EPILEPSY
Toronto

Annual Report

2009

President's Message

This year marks the culmination of my three-year term as President of Epilepsy Toronto. It is with a great sense of pride and accomplishment that I pass on the reins to my successor, and look back upon our many achievements and successes.

I'm proud of the way we've evolved, as an agency, from a clinical environment to something more akin to 'home', - warm and engaging; with a real sense of community. Our members feel a connection - to each other, to the agency; to the epilepsy fraternity at large. You see it at our annual winter retreat in a spirited game of family broomball and in the heart-to-heart discussions of the pregnant women's support group. You see it every Friday in the recreation drop in, and once a year at the holiday feast when hundreds of our members cram into every nook and cranny at the office, celebrating each other's company. You see it at the Scotiabank Toronto Waterfront Marathon, where a sea of epilepsy purple blankets our city streets.

I'm proud, too, of how our busker festival has grown into the single largest epilepsy awareness event on the globe, attracting over a million visitors last year.

I'm proud that Epilepsy Toronto played host to the first conference ever to be held in Canada for youth with epilepsy, resulting in a multi-media epilepsy awareness campaign by and for youth in the nation. I'm proud of our partnership with the University Health Network that provides for a seamless integration of hospital and community support, and with the Toronto Police Force to train all of its officers in seizure recognition. I'm proud of our employment program that, despite challenging economic times and deeply entrenched concerns about epilepsy in the work force, consistently placed into jobs 65% of its clients.

I'm proud that we answered a call to action from a 12 year old child in Nova Scotia to rally the world's support for epilepsy by joining her in setting our community – and the internationally recognized CN Tower - awash in the colour purple.

Indeed, I'm sincerely proud to have played a small role in all of this, and to have served with such an amazing group of passionate and dedicated staff, volunteers and, of course, my Board colleagues.

In 2010, we will embark upon a new journey to purchase a permanent home for our agency which will facilitate the delivery of our services. We will create a new staff position to spearhead outreach to persons with epilepsy and their families in Toronto's communities of diversity, and we will form a partnership with our Board of Education to incorporate epilepsy instruction into its science curricula for all students. The challenges are many; our resolve is strong.

I thank you, the membership, for having afforded me the great privilege to have served on your behalf, and wish you every continued success.

Barry Pickford

EPILEPSY
Toronto

One in 10 people will have a seizure in their life.
One in 100 people will be diagnosed with epilepsy.

That one in 100 now equals about 40,000 people in the GTA alone who are living with epilepsy. Epilepsy Toronto understands the unique nature of each of their experiences and for over 50 years has been delivering innovative services that address all aspects of living with epilepsy. Epilepsy Toronto's team of professionals have thoughtfully designed programs and services that provide our members with a secure environment where they can gain the knowledge, confidence and capacity to reach their fullest potential.

OUR VISION

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

OUR MISSION

We dedicate ourselves 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.

Support 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
- Partners Support Group
- Pregnant & New Moms Network
- Professionals Group
- Epilepsy Surgery Support Group
- Job Club
- Parents Support Group

Educational Programs

- Annual Education Conference
- Lectures & Seminars
- Epilepsy Training for Parents of Newly Diagnosed Children
- Epilepsy Library & Resource Centre
- E-newsletters and ET Facebook
- Internet Resource Centre
- Community Outreach Programs and In-service Training
- Public Awareness Initiatives
- Teaching Awareness Through Puppetry

Signature Events

- Scotiabank Toronto International BuskerFest
- BuskerBall
- Family Winter Retreat
- Scotiabank Toronto Waterfront Marathon
- Annual Gift Wrap Campaign

Staff

Geoff Bobb - *Executive Director*
Pam McDonald - *Office Manager*
Pia Marin - *Finance Services Coordinator*
Fatima Santos - *Director, Child & Youth Services*
Rosey Smith - *Director, Adult Services*
Nora Dobell - *Manager, Employment Services*
Tim Nourse - *Employment Consultant*
Lise Schofield - *Director, Communications*
Chris Rotolo - *Director, Capital Campaign*
Nicole Nelson - *Director, Development*
Christina Chew - *Volunteer Coordinator*
Kaia Grosso - *Recreation Coordinator*
Judi Egelnick - *Coordinator: Teaching Awareness through Puppetry*
Kirsten Sixt - *Coordinator: Teaching Awareness through Puppetry*

