



epilepsy

south eastern ontario



Newsletter

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Welcome Tom Coke *Executive Director*

A Message from the new Executive Director

Greetings everyone!

I am happy to be the new Executive Director for Epilepsy South Eastern Ontario.

Originally I grew up in the Sarnia Lambton Area, attended University in Windsor Ontario, and in 2011 became a resident of Eastern Ontario. I'm looking forward to apply my experience working in local government to this agency and to make my mark on an organization like Epilepsy South Eastern Ontario which will continue to strive to make a difference in people's lives that live every day with epilepsy.

Welcome!



Welcome Emilia Leslie!

Client Services Coordinator

Please join us in welcoming our new Client Services Coordinator, Emilia Leslie. She has had the privilege of working with members of Toronto and Kingston communities. Professional experiences include four years of service supporting individuals, families and children, and four years working with older adults with a variety of life challenges. Emilia is a registered social worker with the OCSWSSW. Her academic credentials include a Diploma in Social Service Work from St. Lawrence College, Kingston Campus, a Bachelor of Psychology from Ryerson University, and a Masters of Social Work from University of Toronto. Emilia is looking forward to supporting individuals and families affected by epilepsy in our community, in particular through the Epilepsy Clinic at Hotel Dieu and through our epilepsy group. If you would like to contact Emilia, she is available via email at eleslie@epilepsyresource.org, by phone 613-542-6222, or stop by the office and say "hello".



HOLIDAY CLOSURE

Our office will be closed:

Monday, December 26th, 2016-Monday, January 2th, 2017.

Sending wishes from all of us, to all of you for a happy
and healthy holiday season!

Tom, Claire, Emilia and Ruby



Grade 5 “Thinking About Epilepsy” Program– Year 3

The Grade 5 “Thinking About Epilepsy” program has now entered its third year and final funded year. The program, which started in 2014, has been funded by the Ontario Trillium Foundation. Epilepsy South Eastern Ontario will be pursuing funding options to ensure that this valuable program remains available throughout our region.



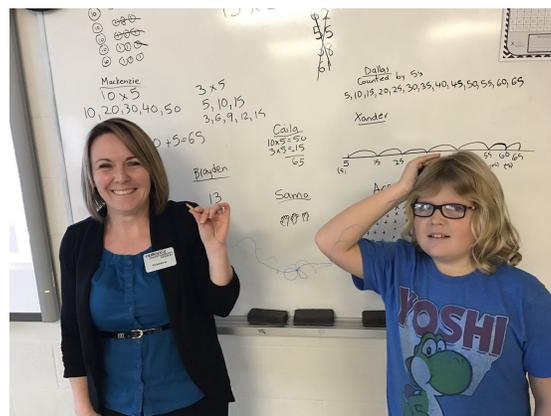
“Thinking About Epilepsy” promotes empathy and understanding, while dispelling myths and providing seizure first aid training for staff and students in all schools across the KFL&A, Leeds and Grenville regions. Facilitated by Claire Notman, our Education Coordinator, the one hour presentation was delivered to over 1800 students and staff last year. With the help of wonderful volunteers and work-study students, the program surpassed its targets, again! The number of schools, classrooms and students participating in the program was up by about 75% over last year.

If you would like more information or to book a presentation, please contact Claire at cnoman@epilepsyresource.org or call 613-542-6222.

VOLUNTEERS NEEDED

This program is not successful without the help of volunteers. Claire is looking for anyone who would like to help her facilitate the program throughout our service region. No vehicle necessary. Volunteers must be comfortable participating in seizure first-aid role play.

If you would like more information or to book a presentation, please contact Claire at cnotman@epilepsyresource.org or call 613-542-6222.



United Way KFL&A 2016 Campaign



Our Workplace Campaign for the United Way KFL&A was a great success this year. During our bake sale we raised \$251.00! Many thanks to the community members that stopped by to enjoy a sweet treat. Thank you to the generous owners of the Subway at the corner of Barrie and Princess for donating their store front, and the Starbucks on Division for the coffee.

