

Voices OF EPILEPSY

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The province will be funding 21 new epilepsy monitoring unit beds at seven hospitals, more than doubling the existing number of beds. Seen at the March 28 announcement are (left to right): Dr. David Steven, neurosurgeon and co-director of London Health Sciences Centre's (LHSC's) epilepsy program; Mary McDonald, whose daughter is living with epilepsy; Health Minister Deb Matthews; Rozalyn Werner-Arcé, Epilepsy Ontario executive director; Dr. Jorge Burneo, neurologist and co-director of LHSC's epilepsy program; and Carol Young-Ritchie, vice-president of patient centred care at LHSC.

Momentum Growing Around Purple Day at Queen's Park

By Deron Hamel

Engaging MPPs at Queen's Park on Purple Day is paying off for Epilepsy Ontario, as evidenced by feedback the organization is getting from government officials.

Epilepsy Ontario representatives were at the provincial legislature on Purple Day (March 26) to raise awareness among MPPs about the issues people with epilepsy and their families are facing.

"We heard that epilepsy has a much higher profile at Queen's Park," says Epilepsy Ontario executive director Rozalyn Werner-Arcé. "MPPs and bureaucrats are hearing about it, talking about it and remembering it. This is good feedback and a reinforcement that we need to keep doing what we are doing."

"Between Epilepsy Action Day at Queen's Park in the fall and March 26, as well as ongoing communications both

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A Mother Calls for Action on Drug Shortage Data

When Diana went to fill her daughter's clobazam prescription recently, she had a big surprise when the pharmacy told her it couldn't supply her with all the medication her daughter needed.

Diana was unaware there was a medication shortage.

With the help of Epilepsy Ontario, Diana was able to get an additional

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Renewed Life and Hope One Year After Surgery

Kerry Jenkins is living proof of the difference successful surgery can make in the life of a person who has epilepsy.

Since having deep brain stimulation (DBS) surgery in December 2012, Jenkins, who was once described by doctors as having one of the most severe

See 'Surgery', page 3

Genetic Researchers Begin 4-Year Study

A team of Canadian researchers has embarked on a four-year study of the genetic contributions to epilepsy to develop personalized approaches to diagnosing various types of seizure disorders early as well as discovering treatments for drug-resistant epilepsy.

Researchers involved with the

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Epilepsy Ontario Engages MPPs on Purple Day

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at the local level and provincially, our combined efforts are paying off.”

Meetings between government officials and Werner-Arcé and epilepsy information specialist Suzanne Nurse covered a myriad of topics. These include the need for legislation to allow teachers and staff members to administer rescue medications in school to children who may need them. The issue of how to deal with drug shortages to ensure the safety of people needing medications is never compromised was also a major topic.

Werner-Arcé and Nurse spoke about the current shortage of clobazam, an anti-seizure medication which has been in short supply for several weeks and is not anticipated to make a full return to Canadian pharmacies until May 8.

Werner-Arcé and Nurse also spoke to the Epilepsy Implementation Task Force and the opportunity to further engage community support organizations as a partner in the broader care cycle.

“Epilepsy has a higher profile at Queen’s Park. MPPs and bureaucrats are hearing about it, talking about it and remembering it.”

— Rozalyn Werner-Arcé,
Epilepsy Ontario executive director

Werner-Arcé is also encouraging people with epilepsy and their families to reach out to their MPPs to invite them to special events and engage them through their organizations’ newsletters.

“It’s important to have those relationships and keep the dialogue going,” she says.

In the morning legislature session, MPPs Helena Jaczek and France Gélinas stated that there was all-party

unanimous consent to permit MPPs to wear purple ribbons in recognition of Purple Day. In the afternoon, there were member statements about Purple Day by Bas Balkissoon from the Liberals and Christine Elliott from the Progressive Conservatives.

In her presentation, Elliot, Whitby-Oshawa MPP, took time to recognize Epilepsy Durham Region executive director Dianne McKenzie.

Purple Day was started in 2008 by Cassidy Megan, a nine-year-old Nova Scotia girl who is living with epilepsy. Purple Day events are now held

worldwide.

Capping off Epilepsy Awareness Month, Health Minister Deb Matthews announced March 28 that the province is funding 21 new hospital beds for patients with epilepsy, more than doubling the number of existing hospital beds for patients with epilepsy in the province. There are currently 17 hospital beds funded for patients with epilepsy in Ontario.

The \$8.7 million investment will help 750 people with epilepsy get quicker testing for drug-resistant epilepsy, the government says.

Mandatory Drug Shortage Notices Needed

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supply of clobazam for her daughter, but it still isn’t enough of the medication to last until the shortage is slated to end in early May.

Since then, Diana has been spending much of her free time phoning pharmacies asking if they have clobazam in stock. This causes another hurdle for Diana because if she has to switch pharmacies, she needs to go back to her daughter’s neurologist and get a new prescription. Once a patient is prescribed clobazam, it can only be switched once to another pharmacy.

Through her efforts, Diana was able to obtain another clobazam supply, but this still isn’t enough medication to last her daughter until the shortage ends.

“It’s very frustrating — I’m very anxious about this,” Diana says, adding she also finds herself checking the online Canadian Drug Shortage Database to see if updates on the shortage are posted.

Diana says the high level of stress she and other people go through during medication shortages could be averted

if pharmaceutical companies were mandated by federal law to provide notices of impending drug shortages so people could get their medications ahead of time, or, if needed, ease off one medication and start a new one.

Diana has a clear picture of what this should look like.

“If there were drug-shortage notices that went out to all pharmacies, patients who have, for example, a prescription for clobazam, could get a phone call or an e-mail notifying them that there is the possibility of a shortage coming up, and an outline would be given for what steps need to be taken,” she says.

