



Epilepsy News

Serving the people of Newfoundland and Labrador for over 25 years!

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Winter 2012

Ask the Doctors - A Question and Answer Forum

Have epilepsy questions you have always wanted to ask an expert?

Want to share the stories and experiences of others who struggle with epilepsy?

WE HAVE YOUR OPPORTUNITY!

On **Thursday, March 22nd**, Epilepsy Newfoundland and Labrador will be hosting our annual province-wide **Ask The Doctors** Forum on Epilepsy. Once again we are very pleased to have two of this province's foremost authorities on epilepsy and seizures:



Dr. A. Ogunyemi,
Epileptologist

and

Dr. D Buckley,
Pediatric Neurologist

Come join two of Newfoundland and Labrador's most knowledgeable neurologists on epilepsy and seizure disorders, in a province-wide Question and Answer Forum. Ask Dr. Ogunyemi and Dr. Buckley the questions that are important to you, and find out even more about epilepsy.

**Participation is open to anyone in the province.
REGISTRATION FOR THIS EVENT IS FREE**

This will be our 23rd year for this event. During all that time, there have been so many thought provoking questions, with something new to learn each year.

Participants are welcome to ask questions pertaining to their specific circumstances, or more general questions. Some past questions have included:

- How to better manage the side effects of AEDs
- Memory loss and epilepsy medications
- New research and treatments for seizures
- Pregnancy and epilepsy
- SUDEP - risk factors
- and countless others.

Don't feel comfortable speaking up? No problem! Just by listening to the other questions, you can learn a great deal that might help you too.

If you live in St. John's and the surrounding areas the conference will be held on March 22nd at 7:00pm, at the new Epilepsy NL Building, 351 Kenmount Road (next door to VOCM Radio).

If you live outside of St. John's, we are pleased to be able to include everyone in the province who wishes to participate in this annual forum via teleconference. If you have access to a phone, you can join us!

Make sure you don't miss out. **Please register in advance** to save your place.

For more information or to register, contact
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Epilepsy Newfoundland and Labrador
(709) 722-0502 or toll free at 1-866-EPILEPSY
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On My Mind

Do you Tweet? Nearly everyone I know does it. Twitter is huge, and I will confess that I do have an account there, but for me it's never been that big of a draw. Reading the random thoughts of friends and celebrities in small 140 character sentences seems so shallow, and so detached.

Perhaps that's why we find so much negativity on places like Twitter, Facebook, chat rooms, and blogs all over the internet - because of the detachment. Not to mention the anonymity. It seems people can say any hurtful thing they want these days as long as they are behind the security of their computer monitor.

Recently on the Health Day website I read this:

In a study published in the February issue of Epilepsy and Behavior, Canadian researchers analyzed nearly 11,000 seizure-related "tweets" and deemed 41 percent of them as offensive. The study authors pointed out that the messages on this social networking service could reinforce negative perceptions of the neurological disorder.

41% of the tweets about epilepsy were offensive. That number floored me.

It's time we all stepped up against this sort of negativity. No matter if you are on Facebook, Twitter, or in line at the grocery store, if someone is making insulting or derogatory comments, say something.

We don't need to be confrontational about it, but by offering the truth of epilepsy, what life is really like with seizures, we can begin to change attitudes.

Pamela Anstey, Information Officer

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-epileptic medications or make changes in activities unless specifically advised to do so by an attending physician.

Welcome to Our New Home!

Epilepsy Newfoundland and Labrador has grown to serve the people of this province better than ever before.

As of January 2012,
**Epilepsy Newfoundland and Labrador and
Previously Loved Clothes and Things**
have moved to their brand new building at
351 Kenmount Road!

We're right next door to VOCM and only three doors away from the Kelsey Drive intersection. There's also a Metrobus stop right in front of our parking lot.

It's been an amazing change! Our thrift store, **Previously Loved Clothes and Things**, is now much bigger. Lots more space means lots more bargains every day of the week. And because we are a charity, everything is always tax-free.

