



Epilepsy News

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

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Fall 2011

Epilepsy Patients Hit by Sudden Drug Shortages

A critical shortage in Canada of medications ranging from antibiotics to chemotherapy is now affecting some epilepsy patients, as drugs get pulled from the market often with little or no warning.



Responding to pressure from Ottawa, drug makers have just agreed to make information about impending national drug shortages available on two websites, the Saskatchewan Drug Information Services and Vendredi PM.

However, manufacturers have done little to address the actual shortages, which largely affect lower-cost generic drugs that have smaller profit margins.

According to a briefing note about anti-epileptic drug (AED) shortages by the Canadian Epilepsy Alliance, patients across the country are reporting that they can't access their medications.

Since 2009, there have been shortages of several anti-seizure drugs, including primidone, phenobarbital, ethosuximide, phenytoin and clobazam. All of the drugs except for phenytoin are generics.

"Sudden discontinuation of an AED is potentially life-threatening for someone with epilepsy," says the briefing note.

Robert Logan kept his epilepsy under control for 20 years with the help of medication, including primidone. When the drug maker stopped manufacturing primidone, his doctor switched him to another anti-seizure drug.

On the new medication, Logan, who also has cerebral palsy, suffered two grand mal seizures in quick succession and ended up in hospital, said his father, Dave.

"Whoever is responsible, they are playing with people's lives," Dave Logan told CTV News. "They are going to have cemeteries full, and the hospitals full."

Diane Sallows had a similar experience. Primidone kept her seizures under control for 60 years until July, when her nursing home ran out of the drug. She was forced to try phenobarbital, and within days she ended up in hospital with seizures.

"What is it going to take, someone to lose their life?" Dianne's sister Debbie Sallows told CTV. "So these drug companies have to supply patients' medications, or these patients have to be admitted to the hospital so they can receive their proper medications till these drug companies fill the right amount for long-term patients to stay alive."

Doctors say the notifications don't address the actual problem: the drug shortages. Dr. Richard McLachlan of the London Health Sciences Centre in Ontario, says patients often have no warning, and are told by the pharmacist that the drug is no longer available when they try to fill a prescription.

"These are drugs that have been around for 50 years or more," McLachlan, who serves as an adviser to the Canadian Epilepsy Alliance, told CTV News. "Why all of a sudden they have these problems when they didn't before is a bit peculiar."

Until drug companies explain the shortages, doctors and patients are left looking for answers. The only clue is that a number of drugs that disappear from the shelves are generics, which cost less and have lower profit margins.

CTV News, October 17th, 2011

Epilepsy medication should never be stopped or changed abruptly. If you have experienced a shortage with regards to your medication, please talk with your doctor or neurologist.

Don't wait till the last minute to refill your prescription!

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On My Mind

**"We do not remember days, we remember moments.
The richness of life lies in memories we have forgotten."
~ Cesare Paves**

My memory is terrible. I know it. I don't like it much, but I do know it. And because I know it, I do lots of things to make accommodations for it. Like keeping lists, and carrying an agenda with me wherever I go. Anything so I don't have that horrible 'oops, I forgot' feeling.

So when I talk with people who have memory problems as a result of their epilepsy or anti-epileptic medication, I can somewhat relate. Forgetting things sucks. Whether it is a meeting or an appointment time, or the name of your best friend's new baby, there is always some level of embarrassment that comes with not remembering.

I've been working on an event that I am hoping many people who live with seizures, and memory glitches will find useful. I want to do a presentation and discussion group on memory; the facts of it, and tips and tricks we can all use to help us along the way.

If this is something you might be interested in, let me know. I'll be sending out more information as some of the details get arranged, but for now, I just wanted to plant a little seed in your memory. :)

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.

