



Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Summer 2007

Good Patients Make Better Doctors

Getting What You Need from Your Appointments

I hear complaints often about the frustrations of doctor visits.

"I like my doctor but he is so busy that when I finally get an appointment, there's too much to cover and I forget half of it."

"My doctor is not all that great, it's like he's sometimes playing a guessing game to figure out what's going on."

While I have no doubt that there are less than perfect doctors out there, there are also less than perfect patients. Sometimes it is the work that WE do, that can make the difference between a very productive visit with the doctor, or one where you leave feeling more confused than when you went in.

We can't and shouldn't expect our doctors to do it all for us. It's our health after all and we need to take an active role in making sure that we are getting the information and the care we need when we visit.

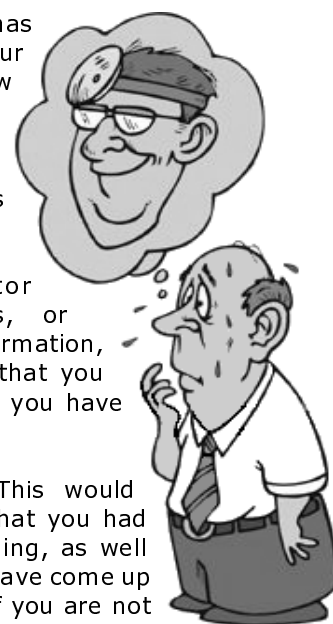
To help do this, we have offered several good practices to follow, including tips for before a visit, during a visit, and after you leave the office.

Before Your Appointment

- Write down a list of any changes in seizure activity, side effects, or general health since your last visit. Be as detailed and specific as possible.
- Make a list of all your medications and vitamins, including dosages, and time of day that you take them.
- Make a list of questions that you want to ask.
- Take all of these things with you. Some people find it helpful to keep all their medical information together in a notebook or small binder.

During Your Appointment

- Review what has happened since your last visit. Show your doctor the information you have written so that you won't miss anything.
- If your doctor suggests changes, or provides new information, write it down, so that you can review it after you have left the office.
- Ask questions. This would include the ones that you had listed prior to coming, as well as any that might have come up during the visit. If you are not sure about something, ask! There is no such thing as a silly question especially when it could mean the difference in your seizure activity.
- Before you leave, make sure you find out about a follow up visit. This is especially important if any changes have been made to your treatment. Also ask what you should do if you experience side effects or increased seizures, and you need another visit before the regular scheduled time.



After your Appointment

- Follow your doctor's suggestions as closely as possible and keep track of any seizure activity.
- Follow up with Epilepsy Newfoundland and Labrador for additional information on epilepsy and seizures.

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On My Mind

Summer is one of those odd periods of time. Busy and slow all at once. Last month I did a series of presentations with the staff of various summer day camps, tourist attractions, and recreation programs. I am very pleased at the response from these groups who showed a sincere interest in having their staff trained to be able to respond to a seizure should it ever happen. They were interested, involved, and very enthusiastic.

I had also contacted a considerable number of daycare agencies, asking if I might come and talk to their staff about what to do in case one of the children in their care, or one of the other care-givers, had a seizure. I am sad to report that out of eighty two requests, only three have arranged sessions. If your child is in daycare, please urge them to have their staff trained.

We have some neat things happening in the fall. First off will be my annual Excursion, this year I am on the road to New-Wes-Valley and Notre Dame Bay. You can read all about the upcoming plans on page 5 of this newsletter. In addition to my trip, we will also be invading Memorial University. At least our information will. Each year, MUN students receive an orientation kit when they register. This year, that kit will include information on what to do for seizures, how to contact us for more information, and one of our magnets. This way, we can reach over 2000 students who we might never have been able to talk with.

Happy summer everyone, and if you're on the Northeast Coast, maybe I'll see you in September!

Pamela Anstey
Information Officer

Seizure First Aid

- ➡ Don't panic! You CAN help
- ➡ Allow plenty of space
- ➡ Protect from injury
- ➡ Loosen anything tight around neck
- ➡ Put something soft under the head
- ➡ Turn to the side to prevent choking
- ➡ NEVER put anything in the mouth
- ➡ NEVER restrain
- ➡ Longer than 5 mins → Ambulance
- ➡ After, offer support and allow rest

**Epilepsy
Newfoundland
& Labrador**
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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.

