



Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Spring 2005

Epilepsy Awareness Month - March 2005 Recap

Epilepsy Awareness Month 2005 was flat-out and fabulous! We got the chance to talk with many amazing people right across the province. Some told us of their experiences with epilepsy, others were eager to learn all they could about the disorder and what they could do to help someone having a seizure.

The month started out with a bang as we launched two, month-long events. One saw every pharmacy in Newfoundland and Labrador receiving information to be publicly displayed and distributed to customers across the province. The other saw us working with Toys R Us at their store in St. John's. During the month of March, every child that came into their store received a free Seizure Activity Book, filled with stories and puzzles to teach all about epilepsy. Through the course of the month we reached over 1000 kids. Now that's a lot of learning!

Brain Day

Our next big event of the month though, saw us on television! To promote not only Epilepsy Awareness Month, but also Brain Awareness week, we wanted a celebration. Our second annual Brain Day was held on March 2nd with Dr. Richard Neuman of MUN teaching all sorts of interesting things about how our brain works. As our guests, we welcomed a large group from Big Brothers-Big Sisters to participate in the learning activities. Also on hand for Brain Day was Karl Wells from CBC's Here and Now who joined in the festivities and chatted on air with Richard Neuman and Pam Anstey of ENL about epilepsy and seizure first-aid. Everyone had a great time, and we look forward to making it even bigger and better next year.

Lots of Chances to Meet and Learn

We didn't stop there. Our month continued with many different public information presentations at lots of locations across the province. We talked with schools, community groups, businesses, and social clubs about epilepsy. Everyone got the opportunity to learn seizure first aid, to understand what epilepsy is, and to hear the true stories of people who live with epilepsy every day. Over the course of the month we personally did sessions with over 300 people, not to mention several other presentations that were done by volunteers in towns across the province. In addition, there were many information booth displays set up for people to browse or gather information. Special thanks to our volunteers who helped out to man these booths. They were a great success and certainly brought epilepsy more into the thoughts of the public.

Provincial Question and Answer Forum and Teleconference

To cap off an amazing month of events, our annual Question and Answer Forum and Teleconference was held in late March. And what a forum it was. Dr. Ogunyemi, one of the foremost epilepsy experts in the country was on hand to answer questions about epilepsy, ranging from the general to the very specific. This year we also welcomed an extra special guest - Dr. Maroun from the HSC, one of the pioneers of epilepsy surgery in Eastern Canada. Dr. Maroun offered a wealth of knowledge on surgery questions as well as stories from his many years of working in the neurology field.



The Best Western Travellers Inn generously donated the use of their board room, where we welcomed 41 participants, both in person and via teleconference from around the province. We had folks join us from St. John's, Grand Falls, Twillingate, Shoal Harbour, Trout River, Corner Brook, Burin, Gander, and Placentia

The forum was an overwhelming success, and we offer our very special thanks to both Dr. Ogunyemi and Dr. Maroun for offering their knowledge and guidance.

More to Come?

With such an interest in the events held during March, we would like to keep the momentum going by holding several events throughout the year. Would you be interested in a forum or event on some specific topic? Perhaps one that focuses on pediatric epilepsy issues, or something especially for women? Let us know. We are open to any ideas you may have. Let's keep the success of Epilepsy Awareness Month growing all through the year.

In This Edition

<i>Epilepsy Awareness Month 2005 Recap</i>	1
<i>Linda's Story - Six Weeks and Counting</i>	3
<i>Solving Sleeping Problems Helps Kids with Epilepsy</i>	4
<i>Skin Problems with Trileptal</i>	5
<i>Neurontin & Potential Suicide Risk</i>	5
<i>Out of the Shadows - Meet Rose</i>	6

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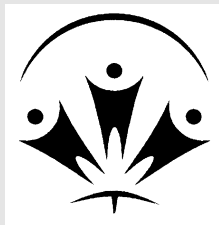
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Notes from Pam

Greetings everyone!

A little while ago I did an information session, and we were talking about how you are not supposed to put anything in someone's mouth while they are having a seizure. I had a gentleman named Frank come up after the presentation was done to talk.

