

2021 Annual Report



Our Vision...

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

Our Mission...

... to promote independence and improve quality of life for everyone affected by epilepsy and seizures through counselling, education, and community support.



Recovery. Growth Perspective.

Who would have guessed that we would still be in the midst of the pandemic throughout 2021? But despite the challenges faced, it did mark a year of recovery, growth, and perspective for Epilepsy Toronto.

As we continue to experience the repercussions of this ongoing pandemic, our members have needed us now more than ever and we refused to let anyone in our community fall through the cracks. Our services are now more accessible than ever before which has allowed us to reach some of the most vulnerable populations across our city, and resulted in our second consecutive year of a significant increase in demand for our services.

As the world consistently shifted around us, Epilepsy Toronto continued to adapt to the growing needs of our community. We established our new Diversity, Equity, and Inclusion Department to help eliminate barriers to healthcare and ensure our services are inclusive and accessible to everyone who needs us. We launched new Employment Services programming to address the precarious employment landscape in the midst of a pandemic. Our Children and Youth Services launched new groups and services designed for youth who have struggled with anxiety and isolation.

I encourage you to read our full 2021 Annual General Report to learn about the many other innovative programs our team developed over the past year.

Our experience throughout this pandemic has also granted us valuable perspective. In collaboration with our staff, our Board of Directors completed a 5-year strategic plan that will guide us moving forward. I can promise you that our future together is bright and I'm excited about all we will continue to accomplish.

I could not be prouder to report that Epilepsy Toronto not only survived, but grew even stronger in the face of such unprecedented adversity. We are grateful for our outstanding members, staff, Board of Directors and volunteers who have persevered with us, as well as the continued support from our community partners, donors, funders, and sponsors. We promise that we will continue to build upon the incredible momentum we have created this past year into 2022 and beyond.

Darvl Yeo

President **Board of Directors**

CHILDREN & YOUTH SERVICES



"We saw an overwhelming increase in the number of children, youth, and their caregivers seeking our services last year. This pushed us to continue to create and deliver new and innovative programming to serve the needs of our members and ensure meaningful connections within our community."

Katie Armstrong, MSW, RSW
 Director of Children & Youth Services

HEARING FROM OUR MEMBERS

"We as a family have a better understanding of what is happening to our child during a seizure and feel more confident in dealing with the situation. This has brought our level of anxiety down and made us more connected as a family.





2021 HIGHLIGHTS

- New Support Group for Siblings: It can be difficult to grow up with a sibling who is living with a seizure disorder. They often experience emotions that are hard to process and are sometimes overlooked. We developed a brand new *Siblings Support Group* exclusively for siblings of children with epilepsy to share experiences with peers in a safe space.
- Increased Support for Parents & Caregivers: A diagnosis is overwhelming for everyone in the family unit and that's why we expanded support for parents and caregivers. We quadrupled our existing Cognitive Behaviour Therapy (CBT) group, <u>UPLIFT</u>, for caregivers and parents impacted by epilepsy and depression/anxiety to meet the increased demand in 2021.
- **Guiding Our Young Adults:** Living with epilepsy and seizures poses a number of unique challenges that young adults must consider as they face their stressful transition into adulthood. We established our *Ready to Launch Program* in order to help guide and support young adults as they prepare for important life phases such as post-secondary education, employment, and living independently.
- Reducing Wait Times for Care: Already long wait lists for children to receive a first diagnosis and proper treatment have grown even longer due to the pandemic. Children and their families should not be stuck in limbo during this vulnerable time as they try to manage their child's first seizures. That's why we've partnered with the Hospital for Sick Children and the Toronto Neurology Center to deliver rapid virtual access clinics so that families can receive the support they need faster than ever before.
- Tackling Anxiety & Depression Among Our Youth: Cases of anxiety and depression have increased among our youth members, especially over the course of the pandemic. We developed a number of new programs to better support them during this difficult time, including our *Preteen Mindfulness Group* to help them develop new coping strategies, manage anxieties, and promote connection with peers.

5

ADULT SERVICES



"Our community members showed us so much strength in the face of uncertainty in 2021 - and it was a reminder of the resilience that defines the epilepsy community. We saw a record number of new clients reach out to us and we initiated new programs including a mindfulness-based CBT group, and targeted programing for functional seizures. We look forward to continuing this work of supporting our adult community."

