



Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Spring 2010

March Awareness 2010 - Positively Purple!

What a Month! In what may have been the greatest show of epilepsy and seizure awareness here in Newfoundland and Labrador, March was just awe-inspiring. Not only did we have all our regular events, but this year purple fever seems to have spread to all corners of our province.

Here are just a few of the sights and events from Epilepsy Awareness Month 2010.

Ask The Doctors - Our signature event of March has always been the 'Ask the Doctors' Question and Answer Forum. The event was held on March 25th, 7pm at the Ramada St. John's on Kenmount Road thanks to the donation of space by the hotel. We had 22 participants and again were honoured to be joined by both Dr. Abayomi Ogunyemi, and Dr. David Buckley, two of the provinces foremost neurologists.

Some of the questions that were asked included:

- meds dosage - seizure free vs. side effect free
- which drugs are most effective for which seizures?
- can childhood seizures return in adulthood?
- can you distract yourself from having a seizure?

Graphic Designs for Epilepsy - This year we once again challenged the students in the Graphic Design program at the College of the North Atlantic to develop a bus shelter ad to promote awareness. The two winners: Nicole Fulford and Kyle Callahan. Have a look for their ads on page 9 of this newsletter! They are still on display at two very prominent bus shelters here in the city.

The Purple Day Bunny Hop - To show just how much kids can do, all daycares across the province were invited to participate in the second annual Purple Day Bunny Hop. The participating centres raised almost \$4000 for epilepsy awareness! They were: Humpty Dumpty Daycare, Creative Learning, Stepping Stones (Corner Br), Pitter Patter Daycare, Itsy Bitsy Daycare, Creative Beginnings, On Your Mark, Right Start, and Stepping Stones (CBS).

Zach Rowe Memorial Tournament - Individuals, businesses, and students were decked in purple in support of Purple Day and the Zach Rowe Memorial Hockey Tournament in Harbour Grace. Zach passed away in 2009 from a seizure. He was only 21 and a popular player within the CeeBees hockey association. ENL was on hand to offer information and accept numerous donations including ones from the Minor Hockey Association, the Friends at Fox Farm, Avalon Appraisals, and the Tournament Proceeds. Through the dedication of those wanting to keep Zach's memory alive, over \$2000 was raised.



ENL's Gail Dempsey and St. John's Mayor Dennis O'Keefe

Proclamations Galore! - Several communities around the province either proclaimed March 26th as Purple Day for Epilepsy within their town, or participated in some sort of event to commemorate the day. These included the City of St. John's, Town of Paradise, Town of Labrador City, Town of Harbour Grace, Town of Grand Bank. If your town is not on the list, find out why, and ask that they participate next year.

Check out even more pictures on page 3. And for all the March events visit our website at www.epilepsynl.com.

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On My Mind

The cure is often more to be feared than the disease.

~French Proverb

I taught some workshops about a month ago at Memorial University about Epilepsy and treatments throughout history. The research was really interesting stuff, and some of the supposed 'cures' for epilepsy in the past just seemed to get stranger and stranger. For example:

- Wrap a tourniquet around the shaking body part to stop the seizure poison from spreading. Amputate if needed.
- Drain the body of one pint of blood regularly.
- Since crowded teeth cause seizures, pull all the teeth.
- Use Exorcism to rid the body of the demons that are causing the seizures.

Good thing we're living in an age where things like that don't happen anymore.

Or are we?

The more I researched, the more evidence I found that in places all over the globe, there are still people who believe that exorcism can cure epilepsy. I found videos from countries in Africa, one from Russia, and another from an Islamic nation that all clearly showed the person having very obvious tonic clonic seizures while people pinned them down, chanted, and tried to perform an exorcism. These weren't from centuries or even decades ago. The videos were from 2007 and 2008.

We are fortunate to have access to the highly skilled neurologists and technicians we have here in Newfoundland and Labrador. And fortunate to be living in a society that views epilepsy not as a possession by demons, but a treatable medical condition. After watching those videos, I realize just how fortunate indeed.

Makes me almost want to go out and hug a neurologist.

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.

