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Epilepsy News is
printed quarterly by:

**Epilepsy
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Labrador**

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March: Epilepsy Awareness Month

Here at Epilepsy Newfoundland and Labrador we are excited to be preparing for March 26th Purple Day. This March we want to paint the province purple, and we need your help. We welcome all members to help raise epilepsy awareness at their work of-fices, children's classrooms and community centres, Schools can wear purple, have a Positively Purple bake sale, learn about Epilepsy First Aid and more. Businesses can pledge to wear purple, and hold an event, and day cares can participate in our Bunny Hop. We have posters, tattoos, information pamphlets and ribbons for your event, to help make your corner of the island merry and purple.

Join us and the many people around the world who are helping end stigma associated with epilepsy by giving a better understanding of this neurological disorder. Bring on the purple and be as creative as you can! Throughout the day, we share stories on social media and our web-site, don't forget to share your Purple Day online using #PurpleDay2018, #EpilepsyNL!

Contact Sarah at info@epilepsynl.com to participate!



Welcome to 2018

On behalf of the board and staff of Epilepsy Newfoundland and Labrador we would like to wish all our members a very healthy and happy New Year.

We are very happy to say 2017 was a successful year. In the upcoming year, we look forward to continuing to offer our members and the people of Newfoundland and Labrador our services.

If you or anyone you know, would like to learn more about Epilepsy in the upcoming year or would like to be a part of March Epilepsy Awareness month in any capacity, please contact us: info@epilepsynl.com or call 709-722-0502.

We are happy to offer information sessions and information packages free of charge— as well as many other programs and services.



Epilepsy NL Scholarships

Zach Rowe Memorial Scholarship

Each Year, Epilepsy Newfoundland and Labrador offers three annual scholarships valued at \$1000 each.

The Zach Rowe Memorial Scholarship is awarded to a student living with epilepsy who is currently in, or about to enter, their first year of post-secondary studies. The scholarship honours Zach Rowe, who passed away as a result of seizures in 2009.

This year, ENL was happy to present the Zach Rowe Memorial Scholarship to Deidre Skinner. Deidre was the Purple Day Ambassador in 2017 and she is studying Kinesiology at Memorial University of Newfoundland in St. John's. Joan Parsons, Zach Rowe's grandmother, and her family, along with ENL, would like to extend a big congratulations to Deidre and wish her the best of luck in future endeavours.



Executive Director, Gail Dempsey presents Deidre with the Zach Rowe Memorial Scholarship.

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The Epilepsy NL Family Scholarship



President Ron Stone presents Sara with the ENL Family Scholarship.

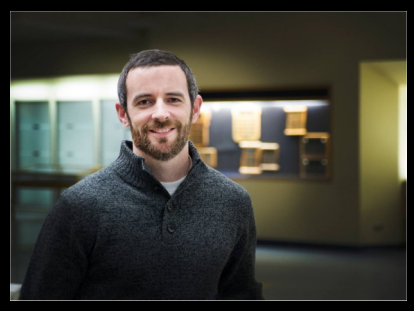
At ENL we recognize that epilepsy not only affects the individual diagnosed, but also has an impact on the families living with epilepsy.

The Epilepsy NL scholarship is awarded to a student who has a family member diagnosed with epilepsy, and is currently in, or about to enter, their first year of post-secondary studies.

This year the scholarship was awarded to Sara George, who's father has epilepsy. Sara is attending her first year of studies at St. Francis Xavier University, and is working towards a Bachelor of Arts & Science in Health, with the hopes of attending medical school. We extend our congratulations to Sara and wish her the best of luck in all future endeavours!

Epilepsy Research

Epilepsy Newfoundland and Labrador is delighted to be contributing to the research of Dr. Matthew Parsons. Donations have had, and will continue to have, a tremendous impact on epilepsy research at Memorial University. As per Dr. Parsons “These generous donations mean we can investigate why a single seizure increases the risk of subsequent seizures, helping those that suffer from epilepsy.”



Dr. Matthew Parsons

Patti Bryant, ENL Vice-President says: “With my daughter’s type of epilepsy, clusters of seizures is a real problem and can lead to death. We’re hoping that Dr. Parson’s research will help make the livelihood of clusters less. Keeping more children alive.”