Epilepsy Newfoundland and Labrador is upstairs in the fully accessible building. We now have a conference room for events like our upcoming Ask The Doctors Forum, as well as a library, where visitors can browse epilepsy information, watch a video, or borrow a wide variety of books on the different aspects of seizures.

Come visit us and have a look for yourself.



Christmas Tea for Epilepsy

The 2011 - 12

Christmas Tea for Epilepsy!

Our Christmas Tea for Epilepsy has wrapped up for 2011. It was nice to see so many familiar faces once again. Businesses, individuals and organizations were all very supportive of our project, touted as the most relaxing fundraiser ever.

Not surprising considering all participants had to do was sit back, relax, and enjoy a cup of tea on us, any time during early December.

We provided the tea, goodies, information about seizures, and a special surprise, and they provided the good will, community spirit, and a donation to help support the programs and services of ENL. It was that easy.

Again this year, we are very grateful to Tetley, who donated 10,000 individually wrapped teabags to start the program off right.

We also have to extend special thanks to Costco Bakery, who generously provided most of the sweet treats and goodies that filled our Christmas baskets.

All in all it was a great success, as you can see by the number of community minded people who supported this cause. We thank each and every one of you for doing your part. With just a cup of tea, you have made a difference.

Sit back, relax, enjoy your tea, and think how different your life would be if I were you, and you were me, and you were the one with epilepsy.

Hall of Fame 2011-12

Our Most Flavorful Sponsors




The Benevolent Bakers (In-Kind Cookies and Treats Donations)

Purity Factories

Marie's Bakery

Our Grand Givers (\$500 and up)

Husky Energy

The Tea Masters (\$100.00 donations and up)

Barrett's Funeral Home
BMO Water Street
E. Nofall & Friends
Penney Mazda
VOCM Cares

MUNN Insurance
Adjusters Inc.
The Telegram
Scotiabank - Water Street
Scotiabank Centennial Sq

The Tea Specialists (\$50 and up)

BMO - Elizabeth Ave
Cox & Palmer
St. Pat's Mercy Home

Scotiabank - Eliz. Ave. E
AON Risk Services
TD Bank - Water St.

City of St. John's Finance Dept.

The Tea Apprentices (Donations up to \$50)

Scotiabank - Cornwall
Scotiabank - Paradise
ProActive - Kelligrews

ProActive - Atlantic
ProActive - Aberdeen
ProActive - Mt. Pearl

City of St John's Engineering & Planning

Epilepsy Awareness Month - Our Biggest Ever!

March is here and that means Epilepsy Awareness Month in Newfoundland and Labrador. This year, it's bigger than ever!

We have so many things happening; from hopping bunnies to quizzing doctors, we're working hard to get the word out, and to let anyone who lives with epilepsy know that they are not alone.

Purple Day Bunny Hop

We're turning the province's pre-schools purple with our Any-Bunny can Have Epilepsy Purple Bunny Hop.

Daycares and Preschools all over the province have been invited to hop along with us on Purple Day in support of Epilepsy Awareness.

Every 'bunny' that hops for Epilepsy on Purple Day will be eligible to win prizes, and everyone who participates will get information all about seizures.

Positively Purple Schools

We're sending out the call to all schools, inviting them to become one of our Positively Purple Schools for Epilepsy. Invitations have gone out to every school in the province and we want to see a province of purple from coast to coast!

2011 saw several schools show their purple with events and activities to bring awareness to their school about what life is like with seizures. It was awesome! If your school hasn't signed on yet, it's not too late. We can rush all the information, handouts, and fun bits to make your school a Positively Purple School for Purple Day 2012.

CNA Graphic Design

Partnering with Metrobus City transit, and the College of the North Atlantic, again this year we have challenged students in the Graphic Design program to develop bus shelter ads that would give people pause to consider what living with seizures might be like.

