

Epilepsy News



The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Fall 2012

Epilepsy NL Scholarship Winners 2012-2013

It's Scholarship Time! Each year ENL proudly offers two scholarships, each valued at \$1000 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, and supported by the fundraising efforts of the Rowe family, is awarded to a student with epilepsy in their first year of 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.



Andrea Rowe, Zach's sister, and Joan Parsons, Zach's Grandmother, present the Zach Rowe Memorial Scholarship to Kyle Sparkes.

This year's recipient is Kyle Sparkes of Clarke's Beach. Kyle is currently studying Plumbing at Academy Canada in St. John's. Only recently diagnosed in January of 2011, Kyle is only just now regaining his bearings after his whole life seemingly changed overnight.

I lost my driver's permit in January 2011 and I've only just got it back a year later. Anyone that I have been around, I have to teach them about my "reserve" medication. The worst of it is when my friends try to stop me from doing something, even if it isn't dangerous, just because of my seizures.

The Jim Hierlihy Memorial Scholarship

The **Jim Hierlihy Memorial Scholarship**, also valued at \$1000, 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.

It honours one of ENL's incredible volunteers, Jim Hierlihy, who was on the Executive of the ENL support group in Gander and a great supporter of all those living with seizures.



Kelly Tompkins, Cabinetmaking Instructor (left), presenting the Epilepsy NL Jim Hierlihy Scholarship to Merrill Billard (right)

Congratulations to Merrill Billard of Isle aux Morts. Merrill is currently studying Cabinetmaking at College of the North Atlantic in Port aux Basques. Diagnosed with Epilepsy in 1982, Merrill has had to fight for his career because of his seizures.

I like working with my hands and problem solving, but Epilepsy has put up a lot of road blocks when it comes to getting employment. You face the choice of what you want to do versus what you are allowed to do. Will employers want to take a chance with you if they think you are a liability?

Epilepsy Newfoundland and Labrador takes great pleasure in congratulating Kyle and Merrill. We are tremendously proud of both of you.

Epilepsy News

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Purple Day For Epilepsy What will you do?

In 2008, nine year old Cassidy from Nova Scotia was diagnosed with epilepsy. She was scared and wondered if there were other people like her. She asked her school if they would help her arrange a special day so 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 26th.

As we all know by now, **Purple Day** has become a huge success, spreading far beyond Nova Scotia to countries around the globe! Thousands of people have worn their purple proudly to let everyone who lives with seizures know that they are not alone.

In just a couple short months, March will be here yet again. On this, the upcoming fifth anniversary of **Purple Day**, what will YOU do to promote awareness and understanding in your home town?

It can be as simple as asking everyone to wear purple that day. Or make it even more special: hold a fundraiser, a contest, or a purple event and get people really fired up.

If you would like to do something special for **Purple Day** this year, let us know. We can send you lots of information and other goodies to help promote your **Purple Day**, and reach out a hand to everyone who lives with seizures.



Pitter Patter Daycare Purple Day Bunny Hop

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.

Purple Day Now Legally Recognized in Canada Act Receives Royal Assent



An Act representing a day to increase public awareness about epilepsy, Bill C-278, has received Royal Assent and is now a legally recognized day for epilepsy awareness in Canada. The Bill establishes March 26 as Purple Day, 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. Inspired by Cassidy Megan, Purple Day dispels the myths about epilepsy and helps people living with the disorder understand that they are not alone.

Hon. Geoff Regan, M.P. for Halifax West, wrote the Private Member's, Bill C-278 (The Purple Day Act), in late 2008. Since then, Bill C-278 has progressed through the necessary steps in the House of Commons and Senate, to become law. "The swift passing of this Bill is a meaningful show of support for the 300,000 Canadians living with epilepsy and their families," said Regan.

"I am so grateful that Mr. Regan and Parliament believed in me and Purple Day, and showed the 300,000 Canadians living with epilepsy that they care and that we are not alone," said Cassidy Megan, Purple Day founder. "I also want to thank the Epilepsy Association of Nova Scotia and the other member agencies of the Canadian Epilepsy Alliance for helping me make my dream come true."

