

Voices OF EPILEPSY

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WINTER 2014  



Purple Pride

Chelsea Kerstens poses for a photo with Epilepsy Durham Region's Epic Climb ambassador Cameron Shiels. Kerstens was a participant in the agency's fundraising climb at the Grand Canyon in October. See story at right.

Epilepsy Action Day Continues Dialogue with Gov't on Important Issues

By Deron Hamel

The fifth annual Epilepsy Action Day at Queen's Park on Dec. 1 was successful in its mission to engage MPPs in the important issues facing people with seizure disorders, says Epilepsy Ontario executive director Rozalyn Werner-Arcé.

During the event there were three areas that representatives from Epilepsy Ontario and seven other epilepsy support agencies across the province asked the nearly 40 MPPs attending to focus on.

One is ensuring community-based

services and Community Epilepsy Liaisons are expanded across the province. Epilepsy agencies are also asking the government to protect and keep children safe at schools through programs devoted to seizure awareness, first-aid training and administration of rescue medications. Lastly, the MPPs were asked to dialogue with Education Minister Liz Sandals to ensure neurological conditions are considered during the review of the "categories of exceptionalities"

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How Chelsea Kerstens Faced — and Overcame — Epilepsy's Challenges

When Chelsea Kerstens scaled a 4,500-foot side of the Grand Canyon as a participant in Epilepsy Durham Region's Epic Climb in October, it was one more challenge she successfully met in the 13 years since she had her first seizure.

See 'Challenges' page 4

Online Toolkit Designed to Help Employers of People with Epilepsy

A first-of-its-kind online toolkit is now available to provide training and resources to companies and organizations that have employees with epilepsy.

Developed by Epilepsy Toronto, the epilepsy@work toolkit was recently launched. It was developed with the

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EpLink Study Aims to Alleviate Depression in People with Epilepsy

A study undertaken as part of the Ontario Brain Institute's (OBI's) EpLink program is seeking to provide help to people living with epilepsy who are also experiencing symptoms of depression.

An estimated 30 to 40 per cent of people living with epilepsy experience depression that often goes unrecognized

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Mother Attests to Summerfest's Value

Philippa Howell says attending Summerfest for four years has helped her daughter, Georgina, enhance her social skills and build self-confidence while enjoying a summer camp experience at Camp Couchiching near Orillia.

Georgina, 12, is living with intractable myoclonic epilepsy as well as autism. She has been attending the camp since she was eight, and Philippa says she has seen a steady progression in Georgina's social skills.

Although she doesn't talk about her positive experiences at Summerfest, Georgina gives social cues to her parents of the good times she's having. For example, Philippa recalls how a couple of weeks before Georgina was to go to Summerfest one year she pulled out her Camp Couchiching T-shirt and said "campfire."

"And then she wore that T-shirt as often as she could ... and she kept saying, 'When are we going for a campfire?' It suddenly dawned on my husband and I that she had associated the picture of the campfire on the T-shirt ... as somewhere she enjoyed going," Philippa says.

"Immediately, any worry, or fear or stress we might have had about her being anxious about being away from us evaporated. ...

"Four years later, I am shocked at how young (Georgina) was when I let her go (to Summerfest) but now I think, 'Thank goodness' because the experience she has at the age of 12 has blossomed — she's grown and grown because of (Summerfest)."

Now in its 20th year, Summerfest has an average of 20 to 40 children and youths who have epilepsy attend the program; they participate in activities such as swimming, hiking, kayaking and sports.

Summerfest enables children and youths aged six to 15 who are living with seizure disorders to attend camp together. The camp provides a setting where children can "forget about their epilepsy and just be a kid," says Epilepsy Ontario executive director Rozalyn Werner-Arcé.

Toolkit Unique to North America

Continued from front support of the Government of Ontario, Epilepsy Ontario and CIBC.

The goal of the resource is to help those employing people with epilepsy better understand, address and manage the needs of employees living with a seizure disorder, says Tim Nourse, an employment consultant involved with the project.

"We know that this is unique — there's nothing out there like this in North America," Nourse tells *Voices of Epilepsy*.

"We know that this is unique — there's nothing out there like this in North America . . . and it's going to dispel a lot of the myths and stigmas associated with epilepsy."

— *Tim Nourse, employment consultant*

"It gives all of the epilepsy organizations in Ontario a resource that they can send employers to, or that they can send people with epilepsy to, and it's going to dispel a lot of the myths and stigmas associated with epilepsy."

Employers using the toolkit will find information about strategies they can use to best accommodate employees with a seizure disorder. The toolkit offers resources focused on three primary areas: understanding epilepsy; seizure safety; and first aid, just-in-time resources for human-resources professionals, managers and occupational health and safety specialists.



A screenshot of the epilepsy@work website.

Once on the website, co-workers, front-line supervisors and HR staff can take a 30-minute course to help them understand the condition and why having an employee with epilepsy is actually good for business.

Employees with epilepsy are encouraged to share the toolkit with their employer. Generally, people living with epilepsy have a greater challenge retaining a job than finding employment, Nourse says. The information garnered through epilepsy@work can be used to curb discrimination and guide employers to appropriate resources, he notes.

"People may choose not to disclose (that they have epilepsy), but when they have that first seizure at work things get a little bit dicey," Nourse says. "For the person with epilepsy, they may not have a local (epilepsy support agency) that can help them, but they can steer their employer towards this website."

