



epilepsy
southwestern
ontario

www.epilepsyswo.ca

2019–2020
**ANNUAL
REPORT**



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OUR
MISSION

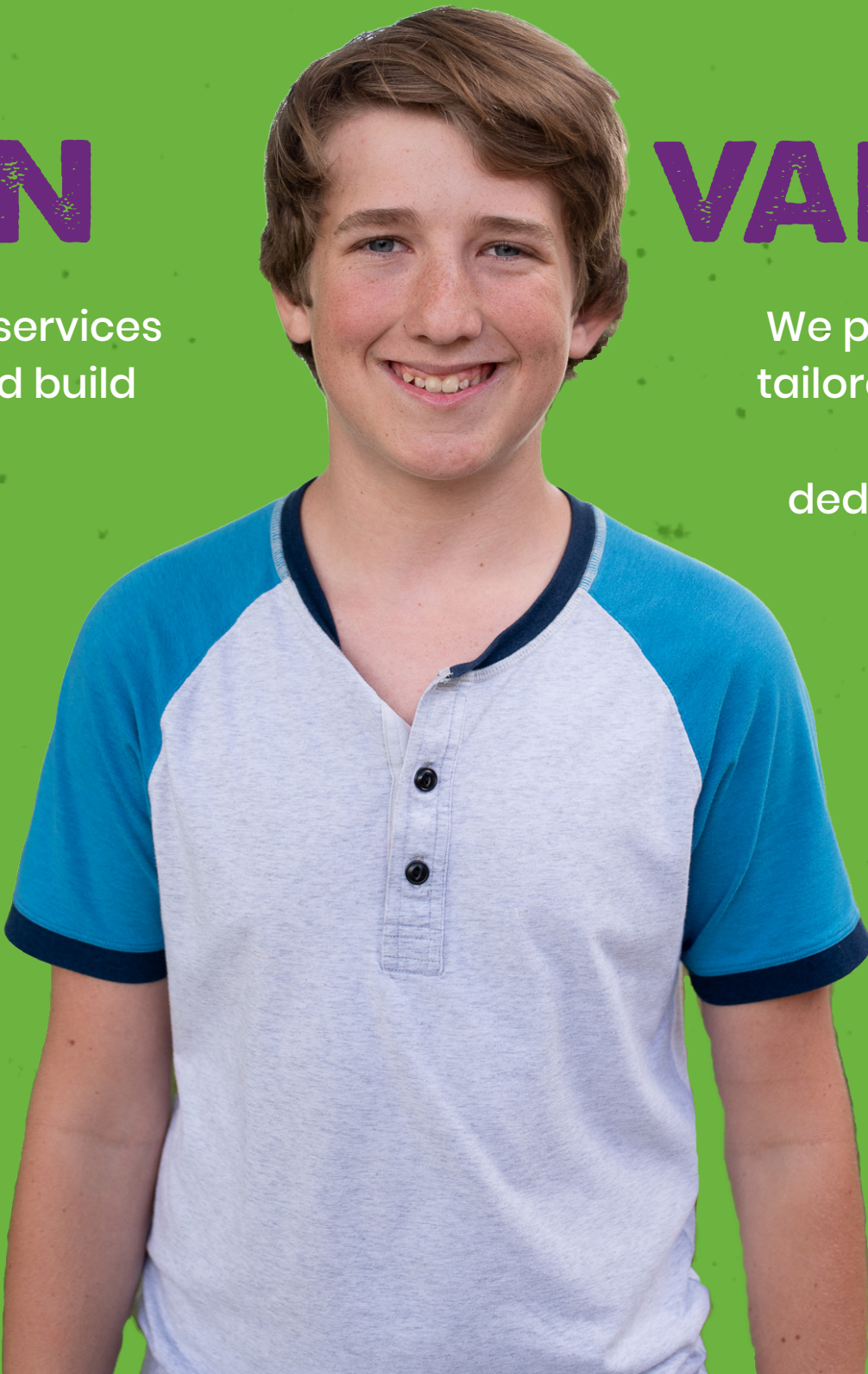
We provide a network of services that educate, support and build community awareness.

