

A close-up, slightly blurred photograph of a field of lavender flowers. The flowers are in various stages of bloom, with some in sharp focus and others blurred in the background. The colors range from light purple to a deeper lavender. The stems are thin and green.

eO Epilepsy Ontario
ANNUAL REPORT 2009

PRESIDENT'S REPORT

June 23, 2010



I have two topics I want to briefly discuss: governance and the ripple effect and growth of our scholarship program.

Governance: During the past year, we at Epilepsy Ontario have been revising our By Laws and will be finalizing these changes once we have completed a retreat in August to work on a Strategic Plan. Why are we doing this? The Strategic Plan will determine strengths, challenges and opportunities of Epilepsy Ontario and set forward a plan of how we intend to deliver our mission. A revision of the By Laws will allow Epilepsy Ontario to assist our Agencies better by being more in tune and in alignment with their areas of need. For instance, we have been asked to assist several agencies with their human resources and governance issues. The circumstances surrounding these issues have encouraged us to revisit how we will conduct the business of the provincial office, as supported by our by-laws and policies, procedures and objectives. Concurrently, we are reviewing our processes to ensure everything is in sync. It is very important that we, Epilepsy Ontario and the Agencies, are realistic about our goals and what can be achieved by building new partnerships between our organizations.

Scholarship ripple effect: I was left with emotion and just a little pride after I read the essay from the Dandelion Person.

Who is the Dandelion Person? In 2008, the OBCL Scholarship review team was presented with an essay about living with epilepsy that won a scholarship. This essay used the parable of a healthy person resembling a dandelion that did not need special attention and someone living with epilepsy resembling an orchid that required tender, loving, care 24-7.

The author of that essay, Sally, is also the author of the small booklet called "Siblings and Epilepsy", published in our newsletter Sharing. This is a guide for parents and the siblings and associated family members of those who have been touched with epilepsy. She explains how epilepsy can affect all family dynamics especially regarding the siblings. What stands out for me and what I will remember most are Sally's words:

"There's bravery in looking that in the face. No matter how you feel or what you do, no matter if you say, "I give up", or want to, or mean it, or lose your mind – no matter

how many times – you're brave for being here."

We received one response from a parent of a young man living with epilepsy who shared the comment that, after reading Sally's paper, she realized that this was the first time she had ever seen such information in print and congratulated Sally for her bravery in sharing her insights. "Siblings and Epilepsy" is on our website at www.epilepsyontario.org.

As most of you know one of my favourite initiatives is the OBCL Scholarships. In 2009 we presented twelve OBCL scholarships. It was decided to review the criteria and increase the number of scholarships available to make them more accessible to a broader group of applicants. New categories include - one Margaret Burka award for someone indirectly affected by epilepsy, such as a sibling; one artistic merit award for a student who excels in artistic/visual/creative expression rather than a written essay; one continuing studies award for a student over the age of 21; and, an award of excellence for a student who has exceeded in exceptional circumstances. We are delighted that this will increase the total number of scholarships available for 2010 to 14. The award winners will be announced later in the summer.

I would like to thank the staff of Epilepsy Ontario, specifically Dianna Findlay, our Executive Director, whose support has been invaluable. Also, I have been very fortunate to work with a dynamic Executive Committee whose members are: Dr. McIntyre Burnham, Past President, Ms. Jacqueline Medley, Treasurer, Ms. Elisa McFarlane, Secretary, Dr. Paul Hwang, Dr. Taufik Valiante, Gino Piazza, Kathryn Hum and Fahim Kaderdina, for their support and leadership over the past year. I look forward to the challenges of the upcoming year.

Epilepsy is so much more than just seizures. More and more, it is becoming clear that there is much untold about epilepsy, seizures, co-morbidities, and wellness. Epilepsy Ontario is part of this story, providing provincial programs and services and assisting agencies and people living with epilepsy in our province. Our staff and volunteers at Epilepsy Ontario continue to be an integral and pivotal part of the story to help people living with epilepsy in our province today.

Respectfully submitted.

Lawton Osler
President
Epilepsy Ontario

REPORT OF THE CLINICAL CARE COMMITTEE

June 21, 2010



The mandate of the Clinical Care Committee is to consider ways in which clinical care for epilepsy patients in Ontario could be improved. We hope to evolve schemes that may eventually be promoted by Epilepsy Ontario.

The Committee this year was chaired by Mac Burnham, and consisted of Mac, Kathryn Hum (members of the Executive Committee) and Dr. Kirk Nysten (lay member). Advisers included Dr. Paul Hwang, Dr. Taufik Valiante (members of the Executive Committee), and Ms Heather Walker (NHCC Neurological Health Charities Canada). The Committee met roughly once a month.

Over the years, the Committee has considered several plans for improved care, including Comprehensive Care (team approach for a spectrum disorder) and Integrated Care (case management by a nurse practitioner in each LHIN – Local Health Integrated Network). A nearly successful effort to establish Comprehensive Care in Toronto was de-railed by the installation of the LHIN system. Also, the Committee has come to feel that the Integrated Care plan is impractical – both because of the LHIN system, and because of a lack of support by some of the regional associations.

