



## A Province of Purple

**D**uring Epilepsy Awareness Month, politicians, both federal and provincial, stepped forward to share what Purple Day meant to them.



Premier Kathy Dunderdale (centre) signs the Purple Day Proclamation for the province of Newfoundland and Labrador. Front - Minister Susan Sullivan, Premier Kathy Dunderdale, Joey Callanan, NL Purple Day Ambassador. Back - Gail Dempsey & Pam Anstey of ENL, Cindy & Laus Callanan.

From the floor of the House of Assembly, Health & Community Services Minister Susan Sullivan gave a statement in support of Purple Day. She was then followed by responses from Opposition Member Andrew Parsons, and NDP Member Gerry Rogers.

We want to thank all municipalities, MPs, MHAs, and Senators for recognizing the challenge that seizures can bring and for publicly declaring their support and encouragement. Here are some excerpts from their statements.



Susan Sullivan

*Purple Day is intended to help raise the awareness of epilepsy and reduce any stigma that exists around the disorder. I encourage people to visit the Epilepsy Newfoundland and Labrador web site to learn about epilepsy, the different types of seizures, and to become familiar with the correct methods of first aid.*

*I invite the residents of Newfoundland and Labrador to participate in Purple Day activities in their communities and to wear purple next Tuesday as a show of support for people living with epilepsy.*



Andrew Parsons

*I am very proud to wear my purple wristband here today. It is touching to read about the choice of the lavender flower, as it represents solitude. This would relate to the stigma around epilepsy stemming from not understanding the condition.*

*Epilepsy throughout history has typically been misunderstood and regarded with superstition. Awareness is key, and with this and knowledge we can better equip people with an understanding that we need, and we can all do our part to raise awareness of epilepsy in this Province.*



Gerry Rogers

*I will proudly wear purple on Purple Day to help raise awareness.*

*There is still stigma around epilepsy, and because of that often people are afraid to say if they or someone close to them has this condition. The fact is that people living with epilepsy can have full lives. With 10,000 people in the Province living with epilepsy, we need to do everything possible to combat this stigma.*

*It is imperative that government support their effort to help both adults and children better understand epilepsy. I am sure everyone in this House would like to join me in saying: Bravo, Epilepsy Newfoundland and Labrador for the work you continue to do.*

### Also showing their support for Purple Day were:

Jack Harris, MP St. John's East  
 Scott Andrews, MP Avalon  
 Ryan Cleary, MP St. John's South - Mount Pearl  
 Scott Simms, MP Bonavista-Gander-Grand Falls-Windsor  
 Elizabeth Marshall, Senator  
 David Wells, Senator  
 Steve Kent, MHA Mount Pearl North

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## Giving From The Heart

*No one can do everything, but everyone can do something.*

In this great and diverse province, epilepsy has affected so many people, touching lives on a very personal level. We want to recognize some of the great supporters who went out of their way to make Purple Day extra special:

- Joey Callanan, our 2013 Purple Day Ambassador, for being so willing to share his story of life with epilepsy.
- Leanne Vail and Rocket Bakery, who hosted Purple Day at the bakery complete with tasty purple cookies. Both Joey and Leanne were featured in the Telegram. You can read that article on page 5 of this newsletter.
- The Spicer Family of Pasadena for sharing their story with The Western Star. As well as Rachel Spicer for her creative FoamRaising project, and her sister Heather for being such a strong advocate for epilepsy education.
- The Edmunds Family of Bay Roberts who encouraged several businesses in their area to hold Purple Day events, with the help and participation of their daughter Holly who has epilepsy.
- The Atkins Family of Mount Pearl who arranged events at both workplace and school, and especially Faith Atkins who held an awareness day at her school, Mount Pearl Intermediate.
- Don Lynch, caretaker at Coley's Point Primary, who has epilepsy. Don helped the students learn what life with epilepsy is all about.
- Businesses and organizations across the province, including all offices of the Provincial Court of NL, Scotiabank Paradise, Health & Community Services Mount Pearl Square, all locations of ProActive Physio, Dominion, Shopper's Drug Mart, Foodland, and Powell's Grocery in Bay Roberts.

