



## Politicians Show Their Purple Side

**D**uring Epilepsy Awareness Month, in a tremendous show of support, several politicians, both provincial and federal, stepped forward to share what Purple Day meant to them. Among them were Premier Kathy Dunderdale, who signed the documents proclaiming Purple Day for the entire province of Newfoundland and Labrador (see the picture on page 4), and Senator George J. Furey who spoke in the Senate on the importance of epilepsy awareness and understanding.

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 Leader Dwight Ball, and leader of the NDP Lorraine Michael.

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

*I commend the work of Epilepsy Newfoundland and Labrador. For nearly thirty years this organization has provided support and information to individuals and their families throughout the Province.*

*Epilepsy is one of the most common neurological conditions and affects over 10,000 people in our Province. I invite the residents of Newfoundland and Labrador to participate in Purple Day activities and support those who live with epilepsy each day.*



Dwight Ball

*It is great to have a day like Purple Day as we bring public awareness to epilepsy. What this does of course is educate the general population, not only about epilepsy but how to intervene in case of emergency.*

*It is important that we do acknowledge days like Purple Day and epilepsy, it gives us all an opportunity to learn more about this prevalent condition, and another opportunity to thank all the volunteers and the associations across Newfoundland for the great work that they do on behalf of the people with epilepsy.*



Lorraine Michael

*I congratulate all the children and parents affected by epilepsy who are involved in making the public more aware of this condition and dispelling the myths and stigma that have existed for too long a time.*

*Wearing purple ribbons and purple in any way we can is one important thing to do, but the 10,000 people in this Province with epilepsy deserve every effort we can make to make their lives easier. Government should support education and awareness sessions in every school in the Province on a yearly basis, beginning at the elementary school level and on through high school. Regular on the ground education in our schools will make a difference in the attitudes of the next generation and it will paint the Province purple all year-round.*



Senator  
George J. Furey

*Honourable senators, March 26 marked World Epilepsy Awareness Day, a day dedicated to increasing awareness about epilepsy worldwide and a day to shed light on courageous individuals like Luke, who is the Epilepsy Ambassador for Newfoundland and Labrador. As long as we have young people in Canada who, like Luke, are determined to succeed no matter what obstacles they face, we can all continue to have great hope for the future.*

*Honourable senators, please join me in recognizing the outstanding courage and determination of Luke Nofall and the 300,000 Canadians who deal with epilepsy on a daily basis.*

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

- Sandy Collins, MHA for Terra Nova
- Paul Lane, MHA for Mount Pearl South
- Gerry Rogers, MHA for St. John's Centre
- Steve Kent, MHA for Mount Pearl North
- Paul A. Davis, MHA for Topsail
- Judy Foote, MP for Random - Burin - St. George's
- Scott Simms, MP for Bonavista - Gander - GFW
- Jack Harris, MP for St. John's East

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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. Because of this, friends and supporters of ENL are sometimes motivated to make epilepsy awareness in their community just a little more special.

Our sincerest thanks to:

- ☺ Luke Noffall of St. John's, our 2012 Purple Day Ambassador, for sharing his story of challenge and determination to live his absolute best life in spite of seizures.
- ☺ Rachel Spicer of Pasadena, for her creative and artistic FoamRaising project, and her sister Heather for being such a strong advocate for epilepsy education.
- ☺ Karen Milley of Corner Brook, who used her birthday party as an opportunity to share information, spread awareness, and sell lavender wristbands.
- ☺ Tracey Rheault of Grand Falls-Windsor, who spearheaded a number of projects in Central. She was interviewed by Rogers Cable, and interviewed by the Grand Falls Advertiser. She arranged for three daycares in the area to participate in the purple day Bunny Hop, and held a booth at the local mall selling baked goods, and wristbands. She had a friend and local artist do a painting for Purple Day. With every donation to ENL, people got an entry for the painting.
- ☺ Faith Atkins of Mount Pearl, who held an awareness day at her school, Mount Pearl Intermediate, and donated the money raised.
- ☺ The Provincial Court of NL in Corner Brook, who decorated their office, had a bake sale, a photo challenge and sent around a request for donations.

It's a touching thing, when someone cares that much, and we are so proud and grateful for every single thing that helps bring epilepsy out of the shadows for good.

What will you do?

