



Epilepsy News

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

THE QUARTERLY NEWSLETTER OF EPILEPSY NEWFOUNDLAND AND LABRADOR

FALL - WINTER 2009

Epilepsy NL Scholarship Winners 2009

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

The **Mature Student Scholarship**, valued at \$1000 honours a current student with epilepsy who has taken the initiative to return to studies to advance in their present job or train for a new career.

This year the Mature Student Scholarship was awarded to **Antje Springmann** of Clarke's Beach, currently studying at Memorial University to become a Counsellor.

I was diagnosed with epilepsy over a decade ago but it has been part of my life for much longer. The seizures I live with are difficult to diagnose and mimic many other conditions. Sudden onset of dizziness, nausea, extreme fatigue, disorientation, feeling faint, night-terrors - all were something I tried to accept until they eventually became so frequent that I became close to incapacitated.



Some may say that living with epilepsy is a burden, and it can be. I have learned that there are sacrifices to be made. Many times I have had to work hard to stay calm and confident, to not allow epilepsy determine how far I can go. At

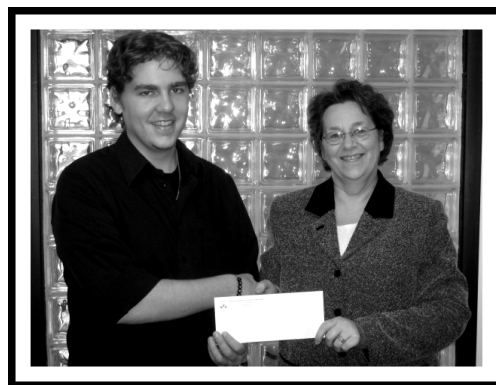
my lowest times it was hard to leave my house for fear I might have a seizure.

I put off going back to academics for many years. I was afraid that my brain would let me down. It was a lot to risk. But when you have been very ill you receive a gift of grace. You carry in you the crystal clear knowledge that life is fragile and passes by so very quickly. If something is truly important to you, you had better go after it while you can.

The **Jim Hierlihy Memorial Scholarship**, also valued at \$1000 is awarded to a student with epilepsy who will be continuing on to Post Secondary studies after High School.

Our winner for 2009 is **Joey Callanan** of St. John's, a new student at the College of the North Atlantic, working towards a career in the computer field.

I had my first seizure when I was eight years old. I did not know how serious it would become and what a big affect, both bad and good, that it would have on my life. By the time I was in junior high school I was having as many as three seizures a week and they would come in clusters that could last forty minutes.



I missed a lot of school and time with my friends. People seemed to treat me differently and school was extremely difficult. I was always tired and I had no concentration.

I think my experience with epilepsy has taught me a lot about life and people. My experience with people I have met through epilepsy has helped me become more caring, understanding and patient. Four years ago I had a very complicated and successful brain surgery to treat my epilepsy. The recovery was long and slow but now things are really looking up.

Epilepsy Newfoundland and Labrador takes great pleasure in extending our sincerest congratulations to Antje and Joey on all their achievements.

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

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On My Mind

An epilepsy sufferer has courted controversy in Britain by creating a public performance in which she will attempt to bring on a seizure and allow the audience to film it on their mobile phones.

Rita Marcalo, who suffers around two seizures a year even on medication, has stopped taking treatment ahead of next month's production of "Involuntary Dances," which she claims is to raise awareness of epilepsy.

But Marcalo is facing criticism for putting herself at risk and for the voyeuristic nature of the 24-hour event which is being funded by a 13,889-pound (\$22,910) government arts grant.

Seizures as art? When I read this news clip a while ago I was initially dumbfounded. That someone would want to willingly provoke a seizure just so other people can watch, and record it, seems absurd to me.

I do understand what she is trying to achieve. What better way to raise awareness than to offer people the opportunity to see a seizure in a personal and live setting? It is dramatic, controversial, and it certainly has people talking.

But the thought of seizures as a spectator sport just leaves a bad taste in my mouth. Stopping medications abruptly is dangerous, and could bring on life-threatening status seizures. Add to that the fact that the government is funding her to do this.

