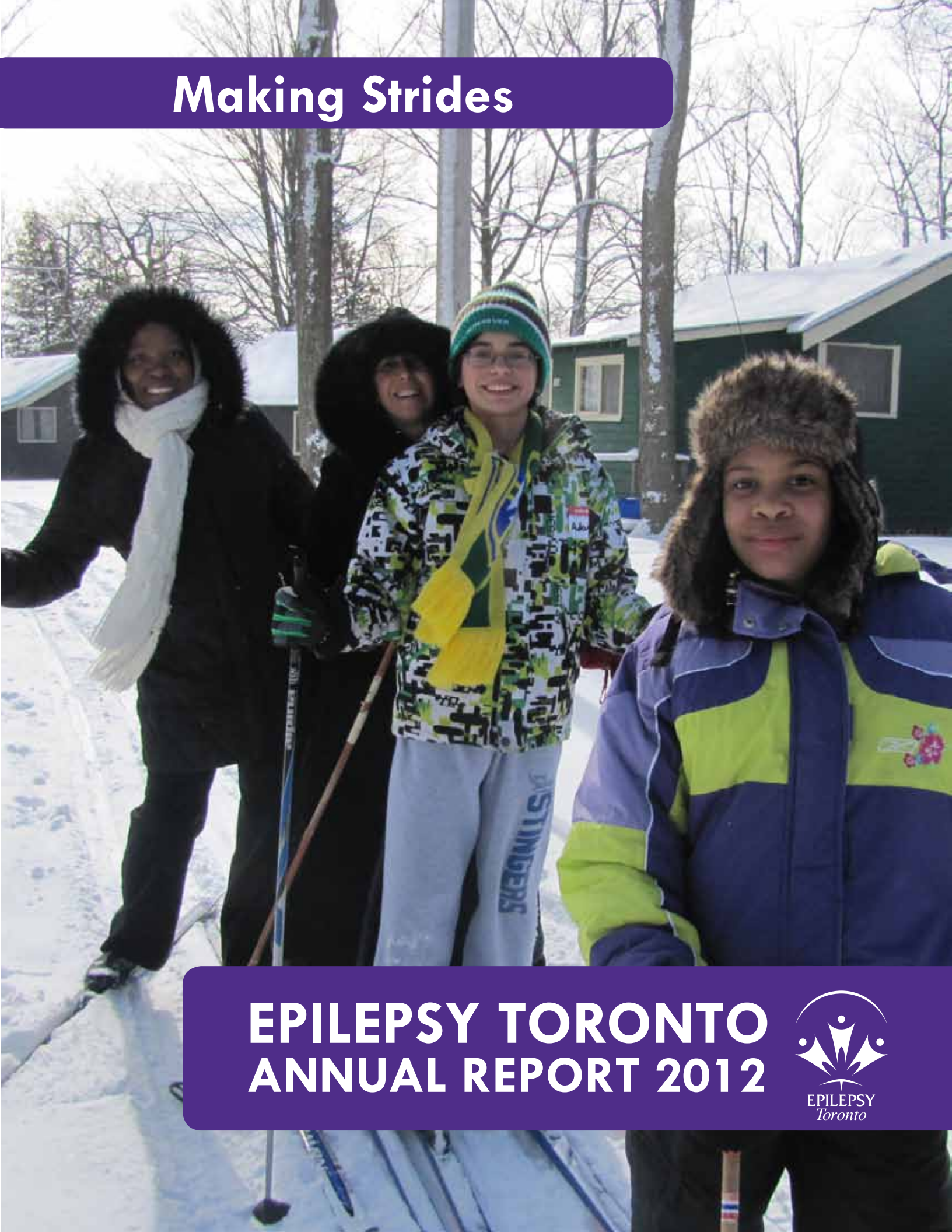


# Making Strides



**EPILEPSY TORONTO  
ANNUAL REPORT 2012**



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education

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For over 50 years, Epilepsy Toronto has been the place where Torontonians living with epilepsy can learn more about their condition, get the help they need, and be a part of a family of caring and supportive people. Epilepsy Toronto prioritizes individual needs, the importance of living as independently as possible and the benefits of community engagement. Our programs address all aspects of the epilepsy experience from the first diagnosis of a child, to the struggles that young people face, to adult needs such as employment and relationships.

