epilepsy southwestern ontario

2022 – 2023 ANNUAL REPORT

A YEAR OF ACCOMPLISHMENTS

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About Epilepsy Southwestern Ontario

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

Board of **Directors**

President

Katelynn Thibert

Vice PresidentElaine Swan

TreasurerDaniel Wana

Medical Advisors

Dr. Andrea Andrade Dr. Seyed Mirsattari

Directors

Andres Usma
Ashmitha Umaharan
Carmela Redhead
Evie Lipton (Windsor Essex)
Joe Longmoore (Windsor Essex)
Michelle Scott
Rebekah Gilliland
Sharon Berry Ross (Sarnia Lambton)
Tabitha Cook (Chatham Kent)
Valerie Smith



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 **Chief Executive Officer**

To our community of relentless warriors,

As I reflect on the year that has gone by, and the accomplishments of ESWO, I am overwhelmed with pride. This report contains several highlights from the past year that we are delighted to share with you. If I had to name one accomplishment from 2022 that stands out for me, it would have to be the Inaugural SUDEP (Sudden Unexpected Death in Epilepsy Patients) Memorial Event we held. Sadly, there are many families in our Purple Nation that have lost a loved one to SUDEP or a seizure related death, who remain involved with ESWO in honour of their loved one. SUDEP can be a scary topic, but as awareness grows, so does the number of impacted families sharing their stories. This event brought families together to share treasured memories, honour their loved ones, and connect with others

who can truly relate. Due to the positive impact of the event, ESWO will host a Memorial Event yearly and will be introducing a SUDEP support group in the very near future. ESWO strives to provide support services to everyone in our Purple Nation, and this new support group and annual event is just one example of that.

On another note, there is absolutely no way we could accomplish so much without the support of our volunteers. In fact, over the last year alone, 244 volunteers gave 1074 hours of service to ESWO! We are so grateful that so many share their talent and time to help improve the lives of people living with epilepsy. These volunteers include our Board of Directors, who I cannot thank enough for their guidance, support, and leadership. I would also like to give a shout out to our donors and sponsors who help to raise funds for ESWO to continue providing support and educational services to families living with epilepsy.

I will end by saying that my reflections on the year gone by also overwhelm me with gratitude for the privilege of working for ESWO. A special thank you to our amazing, dedicated and passionate staff team! Lastly, thank you to our Epilepsy Warriors who continue to share their stories of strength and resilience. You are why we do what we do, and you continue to push us forward on our collaborative journey to raise awareness!

Kind regards,

Michelle Franklin

Michell Franklin

Letter from the **President**

Time flies when you're representing a wonderful cause!

I have officially been Epilepsy Southwestern Ontario's President of the Board of Directors for one calendar year, and oh what a year it has been. A year of personal growth through Board leadership, a year of community growth among our Purple Warriors and their families/loved ones, and a year of agency growth with new faces, new babies, and stronger bonds.

In unity with the seizure disorder community, ESWO and its
Board members have participated in annual fundraising
and awareness events, spread epilepsy knowledge to reduce
stigma, and advanced agendas for personal safety and
inclusion. I am so proud of everyone's efforts over the past year in
their continued work to spotlight epilepsy and celebrate successes.



It is with sincere gratitude that I pen a note of thanks to our generous sponsors, whose donations make it possible to continue our important mission. I would also like to thank our hard-working staff and CEO for their tireless work improving and growing ESWO. Other thanks belong to the Board, who continue to volunteer their time passionately to oversee agency success. Finally, a grand shout out to our Purple Warrior nation, whose resilience drives our advocacy.

I wish you all a safe and healthy transition into Fall, and please do not hesitate to reach out with any questions, concerns, or simply to chat; having a child living with epilepsy allows me to offer an empathetic response in times of need.

Sincerely,

Katelynn Thibert

Living with **Epilepsy**

Cooper Sanchez-Skellett

Hi everyone! My name is Cooper Sanchez-Skellett. I'm a twenty-two-year-old student at the University of Western Ontario. When I was fifteen years old, I was diagnosed with epilepsy. It was a life-changing ordeal, but thanks to the love and support of my family and friends I was able to adapt and live with my condition. I was lucky to have a great support system, but I was also able to utilize services from ESWO to help me understand and support others with epilepsy.

Great people work for Epilepsy Southwestern Ontario, and I have been lucky to learn and work with these individuals. From their informative lectures and presentations on epilepsy to the amazing Summer Kids Camp for children with epilepsy, ESWO does

amazing work for people living with epilepsy. Over the summer, I volunteered for the ESWO Kids Camp, and it was a tremendous experience. There are amazing people who dedicate their time and hard work to help people like myself, understand that I am not alone in my journey with epilepsy.

