



**Epilepsy
Support
Centre**

30th anniversary | 2013 annual report



Seizure Education & Support Services

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.

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.

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)
- **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**
- **Peer & Support Networks**
- **Social Events**
- **Volunteer Opportunities**
- **Workplace Support**
- **Fundraising Events**
- **Purple Day for Epilepsy**



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Designer	Rodney Hagle

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Board of Directors

President	Steve Gillis
Secretary-Treasurer	Sara Martin
Medical Advisors	Dr. Dave Diosy Dr. Narayan Prasad
Directors	Bob Harvey Cezanne Charlebois
Chatham/Kent County Windsor/Essex County Oxford County	Ken Taylor Joe Longmoore Chris Brittain

Staff

Executive Director	Donna Pammer
Director of Strategic Initiatives	Mary Secco
Support Services Coordinator	Nicole Zwiers
Special Events Coordinator Public Education Coordinator	Rochelle Sorzano
Public Education Coordinator, Chatham/Kent	Christine Canniff
Public Education Coordinator, Sarnia/Lambton	Samantha-Anne Manser
Communications Liaison Public Education Coordinator, Windsor/Essex	Nikki Porter

Letter from the President

It's been my pleasure to be a part of a great community support team this past year. On behalf of Epilepsy Support Centre, I hope our contributions are appreciated. I know we will continue to discover new ways to add value to the communities we serve.



For the management team, it has been a year of challenges. We created new and sustainable funding models. We've been proactive in taking important steps to reorganize and change the agency's structure. Mary Secco, former Executive Director, has assumed a strategic role of finding ways to integrate epilepsy support as part of patient services provided by our health care system. We are pleased that Donna Pammer has assumed the role of Epilepsy Support Centre's Executive Director for Southwestern Ontario. Finally, we made an important move forward through our board's conscious decision to find ways to maintain and improve the services we provide to our communities.

I would be remiss if I did not welcome Donna to her new role as she leads this organization into the future. I'm also happy to extend our sincere thanks to Mary Secco for her leadership of the agency for over 10 years. Mary's style was well suited

to the needs of this community. It was through her courage, and determination that helped to create a vibrant, service based organization.

As we head into a new year of operation, I ask each and every member to continue to find ways to add value to this important organization. The needs of our members are many; there are numerous ways to contribute in terms of volunteerism and financial support. There are countless ways we can engage the extended network of friends and family to continue supporting the members of this community.

In closing, please know it's my pleasure to be a part of this group of community minded individuals who lead and support the needs of our members.

Steve Gillis
President, Board of Directors



Executive Director's Message

Hello everyone,

If we have not yet had the chance to meet, let me introduce myself. My name is Donna Pammer and I'm the new Executive Director here at Epilepsy Support Centre, effective July 15.

I am thrilled to be here and am truly amazed at the dedicated staff, board, volunteers, parents, and community members working together to help improve the lives of the individuals we serve. I bring to this role over 15 years' experience in the not-for-profit sector as a past Executive Director of Shelterlink, a youth shelter in Perth County, and a former manager of services for persons with disabilities at Goodwill Industries. I am a Certified Fundraising Executive with development experience working at the United Way of London-Middlesex and Women's Rural Resource Centre.

I am pleased to announce that Mary Secco will maintain her strong ties to the epilepsy community in her role to develop strategic new linkages at the provincial, national, and international levels. Mary has been appointed to the Ontario Ministry of Health's Epilepsy Implementation Task Force. In addition, she is the recipient of an Ontario Brain Institute Research grant called 'Clinic to Community'. She will continue to represent the Canadian Epilepsy Alliance with Neurological Health Charities Canada and is excited to be appointed to a four year term as Co-Chair of the IBE/ILAE/WHO Global Campaign Against Epilepsy Task Force.

These are exciting times for our organization with lots of opportunities (as well as some challenges) in the years ahead. I am always interested in hearing ideas and suggestions from our members and I look forward to working with you to fulfill our vision where persons affected by epilepsy and seizure disorders are empowered and supported to live a life of dignity, self-worth, and hope.



