



Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Spring 2007

SUDEP

Nobody is Talking, But Maybe We Should Be

It's one of those topics in epilepsy that many never talk about, or if they do, only lightly glance over because it is scary stuff - SUDEP, or sudden unexplained death in epilepsy.

It's controversial for certain. Even most experts can't really agree on how prevalent it is. The latest statistics from the World Health Organization put the total number of epilepsy related deaths per year around 220 in Canada, and researchers feel that anywhere between 7 and 17% of those may be related to SUDEP.

But what is SUDEP really, and more importantly, are there any steps that people with epilepsy can take to reduce their risk?

In technical terms, SUDEP is defined as:

"the sudden, unexpected, witnessed or unwitnessed, non-traumatic and non-drowning death in patients with epilepsy, with or without evidence for a seizure, and excluding documented status epilepticus, in which post-mortem examination does not reveal a toxicological or anatomic cause for death." Nashef L, *Epilepsia* 38 (Suppl.11): 56-8

In plain English, SUDEP is when a person with epilepsy dies suddenly and no other cause of death is revealed.

While no one has yet to determine an actual cause, research has shown some people seem to be more at risk than others.

- Having frequent changes of anti-epileptic drug dosage .
- Experiencing nocturnal seizures (during sleep).
- Being alone at the time of the seizure.
- Being a young adult, particularly male.
- People with uncontrolled or poorly controlled epilepsy
- People with severe epilepsy and learning difficulties
- People with a long history of tonic-clonic seizures
- People who take 2 or more anti-epileptic drugs (especially if combined with psychiatric agents)
- Poor compliance with anti-epileptic medications
- Alcohol abuse (definite links found)

When considering the risk factors, remember that just because some or more of these may apply it does not mean that someone will die from SUDEP.

However if several of the factors do apply, it may be worthwhile to consider making some changes to minimize the risk.

Controlling seizures seems to be most important, discuss your management plan with your doctor

Keep appointments so your doctor can monitor any changes, and adjust your medications accordingly.

It is vital to take all medications at the time prescribed and in the correct manner every day.

Avoid sudden drug withdrawal, or dosage changes

Adopt a healthy lifestyle including regular sleep, exercise, nutritious meals, and stress reduction.

Avoid alcohol and street drugs

Stay with company whenever possible so that someone can help during seizure

Nocturnal seizures seem to have a higher incidence of SUDEP. Preventive measures could include having the bed near the floor, changing from a regular to a corrugated foam pillow to reduce the possibility of suffocation, and having a monitor to alert others when a seizure occurs.

Pamela Anstey
Information Officer
Epilepsy Nf & Lab
April 2007



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On My Mind

We live in a big province! Ok, so that may not exactly be earth-shattering news, but at no time does it become more obvious to me than when I set about trying to plan events and speakers for the people we serve here at Epilepsy Nf & Lab.

Just how does an organization arrange opportunities for people sharing the experience of seizures to come together, when it could take hours (and a possible plane ride) for some folks to actually attend?

Even when people actually do live within driving distance of us here in the city, participation in group things still tends to be low. Which, of course, leads me to pondering.

Is it simply because we are just so busy in our daily lives that we have no time or energy at the end of the day to go out yet again? Or is it something even more personal? Could it be that in attending events and groups centered around seizures, a person might feel outed and exposed in what may be a very private matter for them? If this is the case, then what might the solution be?

I wish I had all the answers. I wish that everyone in this province knew about the assistance that is available to them, not just through their doctor's office, but for after, when all of the day to day questions pop up. I wish that no person would ever feel like they are alone in their struggles with this disorder, because they aren't. I tend to do a lot of wishing it would seem.

On May 2nd at 7:30 pm, we will be hosting a coffee break at Chatters Café on Duckworth Street in St. John's. Just a relaxed and laid-back evening out with the chance to meet others for a chuckle and a friendly ear. Why not take an hour and come join us if you can.

And if you have any thoughts on how we can best serve all of this province, and not just those inside the overpass, bring 'em on. I would love to hear them.

Pamela Anstey
Information Officer

Disclaimer

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

*Tough times never last, tough people do.
~ Robert H. Schuller*

Epilepsy Awareness Month - March 2007 Recap

March was Epilepsy Awareness Month - a special time of the year right across Canada when grassroots associations work extra hard to get the word out about epilepsy and seizure awareness. And boy did we this year!

