

a vision for an empowered community



# **EPILEPSY TORONTO**

## **Annual Report 2011**

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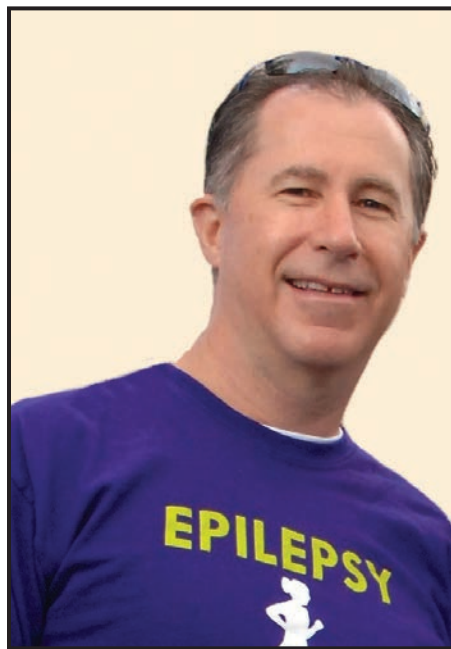
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# President's Message



A recent national epilepsy survey, *The Impact of Epilepsy on Canadians*, highlighted the fundamental need to eliminate stigma facing those living with epilepsy in this country by supporting greater public education and awareness of the disorder. It was here that Epilepsy Toronto concentrated the bulk of its efforts in 2011, establishing several exciting new programs, certain to elicit far reaching change for years to come.

An education and outreach program was developed that specifically targets communities of diversity throughout the city, where cultural myths and stereotypes of epilepsy are deepest entrenched. Over 150 workshops were delivered throughout the year to a combined audience of thousands, including the first ever epilepsy First Aid Certification program created, for foreign trained Toronto nurses.

Also new, was an epilepsy awareness program for grade five students in the Toronto Public and Catholic District School Boards. Grade five is when kids are first introduced to the science of the brain. It is an impressionable age, and a perfect opportunity to influence informed attitudes for generations.

2011 marked the fourth annual Purple Day for Epilepsy. Now a world-wide phenomenon, it is the one day a year when everyone is invited to wear purple as an expression of solidarity with the epilepsy community. Here in Toronto, we held Purple Day celebrations at public schools and universities, hospitals and places of work from one end of the city to the other, and staged an outrageous purple fashion show that garnered national media attention and featured the young founder of Purple Day, Cassidy Megan. We look forward, with eager anticipation, to the third and final senate approval of Bill C-278, the Purple Day Act, that will enshrine this inspiring expression of public support for Canadians with epilepsy, forever within the fabric of the nation.

2011 was another hugely successful year for agency fundraising events, as well, which are crucial to our existence as they represent over 40% of our net revenue. Scotiabank BuskerFest and BuskerBall were again blessed with great weather and contributed record results, and Epilepsy Toronto continued its participation in the Scotiabank Toronto Waterfront Marathon where we once more had one of the largest charity teams, with over 200 members, raising in excess of \$75,000. One cannot underestimate the value of these events toward strengthening the agency community and building epilepsy awareness in the public at large.

On behalf of Epilepsy Toronto and its members, special thanks to our staff and many volunteers, community partners and generous sponsors for your remarkable ongoing support. We should all take great pride in everything that has been accomplished in the past year. I look forward to continuing our work together in the year ahead and for many years to come.

Daryl Yeo  
President,  
Epilepsy Toronto

# 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 meaningful in their own health management.

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

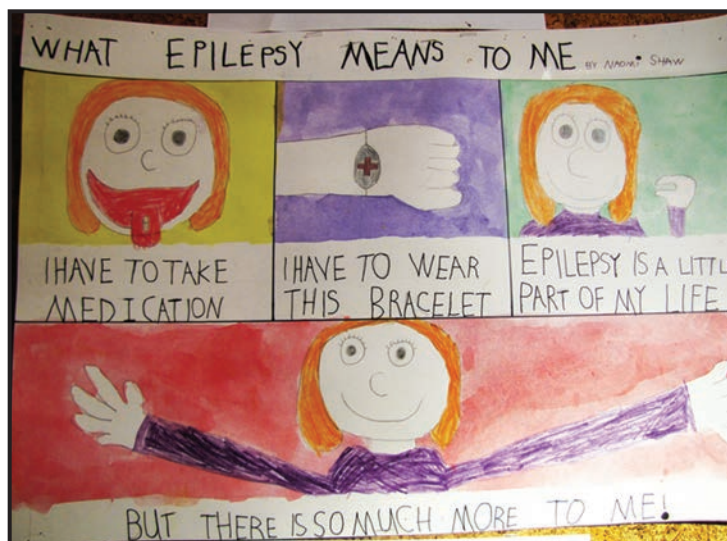
We value self-determination and choice.

