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## Epilepsy News

is printed quarterly by:

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## Purple Day 2016



Purple Day was a great success this year. People participated all across the province in many different ways.

The Kavanaghs of Burin wore their purple and made many purple crafts to sell in support of ENL. They also got a lot of people to participate in Purple Day this year.

The Spicers of Pasedena had story time for Purple Day.

The Browns and Edmunds had a Bingo Tournament in Tilton and also celebrated at Dominion Bay Roberts.

Daycares Bunny Hopped. Schools wore Purple and learned about Epilepsy.

Towns signed Proclamations, MHAs and MPs signed commitments and Signal Hill was lit up in purple!

Even with Easter right around the corner and March 26 on a Saturday, the people of New-

foundland and Labrador dressed proudly in purple to support those living with epilepsy in this province.

Purple Day is celebrated every March 26 during Epilepsy Awareness Month to let those living with epilepsy know they are not alone. It also helps spread awareness about the neurological disorder and how to perform First Aid, while also helping end the stigma associated with Epilepsy.

If you would like to participate or volunteer for next year's Purple day or if you have any ideas for events during the month of March. Please contact Epilepsy NL: 1-709-722-0502



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M.D., FRCP ©**Information Officer**

Gina Hartmann

**Purple Day Ambassador: Christine Facey**

Christine Facey was diagnosed with epilepsy in 1999, when she was in grade eight.

Throughout Junior High, Christine had Petit Mal Seizures and by high school, she was experiencing tonic clonic seizures.

Christine would not have an aura and when she woke up she would not remember what had happened.

However, once her medication became stabilized, things started to get better.

Christine speaks openly about

her experience and loves to spread awareness about epilepsy and First Aid.

She was the Purple Day Ambassador 2016.

Christine witnessed the House of Assembly speak about Purple Day, met MHA Dr. John Haggie, who signed the Purple Day Proclamation for the province.

She met with the Mayor of St. John's for his signing of the Proclamation and she spoke on the radio about her experience.

**Zach Rowe Memorial Tournament**

Zach Rowe grew up playing minor hockey as a goalie for the CeeBees and this tournament is put off every year in honour of Zach who passed away as a result of seizure in 2009.

The tournament is meant for young kids to enjoy a day with their peers playing hockey, as well as bringing awareness for epilepsy.

The tournament consists of

over 200 players from over seven different communities.

Proceeds go to the Zach Rowe Memorial scholarship fund for a student with epilepsy who is in high school and will be attending post secondary institute.

The tournament raised \$272!

Thank you to all the players, volunteers and coordinators of



this event. What a great opportunity to help bring awareness, celebrate the memory of Zach and have the community come together for a great cause.

**Evan's Bookmarks**

Evan Newhook of Dildo was ENL's Purple Day Ambassador for 2015.

Last year he wanted to help support people with epilepsy so he made a bookmark and sold it for two dollars.

Evan decided he would continue to make bookmarks every year with a different design.

This year, Evan sold over \$900 with all contributions going to ENL.

Evan presented a cheque to Executive Director, Gail Dempsey.

We are truly thankful for all your hard work and effort, Evan.

We appreciate you spreading awareness throughout the province and letting others know about ENL.



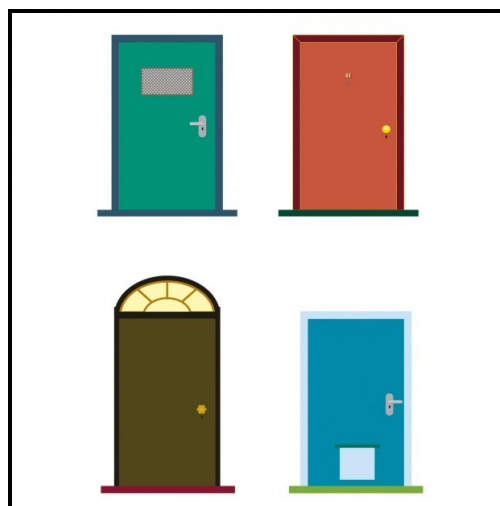
## Door to Door Campaign

We would like to extend our sincerest appreciation to all individuals who participated in the Door to Door Campaign. People throughout the province collected money for Epilepsy Newfoundland and Labrador.