A Province of Purple - Purple Day 2010

Proving beyond a doubt the adage that **"while not everyone can do everything, everyone can do something,"** people all over this province stepped out of the shadows and proudly proclaimed their Purple in March. With every person who took just that one step, we were able to reach people in small communities all across this province, letting even more people who live with seizures know that they are not alone.



The Spicer Family



Pitter Patter Daycare



Creative Beginnings



Corner Brook Court



On Your Mark Daycare



St. Kevin's Jr. High



The Jackman Family



Provincial Court - St. John's



St. Kevin's Jr. High

Scared, Traumatized & Coping

Although Barb Evans is well into her 40s, for the past year and a half her family has feared leaving her alone.

The Goulds native was healthy and active throughout her life, until a grand mal seizure less than two years ago foreshadowed that something terrible was wrong.

The Initial Seizure

Both she and her husband Robert were shocked when they were told a brain tumor, about the size of a golf ball, had caused her initial seizure. "It happened October 26, 2008. I was 43 years old. It was very scary to say the least."

While news of the brain tumor was disturbing, hearing that it was cancer-free helped Evans and her family cope with the diagnosis. "At least we had some hope."

Several weeks after learning about the tumor, Evans was in the operating room where surgeons cut her from one ear over the top of her head to the other ear to remove the mass.

Hospitalized for less than a week, her recovery went well, until May 2009. She then developed an infection in her forehead which caused another grand mal seizure. The infection lasted throughout the summer, she says. "I was having more seizures because my scar tissue couldn't heal."

In August, surgeons decided they had no other option but to remove her forehead. "Three months later they were going to put a new one back in," she says of the reconstructive surgery she'd need. Prepped and ready to be taken into the operating room, things changed in just a few seconds.

Change of Plans

Robert had asked to speak with his wife's surgeon before the operation took place. When the surgeon looked at her incision, he agreed with Robert that the wound looked like it was improving. "He said he didn't feel comfortable doing my surgery that day," Evans says of the abrupt change in plans. She credits a higher power for the fact that the infection eventually cleared on its own. "My father passed away 13 years ago and I prayed really hard to my dad."

Although her forehead has healed, Evans has had several more grand mal seizures, the most recent on New Year's Eve. In total she's had 13 over the past 15 months.

Until her scar tissue heals completely, the seizures will continue. "The most I've gotten is three months and six days," she says of her time between seizures. Because of the severity of her seizures, she is taken to the hospital by ambulance each time she has one. Barb and Robert have been together for over two decades and have a son Chandler who is 13 years old.

Family Support

It's been said that when people have seizures, it's their loved ones who are most traumatized.

Evans agrees. "My husband gets me on my side and he's told me that he watches in horror: my lips turn blue and I start frothing from the mouth. He tells me it's a major workout with the shaking and trembling and that he's been pretty scared."

A court officer with the provincial courts, Evans was off work for 15 months and returned to her job on January 18th. Evans credits her supportive co-workers - from judges to clerks - for making her return to work possible. "They've all undergone seminars through Epilepsy Newfoundland and Labrador. And that's really helpful to me because I feel a really big comfort zone that they know what to do in the event I have a seizure at work."

Although she puts on a brave face, Evans admits her medical condition has taken away many things she often took for granted. Including hopping into her car and driving wherever she wants to go. "At the rate I am going I may never get it back," Evans says, her smile trying hard to conceal her disappointment.

The surgery took not only her tumor, but also her sense of taste and smell. "I remember how fresh my clothes would smell when I took them off the line and how good a barbequed steak smelled. I remember what french fries used to taste like and hold on to those memories."

...continued



Scared, Traumatized & Coping cont.

In addition to her relatives and co-workers, Evans says Pam Anstey, Information Officer with Epilepsy Newfoundland and Labrador, has been a great support to her and her family. "She's been willing to come speak with my five brothers and their families and my husband's family. The society has told me things I never knew."

Evans is also grateful to her team of health professionals within Eastern Health. "From doctors to the front line workers, from paramedics to the local fire department, I have had fantastic service."

This woman's glass is always half full rather than half empty.

Returning to work has meant socializing with her friends rather than sitting at home worrying about what the future holds for her.

"My life is restricted now but I'm learning to move on. One day I'll look back at all this as a memory. But I'm still waiting for that day to come."

