



ANNUAL REPORT

EPILEPSY
Toronto

2010



EPILEPSY TORONTO



EPILEPSY TORONTO STAFF

Geoff Bobb - *Executive Director*
 Christina Chew - *Volunteer Coordinator*
 Julie Despaties - *Employment Counsellor*
 Nora Dobell - *Manager, Employment Services*
 Kaia Grosso - *Recreation Coordinator*
 Pia Marin - *Finance Services Coordinator*
 Jodi Maruncic - *Director, Child & Youth Services*
 Pam McDonald - *Office Manager*
 Nicole Nelson - *Director, Development*
 Lise Schofield - *Director, Communications*
 Rosey Smith - *Director, Adult Services*
 Leah Sultan-Khan - *Manager, Public Education and Diversity Outreach*
 Judi Egelnick - *Teaching Awareness Through Puppetry*
 Kirsten Sixt - *Teaching Awareness Through Puppetry*

Scotiabank Toronto International BuskerFest in support of Epilepsy Toronto

Mackenzie Muldoon - *Marketing & Entertainment Manager*
 Bonnie Taylor - *Event Producer*
 Sarah Weaver - *BuskerBall Auction Coordinator*

BOARD OF DIRECTORS

Daryl Yeo - *President*
 Barry Pickford - *Past President*
 J. David Yeilding - *Treasurer*
 David Caplan, MPP
 Jim Feyerer
 Tamzin Jeffs
 Jonathan Lipszyc
 Dr. Peter Tai
 Caroline Tapp-McDougall
 Cindy Usprech
 Dr. Taufik Valiante

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Epilepsy Toronto



Epilepsy Toronto

SERVICES

- Individual & Family Counseling
- Child & Youth Services
- Recreation Programs
- Special Member's Events
- Social Groups
- Peer Support Services
- Employment Consultation, Outreach & Job Development
- Assertiveness Training
- Partner's Support Group
- Expecting & New Mom's Network
- Professionals Group
- Epilepsy Surgery Support Group
- Job Club
- Parent's Support Group

EDUCATION

- Public Awareness Initiatives
- Annual Epilepsy Conference
- Community Outreach Programs and In-service Training
- Lectures & Seminars
- Epilepsy 101 Training for Parents of Newly Diagnosed Children
- Epilepsy Library & Resource Centre
- E-newsletters and Social Media
- Website Resource Centre
- Teaching Awareness Through Puppetry

SIGNATURE EVENTS

- Purple Day for Epilepsy
- Family Winter Retreat
- Scotiabank BuskerBall
- Scotiabank Toronto International BuskerFest
- Scotiabank Toronto Waterfront Marathon
- Annual Gift Wrap Campaign



OUR VISION

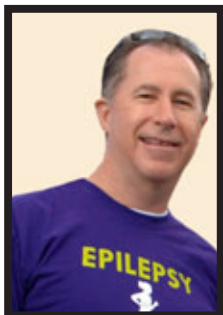
A community where people with epilepsy are included as equals and treated with dignity.

OUR MISSION

Dedicated to the promotion of independence and quality of life for all people with epilepsy and their families, through support services, information, advocacy and public education.



President's Message



Daryl Yeo
President
EPILEPSY TORONTO

I am honored to have assumed the role of President of Epilepsy Toronto on January 1st, 2011 after serving on the Board as a Director for the past three years. It is indeed a privilege to serve an organization with such a long history of supporting and making a difference to the lives of the many individuals and families here in Toronto who are impacted by epilepsy.

Firstly, on behalf of all of our members, our staff and my Board colleagues, I would like to thank our past President, Barry Pickford, for his dedicated and strong leadership during which Epilepsy Toronto enjoyed many achievements and successes, not the least of which were enhancing the relationships with our many members, our business partners and sponsors, and further strengthening the organization's solid financial position. We are fortunate that we will still have the benefit of his sage advice as he continues to be an active Board member. The future does indeed look bright under the legacy that Barry has left us with.

2010 has been another year of significant growth and accomplishment for Epilepsy Toronto. The efforts of our highly committed staff who constantly put out that extra effort to ensure our service programs are of real value to our members and the generosity of our major sponsors and our many members and volunteers, have truly made our successes possible.