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





# Knowledge is Power



## Are You Smarter than a 5th Grader?

They say that the lessons we learn at a very young age are those that carry the greatest lasting impact in our lives. It was with this in mind that Epilepsy Toronto launched Thinking About Epilepsy, a creative new epilepsy education program for grade five children and their teachers.

Sponsored by The Ontario Trillium Foundation, the program will teach thousands of children at public and private schools throughout the community, epilepsy awareness and seizure first aid; debunking common myths and stereotypes before they become

woefully entrenched, and promoting messages of anti-discrimination and tolerance. It is our hope that these kids will grow up and teach their kids who will grow up and teach theirs, and the misinformed attitudes that have enshrouded this disorder for generations, will change forever.

## Great Minds Meet

Knowledge, we contend, is the key to living well with epilepsy. The better informed one is about how one's seizures manifest, the personal impact they have, and alternatives for care, the better positioned one is likely to be to maximize success. This is why we partner, each year, with the Krembil Neuroscience Center at Toronto Western Hospital, the Hospital for Sick Children, and the University of Toronto Society for Epilepsy Care and Awareness to organize a major annual educational conference. The largest of its kind in the nation, this educational forum combines medical information with practical life coaching and psychosocial support in an accessible and interactive format. Each year features a different topic and theme and a fresh perspective on the condition, and the atmosphere is informal, engaging, and safe.

There are more than 40 different kinds of epilepsy, and new information about each type is coming to light all the time. The Epilepsy Conference presents the important opportunity to meet with the experts.



## Understanding at Work

Many people spend more waking hours at work than at home with family and friends. That is why it's important for employers and colleagues of people living with epilepsy to know how to respond to a seizure.

The Hydro One Telecom Network Operations Centre in Etobicoke employs approximately 80 people, including two who have epilepsy. Recently, an employee experienced a seizure at work. Many employees witnessed the seizure, but few knew how to respond.

"Safety is our number one priority and we want employees to know how to respond if an emergency situation arises," said Bryan Brennan, the Support Network Manager. Bryan, who is also the Health and Safety coordinator for Hydro One Telecom, took the initiative and contacted Epilepsy Toronto to come in and deliver epilepsy education presentations to the team.

"Most people who witnessed the seizure felt they shouldn't talk about it to protect his privacy. But during the presentation there were a lot of questions and a real curiosity about seizures and epilepsy. Everyone wanted to learn more," said Bryan.

The employee who experienced the seizure was initially quiet during the presentation but once he saw how genuinely interested and engaged his colleagues were, he felt comfortable to open up and discuss what happened.

"It was as if something was lifted off his shoulders," said Bryan. "After having a seizure, you rely on other people to tell you what happened and my co-worker was hearing what his seizure looked like for the first time."

Knowledge is critical and now, employees at Hydro One Telecom know how to help.

Epilepsy Toronto facilitates education and seizure first aid training in workplaces all over the GTA. Epilepsy education is just one of our many programs and services that help inform, keep people safe and find solutions to issues that arise in the workplace.

## Sharing Knowledge Makes for Good Partnerships

Epilepsy Toronto has created an exciting new training partnership with the Centre for Internationally Educated Nurses (CARE) as part of an outreach initiative to communities of diversity throughout Toronto.

The nurses are provided state-of-the-art information on contemporary epilepsy diagnostics and care that they deliver to their patients in a culturally sensitive context. This allows us to address culturally based misinformation of the disorder and connect with segments of the population we would never otherwise be able to reach.

According to Lourdes Vicente, Case Manager at CARE, "Epilepsy Toronto presentations provide awareness of the disorder and tools for our nurses that are invaluable to their work."

This epilepsy certification program will now be incorporated as a matter of course in future foreign trained nursing orientations, and extended next to health promotion practitioners.





# Outstanding Support

## The Perfect Balance - Scotiabank BuskerFest & BuskerBall

Every year, the internationally acclaimed **Scotiabank BuskerFest** and **Scotiabank BuskerBall** events strive to strike the perfect balance between generating public awareness of epilepsy and raising much needed funds.

Recognized, for the fourth consecutive year by Festivals & Events Ontario as one of the leading festivals in the province, Scotiabank BuskerFest has evolved into the single largest epilepsy awareness event in the world. Attracting over a million spectators in a four day period, this international street performer's festival garners coverage from every major broadcast and print media in the GTA.

Bizbash Magazine named Scotiabank BuskerBall the “new, fresh and upcoming event on the Toronto entertainment scene”, thanks in part to the majestic work of world renowned designer, Jamie Alexander.

Staged in a unique setting that combines upscale swank with St. Lawrence Market neighbourhood charm, Scotiabank BuskerBall offers an exclusive preview of the festival to follow. More than a gala, the event is a breathtaking spectacle, and a tribute to the indomitable spirit of the epilepsy community that is its inspiration.