According to a survey titled The Impact of Epilepsy on Canadians, conducted in late 2011 by Leger Marketing, many Canadians living with epilepsy experience social isolation, work barriers and relationship issues. Over half of the survey respondents (56 per cent) say that restricted independence due to epilepsy is their number one challenge. Stigma, discrimination and a lack of awareness about epilepsy is cited by 38 per cent as the number two challenge, along with the impact of the disorder on their social life. The third biggest challenge facing Canadians with epilepsy is maintaining employment, with half saying their job choices are restricted, and just under 40 per cent unable to get a job if they disclose their condition.

"On behalf of the Canadian Epilepsy Alliance, I would like to thank Mr. Regan for writing the Private Member's Bill and Parliament for passing this legislation," said Deirdre Floyd, Chair of the Purple Day Campaign and Vice-President of the Canadian Epilepsy Alliance. "To my knowledge, this is the only legislation of its kind in Canada. I strongly believe that Purple Day will help to further our national mandate to support public awareness for epilepsy and research for those living with this serious neurological condition."

Halifax, NS (June 28, 2012)

As We All Come Together



Epilepsy and Memory

Strategies and Tips to Help You Remember

*"Memory is a way of holding on to the things you love, the things you are, the things you never want to lose."
~ Kevin Arnold*

No one remembers everything. Who would want to? The frustration comes when we forget things that are important and remember things that are absolutely trivial.

However, sometimes we do want to remember things. There are a great many tricks and techniques to improve your memory. Not all of them work for everybody because not everyone remembers in the same way. Some people remember best by listening, others by reading, still others by writing things down. Not all of these techniques will work for you. If one does not work, try another.

Have Confidence in Yourself - If you convince yourself that your memory is bad, you may not even try to remember. If you are thinking, "I'll never remember all this," replace that thought with, "I may not remember all of it, but I will try to remember what is important."

Decide What You Want to Remember - Get mentally organized. If you are juggling six different things, you will probably forget one or two of them. Concentrate on what is important to remember. Do not try to remember everything.

Focus on What You Want to Remember - Pay attention to it, think about it. Pay special attention to landmarks when you are driving or walking. This will help sharpen your awareness.

Eliminate Distractions - Recognize the limitations of short-term memory. If you have trouble remembering what you read, turn off the radio or television.

Don't Rush - Give yourself time to think about what you are doing and what you need to do. Give yourself time to learn and to remember.

Use All Your Senses - Use as many senses as you can when you want to remember something. Say the words out loud, listen to them. Write it down and look at it twice. If you want to remember the size and shape of something, do not just look at it. Pick it up, feel it, weigh it in your hand. Smell it, taste it.

Organize Yourself - Train yourself to put things in the same place every time. If your purse is always on the kitchen counter, you will not have to look for it. If the keys are on a hook by the door, they are not lost. If you always take a pill with breakfast, you will not need to wonder whether or not you took it.

Relax - Anxiety, tension, and stress interfere with memory. If you worry that you have forgotten something, you may become too anxious to recall it. Relax, breath deeply, it may come back to you.

Use your memory - Give it some exercise. Think about the people, places, and things that you have enjoyed, or try to remember three things you see on the way home.

Names and Faces - If you are supposed to know someone and can't remember them, ask questions. "How are you?" "What have you been doing lately?" "Bring me up to date on your comings and goings?" If they talk long enough, they will almost certainly say something that will identify them as the woman from the hardware store, your neighbor's brother, or whomever.



If you are with two people whose names you can't remember, get them to focus on each other. Say, "You two know each other, don't you?" If they do, one or the other of them will almost always say, "Oh, I've known so and so for ages." Or they might say, "John and I are neighbors." This will get them talking to and about each other. They may say enough to remind you who they are.

