

Building Community





468 Queen Street East Suite 210, Toronto, Ontario M5A 1T7
416 964-9095 • info@epilepsytoronto.org

facebook.com/EpilepsyToronto • twitter @EpilepsyToronto • epilepsytoronto.org

We envision a world in which epilepsy is widely understood, and where those who live with it feel fully supported.

Board of Directors

Daryl Yeo-President

David Caplan

Tracy Day

Brad Freelan

Mark McAllister

Barry Pickford

Wende Rapson

Caroline Tapp-McDougall

Sundra Toor

Cecilia Williamsms

Staff

Brooke Barrington, RSW
Social Worker

Geoff Bobb
Executive Director

Brandon Fairley
Director, Development

Carter Hammett
Coordinator, Employment Services

Joanna Kapusta
Office Manager

Katie Lundy, MSW, RSW
Director, Children & Youth Services

Tanya McCormack
Coordinator, Recreation Group

Pia Marin
Financial Services Manager

Mackenzie Muldoon
Marketing & Entertainment Director,
Toronto International BuskerFest

Nicole Nelson
Director, Development

Tim Nourse
Co-ordinator,
Enabling Change

Jesse Preston
Job Developer

Rachael-Lea Rickards
Director, Public Education and
Outreach

Rosalee (Rosie) Smith, MA, RP
Director, Adult Services

Kirsten Sixt & Rindy Bradshaw
Teaching Awareness Through Puppetry

Bonnie Taylor
Festival Director, Toronto International
BuskerFest

Drew Woodley
Director, Communications

Family Retreat



President's Message

It has been another eventful year in the life of Epilepsy Toronto, characterized by unparalleled challenges and opportunities. We remain committed to supporting and building the epilepsy community here in our city and nationwide.

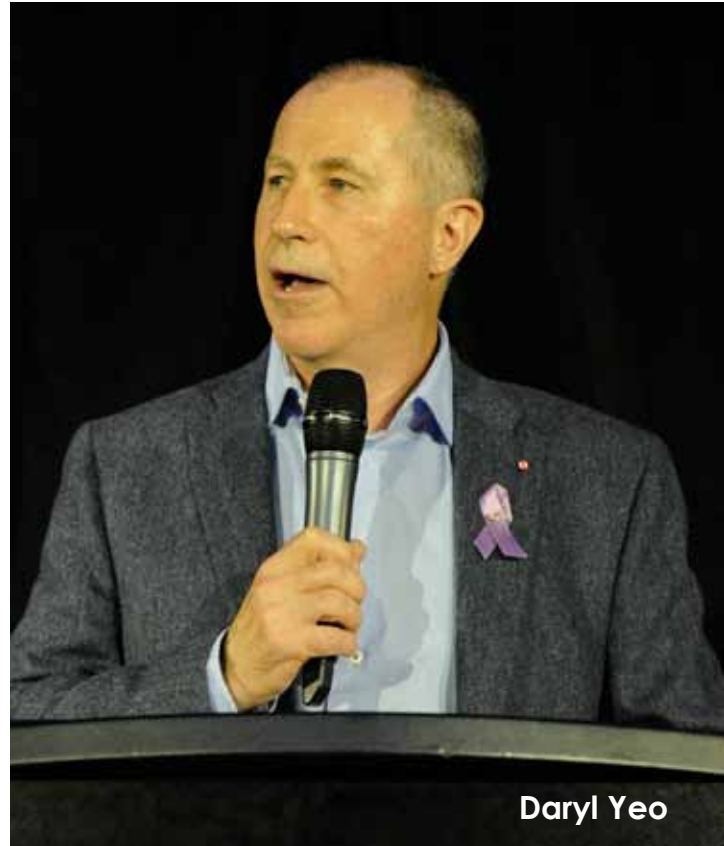
Our agency's financial position is stable. While we have been unable to secure a presenting sponsor for our signature fundraising event, Toronto International BuskerFest, we have retooled the event and moved it to a new location at Woodbine Park, allowing us to produce an equally amazing event without that type of sponsorship. Simultaneously, Scotiabank has generously provided us with a 3-year grant to support our Children and Youth program, and our first ever Purple Walk for Epilepsy Toronto has proven to be a smashing success, both in terms of raising funds for our work and in helping to bring Toronto's epilepsy community together.