The Committee is currently working on a new initiative - a plan for “Epilepsy Care Ontario”. This is a fairly modest plan, related to the present institution Cancer Care Ontario, a semi-governmental organization that oversees cancer care in the Province.

Cancer Care Ontario essentially represents a governmental approach to the management of one chronic disorder – cancer. A similar approach might be extended to other chronic disorders, such as epilepsy. Cancer Care Ontario already has a department that oversees kidney care in the Province. We would like to see them create a new small department devoted

to epilepsy care.

The gist of the scheme would be to have a small department in Cancer Care Ontario that would handle inquiries about epilepsy. The departmental phone number /email address would be advertised throughout the Province, and people with seizures would be encouraged to get into contact. They would then be advised of their medical treatment options, and of the nearest epilepsy treatment centres. They would also be referred to the local regional associations for non-medical support. In cases of job loss related to seizures, they would be appraised of their legal rights. They would also be advised on possible sources of financial support for families coping with epilepsy.

There would be follow-ups at regular scheduled intervals, with the Epilepsy Care Ontario staff essentially functioning as case managers for people with seizures.

At present, the Clinical Care Committee is working (in concert with the University of Toronto Epilepsy Research Program or “UTERP”) on a Position Paper – a background document designed to answer any questions about epilepsy that politicians/ bureaucrats might ask when we present our plan for Epilepsy Care Ontario. This work is being carried forward in Dr. Burnham’s office by two summer students, Mr. Alex Dolan (supported by Epilepsy Canada) and Mr. Thomas Drag (supported by UTERP). It should be completed by September 2010 at which time it will be presented to the Epilepsy Ontario Executive Committee for approval. Subsequent to that, it is our hope that Epilepsy Ontario will present the Position Paper to the Provincial government, along with a proposal for Epilepsy Care Ontario.

Our Position Paper will argue that improved epilepsy care could be obtained at no extra cost to the government.

Respectfully submitted,

W. M. Burnham
Chair
Clinical Care Committee

EXECUTIVE DIRECTOR'S REPORT

June 22, 2010



There are over 1.5 million reasons why we help! This is the estimated number of people living in Ontario who are directly or indirectly affected by epilepsy and seizure disorders. Ontario is home to 1/3 Canadians or 13 million people with 1% or 130,000 people directly living with epilepsy and seizure disorders. For every person living with epilepsy, the impact of their seizure disorder affects about 12 other people, or 1.5 million people. Our mandate is to provide support programs and services for these individuals as well as to provide educational materials to dispel the many myths and misconceptions about epilepsy for everyone in Ontario.

I would like to take this opportunity to extend my sincere appreciation and gratitude to our full time staff - Rose Pacione, Administration, Gula Aitkulova, Gaming and Direct Mail and joining us in December, Karla Amirault, Communications. In addition, Thomas Cheng, Angela Chen, Craig Bonk helped on a part-time basis. A special thanks to Jennifer Giffen our internship student from Seneca and our three summer 2009 students Tara Hill, Jessica Fenson, and Angela Chen. We would not be able to provide all of our programs without our dedicated volunteers; Nancy, Iris, Lawrence, Rose, Carol and her team who contributed over 3,000 hours towards our bingo, summer camp, scholarship, events, direct mail and general office help. A special thanks to Denis Morrice and Heather Walker. Denis has been representing us on the Neurological Health Charities Canada (NHCC) and attended the annual Canadian Epilepsy Alliance (CEA) last October in Saskatoon on our behalf. Heather was our lead volunteer in the Ontario Neurological Strategy (ONS) portion of the NHCC and has since, on recommendation from Denis replaced him as our lead on the NHCC. Heather is an independent member of the CEA and represents them on the NHCC.

MARCH AWARENESS MONTH

Purple Day, March 26 - Purple Day for Epilepsy is now celebrated around the world. Events in Ontario included numerous fundraising receptions and dinners, as well as lighting of the CN Tower and Niagara Falls in purple. Purple Day was founded in 2008 by a nine year old Cassidy Megan of Nova Scotia and this grassroots initiative is now celebrated around the globe by people wearing purple and spreading the word about epilepsy. EO launched the initiative on March 1st with our guest speaker, Sally Hudecki Walker reading her award

winning scholarship essay.

On March 31, 2009, Margaret Maye, a volunteer, arranged our first awareness day at Queen's Park. It was an opportunity to meet our members of Parliament, inform them about epilepsy and share ideas with partner agencies. It was decided that this initiative should be repeated as a kick-off for March events to be held on the first day of the month in 2010.

To further assist local community agencies with their March Awareness Communications, Epilepsy Ontario had agreed to contribute up to \$24,000.00 to Epilepsy Durham Region. These funds were used towards the salary to cover provincial march awareness events such as the illumination project – Toronto City Hall and Niagara Falls in purple lights.

