

epilepsy
southwestern
ontario

2017–2018

EPILEPSY SOUTHWESTERN ONTARIO
ANNUAL REPORT

EPILEPSY SOUTHWESTERN ONTARIO (ESWO)

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ESWO AT A GLANCE

VISION

Our vision is a community free of barriers where persons affected by epilepsy and seizure disorders are empowered and supported to live a life of dignity, self-worth and hope.

MISSION

Epilepsy Southwestern Ontario enhances the lives of people who are affected by epilepsy and seizure disorders by providing a network of services that educate, support and build community awareness.

VALUES

We are dedicated to providing innovative services that are responsive to individual needs. We are both inclusive and collaborative in our approach to ensure that all individuals with epilepsy have the opportunity to fully participate in their community.



LETTER FROM
THE PRESIDENT

Sara Martin



It is hard to believe another year has come and gone. The year has brought many challenges but many new and exciting opportunities. This year we sold our home on Hale Street and have settled in nicely to our new location on York Street. We have truly made it our own and I encourage everyone to stop in, say hello and check it out. Many of our amazing programs such as YEP!, Game On, Wacky Wednesday's Summer Camp and Thinking about Epilepsy (and many more) continue to successfully run and gain traction. Thank you to everyone who has come out to an event, donated, volunteered or had a hand in our success, we are truly grateful!

Sara Martin
President, Board of Directors

BOARD OF DIRECTORS

President

Sara Martin

Treasurer

Murray Jones

Vice President

Tom Stadnisky

Medical Advisors

Dr. Andrea Andrade
Dr. David Steven

Directors

Bob Harvey
Chris Turino
Elaine Swan
Irena Kramer *
Joe Longmoore (Windsor Essex)
Judy Cartwright-Therault (Windsor Essex)
Sharon Berry Ross (Sarnia Lambton)
Stacy Rybansky (Chatham Kent)
Ashley Herron (Oxford)

*Resigned in the fiscal year

MESSAGE FROM
THE CEO

Michelle Franklin

Epilepsy Southwestern Ontario (ESWO) has had a year full of activity, exciting changes and solid growth. In fact, we have experienced growth throughout our database, epilepsy presentations, volunteer hours and fundraising dollars. We have also expanded our staffing compliment to include a Multimedia Designer, which has allowed us to fully complete our rebranding transformation from Epilepsy Support Centre to Epilepsy Southwestern Ontario.

The relocation of our Head office to 797 York Street was a venture requiring a lot of energy, organizing and volunteers! A postal code search of our local client base, dictated the relocation choice and we are delighted with our new space!

Our Clinic To Community© (C2C) program was a pilot demonstration project designed to collect evidenced based data to articulate the need for community epilepsy supports. ESWO has now published the C2C data we collected in a report called "Living with Epilepsy: Voices from the Community", which is the only report in Canada to document the community based needs and preferences of people living with epilepsy. Through this data, we now have evidence to suggest that C2C has the potential to reduce costs in both the economy (under/unemployment) and the health-care system (diverting non urgent emergency room usage). Our ultimate goal is to obtain Ministry of Health funding and therefore we have been meeting with our Local Health Integration Networks to keep them abreast of our progress and findings related to the program.

On a larger scale, C2C has become the gold standard method of providing epilepsy information to families. As a direct result, ESWO has shared the program with other community based epilepsy organizations across the province, and to date, the program has been fully implemented by Epilepsy South Central Ontario

and Epilepsy Durham Region. A provincial committee proposed a pre-budget submission to the Minister of Finance for consideration. The submission asked for \$3 million (per capita) to provide C2C across Ontario and an additional \$1 million (per capita) for ongoing counselling services. Although this submission was not approved, we are committed to gathering additional evidence to support our case.

ESWO received a grow grant from the Ontario Trillium Foundation to develop a School to Community (S2C) program which is based on the school needs identified by parents in the C2C research. S2C aims to create both parent and educator resources to improve social and emotional skills in children with epilepsy. This is just one of the exciting projects for the upcoming year, and we are hopeful that the research of these interventions will provide evidence of real change in the quality of life and outcomes for children living with epilepsy.

As the CEO of ESWO, I could not be more proud of our passionate and dedicated staff team and our collective accomplishments over the last year! I am thankful for the mentorship, oversight and guidance of our Board of Directors and Medical Advisors. I would like to extend a heartfelt thank you to our volunteers and donors whose contributions are essential to our services. Last but not least, a special mention to people living with epilepsy in our communities. You are the passion and motivation behind the mission of ESWO.

#EpilepsyWarriors
Looking forward to the year ahead!

