EPILEPSY
*Toronto*
See the Person

# Annual Report 2014

Tristan Thompson, Epilepsy Ambassador, and Amari Thompson

# President's Message

We have had another eventful and productive year at Epilepsy Toronto, with continuing achievement and progress on a number of projects that will help the epilepsy community, not just in Toronto but across Canada. Our Board of Directors and agency staff remain firmly committed to providing the programs that best meet the needs of our many members, and to speak as the voice of the epilepsy community to enhance public understanding of the challenges of living with seizures.

One of our most important successes was on the continuing issue of drug shortages and their impact on the epilepsy community. Our agency has been working very closely with our partners in the Canadian Epilepsy Alliance over the past years to bring more public attention to this crucial issue and to advocate on our members' behalf with the federal government to ensure the issue is getting the attention it deserves. After ongoing communication with politicians and senior officials at Health Canada, and ensuring our members had their voices heard during public consultations in mid-2014, we were very pleased with the announcement by the federal Health Minister in early 2015 that actual or anticipated drug shortages will now require mandatory reporting by drug manufacturers. While this does not resolve the issue of shortages entirely, mandatory reporting is seen as an essential first step in addressing the problem of shortages while allowing patients, families, and physicians to better manage the situation. We will continue in our efforts to see an effective and timely drug shortage management plan put into place.

Another major accomplishment came from our employment accessibility efforts for our members, and culminated in the development and public launch of our epilepsy@work project to much acclaim. Funded by, and developed with the Government of Ontario EnAbling Change program, this innovative online toolkit includes a course featuring a realistic workplace scenario, an interactive video simulator featuring a pubic seizure situation, and employment related-resources. We officially launched the toolkit in December with the participation of CIBC which has been an active supporter of the project. Since its launch, we have received significant positive feedback from the Government which has been using the toolkit as an example of the type of project public health service organizations should be working towards. We have since been awarded additional funding to assist in increasing the accessibility and distribution of the toolkit to employers throughout Ontario. We have no doubt that this initiative will have a lasting impact on the development of employment prospects for our members.

Our signature fundraising events, Scotiabank BuskerBall and BuskerFest, enjoyed their second year in the Downtown Yonge Street neighborhood. That location continues to provide us with significant opportunities for outreach and relationship building. This year's BuskerBall also served as the backdrop for the announcement that Canadian NBA star basketball player Tristan Thompson will be working with Epilepsy Toronto to create and build the Amari Thompson Fund in support of Epilepsy Toronto, named for Tristan's brother who lives with epilepsy. We are incredibly excited about Tristan's on-going support for our work and are looking forward to some exciting future partnerships with him.

Unfortunately, we have recently been advised by Scotiabank that it will be refocusing its future sponsorship priorities, and that 2015 will be its final year as the marquee sponsor for BuskerBall and BuskerFest. Epilepsy Toronto has been very fortunate to have enjoyed a long and productive relationship with Scotiabank since the inception of BuskerFest, and their support for the events will certainly be missed. We are thankful for the substantial notice they have provided and have begun the process of actively exploring opportunities to secure new major sponsorships to ensure ongoing future successes for the Ball and Festival, and their crucial financial contributions to fund our core program activities.