Fall Excursion 2011 - Bonavista to Fortune

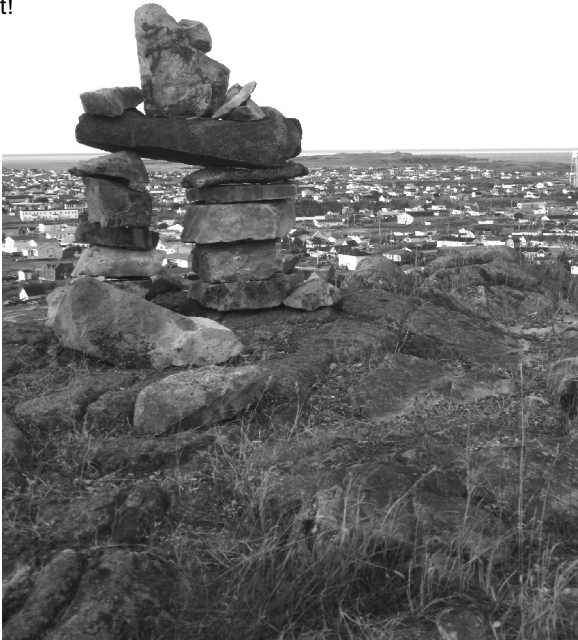


I love getting out and talking with people. It's one of the most rewarding parts of my job, to be able to share information, and hear stories in return.

Which is why I always eagerly look forward to Fall Excursion time, and pack as many presentations, workshops, meetings, and sessions into one week as I possibly can. It makes for a very busy week, but I wouldn't want it any other way.

This year, I pointed the car beyond the overpass and initially headed to Bonavista, doing several sessions there, plus another in Catalina. From there I took the long way around to Clarendville, stopping at King's Cove and Lethbridge. After Clarendville, I headed down the Burin Peninsula, spending time in Marystown, Burin, Burin Bay Arm, St. Lawrence and Fortune.

This year, I had the opportunity to do a lot more post-secondary schools than usual, just because of my locations. They were great!



In one post-secondary school, I did two sessions, each was supposed to have about 25 people. The first went well, with people asking lots of questions and sharing their own personal stories. After a break, I returned to the classroom to do the second session and thought I was in the wrong room. The class was full; it was standing room only! Apparently the folks in the first class had such positive things to say, that word spread, and anyone that could, decided to slip into the second presentation to see what it was all about. Very cool!



I also got the opportunity to meet with several clients one-on-one along the way as well, which I am always happy to do.

Throughout the week, I talked with groups at daycares, elementary students, high school students, post-secondary students, home care workers, RCMP officers, community organizations, and individuals.

I did 33 presentations while I was away, sharing information and awareness with over 1200 people, and left information behind at many more places. Whew! What a great week.

If you would like us to come to your town, let me know. Perhaps it'll be your corner of the province we visit next!



Handy Gadgets and ADPS for People with Epilepsy

Technology has come a long way in a relatively short period of time. We've gone from adding machines, to calculators to computers seemingly at lightening speed.

Along with all those technological advances has come some really handy gadgets and computer programs that can assist people with epilepsy in everything from staying safe, to keeping more informed.

If you would like information on how each works, or where to buy them, call us at 1-866-374-5377 or email info@epilepsynl.com and we would be happy to help you out.

SEIZURE TRACKERS

We all know how much we can learn from tracking seizures. Documenting the details of each seizure, the duration, possible triggers, what happened after, can be helpful in understanding the characteristics of an individual person's epilepsy. But how many of us do it? **Solutions we have found:**

- SeizureTracker.com provides easy to use and free software to assist in keeping track of all the details surrounding your seizures. The information is downloadable and printable, making it easy to bring with you on a visit to the doctor.
- If you own an iPhone, SeizureTracker.com has made your information even more portable with the release of the Seizure Tracker iPhone app. All your information on the go.
- Not a technological soul? Seizure journals, allow you to simply document your information on pen and paper, and are available through our office upon request.

REMINDERS

Taking medication on-time can be such an important step in achieving or maintaining seizure control. But for some people, epilepsy, and epilepsy medication can cause memory issues, so remembering to take meds in a timely manner can be a real challenge. **Solutions we have found:**

- CADEX, and other companies have wristwatches that will remind you of the exact time to take your medication.
- Also available are vibrating pill cases, and multi-alarm cases that will buzz or beep when it's medication time.



