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Epilepsy News is
printed quarterly by:

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Labrador**

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Winter 2017

Celebrating Purple Day 2017

Once again, Purple Day was a huge success. We are very proud of the events, participation and fundraising initiatives that occurred throughout the month of March.

Because March 26 fell on a Sunday, we mainly celebrated on Friday, March 24 making it easier to access more people and bring awareness to more areas.

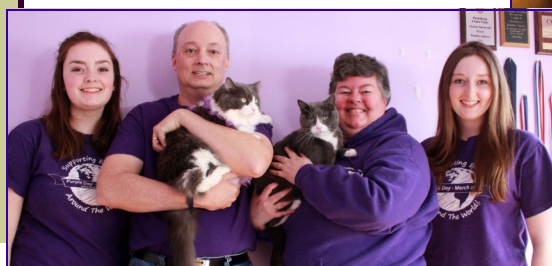
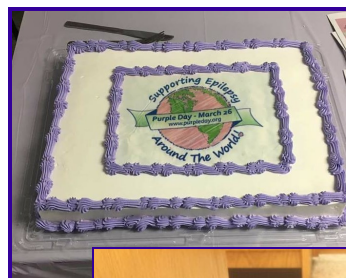
Many people celebrated Purple Day throughout the month. Day Cares Bunny Hopped; Schools booked presentations, learned about epilepsy and wore Purple. Businesses took this opportunity to hold events in so many different ways. It was great to see Purple Day being enjoyed by so many people all over this province.

Towns across Newfoundland and Labrador signed Purple Day proclamations. MPs and MHAs signed a Purple Day commitment dedicated to spreading awareness on social media and government officials spoke about Epilepsy at the House of

Assembly and showed their appreciation to ENL.

We want to extend our sincerest appreciation to all the volunteers who helped make this day a success and took their own personal time to spread awareness about epilepsy.

Every year Purple Day is more successful than the last, with more schools dressed up, more towns signing proclamation, more people getting involved. It's such an honour to be a part of a fun and meaningful celebration. Here at ENL we look forward to working with everyone again next year!



Purple Day Ambassador

The 2017 Purple Day Ambassador was Deidre Skinner. Deidre is from Grand -Falls Windsor and attends Exploits Valley High, where she helped spread awareness about the neurological disorder.

"I am excited to be a part of Purple Day because it is a prime opportunity to educate others about seizure disorders and how they can support those living with it," said the Ambassador to The Herald. Deidre was diagnosed with a brain tumor in 2010 and immediately had to start taking anti-seizure medication. She underwent surgery a week after the tumor was discovered. Once the tumor was removed, it was diagnosed as benign and Deidre returned to school and figure skating.

She was seizure free for eight months until they started up again. Over the next five years Deidre tried different medications to try and get her seizures under control. After many tests, it was determined she was a candidate for surgery. In 2015, Deidre had a Right Temporal Lobectomy at the Toronto SickKids Hospital.

"Despite the challenges, I refused to let my seizures interfere with my activities, my school work, or skating. I always tried to persevere despite the obstacles," said Deidre. "I had to continue to take seizure medication and will continue to do so for a while but I am happy to say that I have been seizure free ever since the second brain surgery"

Since the initial diagnosis, Deidre has achieved numerous awards through skating, as well as many academic successes.

"One thing I've learned though this entire experience is not to give up and always believe in yourself. There were times during my journey when it would have been easier for me to give up on everything, but I always believed I was capable of accomplishing anything I set my mind to. I kept fighting and I proved to myself that anything is possible," said the figure skater.

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Gail Dempsey

Medical Consultant

Dr. A.O. Ogunyemi, M.D., FRCP ©

Information Officer

Gina Hartmann



Meet JAC: we create

This year the team at JAC put in so much effort to celebrate Purple Day– they made it a week long event at the office.

They took to social media with the Don't Fear The Purple campaign and helped spread epilepsy awareness. Through graphics and videos, the social media accounts were filled with purple coloured facts about epilepsy and how others could help.

Everyone on the JAC team was put to the test with their swear jar. Every time someone swore, money went to the jar and team member Faith was responsible for record keeping. JAC decided it would match contributions to the swear jar at the end of the week. The office held a bake sale and JAC matched the contributions from that as well. As a marketing agency, they had plenty of ideas on how to get the word out and how to help raise funds in support of Purple Day.

