

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

A Season of Change Comes to the Epilepsy Resource Centre

Welcome Debra Swan
New Executive Director



This July we warmly welcomed Debra Swan into the Executive Director position.

Debra has been assisting communities, organizations and individuals for over 25 years. A pioneer in the field of capacity building, Debra's background and experience in non-profit organizations will be an asset to the Epilepsy Resource Centre as it continues to grow and support those affected by epilepsy and seizure disorders.

Debra can be reached at dswan@epilepsyresource.org or 613-542-6222



**PULL TOGETHER
FOR EPILEPSY
2015**

Our third annual Fire Truck Pull, *Pull Together for Epilepsy*, was a wonderful success and raised over \$10,000!

Thirteen teams competed for four titles:

Sadie's Clydsdales-Fastest Pull

Sadies' Clydsdales-Team Spirit,

Tonic for the Clonic-Most Funds Raised

Ottawa Fire Services-Overall Winner

We would like to extend a huge thank you to our competitors, volunteers, spectators and generous sponsors, including: Kingston Fire and Rescue, Par-T Perfect, Fresh Radio, Corus Entertainment, CKWS TV, FM 96, K-Rock 105.7, 93.5 Country, Kiss 102.7, Farm Girl, Jack Astors, Taylor Auto Mall, Kingston Frontenacs, Kingston 1000 Islands Cruises, Kingston Brewing Company, Tim Hortons, Shoppers Drug Mart, Taylor Studios, Loblaws, Starbucks, Centennial Engravers, Keny's Hot Dog Stand, Dairy Queen, KCCU, Trailhead, Queen's ARC and Centennial Engravers.



Thank you to everyone involved in the event for helping to raise money and awareness for epilepsy. We hope to see you next year!

A special thank you to board member Kim McFarlane for being the official photographer.

A big thank-you to Siobhan Bradley our Special Events Coordinator this summer. Your hard work and dedication to this event made it such a success!

Check out all the fun photos on our Facebook page:
<https://www.facebook.com/EpilepsyResourceCentre>



The Impact of Epilepsy in Ontario

The Ontario Brain Institute (OBI) and the Institute for Clinical and Evaluative Sciences (ICES) recently released a report with Ontario-specific findings for thirteen neurological conditions, including Epilepsy. Some highlights from the study include:

- From 1995-2011, 89,867 Ontarians with epilepsy were identified
 - From 2004-2011, there was no overall change in the annual rate of new epilepsy cases
 - In 2010, the demographics of individuals diagnosed with epilepsy were as follows:
 - 16% were children (0-17 years)
 - 69% were adults (18-64 years)
 - 15% were older adults (65 years and older)
- *Contrary to popular belief, the data does not indicate that epilepsy is seen more commonly in seniors***
- A higher percentage of people identified with epilepsy live in neighbourhoods with lower household incomes
 - Our LIHN (Local Integrative Health Network) – South East region – has the highest prevalence of epilepsy in Ontario

To read more, please visit:

<http://www.ices.on.ca/flip-publication/BrainDisordersInOntario2015/index.html>

Purple Day in Review



March looked a little different at the Epilepsy Resource Centre this year. Two awareness events ran for the first time: Purple POP Pilates in Kingston and a Purple Princess and Pirates Party in Brockville. We also hosted our third annual Purple Pancake breakfast in Kingston. In addition, we created and sold Purple Day Ambassador kits that proved to be very popular. Students at many schools wore purple to show their support, and Newburgh Public School hosted a school presentation to educate their entire population about Purple Day and epilepsy.

We were thrilled to be selected as the community partner of 99.9 myFM radio in Gananoque for the month of March. The station provided extensive promotion of our Purple Day events, while also raising general awareness of epilepsy and the support services available in our community.



Welcome New Board Members



Kyle Lawlor-President

Kyle is a resident of Napanee, and has been supporting the KFL&A community for 6 years, helping raise funds and awareness for epilepsy, youth diversion and Multiple Sclerosis. He joined the Epilepsy and Seizure Disorder Resource Centre in 2014. Kyle has a wealth of outreach and communications experience through his education and work as a Public Servant.

