

# e+bulletin

Epilepsy Toronto's publication of community news and events



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## Comings & Goings at ET

### Staff

Brooke Barrington, RSW  
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director, development

Carter Hammett  
coordinator, employment services

Joanna Kapusta  
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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  
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Tim Nourse  
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enabling change project

Jesse Preston  
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Rachael-Lea Rickards  
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Rosalee (Rosie) Smith, MA, RP  
director, adult services

Kirsten Sixt & Rindy Bradshaw  
teaching awareness through  
puppetry

Bonnie Taylor  
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Drew Woodley  
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### Best Wishes Pia

Pia Marin, our long-serving Financial Services Manager, has left us for a much-deserved retirement. Pia first came to Epilepsy Toronto as a volunteer and eventually became an integral part of the staff team. Pia cared deeply about people living with epilepsy and the challenges they faced and she will be missed by staff and members alike.



### Welcome Afroza

We would also like to welcome Afroza Hossain to the Financial Services Manager role. Afroza comes to us with a wealth of experience and we all look forward to working with her.



## Good Business

Jaspreet Basra has been living with epilepsy since she was 18 after contracting viral encephalitis; as someone with photosensitive seizures, she knows how much of a challenge it can be to navigate venues with flashing lights.

So when Jaspreet organized a birthday party for her oldest son at a Brunswick Bowl in Brampton, she asked the manager to turn off the flashing lights in their lane. He did, without hesitation, and then turned off any of the other flashing lights and effects that she might run into.

“He said ‘we have a duty to be accommodating to people with epilepsy,’” Jaspreet explained. “He wanted to make sure I wasn’t going to be affected.” That type of support was a refreshing change from what Jaspreet has experienced in the past; many businesses say they have no control over their lighting, as its automatic.

The bowling alley was also careful to provide peanut free-refreshments, as several of the children attending had allergies. It’s this kind of attention to the needs of its clients that Jaspreet appreciated.

“These are the moments we’re going to remember.”





**HOLIDAY FAIR**  
nathan phillips  
SQUARE

Supporting Epilepsy Toronto

Following an exciting first year in 2016, Epilepsy Toronto's newest fundraising initiative, the Holiday Fair in Nathan Phillips Square, will be returning in December. Combining the best parts of a holiday market and a winter carnival, the Holiday Fair is on its way to becoming Toronto's next holiday tradition.



## School Navigation

Epilepsy Toronto is producing a new guide for parents of children navigating the school system. Adapted from material by Epilepsy Ontario, *Epilepsy & Special Education and Accommodation* will provide parents with a step-by-step process for advocating and supporting their children in schools. The guide will also compliment the TDSB epilepsy accommodation support plan that is due to come into effect in the near future.

## The Power of Friendship

Sometimes only a friend can understand: what you're going through; how you feel. When what you're going through is living with epilepsy, sometimes only a friend who also lives with seizures can understand.

For Ella Fagan and Isabella De Sousa, finding that friend made a big difference in their lives.

"I feel better talking about it with Ella than with anybody else," says Isabella.

"I usually don't tell my parents things; I'll tell Ella first. If someone is making fun of my epilepsy, I'll tell her about it."

The two thirteen year olds are typical teenagers, talking by phone, text, and Facetime. In the few months they've known each other, they've become close friends, organizing sleepovers and dinners-out. The big difference is that many of their conversations are about living with epilepsy.

They didn't meet by accident.

"Isabella never really talked about her seizures," says her mother Sabrina. "Isabella would say 'as long as we don't talk about it, I'm fine.' As a Mom I said, 'that's not ok'. That's why we reached out to Epilepsy Toronto."

Epilepsy Toronto's director of Children and Youth Services, Katie Lundy, invited the de Sousa family to the agency's annual Winter Family Retreat, a chance for families affected by epilepsy to get out of the city and meet. She made a point of making sure Ella and Isabella connected. After they started talking and bonding, it became clear there had been a change.

"After the winter retreat, Ella would say, 'Mom, Dad you can't relate. That's why I'm talking to Isabella,' says Ella's father Cory. "We're very supportive, but she's right; we can't understand, but Isabella knows what she's going through."

"When she met Ella we noticed right away," says Sabrina. "They went off in this little corner and they were talking. We could see the very next day that there was this glimmer in Isabella's eyes that we just hadn't seen in almost 10 months. I knew she got something off her shoulders so I felt like it was off my shoulders too, because she's talking about it."

That connection between Ella and Isabella became more than just a person to talk to; it was an opportunity to open up to the world.

"The retreats every year have really helped me to relate to other people," says Ella. "I got to meet Isabella and that was really great for me because I couldn't really relate to anybody before. I was talking to my other friends about it; I could tell they were trying to understand but couldn't get an idea of what it was."



"It really helped her confidence," says Cory. "After the retreat she was very confident in school and how she would speak to other people, speaking her mind".

"I find it a lot easier to talk about it," says Isabella "When I met Ella, just the fact that she could talk about it so easily, meant I could talk about it. After the retreat I started a Purple Day at my school. I went on the announcements and talked about epilepsy and at the end of the week did trivia questions with prizes."

