

EPILEPSY SOUTHWESTERN ONTARIO

2018–2019 ANNUAL REPORT





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OUR MISSION

We provide a network of services that educate, support and build community awareness.

OUR VISION

We strive to create a community free of barriers for persons affected by epilepsy and seizure disorders.

OUR VALUES

We provide services tailored to individual needs and are dedicated to being inclusive and collaborative.



I would first like to thank everyone for all the work, support and communication that happens within Epilepsy Southwestern Ontario (ESWO).

I am very proud to serve as the President of the Board for ESWO, a not-for-profit agency that has truly changed my life. I am extremely thankful for all this organization has done for me personally and that they have provided me an opportunity to give back.

My personal experience with epilepsy has been a long road, with many challenges and many obstacles but the most amazing part of these difficult times was meeting the people at ESWO. I am the type of person who is hesitant to do anything to help myself – I am focused on other people and helping them, so when I was faced with needing support myself – it was hard to admit. The simple fact that we are able to offer community epilepsy support to so many individuals across Southwestern Ontario is incredible!

I did not think I would have any success (getting help for myself) until I met ESWO. In essence, their support helped me to open my eyes and see what it was that I needed to do, or could do – to both give & receive support for my family, my friends, my clients and my staff that I supervised at work in relation to my epilepsy.

This all started with the simple acceptance of seeing myself as an individual with epilepsy. It was tough for me. I remember when I had to get a medic alert chain, I chose to have “seizure disorder” written on it instead of “epilepsy”, but then my learning began.

I found a great new Neurologist; I spent time in the Epilepsy Unit at University Hospital surrounded by other patients suffering from seizures. I was able to meet other people with similar stories, meet their families, and discuss the range of community supports that I could access. After all of these experiences, I was lucky enough to be offered surgery which has been life changing. My surgery was filmed at University Hospital for a television show called “W5: Brainstorm Within”.

This meant that I could be a part of other people learning from my epilepsy journey and my experiences. I was proud to show my seizures, my surgery and my recovery because it told my story of hope.

When I was asked to be on the Board of Directors of ESWO – I was incredibly proud and honored to participate. My involvement allows me to give back as much as I can to an agency that helped me so much!

I am honestly proud to now say that **I AM** an **INDIVIDUAL** with **EPILEPSY** and will continue to volunteer with an incredible team of both employees, volunteers, families and members across Southwestern Ontario.

Thank you again to everyone for everything you do with our agency! We truly appreciate all of you!

Sincerely,



President



BOARD OF DIRECTORS

President

Tom Stadnisky

Vice President

Elaine Swan

Treasurer

Murray Jones

Medical Advisors

Dr. Andrea Andrade

Dr. Seyed Mirsattari

Directors

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Bob Harvey

Chris Turino

Joe Longmoore (Windsor Essex)

Judy Cartwright-Theriault (Windsor Essex)

Sharon Berry Ross (Sarnia Lambton)

Stacy Rybansky (Chatham Kent)

Tabitha Cook (Chatham Kent)

Vincent Mazza

LETTER FROM CHIEF EXECUTIVE OFFICER

Annual reports are such a great way to reflect on the past years’ trials and tribulations, as well as accomplishments and celebrations. Epilepsy Southwestern Ontario (ESWO) continues to grow and expand to better serve people living with epilepsy throughout Southwestern Ontario.

On a Provincial level, our Clinic To Community (C2C) program continues to be an evidence based gold standard for delivering epilepsy information to families, and has now been implemented at Epilepsy Durham Region, Epilepsy South Central Ontario, Epilepsy Ottawa and most recently, Epilepsy South Eastern Ontario.

In 2018, we published a report entitled “Living with Epilepsy: Voices from the Community”, where we documented evidence which suggests that C2C (as an intervention) has the potential to reduce costs in both the economy (under/unemployment) and the healthcare system (diverting non urgent emergency room usage). While we continue to partner with our provincial colleagues to work towards obtaining Ministry of Health funding to implement C2C across Ontario, ESWO is also committed to gathering further evidence to strengthen our funding ask. In fact, ‘EpLink: a program of the Ontario Brain Institute’, has granted funding to ESWO to formally document whether C2C decreases non urgent emergency room usage. This research project will be implemented this year through a partnership with London Health Sciences Centre emergency room departments.

