



ANNUAL REPORT 2023



EPILEPSY
Toronto
See the Person



VISION

We envision a world in which **epilepsy and seizures** are widely understood, and where those who live with them **feel fully supported**.

MISSION

To promote **independence** and improve the **quality of life** for people with epilepsy and their families through **support services, information, advocacy, and public awareness**.



Purple Walk, 2023

2023

GROWTH AND CHANGE

In 2023, Epilepsy Toronto experienced significant growth and change, marked by the move to our new office in Leaside. This bright, open, and welcoming space has quickly become a hub for our community. With a cozy fireplace perfect for socializing, a kitchen ideal for our life skills program, and a backyard ready for barbecues, our new home embodies the warmth and support that Epilepsy Toronto strives to offer.

One of the most exciting developments in 2023 was the significant leap forward in epilepsy advocacy in our schools. Working closely with our friends at Emma IS and Epilepsy Ontario, we proudly supported the passing of Motion 68 in the Legislative Assembly of Ontario. Passed on November 15th, this motion mandates comprehensive epilepsy policies in all Ontario school boards, including training for teachers and staff on administering emergency epilepsy medication. This ensures a safer and healthier learning environment for students with epilepsy. There is still much work ahead, and Epilepsy Toronto is eager to play a key role in the next steps.

In addition to these advocacy efforts, we forged our first-ever partnership with OUTEDGE (formerly Outfront) Media to launch an Epilepsy Month awareness campaign. The captivating images by artist and Epilepsy Toronto member, Sarah Hysenaj dispelling epilepsy misconceptions were displayed on screens throughout the city over 1.4 million times throughout March, generating nearly 50 million impressions.

This is the kind of reach we need and strive for to significantly increase public awareness about epilepsy.

As we look back on these and the many other accomplishments of our service departments, highlighted in the next few pages, we are reminded that our community is at the heart of everything we do. Your unwavering support has been instrumental in making these achievements possible, and we are deeply grateful. We are excited about the future and the many ways we will continue to grow, advocate, and support our members.

Thank you for being part of our journey,

Daryl Yeo

President of the Board
Epilepsy Toronto



Our New Office



Daryl Yeo



Awareness Campaign,
Yonge Dundas Square

CHILDREN & YOUTH SERVICES



*Our new office space has reinvigorated the programs and services we offer to children and youth. From our Babies and Tot meet-ups to agency-wide family events, laughter and smiles permeated the space. Children played together, Youth found a welcoming space to meet their peers, and parents formed connections and friendships over a cup of coffee or tea. We're proud of our efforts to establish a truly **hybrid service delivery model**, developing a dynamic program that was accessible to more families and able to meet a variety of needs and interests.*

— **Eden Peters & Elana Ellison, Coordinators, Children and Youth Services**



HEARING FROM OUR MEMBERS:

Uncertainty is part of raising children but uncertainty is always present in [caring for] a child with epilepsy. Since **I got connected with Epilepsy Toronto I feel that I have a secure place to ask for support.**

— **Parent response from the 2023 annual survey**

2023 HIGHLIGHTS



Family Events

from our **Family Summer Picnic, Purple Pumpkin Party, Holiday Party and more**, gathering with our families for our signature events was a special highlight of the year. We were thrilled to welcome our members into our new office to mark the changing seasons and join in holiday celebrations together. **We look forward to creating new traditions together in this community-oriented space!**

Teen Paint Night

We know that young people living with epilepsy can experience isolation and are often curious to meet others who 'get it.' Our Teen Paint Night in November facilitated new connections and a sense of shared experiences for youth with epilepsy.



Babies and Tots Group

The Babies and Tots group at Epilepsy Toronto started as a supportive way to nurture early child development and encourage virtual connection for families with young children isolated during the pandemic. We relaunched the group in 2023 in person at the Epilepsy Toronto office. Families enjoyed a special circle time followed by free play and parent-led chat.

Parent Speaker Series

We kicked off our Parent Speaker Series, taking place virtually every other month. The series provided an opportunity to promote the voices of our members and foster community through the sharing of parent stories.

Mighty Me Self Esteem Group

We piloted a self-esteem group. The group ran virtually over the span of 4 weeks. Throughout the group, participants learned about the growth mindset, developed tools to cope with negative thoughts and feelings, and made meaningful connections with other children living with epilepsy.