In its sixth year, this awesome, yet friendly competition gives first year students the opportunity to work on a real-life business project, and a chance for Epilepsy NL to showcase some amazing talent.

Paint the Province Purple

Last year, communities all over NL either proclaimed March 26th as Purple Day for Epilepsy within their town, or participated in some sort of event to commemorate the day. As well, lots of businesses, and workplaces also got involved, with their staff decked out all in Purple and offering information, and treats for all who stopped by.

This year we're working even harder to Paint the Province Purple by encouraging our MHAs, MPs, municipalities, businesses, and workplaces to be active supporters. Wear Purple on March 26th, light up your town hall with purple lights, or participate in any creative way you choose.

The Perfectly Proper Purple Day Tea

Keep your eyes peeled at your favourite store, doctors offices, dentists, and pretty much any place that people gather for the Perfectly Proper Purple Day Tea (best said in a fancy voice!)

What is the Perfectly Proper Purple Day Tea? It's really very simple. All over the province we are placing baskets of individually wrapped Tetley Tea, inviting people to take one or two home with them, then sit and enjoy a cup of tea on us, anytime on March 26th.

Purple Day

Founded in 2008, by nine-year-old Cassidy Megan of Nova Scotia, Canada, Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th, people from around the globe are asked to wear purple and spread the word about epilepsy.

*Join with us in turning the province purple on **Purple Day!***

On Monday, March 26th, wear purple and encourage others to do the same. (Let us know and take pictures!)



Residential Energy Efficiency Program

Newfoundland and Labrador Housing Corp. (NLHC) is now accepting applications for the Residential Energy Efficiency Program. The program is designed to assist as many as 1,000 homeowners with low incomes carry out retrofits to their homes for improved energy savings this year.

"The Residential Energy Efficiency Program has had excellent results with respect to improving energy efficiency of houses," said Tom Hedderson, minister responsible for NLHC. "This program is one of several that make it possible for homeowners with low incomes to upgrade their homes, in ways that make them more affordable in the long term."

Assistance will be available in the form of a grant of up to \$3,000 per household on the island and up to \$4,000 per household in Labrador. NLHC will provide funding for energy audits at the homes of successful applicants by an independent energy advisor.

The province allocated an additional \$12 million in its 2011 budget to extend this program for three years. Applications will be processed in the order in which they are received to a maximum of 1,000 applications each year.



Homeowners whose annual household income is \$32,500 or less are eligible to apply.

The program was run as a pilot project for two years. During this period, about \$7 million in grants enabled 2,000 homeowners to make retrofits. The province says this resulted in an average household

energy savings of 35 per cent and cash savings of nearly \$800 a year.

Applications can be downloaded from www.nlhc.nl.ca, or can be attained by calling 709-724-3132 or 709-724-3211 or toll-free, 1-866-331-3436.

Applications are also available at regional NLHC offices, or feel free to contact ENL at 1-866-EPILEPSY for assistance.

Added Safety for Those Who Live Alone

Most of us at some point over the years have seen, or at least heard of, personal alarms that can contact emergency services at the push of a button in case of a medical crisis. These devices can be excellent for people living alone who might need help but be unable to get to the phone.

However, it's hard to push a button when you're in the midst of a seizure.

Enter the **Philips Lifeline** with **Auto Alert** option.

This new bit of technology that goes one step beyond most personal alarms and adds something that's been lacking for people with epilepsy - the ability to call for help even if you are unconscious.



From their website:

AutoAlert offers all the benefits of our Standard Lifeline Medical Alert Service - push the button for help at any time - plus an added layer of protection: Lifeline with AutoAlert is the only pendant-style help button that can automatically place a call for help if it detects a fall and you're unable to push the button yourself.

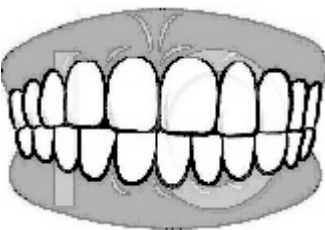
How cool is that?!

