

211 Bronson Ave #207,
Ottawa, ON
K1R 6H4

Phone: 613-594-9255
Toll Free: 1-800-374-5377
Fax: 613-594-5189
Email: info@epilepsyottawa.ca

epilepsy ottawa
épilepsie ottawa

ANNUAL REPORT 2016

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).

Letter from the Executive Director

2016 was a busy and exciting time at Epilepsy Ottawa. We began the process of revitalizing the organization, which was kick-started by the development of a three-year strategic plan.

At the heart of this plan is a focus on community building, which continues to be the main driver behind our programming – whether it's facilitating an engaged community among people with epilepsy, strengthening ties with the local medical community, or developing partnerships with epilepsy agencies across Ontario. Dismantling silos and reducing social isolation are critical to improving the quality of life of people with epilepsy and their loved ones.


The five areas we've identified as being key to achieving Epilepsy Ottawa's mandate are:



1. Become a part of the continuum of care
2. Develop strong, stable, and diversified funding sources
3. Become the one-stop resource for information and support groups within the region
4. Increase awareness and understanding of epilepsy in the community
5. Engage with the larger epilepsy community

Volunteers will continue to play a crucial role in helping us achieve this mandate. We are indeed fortunate that some of our volunteers have years, even decades, of professional experience that they have been able to draw upon to improve our services. In 2016, with the help of volunteers, we maintained the Seizure Smart program and Parents Supporting Parents Group, relaunched the Social Group and Public Information Meetings, and developed the new Intake and Referral program.

I'm excited to share with you the progress we made in 2016. We are looking forward to continuing this strategic plan in 2017, with the goal of 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.



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.

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.

Continuum of Care

Epilepsy doesn't stop at the door of the doctor's office or once someone walks out of our office. Epilepsy Ottawa knows that becoming part of the continuum of care is an important step to best serving people with epilepsy in our community. Our long term goal is to be better connected with the medical community, first responders, educators, etc. In 2016, we made the following connections:

- Set up a referral program for The Ottawa Hospital, CHEO, and other interested neurologists. Now, health care professionals treating people with epilepsy who would benefit from our services can easily refer patients to Epilepsy Ottawa and we will follow up directly with them.
- Provided educational material to CHEO and The Ottawa Hospital, including information booklets, strategy sheets, and seizure journals.
- Held productive initial discussions with Dr. Tad Fantaneanu about partnering on upcoming epilepsy-related projects in the region. Dr. Fantaneanu joined the Neurosciences Clinic at The Ottawa Hospital, Civic Campus in August 2016 and he's introduced an exciting vision for comprehensive epilepsy care in the Ottawa community that includes Epilepsy Ottawa.

Diversified Funding

Historically, Epilepsy Ottawa has relied primarily on private donations to sustain the agency. As part of our three-year vision for success, we are working to create strong, stable, diversified funding sources. In 2016, we revived successful fundraising efforts and explored some new ones:

- Revived our signature Sip N Style event. The combined net revenue from the event itself, sponsorships, and donations in response to event promotions was close to \$15,000.
- Launched our first official Giving Tuesday campaign, which raised over \$2,000.
- Received funding from the Canada Summer Jobs program to hire two summer students to help us develop educational, awareness, and fundraising material.
- Structured and promoted a third-party fundraising program that drew almost \$7,000 from first-time events.



Estelle was inspired by meeting other people living with epilepsy at our Purple Day Celebration in March 2016. When planning her 9th birthday party, she asked guests to make a donation to Epilepsy Ottawa instead of giving her a gift. The following week, Estelle delivered an envelope filled with \$165 to our office in the Bronson Centre. What an incredible 9 year old!

Information and Support Programs

Intake and Referral

One of the exciting new initiatives at Epilepsy Ottawa is our Intake and Referral program. The Intake and Referral team can assist if someone is dealing with a new epilepsy diagnosis, trying to apply for ODSP or get their driver's license back, figuring out how to talk to an employer about their epilepsy, or simply wants to learn more about seizure first aid to support a loved one with epilepsy.