The audience will be provided with sleeping bags and breakfast. They will be awakened by a siren the moment that Marcalo suffers a seizure, which they are permitted to record on their mobile phones.

Breakfast!? When did we all become so desensitized that this passes for entertainment? What are your thoughts on this? Write or call and let me know. I would love to hear what everyone else thinks.

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.

Special Authorization

What would you do if you couldn't afford the medication that your neurologist felt would assist you in controlling your seizures?

That is a question that many with epilepsy have faced throughout the years. Fortunately, here in this province, the provincial government implemented the NL Prescription Drug Plan (NLPDP) a few years ago to help in just these situations.

This plan has assisted thousands of people in NL so far, and for the most part, runs smoothly and effectively. Sometimes, however, there is a little snag.

Not all drugs are automatically covered by the NLPDP however. Some require Special Authorization. Among these are several anti-epileptic drugs including carbamazepine (Tegretol suspension), topiramate (Topomax), oxcarbazepine (Trileptal), levetiracetam (Keppra), and gabapentin.

In order for any of these drugs to be covered under the NLPDP, certain conditions must be met, and this can often include considerable forms, paperwork, and red tape.

In addition, depending on the number of requests being submitted, the wait times for authorization can be lengthy, sometimes stretching to well over a month.

This leaves a person with two options:

- pay for the drugs out-of-pocket. When the authorization comes through, people can submit the receipts for their medications, and be reimbursed. However, anti-epileptic medication can be costly, and for people with limited funds, it may mean having to choose between their epilepsy drugs and other household expenses, like groceries and heat.
- or wait, putting the possibility of better seizure control on hold for weeks.

Neither option is very appealing. No one should have to risk additional weeks of seizures, or go broke, in order to get their medications.

If you find yourself in this situation, please let us know. We can help you navigate the paperwork involved in the Special Authorization application.

We can also work with you and your pharmacy to find a way for you to begin your medications without having to wait, or go broke from the expense of it all. You can reach us by calling 1-866-EPILEPSY (1-866-374-5377).

Phenobarbital Supplies Delayed

Back in June, ENL sent out an alert to all members regarding Phenobarbital. Health Canada had announced that :

Phenobarbital tablets in the 60 milligram (mg) format (DIN 00178810) are being recalled because some oversized tablets were recently found on the Canadian market. The oversized tablets were found to contain more Phenobarbital than the label indicates, exposing patients to the potential risk of accidental overdose. The Canadian distributor, Pharmascience Inc. of Montreal Quebec, has initiated a recall of all lots presently on the market.



That was a few months ago. Now, possibly as a result of this recall, it would seem that in some parts of the country, the supplies of phenobarbital are pretty scarce. Pharmacies are running out of some dosages. The most recent information we have from Pharmascience Inc, the distributor of phenobarbital, gives the following time lines for additional shipments:

15mg & 30 mg tablets - shipping mid to late December

100mg tablets - backorder until the end of January

60mg tablets - currently being delivered to pharmacies

Elixir (liquid) - currently being delivered to pharmacies

If you are taking phenobarbital in any form, please check with your pharmacy to ensure they have adequate supply. If your pharmacy has run out, contact us at Epilepsy NL for assistance.

'Tis the Season to Indulge... with Caution

It's the season of parties and socialization to be sure. This time of year can bring on an overabundance of opportunities to indulge. It seems that everywhere you turn someone is offering you a glass of wine or a nip of a festive toddy.



But if you have seizures, how much is too much? Is it even safe for people with epilepsy to drink at all?

Is alcohol harmful?

Alcohol is one of the oldest and most widely used drugs. When it is abused it can cause serious harm. The acute effects of an overdose are well known. When we are "drunk" we lose our ability to think clearly, and our ideas change about what is right and wrong. Our ability to carry out activities such as driving a car is markedly impaired. Many people die unnecessarily each year from both alcohol-related motor accidents and simple overdoses of this drug. Too much alcohol is frequently associated with poor nutrition and damage to the liver, pancreas, nerves and brain can occur.

Alcohol can produce a calming affect and a sense of relaxation when taken in small doses. In many social situations its use is encouraged, and people who do not engage in "social drinking" are considered "different" or even "abnormal".

