

Epilepsy Ontario 2013 Annual Report



Educate.



Engage.



Empower.

Photo Credit:

Educate: Taken at KPMG “Thumbs Up for Epilepsy” Awareness Day from left to right: Elisa McFarlane, Olga Lapshinova, Jose Castillo, Rozalyn Werner-Arcé, Kelly Cjanovich, Jeanette Schepp

Engage: Taken at the Run for Epilepsy in Thunder Bay featuring The Lewis Family

Empower: Taken at Toronto Launch of Ontario Non-Driver’s Photo ID featuring Hon. Harinder Takhar; representative from CARP; Elisa McFarlane, President Epilepsy Ontario; and representative from Canadian Hearing Society.

Message from the President and Executive Director



(l-r) Elisa McFarlane, president and Rozalyn Werner-Arcé, executive director

The old adage ‘time flies when you are having fun’ sure applies when it comes to Epilepsy Ontario. It is hard to believe that a year has passed already, and what a whirlwind year it has been! We are pleased to provide this overview of the strategic initiatives undertaken this past year:

Governance and Engagement: The passing of the Ontario Non-Profit Corporations Act (ONCA) provided Epilepsy Ontario with the impetus and opportunity to re-visit and its relationship with local epilepsy agencies which will then inform our by-laws. The provincial organization is committed to working collaboratively with local epilepsy agencies in a manner which advances the cause of epilepsy, improves the quality of life of people living with the condition, and enhances the sustainability of epilepsy support agencies.

To begin the process, we applied for and were successful in securing a grant from Endeavour Consulting, a non-profit organization that provides pro-bono consulting. The grant, which was worth approximately \$73,000, enabled Epilepsy Ontario to provide a transparent and confidential way for local epilepsy agencies to provide feedback about their relationship with the provincial organization and the roles that they would like to see Epilepsy Ontario fulfil in the future. The roles include advocacy, provider of best in class tools and templates and provincial resourcing. The board and staff welcomed the feedback and look forward to working with local epilepsy agencies in Ontario to determine a relevant governance model.

Information and Education:

We were pleased to launch the “Voices of Epilepsy” e-news in March 2012. This online news source of issues related to epilepsy is designed to give a voice to the people who live with the condition every day. It is also meant to inform others (decision-makers, employers, families, friends and funders) about the issues and possibilities surrounding epilepsy. News stories are posted every Thursday and distributed electronically Friday mornings. We hope you enjoy these weekly stories and gain greater insight into not only the challenges that people face 24/7, but also their resilience and their determination to not let epilepsy control their lives.

The 1-800 Epilepsy Information Help Line continues to be a source of information and support for people living with epilepsy. Suzanne Nurse, PhD., who joined the Epilepsy Ontario team in October 2011 in the capacity of Epilepsy Information Specialist, responds to the calls and online queries for information, support and assistance to navigate the health care system, especially from areas where there are no local epilepsy agencies.

More and more people seek their information on the internet versus more traditional ways such as by accessing physical libraries. While we saw a decrease in the number of people who visited our resource centre, increasingly people are accessing the online resources.

We will continue to seek opportunities to build the online information and increase access to the Epilepsy Information Specialist.

The Epilepsy Information Specialist has also developed the provincial organization's capacity to provide training to educators, specifically those in areas where there is not an epilepsy support agency. Using technology, she has been able to provide teacher training about epilepsy and how best to include children with epilepsy in the classroom. The training is increasing understanding and willingness to welcome children with epilepsy in the classroom. In 2013, we will be creating an online training resource that can be accessed by teachers thanks to grants from the Takla Foundation and Rx&D.

Advocacy:

In July 2013, Health Quality Ontario released its final set of recommendations for a proposed Provincial Epilepsy Care Strategy. For Ontarians with epilepsy, it promises equitable access to evidence-based quality care. Within the strategy it has been identified that standards of care will be developed including appropriate protocols for treatments; education for medical professionals and other allied health care workers; establishment of five epilepsy resource centres; establishment of an expert panel; and wait time strategies.

