

THE EPILEPSY  AND SEIZURE
DISORDER RESOURCE CENTRE
OF SOUTH EASTERN ONTARIO

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Purple Day 2013

Purple Day is upon us again, and this year we are dedicated to increasing awareness about epilepsy in the communities that are served by the Epilepsy and Seizure Disorder Resource Centre. Every year on March 26th, people around the world are invited to wear purple in support of epilepsy awareness.

What started as a dream for 9-year-old Cassidy Megan of Nova Scotia, to bring attention, awareness and understanding to epilepsy, has grown into an international day of awareness around the world. Some of the countries that celebrated Purple Day in 2012 are China, Saudi Arabia, India, Mexico, Czech Republic, Yemen, Kenya, Indonesia, Australia, Pakistan, USA and of course, Canada.

Approximately 300,000 Canadians, and 50 million people around the world are affected by epilepsy. Please help promote epilepsy awareness in our community by wearing purple on March 26th and by coming out to enjoy our wonderful events. Please see Page 2 for details of these events.

For more information on Purple Day, visit the official Purple Day website at www.purpleday.org

Thank you to *UCB: The Epilepsy Company* for their continued support.



THE EPILEPSY COMPANY™



Thumbs up for Purple Day



1 in 100 Canadians have epilepsy, which includes approximately 4000 individuals in our community. Because epilepsy is still a frequently misunderstood disorder and not often discussed, stigma, discrimination, and social exclusion are among the greatest challenges for people living with this neurological disorder.

On March 26th we invite you to paint your thumb nail purple to join the crowd. It's more than a way to show support for people living with seizure disorders; it can start conversations about epilepsy and provide a fun approach to raising awareness. This creative campaign was created by Jaime Van Velzen of Windsor, Ontario and Jessica Wächter of St. Thomas, Ontario in collaboration with the Epilepsy Support Centre.

When Canadians come together to support people affected by epilepsy, we become impossible to ignore.



Purple Day Legally Recognized in Canada

On June 26th, 2012, the Purple Day Act received Royal Assent, establishing March 26th as a legally recognized day for epilepsy awareness in Canada. The bill, Bill C-278, recognizes Purple Day as a day each year when Canadians wear purple to promote a greater awareness of epilepsy and support the 300,000 Canadians living with the disorder.



On March 26th, Wear Purple. It's the Law.



Celebrate Purple Day with Us!

Throughout the month of March, the Epilepsy Resource Centre is hosting a variety of Purple Day events to bring awareness to the Kingston, Frontenac, Lennox & Addington and Leeds & Grenville communities.

Purple Pancake Breakfasts

The Epilepsy Resource Centre is hosting two purple pancake breakfasts to promote epilepsy awareness. Please come out and enjoy some pancakes (including "purple" blueberry pancakes) and learn more about epilepsy. Entrance is by donation.

- **Gananoque Pancake Breakfast**

Date and Time: Saturday, March 9th, 2013 from 9am to 11am

Location: St. Andrew's Presbyterian Church, 175 Stone St. S., Gananoque

- **Kingston Pancake Breakfast**

Date and Time: Saturday, March 16th, 2013 from 9am to 11am

Location: Loblaws (at the Kingston Centre), 1040 Princess Street, Kingston

Purple Day in Your School

The Epilepsy Resource Centre has partnered with area schools to bring awareness and knowledge to students in our communities. Students are taking part by promoting Purple Day in their schools, participating in Thumbs Up for Epilepsy, and wearing purple on March 26th. If your school would like to celebrate Purple Day, please contact us to find out how we can support you!

Pesky Pennies @ KCCU

Throughout the month of March, the Epilepsy Resource Centre will partner with the Kingston Community Credit Unions to promote our Pesky Pennies campaign. Come into any of the 3 KCCU locations in Kingston and donate your pennies to epilepsy awareness. With the penny going out of circulation, this is a great opportunity to get rid of those pesky pennies.