OUR
VISION

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

OUR
VALUES

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

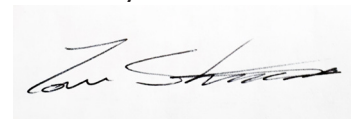


LETTER FROM THE PRESIDENT

When I was named President of the Board of Directors about two years ago, my goal was to continue to promote the supports we offer and education we provide as a very dedicated team. That same team of frontline workers makes our role as the Board of Directors a very easy, but proud one to own!

Year after year, our commitment to keeping our mission focus, inspires support from passionate donors, enthusiastic fundraisers, long standing clients and families, and of course, loyal volunteers. Our Board of Directors continues to strive to maintain our diversity, motivation and enthusiastic nature as we promote our organization's direction towards success. I would like to offer my thanks to our many volunteers, staff and board members for your dedication to this organization and its clients and their families. Lastly, I would like to thank our clients and stakeholders, you enable us all to continue a passionate dedication towards supporting people living with epilepsy within our community!!

Sincerely,



Tom Stadnisky
President



LETTER FROM CHIEF EXECUTIVE OFFICER

In reflection, 2019 was a year of great accomplishments for Epilepsy Southwestern Ontario (ESWO): an empowering conference designed specifically for youth living with epilepsy focused on topics and speakers selected by youth, for youth; a formal partnership for an ESWO Educator to attend Comprehensive Epilepsy Clinics at CHWO; a presentation of ESWO's school based supports and programs to an international audience at the 33rd International Epilepsy Congress in Bangkok, Thailand.

Despite such amazing achievements, I would be remiss if I did not mentioned the Coronavirus pandemic. Although COVID-19 arrived in the final month of our fiscal year, it certainly had a devastating impact on the overall finances of ESWO. March Epilepsy Awareness Month typically brings in significant revenue through merchandise sales, donations, third party fundraisers and special events totalling approximately \$70,000. However, COVID-19 and associated social distancing measures prevented us from realizing this income, causing us to end our year in a deficit position.

Having said that....we continue to be inspired by the resilience of people living with epilepsy who face adversity every day, and won't let COVID-19 take us down! We remain determined to do everything possible to ensure we can continue to provide support and educational services for people living with epilepsy, not only in the current crisis, but long into the future as well.

I am enormously proud of our role in the community and our dedication to providing support to families living with epilepsy. This would not be possible without the support of our passionate staff team, our skilled Board of Directors, our dedicated volunteers, our generous donors, and our clients that inspire us to do the work we do.

Warm Regards,



Michelle Franklin
Chief Executive Officer



BOARD OF DIRECTORS

President
Tom Stadnisky

Vice President
Elaine Swan

Treasurer
Murray Jones

Medical Advisors
Dr. Andrea Andrade
Dr. Seyed Mirsattari

Directors

Ashley Herron (Oxford)
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

LIVING WITH EPILEPSY

"I first became involved with ESWO when I moved to London for University. I was looking for a support system to help me deal with my epilepsy. Through ESWO, I was able to participate with a group of youths affected by epilepsy. I was exposed to the daily lives of people with epilepsy, their own personal struggles, and how their lives mirrored mine in several ways. Nothing was more comforting than speaking about my seizures and knowing that the people around me completely understood. I also had the opportunity to volunteer at ESWO's gala. Epilepsy can be an unexplainable and puzzling disease, often without many concrete answers or solutions. To witness a large room full of people devoted to helping those affected by epilepsy was beyond heartwarming and encouraging. Every outlet ESWO has brought my way, has allowed me to connect with others and feel like I am not struggling alone.

My first seizure made for an unexpected morning. I was 17 and getting ready for school when my mom heard a loud bang. She found me having a generalized tonic clonic seizure on the bathroom floor. I do not remember much from that morning but I do recall being scared and completely unaware of what had just happened. My sister, who is one year younger than me, had also experienced her first tonic clonic seizure a few months earlier. With no other family history of epilepsy, I remember thinking that after a few tests, we would both go back to being our normal, healthy selves, and this would all be in the past. A short while after, my sister and I were both diagnosed with Juvenile Myoclonic Epilepsy. I have since been prescribed countless



medications, and have also received a Vagus Nerve Stimulator. Ten years later, it is still not uncommon for me to wake up on the bathroom floor after a seizure.

