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Epilepsy Toronto's publication of community news and events



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New Staff at Epilepsy Toronto

Staff

Brooke Barrington
social worker

Geoff Bobb
executive director

Brandon Fairley
director, development

Joanna Kapusta
office manager

Archna Kurichh
job developer/
employment counsellor

Katie Lundy
director, children & youth services

Tanya McCormack
coordinator, recreation group

Pia Marin
financial services manager

Mackenzie Muldoon
marketing & entertainment director,
Scotiabank BuskerFest

Nicole Nelson
director, development

Tim Nourse
co-ordinator,
enabling change project

Rachael-Lea Rickards
director,
public education and outreach

Rosalee (Rosie) Smith
director, adult services

Kirsten Sixt & Rindy Bradshaw
teaching awareness through
puppetry

Bonnie Taylor
festival director,
Scotiabank BuskerFest

Drew Woodley
director, communications

Board of Directors

Daryl Yeo
president

Tracy Day

David Caplan

Irene Elliott

Jim Feyerer

Brad Freelan

Jonathan Lipszyc

Mark McAllister

Barry Pickford

Wende Rapson

Natasha Stoddart

Dr. Peter Tai

Caroline Tapp-McDougall

Sundra Toor

Dr. Taufik A. Valiante

Cecilia Williams



Epilepsy Toronto would like to welcome 2 new members of our staff team. Here are a few words from them.

Brooke Barrington, Social Worker

Hi there! I'm Brooke and I am a social worker and part of the Adult Services team. I am here to support you in any way I can. I provide counselling and advocacy to adults, couples and families affected by epilepsy and I strive to create awareness and an informed understanding of epilepsy within the community. I am very passionate about working collaboratively with people and am honoured to be a supportive figure in people's lives. Hearing people's stories of strength and resilience is a privilege and I work hard to ensure that my work with individuals is an empowering experience. If you have any concerns regarding your health, relationships or simply need someone to talk to, I am here for you!



I hold a Masters degree in Social Work as well as a Bachelors in Social Work and Family Studies. My education and experience working in the field of mental health with diverse communities helps to prepare me for my role. I am passionate about the work that I do and am committed to providing support in a friendly and accepting environment.

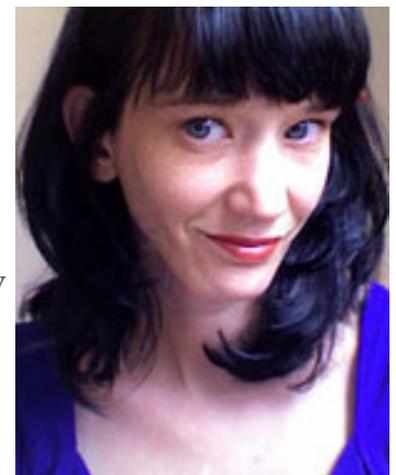
Please feel free to call or e-mail me if you are an adult living with epilepsy or if you know someone with epilepsy. I look forward to hearing from you!

Joanna Kapusta, Office Manager

Hello there! I am Joanna Kapusta the Office Manager at Epilepsy Toronto. I am usually the first face you see when you enter our office and the first voice you hear when you call, and if it needs to be done, I am probably doing it.

I am a true generalist who lives to serve others and I truly believe that there is no job that is too big or too small. As a result, I have done event planning, fundraising, research, knowledge mobilization, database management, business analytics, and even some human resources.

I represent Epilepsy Toronto and our community at the Ontario Brain Institute, working to bridge the gap between community need and research. If you need something, give me a call. If I can't help you, I will find someone who can!



Mandatory Drug Shortage Reporting

It's something too many people living with epilepsy have had to face: the uncertainty that comes from finding out your medications are in short supply. The news is often sudden, coming from your pharmacist or reading about it online, and the fear very real; will your prescription last until it can be refilled and what happens if it doesn't?