Epilepsy Ontario and local epilepsy agencies together have actively supported the Health Quality Ontario recommendations by meeting with Members of Provincial Parliament (MPP's) and Ministry of Health and Long Term Care officials. In addition to supporting the strategy, we have also advocated for the inclusion of local epilepsy agencies within the strategy. Local agencies provide vital services such as information about the condition of epilepsy; seizure safety training; employer and educator education; psych-social support, and advocacy. We are awaiting Ministry approval on the Provincial Steering Committee which will drive the Strategy. Epilepsy Ontario requested two positions on the Steering Committee which will be very adeptly filled by Mary Secco, Executive Director, Epilepsy Support Centre and Rosy Smith, Director of Adult Services at Epilepsy Toronto. We continue to meet with MPP's of all parties to educate them about the Strategy. Ontarians with epilepsy deserve no less.

Anti-epileptic drug shortages have plagued Canadians with epilepsy for decades. The Canadian Epilepsy Alliance (CEA), of which Epilepsy Ontario is a member, has been advocating for mandatory reporting by pharmaceutical manufacturers for several years, to no avail.

Epilepsy Ontario took on the challenge provincially, writing to Health Minister Deb Matthews requesting that her Ministry work with the federal government. We also met with the health critics enlisting their support as well. Epilepsy Ontario is also a member of the CEA's National Drug Shortages Committee working with colleagues from across the country to develop strategic initiatives to address the issue.

Provincial Programs:

OBCL Epilepsy Scholarship Awards: We were pleased to provide eight scholarships in 2012 to deserving students pursuing the educational goals. We are grateful to Osler Business Consulting Limited for their continuing and generous support in making this scholarship possible. It provides a helping hand to students who have overcome the challenges of their epilepsy and are now facing the challenges of paying for their post-secondary education.



OBCL president Lawton Osler (right) congratulates three students at the 2012 awards ceremony. Pictured from left to right are Rahman Mohamed, Jaimie Morgan-Lynette and Brooke Corner.

Summerfest: This residential camp program is now in its 19th year. Started by Anita Allen, Nursing Coordinator at SickKids Hospital, this program is truly valued by the children and youth who access it. We are in the midst of having the program evaluated, to make this tremendous experience one that can benefit more children. The children have the opportunity to just be kids enjoying activities such as swimming, sailing, camp fires, arts and crafts, and ropes, while parents enjoy a well-deserved break. Parents use the one and two week camp sessions as an opportunity to either spend time with their other children, and/or take time to rejuvenate their energy and spirit.



We are grateful to our 2012 partners and express our sincere appreciation to: Andrew Martin at Camp Couchiching, Anita Allen at SickKids, and Jodi Maruncic and Katie Lundy at Epilepsy Toronto.

Research:

A few years ago we received a generous bequest of \$400,000. It was the donor's request that the funds be used to find a cure for epilepsy. Although medical research is not a focus of Epilepsy Ontario, the board is concerned with improving the quality of life of people living with epilepsy through effective care, treatment and psycho-social supports. After researching best practices, a terms of reference was developed for the **William Donald Willis Fund**. In year one, funds will be dedicated to an **Innovator Award for Epilepsy Research**. The innovator grant will provide seed funding (e.g., to researchers who have a novel idea that has not been tested or who plan to develop licensed intellectual property and/or a new technology for a consumer product in line with the purpose of the Fund). The first call for applications will take place in 2013.

In 2012, the executive director of Epilepsy Ontario was invited to chair the Non-Profit Advisory Committee of the EpLink research program at the Ontario Brain Institute. We were thrilled when the Ontario government renewed the funding for the Ontario Brain Institute. Through the EpLink Research program, \$1,000,000 was invested in epilepsy research. It is an investment that gives people hope. Hope in an improved quality of life for themselves and their loved ones. Hope, that one day a cure may be found.

