



Going Purple

Epilepsy Ontario executive director Rozalyn Werner-Arcé, Purple Day founder Cassidy Megan and the Hon. Geoff Regan, MP, Halifax West celebrate Purple Day for Epilepsy on Parliament Hill. This year, Purple Day was observed for the first time across the country as the official day for epilepsy awareness, since the Purple Day Act passed with unanimous support in June 2012. See story at right.

Freelance Writer Proving Career Goals Can Overcome Epilepsy

By Deron Hamel

Finding meaningful employment when you have an unpredictable seizure disorder can be challenging, but it's an obstacle Pamela-Anne Kinney has overcome by pursuing her dream and harnessing her

strengths as a storyteller.

Upon completing a freelance writing course in November 2011, Kinney embarked on a career that satisfies her love of writing while allowing her to

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KPMG Hosting Lunch-and-learn to Raise Epilepsy Awareness

Business advisory firm KPMG's downtown Toronto office hosted an employee lunch-and-learn March 22 to raise awareness of epilepsy and arm people with the knowledge necessary to foster conversations about seizure disorders.

This is one example of what private

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Advocates Encouraged by Gov't Response to Epilepsy Awareness Month

Representatives from epilepsy support agencies say they're encouraged by the reception their advocacy work with government officials received in March and hope their colleagues provincewide will continue talking with politicians about the epilepsy

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National Action Plan Could Curb Impact of Drug Shortages

Daryl Yeo discovered there was a clobazam shortage after receiving an e-newsletter from Epilepsy Ontario Jan. 4 announcing a warning to those needing the seizure control drug. For Daryl, the president of Epilepsy Toronto and father of a woman with epilepsy who takes clobazam, this is a sign that things need to change.

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Need for Epilepsy Strategy Top of Mind

Continued from front community's needs.

March was Epilepsy Awareness Month, and leaders from within the epilepsy community met with politicians from all government levels to provide information and education about the neurological disorder.

The need to see Ontario's proposed epilepsy strategy move forward was a major topic during meetings, as were the benefits the epilepsy community will see from the province's recent five-year, \$100-million funding to the Ontario Brain Institute, much of which will be spent on epilepsy research.

"... what we came away with was support."

— *Melanie Money, executive director, Epilepsy Simcoe County*

As part of the proposed strategy, which was designed by an expert panel, epilepsy care centres with state-of-the-art equipment would be established provincewide and serve as primary access points for people with epilepsy. Through these facilities, patients would have access to epileptologists, psychologists and social workers. The sites would be equipped with the latest in epilepsy monitoring and imaging equipment.

Epilepsy Simcoe County executive director Melanie Money says the greatest success she saw from her advocacy work was bringing local, provincial and federal leaders together at the same time to discuss issues facing the epilepsy community — particularly the need for a provincial strategy and the urgency of legislation to address medication shortages.

The agency recently hosted a luncheon that brought together Barrie MP Patrick Brown, Barrie

Mayor Jeff Lehman, Orillia Mayor Angelo Orsi and a representative from Barrie MPP Rod Jackson's office.

"We were able to educate those politicians to make them aware of the drug shortage, to make them aware of the strategic plan that we have going



Susan Harrison, the executive director of the Epilepsy and Seizure Disorder Resource Centre for South Eastern Ontario, is pictured here with Leeds-Grenville MPP Steve Clark. Harrison was one of many epilepsy community advocates who met with politicians as part of Epilepsy Awareness Month in March.

on — what we came away with was support," says Money, who has also been working with Brown, a member of the standing health committee, to develop a strategy to address drug-shortage issues.

"We had people who didn't know what was going on in (the epilepsy community). By being able to educate them, they were able to take away some knowledge, and they could see that this was very important to us, so we are going to help."

Advocacy was also in full swing at Epilepsy Durham Region. On March 6, agency representatives, along with the parent of a child living with epilepsy, met with the Opposition Progressive Conservatives at Queen's Park. Plans are underway to meet with

the governing Liberals soon.

The need for a provincial epilepsy strategy was a key point of the conversations, and the group's concerns were met with a positive response, says Epilepsy Durham Region executive director Dianne McKenzie.

The group's success was apparent when health critic and Whitby-Oshawa MPP Christine Elliott wrote a letter on Epilepsy Durham Region's behalf to Health and Long-Term Care Minister Deb Matthews underscoring the need for a provincial epilepsy strategy.

Durham MPP John O'Toole sent Epilepsy Durham Region a letter thanking the agency for speaking with the Opposition party members. He emphasized the importance of having the most up-to-date information available to politicians.

"The material you provided about the need for an Ontario epilepsy strategy will be most helpful as health-care priorities for Ontario are considered in the legislature," he wrote.

Asked about the best long-term result from the conversations with the government and Opposition, McKenzie doesn't hesitate in her reply.

"(It would be to) have their unanimous support for the proposed Ontario epilepsy strategy, 100 per cent, across the board, all parties. That would be the ultimate goal," she says.

On March 26, members of the Canadian Epilepsy Alliance gathered on Parliament Hill in Ottawa to celebrate the first anniversary of Purple Day legislation, which was initiated by Halifax West MP Geoff Regan.

"(Parliament) was a sea of purple," says Epilepsy Ontario executive director Rozalyn Werner-Arcé, who attended the event. "I was so proud and am so appreciative of the support across all parties." — *DH*

Advocacy Groups Need to Unite for Action Plan

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Upon learning of the medication shortage, Daryl called his 33-year-old daughter, Lindsay, to let her know she needed to contact her pharmacy to get more information about the shortage. It turned out the pharmacy was out of stock.