COMMUNITY DEVELOPMENT FUND

On a one-time only basis, Epilepsy Ontario was able to award up to \$25,000 in five grants for affiliated agencies in Ontario. These grants enabled community agencies to expand and/or continue their client services programs that were affected by the financial downturn early in 2009. applicants review team were pleased to award \$5,000 to Seizure and Brain Injury in Timmins, Epilepsy Ottawa-Carleton, Epilepsy Resource Centre in Kingston and Epilepsy Huron Perth Bruce and an additional \$3,000.00 grant to Epilepsy Halton Peel. These funds enabled agencies to expand their community services or extend the reach of programs and services to surrounding areas to assist people living with epilepsy.. We were very pleased that we were able to help, especially during a time of funding constraints.

EPILEPSY AGENCIES

There were several changes in 2009 including the expansion of Epilepsy Halton Peel Region to provide programs and services in the Halton Region including the city of Burlington, previously in the Hamilton area. Early this year, Epilepsy Niagara turned over their registration numbers to Epilepsy Ontario. We were delighted that six months later Epilepsy Niagara has been re-formed providing direct client services under the leadership of a new board of directors with two full time staff and two contractual staff. Epilepsy Simcoe County also required some special legal and Human Resource assistance and is now starting to do some outreach into Duf-

ferin County. Epilepsy Waterloo Wellington was helped through some challenging times with former board and staff people. We are delighted that the Epilepsy Support Centre in London is now providing direct client services in Windsor/Essex County. Kingston has expanded services into Quinte and Huron Perth Bruce is now providing services in Grey County and Ottawa is now responsible for the Cornwall area. Epilepsy Ontario is responsible for the ongoing programs and services in the un-organized areas of Rainey River, Thunder Bay, Sault Ste. Marie/Algoma, Sudbury/Manitoulin, Parry Sound/Muskoka/Haliburton, and Grand Erie.

Epilepsy Ontario was pleased to host two Ontario Agency meetings. The last meeting was to help arrange French translation of the Neuro Science, Grade 12 materials prepared by the Epilepsy Support Centre in London. The provincial office will disseminate these materials to all the boards of education in the un-organized areas of the province. We are also happy to be included in the branding committee organized by Epilepsy Toronto and continue to partner with Epilepsy York Region and Epilepsy Peterborough.

Affiliated agencies: Timmins, Simcoe, Peterborough, Ottawa, Kingston, York, Huron/Perth/Bruce/Grey, Hamilton Niagara, Waterloo/Wellington, Halton/Peel – 11

Non affiliated agencies: Toronto, London, Durham – 3

Non organized areas: Thunder Day, Sault Ste. Marie/Algoma, Sudbury/Manitoulin, Parry Sound, Muskoka, Haliburton, Grand Erie

PARTNERSHIPS

Neurological Health Charities Canada - Four years ago we were approached by the Parkinson Group to help form the Neurological Health Charities Canada (NHCC). The Ontario Neurological Strategy was part of this committee and we would like to thank both Heather Walker and Denis Morrice for their initiatives in keeping epilepsy a forefront during the meetings for this group over the years.

Canadian Epilepsy Alliance - We are delighted to be involved with the Canadian Epilepsy Alliance (CEA), a partnership for epilepsy agencies from coast to coast. Epilepsy Ontario has been asked to chair the membership committee and also serves on the literature committee.

Epilepsy Canada - Epilepsy Ontario is also a member of Epilepsy Canada (EC) and supports their epilepsy research initiatives.

FUNDING

The Richardson family held the fourth annual Richardson golf tournament on behalf of Epilepsy Ontario. We appreciate all the volunteer hours from this family, especially Ian for his commitment and support to raise awareness about epilepsy and funds for our children's summer camp program.

Direct Mail – still waiting for some final stats

PROVINCIAL PROGRAMS

Scholarships – The criteria for the scholarships was changed in December 2009. It was decided that the criteria should be reviewed and the number of scholarships increased. New categories include 1 Margaret Burka award for someone indirectly affected by epilepsy, one artistic merit award for a student who excels in an artistic visual creative expression rather than a written essay, one continuing studies award for a student over the age of 21, and one award for excellence for a student who has succeeded in exceptional circumstances. The total number of scholarships available for 2010 will be 14.

Summerfest – Over the years we have seen campers enter the camp as young children and eventually become leaders at the camp. Last year, to our delight five of our campers completed this cycle and added some new young campers. We continue to employ nurses from our partner the Hospital for Sick Children in Toronto (HSC). A special thanks to Anita Allen from Hospital, Andre Martin from Camp Couchiching, Fatima Santos from Epilepsy Toronto and our volunteer at the provincial office, Nancy Kimura for their help in providing the optimum quality of camping life for children living with epilepsy.

Educational materials

Several brochures have been revised and we are currently editing the Women & Epilepsy Brochure as well as writing new brochures for Diagnostic Testing and Epilepsy and Epilepsy and the Gene. We continue to work with Information Display Systems (IDS) at an approximate cost of \$15,000.00 per annum. This provincial program permits us to distribute our educational pamphlets three times per year to all the medical waiting rooms.

Finally, I would like to take this opportunity to thank our President Lawton Osler, and all the members of the Executive Committee for their leadership and support towards improving the quality of life for all Ontarians affected by epilepsy and seizure disorders.

Respectfully submitted,

Dianna Findlay
Executive Director
Epilepsy Ontario