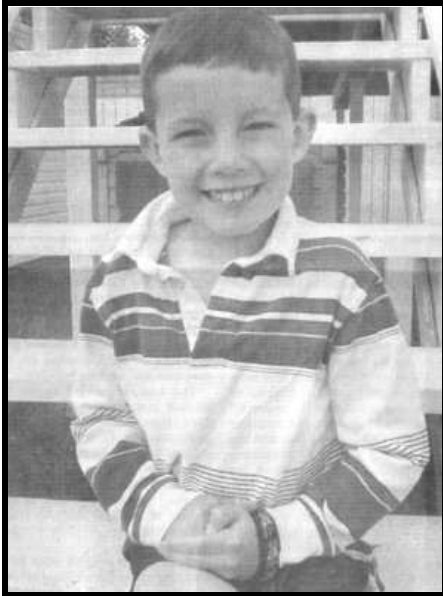
People with epilepsy should never discontinue anti-epileptic medications or make changes in activities unless specifically advised to do so by an attending physician.

Nathan Looks to End 'Episodes'

Nathan Jackson is looking for someone to find a cure for his 'episodes.'

"Sometimes, when I have an episode I hurt myself, and if you look up here, you'll see a little scar," the eight year old says, pointing to just above his left eyebrow.

"Because when I was in play school, I had a little episode and I flicked a chair and the side of it hit here and cut it open. There was lots of blood coming down and that's when mom came in."



Nathan began having seizures at age three. He's been diagnosed with juvenile myoclonic epilepsy..

The seizures are caused by an abnormal discharge of electrical activity in the area of his brain responsible for muscle control.

Nathan is the driving force behind a golf tournament taking place at The Willows in Holyrood, with all proceeds going to Epilepsy Newfoundland and Labrador (ENL).

His mother, Darlene Delaney, says the idea for the fundraiser came about when she and her son were participating in a walk for juvenile diabetes recently.

"Nathan wondered how come nobody walks for him and his epilepsy. So I brought the idea to my boss and we decided having a fundraiser was a great idea."

During an interview at their Mount Pearl home, Nathan talks about his love of sports.

Dressed in sneakers, black shorts, and a long-sleeved white shirt with blue and black stripes, he talks excitedly about joining soccer.

"If you want, I can tell you all about my episode rules," he says. "I have to stay away from hard wood, stay away from metal, and stay away from concrete."

Nathan's mother says that while the seizures are embarrassing for Nathan, it's the injuries he sustains that cause her the most concern.

"That's frustrating as a parent," she says.

"But Mom's always telling my teachers about my episodes so they're always keeping an eye on me," Nathan says of his teachers at Newtown Elementary.

A single mother, Delaney is originally from Conception Bay North and is an executive assistant at Investors Group.

She spent more than a decade in Alberta before returning to Newfoundland last summer with her son, in order to be closer to her family.

She said she's grateful to the doctors at the Janeway for helping her understand her son's condition and she's found support through ENL.

"(ENL founder and executive director) Gail Dempsey is going to come to Nathan's classroom in September and educate the kids about his epilepsy," Delaney said.

"And they have given us lots of information and goodies to pit in our loot bags for the golf tournament."

Funds raised through the tournament will be matched by Investors Group's National Office, according to the company's regional director, Robert Campbell.

And, thanks to Nathan, other charities will benefit in the future if it becomes an annual event.

"We're going to hold a tournament every year and we'll pick another worthy charity to support next year," Delaney explained.



New Board & Lodging Supplement

A brand new 'Board and Lodging Supplement for Persons with Disabilities' has just come into effect. Families and individuals with disabilities can avail of additional funding through Human Resources, Labour and Employment

We have included excerpts from the press release below.



Effective July 1, 2007, the Provincial Government will provide an enhanced board and lodging supplement for adults with disabilities residing with their own family members.

Through this \$8 million initiative a single adult aged 18 to 64 years with a disability who is living with relatives and is in receipt of the maximum family board and lodging income support rate will receive the same board and lodging supplement as those living with non-relatives. This means an increase of up to \$362 a month, or \$4,344 annually.

This supplement will assist with the cost of items associated with maintaining a quality standard of living such as clothing, personal care items, recreation and social events, over the counter drugs and dental work. Approximately 2,500 individuals will benefit as a result of this enhancement.

