



# Epilepsy News

Serving the people of Newfoundland and Labrador for over 25 years!

The Quarterly Newsletter of Epilepsy Newfoundland and Labrador

Winter 2010

## Ask the Doctors - A Question and Answer Forum

Have epilepsy questions you have always wanted to ask an expert?

Want to share the stories and experiences of other individuals and families who struggle with epilepsy?

### WE HAVE YOUR OPPORTUNITY!

On **March 25<sup>th</sup>**, Epilepsy Newfoundland and Labrador will be hosting our annual province-wide **Ask The Doctors** Forum on Epilepsy. Once again we are very pleased to have two of this province's foremost authorities on epilepsy and seizures:



Dr. A. Ogunyemi,  
Epileptologist

and  
Dr. D Buckley,  
Pediatric Neurologist

Come join two of Newfoundland and Labrador's most knowledgeable neurologists on epilepsy and seizure disorders, in a province-wide Question and Answer Forum. Ask Dr. Ogunyemi and Dr. Buckley the questions that are important to you, and find out even more about epilepsy.

**Participation is open to anyone in the province.  
REGISTRATION FOR THIS EVENT IS FREE**

This will be our 21<sup>st</sup> year for this event. During all that time, there have been so many thought provoking questions, with something new to learn each year.

Participants are welcome to ask questions pertaining to their specific circumstances, or more general questions. Some past questions have included:

- How to better manage the side effects of AEDs
- Memory loss and epilepsy medications
- Mood swings in relation to epilepsy
- New research and treatments for seizures
- Pregnancy and epilepsy
- SUDEP - risk factors
- and countless others.

Don't feel comfortable speaking up? No problem! Just by listening to the other questions, you can learn a great deal that might help you too.

**If you live in St. John's and the surrounding areas** the conference will be held the day before Purple Day - March 25<sup>th</sup> at 7:30pm, in the Cabot Room of the Ramada Hotel on Kenmount Road.

**If you live outside of St. John's**, we are pleased to be able to include everyone in the province who wishes to participate in this annual forum via teleconference. If you have access to a phone, you can join us!

Make sure you don't miss out. **Please register in advance** to save your place.

For more information or to register, contact  
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**Epilepsy Newfoundland and Labrador**  
**(709) 722-0502 or toll free at 1-866-EPILEPSY**  
**info@epilepsynl.com**



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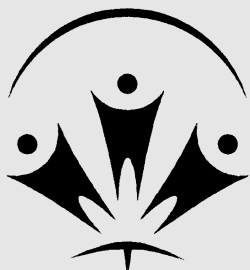
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## On My Mind

"Today you are You, that is truer than true.  
There is no one alive who is Youer than You."  
~ Dr. Suess

I was watching a presentation not so long ago by Aimee Mullins, an amazing lady who is a model, actress, activist and runner, who just happens to have been born without shin bones, leaving her a double amputee. She walks now with the assistance of two state-of-the-art prosthetic legs. She talked about how we look at people sometimes and instantly make judgements about their ability and worth based on seeing that person as something other than normal.

Sadly, she's right. Perhaps it's time we started seeing people differently.

Each and every one of us has our own challenges to face. That's part of living. It is the challenges that shape us. But when people start judging based on those challenges, when they attempt to label, or devalue our worth just because we don't fall into their ideas of 'normal' that we must take a stand.

What is normal anyway? I'm not sure there is any such thing, thank goodness! Normal is a myth that only serves to exclude people, when what we should be doing is seeing people as individuals, with all the variety and differences and potential that people have. It is about accommodation and understanding as opposed to labelling and excluding.

I talk with many people that are so fearful of what others will think when they find out about someone's epilepsy. People who are oftentimes afraid to be outside for fear of someone seeing them have a seizure, and judging them for it. It shouldn't be that way.

Make a pledge to yourself today, that you will see the whole person in yourself; your potential, your abilities, and your worth, and celebrate your own uniqueness. You are a stronger person because of it.

Pam

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.