Thank you for choosing to get involved, and for going the extra mile to help bring epilepsy out of the shadows.

## 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.***

# Epilepsy Awareness 2013 - Our Biggest Ever

March was Epilepsy Awareness Month and March 26<sup>th</sup> was Purple Day for Epilepsy & Seizure Awareness. Here in Newfoundland and Labrador we celebrated our biggest Purple Day ever! More than 6000 people from all corners of our great province hopped, danced, sold cupcakes, dressed in silly clothes, created art, donated their spare change, signed proclamations, held events, shared information, and most of all, wore their purple very proudly to support individuals and families who live with seizures.

Here are just some of the fantastic events that happened all across the province.

## Ask The Doctors

This year marked the 24<sup>th</sup> year of our Forum. Twenty-nine participants in person at our facilities on Kenmount Road, St. John's, plus 7 more connecting via teleconference from across the province joined together to question Dr. Buckley and Dr. Ogunyemi, and to share their personal stories.

Some of the questions that were asked included:

- Coordinating AEDs with other drugs
- Nocturnal seizures
- EEGs and seizure testing
- Genetic influences on epilepsy and seizures
- Photosensitivity and seizures
- New treatments and medications for epilepsy
- Drug coverage for anti-epileptic medication

## The Purple Day Bunny Hop

To show just how much even little kids can do, daycares across the province were invited to participate in the third annual Purple Day Bunny Hop. We want to send out a great big shout of thanks to the following centres who raised a combined total of over \$6000.00! Please know that you really do make a difference.

- A Child's Place Daycare - St. John's
- Adventure Place Child Care - Pouch Cove
- Bayshore Daycare Inc. - Bay Roberts
- Blue Skies & Butterflies - Happy Valley - Goose Bay
- Chatterbox Preschool & Daycare - Mount Pearl
- Confederation Building Daycare - St. John's
- Creative Learning Child Care Centre - Grand Falls
- Kidz at Heart Learning Centre Inc. - Carbonear
- Mes Amis Daycare - Mount Pearl
- Reach for The Stars Daycare - South River

## Positively Purple Schools

We challenged schools to come up with creative ways to support Purple Day and seizure awareness. And did they ever! Some schools asked everyone to wear something purple that day, some schools held information sessions, some schools had fun events like Purple Pyjama Parties, and Pizza Parties. Whatever the activity, every school became a part of something very special in helping people truly understand what epilepsy is all about and helped to raise almost \$800.00!

- Bayside Academy - Port Hope Simpson
- Bayview Regional Collegiate - St. Lunenburg-Griquet
- Beachy Cove Elementary - Portugal Cove-St. Phillip's
- Cape St. Francis Elementary - Pouch Cove
- Coley's Point Primary - Bay Roberts
- Corner Brook Regional High School - Corner Brook
- Dunne Memorial Academy - St. Mary's
- E.A. Butler All-Grade - McKays
- Frank Robert's Junior High - Foxtrap
- Goulds Elementary - Goulds
- Gros Morne Academy - Rocky Harbour
- Hazelwood Elementary - St. John's
- Hillside Elementary - La Scie
- Jakeman All-Grade - Trout River
- Marystown Central High - Marystown
- Mount Pearl Intermediate - Mount Pearl
- Our Lady of the Cape School - Cape St. George
- Pasadena Academy - Pasadena
- Random Island Academy - Hickman's Harbour
- Sacred Heart All-Grade - Conche
- St. Anne's School - South East Bight
- St. George's Elementary - Manuels
- St. Mark's Academy - King's Cove
- Truman Edison Memorial - St. Lunenburg-Griquet
- William Mercer Academy - Dover

## Proclamations Across the Province

Communities all over the province painted their hometowns purple by proclaiming March 26<sup>th</sup> as Purple Day in support of all those who live with seizures every day. We want to thank the following cities, towns, and communities:

Town of Grand Falls - Windsor	Town of Avondale
Town of Bay Roberts	Town of Norris Point
City of St. John's	Town of Gander
City of Corner Brook	Town of Grand Bank
Town of Conception Bay South	Town of Spaniard's Bay
Province of Newfoundland and Labrador	

## Purple Day Across the Province



*Provincial Court - Corner Brook*



*Jack Harris, MP St. John's East*



*Rocket Bakery - St. John's*



*The Spicer Family*



*Proclamation Signing - City of St. John's*



*Pasadena Academy - Grade 7*



*Pasadena Academy - Grade 12*



*JAC Marketing*



*Powell's Grocery - Bay Roberts*



*Foodland - Bay Roberts*



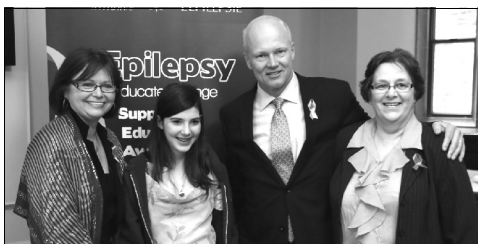
*Ryan Cleary,  
MP St. John's South - Mount Pearl*



*Creative Learning - Grand Falls*



*Bayside Academy - Port Home Simpson*



*MP Judy Foote with Cassidy Megan, founder of Purple Day, MP Geoff Regan who introduced the Purple Day bill, and Gail Dempsey, Executive Director of ENL and President of the CEA.*



*Dominion - Bay Roberts*

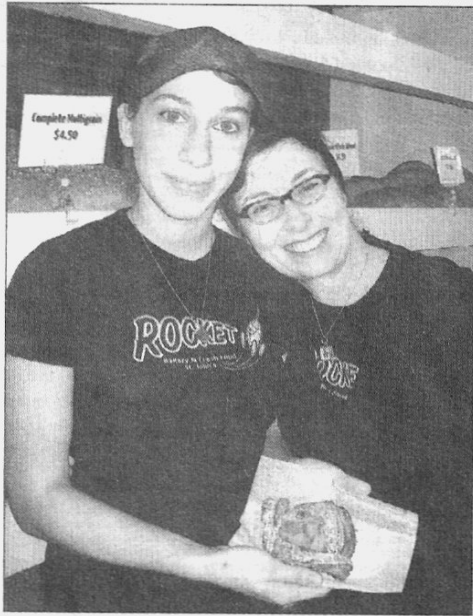
## Purple Day Aims to Raise Epilepsy Awareness

By Danette Dooley, *The Telegram*, March 25<sup>th</sup>, 2013

If you notice the Premier and others wearing purple Tuesday it's not that they're big fans of children's much-loved dinosaur Barney. People will be wearing the colour in recognition of Purple Day for Epilepsy.

Leanne Vail will be marking the day at her workplace - Rocket Bakery and Fresh Food on Water Street in St. John's. She's baking purple cookies and will have information for customers on the seizure disorder she has.

The 20-year-old Harbour Grace woman was diagnosed with epilepsy three years ago.



Leanne Vail (left), who has epilepsy, poses with Rocket Bakery and Fresh Food co-owner Kelly Mansell.

— Photo by Danette Dooley/Special To The Telegram

"I went through a really hard time. At first I was just having fainting spells. They thought I had a tumor in my ear. So I was on pills for that. They thought it was anxiety, so I was on pills for that. They thought it was my heart and I was on steroids to bring my heart rate up."

A neurologist diagnosed Vail with epilepsy. By that time her fainting had developed into seizures.

Vail started working at Rocket almost a year ago.

"I told them during the interview that I have epilepsy. They told me it was OK as long as I told them when I wasn't feeling well."

Vail initially worked the night shift, baking bread, but became tired and stomach sick as the night wore on - likely because of her medication, she says.

"Whenever she told her boss she wasn't feeling well, Vail says she was encouraged to go home and get some rest.

Vail said when she asked if she could switch from nights to days, she was told that wouldn't be a problem. The change made all the difference to her success on the job, she says.

"I'm the croissant baker now. I'm very happy. I look forward to coming to work every day," Vail said.

