

e**t**bulletin

Epilepsy Toronto's publication of community news and events



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The Michele Edwards Bursary

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

Afroza Hossain
financial services manager

Mackenzie Muldoon
marketing & entertainment director,
Toronto International BuskerFest

Nicole Nelson
director, development

Tim Nourse
co-ordinator,
enabling change project

Jesse Preston
job developer

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

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Epilepsy Toronto presented the Michele Edwards Bursary at the 2017 Annual Epilepsy Conference and AGM in May. The bursary is awarded to someone who identifies as a female person of colour and lives with epilepsy.

Whether it was running track or playing piano, Michele was always determined to excel. As a working woman, she developed accounting techniques that won the respect of multi-national corporations, but had to fight constant workplace discrimination because of her epilepsy. Inspired to study law and advocate for others, she took her college to the Human Rights Commission after facing discrimination by her instructors in the classroom, and forced her school to create new policies to accommodate people with disabilities. Michele passed away in December 2013 after a lengthy illness. This bursary was established with love by her children and family to honor her legacy.



Michele Edwards

The bursary was awarded to two exceptional Epilepsy Toronto clients, Michelle Buckland and Amanda Kelly. Both have overcome the challenges of living with epilepsy and show great initiative and determination in pursuing their education and goals.



Michelle Buckland



Amanda Kelly



Research

Epilepsy Toronto staff had a chance to meet with some of the amazing researchers in The Valiante Lab from Krembil Research Institute at Toronto Western Hospital and hear about their work on everything from memory, to Responsive Brain Stimulation & VNS technology, visualizing intracranial data, pre- and post-surgery support, and music to control seizures. Thank you for your visit!



Ministry of Education

After several years of work by our provincial partners at Epilepsy Ontario, as well as by advocacy groups representing other medical conditions, the Minister of Health announced in October that Ontario school boards will be required to provide individual care plans for students with prevalent medical conditions to manage their daily medical needs, including epilepsy. Boards will need to have policies in place by the start of the fall 2018 school year.

“This new policy essentially reinforces what Epilepsy Toronto has been communicating to schools for years: the need to individualize the specific needs of each student with epilepsy, ensure proper training in terms of seizure first aid, and strengthen accessibility in terms of accessing rescue medications,” said Katie Lundy, Epilepsy Toronto’s Director of Children and Youth. “This is a vital first step in supporting the unique needs of students with prevalent medical conditions, and creating the awareness of seizure safety within the school environment.”

The announcement comes as the Toronto District School Board is finalizing its own procedures for providing individual care plans for students with epilepsy in its classrooms. The procedure, which includes an epilepsy training component for educators and school personnel, was developed in partnership with Epilepsy Toronto and Sick Kids Hospital staff.

Facing the Word

By Michele Santoo

Admitting I had seizures was one thing. Saying I had epilepsy was quite another. It was a word I found difficulty in addressing who I had become.

My seizures started when I was 32 years old, after the sudden loss of my father. Two years



later, a neurologist confirmed my dreaded word, Epilepsy. To my dismay, the report sent to my doctor stated, "When I first saw her she did not look like someone who was epileptic". This angered me a lot. I did not know there was a certain look for those living with epilepsy

I wondered if there was a place that would accept me and my seizures, without "the look". It was at one of my favourite street festivals, BuskerFest, that I first became aware of Epilepsy Toronto. Amidst all the fanfare, I collected every bit of information related to epilepsy. However that was not enough to give me the courage to ask for much needed help. I was too ashamed.

Tired of being controlled by fear, I eventually and nervously called Epilepsy Toronto. I immediately knew the right decision was made by the courteous assistance I received over the phone. I was transferred to a counsellor who professionally and patiently calmed my fears. That started my road to major recovery.

On my first appointment I was overcome with anxiety which quickly vanished when I entered the office. I was warmly welcomed and introduced to my counsellor, with whom I instantly felt a sense of ease. Eventually I became

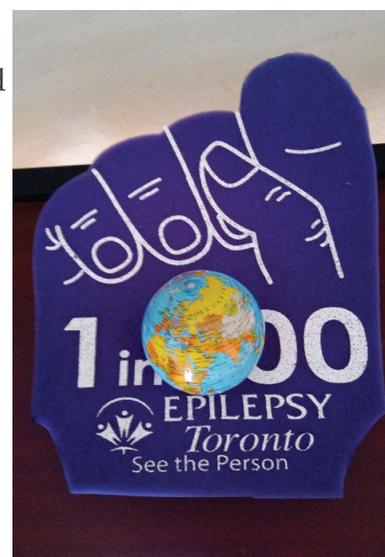
secure enough to confess that I cannot even say the word "epilepsy". With consideration, I was patiently guided. For a while I wrote the first three letters only. Today I am proud that I can say and write the word "epilepsy".

My counsellor supported and encouraged me to embrace my future, and kept reassuring me of my value and self-worth.

She introduced me to the Coordinator of Employment services. His wealth of experience was exemplified on our first meeting. He knew exactly what was best for me. A single phone call on my second visit got me accepted and enrolled in a full time course at George Brown College.

