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admin@epilepsyresource.org ~ www.epilepsyresource.org

## Purple Day 2015 A Month of Epilepsy Awareness

### POP Pilates in Kingston

**When:** Saturday, March 7th

**Time:** 9am and 1pm sessions

**Location:** Combative Room 1, 3rd Floor of the Athletic & Recreational Centre (ARC) at Queens University, 284 Earl Street, Kingston

**Cost:** \$7 or \$5 if you come wearing purple

POP Pilates is a fusion of ab chiseling, total body defining moves choreographed to Top 40 Hits. Created by social media star, Cassey Ho, this is an intense mat-based workout challenge. We're lucky to have Canada's ONLY official POP Pilates instructor coming to Kingston to teach two classes. All fitness levels are welcome for ages 14 and up

### Purple Pancake Breakfast in Kingston

**When:** Saturday, March 14th

**Time:** 9am to 11am

**Location:** Sydenham Street United Church, 82 Sydenham Street, Kingston

**Cost:** By Donation

Our 3rd Annual Purple Pancake Breakfast in Kingston. Please come out and enjoy some "purple" blueberry pancakes and learn more about epilepsy.

### Purple Princess and Pirate Party in Brockville

**When:** Saturday, March 21st

**Time:** 1pm to 3pm Drop-In

**Location:** Community Room at the 1000 Islands Mall, 2399 Parkedale Avenue, Brockville

**Cost:** By Donation

Everyone is invited to dress up as perfectly purple princesses or pirates and enjoy some yummy treats. Come and enjoy crafts, stories, games and more! Fun for the whole family!

### Purple Day for Epilepsy

**When:** Thursday, March 26th

**Time:** All Day

Put on your best purple outfit for epilepsy awareness!



# PURPLE DAY

## FOR EPILEPSY

### March 26

It's that time of year again! Purple Day is quickly approaching. This year we are excited to be hosting some new events as well as an annual one to aid in increasing awareness of epilepsy in the communities that the Epilepsy and Seizure Disorder Resource Centre serves.

On June 26th, 2012, the Purple Day Act received Royal Assent, establishing March 26th as a legally recognized day for epilepsy awareness in Canada. 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.

For more information about the Purple Day month events that the Epilepsy Resource Centre is hosting, please visit our website at [www.epilepsyresource.org](http://www.epilepsyresource.org), or contact our office by phone, (613) 542-6222 or by email, [admin@epilepsyresource.org](mailto:admin@epilepsyresource.org). You can also find us on Facebook (/EpilepsyResource Centre), Twitter (@EpilepsyResourc) and Instagram (@EpilepsyResource).

## Purple Day Ambassadors

For those looking for inspiration for ways to celebrate Purple Day, consider becoming a Purple Day Ambassador throughout the month of March.

Ambassadors raise awareness about epilepsy, seizures, and seizure first aid in whatever way they can. Some suggestions could include hosting an event, running a fundraising, or volunteering for the Epilepsy Resource Centre. To help spread the word about epilepsy, consider purchasing a Purple Day Ambassador kit.

For more ideas on ways to celebrate Purple Day, check out our website, [www.epilepsyresource.org](http://www.epilepsyresource.org)

### Purple Day Ambassadors Kits

Purple Day Ambassador kits are put together by the Epilepsy Resource Centre and include all the materials you need to spread the word about epilepsy.

The price of each Purple Day kit is determined by size:

<b>Bronze</b>	<b>\$15</b>	Suitable for up to 10 people
<b>Silver</b>	<b>\$20</b>	Suitable for up to 15 people
<b>Gold</b>	<b>\$35</b>	Suitable for up to 25 people
<b>Platinum</b>	<b>\$75+</b> (Price negotiable depending on quantity required)	Suitable for up to 50+ people

Each kit will contain:

- Purple bracelets
- Purple temporary tattoos
- Purple Pencils
- Purple Day Poster
- Purple ribbons
- Purple pens
- Purple Day Bookmark

If you would like to purchase your Purple Day Ambassador Kit please contact us at 613-542-6222, or email Claire Notman at [cnotman@epilepsyresource.org](mailto:cnotman@epilepsyresource.org).

# Epilepsy Social Night Drop-In

The Epilepsy Resource Centre is hosting a special social night drop-in session to discuss interest in developing on-going epilepsy services, including social and peer groups, as well as support groups. Whether you are a person with epilepsy, or a parent/caregiver of someone with epilepsy, please join us for an evening of treats and discussion.