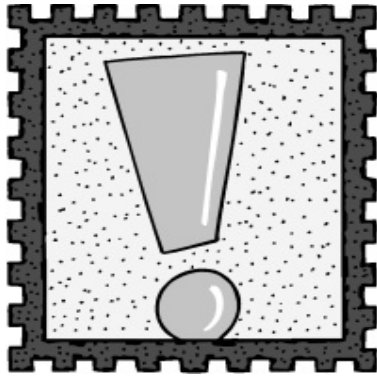
**People with epilepsy should never discontinue anti-epileptic medications or make changes in activities unless specifically advised to do so by an attending physician.**

## Special Notice to Our Members

**W**e have received information that once again this year, an epilepsy association based in Ontario has been fundraising in our Province.

You need to know that Epilepsy Newfoundland and Labrador is the only epilepsy association operating in our Province to meet the needs of the more than 10,000 men, women, and children living with Epilepsy in Newfoundland & Labrador.

**We have no affiliation whatsoever with the group that may have called you, or sent you a letter seeking support.**



There is some indication that they may have been portraying themselves as the national epilepsy association - **this is not the case.**

Epilepsy associations from coast to coast across Canada are united under the umbrella of the Canadian Epilepsy Alliance, in which our own Executive Director, Gail Dempsey, serves as Vice President. The calls and letters **did not** come from them.

Please be careful. If the call or letter is coming from outside the Province, you can be sure that your money will be leaving the Province as well.

We appreciate the fact that you want to donate to epilepsy, I don't know where we would be without you, just be sure your hard-earned money is going where you intended.

## Introducing the Collective Kitchen

**W**e all know how important good nutrition is. But sometimes it's not easy to cook right. And for many people who may be single, it hardly seems like it would be worth the effort

Which is why we are looking to see if there may be enough interest to start a Collective Kitchen here in the St. John's area.

### What's a Collective Kitchen?



A Collective Kitchen is a group of people who come together once or twice a month to learn how to plan healthy meals, decide on a menu, budget for groceries, and cook a meal. Meals are made in large batches, so everyone can take several meals home with them to

store in the freezer or share with other people.

Meals commonly prepared at collective kitchens include meat loaf, shepherd's pie, casseroles, soups and stews.

A collective kitchen is a great way to learn cooking skills and have fun at the same time. Previous cooking experience is not required and everyone learns together.

### Is There Any Cost Involved?

The only costs involved will be the cost of buying the food itself. But by pooling the class money together and buying in bulk, everyone will get to take home several healthy meals for a fraction of the cost!

### Who Can Join?

Anyone who has an interest in saving money and learning to eat healthier. People with epilepsy, their friends, and their families are all welcome to register.

### How Do I Find Out More or Sign Up?

Space will be limited, so if you are interested, please call Pam Anstey at the ENL office at 722-0502 or email [info@epilepsynl.com](mailto:info@epilepsynl.com).



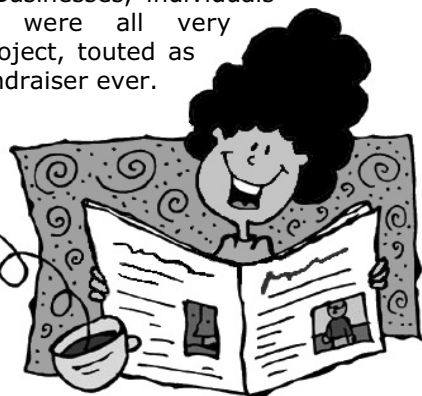
## Christmas Tea for Epilepsy

The 2009

# Christmas Tea for Epilepsy!

Our Christmas Tea for Epilepsy has just wrapped up for 2009. It was nice to see so many familiar faces once again. Businesses, individuals and organizations were all very supportive of our project, touted as the most relaxing fundraiser ever.

Not surprising considering all participants had to do was sit back, relax, and enjoy a cup of tea on us, any time during early December.



We provided the tea, goodies, information about seizures, and a special surprise, and they provided the good will, community spirit, and a donation to help support the programs and services of ENL. It was that easy.

Again this year, we are very grateful to Tetley, who donated 10,000 individually wrapped teabags to start the program off right.

We also have to extend special thanks to Costco Bakery, who generously provided most of the sweet treats and goodies that filled our Christmas baskets.