On March 24th, the team arrived to ENL's thrift store , Previously Loved Clothes and Things with loads of filled bags after they ran a clothing drive. They stayed for a Facebook Live feed video, helping the public understand about Epilepsy, the operations at the Thrift Store and how everyone could help out.

"We are thrilled that JAC would donate their time and resources to come and help us educate about epilepsy because epilepsy is a big issue here in Newfoundland. There are approximately 10, 000 men, women and children living with epilepsy and Epilepsy Newfoundland and Labrador is the only association in the province that supplies programs and services," said executive director, Gail Dempsey on the Live video.

John and Pat Atkins are the owners of JAC and they have been participating in Purple Day for many years.

"As many of you know our daughter (Faith) has epilepsy. She had it since she was about three. We have been doing this every year for awhile now and it's very close to our heart. I think it's important to understand this condition. There are a lot misconceptions about it," said John in the live feed.

One March 26th, Jeep Girls NL and Crawl the Rock jeep groups organized a Purple Day Jeep Run with John and Pat's help, and all proceeds were added to JAC's ENL donation. All the efforts brought in over \$800 in donations.

Epilepsy Newfoundland and Labrador would like to thank everyone at JAC for all their efforts and the Don't Fear the Purple Campaign for all their hard work and time.



Left: John, Faith and Pat at the Clothing Drive
Centre: Team JAC at the Clothing Drive
Right: Gina receiving a donation from Faith, Pat and John on behalf of JAC, Jeep Girls NL and Crawl the Rock



Membership Cards

Epilepsy Newfoundland and Labrador offers an annual membership with our association. We invite you to become a member of Epilepsy Newfoundland and Labrador. By becoming a member you gain access to a wide range of benefits, services and information such as:

- Access to support programs and advocacy services
- Invitations to special events, teleconferences and information sessions on various social and medical aspects of epilepsy
- Quarterly Newsletter
- Three Scholarships exclusively available to members
- Support: Strength comes in numbers. The more members we have the more support ENL will receive for research, proposals etc.
- Voting privileges at the Annual General Meeting
- Notification of changes in seizure medications or treatments that matter to you

If you currently own a membership, now is the time to renew! Memberships run out at the end of May. If epilepsy is important to you and you want to make it important to others, please apply.

To apply for membership, you can contact us and we'll mail you a form (one is attached to the end of this newsletter) . You can give us a call 709-722-0502 and pay over the phone, or contact us about an online payment. Membership forms may be mailed to:

351 Kenmount Road
St. John's, NL
A1B 3P9

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 to save on postage. You can also submit your form online (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

Towns Across the Province sign the Proclamation



Mayor Dennis O'Keefe of St. John's with Gina Hartmann



Mayor Dan Bobbett of Paradise with Gina Hartmann



Kippens: Miss Teen NL Jessica Skinner, ENL Board Member Pauline Duffy, Deputy Mayor Debbie Brake-Patten, MHA John Finn and Lenny Hann, Town Manager



Mayor Barry Manuel of Grand Falls-Windsor with Purple Day Ambassador Deidre Skinner



Board Member of ENL Tim Spicer with Mayor of Pasadena, Otto Golding



Mayor Claude Elliott of Gander with ENL Member Marie Matheson



With Mayor Ralph Tapper of Torbay and Councillor Craig Scott



With the Deputy Mayor of Mount Pearl, Jim Locke

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 re-

sponsibility 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.

Purple Day Around the Province: A Few Highlights

Many people celebrated Purple Day in so many ways and it was so exciting to see the different approaches to help bring awareness to Epilepsy.



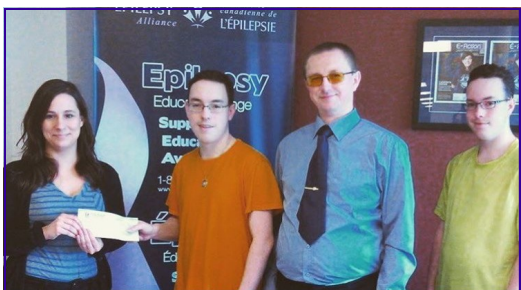
Every year Evan Newhook of Dildo designs an Epilepsy bookmark and sells it with proceeds going to ENL. He was the 2015 Purple Day Ambassador and his ambitions and passion have remained consistent ever since. He spread awareness in his school and throughout his community. This year he designed a postcard and his efforts raised over \$600. Evan's family runs Active Printing located in Dildo, which helped design and print our Purple Day t-shirts with all proceeds going to ENL. Thank you to Evan and the Newhooks for all your efforts.