March-Long Events

At the beginning of March we launched several month-long events. One saw every pharmacy in Nf and Lab receiving information to be publicly displayed and distributed to their customers.

Another saw every single medical clinic in the St. John's, Mount Pearl, Paradise, and the Goulds areas received resources to set up in their waiting rooms as well as additional resources to hand out to patients needing information. I'm hoping that over the course of the year we can do the same in almost all the clinics in the province. If you are able to help, please let me know.

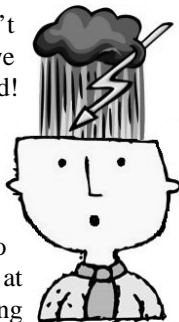
Brain Day Parties

For the past four years we have held our brain Day Party, a fun event where students learn about how their brain works and receive information on seizures and first aid through interactive activities. This year we decided to send the invitation out to the schools in the area to see if they would like to have a Brain Day party with their students. Did they ever!

With the help of a handful of volunteers, we took Brain Day to six different schools, which included 49 presentations, 111 classes, and a total of 2530 students!

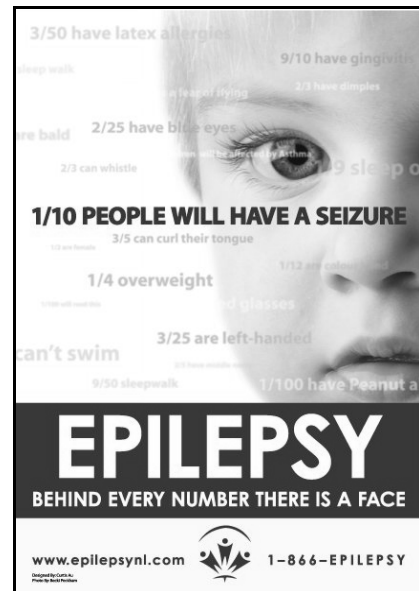
Brainstorm

March was so full this year that we couldn't squeeze everything into one month. So we started some things in February instead! Brainstorm is a Q & A competition that tests high school students' knowledge of the brain and nervous system. Brainstorm is an international event and the winner of the provincial competition held February 17th also won the opportunity to represent this province at the international finals in Maryland during March. There were over 40 students from schools around the province competing. ENL was invited to be a guest quiz-person and to give a brief familiarization with our organization and its activities. Some excellent prizes were given and everyone went home with not only a prize, but a better understanding of the brain as well.



Graphic Design Contest at CONA

Each year during March ENL advertises like crazy, to make sure people better understand epilepsy and seizures. One of the ways we have done this is through Bus Shelter ads.



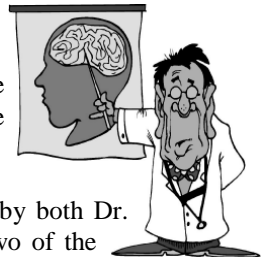
This year we threw a little spin on that idea and invited all of the students in the Graphic Design Program at the College of the North Atlantic to develop a bus shelter ad that would convey the type of message we want people to know. It was an excellent opportunity for the students to work on an actual business project, and a chance for us to tap into some amazing talent. Curtis Au developed the winning ad which you see here.

It was blown up to 8 feet high and is now on view in a very prominent shelter here in the city. While the black and white version shown here doesn't do it justice, I'm sure you will agree that it certainly has an impact.

Provincial Question and Answer Forum and Teleconference

Our signature event of Epilepsy Awareness month has always been the Question and Answer forum. This year, although the turnout was small, the information shared was just as valuable and relevant as ever.

We were honoured again to be joined by both Dr. Ogunyemi, and Dr. David Buckley, two of the provinces foremost neurologists.



Questions varied from a focus on personal symptoms, to inquiries regarding medication side effects, menopause, alcohol use, behavioural changes, weaning off medications, and many others.

The forum was both educational and inspirational, and we offer our very special thanks to both Dr. Ogunyemi and Dr. Buckley for providing their knowledge and guidance.

A Mother's Nightmare

Emma Murrin had her first seizure at 10 months, and nearly died at a year and a half.