By Danette Dooley, Excerpted from The Newfoundland Herald, May 30th, 2010



Chandler's Story

The following information was taken from 13 year old Chandler Evans' speech about epilepsy. Chandler is the son of Barb Evans. A Grade 8 student at St. Kevin's Junior High in the Goulds. Chandler placed in the top four in his class and won bronze for the French version of his presentation when up against all Grade 8 students in his school.

Imagine waking up one morning and finding a person you love very much, lying in their bed, completely unresponsive to anything you say to them. All of a sudden you hear the person moaning or crying out and you see them turning blue and frothing at the mouth. They have become really stiff and convulsing which is very scary.

This is called having a grand mal seizure. And this is what happened to my mom on October 26th, 2008.

The main thing to remember is to keep calm, even though the seizure can be very scary. Remember, the person having the seizure needs your help. Seizures are not contagious so it's important to remember to treat a person who has a seizure the same as you would anyone else. You can't force a seizure to stop.

Anyone can have seizures. It doesn't matter how old you are or how healthy you are or anything like that. Even animals can have seizures. Just remember, these people are no different than you or me.

Vaccinations - Friend or Foe?

Many have likely heard the debate with regards to vaccinations and autism. While scientific studies have repeatedly shown that there is no connection, there are a great number of families who still feel that vaccines can indeed trigger autism. It is an issue that keeps being raised time and time again.

Last month, a study released in Hong Kong appears to have made a discovery that could have far-reaching consequences in the debate over whether vaccinations are friend or foe. **Researchers have discovered a scientific connection between childhood vaccinations and Dravet Syndrome, a severe form of epilepsy.** While there had been anecdotal evidence of a connection between vaccinations and seizures before, much like with autism, this is one of the first studies to scientifically state the link.

Childhood vaccines may trigger early onset of a severe form of infant epilepsy, but researchers say the disorder is ultimately caused by defective genes and lifesaving vaccines should not be withheld from these children.

The researchers said they feared the study published in the Lancet medical journal would scare parents away from getting their children vaccinated but stressed the babies in the study would likely have developed seizures within months regardless of the vaccine.

The disorder, called Dravet Syndrome, generally begins with seizures around six months of age. These children have poor language and motor skills and difficulty relating to others. Up to 80 percent of them have mutations in the SCN1A gene.

Anne McIntosh of the University of Melbourne's Epilepsy Research Center and colleagues examined the medical records of 40 Dravet Syndrome patients with the genetic mutation who had been vaccinated against whooping cough, or pertussis.

They said 30 percent of these children developed their first seizures within two days of receiving the vaccine but symptoms of their disorder were no worse than the other children who had their first seizures later on.

"In about 30 percent of people, it appears that (first seizures) came on rather quickly after the vaccination. But the overall message is that the outcome to the patients did not differ regardless of whether the onset of the disorder was shortly after the vaccination, or later on," said McIntosh.

"These kids already had that genetic abnormality, (so) regardless of the relationship with the vaccine, they would have actually had that disorder happen to them anyway," she added.

"Essentially, there is no proof that people should not be vaccinated ... from concerns about it causing the onset of that disease," she said in a telephone interview.



The researchers have a right to be concerned. Vaccines are important. It's because of vaccines that we have all but eliminated many serious and sometimes fatal diseases from our society. Measles, mumps, whooping cough, not to mention smallpox and polio, all have been pretty much eliminated as a result of vaccinations.

From the Centres for Disease Control study of 2007:

Rates of death or hospitalization declined more than 90 percent since vaccines against a wide range of childhood diseases were approved, and in the cases of smallpox, diphtheria and polio, by 100 percent.

However, every time something like this surfaces, people become more and more hesitant to vaccinate, and as a result, in some places we are beginning to see a resurgence of some of these previously infrequent diseases.

It's hard to know what is the right thing to do anymore.

Will this study result in people wanting their child to have genetic testing before they get vaccinated? Would it make any difference anyway? Is it likely that the Dravet's would still have developed? The researchers seem to think so, and believe that it made no difference to the eventual outcome. But how do we know?

As with any situation like this, the best advice is to talk with your doctor or neurologist. Through open discussion, you can both decide what the proper course of action should be.

