

Summer 2012

# The Epilepsy & Seizure Disorder Resource Centre Of Southeastern Ontario



## Newsletter

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

### **GLAD Days 2012**

Summer is upon us again and the Epilepsy Resource Centre will be hosting our annual GLAD Days fundraiser and epilepsy awareness campaign.

During the months of July and August, the Epilepsy Resource Centre sells gladiolas in the Kingston, Frontenac, Lennox and Addington communities, as well as the Leeds and Grenville community to help raise epilepsy awareness. During July and the beginning of August, we will be offering pre-order sales to local businesses. Following this, on the weekend of August 16th to 19th, we will be delivering all pre-order sales as well as having local community on-site sales (please see the next page for details of on-site locations).

All money raised benefits the Epilepsy Resource Centre. The proceeds help to assist those in the community who are affected by epilepsy by enabling us to provide support, education, and awareness programs.

All our gladiolas are grown locally at Green Acres Greenhouses in Smith Falls, Ontario. The gladiolas can last up to one month, continuing to remind people of epilepsy and the resources that our centre provides.

If you, or a business you know, would like more information or would like to sell gladiolas at your location, please feel free to contact our office.

Help bring epilepsy awareness to our community by being a part of our GLAD Days campaign!

For more details, please visit our website, [www.epilepsyresource.org](http://www.epilepsyresource.org), or contact Kalla Tonus-Burman, our Special Events Coordinator at (613) 542-6222 or by email, [kallatb@epilepsyresource.org](mailto:kallatb@epilepsyresource.org).



### **Call for GLAD Days Volunteers!**

The Epilepsy and Seizure Disorder Resource Centre is looking for volunteers for our upcoming GLAD Days fundraising campaign. If you are interested in volunteering with us, please contact our office at (613) 542-6222 or by email at [kallatb@epilepsyresource.org](mailto:kallatb@epilepsyresource.org).

# Upcoming Events

## Speaker Nights

- Starting in the Fall of 2012, the Epilepsy Resource Centre will be hosting speaker nights that will provide information on epilepsy, seizures and epilepsy related topics. Dates, times and topics to be announced so please watch for details on our website, [www.epilepsyresource.org](http://www.epilepsyresource.org).
- Speakers will include Dr. MacDonald, pediatric neurologist at Hotel Dieu Hospital, and Dr. Spiller, epileptologist at Kingston General Hospital

## Parent Support Group

- Starting in November 2012, the Epilepsy Resource Centre will be hosting a support group for parents of children and youth with epilepsy. If you are interested in this support group, please contact our office for further details.

## Home Work Club

- In October 2012, the Epilepsy Resource Centre will be starting up our annual Home Work Club. The Home Work Club is for children and youth who are affected by epilepsy, and their siblings, who would like assistance with their school studies. See Page 4 for more details!

## Garage Sale- Aug. 26th

- On Sunday, August 26th, the Epilepsy Resource Centre will be holding a garage sale at the Kingston Community Credit Union parking lot on Gardiners Road, Kingston. If you have items you would like to donate, please contact our office.

For further information and details on all of our upcoming events, please contact our office at (613) 542-6222 .

# GLAD Days On-Site Sale Locations

- **Thursday, August 16th**
  - 11am to 3pm at Rideaucrest Retirement Home (Rideau Street in Kingston)
  - 2pm to 6pm at Metro (King St. East in Gananoque)
- **Friday, August 17th**
  - 10:30am to 3:30pm at St. Mary's of the Lake Hospital (Union Street in Kingston) outside in the front patio
  - 9:30am to 3:30pm at Kingston General Hospital (76 Stuart Street at the Kidd O Cafeteria)
- **Saturday, August 18th**
  - 9:30am to 2pm at Food Basics (Barrack Street in Kingston)
  - 10am to 3pm at Valumart (Stewart Blvd. in Brockville)
  - 8am to 3pm at Foodland (Manitou Crescent in Amherstview)
- **Sunday, August 19th**
  - TBA

Please continue to visit our website, [www.epilepsyresource.org](http://www.epilepsyresource.org), for more information on our on-site sale locations for our GLAD Days fundraising event.



