EPILEPSY
Toronto
See the Person

2018 Annual Report

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President's Message

2018 has been another year of exciting growth and achievement at Epilepsy Toronto. I'll never cease to be amazed by the creativity and tireless work of our dedicated staff, and the courage and passion of those we serve.

In 2018, we laid the groundwork to a new life skills and housing support program for vulnerable adults with epilepsy. This is a HUGE concern for many young adults in our community, whose seizures present significant challenges to independence. Also in 2018, we were successful in establishing a partnership with the Toronto District School Board to ensure all children with epilepsy have formal seizure plans and access to rescue medications at school, should the need arise. This practise has since become policy Province-wide, and is certain to improve school integration for our youngest members. This year, we rolled out our 'See the Person' campaign, telling our members' stories through mainstream and social media platforms, as well as with the publication of a beautiful little book created by and for our members to address feelings of isolation and promote open dialogue about epilepsy. We continue to expand and diversify our groups for adults and children with epilepsy, with an emphasis, this year, on cognitive behavioural therapy and peer support.

As always, a special note of thanks to United Way, the Province of Ontario, City of Toronto, Scotiabank, Mackenzie Investments, CUPE 4400, Tristan Thompson, and all our many committed sponsors and supporters for their remarkable generosity, without which we could not hope to achieve our good work. Many thanks as well, to the hundreds of volunteers who roll up their sleeves each year to produce the Amari Thompson Soiree, Purple Walk for Epilepsy, Toronto International BuskerFest, and Holiday Fair in the Square that collectively, have evolved into the largest showcase for epilepsy awareness on the planet.

I am so proud of the many achievements of Epilepsy Toronto in the past year, and look forward with great anticipation to new and exciting initiatives in 2019, and beyond. Our past and future successes can only be achieved through the hard work, dedication and ongoing contributions of our Board of Directors, staff, volunteers, donors, corporate and other sponsors and supporters, and I wish to extend to them all, the sincere thanks of our agency.

Daryl Yeo
President,
Epilepsy Toronto

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.

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 meaningfully 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.

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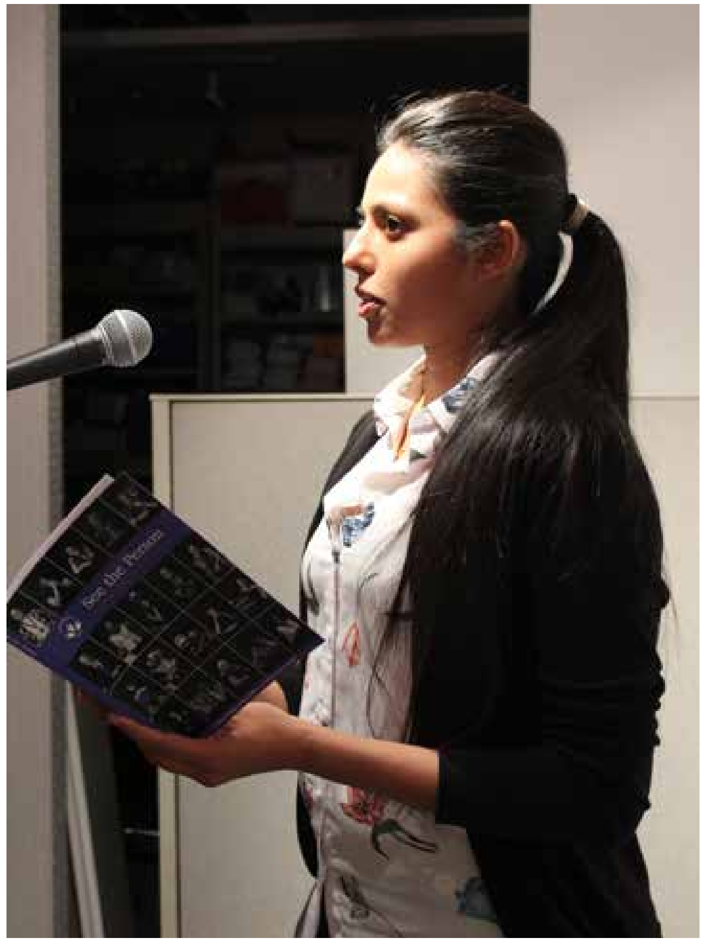
See The Person

The *See the Person* initiative was designed to provide our members a platform to share their epilepsy experience with the world at large. It is a storytelling campaign that depicts the many faces of epilepsy, and the trials and triumphs of people who refuse to be defined by their disorder.