This campaign is only successful due to the effort and time given by all the volunteers in this province and for that, ENL is truly thankful.

Fundraising Coordinator, Elaine Pottle, would like to thank everyone for all their hard work during this campaign.

If you are interested in helping with the Door to Door Campaign next year please contact Elaine at 709-722-0502



## Two Families, One Great Cause

When people come together, great things can happen.

A very long time ago, the Edmunds of Bay Roberts got a call about our Door-to-Door canvassing campaign. Immediately, they decided to volunteer their time for this campaign but they were more excited to hear about Epilepsy Newfoundland and Labrador.

Their daughter had been diagnosed with epilepsy and they wanted to know what the association had to offer. The family also wanted to know how they could help support ENL as well.

Throughout the years since, The Edmunds have worn their purple every March 26 and helped spread awareness about Epilepsy. They have hosted events throughout their region to raise money for ENL and provided information to the public.

In 2015, The Edmunds met up with the Browns, who were also interested in supporting ENL. They have a son with

epilepsy and wanted to spread awareness about the neurological disorder.

The Browns hosted a very successful Bingo at the Tilton Bingo Hall and both families came together to host a variety of events on Purple Day.

This year, both families went above and beyond to show their support and made Purple Day one of a kind in their area.

On March 19, The Browns hosted their second Bingo tournament at Tilton Bingo Hall and raised \$2292. Epilepsy Newfoundland and Labrador is truly thankful for this event and extends its sincerest appreciation for the hard work and effort it took to pull off such a successful occasion.

On Purple Day, March 26, The Edmunds and Browns came together again to wear their Purple proudly at Dominion Bay Roberts.

The store had hot dogs and treats for sale, Barney the dinosaur came to visit, and there were information and ribbons

available to the public. The families raised \$538 that day. We would like to thank both families and Dominion Bay Roberts for establishing a presence in their corner of Newfoundland and helping spread awareness to the people of their area.

ENL is truly thankful for all Purple Day participants and we could not be here without all of our volunteers.

To see the Edmunds and Browns come together to help ENL check out their pictures on our Facebook Page: EpilepsyNL and follow us on Twitter: @epilepsynl

What can you do in your area to help bring awareness to epilepsy? Tell us your story and we will be happy to share it online and social media. What can you do next year or starting now? Contact us at [info@epilepsynl.com](mailto:info@epilepsynl.com) and we can start planning your event!





## 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 advisers, 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 may have.

### Attention:

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



## I would like to help in the fight against Epilepsy

- ☐ I have made a donation of \$\_\_\_\_\_
- ☐ I would like to become a member of Epilepsy NL and my membership fee of \$5 is included
- ☐ I would like to volunteer (we need volunteers throughout the province)

Name:	Email:
Address:	
Phone:	Would you prefer email or postage?

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

Account #	Type of card	Expiry Date
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Please clip and mail this form to Epilepsy Newfoundland and Labrador— 351 Kenmount Rd. St. John's, NL A1B 3P9 or you can email all your information to [info@epilepsynl.com](mailto:info@epilepsynl.com) to save on postage. You can also submit your form online ([www.epilepsynl.com](http://www.epilepsynl.com)) and make a payment through the DONATE button. Please make a note that the \$5 is for a membership and email your mailing address etc. to [info@epilepsynl.com](mailto:info@epilepsynl.com)

## NL Jeep Owners : Go Topless Event

On May 21, the Newfoundland Labrador Jeep Owners Association came together to help fundraise for ENL.

Every year jeeps from around the province came together for a great cause and this year they represented ENL.

Over 100 jeeps gathered at Hickman jeep on Kenmount for a good time. There were hot dogs and hamburgers, a parade of jeeps beeping down the

roads, prize draws, RTI ramp, NLJO Swag and a mini Jeep Draw.