Can alcohol itself cause seizures?

Convulsions can occur to anyone as part of *delirium tremens*, the withdrawal syndrome that may follow when excessive drinking stops.

Can a person with epilepsy drink alcohol?

It has been assumed that alcohol is bad for everyone with epilepsy but there is no clear evidence that infrequent use of small amounts of alcohol would be harmful to people with well-controlled epilepsy. However, in persons with uncontrolled epilepsy, even a small amount of alcohol may aggravate seizures and cause problems. Seizures can also be caused by missing medications when you drink, or by missing a lot of sleep.

Is it safe to drink alcohol while taking AEDs?

Many anti-convulsants have a degree of sedation as a side effect, which will add to the sedative effect of the alcohol consumed. This means it will take fewer drinks to "get drunk" than if you were not taking medication. If you choose to drink alcohol, you will need to know your limits and stick to them. The results of mixing alcohol with anti-convulsants also depend on which medication you are taking, and this should be discussed with your doctor.

Can alcohol affect my medication?

Alcohol can affect the rate at which certain medications are absorbed by the body. Dilantin, for instance, will be eliminated more rapidly. Alcohol may also worsen your medication's side effects.

Should I stop taking my drugs when I drink?

Absolutely not! Alcohol is not an anticonvulsant drug, and it may even lower the seizure threshold.

If a person with epilepsy decides to drink, what rules should they follow?

If you choose to drink, do so in moderation, and be careful not to skip medications or sleep. Remember, you are subject to all the risks and dangers of alcohol consumption. Do not risk becoming dependent on alcohol in an effort to resolve the frustrations that epilepsy has caused in your life. If you find that even small or infrequent alcohol consumption causes you to have seizures, it is best to avoid drinking completely. Be particularly careful when you are starting a new medication or changing the dose of your old medication as these changes, may alter your alcohol "limit". You and your physician are the individuals most familiar with your particular case. Establish and continue a working relationship, and consult your physician for advice about using alcohol.



So if you do choose to indulge during this holiday season, please do so cautiously, and limit yourself. When the next day comes, you'll be glad you did.

The Great Northern Peninsula - Excursion 2009

I don't think there is any spot more beautiful in Newfoundland than the Northern Peninsula. Between the mountains, the ocean, and the wide open sky, it seems they all compete to see who can provoke the greatest awe.

But as beautiful as my trip was this year, it was also a very sad reminder that so much of rural Newfoundland is struggling.

On September 20th I pointed myself west and didn't stop till I landed at the very tip of the Northern Peninsula.



*I made a friend in St.
Anthony!*

The Fall Excursion this year took me to places I had never been before, and a couple I'd never even heard of. I started in St. Lunaire-Griquet, then St. Anthony, followed by Plum Point, Roddickton, Englee, Port au Choix, Port Saunders, and Corner Brook.

Initially, I had no intentions of going to Corner Brook on this trip, however the week previous to leaving, I was contacted by the College of the North Atlantic in Corner Brook to see if I might come to talk with their students while I was on the west coast. They had learned of my trip from the College in St. Anthony.

I'm glad I opted to go to Corner Brook even though it wasn't part of the plan. I did two very full sessions at CNA, and two very full ones at Academy Canada, all of which were received with interest and animated discussions.

It also gave me the opportunity to talk with a daycare in the evening. Because there was only time to meet with one daycare group, the centre that I contacted asked if they could invite the others and then arranged an evening workshop for ALL of the daycare centres in Corner Brook to come and participate in my session. It was incredible.

I thought I would never make it to Roddickton and Englee. The trip across the peninsula is through nothing but woods. And while the trees were turning all sorts of gorgeous colours, it can seem like an eternity when every kilometer is identical. But the people there were wonderful. The school sessions I did there were possibly some of the best I did on this trip.

This was in stark contrast to the neighbouring town of Main Point, where I had contacted the school prior to leaving to see if I might talk with some of their students while I was in the area. The principal there was uninterested, and after several days of avoiding my calls, finally stated that they couldn't accommodate our "little presentation."