"I gave a presentation to my brother's class about epilepsy and to another teacher's class," adds Ella. "I handed out pens and tattoos to the school."

The value of the Family Retreat weekend extended to the whole family.

"It's a relaxing weekend. It was an eye opening

experience to realize there is support and there are others out there going through what we're going through," says Sabrina. "After the retreat, after Isabella started talking to Ella, she started talking to us about it. We would feel bad when she had a seizure and she told us that she would feel bad for us, when she had a seizure."

"It relieved a lot of tension in the house," adds Isabella's father Richard.

"It's amazing how something like that could have such an impact on Ella. It's the highlight of our winter," says Cory.

Now the girls are getting ready for their next adventure together: a week together at Camp Couchiching in August, where they will be joining other young people living with seizures at an integrated summer camp.

Both girls refuse to allow epilepsy, or the stigma that goes with it, to dictate their lives, a strength

that has grown out of their ability to share their experiences.

"Sometimes people will make fun of me but I honestly don't care," says Ella. "They don't go through what Isabella and I go through".

"Epilepsy isn't who you are it's just a part of you," says Isabella. "Don't let it stop you from doing anything. It makes me want to do more because I want to prove epilepsy can't take me over."



## There's No Place Like...Camp Couchiching

Lauren Kotzer

*Every year Epilepsy Ontario sponsors young campers living with epilepsy from across Ontario, including Epilepsy Toronto members, to attend Summerfest at Camp Couchiching in a safe and supportive environment. Lauren Kotzer is an Epilepsy Toronto member as well as former camper and staff member at Camp Couchiching.*

I can recall the day as if it were yesterday, when my parents asked me if I wanted to spend a week at Camp Couchiching (located in Longford Mills on the shores of Lake Couchiching). Attending camp was the experience I relished most about the summer months, so I welcomed the opportunity to attend a new camp. Little did I know that Cooch would become so much more to me than I could have ever expected.

My experiences over the next five summers can only be described as life altering. Not only did I get to spend several weeks each summer playing in the sun, swimming to my heart's content, yelling cheers in Artaban (the dining hall), paddling my way through out trips, competing in Cooch games, and laughing with new and old friends until my belly ached, I also learned what it meant to be a young leader, be part of a community that was more like a large family, and gained a true sense of self.

No matter how much time I spent at Cooch each summer, it was never quite long enough. So, how does one get more time at a camp they love? Obviously become part of the staff; which is exactly what I did! I spent the next five years in various roles, where I was lucky enough to spend two plus months each summer at my home away from home, teaching the activities I loved most (swimming!), interacting with campers and staff that I grew up with over the years, and watching the next generation of young leaders at play.

Without question the ten years that I spent at Cooch shaped me into the person I am today; the person who has a strong sense of independence, respect, and community.

It has been ten years since I have spent a summer at Camp Couchiching, but it is never far from my mind or heart. If I close my eyes I can still feel the warmth of the sun on my face and the freshness of the lake as I jump off the dock, I can hear the singing and laughter of campers and staff alike, and I can see a place where there is always room to play (no matter how old you get).

TORONTO INTERNATIONAL  
**BuskerFest**  
FOR EPILEPSY

Epilepsy Toronto's signature fundraising event, the 18th annual Toronto International BuskerFest for Epilepsy, returns to Woodbine Park in The Beach this Labour Day Long Weekend.



## Mei Chan-Long: Artist

*Mei Chan-Long is an artist and Epilepsy Toronto member. Her work, Feel what you see. Feel what you feel, is part of the Telus Health Brain Project.*

I'm an art lover. Growing up I loved to draw. It was being in my own world. I worked in media coordinating and design. On my own I created with fabric, worked on and with my love of antique and period furniture and goodies.

After my first known seizure my life changed. I felt lost and different. I didn't have awareness and was afraid. When I went to the hospital after a tonic-clonic seizure I didn't know what it was. I wasn't told I had epilepsy. I just knew there was something medically connected to my brain. It sounded frightening.

When I found out it was a cavernoma and I was having seizures from it, it was somewhat of a relief, but I was afraid and felt alone and ashamed. Questions for doctors and thoughts raced through me. I didn't know when I was having seizures but looking back I think it may have been most of my life.



Wanting to have life better was a priority and process. I needed to be stronger and accept being better and different. Having epilepsy is positive in ways. I accept and I am not ashamed. It has naturally directed me to love art even more. I truly enjoy creating with metal as it helps me physically and emotionally. It is my art therapy.

The Telus Health Brain Project is an art exhibit of 100 brains in different locations in Toronto. It will draw attention, to enjoy looking and thinking about brains. We all have a connection to brain health.

The Brain Project is connected with Baycrest Health Sciences to research and educate brain health and awareness. This is the second year of the project, and it aims to promote awareness of the importance of brain health and start a conversation about it among Canadians.

I am fortunate to be involved and have a true brain connection. I saw the event at Nathan Phillips Square by chance last year being their first year. I was overwhelmed and happy to see art for brain awareness. Excitement as all my work is connected to my brain.

My sculpture is at Nathan Phillips Square until the end of August.



Photo by Henry Chan

# Purple Walk

for Epilepsy Toronto  
August 19<sup>th</sup> 2017

