



Epilepsy News

THE QUARTERLY NEWSLETTER OF EPILEPSY NEWFOUNDLAND AND LABRADOR

SUMMER 2007

From Burnt Toast to Chirping Birds

Auras - More than Just Odd Feelings

Some know them as Auras, others by the more technical name of Simple Partial Seizures, but whatever you may call them, they may just be one of the most useful seizures you ever have.

What is an Aura?

Auras are really small seizures. They are brief, localized, electrical brain discharges that often precede more serious seizures. The part of the brain where the electricity comes from, will influence what kind of aura that person has



Auras range from the horribly frightening – feelings of uncontrolled terror – to the pleasurable – ecstasy and unbridled euphoria. Some can be downright bizarre:

- "I almost enjoy them. The feeling of déjà vu, as if I've lived through this moment and I even know what's going to be said next. Everything seems brighter and more alive."
- "It is a pressure that starts in my stomach, then rises to my chest and throat. When it reaches my chest, I smell an unpleasant odor of something burnt. At the same time I feel anxious."
- "I never know when it might happen, and nothing ever happens after. But every once in a while for no reason, it makes me chirp like a little bird. I can't stop it."

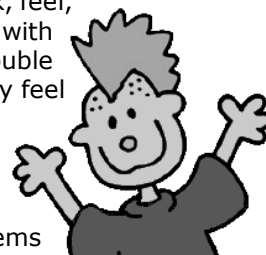
Types of Auras

Motor: change in muscle activity such as abnormal movements like jerking of a finger, stiffening of part of the body, or weakness. This can affect speech, and laughter and the person may or may not be aware of these movements.

Sensory: changes in any one of the senses. People may smell or taste things that aren't there; hear clicking, ringing, or a person's voice when there is no actual sound; or feel a sensation of "pins and needles" or numbness. They may have visual hallucinations, or may experience illusions—distortions of true sensations.

Autonomic: changes in the part of the nervous system that automatically controls bodily functions. These common seizures may include strange or unpleasant sensations in the stomach, chest, or head; changes in the heart rate or breathing; sweating; or goose bumps.

Psychic: change how people think, feel, or experience things. Problems with memory, garbled speech, or trouble understanding language. They may feel emotions like fear, depression, or happiness for no outside reason. Some feel as though they are outside their body or have feelings of déjà vu (the unfamiliar seems familiar) or jamais vu (the very familiar seems unknown and never seen before).



The Advantage of Auras

Auras can be incredibly useful for two big reasons:

1. Since they often precede a complex partial or secondarily generalized seizure, auras can serve as a warning for many people to know that a larger seizure may be about to happen. This can allow time to find a safe place to lie down, or time to tell someone nearby what is going on.
2. The type of aura a person has can help the doctor to better determine where a person's seizure focus (the part of the brain where that seizure is originating) might be. As a result, more targeted and effective treatment options may be found sooner.

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On My Mind

I have been with the association for several years now, and in that time, I would like to think that I have learned a great deal about seizures both on the medical side as well as the social and emotional side. I keep up on new information and technology, treatments, and medications. I teach classes and give sessions on what to do if someone has a seizure, I talk with people who are newly diagnosed and are so very afraid of what the future holds.

But sometimes I am caught off guard so much that I have no answers.

I recently talked with a group of students about seizures, safety, and first aid where a little girl kept asking question after question to the point of almost being disruptive. And then she asked if someone could die from a seizure. Not wanting to scare the students, but still wanting to be truthful, I answered that yes, it was possible, although it was most likely not something she would ever have to worry about.

She nodded and then started crying. She later told me that her mom had died only a few months before from a seizure. She said she wished she had known then all the things to do, so maybe she could have saved her somehow.

I have never felt so at a loss for an answer. There was nothing she could have done. Sadly, death from a seizure it is something that can happen to some people as rare as it is. But telling her all those things, seemed so insignificant to me, they seemed not quite enough.

There are so many stories in the course of my work - of struggle, and sadness, of success and joy. Some I carry very close because they serve to remind me why I do what I do here, and keep me pushing even harder to reach the people who do need answers, and a hand to hold.