He said, "I have a story for you. You know how you said that you should never stick anything in anyone's mouth... Well I was up in the woods with my buddy last year moose hunting. He had a seizure and I didn't know what to do... I didn't have anything to stick in his mouth like I thought you were supposed to do... So I used my fingers."

His fingers!!! Anyone who had seen a tonic clonic or grand mal seizure knows that people will often clamp down or clench their jaws during a seizure. And that's exactly what his friend did. He accidentally clamped down hard on the fingers. Frank showed me the result... Scars from where he had pulled his fingers out quickly, and a now crooked ring finger that had gotten the knuckle crushed from the strength of his friend's jaw. As Frank walked away from me he said, "I wish I'd knowned then what I knows now."

Moral of the story is that a little education can make a huge difference when it comes to epilepsy. That's why I've been putting a real push on to carry out as many information and training sessions as I possibly can. I've also recently begun working in partnership with the RNC to bring epilepsy information and seizure first aid to every officer in the St. John's and Mount Pearl Area.

If you know of a group that could benefit from learning about epilepsy, let me know. I provide fun and interactive sessions for all age groups, from primary to seniors, and can do a session custom tailored to your group. So pass the word along, and maybe together we can save a few more fingers along the way! :)

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.

Give a man a fish and he eats for a day. Teach him how to fish and you get rid of him all weekend.
 -- Zenna Schaffer

Linda's Story - Six Weeks and Counting

Every night, Linda Green battles with a decision that most of us take for granted. Should she wear her nightgown or her clothes to bed? Because, no matter how often or how professional the emergency health-care professionals are when they respond to her 911 call, it's always embarrassing to be found in a state of disarray both during and after a seizure. Then there's the issue of getting home again once she's released from the emergency department, which is harder still if she's wearing just her pajamas. "My nightgown is shorter, and with all these male firemen who often get here before the ambulance, even though they're professionals, it's still not nice to be found that way."



Green was about eight when she was diagnosed with nocturnal epilepsy. The seizures start just before, during or while waking from her sleep. "My parents were totally supportive, but when I was a child back in the '70s, that was a hard time because of the stigma and the potential for rejection. But they did everything they could to protect me from being hurt. They became very light sleepers."

Green describes her seizure disorder as terrifying. The seizures begin with an aura - a warning of what is about to occur. The fear she'll injure herself or even die is always present as the seizure takes total control of her body.

"When I was a child, my sister and I had twin beds. Mine was next to the wall, and I'd be awakened by the aura and my signal (to my parents) was three knocks on the wall. They would come racing down the hall and, if I didn't lose consciousness, I'd hear the fear in their voices... They'd hold me and comfort me and do whatever the doctors told them to do to help me," she says, wiping tears from her eyes.

While she's lived quietly with her seizures for almost four decades, she now wants to explain her condition and to describe just how terrifying the seizures are. "It's definitely not over when the shaking stops. There's a post-nocturnal phase where you're confused, you have a headache and you feel like somebody has beat the stuffing out of you. My muscles hurt and, cognitively, I'm held back. It's like my brain has been insulted and it's trying to rebound. And, I even used to apologize for my seizures as a child because I thought that I was causing too much trouble." She says people tend to minimize the effect seizures have on a person. "They feel helpless because it's not pretty to look at.

For Green, having a seizure disorder goes well beyond the physical aspects of epilepsy. Yet the disorder is misunderstood by many, including health-care professionals, she says. There is no accident to point to as its cause, no brain tumour or abnormality on a CT scan or MRI.

"People talk to diabetics because it's a major change in their life. If someone is hurt in a car accident, they recognize that they have to mourn what they lost. So in any other illness, the emotional repercussions are recognized. But if you have a seizure, they think it's all over with."

Green is grateful to her counsellors and her neurologist, Dr. Abayomi Ogunyemi, for supporting her through every step of the way. While her seizures have increased greatly over the last year and a half, it's now been six weeks since she's had a seizure - the longest period in nearly two years.

