

# Epilepsy News

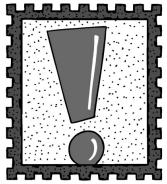
The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Summer - Fall 2010

## Lamictal Alert

new and troubling drug alert was recently released by the American FDA regarding Lamictal (lamotrigine) and the risk of Aseptic Meningitis.

On August 12<sup>th</sup>, 2010, a Drug Safety Communication from the FDA advised the following:



#### THE ALERT

**ISSUE**: FDA notified healthcare professionals and patients that Lamictal (lamotrigine), a medication commonly used for seizures in children two years and older, and bipolar disorder in adults, can cause aseptic meningitis. Symptoms of meningitis may include headache, fever, stiff neck, nausea, vomiting, rash, and sensitivity to light. In cases of meningitis, it is important to rapidly diagnose the underlying cause so that treatment can be promptly initiated.

**BACKGROUND**: The decision to revise the Lamictal label is based on FDA's identification of 40 cases of aseptic meningitis in patients taking Lamictal (from December 1994 to November 2009). See the Data Summary section of the Drug Safety Communication for additional information.

**RECOMMENDATION**: Patients should be advised to contact their healthcare professional immediately if they experience signs and symptoms of meningitis while taking Lamictal. If meningitis is suspected, patients should be evaluated for other causes of meningitis and treated as indicated. Discontinuation of Lamictal should be considered if no other clear cause of meningitis is identified.

So far there has been no equivalent warning issued here from Health Canada, but that is not to say it does not apply to us as well. Lamictal is the same drug regardless of whether you are in Canada or the US.

#### WHAT TO DO?

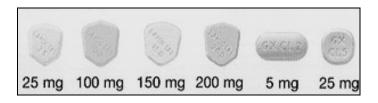
If you are taking Lamictal and are not experiencing any of the symptoms mentioned in the alert, there is no need for action. But talk with your doctor or neurologist at your next appointment just to be certain if Lamictal is still the best drug for you.

If you take Lamictal and you are experiencing flu like symptoms, a stiff neck, or any of the other symptoms mentioned, talk with your doctor or neurologist immediately.

Do NOT stop taking your medication as this could potentially cause sudden and severe breakthrough seizures.

As worrisome as medication alerts can be, always realize that the chances of developing severe side effects from medication are rare, and most people will never experience any significant adverse reactions from their epilepsy medication.

If you want more information about Lamictal, or any other anti-epileptic drug, talk with your doctor, or get in touch with us here at Epilepsy Newfoundland and Labrador.



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# On My Mind

You have a choice.

Every Breath is a choice. Every minute is a choice.

~ Chuck Palahniuk

ot so long ago, there was yet another warning released about the effects of epilepsy drugs and increased suicide risk.

Neurontin and Trileptal are the latest two that have been shown to increase suicidal thoughts and behaviours in people who take them.

So if you're keeping score like I do, that makes Sabril, Topomax, Keppra, Lamictal, Depakote, and now Neurontin and Trileptal.

But in an confusing twist to it all, a study from just last month makes the claim that epilepsy drugs DON'T increase suicide risk at all.

So, who's right?

I'm no neurologist, but I do like to think I have a little common sense. And I'm not sure either of these studies really matters one way or the other.

Whether you take the epilepsy medications in the alerts, take a different epilepsy medication, or take no medication at all, if you are experiencing symptoms of depression, are thinking about suicide or self- harm, please tell someone and get the help you need to feel better.

There is help, and there is hope.

The Crisis Prevention hotline is available 24 hours a day 7 days a week from anywhere in the province. 1-888-737-4668.

#### 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.

# Public Discussions on Disability and Inclusion

s part of its ongoing commitment to ensure equal opportunities for all members of society, the Provincial Government has announced consultations to develop a strategy for the inclusion of persons with disabilities.

#### An Opportunity for Input

"I am extremely pleased to announce these sessions and encourage input into the development of this very important strategy," said the Honourable Susan Sullivan, Minister of Human Resources, Labour and Employment and Minister Responsible for the Status of Persons with Disabilities. "These consultations will focus on how best to remove existing barriers and how to prevent new ones. The community has done extensive research to identify barriers and our government is ready to focus on addressing them."