Warm Regards,
Michelle Franklin
Michelle Franklin



SPOTLIGHT:
LIVING WITH EPILEPSY

JAYME ARTS

Jayne is a client and staff member of ESWO that is currently 24 years old and lives in London, Ontario. Before her diagnosis, she experienced dizzy spells and vision loss which were undetected absence seizures. She was diagnosed at the age of 14, after having increasingly painful headaches and experiencing periods of “missing time” she could not account for. Absence seizures can be hard to detect as they are short and often present subtle symptoms.

Immediately, she was prescribed valproic acid, a common anti-convulsant, until the age of 18 when she was taken off the medication. Unfortunately, her seizures increased in number and severity, and she began to experience tonic-clonic seizures in addition to absence seizures. She then decided to try medicinal cannabis in the form of non-psychoactive CBD oil and has been seizure-free since beginning the treatment five years ago.

Through the leadership program that Jayme attended while studying for her family studies degree at Western, she was introduced to ESWO as a summer student, and was subsequently hired to run the YEP! program. Aside from working with ESWO, she also does community development research for the City of London.

Through her experiences with epilepsy, Jayme would like to see more awareness of seizure first-aid in the community, as she has experienced situations where people do not know how to respond to a person having a seizure. She advocates for education efforts to achieve that goal.

Thank you, Jayme for sharing your story! We're honoured to have Jayme as one of our team members!



WINDSOR'S 1ST SEIZE THE DAY



Windsor's 1st Seize the Day Event took place on Saturday, October 28, 2017 at Sandpoint Park. Although it was an extremely cold day, many families and individuals joined us for a fun 5K run and 2.5K walk. The event also included a community BBQ, kid's games, music, and door prizes. AM800 CKLW's Kara Ro kicked off the event and Joey Nehme shared his story about living with epilepsy.

Together, approximately **250** participants raised over **\$28,500** towards ESWO's support and education programs in Windsor Essex. We need to say a special thank you to Mr. Ray Holland and the students at St. William's Public School who came together and raised over **\$5,000**! We are beyond excited with the success of our first event, considering our goal was to raise \$10,000. Thank you so much everyone for your hard work and dedication.



H.O.P.E. **AWARD**

Chase Cartwright



Chase Cartwright's Ride for Epilepsy from Windsor to Toronto started off with an ambitious fundraising goal of \$5,000. With his determination and support from donors and sponsors, Chase surpassed his goal with over **\$7,500**. The pledges and sponsorships created a discretionary fund called "The Chase Cartwright Fund". This fund will help people living with epilepsy access crucial safety seizure items to help them live well.

ESWO has been presenting a H.O.P.E. award (Helping Out People with Epilepsy) since 2005. Each year, it is awarded to an individual, group of individuals or organization who



has demonstrated compassion and caring for people living with epilepsy. This is ESWO's highest honour and we are pleased that Chase Cartwright has been chosen to receive the 2017 H.O.P.E. award for his compassion, determination and desire to raise epilepsy awareness.



OUR YEAR IN REVIEW
APRIL 2017 – MARCH 2018

All Regions



Annual Spring Gala
Back to the 80's (April 1, 2017)



RBC Day of Caring
(May 18, 2017)



C2C Training Day
(June 16, 2017)



Windsor's 1st Seize the Day
(October 28, 2017)



2nd Annual Dueling Pianos
(November 4, 2017)



London Lightning Game
(December 22, 2017)



Windsor Book Sale
(June 24-25, 2017)



Wacky Wednesday Summer
Camp (July-August 2017)



AGM & Summer BBQ
(July 19, 2017)



Windsor Essex - Zehrs
Epilepsy Awareness Month
Booth (March 11, 2018)



New Office Grand Opening
Party (March 15, 2017)



Huron Perth Epilepsy
Awareness Month - School
Awareness (March 23, 2018)



Sarnia Meet & Greet
(July 21, 2017)



London's 4th Seize the Day
(September 24, 2017)



First YEP! Session
(October 28, 2017)



Chatham Kent's Purple
Pansy Fundraiser
(March 24, 2017)



Windsor Essex's Strikeout
Epilepsy Bowling Event
(March 25, 2018)



Chatham Kent Health
Alliance Purple Nation
(March 2018)

THIRD PARTY EVENTS HIGHLIGHTS

All Regions



Leaping Deer Event – Oxford
(May 27, 2017)



Quarter Auction – Windsor
Essex (August 13, 2017)



Chase's Ride – Windsor Essex
(August 26, 2017)



Party in the Park – Middlesex
(September 2, 2017)



Mug Run Chicken Dinner &
50/50 – Windsor Essex
(September 16, 2017)



Ride for Epilepsy – Huron
Perth (September 17, 2017)



Lucious Bakery Bake Sale –
Grey Bruce (October 12, 2017)



Sam Jam – London
(December 15, 2017)



Beat the Blues – London
(February 3, 2018)

THIRD PARTY THANK YOU

Thank you to all of our Third Party Event organizers for your generous support! We are truly grateful to have been chosen as the beneficiary of your past fundraising activities and we look forward to partnering with you again in the coming years. Over the last year, **\$29,043** was raised through Third Party fundraising!