Being seizure-free means not having to deal with paramedics and fire personnel watching as she staggers around, feeling helpless, trying to comprehend which pant leg goes where. There's still the fear, though, at bedtime that her bladder may not be empty. Incontinence sometimes occurs when people have a seizure. Again, it adds to the embarrassment, she says.

Green now wears a Lifeline pendant around her neck. The monitoring system comes with a home-unit with two-way voice communication. It's a piece of security that she's come to rely on, as one push of the button means help is on the way.

Two years ago, Green retired for medical reasons from her position as a court reporter with the Supreme Court of Newfoundland and Labrador, Trial Division where she worked for more than two decades. It's a job she loved dearly and one that gave her an opportunity to travel throughout the province. Green's tremendous contribution to the province's justice system was acknowledged by a letter written by Hon. Derek Green, chief justice of the Supreme Court of Newfoundland and Labrador, Trial Division. The letter, which she's since framed, is proudly displayed along with other souvenirs from her working years. It reads, in part:

You have the reputation of being one of the best shorthand reporters in the courthouse and many would say the fastest transcriber. In fact there are stories that you operate your computer so fast that smoke has been seen billowing from the keyboard... On behalf of all the judges of this court, I want to wish you every success and happiness in your future endeavours.

Linda's Story - Continued

Green wipes tears from her eyes as she recalls the years she spent working for the justice department. Doing so made her feel both normal and needed. "I had one of the most supportive employers in the world. They were all very kind and went above and beyond. They backed me to the hilt and gave me the utmost respect."

These days, Green spends her time at her computer, and she also knits. She's written numerous articles in which she articulately expresses her feelings about epilepsy. In one paper, she wrote:

"The trauma of a seizure doesn't end when the worst of the physical abates. That's because, as I wake, the nightmare still continues, but in a different form because I am still too weak to even get to a sitting position. This leaves me, then, with no option but to stare at the ceiling or the floor, depending on which way I have landed, saddened it has happened again, wanting to cry but not having the strength and feeling - like the same frightened child I was, despite the fact that I am now 45. During this period of time that seems like it will never end, desolation washes over me and I feel more alone than any human being ever should.

In fact, it is as if I am the only one left on the planet."

Spending much time in front of her computer, Green has begun writing a book about her life experiences that she one day hopes to publish. Since she no longer works, doing so gives her a sense of purpose.

"My doctor tells me I have many skills, despite being on numerous medications. My record (of being seizure-free) was five weeks, but now it's six. You build up your security over the weeks. "But if, God forbid, something would happen tonight or tomorrow, it would be like toppling off the mountain of safety and having to start climbing back up all over again."

Danette Dooley, The Telegram, March 28, 2005

(Editors note: as of the printing of this newsletter, Ms. Green has now achieved 11 weeks of being seizure free, the longest seizure free period in her life.)

Solving Sleep Problems Helps Children With Epilepsy

Problems with their sleeping habits may explain why children with epilepsy are often hyperactive, according to a study undertaken at the University of Florida's Brain Institute.

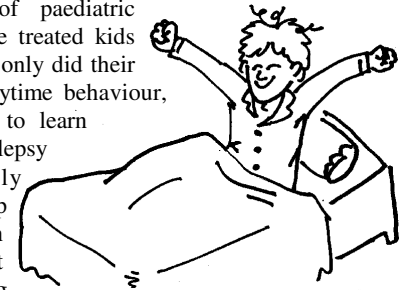
Epilepsy has long been thought to cause excitability and contrariness in children, the researchers said, writing in the journal *Epilepsy & Behavior*. However, they now think that the real reason some of these children cannot sit still or pay attention is because of a lack of sleep.

The study monitored the brain and muscular activity of 30 children with epilepsy between the ages of seven and 14 during single overnight stays. None of the children had seizures, but some awoke hundreds of times because of breathing problems.