"Our government is responding to the needs of persons with disabilities," said the Honourable Ross Wiseman, Minister of Health and Community Services. "We are pleased to provide this enhancement which will result in greater equity for individuals living with family members and will assist families in providing care."

~Government of Nf & Lab Press Release, July 9, 2007

In a recent press release, Newfoundland and Labrador Association for Community Living President, and Executive Director were quick to respond.

"Many individuals and families we represent are unaware of their eligibility for supports and services. Through this wonderful initiative, families now have the opportunity to receive up to an additional \$362 a month through Health and Community Services" explains Ray McIsaac, President of the Newfoundland and Labrador Association for Community Living (NLACL).

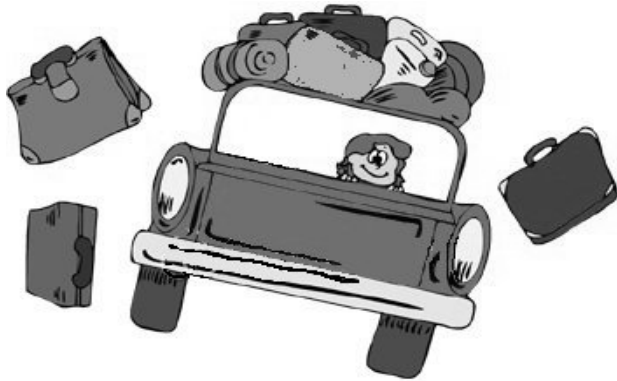
"Every day we hear from individuals and families about their struggles to make ends meet on only a few hundred dollars, or less, each month," says Melanie Thomas, Executive Director with the NLACL. "Persons with disabilities represent 25% of the income support recipients in our province and must be a priority area within the Poverty Reduction Strategy" urges Thomas.

As mentioned, the new board and lodging supplement became available as of July 1st, 2007. It is not an automatic supplement, so families and individuals wishing to apply should contact their social worker, nearest branch of Human Resources, Labour & Employment or the Epilepsy Newfoundland and Labrador Office for more information.



Fall Excursion - All Around the Circle & Loop

From
Saturday, September 15th
to
Sunday, September 23rd



Fall is coming! Yes I know that no one really wants to hear about that while we are deep in the middle of summer, but it won't be long now before kids are back in school and fall creeps back upon us.

As many know, each year for a while now I have been loading up my car, heading out over the road, and visiting a specific area of our province for a while during the fall.

This year I have my sights set and plans in motion to visit

**All Around the Circle -
Fogo, Twillingate, Moreton's Harbour,
and
All Around the Loop - New-Wes-Valley.**

If you, or someone you know, lives in either of these areas and would like to arrange a presentation for a group, organization or business, let us know.

If you would like to sit in on one of the training sessions or presentations, we can arrange that as well.

If you have a child with epilepsy, let the school know that you would like a session for your child's class or teachers.

Some groups I am hoping to talk with include

- K-12 Schools - Both students and teachers
- Post secondary schools
- community and church groups
- Brownies, Guides, Cubs and Beavers
- Home Care workers
- RCMP

Please check with Pam at the office regarding what days I will be in each town. You can get in touch

- by phone at 722-0502 or 1-866-EPILEPSY
- or by email at info@epilepsynl.com

Attendant Passes for Caregivers

The Mayor's Advisory Committee on the Status of Persons with Disabilities wishes to advise community groups representing those with disabilities that Metrobus is now accepting attendants passes. These passes are currently used at the following locations:



- Mile One Stadium
- Wedgewood Park Recreation Centre
- H.G.R. Mews Community Centre
- The Arts and Culture Centre
- Empire Theatres
- Mount Pearl Recreation Facilities
- The Works/Aquarena

Transportation to and from these destinations is now made more convenient by Metrobus. If you wish to find out more information about the Attendants Pass Program, please contact the City's Family & Special Services Coordinator at (709) 576-8025 or mwinsor@stjohns.ca.

The following website link also contains more information on eligibility for the Attendants Pass Program as well as an on-line form:

www.stjohns.ca/cityservices/recreation/specialneeds/attendantpass.jsp

Those of us here at ENL recognize that not everyone who reads this newsletter is from the Avalon Region. If your town offers attendant passes for caregivers, let us know! If they don't, let us know that too, and maybe we can work to change it for the better.