An on-going challenge for our community is the issue of drug shortages. With the number and intensity of shortages seemingly continuing on unabated, there was hope that a mandatory reporting system would be in place by now, but the Federal election and change of government seems to have slowed the process. However, we have seen increased willingness on the part of Health Canada and industry representatives to communicate with each other and with those most affected by shortages, the patients, about the seriousness of the problem. I am proud of the work of our agency, and our partners in the Canadian Epilepsy Alliance, in supporting individuals impacted by shortages and by continuously calling for action by government and industry.

Epilepsy Toronto has also been at the fore-front of addressing difficult topics that are important to our community. Whether working to better educate clients about SUDEP, starting the discussion about how to support the later-life needs of adults with epilepsy, or bringing together experts to help demystify topics like marijuana for seizure control, our agency is working to help engage and educate our community about issues that matter in a balanced and knowledgeable manner.

Our agency continues to address head on the challenges Toronto's epilepsy community faces with passion and commitment. I want to recognize our Board of Directors and staff for their dedication to our work, and thank the many volunteers, donors, corporate sponsors and supporters who make the work of our agency possible.

Daryl Yeo
President
Epilepsy Toronto



Supporting Our Community

Support means different things to different people, but it's at the core of what we do at Epilepsy Toronto.

When someone is facing a new diagnosis of epilepsy, struggling to find work, or simply feeling like they are alone, Epilepsy Toronto is there to provide the support they need.

Epilepsy Toronto 2015 support programs highlights include:

- **Increasing our direct service capacity by 20% with new full-time social work and job development positions;**
- **Providing families with opportunities to connect at our Winter and Summer family retreats;**
- **The introduction of bi-monthly education workshops featuring leading experts and professionals in the field of epilepsy;**
- **Supporting our youngest clients and their families at the Sick Kids Epilepsy Monitoring Unit;**
- **A new website for easier access to epilepsy information, agency events, and member stories, including a series of new videos.**



Summer Camping Retreat

“

My son Tobin was diagnosed with epilepsy when he was in Grade 2. I had noticed him blanking out mid-sentence or mid-stride and it took my breath away. I would ask him if he realized he was doing it and when he asked, “realize I am doing what?” I knew we had a problem. Once he froze up physically in a parking lot and I had to pull him out of the way of a car backing out. Another time, he lay motionless on the ice in one of his first hockey practices and I realized whatever this is, it is a danger.

The doctor confirmed my son has epilepsy. More specifically, he has Absence Seizures. I was devastated. I thought he would never again be able to play hockey, basketball, go to the park unsupervised. He would fall behind in school due to blanking out and missing key information.

He would need extra supervision at school to watch him in the playground and I imagined he would never be able to be out of my sight again. What if it happened while he is crossing a street? What if it happened while he is riding his skateboard or balancing on playground equipment?

Tobin’s newly acquired neurologist prescribed medication for him and encouraged me to connect with Epilepsy Toronto, which I did right away. I remember dialing the number with tears in my eyes feeling so alone with this diagnosis.

Everyone was so supportive and understanding. They knew how I felt and suggested I join them for a family weekend to connect with others in the same boat and others who had far greater challenges than I.

Tobin and I went to Geneva Park with a bunch of other families where we bonded and had a fantastic weekend. I learned more about the different types of epilepsy and found families that had the same type as my son and we connected over discussing medications, side effects and giving each other hope and support. Tobin loved connecting with the other kids and got very involved in cross country skiing, snowball fights and participated in a performance for parents that was funny, adorable and enjoyable. I learned that many parents have much greater challenges than I and if they can be strong, so can I.

Here we are, 5 years later, with Tobin almost 13. He is a goaltender in select level hockey and his team counts on him to be there for them and he always is. He plays on every team that will have him at his school. He even has a cute little girlfriend now that he treats well and is that respectful young man that I had always hoped he would be.

Tobin now has been 2 years seizure free and medication free! We volunteer for BuskerFest together to give back to an organization that had our back when we needed them most. I would say especially I needed them to help me to stay strong and positive. I am forever thankful for everything Epilepsy Toronto did for us.