BUSKERFEST
Bonnie Taylor - *Event Producer*
Mackenzie Muldoon - *Marketing & Entertainment Director*

Board of Directors

Barry Pickford - *President*
Dr. Elizabeth Donner - *Vice-President*
J. David Yeilding - *Treasurer*
Jim Feyerer - *Director, HR*
Christine Crosbie - *Secretary*
David Caplan
Paul Carenza
Tamzin Jeffs
Jonathan Lipszyc
Caroline Tapp-McDougall
Dr. Taufik Valiente
Daryl Yeo

Child & Youth Services

Our Child and Youth Services program is committed to providing information, support and advocacy services to assist individuals and families manage the impact of epilepsy in their lives. Assistance with education involves navigating the special education system, delivering in-services for teachers, conducting age-appropriate presentations for students and connecting children, youth and parents with others who are experiencing similar challenges.

This year, in collaboration with the Ontario branch of the Canadian Epilepsy Alliance, we launched "End Trash Talk" - a public awareness campaign designed by youth with epilepsy. End Trash Talk features a commerical that aired on four television networks, the Internet and YouTube. Together with the endtrashtalk.com website, where youth are telling their stories and the endtrashtalk Facebook page, the campaign has reached 38 million people so far! The campaign helps young people with epilepsy talk openly about what it means for them to live with epilepsy. It's led to new friendships, wiser adults and a better informed community.

> *" Checking out the new End Trash Talk website - it's so great. How brave and inspiring. You have really filled a void for youth and adults, like me, in their 20s who live with epilepsy. "*
>
> STEPHANIE G. *Epilepsy Toronto Member*

Adult Services

The Adult Services program provides adults affected by epilepsy with a comprehensive array of specialized support services, including individual and family counselling, case management, advocacy and group work.

This year, we established groups for Pregnant and New Moms, Spouses of People with Epilepsy and enhanced our "Friday Group Drop-In" program. The Friday Group provides our members with an avenue to socialize and try new activities and experiences in a relaxed and safe environment.

This past summer, Friday Group members joined a Leadership Sailing Program where they were able to master basic sailing skills, and demonstrate to all that epilepsy need not be a lifestyle barrier.

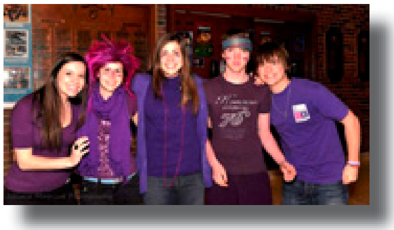
> *" Thank you for the end of loneliness, and for the friendship that comes with fellowship. In this supportive environment, I have been able to accept my disability, and focus on what I can do instead."*
>
> SUE R. *Epilepsy Toronto Member*

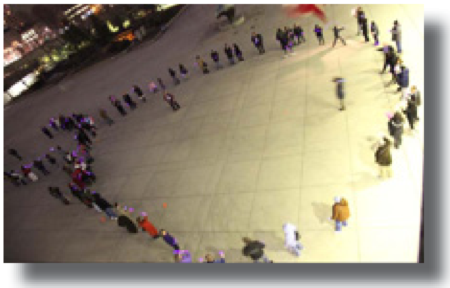
SCOTIABANK TORONTO WATERFRONT MARATHON

This past year, our team of 200 runners raised over $75,000 in support of Epilepsy Toronto's programs and services.
We are proud that Team Epilepsy was awarded 1st prize for the largest team in the marathon.

The funds raised by our awesome marathon participants enable us to continue to build a community that understands what it means to live with epilepsy. But it's more than just numbers; the marathon is a very moving experience for the people who gather for a cause they believe in. We hear from many about how deeply affected they are by seeing so many people with epilepsy running side by side with their family, friends, neighbours and colleagues through the streets of Toronto.

It's hard to find words to express how fulfilling this event is for all who participate in bringing epilepsy out of the shadows and into the public eye.





EPILEPSY AWARENESS

MARCH 26

PURPLE DAY

Twelve-year-old Cassidy Megan, founder of "Purple Day", wants all Canadians to understand that not all seizures are the same, and that people with epilepsy are ordinary people - just like everybody else. She invites all who care to wear purple on March 26th and show their support.