Rocket Bakery co-owner Kelly Mansell says a switch in shift has worked wonders for Vail.

"It's changed her so much. She's blossomed since she started days. She's in with more people. She's a real valuable member of the team."

While Vail's current employer is supporting of her seizure disorder, that hasn't always been the case, she says.

"One boss actually got mad at me because I told my co-workers I have epilepsy. I was pretty disappointed in that."

Epilepsy is a disorder of the central nervous system that causes seizures. About 300,000 Canadians have it.

Joey Callanan of St. John's was eight years old when diagnosed with epilepsy. He spent the next several years trying, unsuccessfully, to control the seizures.

"When word got around in junior high that I had epilepsy, I lost a lot of my friends. I was made fun of and tormented. It was hard," the 22-year-old says.

At age 13, Callanan had brain surgery at Toronto's Sick Kids Hospital. He then went five years without having a seizure.

"In high school I was still back and forth to the Janeway Rehabilitation Centre for speech pathology. I wasn't doing very well in school but I wouldn't give up."

Because of his struggles, during his first year in high school, a plan was put in place for Callanan to complete his high school education in four years rather than three.

He had great support at Bishop's College, he says, and sang in both the school concert choir and chamber choir.

*(Continued, next page)*

## Purple Day Aims to Raise Epilepsy Awareness cont.

Callanan's first job was at McDonald's on Topsail Road in St. John's. The job entailed some overnight shifts. When he told his manager about his seizures and his uneasiness working overnight, accommodations were made for him to work during the day.

"She said that she's worked with other people with epilepsy and that was fine, which I really appreciated."

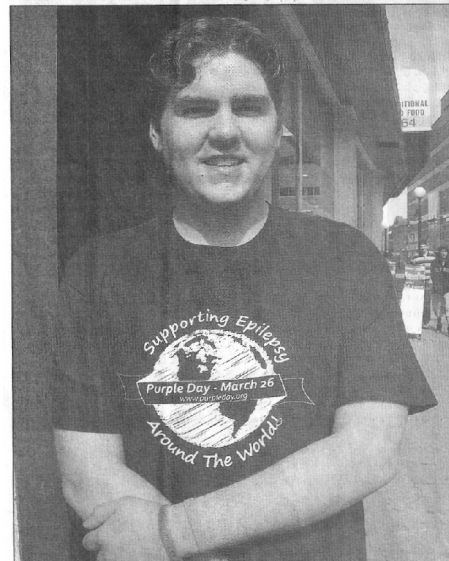
Callanan is a member of the Newman Sound Men's Choir. The choir recorded its first album in 2010 and won gold at the World Choir Games in Cincinnati in 2012.

"When I'm singing, I can forget the seizures for a while and just be me."

Callanan is a graduate of the College of the North Atlantic's computer systems and networking program. The instructors were very supportive of his needs, he says, and he made many friends while enrolled in the program.

He enjoyed his work term with the provincial government and is now intent on finding a job. That's another challenge, he says, for people with epilepsy.

"You've got to be stubborn. It's hard but I have an open mind about what I'm going to do. I'll try for a clerical position. I can do anything that anybody wants me to do. It's all experience for me."



Joey Callanan is the ambassador for Epilepsy Newfoundland and Labrador Purple Day. — Photo by Danette Dooley/Special to The Telegram

*Finding a job is a challenge for people with epilepsy: ambassador*

Callanan is ambassador for the Epilepsy NL Purple Day for Epilepsy. He says he was delighted to be on hand recently when Premier Kathy Dunderdale and Community Services Minister Susan Sullivan proclaimed March 26<sup>th</sup> as Purple Day for Epilepsy.

Purple Day is a global effort to promote awareness of the seizure disorder.

On Tuesday, people will again wear purple to show individuals and families who face epilepsy that they aren't alone. We will do so for people like Joey and Leanne and the other 10,000 people of this province who live with seizures every day.

