

Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Summer 2014

March Month Awareness for Epilepsy Was A Success!

Purple Day

On March 26th, 2014 the province of Newfoundland and Labrador celebrated *Purple Day for Epilepsy* once again and we are proud to say that over **8000** people participated! The highest number of participants thus far and hopefully this will continue to grow more each year!

Many dressed in purple, wore ribbons, wristbands, shared information, donated their spare change, sold cupcakes and more! We would like to thank all of those who participated in Purple Day. On behalf of the 10,000 people in our province living with epilepsy, thank you for creating awareness and being a part of something so special.



Door To Door Campaign

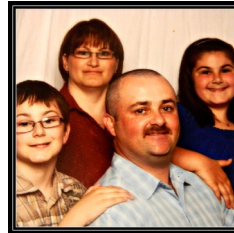
Our door to door campaign went very well thanks to all of the volunteers who participated throughout the province during our March month awareness for Epilepsy.



Special Thank-you's



A huge thanks to **Cassie Singleton**, from *Clareville, NL* for being our *Purple Day Ambassador* this year. Thank you for your dedication during March month awareness and especially for sharing your story with others in our very own province.



A special thank you to **the Edmunds family** from *Coley's Point, NL* for all of your hard work and dedication in supporting *Purple Day* and the *Door to Door Campaign*. You made March month awareness for Epilepsy a very successful and special one this year.

Thank-you to **Pam Van Horn** from *Burgeo, NL* for going above and beyond in the *Door to Door Campaign 2014* and supporting Epilepsy NL during March month awareness. You have made a difference.

Thank-you to **Dr. Ogunyemi & Dr. Buckley** for taking part in our *Ask The Doctors- Question and Answer Forum*. This event continues to be a success because of you.

"We are all like one-winged angels. It is only when we help each other that we can fly."

-Luciano de Crescenzo



Visit our Website and Facebook Page for more photos of Purple Day 2014!

www.epilepsynl.com
<https://www.facebook.com/EpilepsyNL>



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.

Do you or a loved one have seizures?

**Epilepsy NL will be
holding a Social Night!**



Thursday, June 26th, 2014

7:00 - 9:00pm

351 Kenmount Road

St. John's, NL

Space is limited.

To confirm your attendance
please call:

(709) 722-0502

or 1-866-EPILEPSY

email: info@epilepsynl.com

For those of you living with seizures or have a loved one living with seizures, as well as friends, family, and supporters. Come and hear about what we do at Epilepsy NL, then chat with other people whose lives have been impacted by seizures and epilepsy. **There is no charge for this group event.**



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.

Come Visit Us For Some Summer Styles!

The weather is warming up but we never know how long our summer will be here in NL!

Why spend money on a costly summer wardrobe when you can come to Previously Loved Clothes and Things to get more for less?



You never know what you may find!

Swing On By:

**Previously Loved♥
Clothes and Things**

Owned and Operated by Epilepsy Newfoundland and Labrador

351 Kenmount Road, St. John's



Do You Have Time To Chat?

Now that the sun is shining and we are on the move for summer, why not drop by Epilepsy NL for a chat?

Here at Epilepsy Newfoundland & Labrador our information officer is here to provide information, support and help in any way possible for the people in our province who are living with epilepsy or affected by seizures in some way. If you live outside of St. John's but are planning a trip here soon, we can arrange a time during your visit!

Come by to learn more about epilepsy or just to talk!

We would love to see you!

Call today to book an appointment @722-0502



"When Everything Feels Like An Uphill Struggle...."

"When everything feels like an uphill struggle, just think of the view from the top."

Anyone who has accomplished a personal goal will have realized how empowering it can be. It can go a long way in furthering your focus in all aspects of your personal and professional life.

Following university I had the common goals of all new graduates. Things were progressing according to plan until a hurdle in 2001 at the age of 28. I developed epilepsy with frequent, unpredictable seizures.

After multiple trials of medication and eventually brain surgery, my seizures were greatly reduced. I felt very fortunate but still struggled with my restrictions. I felt protected and dis-empowered, while my need for independence and adventure grew stronger.

Finally it became clear I had to shift my perspective. My restrictions were simply obstacles that could be overcome. It was time to get out of my comfort zone. I set a personal goal to travel to a far away place alone, and take on an adventure that would test my limits like nothing I had done before. In the end I was going to climb Mount Kilimanjaro. Towering 19,341 feet above sea level, it is the highest point in Africa.

Next was to commit to a deadline. It would be before the year ended in October 2013. I contacted a Tanzanian outfitter who set me up with a group of climbers who welcomed me into their team. I immediately felt exhilarated, focused and in control.

I continued down my list of steps to achieve my desired outcome. I searched the web for the gear I would need, studied the country and mountain, consulted a local expert and physically prepared myself to take on this adventure.

As the time got closer to the trek I felt prepared and confident but still apprehensive. I'd be traveling to a remote place alone, no experience climbing at high altitude, no idea who I'd be climbing with or their experience level. But this was all a part of the challenge.