Or you could be honest. Admit that your having a memory lapse, and ask the other person to fill you in about how you know each other. If you take it with a little good-humour, people are generally more than happy to fill in the gaps.

Epilepsy and Memory - Continued

Use Labels. If you cannot remember what kind of plant is on your windowsill or in your flower bed, who gave you what for your birthday or anniversary, or the names of the people in photographs, label them. If it is a book, write on the flyleaf, "From cousin Sally, Birthday, 1996." If it is a plant, put a label on the pot. Write names, occasions, and dates on the back of photographs. Just by labeling, you cut out a lot of things you would otherwise have to remember.

Birthdays and Anniversaries - Put them in your address book. Also put in the names of children, partners, and any other information you want to remember--illnesses, deaths in the family, special interests, where they went on vacation, their dog's name, anything that is special to them.

Copy the birthdays and anniversaries into your calendar. Every year when you get a new calendar, take a moment to sit and transfer all the birthdays and anniversaries from the old calendar to the new one.

Appointments and Meetings - Put these into your calendar along with the birthdays and anniversaries. Write them in red or green ink so they will stand out.

Medications - Sort each day's pills ahead of time and separate into compartmentalized pillboxes, which can organize your medications by the day or week. All you need to do is check the box. If the compartment is empty, you took the pills. Also, some pharmacies will prepackage medications into separate labelled packets containing all the pills to be taken at certain times each day. If the packet is gone, then you've taken those pills. Check with your pharmacy to see if they offer this service.

Calendars and Electronic Organizers - There are huge varieties of organizers. Some are small schedule books, others are electronic, others still are applications that can be added to a smart phone, computer, or tablet. All of these can help keep track of appointments, meetings, birthdays, anniversaries, errands, and many of the other details of your life. Some of the electronic organizers can be programmed to buzz and show reminders, as well as hold names, addresses, notes, phone numbers, birthdays, anniversaries, and appointments.

The best way to select the option that is right for you is to go to an office supply or electronic store and try them out. Buy something based on how you will use it, and not necessarily the one with the most bells and whistles.

Notebooks - Take notes. Do not worry about how it looks, it looks efficient. Keep a notebook in your bag, car, or pocket so you can be sure it will be there when you want to jot down something to remember.

Hand Held Recorders - If you have trouble remembering school lectures, meetings, doctor visits, or instructions, record them. As a courtesy, you should get permission before taping anyone. You can also tape messages and reminders to yourself.

Not remembering can be frustrating and upsetting, especially when it feels as though your brain is fighting against you. Just breathe deeply, try to keep a sense of humour about it all, and know that it's not your fault.

2012 Door to Door Campaign

Our 2012 Door to Door Campaign is getting 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 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 to collect among your friends and family?

If you are able to help for even an hour or two, please call me at 722-0502 or toll free at 1-866-EPILEPSY (374-5377).

Elaine Pottle, Campaign Coordinator

Provincial Government Announces Vehicle Modification & Disability Inclusion Grants

Provincial Government Provides \$650,000 to Launch Initiatives that Support Inclusion

Increased accessibility and inclusion for persons with disabilities will be further supported as a result of new **Accessible Vehicle Funding and Inclusion Grants**. The Provincial Government is providing \$650,000 for these initiatives, which complement the provincial strategy for the inclusion of persons with disabilities, Access. Inclusion. Equality., released earlier this year.

“Both the Accessible Vehicle Funding and Inclusion Grants will work to make a real and positive difference in people’s lives throughout our province,” said the Honourable Joan Burke, Minister of Advanced Education and Skills and Minister Responsible for the Status of Persons with Disabilities. “These initiatives are a direct reflection of ideas and solutions we heard from individuals with disabilities. We will continue to engage individuals as we move forward with the implementation of the strategy.”

Accessible Vehicle Funding will support individuals and families to purchase, repair and install eligible accessibility features for a new or existing personal vehicle. Funding to a maximum of \$25,000 will be provided to eligible applicants with annual net incomes of \$46,500 or less. Eligible applicants with an annual net income between \$46,500 and \$64,000 will qualify for partial funding. Accessibility features include items such as hand controls, steering devices, lifts and ramps, door alterations, left-foot gas pedals, wheelchair securing systems and customized seating.

