

# Epilepsy News



The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Winter 2014

## March Awareness For Epilepsy: Join Us For Purple Day!

Join us as we celebrate March Month Awareness for Epilepsy. Last year, in Newfoundland and Labrador, close to 4000 people from all corners of our great province hopped, danced, sold cupcakes, dressed in silly clothes, created art, donated their spare change, signed proclamations, held events, shared information, and most of all, wore their purple very proudly.

On **March 26<sup>th</sup>, 2014**, people here will once again take that one simple step to show the individuals and families who face epilepsy that we understand, and they are not alone: we will wear purple. We will do so for the 10,000 people of this province who live with seizures every day.

Show your  
support &  
Wear PURPLE!



### A Little Purple Day History

In 2008, nine year old Cassidy Megan of Nova Scotia learned that she had been diagnosed with epilepsy. She was scared and wondered if there were other people going through the same thing. She asked if it would be possible to have a special day at her school so that people with seizures would feel less alone. Since lavender is the internationally recognized colour for epilepsy, she decided to call it **Purple Day**, and held it on March 26<sup>th</sup>. But the support went far beyond her school. Her town got involved, then other cities, provinces, and countries. In a few short years, **Purple Day for Epilepsy** has grown into a global event. Thousands of people around the world have worn purple to let everyone who lives with seizures know that they are not alone.

*"I Wanted People Around the World to Come Together  
and Teach Others about Epilepsy"*  
- Cassidy Megan

### Our 2014 Purple Day Ambassador is Cassie Singleton!



Cassie Singleton of Clarenville, is a recent winner of our Zach Rowe Memorial Scholarship. She is a current student at Memorial University and will be attending many March month awareness events within the community to stand up for those living with epilepsy.

*"Epilepsy is most certainly a challenge but it does not define who you are. Now that I have made it this far, I plan to continue to thrive and succeed. Epilepsy may be a bit of an obstacle course, but even the easiest goals in life come with twists and turns."* - Cassie

### Ask The Doctors - Question & Answer Forum

Come join two of Newfoundland and Labrador's most knowledgeable neurologists:

**Dr.A. Ogunyemi, Epileptologist &  
Dr. D. Buckley, Pediatric Neurologist**

**On Thursday, March 20<sup>th</sup> @ 7:00 pm**  
at the office of Epilepsy Newfoundland & Labrador  
**on 351 Kenmount Road.**

***If you can't attend, you can also participate outside of the city/province by teleconference!***

Ask the doctors all the questions that are important to you, or just sit back, listen, and find out even more about epilepsy and seizures for **FREE!**

**Must Register!**  
**709-722-0502 or**  
**1-866-EPILEPSY**



## Epilepsy News

is printed quarterly by:

### Epilepsy Newfoundland & Labrador

351 Kenmount Road  
St. John's, NL A1B 3P9  
Telephone: (709) 722-0502  
Toll Free: 1-866-EPILEPSY  
Fax: (709) 722-0999  
Email: info@epilepsynl.com  
Website: www.epilepsynl.com

#### BOARD OF DIRECTORS

##### President:

Ron Stone (Mt. Pearl)

##### Vice-President:

Ross Hewlett (Springdale)

##### Secretary:

Anne Marie Hagan (St. John's)

##### Treasurer:

Patti Bryant (Paradise)

##### At Large:

Pauline Duffy (Kippens)  
Bernie Larkin (Stephenville)  
Patsy Lush (Corner Brook)

##### Executive Director:

Gail Dempsey

##### Medical Consultant:

Dr. A.O. Ogunyemi, M.D., FRCP ©

##### Information Officer:

Susan Ryder, B.A., B.Ed.

## Purple Day Facts

- ★ Purple Day, a grassroots day for Epilepsy Awareness, is celebrated around the world on March 26 each year. In 2013, more than 70 countries – on all continents including Antarctica – participated.
- ★ Sixty-seven epilepsy organizations in 48 countries have become Official March 26 Campaign Partners. These include many IBE and ILAE affiliated organizations. The Purple Day website sees visitors from more than 140 countries around the world. More than 1,500 schools and 1,200 businesses in countries around the world have worn purple to show their support.
- ★ Purple Day founder Cassidy Megan uses social media to connect with people from all corners of the globe. The official Purple Day Facebook page currently has over 27,600 likes; the Purple Day Twitter account has over 1,950 followers.
- ★ In Canada, the federal Purple Day Act became law in 2012. Other governments are following suit; for example, The State Parliament of New South Wales, Australia, and the Scottish Parliament.
- ★ Media coverage of the epilepsy awareness campaign leading up to March 26 is growing every year. More than 250 stories appeared in the media in 2013. Total coverage to date includes more than 750 stories worldwide and hundreds more blog posts and videos.