Rosie Smith, MA, RP
 Director of Adult Services

HEARING FROM OUR MEMBERS

"Since joining Epilepsy Toronto, I have learned so much about living with epilepsy, treatments, lifestyle, medication side effects, advocating for myself, and that there are others who have had similar stories.





2021 HIGHLIGHTS

- Improving Accessibility: Over the past two years we have been able to establish a successful virtual model of counselling and services which has allowed us to reach new communities and members across our city. As a result of this improved accessibility, we have been able to serve more members than ever before and we expanded our counselling staff to meet this need.
- New Functional Seizures Program: Experienced by approximately 12% of people with epilepsy, functional seizures are incredibly common yet highly misunderstood. Functional seizures cannot be treated with medication and the only proven method of treatment is specialized counselling. Currently, services solely focused on treatment of functional seizures are largely unavailable in Canada. In 2021, Epilepsy Toronto began development and training for a brand new *Functional Seizures Program* in order to address this gap in service across our community.
- Staying Connected with Our Members: Epilepsy is an isolating condition and the pandemic has been especially difficult for our community. Our virtual *Socially Distant Social Club* and our *Recreation Group* continued to provide our members with opportunities to stay connected, have fun, engage in lively conversations, and foster a true sense of belonging that helped to reduce the feelings of isolation many experienced during a difficult 2021.
- **Reaching Diverse Communities:** Toronto is the most diverse and multicultural city in the country and as such, we have a responsibility to ensure that our programs, services, and resources continue to be accessible and inclusive for people from all cultures and backgrounds. In 2021 we introduced a *Diversity*, *Equity and Inclusion Lead* to our team to meet this need, reach new members, and provide epilepsy education to diverse communities across this city.

EMPLOYMENT SERVICES



"Our department experienced a banner year for our job-seeking clients. We added to our already-packed service repertoire including job retention programming and career planning. We remain committed to supporting the whole person in their ongoing search for meaningful employment."

Carter Hammett
 Manager of Employment Services

HEARING FROM OUR MEMBERS

"My experience with the Employment Department services has been diverse, multifaceted, and insightful. **Epilepsy Toronto helped** me with everything from mental health and coping techniques to personality/ career alignment and job maintenance. Their support has provided me with many opportunities to not only apply for positions, but discover ones I didn't know existed."





2021 HIGHLIGHTS

- A New Virtual Office: We officially launched a <u>Virtual Employment Office</u> in order to better support our members at every stage of their employment journey. The office is hosted on an online platform and gives our members easy access to key resources such as employment guides, workshops, and so much more.
- Introducing Wage Subsidy and Client Support Programs: This year we were fortunate to secure funding to offer wage subsidies and client supports to our members. Wage subsidies are employer-focused monies that enable a new employee with epilepsy to receive extra support and training. Client supports equip job-seekers with tools and resources relevant to their job search. This additional funding has already made a significant impact for many of our members who are seeking employment.
- Streamlining the Job Search: With our extensive network of partner organizations, we have been able to create a weekly job search bulletin delivered right to our members' inbox that lists current job listings and employment opportunities available for any given week.
- Strengthening Job Maintenance Skills: Many people with epilepsy are great at finding jobs, but keeping them becomes another matter. This year we developed brand new job retention and job maintenance programming to further support our members after they've secured employment. This includes a new six-week group with a skills building/support model that touches on everything from disclosure, to employment standards, to employment law. Members are able to gain valuable insight from those who "get it" while developing abilities to advocate for themselves.

SECURING FUTURES PROGRAM



"The Securing Futures team along with our community partners has continued to come together to build this robust life skills and housing program. It has been inspiring to see the growth, development, and increased confidence of participants this past year and we look forward to continuing to support their transition to independence."

Leah Sultan-Khan, EdD, MA, CHES
 Director of Community Engagement & Public Education





"I feel we are receiving the most crucial support ever. My son has been enrolled in the Securing **Futures Program and** the life skills he has been learning have been invaluable. I feel more confident that he can make a life of his own even when I can no longer help him. Epilepsy Toronto has been integral in the successes we have seen with him over the years."



