

2017 Annual Report



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President's Message



putting in place essential building blocks for the provision of critical life skills and housing support programs in the years ahead. Our importance and value to the Toronto epilepsy community has never been greater; something I can attest to in a very personal way.

My daughter, Lindsay, has lived with epilepsy for over 25 years, with a combination of tonic-clonic, simple and complex partial seizures, almost daily. We had always hoped that surgery would be an option for her, but each time we explored that possibility, she was deemed an unsuitable candidate; until last year, that is, when everything changed. She was re-assessed in the Epilepsy Monitoring Unit at Toronto Western Hospital, and told that, not only was surgery plausible,

Epilepsy Toronto has had yet another eventful and productive year, with continued progress and achievement on all fronts. We increased counseling to children and adults, attracted unprecedented numbers of people to our signature community events, and began

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 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.

there was a 75% probability she would become entirely seizure free. Of course, it would not be without risk. And there was the rub; should she take a chance or not? It was tantalizing and terrifying decision. She looked to Epilepsy Toronto for support. Our daughter has long been involved with one of Epilepsy Toronto's adult support groups, and was able to draw on her connections there for comfort and guidance with this very difficult choice. She spent hours, as well, weighing her options with ET's Director of Adult Services, Rosie Smith, and through meetings with Dr.'s Gold and Valiente from the Toronto Western assessment and surgical team. Ultimately, she decided to give it a shot. Pretty sure I was more terrified than she. I'm happy to report, that our daughter has come through with flying colours, and has been seizure free for

the better part of five months. While she still has a ways to go with her recovery, everything seems to be unfolding as well as we could have hoped.

My family and I are forever grateful for the support and compassion that we received from this remarkable little agency in our time of need. The value and importance of organizations such as ET cannot be overstated.

On behalf of the Board of Directors, staff, and volunteers of Epilepsy Toronto, I would like to express my sincere appreciation to our many supporters, and proclaim our continuing unwavering commitment to those we proudly serve.

Daryl Yeo
President,
Epilepsy Toronto

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.

Epilepsy Toronto Staff

Brooke Barrington
Social Worker Adult Services

Geoff Bobb
Executive Director

Rindy Bradshaw
Program Director, Teaching Awareness Through Puppetry

Brandon Fairley
Director of Development

Carter Hammett
Employment Manager

Afroza Hossain
Financial Manager

Joanna Kapusta
Office Manager

Katie Lundy
Director of Children & Youth Services

Tanya McCormack
Recreation Coordinator

Angini Mohammed
Public Education Coordinator

Mackenzie Muldoon
Director of Communications

Nicole Nelson
Director of Development

Jesse Preston
Job Developer

Rosalee Robinson-Smith
Director, Adult Services

Kirsten Sixt
Program Director, Teaching Awareness Through Puppetry

Michael Smith
Community Liaison

Bonnie Taylor
Festival Director, Toronto International BuskerFest

Interns:
Umme Afroz
Kiera Sheehan
Jarrett Stoll

See The Person



"I love community care. This is definitely where I should have ended up, it just happened a lot sooner than it probably would have otherwise, so thank you seizures. " - Glenna

The "On The Wall" project is an effort to cover the walls of the Epilepsy Toronto offices with the faces and stories of our members. The intention is that when clients come in, they know they are not alone; that their struggles are shared, but that there is also hope for success and joy in their journey with epilepsy. We want them to know that they have come to a place where people living with epilepsy are seen, heard and celebrated; where they do not need to hide their epilepsy - in fact, they can choose to wear it proudly.

We have heard stories that have moved us, inspired us and at times surprised us; from the story of a new immigrant, single mother of two, one with a condition that would be shunned back in their home country;

to a retired business man, who feels like one of the lucky ones, as medicine has worked to control his seizures and he has excelled in business and is now enjoying his retirement.

