

# 2016-2017 Annual Report



## Executive Director's Message

Dear Friends,

Over the last five years, our biggest hurdle has been the loss of United Way funding (London/Middlesex, Sarnia/Lambton, Oxford and Elgin/St Thomas). In fact, since 2012, Epilepsy Southwestern Ontario (ESWO) has gone from \$190,449 to just \$18,000 (Chatham/Kent) of United Way funding. It saddens me to say that we are not the only organization to experience defunding by United Ways, and some community epilepsy agencies (Epilepsy Huron-Perth and Epilepsy Montreal) have been forced to close their doors after losing the support of their local United Ways. Despite these financial trials, Epilepsy Southwestern Ontario continues to thrive! As I reflect on the last year and anticipate the one ahead, I am filled with hope, optimism and excitement for the future of Epilepsy Southwestern Ontario (ESWO).

Our Clinic to Community program (generously funded by the Ontario Trillium Foundation) has been a tremendous success! So much so, that our pilot program has been identified as the model for standardized patient education and community support in Ontario. To date, five of our provincial colleagues (Epilepsy Durham Region, Epilepsy Ottawa, Epilepsy South Central Ontario, Epilepsy South Eastern Ontario and Epilepsy Toronto) are working on securing funding to implement our Clinic to Community program in their communities. Through this program, we have increased linkages with community healthcare practitioners, allowing us to connect with hundreds of families dealing with a new diagnosis of epilepsy. With an investment from the Ontario Brain Institute to provide research dollars, we have been able to collect data on the efficacy of Clinic to Community and are very much looking forward to releasing this data in a final report this fall.

One of my fondest memories of the past year, is the courage and determination of a 14 year old from Windsor. Chase Cartwright's mother Judy lives daily with seizures and is an inspirational role model who does not let epilepsy define her! Chase decided that he would ride his bike from Windsor to Toronto to raise both awareness and funds for Epilepsy Southwestern Ontario. His original fundraising goal was \$5,000, but with his determination and the generous support from donors and sponsors, Chase surpassed his goal, raising just over \$7,500. This money created a 'Chase Cartwright Fund', allowing people living with epilepsy who are in need, to access seizure safety items to help them live well with epilepsy. As a direct result of Chase's compassion for people living with epilepsy, his unwavering determination and his exemplary desire to raise epilepsy awareness, Chase was awarded the 2017 H.O.P.E (Helping Out People with Epilepsy) award. This is Epilepsy Southwestern Ontario's highest honor, and at 14 years of age, Chase is the youngest recipient!

Next year promises new and exciting adventures with an expanded staff team, a new location, the launch of our new Ontario Trillium Foundation funded youth program (YEP!) and a provincial strategy to work towards solidifying sustainable funding. I would encourage you to get involved and join the #PurpleNation! Join us on social media, make a donation, volunteer your time or just stop in for coffee and share your story! In closing, I would like to express a heartfelt thank you to our staff, our Board of Directors, our volunteers, our donors, our sponsors, our partners in the medical community and most of all, to our clients (aka #EpilepsyWarriors)!

Warm Regards,

*Michelle Franklin*

Michelle Franklin



## Letter from the President

Welcome our new Board President, Sara.

Sara has been engaged with our organization in the past and previously sat as a Board Member for just over 6 years.

"It is no surprise to me and no doubt to many of you that Epilepsy Southwestern Ontario has continued to deliver exceptional service and care in the communities we serve. I am proud to be part of this organization and thank you for putting your trust in me as your new President of the Board of Directors.

I truly believe the programs offered by ESWO such as the student support program, "Game On", "Clinic To Community" and our "Wacky Wednesday Summer Camp" are one-of-a-kind and offer immense support, knowledge and an inclusive environment to allow those with epilepsy and their support networks to thrive. These programs and the many other services offered would not be possible without our incredible staff, dedicated volunteers, knowledgeable Board of Directors and generous donors. While ESWO has in the past and continues to face financial challenges we have always stuck together and come out on top. Our organized events such as the Annual Spring Gala, Seize the Day Run/Walk and Purple Day have always been and continue to be a tremendous component of our financial success. I look forward to another great year and to hearing and sharing new and exciting success stories."

Sara Martin

President, Board of Directors

"If everyone is moving forward together, then success takes care of itself" -Henry Ford



# Our Year in Review

# April 2016 - March 2017



Annual Spring Gala -  
Passport to Paris (April 9, 2016)



Third Party: Kick it Up for  
Kenz (May 28, 2016)



Epilepsy Ontario Retreat  
(June 8, 2016)



AGM & Member BBQ  
(June 8, 2016)



Third Party: Out of the Shadows  
(June 19, 2016)



Third Party: Ride for Epilepsy  
(June 23, 2017)



Wacky Wednesday Camp  
(July/August)



Agency Yard Sale (July 15, 2016)



Windsor Fun in the Sun BBQ  
(August 13, 2017)



Third Party: Komoka's Party in the  
Park (September 3, 2016)



Third Party: Windsor McGregor  
Mug Run (September 16, 2016)



