

# Annual Report

# 2018



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## Epilepsy Ottawa Staff

Nikki Porter – Executive Director

Stephanie Youngdale – Program Coordinator

## Board of Directors

Peter Andrews – President

Allen Wright

Jeffrey McCully

Sherisse Al Sabeih

## Our Vision

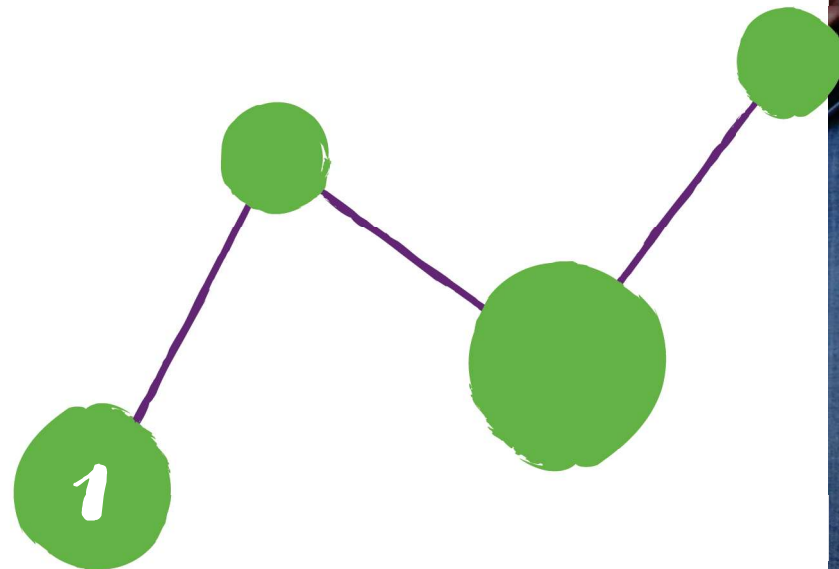
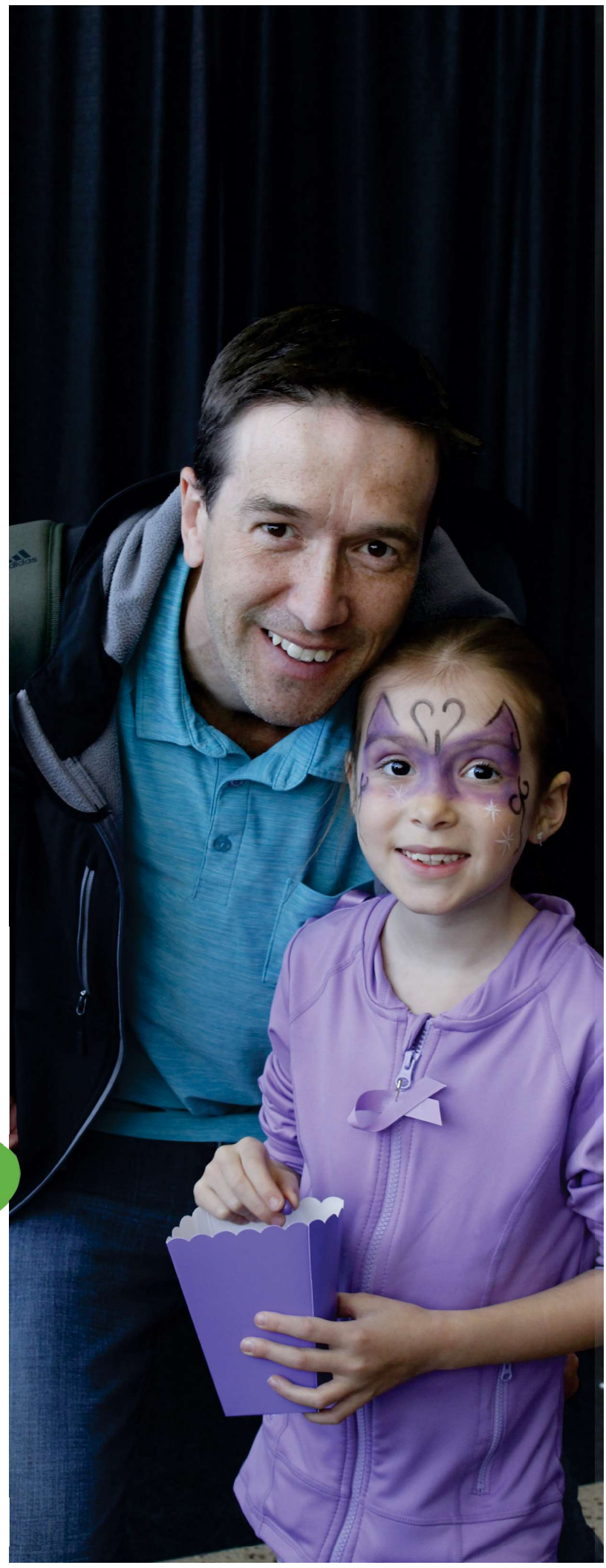
Creating a community where persons affected by epilepsy or seizure disorders are empowered and supported to live life to the fullest, free of stigma and barriers.