This trip was different in many ways. Some of the schools I visited were very small indeed; having no more than 20 or 30 students all the grades combined. Towns were remote, and there were many that I didn't get to at all that I would have loved to have visited.

Throughout the course of the week, I did a total of 23 sessions. Some schools I had booked in with, upon arriving, wanted me to do an extra grade or two. I tried to rearrange things to fit in as many people as I could. With the distance between towns taking up considerable time for driving, sometimes that wasn't easy, but I certainly tried.

Even with all the driving, I was fortunate. I only saw two moose, one from a great distance at L'Anse aux Meadows, and the other stuffed, inside the

Roddickton Town Office, and that was just fine by me.

Pam Anstey,
Information Officer, Epilepsy NL



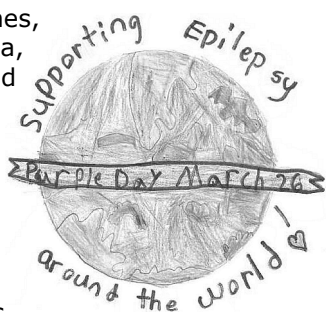
Become an Ambassador of Purple

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

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

Last year, people of many countries came together to bring epilepsy out of the shadows.

People from the UK, Philippines, South Africa, Israel, Australia, Argentina, the US, Canada, and many others, wore their purple proudly to let everyone who lives with seizures know that they are not alone. Actors, celebrities, politicians, models, musicians, and thousands of people young and old. It was inspiring, emotional, and simply beautiful.



We were thrilled to be a part of it all here in Nf and Lab. Organizations, businesses, students, and individuals all over the province joined in and wore purple on March 26th. Some as part of an event or fundraiser, and some just because it was important to them.

Be an Ambassador of Purple for Purple Day 2010!

March 2010 will be here soon, and Cassidy Megan and the Purple Day Committee are looking for ambassadors to help spread the word about epilepsy awareness and make Purple Day 2010 even bigger than last year.

Whether you are a person living with epilepsy, a friend, a family member, or simply someone who believes that it's time to paint the world purple, you can help!

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

By becoming an Ambassador of Purple, you will be an important part of an event celebrated in small towns, remote villages, and huge cities around the globe.

To become a Purple Day Ambassador for your town contact us at ENL, or visit www.purpleday.org.

In Memory of Zach Rowe

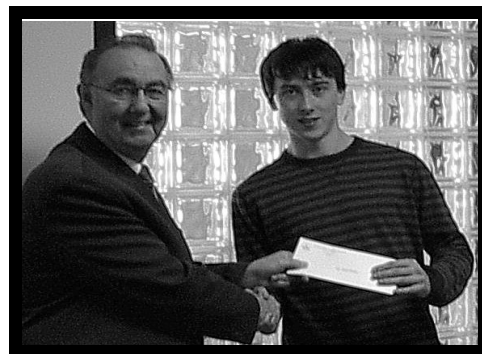
There was some sad news recently when ENL learned of the passing of Zach Rowe from Carbonear on September 20th. He was only 21.

Zach was the winner of the ENL Jim Hierlihy Memorial Scholarship back in 2006. He'd had epilepsy since he was seven but refused to let his seizures interfere with the life he wanted for himself.

Back in 2006 he told us:

"I have never let my disability stop me from having a normal life. I know I'll always be on medication, and I'll never get my licence. All of this make me even more determined"

On behalf of everyone here at Epilepsy Newfoundland and Labrador, we want to extend our deepest sympathies to all of Zach's friends and family. He will not be forgotten.



Zach Rowe, seen here in a 2006 photo, receiving his scholarship from ENL President Ron Stone.

Off The News Wire

Molecular Trigger For SUDEP Found

The most common gene for a syndrome associated with abnormal heart rhythms and sudden death triggers epileptic seizures and could explain sudden unexplained death in epilepsy, said researchers from Baylor College of Medicine.