**Date:** Tuesday, April 21st, 2015

**Time:** 7pm to 8:30pm

**Location:** Ongwanada, 191 Portsmouth Avenue, Kingston

If you are interested in attending this Social Night Drop-In please RSVP to Elizabeth Moss at (613) 542-6222 or by email to [emoss@epilepsyresource.org](mailto:emoss@epilepsyresource.org).



## Upcoming Speaker Nights

The Epilepsy Resource Centre has two upcoming Speaker Night Presentations. One will be in Brockville and one in Kingston. 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 series of Speaker Nights will offer you great information about epilepsy.

### Epilepsy in the Classroom, Brockville - April 2015

**Presenter:** Claire Notman, OCT, Education Coordinator

**Date:** Thursday, April 16th, 2015

**Time:** 7pm to 9pm

**Location:** Community & Primary Health Care (CPHC), 2235 Parkedale Avenue, Brockville

This session will discuss the impact of epilepsy on education and learning as well as strategies for managing the challenges that can arise.

### Epilepsy At Work, Kingston - May 2015

**Presenter:** Tim Nourse, Employment Consultant with Epilepsy Toronto

**Date:** May 7, 2015

**Time:** 7pm to 9pm

**Location:** Ongwanada, 191 Portsmouth Avenue, Kingston

This session will discuss epilepsy in the workplace from multiple perspectives, as well as introduce a new workplace toolkit available to all.

If you are interested in attending either of these Speaker Night events, please RSVP to (613) 542-6222 or by email to [events@epilepsyresource.org](mailto:events@epilepsyresource.org).

## Epilepsy Bingo Event Night

Come out and enjoy a fun-filled evening of bingo while supporting the Epilepsy Resource Centre!

**Date:** Wednesday, April 22nd, 2015

**Time:** 7pm to 9pm

**Location:** Community Spirit Bingo Hall, 900 Montreal Street, Kingston

**Cost:** \$15.00 per ticket

For more information or to purchase your ticket please contact our office at (613) 542-6222.

# Your Support Makes a Difference!

As another Purple Day fast approaches, I'd like to take this opportunity to talk to you about the work we've done at the ERC. Since the summer of 2014, we have implemented two new and highly successful programs: the Grade 5 "Thinking About Epilepsy" program, and the Epilepsy Clinic.

The "Thinking About Epilepsy" program is allowing us to educate youth across our service region about epilepsy. Led by education coordinator, Claire Notman, this opportunity to teach children about epilepsy means that we are actively working to reduce the stigma felt by those affected by epilepsy, increasing our community's sense of understanding and compassion.

Many of you may have also met with Elizabeth Moss, our client services coordinator, at the Epilepsy Clinic at Hotel Dieu Hospital. Our partnership with epileptologist, Dr. Lysa Lomax, is allowing us to provide information and support directly to where it is needed most – at the appointment with an epilepsy specialist.

In the spirit of Purple Day, during the month of March, those of you subscribed to our electronic mailing list will receive weekly emails each with a different topic and theme. These emails will include educational information, updates about upcoming events, as well as the personal stories of our clients, volunteers, and staff members.

It is because of the generosity of donors in our community that we can fulfill our mission: to help those with epilepsy to live well. Without these donations, serving those with epilepsy in our area would not be possible. During the month of March, I ask you to consider making a donation to aid us in continuing to educate our youth about epilepsy, and to sustain our increased outreach to our clients. Our organization's ability to operate is due in large part to the generous support of individuals who believe in and share our mission. By providing a monetary donation, you will be directly aiding us to educate our youth about epilepsy, and to support those experiencing seizures, as well as their loved ones.

I invite you to visit our website ([www.epilepsyresource.org](http://www.epilepsyresource.org)) and to click on the "DONATE" button, or to send a cheque payable to "The Epilepsy Resource Centre" via mail. All donations valued \$20 and above will receive a charitable tax receipt. I also encourage you to consider hosting your own event or appeal to raise both funds and awareness for epilepsy and the Epilepsy Resource Centre.

Together, we can continue to work to bring epilepsy out of the shadows.

Thank you in advance for your consideration,

Susan Harrison – Executive Director

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



# UHN Epilepsy Research Study

Do you have epilepsy?

Have you been feeling sad or stressed out lately?

Would you like to participate in a research study?

**Purpose of the Research:** Researchers are conducting a study to examine whether a psychoeducational program will improve emotional well-being in adults with epilepsy.

**Description of the Research:** Participation involves taking part in an 8-week program of one-hour weekly sessions delivered over the telephone. You will be asked to complete a set of questionnaires online before and after the program.