This past year, Epilepsy Toronto's community was out on Purple Day - proud and loud! We gathered at Nathan Phillips Square to tell our stories and share our hopes. After dusk, we formed a human ribbon of purple light with bright, purple glow sticks for all the city to see. We are grateful to the television and radio newscasters who wore purple and broadcast nationwide segments about epilepsy and our event.

Epilepsy Toronto staged a "Purple Challenge" this year, inviting individuals, schools, offices, businesses, students, and families to dress up in purple and show their support. And we held an Epilepsy Health Talk at Toronto Western Hospital, which was broadcast as a web conference across the internet.

Epilepsy Toronto is a part of a growing, international movement that is painting the world purple every March 26th. Next Purple Day, come and join us in shouting out that Epilepsy Matters!

> *“The employment support services provided at Epilepsy Toronto were the ones that I used to the fullest extent. It helped me get and keep a job for more than two years now and they still want me to work there.”*
>
> JASPREET B. *Epilepsy Toronto Member*

Employment Services

Epilepsy Toronto’s Employment Services apply a well-crafted set of tools that assist people with epilepsy looking for work to be job prepared, search for employment opportunities, learn their rights and responsibilities in the workplace and embark on employment with confidence. This year, one of our Employment Counsellors was awarded for his “outstanding work in promoting the rights of people with disabilities” by Mayor David Miller. Our Job Club continues to grow; providing our members with the opportunity to share job leads, meet with employers, attend workshops, conduct video-taped mock interviews, and join financial management and assertive training sessions.

To encourage employers to hire people with epilepsy, the Employment Services team proactively seeks opportunities with potential business partners. Members who are already employed are assisted through consultations with their employer, workshops with their co-workers and additional job retention supports. In the past year, we enjoyed notable partnership success with the Canadian Imperial Bank of Commerce, the Bank of Montreal, George Brown College and Ryerson University; the latter with an initiative that enriched both the teacher and the students’ understanding of the issues around epilepsy and employment.

Communications & Education

Epilepsy Toronto’s Communications and Education program addresses the urgent need to eliminate the stigma of public misconceptions that impact the lives of people with epilepsy. Public outreach, community education, awareness campaigns, the internet (including our website and Facebook) and our routine publications are all media we utilize to change behaviour and change attitudes. Epilepsy Toronto’s new Media Watchdog program involves actively responding to portrayals of seizures in entertainment and news that send the wrong messages. We’re interacting productively with local newspapers and radio stations and look forward to our member’s participation as we expand our scope of influence. This past year, through workshops and presentations, we’ve provided information on epilepsy to over 100 organizations including schools, corporations, health organizations, and social service agencies as well as seizure response training to 180 Toronto Police Officers, 100 TTC workers and numerous childcare and personal support providers.

Capital Campaign

In the past 15 years, we have moved five times - forever chasing affordable space that meets our many needs. In 2010, Epilepsy Toronto will be embarking on a journey to obtain a permanent home for our community. Our own home would enable us to do what we do - only better! Without the costs of moving and renting, we could ensure the long-term financial feasibility of our programs. The Toronto epilepsy community needs a place it can call its own; a warm, inviting, thriving hub of activity. This must be a place wherein our members feel a sense of real ownership; a place where they can relax and be themselves. We look forward to the day when we can welcome you to our new home.

SCOTIABANK
BUSKERFEST
in support of EPILEPSY TORONTO

> “BuskerFest is an eclectic display of advanced street performances – the kind you’re likely never to see anywhere else – from Canada, the U.S., Japan, England, Australia, Hungary, Sweden, Argentina and the Netherlands.”
>
> Greg Quill, Toronto Star

Scotiabank BuskerFest, held in support of Epilepsy Toronto is the largest epilepsy awareness raising event in the world, attracting more than a million people each year to our four-day extravaganza. BuskerFest is our primary fund-raising event and each year our fantastic festival gets bigger and better!

This past year, we launched the BuskerFest with our 1st Annual “BuskerBall”, an elegant evening affair showcasing our line up of performers from around the world and featuring a silent auction of objects d’art in support of epilepsy.

We integrated targeted, social media in our BuskerFest epilepsy awareness activities and found we had a lot more fans than we ever imagined! In fact, there are now so many YouTube videos about BuskerFest that we are starting our very own channel. BuskerFest provides us with many opportunities to raise awareness about epilepsy and we were thrilled with the range of media coverage we received in the newspapers and on the television, radio and web.