All in all it was a great success, as you can see by the number of community minded people who supported this cause. We thank each and every one of you for doing your part. With just a cup of tea, you have made a difference.

### Hall of Fame 2009

#### *Our Most Flavorful Sponsors*

#### *The Benevolent Bakers (In-Kind Cookies and Treats Donations)*

Paradise Bakery  
Purity Factories

Marie's Bakery

#### *Our Grand Givers (\$500 and up)*

Husky Energy

#### *The Tea Masters (\$100.00 donations and up)*

Barrett's Funeral Home  
CNA - Prince Philip Drive  
Cox & Palmer Law Offices  
Penney Mazda  
Re-Max Plus Realty

Rogers Cable  
The Telegram  
St. Patrick's Mercy Home  
Scotiabank - Water Street  
VOCM Cares

#### *The Tea Specialists (\$50 and up)*

Academy Canada  
BMO - Water Street  
BMO - Elizabeth Ave  
St John's Eng. & Planning

MUNN Insurance  
Scotiabank - Eliz. Ave. E  
Scotiabank Centennial Sq.  
HCS - Cordage Place

#### *The Tea Apprentices (Donations up to \$50)*

CNA - Ridge Road  
Jay Sheppard  
Krista Gilles  
AON Reed Stenhouse  
St. John's - Finance

ProActive Physiotherapy.  
Scotiabank - Cornwall Ave.  
Scotiabank - Paradise  
City Tire  
St. John's - Info Services

Sit back, relax, enjoy your tea, and think how different your life would be if I were you, and you were me, and you were the one with epilepsy.

## March Awareness - 2010

**M**arch is almost here and that means an all out blitz to promote epilepsy awareness and understanding not only throughout this province but across the country and the world.

We have many things happening this March. From hopping bunnies to quizzing doctors, we're working hard to get the word out, and to let anyone who lives with epilepsy know that they are not alone.

### Purple Bunny Hop

We're turning the province's pre-schools purple with our Any-bunny can Have Epilepsy Purple Bunny Hop.

Daycares and Preschools all over the province have been invited to hop along with us on Purple Day in support of Epilepsy Awareness.

Every 'bunny' that hops for Epilepsy on Purple Day will be eligible to win prizes, and everyone who participates will get information and goodies all about seizures.

### Coffee Club

Want to gather with friendly faces over a cup of tea or coffee? Here's your chance to meet other people who are also living with seizures. Come out to our Coffee Club on St. Paddy's Day, Wednesday March 17<sup>th</sup>, 7pm at Coffee Matters, located at #1 Military Road, just across from the Sheraton Hotel Newfoundland.

### Graphic Design Contest

Again this year we are partnering with the Graphic Design Program at the College of the North Atlantic to develop bus shelter ads that will help spread a greater understanding of epilepsy. Each year the entries are impressive, and we expect this year will be every bit as good. Watch for them coming up on our website sometime in March.



**EPILEPSY**  
WHAT ELSE DON'T YOU KNOW?

1-866-EPILEPSY  [www.epilepsynl.com](http://www.epilepsynl.com)

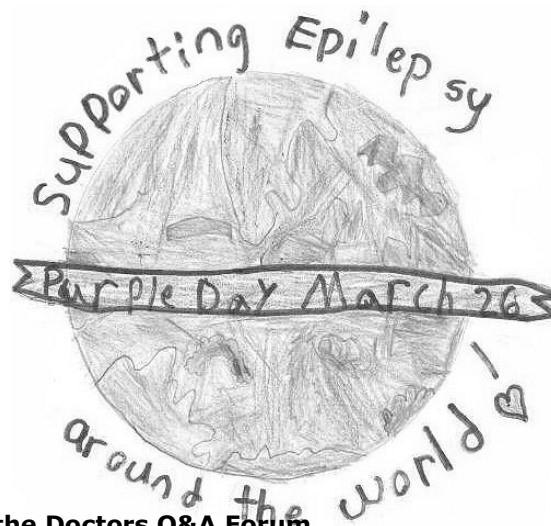
Additionally, the winner of this contest from 2007 will soon be having his design turned into a poster that will be sent to every doctor's office in the province. Don't see one in your doctor's office? Let us know and we will get one sent right away.