Heather Christie-Director

Heather has worked in the financial services industry for 10 years and is currently the Assistant Corporate Secretary at a life insurance company, working as liaison to the Board of Directors and shareholders. Ms. Christie is also the proud parent of a young child with epilepsy. Her professional and personal experiences will be an asset to the Epilepsy Resource Centre.

Kim McFarlane-Director

Kim is a teacher with the Algonquin-Lakeshore Catholic District School Board, and is entering her seventh year and second term with the Epilepsy Resource Centre. She has held various positions on the board including Secretary, Vice President, and President. Kim is a strong advocate for education and epilepsy awareness, having grown up with it since being diagnosed at the age of 9. When not pulling fire trucks or baking goodies for the United Way Bake Sale held by the Epilepsy Resource Centre, she can be found volunteering at most events held by the agency as the official photographer.

Board of Directors

President

Kyle Lawlor

Vice-President

Tracey Augustyn

Treasurer

Valerie Robb

Secretary

Jim Docherty

Directors

Jessica Gies

Karen Labbett

Heather Christie

Kim McFarlane

Dr. Athen MacDonald

Volunteers Wanted for Charity Bingo Events

Do you have 2 hours once a month to give?

The Epilepsy Resource Centre 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. However, to receive this portion, the Epilepsy Resource Centre 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 for the Epilepsy Resource Centre, please contact Claire Notman at our office at (613) 542-6222, or by email at cnotman@epilepsyresource.org.



A Fond Farewell!

In July we said good-bye to our Executive Director, Susan Harrison. Susan has worked diligently over the last four years to build the Epilepsy & Seizure Disorder Centre of Southeastern Ontario by promoting independence and optimal quality of life for those living with epilepsy and seizures in our region. Her commitment, leadership and dedication to the organization will be missed. Susan's depth and breadth of knowledge, infectious positivity, and willingness to face any challenge have brought the ERC to place that can grow and become a driving force for change in the community and a comprehensive place for support for those affected by epilepsy.

Thank-you, Susan, for all you have done!

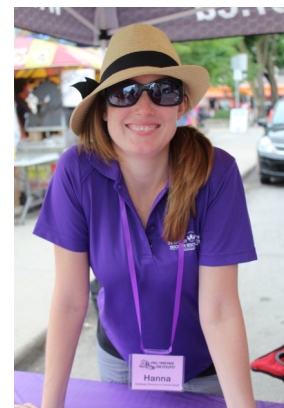


Good-bye Hanna!



We are wishing our Youth and Administrative Coordinator, Hanna Kitchingman a fond farewell after her many years of service at the Epilepsy Resource Centre. Starting out as a volunteer, Hanna became an integral part of the ERC as it grew and developed under Susan Harrison's leadership. Hanna was often the face and voice of the organization as she worked tirelessly at whatever needed to be done. From flipping pancakes, to presentations, community displays and bookkeeping she was a "jack of all trades".

Hanna's creativity and passion to support those affected by epilepsy in the community will be greatly missed! Thank you, Hanna!



“Thinking About Epilepsy” Grade 5 Program Update

The Grade 5 “Thinking About Epilepsy” program premiered this year. It is a program funded for three years by the Ontario Trillium Foundation that promotes empathy and understanding, while dispelling myths and providing seizure first aid training for staff and students across the KFL&A, Leeds and Grenville regions. Facilitated by Claire Notman, our Education Coordinator, the one hour presentation was delivered to over 1200 students and staff. With the help of wonderful volunteers and work-study students, the program surpassed its target of 850 students. By the program was received enthusiastically by students and staff alike.

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.



Science Rendezvous 2015

This May we took our giant brain to Science Rendezvous at the K-Rock Centre. Hosted by Queen’s Outreach the event was a free science day for kids (and kids at heart). While children made play-doh brains they learned about the different lobes of the brain and their function in relation to the body and seizures. Our booth was incredibly popular with over 250 children walking away with a colourful brain activity sheet and information about epilepsy and seizures. We cannot wait to do it again next year!

VOLUNTEERS NEEDED!

