

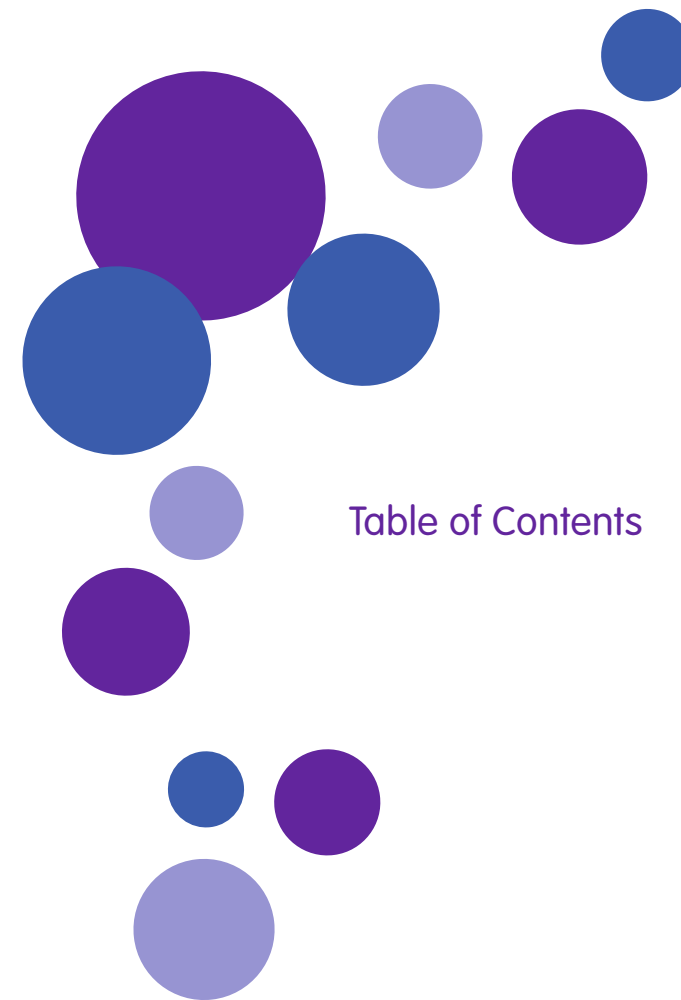


**Epilepsy
Support
Centre**

Annual Report 2011/2012



Get Involved.



Annual Report 2011/2012

Table of Contents

President's Message	4
Mission & Vision	5
Programs & Services	6
Executive Director's Highlights	7
Support	8
Educate	8
Raise Awareness	9
Financials	10
Success Stories	11

Board of Directors

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Secretary/Treasurer	Sara Martin
Medical Advisors	Dr. David Diosy Dr. Narayan Prasad Dr. David Steven
HR Advisor	Danielle Denault
Directors	Bob Harvey C��zanne Charlebois Chris Brittain
Chatham/Kent County Windsor/Essex County Elgin County/Youth Representative Oxford County	Christine Canniff Shelley Regier Sarah Murray Kim Pilkey

Staff

Executive Director	Mary Secco
Support Services Coordinator	Nicole Zwiers
Public Education Coordinator	Rochelle Sorzano
Public Education Coordinator; Sarnia/Lambton	Sharon Berry Ross
Communications Liaison / Public Education Coordinator; Windsor/Essex & Chatham/Kent	Nikki Porter

Letter from the President

As a person directly affected by epilepsy, it is gratifying to be involved with Epilepsy Support Centre in various capacities. This year, I have had the privilege of acting as President of the Board. I am honoured to serve, and proud of the dedication, professionalism, and compassion that our staff and volunteers devote to this organization and its members. The past year was one of internal transformation and reflection. Challenged to redefine ourselves as an organization, we restructured our operating plans and changed the way we communicate our role within the community. I believe we have met and exceeded the challenge with the help of our community partners, volunteers, and staff, while maintaining delivery of a wide range of services to our members.



It has been a year of success stories. We had the pleasure of moving into our new location in The Rick Berg House at 690 Hale Street. We're implementing a formalized business planning process, aiming to secure a more robust funding model by further developing connections in our community. We successfully ran our Annual Spring Gala, John F. Lemieux Memorial Run, Rick Berg Invitational Golf Tournament, Purple Day for Epilepsy celebrations, and other fundraising events across

Southwestern Ontario. We also expanded our children's camp, a successful and meaningful part of our inclusive programs.