Seventy-three per cent of the children studied met clinical criteria for inattention or hyperactivity. Of these, each had a sleep disorder, 14 had problems paying attention during the day and eight had hyperactive symptoms, supporting the idea that a poor night's sleep is associated with children's daytime attention problems. In all, 80 per cent breathed shallowly or had breathing disruptions caused by apneas (a temporary stopping of breathing), which usually happens when the soft tissue in the rear of the throat relaxes during sleep and blocks a person's airway.

As the breathing disruptions increased in duration, the children spent less time in REM sleep, a period in the sleep cycle when brain activity is highest and people dream intensely. The children in the study spent 17 per cent of total sleep time in the REM stage, whilst the normal for young adults is 25 per cent.

Dr Paul Carney, chief of paediatric neurology, said: "When we treated kids with sleep disturbances, not only did their epilepsy get better, their daytime behaviour, concentration and capacity to learn increased. Many kids with epilepsy aren't being adequately assessed for underlying sleep disorders. We can significantly have an impact over their cognition, learning and maybe even improve their epilepsy by improving their sleep."



"Removing the sleep problem does seem to improve the behaviour problem because it changes the child's level of alertness, commonly, adults are just not as awake if they have a sleep disorder. But children who haven't taken their nap are wound up instead. Treating their sleep disorder, we think, can enable their brain to have some control over unwanted behaviour." The researchers found no correlation between seizure frequency and behavioural problems. Epilepsy alone did not appear to predispose them to behavioural problems.

Research with different groups of children is now under way to determine whether treatment of sleep disorders will reduce seizure frequency and severity, and to more fully understand the effects of sleep disorders on children's behavior and cognitive abilities.

Epilepsy Action News, April 5, 2005

Skin Problems with Trileptal (Oxcarbazepine)

The epilepsy drug Trileptal has a new warning about life-threatening skin reactions reported by patients who took the medicine, the company recently announced.

"Such serious skin reactions may be life-threatening, and some patients have required hospitalization with very rare reports of fatal outcome," Novartis, the company which makes the drug, said in a letter to physicians.

The problems, reported in both adults and children, included two serious skin disorders called toxic epidermal necrolysis and Stevens-Johnson syndrome. The reported rate of those conditions among Trileptal patients was three to 10 times higher than what would be expected in the general population, the Novartis letter said.

"Therefore, if a patient develops a skin reaction while taking Trileptal, consideration should be given to discontinuing Trileptal use and prescribing another anti-epileptic medication," the company said.

Trileptal is approved for treating partial seizures in adults and children ages 4 to 16 with epilepsy.

A "limited number" of other life-threatening reactions involving multiple organs also have been reported following the start of Trileptal therapy, Novartis said. Symptoms varied but included fever, rash and liver and kidney inflammation.

Reuters, April 19, 2005

Neurontin (Gabapentin) and Potential Suicide Risk

The Food and Drug Administration has begun a preliminary inquiry into whether epilepsy drugs might increase the risk of suicidal behaviour in some patients.

Prompted in part by an attorney's claims against the leading anti-convulsant, Neurontin, the FDA last month asked makers of all epilepsy medicines to reanalyse studies of the drugs to see if there's any evidence of increased suicide risk.

"I don't think we have any suspicion yet that these drugs actually do that," cautioned FDA drug policy chief Dr. Robert Temple.

It's the same type of analysis the FDA ordered last year for antidepressants amid controversy over their use by children and teenagers; those drugs ultimately were linked to an increase in suicidal thoughts and actions in a small fraction of young patients, about two to three per cent.

In addition to use by millions of people with epilepsy, anti-seizure drugs are widely used to treat illnesses such as bipolar disorder as well as pain and other conditions. Some epilepsy drugs have FDA approval for other uses, while others are prescribed "off-label."

There are reports of suicides among anti-convulsant users, Temple said. But without a close examination of research studies, it is impossible to tell whether a drug played a role or the disease itself was to blame, he explained.



But "we are taking this matter very seriously," Dr. Russell Katz, FDA's chief of neurologic drugs, wrote New York attorney Andrew Finkelstein last week.

Finkelstein last summer filed a petition with the FDA asking that a black-box warning - the FDA's toughest - about suicide be placed on Neurontin's label. In the petition, Finkelstein cited 25 reports of suicides among Neurontin users from the FDA's own database.