SENSORS

Nocturnal seizures can be scary because there might not be anyone else awake to know that a seizure is happening. While someone sleeping in the same bed might wake up, a person in another room might hear nothing at all. However, maintaining a balance between safety and personal space is important for fostering independence. **Solutions we have found:**

- Under the mattress motion sensors can either sound an alarm or send a message to a monitor in a different room indicating that unusual movement is occurring.
- For a lower cost alternative, baby monitors can be very useful for younger children. For older children and adults, the loss of privacy must always be weighed against the benefits gained.
- For individuals with Complex Partial Seizures who are prone to wandering, motion activated door sensors can also send an alert when a door has been opened.



ALERTS

Many individuals with epilepsy live alone, and cherish their independence. But what happens if someone had a seizure and got hurt? What if there was no one close by, or they couldn't reach the phone? **Solutions we have found:**

- Companies like Lifeline and Direct Alert provide wearable push button alarms that will notify medical assistance or a family member in case of an emergency.
- Some companies also provide motion sensors within their call buttons, so that if unusual motion is detected, and a person doesn't respond to a call, assistance will be automatically notified.

Want to know if any of the gadgets listed here are right for you? Talk with your doctor or neurologist.

The New Home of ENL



October 22, 2011

Back in the summer we made a huge announcement: that within the next short while, **Epilepsy Newfoundland and Labrador and Previously Loved Clothes and Things** will be moving to its very own building at 351 Kenmount Road, St. John's!

Well, it's been a couple months since then, and work has now begun. Actually, things are progressing fairly quickly at the new building site as you can see. With a little bit of luck and hard work, we will be moved in and settled away early in the new year.



November 7, 2011

Christmas Tea for Epilepsy

*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*

*The 8th
Annual
Christmas
Tea for
Epilepsy*



How it works - Gather your staff, family or friends and sit back, relax, and enjoy a cup of tea on us, any time during the weeks of November 29th – December 10th, 2010.

In return, you can do one of several things:

- Share the goodies over a tea break, and have everyone contribute a loonie or twoonie.
- Make a direct donation from your company or staff social fund, and offer the tea and sweets to all as a treat.
- Raffle the basket of goodies off, and donate the proceeds.
- individuals can buy one directly as a gift for someone special.

Every individual or group that participates will also be included in our **Tea Folk Hall of Fame**, which will be posted on our website at www.epilepsynl.com, as well as mailed to several hundred homes in our January newsletter.

Getting involved is easy - just call **722-0502** or email info@epilepsynl.com and we will do the rest.

Remembering Zach

Back in 2009 ENL Member and former scholarship recipient Zach Rowe passed away as a result of his epilepsy. He was only 21.

In 2006, when Zach was awarded one of our scholarships he wrote:

"I have never let my disability stop me from having a normal life. All of this just makes me even more determined."

As a fitting tribute we established the **Zach Rowe Memorial Scholarship**. A \$1000 annual scholarship, available to graduating high school students with epilepsy throughout the province, who continue on to pursue their career dreams through post-secondary training.

To support Zach's legacy, for the past two years, his family and friends have gathered each year on Labour Day weekend for a day of fun, food, games, and happy memories. All funds raised, have been donated to ENL to support our scholarships so that even more young people will get a helping hand in their post-secondary studies.

This year, their event raised a whopping \$1761.

Epilepsy Newfoundland and Labrador would like to thank Joan Parsons (Zach's grandmother, and all of the Rowe family for organizing this event and the support of our programs.

We would also like to thank Jim & Donna White who so graciously offered space for the event and all the family and friends who donated throughout the day.

As well, we want to recognize Neal Saunders of Molson, and Atlantic Towing for their generous contributions.



Zach's grandmother, Joan Parsons presents a donation of \$1761.00 to Pamela Anstey, Information Officer with ENL.

Asked and Answered

Q My son was recently diagnosed with substantial subclinical epilepsy activity. He is having a lot of behavioural and attention problems at school, but the teachers are having difficulty believing that it is epilepsy related, because there is no visible seizure activity. What can I do?

A Before we get into your question about what to do, let's pause for a second and review the difference between clinical and subclinical seizure activity.

