ANNUAL REPORT 2013

EPILEPSY
Toronto

See the Person

President's Message

The past year has been a very interesting one for Epilepsy Toronto, with some significant achievements and growth, combined with some challenges on the funding front. Our core programs and services continue to focus on providing support to our city's epilepsy community. Throughout this report you will see highlights from a year we can take pride in as we continued and expanded our services for adults, children, youth, and job seekers.

While our financial position remains strong and stable, you will note from our annual financial report that we ended the year with a fiscal deficit compared to our annual objective of ending in a breakeven or better position. We have been very fortunate over the past number of years as our fundraising activities have exceeded expectations, leading to a number of annual surpluses which we have set aside for our long term vision of purchasing a permanent home for the Agency.

You will know from last year's Report that your Board of Directors made the decision to move our signature fundraising events, Scotiabank BuskerFest and BuskerBall, to Yonge Street – the biggest stage in Canada. The long term prospects in our new venue and with our partner, the Downtown Yonge Business Improvement Area, are very exciting indeed, however, and not unexpectedly, the move resulted in significant new costs to put on the events. This resulted in net contributions being below what we had budgeted, and led to our financial deficit for the year. That said, with a record of close to 2 million attendees last August, and with the enthusiasm that was generated in the Yonge Street community when introduced to our renowned BuskerFest, we are highly confident that the financial contributions in the future will be greater than in the past, and will greatly help support the growth we see in the services that we are able to offer.

While most of Epilepsy Toronto's efforts are devoted to providing support at a very personal level that assists our clients in their day-to-day lives, an important part of our efforts focuses on public advocacy with governments and other organizations, with the goal of achieving the larger changes that can have an impact on our entire community.

As a proud member of the Canadian Epilepsy Alliance, we have been continuing our efforts to make the on-going problem of drug shortages a government priority. The frequent and continuing shortages of anti-seizure medications puts too many people living with epilepsy at serious risk and Canada is lagging behind in addressing this issue. While the problem is far from resolved, an NDP proposal to create a mandatory reporting system, and enhanced reporting guidelines brought in by the Conservative government in the fall of 2013 demonstrate that our proactive efforts are having a positive effect, and have gotten this important issue on the radar of policy-makers. We are continuing to work with our partners across the country in our push for development of an effective drug shortage management program.

Epilepsy agencies from across Ontario, including a team from Epilepsy Toronto, descended on the provincial legislature last October for our annual Epilepsy Awareness Day at Queen's Park, to further the case for increased funding and support for medical and social programs across the province that will help people living with epilepsy. I want to acknowledge the work of our friends at Epilepsy Ontario in coordinating the day's events and I am pleased to report that this push from Ontario's epilepsy community over the past few years has resulted in the very recent announcement that the Ontario government will be funding 21 new epilepsy monitoring beds in hospitals across the province, including 5 at Toronto Western and 4 at Sick Kids Hospital.

We are also indebted to Mark McAllister and the Global Toronto news team for their efforts to educate the public about epilepsy. Mark's bravery in sharing his personal experience with epilepsy in the lead-up to Purple Day 2013 has led to excellent on-going reporting by Global and has brought greater public awareness about epilepsy.

Finally, I want to thank our Board of Directors, staff, volunteers, donors, corporate sponsors and supporters who are essential to the work of Epilepsy Toronto; our successes in the past year and in the year to come would not have been possible without you.

Daryl Yeo
President
Epilepsy Toronto

Adult Services

Rochelle W. migrated to Canada from the Caribbean. During the process of adjusting to life in Canada, settling into a new job and making friends, she was hit by a curveball; she started having seizures. At the time she had no idea what these episodes were and like a lost soul she struggled to understand what was happening to her.

After seeing a doctor and numerous tests, she was diagnosed with epilepsy. What does this mean? How will this affect my life? With more questions than answers, Rochelle's journey began. This was a very challenging journey worsened by the fact that many in her cultural community held on to strange myths and misconceptions about epilepsy.

> ***"I feel that I now have a support system outside my family that knows what I am going through. I no longer feel alone."***

Work colleagues kept away from her and whispered about her 'strange' actions during complex partial seizures. She started to believe what some were saying about her; that she was 'weird' and 'not normal'.

Rochelle had what she recalls was a very embarrassing seizure while attending a relative's wedding. This proved to be a significant turning point in her life as a member of Epilepsy Toronto was also at this wedding and told her about the agency. She was encouraged to attend one of our support group meetings.