The FDA still is investigating the petition. Last month, Finkelstein sent the agency 258 reports he had collected of suicides by people apparently taking Neurontin. Finkelstein has filed 72 lawsuits against Neurontin manufacturer Pfizer Inc. Finkelstein also produced a 1992 FDA review of Neurontin that called depression a potential rare side-effect.

Pfizer will comply with the FDA's request to reanalyse its studies, but patient data already submitted to the agency "shows no link between Neurontin and suicidal thoughts or behaviour," said spokesman Paul Fitzhenry.

Neurontin is approved for particularly hard-to-control epilepsy, a serious condition. The FDA gave Pfizer and manufacturers of all other epilepsy drugs six months to review their databases and report back to the agency.

The whole category of epilepsy drugs "is potentially very important" in treating other serious illnesses, "and we thought we ought to know this," Temple said.

The Associated Press, April 21, 2005

Out of the Shadows

Dear Readers,

I was diagnosed with epilepsy when I was seventeen. I am thirty-four now and I know that no matter where I go or what I do, I will always have epilepsy.

Sometimes, when people find out that I have epilepsy they get a little nervous to be around me because they are afraid that I may take a seizure. Most of the time it's not the seizure itself that scares them, but whether or not they will be able to help me.

For a long time, I did not want to go anywhere because I was afraid of what people would think if I took a seizure, but, with the help of Epilepsy Newfoundland and Labrador, I was able to go out and face the world again. All I had to do was pick up the phone and make a call.

I have made a good many friends along the way, but none of whom have Epilepsy. It was so nice to be able to talk with someone who really understood what I was going through.

That is why I have teamed up with ENL to invite you, and anyone you know who may live with epilepsy, to write us with questions, concerns, or to tell us your story. You can even contact us on the website at www.nfld.net/epilepsy to email us.

It's time for us to come out of hiding and have our say. Will you join me?

Your friend,

Rose

No Longer Am I Blue

by Rose Bradbury-Sparkes

dedicated to

Pamela Anstey and Epilepsy Newfoundland & Labrador

I have a beautiful family
who are there the whole way through
and even though they love me
they don't understand why sometimes I feel so blue.

My friends they are beside me
and hold me when I'm scared
I know that whatever happens
the true ones will always be there.

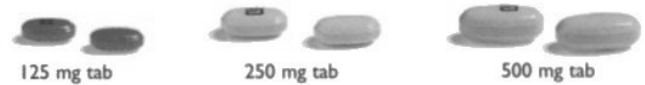
But sometimes I get down
and feel so all alone
and then I remember you
and go pick up the phone.

You let me know there are others
who feel the way I do
and no longer am I lonely,
no longer am I blue.

Medication Profiles

Each quarter we will be profiling the most common anti-epileptic medications in Newfoundland and Labrador. If you would like more information than what is printed here, or information on a different drug, visit our website at www.nfld.net/epilepsy or feel free to give us a call and we'll mail the information.

Epival (divalproex sodium)



What is Epival (divalproex sodium)

Divalproex sodium is used to treat various types of seizure disorders, to prevent migraine headaches, and to control mania associated with bipolar disorder.

Divalproex sodium works best on absence and tonic clonic (grand mal) seizures. It works less well for complex partial seizures.

What are the most important things to know?

In rare cases, divalproex sodium has caused liver failure, sometimes resulting in death. Notify your doctor immediately if you develop loss of seizure control, weakness, fatigue, swelling of the face, vomiting, or loss of appetite. These symptoms may be early signs of liver damage.

In rare cases, divalproex sodium has also caused severe, even fatal, cases of pancreatitis. Some of the cases have progressed rapidly from initial symptoms to death. Cases have been reported soon after starting treatment with divalproex sodium, as well as after several years of use. Notify your doctor immediately if you develop nausea, vomiting, abdominal pain, or loss of appetite. These symptoms may be early signs of pancreatitis.

Do not crush, chew, or break the capsules or tablets. Swallow them whole.