ADULT SERVICES



*Epilepsy Toronto offers hope and a safe and caring community to adults with epilepsy looking to share their thoughts and feelings; an opportunity to learn more about their condition and gain skills to cope with its impact. **It was our joy to serve those who joined our community in 2023 and we hope to continue developing new and creative programs to meet their needs in 2024.***

— Rosie Smith, MA, RP
Director, Adult Services



Holiday Party, 2023

HEARING FROM OUR MEMBERS:

"I honestly don't know what I would have done without Epilepsy Toronto. My life was heading down a dark path and since working with [them] I have learned to accept my epilepsy and now have new ways to manage the changes in my life. I'm no longer as anxious and depressed as I was before I started counseling sessions. Thank you!"

— Individual adult therapy client



2023 HIGHLIGHTS

Functional Seizure Programming

With a grant from the **Ontario Brain Institute (OBI)**, we were able to **offer Neurobehavioural therapy to 15 patients with functional seizures** and **functional seizure psychoeducation to over 115 clients** to help them better understand and accept their diagnosis. This served to address a huge gap in the healthcare system.

UPLIFT

As people with epilepsy often struggle with their **mental health**, we **offered this 8-week mindfulness-based cognitive behavioural therapy group** to address the needs of those with anxiety and depression. Outcomes suggest all clients found the group helpful in validating their feelings and learned skills they can use to manage their mood.

VNS Support

With more and more clients considering **Vagus Nerve Stimulator (VNS) as a treatment option**, we **hosted a peer support group for persons with epilepsy and their caregivers**. This provided a space to learn from the experiences of those who had that procedure done. The group strongly recommended we make this a regular part of our programming.

Epilepsy Education

We transitioned from providing individual epilepsy education to a group format. These monthly sessions provided opportunities for newly diagnosed clients and their families to meet others with epilepsy who are struggling with the same questions they have. Many clients reported finding this therapeutic, validating and very informative.

EMPLOYMENT SERVICES



*In 2023 we moved to our new home on Bayview Avenue and welcomed clients in person for the first time in almost three years! We were able to offer the Epilepsy Employment Group (EEG), Speed Mentoring, and employment workshops in person again at last. We formed relationships with several employers and secured opportunities for clients through wage subsidies and client supports. **Our clients have been with us every step of the way, challenging, motivating and inspiring us.***

— Carter Hammet,
Director, Employment Services



HEARING FROM OUR MEMBERS:

*"I entered the employment program battered and with little hope of success. I had so many rejections and negative experiences before seeking this help. I learned from **Epilepsy Toronto to see the positives, understand my choices and actions matter and that there is hope.** Since starting with Epilepsy Toronto I have had more interviews, and possibilities of employment and I'm even learning to stand up for my rights and keep my respect."*

— J.V. (Employment Services Client)



2023 HIGHLIGHTS



HOBSCOTCH

We supported multiple clients with a new, personalized **eight-week memory enhancement program**.



Serving Job Seekers with Autism and Epilepsy

We formed a partnership with Dori Zener and Associates to offer pre-employment services to people living on the ASD Spectrum.



Return To Work Program

Launched formalized Return to Work services to provide faster and more tailored support for returning to work after a seizure or brain surgery.



Chat-GPT for Job Search Services Training

Epilepsy Toronto was among the first employment service providers to embrace **artificial intelligence (AI) as a tool for employment**. As a result, we launched new workshops and spoke about AI and employment at **ODEN's Rethinking Disability Conference** and on NOW with Dave Brown (Accessible Media Inc.).



Relaunch of Speed Mentoring in person

Closed the year and celebrate the opening of our new office by bringing back our signature favourite event, Speed Mentoring!



SECURING FUTURES



Our Securing Futures Program aims to support adults living with epilepsy to gain the life skills and housing opportunities they need to live independently. This past year **we modified the curriculum and delivery of the program based on the diverse needs of the second cohort to produce a more client-centered and holistic learning experience.** We are very thankful to the 20+ content specialists and community partners who have continued to collaborate with us plus the new professionals who have joined to share their expertise in supporting this novel program.

— Leah Sultan-Khan, Director, Community Engagement, Public Education & Life Skills Training



HEARING FROM OUR MEMBERS:

"Securing Futures, helps people with Epilepsy live with dignity and self-determination. In the program, our daughter is learning that she is not alone after all! She is meeting new friends, who are the best support group one could hope for; with guidance from the wonderful staff of Securing Futures, she is re-learning how to accomplish things she did not think she could on her own; she is much more confident, she has new found self-worth. **Finally, for the whole family - the feelings of anxiety of no future are gradually diminishing with the prospect of a hopeful future for her.**"

— Andrew, Parent of a client in the Securing Futures Program



2023 HIGHLIGHTS

More Personalized Approach

We successfully **launched the second cohort of the Securing Futures program with a new group of participants of diverse abilities offering a more personalized approach and flexible learning plan.** This included individualized schedules where clients could select training in the specific life skill sector of their choice.

