



2020 Annual Report



EPILEPSY
Toronto
See the Person

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 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.

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.



2020

A year of resilience

If I had to use one word to describe 2020 from the perspective of this organization it would be resilience.

I've heard numerous stories of resilience from our members who, in face of this ongoing pandemic, have experienced increased isolation, higher rates of anxiety and depression, increased frequency of seizures and hardship. This has resulted in a 30% increase in demand for Epilepsy Toronto's services over the past 12 months. Despite this, I've been inspired by seeing their smiling faces attending many of our online events throughout the past year, such as our Purple Day Celebration and our Virtual Purple Walk.

Similarly, I witnessed resilience from the Epilepsy Toronto staff whose clients and members have needed them now more than ever. They've reinvented the way the organization operates, quickly adapting all of our services and developed new programming to help stay connected to all of our members and their families in this new digital environment. We're very pleased with how the rapid expansion of our services and our new, innovative online programming has been able to support and make a positive impact on our members' lives.

With all the challenges of the pandemic, there is a bit of a silver lining in the dark cloud that we have all been living under. Staff and your Board of Directors are currently undertaking a major review of our services as we update the agency's strategic plan for the next few years. With the new service initiatives launched in 2020 and the new ways that we have utilized the Internet and social media to stay in contact with our members, there are a number of things to consider about what a post pandemic world will look like, and how does Epilepsy Toronto continue to deliver and expand our services in the most effective fashion and in ways that make all of our services more accessible to our many members.

With challenges come opportunities, so we are excited to benefit and grow from all of our learnings over the past year, and become even more supportive of our Epilepsy Toronto family in the future. I am very proud of what we were all able to accomplish together in the face of this ongoing pandemic. I hope that we will all be able to see each other in person one day very soon.

Daryl Yeo
President
Board of Directors



“2020 tested us in ways we could have never imagined but the Children and Youth Services Department was up to the task. We worked hard to adapt all of our services and also developed new and creative programming that helped us stay connected to our members and their families in this digital environment.”

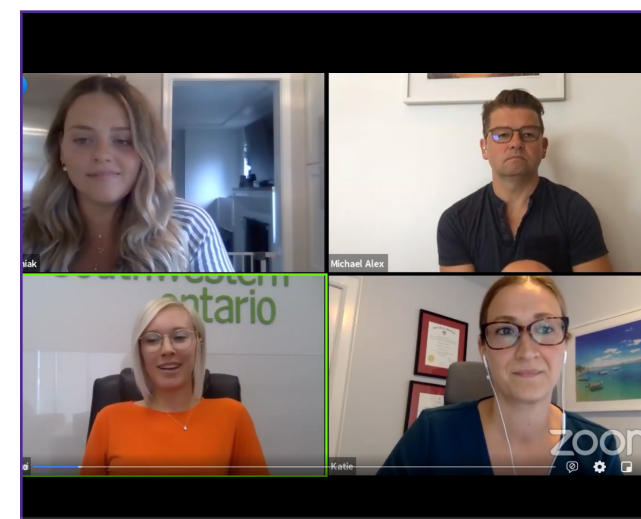
— **Katie Armstrong, MSW, RSW**
Director of Children & Youth Services

8,500+
 online views
 of Live with Lily!



“Meeting with staff and other members of Epilepsy Toronto made me feel less alone as a parent of a newly diagnosed son; I now have a whole community that I never knew was there.
 Thank you for everything that you do.”