The service is a subscription service, meaning that there is a monthly fee, but for people prone to convulsive seizures, it could mean that added reassurance that help is never far away.

To learn more and find out if Lifeline might work for you, call them toll free at 1-866-784-1992.

New Adult Dental Program Announced

The provincial government's new adult dental program, which will provide enhanced diagnostic and therapeutic dental services to about 98,000 adults, became effective Jan. 1, 2012.



Health Minister Susan Sullivan says dental health is often linked to a person's physical and mental well-being and now the expansion of the province's dental health plan will ensure that more residents, who have difficulty availing of regular dental services, will have the ability to access proper dental care.

The new program includes examinations, extractions and fillings, as well as dentures.

The program will be available to clients who are enrolled in Newfoundland and Labrador Prescription Drug Programs.

Joan Burke, minister of advanced education and skills and lead minister for the poverty reduction strategy, said the adult dental program is a key example of a poverty reduction strategy initiative that will significantly improve the quality of life for people in vulnerable circumstances.

"This investment directly responds to requests received during our poverty reduction consultations, and will further our fight against poverty to help ensure all citizens have an opportunity to succeed and prosper," Burke said.

Information packages on the new adult dental program have been sent to all dentists and denturists in the province. The provincial government says it continues to work to address the current fee guide for dentures.

Clients who choose a provider who has not yet been registered under the plan may have to pay up front for their eligible services and then be reimbursed, at the province's approved rates.

"We recognize this may place a burden on some individuals," said Sullivan. "However, our government is working toward providing a solution that will hopefully see all providers participating in and billing the plan directly in the near future."

Residents with questions regarding their eligibility can call 1-888-859-3535. Beneficiaries seeking further information on eligible services and whether their provider is registered and/or how to submit receipts for reimbursement can call 1-800-563-2163.

2012 Door to Door Campaign

We Need Your Support!

Our 2012 Door to Door Campaign is underway across Newfoundland and Labrador.

With the help of many generous and caring people just like you, I am sure that this year will be a resounding success once again.

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.

Will you give just a little time to help? If so, perhaps you could collect a street or small area in your hometown, or perhaps you would be willing collect among your friends and family?

If you are able to offer even an hour or two of your time, please call. You can reach me at 722-0502 or toll free at 1-866-EPILEPSY (374-5377).

Elaine Pottle

Campaign Coordinator



ENL Scholarships

Each year ENL offers scholarships to post secondary students with epilepsy to assist them with continuing their education and pursuing their dreams.

The Zach Rowe Memorial Scholarship

The **Zach Rowe Memorial Scholarship**, valued at \$1000 is awarded to a student with epilepsy who will be continuing on to Post Secondary studies after High School. It honours Zach Rowe, recipient of the ENL scholarship in 2006, who passed away as a result of his seizures in 2009. Because of fundraising efforts of Zach's family and friends, this year we were able to offer Zach Rowe Memorial Scholarships to two very deserving students.

This year's first recipient is **Luke Nofall** of St. John's. Luke is currently studying at Memorial University hoping to pursue some branch of therapy. Since his epilepsy diagnosis in 2005, it's been a roller coaster ride for Luke and his family; one that included multiple types of seizures, brain surgery, and an outpouring of support from everyone who knew him.



Luke Nofall being presented with his scholarship
by Zach Rowe's mother Janice

Before my first seizure, I was a good student with a great social life. I was a competitive swimmer and played on my school soccer and volleyball teams. [After my diagnosis] my doctor tried many medications, but I continued to have seizures and side effects from all the medications. I started failing academically, I

was forced to give up all my sports, and I lost most of my friends. In January of 2008 I travelled to Sick Kids Hospital in Toronto where I underwent a major brain resection. I had three brain surgeries in five days. After the surgeries, my seizures continued. I spent months working with therapists, and had to repeat Grade 10. I worked hard and things slowly improved. I am happy to say that I continue to improve and am now two and a half years seizure-free.