"We almost lost her," her mother, Trina Murrin, says.

"She went to take a sip of her sippy cup. She went back, hit her head off the floor, went into a grand mal (seizure) and stopped breathing."

Murrin's sister and cousin performed CPR before the baby was driven to meet an ambulance.

Thankfully, Emma survived the incident.

But, now 2 ½ years old, her seizures are worse - up to two hours long.

"She's had to be intubated now twice and put in ICU," Trina says during an interview at her parents' home in Pouch Cove.

Doctors first suspected the seizures were related to a high fever, but Emma was subsequently diagnosed with an as yet unidentified and alarming form of epilepsy.

"They know it's epilepsy, but they don't know which kind it is yet," her mother said.

Epilepsy is a brain disorder. Many people who have it lead healthy and productive lives; Murrin hopes the same for her daughter.

But the fear of not knowing exactly what's wrong with her worries Murrin.

"Emma started having seizures every month since October. And ever since then she's been sick," she said.

"She's a totally different child. She's not eating like she used to ... she's not sleeping well. She's very moody. She can't concentrate on one thing."

Murrin said she's been told Emma's seizures are life-threatening. And while she said she has every confidence in Emma's neurologist, she is taking her daughter to Sick Kids Hospital in Toronto for a second opinion.

"They don't understand why her seizures last so long or why she stops breathing. So we just want to see if there's anything they can find up there with the technology they have."



Emma's chart has been studied by a Toronto-based neurologist, who is going to see her on May 29.

Murrin has turned to Epilepsy Newfoundland and Labrador (ENL) for advice.

"I called (information officer Pam Anstey) and I told her that I feel like I'm alone in this. My family is trying to be there for me, but outside I'm not getting anything. ... So, Pam is going to try to do her best to help me."

ENL educates the public about epilepsy and aims to improve the lives of those with the disorder.

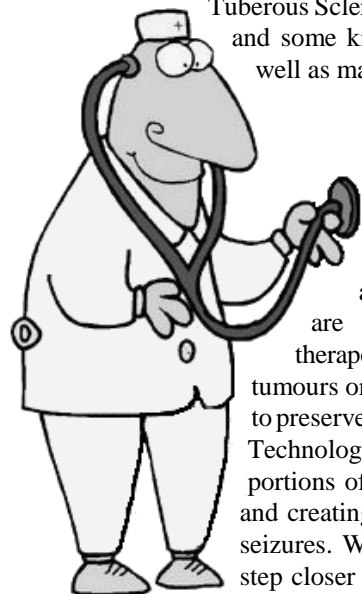
"I've going to talk to Pam about going to a support group about epilepsy," Murrin said.

"But everything's just too fresh for us right now, dealing with Emma having to go to Toronto. But we're taking it day by day. And we'll just have to wait and see what happens."

Danette Dooley, The Telegram, March 2007

Student Seeks Input for Tuberous Sclerosis Booklet

Tuberous Sclerosis is a potentially life threatening disease that causes tumors to form in all organs of the body - heart, kidneys, lungs, eyes and brain. Most individuals with Tuberous Sclerosis experience severe seizures and some kind of neurological damage as well as many other complications.



1 out of every 6000 children are born everyday with Tuberous Sclerosis.

Early intervention is helping and advancements in research are bringing new and improved therapeutic options. Surgery to remove tumours or stop tumour growth is helping to preserve the function of affected organs. Technology is pinpointing the exact portions of the brain stimulating seizures and creating new therapies to help control seizures. With every new day we are one step closer to finding improved treatment.

~ from www.tscanada.ca

A Newfoundland university student is seeking input from families as she completes her studies. Taryn Stone is studying for a degree in post-secondary education. She is required to develop a course on a particular topic and has chosen Tuberous Sclerosis Complex.

Taryn, who lives with the effects of TSC, says she decided on the topic after looking into a standardized patient program in St. John's, where she lives.

"I realized that I have heard many frustrations by people with TSC, from what doctors do not tell them, lack of awareness, lack of support from families and friends, and lack of understanding from humanity as a whole," says Taryn in an e-mail interview.

Taryn says she decided she wanted to raise awareness and educate people in the general community about TSC through her course. This, she believes, will contribute to easing the difficulties of individuals with TSC and their families. She is also planning to develop a booklet from the course material that hopefully will provide additional support for families.

