

THE EPILEPSY  AND SEIZURE
DISORDER RESOURCE CENTRE
OF SOUTH EASTERN ONTARIO

100 Stuart Street, Kingston Ontario K7L2V6 ~ Phone: (613)542-6222 ~ Fax: (613) 548-4162
admin@epilepsyresource.org ~ www.epilepsyresource.org

New Epilepsy Education Grant

Resource Centre Awarded Grant from the Ontario Trillium Foundation

We are thrilled to announce that the Epilepsy Resource Centre has received a three-year grant from the Ontario Trillium Foundation to fund an educational program called, *Thinking About Epilepsy*. This program will be delivered to Grade 5 students throughout the Kingston, Frontenac, Lennox & Addington and Leeds & Grenville regions.

The Ontario Trillium Foundation (OTF) is Canada's leading grant-making foundation and is an agency of the Government of Ontario. Its mission is to build healthy and vibrant communities throughout Ontario by investing in community-based initiatives. This investment in our community and the *Thinking About Epilepsy* program, will help us to remove barriers for youth with epilepsy, create safer and more inclusive schools that support students with epilepsy, and keep them engaged in learning and life.

Many thanks to the Government of Ontario and the Ontario Trillium Foundation for funding this exciting project.



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United Way 2014 Campaign

The Kingston, Frontenac, Lennox & Addington United Way and the Leeds & Grenville United Way 2014 campaigns kicked off this September with some big fundraising goals. The Epilepsy Resource Centre is privileged to be a member agency of both United Ways. Because of their support, we are able to offer programs and services to the KFL&A and L&G communities. Every year, these two United Ways fund over 100 programs and services in the areas that they serve. An average of 1 in 3 people across our region access at least one of the services the United Way supports.

In support of the United Way Campaign, the Epilepsy Resource Centre hosted a Bake Sale on Oct. 1st to support the KFLA United Way. During our Bake Sale we raised \$305.00 towards the United Way goal.

Please consider supporting the United Way in your region by making a donation, holding an event, or volunteering your time. More details about the campaigns can be found at www.unitedwaykfla.ca and www.uwleedsgrenville.org



Thinking About Epilepsy Program to Hit Grade 5 Classrooms Late Fall

Grade 5

The *Thinking About Epilepsy* program, developed by the Epilepsy Support Centre in London, Ontario, is designed to provide students and staff with seizure first-aid and information about epilepsy. More importantly, the program promotes tolerance and acceptance of people living with epilepsy. The program has been thoughtfully designed to meet specific expectations in the Ontario curriculum for Science and Health. The 45 minute presentation is fun and engaging, including videos and even a chance for students to experience some “hands-on” first-aid.

By empowering students and staff with knowledge and correcting misinformation regarding those living with epilepsy, this program endeavors to make schools a safer and more inclusive place. The program has run to great success in more than 14 schools boards across Ontario. Education Coordinator, Claire Notman, is excited to bring this program into our schools and hopes that it will not only help support those with epilepsy, but also bring the valuable services provided by the Resource Centre to the forefront.

If you are interested in the *Thinking About Epilepsy* program for your child’s class or if you are a teacher and are interested in the program for students and/or staff, please contact Claire Notman at cnotman@epilepsyresource.org or 613-542-6222. Presentations are available for other grades or audiences upon request.

Speaker Night 2014: Epilepsy in the Classroom Presented by Dr. Elizabeth Kerr

This November, we are hosting our first speaker night presentation of the season with special guest speaker Dr. Elizabeth Kerr. Dr. Kerr will be speaking about the impact epilepsy has on education. She will be discussing how epilepsy can affect learning, and share strategies for managing the challenges that can arise.

Dr. Kerr is a Clinical Neuropsychologist at Sick Kids Hospital in Toronto. As a full-time clinician, Dr. Kerr heads up the Epilepsy Classroom, which is a Ministry of Education classroom catering to the individual learning and socio-emotional needs of children with intractable epilepsy.

Dr. Kerr’s presentation will be of interest to parents, educators, clinicians, and students. Everyone is welcome!