Divalproex sodium may interact with other drugs that cause drowsiness, including alcohol, antidepressants, antihistamines, pain relievers, anxiety medicines, and muscle relaxants. Dangerous sedation, dizziness, or drowsiness may occur if divalproex sodium is taken with alcohol or any of these medications. Talk to your doctor before taking divalproex sodium in combination with alcohol or any other medicines, including herbal products.

Side effects of Divalproex Sodium

If you experience any of the following serious side effects, stop taking the drug and seek emergency medical attention:

- ! an allergic reaction (difficulty breathing; closing of your throat; swelling of your lips, tongue, or face; or hives);
- ! a rash;
- ! unexplained lethargy (fatigue), vomiting, or changes in mental status;
- ! unusual bleeding or bruising; or
- ! double vision or back-and-forth movements of the eyes.

Other, less serious side effects may be more likely to occur. Continue to take the drug and talk to your doctor if you experience

- ! tremor (shaking);
- ! weight gain;
- ! menstrual changes;
- ! hair loss;
- ! drowsiness or weakness;
- ! depression or other psychiatric changes;
- ! headache; or
- ! low red blood cells (anemia).

Announcements and Appreciations

You were amazing! - Thank you to all who participated, either by collecting or donating during our annual March Door to Door Campaign this year. It is with generous donations and time from folks right across the province that we are able to continue to bring numerous programs and services to families who live daily with epilepsy.

These contributions are still coming in from our collectors even as we speak. **However**, if you still have your kit and collection money not sent in, please mail them back to us soon, or give the office a call for advice.

Calendar Campaign

Our summer campaign is starting to build up momentum. We have selected the winners of the Epilepsy Poster Contests from the many that were submitted by Grade 4 students right across Newfoundland and Labrador to be featured in our 2006 Epilepsy Newfoundland and Labrador Calendar.

How can you get one of these special calendars? It's easy. These unique calendars come as a thank you gift to anyone who generously donates \$20 or more to our calendar campaign.

If you are interested in receiving one of these collectible calendars, just give us a call at the ENL Offices. You can reach us at (709) 722-0502 or toll free at 1-866-EPILEPSY

Michelle Monahan
Resource, Volunteer, and Campaign Coordinator



Epilepsy Express Secret Word Contest - Each quarter we will be drawing for a winner in our *Epilepsy Express Secret Word* contest. You may have seen it. If not, drop us a line and we will gladly send you a copy of the *Epilepsy Express* which will tell you just how you can enter and win.

The spring winner of the Secret Word for Understanding Contest is:

Richard Woolridge
of *St. John's*

Richard wins a special prize pack, as well as a free subscription to *Epilepsy News*, *Epilepsy Matters*, and *Talking about Epilepsy*



Thank You! To all the individuals, community groups, and businesses that helped out during Epilepsy Awareness Month. Your support makes a world of difference.