Curriculum Modifications

We hired a full-time life skills facilitator to conduct individual sessions with clients; **created protocols to ensure safety and accountability among participants and family members; incorporated new evaluation tools to measure progress;** opened up sessions to family members to support their learning; and established action items for caregivers to reinforce training at home.

Hands on Experience

We started **a cooking segment twice a month** which builds on all essential life skills and provides practical experience.

Peer Support & Mentorship

We formed a **virtual parent support group** (Support Circle) and in-person **participant support group** (Support Squad) which fosters peer mentorship between graduates and new participants.



PUBLIC EDUCATION AND DIVERSITY & INCLUSION



Our Public Education Team **has increased engagement and visibility to communities of diversity and new sectors this past year which is reflected in our outreach efforts.** We continue to foster positive relationships and strengthen partnerships with community agencies alongside our clients to raise awareness of epilepsy.

— Leah Sultan-Khan, Director, Community Engagement, Public Education & Life Skills Training



HEARING FROM OUR MEMBERS:

"In 2023, Epilepsy Toronto graciously donated their time to present to our senior clients at Rexdale Community Health Centre (RCHC). Not only did presentations occur in English but also, they were translated into Spanish and Somali. It's our goal to create a welcoming and barrier-free environment at RCHC and Epilepsy Toronto certainly helped us with that vision."

— Rexdale Community Health Centre



2023 HIGHLIGHTS

Advisory Committee:

We formed a client committee to expand outreach efforts and **improve engagement and allyship with diverse communities and new sectors.**

Curriculum Modifications:

We expanded the pool of clients to share their stories of living with epilepsy and to become advocates through individual coaching.

Communication Approaches:

We added new methods to deliver epilepsy education sessions, including **teleconference, virtual, in-person, hybrid and over the radio.**

Increased Outreach:

We facilitated 17 presentations and participated in 7 events which significantly **increased our engagement and visibility to almost double that of the previous year.** One such presentation was for the staff at Native Child and Family Services Toronto who honoured us with an invitation to their cultural night and Pow Wow where we shared in an exchange of teachings that provided knowledge about epilepsy and learning about the indigenous community and culture.

RECREATION SERVICES



2023 saw continued enthusiasm for recreational services at Epilepsy Toronto. **Trivia, Bingo, Social and Friday Recreation Group** all continued throughout the year. Most of the activities took place virtually, however, we had a full year of in-person Friday Recreation Group every other week. **Clients had great fun and learned to collaborate, create friendships, and create a true sense of connection** with others. I am very proud of the work our members have done to stay connected with each other during our groups and outside of them as well.

— John Spataro, Recreation Manager



HEARING FROM OUR MEMBERS:

"Thank you for making the group such a fun and safe space that allows me to look forward to something being held throughout the week."

— Friday Group Member

2023 HIGHLIGHTS



Personal Approach

We had many **new members** join our recreation programs and continue to attend throughout 2023. In addition, many hours of **1-on-1 support** were provided when members needed it.

Social Connectons

Recreational therapy can help **rebuild skills, improve mood, boost quality of life, and strengthen social connections**. The result can be greater self-confidence, an increase in self-esteem, motivation, strength, a sense of purpose, and an overall higher level of well-being. That is what we have found this year in our recreational groups. **Social connections were made beyond the groups** and many members went out in the community together, visited each other's homes, and participated in other events together.



In-Person Friday Rec Group

Our in-person Friday Recreation Group saw us admiring the beautiful cherry blossoms as they bloomed in High Park in the spring, visiting Allan Gardens, the Royal Ontario Museum, the Bata Shoe Museum and BuskerFest; along with trips to the movie theatre, bowling, and Holiday Fair in the Square.



MORE ABOUT 2023

We welcomed our clients into our new office for in-person events again!



HOLIDAY PARTY

We closed the year with a beautiful holiday event at the Epilepsy Toronto office, that brought staff and members together to celebrate the season!



PURPLE WALK

Last year's Purple Walk saw our community come together in a celebration of pride and connection the likes of which we had not seen since pre-pandemic days.



BUSKERFEST & BARK IN THE PARK 2023

We expanded BuskerFest to include a dog component, attracting a new audience and featuring numerous talented K9 performers in addition to the incredible lineup of humans!