Special Speaker Night Presentation:

Topic: Epilepsy in the Classroom
Speaker: Dr. Elizabeth Kerr
Date: Tuesday, Nov. 25th, 2014
Time: 7pm to 9pm
Location: Queen’s University - Location TBD

All our Speaker Night Presentations are free to everyone. To register, or for more details about our upcoming speaker night (locations) please contact our office, (613) 542-6222 or visit www.epilepsyresource.org.

We look forward to seeing you there.



First Seizure Clinic at Hotel Dieu Hospital

The Epilepsy Resource Centre is proud to announce the opening of the new “First Seizure Clinic” at Hotel Dieu Hospital. The clinic will not only drastically reduce the waiting period for adults who have experienced a first seizure to meet with an epileptologist, but will also provide an immediate point of contact to connect clients with the Epilepsy Resource Centre. At the clinic, an epileptologist will provide a diagnosis, allowing appropriate treatment to begin as soon as possible,

Dr. Lysa Lomax, one of Kingston’s epileptologists, participated in such a clinic in Australia, and was pleased to bring this much needed service to the Kingston area.

Individuals who have experienced a seizure for the first time will be referred to Dr. Lomax by either the emergency room, or a physician. After Dr. Lomax has met with the patients, those diagnosed with epilepsy will be seen by Elizabeth, our new Community Liaison, to provide support, resources, advocacy, and referrals as necessary. Elizabeth will also be meeting with long-time and follow-up patients of Dr. Lomax, as well as pediatric patients now transitioning to adult care, further increasing the presence of the Epilepsy Resource Centre in the community and bringing greater awareness of the organization and the services it offers.



Introducing Our New Staff Members

Claire Notman, Education Coordinator

Claire is excited to join the team at the Epilepsy Resource Centre as Education Coordinator. After graduating from Trent University with her Bachelor of Arts (History) she gained her Education Assistant Diploma and worked for many years supporting a student with a seizure disorder. In 2010, Claire attended the Faculty of Education at Queen’s University and became an Ontario Certified Teacher (History, English, Special Education), accomplishing a lifelong dream. For the past several years she has worked implementing programs for students with learning disabilities in Kingston and the surrounding area. With her many years working with and for students with special education needs, Claire is thrilled to be continuing to work in the area of public education and awareness through the *Thinking About Epilepsy* program. She thanks Susan, Elizabeth and Hanna for her warm welcome!



Elizabeth Moss, Epilepsy Community Liaison

My name is Elizabeth Moss, and I am thrilled to be the new Epilepsy Community Liaison for the Epilepsy Resource Centre. I graduated from Nipissing University with a bachelor of psychology, and from Lakehead University with a bachelor of social work. I am excited to provide a much needed service to individuals and their families, and am proud to be involved in Kingston’s “First Seizure Clinic” in collaboration with Hotel Dieu Hospital and Dr. Lysa Lomax. I feel so fortunate to be working for a non-profit organization that does such great work for its clients and the surrounding community, and am looking forward to supporting people with epilepsy in our community.



Thinking about Epilepsy Grade 5 Education

Volunteers Needed!

The Epilepsy Resource Centre is calling for volunteers who are interested in helping to facilitate the *Thinking About Epilepsy* program to Grade 5 classrooms throughout the region.

Is this YOU?

- Want to learn more about epilepsy and help spread public awareness?
- Enjoy working with, and empowering, children?
- Availability during the day?

For more information, please contact Claire Notman, Education Coordinator with the Epilepsy Resource Centre at (613) 542-6222 or by email at cnotman@epilepsyresource.org



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Purple Day Committee

Call for Volunteers

The Epilepsy Resource Centre is looking for eager and energetic volunteers to assist with our upcoming 2015 Purple Day campaign, which occurs annually in March. Our committee volunteers will assist in planning and preparing our Purple Day campaign, fundraisers and events. This opportunity is a great way to assist with bringing awareness and information to the community we serve about epilepsy, seizures, and the programs and services our agency provides.

Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness.

If you are interested in joining our Purple Day committee, please contact Elizabeth Moss at our office, (613) 542-6222 or by email at emoss@epilepsyresource.org. We look forward to hosting some new and exciting events this year!

If you would like to learn more about Purple Day, please visit their website at www.purpleday.org



Courtney Tobin - OBCL Scholarship Recipient

The OBCL Epilepsy Scholarship Awards were presented June 13 to six Ontario students this year. OBCL has been supporting students with epilepsy through the scholarship awards since 2006. Each year, up to 10 students in Ontario can win a \$1,000 scholarship for post-secondary education. Since 2006, Lawton Osler, president of Osler Business Consulting Ltd., has supported students with epilepsy by funding the OBCL Scholarship Awards.

One of this year's recipients was Courtney Tobin, a Kingston native. Courtney lost her sister, Chelsea, to SUDEP in 2012. While Courtney says the impact of Chelsea's death will never leave her, she is determined to carry on her older sister's memory. Courtney, who is also living with a seizure disorder, has become an advocate for epilepsy awareness. "I have made it my mission to inform and educate as many (people) as I can about epilepsy and what they may be able to do to help," Courtney says.

This past spring, Courtney completed the pre-health sciences certificate course at St. Lawrence College. She is using her scholarship to help finance the program she's taking at the college to become a medical laboratory technician.

Congratulations Courtney!

For more information about the OBCL epilepsy scholarship, please visit the Epilepsy Ontario website at www.epilepsyontario.org



Courtney Tobin and Lawton Osler

Photo and content credit to Epilepsy Ontario

Community Health Promotion: A Collaboration with Queen's School of Nursing about Living with Epilepsy

The Epilepsy Resource Centre has recently begun collaborating with the Queen's School of Nursing to provide nursing students with experience in community health promotion. Each school term, our centre will have a pair of nursing students working on a project to enhance community supports for individuals affected by epilepsy.

This fall, we are thrilled to be working with Brianna Thompson and Anna Kerr, who are creating an information session for individuals recently diagnosed with epilepsy. The session will be developed with the option of both an in-person and a live webcast delivery method.

In order to develop an information session that is useful and comprehensive, the students have developed a survey for individuals living with epilepsy. The survey asks you to reflect on your initial diagnosis of epilepsy, as well as the impact that epilepsy has had on your life. We kindly ask that those who feel comfortable completing the survey do so, and follow the provided link to complete the survey online. The survey is completely anonymous, and the data gathered will be used only for the purposes of creating this information session. It should take approximately 10-15 minutes to complete. Your views are highly valued, and we thank you for taking the time to assist us in this project.

Survey Link: <https://www.surveymonkey.com/s/CM5YTNW>

Epilepsy Ontario Blog ~ Huffington Post

Epilepsy Ontario produces a monthly column about epilepsy and seizures for *The Huffington Post Canada*. It's an exciting opportunity to change the way the general public thinks and talks about epilepsy. In September, Epilepsy Ontario published an article written by Kimberley Wright, a local mom and strong advocate for epilepsy awareness.

How Schools Can Better Prepare For Students With Epilepsy

By Kimberley Wright ~ an Epilepsy Mom

Starting school is always an emotional experience. As the mother of a child with epilepsy, it is terrifying!

My daughter Journey is a clever, beautiful, 11 year old girl who loves life and all it has to offer. She loves to make people laugh and lives to dance and sing. She loves to swim, climb, swing, and ride her bike.

Journey was diagnosed with epilepsy at five months old. We were fortunate that her seizures became well controlled shortly after her diagnosis. When she was four years old, her seizures changed. They became unpredictable, but relatively mild and infrequent until the age of nine. When Journey entered pre-pubescence, she began to have seizures that caused her to suddenly drop to the ground, creating significant risk to her safety and sometimes resulting in injuries. The seizures became difficult to control. As she got older, with changes to her hormones and continued brain development, the seizures became increasingly unpredictable, changing in their presentation and their triggers, and growing more frequent and intense.