This year's second recipient of the **Zach Rowe Memorial Scholarship** is **Allison King** of Victoria. Allison is attending the College of the North Atlantic in Carbonear. Allison was diagnosed with Epilepsy at age 12, and says it has had a significant effect on her teen-age years. Like far too many people with Epilepsy, Allison was bullied by others who had no true understanding of what seizures were all about. She also felt restricted in what she could do, and avoided sporting activities as a result of her seizures.



Allison King being presented with her scholarship
by Zach Rowe's mother Janice

Allison has a personal connection with the Rowe family. As the scholarships were awarded, we learned that Allison's brother and Zach had been very close friends. With Allison now being awarded a scholarship as Zach did in 2006, the moment was made even more touching.

The Jim Hierlihy

Memorial Scholarship

We also awarded our annual **Jim Hierlihy Memorial Scholarship**, which is valued at \$1000. This honours a mature student with epilepsy who has taken the initiative to return to studies to advance in their present job or train for a new career.

This year's recipient is **Mona Earle** of St. John's. Mona is currently studying Geomatics Engineering at College of the North Atlantic with the goal to become a surveyor or hydrographer. Despite being diagnosed with Epilepsy in 1993, Mona is involved in numerous volunteer and charitable activities focusing on construction and re-development, both here at home, as well as in New Orleans.



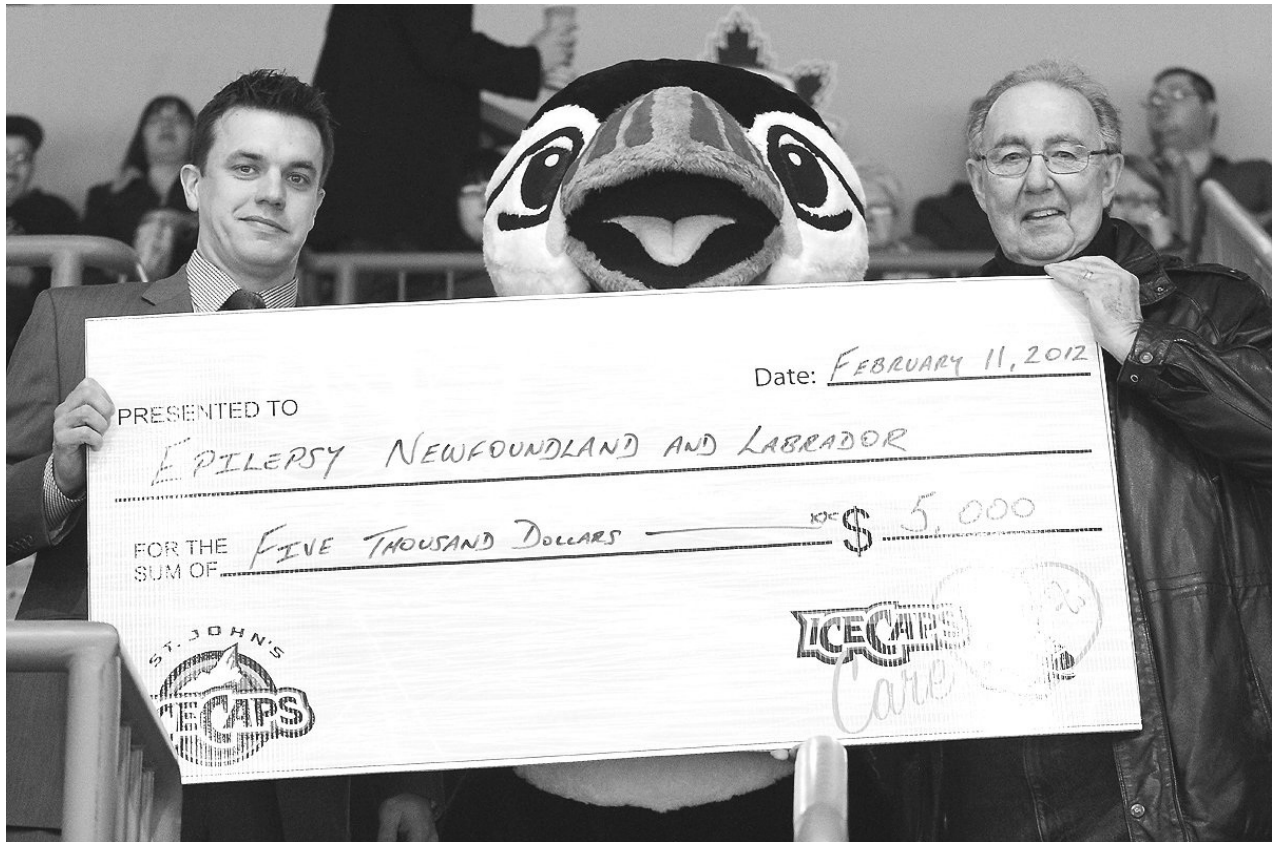
Mona Earle, accepting her scholarship from
ENL President Ron Stone