The booklet will be for the individual with TSC, their families and friends with a focus on the emotional and social impacts of the disease.



"I would like [people] to realize that they are normal and everyone is scared when they find out about this disease," says Taryn. "Knowing that we are all scared and feel alone, and that there are others out there going through the exact same thing as we are, makes a huge difference with someone emotionally."

Taryn also plans to include a component for physicians and other health professionals and specialists who work with people with TSC in the booklet. She would like to bring awareness about the emotional needs of individuals with TSC to the health-care community.

The proposed booklet would also include main contact numbers and website addresses for TS Canada, TS Alliance and other relevant websites.

Taryn is looking for help in completing both the course and the booklet. She has developed a survey for individuals with TSC and is looking for people to participate in it.

CALL TO ACTION:

Anyone who is interested may e-mail Taryn at taryn.stone@gmail.com. She says that all answers will be incorporated into her report, but no names or personal information will be used.

For more information on Tuberous Sclerosis visit www.tscanada.ca

Epilepsy Syndromes

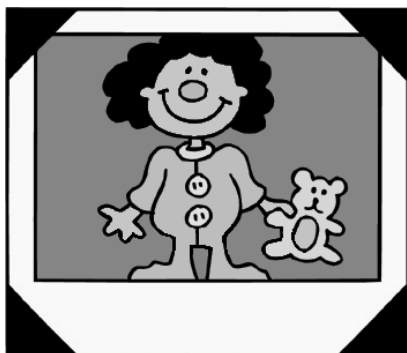
When a person's seizure disorder has a characteristic group of features, it is called a syndrome. Syndromes have a cluster of symptoms or signs that define them.

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.

Benign Rolandic Epilepsy

Overview

Benign Rolandic Epilepsy is also referred to as 'benign partial epilepsy of childhood' or 'benign focal epilepsy with centropetal spikes' and is one of the most common types of epilepsy in children; about 15-20%. It is known as benign because of the high probability that it will be outgrown during puberty. By age 14, 95% will have undergone permanent remission. It affects boys and girls equally.



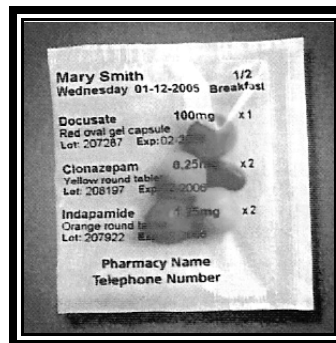
Symptoms

- Seizures often start upon the child beginning to wake up or during sleep.
- Begins with a tingly sensation on one side of the mouth and may involve the throat which can garble speech and make the child hard to understand. May make gurgling noises and drool substantially.
- Seizures may cause twitching movements and stiffness on the side of the face being affected, and may then spread to the rest of that side of the body.
- Sometimes the seizure will spread to the whole body, causing a generalized tonic-clonic seizure. The child will become unconscious, fall to the floor and body and limbs convulse and jerk.

Treatment

- Often children with Benign Rolandic Epilepsy do not need treatment at all. If treatment is required, anti-epileptic medications are most often used, which may limit or eliminate the seizures entirely. Benign Rolandic Epilepsy responds well to treatment.

A Neat Idea!



Have you ever heard of PacMed? Me neither until recently when I received a visit from a pharmacy representative here in the St. John's area who showed me a medication system which can really help people with their prescriptions.

The PacMed system basically it involves the pre-packaging of a person's monthly prescriptions based on the date and time the medications are supposed to be taken.

Say for example you had three prescriptions that you took every day - Tegretol, Topamax and Lamictal. The Tegretol twice a day, morning and evening; the Topamax three times a day, and the Lamictal two pills just once in the morning. As anyone who takes multiple medications can attest, things can get pretty complicated sometimes. Not to mention making sure that you take your medications with you if you're going to be out and about.

This system makes it all much easier. Monthly, you are provided with a box containing little packets like the one shown above, in a tear off strip. Each package is labeled with the date and time that packet of medication is supposed to be taken, the contents of the packet, and what each pill is supposed to look like.

