



*Serving Ontario  
Since 1956*



---

# 2012 Annual Report





## Message from the President

AGM's are often a time of reflection, but reflection has little value unless it is turned into learning and actions. In 2011 we finalized Epilepsy Ontario's (EO) four-pillar strategy – knowledge base, research, provincial programs and advocacy and started to align our activities to these. Central to all of this is a shared mission among all epilepsy agencies and volunteers – to improve the lives of those affected by epilepsy.

A guiding principle was penned at the same time and it will continue to frame the roll out of the strategy.

*EO and agencies each bring unique strengths to the table and can benefit by working together, presenting a unified front with a stronger, consistent message. Accordingly, EO will seek positive, collaborative relationships with the agencies.*

EO needs to be able to deliver its strategy in a changing world for non profits. I'd like to borrow from a recent article written by Jack Shand for Charity Village on the trends that are becoming mainstream as these are likely to influence the epilepsy sector.

### **Communication:**

We should not underestimate both the value and power of communication to make or break a charity. Donors increasingly rely on websites to inform their philanthropy. The Canada Revenue Agency (CRA) routinely tells the world when a charity loses its charitable registration. While the growth of social media as a vehicle to engage stakeholders is exciting, it can be a tremendous resource drain on already strapped NFP's.

One size does not fit all – which means EO will need to consider which size and what outfit it should be wearing and can afford! What is clear is the potential to leverage the communication platform collaboratively across epilepsy agencies or indeed outside our sector, to make best use of our collective scarce resources. Let's put that on the agenda.

### **Transparency:**

Transparency simply means doing our work in such a way that we would be comfortable for it to be published on the front page of the Globe and Mail. Both our regulators (CRA and the Public Guardian and Trustee) and our members and other stakeholders are expecting to have a more direct voice and real influence on our decision making. This is a good thing and is one way for EO to distinguish itself from thousands of other causes vying for the same dollar.

### **Governance:**

“Accountability and scrutiny breeds more attentive governing boards”. The days of kitchen table boards with well meaning, but uninformed board members are over. EO has come a long way in this area, including education on roles and responsibilities and an

open transparent board nomination process. Our next step is to tackle our bylaws which are more than 20 years old and out of step both with where regulation is taking us and effectiveness in delivering our mission. The bylaw review will be a collaborative discussion with the agencies.

**Mergers:**

Return on investment (ROI) has been a fixture in the for profit world. More recently, in the giving patterns of corporate donors, they seek a better ROI in how they give by supporting one or two highly effective non profits rather than scattering resources across several.

As an epilepsy community, we need to discuss this issue and determine how we can be most effective in delivering services to clients and be accountable to donors and funders. In the fall, EO will invite affiliate and partner agencies to participate in a broad discussion on the structure of the epilepsy sector in Ontario.

**Demand for Services:**

This is a two edged sword. In some cases, where government or other major funders e.g. United Way were major supporters of funding or programs, this is now falling away leaving agencies to fend for themselves and pick up the services with less dollars. In other areas, government has decided to step in, for example the Ontario Brain Institute research initiatives or the provincial epilepsy strategy. In that instance, agencies will need to reframe how they organize themselves to be part of those initiatives or they risk missing out and find it even tougher to deliver their services.

As Bob Dylan penned 50 years ago: “Times, they are a-changing”. EO intends to be a supportive, collaborative leader in this new arena.

*Elisa McFarlane*

*President, Executive Committee*



## **Message from the Executive Director**

2011 has been a year of significant change at Epilepsy Ontario. As we pay tribute to those who helped the provincial organization grow, we look to a bright future with new partnerships, opportunities and challenges.

### **Honouring the Past**

After 28 years at the helm, former executive director, Dianna Findlay, retired May 31, 2011. Dianna dedicated herself to building the Ontario epilepsy community and providing expert information and valued support for people with epilepsy. She nurtured dozens of local epilepsy agencies, some of which took root and have grown to become strong, thriving organizations providing much-needed supports and services in their local communities. Dianna's legacy of determination, perseverance, commitment and passion for improving the lives of people with epilepsy will be long felt at Epilepsy Ontario.

The torch is also being passed at the volunteer leadership level too. In April 2012, Dr. McIntyre Burnham announced that he will be stepping down from the Executive Committee. Dr. Burnham has served Epilepsy Ontario for nearly 20 years in a number of capacities including serving as president twice!

