



Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Fall 2010

A New Hope for Control

Health Canada recently approved Vimpat™ (lacosamide), a new antiepileptic drug. It is indicated for use as adjunctive therapy in the management of partial onset seizures in adult patients 18 years of age and older who are not satisfactorily controlled with conventional therapy. "Vimpat™ is an innovation in epilepsy therapy and has been shown to work effectively in conjunction with a broad range of existing treatments," says Dr. Fred Andermann, Professor in Neurology and Pediatrics, McGill University, and Epileptologist, Montreal Neurological Institute and Hospital. "Vimpat™ is an important consideration for use by physicians and their adult patients with partial onset seizures who are still uncontrolled despite their current treatment."

Controlling Partial Onset Seizures

Partial onset seizures are one of the most common types of seizures experienced by patients with epilepsy. Up to one-third of Canadian patients do not have seizure control.

"After almost a decade, we are thrilled that there is a new treatment for people with epilepsy in Canada," says Gail Dempsey, President, Canadian Epilepsy Alliance. "Lack of seizure control severely impacts independence, productivity, and overall quality of life for Canadians living with epilepsy. These individuals and their families deserve better, and we're so pleased that patients now have a new option in Vimpat™."

Epilepsy and Quality of Life

Lack of seizure control severely impacts independence, productivity and overall quality of life for Canadians living with epilepsy. The disorder can cause significant challenges, including difficulty finding employment, loss of driving privileges in some Canadian provinces, cognitive decline and memory impairment, and higher mortality rates. People living with epilepsy also live with a significant social stigma associated with seizures.

New Way of Targeting Pathways

Preclinical studies indicate that Vimpat™ has a novel mode of action. While the precise way in which Vimpat™ exerts its antiepileptic effect in humans is unknown, in preclinical studies Vimpat™ has been shown to modulate sodium channel activity differently compared with other sodium channel blocking AEDs.

Sodium channels play a crucial role in regulating the activity of the nervous system to help nerve cells communicate. Sometimes sodium channels become abnormally overactive which may produce a seizure. Vimpat™ is thought to reduce this sodium channel over-activity, which may contribute to the control of seizures.

Improved Seizure Control

The approval of Vimpat™ was based on efficacy and safety data from three multicentre, randomized, placebo-controlled clinical trials with approximately 1,300 people with epilepsy aged 16 and older who had uncontrolled partial-onset seizures. Before adding Vimpat™, patients experienced a median baseline seizure frequency ranging from 10 to 17 seizures per month, despite being on one to three other AEDs. In the trials, patients randomized to Vimpat™ experienced reductions in median seizure frequency and had their seizures reduced by half at rates that were significantly greater than those in placebo groups. The most common adverse events (>10 per cent and greater than placebo) reported in these trials included dizziness, headache, nausea and diplopia.

Vimpat™ demonstrated efficacy and was generally well-tolerated when combined with a broad range of existing AEDs. (UCB Canada press release, November 11th, 2010)

To learn if Vimpat™ might be right for you, talk with your doctor or Neurologist.

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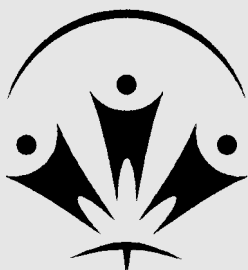
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On My Mind

"If your dog doesn't like someone you probably shouldn't either."

- Unknown

Compared to larger places, we don't have a lot of people with service dogs in Newfoundland and Labrador. So to see someone with one is a little rare.

Rarer still are seizure response dogs. But that doesn't mean we don't have them. I know of three just off the top of my head.

So then why is it in our informed age, that people still assume that someone with a service dog is either visually impaired, or faking it.

One of our members told me that frequently, when she is out with her dog she gets hassled. People refuse her access to stores, she's been kicked out of restaurants, and passers-by continuously give her very odd looks - UNLESS she just happens to be wearing her sunglasses, then she gets no bother at all.