### Purple Day

Founded in 2008, by nine-year-old Cassidy Megan of Nova Scotia, Canada, Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26<sup>th</sup>, people from around the globe are asked to wear purple and spread the word about epilepsy.

*Join with us in turning the province purple on **Purple Day!***

- On Friday, March 26<sup>th</sup>, wear purple and encourage others to do the same. (Let us know and take pictures!)
- Host a Purple Day party or fundraising event at your home, school or business.
- Visit [www.purpleday.org](http://www.purpleday.org), or [www.epilepsynl.com](http://www.epilepsynl.com) share your story and get real facts about epilepsy.



### Ask the Doctors Q&A Forum

As mentioned on page one of this newsletter, March 25<sup>th</sup> will be the date of our annual Ask the Doctors Forum. Come and ask Dr. Ogunyemi and Dr. Buckley all the questions you ever had about epilepsy and seizures, or just sit, listen, and learn. Check the front page for details, or call the office to register.

### Other Events and Promotions

Do you have an idea to promote epilepsy and seizure awareness? Would you like someone to come and talk with your group about seizure first aid? Get in touch with us. We will do everything we can to make it happen.

## It's Tax Time - Make the Most of It

It is indeed that time of year again - tax time. While that may leave many of us grumpy and pulling our hair out, for individuals living with a disability, tax time also provides two different opportunities to avail of programs specifically designed to make life just a little easier.

### **Disability Tax Credit**

The Disability Tax Credit is a non-refundable tax credit used to reduce income tax payable for eligible individuals. To be eligible, you must meet all three of the following conditions:

- You must have a severe impairment in physical or mental functions.
- Your impairment must be prolonged - which means it has lasted or is expected to last for a continuous period of at least 12 months.
- A qualified practitioner certifies that your impairment is severe and prolonged and completes Form T2201, Disability Tax Credit Certificate, detailing the effects of the impairment applicable to the basic activities of daily living.

If you are eligible for this credit but are unable to use all or part of it because you have no taxable income, you can transfer it to your spouse, common-law partner, or other supporting person.

A supporting person may be able to claim all or part of a dependant's Disability Tax Credit providing that both the supporting person and the dependent were residents of Canada during the tax year.

### **Registered Disability Savings Plan**

The Registered Disability Savings Plan (RDSP) is a savings plan designed specifically for people with disabilities in Canada. The first of its kind in the world, this new tax-deferred savings program will assist families in planning for the long-term financial security of their relatives with disabilities.

Over time, the RDSP will provide billions of dollars to supplement income, enable home ownership, and enhance quality of life for as many as 700,000 Canadians with disabilities.

In addition to the RDSP, some individuals may also be eligible for the Canada Disability Savings Grant and Bond.

### **Highlights of the Registered Disability Savings Plan**

- Funds can be invested tax-free until withdrawal
- Anyone eligible for the Disability Tax Credit may set up an RDSP
- In the case of a minor child, a parent or guardian can establish and direct the RDSP
- A \$200,000 lifetime contribution limit
- Contributions by individual, family or friends
- No annual limit on contributions
- Contributions grow on a tax deferred basis
- No restrictions on when/why the funds are used
- Upon withdrawal, the income, the Grant, and the Bond are taxed in the hands of the beneficiary, and are likely to be taxed at a much lower rate

### **Highlights of the Canada Disability Savings Grant**

- The CDSG will provide a federal contribution to assist families in saving for the future
- Grants are greater for families in the lower and middle-income categories
- When annual net income is less than \$74,357 the grant will contribute:
  - \$3 for every \$1 contributed on the first \$500
  - \$2 for every \$1 contributed on the next \$1,000
- When annual net income is over \$74,357, the grant will contribute:
  - \$1 for every \$1 contributed up to \$1,000
- The Grant can be received for 20 years, until the beneficiary turns 50.