While Lindsay eventually obtained the medication from another pharmacy, Daryl says it was only because of Epilepsy Ontario's e-mail alert that she found out in time.

“Clobazam, for instance, you can't just quit cold turkey, you need to wean yourself off, and if you're going to move to an alternative drug you need to do that over a period of time.”

— Daryl Yeo, father

“If I hadn't got the notice from Epilepsy Ontario giving us the heads-up, Lindsay wouldn't have found out until (later),” says Daryl, adding that if people needing a medication only find out about shortages when they go to refill their prescription it can be too late.

This incident, says Daryl, underscores the need for pharmaceutical companies to announce warnings of drug shortages before they happen — and a push from government to communicate to the public whenever drug shortages occur to ensure people can make necessary arrangements, should their medication become unavailable.

Daryl says many people in the epilepsy community share this opinion. What's needed, he says, is a unified voice to make things happen — and not just from the epilepsy community.

Drug shortages can affect anyone undergoing medication therapy for any number of medical conditions. Daryl says

the best possible way to address the need for a national warning system would be for epilepsy agencies to collaborate with other advocacy groups, such as cancer, heart and stroke and mental health agencies, to create a unified voice.

“(We need) to speak with one loud voice where people . . . can inundate their MPs, ministers and the prime minister with e-mails saying that in a country like Canada, there's no reason why we can't have a more effective system and here's (what can be done),” says Daryl.



Daryl and Lindsay Yeo

Giving people ample notice of medication shortages would maximize the time needed for people to refill prescriptions or work with their doctor to develop alternative medication plans, says Daryl.

Additionally, there's a safety benefit to having a warning system in place, he says.

“Clobazam, for instance, you can't just quit cold turkey, you need to wean yourself off, and if you're going to move to an alternative drug you need to do that over a period of time,” Daryl says.

Although there is a national website — drugshortages.ca — where pharmaceutical companies post medication shortage advisories, it's a voluntary system.

Daryl says posting advisories needs to become mandatory and that push needs to come from government. — DH

THANK YOU!

At Epilepsy Ontario, we rely on the generosity of our volunteers and donors so we can continue to work to improve the quality of life for Ontarians with epilepsy. We thank you for your generous gifts of time, talent and donations.

Please join us at our upcoming events:

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Event Convenes Many Speakers

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industry did in recognition of Epilepsy Awareness Month. The event was organized by KPMG's AdaptAbility Network, a group of team members that creates events advocating for people with disabilities. The lunch-and-learn featured several speakers, including staff.

Olga Lapshinova, manager of global tax learning and development for KPMG's Tax Business School and an AdaptAbility Network organizer, shared her story of managing epilepsy for more than 10 years.

Epilepsy Ontario president Elisa McFarlane took time to recognize the KPMG team for raising awareness about epilepsy.

Attendees also heard from guest speaker Kelly Cvijanovich, who is the mother of two boys living with epilepsy. She focused on the importance of employers understanding the challenges of staff members who are parents of children with epilepsy.

Epilepsy Ontario executive director Rozalyn Werner-Arcé spent time dispelling some of the common myths about seizure disorders.

"We (wanted) people (to have a greater

understanding and to be more aware of what epilepsy is — that was the whole point (of the lunch-and-learn),"



Epilepsy Ontario volunteers and staff and KPMG volunteers giving the Thumbs Up for Epilepsy signal are seen here.

says Lapshinova.

"If (staff members) know someone who has epilepsy, they will know how to respond, they will know what epilepsy is about and they will know that this is not something to dread.

"They will be able to react with a full conversation about epilepsy," she says.

About 40 attended the event, which Lapshinova says is "a very good response."

A highlight of Epilepsy Awareness

Month was Purple Day. Held March 26, Purple Day is an international event aimed at raising epilepsy awareness.

KPMG participated in the Thumbs Up for Epilepsy campaign as part of Purple Day. A highlight of the campaign was encouraging people to paint their thumbnails purple to show support for epilepsy awareness.

Purple nail polish and purple ribbons were available on every floor at KPMG's office.

It's estimated that one in every 100 Canadians is living with epilepsy. With such a high number of people living with the neurological disorder, most of us will know someone who has epilepsy or know someone who's affected by it.

Werner-Arcé is commending KPMG for appreciating the diversity of employees.

"KPMG is demonstrating great corporate leadership by hosting this awareness event," says Werner-Arcé.

"Not only did management take the time to educate themselves about epilepsy, but they also showed, in a tangible way, that they are a caring employer who values their staff." — *DH*

'I Know There is Life and Happiness Beyond the Seizures'

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work from home and be her own boss.

Kinney, who lives in Kitchener, Ont., says she long felt "frustrated" in her search for a career that met her ambitions and would not be affected by her epilepsy. She had several jobs before pursuing a writing career, but her seizure disorder was always an issue affecting her employment.

"The thing I find frustrating is never knowing when the next seizure is going to occur," says Kinney.

"Freelance writing is a career that can

work around my seizures. I can work from home and be able to work on my own schedule. I still have much to learn in this field but I am enjoying learning as I continue my journey towards becoming a successful writer. . . .

"I know there is life and happiness beyond the seizures and I'm reaching out to grab a piece of it."

Kinney says she can't pinpoint the



Pamela-Anne Kinney

moment when she decided to become a freelance writer, but the important thing others living with a seizure disorder should know is that success comes down to setting personal goals and sticking to them.

Anyone living with a seizure disorder needs to keep this top of mind, she says.

"Start with small goals that are within reach."