

# Epilepsy News

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Summer 2012

## **Epilepsy NL Presents a Very Special Event:**



## An Information Session on Memory Problems

with Guest Speaker  
**Jim Woodrow**  
Registered Psychologist with  
Eastern Health

**Monday, October 22<sup>nd</sup>, 2012**  
**7:30pm**  
**at Epilepsy Nf. & Lab.**  
**351 Kenmount Road, St. John's**

**Gain practical strategies for  
using your memory to the  
very best of its ability.**

Come learn about how  
memory works, what can  
keep us from forming new  
memories,  
or accessing ones we  
already have.

**Space is limited!**  
To guarantee your seat,  
please register by calling  
Pam at 722-0502  
or by email at  
[info@epilepsynl.com](mailto:info@epilepsynl.com)

## Epilepsy News

is printed quarterly by:

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## **Epilepsy NL Scholarships**

*The purpose of learning is growth, and our minds, unlike our bodies,  
can continue growing as long as we live.  
~ Mortimer Adler*

School is expensive! But did you know about ENL's scholarships especially for post-secondary students with epilepsy?

Each year, Epilepsy Newfoundland and Labrador is proud to award two scholarships, each valued at \$1000, to deserving students with epilepsy, for tuition, books, or any of the other many necessities that come along with school.



#### **The Zach Rowe Memorial Scholarship**

- ➔ For students who have just graduated from high school and are moving into their first year of post-secondary studies.

#### **The Jim Hierlihy Memorial Scholarship**

- ➔ For students who are beyond their first year, or who have decided to return to school after a period of being in the workforce.

### **Deadline for both is November 1st**

For full scholarship information, or an application form, visit our website at [www.epilepsynl.com](http://www.epilepsynl.com), or call the office at 1-866-EPILEPSY.

## **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.***

## Get E-Action Magazine - FREE!

### Free Magazine & MEMBERSHIP

Join a community of people  
who are living well with epilepsy



free

### *Have you heard about this yet?*

**E**-Action is a new online community and resource for anyone living with epilepsy and seizures. The magazine is filled with great stories, and lots of epilepsy related news and information.

E-Action will:

- provide you with information on important epilepsy-related issues
- introduce you to people with epilepsy who are facing life's challenges with perseverance and courage
- relate stories to reassure, empower, and inspire you
- help answer your questions

Best of all, it is FREE!

Simply register online or by postal mail and you will receive the bi-yearly E-Action Magazine, completely free of charge.

Don't miss this opportunity to learn more about epilepsy, and read stories from people all over the country who are not letting their seizures stop them from living a full and productive life.

Just head to [www.e-action.ca/](http://www.e-action.ca/) to register.

Don't have the internet at home? No problem. Just call Pam at Epilepsy NL and she can help you register over the phone.

The number is:  
(709) 722-0502 or toll free at 1-866-EPILEPSY.

## Previously Loved Clothes and Things

**A**re you shopping at ENL's thrift store, **Previously Loved Clothes and Things** yet? We are now bigger and better than ever before!

Our new location is full of quality merchandise, including:

- clothes, outerwear, and footwear for everyone
- household items & small appliances
- bedding, curtains, & furniture of all descriptions
- toys & sporting equipment
- vintage glassware & unique collectibles

**Never pay sales tax!** - Because we are a charity, 100% of the proceeds from the sales at our store stay right here and go directly back into the community through the programs and services of Epilepsy NL.

Come visit us at 351 Kenmount Road, next door to VOCM Radio. We're open seven days a week 9:30am to 9:30pm.

### **It's easy to help make a difference!**

- Donate your unwanted clothes and household items to us for sale in our store. You can drop donations off at the store or, if you live in the metro area, we can often arrange to pick them up for free. Just call 722-5571 to arrange a time.
- Shop at our store. Open 7 days a week and always tax-free! You'll never know what treasures you might find. Plus, you'll feel good knowing that you have helped people with epilepsy right here in NL.

## Biffy's Wish



### Mary Beth's Dream Comes True! Unique Equestrian Wish Granted

**T**he Make-A-Wish Foundation of the Atlantic Provinces has been making plans over the last few months to grant the wish of a special girl from St. John's.