Pamela Anstey
Information Officer

Disclaimer

The materials contained in the Epilepsy Newfoundland and Labrador newsletter are to provide general information about epilepsy to the public. The information presented is not intended as medical or legal advice. Epilepsy Newfoundland and Labrador, its employees, board members, medical advisors, volunteers, agents and sponsors do not assume responsibility for inaccuracies or omissions or for the consequences from the use of the information obtained in this newsletter. Epilepsy Newfoundland and Labrador is not liable for any outcome or damages resulting from information in either a direct or indirect form. We recognize that each individual's experience of epilepsy is different. Consult your physician and/or neurologist with any questions you have.

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

Fall Excursion 2007

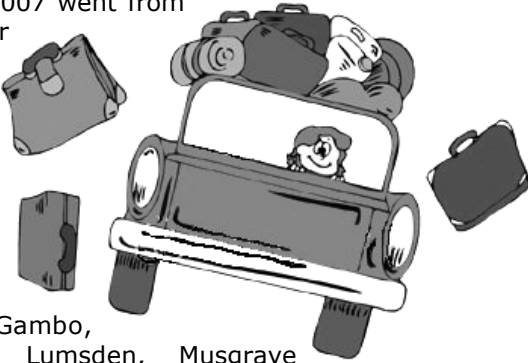
Pam hits the Northeast Coast!

Every year after I have returned from the Fall Excursion, I come back and sit, to write and tell people all about it. I often extol the beauty of the various areas I have visited, or tell of the mishaps that might have gone on during my time away.

This year, I could easily go on and on about the beauty of the areas I visited, but as for mishaps, it was one of the smoothest trips I have ever had.

My trip for 2007 went from September 16th to the 23rd and

took me all around the Northeast Coast of the province. I started in Glovertown, then to Gambo, Wesleyville, Lumsden, Musgrave Harbour, Carmanville, Gander Bay, all over Fogo Island and Change Islands, and finally ending in my hometown of Twillingate and New World Island (which, of course, made my folks thrilled).



The presentations arranged were mostly schools this year, nine different ones in all. Of all the sessions I did this time, these were some of my favorites. Most all of the kids were so interested, and even the teachers got involved with the role-play sessions. As I was leaving, I overheard a student at one of the schools saying "We'll never have another assembly as good as this again."

In addition I met with staff of two daycare facilities, two Employment Assistance Services offices, and a couple of RCMP detachments.

The RCMP is an interesting issue in rural Newfoundland. There were five detachments along my route - Gambo, Wesleyville, Carmanville, Fogo, and Twillingate. In each of them, there was at most two staff. Most were supposed to have more, but due to vacant positions, or leave of absences, or sickness, the police presence was pretty sparse.

Aside from the two where I actually sat and talked with the staff present, I also left information and resources with the other offices so that absent members could avail of the information.

Information and resources were also left in numerous other spots along the route. All Health and Community Services, Human Resources Labour and Employment, health facilities, clinics, and pharmacies.

In total, I did 26 presentations/sessions, with nearly 700 people, plus left information behind that will reach many more. The reception is always so welcoming, especially in areas such as Change Islands or Fogo where presenters barely ever visit. I would love to be able to do more of these trips, so that we can have a real presence beyond St. John's and area.

ENL would also like to offer a warm thank you to the Village Shopping Centre Foundation. The Foundation was the sponsor of our Fall Excursion this year and as a result of their generous donation of \$1500, we were able to bring Epilepsy and Seizure education throughout the Northeast coast.



ENL President Ron Stone accepts a \$1500 cheque from Kimberly Ryan of the Village Shopping Centre Foundation.

Be tolerant of the human race. Your whole family belongs to it --
and possibly some of your spouse's family does too.

Christmas Tea for Epilepsy

Walk-A-Thons have you
going around in circles?
Canvassing leave you out in the cold?
We have a way to help
that might just be your cup of tea!



**Join with us by hosting one of the
most relaxing fundraisers ever**

The 4th Annual

Christmas Tea for Epilepsy!

Gather your friends, family, the girls from work, your sports team, or anyone you like. Then all you to do is sit back, relax, and enjoy a cup of tea on us, any time during the weeks of December 3rd – 14th, 2007.