We must stop assuming that we know everything about someone just because of the furry four-legged helper at their side. There are so many kinds of service dogs these days, dogs for people who are differently-abled, dogs for people with impaired hearing, dogs for people with epilepsy, dogs for people with autism, and yes, dogs for people with visual impairments.

Service dogs can provide an enormous amount of freedom and security that a person might not otherwise be able to achieve. To stand in the way of that gained freedom would be especially hurtful. If you know of someone with any type of service dog in your town, make sure that your community is a welcoming place for both the two-legged, and the four-legged.

Pam

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.

A Rare Breed - Seizure Response Dogs

(from the Lions Foundation Dog Guides Fact Sheet)

Although some dogs do learn to detect seizures before they occur, it is not known how and why some dogs seem to have this ability. It is not known if the dogs react to a chemical or physical change in the person before an epileptic episode.

Seizure Response Dogs are trained to **react** to the seizures and are unable to predict them. These Dog Guides are trained to react to the person's physical cues (dropping, convulsions etc) once the seizure has started and to get people's attention by barking. Here are some frequently asked questions which might help you decide if a Seizure Response Dog Guide is right for you or not.

1. Can the dog prevent me from walking towards dangerous areas (traffic, stairs, pools, etc)?

- Dogs do not have the same concept of danger as humans, so our dogs are trained to heel (follow) with the person who is holding the leash. The dog has no way of knowing if you are crossing the street voluntarily or involuntarily.

2. Will the dog be able to prevent me from falling or help break my fall?

- No. As the dogs are not trained to detect seizures before they occur, they are not able to predict a fall. It can also be dangerous to the dog's health to be trained to break a person's fall.

3. Can the dog leave my side to go get help?

- Yes, but only inside. Our dogs can be trained to get a person on command but this skill can only be used inside your home. The dog can get a family member who is in a different room/floor if you are not feeling well. The dogs will not be able to get help when you are in an outside area. This is because dogs do not have the same concept of danger that humans do, and could potentially be injured if they had to cross a street looking for a person to help.

4. What types of seizures are the dogs trained to react to?

- Tonic clonic (Grand mal) and Atonic seizures (drop attack) are two types of seizures that we train our dogs to react to. The person falling and/or convulsing is the dog's cue to start barking and do so until the person's seizure has subsided, or someone comes to offer assistance. Absence seizures (Petit mal) are seizures that the dogs will not react to due to the lack of obvious change in behavior. Depending on the person, we train the dogs to react to obvious cues; dropping, convulsions, etc. As explained in question 1, we do not train the dogs for walk away seizures.

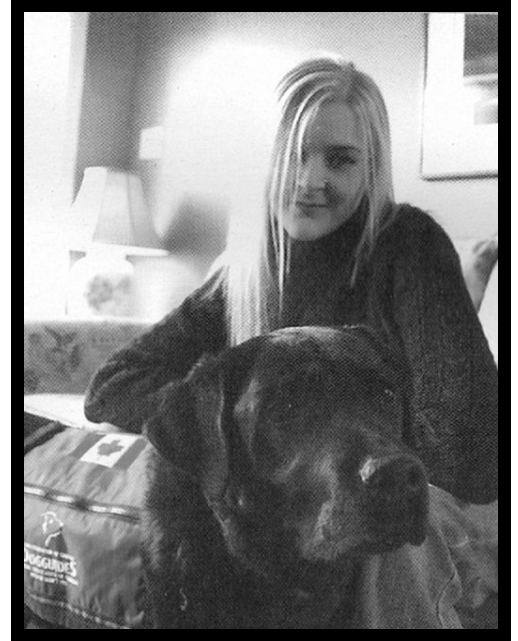
5. Can the dog take me home after a seizure if I'm confused and disoriented?

- The dog is trained to follow you, not guide you. Dogs do not have the cognitive ability to safely guide their handler home.

6. Will the dog protect me if someone with ill intentions was approaching me during a seizure?

Our dogs are trained to not have any form of aggression towards people as they will be out and about with you at all times in public places. We train the dogs to not become protective of you as this may cause rescue workers to be unable to assist you if your dog is showing aggressive behaviors.