Idiopathic (unexplained) epilepsy is one of neurology's oldest mysteries. While most persons with epilepsy will have a normal lifespan, our finding now points the way to a simple and essential test to identify risk for sudden death in persons with seizures of unknown origin. In these patients, a routine cardiology evaluation consisting of an EKG, and if indicated, a genetic screening test for this family of genes can positively identify this new risk factor. If the gene test is positive, there are effective treatments for the heart irregularity, including drugs known as beta blockers, as well as the use of a cardiac pacemaker to prevent lethal arrhythmias.

As many as 18 percent of deaths in epilepsy come suddenly without warning, devastating families.

Living with epilepsy is difficult enough, but unexpectedly dying from it, as happens in young adults with the disorder, is one of the greatest fears a family must face.

No one knew why young people with epilepsy died suddenly, but researchers found that an ion channel gene thought to work only in the heart was active in the brain as well. She examined five ion channel genes linked to long QT syndrome, a disorder associated with heart rhythm disorders and sudden death.

Long QT refers to an interval in electrocardiograms – the QT interval, which is prolonged in this disorder. An ion channel is a tiny pore in a membrane that controls the flow of ions such as calcium and potassium in and out of a cell.

They found that mice with a mutation in the gene that encodes for the KvLQT1 ion channel had frequent epileptic seizures as well as life-threatening heart rhythm irregularities.

This demonstrates the long-sought molecular link between heart and brain in epilepsy. We are now screening epilepsy patients to determine whether they have the same gene mutation.

ScienceDaily (Oct. 15, 2009)

Current Cigarette Smokers at Increased Risk of Seizures

A recent study determined there is a significant risk of seizure for individuals who currently smoke cigarettes. Boston-based researchers from Brigham and Women's Hospital and Harvard Medical School also found that long-term, moderate intake of caffeine or alcohol does not increase the chance of having a seizure or developing epilepsy. This is the first prospective study to examine the potential risks associated with cigarette smoking, caffeine intake, and alcohol consumption as they independently relate to epilepsy.

After adjusting for stroke, brain tumour, hypertension and other potential confounding factors, researchers observed a significant association between current cigarette smoking and risk of seizure. "Our analysis showed risk of seizure was significantly higher for current smokers, but not related to the amount of cigarettes smoked daily. It does appear, however, that the number of years of smoking does increase seizure risk."

The analysis of caffeine consumption showed that a long-term average intake of 400 mg of caffeine/day compared with <200 mg/day was not associated with greater risk of seizures or epilepsy. Researchers also observed no trend of increasing seizure or epilepsy risk with increasing caffeine consumption.

Further results indicate that risk of seizures or epilepsy was not significantly different between moderate alcohol drinkers (0.1-15.9 g/day) and alcohol abstainers.

This study cohort was primarily comprised of Caucasian (91%) women who had better health knowledge and access to healthcare than women in the general population. "Given the composition of the study group, our findings may not apply to men, younger or older populations, groups with lower socioeconomic status or lower attained education, or populations with higher percentages of minorities." The authors suggest that further studies are needed to increase knowledge of modifiable risk factors to prevent seizures and epilepsy.

ScienceDaily (Nov. 20, 2009)

Many of us spend half our time wishing for things we could have if we didn't spend half our time wishing.

~ Alexander Woolcott

Info Sessions!

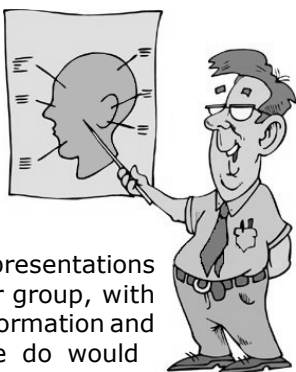
One of the best ways to explain about epilepsy and seizures is through public presentations and information sessions.

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

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

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

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



Happy Holidays

With the holiday season upon us, it's easy to get caught up in the madness of it all. What with people pushing and shoving their way through the stores, traffic whizzing by, and all the things that need to be done at home, it's enough to make anyone frazzled.

It doesn't have to be that way. When it all starts to overwhelm you, stop, take a deep breath, and remember all the joys of this season; the caring, the laughter, and the goodwill among family and friends.

All of us here at Epilepsy NL would like to wish all our members and friends a very blessed and merry holiday, and a safe and healthy 2010.

Our offices will be closed from Thursday, December 24th at noon and will re-open on January 4th.