Over the past year, the *See the Person* campaign profiled dozens of Epilepsy Toronto members from all walks of life at conferences, workshops, and public events, and through all manner of print, digital, and social media. We conducted an exhibit for Members of Provincial Parliament at Queen's Park, and published our very first See The Person book, that disappeared off the shelves, and is already in line for a second print.

Epilepsy is, for many, a tumultuous and unpredictable journey. Our hope, is that these stories will provide those newly diagnosed with this disorder, strength and encouragement, a sense of community, and hope for the future. They will see a reflection of themselves, and know that they are not alone.

Adam Shapiro poses proudly with his "On the Wall" photo

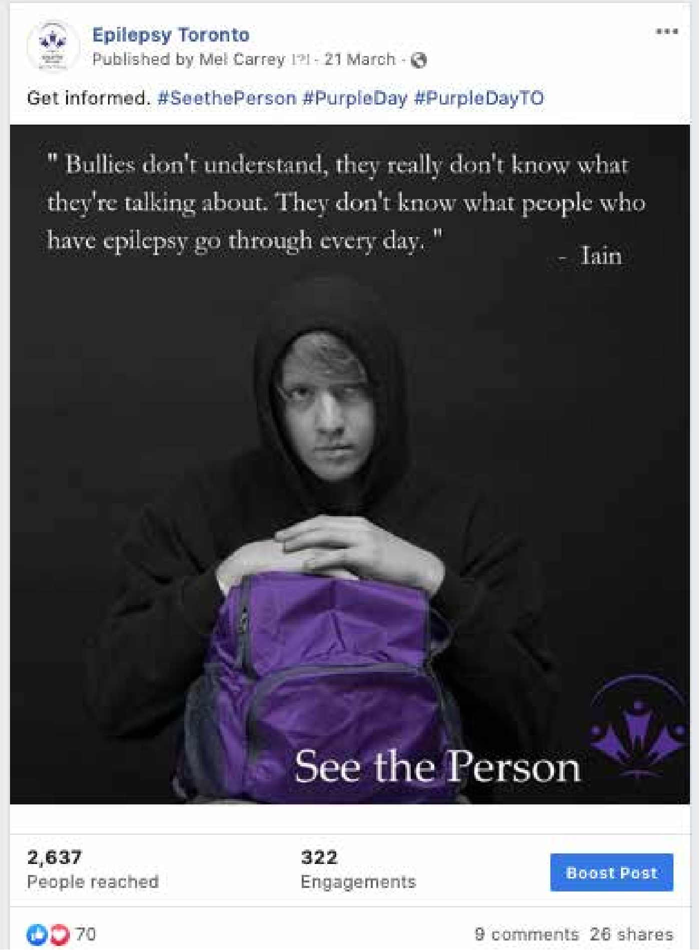


Cheryl Mendes reads from her short story at the **See The Person** Book Launch in November, 2018

Last year, with this in mind, we introduced the "On the Wall" project; a series of professional images capturing raw moments and captivating quotesW, that now cover our office walls with the faces and stories of our members. These same images are featured in our *See the Person* anthology, which showcases the experiences of fifty of our members through short stories and poetry, and their expressions of hope, struggle, accomplishment, and wisdom. Each story is different from the next, much like each person's epilepsy and treatment. Though the experiences differ, one is drawn to the common threads that weave throughout.