Parents Supporting Parents Group

The Parents Supporting Parents Group is a group of parents and caregivers of children living with epilepsy. They meet once a month to support each other and discuss the various topics and or challenges of life from a parent's perspective.

Social Group

Living with epilepsy can be an isolating experience. Whether someone is looking for support or simply wants to spend time with other people who understand what they've gone through, the social group offers a welcoming, positive space for adults with epilepsy.

Public Information Meetings

We revived the Public Information Meetings initiative from the past and invited special guests to talk about Financial Planning for People with Disabilities. We will continue with this informative series in 2017.





Samah's Story

Volunteers are the lifeblood of Epilepsy Ottawa. We are fortunate enough to have volunteers with many years of knowledge and experience that can help to support our clients. Samah Ahmed is one such volunteer.

Samah is an internationally trained healthcare professional with over 20 years' experience in the pediatric medical field, where she specialized in pediatric neurology disorders. She has worked as a pediatric neurologist in The Children's Hospital at Cairo University in Egypt, and the Pediatric Neurology Department in the Children's Hospital KSMC in Saudi Arabia.

Samah became an essential part of our Intake and Referral team from the moment she began volunteering for us in April 2016. She meets with individuals and families struggling with epilepsy and provides general epilepsy education. In these meetings, Samah and our clients discuss their concerns about seizures, comorbidities, work accommodation, and financial support. Although Samah does not provide medical advice, she helps clients prepare for meetings with their neurologist with information about tracking seizures, detecting seizure triggers, recognizing new symptoms, identifying medication side effects and much more.

"I joined Epilepsy Ottawa because it is a great way to be able to help others with the knowledge and experience I have acquired throughout my years as a physician," said Samah.

Her experience in this field has taught her how much support people with epilepsy require.

"I have learned that there needs to be more epilepsy awareness as people who suffer from epilepsy need major support from the community as well as their family."

Public Education and Awareness

Epilepsy stigma, as well as lack of knowledge about seizures and seizure first aid, remain significant barriers to full inclusion in our community. Demystifying epilepsy by talking about it, its prevalence, and how to help someone who is having a seizure are key to breaking down these barriers.

Seizure Smart

Seizure Smart is a free program designed for schools, workplaces and other organizations to educate and build awareness about epilepsy. Entirely volunteer run, eight Seizure Smart presentations were delivered to schools and Child Care Centres in 2016, reaching close to 100 people.

Perfect Pie talkback

Theatre Artists' Co-operative: the Independent Collective Series (TACTICS) invited Epilepsy Ottawa to participate in talkbacks after two performances of the play "Perfect Pie". In the play by Canadian playwright Judith Thompson, one of the characters struggles with epilepsy. Although it isn't a central theme of the play or the defining characteristic of the character Patsy, she has a seizure on stage and delivers a moving monologue about the experience of living with the fear of her next seizure. The audiences during both talkbacks were as interested in finding out more about epilepsy and living with epilepsy as they were about the performance.

Infographic & Website

Epilepsy Ottawa launched two vital public education pieces:

- The "About Epilepsy" infographic postcard is now a standard feature on our information tables. Its colourful design has an appeal that reaches beyond the epilepsy community, drawing passersby to look over the bite-size facts and statistics, teaching them about seizures, epilepsy, and seizure first aid.
- The Epilepsy Ottawa website was redesigned in order to more effectively share content, such as "Epilepsy Stories", Seizure First Aid Videos, our agency newsletter, the latest news from Epilepsy Ottawa, and other items of interest for people with epilepsy or those impacted by it. Our new website is easier to navigate, and is full of resources, educational materials and information for the epilepsy community.

"Marie, I live in fear. I live in fear of the next seizure. It's like there's a stalker and he's always there, parked in the driveway, in his old car, waiting. I come down to turn out the lights, his face, in the window, his eyes, goin through me..." - Patsy in Perfect Pie

Engagement with the Larger Community

For too long, epilepsy agencies have worked alone, duplicating work and unnecessarily depleting limited resources. Over the last few years, there has been a concerted effort by epilepsy agencies in Ontario to coordinate our messaging, share resources, and work together more effectively. In 2016, Epilepsy Ottawa joined these efforts.