<i>Individuals</i>	
Dr. A Ogunyemi Dr. F.B. Maroun Karl Wells - Here and Now Jason Newman	Dr. Richard Neuman Danette Dooley - The Telegram Linda Green Heather House-Walters
<i>Community Groups and Organizations</i>	
Rabbittown Community Centre Health & Comm Services Froude Avenue Comm. Centre Big Brothers Big Sisters	Mundy Pond Boys & Girls Club MacMorran Community Centre Virginia Park Community Centre VOCM - Claudette Barnes
<i>Businesses</i>	
McKesson Canada Toys R Us Metrobus Dominion Zellers - Mount Pearl Square Best Western Travellers Inn Hotel Gander Vincor Living Rooms - Murray Premises Hughes and Grant The Dollar store Lawtons Corby Distilleries West End Electronics H. Collingwood Spirits & Wines W.L. Edmonds Ltd. Hair Connection Weil Winery/Notre Dame Wines The Downhomer Shoppe J.B. Hand & Sons Ltd. Hickman Motors Dominic Ryan Agencies O'Keefe Flowers Shopper Drug Mart - Commonwealth Paradise Farms Brookfield Ice Cream Professional Beauty Supplies Griffiths Guitar Works Belbin's Steak House The Village Dooley's Molson Roy Pitcher Photography Vision Packaging Subway Merle Norman Mainbrace International Ltd. Browning Harvey Lester Lube Quidi Vidi Brewery D'Angelo Golf David Hoddinott Painting Masterpiece Framing Hibernia Tim Hortons Marketing International Avalon Mall LSPU Hall HMV Music Brookfield Ice Cream Nf & Lab Credit Union	Nord Marine services Morris Foods East Coast Beauty Supply Sobeys Pipers - Topsail Road Bogarts Kents Building Supplies F.J. Waddens Country Ribbon Chicken M&M Pre Pak Sales Spurrell Gallery Maersk Jungle Jims Terra Nova Foods Purity Factories The Herald Rogers Cable Quality Brand Meats Steele Communications Mazda Capital Motors Rodriguez Wines Hamilton & Sons The Young Group of Companies Hickey Building Supplies Labatt Ed Roche Fine Art Price Choppers Only Deals Chester Dawe Professional Beauty Supplies Terra Nova Golf Course Pizza Experts Riche Investments Bacardi Canada Inc. St. John's Sports & Entertainment Signature Salon A Buck or Two Empire Theatres Canadian Tire East Coast Converters Scademia Boat Tours Swiss Chalet City Tire Kriscott Distributors Ltd. Toyota Plaza International Spirits Wal-Mart O' Brien Boat Tours Coastal Marine Ledrew Lumber Associated Marine Equipment

Asked and Answered

Q *I have had epilepsy since I was a child, and have seizures occasionally. I'm about to have my first baby and I'm worried about having a seizure while I am taking care of the baby.*

A Although most parents with epilepsy can provide safe care for their children, changes in routine may be necessary depending on your frequency and type of seizures.

If your seizures are not controlled, working with health care professionals will help to assure your child's safety. If you experience auras or warnings before seizures, you may have the opportunity to take the necessary precautions for your child's safety. Developing a network of family and friends to assist you in case you need help is also worthwhile.

The following safety tips may give you further ideas on how you can best make sure you safely raise your beautiful new baby.

- T Use safety gates and playpens in case of a seizure.
- T Use a stroller for transporting your baby rather than carrying your child, even in your own home. Outside, use a stroller with brakes, a child harness or a wrist cord.
- T Change diapers or clothes on a pad on the floor or on a change table that has a strap to secure your child.
- T Keep baby supplies on each level of your home to avoid unnecessarily having to climb stairs with your baby.
- T Give your baby a sponge bath rather than using a bathtub.
- T Avoid carrying /drinking hot liquids or smoking near your baby.
- T Secure your baby into an infant seat on the floor or in a high chair for bottle feedings and meals.
- T If you are breast-feeding, feed your baby while sitting on the floor surrounded by a soft surface.
- T If sleep deprivation is one of your seizure triggers, then arrange for someone to help out with either night time feedings or a daytime feeding when you can catch up on your sleep.
- T When your child is old enough to understand, discuss your epilepsy with them. This may alleviate some fears and will help your child know how to respond if you have a seizure.

Q *What is the real deal when it comes to smoking, drinking or drugs for someone with epilepsy? I hear so many stories that I don't know what's the truth.*

A Smoking, alcohol, and recreational drugs can be harmful, and not just for people with epilepsy. However for folks who have seizures, there are additional things that need to be kept in mind.

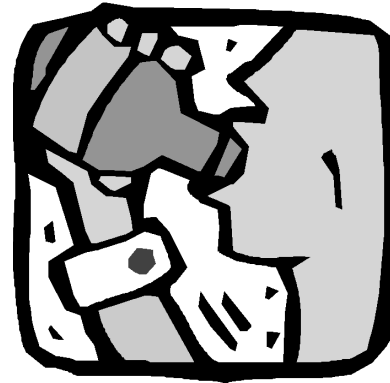
Smoking

We all know that smoking is bad for us, but it can be a hazard too. If you have a seizure while smoking, burns or a fire could result. That having been said, smoking for people with epilepsy does not affect your seizure control or medications, and will not cause a seizure.