I want to extend my personal thanks and recognition to all the staff of Epilepsy Support Centre across Southwestern Ontario, as well as our Board of Directors, for the time and extra effort they dedicated to ensuring a seamless delivery of services. They are all to be congratulated for the value and leadership they bring to our members, each and every day.

As we look to the future of Epilepsy Support Centre, I want to extend a challenge to each and every person who has been affected by epilepsy and seizure disorders. Please, offer your support to this organization: we are always looking for volunteers; we depend on you and your network of family and friends for ongoing financial support; and we rely on your leadership and ideas to sustain us as a viable organization in these complex and changing times.

I look forward to the coming year as we work together and continue to help those most affected by epilepsy and the varied complications of their condition.

Steve Gillis
President, Board of Directors

Our Mission

Epilepsy Support Centre 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.

Our 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.



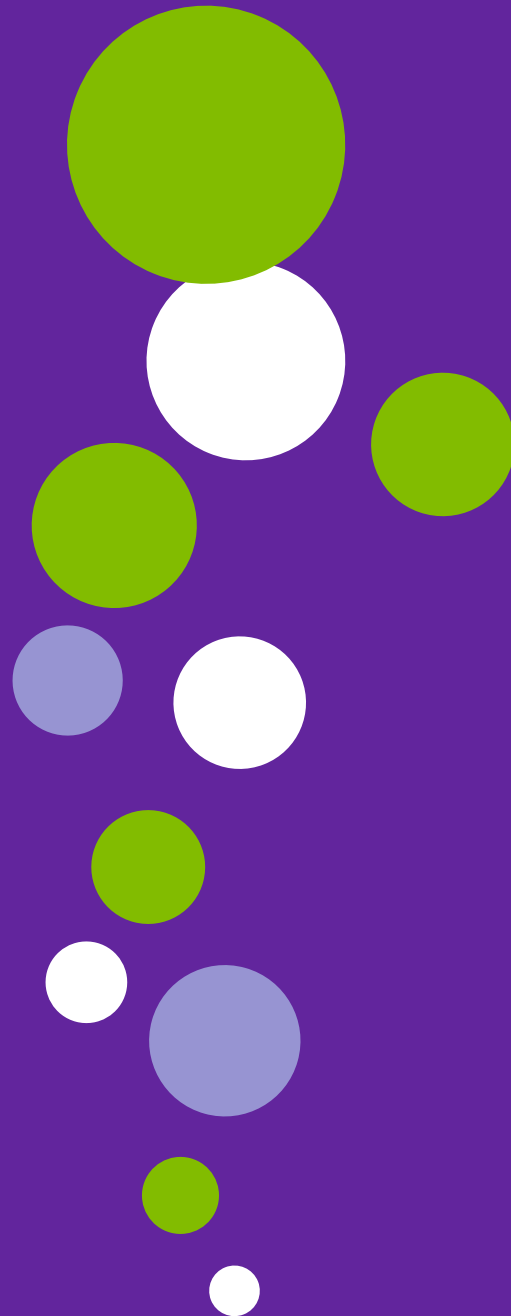
Programs & Services

- **Information** (brochures, videos, newsletter, workshops, displays)
- **Presentations** (classroom, workplace, community)
- **Seizure First Aid Training**
- **First Seizure & Newly Diagnosed Consultations**
- **Referrals/Assistance** (Trillium Drug Program, Ontario Disability Support Plan, Ministry of Transportation)
- **Peer & Support Networks**
- **Social Events**
- **Health Care Materials** (physicians, first-responders, health clinics, and other health care providers)
- **Parent Respite**
- **Children's Recreation Programs**
- **Student Support Program** (teacher in-service, peer education, help with individual safety and education plans)
- **Youth Initiatives**
- **Volunteer Opportunities**
- **Workplace Support**
- **Fundraising Events**
- **Purple Day for Epilepsy**

Our 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.



