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Epilepsy
Ontario

Annual Report 2013



Gino Piazza
President

Message from



Rozalyn Werner-Arcé, CAE
Executive Director

Epilepsy is one of the most common neurological conditions with at least 72,000 people in Ontario living with the condition, and it is finally getting the attention and focus it deserves. In recognition of the new interest and commendable efforts to advance epilepsy care, support and research in the province, the board of directors and staff of Epilepsy Ontario reinforced their commitment to improving the lives of people who live with epilepsy and to strengthening community-based epilepsy support. We did this by: advocating for better health care policies and funding for effective community-based supports; providing current information and education; delivering quality provincial programs; and sharing information about the latest in Ontario epilepsy research. We are proud to report on the major highlights below:

Advocating for Better Health Care Policies and Community Supports:

Purple Day at Queen's Park: March 26 marks the international awareness day for epilepsy. Purple Day was celebrated at Queen's Park where there was unanimous consent in the legislature by all parties for MPP's to wear purple ribbons in recognition of epilepsy. Meetings with key stakeholders were held throughout the day to discuss issues including drug shortages and the proposed Provincial Epilepsy Care Strategy.

Epilepsy Action Day at Queen's Park is becoming an important signature event for epilepsy. On September 24, 2013, dozens of epilepsy agency staff and volunteers descended on Queen's Park to advocate for the recognition of community-based supports and services. This year, Epilepsy Action Day at Queen's Park focused on the social burden of epilepsy as well as improving epilepsy awareness through education curriculum. Ensuring there is access to all treatments and finding a solution to the serious problem of drug shortages remains a top priority for those living with epilepsy.



L-R Daryl Yeo, Hon. Tracy McCharles, Robert Tam, Jessica Scheffe, Dianne McKenzie, Laura Albanese MPP



L-R Gino Piazza, and UCB Canada's Robert Tam and Hervé Lilliu

All people living with epilepsy have the right to lead quality lives and local epilepsy agencies are committed to helping people in Ontario living with epilepsy once they receive their diagnosis. We believe that people living with epilepsy should be supported to live the highest quality of life possible and we believe that this is possible when people have access to community-based patient education and self-management programs. We also believe that community-based epilepsy education will reduce health care costs to the province.

The day concluded with a reception attended by MPPs, government officials and stakeholders at Queen's Park. Minister of Health Deb Matthews, PC Health Critic Christine Elliott and NDP Deputy House Leader Cindy Forster all gave remarks at the event.

Rescue Medications for Children and Youth with Epilepsy in Schools:

Most seizures last anywhere from a few seconds to a few minutes ending naturally on their own. Prolonged seizures (convulsions > 5 minutes), or seizures that repeat without recovery in between, can indicate a life-threatening situation known as "status epilepticus". Prompt administration of an anticonvulsant is the most effective treatment for status epilepticus. The sooner an anticonvulsant is administered the greater its ability to stop a prolonged seizure. These medications are called rescue medication. If an episode of status epilepticus is not stopped early it can result in permanent brain damage, injury to other organs, or death. Children and youth with epilepsy who have an increased risk of status epilepticus may be prescribed an emergency medication to be given during a prolonged seizure or seizure cluster. Prompt treatment can mean the difference between life and death.

Despite written doctor orders and parental wishes, staff may, and do refuse to provide rescue medication for students with epilepsy. That is why Epilepsy Ontario has been advocating for legislation that enforces appropriate policies and procedures to ensure that students with epilepsy are protected. We have had several meetings with several MPP's as well as officials in the Ministry of Health and Long Term

Care (MOHLTC) to raise awareness about the issue. There is agreement that legislation is needed in order to protect students and teachers, while giving parents peace of mind. Epilepsy Ontario will continue to advocate for this critical issue.

Provincial Epilepsy Care Implementation Task Force:

Formed by the MOHLTC in June 2013, the role of this Task Force, which is co-chaired by Dr. Carter Snead and Brenda Flaherty, is to develop and implement a provincial framework to maximize value from the system of epilepsy care in Ontario. In January 2014, the Task Force released the Provincial Epilepsy Monitoring (EMU) Unit Guidelines for Ontario. This is good news, and what is even more exciting is the acknowledgement and public recognition of the role of a Community Epilepsy Liaison. This will be a staff member from the local Community Epilepsy Agency who has specialized training in epilepsy with knowledge of available community services and the day-to-day psychosocial needs of affected patients/families. This person will be a point of contact between the community and local EMU.

Epilepsy Ontario would like to thank Mary Secco, Director of Strategic Initiatives at the Epilepsy Support Centre and Rosie Smith, Director of Adults Services at Epilepsy Toronto for representing community-based agencies and for their advocacy on behalf of people living with epilepsy.



2013 Epilepsy Action Day at Queen's Park: L-R Rozalyn Werner-Arcé, Christine Elliott, Hon. Deb Matthews, Cindy Forster and Gino Piazza

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Strengthening Ontario Community-Based Epilepsy Agencies:

The Ontario Non-Profit Corporations Act (ONCA) provided the impetus for the Governance Committee to launch the re-writing of the by-laws. The Committee, which includes agency executive directors, a community volunteer, and board directors and the executive director, has diligently researched various non-profit organizations with the intention of developing a couple models for consultation with local Ontario-based agencies. Our goal is to develop a governance model that unites, builds and strengthens community-based epilepsy support community in Ontario.