Epilepsy Toronto is working with other epilepsy support agencies throughout the province to get the word out about the resource, Nourse says.

"It's not meant to replace (epilepsy support agencies); it's a tool to augment the services that they already provide in communities," he says. — *DH*



Epilepsy Ontario executive director Rozalyn Werner-Arcé (third from left) and Donna Blair of Epilepsy Ottawa (second from right) are seen here with government officials at Queen's Park during Epilepsy Action Day Dec. 1.

Political Support Gained

Continued from front
which is currently underway.

"Each year it keeps getting better and better," Werner-Arcé says of Epilepsy Action Day. "I think that there is an increasing recognition about the impact that epilepsy has on our health-care system and on the lives of Ontarians."

"We were able to make new contracts and gain support for all three of our key messages."

— *Epilepsy Ontario executive director Rozalyn Werner-Arcé.*

Aside from having MPPs' keen interest in the issues facing

Ontarians living with epilepsy, Werner-Arcé says Epilepsy Action Day is also proving to be an excellent forum for strengthening relationships between epilepsy support agencies and the government.

"We were able to make new contacts and gain support for all three of our key messages," she says.

Meeting with MPPs on a one-to-one basis also proved to be fruitful, Werner-Arcé notes. By taking time to speak with politicians individually the agencies' representatives were able to get their buy-in, she adds.

Looking ahead, epilepsy support agencies will be meeting with the MPPs in their communities to continue fostering relationships and ensuring the dialogue is ongoing.

"We want to continue to work with government to ensure that people with epilepsy have access to the services that they need, whether it's through getting treatment and community-based care, or keeping kids safe at school and making sure that they get the kinds of educational supports they need so they can reach their full potential and develop into productive, contributing citizens," she says.

Aside from Epilepsy Ontario staff attending the event, representatives were on hand from Epilepsy Toronto, Epilepsy Ottawa, Epilepsy Niagara, Epilepsy Durham Region, Epilepsy Halton Peel Hamilton, Epilepsy Kingston and London's Epilepsy Support Centre.

PURPLE DAY IS JUST AROUND THE CORNER!

MARCH 2015

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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 Rozalyn Werner-Arcé at rozalyn@epilepsyontario.org

For more information on Purple Day, visit www.purpleday.org

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Study Divided in Two Parts

Continued from front

and untreated, says EpUp lead investigator Kathryn Hum. It's a widespread issue, but there are few existing programs to intervene, she adds.

With this in mind, EpLink saw a need for further investigation, so resources have been devoted to address depression and mood disorders in people living with epilepsy.

"The main purpose of this study is really to see if we can improve symptoms of depression in people with epilepsy," explains Hum.

The EpUp study aims to examine how psychoeducation programs that provide people with a better understanding of epilepsy, emotions and coping skills can improve emotional health in adults affected by the condition.

The study is divided into two parts. The first involves sending participants online questionnaires. The second component sees participants attend an eight-week psychoeducation program which is conducted by telephone.

The two psychoeducation programs consist of weekly sessions that will take place starting in mid-October to December. Following programs will be run January to February and March to April.

It was decided to host the program via telephone to increase access, since many people affected by a seizure disorder do not drive and many will be living outside of Greater Toronto.

Each session of the program is one hour long, one day per week. Participants can expect to learn skills and strategies designed to improve their symptoms of depression.

If you are a person living with epilepsy and would like to participate in the study, please contact Kathryn Hum at 416-978-0779, or by e-mail at khum@uhnresearch.ca.



OBCL Scholarships

From left to right, Courtney Tobin, Heather Girardin, Samantha Hetherington, Lia Turner and Duncan Green were 2014 OBCL scholarship recipients. OBCL scholarships support students with epilepsy.

Challenges No Match for Determination

Continued from front

Following her accomplishment, Kerstens, 27, spoke with Voices of Epilepsy, reflecting on the challenges she has faced since she was 14 and how her experiences led to her becoming an advocate for epilepsy awareness with Epilepsy Durham Region.

Kerstens had her first seizure at 14, but her condition went undiagnosed until she was almost 18. Once diagnosed, she faced the challenge of finding the correct medication to address her seizures. This trial-and-error process took several years, but doctors eventually discovered a combination of medications that caused her seizures to stop.

She has now been seizure-free for three years.

Since her first seizure, Kerstens has faced many hurdles. Her teenage years, when she experienced the most seizures, weren't easy and this was compounded by the fact she was a high-school student at the time, she says.

It wasn't until she had completed university that Kerstens learned

about Epilepsy Durham Region. She reached out to the agency and eventually began volunteering. She credits Dianne McKenzie, the agency's executive director, for encouraging her to share her story with students at educational events to help raise awareness of epilepsy, which affects an estimated one in every 100 Canadians.

Kerstens is an advocate for people living with epilepsy through her work at Epilepsy Durham Region and as a team leader with E-Action, an online community that provides information for those wishing to learn more about the condition.

"I see (my volunteering experiences) as positives that give me a lot of skills that many others don't have, so I was more than happy to have that on my resumé," Kerstens says.

And how does it feel to now work as an epilepsy awareness advocate?

"It's an excellent feeling," Kerstens says. "The only way I can describe it is that it feels like I'm doing what I'm meant to be doing." — DH