Epilepsy Syndromes

When a person's seizure disorder has a characteristic group of features, it is called a syndrome. Syndromes have a cluster of symptoms or signs that define them.

Over the next few editions of *Epilepsy News* we will give you an overview of some of the most prevalent epilepsy syndromes. For more detailed information on any of the epilepsy syndromes listed here, please contact Epilepsy Newfoundland and Labrador.

Febrile Seizures

Overview

- Febrile Seizures are not considered to be epilepsy. They occur in children and infants whose temperatures have been elevated due to some infection in the body. Thirty to 40% of children who have a febrile seizure will experience some sort of recurrence. However only 3% will develop epilepsy during childhood.



Symptoms

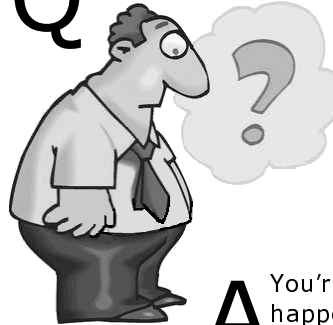
- Generalized convulsive episode involving a trembling or shaking of the body and limbs. May be only slightly visible in some instances.
- Risk factors which may indicate subsequent presence of epilepsy include:
 - ✓ a seizure that is prolonged lasting more than 15 minutes
 - ✓ recurrence of further seizures within a 24 hour period

Treatment

- In most cases physicians do not prescribe the long-term use of anti-epileptic drugs for febrile seizures. Instead the fever itself may be treated in an attempt to lower the body temp and in turn control the seizure. Children prone to febrile seizures may be treated at the time of the seizure with an oral or rectal treatment

Asked & Answered

Q I started having seizures about a year ago. The doctor scheduled me for an MRI to see if something would show up as the cause of the seizures, but when I went to the appointment I was told that I was too large to fit! What do I do now?



A You're not the first person this has happened to. MRI or Magnetic Resonance Imaging machines can be rather restrictive for some people. Designed like a giant tube, the opening for a person to fit into is kept reasonably small in order to enhance the imaging. Generally, the machine can accommodate someone no more than 300 pounds or so, and with a maximum shoulder width of 24 inches. This certainly excludes a lot of people.

In addition to people of size who may not fit, many people are simply too claustrophobic to be able to remain in such an incredibly narrow space, or may have mobility impairments which limit their ability to lie flat and completely straight.

The alternative is something called an Open MRI. The open MRI is, as it sounds, an open machine that can accommodate any size, and because it is not enclosed, works equally well for someone with claustrophobia or a disability. The results are only very slightly less as precise as a regular machine.

Sounds good, right? Here's the downfall - there isn't one in Newfoundland. The closest ones we have found are in Laval and Montreal, Quebec, and Brampton, Ontario.

If you require the MRI, the Department of Health and Community Services may be able to assist with the cost of travel in part or in full.

In addition, programs like HopeAir (www.hopeair.org) can provide low-cost airfare to and from appointments.

Last but not least, Epilepsy Newfoundland and Labrador can assist with medical travel in some instances.

If you would like further details on how to go about arranging an out-of-province Open MRI, give us a call at the office and we will do all we can to help make it happen.

Off the News Wire

Researchers Identify Genes for Febrile Seizures

French scientists studying four generations of a single family have honed in on two genes associated with fever-related seizures in infants and children.

These "febrile" seizures are the most common seizure disorder in children, affecting 2 to 5 percent of children by age 6. Most children with the disorder experience seizures only once or a few times and suffer no permanent brain damage. Some children with febrile seizures do develop other seizure disorders, such as epilepsy, later in life.

Of the 51 people in the family, 13 had febrile seizures. In all cases, the seizures stopped by age 7, but six of the 13 developed epilepsy later on. The study found that those who had febrile seizures shared similarities on chromosome 3 and chromosome 18.

"Identifying the genes responsible for febrile seizures could improve the understanding, treatment and even prevention of this disorder." *HealthDay, April 26, 2007*

Anti-dandruff Compound May Treat Epilepsy

Researchers at Johns Hopkins University have discovered that an ingredient used in anti-dandruff shampoos can also calm overexcited nerve cells in the brain, making it a potential treatment for epilepsy.