Purple Picture Month

Want to be featured on our website and/or Facebook page? It's easy... just take a picture of yourself and your friends/family wearing purple to support epilepsy awareness and Purple Day. Don't have something purple to wear? Get creative and incorporate purple any way you can in your picture. Please email all pictures to hannakitchingman@epilepsyresource.org to have them posted.

For more information about Purple Day and our upcoming events, please visit our website at www.epilepsyresource.org or email us at hannakitchingman@epilepsyresource.org.

Speaker Night

Living Well with Epilepsy: Stories and Strategies

The Epilepsy Resource Centre has been hosting a series of Speaker Nights in both the Kingston and Brockville areas. Whether you are an individual living with epilepsy, care for someone with epilepsy, or are a member of the community who wants to know more, our new series of Speaker Nights will offer you great information and discussion about epilepsy.

Our next Speaker Night topic is *Living Well with Epilepsy: Stories and Strategies*. We will hear stories from individuals who are living with epilepsy, and have a discussion about strategies for coping with the impact of epilepsy. Everyone is welcome to attend!

Brockville Speaker Night:

Date: Tuesday February 26th, 2013 at 7pm

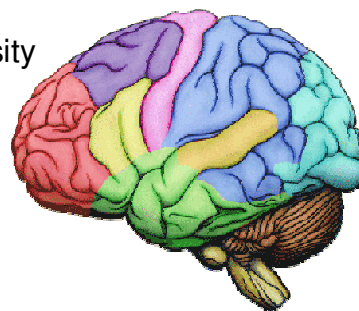
Location: Community and Primary Health Care (CPHC), 333 California Ave, Unit 13B (Diabetes Education Centre)

Kingston Speaker Night:

Date: Tuesday March 5th, 2013 at 7pm

Location: Mackintosh-Corry Hall, Queen's University, 68 University Ave., Room: E229

If you are interested in attending these events, please RSVP to (613) 542-6222 or by email to admin@epilepsyresource.org.



10 Reasons to Talk About Your Epilepsy

When you take the time to talk to people about how epilepsy and seizures have effected your life and the lives of the people around you, you challenge many misconceptions that other people may have. You also have the opportunity to provide correct information about seizure first aid techniques and to let people know how common epilepsy is, affecting 1 in 100 Canadians. Take the opportunity to change the way people think about epilepsy and seizures by talking about it!

Here are 10 great reasons to talk about your epilepsy:

1. Raise awareness.
2. Educate others and bust myths.
3. Teach others that people living with epilepsy deserve to be treated with dignity and respect.
4. Help others realize that people with epilepsy are just like everyone else.
5. Let people who have epilepsy know they are not alone.
6. You will encourage others to self-disclose.
7. You may find out that other people you know also live with epilepsy.
8. Reduce stress. You'll no longer spend energy on protecting your secret.
9. Feel more comfortable with friends, colleagues and acquaintances by building open and honest relationships.
10. Honour how epilepsy has helped define your character.

Source: Epilepsy Support Centre

Finding Hope Through Research

What do a Himalayan flower, a microscope the size of a city block, and Omega-3 fish oil all have in common?

They are key components of three research projects that are part of EpLink, an epilepsy research group being funded by the Ontario Brain Institute. In 2010, the Ontario government created the Ontario Brain Institute (OBI) to bring together the province's top brain researchers and business experts who can turn their discoveries into products and services. Epilepsy was chosen as one of the first three project areas to receive funding. Since then, epilepsy researchers have been hard at work on a wide variety of over twenty projects.

Scientists involved in these projects, which include research into new medications, breakthrough diets and brain stimulation, among others, gathered in Hamilton this past November to share updates on their research since funding was granted by the OBI earlier that year. Susan Harrison, Executive Director of the Epilepsy Resource Centre, was in attendance as part of a non-profit advisory committee for the EpLink project. "It was inspiring to learn about the epilepsy research that is taking place in Ontario, and to see the energy and enthusiasm that is being committed to finding better assessments, treatments, and supports for people living with epilepsy", said Susan. The research that is underway is expected to lead to improvements in the diagnosis and treatment of epilepsy within the next few years.