Given that pharmacies already have systems in place to notify people when prescriptions are due to be refilled, Diana says she doesn’t see why existing systems can’t be updated to include shortage notices.

Diana is also taking the initiative to write her MP’s office to explain the need for a mandatory drug-shortage database — and she’s encouraging others to follow suit.

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Surgery Reduces Seizures

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cases of epilepsy in the world, has had her seizures reduced by half and her tonic-clonic seizures have disappeared.

For Jenkins, the journey with epilepsy has been on a road rife with challenges. Her marriage ended because of her condition, which also strained her relationship with one of her two children. She lost her driver's licence because of her epilepsy, which presented transportation challenges for her, as she was living in Lindsay and having to travel more than 40 kilometres to her job in Peterborough every day.

With the challenges presented by her

condition adding up, Jenkins says she saw little hope for the future. Clinical depression set in and became so severe that on two occasions she almost committed suicide.

But things would change for the better.

Now 45, Jenkins began having petimal seizures at seven, with up to 100 per day. Because these episodes only lasted two or three seconds and looked like quick pauses, her parents didn't know they were seizures. It wasn't until several years later she was examined by a physician for her seizures.

In August 2000, Jenkins had her first tonic-clonic seizure. The seizures progressed to an average of 15 per month. She was diagnosed as having both generalized seizures and temporal-lobe seizures.

In November 2010, she had an electroencephalogram (EEG) to examine her temporal lobe. Thirteen months later, upon recommendation from her neurologist, Dr. Richard Wennberg, Jenkins underwent DBS surgery. This operation involves implanting a "brain pacemaker" which sends electrical impulses to the brain.

Prior to the DBS surgery Jenkins

was on several medications, but she was having allergic reactions and severe side effects — including glaucoma and asthma — to most medications.

The DBS surgery, says Jenkins, was the major game-changer in her

life. Since the surgery, the number of seizures Jenkins experiences has declined from 15 to eight per month, with no more generalized seizures.

Jenkins credits Wennberg, neurosurgeon Dr. Taufik Valiante and her current neurologist, Dr. Danielle Andrade, for their tireless compassion and diligence which ensured she received the treatment she needed to change her life.

The fact that her seizure condition was so severe she almost ended her life because of it is the No. 1 reason Jenkins says she wants to share her story with the Voices of Epilepsy.

"Even if I can inspire one person to turn around and not (harm themselves)," she says. "It is not worth it; you can fight if you keep trying and you get the help you need."
— DH



Kerry Jenkins is seen here on Purple Day 2013.

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Up to 10,000 Epilepsy Patients Could Have Genome Sequenced

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Canadian Epilepsy Network (CENet) are sequencing genomes from 2,000 patients. CENet researchers are collaborating with U.S. scientists who are sequencing 4,000 patients' genomes as part of the Epi4K project, and Europe's EpiPGX initiative, which is sequencing 2,000 patients' genomes.

Encoded in the DNA of every organism, genomes contain the entire heredity of a person's genetic history. By using a process called next-generation sequencing, researchers will be able to examine genetic changes that predispose people to epilepsy and even predict a person's response to anti-seizure medication.

"Looking forward, this study will (examine) how these genomic technologies will save money to the system and improve the care of patients," Dr. Berge Minassian, one of CENet's leaders, tells *Voices of Epilepsy*.

"At the end of the whole project, we are hoping to come up with a test . . . where anybody with epilepsy will have their genome sequenced and we will be able to predict what type of epilepsy

"At the end of the whole project, we are hoping to come up with a test . . . where anybody with epilepsy will have their genome sequenced and we will be able to predict what type of epilepsy they have . . ."

— Dr. Berge Minassian

they have; whether they have easy-to-treat epilepsy or hard-to-treat epilepsy."

At the end of the project, as many as 10,000 epilepsy patients could have their genomes sequenced, which

Minassian says would be a major step forward in epilepsy research.

"That's a huge amount of information — it's massive," he says. "We will know



Dr. Berge Minassian

everything we need to know about the genetic contributions to epilepsy. When it's all said and done, it will have a major impact on epilepsy."

Minassian underscores the importance of knowing a disease's cause. Once the cause is understood, he says, researchers can start to learn about the mechanisms of the disease and why it occurs.

"(Knowing the cause of epilepsies) opens lots of entryways to treatment, because now you understand why one person's brain is making seizures and another person's brain is not," he says.

"Finding the cause of a disease is like finding the Holy Grail."

The other CENet research leaders are Dr. Patrick Cossette of the University of Montreal Hospital Research Centre and Dr. Jacques Michaud of Montreal's

Sainte-Justine University Hospital Research Centre.

Genome Canada and Génome Québec are the primary funders of the \$10.8-million research project. UCB Canada Inc. recently contributed \$200,000 to the research. — DH

Mother Seeks Drug Shortage Action

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Clobazam, which is marketed by several pharmaceutical companies in Canada, is a common medication prescribed to people with seizure disorders. The medication is usually prescribed to work in tandem with other pharmaceuticals. While several companies manufacture the drug, some people with epilepsy can experience changes in their seizure control when they switch brands.

There have been multiple shortages of anti-seizure medications over the past few years, and this is at least the second clobazam shortage in 14 months. In January 2013 Epilepsy Ontario issued a notice that pharmacies had back orders of clobazam.

In September, new guidelines were established that have been developed by government, industry and other stakeholders clearly outlining the expectations, roles and responsibilities for all stakeholders during a medication shortage.

Adhering to these guidelines is important to ensure safety for people with chronic conditions requiring medications, says epilepsy information specialist Suzanne Nurse.

"When it comes to managing drug shortages, early notification from drug manufacturers is key," she says. — DH