However, a dog barking and drawing attention to you might be a deterrent to people with bad intentions.



Lesleigh and her Seizure Alert Dog Ashton

7. How soon after I get the dog can I expect the dog to work for me?

The more you practice with your dog and the more consistent you are, the better your dog will work for you. It will take approximately six months to one year after graduation for you and your dog to develop a strong bond. All people and dogs will adapt differently to new situations - some will bond faster, and some will take a little longer. It also depends on the time you spend working and practicing with your dog. This also includes play time, grooming, feeding, walking and time spent interacting. With any training, it is imperative that the trained behaviours be practiced. If you stop working with your dog, the dog will stop working and will not respond when you have a seizure.

Since 1983, the lives of over 1200 men, women and children from the age of 8 to 84, have been enriched by the services of specially trained Dog Guides from Lions Foundation of Canada.

All Lions Foundation Dog Guides are provided cost free.

If you would like more information contact the foundation at 1-800-768-3030 or email info@dogguides.com

Scholarship Winner - 2010

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

The **Jim Hierlihy Memorial Scholarship**, valued at \$1000 honours a current 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, **Paul Hanlon** of Upper Gullies, is currently studying Occupational Health and Safety at Academy Canada. Paul, in his mid-40s, was only diagnosed with Epilepsy four years ago. It has had an incredible effect on his life.

In his words: *Epilepsy has limited me and I feel like I can't be left alone. I am always fearful of reliving another episode of grand-mal seizures.*

Epilepsy Newfoundland and Labrador takes great pleasure in extending our sincerest congratulations to Paul and wishes him every success in the future.

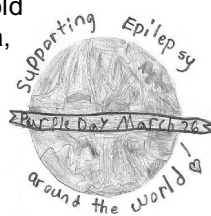


Paul Hanlon accepting his scholarship from ENL President Ron Stone

If you would like to find out how to apply for one of our scholarships, call us at 709-722-0502 or toll free at 1-866-EPILEPSY(374-5377) or visit www.epilepsynl.com.

Become an Ambassador of Purple

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



Why purple? Lavender is not only the internationally recognized colour associated with epilepsy and seizures, but the lavender flower has traditionally been a symbol for things that are hidden or isolated, much like epilepsy. Because epilepsy is often controllable with medications, it becomes invisible to most people, becoming something scary and unknown. It is by stepping out of the shadows that epilepsy will be understood, the stigma eliminated, and people who live with seizures more accepted.

Last year, people of many countries came together to wear their purple proudly to let everyone who lives with seizures know that they are not alone. We were thrilled to be a part of it all here in Nf and Lab.

Be an Ambassador of Purple for Purple Day 2011!

March 2011 will be here soon, and Cassidy Megan and the Purple Day Committee are looking for ambassadors to help spread the word about epilepsy awareness and make Purple Day 2011 even bigger than last year. Whether you are a person living with epilepsy, a friend, a family member, or simply someone who believes that it's time to paint the world purple, you can help!

As an Ambassador of Purple, you will be responsible for promoting Purple Day for epilepsy awareness in your area. This could mean hosting a Purple Day event in your community, inviting local schools and businesses to wear purple on March 26th, and/or getting local media to cover Purple Day activities in your region. If you're not sure what to do, don't worry, we can give you lots of ideas!

By becoming an Ambassador of Purple, you will be an important part of an event celebrated in small towns, remote villages, and huge cities around the globe. **To become a Purple Day Ambassador for your town contact us at ENL, or visit www.purpleday.org.**

Off to the Southwest Coast!

In the days leading up to the Fall Excursion, it is always a mad flurry of activity, and anticipation. Will schools be receptive? How can I reach as many people as possible? Will the weather cooperate?

Each year the questions are the same, but there are always reactions, both good and bad, that will invariably surprise me.

The 2010 Fall Excursion saw me heading west once again. But instead of making a right in Deer Lake, this year I swung left and started the trip off in Port aux Basques. From there I headed to Stephenville, St. George's, Cape St. George, Lourdes, Deer Lake, and finished off in Rocky Harbour.