We will feature some of these research projects in each newsletter, so watch for details!



The Delphinium Denudatum: EpLink Research Project

Delphinium denudatum, otherwise known as Jadwar, is a flower found on the outer ranges of the western Himalayas around 1200 feet above the sea level. You might be wondering how this exotic flower is related to epilepsy. The roots of this plant have been used for centuries in traditional Indian medicine as remedies for many conditions, one of those being seizures. Hence, many researchers are currently investigating the phytochemical properties and pharmaceutical potentials of this plant.

So far, results are very promising.

Through funding from the Ontario Brain Institute, Dr. Michael Poutler at the University of Western Ontario has found that even at very low doses, an extract from *D. denudatum* is capable of reducing neuronal electrical activities in the brain. As a result, it may lead to an effective method to treat complex partial seizures and related conditions. Furthermore, what makes this advancement exciting is that producing the chemicals responsible for these effects from non-plant sources is relatively easy, cheap and reliable.

Although investigative studies are still in their preliminary stage, this exotic flower may bring us one step closer to a new treatment for epilepsy!

OBCL Scholarship

Are you a student living with epilepsy?

The OBCL Epilepsy Scholarship Awards offer up to five, \$1,000 scholarships to students across Ontario who are living with epilepsy, and who are continuing their studies in post-secondary education. Applications can be found at <http://epilepsyontario.org/?p=167>. The deadline is May 1, 2013.

If you plan to apply, please contact our office so we can support you in your application. Please contact Susan Harrison by email at susanharrison@epilepsyresource.org or by phone at (613) 542-6222.

Anticonvulsant Drug Shortages



Drug shortages are an ongoing global issue that are affecting many people. Recently, Canadians have been facing shortages of all kinds of prescription drugs, including anticonvulsant medications that are used to treat epilepsy.

Reasons why drug shortages occur:

- Production delays due to delays in receiving raw materials and components from suppliers
- Problems with the quality and availability of the raw materials and components
- Discontinuation of certain types of medications
 - ⇒ Medications may be discontinued in favour of newer, more effective, medications with fewer side effects
- Other regulatory or marketplace issues

Drug shortages of anti-epileptic drugs (AEDs) can cause a great deal of stress for people who take these medications to control their seizures. Some of the questions and concerns that people with epilepsy are facing are:

- If my AED is shorted and unavailable, will I start to have seizures again?
- If I have to alter my medication due to drug shortages, will a different AED be as effective as the one I take now?
- If I have uncontrolled seizures at work due to not having my AED medication, will I lose my job?
- If I have a seizure and lose my driver's license, how will I get to work and support myself/my family?
- What added stress will be put on myself and my family if the AED I take is shorted?

These are all important questions and concerns that people have regarding drug shortages. As well, abruptly stopping your epilepsy medication can cause break-through seizures, or have life-threatening consequences. If you are required to change medication due to a drug shortage, the new AED may not be as effective as your previous medication.

What you should do:

- Always refill your prescriptions early so that you have time to develop a plan if your medication is in short supply
- Stay up-to-date about any current shortages by visiting epilepsyontario.org, or by checking our Facebook page

What to do if your medication is in short-supply, or not available:

- Work with your pharmacist to find alternative supplies of your medication
- Contact your health-care provider immediately to discuss possible alternative medications
- Do not make any changes to your treatment - for example, skipping doses, reducing the dose, or discontinuing the drug - without consulting your doctor

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?

- Towards the start of the 20th century, some US states had laws forbidding people with epilepsy to marry or become parents, some even permitting sterilization.
- Early in the 19th century, people with severe epilepsy were cared for in asylums, and one of the reasons they were kept separate from psychiatric patients was because of the misconception that seizures were contagious.
- Hippocrates wrote the first book on epilepsy, *On the Sacred Disease*, around 400 BC, recognizing that it was a brain disorder and claiming that people with epilepsy did not have the power of prophecy.

THE EPILEPSY AND SEIZURE DISORDER RESOURCE CENTRE

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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: _____

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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*