Pam Anstey, Information Officer, ENL

Off The News Wire

Language Dysfunction in Children May Be Due to Epileptic Brain Activity

Epileptic activity in the brain can affect language development in children, and EEG registrations should therefore be carried out more frequently on children with severe language impairment to identify more readily those who may need medical treatment, reveals a thesis from the University of Gothenburg.

The thesis studied 60 children of varying ages, divided into groups. The first group comprised children with language dysfunction, for example children with slow speech development who find it difficult to express themselves or who have an inadequate language comprehension. The second group consisted of children with epilepsy, while the third comprised children with language dysfunction and epileptic brain activity, sometimes without epileptic seizures.

The study showed that epilepsy (with seizures) and epileptic brain activity with or without seizures were more common in these children than in children in general. The researchers then wanted to investigate whether the epileptic activity was the cause of the children's language dysfunction or whether other factors affected their language development.

"So we also looked at speech and language ability in preschool children with various forms of epilepsy. We found that these children had certain language problems – they found it difficult to express themselves but had a good understanding of language." The greatest problems were to be found in children with epileptic activity in the left side of the brain, which controls our linguistic ability.

The next step was to look at children with both speech and language dysfunction and epileptic brain activity in their sleep as young children. and follow up their speech, language and other cognitive abilities after some years.

"We found that more than half the children of school age and young adults still had some form of language difficulties, while a few had normal linguistic abilities. There was no difference between the children with continuously slow language development and those who had experienced a loss or deterioration of their language - so called epileptic aphasia."

More children with language dysfunction should be given EEG registrations to find an explanation for underlying mechanisms, and so that the right care and treatment can be given. In some cases medical treatment could be considered to block the epileptic activity in the brain, and in this way reduce the impact on a child's language development.

"We hope that the results of our research will lead to a new way of looking at various diagnoses of language dysfunction and epileptic brain activity. More than anything, we need a completely new diagnosis for children with slow language development and epileptic brain activity."

Children With Epilepsy Say Their Quality Of Life Is Better Than Their Parents Think It Is

Children with epilepsy and their parents have different perspectives of the impact of their illness on the child. Assessing quality of life is important for measuring endpoints in clinical trials of new therapies in children with epilepsy. In many research trials parents are the ones reporting these outcomes. Measuring quality of life in children, however, can be complex due to the fact that parents may have different viewpoints than their children.

A recent study, published in *Value in Health*, found that children with epilepsy report quality of life that is comparable to that of their healthy siblings. In contrast, parents rate their children with epilepsy as having substantially worse quality of life than their healthy siblings.

"Children with epilepsy and their parents may have different, yet valuable, perspectives about the impact of this disease. We need to recognize both perspectives in research studies evaluating endpoints reported by patients, and also in clinical care, particularly as we develop support services targeted for children with epilepsy as they transition into adulthood."

Fetal Alcohol Spectrum Disorder Linked to High Prevalence of Epilepsy

Children with Fetal Alcohol Spectrum Disorder (FASD) show a very high prevalence of developing epilepsy and having seizures, according to a national study by Queen's University researchers. Six per cent of study participants had epilepsy and 12 percent had one or more seizures in their lifetimes. By comparison, less than one percent of the general population is expected to develop epilepsy. The study results also showed that individuals were more likely to have epilepsy, or a history of seizures, if exposure to alcohol had occurred in the first trimester or throughout the entire pregnancy.

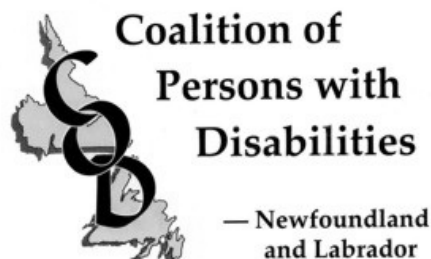
"The consensus recommendation of scientists, clinicians, and public health officials around the world is very clear—a woman should abstain from drinking during pregnancy as part of an overall program of good prenatal health care that includes good nutrition, adequate exercise, and sufficient rest."