Patti Bryant with daughter Marybeth

Why is Your Pumpkin Purple?

On October 25th, Epilepsy NL celebrated Halloween with Corner Brook Regional High. A student at the school is living with epilepsy and got in touch with ENL to organize a Purple Pumpkin Decorating Halloween fundraiser. Students and staff could pay a loonie to decorate a paper pumpkin or a toonie to decorate a real pumpkin. Decorating the pumpkins in the internationally recognized colour for epilepsy, and posing the question “Why is your pumpkin purple?” got many staff and students involved and opened the door for discussion around epilepsy, greatly raising awareness.

We want to thank all students and staff at Corner Brook Regional High for their support. Next Halloween, why not have a purple pumpkin party of your own?

Don’t forget to ask: “Why is your pumpkin purple?”



Friends and Family Campaign

March is Epilepsy Awareness Month and we will be continuing our Friends and Family Campaign.

What used to be known as our Door to Door Campaign, now encourages many to simply fundraise by asking their Friends and Family for a donation. This allows everyone to help out in their own way.

We would like to take this opportunity to thank all of our past participants for your dedication and support. 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.

If you would like to pick up a kit and collect donations from your Friends and Family, or canvass door to door in your area, please contact Elaine at 709-722-0502 or 1-866– EPILEPSY.



Canadian Epilepsy Alliance 20th Anniversary

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www.epilepsymatters.com
Charitable Registration Number
88753 6522 RR0001

MEMBERS:

BC Epilepsy Society

Centre for Epilepsy and Seizure
Education in British Columbia

Victoria Epilepsy and Parkinson's
Centre

Edmonton Epilepsy Association

Epilepsy Association of Calgary

Epilepsy Durham Region

Epilepsy Niagara

Epilepsy Ontario

Epilepsy Ottawa

Epilepsy Peterborough and Area

Epilepsy Simcoe County

Epilepsy South Central Ontario

Epilepsy South Eastern Ontario

Epilepsy South Western Ontario

Epilepsy Toronto

Epilepsy York Region

Seizure & Brain Injury Centre

Association Épilepsie Abitibi
Temiscamingue

Association régionale pour les
personnes épileptiques (Région 02)

Épilepsie Gaspésie Sud

Épilepsie Mauricie Centre du
Québec

Épilepsie Montréal Métropolitain

Épilepsie Outaouais

Épilepsie Section de Québec

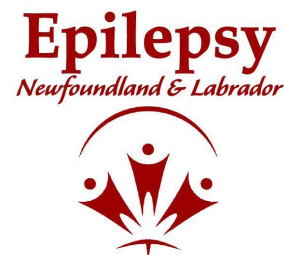
Épilepsie Montérégie

Epilepsy Association of Nova Scotia

Epilepsy Newfoundland and
Labrador

Epilepsy Newfoundland and Labrador is proud to be a member of the Canadian Epilepsy Alliance (CEA). This year the CEA celebrates its 20th anniversary, and Epilepsy Newfoundland and Labrador has been a part of the CEA since its inception in 1998!

We are celebrating 20 years of working together for the betterment of all Canadians living with epilepsy, and are happy to have received the following letter from Deirdre Floyd, President of the Canadian Epilepsy Alliance:



Dear Board of Directors,

As the Canadian Epilepsy Alliance/ Alliance canadienne de l'épilepsie marks its 20th Anniversary this year, I would like to extend my sincere thanks to your agency for your ongoing support and involvement as one of the twenty-seven local agencies that make up the CEA/ACE.

In the true spirit of the CEA/ACE, agencies from across Canada have contributed time and resources to make Canada a better place to live for persons with Epilepsy.

In 1998, Epilepsy Newfoundland and Labrador was one of the founding members of the CEA/ACE. Over the years your Executive Director, Gail Dempsey, has been an active participant in filling many roles on our national board including the role as CEA/ACE President. The CEA/ACE toll free 1-866-EPILEPSY Canada wide number set up by Gail Dempsey has helped all Canadians living with Epilepsy connect with the local CEA/ACE member agency.

Your ongoing support for CEA/ACE national initiatives over the past 20 years has truly made a difference to the lives of all Canadians living with epilepsy.

As we enter the next era our passion remains the same as we will continue to advocate and support all Canadians with Epilepsy.