Special kudos to our "Bridge the Gap" ambassadors who volunteer their time to share their personal epilepsy stories at workplaces and community agencies across the city. They have set their sights on delivering three hundred and sixty talks, this year, to over seven thousand people. It's a remarkable commitment, certain to leave a lasting impact for generations.

Bridge the Gap ambassadors, Donovan Mckenzie, Tannys Williams, and coordinator Angini Mohammed representing Epilepsy Toronto at a Community event



Epilepsy Toronto
Published by Mel Carrey · 21 March ·
Get informed. #SeethePerson #PurpleDay #PurpleDayTO

" Bullies don't understand, they really don't know what they're talking about. They don't know what people who have epilepsy go through every day. "
- Iain

2,637
People reached

322
Engagements

70

9 comments 26 shares

When our 'On the Wall' campaign was released online, our Facebook interaction grew by 314%, and Twitter and Instagram's reach both doubled.

It is our hope that all of our members, past, present and future, will turn to these stories for guidance, empowerment and comfort as they navigate the world of epilepsy. And perhaps they too will be inspired to one day share their own story to help others *See the Person*.

Rochelle Desrosiers and her wife Barb McCutcheon stand together in front of their "On the Wall" portrait

Knowledge and Connection

M.P. is living with epilepsy. She and her husband have been looking into having a child. They are pretty scared. They have plans to discuss this with their health care professional but thought it would be great to speak with someone who has been down this road who would be able to share their experiences relating to pregnancy and raising a child while still struggling with seizures.

This is a story we hear often; whether it is related to someone considering epilepsy surgery; a recent epilepsy diagnosis or just someone struggling with the impact of epilepsy. They need Peer Support.

The Mental Health Commission of Canada defines peer support as "a supportive relationship between people who has lived experience in common." Persons with similar experiences are better able to relate and provide others with empathy and validation.

This past year Epilepsy Toronto trained its first official group of Peer Support Workers and will continue to do so annually as a means of building the capacity of our agency and empowering those with lived experience to give back to others who are now where they were.

Thank you to all our clients who have always been ready and willing to be the shoulder another client can lean on when needed.

> *"I did not think I was capable of doing this role but I left the workshop feeling confident that I am now at a place where I can offer support to others through my own experiences."* Peer Support Worker

Our first Peer Support Workers have completed their training.

Our Speed Mentoring program has proven beneficial for both Mentors and Mentees

> *"I really appreciated the diversity of the mentors and how they each took the time to hear my question and give empathetic, meaningful insight. Speaking with them has improved my confidence."*
> - Speed Mentoring Participant

In 2018, our Employment Department had a hand in supporting well over 100 job seekers through assessment, counselling, referrals, advocacy and job readiness training. We helped over 30 people obtain employment.

Integral to our department's programming were several special events we hosted throughout the year. As demand continues to grow, we increased the frequency of our signature **Speed Mentoring** nights, and hosted our second annual **Work in Progress Community Forum** for job seekers with episodic disabilities. We introduced a new **Cognitive Behavioural Therapy (CBT) Based Job Search Support Group**, which really resonated with participants. Our first ever **Career Planning Week** was an interactive group workshop series that helped people identify and map out realistic occupational goals. Add to that an appearance on the AMI series *Employable Me*, speaking at a Federal Inclusion Symposium, and the launch of our new Advisory Committee, and it all adds up to a pretty packed year!

We cannot begin to convey the joy of witnessing someone discovering their own inner strength, then bringing that forward to find and maintain meaningful employment. We're honoured to be able to contribute in some small way to that joyous outcome.

> *"It has helped me to identify what is driving my actions and how they are impacting my life. It has brought up some deep emotions and it is challenging, but I feel now a little more hopeful and clearer on what I want to achieve in my life"-*
> CBT Workshop Participant

Our CBT Group was in part facilitated by our BREM (Bridge to Registration and Employment in Mental Health) Intern, Krystal Dodd

Support When It Counts

"The best thing about the retreat was that I made new friends and went swimming." - Child participant in Summer Family Retreat, 2018

Our Child and Youth Services Department had a busy and productive 2018, with many new and exciting initiatives.

