

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



Introducing Our New Summer Fundraiser!

As many of you are aware, GLAD Days has been a significant fundraiser for the Epilepsy & Seizure Disorder Resource Centre for a number of years. The support that we have received from our volunteers, community members, and local businesses has been tremendous, and we cannot thank you all enough for the efforts that you have shown in creating epilepsy awareness within our community. While everyone always enjoys the beautiful gladiolas, GLAD Days has become less successful as a fundraising event over the past several years, and we have decided to try something new this year.

As we move forward into the summer months, we are excited to announce that this year, we will be hosting a new fundraiser in Kingston: *Pull Together for Epilepsy!* Taking place on **Ontario Street**, in front of **Kingston City Hall** on **July 21st**, *Pull Together for Epilepsy*, our first annual fire truck pull, will be a fun-filled family event that will raise funds and epilepsy awareness in the Kingston community!

From **1:00pm to 3:00pm**, 15 teams of 8 people will work together to compete in a variety of fire truck pull competitions, such as the fastest pull, the most funds raised, and the most spirited team! Alongside the main event, there will be food, activities, and fun to be had for everyone from **12:00pm-4:00pm!**

We hope that you will join us in Kingston on **July 21st** to participate in the many festivities that will be happening. For more information on how to get involved, please see the enclosed flyer or visit www.epilepsyresource.org/pulltogether



Support for Parents: On-Line and In Person

We know that being a parent of a child with epilepsy presents many unique challenges, and so we are working to build parent support networks. These support networks will provide the opportunity for caregivers to come together as a community, and share information and experiences in a safe and respectful environment.

Last year we wrote about offering a parent support group, which we still hope to do. At the moment, however, we require more families to be able to run a successful group. If you are interested in attending a parent support group, please contact our office to be added to our list. We will begin offering monthly parent support group meetings when we have enough families registered to attend.

In the interim, and to offer support to those who cannot travel to Kingston, we will be launching a parent group on Facebook, through which members can share their questions, challenges, and successes with each other. Watch our Facebook page for details!

If you are interested in learning more about our parent support networks, please contact Susan Harrison at (613) 542-6222 or by email at susanharrison@epilepsyresource.org.



No Child Without Medic Alert Free Medical Alert Program for School Children

The Canadian MedicAlert® Foundation is a charitable organization and the leading provider of emergency medical information services linked to customized medical bracelets and necklets. They have partnered with the Lions Club of Canada to create the *No Child Without*

program that offers a free MedicAlert membership for children ages of 4 to 14 who attend a participating public school in Canada. The Canadian MedicAlert Foundation and its *No Child Without* Program is active in 240 school boards across Canada, including all school boards in our area.

It is easy to have access to the benefits of this program. All you need to do is pick up a brochure from your school principal, follow the instructions and complete the back of the form to register your child. Membership includes a bracelet or necklet ID that provides a description of the particular medical condition and also a specific case number linking to the person's medical file which is kept in a confidential and centralized location. There is also a hot line phone number so that medical responders can access the detailed file within seconds. The file can contain details of the child's condition, as well as specific protocols to take if necessary. The system is meant to supplement the emergency care plan that should be in place at school, for each child with epilepsy. If your child does not have a seizure plan or action plan at school, contact our office and we will assist you in putting one in place. Throughout the course of a day, your child is under the care of many people outside of school. He or she may be in daycare, visiting friends, or attending various sport or enrichment activities. The Medic Alert system ensures that wherever your child is, the means will be there to manage a medical emergency.

To find out more information about the *No Child Without* program please visit www.nochildwithout.ca/index.asp

Is your child over the age of 14? If so, there are still options available to you and your family to ensure the safety of your teenager. Once a child reaches his or her 14th birthday, she/he might be eligible for the StudentsFIRST Program. The StudentsFIRST program ensures teenagers across Canada, with medical conditions, allergies or special needs are protected by MedicAlert. This program offers a 20% reduction on regular monthly rates for students up to the age of 18. For more information on this program and to see if your child is eligible please visit www.medicalert.ca/studentsfirst/

Thank You From the Epilepsy Resource Centre



The Epilepsy and Seizure Disorder Resource Centre has had many wonderful volunteers and supporters over the years. We would like to extend a warm and heartfelt thank you to two of our long-standing supporters who are moving on to new adventures.

We would like to thank **Jason Field** for the time and dedication that he has provided to the Epilepsy Resource Centre through his support as a volunteer and board member. For seven years, Jason has been an integral part of the leadership of our organization. We extend our sincere thank you to him for all his hard work.

We would also like to take the time to thank **Mary Tao** who has been superb in her dedication to the organization. Mary has been involved in our Homework Club, fundraising and Purple Day events, as well as being our Queen's work study student for the past 7 months. We wish Mary all the best with her upcoming medical school studies at the University of Toronto.