Donna Pammer
Executive Director

Educate & Raise Awareness

Dispelling myths about epilepsy and training people in seizure first aid are at the core of our public education programs. Our audience continues to grow each year. Community presentations in London/Middlesex alone reached 130% more people than last year. This was the first year we provided epilepsy education to Educational Assistants for Thames Valley District School Board, and London & Area St. John Ambulance Volunteer Paramedics, as well as Mission Services, and Participation House.

Public Education Coordinators presented our Thinking About Epilepsy primary school program to 136 classrooms and educated 264 teachers on how to support students who have epilepsy. In addition, they staffed or supported 15 epilepsy information tables across our service area.

Epilepsy Support Centre also educates people with epilepsy and their families. In addition to providing much needed information to families dealing with a new diagnosis, we hosted guest speakers on a variety of topics including medication, Registered Disability Savings Plans (RDSPs), and healthy eating.

We taught

6923

people in Southwestern Ontario about epilepsy and seizure first aid!



Support



We support people living with epilepsy and their families with one-on-one meetings, educational sessions, a peer-to-peer support network, support groups, school and workplace advocacy, summer camp for kids with epilepsy and their siblings, and parent respite. Our members build a sense of community in London's social committee, Windsor's youth group, and at events such as bowling parties, Crock A Doodle painting, member barbecues, and movie nights. These activities provide people living with epilepsy an environment in which they are not isolated in their diagnosis and can connect with other people who've been through similar experiences.

Support Services Coordinator Nicole Zwiers provided support in 63 meetings and 335 support and/or crisis calls!

Outreach

In an effort to connect with more people with epilepsy, we launched our first physician campaign. This outreach initiative provided family doctors, specialists, medical clinics, hospitals, health teams, and urgent care centres information about our services and critical issues in epilepsy care. Epilepsy Support Centre reached 900 physicians in Windsor/Essex, Sarnia/Lambton, Chatham/Kent, Oxford and Elgin Counties.

Building relationships with other community members and organizations is a critical tool in connecting with people living with epilepsy and their families. Over the past 12 months, we reached out to over 130 community agencies providing them with information about epilepsy and our agency services.

Partnerships with other community agencies help extend our reach to raise awareness about epilepsy.

950

members

Volunteer & Summer Employment



This year, four students from Kings University, Western University, and Fanshawe College completed their volunteer placements with us. We had the benefit of their diverse expertise as they specialized in medical administration, social work, public relations, and early childhood leadership. Over the summer, we employed three summer students with a grant from Canada Summer Jobs as Kids Camp Coordinator, Graphic/Web Designer, and a Governance Project Coordinator.

390

volunteers

8369

donated hours



Celebrating 30 Years of Epilepsy Support and Education in Southwestern Ontario

This year, Epilepsy Support Centre celebrates 30 years of service in Southwestern Ontario. The Centre's work continues to reflect the region's earliest epilepsy programs decades ago.

In 1966, Eleanor McLean, hosted the first support group for parents whose children have epilepsy. As the parent of a child with epilepsy, Eleanor knew firsthand the challenges these families faced. The group called themselves "Concerned Parents" and met regularly to share their coping strategies.

A few years later, Bill and Margaret Holmes' daughter was diagnosed with epilepsy shortly before her ninth birthday. Bill and Margaret joined the original Concerned Parents group and discovered countless ways, as parents, to manage living with epilepsy. They took a proactive approach and met with their daughter's teacher. Margaret recalls, "In essence, I told her what a divine opportunity she had to teach what epilepsy was all about. Big mistake.

She put my daughter in the back row and ignored her." Over the next several years, the Concerned Parent's group expanded its program to include guest speakers and received assistance from the Ontario Epilepsy Agency. Bill and Margaret became active members, even hosting some meetings in their home.

By 1976, London/Middlesex, Oxford, Elgin, Huron and Perth counties forged the Midwest Region chapter of Epilepsy Ontario, with Bruce County joining a few years later. People from those areas requiring epilepsy medical services were directed to London. The decision to co-ordinate the medical and social epilepsy services in London seemed practical.

The following year, Epilepsy Ontario's Midwest Chapter opened their first office on Dundas Street in London where they organized an action group, a parent group, and a recreational/social group. They hired staff to promote a public education program targeting primary and secondary schools.