Epilepsy has affected my life in just about every aspect. It's who I am; but only a part of who I am. I am fortunate to have been able to complete school and hold a full-time position. I am engaged, and my fiancé has already devoted a lot of his love and care to helping me with my seizures; which I am forever grateful for. Epilepsy has affected my mental health in ways that I did not anticipate. The fear of being alone or in public when I have a seizure can cause me to overthink and create feelings of anxiety and depression.

Throughout my epilepsy journey so far, I have discovered how strong I can be, and that strength flourished when I accepted that the seizures will still come, and what matters is that I am still here to face them. I have allowed much more time for self-reflection, and have come to accept that epilepsy is beyond my control. I am far more accepting of myself and refuse to view my seizures as a flaw. We need to remember that our health and happiness is in our control, even if our seizures may not be."

– Brady Hedges, client living with epilepsy

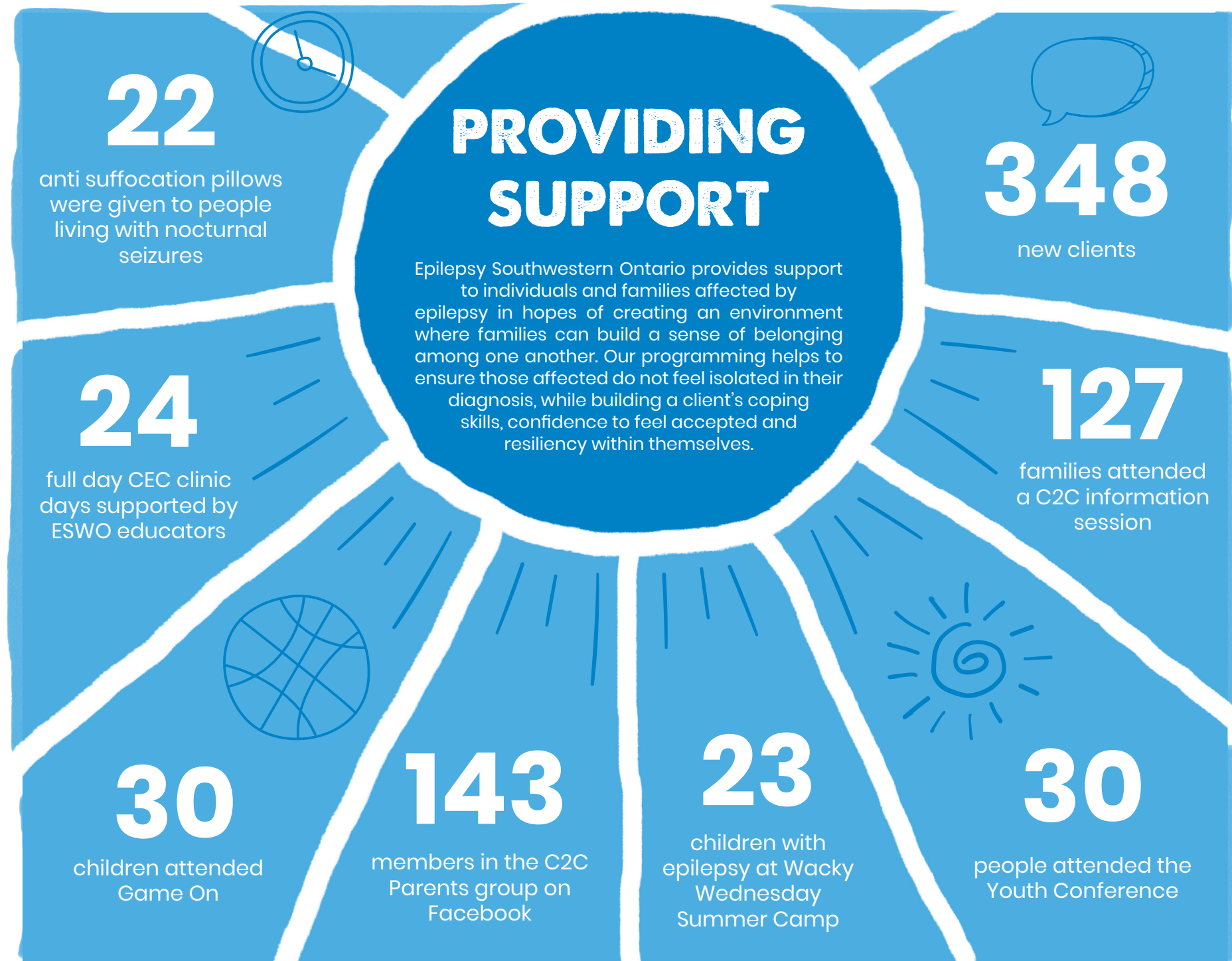
H.O.P.E. AWARD

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.