Consultations will take place in the form of public meetings throughout the province. Direct input is also invited through written submissions, phone and TTY.

"Having perspectives on solutions from the community of persons with disabilities across the province is essential as we develop this strategy," said Minister Sullivan. "These consultations will focus on solutions and will guide the Provincial Government as we work towards achieving inclusion in all aspects of society."

#### **How To Get Involved**

Individuals wishing to attend a public meeting or provide direct input are invited to contact the Disability Policy Office. A discussion paper Inclusion for All – Developing a Plan to Remove Barriers for People with Disabilities in Newfoundland and Labrador is available from the Disability Policy Office or its website. The paper provides information on the Provincial Government's commitment to inclusion and on barriers identified by community-based research. It includes an overview of some programs as well as questions to generate discussion during the consultations. This document is available in alternate formats.

For more information contact:

#### **Disability Policy Office**

Phone: 729-6279 or 1-888-729-6279 E-mail: disability.policy.office@gov.nl.ca Web: www.gov.nl.ca/DisabilityPolicy

#### **Schedule of Consultations**



Tuesday, September 21 Hopedale, Council Chambers, 7 - 9 p.m.

Wednesday, September 22 Happy Valley- Goose Bay, CNA Campus, 7 - 9 p.m.

> Thursday, September 23 Labrador City, CNA Campus, 7 - 9 p.m.

Monday, September 27 Gander, Albatross Hotel, 7 - 9 p.m.

Tuesday, September 28 Lewisporte, Kinsmen Centre, 7 - 9 p.m.

Wednesday, September 29 Grand Falls- Windsor, CNA Campus, 7 - 9 p.m.

Thursday, September 30 Conne River, Great Hall - Band Office, 2 - 4 p.m.

Thursday, September 30 Harbour Breton, Elliot Premises, 7 - 9 p.m.

Monday, October 4 Port aux Basques, Hotel Port aux Basques, 7 - 9 p.m.

Tuesday, October 5 Stephenville, Holiday Inn Stephenville, 7 - 9 p.m.

Wednesday, October 6
Corner Brook, CNA Campus, 7 - 9 p.m.

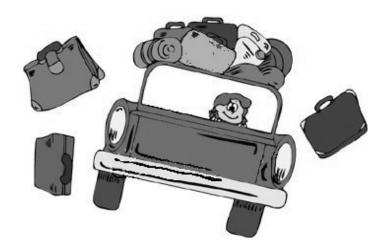
Thursday, October 7 Deer Lake, Elwood High School, 7 - 9 p.m.

Tuesday, October 12 St. John's, Capital Hotel, 7 - 9 p.m.

Wednesday, October 13 Marystown, St. Gabriel's Hall, 7 - 9 p.m.

Tuesday, October 19 St. Anthony, Lion's Centre, 11 a.m. - 1 p.m.

## Fall Excursion - Southwest Coast



September has arrived, and with it our annual Fall Excursion. For a week each year, I pack up and set out to an area of the province we don't usually get much chance to visit. I will spend the week talking with students, groups, organizations and individuals about seizure awareness and first-aid.

I love the fall, and getting to meet so many people and share their stories is one of the highlights of my year.

This time around I am heading back to the west coast of the province, but instead of going north like last year, this year I am heading south to Port aux Basques. From there I will be making my way up the coast and ending in Rocky Harbour.

My week will look something like this:

Monday, September 20<sup>th</sup> - Port aux Basques Tuesday, September 21<sup>st</sup> - Stephenville and St. Georges Wednesday, September 22<sup>nd</sup> - Port au Port Peninsula Thursday, September 23<sup>rd</sup> - Stephenville and Deer Lake Friday, September 24<sup>th</sup> - Rocky Harbour and Norris Point

Some of the groups that I will be talking with include:

- K-12 Schools Both students and teachers
- Post secondary schools
- Community and church groups
- Home Care workers
- RCMP
- Daycares
- Government Agencies
- General public

If you, or someone you know, is at any of my stops, I would love to talk with you. We can meet over tea, or you are welcome to sit in on any of the sessions that I will be doing throughout the week.