Dr. Burnham's leadership will be missed, but we take satisfaction knowing that he will continue to serve the epilepsy community in his capacity as president of Epilepsy Canada and through his continued teaching and research at the University of Toronto, and as co-leader of the Ontario Brain Institute Epilepsy Research project.

### **The Year in Review**

Being new to Epilepsy Ontario, I spent the past year learning much about the work of the provincial organization and the local epilepsy agencies. The work at both levels truly makes a difference in the lives of people:

#### **Provincial Programs:**

**Affiliate and Partner Agencies:** It has been a pleasure visiting each of the affiliate and partner agencies. It is clear that the staff, boards and volunteers have a passion for the work that they do and in spite of funding challenges, they are creative in developing and delivering supports and programs in their respective communities. For example, the Epilepsy Support Centre developed the [Brain Matters: An Introduction to Neuroscience](#) resource to be complementary with the grade 12 science curriculum and has trained science teachers in more than six school boards to deliver it to students. They are also mentoring other epilepsy agencies to do the same in their communities too. When the Hamilton agency disbanded, Epilepsy Halton Peel stepped up to the plate to ensure that people in Hamilton were not without service and has since changed its name to Epilepsy Halton Peel Hamilton. Epilepsy Niagara recently received funding for a pre-employment program. In agencies where there has been a change in leadership, the new staff have brought new energy and new ideas.

There is still a large part of the province where agencies do not exist. Epilepsy Ontario continues to provide information support through its 1-800 line and online.

**Summerfest:** The 2011 summer camp program provided 24 children, aged 7 – 15, a wonderful residential camp experience. The youth had tons of fun swimming, sailing, enjoying campfires, and most of all, making new friendships, some of which may last a lifetime. At the same time, parents enjoy a brief respite with peace-of-mind knowing that their child has access to expert nursing care. Epilepsy Ontario works in partnership with *Camp Couchiching*, *Anita Allen at SickKids* and *Epilepsy Toronto* to provide this unique experience and looks forward to continuing to build and grow this partnership. We would like to acknowledge *The Toronto Star Fresh Air Fund* for their continued and generous support of the summer camp program.

**OBCL Epilepsy Scholarship:**

In 2011, the OBCL Epilepsy Scholarship provided 10 deserving students each with a \$1,000 scholarship. Members of the Selection Committee appreciate the time and effort that the young people put into the application process and wishes these students all the best of success. It's clear from the submitted essays that youth are not letting epilepsy run their lives; indeed, they are in control and acknowledge that epilepsy is just one facet of their whole life.

Epilepsy Ontario wishes to thank *Osler Business Consulting Limited* for its generosity in continuing to support this important program.

**Advocacy:**

The provincial government formed the Social Assistance Review (SAR) Commission to undertake a review of all social assistance programs. Epilepsy Ontario provided input to their summer consultation. Working with Epilepsy Toronto, we ensured that the voices of people with epilepsy were heard by surveying people with epilepsy who have had experience with any social assistance program and reported their feedback and the overall results to the Commission.

Queen's Park Action Day 2011 was a success. Volunteers and staff from Epilepsy Ontario, epilepsy agencies and the Epilepsy Cure Initiative enthusiastically visited with MPPs and their staff to provide education about the issues related to epilepsy. There was a very positive feeling about the day and that it would lead to even greater possibilities. Planning for the 2012 Action Day began in May and a small working group was formed to focus on the key messages.

For the first time ever, a Provincial Epilepsy Care Strategy for Refractory Epilepsy has been proposed to the provincial government. This has the potential to have significant impact on the lives of Ontarians with epilepsy. The implementation of a coordinated care strategy will include standards and guidelines of care, training for doctors and other professionals, and the establishment of four regional epilepsy centres throughout the province. When the Ontario Health Technology Advisory Committee

(OHTAC) sought comments, the epilepsy community responded overwhelmingly. This is largely due to the efforts of local epilepsy agencies to get word out. If approved, the epilepsy care strategy will prove to be one of the most significant milestones in the care of epilepsy. We are hopeful that the government review processes will result in improved care for people with epilepsy *and* will recognize the necessary supports provided by epilepsy agencies.

