

et community bulletin

Epilepsy Toronto's publication of community news and events



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The Night Is Yonge

The second annual 'The Night Is Yonge' Soiree brought home NBA Basketball star and 2016 champion Tristan Thompson (founder of the The Amari Thompson Fund) for this special fundraising event in support of Epilepsy Toronto. Held at the exquisite Aperture Room, the evening was hosted by journalist and epilepsy ambassador Mark McAllister and basketball Superfan Nav Bhatia.



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Epilepsy And U

Epilepsy Toronto and York University have partnered on a new educational tool. Epilepsy And U: Understanding Epilepsy in the Higher Education Classroom works to educate post-secondary professors and instructors about the realities of epilepsy and how to accommodate students with seizures. The interactive toolkit teaches basic seizure information and provides practical examples of how to support students in classrooms and exams.

www.epilepsyandu.com




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Student's name: Aisha

Student's information: Aisha is a history major. She has complex partial seizures. You initially thought Aisha was a good student. The essays she has turned in were both well written. She had a seizure during a three-hour lecture, but she was with a friend who helped her. You gave the class their break early, and she was able to continue.

Situation: Aisha's mid-term exam was a mess; she missed many obvious answers on the short answer portion and her essay question seemed to be vague and lacking in specifics. Aisha has asked that she be allowed to take her final exam open book or with a cueing sheet and be given extra time.



What would you do?

Refuse the open book request, but tell her that if she has a seizure during the exam she'll be given extra time. You want to accommodate her if she has a seizure but anything else is unreasonable.

Tell her you are worried about other students seeing her with the book in the exam, so instead you will excuse her and re-weight her other work. This will give her a 68% in the course.

You allow Aisha to use an open book with extra time if she needs it, but you arrange an alternate exam location.

Click on the options above to reveal the solution

Volunteers

Staff-member Rachael-Lea Rickards has taken on the new role of Director of Community Engagement & Volunteers.

“Since working at Epilepsy Toronto, I’ve always loved working with volunteers. Being a generally outgoing and creative person, I love working with people and finding new ideas on how to get our volunteers involved. Buskerfest was my first transition into the role, and I LOVED it! It’s amazing to work alongside some of the best volunteers, EVER!

I have big plans for 2017, where we can involve clients and community members in spreading the word about Epilepsy Toronto. We rely heavily on the support of our community and believe that volunteers are so important. I’m extremely excited to be giving the opportunity to build a year round program.

Want to get involved? Do you have a great idea on how you can help raise awareness and donations for the agency? I’d love to talk to you.”

Send an email to volunteers@epilepsytoronto.org

Purple Walk

For one Sunday in June, the streets of Downtown Toronto were filled with a sea of purple as hundreds of people took part in the second annual Purple Walk for Epilepsy Toronto.



Following the huge success of the first annual walk in 2015, Epilepsy Toronto made the Purple Walk into one of our signature events with people living with epilepsy, the families and friends, and community supporters donning their best purple outfits to raise money and awareness about epilepsy.

Over 700 hundred people of all ages turned the Downtown Yonge Neighborhood purple and raised over \$130,000 for Epilepsy Toronto's services. Thank you again to all the walkers, donors, and volunteers.



Congratulations

Congratulations to Team Ayotte, Andy, Michael, Stephanie, and Kyle, who took part in the half-marathon during October's Scotiabank Waterfront Marathon and raised \$16,000 to support the work of Epilepsy Toronto.

Thank you so much and well done!



EMU Volunteers

The Epilepsy Monitoring Unit at Toronto Western Hospital is a place many people with seizures have visited. While it plays an important part in assessing seizure activity with the hope of finding treatment options, it can also be quite lonely, sitting in a bed, waiting for a seizure to happen.

Two Epilepsy Toronto clients are helping to change that. Ravi Raman and Jerry Catalfo both volunteer once a week in the EMU. Neither are medical professionals, simply people who know what it's like to live with seizures and spend time in the EMU.