I will be checking in with the office and checking my email along the way, so even if I have already left, you can still reach me.

Phone at 722-0502 or 1-866-EPILEPSY Email at info@epilepsynl.com

## No Child Without

ow that school is starting up again, it is important that any child with epilepsy owns and wears a medic alert bracelet or pendant. In an emergency, it can make an enormous difference.



**No Child Without**® is a charitable program that offers all elementary school aged children with medical conditions or allergies, **FREE** MedicAlert protection regardless of their financial resources.

Their vision is to help protect the estimated 300,000 children with medical conditions across Canada by offering **No Child Without**® to all 12,000 elementary schools over the next 5 years.

#### Most Nf. and Lab. schools are already covered!

Find out more information and how to apply by visiting: http://www.nochildwithout.ca/index.asp or call 1-866-679-3220

# Speaking Out Loud

he story that I am about to type is a very painful one. I am the mother of two children who today are 19 and 17 years old. I am also a mother who has spent all her life sick. I was born with a bad heart which required surgery, and as a baby also suffered a stroke. When I got older, I had to have part of one of my lungs removed. And I have seizures.

I was always told never to have children, but me being me, I went against the odds and had not one but two healthy children.

When my children were eight and ten years old, I suffered another stroke. This one left me paralyzed from my hip down to my knee. Within six months, I lost the ability to read or write, and for the longest time I had no memory of my children. When they would hug me it was as though I was hugging a stranger.

At the same time my marriage was failing and I was having a hard time between the stroke, the seizures, and battling for the custody of my children. Needless to say, it was a nightmare.

I wasn't coping well and my mother wanted me to see someone. I didn't want to, because I knew that once you go in under mental health, you are looked upon differently. But through great persuasion and great need, I eventually went and was diagnosed with post traumatic stress disorder. I remained under care for two months that first time. And then, after being home for only a month, I had to be admitted back again.

While I was receiving treatment, I began to understand what I had been hiding all these years; a pattern of abuse and rape that had happened to me as a child, and continued for decades. With the abuse into the light, I decided to do something about it. I tried to have my say, hoping for long overdue justice. I am still waiting. When I finally came forward, they did nothing. To this day I still have nightmares and trouble coping from time to time. I keep asking myself "Why me?"

And then, I lost my children. The courts said I couldn't have them anymore, and within 48 hours a mother who loved her children dearly had them taken away.

The sad part of it all, is that they could not find me to be an unfit mother in my actions, so they used my seizure drugs, along with the fact that I had gotten help through health services to justify their case.

The system failed me in many ways. Here I was, a mother of two who could not write, read, or walk, faced with court papers that to this very day I do not understand.

To cope with everything, I worked hard to re-learn to write. I wanted to tell the story of my life. I still feel lucky in a way. I am still here, and my writing has helped me deal with a lot of things in my life. I am no longer on any medication for my depression. My writing is my medicine.

When I get down, I turn on the computer and write. It's not an easy process and we all need help from time to time, but usually when I have stopped writing, I feel better.

There are times I still have more bad days than good, but through the loving support of kind friends, I am making it through.



Christina Keough ENL Member

Christina Keough's story has been featured in the new book from Breakwater Publishing - **Out Loud** 

**Out Loud** is a collection of more than fifty essays by people affected by mental illness. There are essays by those who have experienced mental illness themselves, by family and friends, by community members, and by professionals who deal with mental illness. The voices here are ones of hope, pain, and honesty. The true meaning in this collection is found in the willingness of the essayists to step forward and share their experiences in hopes of lessening stigma and broadening the conversation about mental illness.

The opinions expressed here are the opinions of the author, and her life experiences.

Every life has a story. Want to share yours? Let us know and we would be happy to feature it in an upcoming edition of our newsletter.

# Epilepsy Newfoundland and Labrador Scholarships!

id you know that ENL of fers two scholarships every single year?