Summer Safety Tips for Epilepsy and Seizures

How to Stay Safe This Summer

Summer is finally here! Having epilepsy doesn't mean that you can't enjoy all that summer has to offer, but there are some extra safety tips to consider if you have seizures. Here are some helpful safety tips:

- Swimming can be the most fun and enjoyable way to cool off in the summer. However, if you have epilepsy and/or uncontrolled seizures, it is always recommended that you NEVER swim alone. Ensure that you are with someone who understands your epilepsy/seizures, can help if necessary, and who is a strong swimmer. It is also recommended that you swim in a pool rather than in open water and you always wear a life preserver.
- Always use proper safety gear such as helmets, flotation devices, and knee/elbow pads.
- Take extra precautions in sports that may increase your risk of head injury, such as soccer, karate, football, or any other contact sport.
- To avoid bike accidents, avoid riding on the side of busy roads; stick to side roads, bike paths and trails which have less traffic.
- Avoid related problems such as low blood sugar, dehydration or overexertion which could increase your risk of a seizure.
- If you are involved in camp or sports this summer, ensure that you inform the camp, counselors, lifeguards, and/or coaches about your epilepsy/seizures and let them know how to respond if you have a seizure.
- It is always important to take your medication regularly as directed and to ensure that you are eating well and getting enough sleep, to assist in minimizing the risk of seizures.

Remembering how to stay safe can ensure that your summer is fun and exciting and lower the risk of any medical injuries or issues. For more information about summer safety and precautions for you and your family, please discuss them with your healthcare provider, or call our office.





Purple Day 2013 Wrap Up

The Epilepsy Resource Centre would like to thank everyone who assisted in raising epilepsy awareness throughout March and on Purple Day. Thanks to our wonderful Purple Day volunteers who assisted us with our first-ever Purple Pancake Breakfasts in Kingston and Gananoque. They were a huge hit!

We would also like to say a special thank you to the following businesses and individuals that hosted Purple Day campaigns: Wal-Mart in Kingston, Dupont, Avanta Spa, Kingston Community Credit Union, StarTek, Jordan Bell with Arbonne Cosmetics, and all the staff and management at Loblaws Princess Street Market.

Our appreciation also goes out to the following sponsors, whose generous donations assisted us in running a successful Purple Day 2013 campaign: UCB the Epilepsy Company, Baldrees No Frills in Gananoque, Metro in Gananoque, Mega Dollar in Gananoque, Tim Hortons in Gananoque, Gord and Kim's No Frills in Kingston, St. Andrew's Presbyterian Church in Gananoque, MyFm 99.9, and the St Lawrence EMC.

We would also like to extend a heartfelt thank you to the many schools that hosted their own Purple Day Campaigns. This year, over 5000 students in our area were exposed to Purple Day!

SmartWatch and LifeLine with Autoalert New Seizure Monitors for Peace of Mind

For the one third of individuals living with epilepsy who experience uncontrolled seizures, a common source of stress is worrying about having a seizure and not being able to contact someone for assistance. Seizure monitors can help provide the peace of mind individuals and families are looking for when it comes to the safety and security of their loved ones and themselves.

Two different companies, SmartWatch and LifeLine with Autoalert, have developed new technologies to monitor for seizure activity and automatically call for help when a seizure is detected.

SmartWatch acts as an early warning system for generalized tonic-clonic seizures. SmartWatch is an intelligent wristwatch that continuously monitors body movements and alerts when there is an onset of excessive or repetitive shaking motion. This system is set up to automatically send text messages and phone call alerts to designated family members and/or caregivers. Users of this device can also summon help with a push of a button. In addition, this device has the ability to track and record motions of the individual user, including time and duration, which can provide useful information for your family doctor or neurologist. Unfortunately this product is only available in the United States at the moment, but testing is underway to bring this product to Canada.

For more information about the SmartWatch monitor please visit their website at www.smart-monitor.com.

You may be familiar with **Philips LifeLine**, a monitoring system that enables a person to summon help by pushing a button on a pendant worn by the individual. A new additional feature called **Autoalert** is now available. LifeLine with AutoAlert can detect a sudden fall as may be experienced during a generalized tonic-clonic seizure, and will automatically place a call for help if you're unable to push the button yourself. For more information about LifeLine and the Autoalert system please visit their website at www.lifeline.ca or at www.lifeline.ca/content/english/medical_alert_service/auto_alert_service.

E-Action Website

New support network and Information



E-Action is an online community that strives to provide a caring and informative environment for those wishing to learn more about epilepsy. The E-Action website and community offers information about the different types of epilepsy, treatment options, lifestyle tips as well as personal stories from people and families that are affected by epilepsy. It is designed to inspire, educate and inform Canadians about the importance of epilepsy management and reduce stigma.