Some places were a hard sell, with school administrators failing to see the value of the information I had to share. And others were just blatantly disinterested altogether. In the beginning days of planning, I called St. Thomas Aquinas school in Port au Port East. The secretary answered the phone, I told her my name and that I was calling from Epilepsy Newfoundland and Labrador. She passed this bit of information along to the principal who must have been standing close by. His comments, passed on to me word for word by the secretary, took me aback. "I don't have time for any of that stuff." My response, "You don't even know why I am calling yet." It didn't matter. After being told to email anything I had to send, I never heard from them again.

On the other hand, other people were incredibly accommodating and welcoming. A quick call to the Bonne Bay Hospital in Norris Point got me in touch with a lady at Community Health. I had called to see if there might be any groups or organizations I could talk with during my evening in Gros Morne. She asked me to hold for a moment, and five minutes later came back to tell me that not only had she booked a room for me, she would handle all the notices and publicity. Amazing what a quick phone call can do.



At the most westerly point in Newfoundland. Windy!

In several places, between the time I had booked the sessions, and the time I got there, the number of people I talked with had often increased greatly. In one school, I was scheduled to present to 50 students. When I got there, that number had been changed to 262, the whole school. In another place, the numbers went from 60 to 110. Great stuff! The only glitch was fretting whether I would have enough information to leave behind for everyone. Fortunately I just managed it, coming back with nothing more than a dozen or so bookmarks and 5 pamphlets out of the thousands I had taken with me.

I talked to over 1100 people in the course of five days! This included everything from K-12 and post-secondary students, to teachers, RCMP officers, nurses, daycares, home care workers, supported employment workers, members, and concerned parents.

I may have picked the best week possible to head to the West Coast, given the battering from Hurricane Igor in many parts of the province. It was sunny and nice for nearly my whole trip. But sun, wind, or rain, the fall excursion continues to be one of the highlights of my year and I am always grateful to share the stories, struggles, and successes of so many people across this province.



Drying fish along with the clothes in Rocky Harbour.

CEA President Gail Dempsey

Epilepsy Newfoundland and Labrador would like to extend congratulations and well wishes to our very own Executive Director, Gail Dempsey.

Gail was recently elected President of the Canadian Epilepsy Alliance, an umbrella group of grassroots epilepsy associations from all over Canada.

As a member of the CEA, ENL is able to share information with dozens of organizations across the country, and to have a united voice on the international stage, representing the millions of people in this country who are affected by seizures in some way.

As President, Gail will be a strong presence and incredible asset to epilepsy awareness and advocacy in this country, just as she has been here in our own province for many years.

The CEA is tremendously fortunate to have someone with the dedication and devotion that Gail Dempsey has given, and will continue to give. Congratulations! We know you will do great things.



Current Strategies in the Treatment Of Adult Epilepsy

Something very special is coming on March 1st, 2011. Epilepsy Newfoundland and Labrador is partnering with Epilepsy Nova Scotia to develop and present an online webcast!

Current Strategies in the Treatment Of Adult Epilepsy, an online presentation featuring Dr. Mark Sadler, renowned neurologist from Halifax, Susan Rahey, Program Coordinator of the Epilepsy Program in Halifax, and hosted by CEA President (and ENL Executive Director) Gail Dempsey, the webcast looks to be an incredible opportunity for people all over the Atlantic provinces to avail of up to the minute information and real-life practical tips on how to better manage their epilepsy.

There will also be opportunities for participants to ask questions and offer comments during the session, and best of all, **it's free, and you can join in right from your own home computer!**

Some of our members may remember Dr. Sadler, who, for years, worked here in Newfoundland and Labrador and was much admired for his ability and caring with all his patients.

We're still working out all the details just yet, but when we know more, we will be sending it out to all our members. We wanted to give everyone plenty of notice to mark the date on their calendar. For any adult with epilepsy, this will be an event not to be missed.