## Welcome to our Special Events Coordinator

**Kalla Tonus-Burman**

My name is Kalla Tonus-Burman and I am a fourth year Political Science Major and Global Development Studies Minor at Queen's University. I am very excited to be this summer's Special-Events Coordinator for GLAD Days. My interest lies in event coordinating, especially events for non-profits that raise awareness while helping bring people together and making a change in the community. I have a lot of previous experiences in event logistics and non-profits working closely with the Make-A-Wish Foundation at Queen's as well as the Queen's International Development Conference. I am very excited to be a part of the Epilepsy Resource Centre this summer and cannot wait to sell Gladiola flowers for a great cause!

**Service  
Canada**

## Welcome To Our New Outreach Assistant

**Zack Bell**

Hi, my name is Zack Bell. I am a recent graduate of the Marketing Coordinator program at Academy of Learning. I became a volunteer with the Resource Centre in February and was involved in the planning and implementation of the Purple Day events. I am looking forward to working here as the Outreach Assistant, helping with GLAD Days, and helping to raise awareness of epilepsy in the community. I have a close connection with the Resource Centre as I was diagnosed with epilepsy when I was 14. I have a strong interest in helping to promote this organization to people in the community affected by this disorder, both directly and indirectly,

## Find us On-Line! New Website, Facebook Page and Twitter Account

The Epilepsy Resource Centre has given our website a facelift and now offers more information on who we are, and what we are up to in the community. As well, our website will offer current and valuable epilepsy information, materials and resources.

We have also created a new Facebook page: Epilepsy and Seizure Disorder Resource Centre to replace our current Epilepsy Kingston profile page. Over the next 60 days we will be transitioning to our new Facebook page. To ensure that you don't miss any of our updates or epilepsy news, please "Like" our new Facebook page. To "Like" us on Facebook, please log into your Facebook profile and search for 'Epilepsy and Seizure Disorder Resource Centre'.

Also, you can now follow us on Twitter or send us a tweet @EpilepsyResourc to stay up-to-date on upcoming events, and epilepsy news and information. #supportepilepsy

We would like to extend an enormous thank you to our volunteer, Kelvin Chan, who has worked tirelessly in redesigning our website, and launching our renewed Facebook and Twitter accounts. Thank you for your amazing work!





## Homework Club

The Epilepsy & Seizure Disorder Resource Centre is starting our annual Homework Club for children, youth, and their siblings who are affected by epilepsy or seizure disorders.

The Homework Club is a free tutoring program that offers assistance in all subject areas to students at both the elementary and secondary school levels. The Homework Club will run weekly on **Wednesdays** from **4pm to 6pm** at our office at 100 Stuart Street next to Kingston General Hospital.

For more information or to register for the Homework Club, please contact Hanna Kitchingman at our office by phone at (613) 542-6222 or by email at [hannakitchingman@epilepsyresource.org](mailto:hannakitchingman@epilepsyresource.org).

## Epilepsy Impact Study

### The Impact of Living with Epilepsy: A New Study in Canada

Recently, UCB Canada funded a study on the Impact of Epilepsy on Canadians, conducted by Leger Marketing. The survey is the first of its kind in Canada to explore the impact on life and health among adults living with the disorder. The Impact Study findings reveal that Canadian adults living with epilepsy face serious health obstacles, including access to specialized care and treatment, as well as face numerous social impacts.

The Impact Study findings highlight the urgent need to address the many barriers faced by people living with epilepsy. By sharing the survey results, it is hoped that Canadians will improve their understanding of the many challenges people with epilepsy encounter, and reduce the stigma surrounding epilepsy.