E-Action™ is an initiative of UCB Canada Inc. It includes a broad range of interactive resources that are educational, informational, and most of all, inspirational. They include a magazine, a website, and an exciting new mobile application (App) available through the App Store (search 'e-action') for iPads, iPhones and iTouch. At E-Action's core is a leader program, which features 10 Canadians who are living well with epilepsy and who share their story to reduce stigma and educate others who have been diagnosed with the disorder.

If you are interested in learning more about this new website and information forum, please visit www.e-action.ca.

Spotlight on Research

An EpLink Project Designed to Improve Working Memory

In our last newsletter, we introduced you to the EpLink Research Project, funded through the Ontario Brain Institute. EpLink sponsors more than twenty-five different research projects related to every aspect of epilepsy care. Some of the projects are highly technical - like Dr. Peter Carlen's attempts to teach computers to recognize seizure onset. Others are very straightforward, like Dr. David Stevens survey designed to find out why physicians don't refer drug-resistant patients to surgical programs. One study that may be of interest to many people with seizures is Dr. Elizabeth Kerr's study. It is designed to determine whether a computer-based training program can improve children's working memory.

People with epilepsy have a lot of problems besides seizures, including cognitive issues that include many aspects of attention and memory. People with seizures – particularly uncontrolled seizures - often have problems with their memory. Unfortunately, there have been very few attempts to help people with their attention and memory problems. Dr. Kerr is trying to change that.

Dr. Elizabeth Kerr is a clinical neuropsychologist working at the Hospital for Sick Children in Toronto. She has over fifteen years of experience in working with children with drug-resistant epilepsy. Her current study involves the use of a computer-based training program designed to help children improve their working memory (juggling ideas in one's mind), which can support memory. The program – which is not unlike a computer game - takes about five weeks, and can be done by the children at home, with coaching over the telephone. Assessments of the children's cognitive functioning are done at the beginning of the program, at the end of the program, and then again four months after the completion of the program.

Although the study is presently taking place in Toronto, there is no reason why it couldn't be done everywhere in Ontario if it is successful. It could be done with adults as well as with children, and it is possible that the phone counselling might be done by trained personnel at the non-profit epilepsy associations.

Finally, there are also computer-based programs available to help people with anxiety and depression. EpLink is now designing a study to see whether these might also be used to help people with epilepsy. Readers interested in more information can email Dr. Kathryn Hum at eplink.obi@gmail.com.

Call for New Board Members

The Epilepsy and Seizure Disorder Resource Centre is looking for new members to join our Board of Directors. If you are interested in volunteering on our board and would like more information, please contact Susan Harrison by phone at (613) 542-6222 or by email at susanharrison@epilepsyresource.org.

Did You Know?

- A seizure threshold is the level of stimulation at which your brain will have a seizure. A very high fever, for instance, can sufficiently excite anyone's brain to produce a seizure. People with epilepsy have a lower-than-normal seizure threshold, meaning that only slightly increased excitement will cause them to have a seizure. Your seizure threshold is mostly genetically inherited, but other factors can affect this level.
- The word "epileptic" should not be used to describe someone who has epilepsy, as it defines a person by one trait or problem. A label is powerful and can create a limiting and negative stereotype. It is better to refer to someone as "a person with epilepsy" or to a group of people as "people with epilepsy."

THE EPILEPSY AND SEIZURE DISORDER RESOURCE CENTRE

BOARD OF DIRECTORS

James Docherty - Board President

Kim McFarlane - Vice President

Valerie Robb - Treasurer

Alix Blake - Secretary

Peggy Davidson - Director

Jessica Gies - Director

Tariq Hassanein - Director

Karen Labbett - Director

Dr. Athen MacDonald - Director

STAFF

Susan Harrison - Executive Director

Hanna Kitchingman - Youth and Administrative Coordinator

Laura Casselman - Special Events Coordinator 2013

Donations

Please send this information form along with your cheque or cash donation to:
Epilepsy and Seizure Disorder Resource Centre of South Eastern Ontario
 100 Stuart Street
 Kingston, Ontario, K7L 2V6
 Phone: (613) 542-6222 ~ Fax: (613) 548-4162

Payment Method: Cheque Cash
 Amount: \$25 \$50 \$75 \$100 Other: _____

Full Name: _____

Address: _____

Mailing Address if different from above: _____

Signature: _____ Date of Donation: _____

You can also donate to the Epilepsy and Seizure Disorder Resource Centre online using a credit card. Please visit our website, www.epilepsyresource.org and click on the CanadaHelps.org logo.

**Tax Receipts are provided for all donations*

Email Address: _____

**Please make all cheques payable to the Epilepsy & Seizure Disorder Resource Centre*