— Epilepsy Toronto Child and Youth Services member



Youth Mental Health & Epilepsy Webinar



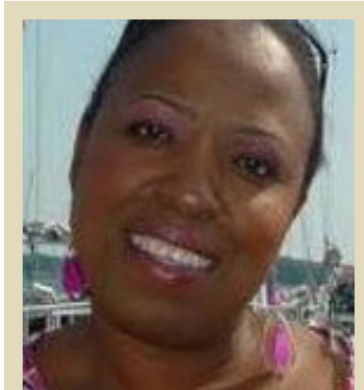
Halloween 2020 Purple Pumpkin Project



Family Games Night

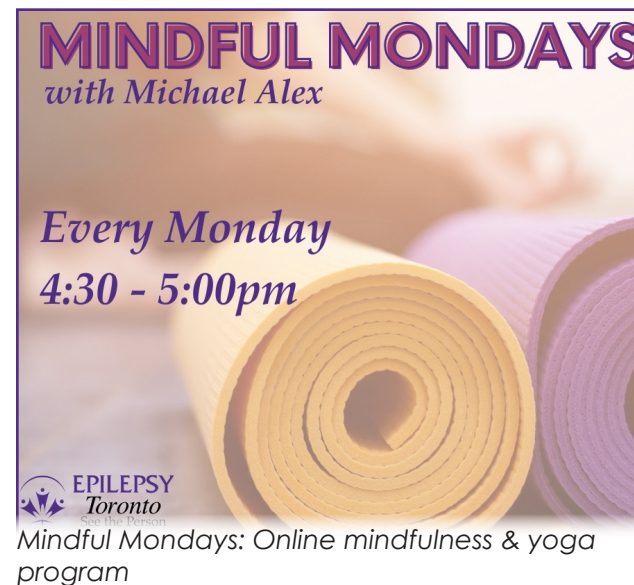
A Snapshot of 2020

- **Live with Lily!:** Is an [innovative online children's program](#) we developed in collaboration with Teaching Awareness Through Puppetry that offers information, support, and community for children who are living with or impacted by epilepsy.
- **Family Games Night:** Our new *Family Games Night* has been a big hit! Once a month, we began hosting a Virtual Family Games Night where children and their families gather and connect over fun and interactive games via Zoom.
- **Music & Movement with Babies and Tots:** Another brand new program we developed to help parents of young children who experience seizures to connect with one another. We take our families through a virtual song circle, rhymes, and stories with their little ones.
- **Virtual Rapid Access Clinic for Pediatric Epilepsy:** This year, we developed a key partnership with the Neurology Centre of Toronto. Through this partnership, we are able to make direct contact with pediatric patients with epilepsy to ensure direct community support and a new source of service referrals for Epilepsy Toronto.
- **Youth and Mental Health Webinar:** Epilepsy Toronto and Epilepsy Southwestern Ontario [co-hosted a webinar to discuss youth mental health](#) and its relationship with epilepsy. Joined by an expert panel, viewers were able to learn through their experiences working with youth mental health, and provide strategies to assist youth during COVID-19.
- **Return to School for Parents of Students with Epilepsy Webinar:** We brought together a panel of experts to help parents and [offer insight into a new school year with COVID-19](#).
- **New Resources:** Developed new, epilepsy-focused teaching material for elementary classes in collaboration with Teaching Awareness Through Puppetry.



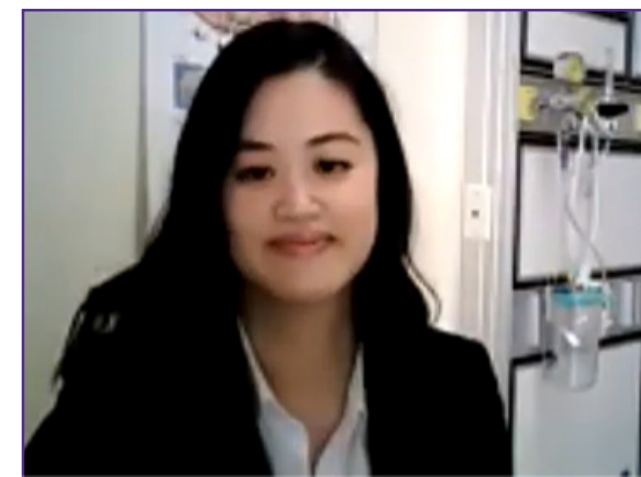
“Despite the obvious challenges of the past year, there are many achievements for us to celebrate. We were able to quickly pivot with the onset of the pandemic and transition seamlessly from in-person to virtual services. During this transition we maintained connections to all of our existing members and managed a steady flow of new clients. We continued to deliver ongoing and produce new supportive services to meet the diverse needs of adults with epilepsy.”