The day finally arrived and although uneasy as my husband and son said goodbye, I felt an incredible sense of empowerment. I was headed to Tanzania to climb the tallest free-standing mountain in the world.

Seven days after commencing the climb and with no contact with anyone at home, I emailed my husband a photo. It was me on the summit, I had accomplished my goal. I was proud not only of my perseverance to get to the top, but of the many steps I had taken to start this journey.

It still pleases me whenever my son asks questions about my climb as we go for walks in the woods. I relish every opportunity to share my enthusiasm for adventure with him. Some valuable lessons can be taught outside the classroom and away from the comforts of home.

We all know how easily we get caught up in the whirlwind of our busy schedules. Personal goal setting can drive you forward making the very most of your life. Deciding what you really want is always the first step. Set a plan in action and as they say, "a goal without a deadline is only a dream".

People often ask me what's next. I enjoy reading a quote each day that's aimed to motivate. This one I picked up from the famous Dr. Seuss in one of his later children's books, ***"You're off to great places! Today is your day! Your mountain is waiting, So...get on your way!"***

I am ready for a harder challenge. The funny thing is that once you accomplish something big, you can look back and wonder just why you thought it was difficult to begin with!

By, Debbie Byrne

***Thank you Debbie,
for sharing your
fabulous story.
You are a great
inspiration for all!***



Take A Moment...

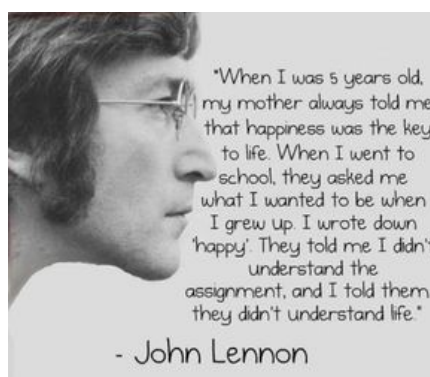


Know the answer?



(Answer is on page 6)

Just A Little Inspiration...



Public Consultation On Approach To Drug Shortages: **We Need Your Help!**

Health Canada is holding a public consultation on the approach to drug shortages from, **May 22 to July 5, 2014.**

The Canadian Epilepsy Alliance encourages everyone concerned about drug shortages to participate. We need your help to make the change we have been aiming for.



Many people's first introduction to drug shortages is hearing their pharmacist say **"your medication isn't available"**. This shocking news comes out of the blue with little time to seek solutions. Suddenly switching treatments is not advisable for people with epilepsy. Drug changes should be made gradually and preferably not at all if a medication is working well to control seizures.

Drug shortages have put people in the untenable situation where they have had no choice but to suddenly switch to a different drug.

Over the past five years there have been an increased number of drug shortages in Canada, including multiple shortages of epilepsy medications. There is no indication that the situation is improving. If nothing is done to identify and address the causes of drug shortages we expect to see a greater frequency of supply disruptions in the coming years.

Even though a website has been established where pharmaceutical companies can voluntarily report shortages (drugshortages.ca), the reality is that most people still learn about a drug shortage when they **need** their prescription refilled and the drug is not available. Often patients are still the first to inform health care providers about a drug shortage.

Who can participate in the public consultation?

The public consultation on drug shortages is open to anyone who would like to participate. If you are concerned about drug shortages, **this is your chance to share your opinion with the Government of Canada.**

Estimated time to complete the consultation:

Health Canada estimates it will take about ten to twenty (10 to 20) minutes to complete the consultation.

Different ways to participate in the public consultation:

A. Complete the consultation online. Go to the public consultation information page and click on the "PARTICIPATE NOW" button to answer the questions online. (Link below)

www.hc-sc.gc.ca/dhp-mps/consultation/drug-medic/consult_shortages-penuries-eng.php

B. Download a copy of the consultation document to your computer and send your responses by email or regular mail. (Pdf document to download below)

http://www.hc-sc.gc.ca/dhp-mps/alt_formats/pdf/consultation/drug-medic/ds-consult-public-publique-eng.pdf

Once you have answered the questions your saved file can be sent by email OR the file can be printed and sent by Canada Post. (See below)

Email: ds_pmconsultation@hc-sc.gc.ca

Mail:

Attention: Drug Shortage Consultations
Strategic Horizontal Policy Division
Health Products and Food Branch, Health Canada
250 Lanark Ave, 4th Floor, Address Locator: 2004D
Ottawa, ON, K1A 0K9

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:

709-722-0502
OR 1-866-EPILEPSY
info@epilepsynl.com

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



Find Us on Twitter

Epilepsy NL now has a Twitter page!

Find out what is happening here at Epilepsy Newfoundland and Labrador on a regular basis by checking in with us on Twitter!



Follow us today **@EpilepsyNL**

There are Ben's legs plus the four table legs.

Answer to Brain Teaser:

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