Hopefully some of that uncertainty and fear will be eased thanks to a recent announcement by Federal Health Minister Rona Ambrose: drug manufacturers will now have to report expected shortages publicly. The announcement follows years of urging by Canadian Epilepsy Alliance members, including Epilepsy Toronto, for Health Canada to take stronger action on drug shortages

The voluntary notification system, where manufacturers may provide information on an industry administered website, has often seen shortages not reported until patients discover the shortage on their own, if at all. The new mandatory system will have manufacturers report real or anticipated shortages on a third-party website.

“This is a major step forward.”

“This is a major step forward for people living with epilepsy, and other diseases and disorders who require ongoing access to their medications,” said Deirdre Floyd, President of the Canadian Epilepsy Alliance. “It's terrifying when someone living with seizures goes to the pharmacy to refill their prescription only to find out there is a shortage.”

Epilepsy Toronto President Daryl Yeo, whose daughter Lindsay has faced clobazam shortages in the past, has been actively involved in the CEA's work to address the issue.

“We're very, very pleased that the government has finally concluded that the voluntary system just wasn't working,” said Yeo. But, he adds, it's not a solution to drug-shortages. “There needs to be work done to better manage drug shortages when they do happen. There's a lot more work that can be done here,” Yeo said.

“Now that we have mandatory notification when there is a medication shortage, what kind of system can we put in place to more effectively manage the shortages when they do occur – because they will occur,” Yeo said.

Suzanne Nurse, chair of the CEA's Drug Shortage Committee, who was on hand for Minister Ambrose's announcement, emphasized how important it is that government take action to manage shortages.

“There must be two priorities for governments: prevention of drug shortages and better management for situations when a shortage cannot be avoided,” says Nurse.

“Ontario and other provinces have been working on management strategies, but so far this work has been related to hospital pharmacy shortages and has not addressed the needs of patients who encounter shortages at their community pharmacy.”

With files from Deron Hamel, Epilepsy Ontario.



Adam Shapiro: Just Like Everybody Else

As part of this year's Scotiabank BuskerFest activities, the Canadian Epilepsy Alliance launched a new comic book designed to educate children about epilepsy. The Medikidz Explain Epilepsy comic tells a fictional story of 14-year-old who is navigating middle school while living with epilepsy. Epilepsy Toronto member Adam Shapiro, who was part of the launch event, later delivered his speech to staff at Eisai, the comic book's sponsor. Here is an abridged version of Adam's speech.

Last summer I was asked to introduce the Eisai comic book that was created to explain epilepsy. I spoke about situations similar to the hero, Jack, in the comic book.

I spoke about being diagnosed with epilepsy at age 12. With no understanding or previous experience I suddenly had a grand mal seizure at 6 am on the bathroom floor. It scared my mom to death. I ended up with bumps and bruises on my head.

When I was first diagnosed at age 12 I didn't understand epilepsy. I actually thought my epilepsy was caused by keeping the class pet, a bird in my bedroom. The weekend I brought home the bird, was the weekend I had my first seizure.

Isn't it funny the weird things you will believe if you don't have the correct information? Now that I have better information, I try to do things to control my epilepsy. I take my medication at the same time every day. I try to go to sleep early and get a good night's rest. I try to exercise and eat well. I work with my neurologist and the different types of medication to keep my epilepsy under control.

Stress can cause me to have a seizure but stress is hard to control. I just turned 18 years old and there are lots of things that stress me out and keep me up at night; tests, exams, birthdays, career, part time job, dating, college, good hygiene and weight. And of course the two biggest stressors are girls and good hair.



Adam with the Medikidz Team

Unfortunately for all the extra steps I take my life has changed and people's view of me has changed.

I don't ride my bike alone anymore. I must keep a strict sleep schedule which means no more late night shows and events. I never lock the bathroom door any more in case someone needs to come in to help if I have a seizure in the shower (which is embarrassing when my mom comes in to check on me).

I have been discouraged from trying different sports because they are considered dangerous.