In August 2013, The Ontario Trillium Foundation announced that Epilepsy Ontario was the recipient of a \$280,000 grant over three years to conduct market research, identify best practices, and develop consistent messaging. Our goal is to ensure members of the community are aware of and reach out to community-based agencies when they require information, education and support, and to ensure that community-based agencies are delivering quality programs consistently across the province.

Awareness and Education

Social and online media continues to play an important role in communicating with existing stakeholders and engaging new people. Over the past year we have seen a significant increase in engagement as demonstrated in the chart below:

| Social Media and Online Mediums | Increase / Decrease |
|---------------------------------|---|
| Twitter | 76% increase. |
| Facebook | 31.5 increase |
| LinkedIn | 825% increase (this stat is representative of the medium being introduced in 2013.) |
| Website | 28.2% increase of new views. Monday has the peak views followed by Wednesday and Thursday, coinciding with our Voices of Epilepsy column. |

Readership of Voices of Epilepsy continues to grow. Engagement with our readers is also on the rise. Readers regularly comment on stories that resonate with them, whether they are issue based such as drug shortages, or when people share their personal stories about things that impact their lives such as CBD, guide dogs or employment.

We were excited to launch Epilepsy Ontario's blog in Huffington Post Canada in January 2014. Guest writers have provided thought-provoking content about issues related to epilepsy and the lives of people who live with the condition. Many thanks to Gena Meldazy for bringing this opportunity forward and for writing our first column. We also extend our thanks to other guest columnists including: Michelle Wilson of the Ontario Brain Institute, Lia Turner, and Shane Gracey.

Epilepsy Ontario will continue to focus on building engagement through the use of on social and online media.

On the Edge: Living with Epilepsy

October 23, 2013 was a proud day for Epilepsy Ontario as we presented the Canadian premiere screening of *On the Edge: Living with Epilepsy* at the Li Ka Shing Institute in Toronto. In addition to the film screening, the evening, which was MC'd by Global TV reporter, Mark McAllister, included a panel discussion facilitated by Dr. Donald Stuss, CEO of the Ontario Brain Institute. Panel members included Lia Turner, Tina Turner, Dr. Suzanne Nurse, and Dr. Elizabeth Donner. *On The Edge: Living with Epilepsy* was more than an evening for community stakeholders, healthcare professionals, educators and the general public to experience the Canadian premier of this artistic and thought-provoking film; it was an opportunity to gain meaningful insights of how living with epilepsy affects individuals, family members and our society today.

Thanks to a generous education grant by UCB Canada, Epilepsy Ontario will be taking the film on a Road Tour in 2014 with screenings in Ottawa, Whitby and London.

Epilepsy Ontario launched its 'Education is Power' webinar series in 2014. Our goal is to build our online resource centre by making information about epilepsy available in an accessible format, online, 24/7, so people with epilepsy and their families, along with new volunteers and staff can access it at their convenience. Most webinars have been recorded. Be sure to check out the line-up of topics and speakers on our website.



On the Edge participants: L-R Joseph Stanislaw, Dr. Elizabeth Donner, Suzanne Nurse, Tina Turner, Lia Turner, Dr. Donald Stuss and Mark McAllister

Summerfest:

The Summerfest Camp program continues to make a big difference in the lives of children and youth who attend the program. In 2013, 13 campers headed off to Camp Couchiching for a fun-filled one or two week vacation at Camp Couchiching where counselors made sure campers felt welcomed and included. Summerfest provides sponsorship to families to help cover the cost of camp. They are learning life-long skills, increasing their self-esteem and self-confidence, and all the while having fun. Here's what some parents had to say:

"...to rely on others that she [name of child] doesn't even necessarily know, and to have faith that that community is going to be able to provide, you know, the best care possible for your child, I think is something that definitely helps you as a parent to let your kid have some of that independence..."

"...I'm gonna say it in the way that [child's name] explained it to me, he said mom you go there and there is no illness, there is just people. There's just kids who want to be accepted, and he said that you get a strength that you never knew you had, and they explain it a lot different than you mom, and a lot different than other people, and they let me know that I'm special no matter what..."

Epilepsy Ontario is grateful to its donors for their generous support of this program. For some young people this sponsorship makes the difference about whether they are able to go to camp at all.

Provincial Programs:

OBCL Epilepsy Scholarship:

Thanks to the generosity of OBCL Ltd., the OBCL Epilepsy Scholarship was pleased to support six recipients.

Congratulations
to the following:

OBCL Epilepsy Scholarship Awards:

Alexander Johnson
Kirsten Leusink
Katelyn Lewis

Continuing Studies Award

Suzanne McGuire

President's Award of Distinction

Chloe Gallagher
Tori Gleason



L-R Suzanne McGuire, Alexander Johnson, Kirsten Leusink, Chloe Gallagher

Toronto Waterfront Marathon

On October 19, 2013 walkers and runners tied up their laces to participate in the Scotiabank Toronto Waterfront Marathon in support of Epilepsy Ontario, Epilepsy York Region and Epilepsy Halton Peel Hamilton.