We will provide the tea, goodies, information about seizures, and a special surprise, and you provide the good will and community spirit. It's that easy.

For your cup of tea, we're asking that you pitch in a loonie or twonie per person to help people with epilepsy right here in Newfoundland & Labrador.

Alternatively, if you know a community minded group or business, we will be happy to provide a tea basket for them too. Some businesses and offices donate their break money, some sell tickets on the basket, and some choose to make a direct donation to Epilepsy Newfoundland and Labrador and offer the tea and sweets to their staff, clients, or customers as a special treat.

Every group, business, or office that participates will also be included in our Tea Folk Hall of Fame, which will be posted on our website as well as mailed to several hundred homes in our January newsletter.

More than 10,000 people in Newfoundland and Labrador have epilepsy, and at least one in every ten of us will have at least one seizure in our lifetime. Epilepsy Newfoundland & Labrador is the only epilepsy association in our Province, and we are working hard to provide information, advocacy, support and education to anyone who needs assistance. With your cup of tea, we can do even more.

Getting involved is easy - give me a call or send me an email letting me know how many people you would like to have tea for, and when you would like to hold it, and I will do the rest. If you have any questions at all, feel free to get in touch.

Happy Sipping,

Pamela Anstey
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Supporting Students With Seizures

Inadequacies in the provincial K-12 education system regarding support for students with additional needs still exist. Parents note that there is inadequate student assistant support available and they question whether or not the curriculum is designed broadly enough to meet the needs of all students.

How do we insure that children with additional educational needs receive the assistance and educational supports they need?

Creating the Right Program for Your Child

- Talk to other children and parents about school staff attitudes and experiences. Talk to the staff about their training, experience and philosophy. Do they listen to parents and encourage them to be involved in school life? How do they plan to provide the support necessary to build self-esteem and encourage independence in your child? Will they offer a balanced program by providing extra supports in the class and by taking the child out for individual attention when necessary? A warm and supportive relationship with peers will be very important for your child's development. How does the school encourage full participation in school activities?
- Set up Individual Support Services Plan (ISSP) meeting prior to starting kindergarten or early in the fall of each year. This meeting should include the parents, the teachers, principal, children's rehabilitation therapist and school board consultants. A parent should be the "manager" or "co-manager" of the ISSP because he or she will be the most constant person in the child's life. Decisions made in elementary school will have an impact on high school graduation.
- Document everything in writing and encourage follow-up of issues and concerns. Keep copies in your own file at home. Share copies of pertinent information with teachers who may not be up to date on current research concerning your child's condition.
- Ensure that field trips are planned with your child's needs in mind. Your child should not have to miss a field trip because it is not safe, or there is not enough support staff.



→ Attend school activities as much as possible and ensure that your child is being included in all activities such as assemblies, gym, choir, and after-school programs.

- Advocate for your child. Make your wishes and concerns clearly known to the teachers and principal. Discuss problems immediately because the process of dealing with these issues can take some time. If you are not happy with the policy, initiate change by contacting the schools, school board, Department of Education, Government and/or media. Don't give up! Take time to let the staff know what they are doing right.

Creating a Supportive Home Environment

- Avoid having your child miss too much school by combining doctor's appointments or booking the appointments for after school hours or during holidays.
- Have the teacher lend you extra books so you can help with homework on a regular basis. If necessary, the parent can write out Math problems the day before so the child can focus on learning the concepts instead of laboriously writing out problems.
- Provide many opportunities for your child to socialize with school friends in your home, in social clubs, recreational activities, movies and parties.
- Teach your child to be a self-advocate as he or she progresses through the school system. Your child will be empowered and become more confident when he or she initiates changes that improve quality of life.

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.

Infantile Spasms/ West's Syndrome

Overview

- ➔ Although West's Syndrome and Infantile Spasms are not exactly the same thing, they have come to be used interchangeably because one almost always accompanies the other when it develops in children. This type of epilepsy occurs in about 1 in every 2-4000 children and usually appears in the first 3-6 months of life at which point development usually halts or regresses. Eighty five percent of children who will develop it will do so before the age of 12 months.