I was diagnosed with epilepsy when I was 13. It was a difficult time for me. I was young and scared. Having a seizure always terrified me. I felt that there was this power inside of me that I wasn't in control of; that my body could become hijacked at any time and there was nothing I could do

about it. I often cried to my mother, asking when it would stop. It took another couple of years for doctor's to find the correct medication for me. I realize that, for me, it's about not allowing any type of 'affliction' to interfere with your life, how I've not only overcome, but also excelled in many of the things I wanted to accomplish for my life, and it's not over!

Epilepsy Newfoundland and Labrador takes great pleasure in extending our sincerest congratulations to Luke, Allison, and Mona.

A Little Time Out



Epilepsy Newfoundland and Labrador was honoured to be a recent recipient of a \$5000.00 donation from the St. John's Ice Caps Care Foundation.

Shown here, ENL President Ron Stone ® accepts the cheque from the Ice Caps Care Foundation, with the assistance of Buddy the Puffin. (February 11, 2012)



A lady was picking through the frozen turkeys at the grocery store, but couldn't find one big enough for her family.

She asked the stock boy, "Do these turkeys get any bigger?"

The stock boy replied, "No, ma'am, they are dead."

A large family, with seven children, moved to a new city. They were having a difficult time finding an apartment to live in. Many apartments were large enough, but the landlords objected to the large family.

After several days of searching, the father asked the mother to take the four younger children to visit the cemetery, while he took the older three to find an apartment. After they looked most of the morning, they found a place that was just right.

Then the landlord asked the usual question: "How many children do you have?" The father answered with a deep sigh, "Seven...but four are with their dear mother in the cemetery."

The landlord, feeling sympathetic towards the man's situation, rented the apartment to him.

Email or Postal Mail?

Help us, and help the environment too! Here at ENL, one of the greatest expenses we have is postage. Because of this, and in the interests of being as environmentally friendly as possible, we want to offer our members the option of receiving newsletters and notices by email instead of postal mail.

Privacy is not a concern.

Nobody else will see your email address. And we would never make our email or mailing lists available to anyone else.

If you wish to sign up for e-mail communication from us, just drop us a line at info@epilepsynl.com. If you ever want to change back, just let us know and we will be happy to do so.

If you don't have e-mail, or don't want to receive email newsletters and notifications from us, you don't need to do a thing. We will continue to send you your information through postal mail like always. Have questions? Call us at 1-866-EPILEPSY



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 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.

"People are very open-minded about new things... as long as they're exactly like the old ones."

~Charles Franklin Kettering~

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:
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Address:

Phone:	Would you prefer mail-outs by email or postal mail?:
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If you would prefer to pay by credit card, please complete the following:

Account #	Type of card:	Expiry:
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Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9