The medication that I am on often makes me feel dopey (not every day though) and I know this affects my school work. Could I get better marks if I didn't have epilepsy?

The worst thing was overnight camp. I loved camp, but the camps I used to go, or apply to, wouldn't take me. My family makes sure I am never alone for a long period of time, especially when I've been going through a period where it seems my seizures have increased. Despite some of these issues I am usually very happy and enjoy doing things I can do. Chess anyone?

Ever since I had epilepsy I have had a shorter memory. This is very frustrating to have a short memory because I can't remember what I did the previous day, forget upcoming events, forget my birthday, which is embarrassing, and forget to bring stuff home from school and bring stuff back to school.

I can rarely have friends and if I do they have to know what to do if I have a seizure. This means not many friends can come over to my house unless there is an adult present. I also can't visit most of my friends which sucks.

In grade 6 I told my class I had a seizure and they looked at me like they never heard that word before and even the teachers were confused too. I now was left out of swimming in the school (we had a pool in our school) but I could talk to no one about it because they could not help me.

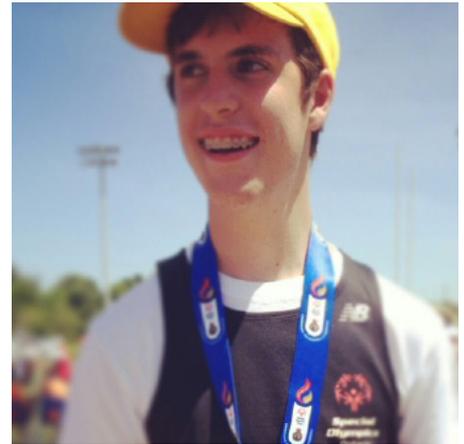
After a seizure you've completely lost track of the time. To a person who has a seizure it feels like only a second has passed but to the people who are watching it feels forever and is very scary. When I wake up from a seizure my body feels numb, I feel no pain and I am exhausted. My energy is drained and I can't walk for a whole minute. Sucks for me and my body.

I do believe my seizures are under control for the most part but I am still growing and my body is still changing so maybe I can have a few unexpected seizures that can happen in the future. Still with my medicine keeping me in check I will not have a seizure without an adult making sure I am ok. I will also never purposely miss my medicine (that could be dangerous if I miss my medicine).

The more people know about Epilepsy the less people will judge me and others like me in a negative way.

Even more importantly many people that I am around especially at school have been able to help me when I have had a seizure because they have been told what to do. Even on the School bus where I had a seizure. Both the School Bus Driver and the other kids jumped into action and helped me out until I got to the school. I was lucky on the bus because one of my best friends was sitting beside me and we had talked about what to do... It made a situation that could have been a lot worse turn out okay.

So the last thing that I would like to say is that the more people who are informed about epilepsy the chances are I will be able to do more things just like everybody else.



TDSB Partnership

As Toronto's epilepsy community approaches Purple Day, the international day for epilepsy awareness, on March 26th, Epilepsy Toronto and the Toronto District School Board are pleased to announce a new partnership to support students with epilepsy in the classroom.

The two organizations are producing resources for use by staff, parents, and physicians to develop individualized support plans for students with epilepsy. The resources will include information for staff about how epilepsy affects a particular student and how to respond to their individual seizure types, general information about epilepsy, including the social and emotional impacts epilepsy can have on children, and an epilepsy protocol outlining how school staff, parents, and physicians can work together for student success and support.

The partnership materials, which have been developed with input from staff at Sick Kids Hospital, will be released in the coming months.

Isabel Estrada

“I was afraid of dancing and I hated that”.

For Isabel Estrada, who has danced since she was ten years old, epilepsy didn't simply mean having seizures; it meant something she loved, something she had intended to do professionally, was put in doubt.