### Our 2014 Door To Door Campaign

Our 2014 Door to Door Campaign is now taking place. Help your community by making 2014 the best year ever!

It's because of our volunteers and the generosity of those who give even a small donation that we can continue to bring numerous programs and services to individuals, family and friends who are influenced by the effects of epilepsy.



## Disclaimer

*The materials contained in the Epilepsy Newfoundland and Labrador newsletter are to provide general information about epilepsy to the public. The information presented is not intended as medical or legal advice. Epilepsy Newfoundland and Labrador, its employees, board members, medical advisors, volunteers, agents and sponsors do not assume responsibility for inaccuracies or omissions or for the consequences from the use of the information obtained in this newsletter. Epilepsy Newfoundland and Labrador is not liable for any outcome or damages resulting from information in either a direct or indirect form. We recognize that each individual's experience of epilepsy is different. Consult your physician and/or neurologist with any questions you have.*

**People with epilepsy should never discontinue anti-seizure medications or make changes in activities unless specifically advised to do so by an attending physician.**

## Are You In The Mood To Go Shopping?

*Hear what Paula Gale from  
the CBC News has to say!*

My CBC colleague Krissy Holmes is always dressed to the nines! And believe it or not, she gets a lot of her clothes from second-hand stores. Her favourite place to shop for unique vintage finds is Previously Loved Clothes & Things on Kenmount Road in St. John's. One of the nice things about this expansive store is that all proceeds go to pay for programs and services offered by Epilepsy Newfoundland and Labrador. Another nice thing? Unlike some other thrift shops, the prices are very reasonable!

It's so much fun to browse thrift-store racks because you never know what you're going to find. Krissy and I went shopping at Previously Loved this week and picked out a bunch of fun outfits.

*By, Paula Gale Mar 07, 2014*

**Swing On By:**

**Previously Loved♥  
Clothes and Things**

Owned and Operated by Epilepsy Newfoundland and Labrador

351 Kenmount Road, St. John's



To check out the fashions found, go to:

<http://www.cbc.ca/news/canada/newfoundland-labrador/fashionl-vintage-vote>

## Would You Like To Donate Some Of Your Used Items?

Do you have clothes or other items that you no longer love, want or use? Pass them on so they can be loved again! We take clothes of all descriptions for men, women and children, outerwear and footwear for the whole family, household items, small appliances, bedding and curtains, furniture, seasonal decorations, vintage glassware, toys, sporting equipment and unique collectibles!

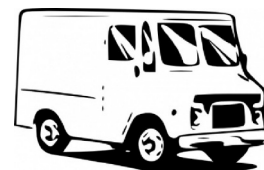


You can donate items in two ways :

Drop them off at our store anytime during business hours at 351 Kenmount Road

Or we would be happy to come pick them up for free in St. John's and surrounding areas!

Call 722-0502 to arrange a pick-up time



## Dravet Syndrome: *A Form Of Developmental Epilepsy*

### WHAT IS DRAVET SYNDROME?

Previously known as severe myoclonic epilepsy in infancy (SMEI), Dravet syndrome is a neurological disorder with onset during the first year in an otherwise healthy infant. Dravet Syndrome develops as the child grows older; symptoms include prolonged, recurrent seizures and a wide spectrum of related problems such as learning disability, ataxia and behaviour difficulties. Outside specialized epilepsy and neurology circles, Dravet Syndrome remains relatively unknown. Scientific understanding of the disorder has improved significantly since it was first described by Dr Charlotte Dravet in 1978. Molecular research shows that mutations in the gene for the brain sodium ion channel, SCN1A, are found in about 80% of children with Dravet Syndrome. These advances mean it is now possible to use genetic testing to help make an early and accurate diagnosis of Dravet Syndrome.

### DIAGNOSING DRAVET SYNDROME

Dravet Syndrome is under-diagnosed. Being aware of the typical features of the syndrome and intervening early to request testing is critical to help reduce the burden of disease and ensure an appropriate treatment plan is in place.

*When to test for Dravet Syndrome:*

SCN1A testing should be considered when an infant presents with first seizure earlier than 12 months, particularly when the medical history reveals:

- **Seizure episodes are frequent**
- **Epilepsy is drug resistant**
- **Seizure pattern changes with age**
- **Modest temperature elevation**
- **Photosensitivity** (may appear)
- **Initial development seems normal**
- **From the second year development problems become apparent**

### WHAT TO DO IF YOU SUSPECT DRAVET SYNDROME

Confirmation of diagnosis is essential. Early diagnosis and effective treatment of Dravet Syndrome makes a huge difference! It saves unnecessary investigations, reduces seizures and may improve long-term outcomes. If you suspect a child or adult is presenting features of Dravet Syndrome, **please refer without delay to a neurologist who has expertise in epilepsy, with a recommendation for SCN1A testing.** Even if the SCN1A test comes back negative, Dravet Syndrome should not be ruled out if the patient fits the diagnosis clinically.



