

Annual Report 2017



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Letter from the Executive Director



Dear friends,

2017 was a year of table-setting for Epilepsy Ottawa, focused on building a solid foundation for a strong agency ready for future growth. The year featured strengthened relationships with the medical community, newly secured resources, and improved programs.

To foster a sustained and growing epilepsy community, Epilepsy Ottawa increased the frequency of the Parent Support Group and Social Group to monthly meetings.

Dr. Tadeau Fantaneanu (Dr. Tad), Director, Adult epilepsy program and EEG laboratory at The Ottawa Hospital, joined the team as Epilepsy Ottawa's medical advisor. Dr. Tad helps ensure that the educational material the agency develops is accurate.

Epilepsy Ottawa secured a Seed Grant from the Ontario Trillium Foundation to develop the first formalized peer mentor program specifically for people with epilepsy in Ontario. People with epilepsy new to the agency often report that they have never met someone else who has had a seizure and whose friends and family don't understand what it's like to live with a seizure disorder or have a child with a seizure disorder. This sense of not being heard, understood, or supported, and feeling socially isolated can impact physical and emotional health. It can increase susceptibility to depression and anxiety – for which adults with epilepsy and parents whose children have epilepsy are already at higher risk than the general population. Stress, like the stress of being socially isolated, can trigger seizures. In 2017, Epilepsy Ottawa began to develop a new program dedicated to combatting this social isolation by introducing people struggling with epilepsy to those living well with a seizure disorder. Like peer mentor programs for other health conditions, this new program promises be beneficial for all participants – mentors and mentees.

I'm excited to share with you the progress we made in 2017 creating a stronger organization with the capacity for growth and flexibility. This will best serve the needs of those impacted by epilepsy across Ottawa, Lanark County, Renfrew County, Prescott-Russell County, and Stormont, Dundas & Glengarry Counties.

Sincerely,

Nikki Porter, PhD
Executive Director

Community

The epilepsy community returned to Ottawa City Hall to celebrate Purple Day for Epilepsy. Well over 100 people braved the chilly March weather to Epilepsy Ottawa's Purple Day Celebration featuring ice skating on the Rink of Dreams, face painting, cotton candy, epilepsy trivia, a photo booth, and great company.



Support

A core Epilepsy Ottawa service is responding to calls and emails from people with epilepsy, often when they are in crisis. They may be looking for guidance on financial assistance available to people with epilepsy, concerned that they are facing discrimination at work, seeking advice on when they can get their driver's license back after an extended period of seizure freedom, or concerned about their new epilepsy diagnosis. Responding to these calls and emails is one of the most crucial services we provide.

Intake & Referral Meetings

The Intake & Referral Team provides information, resources, and community referrals to people with epilepsy and their families.

Parent Support Group

Parents and caregivers of young or grown children with epilepsy meet once a month to provide support to one another and discuss various topics from a caregiver's perspective, including the challenges they're facing.

Social Group

The social group is an opportunity for adults with epilepsy and their loved ones to meet other people living with epilepsy in a relaxed, informal setting.



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In the 2017, Epilepsy Ottawa provided support services to

people, epilepsy education to **213** people, and

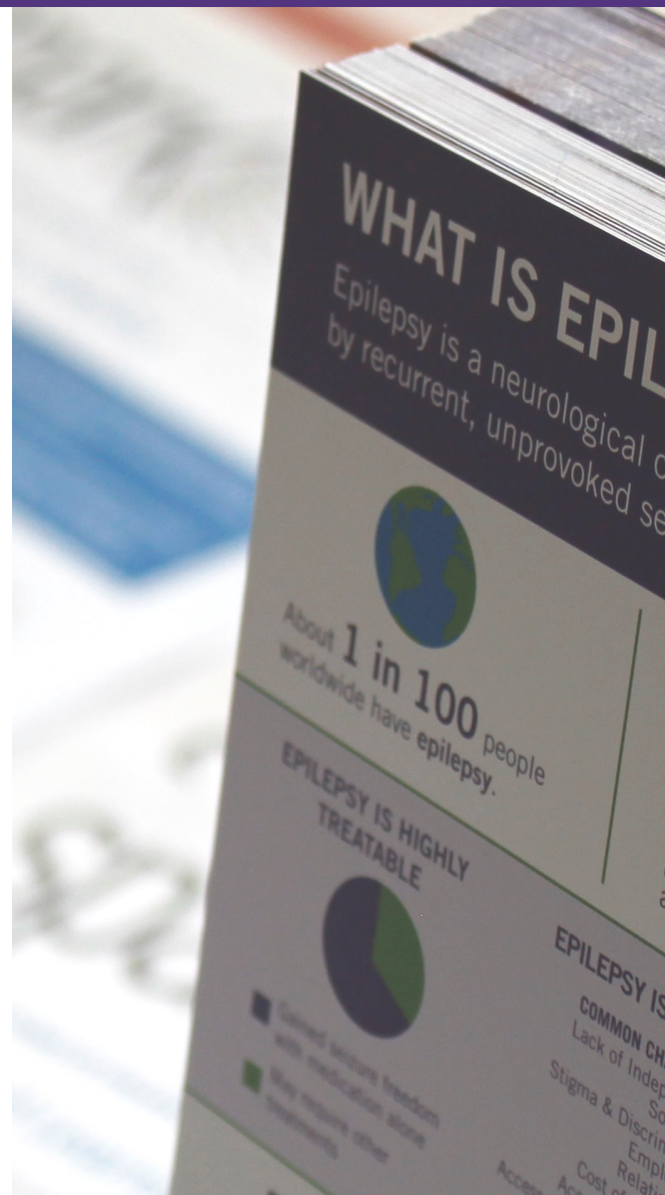
293 people participated in our community activities and events.