— Rosie Smith, MA, RP
Director of Adult Services



A Snapshot of 2020

- **Virtual Peer Support Program:** This year, we trained 22 new peer mentors to provide support for people living with epilepsy. This was integral during the pandemic when many of our most vulnerable and socially isolated clients required much-needed and ongoing assistance. Peer mentors were connected to clients, with priority on our senior members, but also others who were struggling with loneliness and just needed a friendly voice or ear that could understand and relate to what they were experiencing during this difficult time.
- **Virtual Rapid Access Clinic for Epilepsy:** Via Epilepsy Toronto's participation in the Virtual Rapid Access Clinic (VRAC) with the Neurology Centre of Toronto, we have been able to meet with newly diagnosed adults with epilepsy from across the province and serve their needs and/or connect them with their community epilepsy agency.
- **Hosted 6 Webinars:** Our clients had questions and we provided the answers and support they needed through organizing and hosting 6 online webinars with leading experts. Some of these webinar included: [Women & Epilepsy Webinar](#), [Anxiety and COVID-19 Webinar](#), [Epilepsy Medications and COVID-19 Webinar](#), and more!
- **Socially Distant Social Club:** In response to the increased social isolation caused by the pandemic, we developed a weekly program designed to help mitigate the intense feelings of loneliness felt by many of our members. Our online social club provides our clients with a chance to connect with other members of the Epilepsy Toronto community, engage in lively conversations, catch up with old friends, and make new ones.
- **Peer Support Groups:** In addition to our new programming, we've successfully transitioned all of our existing support groups into an online platform including Adults With Epilepsy Support Group, Support Group for Professionals, Friday Recreation Group, and our Surgery Support Group.



COVID-19 & Epilepsy Webinar with Dr. Evan Lewis, and Nurse Practitioner, Ivanna Yau



Women & Epilepsy Webinar with adult neurologist, Paula Marques, and nurse practitioner, Darcia Paul

8,250+
 webinar views



Socially Distant Social Club

“Epilepsy Toronto has given me a safe place to talk about my seizures, whether support groups or individual counselling sessions. Also, the social groups are a fantastic place to get rid of stress and have a fun time!”

— Epilepsy Toronto Adult Services member



“Following an unprecedented societal shift that challenged all of us in ways we never could have imagined, 2020 was a year to remember. We successfully migrated all of our services online, learning as we went, while meeting our clients at the intersection between technology and service. Along the way, we developed some innovative programming to keep clients engaged, connected and supported.”

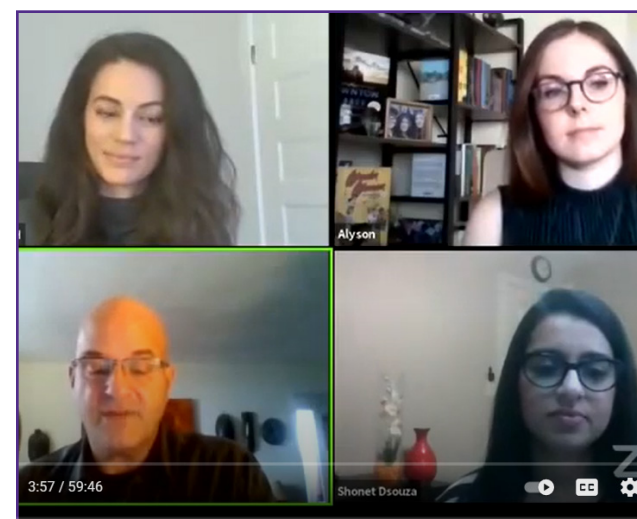
— **Carter Hammett**
Employment Services Manager



51
 online
 employment
 workshops

“Epilepsy Toronto has supported me and has given me the knowledge I need to live a ‘normal’ life. They are very supportive not only about my health but also about my personal growth and wellbeing.”

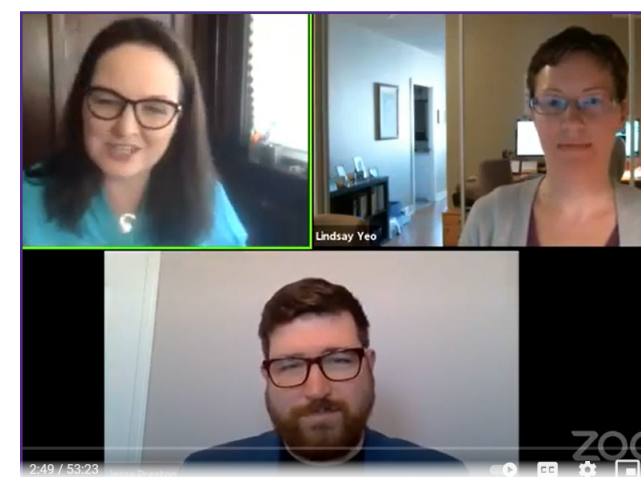
— *Epilepsy Toronto Employment Services member*