Research:

EpLink:

EpLink, the research program funded by the Ontario Brain Institute (OBI), has been renewed for a second phase of funding. It will receive \$1.5M per year for five years (2013-2018). This is unprecedented funding for epilepsy research in Ontario and was greeted with great hurrahs! The EpLink research program is unique in that not only are there researchers seeking better care and treatments, but there are also researchers who are looking to improve quality of life for people with epilepsy. Epilepsy Ontario commends the team at EpLink for being open to charting new ground.

Looking to the Future:

So where do we go from here? The board of directors has implemented a process to update the 2011 - 2014 strategic plan. There are a vast number of priorities and limited resources, so the board is grappling with how to sharpen our focus on activities that will have the most effective and sustainable impact.

Of course, developing sustainable funding for the provincial organization and where possible, local epilepsy organizations, is an ongoing challenge. We now have a provincial epilepsy committee which includes executive directors and fundraising staff that is exploring opportunities.

Epilepsy Ontario recognizes that it is time for change. It is time to do things in a new way so together, we can build a strong and viable community-based agency system that educates, informs and supports people living with epilepsy and their families across this province. We are committed to working with epilepsy agencies, donors and stakeholders over the coming months and years to determine the most effective and viable way to best serve people with epilepsy. We welcome this challenge and invite everyone to join us as together, we lead the way.

With Heartfelt Thanks!

Epilepsy Ontario replies 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.

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Events, Foundations, Community & Employee Groups:

Rx&D - Canada's Research-Based Pharmaceutical Companies
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Hydro One Employee's & Pensioner's Trust Fund
Liquor Control Board of Ontario
Langham Hospitality Group
Lonsdale Women's Institute
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Ontario Telemedicine Network
Ontario Trillium Foundation
OPSEU - Local 421
Shoppers Drug Mart, Life Foundation
Suncor Energy Foundation
The Catherine & Maxwell Meighen Foundation
The George Lunan Foundation
The Richardson Family Golf Tournament
The S. M. Blair Family Foundation
The Toronto Star Fresh Air Fund
UCW Toronto Conference
United Way - Centraide Ottawa
United Way of Greater Toronto

Executive Committee

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

Gino Piazza, President
Kirk Nysten, Vice President
Jasmatie Suchit, Treasurer
David Zelek, Secretary

Elisa McFarlane, Past President
Melanie Jeffrey, Director
Bruce Milburn, Director
Lawton Osler, Director

Volunteers

We also raise our glass to the following volunteers (one-time and ongoing), summer and placement students, staff and contractors for their dedication and contributions to the mission of Epilepsy Ontario. They are:

| | |
|----------------------|-------------------------------|
| Anita Allen | Mary McDougall |
| Jana Azizeh | Suzanne Moffatt |
| Carol Benn | Gena Meldazy |
| Brittney Black | Donna Pammer |
| Geoff Bobb | Dalene Pillai |
| Jim Burnett | Jay Polczer |
| Brenda Calleja | Mary-Alice Policicchio |
| Kelvin Chan | Paul Raymond |
| Priyanka Choudhory | Cathy Ryan |
| Jeff Coburn | Celia Schepp |
| John Cvijanovich | Kimberley Scott |
| Kelly Cvijanovich | Lisa Shim |
| Dr. Elizabeth Donner | Kyle Sing |
| Charlene Ford | Dr. Donald Stuss |
| Melissa Ghelman | Lia Turner |
| Tom Harmond | Tina Turner |
| Susan Harrison | Faith Valliere |
| Olga Lapshinova | Anika Wallia |
| Rhonda Latendresse | Joanne Welton |
| Florence Liberski | Kristin Welton |
| Katie Lundy | Staff at Universus Media Inc. |
| Mark McAllister | especially Todd Phillips & |
| Dianne McKenzie | Niel Hiscox |
| Cynthia Milburn | Students of the 2013/14 |
| | Humber College Fundraising |
| | Program |

Staff and Contractors:

Gula Aitkulova, Administrative Assistant
Suzanne Nurse, PhD, Epilepsy Information Specialist
Nikki Porter, PhD, Project Manager, From Isolation
to Inclusion
Jeanette Schepp, Resource Development Coordinator
Rozalyn Werner-Arcé, CAE, Executive Director

Affiliate and Partner Agencies in Ontario:

Epilepsy Durham Region
Epilepsy Grand Erie
Epilepsy Halton Peel Hamilton
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)

Allied Memberships and Partnerships:

Camp Couchiching
Canadian Epilepsy Alliance
Neurological Health Charities Coalition – Ontario
Working Group
Ontario Brain Institute – Non-Profit Advisory
Committee
Parents Association Advisory Council on SEAC
(PAAC on SEAC)

Every effort has been made to recognize volunteers, individuals, foundations and corporations who have generously supported Epilepsy Ontario and its mission between January 1, 2013, and December 31, 2013. Please accept our apologies should any errors or omissions have occurred and notify us at 1.800.463-1119.