Sixteen year old Mary Beth Thistle was born with a condition known as Dravet Syndrome. This is a life-threatening seizure disorder that comes with a number of other complications. Life hasn't always been easy for Mary Beth or her family but there will be a bright spot in her life going forward, thanks to her most cherished wish.

When Mary Beth's mom applied to the Make-A-Wish Foundation for a wish, the number one item on Mary Beth's list was something related to horses. She rode when she was younger; however, due to her illness and limited abilities, she requires much assistance and is unable to continue riding.

Executive Director of the Atlantic Provinces Chapter of Make-A-Wish, Daphne Carter, tells us, "We heard about Mary Beth's love of horses and that she was no longer able to ride. Her family told us about a unique item called an Equicizer. Not knowing what that was, we researched the manufacturer in Ohio and discovered that it is a custom-made riding simulator in the shape of a horse."

The customization of Mary Beth's horse also includes a naming opportunity. As her nickname is "Biffy", she has christened her stead "Biffy's Wish". For good measure, Mary Beth ensured that the horse's forehead included a star, to represent the Make-A-Wish logo. Along with a long mane and tail to groom, Biffy's Wish will also help with building Mary Beth's core body strength and bring a great source of lasting joy into her life.

Mary Beth, her friends, and family have been eagerly awaiting the new arrival to the Thistle family. In fine cowpoke style, volunteers have helped organize a barn party on Saturday at Rainbow Riders to celebrate the anticipated arrival of Biffy's Wish. It is sure to be a great celebration for a deserving young woman. YEE HAH!!!

### About the Make-A-Wish Foundation Atlantic Provinces

The Make-A-Wish Foundation Atlantic Provinces is a dynamic wish granting organization that brings hope, strength and joy to children in Atlantic Canada living with life-threatening medical conditions. There are seven independent regional chapters granting magical wishes to children in need from coast-to-coast, as well as a national office of Make-A-Wish Canada. Make-A-Wish Canada is an affiliate of Make-A-Wish® International, the largest wish-granting organization in the world, making dreams and wishes come true for more than 270,000 children since 1980. To learn more visit [www.makeawish-atl.ca](http://www.makeawish-atl.ca)

(Press release, Make-A-Wish Foundation Atlantic Provinces, Nov 2011)



Atlantic Provinces Canada

*Congratulations Mary Beth!  
All of us here at ENL hope you and your family  
have years of fun with Biffy's Wish.*

## Steripentol and Dravet Syndrome

**W**hat's in a name?

A whole lot if you talk with families who are affected by Dravet Syndrome.

Dravet Syndrome, also known as Severe Myoclonic Epilepsy of Infancy (SMEI), is a very rare and catastrophic form of Epilepsy, which begins in infancy and will affect almost every aspect of a child's life.

Seizures usually begin during the first year of life, and are most often convulsive, tonic-clonic seizures triggered by a fever. These seizures are often prolonged, difficult to control, and require emergency treatment.

Within months, seizures can occur without fever and other seizure types can develop, such as myoclonic jerks, complex partial and absence seizures.

Over time developmental delays, behavioural problems, orthopedic issues and ataxia develop.

As children with Dravet Syndrome get older, their movement and walking may get worse and they may develop a crouching posture and walk with bent knees.

Children with Dravet Syndrome are at an increased risk of accident, infection and sudden unexpected death.

Treatment for Dravet Syndrome is difficult, and many children do not respond to most medications.

However, there is one drug that has been critical for the treatment of Dravet Syndrome. It's called Stiripentol, and it has been proven to be beneficial in the management of children with Dravet Syndrome.

The biggest challenge:  
**Stiripentol is not marketed in Canada.**

Until recently, patients needing the drug were able to access it from France through Health Canada's Special Access Drug Program.

But a recent change had been preventing physicians from starting any new patients on Stiripentol.

One of the main issues seemed to be all in the name.

Health Canada had Stiripentol listed on their Special Access Program as being useful for patients with Severe Myoclonic Epilepsy of Infancy (SMEI), but not for Dravet Syndrome, the new name for the same disorder.