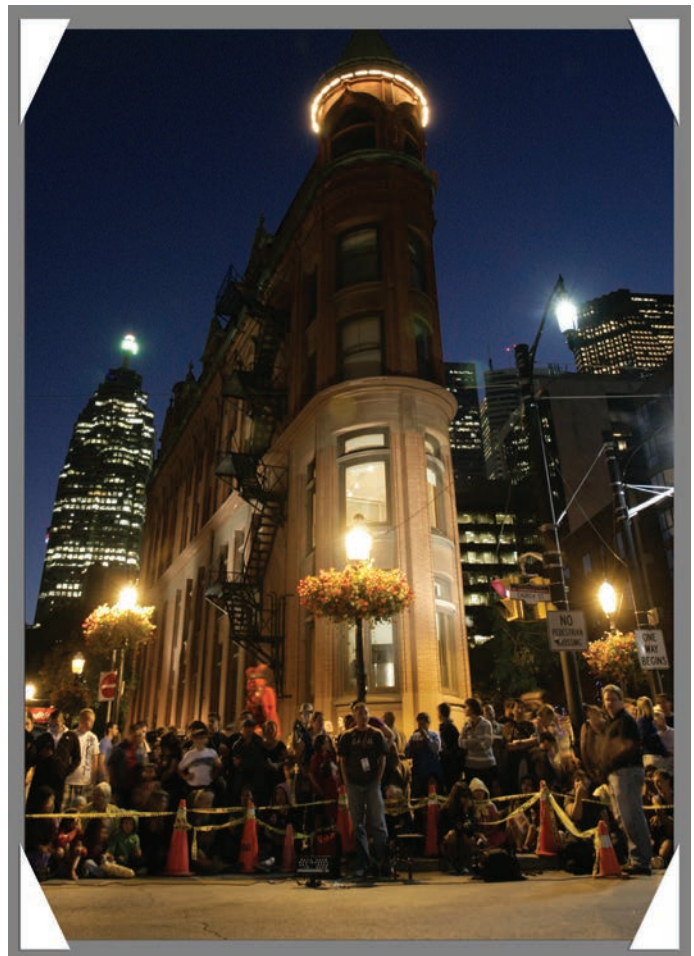


## TEAM EPILEPSY - Making a Splash on the Waterfront

25,000 people walked or ran in last year's Scotiabank Toronto Waterfront Marathon on behalf of their charity of choice; Team Epilepsy once again among the leaders. Not a year has passed since the race's inception that Epilepsy Toronto hasn't been top three among nearly 200 charities in either monies raised or team size, or both; a remarkable achievement for a comparatively tiny organization, and a testament to the enduring strength of the epilepsy community.











## Purple Day - Everywhere

March 26th is Purple Day, when people around the world join together in celebrating epilepsy awareness. Here in Toronto, we did our part by organizing epilepsy education workshops for thousands of students at elementary schools across the city. The kids were invited to show what they learned by entering a poster contest, with the winning entry to be used as a transit ad in the subways, teaching epilepsy awareness to the public at large.

We conducted Purple Day events at 4 major hospitals in the Toronto community, and collaborated with students at York University and the University of Toronto to stage a Purple Day Olympics and the Amazing Purple Race. Purple Ambassador kits were given to our members and their families so that they could conduct their own epilepsy awareness events in the community, and the agency staged its very first Purple Day fashion show at the downtown Novotel, where hundreds of our supporters proudly strutted their stuff on the purple catwalk. The buzz of excitement reached fever pitch with the arrival of **Cassidy Megan**, who founded Purple Day when she was just nine years-old.

## Volunteers Matter

In March Epilepsy Toronto welcomed the expertise of people committed to empowering our members, where it counts - in the pocket book.

Folks from the Canada Revenue Agency came to the Epilepsy Toronto office to give a Tax Information Session, which included information about: Disability Tax Credit, Eligible Expenses and the Registered Disability Saving Plan. And later in the month, a group of Chartered Accountants from the Institute of Chartered Accountants of Ontario stepped forward to prepare tax returns free of charge, for members who met the eligibility criteria.

Volunteers are the life blood of this agency, last year contributing an astounding 21,000 volunteer hours to the work of the organization.