Education

Epilepsy Ottawa's **Seizure Smart** got a makeover in 2017, with updated information aligning the agency's signature educational program with new provincial best practices. This program is available to educators, employers, and community groups interested in learning about epilepsy, identifying different types of seizures, and how to provide seizure first aid.

Public Information Meetings feature guest speakers discussing their particular area of expertise. In 2017, topics included

- Epilepsy and Ketogenic Diet Therapy for Adults with guest speaker Dr. Eduard Bercovici
- Epilepsy Care in Ottawa with guest speakers Dr. Tadeau Fantaneanu and Gillian Reid McDonald
- Navigating the Healthcare System with guest speakers Susan Hagar, Marian Meade, and Lynn Joseph from Nurse on Board



Awareness

Shine Light on Epilepsy

Rideau-Vanier City Councillor Mathieu Fleury hosted Epilepsy Ottawa's Shine Light on Epilepsy immersive project at Ottawa City Hall over the last week of Epilepsy Awareness Month and helped launch the project during the agency's Purple Day Celebration. Inspired by the Subway Therapy Project in New York City, the Shine Light on Epilepsy project was an opportunity for anyone in the community to show support for people and families living with epilepsy.

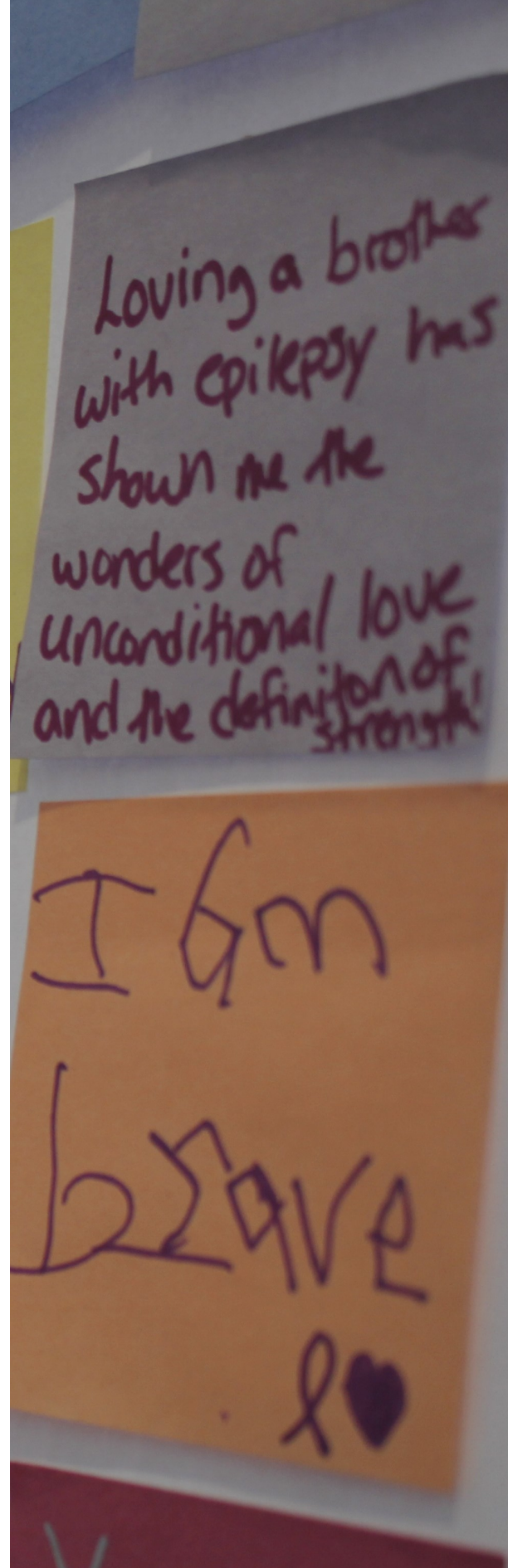
Post-it Notes and markers were provided for passers-by to write notes about how epilepsy impacted their lives, what they wished more people knew about epilepsy, or positive messages for people with epilepsy. They could then adhere the Post-It Note on one of the boards sitting on a row of easels. Participants filled 6 foam boards with Post-it Notes. They ranged from heartfelt stories about being inspired by a boss or sibling with epilepsy, to frank statements about how people with epilepsy are treated or the challenges people live with, to heartwarming notes from children with epilepsy.