So in our example, you would get up in the morning and tear off the first packet of the day, which should contain one Tegretol, one Topamax, and two Lamictal. When lunchtime rolls around, you can't remember if you took your pills. A quick check at the meds box will show the next packet is the lunchtime one, not yet taken, containing one Topamax. You have plans for the evening and know you won't be home, so as you leave, simply tear off the sealed packet containing your evening pills to take along with you.

If your prescription changes in the middle of the month, the pharmacy will take back your pills and repackage them for you, and best of all, they deliver right to your home.

I thought it was all a pretty neat idea.

The PacMed system is available through *New Edge Pharmacy*, and the dispensing fees are comparable to regular pharmacies. They service all of the Avalon, the Clarendville area, and will soon be setting up to serve the Corner Brook area. To learn more about PacMed, call 754-0115 or email bev_russell@nf.sympatico.ca.

Off the News Wire

Epilepsy Patients Can Sometimes Predict Seizures

Epilepsy patients quite often know when a seizure will occur. According to a report in the medical journal *Neurology*, when an epilepsy patient predicts a seizure in the next 24 hours, the likelihood that it actually will occur more than doubles.

The team studied 71 adult patients with epilepsy who had at least one seizure in the last 12 months. In the overall analysis, when subjects predicted a seizure they were 2.25-times more likely to experience one than when they did not, the report indicates. Yet, they only predicted 32 percent of the seizures that occurred.

Some patients were better than the others at predicting seizures. When these patients, who were younger and had frequent attacks, predicted a seizure, the odds of one actually occurring increased more than three-fold. Even this group, however, predicted just 37 percent of seizures.

Being able to predict when a seizure will occur is important. It gives more peace of mind and a sense of control. It allows people to better plan their daily activities. And it opens the way for preemptive therapy, which is currently not used for epilepsy.

With appropriate training in recognizing early warning signs, the accuracy of predicting seizures could improve.
Neurology, January 23, 2007

Tooth Brushing Can Trigger Epileptic Seizures

In some people with epilepsy, brushing their teeth may stimulate a certain area of the brain and cause seizures, researchers report.

"The rhythmic act of brushing teeth may excite an already overly excitable area of the brain. This is similar to photosensitive epilepsy, which involves seizures triggered by flashing lights."

They studied three adults with epilepsy who had seizures while they brushed their teeth. The researchers used magnetic resonance imaging (MRI) to examine the brains of the three patients and found that they all had lesions in the somatosensory area of the brain, which is near the hand and speech motor areas.

"Since tooth-brushing involves persistent rhythmic action, this may explain why this trigger is more likely to induce seizures in the somatosensory area of the brain compared to other oral stimuli, such as eating."

American Academy of Neurology, March 5, 2007

Epilepsy Linked to Deprivation

Epilepsy is more common in people living in poorer areas than in more affluent areas, according to data recently collected.

Professor Chadwick, at the University of Liverpool, said: "There is always a strong correlation between socio-economic grouping and prevalence of epilepsy. This is the most likely explanation for the patterns of epilepsy shown in the map." People with epilepsy were more likely to be economically disadvantaged and living in poorer areas.

Epilepsy is more common in older people, so areas with a high proportion of older people will have a higher prevalence of epilepsy. It may be less common in major cities because of better epilepsy services and a higher proportion of practices which have reviewed epilepsy diagnoses.

Epilepsy Action, March 2007

Many Seizure-Prone People Continue to Drive

Many people with epilepsy whose seizures are poorly controlled continue to drive, even though they're at high risk for crashes, researchers report. In most cases, people get behind the wheel because it's the only way they can get to work. That suggests that more must be done to help people with epilepsy stay both productive and safe.

The researchers surveyed more than 300 epilepsy patients and found that nearly 20 percent of those who had at least one seizure a year drove. Even more alarming, nearly 25 percent of patients who suffered daily seizures still drove occasionally.

"This has always been a problem for epilepsy patients because driving serves both a social and a practical purpose," the co-author said. Most of the patients in the study said they continued to drive not because they had achieved good seizure control or did not suffer any side effects from their medications, but because they had to get to work.

"In many ways, we have all these nice rehab programs for epilepsy patients but part of the reason they don't become fully successful is because we fail to consider the more practical things. These folks are not bad folks. They're not (driving) because they want to hurt someone. They're doing it because they need to," he said.