If you would like to participate in Science Rendezvous 2016 contact:
Claire at cnotman@epilepsyresource.org



NEW

Epilepsy Support Group

Our first support group meeting was held Wednesday, July 29th. Facilitated by Elizabeth Moss, Client Services Coordinator, clients and family members discussed various topics related to the effects of epilepsy.

The group will meet the last Wednesday of each month from 7:00pm-8:30pm 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.

Peer Support Volunteers Needed

Are you someone living with epilepsy? Would you like to share your experiences with someone in need of support? There is a need in the community for peer support. Support can be given by phone, online or in person.

For more information please contact Elizabeth Moss at emoss@epilepsyresource.org



From Disorder to Disease: A Change in Terminology

The ILAE (International League Against Epilepsy) recently accepted the recommendations of a task force to change the current definition of epilepsy.



Epilepsy is now considered to be a “*disease*”, rather than a “*disorder*”. It was thought that the term “*disorder*” was poorly understood, and minimized the serious nature and long-lasting impact of epilepsy.

Epilepsy is now considered to be “*resolved*” in individuals who have been seizure-free for at least 10 years, and who have not taken antiseizure medication in at least 5 years. However, if an individual’s epilepsy is resolved, it does not guarantee that it will not return; a

history of seizures always places you at a greater chance of having another seizure compared to someone without a history of seizures.

It is important not to confuse the term “*resolved*” with terms like “*remission*”, or “*cured*”. “*Remission*” would imply that seizures are temporarily absent and will come back, while “*cured*” would imply that the individual’s risk of having another seizure is the same as someone who has never had a seizure.

Definitions of the causes of seizures were also changed:

Old term	New Term	Definition
Symptomatic	Structural/metabolic	The cause of seizures is known (e.g. birth injury, brain trauma, infection, brain tumour, stroke)
Idiopathic	Genetic	The cause of seizures is unknown

Fisher et al. (2014). A practical clinical definition of epilepsy. *Epilepsia*, 55(4), pp. 475-482.

“A Rose by any other Name”: New Seizure Terminology

Definitions of seizure terms have changed recently. It is important to be aware of these changes; while your doctor may use one term, your specialist may use another, despite meaning the same thing.

Old Term	New Term	Definition
Partial seizure	Focal seizure	A seizure that is limited to one part of the brain
Simple partial	Focal seizure without impairment of consciousness	A seizure that is limited to one part of the brain; the person typically remains conscious and aware of his/her surroundings
Complex partial	Focal seizure without impairment of consciousness or awareness; may also be called focal dyscognitive	A seizure that is limited to one part of the brain; the person's awareness and consciousness is typically altered
Aura	Sensory or psychic phenomena	A seizure that results in an unusual sensation, feeling, movement, sight, sound, or smell. This may alert a person that s/he is about to have a different type of seizure
Partial seizure secondarily generalized	Focal seizure evolving to generalized convulsions or evolving to a bilateral convulsive seizure	A seizure that was limited to one part of the brain spreads and becomes generalized to the whole brain

Old Term	New Term	Definition
Generalized seizure	(Generalized seizure)	A seizure that involves the whole brain; it may or may not be convulsive
Petit mal	Absence	A seizure that involves the entire brain; awareness is altered and may include a blank stare, rapid eye blinking, or eye rolling.
Grand mal	Tonic clonic	A seizure that involves the entire brain. Tonic phase: typically involves a crying out or groan, loss of awareness and consciousness, and muscle stiffness Clonic phase: typically involves convulsions in which there is jerking and twitching of the muscles in all four limbs.
Atonic	(Atonic) May be referred to as a “drop attack”	A seizure that involves the whole brain the results in a sudden loss of muscle tone and head nodding; awareness is typically lost and the individual may fall to the floor abruptly
Myoclonic	(Myoclonic)	A seizure that involves the whole brain that results in a sudden jerk of a part of the body, such as an arm or leg. The individual may or may not fall; awareness is typically retained.

To read more about the recent changes, please visit:
<http://onlinelibrary.wiley.com/doi/10.1111/epi.12550/full>