

2016
spring/summer

e+bulletin

Epilepsy Toronto's publication of community news and events



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The Family Retreat

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Epilepsy Toronto held its annual Family Retreat in February. Fifteen families living with epilepsy came together, with Epilepsy Toronto staff, for a weekend of fun and learning at the YMCA Geneva Park Centre near Orillia.

The weekend retreat provided an opportunity for fun indoors and out (despite the unseasonably warm weather) with board games, crafts, workshops for parents, sports, a low-ropes course and a campfire.

More importantly it gave families, some with a child living with seizures, some with Mom or Dad, an opportunity to learn, share their experience, and build a sense that they are not alone.



I wanted to write and thank you for inviting us to the retreat this weekend. I can't begin to thank you enough. Not only was it great fun but it was such a learning experience. I met some great people, including an amazing mom, Andrea, who shared her knowledge with me. Rachel had a life changing experience, she has never spoken with anyone, other than her doctor and family members about epilepsy, but this weekend she not only spoke about it but met several people her age who also have epilepsy. She made a great friend in Emily, those girls are so much alike and get along so well, it is truly a blessing.

This experience has truly made a difference and I hope to be able to attend many more events with Rachel and maybe even bring my husband and daughter along next time.

Kindly and warm wishes,

Pam



The Ade Adegbite Memorial Scholarship

The scholarship is dedicated to the memory of Ade Adegbite, a remarkable young woman who would not allow the challenges that epilepsy presented to prevent her from achieving her goals. An excellent student, Ade studied at the University of Toronto, Scarborough, was fluent in French, and completed teachers college, all while actively volunteering in the community. She worked enthusiastically to educate others about the challenges faced by people living with epilepsy. She supported the work of Epilepsy Toronto as an educator, spokesperson, and fundraiser.

The Ade Adegbite Memorial Scholarship recognizes students with epilepsy who have overcome barriers and who continue to demonstrate resilience in coping with the challenges of epilepsy.

Two scholarships of \$1500 each are awarded annually to assist students with epilepsy to achieve their academic goals.



Successful candidate must meet all of the following eligibility criteria:

- Must have Epilepsy.
- Be age 17 or over.
- Canadian citizen, Protected Person or Permanent Resident of Canada.
- Must be a resident of Ontario.
- Enrolled in or accepted for full-time or part-time post secondary studies in a College or University, or accredited professional or apprenticeship training institution in Ontario. (Part-time students must be completing at least one course each semester).
- Should not be related to any member of the Board or staff of Epilepsy Toronto.

Visit epilepsytoronto.org/scholarship for more details.

Application deadline is **May 6th 2016**.

Being awarded the Ade Adegbite memorial scholarship was a life changing event. Upon receiving it I broke into tears in front of the whole congregation because I simply could not believe I was receiving such an honour. I was moved by the generosity and kindness of not only the family giving it to me, but of everyone who came out and was supporting me. The experience was truly uplifting and humbling.

With the money received I was able to help my parents pay off my first year of my university tuition. Getting the award and then becoming involved with Epilepsy Toronto motivated me to want to give the same help and support to others so I am currently pursuing a degree in socio-cultural anthropology with a focus on activism in society.



Tamarra Zlicic, 2013 Scholarship Recipient

Drug Shortages

What should I do if my drug is not available?

If a shortage occurs and your pharmacist is not able to find a supply of the drug for you, contact your health care provider immediately. Do not make any changes to your treatment plan without consulting with your health care provider. Continue to take the same amount of medication at the same time of day as usual. Your healthcare provider can discuss the situation with you and provide medical advice.

Are there any precautions I can take?

Making a plan to fill prescriptions for anti-seizure medication several days before you run out is helpful. This provides some extra time to seek solutions if your anti-seizure drug becomes in short supply.

Taken from *Frequently Asked Questions About Drug Shortages* by Epilepsy Ontario.