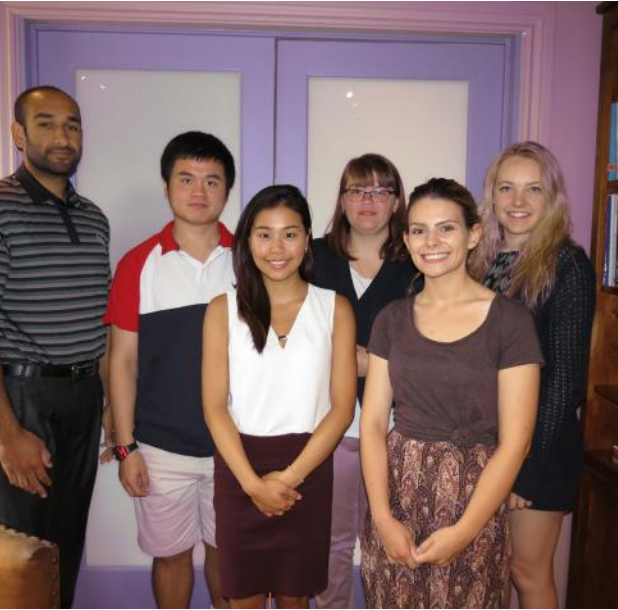
Third party fundraisers are any fundraising event that friends, companies or community groups host to support ESWO. All proceeds raised from your initiative, whether a dress down day, bake sale or golf tournament, are donated to ESWO.

By organizing and hosting a fundraiser, your efforts will help sustain ESWO and you'll make a difference in the lives of people affected by epilepsy in your community. It is through education and awareness that we are able to help dispel the myths that many living with epilepsy face, your fundraising dollars help us to further our mission.

VOLUNTEERS AND STUDENT PLACEMENTS

Throughout the year, we are fortunate to have various students assist with office administration, events, program design and evaluation. Thank you to each one of our hard working student placements!

Our volunteers dedicated **3,506** hours of time, valued at approximately **\$84,144.**

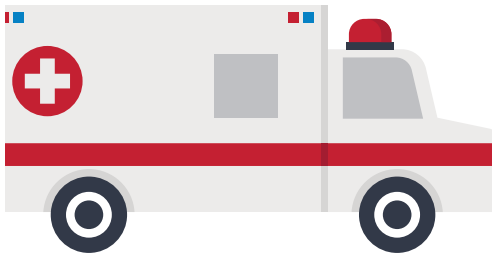
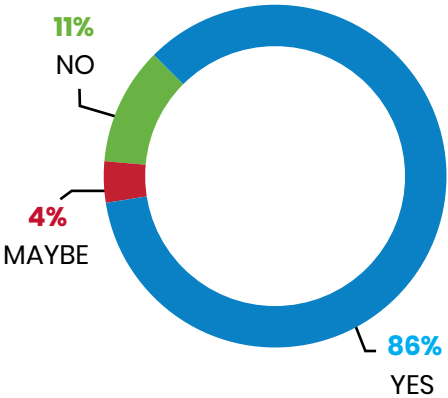


CLINIC TO COMMUNITY© HIGHLIGHTS

The C2C program combines health information with patient education. Patient education is the process of influencing patient behaviour to produce changes in knowledge, attitudes and skills calculated to maintain and improve health. The strength of the C2C program is that it is individualized to meet the identified needs of the patients with epilepsy (PWE) and their family. In the initial meeting (approximately 60 minutes), the C2C educator is able to answer individual questions and cover the Epilepsy Education Checklist as recommended in the Provincial Guidelines for the Management of Epilepsy in Adults and Children.

We have demonstrated that the program develops skills in PWE and their families. We have positive feedback from 46 healthcare providers who referred 305 PWE to the program during the demonstration period that the program works to coordinate care. In other chronic conditions, patient education and training in self-care has been found to be associated with reduced health care service utilization.

Did the education session help you feel confident that you know when a seizure is a medical emergency and when it is not?



Outpatient education is a valuable tool to reduce emergency department use, which may, in turn, cut down on health-care cost.

Paediatric Enrollment in the C2C Program

236

children and youth were enrolled in the demonstration program

Three age groups:



23

Birth to 3 Year Olds



144

4 to 12 Year Olds



69

13 to 18 Year Olds

Parents of Children Living with Epilepsy

A mixed methods design with field notes, clinic journals, parent surveys, in-depth interviews, website analytics, and tracking sheets was used to identify the information and program requests of each family.

Parents provided information related to their child's age of seizure onset, seizure types, seizure frequency, number of medications tried and comorbidities (both diagnosed and undiagnosed).