A very special thank you to Board member Kim McFarlane for baking all our delicious goods!



As part of their yearly campaign, the United Way asks member agencies to provide speakers for their Speaker's Bureau. These speakers travel to various businesses throughout the community telling their story and speaking of the services they have received from member agencies like us. This year we welcomed a new speaker, Michelle Reynolds. Many, many thanks to Michelle for sharing her epilepsy story! A big thank you, as well, to Sadie Augustyn who has been a part of the Speaker's Bureau for many years.

Read Michelle's Story on the next page!



Pull Together For Epilepsy: Fire Truck Pull 2016

Thank you to everyone who participated, donated and volunteered for our annual fundraiser. It was a great day! \$10,000 was raised.

Congratulations to **Sadie's Clydesdales** for been awarded the Overall Winner trophy.

Medals also went to:

Kingston Fire and Rescue- Team Spirit

CUPE 1974 Purple Cobras- Most Funds Raised \$2200

Sadie's Clydesdales- Fastest Pull

Many thanks to our fantastic summer students Matthew Meagher and Zina Al-Sabbagh for all your hard work!



Epilepsy Stories: Michelle Reynolds



Fifteen years ago at the age of 14, I began having simple and complex partial seizures. At the time, I didn't know that they were seizures; they were just strange, out-of-my-body experiences that had to do with words. Approximately eight years later, I started having tonic-clonic seizures – those are the “grand-mal” type that everyone thinks of when they hear the word seizure. It wasn't until then that we knew that I was having different types of seizures all along.

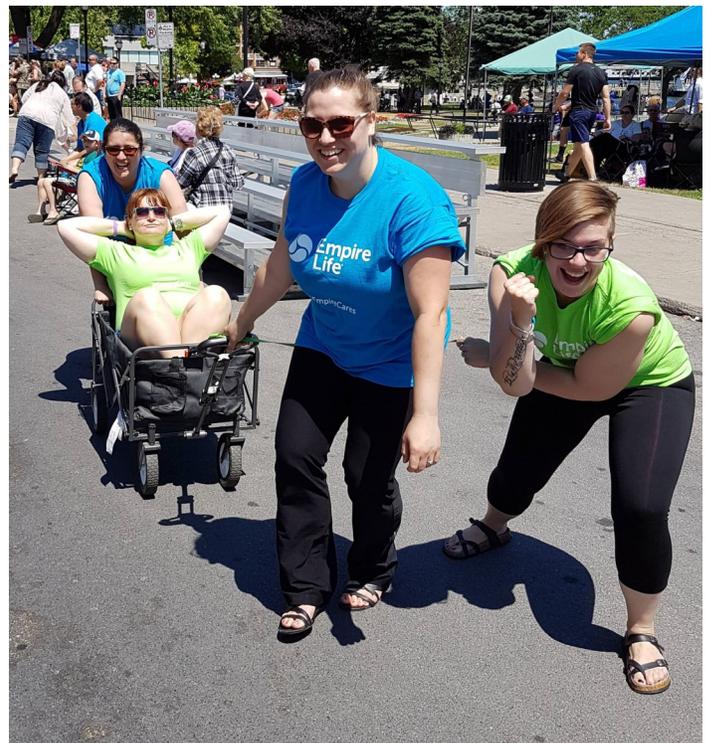
With that, I was officially diagnosed as a person with epilepsy and began taking medication. Things went very well until three years ago when I became non-responsive to the prescription medication. I tried dozens of different types and none of them seemed to be absorbed. My seizures became more and more frequent; almost daily. I ended up having to leave work, losing my driver's license, feeling like a full-time supported individual with no independence, and constantly exhausted and defeated. I no longer felt like myself with a major change in my personality. Though many things felt negative and upsetting, there were certainly positive sides to this. I found that this was something to research and to work on with extreme passion and to talk about with others in similar situations. I am glad to openly share my experiences in order to help others and to take away stigma related to epilepsy.