As she sat in that first meeting and looked around the room, she saw what looked like 'regular' people. As she listened to the group members share, she heard what sounded like 'her story'. Like a lightning bolt, she was hit by the realization that she was not alone and that she was not 'weird'; rather, she had a neurological condition that affected 1% of the population. Rochelle has not missed a meeting since that day and looks forward to attending the monthly meetings where she feels comfortable talking about her challenges and concerns.

150
clients participated in support groups during 2013

Support Groups are at the core of Epilepsy Toronto's services. Rochelle's story is not unique. Support groups provide opportunities for clients to connect with others who are also dealing with the impact of epilepsy. They are a forum for sharing information, coping strategies and resources; an environment to talk freely without feeling judged.

Our members have told us that they have formed lifelong friendships and have become more comfortable talking about their epilepsy since joining a support group. As one client shared, "I feel that I now have a support system outside my family that knows what I am going through. I no longer feel alone."

As Epilepsy Toronto works to meet the diverse needs of the epilepsy community, we continue to create and transform support groups so that new groups of people can come together and share their stories.

Adult Support groups include:

- **Adults with Epilepsy Connection**
- **Support Group for Professionals Living with Epilepsy**
- **Support Group for Partners of People with Epilepsy**
- **New and Expecting Moms Network**
- **Surgery Support Network**
- **Friday Recreation Group**
- **Support Group for Parents of Adults with Epilepsy**
- **Etobicoke Support Group & Information Sessions**

Children and Youth Services

Having two young children can be a challenge at the best of times, but when one of them experiences weekly Tonic-Clonic seizures, those challenges are magnified.

So when Scott and Jackie Spicer and their two children took part in Epilepsy Toronto's Annual Winter Retreat, they not only found comfort and made personal connections, they knew that they wanted to see something like it happen again during the summer months.

Scott and Jackie are avid summer campers and were determined to help champion a Summer Retreat. Thanks to their encouragement and efforts, Epilepsy Toronto jumped on board to create a summer version to complement our Winter Retreat!

New For 2014: Brain Matters Program at the TCDSB

Epilepsy Toronto has been working throughout 2013 to incorporate Brain Matters into the science curriculum of Toronto high schools. The Program uses epilepsy as a way to teach students about how the brain functions. By using more concrete examples and information, students can gain a better idea of how the brain works.

In early March 2014, thanks to the support of the Toronto Catholic District School Board's Program Co-ordinator, Epilepsy Toronto and Epilepsy Information Specialist Suzanne Nurse were able to successfully provide the Brain Matters Science program to 50 Grade 12 Biology teachers, introducing them to the world of neuroscience and how it relates to Epilepsy.

Toronto can now be added to the many school boards in Ontario that have already adopted this teaching resource. Epilepsy Toronto will continue to strive for the goal of now bringing this program to the Toronto District School Board Science program.

For one summer weekend, individuals and families spent their nights around the campfire, singing songs and making s'mores, and their days swimming, fishing, and canoeing in the sunshine along the Pigeon River in the Kawartha Lakes community. But the number one activity tackled at Epilepsy Toronto's first ever Camping Retreat was making personal connections within the epilepsy community.

> ***"It was a time to meet lots of new people, to hear about other's experiences dealing with epilepsy and, most of all, for great company, great food and lots of fun activities!"***

With the help, experience and perseverance of the Spicer clan, the Epilepsy Toronto Team successfully took 10 families to Emily Provincial Park where families were given the opportunity to meet and bond with other families in a fun and stress-free environment.

This year we visited over
100 classrooms
and educated over
2600 students
about epilepsy

They learned team building and self-confidence skills, and reduced the feelings of isolation that the family may experience because of a family member's epilepsy.

As one family member, whose daughter has epilepsy, said, "It was a time to meet lots of new people, to hear about other's experiences dealing with epilepsy and, most of all, for great company, great food and lots of fun activities!"

Diversity Outreach

Maralyn has never shied away from talking about epilepsy.

Despite the challenges she's faced living with seizures throughout her lifetime, she has always found a way to overcome them. She completed a university degree later in life and is always willing to talk to the media to help raise awareness about epilepsy.

Now, she is speaking out, not just as someone living with epilepsy, but as one of the growing number of seniors with seizures.

She has joined a team of seniors working with Epilepsy Toronto to develop resources to assist other seniors living with epilepsy. As Toronto's population ages, Epilepsy Toronto has recognized the need to develop resources and programs specifically designed to support seniors.

We are working to address the particular challenges faced by seniors, especially the increasing numbers of seniors who develop epilepsy later in life.

Key to developing this new program has been a series of focus groups and meetings with seniors to help us identify what kinds of information and support they need.