The Rick Berg Legacy Fund



This year, \$6,600 from the Rick Berg Legacy Fund was contributed to ESWO programming aimed at empowering youth with epilepsy to take leadership roles within their communities. Rick Berg sadly died of SUDEP (Sudden Unexpected Death in Epilepsy Patients) in April, 2010. His family and friends raised money through golf tournaments and donated the funds to both SUDEP research and toward the support of people living with epilepsy. We are grateful for this contribution to our youth in Rick's honour.

YOUTH CONFERENCE

On Saturday, July 27th, ESWO hosted a Youth Conference. This conference targeted youth ages 10-30 living with epilepsy, their families and caregivers. The 30 attendees were able to listen to a vast variety of experts that presented on a range of topics pertaining to diagnosis, treatment, and living well with epilepsy.

"It was a wonderful day, thank you! I love seeing the kids from the YEP! programs connect. They have a commonality and a love for each other that gives me great comfort as a mother of a daughter with epilepsy."

– Parent of a youth living with epilepsy



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Teacher In-Service Presentations



4,775



people recieved public education presentations in their community throughout Southwestern Ontario

54

Seizure 101 Presentations

SCHOOL TO COMMUNITY

ESWO is working with local educators to further develop materials which will support students living with epilepsy and ensure the classroom is a safe and inclusive environment for them to thrive.

In October 2019, we hosted a focus group with ten experts including classroom teachers, a Principal, a Vice President, Special Education Teachers, Superintendents, and a parent of a child living with epilepsy- representing all six school boards in our service area.

These experts provided guidance on the development of four booklets and one video for use by teachers. The video will focus on focal and generalized seizures, first aid, when a seizure is a medical emergency, and administering rescue medication. The four booklets to be developed will cover relevant issues for school and general strategies for children with epilepsy; and cognitive, psychological, and social consequences of epilepsy.

We look forward to working together with our community educators in order to further our school based programming.



INTERNATIONAL INVOLVEMENT

Our CEO, Michelle Franklin, was a speaker at the 33rd Annual International Epilepsy Congress in Bangkok, Thailand. She was invited to speak about implementing school programs in a session entitled: Moving Beyond the Medical Management of Epilepsy. Other speakers from this session included experts from Brazil, India and Zimbabwe.

Michelle was honoured to share ESWO's school based programming research and initiatives and to learn about what is happening around the world to improve the lives of people living with epilepsy!



Implementing School Programs

Michelle Franklin
Chief Executive Officer
Epilepsy Southwestern Ontario
Canadian Epilepsy Alliance

June 25, 2019



AWARENESS

Providing information and creating awareness throughout our region is one of the many ways we help break down barriers preventing those living with epilepsy from fully and actively participating in their communities. March Epilepsy Awareness Month is a national platform to begin a discussion about epilepsy. We encourage individuals throughout our community to participate in this initiative.

Unfortunately, March Epilepsy Awareness Month 2020 was impacted by the COVID-19 pandemic. This resulted in a reduction in our ability to host special events, for schools and workplaces to participate in our purple door campaign, for sports teams to join in our #purplenation movement, and other engaging activities to occur. While the current circumstances of the world have challenged our typical ways in which we celebrate March Epilepsy Awareness month, the epilepsy community has come together to persevere.



COVID-19 disrupted EAM this year, but we are thrilled that our **Purple Door and Purple People Campaign** still encouraged

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individuals, classrooms and workplaces to submit photos of themselves, their homes or their offices in purple to spread awareness about epilepsy.



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

\$5,793

was raised locally for ESWO.

VOLUNTEERS AND STUDENT PLACEMENTS

Volunteers play a vital role in our vision to create a community free of barriers for persons affected by epilepsy. Throughout the year, we are fortunate to have various students and volunteers assist with administration, fundraising and events, program delivery and evaluation. Thank you to all of our volunteers for their hard work and dedication to our agency!