Researchers examined the histories of 425 individuals between the ages of two and 49 years from two FASD clinics. They compared risk factors such as the level of exposure to alcohol or other drugs, type of birth, and trauma with the co-occurrence of epilepsy or a history of seizures in participants with confirmed FASD diagnoses. The report builds on a growing body of evidence that maternal drinking during pregnancy may put a child at greater risk for an even wider variety of neurologic and behavioral health problems than thought before.

COD Scholarship

The Coalition of Persons with Disabilities or COD is an advocacy organization concerned with all persons with disabilities, promoting their rights and raising public awareness of their needs.

COD is currently seeking applications for their 2010-2011 \$1,000 scholarship.



To be eligible, a candidate must:

- be a person with a disability
- be entering a Canadian post-secondary institution
- not hold an undergraduate degree
- not be a board member of the COD Board of Directors, nor be a relative of a Board Member or staff. Also, Scotiabank employees and their relatives cannot qualify.

To apply for this scholarship, please contact the COD office at 722-7011.

Summer Awareness

Now that summer is quickly approaching, ENL will be visiting recreation programs, camps, and tourist destinations around the Avalon to speak with summer staff and volunteers about epilepsy and seizure first aid. Sessions are generally 60 minutes in length and can be adjusted to fit the specific needs of any group. We offer all of this **cost free!**

If you know anyone who could benefit from such a presentation, let them know about us. These **fun** and **interactive** sessions include information on:

- different seizure types
- how to recognize difficult-to-spot seizures
- what to do when a seizure happens
- strategies to help people with epilepsy thrive
- how to help kids (and adults!) be more accepting and understanding

It has been shown that **1 in every 10 of us will have some type of seizure at some point in our lives.** Make sure people know what to do when it happens. To arrange a time for this free session, please contact Pam at 722-0502 or toll free at 1-866-EPILEPSY. Have a safe and enjoyable summer.

Door to Door Campaign - Our Volunteers Rock!

Another successful March Door to Door Campaign has just concluded. It could never have been the success it was without the help of our dedicated team of volunteers from right across the entire province.

The winners of our Door to Door draws for 2010 were:



Zone Captain - Connie Wicks, Glovertown

Over \$100 Canvasser - Olga Noseworthy, GFW

Over \$25 Canvasser - Marlise Ball, Manuels


We would like to take this opportunity to thank every canvasser and zone captain who so willingly gave of their time and efforts to make this campaign a success, as well as a thank you to everyone who donated even a little. Your efforts will go a long way towards the promotion of epilepsy support and awareness in NL.

We use the money collected from our Door To Door campaign to keep our doors open and our association operating. If you didn't have an opportunity to help out this year, please plan to do so next year. We need the support of every person who cares about Epilepsy to do whatever they can to make a difference. We need you.

Charlene Stoyles
Campaign Coordinator

A Little Time Out

Imagine your **life**,
in a stranger's **hands**.



EPILEPSY

www.epilepsy.nl.com  1-866-epilepsy

Design By Nicole Fulford

Today I ...

Today I smiled, and all at once things didn't look so bad.

Today I shared with someone else, a bit of hope I had.

*Today I sang a little song, and felt my heart grow light,
And walked a happy little mile, with not a cloud in sight.*

*Today I worked with what I had and longed for nothing more,
And what had seemed like only weeds, were flowers at my door.*

*Today I loved a little more and complained a little less,
And in the giving of myself, I forgot my weariness.*

~ Author Unknown

Two friends were standing in a bank when a pair of robbers entered. Not only did the thieves clean out the tills, but also they walked around with bags and ordered everyone to throw their valuables in. Just before the robbers got to the pair, one of the friends turned to the other and, passing him a bill, said, "By the way, Joe, here's that twenty bucks I owe you."

If you knew,



would you treat
me differently?

1-866-epilepsy  www.epilepsynl.com

Design By Kyle Callahan

A man came into the house dripping wet and disheveled. His sympathetic wife exclaimed, "Oh, dear. It's raining cats and dogs outside!"

"You're telling me," the man replied. "I just stepped in a poodle."

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! 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.

Do More

by William Arthur Ward

Do more than belong: participate.

Do more than care: help.

Do more than believe: practice.

Do more than be fair: be kind.

Do more than forgive: forget.

Do more than dream: work.

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