



Epilepsy News

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

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Winter 2011

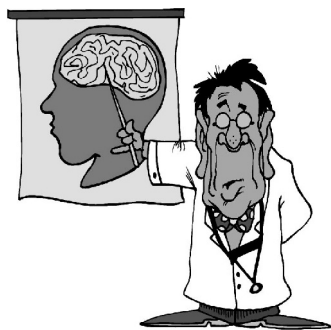
Ask the Doctors - A Question and Answer Forum

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

Want to share the stories and experiences of other individuals and families who struggle with epilepsy?

WE HAVE YOUR OPPORTUNITY!

On **Thursday, March 24th**, 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 22nd 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 24th at 7:00pm, at the Ramada Hotel on Kenmount Road.

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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(709) 722-0502 or toll free at 1-866-EPILEPSY
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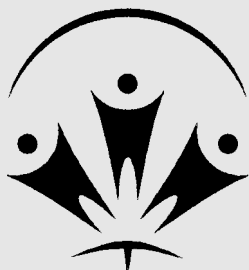
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On My Mind

**"Those who danced were thought to be quite insane
by those who could not hear the music."**

~ Angela Monet

I don't like the cold. I confess. I'm one of those chilly souls that usually has the heat up on cremate. Just ask the other poor folks here at the office that have to work with me every day. Which, of course, also means that I'm not much of a fan of winter. Oh I try, I really do, but watching the growing plow rows of dirty blackened snow and slush, navigating the icy roads and pathways, and bundling up with more layers than fingers can count, just doesn't do it for me. Winter settles into me like a heavy lethargy that I just can't shake.

Which is why I am always thrilled at even the briefest glimpse of spring. The evenings get brighter, the temperature begins to creep north of the freezing mark, people start smiling more, and life just seems a little bit better all around.

It is a chance to start new and fresh once more. Not just for nature, but for us too. We put off all sorts of things over the winter because we would rather hibernate than brave the elements. But now is our time to get out and do all the things we spent the winter waiting for.

Life is a lot like that too. When things are dark, and it seems as though everything around is cold and hopeless, we hunker down, bearing the burdens day by day, until, eventually, we can begin to see the light once more.

Let's not waste another minute of it.

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.

Our First Ever Live Interactive Webcast



Some of our members may remember Dr. Mark Sadler, who was a neurologist in St. John's at the Health Science Centre for many years. Joining him will be Susan Rahey, Coordinator of the Capital Health Epilepsy Program in Halifax. Moderating the webcast will be Epilepsy NL Executive Director and President of the Canadian Epilepsy Alliance, Gail Dempsey.

Sponsored by UCB Canada Inc., the webcast will be presented in front of a live audience at the Halifax Infirmary, Royal Bank Theatre, 1796 Summer Street.

Not in Halifax? No problem! The talk will be broadcast across the internet throughout Newfoundland and Labrador, Nova Scotia, New Brunswick and P.E.I.

On March 29th at 7pm NL time, head to your computer and point your browser to www.epilepsynl.com or www.epilepsyns.com. Click on the webcast icon, and it will bring you directly into the live interactive webcast. No setup or preparation necessary. A high speed internet connection will give you the best results.

Anyone with questions during the event, can submit them by email (preferred) or through the webcast chatroom.

For people without a computer or internet connection, Newfoundland and Labrador has a number of public Community Access (CAP) sites throughout the province. To find the one closest to you, get in touch with us at 1-866-EPILEPSY.

Find even more information though the even notices on our Facebook page, and check out our website a few days before the webcast to get even more details on how to access this rare opportunity from the comfort of your own home.

Epilepsy Newfoundland and Labrador, in partnership with Epilepsy Nova Scotia is proud to present a very special event.

"Current Strategies in the Treatment of Adult Epilepsy: What's New and What's Not"

On March 29th, 2011, Dr. Mark Sadler and Susan Rahey will broadcast via the internet, offering an educational and fascinating look at the new and latest in the world of epilepsy.