I would like to thank Epilepsy Southwestern Ontario for all their hard work.







H.O.P.E **Award**

Ava Pitre

Ava Pitre is a very special nine-year-old epilepsy warrior, who has made helping people with epilepsy her main agenda. Recognizing the peace of mind that her anti-suffocation pillow brought to her own family, she began a fundraising mission to provide pillows to other local families. Ava's passion for spreading epilepsy awareness drives these Epilepsy Awareness Month fundraising efforts, which have raised thousands of dollars and provided pillows to 28 families (and climbing) living with nocturnal seizures!

Ava's compassionate heart and commitment to spreading epilepsy awareness have earned her this year's H.O.P.E. (Helping out People with Epilepsy) award.











Providing **Support**

Epilepsy Southwestern Ontario has built a support system for individuals living with epilepsy and their families that provides a community where those affected do not feel alone in their diagnoses. Our programming helps to form a sense of belonging among our clients by building confidence to feel accepted, strengthen coping skills, and finding resiliency within themselves.

194

newly diagnosed families received a Clinic to Community session with an Epilepsy Educator

217

individuals attended Project UPLIFT session aimed at improving well-being 72

sessions of Making Mindfulness Matter were facilitated for children and their caregivers

167

new clients



Epilepsy Education

Our public education programming allows us to provide information about epilepsy and train our community in seizure first aid across Southwestern Ontario. We reduce the associated stigma of epilepsy by delivering real facts to the future generation during our age-appropriate presentations. These programs will reduce stereotypes and increase knowledge, therefore creating supportive, safe, inclusive and inviting spaces for people living with epilepsy.

1770

students received classroom presentations in 43 schools 1812

individuals were provided epilepsy information and seizure first aid training

Raising **Awareness**

We provide information to create awareness within our community to help remove the barriers that prevent those living with epilepsy from actively being involved in their community. March Epilepsy Month is a national platform to start a discussion around epilepsy and we encourage our entire Purple Nation to get involved. During March Epilepsy Awareness Month 2023 we were so pleased to see all of the purple doors, purple people and landmarks lit in purple lights. Many of our little Warriors even made presentations to their classmates! #soproud











SUDEP Awareness Memorial Event

We welcomed several families to an inaugural memorial event for those who have tragically lost loved ones to Sudden Unexpected Death in Epilepsy or an epilepsy-related death. Families were encouraged to share a photo of their loved one and to light a candle in their honor. Throughout the beautiful scenery of Graham Family EcoPark, a specially chosen space due to the Graham family's connection to SUDEP, memory stations were set up with invitations to reflect on relationships with loved ones in the past, present, and future. Memories and messages were written on paper hearts that were hung with care on our memorial tree, and families went home with their own saplings to plant and to watch their love grow. While it was a chilly day, there was much warmth to be found in the small community and the stories they shared with each other as they stood together with their hands cupped around hot coffee that was kindly donated for the event.

We appreciate all of those who attended for their continued connection with ESWO and their willingness to be both vulnerable and brave.



Third **Party**

School Project to Raise Awareness

Damon, brother of ESWO client Gabe, decided to use his school project to support his family's fight against Epilepsy. Damon designed bags with the outline of his brother's hands and sold these bags to raise money which he donated to Epilepsy Southwestern Ontario. The hands on the bag are that of Gabe and his younger brother who wanted to help as Epilepsy is a family fight.

Thank you so much to Damon and his teacher Mr. Jones of George P. Vanier Catholic Elementary School in Chatham for your project and the donation of \$160 towards the services that we provide.





Annual Skate for David

This memorial event was held in memory of David Postma who died of SUDEP on March 3, 2021. David's friends and family raised \$371.70, which was donated to ESWO. What a wonderful tribute to David.









Financial **Report**

REVENUE	2023	2022
Ontario Trillium Foundation	\$93,800	\$4,900
Net Fundraising	\$140,143	\$167,891
Donations	\$101,105	\$102,917
United Way	-	-
OBI	\$42,910	\$42,963
Grants	\$56,147	\$78,808
Summer Camp	\$3,525	-
COVID Government Subsidies	\$6,570	\$57,211
Other Income	\$1,831	\$8,157
Total Revenue	\$446,031	\$462,847
EXPENDITURES	2023	2022
Program Expenses	\$406,560	*359,896
Administration Expenses	\$91,183	\$76,127
Total Expenditures	\$497,743	\$434,62 1
Excess of revenue over expenses	(\$51,712)	(\$28,226)



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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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