Epilepsy and other seizure disorders result when nerves excessively or inappropriately "fire" in the brain. The brain's 'off' switches fail partly because of protein defects that prevent potassium from exiting nerve cells and calming them. Channels that carry potassium must open on cue to make sure nerve cells only fire for defined periods of time. The researchers developed a new way of testing molecules to find any that could turn the potassium switch on or off. They chemically shaved off all the potassium channels on the cell surface and forced the cells to make new channels. By measuring the activity of the new channels, the researchers could identify the molecules that accelerated the recovery.

One chemical that proved quite effective in improving channel recovery was zinc pyrithione, the active ingredient in many dandruff shampoos. "Most drug discoveries uncover chemicals that stop things from working, but here we found a chemical that makes a defective protein work better. So now we have a chance to actually try to fix the causes of epilepsy, rather than traditionally circumventing them." *Epilepsy Action, June 6, 2007*

Epilepsy Increases Suicide Risk

People with epilepsy are three times more likely to commit suicide than other people according to new research, and women with epilepsy are more likely to kill themselves than men.

Accounting for factors such as mental health, job status, financial status and marital status, people with epilepsy were still twice as likely to kill themselves. And people who had been diagnosed within six months were more than five times more likely to commit suicide. People with both epilepsy and a psychiatric illness were nearly 14 times more likely to commit suicide than people with neither condition.

"There may be a number of factors that have a major impact on well-being. We know that epilepsy lowers the overall quality of life of the affected individuals – especially shortly after the diagnosis is given: job opportunities disappear, patients usually lose their driver's licence, drug treatment may decrease fertility, and pregnancy is associated with an increased risk of congenital malformations of the newborn child. The latter may be part of the explanation of why the impact of epilepsy with regard to suicide seems greatest in women." *Epilepsy Action, July 4, 2007*

Herpes Virus & Mesial Temporal Lobe Epilepsy

There is strong evidence that one particular type of epilepsy is associated with a viral infection. Researchers found DNA from the virus, Human Herpes Virus 6B (HHV-6B) in the brains of several patients with mesial temporal lobe epilepsy (MTLE) referred for investigation.

MTLE is a common, severe, type of epilepsy that usually begins in childhood. Mesial temporal sclerosis is a change often seen in the brains of patients with this form of epilepsy. HHV6 is usually acquired in early childhood. After primary infection, HHV-6 can persist lifelong in some white blood cells, salivary glands, and in the central nervous system. Active infection or reactivation of HHV-6 in the brain has been previously shown to be associated with neurological disorders, including epilepsy and encephalitis.

Overall, the researchers have now detected HHV-6B in 15 of 24 patients with mesial temporal sclerosis or MTLE, in contrast to zero of 14 with other syndromes. If these findings are confirmed in other groups of patients with this form of epilepsy, it may open up new avenues of therapy. *Public Library of Science, May 30, 2007*

Announcements and Notices

calendar campaign 2007



Our 2007 Calendar Campaign is underway!

For a donation of \$20 or more to Epilepsy Newfoundland and Labrador, we will be happy to send you our 2008 Pocket Calendar with artwork by grade 4 children from all over our province.

The 2008 calendar includes artwork from kids at the following schools:

- * Torrent River Academy, Hawk's Bay
- * Sandstone Elementary, Ladle Cove
- * D.C. Young School, Port Hope Simpson
- * St. Mary's Elementary, St. John's
- * St. Michael's Elementary, Stephenville Crossing
- * St. Joseph's All Grade, Terrenceville
- * J.R. Smallwood Middle School, Wabush

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

THE PEOPLE'S PAPER
The Telegram



**A Proud Supporter of
Epilepsy Newfoundland and Labrador**

Membership Renewals

May 31st was the end of our membership year, and it's renewal time again. Our members are very important to us and we are dedicated to helping them in any way we can. We are now inviting you to renew your membership for 2007-2008. Renewals are very important because it lets us know that you are still interested in receiving information such as this newsletter!



Our membership year runs from June 1st to May 31st and registration costs only \$5.00 for the whole year. If you would like to renew but find that the membership fee would be difficult, let us know and we should be able to waive the fee.

Your annual membership with ENL offers great benefits, services and information such as:

- Access to support programs and advocacy services - We will fight for you.
- Invitations to special events, teleconferences, support groups and info sessions
- Subscription to **Epilepsy News**, ENL's own quarterly newsletter
- Voting privileges at the Annual General Meeting
- Medication Alerts - Notification of critical changes in seizure medications or treatments
- Participation in our Connections program.
- Two \$1,000 post secondary educational scholarships **open only to ENL members**.