### **Highlights of the Canada Disability Savings Bond**

- When annual net income is \$20,833 or less, **the Canada Disability Savings Bond will provide \$1,000 per year whether or not contributions are made to the plan**
- The RDSP thus becomes accessible to persons with disabilities whose family does not have the resources to make contributions
- Like the Grant, the Bond can be received for up to 20 years until the person reaches their 50th birthday

*The Registered Disability Saving Plan is exempt from the calculation of Income Support benefits in Nf & Lab!*

### **For More Information**

Disability Tax Credit:

- Contact Canada Revenue Agency at 1-866-741-0127

RDSP

- Contact your bank or financial institution

## Off The News Wire

### **TV Doctors & Nurses - Good Drama, Not Good Epilepsy Education**

New research from Nova Scotia shows that almost half of the time, doctors and nurses on popular TV medical dramas respond inappropriately to seizures, suggesting that watching TV is not the best way to learn what to do if you are present when someone has a seizure.

Study author Andrew Moeller, a third year medical student at Dalhousie University in Halifax, said in a statement that TV drama is a powerful medium for educating the public about how to deal with first aid and seizures, but he and colleague Dr R. Mark Sadler, also with Dalhousie, found that half of the time the public is being misinformed.

For the study, Moeller and Sadler screened all episodes of the higher-rated US medical dramas, namely:

- \* Grey's Anatomy,
- \* House, MD,
- \* Private Practice, and
- \* the last 5 seasons of ER.

They found 59 seizures depicted in a total of 327 episodes. 51 of the seizures took place in a hospital, and nearly all the first aid was administered by "nurses" and "doctors".

The researchers compared what happened on screen with guidelines on seizure management to establish whether each seizure was handled correctly.

They counted 25 cases, nearly 46 per cent of the time, of seizure handled incorrectly by either holding the person down, trying to stop the involuntary movements, or putting things in the person's mouth: all these measures are wrong ways to manage seizures.

They found 17 cases, or 29 per cent of the time, of seizures handled correctly, and 15 (25 per cent) cases where they couldn't establish whether the first aid given was appropriate or not.

Guidelines on seizure management were used to determine whether the seizure was handled properly.

In a statement, Moeller described their findings as a "call to action" and urged people with epilepsy to:

"Lobby the television industry to adhere to guidelines for first aid management of seizures."

### **Ginkgo Herbal Medicines May Increase Seizures in People With Epilepsy**

Restrictions should be placed on the use of Ginkgo biloba, a top-selling herbal remedy, because of growing scientific evidence that Ginkgo may increase the risk of seizures in people with epilepsy and could reduce the effectiveness of anti-seizure drugs, a new report concludes.

The study notes that consumers use pills, teas, and other products prepared from leaves of the Ginkgo tree to treat a wide array of health problems. Those include Alzheimer's disease and other memory loss, clinical depression, headache, irritable bladder, alcohol abuse, blockages in blood vessels, poor concentration, and dizziness. Scientific concern focuses mainly on one chemical compound in the herb. It is a potentially toxic material known as ginkgotoxin.

They reviewed scientific research on Ginkgo, and found 10 reports indicating that patients with epilepsy who take Ginkgo products face an increased risk of seizures. They note that laboratory studies explain how Ginkgo could have that unwanted effect. Ginkgotoxin seems to alter a chemical signalling pathway in ways that may trigger epileptic seizures. Further evidence showed that Ginkgo can interact with anti-seizure medications and reduce their effectiveness.

"Contrary to our own previous assumption, we are now convinced, however, that G. biloba medications and other products can have a detrimental effect on a person's health condition," the report concludes. "It is therefore important that the large number of G. biloba product users and their health care providers be made aware of these risks, in order to enable them to make informed decisions about the use of these preparations."

*ScienceDaily (Feb. 2, 2010)*

*Three friends die in a car accident and they go to an orientation in heaven. They are all asked, "When you are in your casket and friends and family are talking about you, what would you like them to say?"*

*The first guy says, "I would like to hear them say that I was a great doctor of my time, and a great family man."*

*The second guy says, "I would like to hear that I was a wonderful husband and school teacher which made a huge difference in our children of tomorrow."*

*The last guy replies, "I would like to hear them say...  
Look, He's Moving!"*

## Empire Theatres Attendant Pass

Empire Theatres will no longer be accepting City of St. John's Attendant Passes after March 1, 2010. In its place, they will begin adopting the Access 2 Entertainment Card that is used at theatres across Canada.