Inclusion Grants will provide funding to non-profit, community-based organizations, supporting the removal of barriers through two categories: Accessibility Grants and Disability-Related Accommodations Grants. Accessibility Grants are for renovating or retrofitting buildings to be more accessible through alterations such as installing automatic door openers or lowering sinks and counters. Disability-Related Accommodations Grants are for providing supports at community events and activities. This includes sign-language interpretation, captioning and audio support for assistive-listening devices.

“Improving accessibility so everyone can participate in community opportunities will ultimately enhance the social, economic and cultural fabric of our province,” said the Honourable Keith Hutchings, Minister of Innovation, Business and Rural Development and Minister Responsible for the Office of Public Engagement. “The new Inclusion Grants program will help create a more inclusive environment within community-based organizations across our province as they continue to improve the lives of Newfoundlanders and Labradorians.”

Applications for Accessible Vehicle Funding and Inclusion Grants are available, including alternate formats, at www.aes.gov.nl.ca/disabilities/default.html or upon request at 709-729-6048, or 1-888-729-6279, TTY 1-888-729-5440.



**Application deadline is
January 15, 2013.**

Ministers Burke and Hutchings emphasized how inclusion is essential for creating a dynamic and strong province. It means having access and choices on an equal basis with others. This includes access to opportunities or events that happen within any community.

The Provincial Government recently introduced other initiatives to advance inclusion, including introduction of the progressive Service Animals Act, which expands the types of animals that can be used as service animals and protects the right of access for persons with disabilities; legislative amendments that help adults with intellectual disabilities access Registered Disability Savings Plans; increased fines for illegal parking in blue zone spaces, and; stronger requirement for blue zone parking spaces to be clearly identified, with signage permanently mounted and kept in good condition.

Budget 2012: People and Prosperity provided \$6.5 million for initiatives that complement the provincial strategy for the inclusion of persons with disabilities, including Accessible Vehicle Funding and Inclusion Grants.

*Executive Council, Advanced Education and Skills
November 16, 2012*

Fall Excursion 2012 - Connaigre to Exploits

This year I had the privilege of visiting several places that were completely new to me. I travelled down the Connaigre Peninsula to Hermitage, Harbour Breton and Conne River, then came back up to central for Bishop's Falls, Grand Falls, Norris Arm, Lewisporte, Glenwood, and finally Gander.

It was almost the Fall Excursion that never happened. In order for us to go into the schools in Central, we needed authorization from the School District. Even though we had lots of schools interested, getting that approval took a very long time and for a while it was uncertain whether the approval would come in time for us to go in the fall at all. But everything worked out in the end and on October 14th I ventured forth.

The trip was excellent. Every day was filled to capacity with school and community presentations. In the evenings, I talked with daycares and preschools, presenting to staff from 17 different daycares throughout the week.

The financial cost of going to the remote areas is high, which is why we are not able to go as often as we might like. But the impact we can make in smaller towns is equally as high, and I witnessed that during this trip, with my stay in some of the smaller communities in the Coast of Bays.

Conne River was one of the highlights of the week. I had never been there before, and not only is the area truly beautiful, the people are even more so. They could not do enough for me. People were deeply engaged in the sessions, with great discussions and involvement at every turn. By the time I had left, I'm sure that every home had received information, either through their children at school, at the health centre, or through the evening workshop.

Within the span of one week, I gave 30 presentations, to 816 students, daycare workers, and interested individuals. It is so rewarding to hear the stories and share information and support with so many people in communities we have never visited before.

If you would like us to visit your area, please let us know. Even if we can't make it right away, we can always arrange for someone in the area to give the workshop or classroom session on our behalf.



Percheron Horses in Bishop's Falls



The Miawpukek Walking Trails in Conne River



Sold! - A beaver lodge near Gander

Our Supporters Are Awesome!