Did you know:

From a height of three kilometres, it takes 30 minutes for a snowflake to reach the ground on its own.

Off The News Wire

People at Highest Risk of Sudden Unexpected Death in Epilepsy

Sudden unexpected death in epilepsy (SUDEP) is the most common condition-related cause of death in chronic epilepsy. Case-control studies using living people with epilepsy as controls have aimed at identifying factors that distinguish the epilepsy patient at risk of SUDEP, but there are disagreements between studies and a lack of precision in the risk estimates attributed, in part, to the small number of cases in each study.

To counterbalance these study limitations, the Epidemiology Task Force of the International League Against Epilepsy (ILAE) pooled data from four published studies of SUDEP from the U.S., Sweden, Scotland and England.

SUDEP in the study was defined as 1) having a history of epilepsy (one or more seizures during a five-year period), 2) death occurring suddenly, 3) death unexpected with no life-threatening illness, 4) death remaining unexplained after all investigative efforts, including autopsy. (Platform C.03)

Analysis of the pooled data revealed statistically significant risk factors for SUDEP, including increased frequency of generalized tonic-clonic seizures (GTCS), taking more than one anticonvulsant medication (AED), long duration of epilepsy, young age at onset, gender, symptomatic cause, and lamotrigine therapy. The results persisted for both people younger than age 16 and for adults over the age of 16.

According to epidemiologist Dale C. Hesdorffer, Ph.D., of Columbia University, "The emerging profile from our pooled analysis indicates that people with early onset refractory symptomatic epilepsy who have frequent GTCS and take more than one AED are at highest risk. The results suggest that reducing the number of these generalized seizures is a priority of more importance than reducing the number of AEDs."

The researchers also say the role of AEDs and other forms of treatment should be analyzed further in future studies. A further challenge for future research is to focus on patients with refractory epilepsy to clarify what features may distinguish the patients in this high risk population that die in SUDEP from those who survive.

ScienceDaily, Dec. 7, 2010

Mayo Clinic Finds Long-term Prognosis Is Excellent for Most Children with Seizures

Mayo Clinic researchers studied more than 200 children with epilepsy and found that even if the cause of focal-onset seizures cannot be identified and they do not fit into a known epilepsy syndrome, long-term prognosis is still excellent.

"This study is important because even if we cannot identify a cause of focal seizures in children and they do not fit into a known epilepsy syndrome, most of the children outgrow the seizures, and very few have seizures that are unable to be controlled by medication," says Elaine Wirrell, M.D., a Mayo Clinic epileptologist and an author of this study.

Mayo Clinic researchers identified children ages 1 month through 17 years from 1980 to 2004 with newly-diagnosed focal-onset epilepsy. They found 215 children with newly-diagnosed focal-onset epilepsy that was non-idiopathic, meaning that they did not have benign rolandic or benign occipital epilepsy. Focal-onset means that the seizures are produced in a small part of the brain, not the entire brain. The team reviewed medical records, imaging, EEG studies, treatments used and long-term outcomes. They also reviewed follow-up information for more than 12 months for 206 of the children. Children were categorized as having "symptomatic" epilepsy if they had a known genetic or structural/metabolic cause for their seizures, and they were categorized as "cryptogenic" if they did not. The researchers found that more than half of the children had cryptogenic epilepsy, and that this group had a significantly better long-term outcome than those with symptomatic epilepsy. For example, of those who achieved seizure freedom at final follow-up, 68 percent of the cryptogenic group versus only 46 percent of the symptomatic group were off medications.

"This study shows us that it is important to distinguish cryptogenic epilepsy from those children with symptomatic causes, as the prognosis can differ," says Dr. Wirrell. "We will continue to look at the data to see if we can identify specific genes responsible for some of these conditions in order to help us predict which children may have intractable epilepsy, or epilepsy that cannot be controlled by medications."

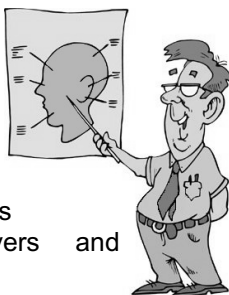
December 6th, 2010

Info Sessions!