The top 3 identified needs of parents:



Parents identified that improving their child's school experience through education and support is a top priority. Providing school based support to children living with epilepsy has the potential to reduce the burden of epilepsy on the child, parent, family, teacher, health care team and economy.

Adults Living with Epilepsy

189

adults received a 60 minute education session

64%

(121 / 189) of adults used at least two other programs or services

222

presentations were requested during the demonstration period

9.7

years was the average length of time from diagnosis to receiving the C2C education session

The top 3 priorities of adults (19- 50 years):



The top priorities of adults (51+ years):



Financial and Drug Benefits

LAUNCH OF
SCHOOL TO COMMUNITY

\$263,400 OTF Grant Helps ESWO Improve Social and Emotional Skills in Children Living with Epilepsy

This year, ESWO was fortunate enough to receive a three year investment from the Ontario Trillium Foundation to launch our new School To Community Program. This new Program will support children living with epilepsy in their school environments by working to improve social and emotional skills and to foster responsible individuals who are confident, resilient and adaptable. School To Community will be delivered in Windsor Essex, Chatham Kent and Sarnia Lambton areas and has derived as an extension of Clinic To Community. Based on our Living with Epilepsy: Voices in the Community report, school support was identified by 73% (105/144) parents as their top priority. Through teacher training, individualized advocacy and class-room presentations, School To Community has the potential to reduce the burden of epilepsy on the child, parent, family, teacher, health care team and economy.

“With this investment, 120 children living with epilepsy in Southwestern Ontario will have the opportunity to develop new skills and build a strong foundation for success later in life”
– Deb Matthews, MPP London North Centre.



“Social supports for children with epilepsy are an integral part of learning to live with epilepsy and how to thrive. This program will play an important role in helping kids feel confident and to succeed in school, and set them up for success for the rest of their lives.”
– Teresa Armstrong, MPP London – Fanshawe



ESWO KEY FIGURES



5,786 clients, families, and community groups were given presentations in Southwestern Ontario.

Epilepsy Awareness Month

Zehrs stores and their hardworking and dedicated employees in Ontario were able to raise

\$62,753

89 + Local businesses, schools and individuals participated in EAM fundraising.

JOIN THE #PURPLE NATION

ESWO delivered **12** YEP! sessions this year



ESWO
THE BIG MOVE

It was bitter sweet to offically close the door on another chapter of ESWO at 690 Hale Street! However, our office relocation has been a wonderful change. After a postal code search of London and area clients, we settled on 797 York Street; a cental location closer to the downtown core. Our new home is a brighter space, more accessible and has higher functionality. Now that we are settled in, we couldn't be happier. Please drop in for a tour if you are in the area!



FINANCIAL REPORT
BREAKDOWN

REVENUE	2018	2017
Ontario Trillium Foundation	\$110,610	\$161,225
Net Fundraising	\$146,970	\$99,326
Donations	\$80,027	\$100,661
United Way	\$19,925	\$23,087
Ontario Brain Institute	\$31,414	\$64,392
Grants	\$28,163	\$17,924
Rental Income	-	\$14,581
Summer Camp	\$15,023	\$9,005
Other Income	\$4,124	\$15,802
Realized Gain on Sale of Building	\$41,526	-
Total Revenue	\$477,782	\$506,003

EXPENDITURES	2018	2017
Program Expenses	\$375,807	\$293,256
Administration Expenses	\$112,834	\$170,284
Total Revenue	\$488,641	\$463,540
Excess of revenue over expenses	(\$10,859)	\$42,463

*Differences may arise due to a policy change to how wages are reported

epilepsy southwestern ontario

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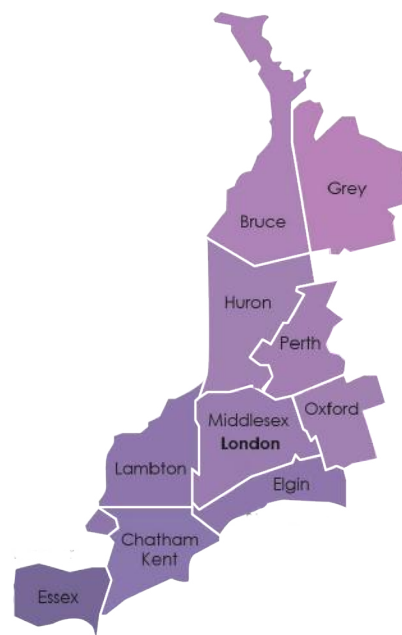
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Chatham 519.365.5131 **Windsor** 519.890.6614

Find Us On Social Media @epilepsyswo



Epilepsy Southwestern Ontario provides service in London Middlesex, Sarnia Lambton, Chatham Kent, Windsor Essex, Oxford, Elgin, Huron Perth, and Grey Bruce.

Charitable Reg No: 11890-0802-RR0001