Viral Video

Epilepsy Ottawa posted the new Tonic Clonic seizure video to the agency's Facebook page in March and the video went viral. Within two days, the video had 7,000 views – more than triple previous videos over much longer periods of time. Views, shares, likes, and comments skyrocketed from there. After a single month, the video reached 20 million people, was viewed by 7.1 million people, was shared by 155,000 people and received 23,000 reactions and 1,200 comments from around the world!

The agency posted the new Focal Impaired Awareness Seizure Video a week later. The second video didn't reach quite as far as the first, but it still far surpassed the reach of other videos on the agency's Facebook page. In less than a month, it reached 74,000 people and was viewed by 15,000 people. Many people who shared the Focal Impaired Awareness Seizure video told their friends to watch it in order to understand their seizures and how to help.

These videos are available at epilepsyottawa.ca/videos.



Laith's Story

Laith first started having seizures when he was about six-years-old. He would see a blinking bright light for a few seconds or minutes and then his eyesight would return to normal. By his late teens, he had different types of seizures, mostly absence seizures which are very brief and, for Laith, on average lasted around 9 seconds each. Laith is one of the nearly 10,000 people in the Ottawa region who are living with epilepsy and he continues to experience frequent absence seizures to this day.

The most striking feature of an absence seizure is a blank or vacant look that could be misinterpreted as a brief episode of daydreaming. The blank look may be the only outward sign, although some people have other features that could include eye movements, blinking or automatic behaviours.

Laith has never been seizure-free. In fact, his seizures have become worse and more frequent with time. "I have tried lots of medications, so many different medications but nothing has worked," said Laith. "Doctors just keep trying different combinations and dosages of medications, hoping they'll land on the right one. Sometimes it works, things are controlled for a while, but then it relapses."

Laith had an appointment with a doctor who referred to this search for the right combination of medication, as a "guessing game". People with epilepsy know all too well how frustrating this process can be.

Laith doesn't talk about his epilepsy a lot unless the topic comes up, often when somebody asks him why he doesn't drive. "Many people don't know what epilepsy is or just know it by the name, so I have to explain it and I would explain what to do in case anything happens," said Laith. "Reactions are varied – some feel sorry, others take it normally and some ask for details either out of interest or to be more aware in case I have an event."

Like many people with active seizures, Laith says not being able to drive is one of the biggest barriers that epilepsy places on him in everyday life. Laith also has concerns about how medications impact his memory which can affect his work, productivity, and personal life. "I'm not an efficient worker, sometimes I repeat tasks even though I started them before but never completed them. A lot of times, I don't remember special events. For example, people's wedding parties that friends talk about," explained Laith.

Laith discovered Epilepsy Ottawa through Epilepsy Toronto when he was getting some medical tests at Toronto Western Hospital. "Epilepsy Ottawa is an excellent, valuable group that brings awareness to the community," said Laith. "To me, Epilepsy Ottawa means care, awareness and safety. It is a place where someone with epilepsy can become more active and get involved in the life of the epilepsy community."



2017

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Epilepsy Ottawa is a not-for-profit, charitable agency dedicated to improving the quality of life for those living with epilepsy or seizure disorders and those closest to them through support services, education, advocacy, and on-going public awareness.

Epilepsy Ottawa provides services to those affected by epilepsy in the Ottawa region, including the wider rural communities (Lanark County, Renfrew County, Prescott-Russell County, and Stormont Dundas & Glengarry Counties).

Almost 10,000 people in this area have been diagnosed with epilepsy. The effect of an epilepsy diagnosis goes beyond the individual; it impacts the entire family.

Our Vision: Creating a community where persons affected by epilepsy or seizure disorders are empowered and supported to live life to the fullest, free of stigma and barriers.