Drinking

Consuming excessive amounts of alcohol and the subsequent withdrawal from that alcohol can trigger seizures. Although modest occasional drinking of alcohol doesn't seem to increase seizure activity in people who aren't alcoholics or who aren't sensitive to alcohol. Drinking can lower the metabolism. This can result in lower blood levels of the seizure

medication that is metabolized by the liver. Drinking alcohol can also lower your seizure threshold - the level of disturbance at which your brain will have a seizure.



Some doctors recommend that if your seizures are not fully controlled, you should not drink alcohol. If you choose to drink, it is vital that you continue to take your seizure medication as prescribed.

Drugs

Recreational drugs can provoke seizures. Withdrawal from marijuana can result in an increase in seizure activity. Cocaine can cause seizures and may also cause brain damage leading to epilepsy. Amphetamines (speed), ecstasy, and LSD (acid) are also commonly associated with seizures.

Whatever choices you make, check with your doctor/neurologist who will have an understanding of your types of seizures and how certain substances may affect them. Above all else, if you do indulge, please do so safely.

It's Membership Renewal Time

Just a little note to remind everyone that May 31st is the end of the membership year. If you have not renewed your membership with us, now is the time. We have even included a membership application/renewal form with this newsletter. Membership is only \$5.00 for the entire year.

Your fee helps us continue to bring you up to date programs, services and information on epilepsy. If you can't afford the membership fee but want to be a member, just drop us a line with your application and we can waive it for you. Not getting all you want from your association? Please let us know how we can make things better. We are here for YOU.

Bits and Pieces

Suggested Reading

Did you know that Epilepsy Newfoundland and Labrador has its own lending library? You can borrow books, videos and kids story books from us cost free. From time to time we will feature some of the books in our lending library. If it interests you, give us a call and we will gladly lend it to you.

For a full listing of the resources in our library, check our website at www.nfld.net/epilepsy.

Epilepsy - A New Approach, Adrienne Richard and Joel Reiter, MD. - At the age of twenty six, when Adrienne Richard was seven months pregnant, she was diagnosed with epilepsy. For years she took anticonvulsant drugs to control her seizures, but she wanted to wean herself from the powerful drugs if she could. Her Goal was to live seizure free, Through yoga, biofeedback, and with mind and body techniques, she reached her goal. This book explains these techniques and how to use them for better control.

Views from Our Shoes - Growing up with a brother or sister with special needs, Edited by Donald Meyer. - A collection of accounts from kids who have a brother or sister with special needs. This book speaks clearly to siblings letting them know they are not alone, that other kids have had similar experiences, had their worries, frustrations, felt their joy, and successfully met their challenges. Not specific to epilepsy, this book lets siblings know that other kids feel just like they do.

Puzzle Answers

Thinking Caps On -
TONIC CLONIC
SIMPLE PARTIAL
COMPLEX PARTIAL
ABSENCE
SECONDARILY GENERALIZED
< TYPES OF SEIZURES

Long Weekend? - Bill would need to come back on Thursday. To figure it out start at the end of the sentence. You know today is Monday, therefore the day after tomorrow would be Wednesday. The day before that would be Tuesday and two days after Tuesday would be Thursday.

Did you know Epilepsy Newfoundland and Labrador offers its members two \$1000 scholarships annually?

- **The Jim Hierlihy Memorial Scholarship** for students just graduating from high school and moving on to post-secondary education.

- **The Mature Student Scholarship** - For individuals 21 and older who have decided to return to school to upgrade or change their career.

To find out more, contact Pam at the ENL office.
(709) 722-0502 or Toll Free at 1-866-EPILEPSY

I WOULD LIKE TO HELP IN THE FIGHT AGAINST EPILEPSY

9 I am enclosing a donation of \$_____

9 I would like to become a member of Epilepsy Newfoundland and Labrador. I am enclosing my \$5.00 membership fee.

9 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 - 261 Kenmount Road, St. John's, NL A1B 3P9