In **clinical seizures** there is an obvious change that occurs during the seizure. What actually happens will depend on what part of the brain is having the seizure. The person may twitch or have convulsions, they may go blank and stare off for a few seconds, they may wander, or do odd repetitive movements with their hands, or they may even experience a strange taste or smell.

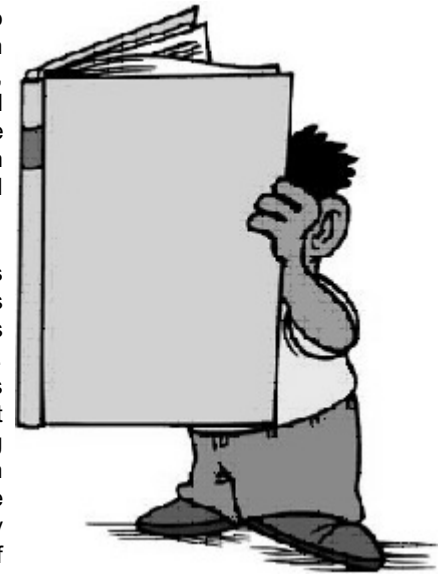
In **subclinical** seizure activity there is no obvious change or movement at all, even though the EEG records electrical seizures. This does not mean the seizures are not having an effect on the person, but this effect may be on acquired skills such as language, social communication or abstract thought.

So if your son is having only subclinical seizures, there really isn't anything to see, but there is lots happening within his brain, affecting how he learns, how he understands, and how he relates to other people.

If his teachers are having challenges differentiating naughty behaviour and seizure activity, one of the best things you can do is educate them.

We can offer lots of educational resources that you can pass along. Additionally, we can also arrange a session to talk with the teachers and explain just what is happening.

I know it can be really frustrating when people don't recognize seizure activity for what it really is, but with a little support, and a little willingness on the part of the teachers, we can make things a whole lot easier for your son.



Off The News Wire

Epilepsy Surgery Keeps Half Of Patients Seizure Free For At Least Ten Years

Patients with epilepsy who do not respond properly to medication should be considered for surgery more promptly, researchers from University College London's Institute of Neurology reported in *The Lancet*. The authors wrote that nearly half (47%) of all epilepsy patients who underwent surgery were seizure free ten years later.

The authors explained that surgery for refractory focal epilepsy is becoming more common. However, there have been few thorough reports on the long-term outcome of such procedures.

Prof John S Duncan, FRCP, and team set out to determine what long-term effect surgery might have on patients with epilepsy - they focused on patterns of seizure remission and relapse after surgery. They monitored 615 adult patients yearly for eight years. The patients underwent the following surgical procedures:

- * Anterior temporal resection - 497
- * Temporal lesionectomy - 40
- * Extratemporal lesionectomy - 40
- * Extratemporal resection - 20
- * Hemispherectomy - 11
- * Palliative procedures - 7

They found that 52% of them were still seizure free after five years (apart of simple partial seizures). After ten years 47% were still seizure free.

The longer a patient remained seizure free the lower his chances were of a subsequent relapse, the researchers found. In 18 of 93 patients, a late seizure recurrence was linked to the usage of an untried antiepileptic medication.

At the latest follow-up, 28% of the seizure-free participants were not on medications.

A patient who had a simple partial seizure (SPS) within two years of temporal lobe surgery was 2.5 times as likely to experience further seizures compared to those with no SPS.

Experts say patients should consider surgery sooner rather than later. Prof. Duncan said patients should also be realistic about the risks.

The authors say that the surgical methods and selection process for surgery need improving so that success rates are boosted. More care also needs to be taken to identify those who are not suitable for surgery.

Excerpted from: Christian Nordqvist, Medical News Today, 14 Oct 2011

Researchers Find Link Between Epilepsy, Schizophrenia Risk

Connection may stem from genetic or environmental factors, experts say

People affected by epilepsy are nearly eight times more likely than those without it to develop schizophrenia, and those with schizophrenia are also six times more likely to have epilepsy than people who are not schizophrenic, a new study suggests.