One of the best ways to explain about epilepsy and seizures is through public presentations and information sessions.

Epilepsy Newfoundland and Labrador offers **cost-free** information sessions to people of all ages. We can customize presentations for any type of organization, or group, with age and interest appropriate information and activities. Some sessions we do would include:

- school classrooms (both students and teachers)
- daycares and preschools (both kids and staff)
- community organizations
- seniors groups
- parents & homecare workers
- workplaces (for employers and employees)



Want a presentation done for a group that you are involved with? Or perhaps you would like someone to visit your child's classroom and talk with the students there? Give us a call and we will make the arrangements.

The more we can get the word out, the greater the awareness and understanding of seizures right across this province.

Happy Holidays

All of us here at Epilepsy NL would like to wish all our members and friends a very blessed and merry holiday, and a safe and healthy 2011.

Our offices will be closed from Friday, December 24th at noon and will re-open on January 3rd.

We look forward to working even harder to share the message of epilepsy acceptance in the coming year.



Door to Door

We Need Your Support!

Our 2011 Door to Door Campaign will begin in full force on March 1st.

We are still looking for canvassers in all areas of the province.

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).

Charlene Stoyles

Campaign Coordinator

A Little Time Out

A police officer stops a man for running a stop sign.

The driver immediately protests "Oh come on, I slowed down! Stop, slow down, what's the difference?"

The police officer politely says, "Step out of the car please", and then proceeds to stamp on the man's toes over and over with the heel of his boot.

"Now Sir, would you like me to stop or slow down?"



Some people go through life trying to find out what the world holds for them only to find out too late that it's what they bring to the world that really counts.

From Anne of Green Gables

How to Paint A Wall

While I went off to work one day,
She decided to paint the wall.
And when I came back home that night,
She was curled into a ball.

Her eyes were closed, she was breathing hard,
Her hair was very wet.
From her head to the tips of her every toe,
She was covered all in sweat.

She was wrapped in a jacket made of down,
With a fur coat on top of that.
The wall was glowing with new, fresh paint,
On the floor, the paint can sat.

"Sweetheart!" I cried, with a worried look
"Are you all right, my dear?"
She lazily opened her lovely eyes,
And smiled from ear to ear.

"I knew I could do it,"
she said with a grin,
"I followed the paint can notes.
It clearly said 'For best results,
Be sure to put on two coats.'"

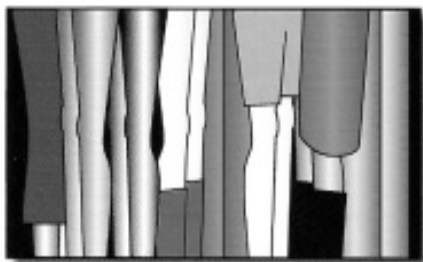
By Joanna Fuchs



Last Legs

Hiding under a table at his sister's birthday party, Ben can see eight pairs of legs walking around in the living room. After a while, he watches everybody go into the kitchen to get some food.

How is it that there are still six legs in the living room?



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! We have a new group created on Facebook just for Epilepsy Newfoundland and Labrador.



On it, we will be posting upcoming events and happenings, and well as pictures, and bits of news.

If there was ever a place to stay up to the minute with ENL, this is it! Just do a search for Epilepsy Newfoundland and Labrador and you are sure to find us.

Coming soon - Details on the upcoming Webcast. When we have further details, it will be posted on our Facebook page right away.

*If you add a little to a little and do this often,
soon the little will become great.*

~ Hesiod ~

Answer - There are Ben's two legs, plus the four legs of the table he is hiding under.

Last Legs

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 Newfoundland and Labrador. 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: _____

If you would prefer to use your credit card, please complete the following:

Type of card: _____ Account #: _____ Expiry Date: _____

Signature: _____ Date: _____

Clip and mail this form to Epilepsy Newfoundland and Labrador - 26 O'Leary Avenue, St. John's, NL A1B 2C7