The agency took a major step forward in 1983 and passed its first constitution as Epilepsy London and Area, serving London-Middlesex, Elgin, and Oxford counties. Since 2001, Epilepsy London and Area expanded to include Sarnia-Lambton, Chatham-Kent, and Windsor-Essex and became known as Epilepsy Support Centre.

Rooted to the original concepts of the "Concerned Parents" group, Epilepsy Support Centre helps families cope with the challenges of living with epilepsy through coordinating a peer-to-peer support network, providing educational sessions for families, and holding a seizure-safe summer camp in London. The camp successfully provides kids with epilepsy an inclusive social outlet, and their parents with much-needed respite.

Today, Participation House cares for Bill and Margaret's grown daughter. They report she is doing well and is actively volunteering, bowling, knitting, and taking trips. Reflecting on Epilepsy Support Centre Bill and Margaret

remark, "Now, in 2013, there is so much information available and information is power. The scary part was always, when you don't know. Epilepsy has come a long way, but still has further to go."

The Centre continues public education as the original staff did, only now new groundbreaking programs *Thinking About Epilepsy* and *Brain Matters: An Introduction to Neuroscience* are used throughout the service area. The Centre has a close working relationship with the Epilepsy Unit at London Health Sciences Centre to ensure those who struggle with seizure management get the non-medical epilepsy services they require. With seven staff members, nine board members, and a team of volunteers, Epilepsy Support Centre is thriving and currently covers most of the Southwestern Ontario region which includes the estimated 12,000 families living with epilepsy. We look forward to serving our community for the next 30 years and beyond.



HOPE Award

The HOPE Award (Helping Out People with Epilepsy) is granted to an individual, group, organization, small business or corporation who has demonstrated a commitment to improving the quality of life of people living with epilepsy in our community. Past recipients of the HOPE Award include Happy Hills Resort, Ernst & Young, CIBC Wood Gundy, rTraction, TD Canada Trust, All About Horses, and the founders of the epilepsy surgery program: Drs. Blume and Girvin.

Epilepsy Support Centre presented the 2013 HOPE Award to 3M Canada. A group of dedicated 3M employees organized the Rick Berg Invitational Golf Tournament, which raised over \$150,000 in the past 3 years. The proceeds from this tournament support the operation of The Rick Berg House and SUDEP (Sudden Unexpected Death in Epilepsy) education/ research.

John F. Lemieux Memorial Run

On October 21, 2012, families, supporters, and members of our community participated in The 10th Annual John F. Lemieux Memorial Run/Walk. This year's event was dedicated to those living with epilepsy or in memory of someone who passed away from a seizure. Two hundred walkers dressed in purple laughed, cried, and cheered as they made their way around Springbank Park on a beautiful Sunday morning. Individuals, families, and teams raised \$11,000, blowing past this year's goal of \$8,000.



Purple Day for Epilepsy 2013

Epilepsy Support Centre empowered our members to raise epilepsy awareness in their communities throughout Epilepsy Awareness Month in March, culminating in Purple Day for Epilepsy on March 26. The Centre supported students and teachers who brought epilepsy education to their classrooms, as well as local businesses and other agencies who raised awareness in their communities. Epilepsy Support Centre sold 25 Purple Day for Epilepsy kits, promoting epilepsy education across our service area.