Symptoms

- Characterized by three recognized features: spasms, mental retardation, and chaotic brain activity on the EEG (hypsarrythmia),
- The spasms appear as sudden contractions lasting 2-10 seconds and can include stiffening of the body or an arching and extending action of body, arms or legs.
- Spasms usually occur in a series of several in a row and the series usually abates within 10-30 minutes.

Treatment

- Treatment is typically anti-convulsants or steroids, with the AED vigabatrin (Sabril) being most effective, but used with caution due to its potentially permanent effects on vision.
- Outcome is variable and depends in great part on what the cause of the syndrome is.

Asked & Answered

Q I am writing on behalf of an individual who had a seizure almost 3 years ago and has been on a low dosage of medication ever since. He has not had anymore seizures since that first one. He is pursuing commercial drivers license and Motor Vehicle Registration told him that he needed to be Seizure free for 5 years before he could apply for one. Is this accurate even if he is on medication?

A Currently, regardless of whether a person is on or off medications, five years is the magic number for commercial class licences.

From the "**Determining Medical Fitness To Drive**" guidelines by the Canadian Medical Association, which Motor Registration uses in deciding eligibility, the regulations surrounding epilepsy and commercial licencing are as follows:

10.4.2 After a diagnosis of epilepsy: patients may drive any class of vehicle if they have been seizure free for 5 years with or without anticonvulsive medication. However, patients with Juvenile myoclonic epilepsy (Janz syndrome) may not drive any class of vehicle unless they are taking appropriate anti-seizure medication.

Commercial drivers: It can be unsafe for commercial drivers who must take anti-seizure medication to operate passenger-carrying or commercial transport vehicles (Classes 1 - 4). For these drivers, there is a need for even greater certainty that another seizure will not occur while they are driving. Commercial drivers are often unable to avoid driving for long periods of time, frequently under extremely adverse conditions or in highly stressful and fatiguing situations that could precipitate another seizure. Unfortunately, seizures do sometimes recur even after many years of successful treatment.

So basically, if a person has been diagnosed with epilepsy, it will be five years before they are eligible for a commercial class licence. However, not discussed above, is the other side of the guidelines. If a person has had only one seizure, and has **not** been given an official diagnosis of epilepsy, the commercial guidelines are different and the time may be as little as one year.

Off the News Wire

Alzheimer's Patients Suffer 'Silent' Seizures

According to researchers, seizures may explain why some people with advanced Alzheimer's have "spells" of increased confusion. The seizures would not be recognizable in the same way a convulsion or epileptic seizure can be noticed.

These subtle seizures may be linked to cellular changes caused by high brain levels of the Alzheimer's-linked amyloid beta protein.

Understanding the process behind the seizures may lead to treatments that can prevent or even reverse the progression of the disease.

Prior to this research, spells of increased confusion were thought to be a result of degenerating nerve cells. According to the researchers, the study indicated that they may result from excess amyloid beta and could signal future cognitive failure. Amyloid beta is a toxic protein fragment found in the brains of people with Alzheimer's disease and similar disorders.

Baylor College of Medicine, September 5, 2007

Clearer Window on the Brain

A new MRI scanning technique could mean life-changing curative surgery for more people with epilepsy. The technique helps to pin-point the exact source of seizures in the brain and, where surgery is possible, the area may be removed. This can mean a future that is seizure free for people whose epilepsy cannot be controlled by drugs.

In this most recent research the team has further advanced the MRI scanning methods to identify where seizures may be originating. They have also looked at the changes that happen in the brain immediately following an epileptic seizure, to see whether it causes any damage.

"Our work in a UK study has found that in 29 per cent of patients whose brains appeared normal using conventional MRI scanning, our new techniques have found changes suggesting an epileptic seizure. This would have been missed without our new techniques. This is a real leap forward in the treatment of epilepsy and it could mean life-changing surgery for many more people. The potential benefit to patients is tremendous."

Epilepsy Action, September 3, 2007

Ways To Control Fever-induced Seizures

For about one in 25 infants or small children, a high fever can trigger fever-induced (febrile) seizures. While these seizures themselves are generally harmless, a prolonged fever resulting from infection, or heatstroke of over 108 °F (42 °C) can lead to respiratory distress, cognitive dysfunction, brain damage or death.