Major accomplishments for the year include Scotiabank Toronto International BuskerFest, the organization's signature event, which attracted 1.2 million spectators and 700 million media impressions, making it the largest epilepsy awareness initiative in the world. BuskerBall - being the official launch of BuskerFest, with over 400 supporters in attendance to have a sneak preview of the best of our buskers, and to raise funds for epilepsy. This VIP event raised over \$85,000 and is quickly becoming one of THE charity fundraising events in Toronto. We launched our inaugural Purple Day for Epilepsy concert at Dundas Square, building on the phenomenal public attention that the idea of a 12 year girl from Nova Scotia to expand epilepsy awareness globally has gotten, with excellent media coverage of the festivities. Epilepsy Toronto once again had the largest charity team, with close to 300 members participating in the Scotiabank Toronto Waterfront Marathon, raising over \$75,000 to support our programs. The year saw a continuation of our efforts to expand the Toronto Police education campaign - now in its third year, steadily moving forward division by division; and at having an epilepsy awareness program incorporated within the academic curricula of the Toronto Public and Separate School Boards.

All of us can take great pride in what has been accomplished in 2010, and look to more successes in the future as we leverage new and evolving social media to strengthen our members' communication and connection with one another and the agency, embark on new service programs, and further our journey towards establishing a permanent home for the agency to enhance delivery of our services.

On behalf of Epilepsy Toronto, thank you for your support over the past year and we look forward to connecting again in 2011.



ADULTS

Individual & Family Counseling

Case Management & Community Referral Services

Adult Support Group

Partners Support Group

Professionals Support Group

Epilepsy Surgery Support Group

Yoga Group

Recreation Program

Expecting and New Mom's Network

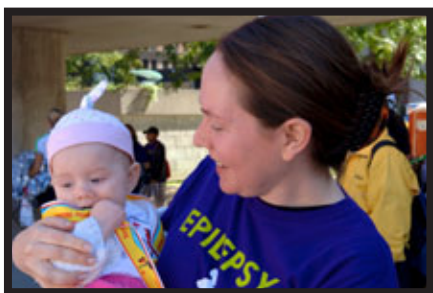
You've just been diagnosed with epilepsy and it feels like the end of your world. You're frightened, overwhelmed, desperate; lost. You are not alone.

Epilepsy Toronto provides counseling and support to thousands each year who face personal, social, and emotional challenges related to epilepsy. We offer strategies for addressing community barriers and information critical to assuming a meaningful role in the management of one's own health. And we bring together people with epilepsy and their families from all walks of life to share experiences and support. We believe that community is strength.

In 2010, Epilepsy Toronto established a network for new and expectant mothers that is the first of its kind in North America and fast becoming a support staple for women with epilepsy in our community.

Historically, women with epilepsy have been discouraged from becoming pregnant. **The New and Expecting Mom's Network** encourages women with epilepsy to explore their options and make reasoned decisions on starting a family based on medical facts.

The group shares tips on how to cope with mom's seizures while juggling the responsibilities of a new baby, how to manage medications and pregnancy and how to deal with the changes a new baby brings. They meet regularly to share strategies and experiences, arrange seminars from medical specialists and circulate monthly e-newsletters with relevant resources, articles and up-to-date news about women and epilepsy.



Have a peek on our website of our growing collection of photos of happy moms with new babies. We're thrilled to be a part of each of their miracles.



CHILDREN AND YOUTH

Parent Support Groups

Youth Group

*Epilepsy 101: A Course for
Parents of Newly
Diagnosed Children*

*School Presentations &
Educator Consultations*

*Individual & Family
Counseling*

Family outings

Resource Center

Epilepsy in childhood can be a difficult experience with significant social, emotional, and developmental implications. It can play a fundamental role in shaping family dynamics, academic achievement, community integration, and personal self-esteem, and have long term and life-defining consequences.

Our Children and Youth Program provides a full range of counseling, education, and support services to young people with epilepsy and their families that promote healthy development and community participation.