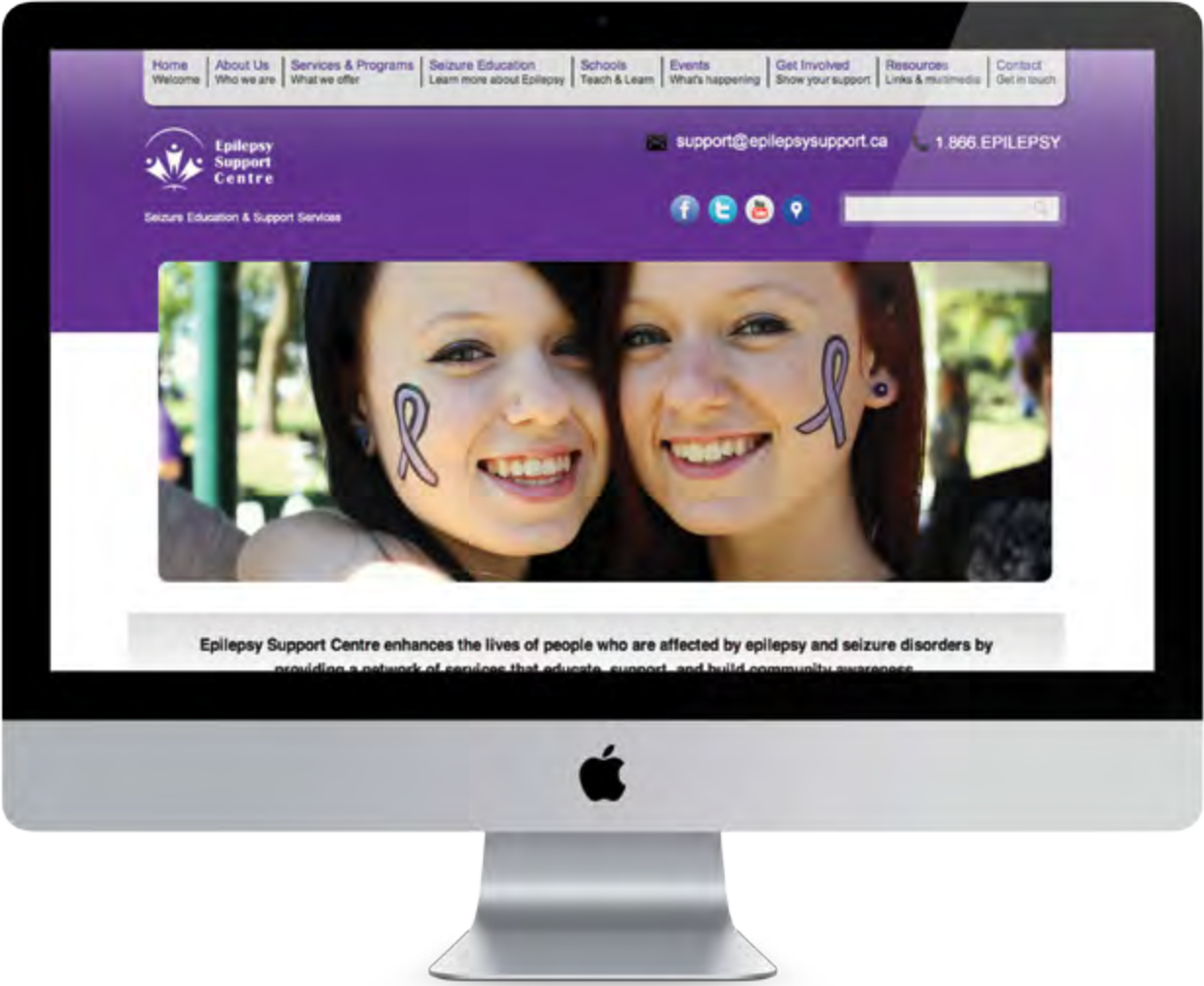
Windsor members achieved several public successes this March. 10 Tim Hortons in Windsor/Essex sold purple



sprinkled donuts to raise epilepsy awareness on March 26, **The Windsor Star** made epilepsy front page news featuring two Epilepsy Support Centre members in their story "Epilepsy: It's more common than you think", and Mayor Eddie Francis officially proclaimed March 26, 2013 Purple Day for Epilepsy in Windsor.

Epilepsy Awareness Month is also an opportunity to celebrate the community our members have built. To this end, 280 people in total attended Purple Day for Epilepsy parties in Chatham, Windsor, and London.





Our New Virtual Reality

We've relaunched www.epilepsysupport.ca! In addition to a sleeker look, the website is easier to navigate and more accessible than ever before. We now provide region-specific information for members across our service area. Visitors are informed of the latest media and research reports about epilepsy. They can also access tools such as seizure records to help with seizure management. Other features include archived newsletters, an expanded list of programs and services in each region, our live Twitter feed, a map to our office, seizure education resources, information about our Board of Directors, and previous annual reports.



900+ Twitter followers
Up 70% from last year



445 people like our
Facebook community page.

479 combined group
members on Facebook.