For any new families needing special approval for Stiripentol, please make sure you ask your neurologist to use the disorder name "Severe Myoclonic Epilepsy of Infancy" on the Health application, noting that SMEI is also known as Dravet Syndrome.

If you would like further information, or assistance with Health Canada's Special Access program, please contact Epilepsy NL.

Isn't it amazing the impact a simple thing like a name can make?

## Hard Work and a Song

For Joey Callanan, it's been a pretty big year.

Joey is a member of Newman Sound, a men's community choir from here in St. John's. This past July, for the first time ever, Joey and 22 other members of the Newman Sound Choir flew to Cincinnati, Ohio to attend the World Choir Games, the first one ever held in North America, with over 300 choirs competing from all over the world.

While there, they decided to challenge for the championship category, and got in! Hoping to just not come in last amongst the incredibly talented groups in the competition, Newman Sound showed the world what Newfoundlanders are made of and went on to capture the gold medal, receiving the highest marks in the Men's Chamber Choir category.

Said Joey, **"It was the trip of a lifetime."**

After their win was announced, the members rushed to the stage and proudly sang *O Canada*. "This experience has been quite an honor for a community choir from Newfoundland."

Joey joined Newman Sound in September 2009. Growing up singing in school choirs, and later the Chamber Choir at Bishop's College High School, gave Joey something positive to focus on, even when his seizures made so many other things a constant struggle. After high school, Joey auditioned and was accepted into Newman Sound. He was thrilled beyond words to become a part of this wonderful group of men.

It's a busy life, but he wouldn't change a thing. With the pressures of being a college student, and the effects all that stress can have on epilepsy, those Monday night rehearsals, and concerts with the group were a welcome diversion. This win, just tops it all.



But the gold medal win isn't Joey Callanan's only big success this year. After several years of determination and hard work, he recently graduated from the Computer Systems and Networking program at the College of the North Atlantic and is now completing a work term with the Provincial Government at the Office of the Chief Information Officer.

Needless to say 2012 has been a very proud and happy year for Joey. We hope it is only just the beginning of many more great things to come.

*To learn more about Newman Sound, and their recent Gold Medal win, check out their website at :*

[www.newmansound.ca](http://www.newmansound.ca)

### **Spring Forward - Fall Back**

*Daylight time was first enacted in Germany in 1915, then quickly adopted by Britain and much of Europe and Canada.*

*Because the sun shone for a time while most people were still asleep in the morning, it was reasoned that light could be better used during the day. The solution was to push the clocks ahead one hour in springtime, forcing people to wake an hour earlier.*

*When the days started getting shorter in the fall and people awoke to increasing darkness, the clocks were turned back an hour to get more light in the morning. Fall Back is the first Sunday in November. Don't forget! ☺*

## 2013 Epilepsy NL Pocket Calendars are Here!



**2013 Pocket Calendars are now available. Get yours before they're gone!**

**Call 1-866-EPILEPSY**

**O**ur Calendar Campaign is underway! For each donation of \$20 or more to Epilepsy Newfoundland and Labrador, we are proud to send you a copy of our 2013 Pocket Calendar with artwork by grade 4 children from all over our province.

Students featured in the 2013 calendar are:

- Alyson Thomas, Labrador Straits Acad., L'anse au Loup
- Kelly Wong, Holy Cross Elementary, Holyrood
- Karissa Alexander, Elwood Elementary, Deer Lake
- Emily Mooney, Holy Trinity Elementary, Torbay
- David McDonald, Conrad Fitzgerald Acad, English Hbr.
- Charlotte Gaulton, Christ the King School, Rushoon
- Madeline Skinner, St. James All Grade, Lark Harbour
- Jumana Ihsan, Matthew Elementary, Bonavista
- Tanya-Lee Hurley, Copper Ridge Acad, Baie Verte
- Haley Hurley, Sprucewood Acad., Grand Falls-Windsor
- Ethan Angnatok, Jens Haven Memorial School, Nain
- Morgan Janes, Queen of Peace Middle Sch., Goose Bay
- Jordan O'Gorman, Belanger Memorial School, Doyles

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



## No Child Without - Free MedicAlert® for Kids

**N**ow that school is starting up again, it is so important that every child with seizures **owns** and **wears** a medical alert bracelet or pendant. In an emergency, it can make an enormous difference.