New research has shown that genetic variation in a particular gene results in different tolerance for heat stress, and demonstrates how the use of specific drugs can replicate this effect. While the findings are at an early stage, the researchers suggest that it could lead to ways to rapidly protect the brain from extremely high fevers.

"Our research suggests that manipulation of a single gene or genetic pathway will be sufficient to rapidly protect the nervous system from damage due to extreme heat stress," says senior researcher.

"During heat trauma to the brain, there exists a window of opportunity between the time of occurrence of neural dysfunction and eventual brain damage or death, manipulation of the pathway during this period should increase an individual's chance of survival."

Science Daily, August 22, 2007

Child's IQ Affected by Maternal Epilepsy

A history of maternal epilepsy and its treatment may be linked to impaired intelligence later in life, according to a new study published in *Epilepsia*.

Researchers investigated the IQ levels of boys born to mothers with and without epilepsy, and found a link between intelligence and the condition. Using extensive maternal epilepsy data, and adult IQ measurements taken later in life, the study finds that almost twenty years after birth, the sons of mothers with from epilepsy before or during pregnancy exhibited reduced IQ scores when compared to men whose mothers did not have epilepsy.

Information on the specific antiepileptic drugs used by the mothers in the study was not available. "It remains to be seen whether the newer antiepileptic drugs are safer to offspring exposed during foetal life."

Epilepsia, August 2007

Announcements and Notices

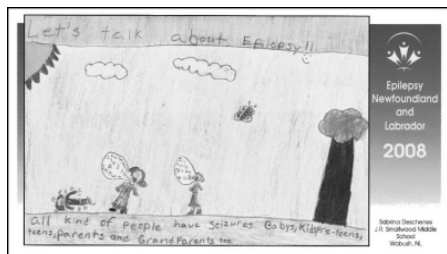
Hellos and Goodbyes

We said goodbye and happy retirement to one of our long time employees this past month. June Bennett has been with us since the 1990s as our Clothing Pick-Up and Confirmation Clerk. If any of you have ever donated used goods to our thrift store, odds are it was June you talked with. June leaves us to spend some quality time with her husband at their cabin by the ocean. Enjoy your retirement June, and know that you are missed!

With June's leaving, in her place we have welcomed Almyra Hodder. Almyra has jumped in and is finding her way admirably. We're happy to have her on board.

In addition, we also welcome Linda MacDonald to her new position as our Door to Door Campaign Coordinator. Linda Mac has been one of our outstanding clothing collection telemarketers, and will no doubt be an outstanding Campaign Coordinator as well. So Good Luck June! Hello Almyra and Linda!

calendar campaign 2007



Our 2007 Calendar Campaign is winding down, do you have your 2008 calendar yet?

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 Telegram*

Door to Door Campaign

We Need Your Support!

Our 2008 Door to Door Campaign will begin in full force on March 1st. While that may seem like a long way off, we are beginning our search for canvassers now. With the help of many generous and caring people just like you, I am sure that this year will be a resounding success once again. It's



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

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

There are collector prizes to be drawn for at the end of the campaign.

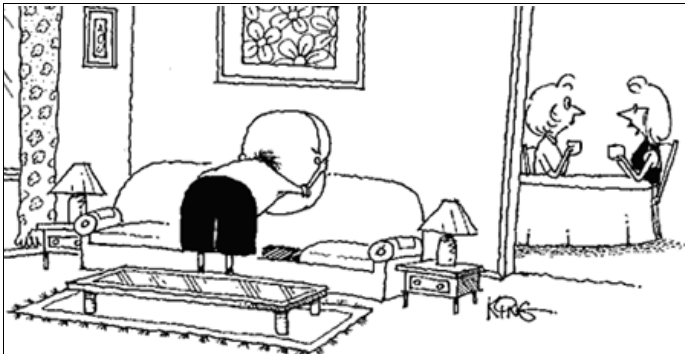
If you cannot help, perhaps you have friends and family who would be happy to collect at a few homes on your behalf? Or if not, please give generously when one of our volunteer canvassers comes to call at your door. Every penny stays right here to help the people of this province live a better life today.