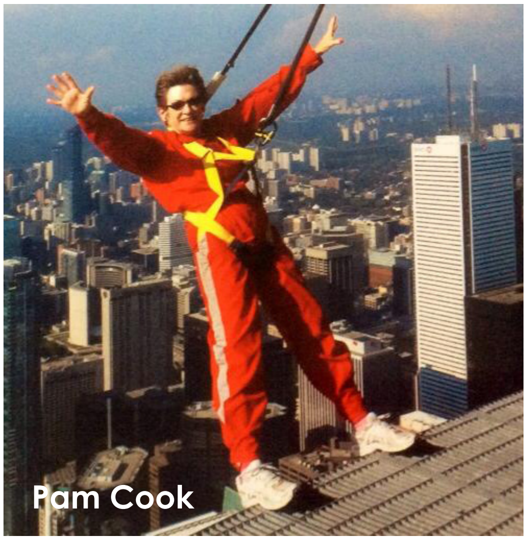
I believe that we should all be proud of the achievements of Epilepsy Toronto over the last year, the highlights of which you will read about in the pages of this report, and I am enthusiastic about the new and exciting initiatives we are undertaking in the year to come. Our past and future successes can only be achieved through the hard work, dedication and ongoing contributions of our Board of Directors, staff, volunteers, donors, corporate sponsors and supporters, and I wish to offer all of them the sincere thanks of our agency.

**Daryl Yeo**
**President**
**Epilepsy Toronto**


Daryl Yeo, BuskerFest Launch 2014

# Diversity Outreach

Being a senior with epilepsy hasn't slowed down Pam Cook one bit. She is working hard in the community to help spread awareness about epilepsy and recently spoke on behalf of Epilepsy Toronto at an "International Day of the Older Person" event.


Pam Cook

When not using her passion to be an advocate for Epilepsy Toronto, you may catch her at the top of the CN Tower doing the EdgeWalk. Pam exemplifies what it means to truly live life with passion, to be a thriving senior who is living with epilepsy, and to enjoy every step of her journey.

## In 2015

**Epilepsy Toronto will be continuing to focus on seniors with the "Seniors Making Change" awareness video, an educational video project by and for seniors with epilepsy, funded by New Horizons.**

**Collaborating with other community groups, Epilepsy Toronto will be creating a Health Fair Summit for the black community, scheduled for Black History month 2016.**

## 2014 Program Highlights

- The diversity outreach program was expanded to include outreach to seniors
- The program reached culturally diverse networks and groups, including South Asian, Asian and African communities, through social media, community radio, and television.
- An important part of our strategy was working with cultural and generational communities to address myths, stigmas, and silence about epilepsy and to tackle out-dated attitudes about seizures.


Seniors Group

# Employment Services

Like so many people living with epilepsy, Marylena Fiorante came to Epilepsy Toronto because she was struggling to find employment. Finding a job was hard enough, but too many employers aren't willing to provide a few reasonable accommodations to someone who might have a seizure at work. Marylena met with Epilepsy Toronto employment staff and after some work they found a good fit at CIBC.

Ten years later Marylena is still working at CIBC and wanted to share her story and the positive experience she has had with her employer. She took part in the *epilepsy@work* project, recording a video interview about how CIBC has been a model for workplace accommodation, and helping Epilepsy Toronto demonstrate the online course at CIBC's Assistive Technology Showcase.


Marylena Fiorante

## 2014 Program Highlights

- The addition of a Job Developer to the Employment Program allowed us to be more proactive at finding job opportunities for our clients in their particular fields of interest.

- The official launch of *epilepsy@work*, an online toolkit (epilepsyatwork.com) of epilepsy employment resources including a realistic workplace training course and an interactive seizure simulator. This has given the employment program a huge boost with an excellent resource and tool to educate both employers and employees about epilepsy in the workplace.

**In 2015**

**Epilepsy Toronto will continue to collaborate with the Accessibility Directorate of Ontario to further promote *epilepsy@work* across the Province.**


A Course for Employees & Co-workers

epilepsy@work
Understanding epilepsy in the workplace

TOPIC 3: MANAGING EPILEPSY

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THE ANXIETY

# Children and Youth Services

## 2014 Program Highlights

- A new partnership with the Toronto District School Board to support students with epilepsy in the classroom with resources for use by staff, parents, and physicians to develop individualized support plans for students with seizures. The partnership materials have been developed with input from staff at The Hospital For Sick Children.
- Starting a joint project with York University students and staff to create a 'classroom accommodation' resource so professors and instructors can better understand the needs of post-secondary students with epilepsy.