During the school day, kids will interact with many different individuals, many of whom will know little to nothing about your child and their medical needs. It could be at recess, at lunch, in the classroom or after school at a friend's house or at a sports activity.



A MedicAlert® bracelet or pendant can ensure that important medical information about your child is readily available no matter where they go, and can be easily and accurately communicated in the case of an emergency.

The Canadian MedicAlert® Foundation is a charitable organization and the leading provider of emergency medical information services linked to customized medical bracelets and necklaces.

Cost-free MedicAlert® memberships are available to students age 4 to 14 through the No Child Without® program in select schools.

The financial support of the Government of Canada and Lions Clubs allows students to receive the MedicAlert® membership for FREE.

**Many of this province's schools are already covered!**

Find out more information by visiting:

<http://www.nochildwithout.ca> or call 1-866-679-3220

## Wrist Sensors For Epilepsy

Researchers at MIT and two Boston hospitals provide early evidence that a simple, unobtrusive wrist sensor could gauge the severity of epileptic seizures as accurately as electroencephalograms (EEGs) do - but without the ungainly scalp electrodes and electrical leads. The device could make it possible to collect clinically useful data from epilepsy patients as they go about their daily lives, rather than requiring them to come to the hospital for observation. And if early results are borne out, it could even alert patients when their seizures are severe enough that they need to seek immediate medical attention.



The sensor measures the electrical conductance of the skin, an indicator of the state of the sympathetic nervous system, which controls the human fight-or-flight response.

In a study conducted at Children's Hospital Boston, the research team - Rosalind Picard, her student Ming-Zher Poh, neurologist Tobias Loddenkemper and four colleagues from MIT, Children's Hospital and Brigham and Women's Hospital - discovered that the higher a patient's skin conductance during a seizure, the longer it took for the patient's brain to resume the neural oscillations known as brain waves, which EEG measures.

At least one clinical study has shown a correlation between the duration of brain-wave suppression after seizures and the incidence of sudden unexplained death in epilepsy (SUDEP), a condition that claims thousands of lives each year in the United States alone. With SUDEP, death can occur hours after a seizure.

Currently, patients might use a range of criteria to determine whether a seizure is severe enough to warrant immediate medical attention. One of them is duration. But during the study, Picard says, "what we found was that this severity measure had nothing to do with the length of the seizure." Ultimately, data from wrist sensors could provide crucial information to patients deciding whether to roll over and go back to sleep or get to the emergency room.

### ***Surprising signals***

The realization that the wrist sensors might be of use in treating epilepsy was something of a fluke. "We'd been working with kids on the autism spectrum and a lot of them have seizures," Picard says. In reviewing data from their autism studies, Picard and her group found that seizures were sometimes preceded by huge spikes in skin conductance. It seemed that their sensors might actually be able to predict the onset of seizures.

"It's a big challenge to make a device robust enough to withstand long hours of recording," Poh says. "We were recording days or weeks in a row." In early versions, some fairly common gestures could produce false signals. Eliminating the sensors' susceptibility to such sources of noise was largely a process of trial and error, Picard says.