### TREATING PATIENTS WITH DRAVET SYNDROME:

Appropriate and aggressive seizure management, and implementation of tailored anti-epileptic therapies are necessary to improve the outcome of all those affected with Dravet Syndrome.

### INTERDISCIPLINARY MANAGEMENT

Dravet syndrome causes children cognitive developmental impairment- often severe. Multi disciplinary management is required in addition to drug treatment tailored to the specific needs of each patient.

For example, in children, expressive and receptive language is often impaired; early intervention with speech therapy optimizes potential. Ensure developmental assessments begin as early as possible and are repeated regularly.

**For more information go to [www.dravet.org.uk](http://www.dravet.org.uk)**

*DravetSyndromeUK: Brunklaus et al. Brain 2012, JJ Millichap et al. Neurology 2009, Rodda et al. Archives of Neurology 2012, Catarino et al. Brain 2011.*

# Taking Medication On Time

*Taking medications on time and in the prescribed doses allows you to experience the full effectiveness of your medication.* This may be a struggle on a day to day basis for the average working individual since our days are so busy and sometimes hectic. It is easy to get caught up chatting on the phone with a friend, out shopping at the mall or even at the grocery store.

**There are ways taking medication can be made easy!**

- Use A Medication Reminder Watch
- Use a pill reminder App on your phone



Some examples of these are:

- **The Cadex Medication Reminder Watch**

*This watch has twelve daily reminders that can be programmed. At scheduled time, the alarm will sound and display the name of the medication to be taken. A 'snooze' feature allows you to turn off the initial beeping and continue to be reminded with subtle double beep every 3 minutes until you have taken the medication. This product can be found on the website [www.cadexproducts.com](http://www.cadexproducts.com)*

- **MediSafe Meds & Pill Reminder (Android)**

*This app can be downloaded for free. MediSafe is a visual and easy-to-use pill reminder and medication management app. It will help you take your medicine on time and safely. It also allows you to help your family members with their pills.*

Take A Moment...

Copyright 2006 by Randy Glasbergen.  
www.glasbergen.com



"I'm inviting you to my seminar on Improving Your Communication Skills. If you'd like to attend, grunt once for yes or twice for no."

"Office Maintenance? Could you send someone up to the 9th floor to adjust my attitude and install more patience?"

Don't Worry Be Happy..

Cross out six letters and you will find a word that we should know.

**SBAIXNLETATNERSAS**

Answer is on page 6

"For every minute you are angry, you lose sixty -seconds of happiness"

PERCOCET



"Being happy doesn't mean that everything is perfect. It means that you've decided to look beyond the imperfections"

-Unknown

## In Memoriam Cards

In many of the funeral homes within our province, you will find our In Memoriam cards.

These cards give anyone the opportunity to make a contribution to Epilepsy Newfoundland and Labrador in remembrance of a loved one.

If you would like to make a donation in memory of someone you know or if you would like to receive some of our In Memoriam cards please feel free to contact Epilepsy Newfoundland & Labrador at:

**709-722-050**

**OR 1-866-EPILEPSY**

**info@epilepsynl.com**

*"When someone you love becomes a memory, the memory becomes a treasure"*



## Find Us on Facebook

**Are you one of the over 400 million people on Facebook?** If so, check us out! Our facebook page has all the latest and greatest from Epilepsy Newfoundland and Labrador.



Event pictures, upcoming events, current happenings, bits of news, and medical alerts are some of the things you will find on our corner of the Facebook world.

If there was ever a place to stay up to the minute with ENL, this is it! Just type [www.facebook.com/epilepsynl](http://www.facebook.com/epilepsynl) into your browser and you are sure to find us.

Or go to our website and click on the Facebook "Like" button on our front page.

**Answer to Brain Teaser:**  
**Bananas. The letters you needed to cross out were (S-I-X-L-E-T-E-R-S)**

## I Would Like To Help in the Fight Against Epilepsy

- ☐ I am enclosing a donation of \$\_\_\_\_\_
- ☐ I would like to become a member of Epilepsy NL. I am enclosing my \$5.00 membership fee.
- ☐ I would like to become a volunteer. (We can use volunteers from right across the province)

Name:

Email:

Address:

Phone:

Would you prefer mail-outs by email or postal mail?:

**To pay by credit card please call 1-866-EPILEPSY or complete the following:**

Account #

Type of card:

Expiry:

Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9