## 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 2012 - Purple and Proud

March was Epilepsy Awareness Month and March 26<sup>th</sup> was Purple Day for Epilepsy & Seizure Awareness. Here in Newfoundland and Labrador, more than 3500 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 23rd year of the Forum, and the first year held at our new building. We had 27 participants in attendance to hear and question Dr. Buckley and Dr. Ogunyemi.

Some of the questions that were asked included:

- Amnesic seizures and memory loss
- Weaning off meds for adults
- Vimpat and side effects
- Seizure types, can one person have multiple types?
- Nocturnal Seizures
- Non-epileptic seizures and treatment options
- Brain cavernomas and the genetics of seizures

## 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 \$5200.00! Please know that you really do make a difference.

- Reach for the Stars, South River
- Play, Learn & Grow, Grand Falls-Windsor
- Creative Beginnings, Corner Brook
- Stepping Stones, CBS
- Chatterbox Daycare, Mount Pearl
- Campus Childcare Toddler Cntr, St. John's
- Campus Childcare Activity Cntr, St. John's
- Campus Childcare Preschool 1, St. John's
- Campus Childcare Preschool 2, St. John's
- Confederation Building Daycare, St. John's
- Humpty Dumpty, Corner Brook
- Tiny Hands, Grand Falls-Windsor
- Tiny Treasures, Grand Falls-Windsor
- After School Zone, Labrador City



## 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 \$600.00!

- Holy Trinity Elementary - Torbay
- Harriott Curtis Collegiate - St. Anthony
- Indian River High - Springdale
- Lourdes Elementary - Lourdes
- Beachy Cove Elementary - Portugal Cove-St. Phillip's
- Mount Pearl Intermediate - Mount Pearl
- Pasadena Academy - Pasadena
- James Cook Memorial - Cook's Harbour
- Gros Morne Academy - Rocky Harbour
- Elwood High School - Deer Lake
- Jakeman All Grade - Trout River
- Dunne Memorial Academy - St. Mary's
- Coley's Point Primary - Bay Roberts
- St. Gerards Elementary - Corner Brook

## Proclamations Galore

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:

- City of St. John's
- Town of Grand Falls - Windsor
- Town of Harbour Breton
- Town of South River
- Town of Rocky Harbour
- Town of Grand Bank
- Town of Carbonear
- Town of Renew - Cappahayden
- Town of Kippens
- Town of Gander
- City of Corner Brook
- Town of Roddickton - Bide Arm
- Town of Colliers



# The Power of Purple is the Power of People



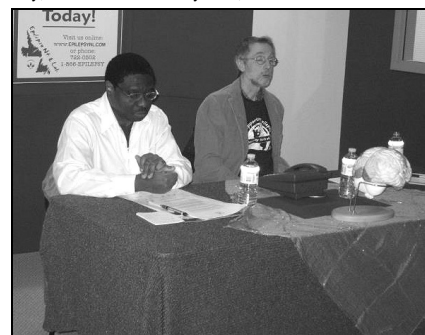
Play, Learn & Grow Daycare, Grand Falls-Windsor



Premier Dunderdale signing the Purple Day Proclamation



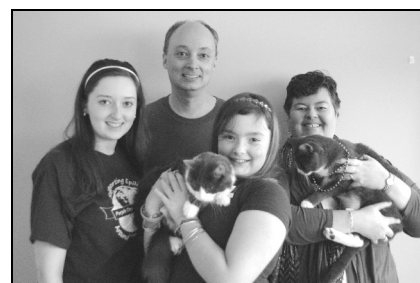
Government of NL - Deer Lake



Dr. Ogunyemi & Dr. Buckley at the Ask The Doctors Forum



Tracey Rheault & Family, Grand Falls - Windsor



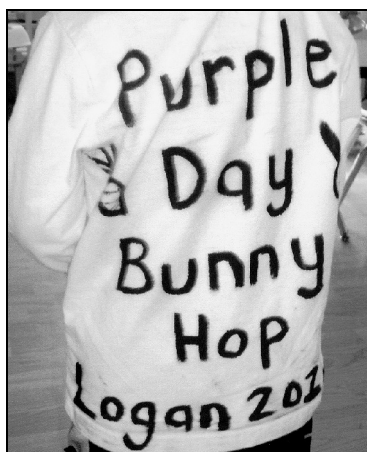
The Spicer Family, Pasadena



Pasadena Elementary



Creative Beginnings - Corner Brook



Reach For The Stars Daycare - South River



Zach Rowe Memorial Tournament - Harbour Grace



Chatterbox Preschool & Daycare - Mt. Pearl

## Province Expands Legislation for Service Animals

**In a press release dated May 31<sup>st</sup>, 2012, the Department of Advanced Education and Skills announced that they are introducing new legislation that would not only expand the definition of service animals, but it would also officially expand the right of access for people with service animals beyond those with visual impairments.**