Linda MacDonald
Campaign Coordinator



We are so often caught up in our destination that we forget to appreciate the journey, especially the goodness of the people we meet on the way. Appreciation is a wonderful feeling, don't overlook it. ~ Source Unknown

A Little Time Out



The doctor said he needed more activity. So I hide his T.V. remote three times a week.

If you ripped the following pages out of a book, how many separate sheets of paper would you remove? The page numbers are 4, 5, 24, 47, and 48.

One afternoon, a man went to his doctor and told him that he hasn't been feeling well lately. The doctor examined the man, left the room, and came back with three different bottles of pills.

The doctor said, 'Take the green pill with a big glass of water when you wake up. Take the blue pill with a big glass of water after you eat lunch. Then just before going to bed, take the red pill with another big glass of water.'

Startled to be put on so much medicine, the man stammered, 'Jeez Doc, exactly what is my problem?'

The doctor replied, 'You're not drinking enough water.'

THE EARLY BIRD
GETS THE WORM,
BUT
THE SECOND MOUSE
GETS THE CHEESE



I hope that my achievements in life shall be these -- that I will have fought for what was right and fair, that I will have risked for that which mattered, and that I will have given help to those who were in need, that I will have left the earth a better place for what I've done and who I've been. ~ C. Hoppe

animals in hiding

There is an animal hiding in each sentence below. Can you find the animals? Example: There's a bee in "I'll be eleven next month." Hint: Some animals actually span three words. When you have found them all, look for them again in the puzzle underneath. The leftover letters in the word search will spell out a hidden message.

1. We can go at six o'clock.
2. It's nice to do good deeds.
3. Take soap and a towel.
4. Most rich people wear fancy clothes.
5. You can keep the watch or sell it.
6. Use a ladder.
7. It will be a rainy day.
8. I came late.
9. Tell me if I should start now.
10. Will a map help you?

O	P	A	N	D	A	I	S
T	S	S	H	A	J	E	U
H	A	T	N	S	A	G	C
O	M	T	R	L	I	G	A
R	A	A	L	I	O	F	M
S	L	O	E	D	C	O	E
E	L	G	U	T	T	H	L
H	E	R	R	A	E	B	E

Bits and Pieces



NEWFOUNDLAND AND LABRADOR

BRAIN INJURY ASSOCIATION

In November 1984, a committee was formed to deal with the many brain injured people who were put in nursing homes and the Waterford Hospital. At that time, community supports were inadequate to deal with the complex neurological and psychiatric difficulties experienced by brain injury survivors.

Major service gaps continue even today and the special needs of this population continue to be ignored. Long-term support for brain injury survivors is poor and fragmented once the person is discharged from the hospital environment and families are left to patch together support services from a variety of sources (development service agencies, vocational rehabilitation, private providers, nursing homes).

Together we can make it better. To find out more information, receive support and resources, contact

Brain Injury Association of Nf & Lab

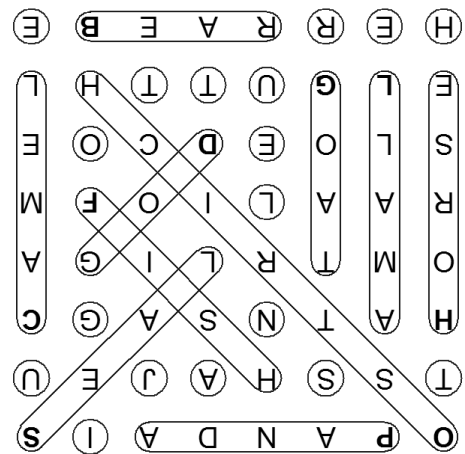
St. John's, NL Phone: 579-3070

email: nbia@nf.aibn.com <http://www.nlbia.ca/>

Puzzle Answers

You would have four sheets of paper. The odd pages of a book are on the right side, and the even pages are on the left. Therefore, pages 47 and 48 are opposite sides of the same sheet of paper.

Hidden Message - It's a jungle out there!



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