”

Tracy Cummins



Building Our Community

A key part of Epilepsy Toronto's mandate is to build a caring community; that means educating and working with people across Toronto, from different neighborhoods and with different needs.

Over the last year, we have reached out to new communities across our city by:

- **Offering expanded satellite locations and services in Etobicoke and Scarborough;**
- **Creating a new video resource focused on connecting with seniors, the fastest growing group of people with epilepsy;**
- **Adapting our acclaimed epilepsy@work employment toolkit to make it more accessible to francophones and persons with communications disabilities;**
- **Developing new Arabic brochures about epilepsy, including Arabic and reaching out to Toronto's Syrian refugee community.**



Etobicoke Information Session

I had my first seizure on January 16th, 2015

I was working 6 or 7 nights a week, 9-13 hours a night in a very stressful job.

I also had other issues that combined may be a factor for that seizure, but I am not sure what triggered it. For sure, my bad luck.

The seizure happened when I was walking to work. I just saw what seemed like lightning and felt a few jerks. Then I regained conscious in the Emergency. I was told that I had a very bad seizure. My head hit a parked car and was cut and bleeding.

I felt like the world and my life had changed. Nervous, scared, I did not understand what happened or what to do. I lost confidence, felt very shy to see people or walk on the street, fearing another seizure anytime and not having the balance to walk. I lost my job, my income. I felt very alone and in a different world. To be honest, even though my family, my wife and kids, took good care of me, life was dark.

After a few weeks, I remembered the doctor in Scarborough Hospital had told me about Epilepsy Toronto. I called the office and I was given an appointment to meet the counsellor. I remember I missed the first appointment because I was feeling too dizzy and did not feel confident to travel downtown.

Travelling downtown for counselling at Epilepsy Toronto meant many transit, time, and health issues. Then Epilepsy Toronto started arranging meetings and counselling in Scarborough. Meeting here, in my community, was very time-saving, made transit easier, was much better for my health, and helpful in connecting with others.

My Counsellor was kind, very understanding and had a very thorough knowledge of seizures and their impact. I felt I was not alone and I had people around me for support.

From then on counselling gave me a lot of hope and confidence in life and very soon I saw so many things start changing in my life.

The confidence I gained through Epilepsy Toronto and through my family's encouragement, I started a part time job as a dishwasher. It was not that easy working at that time but I had to do it for a reason.

I can't say my health is 100% but I am doing far better than in 2015. I work as a security guard; the company understands my health and needs and didn't discriminate against me. I have my drivers licence back.

Life goes on; I wish and pray I don't see another seizure in my life.

Ali Hassan



Connecting our Community

Not only are we working with other epilepsy agencies and researchers, we continue to reach out to other organizations on common causes. We have established or expanded many successful partnerships including:

- **Working with epilepsy agencies from Canada, Jamaica, Puerto Rico and the US to bring together young people with epilepsy who created the Twenty-20's Epilepsy Awareness Group, an international group dedicated to raising awareness about epilepsy**
- **Collaborating with educational institutions, including York University and the Toronto District School Board, to create accommodation resources for students with epilepsy;**
- **Working with EpLink, the Krembil Neuroscience Program at UHN, and Sick Kids Hospital to put on educational events for the epilepsy community;**
- **Partnering with epilepsy agencies in Ontario and across Canada as part of the Canadian Epilepsy Alliance to advocate for government action on issues like drug shortages and ODSP application process;**
- **Working with physicians, administrators, and patient representatives on the Epilepsy Implementation Task Force to develop best practice guidelines for the treatment of individual with epilepsy in Ontario.**



“ When I was 15 years old, I had been having unexplained blackouts for a few months. I saw my family doctor who misdiagnosed me as having extreme panic attacks.

I went through the next 6 years not knowing what was going on in my own body but I started to ignore them because they had subsided and I would have around 2 episodes a year.

By 2013, I had started living my ultimate dream life; then I was at work and I had another blackout. This time it was different. I didn't come back to normal, I started feeling nauseous and my memory started to become blurry. I left work, went home, and they wouldn't stop.

I had gone on a medical leave because my memory was so skewed I barely knew what I did for a living. I knew that these couldn't be panic attacks. I knew I needed to trust my own instincts.