### **Epilepsy Conference Toronto**

In October, John Park and Ellen Novack organized and hosted the Epilepsy Conference Toronto. The purpose of the conference was to provide information about the Andrews-Reiter Approach, a technique that has helped some people learn to control their epilepsy. Epilepsy Ontario was pleased to be invited to be a partner with the Conference as we believe that everyone should have access to information about different types of treatments so that they can make informed decisions about their own epilepsy.

### **Information and Referrals:**

Refreshed Website: The Epilepsy Ontario website was given a face lift. It is based on user-friendly technology enabling information to be posted in a timely manner. It will also be used to provide awareness and education about issues related to epilepsy.

### **Risk Management and Resource Development:**

An administrative review was undertaken in the fall to seek cost savings and ensure that we are utilizing limited resources most effectively. As a result, there was a re-structuring and re-alignment of roles and responsibilities including outsourcing the bookkeeping and human resource functions and a new position was created, Resource Development and Volunteer Officer. This new role will work with the Resource Development Committee to increase revenue for Epilepsy Ontario and develop new funding resources for both the provincial agency and local epilepsy agencies.

### **Looking to 2012**

The stars seem to have aligned for epilepsy. Between the Provincial Epilepsy Care Strategy, the OBI-funded Epilepsy Research Initiative, increased media coverage, and provincial strategies to bring greater attention to the issues, the future looks promising for those living with epilepsy and the agencies that support them.

Epilepsy Ontario is a member of the Canadian Epilepsy Alliance and there is evidence that a stronger, coordinated national patient advocacy voice is growing.

Of course all of this is possible thanks to the outstanding support and superb efforts of the Executive Committee, volunteers, and staff. I am deeply appreciative for all your contributions.

*Rozalyn Werner-Arcé*  
*Executive Director*

## **Epilepsy Ontario – Our Thanks to You!**

Epilepsy Ontario gratefully acknowledges its partners and donors for their generous support in 2011. It is thanks to their generosity that Epilepsy Ontario is able to continue to deliver on the pillars identified in the strategic plan including services to individuals with epilepsy and their loved ones as well as to local epilepsy agencies:

### **Summerfest:**

Anita Allen – SickKids Hospital  
Camp Couchiching

Epilepsy Toronto  
Toronto Star Fresh Air Fund

### **Events, Major Donors and Funders:**

A & A King Family Foundation  
Anna & Edward C. Churchill Foundation  
The Guarantee Company of North America  
Human Resources Development Canada –  
Summer Work Experience  
Oak Lake Annual Golf Classic  
OBCL Business Consulting Ltd.  
Playing for the Kids Golf Tournament  
The Catherine and Maxwell Meighen  
Foundation

Run for Epilepsy  
Randies Wish Foundation  
6<sup>th</sup> Annual Ian Richardson Golf Classic  
Run for Epilepsy  
Suncor Energy Foundation  
Takla Foundation  
Trent Valley Sand & Stone Limited  
UCB Canada Inc.  
Harry & Anne Voortman

### **Allied Memberships and Partnerships:**

Canadian Epilepsy Alliance  
Neurological Health Charities Coalition – Ontario Brain Strategy  
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)

## 2011 OBCL Scholarship Recipients

Lindsay Bennett  
Julia Chriss  
Megan Judith Donnelly  
Johnathan Healy  
Joanna Marie Hearn  
Jasmyne Jagpal  
Alexandra Potvin  
Christopher Rychlo  
Cassidy Sankey  
Jennifer Ward

## 2012 OBCL Scholarship Recipients

Brooke Corner  
Danika Dupuis  
Chelsea Ellis  
Michel Leroux  
Jamie Morgan-Lynette  
Rahman Mohamed  
Mikaela Morrell  
Vanessa Orlando

### Executive Committee

Elisa McFarlane, President  
Kirk Nysten, Vice President  
Lawton Osler, Past President  
Gino Piazza, Treasurer  
Dr. McIntyre Burnham, Secretary  
Alex Dolan  
Howard Fletcher  
Dr. Taufik Valiante

### Staff

Rozalyn Werner-Arcé, Executive Director  
Gula Aitkulova, Administrative Assistant and Gaming  
Dr. Suzanne Nurse, Epilepsy Information Specialist  
Rose Pacione, Resource Development and Volunteer Officer



1 Promenade Circle  
Suite 308  
Thornhill, ON L4J 4P8  
905-764-5099 / 1-800-463-1119 (Toll-Free in Ontario)