[Disclosure Dilemma Webinar featuring experts in employment law, human resources and recruitment](#)



Virtual Employment Office Pilot Project



[Working from Home Webinar with Employment Specialist Jesse Preston, and long time client/member, Lindsay Yeo](#)

A Snapshot of 2020

- **New Partnerships:** Developing meaningful relationships with employment providers is key to helping our clients find meaningful employment. Through community outreach, we are proud to have cultivated new and robust partnerships with employment providers resulting in innovative programming and progressive collaborations.
- **New Workshops:** We introduced a plethora of new workshops to help members adjust to the shift in job search methods during the pandemic (e.g. Job Search During a Pandemic Workshop, Working Remotely Workshop). We also assessed and redesigned some of our existing workshops in order to best support our community during this time (e.g. Memory Workshop, Executive Functions Workshop, Leveraging Social Media Workshop). We hosted 51 online workshops during 2020 and partnered with 17 organizations and experts for these workshops.
- **Virtual Employment Office:** In an effort to better serve and support our members, we began the development of our new Virtual Employment Office. This office is hosted on an online platform and gives our members easy access to necessary resources such as job search boards, workshops, employment guides, and more.
- **Disclosure Dilemma Webinar:** As a part of Epilepsy Toronto's Facebook Live Webinar Series, the Employment Department hosted a well-attended [Disclosure Dilemma Webinar](#). This webinar addressed the common issue of disclosure in the workplace and featured experts who worked in employment law, human resources and recruitment.
- **Working from Home Webinar:** Our second employment-focused [Facebook Live Webinar focused on working from home during the pandemic](#). This presentation was chock-full of tools to help our members face the challenges of working from home, followed by a live Q&A.

A WHOLE NEW WORLD

The pandemic turned all of our world's upside down and forced us to adapt to a new virtual environment.

It was no easy task but Epilepsy Toronto quickly transitioned all of our programs, services, and major events into online platforms to ensure we could continue to serve our community.



4,500+
Facebook
followers



1 Million+
Views on
Youtube



3,250+
Twitter
followers



3,500+
Instagram
followers



Virtual Purple Walk

How can you host a walk when nobody can meet in person?

With many of our major fundraising events such as BuskerFest and the Amari Thompson Soiree being cancelled, we had to get creative with our Annual Purple Walk and figure out how to make it a successful online event. We created the new 1 in 100 Challenge so that our members could participate safely from their homes. People from across the province, country, and around the world joined us to celebrate the Purple Walk and show us their 1 in 100 challenges during our live online event celebrating the completion of the walk. The Virtual Purple Walk raised over \$105,000 for Epilepsy Toronto.

Purple Day

Our first event following the initial lockdown announcement was Purple Day on March 26, 2020. After discovering we had to cancel our scheduled in-person Purple Day events, we developed a social media campaign and two live online celebrations on Facebook Live with only 2 weeks notice. These celebrations were a huge success and garnered over 2,300 views.



Holiday Fair in the Square

Our annual holiday event usually hosted in the heart of Toronto in Nathan Phillip's Square couldn't happen this year. Instead, we created a new Holiday Fair in the Square Online Marketplace. Our marketplace was a fully functional website that hosted nearly 100 small businesses and local vendors who sold their unique gifts and hand-made treasures.

A WHOLE NEW PROGRAM

Epilepsy Toronto has heard parents' concerns about what the future of their family member with epilepsy looks like. Where will they live? Do they have the skills to live independently? What does their future look like once their family members are gone?

We heard our members and realized that they were not alone. These are common concerns that are widespread throughout the greater epilepsy community and there were no programs that addressed these needs. So, we decided to develop one.

The Securing Futures Program aims to support vulnerable adults with epilepsy gain the life skills and housing opportunities they need to live independently. We are working closely with a small group of families and partner community agencies to develop this innovative program.