Isabel came to Toronto from Guatemala City to study in York University's dance department. It was during her third year, during a trip home for the holidays, that she had her first definitive seizure. She'd woken early to get ready to fly back to Toronto. She was twitching and before long she was unconscious on the floor of her parent's bathroom. It happened again in Toronto with her roommate finding her.



Despite her mother having epilepsy, a subject that she never really discussed, it was one of her teachers who suggested she see a neurologist. She was quickly diagnosed with myoclonic seizures, sometimes followed by a tonic-clonic seizure.

While the possibility of a tonic-clonic seizure was challenging enough, for a dancer a jerk during a jump or turn is a real risk for injury. Harder still, Isabel quickly discovered one of her key triggers: exhaustion.

She kept a punishing schedule. In the dance program and the York Dance Ensemble, her rehearsals and classes meant 8-hours of dancing a day, on top of the rest of her course work. Her prescription of lamotrigine was causing her to twitch while dancing, meaning she constantly had to stop and sit-down. The days until her end of year performance were slowly ticking away. It was a large production and her parents were coming from Guatemala to see it.

She set aside everything that wasn't a critical part of her life so she could get extra rest and the side effects of the lamotrigine started to ease. The twitches began to disappear and she was able to carry on.

“Everytime I was able to finish a class it was a relief.”

Her final performance was a success, but she knew it would probably be her last year as a part of the York Dance Ensemble.

As her fourth year started, she had changed her medication and spent the summer contemplating her future, but still wasn't sure what to do next. One of the department staff suggested she drop the early morning ballet class and do a senior research project instead. This came as a relief, as ballet had become a source of anxiety for her following a seizure in class, and an opportunity; her research project would attempt to answer the question, 'how can I continue to be a professional dancer with epilepsy?'

She learned more about epilepsy, about how other performers and athletes with epilepsy have dealt with seizures, and about herself, keeping a health journal. She learned that she could help manage her seizures by getting enough sleep, identifying triggers, breathing, and talking openly about her epilepsy.

She had already been quite willing to talk about her seizures with teachers and classmates. The one person with whom she has had difficulty broaching the subject was her mother. Growing up, epilepsy wasn't something her mother wanted to talk about and that has continued since Isabel has been diagnosed. Isabel worries that her mother feels guilty, that her daughter's epilepsy is her fault.

"If anything, she's just made me realize how much you can do. She is one of the strongest people I know and I admire her so much. Everything she does and on top of it she has this condition she has to live with."



That fortitude is something Isabel has inherited.

As she finished her final year of her degree, she started thinking more about how she would continue on in dance. She refuses to give up on performing but doesn't know if she would be able to do it at the same level that other dancers do, being able to work without worrying about getting enough sleep, wherever and whenever an opportunity comes up.

Instead she has become much more aware of how to balance her love of dance with the practical realities of life with epilepsy. While she has taught dance since she was sixteen, she had never considered it for a career. Now she teaches with a dance studio and with a company that goes into schools.

She has become interested in exploring organizations that work for benefits and health coverage for performers. She wants to get a Masters degree. York wants her to study choreography; she is considering business administration as a first step towards returning to Guatemala to start a university

dance program of her own. She still performs with a company and auditions.

Now a year seizure free, she is working with Epilepsy Toronto to help educate post-secondary professors and instructors about the challenges students with epilepsy face. It's something that she believes is an important part of living with epilepsy.

"Dance, do what you love and don't be afraid to talk about it."

"Everytime I was able to finish a class it was a relief."

York University Project

Epilepsy Toronto is working with students and staff from York University to develop tools for professors and instructor to learn more about how to accommodate epilepsy in the classroom. With information ranging from seizures first aid to issues students might face, like memory problems, a key part of the project is drawing on the personal experience of the students themselves.



PURPLE DAY FOR EPILEPSY

“Epilepsy is nothing to fear. Speak up and spread the word. Together we can make a change”

Cassidy Megan,
Founder of Purple Day Canada

Across the country on March 26th, individuals and groups will be participating in Purple Day to raise public awareness about epilepsy.