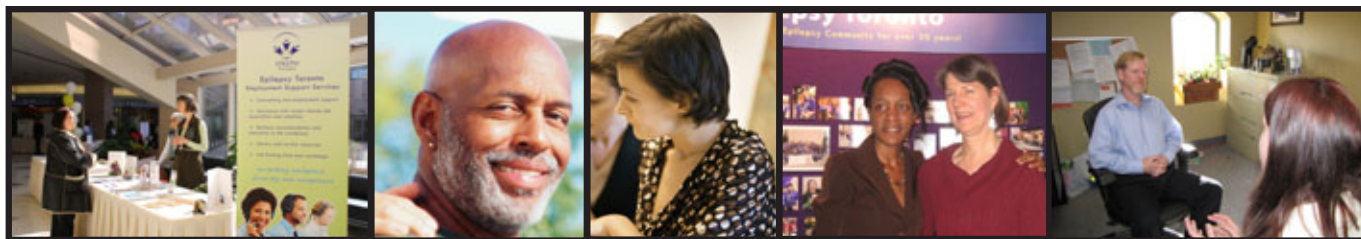
This year marked our **5th Annual Winter Family Retreat** at Geneva Park, providing 30 families with a much deserved break and the opportunity to connect with peers in a casual and stress-free environment. The kids and their families enjoyed magic demonstrations, horse-drawn carriage rides, education workshops, karaoke and an unparalleled spirit of camaraderie.

For some children living with seizures, the sense of 'being different' never goes away. But at the Annual Retreat they can see kids just like themselves having seizures, dusting off and getting back up to join the snow fight outside! Those kinds of moments are very meaningful for the children and their parents.



The Annual Retreat has become a winter tradition for our members and so valued, that plans are afoot to start up in the summer.

Stay tuned!



EMPLOYMENT PROGRAM

Career Counselling

Job Search Preparation

*Job Accommodation & Retention
Strategies*

Job Development

Job Finding Club

Assertiveness Training

Employee Disclosure

Employer Education

Employment Resource Centre

For most, employment is more than a source of revenue; it provides a sense of identity, self-worth and a secure place in one's community. Unfortunately, the rate of unemployment for adults with epilepsy in Canada is twice that of the general population. And those that are able to find work must often settle for jobs outside their areas of expertise and battle job security because of employer misconceptions about safety and liability in the workplace.

Epilepsy Toronto offers full spectrum employment consultation and support services specializing in epilepsy. We help with job search and development, career counselling, skills acquisition, and epilepsy disclosure and accommodation in the workplace. Our online Job Sharing Forum has become a thriving hub of employment opportunities and our weekly Job Club, a source of inspiration and critical support.

Employer education, too, is a vital feature of our service. Many employers are hesitant to hire individuals with epilepsy because of misinformed notions regarding seizures and work performance.

Our presentations and training sessions show employers and their staff how to properly respond to a seizure, and our interventions at the work site promote successful partnerships toward lasting job retention.





PUBLIC AWARENESS



Epilepsy Toronto is always looking for opportunities to bring epilepsy into the public eye. In the past year, we've had continued success in raising awareness and changing public attitudes through our proactive media outreach efforts.

We've had more television exposure than ever, with our own members being interviewed on national television and featured in newspaper articles. We even had a member become a living 'book' for the Toronto Public Library's Human Book program. Consistent exposure through public media is the key to reaching our goal of making epilepsy a condition that is much better understood by all of our communities.

PURPLE DAY FOR EPILEPSY



On March 26th, **Purple Day for Epilepsy**, we presented a public concert in the heart of downtown Toronto to get the word out that all around the globe, millions of people were "going purple" to support epilepsy awareness. Our event, hosted by Zack Werner of Canadian Idol fame, featured Toronto musicians, a Teletoon's star, buskers, and the world's biggest purple ribbon ceremony!

The event brought exceptional media exposure with over 1.6 million impressions made through the television stations that came out to interview our members and report on the concert. It was a cold, but fun event that not only brought Purple Day for Epilepsy to millions of viewers across Canada, but also gave us a platform to educate more people how to properly respond to a seizure. Next Purple Day, we're planning to get bigger and better; we won't rest until the entire city of Toronto goes purple on March 26th!