The 9th
Annual

Christmas Tea for Epilepsy

How it works - From November 26th until December 14th, 2012 organizations and individuals have been showing off their community spirit by participating in the 9th Annual Christmas Tea for Epilepsy.

They have received beautiful Christmas Tea Baskets filled with Tetley Tea and a variety of tasty treats such as muffins, cookies, and croissants.

In appreciation, participants have been donating to support the numerous programs and services of Epilepsy Newfoundland and Labrador.

One in every ten of us will have at least one seizure at some point in our lives.

Because of the generosity of all our Christmas Tea participants, we will be able to reach even more people, with awareness campaigns, first-aid education sessions, classroom presentations, and newly diagnosed support.

We think that's
a pretty amazing
cup of tea!

Hall of Fame 2012-2013

Our Flavourful Sponsors



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

Purity Factories

Marie's Bakery

Paradise Bakery

Our Grand Givers (\$500 and up)

Husky Energy

The Tea Masters (\$100.00 donations and up)

Barrett's Funeral Home
Penney Mazda
VOCM Cares
Rogers

MUNN Insurance
The Telegram
Scotiabank - Water Street
Scotiabank Centennial Sq

St. Patrick's Mercy Home

The Tea Specialists (\$50 and up)

BMO - Elizabeth Ave
Cox & Palmer
BMO Water Street

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

City of St. John's Engineering & Planning

The Tea Apprentices (Donations up to \$50)

Scotiabank - Cornwall
Scotiabank - Paradise
ProActive - Kelligrews

ProActive - Atlantic Place
ProActive - Aberdeen
ProActive - Mt. Pearl

City of St John's Finance Department

The Dangers of Energy Drinks

A warning for students trying to stay awake through those all-night cram sessions: chugging energy drinks such as Red Bull, especially on an empty stomach, has been linked again to causing seizures.

According to a Health Canada release, an 18-year-old man drank two cans of Red Bull in half an hour during a night of studying, without eating. (He was in good health and had no history of seizure or head injury.) An hour later, while still at school, he suffered two grand mal seizures and had to be taken to hospital. He was released the next day. There were no drugs in his system, and other than the Red Bull, he had not had any other caffeine drink.



"This particular case occurred almost a year and a half ago and has been reported to Health Canada according to regulations for Natural Health Products," Red Bull Canada said in a statement. "Two 355 ml cans of Red Bull Energy Drink contain about the same amount of caffeine as two to three cups of coffee (230 mg). Scientists from Health Canada have concluded that the general population of healthy adults is not at risk for potential adverse effects from caffeine if they limit their consumption to 400 mg per day."

This isn't the first time the energy drinks have been linked to seizures. In 2007, research presented at the American Academy of Neurology reported that four patients between the ages of 19 to 28 suffered seizures after heavy consumption of the drinks. One patient, a 25-year-old man, was admitted to the emergency room for two seizures within four months; he'd also consumed two cans of the energy drink Rockstar on an empty stomach, between half an hour to an hour before both seizures. Told to abstain from energy drinks, he didn't have anymore seizures, researchers said.

At the time, researchers pointed out that none of the patients had seizures when they drank energy drinks in small quantities.

The label on a can of Red Bull, touted on the company website as "more than just a hot secret for the night owl and non stop-party animal" recommends one serving a day.

*Erin Anderssen, The Globe and Mail
September 10th, 2012*

What's in a Red Bull?

Caffeine - a stimulant also found in coffee and tea that can increase metabolism, concentration, reaction time and energy. Caffeine can be addictive, and withdrawal symptoms include headaches and irritability.

Taurine - an amino acid that has many functions. It regulates levels of waters and salt in the body, as it can form into bile salts. It works as an inhibitory neurotransmitter in the brain and can also affect learning and memory. Taurine is also an antioxidant and may play a role in formation of fat tissue.