Researchers in Taiwan say this two-way relationship between the two conditions may be due to genetic, environmental or neurobiological causes.

After analyzing information on almost 5,200 patients with schizophrenia and more than 11,500 patients with epilepsy and controls matched for age and sex in both groups, researchers found the prevalence of epilepsy was higher in the schizophrenia patient group at about 7 per 1,000 person-years, compared to just over 1 per 1,000 among those not affected by schizophrenia.

Meanwhile the study, published in *Epilepsia*, showed the prevalence of schizophrenia was about 3.5 per 1,000 person-years for patients with epilepsy, compared to about 0.5 among those without epilepsy. The researchers noted the incidence of schizophrenia was slightly higher among men with the disease than women.

"Our research results show a strong bidirectional relation between schizophrenia and epilepsy," said the study's lead author Dr. I-Ching Chou, an associate professor with China Medical University in Taichung, Taiwan, in a journal news release. "This relationship may be due to common pathogenesis in these diseases such as genetic susceptibility and environmental factors, but further investigation of the pathological mechanisms are needed."

Mary Elizabeth Dallas

Wiley-Blackwell, news release, HealthDay, September 19, 2011

I cannot believe that the purpose of life is to be "happy."
I think the purpose of life is to be useful,
to be responsible, to be compassionate.
It is, above all, to matter and to count,
to stand for something,
to have made some difference that you lived at all.

- Leo C. Rosten

2012 Epilepsy NL Pocket Calendars are Here!



**2012 Pocket Calendars are now available.
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 2012 Pocket Calendar with artwork by grade 4 children from all over our province.

The 2012 calendar includes artwork from across NL.

1. Matthew Milley, Elizabeth Park Elementary, Paradise
2. Robyn Green, Donald C. Jamieson Acad., Burin Bay Arm
3. Sara Drover, Victoria Academy, Gaultois
4. Kaelyn Mercer, Burgeo Academy, Burgeo
5. Julia Rumbolt, St. Mary's All Grade, Mary's Harbour
6. Zoe Steiner, Lewisporte Academy, Lewisporte
7. Kylei Patey, Glovertown Academy, Glovertown
8. Kyle Piercey, Perlwin Elementary, Winterton
9. Adrian Sparkes, French Shore Academy, Port Saunders
10. Danielle Gould, Canon Richards Memorial, Flower's Cove
11. Riley Pye, St. Mary's All Grade, Mary's Harbour
12. Jaydon Alyward, French Shore Academy, Port Saunders
13. Patrick Carroll, Cottrell's Cove Academy, Cottrell's Cove

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

THE PEOPLE'S PAPER
The Telegram

A Proud Supporter of
Epilepsy Newfoundland and Labrador

Happy Holidays from ENL and Previously Loved

This will be the last newsletter of 2011. So although it's a little early, all of us here at Epilepsy Newfoundland and Labrador and Previously Loved Clothes and Things would like to wish all our members, supporters, and friends a very blessed and happy holiday, and an incredible 2012 filled with love and joy.

Our offices will be closed for Christmas week and will re-open after the New Year.

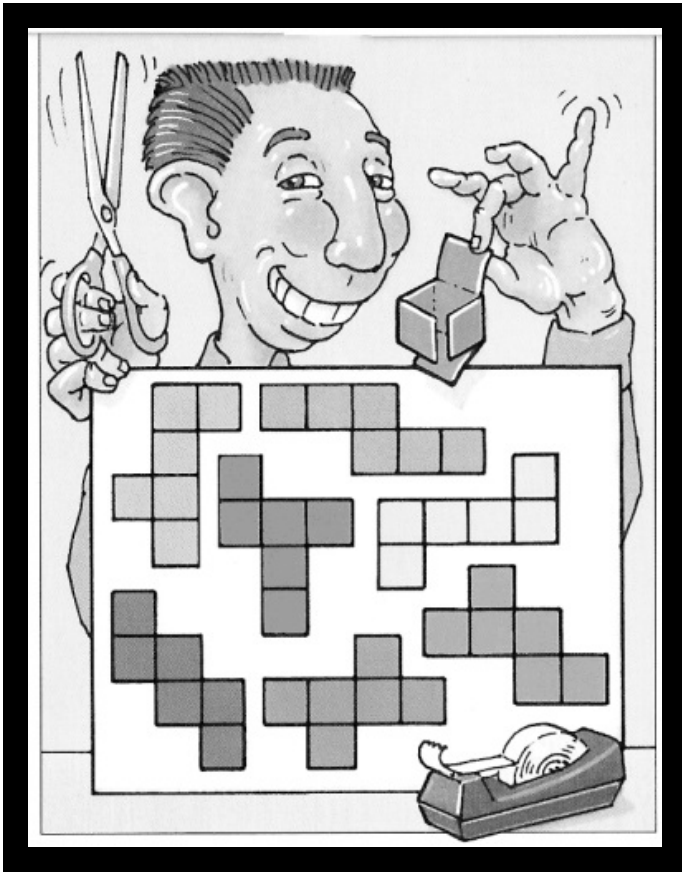
We look forward to continuing to share the message of understanding and acceptance of all those living with epilepsy, through the new year and beyond.