DIVERSITY OUTREACH



Over half of the population in this city was born outside of Canada, including nearly 1.7 million people for whom English is a second language. This means there are a great many people with epilepsy in our community with widely varying cultural views of the condition, and with whom it is a challenge for us to communicate. It is with that understanding that we launched our Diversity Outreach program in 2010.

The Diversity Outreach program operates in collaboration with Community Health Centres, newcomer settlement agencies and religious institutions across the city to reach out and offer support to new Canadians with epilepsy. We are learning to appreciate the role that tradition, religion, beliefs and culture can play in health care, and look forward to broadening our understanding of the epilepsy experience with a blending of world views.

To date, we've conducted over sixty educational presentations for Somali, Tamil, Bengali, Caribbean, Chinese and South East Asian communities. The response has been amazing. Everyone is welcoming and generous, and genuinely interested in working together and learning from one another.



One special highlight involved Yip's Chinese Elementary School where we presented an epilepsy education session through puppetry. The presentation included OMNI television's Chinese Beauty Pageant contestants and was broadcast on OMNI's Chinese TV and featured in Toronto's largest Chinese publication, Sing Tao magazine.

Plans to expand the Diversity Outreach program include further strengthening community partnerships, developing new multi-lingual education resources, and establishing a Train the Trainer program for grass-roots epilepsy health promotion.



EDUCATION & TRAINING

Workshops & Seminars

Website & Forums

*Primary & Secondary School
Presentations*

Health Fairs & Trade Shows

*Library Resources, Brochures,
and Fact Sheets*

Annual Epilepsy Conference
in collaboration with

Krembil Neuroscience Centre,
University of Toronto Society for the
Advancement of Comprehensive
Epilepsy Care and
Hospital for Sick Children

Most people don't know what to do when a person has a seizure, but Epilepsy Toronto is determined to make proper seizure response as commonly known as CPR. That means training and educating our community, one session at a time.

This past year, we continued providing epilepsy and seizure response training to Toronto Police, working our way through the Force, division by division, one platoon at a time. The Police Department has been very supportive of this initiative, determined to have all their officers better understanding seizures and seizure first aid. Two of our young adult members have become involved in the police trainings. They provide first hand stories about their experiences with epilepsy that is especially meaningful for both the officers and the members themselves, who derive immeasurable value in building awareness of epilepsy in their community.

Next, we will focus on schools, where it is hoped that epilepsy awareness at a young age will have a lasting impact for generations to come. Negotiations are underway with Toronto District Public and private school boards to incorporate epilepsy education into grade 12 science curricula.



The Ade Agebite Education Scholarship

Ade Agebite was a long time and beloved member of Epilepsy Toronto, who tragically lost her life this year, at the age of 24. A Friday Recreation Group regular, she is best remembered for her effervescent personality and brilliant infectious smile that could illuminate the darkest cave.

Ade had a dream of becoming a teacher and was determined that no seizure would get in her way. She persisted for years; transcending countless barriers and seemingly overwhelming odds to chip away at her goal, finally graduating from the University of Toronto with Bachelor's degrees in Education and French Linguistics. At the time of her passing, Ade had just registered for a graduate level French course with the intention of pursuing a Master's degree. It was inspiring. Unfortunately, Ade passed away before having had a chance to teach or pursue these advanced studies. We miss her deeply.

To honour Ade, Epilepsy Toronto plans to establish an education scholarship for young people that we hope will keep her love of learning alive. The **Ade Agebite Scholarship** is our way of making sure that this young person's dream will be carried forward by others.



EPILEPSY TORONTO VOLUNTEERS

Epilepsy Toronto could never exist without the tireless support of countless volunteers, from its Board of management straight on down throughout the organization. In 2010, over 1,000 volunteers contributed more than 10,000 hours to the association.

They were there on the front lines helping out with programs and services, assisting behind the scenes at the office, and commandeering special events such as our annual Gift Wrap Campaign, Scotiabank Toronto International BuskerFest, BuskerBall, and our Purple Day for Epilepsy concert. They are the life blood of the organization and we salute them, one and all.