The Provincial Government has introduced new legislation that expands the types of animals that can be used as service animals by persons with disabilities as well as the right of access for persons with disabilities. Bill 17, an Act Respecting the Service Animals Act received second reading in the House of Assembly today. The previous act regarding these matters, the Blind Persons' Rights Act, will be repealed.

"Since the enactment of the Blind Persons' Rights Act in 1981 there have been significant advances in training and use of service animals, beyond the traditional guide dog," said the Honourable Felix Collins, Minister of Justice and Attorney General. "Service animals are used by a number of different people with various disabilities such as autism, epilepsy, vision impairment, brain injury, hearing loss and mental illness. The new Service Animals Act recognizes this and will prohibit discrimination against a person with a service animal with respect to accommodations, services or facilities."

The Service Animals Act expands the definition of service animal so it is not exclusively service dogs and it expands the definition of a person with a disability to be consistent with the Human Rights Act, the United Nations Convention on the Rights of Persons with Disabilities and Provincial Government policy.



"Service animals provide important work and are specifically trained to provide the necessary supports and accommodations that allow persons living with disabilities to access their communities on an equal basis," said the Honourable Joan Burke, Minister of Advanced Education and Skills and Minister responsible for the Status of Persons with Disabilities. "This province established a Disability Policy Office to ensure that people with disabilities are included in all aspects of society. The new Service Animals Act supports the goals of this office by guaranteeing rights and removing barriers to places such as hotels, restaurants, apartments or other services and facilities on the basis of a service animal."



It's about time! Here in Newfoundland and Labrador, we have several people with Seizure Response Dogs; highly skilled and trained pups who assist their owners when they have a seizure. They are registered, wear a service jacket, and have a special ID card.

Yet, over the years, we have had individuals with Seizure Response Dogs kicked off the Metrobus, asked to leave restaurants, been denied admission into stores, and treated with suspicion because their service dog wasn't a "seeing-eye dog" and the only officially permissible service animal.

This new legislation is a great change for the better.

If you, or anyone you know, might be interested in learning more about Seizure Response Dogs, get in touch with us here at ENL or call the Lions Foundation of Canada Dog Guides, a non-profit organization run through the support of Lions Clubs all over the country. They provide a wide range of highly trained service dogs, without cost, to people who need them. Their number is 1-800-768-3030. Or browse their website at [www.dogguides.com](http://www.dogguides.com)

## Getting His Life Back - Luke's Story

**L**uke Nofall has never let epilepsy define who he is. It's just something he's had to deal with, the 19-year-old says - a bump in the road.

But for several years, that bump was more like a crater.

Nofall was diagnosed with epilepsy at age 12. An avid swimmer, he had his first seizure during time trials for a competition. Doctors diagnosed Luke with epilepsy after he had a second seizure about a month later.

The seizures continued and became more frequent even though he was taking anti-seizure medication.

Nofall's grades plummeted. He lost some friends and could no longer swim or play volleyball or soccer. It was a depressing time in his life, he said. Doctors at the Janeway suggested Elizabeth and Frank Nofall take their son to Sick Kids Hospital in Toronto for further assessment.

In January of 2008, surgeons there performed a major resection on Luke's brain. He was 15. The surgery involved opening his skull and placing various electrodes on his brain to pinpoint the origin of the seizures. Then they removed as much of the affected brain tissue as possible.

"I had three brain surgeries in five days," Luke said, turning the pages of a photo album from his time at Sick Kids.

Elizabeth Nofall says there was no guarantee the surgery would cure her son's seizures, but it was his best chance for a better future.



**Luke with MP Jack Harris  
as he signs the Purple Day Proclamation**

He continued to have seizures after the surgery and remained at Sick Kids for about a month. Once he came home, he still had seizures and ended up repeating a year of high school. Still, the surgery was successful.