Third Annual Seize the Day Event  
(September 25, 2016)



Fall Open House & Purple  
Pumpkins (October 11, 2016)



Holiday Party, London  
(December 14, 2016)



Holiday Party, Chatham  
(December 16, 2016)



Third Party: Sam Jam  
(December 16, 2016)



Third Party: Beat the Blues  
(February 27, 2017)



Epilepsy Action Day, Queens Park  
(February 28, 2017)



Quarter Auction Fundraiser,  
Chatham (March 1, 2017)



Epilepsy Information Conference  
(March 4, 2017)



Ontario Trillium Funding  
Announcement, YEP! (March 4, 2017)



Chatham-Kent Fire Department,  
C.H.I.R.P. launch (March 7, 2017)



Huron Perth Meet and Greet  
(March 22, 2017)



Windsor Strike Out Epilepsy  
Bowling Event (March 26, 2017)

## Key Figures



Our volunteers dedicated over 3,057 hours of time, valued at over \$58,000

71%

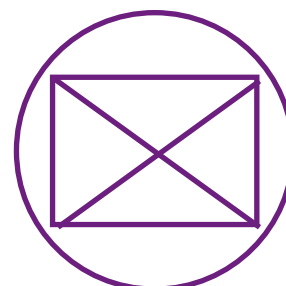
of family members who attended a C2C education session, reported feeling less anxious about their child's epilepsy



332 new clients have participated in Clinic to Community (C2C)

86%

of C2C education session participants reported feeling more confident when determining if a seizure is a medical emergency.



1453 E-MAIL SUBSCRIBERS

1057

PRESENTATIONS GIVEN TO OVER 1,500 CLIENTS, FAMILIES, AND COMMUNITY GROUPS IN SOUTHWESTERN ONTARIO

## Key Figures

### Game On

18 Game On sessions this year

35 Children registered for Game On this year



"Game On has been profoundly positive for my son! Great staff!"

- Parent of Game On participant

"I love this program. He is motivated to come!"

- Parent of Game On participant

### Epilepsy Awareness Month

\$37,310 Raised in donations

60+ Local businesses participated in EAM fundraising

28 Schools participated in EAM fundraising

JOIN THE #PURPLENATION

1 in 100

Canadians have epilepsy

1 in 10

Canadians will have a seizure during their lifetime

70%

of those living with epilepsy are unsure of the cause of their condition



5000+

Epilepsy is the most common neurological condition in children

Social Media Followers

25%

of Wacky Wednesday Camp participants received a registration subsidy

## Third Annual Seize the Day Walk/ Run

Our 3rd Annual Seize the Day event took place on Sunday, September 25, 2016 at Kiwanis Park North. This family fun event was a 5K Run and 2.5K Walk, followed by live entertainment and a community BBQ. Live entertainment was provided by Sarina Haggarty, who also shared her story of living with epilepsy at the event.



As a highlight of our year, we are excited about the success of the event. Together, over **300 participants** raised **\$40,000** towards

Epilepsy Southwestern Ontario's support and education programs!! We also welcomed **22 volunteers** to help support the day of. Special thank you to our highest fundraising team: Team Oke, who raised over \$14,000 to help support programming. We are excited to report that many new families joined the walk this year in honour or memory of someone affected by seizures & epilepsy. This annual event continues to bring families in our community together.

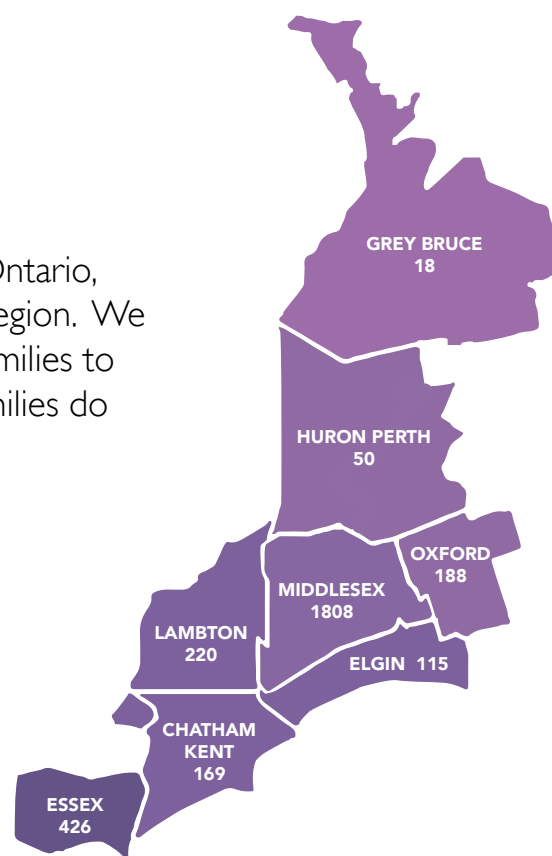


## Our Clients

Epilepsy SWO now services all of Southwestern Ontario, providing support and education throughout the region. We are able to provide services to newly diagnosed families to create an environment in which individuals and families do not feel isolated in their diagnoses.