This initiative raised \$4,784!

Lots of people came out to celebrate and all the drivers and passengers wore Purple for Epilepsy Support.

The weather was wonderful and everyone had a great time.

We would like to thank Pat Atkins, Trent Taylor, Erica

Anstey, Robert Anstey, Mike Flynn and Jeffrey Cook for organizing such a successful event. Thank you to all the drivers and volunteers, we truly appreciate all your effort.

Thank you to Hickman Automotive Group, JAC and NL Light Bars.

Thank you to the volunteers: Jen Wiseman, Katrina Locke, Nancy Blagdon, Faith Atkins, Frank Lowe, Beverley Frost, Miranda Mayo and Nikki Hurley

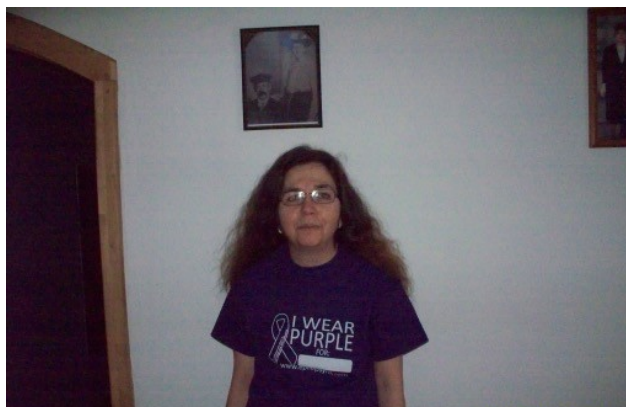


## Programs and Resources

There are a lot of resources throughout the province for persons with disabilities to access. Here are a few for you and your family to check out.

- **Easter Seals:** There are camps, sports, free equipment rental and employment programs. Easter Seals offers many programs and services to people throughout the province and to people of all ages. Visit: [www.eastersealsnl.ca](http://www.eastersealsnl.ca)
- **Empower:** The disability resource centre offers advocacy services, career services, peer support and technology services. Visit: [www.empowernl.com](http://www.empowernl.com)
- **Autism Society of NL:** Aspire Employment Skills Training Program, Asperger's Adult Social Group, Social Thinking Program, Assistive Technology Programming, Parent Support Groups, Music Therapy, Recreational Therapy, resource library. Visit: [www.autism.nf.net](http://www.autism.nf.net)
- **Glenn Roy Blundon Centre for Students with Disabilities:** Located on Memorial Campus at Marine Institute, MUN and Grenfell Campuses. The mission of the Blundon Centre is to provide and co-ordinate programs and services that enable students with disabilities to maximize their educational potential and to increase awareness of inclusive values among all members of the university community. Visit: <http://www.mun.ca/blundon/about/index.php>
- **Labour Market and Career Information Hotline:** The Labour Market Agreement for Persons with Disabilities (LMAPD) is for people with a disability and demonstrated challenges in accessing education or employment. This program is designed to assist individuals with a disability acquire the skills, experience and support necessary to successfully prepare for, enter or remain in the work force. Visit: <http://www.aes.gov.nl.ca/disabilities/services.html> or call: 1-800-563-6600
- **Rainbow Riders:** Rainbow Riders therapeutic riding program has helped Newfoundland and Labrador children with physical, cognitive or emotional disabilities reach their full potential for over 20 years. Therapeutic riding is a modern form of therapy with many benefits. Visit: [www.rainbowridersnl.com](http://www.rainbowridersnl.com)
- **Newfoundland & Labrador Association for Community Living:** To work with and on behalf of individuals with an intellectual disability and their families. To advocate for individuals to live as full participants in the community based on the values of Equality, Inclusion and Independence. Visit: <http://www.nlacl.ca/>

## Christina: A Personal Story



I was born with seizures.

I was told that I had my first seizure at only three days old. Over the years, as I grew up, I mostly had grand mal seizures. I continued to have them until I was 18 and then they seemed to taper off as time went by.