You can find a membership form on the back page of this newsletter, or if you are a current member who has not yet renewed for this year, a renewal form is attached. Membership renewal forms can be sent via mail or fax to:

Epilepsy Newfoundland and Labrador
26 O'Leary Avenue, St. John's, NL A1B 2C7
Fax: (709) 729-0999 - info@epilepsynl.com



Look at a day when you are supremely satisfied at the end. It's not a day when you lounge around doing nothing; it's when you've had everything to do, and you've done it.

~Margaret Thatcher

A Little Time Out



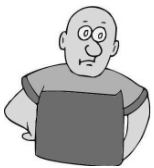
Your mother's brother's brother-in-law is also:
 ❶ your uncle? ❷ your father? ❸ your cousin?

Mary had wanted new kitchen cabinets for a long time, but her husband insisted they were an extravagance.

But, when she went to visit her mother for two weeks, she returned overjoyed to find beautiful new cabinets had been installed in her kitchen.

A few days later, a neighbor came over to visit. After admiring the new cabinets, the neighbor said...

"All of us were so glad the fire your husband had while you were gone was confined to the kitchen!"



A hair in the head
is worth two in the brush.

- Oliver Herford



There are so many summer festivals in this province! Below is a list of just a few of them. Can you identify the hometown for each? We have put the number of letters in each town's name at the end of the clue to help you out. Then find those town names in the puzzle at the bottom. All the leftover letters in the puzzle will spell out a hidden message.

The Beaches Accordion Festival	_____
Klondyke Days	_____
Bakeapple Folk Festival	_____
Bird Island Festival	_____
Brimstone Head Folk Festival	_____
Shrimp Festival	_____
Busker Fest	_____
Flying Boat Festival	_____
Festival of Flight	_____
Iron Skull Folk Festival	_____
Lighthouse Festival	_____
Paddle Festival	_____
The Great Crab Boil	_____
Scilly Cove Festival	_____
The Seabird Theatre Festival	_____
Smallwood Holiday & Logger Fest	_____
Caplin & Cod Festival	_____
Salmon Festival	_____
Fish, Fun, & Folk Festival	_____
Mussel Bed Soiree	_____
Blueberry Festival	_____

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E T R O P S I W E L E T
F B A Y R O B E R T S R
N O S N O S N I B O R O
O C G B R I G U S O X P
T H P O L O Y R E B A T
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Bits and Pieces

The Idea League

The International Dravet Syndrome Epilepsy Action League, is a volunteer-based nonprofit organization founded by parents of children with Dravet Syndrome to promote research and education for the early diagnosis, appropriate treatment, and cure of Dravet Syndrome.

Also known as SMEI (Severe Myoclonic Epilepsy of Infancy), Dravet Syndrome is a progressive childhood neuro-developmental disorder characterized by severe epilepsy that does not respond well to treatment. Estimates of the prevalence of this rare disorder have ranged from 1:20,000 to 1:40,000 births, though incidence may be far greater as new genetic evidence is discovered. It occurs more frequently in boys than in girls, but knows no geographic or ethnic boundaries.

To learn more,
please go to **www.idea-league.org**.



Puzzle Answers

Your mother's brother-in-law is also your father.

Newfoundland and Labrador this summer

Hidden Message - Explore all the fun of Newfoundland and Labrador Summer Festivals

The Beaches Accordion Festival - Eastport
Kiondyke Days - Bay Roberts
Bakeapple Folk Festival - Forteau
Bird Island Festival - Elliston
Brimstone Head Folk Festival - Fogo
Shrimp Festival - Charlottetown (Labrador)
Busker Fest - St. John's
Flying Boat Festival - Botwood
Festival of Flight - Gander
Iron Skull Folk Festival - Belleoram
Lighthouse Festival - King's Cove
Paddle Festival - Ramsea
The Great Crab Boil - Robinsons
Silly Cove Festival - Winterton
The Seabird Theatre Festival - Newtown
Smallwood Holiday & Logger Fest - Gambo
Caplin & Cod Festival - Triton
Salmon Festival - Exploit's Valley
Fish, Fun, & Folk Festival - Twillingate
Mussel Bed Soiree - Lewisporte
Blueberry Festival - Briggs

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