## Our Mission

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).

About 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.





# Letter from the Executive Director

Dear friends,

Over the last few years, Epilepsy Ottawa prioritized re-establishing services at and preparing for future development. I'm pleased to report that our work has paid off; 2018 was a year of significant growth.

Funding from Ontario Trillium Foundation, Ontario Brain Institute, and Eisai Pharmaceuticals helped hire an additional staff member and launch three programs in 2018: Epilepsy Connect Ottawa, Clinic to Community, and Painting in the Park. An Ottawa Community Foundation grant helped revitalize Seizure Smart, our signature epilepsy education program, after the retirement of Kevin Drysdale, the invaluable volunteer who had run the program for many years.

In 2018, Epilepsy Ottawa became an official charity of the Scotiabank Charity Challenge for Ottawa Race Weekend. I was proud to walk with purple-clad Team Epilepsy in the 2k as onlookers cheered. Epilepsy Ottawa supporters from across the Ottawa Race Weekend events raised over \$6,000.

We launched our new signature community and fundraising event, the Ottawa Fire Truck Pull at Lansdowne Park in October. Teams of 10 pulled a 12 tonne fire truck 100 feet in a competition to see who could pull the fire truck the fastest, raise the most money for Epilepsy Ottawa, and demonstrate the best team spirit. Our partnership with Ottawa Fire Services and Lansdowne Park helped make the inaugural event a great success, with \$23,000 net revenue.

These grants and fundraising efforts provided the agency with the capacity to diversify our programming, expand the coordination of care between Epilepsy Ottawa and local neurologists, and provide support to more people in our region struggling with epilepsy. We expect this growth will continue in 2019, increasing our outreach and impact.

I want to thank the Board of Directors for their leadership of our agency, our staff for their exceptional work in supporting people living with epilepsy, and the many volunteers and donors who make the work of Epilepsy Ottawa possible.



Sincerely,

Nikki Porter, PhD

Executive Director



# Support

## Epilepsy Connect Ottawa

This year we launched Epilepsy Connect Ottawa, a one-on-one peer mentor program for adults with epilepsy and parents whose children have epilepsy. Peer mentors are screened and trained before they are matched with a mentee.

Peer mentor programs reduce social isolation and can be beneficial for all participants. Epilepsy Connect Ottawa helps those living with epilepsy establish connections in their community. The program can provide guidance to live well with a seizure disorder.

## Support Programs and Services

- Client Services: information, resources, and community referrals to people with epilepsy and their families
- Epilepsy Connect Ottawa
- Social Group
- Parent Support Group

# Education

## Clinic to Community

Epilepsy Ottawa joined Epilepsy Southwestern Ontario in a pilot project, providing Clinic to Community for adults who have been recently diagnosed with epilepsy and their loved ones.