## **Our Vision**

We envision a time when everyone with epilepsy in our city lives well with seizures. They take an active role in the management of their own health, draw strength from the agency family, and have every opportunity for full and barrier-free participation in a supportive and informed community at large.

## **Our Mission**

To promote health and well-being for all persons with epilepsy and their families in the Toronto community through information, support, advocacy and public education.

## **Our Values**

We value people's right to live with dignity as full participants of their community.

We believe it is a person's right to be informed and to participate meaningfully in their own health management.

We believe society has an obligation to be accessible to all its members and opposing of all discrimination.

We value self-determination and choice.

We believe that strength can be found in the ties that bind.

### **Epilepsy Toronto**

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 Epilepsy Toronto  Epilepsy Toronto

# President's Message



It has been an exciting year at Epilepsy Toronto with new opportunities to support our community while growing and expanding our existing programs and activities.

Our financial position remains strong, allowing the agency to continue providing the services and support that Toronto's epilepsy community needs. Our single largest source of funds continues to be Scotiabank BuskerFest, attracting over a million visitors in 2012.

It is on the strength of this continued interest in the festival that we recently announced that the 2013 Scotiabank BuskerFest will be moving to an even bigger venue: downtown Yonge street, the longest, most vibrant street in our city. This exciting new location positions Scotiabank BuskerFest as the single largest epilepsy awareness event in the world.

A significant part of Epilepsy Toronto's efforts over the last year has been in the area of public awareness and education. Whether working in partnership with other community agencies to train their staff about epilepsy or working alongside our national partners to educate the public about the on-going issues faced by our community, we have been successful on multiple issues.

This year's Purple Day was another resounding success with opportunities to educate the public about epilepsy ranging from an art competition at York University, to quizzes and bake-sales at Toronto hospitals, and volunteer teams at Union Station and in the PATH directly engaging the public. Purple Day continues to be an important opportunity to raise public awareness about epilepsy, both here in Toronto and across the country. This year's Purple Day was made even more exciting with March 26th being officially recognized by Parliament as the official day for epilepsy awareness in Canada.

I want to acknowledge the efforts of Epilepsy Toronto member Mark McAllister for his leadership in spearheading Global Toronto's *Inside Epilepsy* news series in March. Mark was willing to not only share his experience with epilepsy with the public, but to highlight the variety of on-going issues faced by those living with seizures. I know that his work, and the support he received from Global News and Shaw Media, has been enormously appreciated by the epilepsy community across the country.

Amongst those on-going issues is the continued problem of drug shortages and I am proud of the work of Epilepsy Toronto and the Canadian Epilepsy Alliance in working to raise the public profile of this situation, and to push for action by the federal government.

I want to acknowledge the hard work of our staff, volunteers, Board of Directors and community partners without whom we would not be able to achieve our successes in the past year. I also want to thank our many donors, members, and supporters who provide us with the resources we need to support Toronto's epilepsy community. We could not have achieved such a successful year without you and I hope we can count on your continued support in the year to come.

**Daryl Yeo**  
**President**  
**Epilepsy Toronto**



# Adult Services

This has been an exciting year for our adult services program. While continuing our year round support for our members and clients, we have been able to expand our programs to reach new parts of the community and work with partners from across Toronto.

## **Etobicoke Outreach**

Epilepsy Toronto provides support services to people affected by epilepsy throughout the GTA and clients often come to us from the eastern parts of Scarborough and the western parts of Etobicoke. As an agency we strive to be responsive to the needs of our members and many have expressed the challenges they face with accessing direct services at the downtown office due to the distance. Some travel as much as 2.5 hours by transit to get to an appointment.

In 2012, Epilepsy Toronto conducted focus groups and surveys amongst residents of Etobicoke to identify their needs and the feasibility of starting an outreach program for that community. The response strongly supported our belief that there was a real need for targeted programming for that community.

One of our community partners, the Rexdale Women's Centre, kindly agreed to support the new program by providing a space to meet with clients. Members in the Etobicoke community can now set up appointments with Epilepsy Toronto staff and be seen closer to home. We have also started an Epilepsy Support Group that is now meeting on the last Wednesday evening of each month at the Rexdale Community Hub, in Etobicoke.