I got tired of looking at all those leaves in my yard, so I got up off the couch and went into action.

I closed the curtains. 😊

A Little Time Out



If you were to cut each of these shapes out of paper, which of them could you somehow fold into a perfect cube?

An old snake goes to see his Doctor. "Doc, I need something for my eyes, I can't see very well these days."

The Doc fixes him up with a pair of glasses and tells him to return in 2 weeks.

The snake comes back in 2 weeks and tells the doctor he's very depressed.

Doc says, "What's the problem? Didn't the glasses help you?"

"The glasses are fine doc, but I just discovered I've been living with a garden hose the past 2 years!"



A family decided to go on a safari in Africa. They took their faithful pet dog along for company.

One day the dog starts chasing butterflies and before long he discovers that he is lost. So, wandering about he notices a leopard heading rapidly in his direction with the obvious intention of having lunch.

The dog thinks, "Boy, I'm in deep doo doo now."

Then he noticed some bones on the ground close by, and immediately settles down to chew on the bones with his back to the approaching cat.

Just as the leopard is about to leap, the dog exclaims loudly, "Man, that was one delicious leopard. I wonder if there are any more around here?" Hearing this the leopard halts his attack in mid stride, as a look of terror comes over him, and slinks away into the trees.

"Whew", says the leopard. "That was close. That dog nearly had me." Meanwhile, a monkey who had been watching the whole scene from a nearby tree, figures he can put this knowledge to good use and trade it for protection from the leopard.

So, off he goes. But the dog saw him heading after the leopard with great speed, and figured that something must be up. The monkey soon catches up with the leopard, spills the beans and strikes a deal for himself with the leopard.

The cat is furious at being made a fool of and says, "Here monkey, hop on my back and see what's going to happen to that conniving canine."

Now the dog sees the leopard coming with the monkey on his back, and thinks, "What am I going to do now?" But instead of running, the dog sits down with his back to his attackers pretending he hasn't seen them yet.

And just when they get close enough to hear, the dog says, "Where's that monkey. I just can never trust him. I sent him off half an hour ago to bring me another leopard, and he's still not back!!"



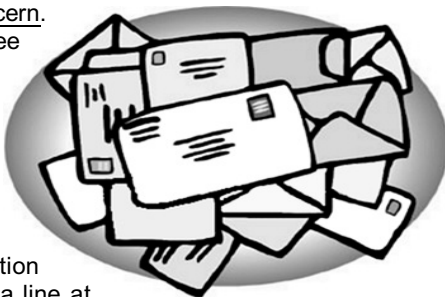
Email or Postal Mail?

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.

If you're clever, each of the shapes can be folded into a perfect cube.

Puzzle Solution:

I Would Like To Help in the Fight Against Epilepsy

- ☐ I am enclosing a donation of \$_____
- ☐ I would like to become a member of Epilepsy NL. I am enclosing my \$5.00 membership fee.
- ☐ I would like to become a volunteer. (We can use volunteers from right across the province)

Name:	Email:
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Address:

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

Account #	Type of card:	Expiry:
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