**Potential Benefits:** Participating in this study may improve your emotional well-being, and the findings of the study may help researchers better understand coping responses in people with epilepsy, which may lead to better treatment interventions in the future.

You will be reimbursed for your participation.

For further information, please contact Kathryn at 416-978-0779.

Please note that this study has received research ethics approval from the University Health Network.



**UHN**

Toronto General  
Toronto Western  
Princess Margaret  
Toronto Rehab

## New Provincial Epilepsy Guidelines January 2015

New guidelines have been published that provide evidence-based practice to support the diagnosis, treatment and referral process from the moment of a person's first seizure. The *Provincial Guidelines for the Management of Epilepsy in Adults and Children* were produced by Critical Care Services Ontario (CCSO), in collaboration with Provincial Neurosurgery Ontario (PNO), and the Epilepsy Implementation Task Force (EITF), in an effort to improve epilepsy care across the province.

Some key information that these guidelines address include:

- Definitions, Diagnosis and Evaluation
- Treatment
- Follow Up
- Women and Epilepsy
- Patient/Caregiver Education and Counselling
- Co-Morbidities



An Epilepsy Education Check List is also included that can be used by both patients and healthcare professionals to ensure patients and their families have all the information they need. Check out page 6 for the checklist.

For more information and to view the guidelines, please visit [epilepsyresource.org/news?n=7](http://epilepsyresource.org/news?n=7)



## Epilepsy Education Check List

*This checklist can be used by both patients and healthcare professionals to ensure that patients and their families have the information they need. Ideally, this information can be shared in a timely manner. The information checklist may be revisited if new concerns develop (IOM, 2012). Healthcare providers may discuss the topics listed below based on their clinical judgement.*

### General epilepsy information

- Definition, seizure types, syndromes, potential causes
- Explanation of investigative procedures
- Prognosis
- Treatment options
- Seizure diary

### Medications

- Choice of drug
- Side effects
- Compliance
- Drug interactions
- Missed and sudden cessation of medications
- Medication subsidies/drug plans
- Rescue medications

### First Aid

- General first aid information
- When a seizure is a medical emergency

### Women and Epilepsy Issues

- Contraception
- Preconception
- Pregnancy and breastfeeding
- Pregnancy registry
- Menopause

### Lifestyle

- Diet
- Exercise
- Sleep
- Alcohol, substance abuse
- Driving regulations
- Employment
- School

### Safety and Risk factors

- Injury prevention at home and in community
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Medic Alert Jewellery

### Possible psychosocial consequences

- Perceived stigma
- Memory loss
- Depression
- Anxiety
- Sexual difficulties
- Low self-esteem

### Community Supports

- Discussion about Community Epilepsy Agency
- Call 1-866-Epilepsy or find list of local agencies at [www.epilepsyontario.org](http://www.epilepsyontario.org)



# PULL TOGETHER FOR EPILEPSY

**It's Back!**

**Save the Date!**

Our 3<sup>rd</sup> annual Pull Together for Epilepsy: Fire Truck Pull will be held on

**Sunday July 19<sup>th</sup>, 2015**

Kingston, Ontario

***Start building your team of 8 now!***



For more information on the event, or to get involved, please call  
613-542-6222 or email [pulltogether@epilepsyresource.org](mailto:pulltogether@epilepsyresource.org)

# Did You Know?

Purple Day is celebrated in over 100 countries all over the world including:

- Algeria
- Argentina
- Australia
- Bangladesh
- Brazil
- Bulgaria
- Cameroon
- Canada
- Chile
- China
- Congo
- Costa Rica
- Croatia
- Cuba
- Ecuador
- Egypt
- Ethiopia
- Finland
- France
- Honduras
- Hong Kong
- Iceland
- India
- Indonesia
- Iraq
- Israel
- Jamaica
- Japan
- Kazakhstan
- Kuwait
- Latvia
- Lebanon
- Malawi
- Malaysia
- Mongolia
- Morocco
- Nepal
- New Zealand
- Nicaragua
- Paraguay
- Poland
- Portugal
- Qatar
- Romania
- Rwanda
- Senegal
- Serbia
- Singapore
- Slovakia
- Spain
- Sri Lanka
- Sweden
- Switzerland
- Taiwan
- Thailand
- Turkey
- Uganda
- Venezuela
- Yemen
- Zimbabwe

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## *Donations*

*All donations are used for programs and services*

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: \_\_\_\_\_

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 'Donate' logo.

*\*Tax Receipts are provided for all donations*

Email Address: \_\_\_\_\_

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