608 friends on the Epilepsy
London area profile.



Approachable, Encouraging, United.

Epilepsy Support Centre rebranded with improved agency materials and a new look. No matter what region you're in, Epilepsy Support Centre has a consistent message and it is easily recognizable. Our new agency brochure, poster, and banner, along with our first aid poster and postcard each present clear, concise information. Furthermore, the new agency brochure now highlights services provided in each region, so current and prospective clients can see which programs they can access locally.

Financial Statement

Year ended March 31, 2013

Revenue	2013	2012
United Way		
London & Middlesex	95,000	111,849
Sarnia-Lambton	22,500	22,500
Oxford	31,000	30,600
Elgin	5,000	9,500
Chatham-Kent	14,718	16,000
Ontario Trillium Foundation	57,800	124,600
Grants	24,700	17,384
Donations	31,784	27,742
Net fundraising	49,296	18,576
Summer camp	1,719	855
Rental Income	22,410	0
Other income	297	506
Revenue from 2012 House Deposit	66,000	0
Total	\$ 422,224	\$ 380,112
Expenditures	2013	2012
Administration expenses	100,924	97,042
Program expenses	240,054	270,556
Total	\$ 340,978	\$ 367,598

Spotlight on Youth: Living Well with Epilepsy

Young adults in Windsor are on the move. Four of our youth members are pursuing post-secondary education, including graduate degrees. Andrew Namespetra recently graduated from University of Windsor with an Honours Bachelor of Science degree, majoring in Chemistry with a minor in Mathematics. In September, he begins a Master of Science degree in Chemistry at Halifax's Dalhousie University. Jessica Longmoore is a recent University of Windsor graduate, with a Bachelor of Environmental Studies degree. She's continuing her education in Fleming College's Geographic Information Systems: Cartographic Specialist program. Twins Emily and Alicia Regier are starting St. Clair College; Emily will specialize in Animation while Alicia goes into Culinary Management. All of these young adults live well with epilepsy as they make great strides in their educations.

Andrew, Jessica, Alicia, and Emily have all mentioned the significance of spending time with others who have similar experiences with epilepsy. Jessica describes the isolation of living with epilepsy; "it's not something you can tell just by looking at someone, so it feels as if no one around you has epilepsy at times and you're the only one going through these things." Emily's involvement with Epilepsy Support Centre activities helped her: "I never knew anyone with epilepsy. Meeting others going through what I'm going through and being part of a group where I'm not the only one with epilepsy is comforting." Andrew further explains, "Even though I had the full support of my family and friends, they could not fully understand how I felt. Speaking openly to others with epilepsy lessened the loneliness I felt and relieved my fears - I became more hopeful about living with epilepsy and began to accept my diagnosis." These youths found Epilepsy Support Centre programs improved their experience of living with epilepsy.



Windsor youth Andrew, Scott, Dave, Alicia, and Emily staffed an epilepsy information table and bake sale at University of Windsor.

Since getting involved with The Centre, they've started speaking more publicly about having epilepsy. They staffed epilepsy information tables during Epilepsy Awareness Month in March. Alicia and Emily participated in a special panel about the social challenges of growing up with epilepsy. Jessica was featured on the front page of *The Windsor Star*, sharing her story of living with epilepsy and the importance of resources like Epilepsy Support Centre. These youths are striving for more epilepsy awareness surrounding epilepsy. They connect this information gap to increased stigma and poor public support for epilepsy initiatives and research. They hope that by speaking out about their experience and teaching people about epilepsy, they will change the way the public thinks about seizures and people with epilepsy. As Jessica so succinctly put it, "We're all different and many of us are still capable of living completely normal lives. With the public more aware, people with epilepsy will also feel more comfortable talking about it instead of suffering alone." Jessica, Alicia, Emily, and Andrew are a wonderful, vibrant group of young people whose very lives challenge stereotypes of life with epilepsy.



**Epilepsy
Support
Centre**

1-866-EPILEPSY

www.epilepsysupport.ca

690 Hale St., London ON N5W 1H4

London 519 433.4073 | **Sarnia** 519 330.0416

Windsor 519 890.6614 | **Chatham** 519 365.5131

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

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United Way