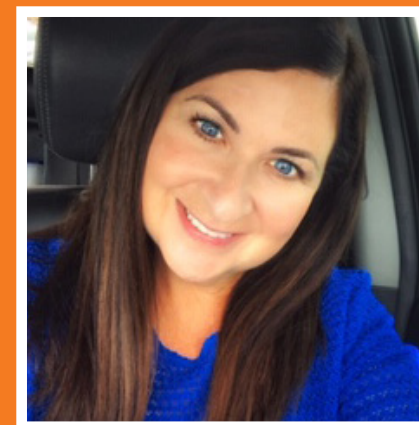
Our volunteers dedicated **3261** hours of time, valued at approximately **\$78,264**.

THIRD PARTY THANK YOU

Thank you to all of the generous support from our Third Party Event organizers! Third party fundraisers are any fundraising event that friends, companies or community groups host to support ESWO. All proceeds raised from these initiatives, whether a dress down day, bake sale or golf tournament, are donated to ESWO.

ESWO relies heavily on donations from the community to operate, and your efforts and fundraising dollars help to further our mission.

Over the last year, **\$25,556.76** was raised through Third Party fundraising.



"I decided early on to volunteer with ESWO because the support they provided to our family was outstanding and always without judgement.

Volunteering for the numerous fundraising activities and initiatives have been enjoyable and a great way to meet others, all while giving back. I was even able to have some of our patients from the Prevention and Early Intervention Program for Psychoses (PEPP) at LHSC help volunteer to make decorations for one of the fundraising galas. Patients were able to earn community service hours, while giving time to a great cause.

Volunteering has been the best decision I made and a life changing one. Eight years later and still volunteering! Seeing firsthand what ESWO does for the family, the individual, the school and the community, is a rewarding experience. I encourage others to get involved and be part of the ESWO family, you won't regret it!"

-Josie Swan-Merrison, London-Middlesex volunteer

THIRD PARTY EVENT HIGHLIGHT

TEE'IN OFF FOR EPILEPSY

Team Oke hosted their first annual golf tournament Tee'in Off For Epilepsy on September 21, 2019 in Grand Bend. Over \$25,350 was raised to help support ESWO!



“Just like other families affected by epilepsy, knowing that there is an agency to provide support when needed, is reassuring. Our son has lived his entire life battling epilepsy and ESWO has been there for us. Putting on a golf tournament to raise money for ESWO is our way of saying “thank you”. It really is an amazing feeling the support we get from local businesses, family and friends by donating, sponsoring or coming out to help raise money for a cause that is so dear to our heart.”

- Joanne Oke, Team Oke Event Organizer



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.



Donations represent
13%
of our total revenue



ESWO's Seize the Day 2019 raised \$85,056 with nearly 500 participants in London and 175 in Windsor.

FINANCIAL REPORT

BREAKDOWN

REVENUE	2020	2019
Ontario Trillium Foundation	\$124,800	\$172,965
Net Fundraising	\$147,044	\$167,965
Donations	\$56,101	\$100,297
United Way	\$16,840	\$17,330
Ontario Brain Institute	\$36,089	\$69,782
Grants	\$21,994	\$53,533
Summer Camp	\$1,915	\$6,815
Other Income	\$9,270	\$6,301
Total Revenue	\$414,053	\$594,988

EXPENDITURES	2020	2019
Program Expenses	\$378,890	\$495,539
Administration Expenses	\$101,461	\$121,464
Total Expenditures	\$480,351	\$617,003
Excess of revenue over expenses	(\$66,298)	(\$22,015)

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



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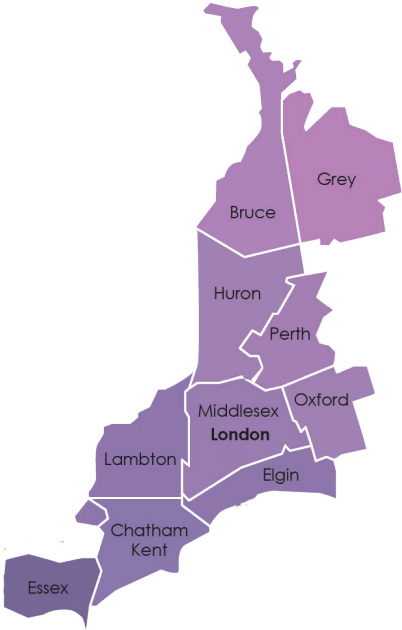
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Find Us On Social Media @epilepsyswo



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

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