## **Toronto Police Services Training**

We are continuing our partnership with Toronto Police Services to provide epilepsy training to our city's police officers. We are proud to report that we have completed training in 12 Police Divisions to date with hopes to complete the remaining divisions by the close of 2013. The response to the training remains positive as many officers have reported that it has changed their perspective about epilepsy and will definitely help them to pause and investigate further before making assumptions about what is causing a particular behaviour. We continue to



encourage our members to share their stories in order for us to assess the training needs of the community and the outcomes of these interventions.



## **Tax Clinics**

We are grateful to the Ontario Institute of Chartered Accountants who have partnered with us for the past two years to host Free Tax Clinics to assist our members in completing their Tax Returns. Members are very grateful for these services as a tax return can cost up to \$75 and for those who are on a fixed or low income this can be a financial burden.

# Diversity Outreach

Epilepsy Toronto's Education and Outreach program has been working hard to connect with Toronto's diverse communities and work to raise public awareness about epilepsy. A priority in the last year has been to establish and strengthen relationships with other organizations serving ethno-cultural communities, new immigrants, and LGBT communities across the city.

As a result, Epilepsy Toronto has partnered with groups connected to Toronto's Aboriginal, LGBT, Afghan, Vietnamese, Russian, South Asian, and Chinese communities to educate their staff and clients about epilepsy. This is especially important in many communities where cultural stigmas about epilepsy can be especially prevalent. We have also translated new epilepsy education materials into Dari, Urdu and Chinese for community use and we are working to produce resources in Punjabi, Tamil, Spanish, and Italian in the coming year.

We are also aware that epilepsy is increasingly affecting seniors as our city's population ages. That's why we have strengthened ties with seniors associations in Toronto and are expanding our training of nurses in Home Care Services, Long-Term Care Facilities and Senior Centres so that they can better support their clients and patients living with epilepsy.



Epilepsy Toronto would like to thank the following community groups for allowing us to help educate their staff, members and clients:

519 Church Street Community Centre  
Access Alliance Multicultural Health and Community Services  
Afghan Women's Organization  
Anishnawbe Health Toronto  
Bernard Betel Centre for Creative Living  
Black Creek Community Health Centre  
Brampton Civic Hospital  
CAMH  
Church Street Community Centre  
COSTI Immigrant Services  
Doorstep Neighbourhood Services  
DramaWay  
East Metro Youth Services  
Family Support Centre, YWCA Toronto  
Firgrove School Community Kitchen  
Gord Irene Risk Community Centre  
Grange Festival  
Health Equity Race Ontario General Membership Meeting  
Healthy at Home Program  
The Hospital for Sick Children: Sick Kids International  
The Hub - Scarborough Centre for Healthy Communities  
Jane/Finch Community and Family Centre  
Kid's Place Family Resource Centre  
Manulife Financial, North York  
Na-Me-Res Native Men's Residence  
Native Canadian Centre of Toronto  
North York Central Library  
Northwood Neighborhood Services  
Ontario Chinese Health Coalition  
Ontario Institute for Studies in Education  
Operation Spring Board  
Pathways to Education After School Program  
Ryerson University  
Salvation Army  
School of Nursing, York University  
South Asian Multi-Unit Health Program  
South Riverdale Community Health Centre  
St. Elizabeth Healthcare  
Student Health Awards, York University  
Toronto Council Fire Native Cultural Centre  
University of Toronto Emergency Medical Response Group  
University of Toronto Women's Centre  
Wellness Fair, University of Toronto Scarborough Campus  
West Scarborough Community Centre  
Weston Family Resource Centre  
York University  
YWCA Toronto

# Children and Youth Services

*"We are not alone. We are not the only ones."* That was a common reflection on this year's Winter Family Retreat that took place during a February weekend at YMCA's Geneva Park on Lake Couchiching in Orillia, ON. The weekend event allowed families living with epilepsy to get out of the city, enjoy some outdoor winter activities, hear from guest speakers, and talk about some of the challenges they've experienced.

Families left feeling connected, supported, and most importantly not alone. Parents shared experiences, struggles and achievements, and were provided workshops by the Hospital for Sick Children's Dr. Cecil Hahn and family therapist, Theo Selles, to add to their own understanding of epilepsy. Children and youth created friendships, and increased their confidence and self-esteem by taking part in a social skills and bullying workshops by Toronto-based company Dramaway.



Sponsored by Mackenzie Financial Charitable Foundation, the Winter Retreat brought together 75 parents and children, in the comfort of a cozy country inn, to share experiences and support. Events like these "make you realize you're not in this alone" said Malak Sidky, a parent of a teenage son with epilepsy.