Given all of my experiences, medical history, and doctor findings, I ended up having surgery in December 2015. A neurosurgical team removed my brain's dominant temporal lobe and hippocampus where most of my seizures tend to begin and I have not had any since then.

Through my entire experiences from time of diagnosis to surgery to today, Epilepsy South Eastern Ontario has been a tremendous help. They've been there to teach me things like the “non-doctor” terms; They've been in their office and in the hospital neurology clinic to meet for any help; They've responded quickly to social media; and they've made wonderful work and school presentations to explain epilepsy to those not familiar.

Being able to go to work with co-workers being aware of my epilepsy and confident in their knowledge has been a fantastic relief. I've been a person living with epilepsy for half my life and am the happiest because of Epilepsy South Eastern Ontario.

Michelle Reynolds



Epilepsy Group



Those living with epilepsy along with family and friends get together once a month to share stories and experiences. We have recently begun to have guests from various organizations who share information and listen to the experiences of attendees living with epilepsy.

The group meets on the last Wednesday of each month from 6:30pm-8:00pm at the Ongwanada Resource Centre Board Room, 191 Portsmouth Avenue in Kingston. Meetings are informal and are open to anyone affected by epilepsy. Refreshments and snacks are provided.

If you would like to make a suggestion or if you are in need of transportation, please contact Emilia Leslie at 613-542-6222 or eleslie@epilepsyresource.org.

PLEASE NOTE:

There will be NO group meeting on Wednesday, December 28th 2016.
Group meetings will resume January 25, 2017.

Epilepsy Clinic Update

Epilepsy South Eastern Ontario is proud to continue our partnership with Hotel Dieu Hospital's Epilepsy Clinic. The clinic not only reduces the waiting period for adults who have experienced a first seizure to meet with an epileptologist, but also provides an immediate point of contact to connect clients with the Epilepsy South Eastern Ontario.

After the epileptologist has met with a patient, those diagnosed with epilepsy can be seen by Emilia, our new Client Services Coordinator, to provide support, resources, advocacy, and referrals as necessary. Emilia will also be meeting with long-time and follow-up patients of Dr. Lomax and Dr. Frauscher, as well as pediatric patients now transitioning to adult care, further increasing the presence of Epilepsy South Eastern Ontario in the community and bringing greater awareness of the organization and the services it offers.



Emily's Fund

Emily was diagnosed with epilepsy when she was 10 years old and struggled off and on over the years with recurring seizures. While attending an Epilepsy South Eastern Ontario meeting she listened to participants share their stories regarding transportation issues, particularly when they had no driver's license. Emily was always caring and concerned for other people's well-being, so it was no surprise to anyone of her concern for these individuals, and she wondered what could be done. It upset her that many people living with epilepsy have limited options when it comes to transportation, and Emily wanted to do something about it. Unfortunately, she passed away before she could fully advocate for change.



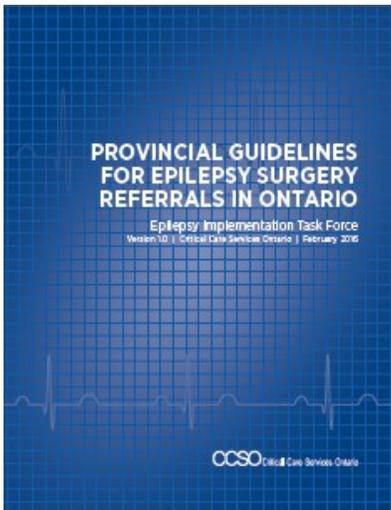
Emily died having a seizure on December 17, 2015 at the age of 25. To honour her legacy, in partnership with her family, Epilepsy South Eastern Ontario has created 'Emily's Fund'. **This fund serves to assist people living with epilepsy travel to doctor's appointments, support meetings, and other required services.** To contribute to Emily's Fund, click on the 'DONATE NOW' button and select "Emily's Fund" from the drop down menu.

