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Purple Walk
for Epilepsy Toronto



EPILEPSY
Toronto
See the Person

Support Matters

Annual Report 2016



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

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Purple Walk

President's Message

Dear friends,

I am happy to report on another successful year in the life of Epilepsy Toronto and our commitment to supporting people living with seizures and their families.

Our financial situation remains stable, thanks in no small part to our on-going efforts to fundraise in creative and innovative ways and to elicit the support of both the epilepsy and broader Toronto communities in an increasingly challenging fundraising environment.

Our signature fundraising event, *Toronto International BuskerFest* moved to Woodbine Park this year, giving the event a more-relaxed family friendly atmosphere. The park setting certainly offers a different experience from that of Yonge Street, and the St Lawrence Market, and while we did not see the massive crowds of recent years, many favorable comments were received from attendees. While the lack of a marquee sponsor posed challenges, the reduced costs and stronger focus on gate donations helped generate profitable results.

Other fundraising events proved successful, including an even larger *Purple Walk* and a very exciting *Night is Yonge Soiree* with our ambassador, Tristan Thompson. Epilepsy Toronto launched a new major fundraising event, *Holiday Fair in Nathan Phillips Square* which brought the holiday spirit and epilepsy awareness to the downtown core for 16 days in December. While we experienced some of winter's worst weather, we were pleased with the exposure we received, and the financial contribution that we achieved. I'm looking forward to these events expanding to new heights in 2017.



Epilepsy Toronto's primary focus, supporting Toronto's epilepsy community, continues unabated. Whether through our ever expanding counselling services and support groups, workshops, community presentations, and public education activities, our agency is excelling in providing the care and information our clients need.

Our concerted efforts around government advocacy continue, with recent major successes on mandatory reporting of drug shortages and projects for supporting students with seizures coming to fruition. We are continuing to work with our partners in the epilepsy community to identify opportunities to work with government, particularly at Queen's Park, for improved community support for our clients.

Over the next few months we will be looking ahead as we review our agency's strategic plan, with the goal of ensuring our services and support meet the growing needs of the epilepsy community and are sustainable and successful in the coming years.

I want to thank the Board of Directors for their leadership of our agency, our staff for their exceptional daily commitment to supporting people living with epilepsy, and the many volunteers and donors who make the work of Epilepsy Toronto possible.

Sincerely,

Daryl Yeo
President
Epilepsy Toronto

Children & Youth Services

The Children and Youth department has been focusing on continuing to increase its reach and breadth of service.

Whether in the classroom, at the Epilepsy Monitoring Unit, or in the great outdoors, Epilepsy Toronto provides critical support to children & youth with epilepsy and their families. In 2016 we focused our efforts towards:

- Developing and implementing a new Parent Support Group, where parents of children with epilepsy can share their experiences and strategies;
- Collaborating with the TDSB to establish Procedures for supporting children with seizures in Toronto schools;
- Creating and implemented a 3-part Mindfulness Group for parents and caregivers of children and youth with epilepsy;
- Rolling out EpilepsyAndU, a post-secondary teaching and accommodation tool developed in partnership with York University;
- Increasing the number of families we connect with at the Sick Kids Epilepsy Monitoring Unit on a weekly basis;
- Doubling the number of participants in our Winter Retreat;
- Continuing to partner with Camp Couchiching and increasing the number of summer camping opportunities for kids with epilepsy in our community.



The De Sousa Family

I didn't know what to feel. A new epilepsy diagnosis can cause uncertainty and fear, but when you are a parent of a child with seizures, that stress multiplies. Questions abound: What do I need to know? How do I keep them safe? Did I do something wrong?

"You think you failed, that you missed something," says Andrea Greaves, whose 17-year old daughter Emily was diagnosed with epilepsy 2 years ago. The initial shock of the diagnosis quickly gave way to uncertainty. "We knew nothing. You don't know the system. What questions am I supposed to ask," she says.

Sabrina De Sousa, whose daughter Isabella was diagnosed with epilepsy in 2016, had some support to draw on: one of her sons was already seeing a neurologist, and as an educator she had some training on seizures. That didn't make the situation any less intimidating.