The Canadian Epilepsy Alliance and Purple Day:



Epilepsy Ontario is proud to be a member of the Canadian Epilepsy Alliance (CEA), a national organization that is dedicated to the promotion of independence and quality of life for people with epilepsy and their families, through support services, information, advocacy, and public awareness. Currently there are 27 agency members. From Victoria, British Columbia to St. John's, Newfoundland epilepsy support agencies are working together to raise awareness and to improve the quality of life of people with epilepsy.

We were very pleased to join CEA colleagues in Ottawa on March 26 as Purple Day was observed for the first time across the country as the official day for epilepsy awareness, since the Purple Day Act passed with unanimous support in June 2012.

Pictured left to right: Epilepsy Ontario executive director Rozalyn

Werner-Arcé, Purple Day founder Cassidy Megan and the Hon. Geoff Regan, MP, Halifax West celebrated Purple Day for Epilepsy on Parliament Hill.

Looking to the Future:

There has been excellent activity over the past year, but it cannot be sustained without ongoing, steady funding. The traditional sources of revenue that Epilepsy Ontario has relied upon in the past, the biggest being gaming, are slowly decreasing. To this end, the board welcomed, with great enthusiasm, Jeanette Schepp, Resource Development Co-ordinator in October 2012. Jeanette is working with the Executive Committee and a dedicated group of volunteers on the Resource Development Committee to develop new streams of revenue for the organization. Additionally, we have also formed a Provincial Fundraising Committee which is exploring bi-level opportunities to raise awareness and funds for agencies across Ontario.

The future of epilepsy in Ontario looks brighter than ever. The stars are aligning for Epilepsy. We see this through:

- the ongoing funding of epilepsy research;
- the proposed epilepsy care strategy;
- the development of an advocacy and government relations strategy, ensuring that the *Voice of Epilepsy* are heard loud and clear;
- the recognition of the value, indeed necessary role, of epilepsy agencies in providing support improving the quality of life for people living with epilepsy; and
- relationships being strengthened between epilepsy agencies in Ontario providing more support to each other and becoming more cohesive.

We continue to work in collaboration with epilepsy agencies to seek grants to develop capacity within local epilepsy agencies and within the community. There continues to be significant stigma that surrounds the condition and one of our goals is to break through barriers and create new opportunities for social inclusion, employment and meaningful education

We have a very committed volunteer in Thunder Bay, Trevor Lewis, who has formed a Steering Committee to develop the Northwest Ontario Epilepsy Association.

Together, with epilepsy agencies we are re-thinking the roles and relationships of the epilepsy support community, with each other and with allied partners.

Epilepsy Ontario is committed to working with local agencies to build a stronger support agency community both provincially and nationally. We believe that by working together, we will be more effective in our messaging to stakeholders, and thus improve the lives of people who live with epilepsy..

Thank you! Thank you! Thank you!

Epilepsy Ontario relies on the generosity of our volunteers and donors to continue to work on behalf of Ontarians with epilepsy. We thank you for your generous gifts of time, talent and financial contributions.

We especially acknowledge and thank the directors for their leadership and many hours of volunteer time providing strategic direction and hands-on efforts.

And finally, we raise our glass to the following full-time employees, contractors, summer students, placement students and office volunteers for their dedication and daily contributions to Epilepsy Ontario and the 55,000 people who live with the condition of epilepsy in this province. They are:

Gula Aitkulova, David Ben-Israel, Julie Dorsey, Nancy Fazari, Kyle Graves, Nancy Kimura, Iris Lee, Sue Meighen, Suzanne Nurse, PhD, Jeanette Schepp, Kyle Sing, Nick Smith, and Veronica Tang.

Respectfully submitted,

Elisa McFarlane
President

Rozalyn Werner-Arcé, CAE
Executive Director

Thank You to our Volunteers, Donors and Supporters!