Epilepsy is an emotional diagnosis and written materials are not effective in reducing fear or helping cope with the day-to-day reality of living with unpredictable, stigmatizing seizures. Often, reading about epilepsy on websites perpetuates fear and feelings of social isolation. Developed by Epilepsy Southwestern Ontario, Clinic to Community is an evidence-based program proven to reduce fear, social isolation, and unnecessary visits to the ER.

Participants in the Clinic to Community pilot project meet with an Epilepsy Educator to learn about epilepsy, how to identify when a seizure is a medical emergency, tips to reduce risks associated with seizures and improve seizure management, and how to live well with epilepsy.

The Epilepsy Educator identifies resources, programs, and services offered in the community that would benefit each client. Through regular check-ins, this becomes an ongoing support service for individuals and families with epilepsy. They also connect the clients to the epilepsy community.

## Education Programs

- Clinic to Community
- Public Information Meetings
- Seizure Smart Presentations





# Community

## Painting in the Park

In September, youth with epilepsy, their families, and members of the healthcare team from the Adult Epilepsy Program at The Ottawa Hospital joined Epilepsy Ottawa at Andrew Hayden Park to paint murals from the Foundation of Hospital Art. Once the murals were complete, they were donated to The Ottawa Hospital and decorate the wall of the Neurosciences Clinic waiting room.

The event helped youth who are transitioning from CHEO's Pediatric Epilepsy Program to The Ottawa Hospital's Adult Epilepsy Program by introducing them to their new patient care teams and their local community support agency in a positive, non-medical environment.

In creating this mural together, youth with epilepsy were introduced to the people who will be caring for them going forward. This introduction occurred outside hospital walls, so that patients and their care providers could get to know each other in a social environment. This could help set the stage for the patient and care provider relationships going forward.

## Purple Day Celebration

We had a lovely afternoon celebrating Purple Day at Ottawa City Hall on March 25. Jean Pigott Place offered a bright and beautiful atmosphere. Guests enjoyed face painting, games, a Candy Bar, and a painting party run by Pop Up Painters. Mayor Jim Watson presented us with a Purple Day proclamation. MPP John Fraser helped us launch Epilepsy Connect Ottawa. Amy Hanes gave a funny and touching speech about her epilepsy journey.

It's always wonderful to see our members at events like this. Meeting new members and seeing new connections forged between members inspires us to continue providing these events, and strive to make them even better.





# Ottawa Fire Truck Pull

The inaugural Ottawa Fire Truck Pull was an unequivocal success. On October 28th, the Honorary Team featuring MP Karen McCrimmon, MP Mona Fortier, MPP Joel Harden, MPP Nathalie Des Rosiers, and Councillor Jeff Leiper kicked off the event. They were followed by 10 teams who gave it their all. Every team got that 12 tonne pumper fire truck moving, which is a win in itself. Ottawa New Country 94's Rebecca Lafrance was delightful as she shared her emcee skills to keep things running smoothly. After an intense, but friendly competition the award winners were:

Teams and other donations brought in \$23,000. As our generous sponsors covered the entire cost of the event, every dollar of that \$23,000 will go directly to programs and services for the nearly 10,000 people with epilepsy in our community.

By the end of the event, some teams were already planning their strategies for next year's Ottawa Fire Truck Pull. We're just as excited about it as they are.