Glucuronolactone - a chemical made naturally in the body when glucose is metabolized. Glucuronolactone may fight fatigue and it is present in many energy drinks.

Vitamins - Niacinamide, better known as niacin or vitamin B-3, is necessary for metabolism as well as DNA repair and production of steroid hormones. Calcium pantothenate, better known as pantothenic acid or vitamin B-5, is necessary to make co-enzyme A as well as synthesize proteins, fats and carbohydrates. Pyridoxine HCL, better known as vitamin B-6, is necessary for protein metabolism and the reaction converting glycogen to glucose. Vitamin B-12, also known as cobalamin, is necessary for metabolism, blood formation and fatty acid production.

Sugars and Flavorings - two types of sugar: glucose and sucrose, as well as artificial flavorings.

Other Ingredients - also contains carbonated water, artificial colors, sodium citrate and inositol. Carbonated water makes it fizzy. artificial coloring makes it yellowish, sodium citrate is a preservative, and inositol is a carbohydrate.

A Little Time Out

W D R I Z Z L E Y I
 B L I Z Z A R D M F
 G O N T W E R I R R
 N C N N O E W F O O
 I S O U N I A R T S
 Z I L N S F L E S T
 E C D U O L E I A N
 E E D G S L A N A D
 R L A B S H R A D H
 F O S E L C I C I R

It's that time of year...
 the wind howls, the snow
 starts falling, mornings are
 shivery and cold.

Find all the weather words in
 the puzzle. The letters left
 over when read row by row,
 left to right will reveal the
 secret theme.



BLIZZARD
 DRIZZLE
 FREEZING
 HAIL
 ICICLES
 SLEET
 SNOW

COLD
 FOG
 FROST
 ICE
 RAIN
 SLUSH
 STORMY

From All of Us to All of You

*A Very Merry Christmas
 and a Joyous New Year*

to all our members, supporters, and friends
 from all the staff and volunteers at

**Epilepsy Newfoundland and Labrador &
 Previously Loved Clothes and Things**

Our offices will be closing December 24th at 4pm,
 and will re-open January 2, 2013.

We look forward to continuing to share the message of
 understanding and acceptance of all those living with epilepsy
 through 2013 and beyond.

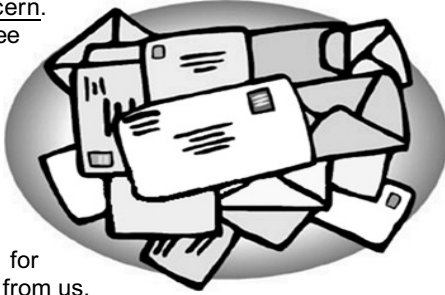


Email or Postal Mail?

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.

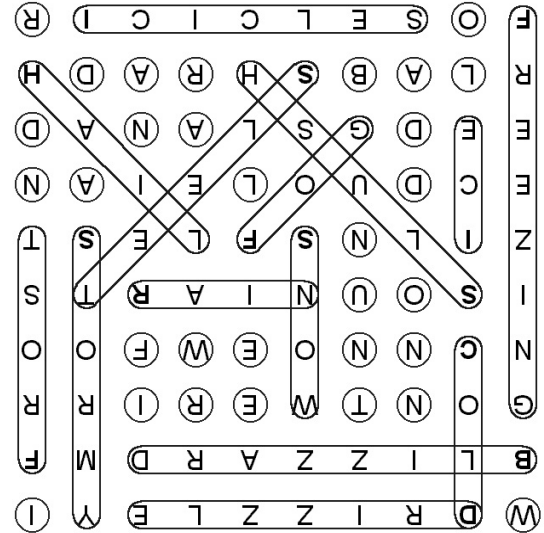
Nobody else will see your email address. And we would never make our email or mailing lists available to anyone else.



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

**Never Let anyone tell you that you can't;
show them that you can.**
~ Gloria Mallette



Hidden Theme:
Winter in Newfoundland and Labrador

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?:
If you would prefer to pay by credit card, please 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