Our scholarships are available to ENL members only and are each worth \$1000.00 towards tuition, books, or any of the other many necessities that come along with school.



There are two different scholarships available:

#### The Zach Rowe Memorial Scholarship

For students who have just graduated from high school and are moving into their first year of post-secondary studies.

#### The Jim Hierlihy Memorial Scholarship

For students who are beyond their first year, or who have decided to return to school after a period of being in the workforce.

#### **Deadline for both is November 1st**

Applications are on our website at www.epilepsynl.com, or are available by calling the office at 1-866-EPILEPSY.

# Even More Training Assistance Opportunities

heck out these websites for even more scholarship and training assistance opportunities, especially for students with disabilities.

#### **Human Resources and Skills Development Canada**

If you have a permanent disability, a physical or learning disability, you may qualify for the following Grants:

- Canada Study Grant for the Accommodation of Students with Permanent Disabilities
- Canada Access Grant for Students with Permanent Disabilities

Get all the details by contacting any HRSDC office or online at <a href="http://www.rhdcc-hrsdc.gc.ca">http://www.rhdcc-hrsdc.gc.ca</a>

#### **IBM Lime Connect Canada**

Scholarship & Internship Program for Students with Disabilities – an outstanding opportunity for Canada university third years (undergraduate and graduate) who are pursuing degrees in computer science, software engineering or other disciplines related to the information technology industry. IBM Lime Connect Canada scholars will receive a \$5,000 scholarship and 2011 paid internship. Application deadline is November 21, 2010.

Find out more at www.limeconnect.com

#### DisabilityAwards.ca

Your portal to awards and scholarships for students with disabilities studying at Canada's colleges and universities.

You can register to search through the extensive database of scholarships, bursaries and grants you are specifically eligible for. Once you have created a profile, you will be able to perform tailored searches, save awards, and receive notifications of new awards. You will also find information on government student loans and grants organized by province.

For more information, visit: www.disabilityawards.ca

#### HRLE Employability Assistance

The Newfoundland Human Resources Labour and Employment office supports to individuals with disabilities to access training and skill development. They provide:

- employment counselling and assessment
- funding to support tuition for first post-secondary degree, diploma, or certificate
- funding for skills training, technical aids and other supports to assist with access to jobs and training
- funding to support other expenses while training including books, lodging and related expenses

Contact any HRLE office for details or check online at www.hrle.gov.nl.ca/hrle/disabilities/services.html

## Off The News Wire

#### Animal Study Suggests A Mutated Protein In Brain Cells Can Lead To Cardiac Arrest In People With Epilepsy.

A mutation in a brain protein gene may trigger irregular heart beat and sudden death in people with epilepsy, according to new research in the April 14 issue of The Journal of Neuroscience. People with epilepsy who are otherwise healthy are more than 10 times more likely to die suddenly and unexpectedly than the general population.

Researchers have long suspected that abnormal ion channels in the brains of individuals that cause epilepsy also put them at risk for sudden unexplained death in epilepsy, or SUDEP, perhaps by harming the heart. An ion channel is a protein that lets charged particles enter or leave a cell to generate electrical signals, a basic process of nerve cell communication.

A team of neuroscientists, led by Jeffrey Noebels, MD, PhD, of the Department of Neurology, Baylor College of Medicine, used an animal model to study a particular type of potassium ion channel called Kv1.1, which helps regulate electrical signals in the brain. In humans, mutation of the gene for Kv1.1 has been associated with spontaneous seizures, abnormal muscle movements, and motor coordination problems. Now Noebels and his colleagues have found that these channels are also required for proper heart function.

The researchers determined that in healthy animals these specific potassium channels are present in the brain and the vagus nerve, a bundle of axons that helps regulate cardiac rhythms, but are barely detectable in the heart. In the mutant mice, the brain signals sent to the heart through the vagus nerve were crippled.

"In mice without Kv1.1 channels, we think the vagus nerve loses control and sends extra nerve impulses to the heart, telling it to slow down - and even stop beating - when it shouldn't," said Edward Glasscock, PhD, first author of the study.