**2,994**

clients have accessed our services



## H.O.P.E. Award



The H.O.P.E. award is given out annually to a group or individual who has demonstrated a commitment to improving the quality of life for people living with epilepsy in our community.

Mike Schlater, CEO, Dominos Pizza of Canada Ltd., has been a significant contributor to the education programs at ESWO. His generosity allowed us to provide classroom presentations, teacher in-services and Seizure 101 presentations in both the Thames Valley and

Windsor/Essex regions. Additionally, Mike sponsors Domino's Pizza Days in local schools, which is our largest Epilepsy Awareness Month fundraising campaign! Mike received the 2016 H.O.P.E award for his efforts in helping to raise awareness throughout Southwestern Ontario. Thank you, Mike Schlater!

## Seizure Education & Support Services

- Information
- Presentations
- Seizure First Aid Training
- Referrals/Assistance
- Peer and Support Networks
- Health Care Materials
- Recreation Programs
- Student Support Program
- Workplace Support
- Special Events
- Epilepsy Awareness Month
- Clinic to Community Program

## Spotlight: Living well with epilepsy



Kassidi Tully is one of the approximately 330,00 Canadians living with Epilepsy. Kassidy is a five-year-old girl living with cerebral palsy as well as epilepsy in Sarnia, ON. Her mother, Kourtnee, describes her as “an old soul” who can “light up the room.”

In March of 2013, Kourtnee took her to the hospital with a fever, and as they were leaving Kassidi had a seizure in her mother’s arms. At that time, Kourtnee was assured that it was nothing. This changed in January 2014, when Josh, Kassidi’s father, went to check on Kassidi, when she didn’t wake up at her normal time. He found Kassidi unresponsive, vomiting and staring blankly at the wall. 911 was called and

this was the beginning of the diagnosis process.

The journey, which started with these seizures and ended in a diagnosis, was long, arduous and stressful for all involved. During this journey, Kassidi has been hospitalized on six different occasions for her seizures; one of which lasted over an hour and a half.

After Kassidi received her diagnosis, and began treatment, her parents connected with the staff at Epilepsy Southwestern Ontario, and became interested in their programs and services offered. The programs and services offered at Epilepsy Southwestern Ontario were viewed as one way that those affected by Epilepsy could share their experiences.

As a result of ongoing treatment and the utilizing the support services available at Epilepsy Southwestern Ontario, this past March marks one-year of being seizure free for Kassidi. While living with epilepsy poses an ongoing challenge for the entire family, they have made connections in the community, which strengthen their support network.

Epilepsy changed the course of not only Kassidi’s life, but that of her parents. The staff at Epilepsy Southwestern Ontario are proud to have made a positive difference in the lives of the Tully family. Kassidy’s story is one of perseverance and bravery and is indicative of the experiences of the nearly 1 in 100 Canadians who have epilepsy and other seizure disorders. We would like to thank families like the Tullys for sharing their stories, and generating awareness for one of the most common neurological conditions.



## Financials

### Statement of Operations and Changes in Fund Balances Year ended March 31, 2017

Revenue	2017	2016
Ontario Trillium Foundation	\$161,225	\$120,967
Net Fundraising	\$99,326	\$108,258
Donations	\$100,661	\$92,098
United Way	\$23,087	\$77,150
Ontario Brain Institute	\$64,392	\$36,471
Grants	\$17,924	\$25,009
Rental Income	\$14,581	\$25,009
Summer Camp	\$9,005	\$2,520
Other Income	\$15,802	\$1,732
<b>Total Revenue</b>	<b>\$506,003</b>	<b>\$489,214</b>

Expenditures	2017	2016
Program expenses	\$293,256	\$322,885
Administration expenses	\$170,284	\$179,791
<b>Total Expenditures</b>	<b>\$463,540</b>	<b>\$502,646</b>
Excess of revenue over expenses	\$42,463	(\$13,432)

## Board of Directors

Bob Harvey  
Chris Brittain \*  
Chris Turino  
Christine Ford \*  
Dr. Andrea Andrade  
Dr. David Steven  
Dr. Michelle Jones \*  
Elaine Swan  
Irena Kramer  
Joe Longmoore

Jon Lavkulich  
Judy Cartwright-Therriault  
Murray Jones  
Pete Hannaberg \*  
Rob Deman \*  
Sara Martin  
Sharon Berry Ross  
Stacy Rybansky  
Tom Stadnisky

\*resigned within the fiscal year



**1-866-EPILEPSY**

[www.epilepsysupport.ca](http://www.epilepsysupport.ca)

690 Hale St., London ON N5W 1H4

**London** 519.433.4073 | **Sarnia** 519.330.0416

**Windsor** 519.890.6614 | **Chatham** 519.365.5131

@EpilepsySC

[facebook.com/epilepsysupport](https://facebook.com/epilepsysupport)

Serving London/Middlesex, Sarnia/Lambton, Chatham/Kent,  
Windsor/Essex, Huron Perth, Grey Bruce, Elgin & Oxford Counties.

Charitable Reg No.: 11890-0802-RR0001