Now it's been three years since he has a seizure. Because there is still some seizure activity in his brain, he continues to take antiseizure medication, but he's back in the pool, works out regularly, plays video games with his friends and Airsoft (similar to paintball) with his 22-year-old brother, Mark.

Nofall says he is grateful for his family's support "Without Mon, Dad and Mark it would have been all downhill for me. They never gave up on me, even when I was really sick and hard to get along with. They just chugged along through it."

Neurologists, rehab staff and therapists at the Janeway were instrumental in his recovery, he said.

"And without my teachers at Holy Heart, I probably would not have gotten through school."

Elizabeth Nofall said the staff at Epilepsy Newfoundland and Labrador (ENL) provided the family with information and stayed in contact with them, particularly during their time in Toronto.

Nofall now relies on Memorial University's Blundon Centre for assistance, which helps people with disabilities.

His long term goal is to become a psychologist. "I've had so many therapists in the past, I thought I might as well become one," he said with a smile.

*(Excerpted from The Telegram, February 27<sup>th</sup>, 2012, by Danette Dooley)*





## 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



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

**T**hank you to everyone who supported the March Door to Door Campaign. It could never have been the success it was without the help of our dedicated team of volunteers from right across the entire province.

The winners of the 2012 Door to Door draws were:

### **Zone Captain**

- Eunice Pinsent, Cavendish

### **Over \$100 Canvasser**

- Ruby Alcock, Grand Bank

### **Over \$25 Canvasser**

- Catherine McCullough, Grand Falls - Windsor

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.

*Elaine Pottle*, Campaign Coordinator

If we look hard enough for something to be angry about...we will surely find it. If we look hard enough for something to be happy about...we will surely find it. The world needs more people looking for something to be happy about.

## Off The News Wire

### ***Response to First Treatment May Predict Epilepsy's Course***

The way someone responds to the first anti-seizure medication given after a diagnosis of epilepsy often predicts how well- controlled their seizures will be over time.

A new study found that about 50 percent of people became seizure-free after the first medication they took. By contrast, only 13 percent became seizure-free after the second drug was tried, and just 4 percent were seizure-free after a third drug was tried.

"The long-term treatment outcome is fairly constant, and thus predictable early on, in most people with epilepsy," said the study's lead author, Dr. Patrick Kwan, a professor of neurology at the University of Melbourne, in Australia. "Few patients become seizure-free after failure of the first two medications tried," he added.

The current study included nearly 1,100 people aged 9 to 93 who were newly diagnosed with epilepsy. They were followed for up to 26 years.

Overall, 37 percent of those trying medications became seizure-free immediately. Another 22 percent became seizure-free within six months of starting treatment.

Sixteen percent had what's known as relapsing-remitting seizures. After being seizure-free for a year or more, they had as many as five periods of seizure relapse. Twenty-five percent never became seizure-free, according to the study.

"Given that epilepsy can be controlled with medications in the majority of patients -- nearly 70 percent -- a lack of response should call for re-evaluation for conditions other than epilepsy," Kwan said, adding that if you haven't responded to the first two drugs your doctor tries, you should be seen by a physician at a specialized epilepsy center for non-drug treatments.

Dr. Cynthia Harden, chief of the division of epilepsy and electroencephalography at the Cushing Neuroscience Institute in Great Neck, N.Y., agreed. "Most people do well on the first or second drug. Some people need a combination to become seizure free. But, if someone fails monotherapy and combination therapy, it's time to think about options other than drugs," she said.

*HealthDay News, May 2012*

### ***Epilepsy Type Signs Linked To Stress***

A team of Johns Hopkins physicians and psychologists found that more than one-third of patients admitted to the inpatient epilepsy monitoring unit had symptoms caused by stress, rather than a true seizure disorder.

According to the researchers, these patients, which included mothers in child-custody battles and returning war veterans, as well as over-extended professionals alike, have psychogenic non-epileptic seizures (PNES).

Signs of the condition include:

- Convulsions
- uncontrollable movements
- far-off stares

The researchers note that signs of PNES appear to be stress-related behaviors that mimic and are misdiagnosed as epilepsy, but are not due to abnormal electrical discharges in the brain that characterize the neurological disorder.

Antiseizure medications fail to stop these patients' symptoms, indicating that there is nothing physically wrong with the their brains' electrical activity, say the researchers. In addition, the incidence of PNES is increasing, at least by what they have observed in recent months.