Professional Development Retreat

Epilepsy Ontario hosted its second annual professional development retreat for community epilepsy agencies from across the province. The all-expense paid retreat drew 28 attendees from 11 agencies for 3 days. Nikki and two volunteers attended from Epilepsy Ottawa to learn about topics critical to the services we provide, share skills, and build a network of support and resources.

Rebranding & Resource Sharing

Epilepsy Ottawa aligned its branding to that of Epilepsy Ontario and other epilepsy agencies in the province in order to coordinate messaging and more effectively share resources with other epilepsy organizations across Ontario. The rebranding effort gives us a foundation upon which to more cost-effectively create and share resources, such as the "About Epilepsy" infographic, which was created by Epilepsy Ottawa but is now being used across Ontario. With this brand alignment, we will no longer need to duplicate resources that already exist and we can provide the best available material to the community.

These achievements have contributed to meeting our goal of becoming a positive advocate and contributor to the provincial epilepsy community as outlined in our strategic plan.



WHAT IS EPILEPSY? Epilepsy is a neurological condition characterized by recurrent, unprovoked seizures.



About 1 in 100 people worldwide have epilepsy.



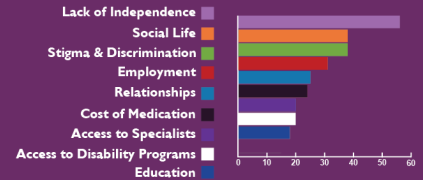
About 6,000 in Ontario are diagnosed with epilepsy each year.

EPILEPSY IS HIGHLY TREATABLE



Legend:
 Gained seizure freedom with medication alone
 May require other treatments

EPILEPSY IS MORE THAN JUST SEIZURES



COMMON CHALLENGES

PEOPLE OF ALL AGES LIVE WITH EPILEPSY



0-17



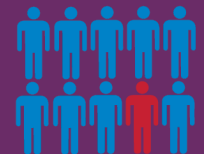
18-64



65+

WHAT IS A SEIZURE?

A sudden burst of electrical activity in the brain that affects the way a person acts. The location of the activity determines what the seizure looks like.



1 out of 10 people will have a seizure in their lifetime, but most people who have a single seizure do not have epilepsy.

WHAT DO I DO IF SOMEONE IS HAVING A SEIZURE?

1. STAY CALM

Most often, a seizure will run its course and end naturally within a few minutes.

2. TIME IT

Call 911 if:

- seizure lasts more than 5 minutes
- seizure repeats without full recovery between seizures
- person is pregnant
- person has diabetes
- person is injured from the seizure
- seizure occurs in water
- you are not sure if the person has epilepsy



3. PROTECT FROM INJURY

- Move sharp objects away.
- If the person falls to the ground, roll them on their side when it is safe to do so and place something soft under their head.
- If the person wanders during their seizure, stay by their side and gently steer them away from danger.
- When the seizure ends, provide reassurance and stay with the person if they are confused.

Financials

Revenue

	2016	2015
Grants	\$4,470.00	\$0.00
Donations	\$27,963.71	\$19,122.51
Nevada Sales	\$2,868.84	\$770.00
Sip N Style	\$13,129.00	\$-421.70
Other	\$3.84	\$1.86
Total	\$48,435.39	\$19,472.67

Expenses

	2016	2015
Program Expenses	\$34,730.66	\$5,815.00
Administration Expenses	\$7,480.45	\$18,458.37
Fundraising Expenses	\$11,220.67	\$1,664.63
Total	\$53,431.78	\$25,938

These are draft financial numbers pending audit.