Finally, my doctor requested an MRI and that's when everything came to a screeching halt. I had complex partial seizures that were caused by a congenital brain abnormality. She tried to explain to me the different types of epilepsy but I was still confused.

Over the next year I had quit my job, started my medications and was trying to get back to what some people would consider a “normal” life. I was so afraid of everything that I got to a point where I could barely leave my house on my own. I had to go on social assistance to help with my bills and I felt like a completely different person.

Thankfully I found Epilepsy Toronto and I finally saw a glimmer of hope. I went to counselling and group meetings with other young adults going through the same things as me. I felt like I had another family who understood me.

I applied for an opportunity through the International Bureau for Epilepsy and the Epilepsy Foundation. It was the chance to go to Washington, DC with 19 other young adults from across North America. I was beyond excited to get the email saying I was one of the Canadians who had been chosen.

We met in Washington to start this initiative built around epilepsy awareness and it was the best thing I have ever done. We are now called the Twenty-20s. We are currently doing a series called the remarkABLE project. Our goal is to create videos about as many members as possible. They show that epilepsy can and does affect everyone. It does not discriminate against anyone



Amanda Kelly

I have finally found a positive side of epilepsy. I am proud of who I am now, of who I have become and excited on this new outlook on life. I have learned that being “normal” is a word that is so misused that it is something I would rather stay away from. I am a remarkABLE person and I will constantly strive to do better and create awareness and better myself on a daily basis.

I have found comfort in my epilepsy and a new strength that I never knew I had.”

Amanda Kelly

Making our Community Possible

Epilepsy Toronto's work couldn't happen without the support of generous donors from across our city. Our agency has become synonymous with creating amazing events that not only provide much needed funds for our agency, but also give our members an opportunity to help raise epilepsy awareness in our community, including:

- **Toronto International BuskerFest, the world's largest epilepsy event, which brings together talented performers from Toronto and around the world to our city;**
- **The Night is Yonge Soiree, our gala event that brought together some of Toronto's best and brightest for a suave evening at the Aperture Room on Yonge Street. The extraordinary event was co-chaired by NBA superstar Tristan Thompson in support of the Amari Thompson Fund for Epilepsy Toronto;**
- **The inaugural Purple Walk for Epilepsy Toronto, our city's first ever epilepsy walk, that brought hundreds of people and a sea of purple to Toronto's streets;**
- **Purple Day for Epilepsy Awareness in March which gave our members the opportunity to join with people from across Canada and around the world in helping raise epilepsy awareness in their communities.**



“ My little brother Amari had his first seizure just after he was born and soon he was diagnosed with epilepsy. Amari’s seizures can strike at anytime and he will have them for the rest of his life. He has to be on a special diet, take multiple medications and endure side-effects. It has had a big impact on Amari and my whole family.