## Fastest Team Award:

Lori's Lumberjacks (Pull Time 00:19:51)

## Best Team Spirit Award:

Brain Stormers (Score: 56/60)

## Most Charitable Team:

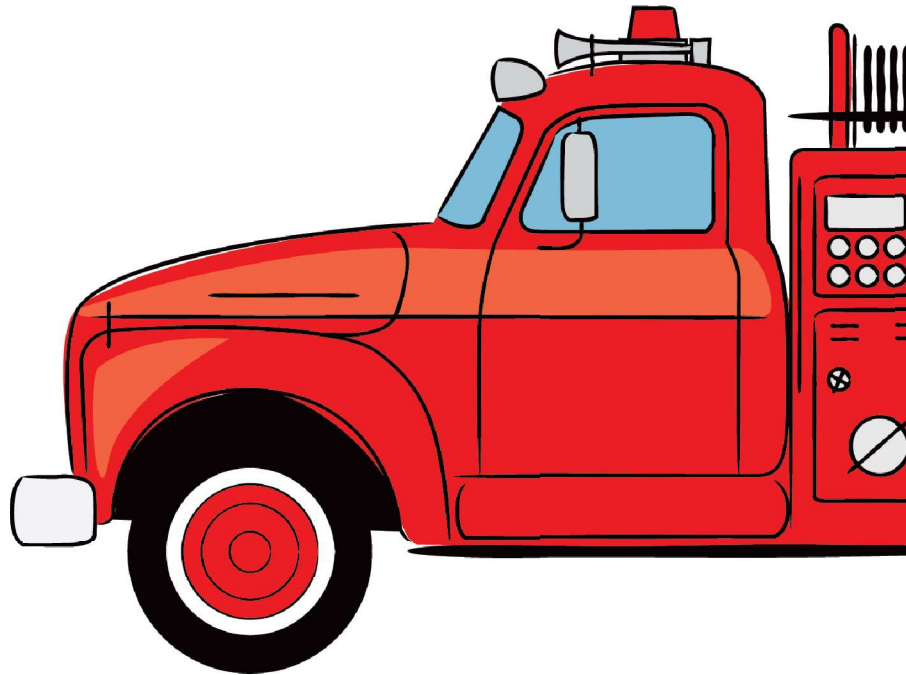
Team Shrek (Raised \$8,275)

## Most Charitable Teammates:

Team Shrek (Averaged \$827.50/teammate)

## Overall Best Team:

Team Shrek (Raised \$8,275; Pull Time 00:20:15;  
Team Spirit score 54/60)





# Stephanie's Story

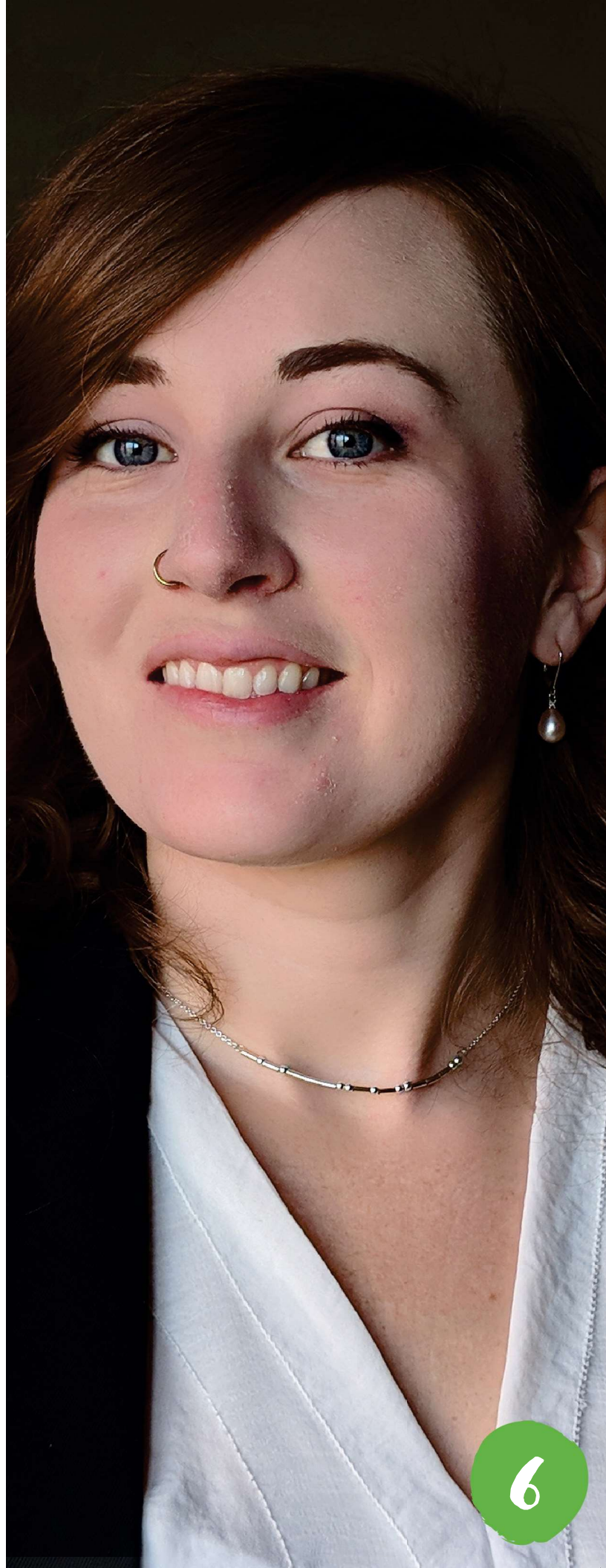
Stephanie was diagnosed with epilepsy at age 11. Now, as the Program Coordinator at Epilepsy Ottawa, she can directly relate to and empathize with clients. Stephanie remembers her exhausted and frustrated tears as a child preparing for a sleep-deprived EEG. She recalls classmates making the classroom lights flicker to see if they could trigger a seizure. She knows the nagging feeling that a tonic-clonic seizure could be right around the corner. She is familiar with the near-constant automatic risk assessment to avoid seizures.