Epilepsy Ontario gratefully acknowledges the many volunteers, partners and donors for helping to improve the quality of life for people with epilepsy. They do this by lending their support, making a donation, hosting a Purple Day event, contributing financially, or telling their personal story, letting others know that they are not alone. By telling their stories, people who have epilepsy are raising the Voices of Epilepsy across Ontario breaking down barriers and smashing the stigma.

Marcel Allen	Carol Benn	Kayleigh and Terry Boyd	Boucher-Ross Family
Kelly Cvjanovich	Alex Dolan	Simcoe Fanshaw College	Nancy Fazari
Howard Fletcher	Lisa Gratton	TerryAnn Guay	Daniel Horvath
Nancy Kimura	Pamela-Anne Kinney	Olga Lapshinova	Iris Lee
Elisa McFarlane	Sue Meighen	Bruce Milburn	Staff at Mohawk College
Kirk Nysten	Lawton Osler	Gino Piazza	The Richardson Family
Cathy Ryan	Kimberley Scott	Kyle Sing	Sue Spencer
Jasmatie Suchit	Lia Turner	Catherine Villar	Wightman Family
Daryl and Lindsay Yeo	David Zelek		

Summerfest:

Anita Allen – SickKids Hospital
Camp Couchiching

Epilepsy Toronto
Toronto Star Fresh Air Fund

Corporations:

Brantford Regional Real Estate Association
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Saputo Foods Ltd.
Scotia Bank
The Guarantee Company of North America
The Promenade Mall, managed by Cadillac Fairview
Tough's Appliance Repair
Turkstra Lumber Company Limited
Wiltshire and Associates Forestry Inc.

Events, Foundations, Community & Employee Groups

7th Annual Richardson Family Golf Tournament
The Boucher-Ross Family event
A & A King Family Foundation
The Catherine & Maxwell Meighen Foundation
CIBC Children's Foundation
Suncor Energy Foundation
TAKLA Foundation
Basilian Fathers of the University of St. Michael's College
Judaea Brotherhood Temple
Brant Haldimand Norfolk OECTA
King George School
Langstaff Secondary School, Cafeteria staff
North Bay Police Service
O.P.G.T.
Ontario Power Generation Inc.
Optimist Club of Stoney Creek
St. John's College
United Food & Commercial Workers Canada Local 175
United Way - Centraide Ottawa
United Way of Greater Toronto

Allied Memberships and Partnerships:

Canadian Epilepsy Alliance
Neurological Health Charities Coalition – Ontario Brain Strategy
Ontario Brain Institute – Non-Profit Advisory Committee
Parents Association Advisory Council on SEAC

Affiliate and Partner Agencies in Ontario:

Epilepsy Durham Region
Epilepsy Grand Erie
Epilepsy Halton Peel Hamilton
Epilepsy Huron-Perth
Epilepsy Niagara
Epilepsy North Bay
Epilepsy Ottawa-Carleton
Epilepsy Peterborough and Area
Epilepsy Sault Ste. Marie and Algoma District
Epilepsy and Seizure Disorder Resource Centre for Eastern Ontario (Kingston)
Epilepsy Simcoe County
Epilepsy Support Centre (Serving Southwest Ontario)
Epilepsy Toronto
Epilepsy Waterloo/Wellington
Epilepsy York Region
Seizure and Brain Injury Centre (Timmins)

2013 OBCL Scholarship Recipients

Chloe Gallagher	Kirsten Leusink
Tori Gleason	Katelyn Lewis
Alexander Johnson	Suzanne McGuire

Executive Committee

Elisa McFarlane, President	Howard Fletcher (resigned)
Kirk Nysten, Vice President	Bruce Milburn
Gino Piazza, Treasurer	Jasmatie Suchit
Lawton Osler, Past President	David Zelek
Alex Dolan, Secretary	

Staff

Rozalyn Werner-Arcé, CAE, Executive Director	Suzanne Nurse, PhD, Epilepsy Information Specialist
Gula Aitkulova, Administrative Assistant and Gaming	Jeanette Schepp, Resource Development Co-ordinator



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