Executive Director's Highlights

- 956 families are registered in our members database.
- 428 individuals asked for one time support in the last year.
- Over the course of the year, Epilepsy Support Centre provided 6859 individuals with information about epilepsy, seizure types, triggers, first aid, employment, human rights, social assistance, SUDEP, driver's licensing, and lifestyle management. This includes 4923 elementary school students, 1480 elementary teachers, and 28 high school teachers.
- March 26, 2012 marked an important day for epilepsy in Southwestern Ontario. Not only did we distribute 44 'Purple Day for Epilepsy' kits ordered by parents and teachers, but we helped introduce events on school campuses across our service area. The Chinese Students & Scholars Association at Western University raised awareness on campus, while students at the Richard Ivey School of Business launched 'Ivey Goes Purple for Epilepsy'. 9 schools in Sarnia/Lambton celebrated Purple Day for Epilepsy with raffles and dress up days, 5 Oxford County schools held bake sales and held assemblies to raise awareness, and Mayor Eddie Francis officially proclaimed the day Purple Day for Epilepsy in Windsor.
- Over 250 guests attended our Annual Spring Gala in April 2012 for a Casino Royale themed evening, complete with dinner, dancing, games, and a silent auction. The event was a tremendous success, raising over \$25,000 for The Centre. We would like to thank all who attended, volunteered, or contributed.
- 100 families walked in memory of Brian Gallagher at the 9th Annual John F. Lemieux Memorial Walk and Fun Run.
- Epilepsy Support Centre moved into its new home, "The Rick Berg House", located at 690 Hale Street. We purchased the building with funds from the inaugural Rick Berg Invitational Golf Tournament and moved with the help of Campbell Brothers Movers. Hard working members and volunteers help us make this house a home. We would like to extend a special thank you to the friends and family of Rick Berg, as well as the entire team at 3M Canada!
- Over the summer of 2012, Epilepsy Support Centre underwent a strategic planning process in order to serve the community better and determine our priorities for the next 3 years. A copy of our Strategic Plan 2012-2015 is available upon request.
- At the beginning of 2012, we were joined by a King's College social work student, who provided 280 hours of practicum support. During the summer, 4 additional students were employed to help with graphic and website design, camp management, program evaluation, youth engagement, and strategic planning. Three of these outstanding students were funded by the Government of Canada and one through the London Life Summer Internship Program.
- We would like to extend a huge congratulations to this year's 2012 HOPE Award recipients, All About Horses and Happy Hills Resort. Thank you for your continued support of our children's recreation programs.
- We successfully created a referral system with all six neurologists in Windsor/Essex.
- 150 friends and family attended the 2nd Annual Rick Berg Invitational Golf Tournament, raising \$20,000 for The Centre and \$35,000 for SUDEP related initiatives.
- 4 staff members participated in Epilepsy Action Day at Queen's Park, speaking with politicians about the need for an Ontario Epilepsy Care Strategy. Over 90 families responded to our request to write a letter to the Ministry of Health in support of establishing a province-wide standard of care for people with epilepsy.



Support people with epilepsy and their families.

Support is always at the forefront of Epilepsy Support Centre services. Whether it is through our peer support network, summer and winter camp programs, family support groups, youth initiatives, one-on-one support, volunteer opportunities that help participants develop skills, or community building social events, The Centre puts our members first. This year, Windsor started a monthly parent support group, and both Windsor and Sarnia introduced youth initiatives that offer support and spur social interaction. Summer 2012 marked the launch of our Hale Street Canteen, where youth are able to volunteer and gain valuable vocational, social, and communication skills. Wacky Wednesday Summer Camp enrollment hit a record high with 52 children. Youth were the backbone of these programs, providing over 2100 volunteer hours at our summer and winter camps. The Ontario Brain Institute provided funding to evaluate both the summer camp program and the counsellor training program. The evaluation will measure the improvement in campers' social inclusion, sense of belonging, and physical activity levels as well as the counsellors' ability to meet the needs of the children with epilepsy they support.



Volunteers are a huge part of this organization, contributing a total of 15,800 hours over the course of this year.

"Not only did Epilepsy Support Centre provide me with HOPE to keep going they gave me the opportunity to volunteer and get my job skills back up to par. Answering phones as a volunteer receptionist allowed me to truly see how much this place means to the community."

-Tiffany, youth with epilepsy

This year, with the help of UCB Canada and Dr. Jorge G. Burneo, MD, MSPH, we were able to reach 200 people living with epilepsy in remote and rural communities through a live and interactive webcast. The webcast is still available for viewing at www.epilepsysupport.ca.