"Now that we are starting to grasp the genes and proteins underlying SUDEP, we can begin to predict and find ways to reduce the risk of death in patients with epilepsy," Noebels said.

Schwartzkroin also pointed out that similar tests have yet to be tried for humans, and there may be multiple genes that contribute to SUDEP in different people.

The research was supported by the National Institute of Neurological Disorders and Stroke of the National Institutes of Health and an American Heart Association Postdoctoral Fellowship. Society for Neuroscience, April 2010

"Autumn is a second spring when every leaf is a flower."

- Albert Camus

# Non-IV-administered medication just as effective in stopping seizures

When seizures strike, the most immediate goal for caregivers is to get appropriate medication to the patient as quickly as possible to stop the seizing activity.

In a paper published in the June Academic Emergency Medicine, UC emergency medicine assistant professor Jason McMullan, MD, found that the best means of stopping status epilepticus (SE) may be with the least direct medication.

His analysis compared the efficacy of two seizure medications, diazepam and non-intravenous midazolam, in stopping SE in children and young adults. Diazepam the more commonly used anti-seizure drug in pre-hospital settings. While diazepam is typically administered by either suppository or IV, midazolam can be administered by a shot in the muscle or intranasally.

In the minutes after a seizure, the method of administration can make a big difference, says McMullan. "Establishing IV access can be challenging, if not impossible, in convulsing patients," he says. While an intravenous medication may access the bloodstream faster, it can take a long time before the patient actually gets the medicine.

"Suppositories present another challenge," adds McMullan, because some caregivers may be unwilling to administer a suppository to a seizing child in a public place.

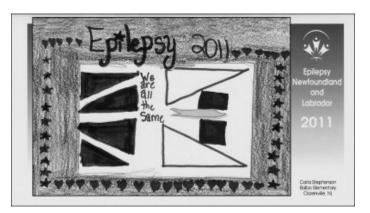
"It may be a little bit slower for midazolam administered via shot or nasal spray to work," he says, "but when you factor in the time to start the IV or administer a suppository, then it becomes a lot quicker."

During a seizure, time saved often translates into a better outcome for the patient. "Most seizures stop on their own, but there are times that they don't—and when they don't, that's a true emergency," says McMullan. "If a person is seizing for five or more minutes, the chances of the seizure stopping on its own are far less. During that time the person can suffer brain damage, muscle damage, a lack of oxygen, kidney damage, any number of things. The sooner that person is treated, the better they're going to do and the less medicine that they need."

In the analysis, McMullan found that midazolam, administered by any route, was superior to diazepam for stopping seizures, by any route. Not only was midazolam administered faster that diazepam, it had no greater rate of respiratory side effects.

"In broad strokes, these results mean midazolam could be a good idea for seizure treatment. It's no worse than the gold standard of putting the drug directly into the bloodstream, it's no more dangerous and it's quicker. The real promise if that it may open the possibility for more EMS agencies to use this medication." University of Cincinnati Academic Health Center, Jun-2010

# 2011 Epilepsy Pocket Calendars



2011 Pocket Calendars are now available. Last year we sold out, so get yours before they're all gone!

Call 1-866-EPILEPSY

Our Calendar Campaign is underway! For a donation of \$20 or more to Epilepsy Newfoundland and Labrador, we will be happy to send you our 2011 Pocket Calendar with artwork by grade 4 children from all over our province.

The 2011 calendar includes artwork from kids at the following schools:

- Balbo Elementary, Clarenville
- Pasadena Elementary, Pasadena
- Straits Elementary, Flower's Cove
- Bishop Abraham Elementary, St. John's
- James Cook Memorial, Cook's Harbour
- Baie Verte Academy, Baie Verte
- Centreville Academy, Centreville
- Fatima Academy, St. Bride's
- Cloud River Academy, Roddickton
- MSB Regional Academy, Middle Arm
- St. Gabriel's All Grade, St. Brendan's
- Woodland Elementary, Dildo

Epilepsy Newfoundland and Labrador would also like to extend sincere thanks to our corporate sponsor



A Proud Supporter of Epilepsy Newfoundland and Labrador

## **RDSP Assistance**

e are all looking for ways to save money. Did you know that the Canadian Government offers people with disabilities a way to do just that?