Glenna was diagnosed with epilepsy as a young adult while she was studying to be a nurse. She found juggling the stresses of seizures and school a major challenge, amplified ten-fold with the start of her first job. She found the demanding schedule, with alternating day and night shifts, exhausting, and it wreaked havoc on her epilepsy. She chose to leave that job and began searching for work that would give her full-time hours, but also the predictable schedule her body required. It was no easy

task, but eventually she landed in Community Care, where she discovered a new-found passion.

Over the years, Glenna has learned to advocate for herself. She has found that being pro-active and taking ownership of her epilepsy gives the people she works with confidence in her abilities. Sometimes this means having difficult conversations, that she may have once chosen to avoid; but she has learned it best to be honest about her epilepsy and put her safety, and the safety of others first.

Nicholas has been a regular at our office from the time he was a child, and is now a mainstay member of our Friday recreation group; a group he loves to attend, and that his mother says is one of the highlights of his week.

Affected by epilepsy and other health challenges, Nicholas has had to work hard for his independence. He was told he would never be able to travel on his own, but he persevered, and now proudly rides the bus to and from our office every Friday. When Nicholas came for his photo shoot, we all learned something new about him. He was asked to bring in something for the photos that he is passionate about, and he showed up with two of his own paintings. We had no idea he had this amazing talent, which is such a strong reminder to us of the importance of seeing beyond epilepsy.



Nicholas

Then there is **Angela**. We received a message earlier that day that she may not make it for the photo shoot as she'd been in hospital for the past few days, after a seizure. We assured her husband that her health was a priority and not to concern themselves about making the photo shoot.

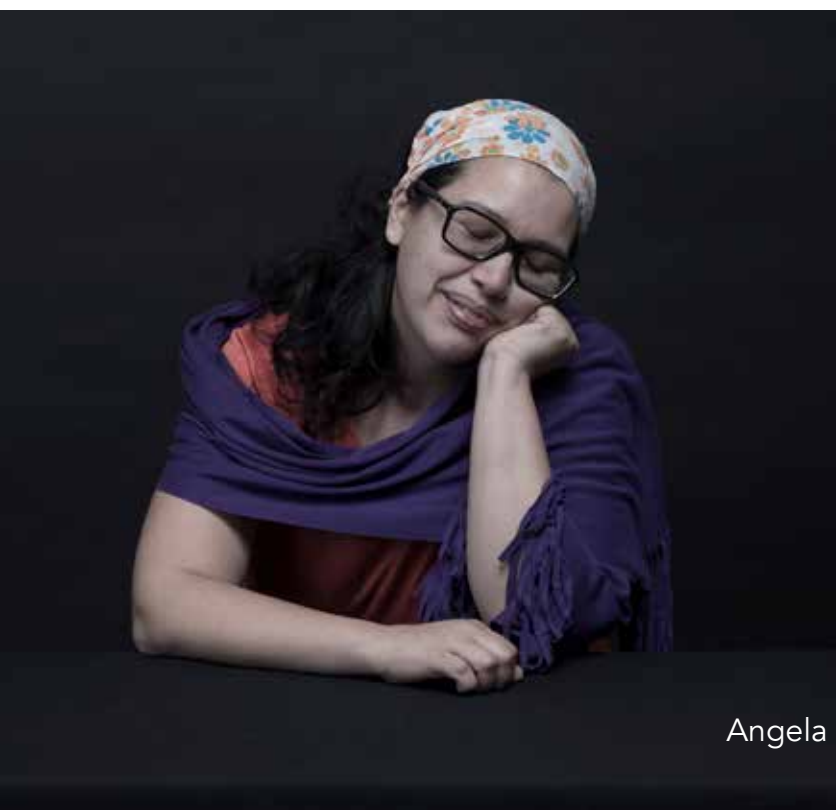
However, at the very end of the day, the four of them, Angie, Peter, Nick and Isabella arrived – direct from the hospital. Angie's exhaustion was visible, but she had insisted. They saw it as a chance for them to give back to the community that had supported them through so many struggles. Angie spoke openly of her fears that her seizures were too much of a burden and responsibility on her children, who had been the witness and the care givers to her so many times.