After I had my first child, I began to have even fewer grand mal seizures and after my second child was born, I seemed to have gone a long while without having a seizure at all.

With things seeming to settle down a bit, I decided to take a course in computers. However, when I graduated high school there was no Grade Twelve education available. I had to return to school to obtain that part of my diploma and get more credits. So I went to the Discovery Centre to complete my credits.

While there I wrote an essay titled "Living with Three Illnesses," I got so many credits for that assignment and boy, was I happy. I was slowly getting the credits I needed and getting closer to being able to take my course in computers.

However, that December I began having grand mal seizures again and by January, my seizures were out of control. Within no time, I was on an ambulance, not knowing what my future had in store and the next thing I remember is waking up in emergency. I tried to get up and walk. When I did, I realized I was paralyzed. I later found out, I had a stroke.

It took me nearly 19 months to learn how to walk again and over three years to regain my memory. Most of my learning has come back but I still have problems with some words. All in all it has been a hard road. I struggle each and every day.

But I never give up. After all, I was once told I would never walk again, or read or write and look at me now.

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Christine is a member with Epilepsy Newfoundland and Labrador. She uses writing to work through some of the struggles she has faced throughout life. She writes poetry, essays and has even started a book.



Epilepsy Newfoundland  
and Labrador

## **DON'T FORGET YOUR 2016/17 RENEWAL**

Membership expires at the end of May every year and we are reaching out to all our clients and current members to renew for the upcoming year. For just \$5, you would be granted exclusive benefits only available to members.

## **STRENGTH COMES IN NUMBERS:**

**THE MORE MEMBERS  
WE HAVE THE MORE  
SUPPORT ENL WILL  
RECEIVE FOR  
RESEARCH,  
PROPOSALS AND  
MUCH MORE**

**ATTACHED IS A MEMBERSHIP  
APPLICATION, WE ENCOURAGE YOU  
AND YOUR FAMILY TO SIGN UP FOR  
AN ENL MEMBERSHIP TODAY!**





# Epilepsy Newfoundland and Labrador

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## Membership with ENL entitles the member to a wide range of services and benefits:

- Support programs and advocacy services. If you need any sort of assistance relating to epilepsy, we are here to help.
- Subscription to Epilepsy News, our own quarterly newsletter
- Voting privileges at the Annual General Meeting
- Invitations to special events, teleconferences and info sessions
- Access to a lending library of hundreds of epilepsy resources including books, videos, and story books
- Notification of important changes in medications or treatments

Membership is valid from June 1<sup>st</sup> - May 31<sup>st</sup> of each year.

Cost of membership is only \$5.00. But if this fee would be a hardship to you, let us know. It can be waived in some circumstances.  
Epilepsy Newfoundland and Labrador is a proud member of the Canadian Epilepsy Alliance

## MEMBER INFORMATION

First Name	Last Name
Address	City/Town
Province	Postal Code
Telephone	Email
I would prefer to receive correspondence/newsletters by (circle one):	
Postal Mail	Email

## MEDICAL INFORMATION

Do you or a loved one have epilepsy? Please circle. Yes No

What is the relationship of this person to you? Please circle. Self Other (specify)

Birth date of person with epilepsy (mm/dd/yyyy)

What type/types of seizures are present?

What medications are prescribed for these seizures?

I would like to learn more about becoming a volunteer. (We can use volunteers from right across the province) Yes!

Additional Comments and Suggestions (How can we serve you better? What services would be helpful? What information do you need?)

## I WOULD LIKE TO HELP

☐ I am enclosing my annual membership fee of \$5.00 ☐ I am enclosing an additional donation of \$ \_\_\_\_\_

## PLEASE SIGN

Signature Date

If you prefer to use VISA or MasterCard simply fill in the following:

Account # Expiry Date

Want to renew your membership online? Go to epilepsynl.com, click on 'Donate to ENL' which links to our Canada Helps page.  
In the drop down list for fund-designation, select Membership.

(Under privacy preferences, please allow your name and information to be sent to us or we will have no idea who sent the membership)