PURPLE DAY

for Epilepsy

March 26

Join us and wear purple
to promote epilepsy
awareness worldwide.

purpleday.org

Cassidy, 12 years old
Founder of Purple Day
with Hon. Mayann E. Francis
Nova Scotia, Canada

Christmas Tea for Epilepsy

The 2010

Christmas Tea for Epilepsy!

Our Christmas Tea for Epilepsy has wrapped up for 2010. 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 2010

Our Most Flavorful Sponsors




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

Paradise Bakery

Marie's Bakery

Our Grand Givers (\$500 and up)

Husky Energy

The Tea Masters (\$100.00 donations and up)

Barrett's Funeral Home
CNA - Prince Philip Drive
Cox & Palmer
Penney Mazda
Re-Max Plus Realty

Rogers Cable
The Telegram
Scotiabank - Water Street
Scotiabank Centennial Sq.
VOCM Cares

The Tea Specialists (\$50 and up)

BMO - Water Street
BMO - Elizabeth Ave
St John's Engineering
Catherine McCarthy
St. Pat's Mercy Home

MUNN Insurance
Scotiabank - Eli. Ave. E
AN Risk Services
TD Bank - Water St.

The Tea Apprentices (Donations up to \$50)

Jay Shepard
St. John's - Finance
Scotiabank - Cornwall
Scotiabank - Paradise

proactive - Atlantic
Proactive - Aberdeen
Proactive - Mt. Pearl
Adjusters Inc.

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 and goodies all about seizures.

Positively Purple Posse

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!

2010 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 you're 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 2011.

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



Free Money in Your Pocket!

It's tax time. Just the sound of it is enough to make most of us shudder. But for individuals living with a disability, tax time can also offer the opportunity to gain something a little more.

Disability Tax Credit

The Disability Tax Credit is a non-refundable tax credit used to reduce income tax payable for eligible individuals. To be eligible, you must meet all three of the following conditions:

- You must have a severe impairment in physical or mental functions.
- Your impairment must be prolonged - which means it has lasted or is expected to last for a continuous period of at least 12 months.
- A qualified practitioner certifies that your impairment is severe and prolonged and completes Form T2201, Disability Tax Credit Certificate, detailing the effects of the impairment applicable to the basic activities of daily living.

If you are eligible for this credit but are unable to use all or part of it because you have no taxable income, you can transfer it to your spouse, common-law partner, or other supporting person.

A supporting person may be able to claim all or part of a dependant's Disability Tax Credit providing that both the supporting person and the dependent were residents of Canada during the tax year.

Registered Disability Savings Plan

The Registered Disability Savings Plan (RDSP) is a savings plan designed specifically for people with disabilities in Canada. The first of its kind in the world, this new tax-deferred savings program will assist families in planning for the long-term financial security of their relatives with disabilities.

Over time, the RDSP will provide billions of dollars to supplement income, enable home ownership, and enhance quality of life for as many as 700,000 Canadians with disabilities.

In addition to the RDSP, some individuals may also be eligible for the Canada Disability Savings Grant and Bond.

Highlights of the Registered Disability Savings Plan

- Funds can be invested tax-free until withdrawal
- Anyone eligible for the Disability Tax Credit may set up an RDSP
- In the case of a minor child, a parent or guardian can establish and direct the RDSP
- A \$200,000 lifetime contribution limit
- Contributions by individual, family or friends
- No annual limit on contributions
- Contributions grow on a tax deferred basis
- No restrictions on when/why the funds are used
- Upon withdrawal, the income, the Grant, and the Bond are taxed in the hands of the beneficiary, and are likely to be taxed at a much lower rate

Highlights of the Canada Disability Savings Grant

- The CDSG will provide a federal contribution to assist families in saving for the future
- When annual net income is less than \$74,357 the grant will contribute:
 - \$3 for every \$1 contributed on the first \$500
 - \$2 for every \$1 contributed on the next \$1,000
- When annual net income is over \$74,357, the grant will contribute:
 - \$1 for every \$1 contributed up to \$1,000
- The Grant can be received for 20 years, until the beneficiary turns 50.