HealthDay News, 2007

Announcements and Notices

March Door to Door Campaign

Hi Everyone!

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

We have received quite a number of our kits back so far, but there are still a number outstanding. If you have one of the outstanding kits, please get it back to us as soon as you can so we can get our project completed for another year.



We have also drawn for the winners of several special prizes from among our collectors and zone captains.

The winner of the \$100 Club - from all who raised \$100+:

📞 **Linda Bown** of Victoria Cove

The winner of our Zone Captains Award:

📞 **Kathleen Power** of Labrador City

The winners of our Canvassers Draws:

📞 **Michel Bourdages** of Gander

📞 **Carla Legge** of Grand Falls

📞 **Marilyn Peddle** of Leading Tickles

I would like to take this opportunity to thank every canvasser and zone captain who so willingly gave of their time and efforts to make this campaign a success, as well as a thank you to everyone who donated even a little.

Your efforts will go a long way towards the promotion of epilepsy support and awareness in Newfoundland and Labrador.

Marilyn Murley, Campaign Coordinator

*The secret to success is to start from scratch
and keep on scratching.
~ Dennis Green*

Coffee Club

You are invited!

Wednesday, May 2nd at 7:30
Chatters Café
Duckworth Street, St. John's
(just across the street from KFC).



Come out and have a coffee (or tea, or pop) and a chat with other members and staff of ENL. Meet other folks who know first-hand what it's like to live with Epilepsy.

Please let us know if you will be attending.
Call Pam at 722-0502.

Volunteers Needed

We are hoping to be able to put information and posters in various medical clinics, waiting rooms, hospitals, Health and Community Services offices and other public areas throughout the province. But as you can imagine, mailing a box of resources to each of these office in every community would be an enormous expense in postage.

We are looking for volunteers from across the province who would be willing to distribute posters and information throughout your hometown. This would save us lots in postage by only having to mail one box per community and keep donations going to programs and services instead of Canada Post.

If you can help, please call Pam at the ENL office at 1-866-374-5377, or email info@epilepsynl.com.



A Little Time Out



*Behind every
successful
woman...
is a basket of
dirty laundry.*

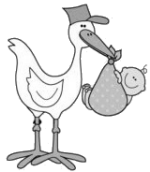
- Sally Poe



The Ladybug Picnic

Which of these two pairs of ladybugs will get to meet and have their picnic in the lovely spring sun first?

Mystery Twins



*Two babies are born on the
same day in the same year
with the same mother and
father, but are not twins.
Can you explain how this can be?*



A man hated his wife's cat and he decided to get rid of it. He drove 20 blocks away from home and dropped the cat there. The cat was already walking up the driveway when he approached his home. The next day, he decided to drop the cat 40 blocks away but the same thing happened.

He kept on increasing the number of blocks but the cat kept on coming home before him. At last he decided to drive a few miles away, turn right, then left, past the bridge, then right again and another right and so on until he reached what he thought was a perfect spot and dropped the cat there.

Hours later, the man called his wife at home and asked her, "Is the cat there?"

"Yes, why do you ask?" answered his wife.

Frustrated the man said, "Put that cat on the phone, I am lost and I need directions."



Bits and Pieces

The Antiepileptic Drug Pregnancy Registry

The AED Pregnancy Registry is dedicated to determine the safety of anticonvulsant medications that can be taken by women during pregnancy to treat disorders such as epilepsy, mood disorder, and chronic pain. The primary goal is to determine the frequency of major malformations, such as heart defects, spinabifida and cleft lip, in the infants exposed during pregnancy to anticonvulsant drugs.

Who is eligible?

Any woman who is currently pregnant and is taking AEDs (antiepileptic drugs) for any reason can enroll in the Registry. A woman enrolls herself by calling us toll-free at 1-888-233-2334.



Participation involves only 3 brief telephone interviews. The first interview is at the time of enrollment, the second takes place in the 7th month of pregnancy, and the third is conducted a few months after delivery.

To learn more, please go to www.aedpregnancyregistry.org or call the toll free number listed above.

Puzzle Answers

Mystery Twins - The babies were two of a set of triplets.



Ladybug Picnic
As you can see, the top pair of ladybugs would never even be able to meet, let alone picnic.

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