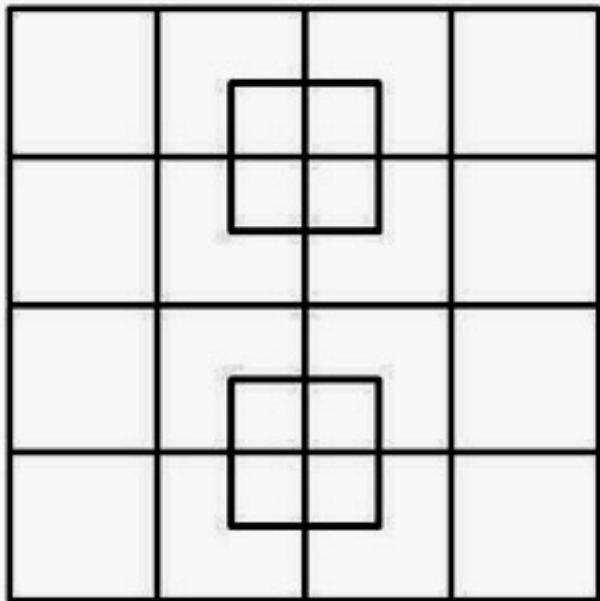
### ***Blending in***

Additionally, Poh says, "I put a lot of thought into how to make it really comfortable and as nonintrusive as possible. So I packaged it all into typical sweatbands." Since the patients in the study were children, "I allowed them to choose their favorite character on their wristband - for example, Superman, or Dora the Explorer, whatever they like," Poh says. "To them, they were wearing a wristband. But there was a lot of complicated sensing going on inside." Indeed, the researchers actually lost five of their homemade sensors because hospital cleaning staff saw what they thought were ratty sweatbands lying around vacated rooms and simply threw them out.

Picard is continuing to investigate the possibility that initially intrigued her - that the devices could predict seizures. In the meantime, however, her collaborators at Children's Hospital are conducting a study that will follow up on the one reported in *Neurology*, and a similar study is beginning at Brigham and Women's Hospital.

*April 27, 2012, Larry Hardesty, MIT News Office*

## A Little Time Out



How many squares in the diagram above?

Are you certain?

Look closely... there may be more than you think.

A couple phoned a neighbor to wish him a happy birthday. They dialed the number and started singing at the top of their lungs as soon as he answered.

When they finished their off-key birthday wishes, they were embarrassed to discover they had dialed the wrong number.

"Don't worry about it," said the unfamiliar but amused voice. "You folks need all the practice you can get."



Bill, Jim and Scott were staying in a 75-story hotel.

One evening they were told that the elevators were broken and they would have to climb 75 flights of stairs to get to their room on the top floor.

Bill said, "The climb will go faster if we distract ourselves. I'll tell jokes for 25 flights, Jim can sing songs for the next 25 flights and Scott can tell sad stories for the rest of the way."



Bill started telling jokes and didn't stop until the 26th floor. Then Jim began to sing and kept going until the 51st floor. Then Jim stopped singing and told Scott to start telling sad stories.

"I will tell my saddest story first," Scott said. "Once upon a time there was a man who left the hotel room key in his car..."



## Email or Postal Mail?

Help us, and help the environment too! Here at ENL, one of the greatest expenses we have is postage. Because of this, and in the interests of being as environmentally friendly as possible, we want to offer our members the option of receiving newsletters and notices by email instead of postal mail.

Privacy is not a concern.  
Nobody else will see your email address. And we would never make our email or mailing lists available to anyone else.

If you wish to sign up for e-mail communication from us, just drop us a line at [info@epilepsynl.com](mailto:info@epilepsynl.com). If you ever want to change back, just let us know and we will be happy to do so.

If you don't have e-mail, or don't want to receive email newsletters and notifications from us, you don't need to do a thing. We will continue to send you your information through postal mail like always. Have questions? Call us at 1-866-EPILEPSY



## Find Us on Facebook

Are you one of the over 400 million people on Facebook?



If so, check us out! Our facebook page has all the latest and greatest from Epilepsy Newfoundland and Labrador.

Event pictures, upcoming events, current happenings, bits of news, and medical alerts are some of the things you will find on our corner of the Facebook world.

If there was ever a place to stay up to the minute with ENL, this is it! Just type [www.facebook.com/epilepsynl](http://www.facebook.com/epilepsynl) into your browser and you are sure to find us.

Or go to our website and click on the Facebook "Like" button on our front page.

There are 40 squares in the diagram shown.  
Did you find them all?

**Puzzle Solution**

## 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 NL. 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:
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Address:
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Phone:	Would you prefer mail-outs by email or postal mail?:
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**If you would prefer to pay by credit card, please complete the following:**

Account #	Type of card:	Expiry:
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**Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9**