When Glenda Samuels-Greenidge contacted Epilepsy Toronto, her son Joseph was having seizures every day; that's hard on a five-year-old. Even with the support of dad Richard, sister Chayah, and brother Joshua, Joseph and the family needed some extra help.

Glenda met with Epilepsy Toronto Director of Children and Youth Services Katie Lundy who answered Mom's many questions. Katie met Joseph's kindergarten class to talk about what epilepsy is. The Greenidge's joined other Epilepsy Toronto families for our BuskerBrunch and trip to see the Raptors in the fall.

No kid wants to spend time in the hospital, so Joseph was happy to see Katie when she visited him in the EMU at The Hospital for Sick Children, ahead of a scheduled surgery that was his best chance for bringing his seizures under control.

Even though Joseph has been seizure-free since his operation in November, epilepsy continues to play a role in the family's life; Glenda now acts as a Parent Mentor for those parents whose children are going through the surgery process. Joseph, and Chayah spoke to their school classes for Purple Day, Joshua wore purple and answered his friends questions, and Richard involved his workplace in epilepsy awareness.

The outlook for Joseph and the family looks good, but Glenda remains cautious. They are "taking it day by day," she says.

### In 2015

Epilepsy Toronto's Director of Children and Youth Services will be visiting patients and families in the Epilepsy Monitoring Unit at The Hospital For Sick Children once a week. She will connect with the EMU team to identify the patients and families who would like a visit and offer information, resources and support.

Joseph and his Epilepsy Toronto Dog, Epi

# Adult Services

Beth MacKinnon has had epilepsy since she was 6 years old and she knows first-hand what it feels like to be told that medications may never give her full seizure control. In her late 20's she was told she is a potential candidate for surgery; her MRI showed a scar on her left temporal lobe. Beth said no to surgery; she was not willing to risk the possible complications, the pain, and the deficits that could result. At the time, most of the seizures were happening in her sleep – one of the many reasons she thought surgery was not needed.

Her seizures however, continued to worsen in her 30's and began happening in public, at work, and at the gym. They were coming more frequently, with a lot less warning and more started to happen during the day. While she always received support from people who saw them, it was starting to impact her life more than it ever had. Her neurologists continued to talk about surgery. She finally agreed to get tested and it turned out she was a surgery candidate but she was still indecisive. "The thought of surgery terrified me," Beth said.

After having what she described as "the biggest tonic-clonic seizure she ever had" on the lawn of Queen's Park where she works, her resolve against surgery was shaken and she agreed to see the neurosurgeon.

Although her medical team was amazing, she felt it was important to hear from others who had been there. Her concerns went beyond seizure freedom. Her job required her to analyze, problem solve, memorize and communicate. Would those abilities be affected?

She contacted Epilepsy Toronto and received help, working out the questions she needed to ask her neurosurgeon and, most importantly, speaking with others who had actually had surgery. "I could see people who had had surgery and know they were okay. They were normal. They healed."


Beth MacKinnon

She felt these insights and the support she received from staff and clients at Epilepsy Toronto, her partner, friends, family, and her medical team was critical to her to move forward with surgery.

Following Beth's surgery she returned to the surgery support group and shared her journey with those who were now considering surgery. She wanted to 'pay it forward'.

Although the post-op period was tough, she has no regrets. "Today I feel amazing and I am 10 months seizure-free and counting." She strongly advises people who are considering surgery to attend the surgery support group as "it makes a world of difference."