Highlights of the Canada Disability Savings Bond

- When annual net income is \$20,833 or less, **the Canada Disability Savings Bond will provide \$1,000 per year whether or not contributions are made to the plan**
- The RDSP thus becomes accessible to persons with disabilities whose family does not have the resources to make contributions
- Like the Grant, the Bond can be received for up to 20 years until the person's 50th birthday

The Registered Disability Saving Plan is exempt from the calculation of Income Support benefits in Nf & Lab!

For More Information

Disability Tax Credit:

- Contact Canada Revenue Agency at 1-866-741-0127

RDSP

- Contact your bank or financial institution

Off The News Wire

Breastfeeding Possibly Linked to Fewer Seizures in Kids

Babies that are breastfed may have fewer seizures after they're a year old, according to a recent study in Denmark. And the longer babies are breastfed, the better. Babies who had mom's milk for more than 9 months had fewer seizures than babies who had breast milk for a shorter time, report the authors in the *Journal of Pediatrics*.

Past studies have shown a link between breastfeeding and risk for mental disorders later in life, such as attention deficient disorder or schizophrenia, said Dr. Michael Kramer, professor of pediatrics at McGill University in Montreal, Canada, who was not involved in the study. But this is the first time anyone's looked at a possible link between the seizure disorder epilepsy and breastfeeding. Breastfeeding does a lot of good things, but this apparent protection against epilepsy "needs to be taken with a grain of salt, because it just hasn't been studied very much," Kramer told Reuters Health.

To see whether breastfeeding influences a child's likelihood of ever having epilepsy, the researchers looked at the early feeding habits of almost 70,000 children in Denmark born between 1996 and 2000 and followed until 2008. They talked to the mothers, and tracked how many kids had seizures after they were a year old.

In the study, kids who had been breastfed for at least 3 months had about a one in 135 chance of developing epilepsy after they were a year old. If they were breast-fed for at least 6 months, this chance dropped to about one in 150. Babies on breast milk for at least 9 months had about a one in 200 chance of getting the seizure disorder later.

The team also looked at whether consuming only breast milk, versus also eating some solid food, affected seizure risk. If a baby ate nothing else besides mom's milk for 4 months, it had about a one in 175 chance of having a seizure later.

This link between epilepsy and breast milk is not surprising, said Dr. Linda Friedman, associate professor of neuroscience at New York College of Osteopathic Medicine. Breast milk contains a lot of nutrients required for normal brain development in babies. "It's known that malnutrition during the developmental period can lead to seizures."

These results don't necessarily mean that feeding your baby breast milk will protect against epilepsy, Friedman said, and more research is needed to explore this link. Breastfeeding isn't as easy as many people think it is, Kramer said, but formula feeding doesn't have any known advantages over breastfeeding.

Reuters Health, February 7th, 2011

Epilepsy Drug Topiramate Linked To Cleft Lip And Palate Birth Defects

Topamax, and its generic version topiramate, taken during pregnancy, increase the likelihood of babies being born with cleft lip and cleft palate, new data suggests. The FDA says that doctors should warn their female patients of childbearing age about the possible dangers to the fetus if they become pregnant while taking topiramate. Topiramate is currently used for the treatment of epilepsy in adults and children.

Cleft lip is also known as cheiloschisis, while cleft palate is also known as palatoschisis. They are both types of abnormal developments of the face while the fetus is in the womb - they are types of clefting congenital deformities. In some cases, babies are born with both - cleft lip and palate. Before the baby is born, natural structures form in the body and fuse (join together). A cleft is when these structures do not fuse, there is a gap, also known as a fissure. When the gap occurs in the upper lip it is a cleft lip, in the roof of the mouth (palate) it is called a cleft palate. When both sides of the lip are affected it is called a bilateral cleft, just one side is a unilateral cleft.