Please contact eleslie@epilepsyresource.org if you are in need of transportation to medical appointments in your region or to any of our services.

[DONATE NOW](#)



New Guidelines for Epilepsy Care in Ontario



In November, Claire and Emilia attended a meeting to review the new Epilepsy Guideline Series, discuss key messages and collaboratively develop messaging for clients to help ease the navigation of the Guideline series. **This is an exciting and promising project that aims to streamline epilepsy care, and give primary care providers the support and information they need to more efficiently treat patients with epilepsy, and refer for surgery whenever possible.**

The Epilepsy Implementation Task Force (EITF) was formed in June 2013 to develop and implement a provincial approach to an integrated system for epilepsy care in Ontario. Supported by CCSO, this committee is co-chaired by Dr. Carter Snead, Paediatric Neurologist at the Hospital for Sick Children, and Brenda Flaherty, Executive VP and

Chief Operating Officer at Hamilton Health Sciences.

The EITF brings together senior clinical and administrative leaders from the epilepsy community to:

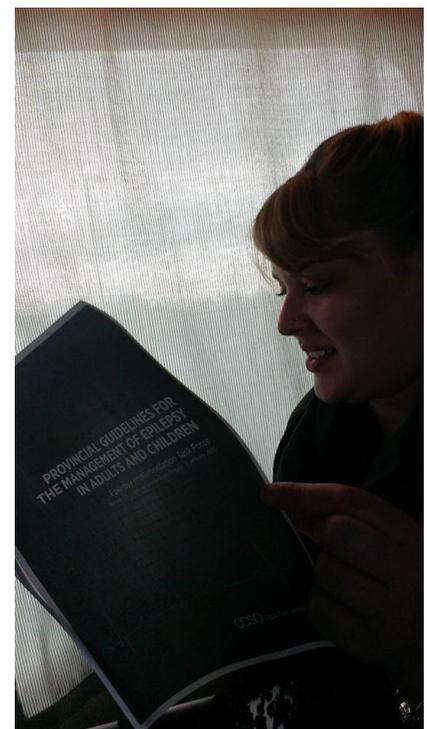
- Improve access along the full continuum of care by coordinating resources and wait lists;
- Establish standardized diagnostic and surgical protocols across hospitals with comprehensive epilepsy programs; and
- Develop supports for primary care providers

The series of includes:

- Guidelines for the Management of Epilepsy in Adults and Children
- Provincial Guidelines for Epilepsy Surgery Referral in Ontario
- Provincial Guidelines for the Management of Medically Refractory in Adults and Children who are not candidates for Epilepsy Surgery

Follow the link below to view the Guidelines. For support, or more information about the Guidelines please contact us.

<https://www.criticalcareontario.ca/EN/Library/Epilepsy%20Guideline%20Series/Pages/default.aspx>



Welcome New Board Members

Harry Smith—Director

Harry has been involved with Epilepsy South Eastern Ontario for many years. He brings with him a wealth of experience having served on other boards in the community. Harry's passion and commitment to our education programs and services is contagious!

Welcome Harry!



Board of Directors

President

Kyle Lawlor

Vice-President

Tracey Augustyn

Treasurer

TBA

Secretary

Kim McFarlane

Directors

Jessica Gies

Dennis Clark

Karen Labbett

Dr. Athen MacDonald

Harry Smith

Volunteers Wanted for Charity Bingo Events

Do you have 2 hours once a month to give?

The Epilepsy South Eastern Ontario is seeking eager volunteers to assist with our charity bingo events that occur monthly. Through a partnership with OLG and Community Spirit Bingo, we are able to promote epilepsy awareness in our community, as well as receive a portion of the monthly bingo proceeds. To receive this portion, the Epilepsy South Eastern Ontario must have two trained volunteers attend each scheduled 2-hour session. We are looking for dedicated volunteers to attend these sessions and help raise awareness of epilepsy!

For more information, or to become a bingo volunteer please contact our office at (613) 542-6222, or admin@epilepsyresource.org.