Isabella and Nick bantered back and forth about their experiences coaching adults on how best to care for their mother when she had had seizures in public.

"Sometimes we do have to look after her, just to make sure she doesn't hurt herself." Declared 12 year old Isabella, and then followed it up with "But she always looks after us."

More responsibility than most children face, but there was a clear sense of pride, that they had been the heros, impressing first responders and onlookers with their confidence, calmness and knowledge.

One of the last shots of the day, is the one on the cover of this report. Their love for each other is palpable. At the end of any day, that seems to be what matters most.



Angela

Finding Strength

Living with epilepsy can be a stressful experience for many, regardless of seizure frequency or diagnosis. It affects everyone differently, and often results in extreme debilitating anxiety and depression. Epilepsy Toronto offers an eclectic array of cognitive behavioural, narrative, and solution-focused therapies that provide our members a safe place to address their issues, and discover within themselves, the personal strength to manage and live well with this condition.

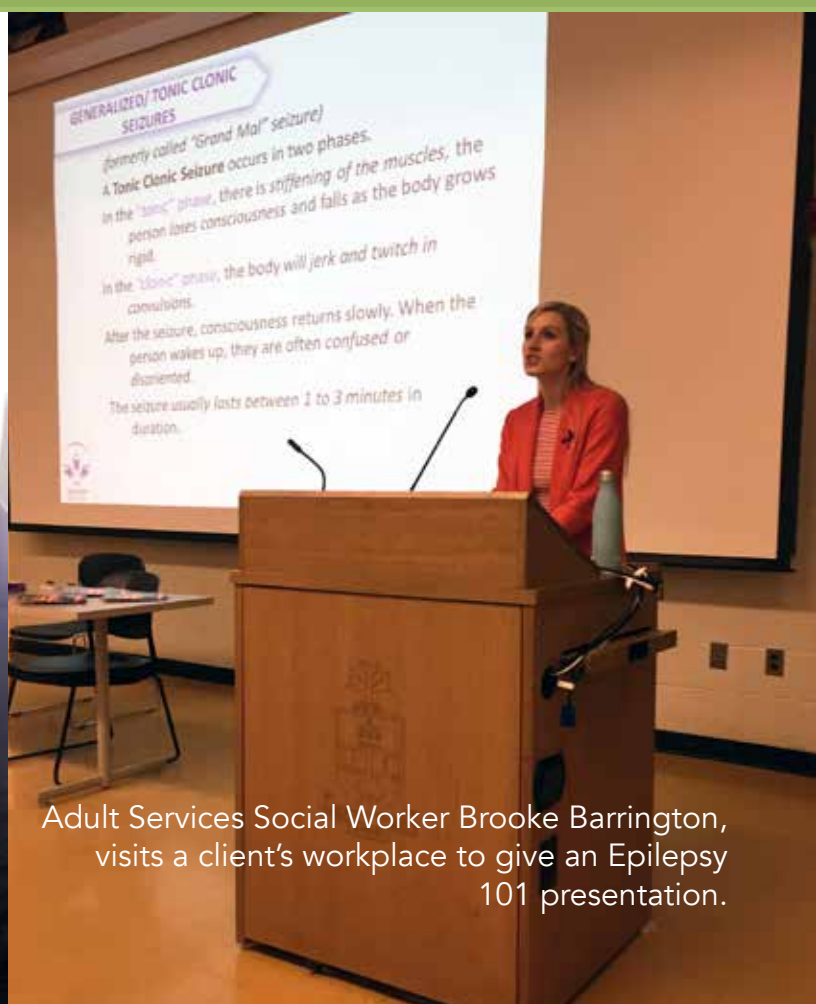
Offered, as well, are a wide selection of psychoeducational support groups and social gatherings that harness the power of community. It is a privilege to watch our members bolster one another through times of crisis, and find strength and validation in shared experience; we all learn from participating in these groups. We are also fortunate to be involved in educating the community to create awareness and reduce stigma surrounding epilepsy. It is truly rewarding to witness people's perceptions of epilepsy change for the better after learning more about the condition.