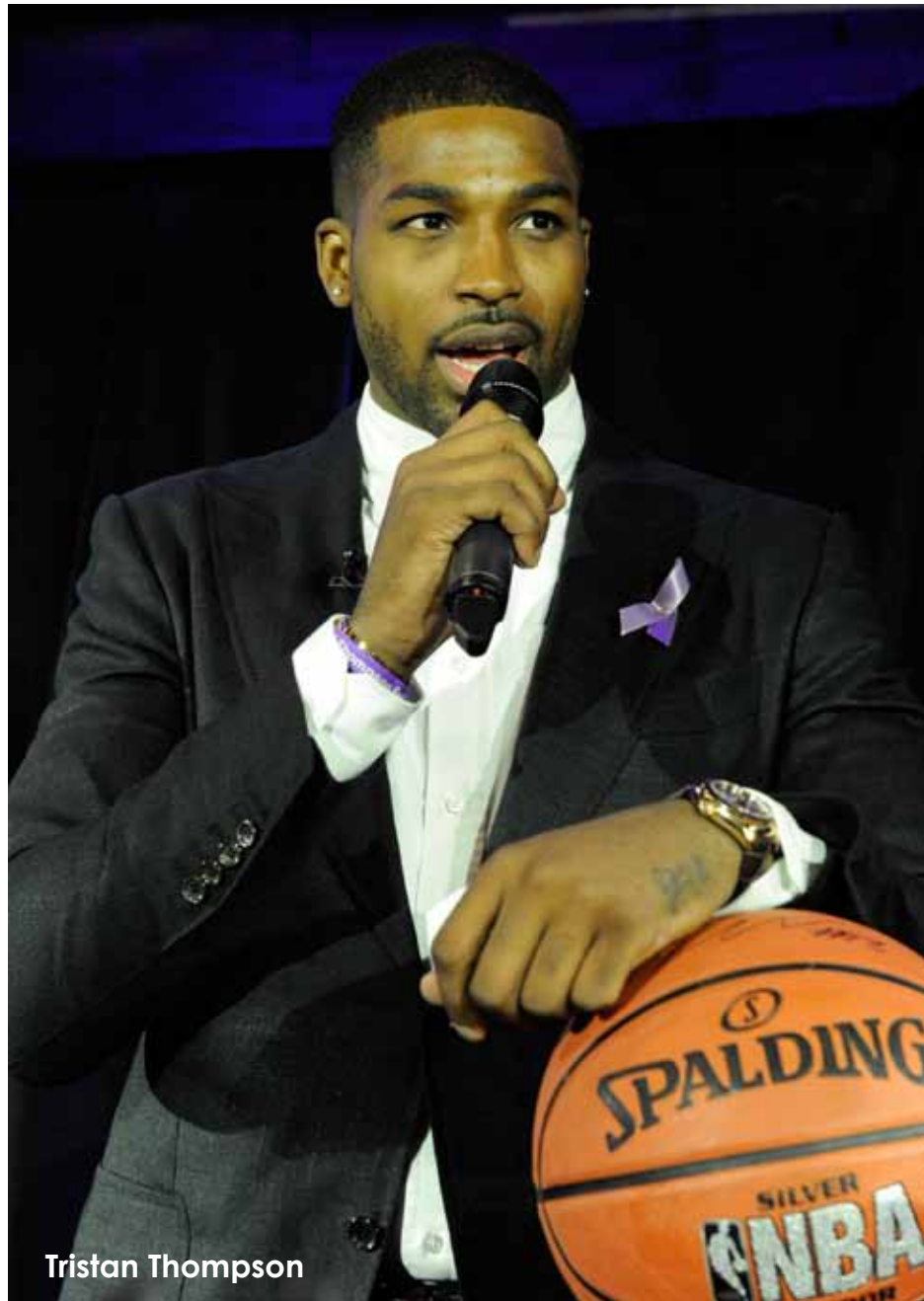
When it’s six in the morning and I don’t want to get up and work out, I think of how strong Amari is to keep going despite his challenges, and that motivates me. He pushes me beyond my limits. My success on the court has meant Amari gets the support he needs and his seizures today are mostly under control.

There are 40,000 people with epilepsy in this city. Too many struggle with epilepsy alone, without the support or resources to see them through the tough times. It is for them that I have decided to create the Amari Thompson Fund.

The Amari Thompson Fund will help Epilepsy Toronto support families affected by epilepsy with the help they need to get through the toughest times. The fund will support education, counselling and recreational services for families affected by epilepsy and make sure they have a place to share their common experiences. The fund will ensure that no one has to face epilepsy alone.

This is a cause dear to my heart, and it is my hope that the commitment and dedication I bring to the fund will inspire you to get involved too.”

Tristan Thompson



Tristan Thompson

Thank You

Thank you to all of our donors, funders, and special friends who make Epilepsy Toronto's work possible. Without the support of the many people, businesses, and organizations that help us in so many ways, we would not be able to provide services to Toronto's epilepsy community. Beyond the individuals, groups and companies listed here, we want to acknowledge the hard work and effort of all the volunteers who help Epilepsy Toronto year-round. Thank You!

We are particularly grateful to our 3 institutional sponsors without whom our work would not be possible.