ESWO is represented on many local, provincial, national and international committees and we feel privileged to work in collaboration with so many other wonderful organizations that care about people living with epilepsy! Due to these amazing

partnerships, ESWO researchers have been invited to present about our C2C findings, our school programs, and epilepsy related stigma at the Pan American Health Organization meeting in Trinidad, the World Health Assembly in Geneva, the Asian Oceanic Congress in Indonesia and the World Health Organization meeting in Paris, just to name a few! What this means, is that epilepsy matters to a lot of people around the world! We continue to learn and share information and programs with a goal of improving the lives of people living with epilepsy.

ESWO is fortunate to have such a passionate staff team, devoted Board of Directors, dedicated group of volunteers, generous donors/funders and last but not least; a resilient Purple Nation! You are the reason our team loves their jobs, the reason ESWO exists, and the reason we band together to reduce epilepsy related stigma. #EpilepsyWarriors

Warm Regards,



Michelle Franklin
Chief Executive Officer



LIVING WITH EPILEPSY

Macarthur Graham is a fourteen-year-old teenager from London / Middlesex. When he's not playing video games or baseball, you can find him practicing Brazilian jiu jitsu or fishing down by the water. He experienced his first seizure when he was 11.

"I was at an art studio looking at one of the paintings. The painting started to warp and I didn't really know what was going on," explained Macarthur. "I blacked out and woke up in an ambulance, and found out that I had a tonic-clonic seizure that was over five minutes long."

A year later, Macarthur was diagnosed with epilepsy, but he has never let his condition alter his positivity.

"In many ways Macarthur's epilepsy has also opened a world to us that has been rewarding for Macarthur, as well as for the rest of this family," said his mother, Charmaine. "He took something that could have been a real drag and turned it into something exceptionally positive. This kid has handled epilepsy like a champion and shown me a thing or two about resilience."

ESWO was a huge aid in helping the London family remain optimistic and become educated about the new journey ahead. Aside from the classroom education that informed Macarthur's peers and teachers about epilepsy, the family also took advantage of participating in the other programs ESWO has to offer, such as YEP!, Wacky Wednesdays, Seize the Day, and Clinic to Community. "My family used Clinic to Community a few times the past few years and it really helped my mom to know when to take me to



Emergency," explained Macarthur. "It helped because now we have learned to manage everything at home instead of using the hospitals." Charmaine agreed with her son about the support ESWO was able to provide for their family, and recommended that others reach out to the organization as well. "The first piece of advice for someone who has epilepsy become part of their new reality is to call ESWO," she said.

As for Macarthur, he continues to embrace epilepsy as an important part of him. "Other people have bigger challenges than me. I just have epilepsy. Everyone has something, this is my something," he said.