Securing Futures fills a gap in current epilepsy-based initiatives by developing pillars of independence through community engagement, counselling, support, life skills and housing options. This holistic model helps each individual gain independence at their own pace and gather the support they need to secure housing and reach their full potential. Client-centered practices guide our program and respect each individual's right and responsibility to consider choices and make life decisions.



"It has been a truly incredible experience working with the *Securing Futures* pilot group. Their voices and narratives were instrumental from the programs conception to the development, and will continue to be throughout implementation and evaluation. We are learning everyday and have realized there is no 'one size fits all' approach to independence. We recognize that each person living with epilepsy has their own unique challenges so we meet families wherever they are in their journey."

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

Only the Beginning: Securing Futures in 2020

- **Environmental Scan:** We conducted a scan of 20 housing/life skills agencies to learn best practices for resource sharing, referrals and community navigation.
- **Pilot Program Launch:** In April 2020, Epilepsy Toronto officially launched the *Securing Futures* pilot program with 6 families. They represent a cross section of individuals with epilepsy and other co-existing conditions.
- **Housing:** We have hosted a variety of information sessions on different housing options for clients and in April, Developmental Services Ontario (DSO), Toronto Region facilitated a workshop series on 'Creating an Individualized Housing Plan.'
- **Steps to Independence Guidebook:** In consultation with the 6 families, we customized the Steps to Independence Guidebook consisting of 500 questions in 7 life skill sector areas (health & medical, domestic & household, self-care, financial & budgeting, community, interpersonal & social, employment & volunteering) with key performance indicators. This guide will be used to assess areas of strength and opportunities for improvement in life skills to prepare an individual for the program and used to reassess individuals throughout the program to measure progress.
- **Life Skills Training:** Life skills training began in the first of seven life skills areas, Financial and Budgeting. This consists of a series of workshops in collaboration with our partners, TD Bank and ABC Life Literacy Canada. To date, we have collaborated with 15 partners and will continue to outsource content specialists in the curriculum development and training in this program.



"Thanks to *Securing Futures*, Adriana recognizes that independence requires hard work, initiative, and thinking a lot about things. **She has also come to the realization that I am not always going to be there.** She is more involved in her future, looking forward."

- Parent of a participant
in the pilot project



THANK YOU

Thank you to our members, supports, 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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Project ECHO
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Reena
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Southern Ontario Epilepsy Clinic
Supported Employment Alliance
TD Bank
TDSB/TCDSB
The Canadian Epilepsy Alliance
The Krembil Neuroscience Center
The Ontario Brain Institute
York University - Student Accessibility Services

Toronto East Quadrant Local Immigration Partnership
UHN Epilepsy ECHO

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Grants & Foundations

Canada Summer Jobs
Canadian Emergency Wage Subsidy
City of Toronto CGSP
Emergency Community Support Fund
Hydro One
IBM
Mackenzie Charitable Foundation
McCain Morneau
Muro Family Fund
Ontario Disability Support Program
Ontario Employment Assistance Services
RLS Charitable Foundation
Toronto Foundation
United Way Greater Toronto



EPILEPSY Toronto

See the Person

468 Queen Street East, Suite 210
Toronto, ON, M5A 1T7
Phone: (416) 964-9095
Fax: (416) 964-2492
info@epilepsytoronto.org
www.epilepsytoronto.org



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Epilepsy Toronto Staff

Geoff Bobb

Executive Director

Stephanie Aniol

Social Worker, Adult Services

Katie Armstrong

Director of Children & Youth Services

Elana Ellison

Coordinator of Children and Youth Services

Brandon Fairley

Director of Development

Noura Hamade

Diversity, Equity and Inclusion Lead

Carter Hammett

Employment Services Manager

Joanna Kapusta

Office Manager

Mackenzie Muldoon

Director of Communications

Christina Muratore

Coordinator of Children and Youth Services

Jaklynn Nimec

Communications and Digital Marketing Coordinator

Nicole Nelson

Director of Development

Jesse Preston

Employment Specialist

Lorraine Ross

Accountant

Rosalee (Rosie) Smith

Director of Adult Services

John Spataro

Recreation Group Coordinator

Jarrett Stoll

Special Projects Manager

Leah Sultan-Khan

Director of Community Engagement & Public Education

Bonnie Taylor

Festival Director, Toronto International BuskerFest

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