Cleft lip and/or palate, also known collectively as oral clefts occur during the first trimester of pregnancy, when most women don't know they are pregnant. The baby can be born with a small notch in the lip to a gap that runs into the palate and nose, which may cause eating and talking problems, as well as ear infections. Surgery can be performed to close the lip and palate, usually successfully.

According to the North American Antiepileptic Drug Pregnancy Registry, there is a raised risk of cleft lip and/or palate in infants whose mothers took topiramate during the first three months of their pregnancy. The risk of being born with a cleft lip and/or palate is:

- 1.4% among infants exposed to topiramate as a single therapy during their mother's pregnancy
- 0.38% to 0.55% for infants whose mothers took other antiepileptic drugs during their first trimester
- 0.07% for infants whose mothers did not have epilepsy and took no antiepileptic drugs

Pregnant mothers and females of childbearing age who are considering taking topiramate should talk to their doctors about alternative treatments. A woman on topiramate who becomes pregnant or plans to do so should let her doctor know immediately. Do not stop taking topiramate unless your doctor tells you to. Those who become pregnant while on topiramate therapy should talk to their doctor about registering with the North American Antiepileptic Drug Pregnancy Registry.

FDA, March 5th, 2011

Scholarship Program for Students with Disabilities

Designed to assist students with disabilities in their pursuit for post-secondary education and training, The Canadian Council on Rehabilitation and Work (CCRW) is offering six scholarships in the amount of \$2,500.00 each, to be available for the academic year beginning September 2011.

To be considered, scholarship applicants must:

- Be a person with a long-term and reoccurring disability that restricts the ability of a person to perform the activities necessary to participate in educational activities. This limitation is expected to remain with the person for life.
- Be a high school student entering the first year of studies in a Canadian post-secondary institution at the undergraduate level.
- Be a full-time student (vs part-time).
- Not be involved in the selection process or be a close family member of any scholarship selection committee member.
- Not have been awarded one of these CCRW Scholarships in the past.

Eligible applications will also be evaluated on a number of factors including:

- * Community involvement
- * Extra-curricular activities
- * Approach to overcoming barriers
- * Academic performance
- * Educational goals and direction

To be considered, the application and all required documentation must be received at The Canadian Council on Rehabilitation and Work (CCRW) no later than 4:30 pm ET on Friday, April 15, 2011.



Application forms are available through The Canadian Council on Rehabilitation and Work (CCRW) website: www.ccrw.org or through info@ccrw.org

For more information, contact Epilepsy NL at 1-866-EPILEPSY or The Canadian Council on Rehabilitation and Work at 1-800-664-0925

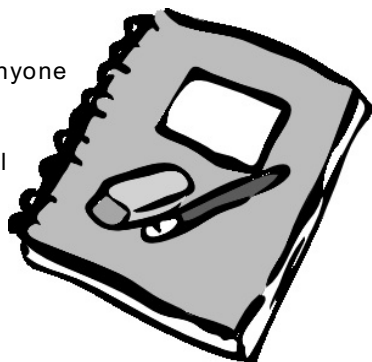
An Easy and Convenient Way to Keep Track

Everyone living with epilepsy knows the benefits of keeping track of seizures: connecting possible triggers with seizure activity, tracking the effectiveness of a new med, or just helping to remember when exactly that last seizure might have been.

The trouble is, hardly anyone actually does it.

But now there is a new tool to make keeping track a whole lot easier:

SeizureTracker.com.



SeizureTracker.com is dedicated to providing people living with epilepsy and their doctors with free tools to help understand relationships between seizure activity and anti-epileptic medications.

The easy-to-use tools found at SeizureTracker.com allow patients to create personalized reports of logged seizure activity and medication history that can be easily shared with their medical team.

Pretty neat stuff. And no more worrying about where you put your seizure journal, because it's all online anytime you want it. **Plus, it's all free!**

Check it out at www.seizuretracker.com.