AWARENESS MONTH

Artist Sarah Hysenaj's photo series Epilepsy Misconceptions appeared on billboards, highway signs and bus shelters all over Toronto with the support of OUTEDGE Media.

HOLIDAY FAIR IN THE SQUARE

We relocated this event to North York's Mel Lastman Square, invested in our own Epilepsy Toronto Coffee Cart, strengthened our presence, building contacts and awareness in a new area.





THANK YOU

Thank you to our members, supporters, funders, volunteers and community partners on whose proud generosity we have come to depend. Your support is making a difference in people's lives every single day.



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- Dr. Roz's Healing Place
- Deloitte
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- Holy Blossom Temple (Holy Grounds Cafe)
- CAN WiN



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- ABC Life Literacy Canada
- Canadian Epilepsy Alliance
- Chartered Professional Accountants (CPA) of Canada
- Developmental Services Ontario (DSO), Toronto Region
- Dori Zener and Associates
- Downtown Yonge BIA
- East Scarborough Storefront
- Ell'Events
- Emma IS
- Epilepsy Ontario
- Kindercare Pediatrics
- L'Arche Hamilton & L'Arche Canada
- Mackenzie Together Charitable Foundation
- Native Child and Family Services Toronto
- Neurology Centre of Toronto
- Ontario Brain Institute
- Ontario Disability Employment Network
- OUTEDGE Media
- Partners for Planning
- Project ECHO
- Rexdale Community Health Centre (RCHC)
- Rexdale Women's Centre (RWC)
- SickKids Hospital
- Students for Epilepsy Awareness, U of T
- Toronto Catholic District School Board
- Toronto District School Board
- TD Bank
- Teaching Awareness Through Puppetry (TAP)
- Toronto Metropolitan University
- Toronto Western Hospital
- University of Toronto

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- Adbands!
- Andrew Adegbite
- Andy & Jennifer Ayotte
- Frank Bar
- Battaglia Family
- Dr. Eduard Bercovici
- Michael Bercovici
- Kealin Bobb
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Grants & Foundations

- Blue Lupin Foundation
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- City of Toronto Cultural Festival Funding Program
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- Mauro Family Fund
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- Ontario Employment Assistance Services
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- Ontario Trillium Fund
- Toronto Foundation
- United Way Greater Toronto





Epilepsy Toronto Staff



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Director of Children & Youth Services
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Recreation Manager
- **Leah Sultan-Khan**
Director, Community Engagement, Public Education & Life Skills Training
- **Bonnie Taylor**
Festival Director, Toronto International BuskerFest

Teaching Awareness Through Puppetry (TAP)

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Co-Director of TAP
- **Kirsten Sixt**
Co-Director of TAP

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MORE ABOUT 2023

We welcomed our clients into our new office for in-person events again!



RECREATION GROUP

Our Friday Group alternated between in-person and virtual sessions throughout the year.



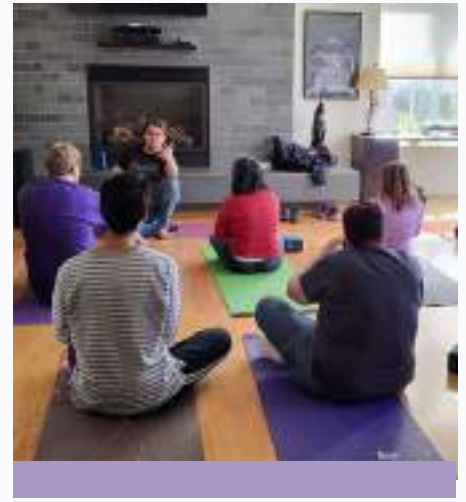
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PURPLE WALK 2023

Last year's Purple Walk exceeded our fundraising target, fostering a meaningful connection with our community and establishing valuable partnerships.

HOLIDAY FAIR 2023

We relocated to North York, invested in our own Epilepsy Toronto Coffee Cart, strengthened our presence, building contacts and awareness in a new area.



RECREATION GROUP

This group offered in-person and virtual sessions throughout the year on Fridays.



BUSKERFEST & BARK IN THE PARK 2023

We expanded BuskerFest to include a dog component, attracting a new audience and featuring numerous talented K9 performers in addition to the incredible lineup of human performers (and a few felines too)!



AWARENESS MONTH CAMPAIGN

Artist Sarah Hysenaj created her photo series Epilepsy Misconceptions to help educate others about myths and misconceptions about epilepsy. This was displayed on billboards, highway signs and bus shelters all over Toronto with the support of OUTEDGE Media.



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