Educate our communities about epilepsy and seizure first aid.



Our school and workplace awareness programs, information stands, and education campaigns have helped us become a model for epilepsy and seizure education in our community. Our response to the media's mishandling of a seizure first aid story was featured in news outlets across Canada. Our Grade 5 program, *Thinking About Epilepsy*, reaches more schools every year. We are pleased to report that over the past year, 4923 elementary students attended classroom presentations and can now recognize different seizure types and provide the correct first aid. 1480 teachers have attended professional development sessions where they learned strategies to help students with epilepsy thrive in their classrooms. A graduate student from Althouse Teacher's College at Western University will undertake a formal evaluation of our *Brain Matters: An Introduction to Neuroscience* program. 28 secondary school science teachers from 5 local school boards will deliver this program to hundreds of Grade 12 biology students this school year alone.

"Epilepsy Support Centre offers a critical service to assist families by buffering the negative attitudes of epilepsy through education programs designed to promote effective advocacy skills parents require to ensure their children receive the resources necessary to succeed at school and socially rather than being marginalized."

- Dr. Kathy Nixon Speechley Professor, Paediatrics, Epidemiology & Biostatistics

Raise Awareness , dispel myths, and break down the stigma of epilepsy.

In 2011-2012, Epilepsy Support Centre raised awareness about epilepsy with a newspaper insert, newsletters, new seizure first aid and agency posters, myth-busting postcards, informative displays, social media, and more. We published 2 issues of our *Spikes and Waves* newsletter for our 1200 subscribers and distributed them at information booths, waiting rooms, and hospitals throughout our community. Providing information to the general public is one of the many ways we help break down barriers that prevent those with epilepsy from fully and actively participating in their communities.



On Purple Day 2012, the Chinese Students & Scholars Association at Western University distributed 500 purple origami pieces with seizure first aid facts.



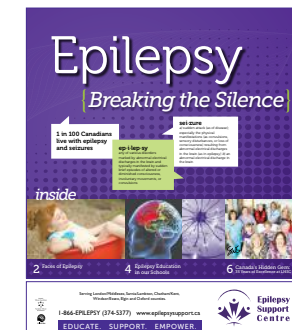
300 Twitter followers



340 combined group members



The Centre created 6 myth busting postcards to dispel misconceptions



We created an 8-page newspaper insert distributed to 154,000 homes across London, Windsor, Chatham, and Sarnia.

"Our experience has shown us time and time again that there is still a tremendous amount of ignorance, fear, and stigma about this disorder. Almost every person you meet or know must be educated before they can be supportive."

- Tracy, parent of youth with Epilepsy



Thumbs Up!

Last March, Epilepsy Support Centre helped members Jaime and Jessica launch Thumbs Up for Epilepsy. Together, we transformed their idea to paint thumbnails purple in support of people with epilepsy into an international epilepsy awareness campaign. *The Windsor Star* and *Sarnia Observer* featured local Thumbs Up for Epilepsy launches at St. Jules Catholic Elementary School and St. Patrick's Catholic High School, respectively. Fanshawe College Paramedic students and Evelyn Harrison Public School teamed up to launch Thumbs Up for Epilepsy in London, painting the thumbnails of 400 children and raising \$835 for epilepsy awareness.

Financials

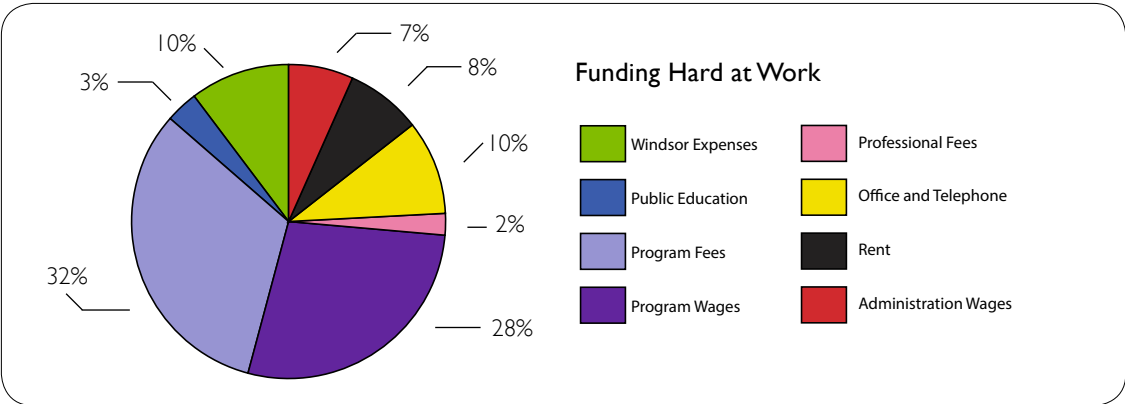
Statement of Activities and Changes in Fund Balances