A registered disability savings plan (RDSP) is a savings plan that is intended to help parents and others save for the long-term financial security of a person who is eligible for the Disability Tax Credit.

Contributions to an RDSP are not tax deductible and can be made until the end of the year in which the beneficiary turns 59 years of age. Contributions that are withdrawn are not to be included as income for the beneficiary when paid out of a RDSP. However, the Canada disability savings grant (CDSG), Canada disability savings bond (CDSB) and investment income earned in the plan will be included in the beneficiary's income for tax purposes when paid out of the RDSP. It can be a little confusing navigating through it all. But there is lots of help available.

The Independent Living Resource Centre is providing info sessions regarding the RDSP and meeting with consumers one on one to help navigate all the information and paperwork. You can reach the ILRC by contacting:

Amanda Lush

Information & Networking Coordinator Independent Living Resource Centre 4 Escasoni Place, St. John's, NL 709-722-4031 or 1-866-722-4031

Email: amanda@ilrc-nl.ca www.ilrc-nl.ca



or you can contact Epilepsy Newfoundland and Labrador anytime and we will do all we can to help you out.

## A Little Time Out

George was on his way to bed when his wife told him that he'd left the light on in the shed. Grumbling, George went outside to go turn off the light soon realized there were people in his shed robbing him.

He ran back to the house and phoned the police. George explained the situation, but the police told him that all patrols were busy, and that he should stay inside, lock his house door, and an officer would be there when there was someone available.

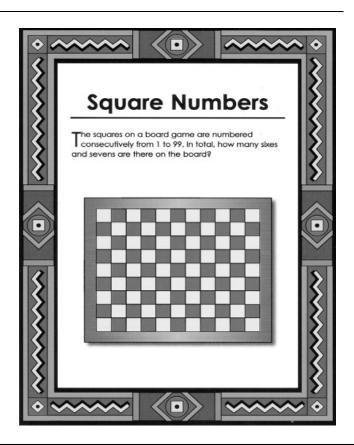
Furious, George said, "Okay," hung up, counted to 30, and phoned the police again.

"Hello, I just called you a few seconds ago because there were people in my shed. You said you couldn't come right away. Well, you don't have to worry about them now because I've just shot them all."

Within five minutes three police cars and an ambulance showed up. Of course, the police caught the burglars red-handed.

One of the policemen said to George: "I thought you said that you'd shot them!"

George said, "I thought you said there was nobody available!"





AN ELDERLY MAN WE CALLED KEITH
MISLAID HIS SET OF FALSE TEETH THEY'D BEEN LAID ON A CHAIR,
HE'D FORGOT THEY WERE THERE,
SAT DOWN, AND WAS BITTEN
BENEATH.

When I was in my younger days,
I weighed a few pounds less,
I needn't hold my tummy in
To wear a belted dress.

But now that I am older,
I've set my body free;
There's comfort of elastic
Where once my waist would be.

Inventor of those high-heeled shoes

My feet have not forgiven;

I have to wear a nine now,

But used to wear a seven.

And how about those pantyhose— They're sized by weight, you see, So how come when I put them on The crotch is at my knees?

I need to wear these glasses
As the prints were getting smaller;
And it wasn't very long ago
I know that I was taller.

Though my hair has turned to grey And my skin no longer fits, On the inside, I'm the same old me, Just the outside's changed a bit.

## **Email or Postal Mail?**

elp 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**

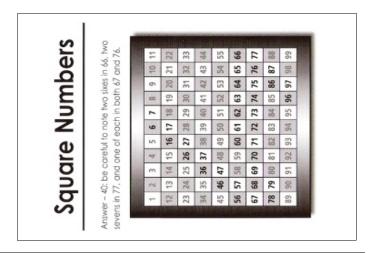
re you one of the over 400 million people on Facebook?

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.



# 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 voluntee	er. (We can use volunteers from righ	t across the province)
Name:	Er	nail:
Address:		Phone:
If you would prefer to use your credit of	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