Each new school year, I remember preparing for Journey's very first year of school. I can't help thinking about the dread that her dad and I felt as we contemplated kindergarten. Like other parents, we were excited and proud to watch our baby girl reach this milestone. Behind Journey's crisp new backpack and the pretty new outfit, we were sick with worry about sending our precious little one off into a community that generally doesn't understand the world our family lives in - the world of uncontrolled seizures.

Ours is a world in which the threats are unpredictable, triggers are inconsistent, and Journey's personal safety is challenged daily. Average activities like being outside in the sun, engaging in physical games, or even walking down the hall can result in an injury, maybe even an ER visit.

It doesn't seem to matter how many 'first days' of school we have; we continue to worry about Journey's social and educational experiences. Will there be playdates and birthday parties or will the other kids and their parents be too afraid of the seizures? What will learning look like? Will she be included with her classmates or will she be left out in the name of keeping her safe? Will we be able to find ways to keep her as safe as possible while still allowing her the dignity of reasonable risks and choices?

With so many fears, my husband and I often find ourselves questioning how we're supposed to send our sweet girl off to an environment that, for her and other children with epilepsy, is filled with danger and risk. Sometimes it feels like it would be much simpler to just keep her at home where we can

protect her; place her upon a shelf, like a porcelain doll, safely away from things that could hurt her. But what kind of life is that? I'm proud to say that we've survived six years in the education system, advocating and supporting our school in creating a welcoming, safe, and inclusive learning environment for Journey and other students with epilepsy. This has been a learning experience for all, involving patience, open minds, trust, a strong vision, and effective communication.

Safety and supervision are priorities with the staff and administration. Our principal is one of our best allies; she's committed to making the accommodations required to fully include Journey in social and academic activities. During periods when seizures are less controlled, the principal secures increased classroom support with an Educational Assistant from the Board to ensure adequate supervision and the ability to respond to Journey's seizure management needs. The education team tracks potential triggers. The school provides a quiet space for Journey to rest following seizures that require her to sleep afterward.

When Journey's classmates became more aware of her seizures, we wanted to equip the kids so they could cope with what they witnessed. The school met us with absolute enthusiasm when we suggested having the Epilepsy Resource Centre of Southeastern Ontario educate students and staff. The school also organized an epilepsy awareness campaign involving the entire school. I'll share the astounding impact of these activities in next month's column.

Journey enters grade six this year and she is the bravest girl I know. She's my warrior princess! Journey expects to participate in all parts of student life at school; she doesn't allow the seizures to keep her from trying anything. With the support of the school administration and staff, Journey is becoming a leader and champion at school. She helps her classmates and educators better understand the world of epilepsy and how they can support her success at school.

Journey will not live on a shelf. We may not be able to protect her from every seizure risk and she may incur some injuries now and then, but she will live life fully and share diverse experiences as a result of the collaborative efforts of her family, friends, educational team, and community. She will learn, play, laugh, love, and dance with her friends at school and beyond!

By Kimberley Wright, a passionate Epilepsy Mom who advocates with a clear vision of a fully inclusive, vibrant life beyond seizures for her daughter.

Previously published by Epilepsy Ontario at The Huffington Post Canada.
www.huffingtonpost.ca/epilepsy-ontario/



Did You Know? Epilepsy and Education

It is a common misconception that all children diagnosed with epilepsy have learning problems. Most children with epilepsy do very well and have no learning issues. However, some students do experience challenges, and school performance may be adversely affected by:

- Side effects of medication (hyperactivity, interference with concentration or memory, drowsiness/fatigue, loss of coordination)
- Absenteeism due to seizures and medical appointments
- Lower expectation from themselves, teachers or family members
- Underlying cognitive or neurological problems (Previous brain trauma or illnesses)

It is also important to note that children learn not only from teachers, but also from peer and social interactions to develop important skills, such as forming friendships, communication, problem solving and sharing. It is important to educate your child's teacher, other school staff, and peers about epilepsy. We can help! Contact us for more details.

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