The course comprises three semesters with 18 subjects. I am pursuing my love for creative and narrative writing, together with Computer Technology. In my first semester I successfully completed 6 subjects with A-plus grades and made the Deans Honour Role list. Recently one of my poems was published in the annual "A Class Literary Journal". It was wonderful to experience that feeling again. I also successfully achieved implementation of a Business Plan in the Career and Transition curriculum that caters to self employment, the first of its kind in the 15 years of the program.

I bravely informed my Professors at George Brown College about my epileptic seizures, as I no longer had hidden secrets regarding my health. I am fully respected and accommodated. on Campus.



Most of my challenges, both mental and physical have been conquered. I have a new neurologist who I am very pleased with. The main issue of speaking in a group has been accomplished by attending "Adults With Epilepsy" meetings. It is a pleasant and safe environment where stigma and judgement cannot prevail. It also caters to our supporters who are a source of our strength and inspiration.

I have fully accepted the realization that there is more to life than seizures, as they no longer control my lifestyle.

My first fears of, coming to Epilepsy Toronto or even acknowledging the word epilepsy, no longer exist. They have successfully been replaced with joyful eagerness.

Epilepsy Toronto is now a place I call my home.

Summer Events



The Amari Thompson Soiree, our gala evening of cocktails, canapés and celebration took place at the beautiful new Globe & Mail Centre with our ambassador Tristan Thompson of the Cleveland Cavaliers.



The 3rd annual Purple Walk for Epilepsy Toronto brought hundreds of people living with epilepsy and their friends and families to downtown streets.



Toronto International BuskerFest returned to Woodbine Park for its second year and hosted the Muslim Association of Canada's Eid celebrations on the Friday.



Speed mentoring

A great time was had by all November 22 at Epilepsy Toronto's second annual Speed Mentoring event.

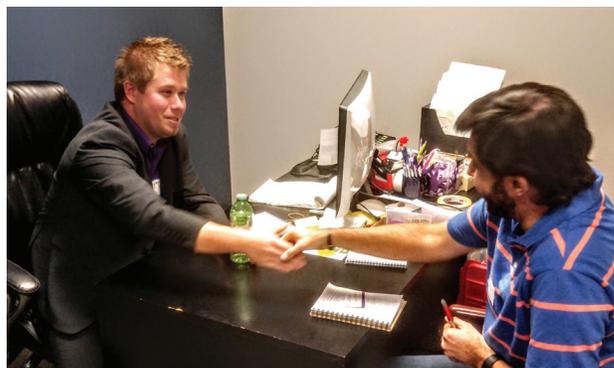
Organized by the Epilepsy Employment team, speed mentoring is an event that consists of pairing experienced volunteer mentors to job seekers with epilepsy in a series of rapid-fire micro counselling sessions.

Job seekers are allowed 10 minutes to discuss an issue with mentors, who, in a tightly structured time frame respond as best they can to the presented problem. It's okay if a mentor doesn't know the answer because the job seeker presents the same question multiple times to other mentors who will most likely have at least a piece of the answer.

Mentors came from all walks of life, including media, banking, coaching and non-profit sectors. Job seekers meanwhile, represented a wide diversity of sectors and presented a series of questions.

A lot of information gets exchanged and the event is great for networking, info sharing and meeting new contacts. Once the mentoring sessions are concluded, a meal is served and job seekers have the opportunity to connect with employers for more in-depth dialogue. Job seekers benefit from an unbiased and objective person offering honest feedback in response to an issue, and mentors develop a sense of the issues relevant to job seekers with epilepsy, while meeting new and potential talent.

The model is flexible enough to be either shortened or lengthened. As well it can be adapted to fit the counselling needs of many groups, including women, youth, new Canadians and other marginalized groups. This is rapidly becoming a signature event and the feedback has been so positive we're thinking of offering it twice a year, instead of once! If you would like more information, please contact Carter at 416.964.9095 or write: carter@epilepsytoronto.org





Did you ever wonder what it is like to have a seizure but you were too shy to ask? Would you like your classmates or your teachers to better understand how to help if a seizure takes place?

Teaching Awareness through Puppetry (TAP) is an educational outreach program that teaches children about acceptance and awareness of differences, including epilepsy. Our life size puppets break down barriers and encourage open dialogue. TAP's workshops help students and teachers better understand what it is like to be a person living with epilepsy. Each workshop includes a puppet performance, a facilitated question and answer period and leave behind activities to reinforce learning and follow up. Children in grades K-6 learn about seizure first aid and see first hand that a person with epilepsy is just like everyone else, they want to have friends and be included.

Our goal for each workshop is to educate, build awareness and acceptance and to create kinder, more inclusive school communities. This month we were delighted to visit Fairbanks Memorial Community Public School, where we worked with the students to learn more about epilepsy and care for their friends who may be living with the condition. The feedback was excellent. These conversations can help to change lives. Fairbanks is just one of the schools who have taking the advantage to work with TAP to help students in their community living with epilepsy feel more included.

For more information about our program or workshops please contact Kirsten or Rindy at 416 964 9095 or email us at info@tap-toronto.com. You can also check out our website www.tap-toronto.com. We look forward to hearing from you!





December 1st-23rd
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