Keeping in touch and reuniting later at our Purple Day Party and scavenger hunt, the families are now busily planning a summer camping excursion, emphasizing the importance of making connections in a supportive environment. It is our hope that with more funding we will be able to provide many similar event in the years ahead to continue creating friendships, connections and support.





# Thinking About Epilepsy Program

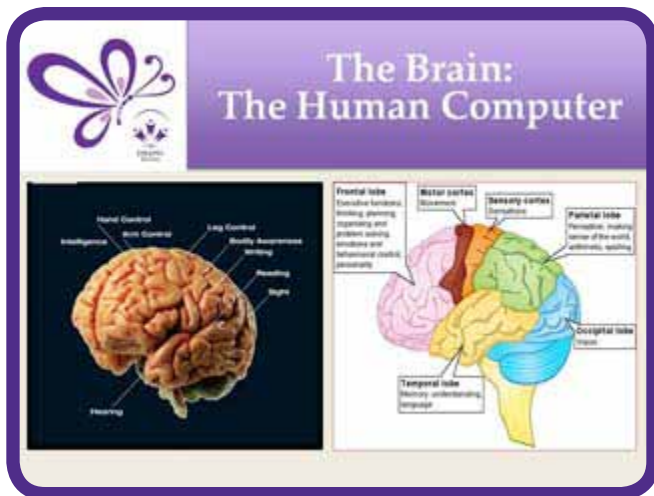
In too many schools in Toronto there is lack of awareness about epilepsy, both among teachers and students. Students with epilepsy face safety issues, teasing, bullying and missed opportunities to excel academically, which can have a long-term impact on their future. By increasing education and awareness within the school system, the school environment can be significantly improved with better learning opportunity for students with epilepsy.

With the generous support of the Ontario Trillium Foundation, Epilepsy Toronto launched 'Thinking About Epilepsy', an educational program designed to bring together Ontario's science, technology and health curricula for grade 5 students while teaching them about epilepsy.

Based on a program that was successfully created and tested by the Epilepsy Support Centre in London Ontario, the aim of 'Thinking About Epilepsy' is to teach students and teachers about epilepsy and seizure first aid while debunking the common myths that contribute to stigma and negatively impact youth living with seizures.

***“There was a student down the hall from us who had a seizure on the very same day you were here (ironic!). Our teachers are definitely interested in having a lunch and learn session. Thank you Epilepsy Toronto for offering this valuable program to us!”***

**– Grade 4/5 Teacher, TDSB**



The program promotes an understanding and acceptance of people with epilepsy and reinforces the fact that epilepsy does not have to stand in the way of achievement.

The program has been incredibly successful with 4,921 students in 182 classrooms in Toronto District School Board (TDSB) and Toronto Catholic District School Board (TCDSB) schools having participated in 'Thinking About Epilepsy' since it launched in 2011.

The impact of this educational program is clear for both students and teachers. As the program funding draws to a close in 2013, we hope to find new funding sources so that we can continue the program, and transform the school environment for children with epilepsy and seizures.

# Employment Services

Epilepsy Toronto provides 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 and provides information on upcoming Job Fairs, current postings and other employment related resources.

## Employment Program

Our Employment Program team assists individuals experiencing difficulties at work and provides education about epilepsy in the workplace or supports negotiations with employers to provide necessary accommodations.

## Coconut Team

This year Epilepsy Toronto Employment Services offered a unique opportunity to its members: the chance to run a micro-business selling coconuts to the public at Epilepsy Toronto's annual Scotiabank BuskerFest! The members were involved in all elements of the business, from planning to implementation. Members learned about marketing, budgeting, customer service, teamwork skills and much more!



Most importantly, members worked together on an experience that helped them gain self-confidence and the recognition that they too have what it takes to be meaningfully employed!

## Job Finding Club

Job seekers come together each week at our Job Finding Club to share tips and strategies for job seeking, hone their resume writing and interview techniques, and hear from guest speakers. Recently, we were joined by representatives from Toronto Employment and Social Services (TESS) to provide information on how Epilepsy Toronto and TESS are working together to help members secure jobs.