SCOTIABANK TORONTO WATERFRONT MARATHON

Once a year, Toronto's downtown streets are awash in a sea of people wearing purple t-shirts in support of Epilepsy Toronto. Team Epilepsy has consistently placed in the top ranks as the largest charity group in the marathon. It's a moving sight to see all of those people running together, proudly proclaiming their support for our cause, too long enshrouded in the shadows!

Last year's team was bigger than ever, with people coming out to represent their sister, brother, mother, father, child or friend with epilepsy. The Waterfront Marathon is a special event for all of us. It's when we see that we aren't alone in our dedication to improving the lives of people living with epilepsy. We see a member helped across the finishing line, a baby in a stroller dressed in an oversized purple marathon t-shirt and we see families, arms raised in excitement congratulating each other when the race is done. It's a special day; not just for the pledges raised, but for the joy that comes from knowing that every person in that purple team is there to show just how much they care.



SCOTIABANK TORONTO BUSKERFEST

"Zany street performers do what they do best to benefit Epilepsy Toronto."

Torontolife.com

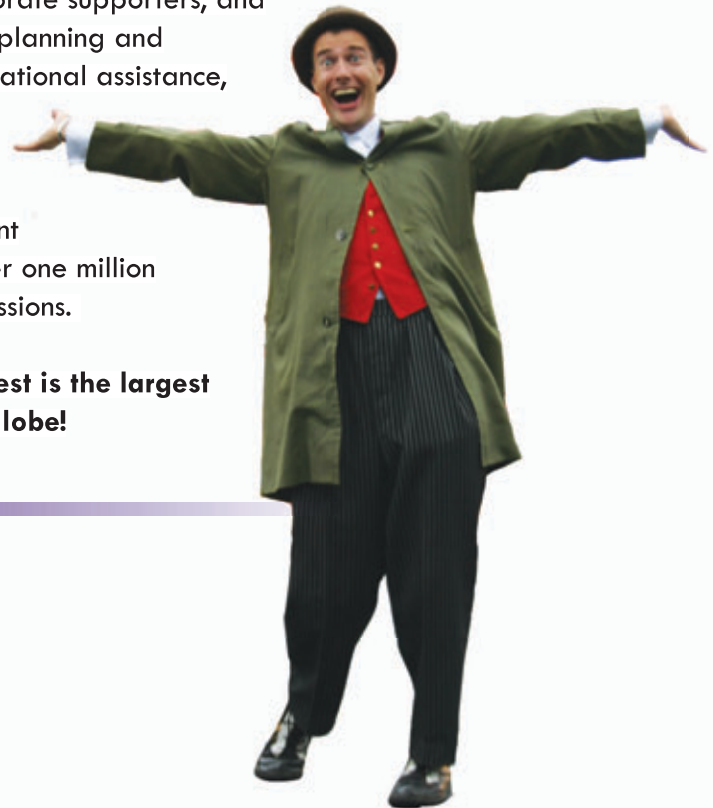
Scotiabank Toronto International BuskerFest was first established in 1999 by Epilepsy Toronto in an attempt to partner entertainment, business, and charity sectors of the community to create a vibrant new entertainment experience for our city. Our aim was to contribute to tourism and economic development and at the same time, garner much needed awareness of epilepsy in the public at large.

Set in the heart of the historic St. Lawrence Market neighbourhood, BuskerFest offers 4 days and 4 nights of mesmerizing theatre in the street. Comedians, contortionists, magicians and mimes, sword swallows and human statues ply their unique trade to the awe and amazement of audiences young and old.

The event is a true example of effective community partnership, featuring a collaboration between Epilepsy Toronto and the St. Lawrence Market, numerous local resident associations and heritage groups, hotels, retailers, corporate supporters, and the City of Toronto. Each is involved in the planning and execution of the event, contributing organizational assistance, as well as volunteer and in-kind support.

Widely recognized as a signature event in the City of Toronto's summer entertainment season, BuskerFest 2010 attracted well over one million spectators, and 700,000,000 media impressions.

Scotiabank Toronto International BuskerFest is the largest single epilepsy awareness event on the globe!



THANK YOU

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In Memoriam

- Ade Agebite

Special thanks to departing team members -

Dr. Elizabeth Donner, Christine Crosbie, Tim Nourse & Fatima Santos for years of dedicated service