## Door to Door Campaign - We Love Our Volunteers!

Thank you to everyone who supported the March Door to Door Campaign. We have just had an incredibly successful year thanks to the help of our dedicated team of volunteer canvassers from right across the entire province.

The winners of the 2012 Door to Door draws were:

### Zone Captain

- Shawna Canning, Botwood

### Over \$100 Canvasser

- Reg Carroll, Margaree

### Over \$25 Canvasser

- Joseph Greene, King's Cove



We 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, and to thank everyone who donated even a little.

Your efforts will go a long way towards the promotion of epilepsy support and awareness in NL. Every penny of your donation stays right here to keep our doors open and our services operating.

If you didn't have an opportunity to help out this year, please plan to do so next year. We need the support of everyone who has been touched by epilepsy to help make a difference.

We need you.

*Clairie Pottle* Campaign Coordinator

# Spotting Seizures in Babies, Children & Adolescents

**W**hen we hear the word epilepsy, we often automatically think about seizures with strong convulsions and unconsciousness. In reality, the signs that a baby or child has epilepsy can sometimes be far more subtle and difficult to spot.

Seizures can also be difficult to recognize in adolescents as well. Parents may sometimes mistake the signs of epilepsy as a phase their child is going through, drug or alcohol abuse, or psychological problems.

## Less Obvious Signs of a Seizure in Babies

- “Jackknife”-like movements when baby is sitting
- Short periods of both arms making grabbing movements when babies are lying on their backs
- Jerking or stiffening of a leg or an arm, or both legs may jerk up toward the belly with the knees bent.
- The baby's facial expression, breathing, and heart rate may change.
- Parents may suspect that responsiveness is impaired when their voices are unable to attract the newborn's attention.

## Less Obvious Signs of a Seizure in Children

- Unusual clumsiness and frequent stumbling, sudden, unexplained falls
- Feeling sudden stomach pain and is confused, unusually sleepy and irritable when wakened
- Short times of staring into space like they were daydreaming at inappropriate times, such as in the middle of a conversation
- Unresponsive or dazed for brief periods of time
- Nodding, rapidly blinking repeatedly, or other repetitive movements that seem unnatural
- Complaining that things taste, smell, feel, sound or look funny
- Unexplainable anxiety attacks

## Less Obvious Signs of a Seizure in Adolescents

- Appearing ‘out of it’ and dazed
- Staring blankly and then mumbling, making random movements, chewing, or picking at clothes
- Parts of the body jerking, or moving uncontrolled
- Sudden unexplained anxiety or anger
- Sensory changes such as saying things feel, sound, smell or look different or strange
- Memory lapses
- Periods when they are not able to talk normally

Not all children or adolescents who exhibit these behaviours will necessarily be experiencing seizures. **If you are concerned, it is important to talk with your doctor.**



**Parents can help doctors better understand and diagnose potential seizures by noting the following:**

- ☐ The time of day the behaviour happened
- ☐ The child's activities before the episode
- ☐ The child's physical condition, such as being tired, stressed or ill
- ☐ Warning signs the child may have said they felt before the suspected seizure
- ☐ The nature of movements of the body, if any, and where the movements were located
- ☐ The sounds made by the child, if any
- ☐ Timing how long the behaviour lasted
- ☐ Explaining how the child felt after the suspected seizure, such as tiredness, soreness or confusion, and whether they were able to talk

*Partial Source: Carola Finch, HubPages*

## Off The News Wire

### **Link Between Epilepsy And Autism Found**

Adults with epilepsy are more likely to have a greater number of characteristics of autism and Asperger syndrome, according to new research by Dr. SallyAnn Wakeford, a PhD student from the University of Bath's Department of Psychology, who revealed a previously unknown link between epileptic seizures and the signs of autism in adults.

Traits of autism, such as impaired communication and social interaction and restricted and repetitive interests, can be serious and go undetected for several years - creating a lasting impact on the lives of those who endure them.

Researchers found that epileptic seizures interfere with the neurological function that affects social functioning in the brain causing the same characteristics that depict autism.