They each devote a few hours a week, walking the floor, offering to spend a few minutes with anyone who might be in for monitoring. They talk, about epilepsy, their experiences, the EMU, or anything else that might come up.

"No two conversations are alike," says Ravi.

"Ninety-percent of people like to talk after I've introduced myself. It can get boring being in the hospital," says Jerry

Both Jerry and Ravi come by their familiarity with epilepsy honestly. Seizures have had a profound effect on both their lives.

Jerry has lived with seizures most of his life, but they worsened in 2003, eventually leading to the breakdown of his marriage and going on Long-Term Disability. Despite being a potential candidate for surgery, he put off exploring it as an option.

"I didn't want my head broken into," he says.

In the meantime he came to Epilepsy Toronto, receiving counselling and joining a support group. He remarried and was settling into a routine, but he was still having two to three tonic-clonic seizures a month. After five years he finally decided to pursue surgery as an option.

The surgery was successful, although Jerry thought at first it had been a mistake. It took time for his language skills to return, his vocabulary was impacted and he had a hard time communicating with his wife and kids. After six months things started to improve, his language skills returning.

He also started volunteering at Toronto Western Hospital, hoping to give back. Initially he volunteered in the ER before eventually moving to the EMU. He also continued attending group at Epilepsy Toronto, where he met Ravi.

Ravi had his first seizure at 22 while behind the wheel of a car on the 401. The car crashed but he walked away, only to be diagnosed with epilepsy. He lost his license and realized that his work as a programmer wasn't satisfying. He graduated from law school but the stresses of practicing law only



Jerry and one of the photos he shows of his time in the EMU.

exacerbated his seizures.

After several years of relying solely on medication his neurologist suggested he contact Epilepsy Toronto for support.

“I’d never met other people with epilepsy. It was a great, new experience.”

He joined the Professionals Support Group, where he met Jerry. They started talking about their shared experiences over lunch, when Jerry suggested volunteering in the EMU, something Ravi was eager to do.

When they each do their rounds of the floor, the conversations they have vary enormously. Jerry likes to start by talking about epilepsy and answering questions (he takes pictures of himself from before and after surgery) but really his goal is to not talk about much about epilepsy.

Ravi, likewise, talks about his experiences including exploring surgery before being told it wasn’t an option. As much as they are both able to share their perspectives of living with epilepsy it’s never the same chat twice.

“The conversations with patients are amazing because of the different people that end up there,” says Jerry.

“The reality is no two people’s issues are the same. They’re all unique,” says Ravi. “There are teenagers; there are sixty year olds on the brink of whether their health is good enough for surgery. You cater to what they want to talk about.”

Both Jerry and Ravi continue to face the challenges of living with epilepsy. Jerry still has seizures although only nocturnally; Ravi has memory issues.

Despite that, both are clearly committed to helping others through their experience in the EMU.

“I’ll get into a conversation and miss the subway home and end up in the middle of rush-hour,” says Ravi.



Ravi, EMU volunteer.

Mindfulness Series

Epilepsy Toronto recently hosted a 3-part Mindfulness Everyday Series. These sessions were for parents and caregivers of child and youth with epilepsy.

The program was designed to help parents become more aware of their thoughts and feelings, with the goal of making more determined choices, and fewer automatic reactions, when dealing with challenging situation.

“My aha moment was when I realized I had been living in automatic pilot,” said parent Lizbeth. “It is time to pay attention to the right now and enjoy life”



TORONTO INTERNATIONAL BuskerFest FOR EPILEPSY

The seventeenth annual Toronto International BuskerFest for Epilepsy moved to Woodbine Park for 2016. The open-air setting was popular with visitors and performers alike, giving the festival a more open, family-friendly feel. The venue also allowed for a stronger epilepsy presence, the new 'Be-A-Busker' Zone, and an expanded kids area. The festival was a huge success, raising funds for Epilepsy Toronto programs and would not have been possible without the generous contributions of our volunteers and sponsors.