It is this kind of approach to outreach that Epilepsy Toronto finds the most successful; working with communities to recognize and develop the resources they need to help educate people about epilepsy.

Epilepsy Toronto produces epilepsy information in 15 languages

In 2013, the Cultural Diversity program continued to connect with groups that are often under-served in Toronto. With a focus on reaching out to the South Asian, Asian, and West Indian communities, we successfully partnered with local agencies and groups to educate their members about epilepsy.

Starting in 2014, the department has also begun focusing on the Italian, Somalia, Portuguese and Tamil populations by presenting to these groups with the assistance of interpreters. The response has been extremely positive.

We are seeing an increase in clients from diverse communities contacting us at Epilepsy Toronto for further assistance and support and with the help of community group partners we now produce epilepsy information in 15 different languages and have plans to continue growing that number in 2014.

Whether working with seniors, or language and cultural groups, Epilepsy Toronto is doing the work to reach the nearly 1-in-100 people living with epilepsy in our city.

New For 2014: Priority Neighborhoods

Epilepsy Toronto is working to target specific high-priority neighborhoods where we can again serve a community that may not be aware of all the access and support that Epilepsy Toronto provides.

Starting close to home, Regent Park is one of the first neighborhoods we want to reach.

Employment Services

It has been a rough ride for Tim. Even though he is well educated with many years of management experience, he has faced discrimination in the workplace and in the hiring process due to his epilepsy.

Working with Epilepsy Toronto's Employment Services, he has felt encouraged to stay positive and keep applying to suitable high-end jobs while being helped with potential employment leads.

Epilepsy Toronto Employment Services continue to provide one-on-one specialized employment counseling for job seekers with epilepsy. The program assists clients with resume and covering letter preparation, mock interviews and job seeking techniques while providing information on upcoming Job Fairs, current postings and other employment related resources.

Our Employment Program also actively engages employers and employees across the GTA in its educational efforts to provide training on what do if someone has a seizure in the workplace. In 2013, we witnessed an increasing interest in educating employees and managers about implementing accommodations for those experiencing seizures on the job. ET Employment Services continues to be active in supporting these negotiations with employers to ensure accommodations are put in place.

For Tim, the support he's received has gone beyond just job leads. Epilepsy Toronto has "pushed me out of my comfort zone," says Tim "to do a major presentation to Scotiabank and to other organizations and professionals where I discussed my health situation and not being able to find and maintain employment due to my disability, even though it does not play a significant role in my performance."

In 2013, Employment Services recognized the need for a Job Developer in conjunction with employment counseling services. The cultivation of employer contacts and employer relations was identified as a key component to providing a fuller spectrum of employment services to our clients. Starting in 2014, we will be working to not just help with job applications but to help find and create employment positions for our clients.

> ***"The Employment Services department has been tremendously helpful and resourceful. As a person with epilepsy, Epilepsy Toronto has been assisting and supporting me throughout the different stages of my life."***
>
> -Angela,
> Employment Services Client

It's this personal approach to support that many of our clients find most helpful. Says Tim, "Beyond employment related assistance, Alex (Keay, ET's Director of Employment Services) has been a great friend that I can talk to and she even visited me when I was trapped in the EMU for 2 weeks. I have really appreciated the services that I have received from Epilepsy Toronto Employment Services this past year on many levels."

New For 2014: Epilepsy@Work

2014 will see the release of Epilepsy@Work, our on-line resource for workplace epilepsy education. Including a realistic course to educate employers and coworkers about epilepsy, a unique interactive simulator that allows the viewer to respond to someone having a tonic-clonic seizure, and a video that shows the realities of someone having a complex partial seizure in public, Epilepsy@Work will be an innovative and useful tool for educating the public about epilepsy. Building on the distinctive nature of this resource, Epilepsy Toronto will be marketing the tool to employers and social media users alike.

Purple Day

"You should have seen their faces. I almost couldn't finish my talk because the kids just wanted to ask questions."

That was the feedback from just one of the many Epilepsy Toronto members who helped raise awareness across Toronto on Purple Day on March 26th.

The day saw Epilepsy Toronto members fan out across the city as part of our Ambassador Program to educate the public. Participants went to over 80 schools, workplaces, churches, community groups, and public locations as part of that day's world-wide effort to raise epilepsy awareness.

Epilepsy Toronto provided the resources, flyers, buttons, and swag to our members who reached out to the public, as well as providing stories and photos to extend our reach through social media. Some members combined the day's outreach events with fundraising for Epilepsy Toronto, hosting bake sales and church teas, and collecting donations at the office.