The Access 2 Entertainment card will allow persons with a disability to receive either free admission or a significant discount for their support person at member movie theatres across Canada. There is a one time administration fee of \$20.00.

Visit their website at [www.access2.ca](http://www.access2.ca) for all the details and to download the application form, or contact us at 1-866-EPILEPSY and we will get a copy sent to you.

Additionally, if you would like more information about the City of St. John's Attendant Passes, **let us know**. Attendant Passes can still be used at events and venues throughout the city, including

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

## Lavender Wristbands Return!

It's been a while, but we now have more lavender wristbands in stock, and for sale at only \$2.00 each!

With OUT OF THE SHADOWS on one side, and 1-866-EPILEPSY on the other, a wristband is the perfect way to share our support and no longer hide in the shadows surrounding the disorder of epilepsy.

For too long people with epilepsy and their families have been hesitant to speak out due to misconceptions about the disorder. Because no one was talking, it was often difficult for the public to understand that individuals with epilepsy are no different than you or I, and that anyone who has a brain, has the potential to have a seizure.

Why Lavender? Because not only is lavender the internationally recognized colour associated with seizures, but the lavender flower has traditionally been a symbol for things that are hidden or isolated, like epilepsy.

**You can help** by selling wristbands at your workplace, your community group, your school, or just among your friends and family.

What better way to show your support for not only Epilepsy Newfoundland and Labrador, but for people everywhere who live with epilepsy everyday. Let's paint Newfoundland and Labrador Purple!

## Door to Door Campaign

### We Need Your Support!

Our 2010 Door to Door Campaign will begin in full force on March 1<sup>st</sup>. We are still looking for canvassers in all areas of the province.

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 call. You can reach me at 722-0502 or toll free at 1-866-EPILEPSY (374-5377).

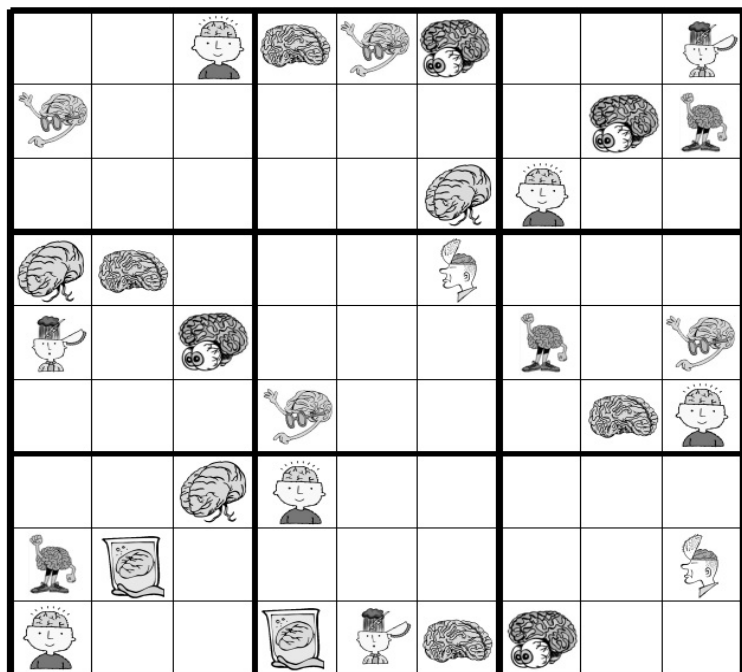
Charlene Stoyles  
Campaign Coordinator



# Brain Sudoku

The concept of sudoku is simple. The puzzle consists of a 9x9 square grid that is divided into nine 3x3 squares, resulting in nine rows and nine columns, for a total of 81 small squares. We have provided a few of the symbols in random squares. To solve the puzzle, the remaining squares must be filled in with the different brains shown below, each appearing only once in each row, column and 3x3 square.

(Answer on next page)



- Karl Stuart Kline

## Email or Postal Mail?

Now you can decide! Want to help us save money and help the environment at the same time?

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. We can guarantee you that 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 866-EPILEPSY.

Being happy doesn't mean that everything is perfect. It means that you've decided to look beyond the imperfections.  
— Author Unknown

## 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**