"It's completely different watching one of your students have a seizure and watching your daughter have a seizure. As parents right away we put on this 'strong' face to reassure our child that everything is going to be okay, but in reality we are worried ourselves. It's nice being able to come to a support group and 'just be ourselves' and share our fears and feelings."

Both Andrea and Sabrina were referred to Epilepsy Toronto's Parent Support Group, where they could meet with other parents whose children were dealing with epilepsy.

"There was no one there judging me," says Sabrina. "Everyone just understood."

"You have a story to tell and it's very emotional," says Andrea, "but you can let it out because everyone in that group knows what you're talking about. You can say 'I don't know what questions to ask'. Everyone there is either going through it or been through it. There's a sense of relief, being able to open up to people."



Being able to access that information and support early on can be a big advantage for both children and parents. Andrea and Emily had to struggle alone for years before being connected with Epilepsy Toronto. Sabrina joined the group within a few months of Isabella being diagnosed, something she found very useful.

"I was able to process my emotions a lot faster. For thirteen years we didn't have to worry about this. We knew what it was like before and we wanted that back. Admitting that we have to deal with epilepsy is hard, but if I wanted my daughter to be ok, I had to be ok." Part of learning to be ok is allowing their children to live their lives.

"You need to try and create some distance, for both your sakes," says Andrea, who valued the experiences of other group members on issues as seemingly simple as the first time the child goes swimming again or as complex as brain surgery.

"When Isabella had her first overnight trip, I was able to hear what other parents did when their kids were away," says Sabrina.

The value of the group is clear for both women.

"Knowing that these people are on the same journey creates an openness," says Andrea.

Employment Services

The past year has been one of growth and change for the Employment Services department at Epilepsy Toronto, including adjustments to improve service delivery while maintaining high-quality programming.

An important focus of Employment Services was building group-based programming, including Group Intakes that enabled us to start off our services with more of a supportive, community feel while also saving dozens of service hours in the process.

Some of the Employment Services highlights include:

- Placement of 38 clients in jobs across multiple sectors;
- Increasing our ODSP service to enhance pre-existing services for clients;
- Introducing job coaching services for select clients and beginning to build a job coaching network;
- The introduction of the Epilepsy Employment Group (EEG), an 8-week practical support group with content generated by the group itself;
- A Speed Mentoring event involved over 25 people in a fast-paced event which paired 10 job seeking clients with 10 community service providers;
- Work in Progress (WIP), a one-day conference for job seekers with invisible disabilities, planned in conjunction with REENA and Woodgreen's WIN program.



Blake, Cassels & Graydon LLP with ET staff on Purple Day

Nicole Asta has been living with epilepsy since before she applied for her first job. Diagnosed at age 12, she has yet to find a treatment that effectively controls her seizures; she currently takes seven medications to provide any control.

Epilepsy isn't something Nicole is afraid to talk about. She has been connected with Epilepsy Toronto for years, taking part in the *Be Heard* public education program when she was younger and helping to facilitate a panel discussion for parents of newly diagnosed children.

Despite being an intelligent, well-educated person, she has struggled to find work in her field, Human Resources, a struggle that epilepsy has only complicated. She finally connected with Epilepsy Toronto's employment team and began the process of doing an employment assessment and developing her job search skills.

"I wanted anything related to recruitment. I wanted to get into the recruitment field," she says.

Nicole needed help developing the skills and contacts to land the job. Even simple things like Epilepsy Toronto's Job Developer reworking her resume made a big difference.

"It was magic," says Nicole. "He has the knowledge of how to do interviews properly, how to get someone on your side." She says the networking connections he offered made a big difference. After sending her frequent job postings and suggestions about potential employers, he connected Nicole with a contact at Scotiabank, just in time to apply for an available contract position.



"I was the last resume in and I got the position!" she says. The job has her developing a variety of tasks you would see in a recruitment department, and a chance to develop skills and job shadow for future opportunities.

It has turned out to be a work environment that is highly supportive of the challenges of living with seizures. Nicole has asked for, and received, a few straight-forward accommodations: shifting her work hours back to prevent sleep deprivation, using visual notes for instructions, and choosing a particular seat during meetings.