Balance Sheet Previous Year Comparison

As of 31 December 2016

ASSETS

Current Assets

Chequing/Savings	31 Dec 16	31 Dec 15	\$ Change	% Change
10001 - General Bank Account 509	37,951.16	41,828.70	-3,877.54	-9.3%
10010 - Nevada Bank Account 502	9,938.88	12,201.69	-2,262.81	-18.6%
Total Chequing/Savings	47,890.04	54,030.39	-6,140.35	-11.4%

Accounts Receivable

11000 - Accounts Receivable	31 Dec 16	31 Dec 15	\$ Change	% Change
11200 - GST Refundable	-3,068.78	-3,068.78	0.00	0.0%
Total 11000 - Accounts Receivable	-3,068.78	-3,068.78	0.00	0.0%
Total Accounts Receivable	-3,068.78	-3,068.78	0.00	0.0%

Other Current Assets

18800 - Prepaid Expenses	31 Dec 16	31 Dec 15	\$ Change	% Change
18810 - Prepaid Rent	1,183.79	1,183.79	0.00	0.0%
18800 - Prepaid Expenses - Other	1,200.97	1,200.97	0.00	0.0%
Total 18800 - Prepaid Expenses	2,384.76	2,384.76	0.00	0.0%
Total Other Current Assets	2,384.76	2,384.76	0.00	0.0%
Total Current Assets	47,206.02	53,346.37	-6,140.35	-11.5%

Other Assets

	31 Dec 16	31 Dec 15	\$ Change	% Change
18600 - Capital Assets	1.00	1.00	0.00	0.0%
Total Other Assets	1.00	1.00	0.00	0.0%

TOTAL ASSETS	47,207.02	53,347.37	-6,140.35	-11.5%
---------------------	------------------	------------------	------------------	---------------

LIABILITIES & EQUITY

Liabilities

Current Liabilities

Accounts Payable	31 Dec 16	31 Dec 15	\$ Change	% Change
20000 - Accounts Payable	-0.50	-0.50	0.00	0.0%
Total Accounts Payable	-0.50	-0.50	0.00	0.0%

Other Current Liabilities

	31 Dec 16	31 Dec 15	\$ Change	% Change
25500 - GST/HST Payable	-8,630.87	-7,486.91	-1,143.96	-15.3%
Total Other Current Liabilities	-8,630.87	-7,486.91	-1,143.96	-15.3%
Total Current Liabilities	-8,631.37	-7,487.41	-1,143.96	-15.3%

Total Liabilities	-8,631.37	-7,487.41	-1,143.96	-15.3%
--------------------------	------------------	------------------	------------------	---------------

Equity

	31 Dec 16	31 Dec 15	\$ Change	% Change
32000 - Unrestricted Net Assets	60,834.78	67,289.67	-6,454.89	-9.6%
Net Income	-4,996.39	-6,454.89	1,458.50	22.6%
Total Equity	55,838.39	60,834.78	-4,996.39	-8.2%

TOTAL LIABILITIES & EQUITY	47,207.02	53,347.37	-6,140.35	-11.5%
---------------------------------------	------------------	------------------	------------------	---------------



Board of Directors

- Peter Andrews – President
- Tom Scholberg – Vice President
- Chris Watt Bickley – Treasurer
- Lorraine Lafrenière
- Velma LeBlanc
- Lori Timmins
- Allen Wright

2016 Volunteers

- Akin Kunutku
- Alana Dall
- Alisson Dykeman
- Amelia Zaglul
- Andrea Wagner
- Andrew Horsfield
- Ashley Craven
- Cathy Hill
- Christina Leduc
- Debbie Beattie
- Dora Dalietos
- Jean-Paul Salameh
- Kaleigh Timmins
- Karen Norris
- Kate Zaporozhets
- Kathy Wright
- Katie Dolan
- Kazi Hossain
- Lillian Cummings
- Lise-Marie Andrews
- Magda Ali
- Marcel Allen
- Michelle Berkvens
- Nathalie Tremblay
- Nicole Chevrier
- Nicole Trolley
- Persia Day-Savage
- Rochelle Porter
- Samah Ahmed
- Sibusisiwe Sibanda
- Tarryn Delaney
- Victoria Doherty