# Support for All

## support groups

- AVEC - Adults with Epilepsy Connection
- Epilepsy Surgery Support Network
- Friday Recreation Group
- Job Club
- New and Expecting Moms Network
- Parents of Young Adults and Teens Support Group
- Partners of People with Epilepsy Support Group
- Support Group for Professionals
- Support Group for Parents of Young Children with Epilepsy



## Core Services

### support services

- Individual and family counseling
- Child and youth services
- Recreation programs and special member events
- Social groups and peer- support services
- Employment consultation, outreach and job development

### educational programs

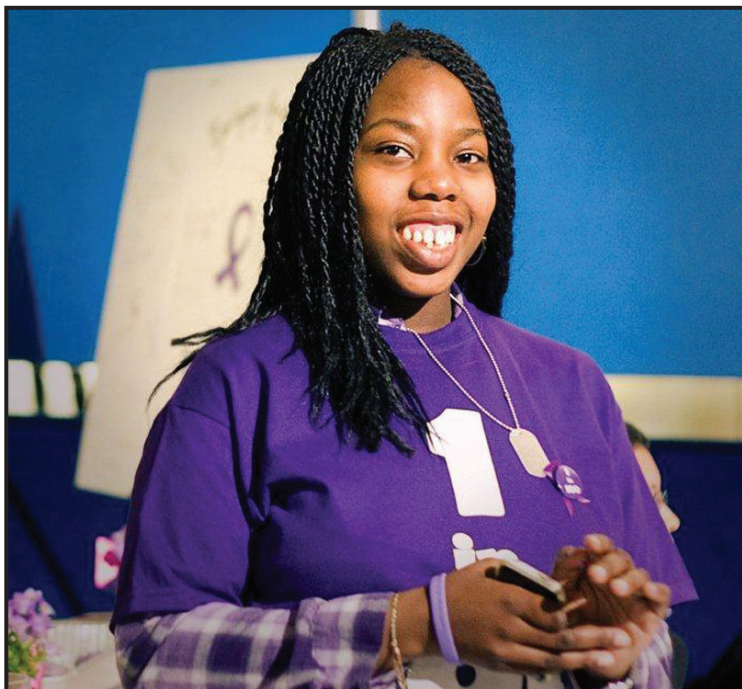
- Annual Epilepsy Conference
- Community outreach programs and inservice training
- Epilepsy training for parents of newly diagnosed children
- Lectures and seminars
- Newsletters and educational materials
- Thinking About Epilepsy, program for grade 5 students
- Public awareness initiatives
- Teaching Awareness Through Puppetry (TAP), disability awareness program
- Winter Family Retreat

### signature events

- Scotiabank Toronto International BuskerFest
- Scotiabank BuskerBall
- Scotiabank Toronto Waterfront Marathon
- Purple Day for Epilepsy Awareness - March 26th
- Annual Gift Wrap campaign



# Remembering Ade



There are certain people that give you reason to believe that ***you can do anything.***

Ade Adegbite is one of those people. How can any of us forget Terry Fox attempting to run across Canada on one leg? It reminded the collective unconscious that the human spirit doesn't know the meaning of disability, only the power of ability.

Ade Adegbite passed away on December 4th, 2010 at the age of 24. Before she died she wrote a poem and in one of the lines she remarked, "A disability is a blessing in disguise." Ade was trying to tell us that sometimes our perceived weaknesses are often our strengths. That triumphing over adversity is within all of us and often comes from a difficult place out of a desire to fight, succeed, and win.

Ade rode horses, she took dance lessons, piano lessons, singing lessons, and loved sports. Her dream was to become a French teacher and prior to her passing she was working toward obtaining her Masters in French. But her ultimate dream was to swim across Lake Ontario to raise awareness for Epilepsy. She did all this while experiencing daily seizures. Ade saw her ailment not as a disability, but as just another hurdle to overcome on the path toward achieving her goals.

Ade was a fighter. All of us at some point in our lives face odds that might seem insurmountable. The only difference between her and the rest of society is that she had an ailment, one that she refused to let hold her back. She could do anything the rest of us could, and in many aspects of her life, did it better.

All of us at Epilepsy Toronto are inspired by the courage and determination that Ade showed toward achieving her goals. With the support of Ade's family, we want to facilitate the opportunity for people like Ade and others living with epilepsy, to pursue their dreams in the future. With a gracious contribution to the Ade Adegbite Memorial Scholarship administered by Epilepsy Toronto, you have the "ability" to help someone like Ade make their dreams come true.

"All of our dreams can come true, if we have the courage to pursue them." – Walt Disney

## Ade Adegbite Scholarship Awards

Karima Panjwani and Laura Chadwick are the very first students to be awarded the Adegbite Memorial Scholarship. Both of these young women encompass the spirit of Ade in their volunteer life, academic ambitions, but most of all, in their determination and resilience in overcoming barriers or challenges related to epilepsy.

Congratulations to **Karima** and **Laura**!

# Special Thanks

Epilepsy Toronto would like to thank everyone who shares our vision and supports our work.

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The Ontario Trillium Foundation  
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## Community Partners

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Canadian Epilepsy Alliance  
CARE Centre for Internationally Educated Nurses  
Davenport-Perth Neighbourhood and - Community Health Centre  
Epilepsy Ontario  
Geneva Centre  
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Krembil Neuroscience Centre at Toronto  
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South Riverdale Community Health Centre  
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