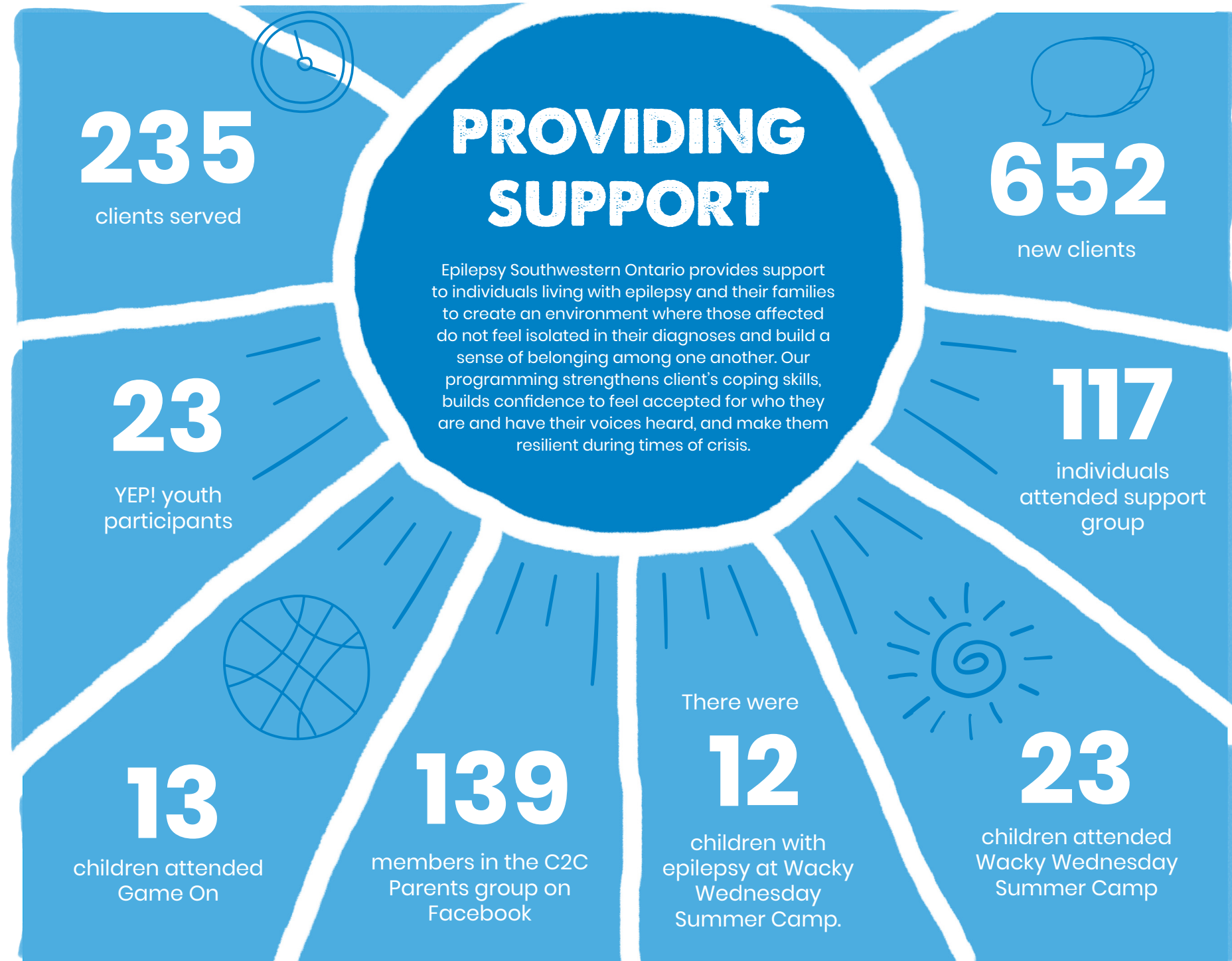
H.O.P.E. AWARD

Dr. Kathy Speechley

Dr. Kathy Speechley is an epilepsy researcher, champion, donor and advocate. She has mentored graduate students who publish research that is vitally important in our advocacy initiatives. Her research is used within our conversations with policy makers and when we develop programs to improve life outcomes of children living with epilepsy. Her evaluation of our grade 5 program has led to over \$1.5 million in funding for Community Epilepsy Agencies to deliver the program to school children across Ontario. Her tireless commitment to supporting families with epilepsy makes her a worthy recipient of this 2019 H.O.P.E. Award.

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.





"I just wanted you to know that my son had a great time last night. It's really beneficial for him to talk to other people who have experienced the same things as him. He was very talkative and full of stories when I picked him up. Thanks again."

– Parent of youth living with epilepsy

"I can attest that both the Game On and the Wacky Wednesday programs have provided our daughter Carly with confidence, support, encouragement and a sense of belonging. She started both programs as an extremely shy child with limited mobility, and is now running, actively participating and helping others! ESWO staff have done a great job helping our little munchkin come out of her shell!"

– Parent of Game On and Wacky Wednesday participant

"Thank you again for everything you do for our kids. Charlie thoroughly enjoys Game On and it has been a great way to keep him active and social. As a parent of a special needs child, I am so very grateful for people like yourself. We love Game On!"

– Parent of Game On participant





YOUTH DIVISION

We are excited to announce that Epilepsy Southwestern Ontario now has a Youth Division. Our Youth Division is an amazing opportunity for youth ages 10–30 to practice their leadership skills, get volunteer experience and run epilepsy awareness activities! Our Youth Division is a group of youth living with epilepsy and seizure disorders who are building a sense of belongingness through shared lived experiences. Together, they raise epilepsy awareness, decrease stereotypes and stigma and empower those affected by seizures. We are looking for more youth to join our Youth Division. Meetings take place once a month in London at our office. If you want to participate but live out of town, you can join via online!