A Little Time Out

Be the Best Whatever You Are

*If you can't be a pine on the top of the hill
Be a scrub in the valley--but be
The best little scrub by the side of the rill;
Be a bush if you can't be a tree.
If you can't be a bush be a bit of the grass,
And some highway some happier make;
If you can't be a muskie then just be a bass--
But the liveliest bass in the lake!
We can't all be captains, we've got to be crew,
There's something for all of us here.
There's big work to do and there's lesser to do,
And the task we must do is the near.
If you can't be a highway then just be a trail,
If you can't be the sun be a star;
It isn't by size that you win or you fail--
Be the best of whatever you are!*

Douglas Malloch

When I'm a little old lady, then I'll live with my children and
bring them great joy.

To repay all I've had from each girl and boy I shall draw on
the walls and scuff up the floor; run in and out without
closing the door.

I'll hide frogs in the pantry, socks under my bed. And
whenever they scold me, I'll hang my head.

I'll run and I'll romp, always fritter away the time to be
spent doing chores every day.

I'll pester my children when they are on the phone. As long
as they're busy I won't leave them alone.

Hide candy in closets, rocks in a drawer ... and never pick
up what I drop on the floor.

Dash off to the movies and not wash a dish. I'll plead for
allowance whenever I wish.

I'll stuff up the plumbing and deluge the floor. As soon as
they've mopped it, I'll flood it some more.

When they correct me, I'll lie down and cry, kicking and
screaming, not a tear in my eye.

I'll take all their pencils and flashlights, and then... when
they buy new ones, I'll take them again.

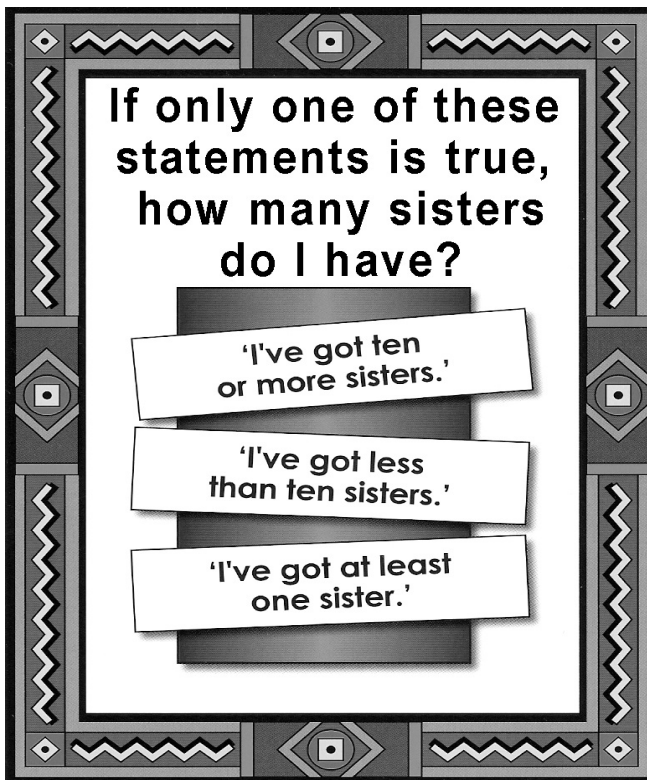
I'll spill glasses of milk to complete every meal Eat my
banana and just drop the peel.

Put toys on the table, spill jam on the floor. I'll break lots of
dishes as though I were four.

What fun I shall have, what joy it will be to Live with my
children....just the way that they lived with me!

Spring is when you feel like whistling
even with a shoe full of slush.

Doug Larson



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 search pages for Epilepsy Newfoundland and Labrador and you are sure to find us.

Or go to our website and click on the Facebook "Like" button on our front page.

Puzzle Answer
I don't have any sisters.
If "I've got at least one sister" is true, then "I've got ten or more sisters can also be true, and vice versa. "I've got less than ten sisters can be true all by itself, but only if I have no sisters at all.

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