Surgery Support Group Meeting


Etobicoke Outreach

## 2014 Program Highlights

- As the waitlist for admission to the Epilepsy Monitoring Unit shortened and more people are weighing surgery as a treatment option, Epilepsy Toronto, in partnership with Toronto Western Hospital, re-established the Surgery Support Group to create a supportive forum for people who are considering surgery to connect with and learn from those who have had surgery.
- Established a strong partnership with TRIOS College to provide epilepsy and seizure first aid training to their Personal Support Worker and Medical Office Assistant students. As a result they have become ambassadors hosting large Purple Day events and participating with a team of seventeen at our Scotiabank Waterfront Marathon.
- Partnered with Rexdale Women's Centre in hosting a Purple Day event at the Rexdale Community Hub. More than 250 people stopped at the booth throughout the day, including family members of people with epilepsy, some of whom have since connected with the agency.

## In 2015

**Following on the success of our Etobicoke satellite partnership, Epilepsy Toronto has partnered with the East Scarborough Storefront to create an outreach and meeting space for clients in the Scarborough area.**

**Our Scarborough outreach will be co-ordinated by our new full time social worker who will also increase our adult services counselling and support capacity.**


TRIOS College Purple Day Event

# Team Epilepsy Toronto

For over 10 years Epilepsy Toronto has participated in the Scotiabank Waterfront Marathon, raising well over half a million dollars to support the programs and services that help people with epilepsy live well. We are so honoured to have our members roll up their sleeves, collect pledges and show up at the crack of dawn to walk for epilepsy.

The Scotiabank Waterfront Marathon involved thousands of people all supporting their own charity of choice, and we were always so proud of how our team stood out, creating a sea of purple representing the epilepsy community.

We have listened to members' suggestions about creating our very own walk for epilepsy. So we are very excited to launch **The Purple Walk for Epilepsy** on Sunday, August 30th, 2015 with the support of the Amari Thompson Fund. This change allows us to involve more members in our walk, build an even bigger fundraiser and garner more exposure for the epilepsy community.

"For four years our family has walked for our son Elijah and raised money for Epilepsy Toronto. It means a lot to us! It brings us great joy in joining other families who care about epilepsy and to show off our PURPLE PRIDE together. " said long-time Team Epilepsy member Marilou Sta. Maria.

We invite all of our members to participate in the first-ever walk for epilepsy in Toronto. Walk in solidarity with your epilepsy family and raise money for an excellent cause.

## 2014: The Amari Thompson Fund

In 2014, Epilepsy Toronto partnered with NBA star Tristan Thompson and his mother Andrea, to launch the Amari Thompson Fund in support of programs and services to people with epilepsy and their families in our city.

"My brother Amari has epilepsy, says Thompson, "he is the greatest inspirational force in my life. I am deeply honored and privileged to be able to serve the Toronto epilepsy community in this way."

The honour is all ours, Tristan; we will forever be your biggest fans!!

Tristan, Andrea & Amari Thompson

Team Elijah

# Scotiabank BuskerFest

This year's Scotiabank BuskerFest was the biggest yet. The Downtown Yonge neighborhood hosted us for 4 days of entertainment, fun, and generosity that stretched from Queen to College Street.

More than 70 acts featuring over 160 entertainers from across Canada, the U.S., and as far away as Australia, Austria, Argentina, Belgium, Germany, Hungary, Ireland, Italy, Japan, Mexico, New Zealand, Russia, Spain, Sweden, and the United Kingdom, came together for an amazing festival to raise funds for Epilepsy Toronto.

**The Sauruses**

## 2014 Festival Highlights

- The new Benefit Stage at Yonge-Dundas Square featured a steady stream of performers throughout the festival with all funds collected benefiting Epilepsy Toronto.
- The biggest festival yet with 1.5 Million attendees, it raised $360,000 for Epilepsy Toronto programs and services and generated $11.9 million in economic impact for Toronto.

### In 2015

**The Sauruses are Back! The larger-than-life dinosaurs are once again coming all the way from Holland. These giant stilt-walking crowd favorites are absolutely thrilling!**

**Kamikaze Fireflies**

# 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!

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# EPILEPSY Toronto

See the Person

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

We build a caring community for people affected by epilepsy, through support, education and awareness.

We are solely dedicated to supporting people living with epilepsy to live well.

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