United Way
Member Agency



Scotiabank

Corporate Supporters

Aird & Berlis LLP
Allied Properties
Allstate Insurance
Baylis Medical Co..
Borden Ladner Gervais
Bousfields
Canadian Basketball
Cassels Brock &
Blackwell LLP
Cavaliers Operating Co
Cityzen Development
Community Trust
Cooltech Air Systems
CUPE 4400
Dorplex Industries
Chelsea Hotel
Eisai Limited
Element Financial
Fedex
Four Seasons Hotels
and Resorts Limited
Glen & Jamie
Goldman, Spring,
Kichler & Sanders LLP
HGC Engineering
Homes Magazine
Hull & Hull LLP
Hydro One Employees
and Pensioners Charity
Trust Fund
KingSett
KPMG
L.A Inc
Liette Locas Claude
Cormier ET Associes.
Mainline Plumbing
Services Inc
McCarthy Tetrault
Medtronic of Canada
Natus Medical Inc
Ontario Power
Generation Inc
Pricewaterhouse
Coopers Canada

Pro Park Management

RBC Royal Bank
Salad King
Samsung Canada
Scotiabank
Sunovion
Pharmaceuticals
Canada Inc.
The Cardy Group Inc
UCB Canada
Ursel Phillips Fellows
Hopkinson LLP
VicBar Marketing
Wilson Vakelich LLP
The Woodbridge
Corporation

Government and Foundation Supporters

Canada Summer Jobs
Celebrate Ontario
City of Toronto
Connor, Clark and
Lunn Foundation
Government of
Ontario
Greay Lennox
Charitable Foundation
Kiwans Club
Mackenzie Charitable
Foundation
McCarthy Tetrault
Foundation
Michael Pinball
Clemons Foundation
New Horizons
Price Waterhouse
Coopers Canada
Foundation
RLS Charitable
Foundation

Community Partners

Camp Couchiching
Canadian Epilepsy
Alliance
CIBC Workability
Downtown Yonge BIA
East Scarborough
Storefront
Epilepsy Ontario
Eplink
Franklin St Public
School
Fraternal Order of
Eagles, Aerie 2311
Military Trail Public
School
Monsignor Johnson SS
National Council of
Jewish Women
Ontario Brain Institute
Ontario Disability
Employment Network
Rexdale Women's
Centre
Ryerson University
Scarborough
Center for Health
Communities
Scarborough Town
Center
St Kevin Catholic
School
St Margaret In The
Pines Anglican Church
The Hospital for Sick
Children
The Kiwanis Club of
North York
Toronto Police Service
Toronto Western
Hospital
Trios College
YMCA Geneva Park

Media Partners

CP24
CTV
Metro News
Toronto Star
Toronto.com

Special Friends

Anastasia Watson
Andy & Jennifer
Ayotte
Anna Argaw
Anne McMaster
Barry Pickford
Brian Miron
Catherine Steele
Cecilia Williams
Chris Humeniuk
Christine Oakey
Danielle Benson
Daryl Yeo
David Gold
David Oxtoby
David Yeilding
Dayl Marks
Deborah Preston
Dennis Wiebe
Dorplex Industries
Eduard Bercovici
Edward & Judith
Martin
Emma Campbell
Esther Cole
Gaetane Ayotte
Gerry Carlino
Grace Fellowship
C.O.G Ministries
Hadley MacDonald
Estate of Helen
McCarthy
James J. Corbett
Jane Landriault
Jerome Calder
Jim Macartney
Johanne Brossard

John Doig
John Kiru
John O'Donnell
Jordan Craig
Josh Phillips
Kara Kljajic
Ken Rutherford
Kristyn Wong-Tam
Lise-Ann Hachey
Marcia Da Costa
Maria del Carmen Terry
Maria Fauceglia
Mark & Margaret
Franklin
Mark & Patricia Davis
Mark Anthony Brands
Marlene Freelan
Matthew Horan
Nina Politzer
Noreen Hains
Pablo Breard
Pam McDonald
Patricia Stevenson
Paula Habra
Peter Tai
Ralph Jones
Rosina A Mete
Rowan Barrett
Roy & Suzanne
Arendse
Sharon Smith
Simon Abboud
Steve Kljajic
Tabitha Raju
Taufik Valiante
Teresa & Gary Joyce
The Estate of Helen
McCarthy
The Thompson Family
Thomas Martin
Toby Francisco
Tom Nesbitt
Wende Rapson
William D. Martin