some Employers Seeking People with Epilepsy

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The reason for this is simple, Nourse says: by hiring people with epilepsy and other seizure disorders, employers are creating a more diverse workforce that is “more responsive to marketing and social needs.”

Many people living with epilepsy are frightened to disclose their condition to their employers or workmates out of fear that it could cost them their job. While Nourse says some employers continue to be wary of hiring people with seizure disorders out of concern that their condition will negatively affect their jobs, others are actively seeking people with disabilities — including epilepsy.

This is especially true for companies, such as banks, where there are federal regulations mandating employers to hire a certain number of people with disabilities every year.

“I’ve often coached clients to not disclose in their covering letter that they have epilepsy, but to indicate that they are a person with a disability and they are applying as per the (employer’s) instructions or wish to be considered as an under-represented part of the population,” Nourse says.

“You can secure an advantage.” There’s also a push in today’s society for employers to have inclusive hiring practices. By having hiring policies that announce their willingness to hire people with disabilities they are increasing the diversity in their workplace and showing themselves to be socially responsible companies.

In other words, says Nourse, it makes good business sense.

“Employers are recognizing all the time that it’s not the right thing to hire somebody with epilepsy; it’s the smart thing to do — you’re creating a more diverse workforce that’s more responsive to marketing needs and social needs,” he says. — DH



Thank You, OTN!

Epilepsy Ontario executive director Rozalyn Werner-Arcé accepts a cheque for \$2,800 from the Ontario Telemedicine Network. OTN raised the money during a two-month campaign focused on epilepsy awareness.

Action Day Marked by Important Discussions

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Ensuring access to all treatments and finding a solution to the serious problem of drug shortages were among other major issues discussed with political leaders.

Ensuring access to all treatments and finding a solution to the serious problem of drug shortages were among other major issues discussed with political leaders.

What was especially noteworthy about the day was the fact that the engagement level was deeper than ever, Werner-Arcé says.

MPPs and other leaders were interested in the discussions and asked “really good” questions, provided valuable feedback and, perhaps most importantly, offered ways they could help, she adds.

For example, some MPPs offered to introduce epilepsy agencies to important

leaders, while others offered to spearhead initiatives or to provide assistance in decision-making processes.

“Epilepsy Action Day at Queen’s Park has come a long way in the last four years,” Werner-Arcé says. “One of the things we heard (from MPPs) was, ‘Keep doing what you’re doing.’”

Looking ahead, Werner-Arcé says increased recognition of the importance of community-based supports and services for people with epilepsy and their families, realized through funding of patient education and self-management programs offered by epilepsy support agencies, would be the best possible long-term outcome from this year’s Epilepsy Action Day at Queen’s Park.

The day concluded with a reception attended by MPPs, government officials and stakeholders. Health and Long-Term Care Minister Deb Matthews, Progressive Conservative health critic Christine Elliott and NDP deputy house leader Cindy Forster spoke at the event.

Film Puts Faces to Epilepsy

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about the neurological condition, told by people who are living with it.

Think about it: we have all caught colds, had headaches or some other malady that was beyond our control. In that sense, epilepsy is no different. People living with epilepsy have no more control over the condition than anyone else has when they, for example, catch a seasonal virus.

Despite this, there's a stigma attached to epilepsy. It frightens people who are unfamiliar with the condition, and this has a detrimental trickle-down effect on those living with epilepsy.

“Transparency makes a difference; it creates understanding. If you don't have transparency, you don't have understanding — instead, you have suspicion and you have fear.”

— Joe Stanislaw, father of *On the Edge* writer-director Louis Stanislaw

This stigma can cost people their jobs and friendships, which can lead to other conditions, most notably depression and anxiety, the film explains.

On the Edge was written and directed by Louis Stanislaw, a U.S. filmmaker who has coped with epilepsy his whole life. The film tells the painful truths, misunderstandings and difficulties of living with epilepsy at every turn; from family life to school, to leaving home, and starting a career and forming lasting bonds.

Perhaps most importantly, the film puts faces to the condition, which is meant to inject a better sense of empathy into those listening to the

many personal stories unfold.