Epilepsy Surgery

Epilepsy affects over 95,000 Ontarians (80,000 adults; 15,000 children) and approximately 30% of those are deemed to be medically refractory, that is, they do not respond to treatment with two or more appropriately chosen anti-seizure medication within a reasonable period of time (Ontario Brain Institute, 2015)

Any patient (regardless of age) who fulfills the above criteria for medically-refractory epilepsy is considered a surgical candidate and is eligible for assessment. These patients should be referred to a District Epilepsy Center (DEC) or a Regional Epilepsy Surgery Centre (RESC) in order to assess surgical candidacy. Recent epilepsy service investments by the Ministry of Health and Long-Term Care have increased access to treatment to improve outcomes for this patient cohort (Provincial Guidelines for Epilepsy Surgery Referrals in Ontario, CCSO, 2016).

There are three Regional Epilepsy Centers in Ontario University Health Network (Toronto Western Hospital), London Health Sciences Centre and the Hospital for Sick Children. These are facilities that houses a comprehensive epilepsy program that provides all epilepsy clinical services including the assessment by an epileptologist, an Epilepsy Monitoring Unit, neuropsychological services and the ability to perform intracranial monitoring and epilepsy surgery

Although these facilities are available to perform epilepsy surgery, this service remains largely underutilized. The decision to have epilepsy surgery is obviously one that should be given careful consideration but it is also true that many are not aware that surgery is a treatment option or are plagued with myths and misconceptions about risks vs benefits. Others may not even be aware of the existence of these Regional Epilepsy Centres and the work they do.

If you have been told you have medically refractory epilepsy and have tried many anti-seizure medications with no success, speak to your doctor about referring you to a comprehensive epilepsy program where you can be assessed for surgical candidacy.

If you are told you are a surgical candidate but you have questions, Epilepsy Toronto is here to assist you with the decision making process. We will provide you with information on the various surgical options, help you weigh risks vs benefits, guide you into decision making practices and connect you with others who have had surgery so you can learn from their experiences.

Peer Support Network

If you have had surgery and would like to be a mentor for others who are considering it, give us a call.

Surgery Support Group

If you would like to hear from others who have done surgery, meet others who are also considering surgery attend the surgery support group held at Toronto Western Hospital.

2016 dates

Thursdays February 18th, May 19th,
August 18th November 17th
6:00pm – 7:30pm

Call us to be added to the mailing list for these meetings.

Denisa Radut: Determination

"I was 2% scared, 98% excited."

Denisa Radut is determined. She loves school, so much so that her heavy course load in the business administration program at Humber College, was causing her seizures to get worse. The stress of her work was acting as a trigger.

It's not the first time epilepsy has impacted her life. She has had multiple kinds of seizures since her first one at 10-months old. It's never been easy; a lifetime of difficulty making friends, and having to take drugs that cause memory loss and weight problems.



Her seizures getting in the way of school was the breaking point. While teachers had worked with her to provide accommodations, like extra time for exams, not being able to balance seizures with her school work meant something had to give, and it wasn't going to be school.

She had thought about going into the Epilepsy Monitoring Unit at Toronto Western Hospital to see if surgery was an option but didn't want to miss classes. Now she was willing to give it a try if it meant even a chance at stopping her seizures.

10 days in the EMU lead to the answer she both hoped for and feared: surgery.

2% scared, 98% excited.

Denisa says her family, her mother, step-father, and younger brother were more scared than she was. She's close with her family, especially her brother Eduard. He did his best to try and make her laugh, like he always does. She had to tell them all not to cry.



Another trip to the hospital. Tests, needles, scans, two surgeries. The night before the last surgery her doctor tells Denisa to get a good night's sleep. She can't, she's too excited.

Then it's over. There are a couple days spent recovering in the hospital and afterwards she has some trouble remembering certain words, but that goes away. Her hair has to grow back, but otherwise it's over.

Her seizures are over.

She hasn't had one in months, not since the surgery. She says life is easier now. Not only has she not had a seizure, she stopped worrying about having seizures.

That's what it all means, she can go on with school, with life, not waiting for the next seizure to happen.

Purple Walk

for Epilepsy Toronto



June 26th, 2016

Register Today

www.epilepsytoronto.org/walk