Our members inspire us. We are honored to be a part of their lives; to share in their trials and triumphs and stand at their side in times of great need.

"Thank you so much for what you did for me. You changed my life and that's the truth. I did not realize how my negative thoughts were impacting my life; I just knew I was not myself. You opened my eyes and taught me skills I will always use." EC, Adult Services Client



Rosie Robinson-Smith, Director of Adult Services, visits with a long-time client to celebrate purple day with her while she recovers from medical treatments.



Adult Services Social Worker Brooke Barrington, visits a client's workplace to give an Epilepsy 101 presentation.

Working Solutions



Employment Manager, Carter Hammett welcomes attendees to the first annual Work in Progress Conference.

Job seekers with disabilities often go from the crisis of not having a job, to the crisis of getting a job. Trying to live with an unpredictable disability and all of the issues that accompany it while unemployed is challenging enough. Issues like disclosure, accommodations and stigma move to the forefront when a job is finally obtained. The dedicated employment team of Epilepsy Toronto understand this and collaborates with job seekers to help find the best match possible for their career goals. We achieve this by offering counselling, action and career planning, advocacy, job development and maintenance services. In addition we also host special events like speed mentoring and an annual 'Work in Progress' Conference aimed at job seekers with invisible disabilities.

New this year is a unique two-year project called 'Bridging the Gap', an outreach and skills development program aimed at employers looking to diversify their teams. Volunteers are recruited, trained and accompany speakers to corporations to share their stories and discuss the benefits of hiring workers with epilepsy. It's a terrific opportunity to learn about the contributions our community can make to a workplace.

"At the WIP Conference I was introduced to a potential employer in an industry that I wanted to be a part of; it led to a period of employment and reassured me that I am still capable of working, and working well. I wouldn't have had that boost to my confidence without it." Jeff, Employment Services Client

Making Connections



"I want to feel normal. Will I still have friends if I have seizures?" Megan, Child & Youth Services Client

Epilepsy is a fearful, isolating experience for many, but doubly so during childhood or adolescence, when fitting-in and being accepted by peers is life-defining. The uncertainty and unknowns of epilepsy can be profoundly anxiety provoking when you're feeling vulnerable and alone. Connection is key; the opportunity to hear another human being say "I have epilepsy too" can spell the difference between strength and desperation; depression and hope. Megan, like so many other young people with epilepsy, craves connection, familiarity, and someone; anyone who understands what it's like.

2017 Winter Family Retreat
at Geneva Park



Epilepsy Toronto's Children and Youth Services prioritize connection and empowerment, by offering opportunities for children and youth to learn, engage and relate to one another, and to the epilepsy community at large; whether marching together as a united front in the annual Purple Walk, chatting with newfound friends while roasting marshmallows at the Summer Family Retreat, or standing up in front of one's class to share what it's like to live with seizures. The stories are unique, but the connection is universal.

**2017 Summer
Family Camping
Trip to Balsam
Lake**



In The Community

We are always striving to eliminate the stigma surrounding epilepsy and bring it more into the public eye. Our public events are attended by thousands of people, both from the epilepsy community, and far beyond; they help us garner media attention, raise funds and increase awareness for epilepsy and the services we provide.



Purple Walk 
for Epilepsy Toronto

**AMARI
THOMPSON
SOIREE**



TORONTO INTERNATIONAL
BuskerFest
FOR EPILEPSY



HOLIDAY FAIR
nathan phillips
S Q U A R E
Supporting Epilepsy Toronto

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.

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