While Stanislaw was unable to attend the Oct. 23 screening of his film at the Li Ka Shing Knowledge Institute in downtown Toronto, his father, Joe, was on hand.

Joe Stanislaw said the most important aspect of the documentary is that it encourages people to talk about the condition. Being transparent and educating others about epilepsy is a major step in eliminating stigma, he said.

“Transparency makes a difference; it creates understanding. If you don't have transparency, you don't have understanding — instead, you have suspicion and you have fear,” he told *Voices of Epilepsy*, following the screening.

Joe Stanislaw noted that many people living with epilepsy hide their condition from others. The reluctance people with epilepsy have about disclosing their condition is also explored in *On the Edge*.

In fact, 40 per cent of people interviewed for the documentary shared a story about epilepsy they had never told anyone before, Joe Stanislaw said.

During his address to the audience following the screening, Joe Stanislaw underscored the importance of people sharing their personal stories about epilepsy to others. It was through people's willingness to discuss the condition openly that made the film possible.

He also commends his son for his strength in making the film to help erase preconceived notions about epilepsy.

“His strength is your strength; you helped him do this.”

Epilepsy Ontario hosted the screening and panel discussion that followed the event.

— DH



Scotiabank Marathon

Thanks to our supporters who participated in the 2013 Scotiabank Marathon! Together, Epilepsy Ontario and Epilepsy York Region raised \$15,223. Special thanks to our T-shirt sponsor, Paul Spark of St. Andrew's Insurance. We were thrilled to have members of Team Epilepsy Halton Peel Hamilton join in the post-race celebration hosted by KPMG.

Trillium Grant Awarded

Epilepsy Ontario is the proud recipient of a \$280,800 Trillium Foundation grant, which will provide increased access to consistent educational resources and supports.

Purple Day Around the Corner!

March 26 marks the international epilepsy awareness day. Please tell us what you are doing and send your photos so we can post them on our website and Facebook page. Need an idea? Contact Jeanette at jeanette@epilepsyontario.org.

You Can Make a Difference

Epilepsy Ontario touches the lives of countless people and their families. To learn more or to make a donation, call 905-474-9696 or 1-800-463-1119 (toll-free in Ontario), or visit our website at www.epilepsyontario.org.



Voices OF EPILEPSY

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There's Hope to End the Nightmare, Parent Says

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Her parents, Barry and Shannon, say there's hope to end the nightmare their daughter lives with, but they need Health Canada to approve a substance derived from the cannabis plant for clinical trials.

It's for this reason the Pogsons have launched an online petition aimed at making Health Canada's office of controlled substances aware of the benefits of Cannabidiol (CBD) on children who are living with a seizure disorder.

Specifically, the petition has three main objectives: to encourage Health Canada to allow the specific strains of cannabis plants needed for CBD production to be imported from the U.S., to allow medical trials to be conducted in Canada and to expedite the process of accessing CBD.

CBD comes from the flower of the cannabis plant, which is causing stumbling blocks for those advocating for its study in clinical trials. CBD is not legal in Canada, nor is it legal in the U.S. at the federal level.

The substance is produced by soaking the flower in alcohol, which is then boiled off. Olive or sesame seed oil is then added to the remaining residue. The CBD oil mixture can then be administered by stirring it into food.

Barry says CBD treatment could have a huge positive impact on the quality of life for children and adults with seizure disorders.

He says he remains hopeful about CBD eventually becoming a widespread intervention for children with seizure disorders. He points to Dr. Orrin Devinsky of New York University receiving Federal Drug Administration approval to conduct a study on the safety of CBD in children living with a seizure disorder as hope for what's around the corner.

Epilepsy Ontario executive director



Kaitlyn Pogson is living with Dravet syndrome. Her parents have started an online petition to Health Canada for clinical trials to be conducted on CBD.

Rozalyn Werner-Arcé says that while the organization is not endorsing CBD as a treatment for catastrophic seizures, “as the voice of epilepsy in this province, we believe Epilepsy Ontario has a responsibility to inform people

about new research and treatments so that they can make informed decisions with their health-care provider. We do this through stories such as these and through information on topics such as CBD on our website.” — DH