The following are some findings published in the study :

- Some of the most common challenges faced by people living with epilepsy are:
  - \* Lack of independence
  - \* Impact on social life
  - \* Stigma and discrimination or lack of awareness
  - \* Maintaining employment and relationships
- 20% of respondents reported also struggling with depression
- The average length of time to be diagnosed with epilepsy was 4 years
- Only 30% of those with epilepsy have seen an epileptologist (a neurologist who specializes in epilepsy)

For further information, please visit the Canadian Epilepsy Alliance website at [www.epilepsymatters.com](http://www.epilepsymatters.com). To receive a copy of the study, or for any questions, please contact our office (613) 542-6222 or by email at [susanharrison@epilepsyresource.org](mailto:susanharrison@epilepsyresource.org).

## Special Education Advisory Committee Representative

The Epilepsy and Seizure Disorder Resource Centre is seeking a volunteer to become the Special Education Advisory Committee Representative (SEAC Rep) for the Algonquin and Lakeshore Catholic District School Board. The individual chosen to represent the Epilepsy Resource Centre must be a separate school supporter. Meetings occur monthly on the third Monday of each month at 5:45pm in Napanee at the Catholic School Board Office. For more information, or if you are interested in representing the Epilepsy Resource Centre, please contact our office at (613) 542-6222 or by email at [admin@epilepsyresource.org](mailto:admin@epilepsyresource.org)

# Purple Day Announcement: Purple Day is Officially 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.

## About Purple Day:

Purple Day for Epilepsy is celebrated each year on March 26th and is dedicated to raising awareness about epilepsy. It helps reduce stigma and empowers individuals living with epilepsy to take action in their communities. Purple Day was founded in 2008 by nine-year-old Cassidy Megan of Nova Scotia, and named after the internationally recognized colour for epilepsy, Lavender. Purple Day was launched internationally in 2009. If you would like more information about Purple Day, please visit [www.purpleday.org](http://www.purpleday.org).

## 2012 Purple Day Wrap-Up

This year, the Epilepsy Resource Centre raised epilepsy awareness on Purple Day by hosting a series of events in the Kingston area.

Our first annual Purple Day Purple Manicure Event at the Cataraqui Mall was a hit! We offered free mini-manicures to everyone who stopped by our booth, and provided information and raised awareness about epilepsy to all people who visited us that day. We also raised epilepsy awareness in our local schools. Students at KCVI, Sydenham High School and Front of Yonge Public School put on their purple to show their support and improved their knowledge of epilepsy by completing epilepsy quizzes.

The Epilepsy Resource Centre would like to extend special thanks to all our volunteers who assisted with planning and executing our Purple Day Awareness Campaign. We would also like express a warm thank you to the St. Lawrence College Esthetician Program staff and students for volunteering their time and services, as well as to Shopper's Drug Mart (Princess/Bagot Street location) for their donations.



Rachel and Bailey at Sydenham High School

Finally, thank you to Kingston Community Credit Union and Jordan Bell with Arbonne Cosmetics for their generous donations to the Epilepsy Resource Centre which were raised by hosting their own Purple Day Awareness Campaign events. As well, thank you to UCB: The Epilepsy Company for their support once again.

Help spread epilepsy awareness by wearing purple on March 26th next year!



## 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](mailto:susanharrison@epilepsyresource.org).

## Call for Volunteers

The Epilepsy and Seizure Disorder Resource Centre is looking for volunteers for our organization. We are looking for enthusiastic individuals to assist with fundraising events, educational presentations and community events.

If you are interested in becoming a volunteer with us, please visit our website, [www.epilepsyresource.org](http://www.epilepsyresource.org), to download our volunteer form. Once completed, it can be submitted by email to [admin@epilepsyresource.org](mailto:admin@epilepsyresource.org), by fax at (613) 548-4162 or in person at our office at 100 Stuart Street in Kingston.

### THE EPILEPSY AND SEIZURE DISORDER RESOURCE CENTRE

#### BOARD OF DIRECTORS

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#### STAFF

Susan Harrison - Executive Director

Hanna Kitchingman - Youth and Administrative Coordinator

Kalla Tonus-Burman - Special Events Coordinator

Zack Bell - Outreach Assistant

## 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](http://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***