Our volunteer team of literally hundreds, of caring people is invaluable at an event of this magnitude.

We thank them all for giving us the support we need to make our festival a success for all people living with epilepsy.

Thank You

Corporate Donors

- Adiuvo Group Ltd
- AMJ Campbell Van Lines
- Altus Helyar
- Apollo Health and Beauty Care
- Assante Wealth Management
- BMO Financial Group
- Bousfields Inc
- Canon Canada
- Canpar Transport LLP
- Century 21
- Cervini Paint
- CIBC Wood Gundy
- Citi Cards Canada
- City of Toronto
- Cityzen Development/Fernbrook Homes
- Cobell Drywall
- Cool Tech
- Creative Edge Group
- Davies Ward Phillips & Vineberg LLP
- Deep Foundations Contractors Inc.
- Dural Flooring Ltd
- Toronto Eaton Center
- Eli Lilly Pharmaceutical
- Ernst and Young LLP
- Fasken Martineau
- Fenwick Automotive Products
- Fidelity Investments
- Fuller Landau
- Guidelines Advertising
- Hillcrest Mall
- Honda Canada
- Howe Gastmeier Chapnik Ltd.
- Jamaica Tourist Board
- KPMG
- Living Realty
- Masters Insurance
- Mayfair Electric
- Michael Wilson and Associates
- Model Railings
- Newhouse Rusin Professional Corp
- Oxford Properties
- Price Waterhouse Coopers
- Promenade Shopping Centre
- Quality Rugs of Canada
- Rainbow Cinemas
- RBC Commercial Financial Services
- RBC Dominion Securities
- Resmor Trust Company
- Russell Investments
- Scarborough Town Centre
- **Scotiabank**
- Scotia McLeod
- St. Lawrence Market Merchants Association
- State Farm Insurance
- Sunset Decks Inc.
- Telus
- Toro Aluminum
- Toronto Eaton Centre
- UBC Pharma
- Wilkinson Chutes Canada
- Wilson Vukelich LLP
- XLTEC
- Xerox

Employee Groups

- Bell Canada
- BMO Employee Charitable Foundation
- Hydro One
- IBM Employee's Charitable Fund

Grants and Foundations

- Better Day Alliance Foundation
- BMO Foundation of Hope
- CIBC Children's Foundations
- City of Toronto Community Support and Recreation Grants Employment Ontario
- Mackenzie Financial Charitable Foundation
- Ontario Disability Support Program
- Ontario Tourism Marketing Partnership Corporation
- Service Canada
- United Way of Greater Toronto

Individual Donors

- Brian Greenspan
- Donna Arnold
- Stephen Wong
- Dorothy Macartney
- Eustace Fernades
- Gaetane Ayotte
- Hysenaj Family
- John Garrow
- John Skogstad
- JR Kingsley Ward
- Lydia Bayon
- Narasimhan Saroja
- Patricia Morgan
- Penelope Sisk
- William Burt
- Yelena Aronov

Special Friends/Community Partners

- Jerry Catalfo
- Andy Charles
- Maria del Carmen Terry
- Joe Cordiano
- Sam Crignano
- Lauren Dubois
- David Fitzpatrick
- Veronika Herring
- Robin Hibberd
- Bruce Hilliard
- Helen Leask
- Steven Lynette
- Dayl Marks
- Bill Sherman
- Paul Palen
- Danny Salvatore
- Patricia Stevenson
- Dr. Peter Tai
- Dennis Wiggan
- Phillip Wootten
- Canadian Epilepsy Alliance
- Community Living Toronto
- Epilepsy Ontario
- Geneva Centre
- Harbord Key Club
- Hospital for Sick Children
- Humberside Key Club
- JOIN - Job Opportunity Information Network
- M&M Meats
- Meta Centre
- Russian Student Association of U of T
- SACEC
- Sonic Deli
- Toronto Police - 51 Division
- University Health Network

Media Partners

- Captivate Network
- CFRB
- CFTO
- CP 24
- CTV
- EDGE
- Eye Weekly
- Metro News
- Mix 99
- Toronto.com

In Memoriam

- Shirley Briffa
- Christina Buffey
- Douglas Gow
- Cornelia Paul
- Karen Posner
- Chris Walsh
- Aimee Wilkinson-Harris