Stephanie lives well with epilepsy and didn't think about epilepsy as a disability. She rarely disclosed her condition to employers, colleagues, or friends. Previous experiences with disclosure often yielded judgment, misunderstanding, and words and facial expressions that stung.

Having epilepsy influenced the decisions that she made when considering whether or not to disclose to an employer. She weighed her own safety against potential for discrimination and misunderstanding because of a general lack of knowledge and understanding about epilepsy. For example, when Stephanie didn't tell her employer or coworkers about having epilepsy, fire alarms with accompanying flashing lights were especially dangerous for her. If there had been a fire and the flashing lights triggered a seizure, she would not have been able to escape and no one would have known to go find her.

Until gaining her position at Epilepsy Ottawa, having epilepsy felt like a secret that was better kept hidden. Stephanie now shares her experiences in advocacy forums so that others with epilepsy don't feel compelled to keep their disease a secret.

Stephanie spoke with MPPs during Epilepsy Action Day at Queen's Park about the common injustices that many people with epilepsy experience. Preparing for meetings with MPPs required self-reflection and deep thought about an issue that she had previously made a conscious effort to brush aside. Exposing the challenges of epilepsy that people in our community may take for granted was empowering.



# Thank you

## Corporate Donors

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Ottawa Professional Fire Fighters Association  
The Printing House  
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## Grants & Foundations

Ontario Brain Institute  
Ontario Trillium Foundation  
Ottawa Community Foundation

## Media Partners

94.7 Ottawa's New Country

## Community Partners

City of Ottawa, Lansdowne Park  
Children's Hospital of Eastern Ontario, Epilepsy Program  
Nurse on Board  
Ottawa Fire Services  
The Ottawa Hospital, Civic Campus, Epilepsy Program

## Outstanding Volunteers

These incredible volunteers dedicated 10 or more hours to Epilepsy Ottawa:

Magda Ali  
Erin Balwood  
Alisson Dykeman  
Amy Hanes  
Naomi Heinz  
Yan Jiang  
Rochelle Porter  
Janet Vu  
Tyobista Worku

**44** volunteers dedicated **455** hours in 2018.

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