2021 HIGHLIGHTS

- Developing a Comprehensive Curriculum: The Securing Futures Program (SFP) focuses training on the development of seven core life skills that participants need to live full and independent lives. These seven life skills include: finance & budgeting, health & medical, self-care, interpersonal & social, employment & volunteering, community, and domestic & household. Last year, we collaborated with 20 content specialists and industry professionals on developing the curriculum in these subject areas and we completed training in five of the seven core life skills with our participants.
- Prioritizing Community Perspective: Nearly 25% of the industry experts that spearheaded our training were professionals who are themselves living with epilepsy. They were able to not only lend their valuable expertise and knowledge, but also provided powerful perspective by sharing their own personal experiences living with epilepsy. This had a profound impact on the Securing Futures curriculum and its participants.
- A Family Journey: We regard the path to independence as a journey for both the participants and their entire family. We conduct regular meetings and feedback sessions with each family in order to evaluate participants' progress and to continue shaping and improving the program. The families of our participants have given us overwhelmingly positive feedback as they're already beginning to see the impact of these newly acquired life skills being applied in the home.
- Building Peer Support: We are thrilled at the progress and growth that our SFP participants have shown since the program began one year ago. As their road to independence becomes a reality, we never could have predicted the impact that our participants would have on one another. Over the course of the program they have completed many hours of training together, celebrated each other's successes, and supported one another through challenging moments. They have now established lasting relationships and a strong peer support network that will continue on even after their journey in the SFP comes to a close.

IMORE FROM 2021



Back for the Holidays! Our Annual Holiday Fair in the Square returned in 2021.



See the Person We continued to share our members' stories in our <u>See the Person campaign</u>.



Epilepsy Awareness Month epilepsy awareness <u>in this video.</u>





Live with Lily and Purple Day

In collaboration with our partners at the Ontario Brain Institute, we developed educational Purple Day kits for our child and youth members. Each kit was mailed to our members and included activities, games, and corresponding educational videos about epilepsy and Purple Day. We also filmed a special Purple Day episode of Live with Lily that was sent to



THANK YOU

Thank you to our members, supporters, funders, 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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Reena

Rexdale Community Hub

Revol

SickKids Hospital for Sick Children

Southern Ontario Epilepsy Clinic

Partnerships Continued...

Supported Employment Alliance TDSB

TCDSB

The Canadian Epilepsy Alliance

The Krembil Neuroscience Center

The Ontario Brain Institute

The Toronto Western Hospital

Toronto Education Workers/Local 4400

Tropicana Community Services

University of Toronto Accessibility & Housing

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Marilyn Sandilands

Mary Burrows

Special Friends Continued...

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Mel Carrey

Michael Antonakes

Michael Alex

Michael Bercovici

Michelle Damota

Monica Balbino

Monica Diaz-Greco & Daniel Greco

Nancy Figueroa

Nancy McCain & Bill Morneau

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City of Toronto Cultural Festivals Funding

Program

Employment and Social Development Canada

Mackenzie Charitable Foundation

Ministry of Heritage, Sport, Tourism and Culture

Industries

Muro Family Fund

Ontario Disability Support Program

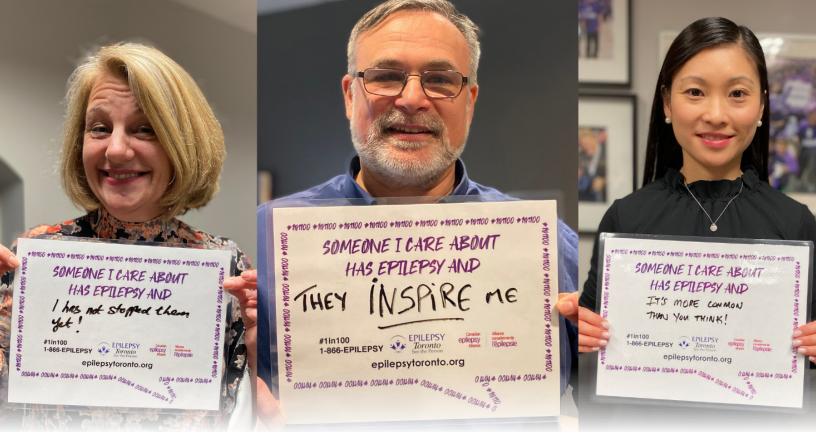
Ontario Employment Assistance Services
Ontario Trillium Foundation

RLS Charitable Foundation

Toronto Foundation

United Way Greater Toronto

15





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