Year ended March 31, 2012

Revenue	2012	2011
United Way		
London & Middlesex	111,849	105,000
Sarnia-Lambton	22,500	22,500
Oxford	30,600	30,000
Elgin	9,500	8,000
Chatham-Kent	16,000	16,000
Ontario Trillium Foundation	124,600	65,900
Grants	17,384	67,160
Donations	25,012	29,263
Net fundraising	21,306	60,686
Summer camp	855	673
Other income	506	1,452
Total	\$ 380,112	\$ 406,634

Expenditures	2012	2011
Administration expenses	97,042	120,034
Program expenses	270,556	263,784
Total	\$ 367,598	\$ 383,818

15,800 volunteer hours @ \$10.25 per hour = \$161,950 in kind support



Scott's Family Couldn't Cope without Epilepsy Support Centre

Seventeen-year-old Scott Ross has had thousands of seizures. After eighteen different medication combinations, two brain surgeries, one stroke, and three

induced comas, Scott has finally achieved seizure control. The Ross family's journey has been tumultuous. Scott's mom Mary Ann credits Epilepsy Support Centre with helping her family make it through the tough times. "Before Scott's seizures were under control, we'd call Epilepsy Support Centre daily asking for help. They are the reason that we coped. We wouldn't know how to manage if we didn't have these services. They were an anchor to us in our times of deepest despair and hopelessness."

Mary Ann credits the team at Epilepsy Support Centre for helping her family deal with Scott's school. She and her husband would call The Centre for assistance. "They would meet with our teachers and Principals and help them to understand how epilepsy impacted Scott. When he was suspended for his behaviour, they would attend team meetings. They are the reason that Scott is still in school today."

Scott was isolated. He didn't have any friends and, after several disastrous attempts, Mary Ann was very reluctant to enrol him in community programs. The Ross family was relieved to discover a different camp experience for Scott at Epilepsy Support Centre. "All of the staff and volunteers were trained to recognize different seizures and to provide the right first aid, so I knew he was safe. They understood his aggressive behaviour and planned activities that reduce triggers that would otherwise escalate his behaviour." The biggest benefit is that camp provided Scott with a social outlet. To this day, his only friends are campers and youth he has met at epilepsy camp. Mary Ann says that she, too, benefited from summer camp: "it's was a stress free day for me. When you have a child with so many seizures, you are glued together 24 hours a day. Getting a break helped me to stay strong."

Mary Ann credits Epilepsy Support Centre and the Epilepsy Program at Children's Hospital for giving Scott a chance to have a future. "Our family has overcome adversity because of the support and care we have received from Epilepsy Support Centre and Children's Hospital. We are grateful to live in a community that provides services to families living with epilepsy."



Scott Ross at Epilepsy Support Centre's summer camp (above) and at Children's Hospital (below)



In the News

When we read about hockey player Mike Danton's supposedly heroic, and definitely dangerous response to a teammate's seizure, we knew we had to act. We couldn't let the media continue to spread the myth that you should stick your hand in the mouth of someone having a convulsive seizure. Nikki Porter, our Communications Liaison, contacted media outlets across Canada to alert them to this unchecked error. We were delighted to see the Canadian Press news service act quickly with a follow up story about our response.

Canadian Press reported that Epilepsy Support Centre challenged Danton's seizure first aid technique as dangerous and included full and accurate first aid directions. Local and national news sources picked up the Canadian Press follow up report, educating readers about proper seizure first aid.

We're committed to challenging inaccurate representations of epilepsy and seizure first aid, but hope we don't see any more misinformed first aid accounts celebrated in the news.



**Epilepsy
Support
Centre**

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

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