"Light it up Purple!" was one of our themes this Purple Day. We wanted to see the province glowing Purple during the month of March. The St. John's City Hall, The Confederation Building, Signal Hill and the Sir Richard Squires Building were all lit up making it Purple from Coast to Coast.



Christine Facey was the 2016 Purple Day Ambassador. This year she celebrated Purple Day at two of her job locations and came up with a very different idea to help bring awareness to Epilepsy. For every signature she received, Christine donated a dollar to ENL!

ENL has been hosting the Ask the Doctors Forum for over a decade now and it is one of our very favourite parts of Epilepsy Awareness Month. We want to thank Dr. Ogunyemi and Dr. Buckley for taking time out of their busy schedule to answer many questions and share new knowledge with all of us.



The Kavanaghs always participate in Purple Day and March Awareness celebrations, and they always tend to try something different to help fundraise every year. This year Leanne (not pictured) made purple baskets, epilepsy candles and collected hand made gifts, including paintings, to sell with all proceeds going to ENL. This year they raised \$250!

Purple Day Commitment

We ask MHAs, MPs and St. John's City Council to sign a Purple Day Commitment. This commitment simply asked them to wear purple and take advantage of their social media presence to spread awareness about epilepsy. This year we had such a great response, almost all government officials signed the Purple Day Commitment and participated in the celebrations. Thank you to everyone who joined us on March 24th!

Gail Dempsey and Gina Hartmann were invited to the House of Assembly to hear statements about Epilepsy and ENL.

"Purple Day plays a big part in helping to further our understanding about epilepsy, reduce stigma and improve the quality of life for people living with epilepsy"

**The Honourable
Dr. Haggie**

Minister of Health and
Community Services



"I'm delighted to stand today and wish congratulations to Epilepsy Newfoundland and Labrador for their work in dispelling the myths about epilepsy"

**The Honourable Lorraine
Michael**

"While we recognize Purple Day let us also recognize those who support the epilepsy community in our province. The association is funded by donations, 100 per cent of which remain in the province to help develop programs and services dedicated to the promotion of independence and the quality of life for all people with epilepsy and their families."

**The Honourable
Steve Kent**





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 1st - May 31st 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)

Epilepsy Research Backed by ENL Donation



Last year Epilepsy Newfoundland and Labrador donated \$25,000 to The Faculty of Medicine at Memorial University. That gift supported Dr. Matthew Parsons' research project "Understanding and preventing the dysregulation of excitatory neurotransmission in epilepsy." Below is a brief outline of the research prepared by Dr. Parsons.

The research aims to increase an understanding of the neurobiology of epilepsy by assessing the contribution of glutamate transporter dysfunction to seizure thresholds and the process of epileptogenesis. Glutamate is a neurotransmitter and it becomes a concern when there is too much glutamate which can cause problems, including uncontrollable brain activity.

Glutamate levels have reported to be elevated after a seizure, but the reason for this increase is unknown.

"When glutamate levels are abnormally high, then neural tissue becomes overexcited, thereby increasing the chances of evoking synchronized and repetitive activity characteristics of a seizures," said Dr. Parsons on the progress date report."

"The funding has permitted us to establish the first 'slice' experimental model of temporal lobe epilepsy at Memorial University. We attempted a variety of different approaches used in the scientific literature, and found one particular experimental model (4-AP) produces the most consistent results in our hands," he continued.

"Over the next few months, we will be focusing our efforts on evoking different patterns of synchronous neural activity, as well as 4-AP induced seizures, and quantifying the resultant long-term effects on glutamate levels," said Dr. Parsons.

"Although we are only a few months into this project, the funding provided by Epilepsy NL has allowed me to accept a new local graduate student into the program to lead this project. Additional funds are being used to pay for the costs of animals, chemicals, and other supplies related to the project. We are already extremely excited by our success in establishing Memorial's first experimental model of temporal lobe epilepsy, and we look forward to the information that we can extract from this model in the future regarding the cellular mechanisms underlying epilepsy," said the doctor.

"I believe that the \$25,000 put towards this project will have a lasting impact long after the termination of this particular project, as I am now eager to continue to use epilepsy as a disease model in my lab throughout my career. I am truly grateful for this opportunity, and know that this would not have been possible without funding from Epilepsy NL."

(In above picture (L—R) Patti Bryant (VP of ENL, Dr. Parsons, Gail Dempsey ED of ENL and Ron Stone, President of ENL)