We organized our first ever summertime family retreat at the incomparable Geneva Park Conference Centre on sparkling Lake Couchiching. Sixty families came together for a weekend of campfires and canoeing, soul searching and support. Friendships were formed that are likely to last a lifetime.

Our Teaching Awareness through Puppetry (TAP) program was expanded to include new shows for young children that address bullying, anxiety, and mental health. The goal is to begin developing self awareness and coping skills from a very early age.

A guide was developed for parents of young children with epilepsy to help with navigating the school system, and an online epilepsy education tool created for university and college professors. The goal is to make schools fully accessible from the time you enter, to the day you graduate.

With this same goal in mind, the agency formed a collaboration with the Toronto District School Board to ensure every child with epilepsy at school has a personalized accommodation plan and access to rescue medication, should the need arise. This is a practise that has since been adopted by the Ontario Ministry of Education as a policy for all schools, Province-wide.

Teaching Awareness Through Puppetry (TAP)

A Guide to Navigating the Ontario School System

For Parents of Children with Epilepsy

EPILEPSY Toronto

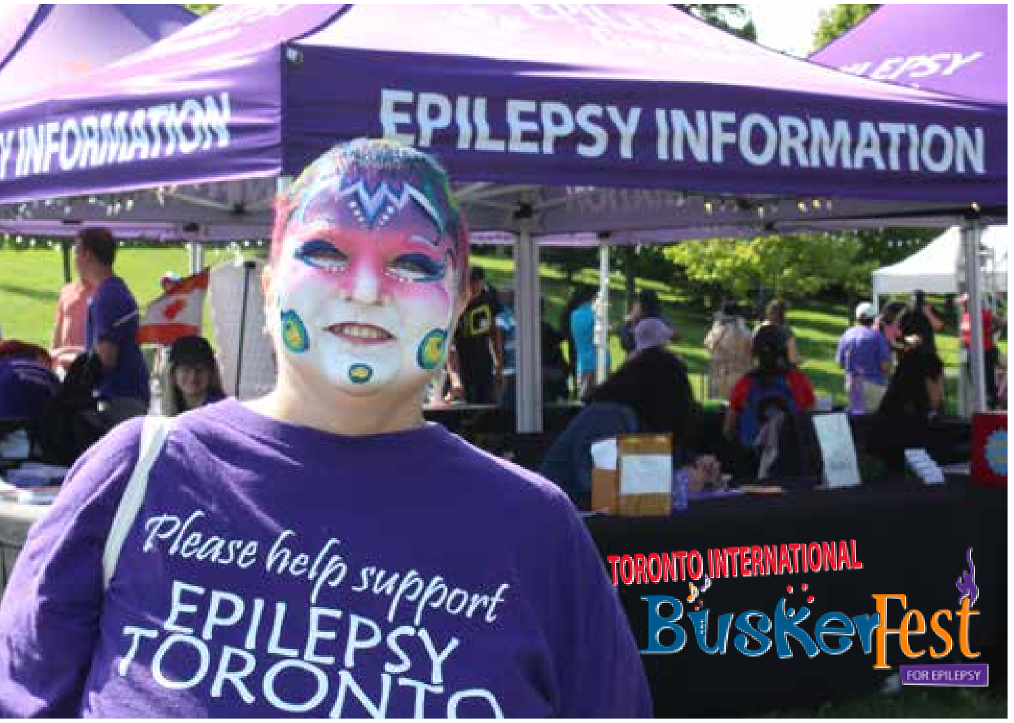
See the Person

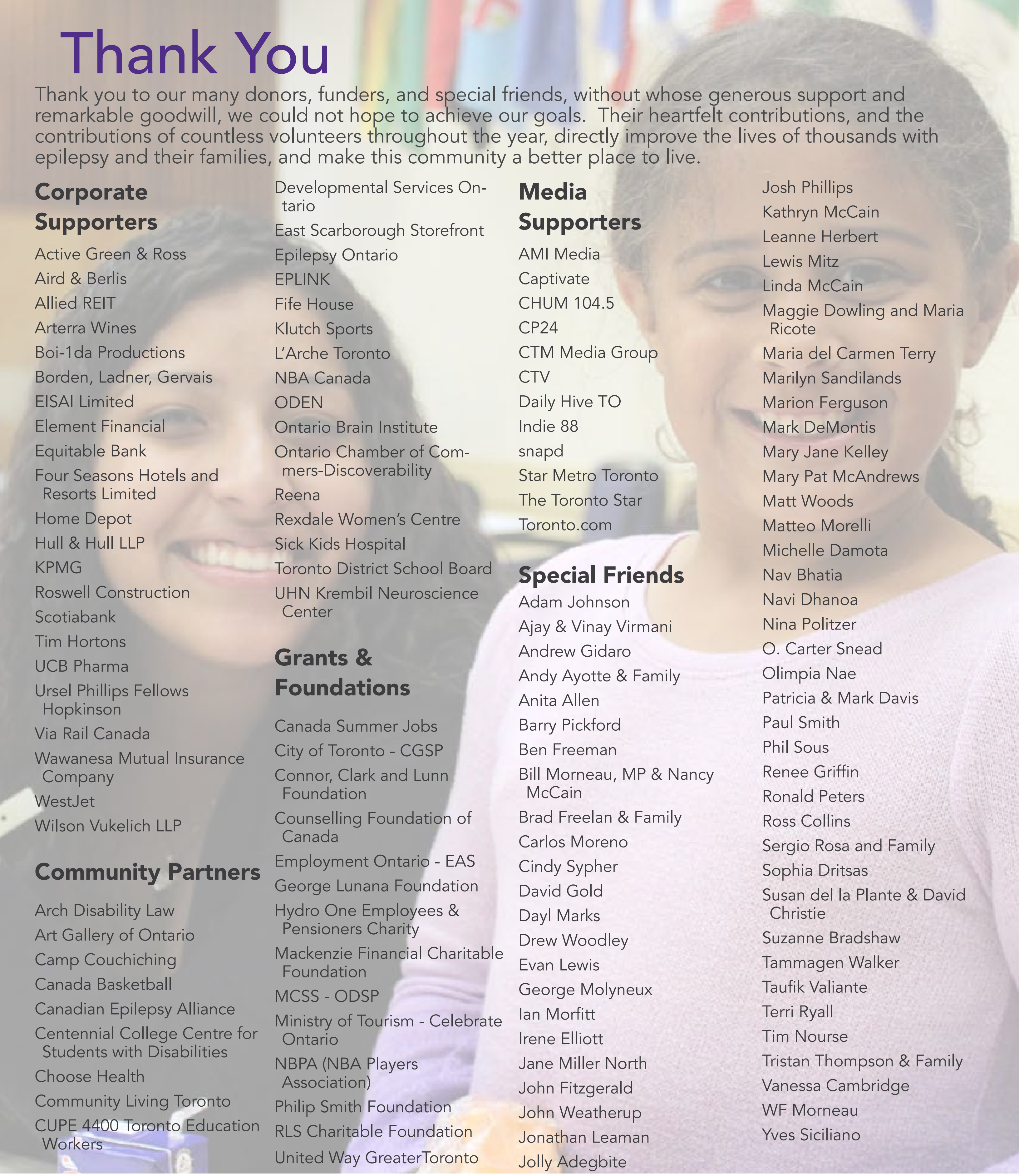
Summer Family Retreat 2018

2018 Summer Family Retreat at Geneva Park

In The Community

We are always striving to eliminate the stigma surrounding epilepsy and raising awareness is a primary way to do this. 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 the understanding of epilepsy and the services Epilepsy Toronto provides.





Thank You

Thank you to our many donors, funders, and special friends, without whose 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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- UHN Krembil Neuroscience Center

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