"I have seizures in rooms with lots of people, and it's hot and claustrophobic, so I go and check out the room ahead. If it's small I sit by the door in case I need to stay cool," she says.

She has a simple message for employers looking to hire someone with epilepsy.

"Don't be afraid of the possible challenges you may think that person has, because those challenges may not be as large as you think. Give them a chance".

Adult Services

At Epilepsy Toronto we provide support when and how it's needed. That could mean helping answer questions after a new epilepsy diagnosis, dealing with the emotional and family challenges of living with seizures, discussing new treatment options, or simply meeting the challenges of day-to-day life.

Epilepsy Toronto Adult Services support program highlights include:

- Assisting 238 adults with epilepsy, including 58 new clients;
- Expanding our Surgery Support Group in partnership with Toronto Western Hospital;
- Hosting workshops on Epilepsy and Memory; Dating & Relationships, and Women & Epilepsy Issues, and offering an 8-week yoga class for adults with epilepsy;
- Advocating for improved TTC Accessibility;
- Adding more members to our Scarborough support group and hosting a guest speaker from Toronto Public Health to discuss Stress Management;
- Outreach to neurologists to promote support services for newly diagnosed clients;
- Laying the foundation for future life-skills programming;
- Embarking on a new project to create a book filled with member's stories, poems, and artwork about their lived experiences with epilepsy. We hope to publish this book by the end of this year.



Toronto Western Hospital and ET staff

If Tanja Stojanovska could have her way, her early experiences with seizures would be very different. Tanja was diagnosed with Type 1 Diabetes at the age of 5 and 31 years later diagnosed with Epilepsy.

Her first seizure was twenty years ago but was attributed to her diabetes and low blood-sugar. Her second seizure happened a year ago, following brain surgery to remove three cavernomas. She was put on anti-seizure medication after surgery and was taken off after her follow up since nothing occurred.

A teacher for 11 years, she thought all was well until she had a seizure while leading her students on a field trip through Kensington Market. The 2nd seizure happened a few months later while she was walking down the stairs of her apartment building.

To make matters worse, despite having visited two hospitals as a result of her seizures, she never received a referral to Epilepsy Toronto.

"I was very disappointed," says Tanja.

She found the agency herself online and began receiving counselling from our Adult Services staff. She also wanted to be connected with our Children and Youth Director, because one of her seizures had happened while she was leading a class trip. With the possibility that another one could happen at school, she wanted to educate the students and other staff members about seizures.

"With my students, it was closure," she says. "It was nice for them to get the information from a professional and now they have the resources to turn to if they ever encounter somebody having a seizure."



Tanja thinks that a referral to Epilepsy Toronto should happen whenever a doctor comes across an epilepsy diagnosis.

"The doctors that I encountered this year didn't have enough time to give me any kind of information about epilepsy. It would have been great if I could have been given a card that said *Epilepsy Toronto* with contact information. Then I would know that there is an agency in Toronto that can give me information, guidance, counselling, and whatever else I may need."

For Tanja, while the internet has enormous amounts of information about epilepsy, it didn't have the wealth of experience that a counsellor can provide.

"It was nice coming in contact with someone that was able to give me information, clarification and an opportunity to release pent-up stress and sadness; having someone that knows about epilepsy hear me and help me deal with it and provide me with answers to the questions that arose and may arise."

Tanja's belief in the importance of early access to counselling and support services has translated into her professional life; she recently recommended Epilepsy Toronto to community members in her school area.

Thank You

Thank you to our many donors, funders, and special friends, without who's generous support and remarkable goodwill, we could not hope to achieve our goals. Their heartfelt contributions, and the contributions of countless volunteers throughout the year, directly improve the lives of thousands with epilepsy and their families, and make this community a better place to live.

We are particularly grateful to our 3 leading sponsors without whom our work would not be possible.



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HOLIDAY FAIR
nathan phillips
S Q U A R E

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Nighttime at the first annual Holiday Fair in Nathan Phillips Square



Tristan, Andrea, and Amari Thompson at the Night Is Yonge Gala.

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