"The social difficulties in epilepsy have been so far under-diagnosed and research has not uncovered any underlying theory to explain them. This new research links social difficulties to a deficit in the brain, explaining these characteristics in adults with epilepsy," Dr Wakeford said.

The researchers revealed that having elevated autistic traits was standard to all types of epilepsy, however, it was more evident for adults with Temporal Lobe Epilepsy (TLE). The authors believe one reason may be because anti-epileptic medications are many times less effective for TLE. These drugs may cause an impact because they are significantly related to the severity of autistic characteristics.

Dr. Wakeford and her colleagues conducted a comprehensive range of studies with participants who have epilepsy and found that all adults with epilepsy exhibited autism traits.

The findings may lead to better treatment for people with epilepsy and autism. Dr. Wakeford suggested that although epilepsy has a cultural stigma, the more understood the physical outcomes of this condition are, the better chance there is to eliminate this stigma.

"These findings could mean that adults with epilepsy get access to better services, as there is a wider range of treatments available for those with autism condition."

*Excerpted from: Kelly Fitzgerald, Medical News Today, May 16th, 2013*

### **Brain Cells Cure Epilepsy In Mouse Model**

UCSF scientists controlled seizures in epileptic mice with a one-time transplantation of medial ganglionic eminence (MGE) cells, which inhibit signaling in overactive nerve circuits, into the hippocampus, a brain region associated with seizures, as well as with learning and memory. Other researchers had previously used different cell types in rodent cell transplantation experiments and failed to stop seizures.

"Our results are an encouraging step toward using inhibitory neurons for cell transplantation in adults with severe forms of epilepsy," Baraban said. "This procedure offers the possibility of controlling seizures and rescuing cognitive deficits in these patients."

The findings, which are the first ever to report stopping seizures in mouse models of adult human epilepsy, were published online in the journal *Nature Neuroscience*.

During epileptic seizures, extreme muscle contractions and, often, a loss of consciousness can cause seizure sufferers to lose control, fall and sometimes be seriously injured. The unseen malfunction behind these effects is the abnormal firing of many excitatory nerve cells in the brain at the same time.

In the study, the transplanted inhibitory cells eliminated seizures in half of the treated mice and dramatically reducing the number of spontaneous seizures in the rest.

In another encouraging step, UCSF researchers reported that they found a way to reliably generate human MGE-like cells in the laboratory. In many forms of epilepsy, loss or malfunction of inhibitory nerve cells within the hippocampus plays a critical role. MGE cells are progenitor cells that form early within the embryo and are capable of generating mature inhibitory nerve cells called interneurons. In the study, the transplanted MGE cells from mouse embryos migrated and generated interneurons, in effect replacing the cells that fail in epilepsy. The new cells integrated into existing neural circuits in the mice, the researchers found.

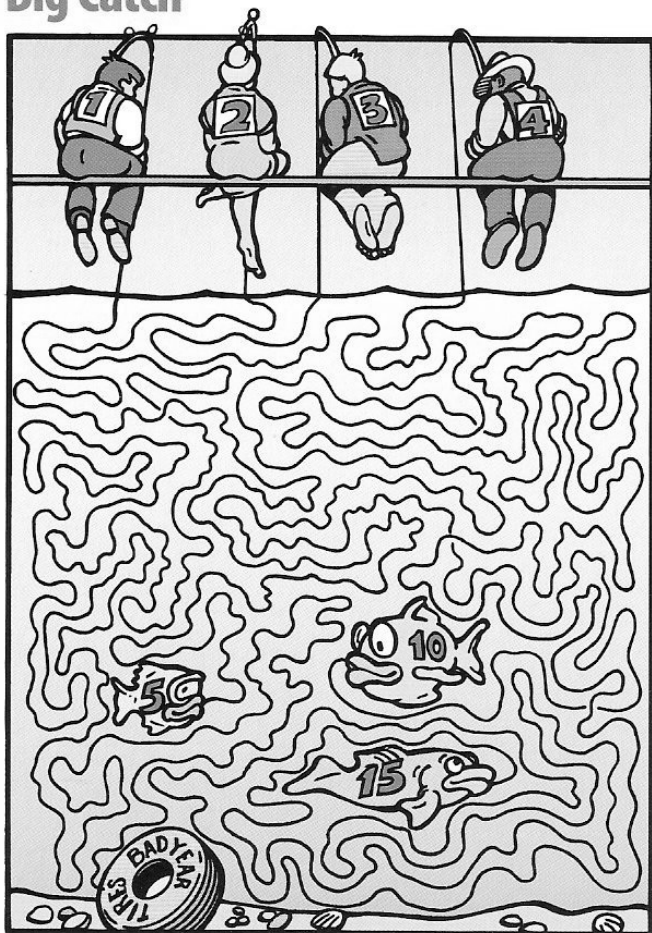
In addition to having fewer seizures, treated mice became less abnormally agitated, less hyperactive, and performed better in water-maze tests.