Gregory L. Krauss, M.D., a professor of neurology at Johns Hopkins and one of the study's co-authors, reveals that it is surprising how many individuals without epilepsy are being referred to his epilepsy unit and that these numbers seem to be increasing. In the past few months, up to half of all patients referred to his unit have pseudo-seizures.

Using a computer analogy, the researchers say that when they discover patients who don't have a hardware problem, but a software glitch, they get the good news. Krauss explains that often symptoms disappear rapidly. However, according to Brandt, these patients usually need cognitive behavior therapy in order to help them develop more effective ways of coping.

Krauss explained: "There's a lot of stress out there in our modern society, and this research highlights that many people don't have the skills to cope with that."

*Medical News Today, April 2012*



## A Little Time Out

E T R O P S I W E L E T  
 F B A Y R O B E R T S R  
 N O S N O S N I B O R O  
 O C G B R I G U S O X P  
 T H P O L O Y R E B A T  
 S A L E G S E N L M T S  
 I R H V A N L W E A F A  
 L L B O N H L O U G N E  
 L O E C D O A T O F T U  
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 O W A A L O L N D L E F  
 N N M I D A P B R A A D  
 O R W T H I X S S U M M  
 E T N O T R E T N I W R

### Exploring Newfoundland and Labrador!

*There are so many summer festivals in this province! Below is a list of just a few of them. Can you identify the hometown for each? We have put the number of letters in each town's name at the end of the clue to help you out. Then find those town names in the puzzle at the bottom. All the leftover letters in the puzzle will spell out a hidden message.*

The Beaches Accordion Festival	_____
Klondyke Days	_____
Bakeapple Folk Festival	_____
Bird Island Festival	_____
Brimstone Head Folk Festival	_____
Shrimp Festival	_____
Busker Fest	_____
Flying Boat Festival	_____
Festival of Flight	_____
Iron Skull Folk Festival	_____
Lighthouse Festival	_____
Paddle Festival	_____
The Great Crab Boil	_____
Scilly Cove Festival	_____
The Seabird Theatre Festival	_____
Smallwood Holiday & Logger Fest	_____
Caplin & Cod Festival	_____
Salmon Festival	_____
Fish, Fun, & Folk Festival	_____
Mussel Bed Soiree	_____
Blueberry Festival	_____

A local hunting guide got himself  
into a fix.  
His party became hopelessly lost in  
the woods  
and they blamed him for leading  
them astray.

"You told us you were the best  
guide in Labrador!"  
they grumbled

"I am," he said, "but I think we're in Quebec now."



Junior had just received his brand new driver's license.  
To celebrate the special day, the whole family went out  
to the driveway and climbed into the car for his first official drive. Dad  
went immediately to the back seat,  
right behind the newly licensed driver.

"I'll bet you are back there to get a change of scenery, right?  
After all these months of sitting up here, teaching me how to drive?"  
Junior said to his dad.

"Nope!" said Dad. "I'm going to sit back here and  
kick the back of your seat as you drive,  
just like you've been doing to me for sixteen years!"

## 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



## Puzzle Solution

**Labrador this summer**  
**Hidden Message - Explore all the fun of Newfoundland and**

**NL Summer Festivals**  
The Beaches Accordion Festival - Eastport  
Klondyke Days - Bay Roberts  
Bakeapple Folk Festival - Forteau  
Bird Island Festival - Elliston  
Brimstone Head Folk Festival - Fogo  
Shrimp Festival - Charlottetown (Labrador)  
Busker Fest - St. John's  
Flying Boat Festival - Botwood  
Festival of Flight - Gander  
Iron Skull Folk Festival - Belleoram  
Lighthouse Festival - King's Cove  
Paddle Festival - Ramona  
The Great Crab Boil - Robinsons  
Silly Cove Festival - Winton  
The Seabird Theatre Festival - Newtown  
Smallwood Holiday & Logger Fest - Gambo  
Caplin & Cod Festival - Triton  
Salmon Festival - Exploit's Valley  
Fish, Fun, & Folk Festival - Twillingate  
Mussel Bed Soiree - Lewisporte  
Blueberry Festival - Brigus

## 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?:

**If you would prefer to pay by credit card, please complete the following:**

Account #

Type of card:

Expiry:

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