## EnAbling Change

The EnAbling Change Program, through the Accessibility Directorate of Ontario, has identified Epilepsy Toronto as an organization that plays a leadership role in identifying, removing and preventing barriers for people with epilepsy. As such, they are funding the development of a "toolkit" of internet-based educational resources, unique in Canada, to be used by diverse organizations to address and better manage the needs of employees and customers with epilepsy in this province.

The Epilepsy Workplace Toolkit will:

- Reduce the stigma attached to people living with epilepsy
- Make workplaces and places of business more inclusive and reduce barriers to people living with epilepsy
- Through education, break down myths associated with epilepsy and assist organizations to better meet their Human Rights and AODA obligations

Consisting of a basic eLearning course, a first aid video, an eLearning course for managers and human resources professionals and an array of printed materials available on-line the toolkit will engage, inform and measure the users acquired level of epilepsy knowledge.

We are also looking to engage employers about their experiences with employees and customers with epilepsy and to connect with businesses that would be interested in hosting and promoting this valuable resource.



# Purple Day

Epilepsy Toronto is proud to take part in the worldwide campaign to raise awareness about epilepsy on Purple Day, March 26<sup>th</sup>. Events took place across the country and this year was especially important as it came only a few months after the Parliament of Canada officially recognized Purple Day as the national day for epilepsy awareness.

Purple Day this year brought a new opportunity to raise epilepsy awareness at York University. Partnering with the Student Association of Health Management, Policy and Informatics and Winters College Council at York University, Epilepsy Toronto sponsored an art contest where 7 talented students submitted original works that were exhibited as part of Epilepsy Toronto's awareness day on York's Keele Campus.

Our public education events brought purple-clad volunteers to Union Station and the PATH to get the word out about



epilepsy with a Purple Day quiz. We continued our partnership with the University Health Network to bring epilepsy awareness activities into Toronto hospitals -where many staff wore purple- with bake sales, raffles, games and quizzes to win great prizes.

Our amazing Purple Day Ambassadors, members and supporters who planned their own awareness and fundraising activities, organized 35 events ranging from family dinners and church bake sales to workplace events and music concerts.

An exciting Purple Day wrapped up with a giant Purple Party for our members with a scavenger hunt through the Eaton's Centre, live music and dancing, and face-painting. Many members talked about how they appreciate the opportunity to not only raise public awareness on Purple Day but to come together as part of Toronto's epilepsy community.



# Scotiabank BuskerFest

Scotiabank BuskerFest and BuskerBall are moving!

The Scotiabank BuskerFest, our largest fundraiser of the year, and the largest epilepsy awareness event in the world, is moving to a new home this year in the Downtown Yonge Street Neighbourhood.

After 10 very successful years in the St. Lawrence Market area, our festival has grown so large, with over 1 million people attending last year, that it was time to find a new location that could accommodate the growing crowds. We are so excited for our new partnership with the Downtown Yonge BIA and the possibilities this move will hold for our festival going forward. More clowns, more comedians, more contortionists, jugglers, daredevils, fire-eaters, sword-swallowers, magicians and musicians; more people coming out to watch great street performers; more people learning about epilepsy and contributing to our cause.



Along with the Festival, our signature gala event, The Scotiabank BuskerBall will also be making the move. Now in it's 5th year, this year's glitzy gala evening will once again feature an up-close preview of some of the festival's top acts from around the globe, fabulous food and drink, and live and silent auctions raising money for Epilepsy Toronto. This year's Ball will be taking place at Ryerson University's newest state of the art facility, the Mattamy Athletic Centre at the Gardens (formerly Maple Leaf Gardens). We will be right down there on centre ice (of course, the ice will be covered up)! This new location promises to deliver a new level of glamour to the event, an ability to accommodate many more people,

and of course it has added allure and appeal to all the hockey fans out there (we know there are a few).

There is no question that 2013 will be a momentous year for our little festival, which is not so little anymore. Onwards and upwards we go: the largest and most vibrant Street Performer festivals in North America will now take place on the longest, most vibrant street in the world!





# Our Volunteers

Thank you to all of our volunteers and supporters who make the work of Epilepsy Toronto possible. From BuskerFest to the Holiday Feast; from Purple Day to the Marathon; from Gift Wrap for Epilepsy to our Annual Conference, Epilepsy Toronto relies on the hard work and generosity of countless dedicated volunteers and we want to thank you all!





# Thank You

Thank you to all of our donors, funders, and special friends who make Epilepsy Toronto's work possible.

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