*Excerpted from: Medical News Today, May 8th, 2013*



## A Little Time Out

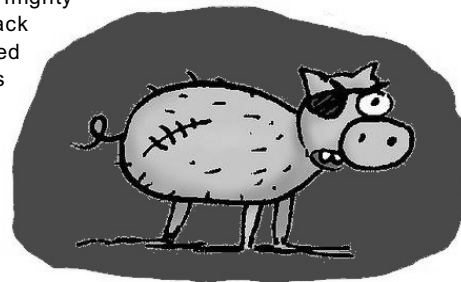
### Big Catch



**Welcome to the annual fishing contest. Which contestant will haul in the biggest fish and who will reel in the tire?**

Farmer Bob got out of his car and while heading for his friend's door, noticed a pig with a wooden leg. His curiosity roused, he asked, "Fred, how'd that pig get a wooden leg?"

"Well Bob, that's a mighty special pig! A while back a grizzly bear attacked me while I was walking in the woods. That pig there came a runnin', went after that bear and chased him away. Saved my life!"



"And the bear tore up his leg?"

"No he was fine after that. But a bit later we had that fire. Started in the shed and spread to the barn. Well, that ole pig started squealin' so loud he woke us up, and 'fore we got out here, the darn thing had herded the other animals out of the barn and saved 'em all!"

"So that's when he hurt his leg, huh, Fred?"

"No, Bob. He was a might winded, though. When my tractor hit a rock and rolled down the hill into the pond I was knocked clean out. When I came to, that pig had dove into the pond and dragged me out 'fore I drowned. Sure did save my life."

"And that was when he hurt his leg?"

"Oh no, he was fine. Cleaned him up, too."

"OK, Fred. So just tell me. How did he get the wooden leg?"

"Well, Bob," said Farmer Fred, "a pig like that, you don't want to eat all at once."

- ★ Each person has about the same number of brain cells at birth as in adulthood, but those cells grow, reaching maximum size at about age six.
- ★ A newborn's brain triples its size in the first year of life
- ★ The sense of touch is the first sense to develop in a fetus, with the lips and cheeks experiencing sensation at eight weeks.
- ★ Keep exercising your brain, because mental activity stimulates the creation of new neurons throughout your whole life.



## Email or Postal Mail?

**H**elp 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

## Social & Support Group

In St. John's and the surrounding area?

Interested in meeting with other people who face seizures in their daily lives?

### ENL will be holding two Support Groups in September:

- one for parents of children with epilepsy
- one for adults with epilepsy

If you would be interested in attending either of these, please call Pam at the Epilepsy NL office  
722-0502 or 1-866-EPILEPSY.

**Answer:** The winner will be contestant Number 3 hauling in the 15 pounder. Contestant Number 2 will reel in the fire. Oh, by the way, Number 4 yanks in the 10 pounder and Number 1 hooks the 5 pounder.

## 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:	
Address:			
Phone:		Would you prefer mail-outs by email or postal mail?:	
<b>If you would prefer to pay by credit card, please complete the following:</b>			
Account #	Type of card:	Expiry:	

**Clip and mail this form to Epilepsy Newfoundland and Labrador - 351 Kenmount Road, St. John's, NL A1B 3P9**