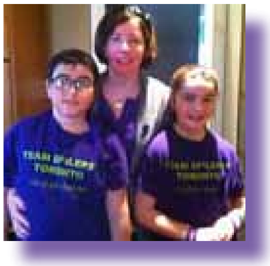
We also built partnerships with businesses from Rogers Communications to stores and restaurants in the Downtown Yonge Street area that will help us educate even more people about epilepsy in the future.

The results were amazing with an estimated 12000 people reached by our members that day.

More than just a public awareness campaign, this was a chance for our members and clients to talk openly about living with epilepsy to their neighbors, co-workers, friends, and complete strangers.

By joining with people across Canada and around the world, our members felt empowered to share their stories and experiences. Many members commented on just how open and interested people were to learn more, providing encouragement to our members to continue working to help change how the public understands epilepsy.

Epilepsy Toronto Ambassadors went to
7 Hospitals
26 Work Places
& 28 Schools
on Purple Day educating over
12000 People



Marathon

For Elijah and his family, the Scotiabank Toronto Waterfront Marathon has become one of the biggest days of the year.

One of the many incredible families that participate in the marathon, Team Elijah has been taking part for 4 years now, lacing up their shoes and bringing the whole family out to show their support for Elijah and Epilepsy Toronto.

The first year Elijah and his amazing mother Marilou were not able to attend because Elijah was recovering from his brain surgery. However, that didn't stop his father, siblings, and extended family members from walking for Elijah.

In 2013, Team Epilepsy Toronto grew to our largest team yet in the Marathon. More than just a fundraiser for Epilepsy Toronto, the Marathon sees out team members walking and running the 5K, half-, and full-marathon with their family and friends, meeting new people, and building a sense of community spirit because they are taking part in this event together.

Since that first year, Elijah has joined his continuously growing team of family and friends who take part in the walk, rain or shine. This past year Team Elijah expressed their love and support for Elijah by carrying placards with his face. So instead of 1 beautiful smiling Elijah, there were over 20!

This Year's
Team Epilepsy Toronto had
254 Members
Running and Walking
supported by
1015 Donors

We are so proud of all the members, families and friends who supported Team Epilepsy Toronto in the 2013 Scotiabank Waterfront Marathon and we can't wait for the sea of purple at Marathon 2014.

Scotiabank BuskerFest

2013 was a huge, landmark year for the Scotiabank BuskerFest in support of Epilepsy Toronto. Our move to our new home in the Downtown Yonge Street neighbourhood was a huge success.

The week began with our signature gala, Scotiabank BuskerBall, taking over the Mattamy Centre with a frenzy of sights and sounds that were a preview of the festival to come.

Scotiabank BuserkFest kicked off with the high-flying escape artistry of Rob Roy Collins 100 feet above Yonge and Dundas and over the next four days Yonge Street, from Queen to College, played host to 10 main stages and 5 music stages featuring more than 130 performers and attracting record breaking attendance!

With acts ranging from the stilt-topping Sauruses, the hula-hooping artistry of Lisa Lottie, and the trumpet-playing, tap-dancing Gabriel Angelo, this was the best collection of astounding performers yet.

After a year on the move, we are looking forward to settling into our new home and further developing our partnership with our new hosts, the Downtown Yonge Street BIA. We are also excited about plans for new Epilepsy Awareness initiatives in the works for this year's festival.

Thank You

Thank you to all of our donors, funders, and special friends who make Epilepsy Toronto's work possible. Without the support of the so many people, businesses, and organizations that help us in so many ways, we would not be able to provide services to Toronto's epilepsy community. Beyond the individuals, groups and companies listed here, we want to acknowledge the hard work and effort of all the volunteers who help Epilepsy Toronto year-round. Thank You!

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Black Creek Community Health Centre
Canadian Epilepsy Alliance
Canadian League Against Epilepsy
Carefirst Seniors & Community Services Association
Epilepsy Ontario
Military Trail Public School
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Ontario Chinese Health Coalition (Hong Fook Mental Health Association)
Ontario Disability Employment Network
Regent Park Community Health Centre
Rexdale Women's Centre
Ryerson University
Sick Kids Hospital
Society for Epilepsy Care and Awareness
South Asian Health Promotion Working Group
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EPILEPSY
Toronto

See the Person

We envision a world in which epilepsy is widely understood, and where those who live with it feel fully supported.

We build a caring community for people affected by epilepsy, through support, education and awareness.

We are solely dedicated to supporting people living with epilepsy to live well.

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