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



Door to Door Campaign

We Need Your Support!

Our 2010 Door to Door Campaign will begin in full force on March 1st. We are still looking for canvassers in all areas of the province.

With the help of many generous and caring people just like you, I am sure that this year will be a resounding success once again.



It's because of our volunteers and the generosity of those who give even a small donation that we can continue to bring numerous programs and services to individuals, family and friends who are influenced by the effects of epilepsy.

Will you give just a little time to help? If so, perhaps you could collect a street or small area in your hometown, or perhaps you would be willing collect among your friends and family? If you are able to offer even an hour or two of your time, please call. You can reach me at 722-0502 or toll free at 1-866-EPILEPSY (374-5377).

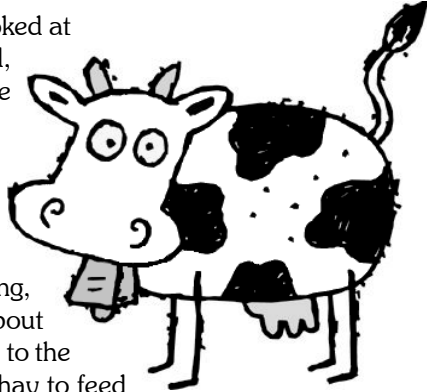
Charlene Stoyles
Campaign Coordinator

A Little Time Out

When the young seminary graduate arrived at the small country Church to preach his first official sermon, he noticed it had snowed about three feet deep just hours before Church was scheduled to begin. Due to the snow, An elderly, white bearded farmer was the only person to show up for the service.

The young minister looked at the farmer and asked, "What do you think we should do?"

The farmer scratched his beard thoughtfully. "Well, I don't know much about preaching, but I do know about farming. If I went down to the pasture with a load of hay to feed my cows and only one cow showed up, I'd feed that cow."



The seminary graduate said, "That's great! You sit right there and I'll preach you a sermon."

After about ninety minutes of preaching hellfire and brimstone, the seminary graduate concluded his sermon. Feeling pretty proud of his accomplishment, the preacher turned to the farmer and asked, "Well, how was it?"

The farmer scratched his beard thoughtfully. "Like I said, I don't know much about preaching, but I do know about farming. Like I told you, if I went down to the field with a load of hay and only one cow showed up, I'd feed that one cow. But, there's just one thing."

"What's that?" the preacher asked.

The farmer replied, "I wouldn't feed her the whole load."

**Love is what's in the room with you at Christmas
if you stop opening presents and listen.**

~ Bobby, 7 years old

MY LIFE

When I was a baby I took a fall
And ended up hitting my head,
The damage was big for someone so small
But for God, "I'm sure I'd be dead";
I now have a disorder of the brain
Which causes seizures for me,
It has been my big ball & chain
But it's better called epilepsy;
I have learned to live & cope
And turn my outlook around,
You always need Faith, Love, & Hope
And all falls in place I've found!

~ Rosie McKeever, 1-28-09



Just a bunch of random black spots?
Or perhaps it's something a little more familiar.
You may have to squint a bit for this one.

Bulletin Board



In August of 2008, 25 youth gathered in Toronto for a conference. The purpose of this conference was for the youth to talk about their biggest concerns and stressors around having epilepsy. The number one thing on their list – the public's misunderstanding and misconceptions surrounding epilepsy.

At that point it was decided that the only way to combat this was to take a stand and inform the public. So they wrote and starred in a commercial, and put together this comprehensive website so youth with epilepsy can know that they aren't alone, and that if we are going to move forward, we need to stand up and stake our claim as valuable, contributing members of society!

If you have epilepsy, or know someone who does, tell us your story, send us your rants, tell the world about your frustrations. In doing so you might give someone else the courage to disclose the fact that they have epilepsy. Giving someone that strength, might encourage them to get involved with their local agency and start educating the public about epilepsy, to stop those misconceptions and misunderstandings

Check it out!

<http://endtrashtalk.com/index/>

or call 1-866-EPILEPSY



What are the three words
guaranteed
to humiliate men
everywhere?

'Hold my purse.'

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