For more information, please contact: jayme@epilepsyswo.ca



37

Teacher In-Service Presentations



5392



people received public education presentations in their community throughout Southwestern Ontario

60

Seizure 101 Presentations



41%

of all classroom presentations were curriculum based Grade 5

EDUCATION

Our public education programming allows us to train our community in seizure first aid and provide information about epilepsy and seizure disorders across all regions. We provide age appropriate classroom presentations to teach a future generation the real facts about epilepsy to reduce the associated stigma. These programs will increase knowledge and reduce stereotypes and stigma, therefore fostering safe, inviting, supportive and inclusive spaces for people living with epilepsy.



71

Classroom Presentations



339

College and University students were trained as part of school curriculum across Southwestern Ontario

“The Educator’s epilepsy presentation was interactive and interesting. Students learned epilepsy facts and emergency response procedures in such a way that they retained this information, and were able to use it to create an informative door design for our school-wide Epilepsy Awareness Campaign in March. Definitely a worthwhile program!”

– Grade 5 Teacher, Lambton-Kent District School Board

212

students were supported individually

AWARENESS

Providing information to create awareness among the public is one of the many ways we help break down barriers that prevent those living with epilepsy from fully and actively participating in their communities. We encourage individuals to actively participate in March Epilepsy Awareness Month as a national platform to begin a discussion about epilepsy, educate the public and breakdown the stigma of seizure disorders.

In March 2019, our community across Southwestern Ontario came together to raise awareness in new and exciting ways.



Over

20

teams across our region participated in our **#purplenation hockey movement** by wrapping their sticks in purple tape, or decorating their equipment with ribbons.

Our **Purple Door Campaign** encouraged over

120

classes and workplaces to decorate their doors or bulletin boards to educate others about epilepsy.

Across the province, Zehrs participated in a provincial campaign to sell t-shirts and collect donations.

\$15,829

was raised locally for ESWO.

VOLUNTEERS AND STUDENT PLACEMENTS

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

The hard work and dedication of our volunteers make our major events so successful & our of-fice run smoothly.

Our volunteers dedicated
2,686 hours of time, valued at
approximately **\$64,464**.



“My favourite part of volunteering with Epilepsy Southwestern Ontario is meeting and working with all the friendly volunteers, clients, and their wonderful support networks! I love hearing how each individual has been positively impacted by the agency’s programs!”

– **Bailey, London-Middlesex volunteer**

THIRD PARTY THANK YOU

Thank you to all of our Third Party Event organizers for their generous support! 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.

Over the last year, **\$17,319.77** was raised through Third Party fundraising.

THIRD PARTY EVENT HIGHLIGHT

ALL ABOUT HORSES

All About Horses hosted a fundraiser on March 24, 2019 in Thedford. Over \$7,500 was raised to help support Epilepsy Southwestern Ontario (ESWO)!



“The family at All About Horses has personally been affected by epilepsy for almost 27 years, 23 of those we have been involved with ESWO. One in a hundred people have epilepsy. But that one in a hundred has family, friends, co-workers, caregivers, school peers and educators who all need support, awareness, education and advocacy in some way. ESWO doesn’t just support the individual; they support everyone that’s on the epilepsy journey with that individual!

We just want to give back to an organization that has reached out and cared about our family, and so many others like us!”
– Tracy Nejim



REASONS TO DONATE

Did you know Epilepsy Southwestern Ontario relies heavily on our fundraising efforts, donations and support from the community to operate? Your donation will help to ensure we can provide services and support to individuals and families affected by epilepsy in your community.



ESWO Windsor held our 2nd Annual Seize the Day Event on September 16, 2018, with approximately 160 participants, raising over \$20,000.



On September 30, 2018 over 400 participants joined us for our 5th Annual Seize the Day Walk/Run in London, raising over \$51,000!

Donations represent
17%
of total revenue

FINANCIAL REPORT

BREAKDOWN

REVENUE	2019	2018
Ontario Trillium Foundation	\$172,965	\$110,610
Net Fundraising	\$167,965	\$146,970
Donations	\$100,297	\$80,027
United Way	\$17,330	\$19,925
Ontario Brain Institute	\$69,782	\$31,414
Grants	\$53,533	\$28,163
Summer Camp	\$6,815	\$15,023
Other Income	\$6,301	\$4,124
Realized Gain on Sale of Building	-	\$41,526
Total Revenue	\$594,988	\$477,782

EXPENDITURES	2019	2018
Program Expenses	\$495,539	\$375,807
Administration Expenses	\$121,464	\$112,834
Total Expenditures	\$617,003	\$488,641
Excess of revenue over expenses	(\$22,015)	(\$10,859)

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



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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