Warmest regards,

Deirdre Floyd, President

Canadian Epilepsy Alliance/ Alliance canadienne de l'épilepsie

Canadian
epilepsy
Alliance

Alliance
canadienne de
l'épilepsie



2017 Christmas Campaign Thank You

Our 2017 Christmas LED Sign Campaign was a great success, and we want to thank all of those who participated this past year. Messages of holiday joy from local and surrounding businesses and supporters were displayed to the city on our bright LED sign outside our store, Previously Loved Clothes and Things. The messages helped spread holiday cheer to St. John's and surrounding area and showed support to our community who lives with epilepsy.

A big thank you to all participants, we look forward to lighting up your name in the future!



Calendar Campaign Thank You



We would like to give our many thanks to everyone who participated in our Calendar Campaign.

Each year, we put together a calendar with the help of grade four students from across the province.

The campaign was a huge success and we would like to extend our appreciation to businesses and individuals alike for your contributions. We look forward to continuing this campaign in 2018.

The following students had artwork featured in our calendar: Kenadie Butler of Arnold's Cove, Charlee Laite of Glenwood, Dakota Dicker of Nain, Courtney Guy of Arnold's Cove, Shaina Lynn Reid of Dildo, Josie Barnes of English Hr. West, Maya Murrin of St. John's, Kirsten Henoche of Nain, Chad Williams of Rigolet, Chloe Ryan of King's Cove, Brandon Power of Dildo, Don Brown of Pollard's Point, and Isabelle Palliser of Rigolet.

Previously Loved Clothes and Things



Located at 351 Kenmount Road in St. John's, Previously Loved Clothes and Things is a thrift store, owned and operated by Epilepsy Newfoundland since 1998! With clothing, footwear, furniture, books, cookware, collector's items and more there is something for everyone, and shopping at Previously Loved Clothes and Things helps provide services and resources to the more than 10,000 people living with epilepsy in Newfoundland and Labrador. Did we mention that because we are a charity you never pay tax, and 100% of the proceeds go directly back into ENL? Unique items, great prices and giving back to your community? It's a win-win! Do you have a donation to make? Drop it off to our store or call 709-722-5571 to arrange a pickup.

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.

Change in ENL Membership

As of February 7th, 2018 Epilepsy Newfoundland and Labrador will be offering membership free of charge. Upon May 31st, 2018 current members will be automatically renewed, without fee, and we will no longer be distributing membership cards.

Current members: Contact Sarah today with your current email address to ensure you don't miss out on important information, such as event invites, scholarship opportunities, Newsletters and more!

Know someone who'd like to become a member? Email info@epilepsynl.com to sign up for our mailing list and receive member information.

I would like to help in the fight against Epilepsy

☐ I have made a donation of \$_____

☐ 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.

You can also submit your form online (www.epilepsynl.com) and make a payment through the DONATE button.

Celebrate Purple Day with Epilepsy NL



Get your school involved

Are you or your family members attending school? Talk to a homeroom teacher or principal about making your school Positively Purple on March 26th. Upon registration we will send a Purple Day Package and publish your school's name on our website, to be shared Canada-wide by the Canadian Epilepsy Alliance!

Check in on Proclamations and Commitments

Is your town council signing the Proclamation? Contact your town council and ask them if they are being a part of the Proclamation. Ask your Town Hall if it is a possibility to Light it Up Purple for Epilepsy Awareness.

We are asking all MPs and MHAs to sign a Purple Day Commitment. Check in with your local representative to see if they are a part of this year's Purple Day!

Bunny Hop

Day Cares across the province celebrate Purple Day by learning about epilepsy and bunny hopping throughout the day! We have great packages for children's centres with temporary tattoos and there are prizes to send out to day cares afterwards. Ask your child's centre about joining in on the Bunny Hop on March 26th!

Ask The Doctors

Every year Epileptologist Dr. Ogunyemi and Pediatric Neurologist, Dr. Buckley join us for an Ask The Doctors Forum. Two Doctors are available for your questions. People can call in or come in person. The session will be at our offices at 351 Kenmount Road, near the end of March. Call us for more details 709-722-0502

Bring on the Purple

Get your work or community centre involved. Let organizations you are involved with know about Purple Day, wear Purple on March 26th and get some pictures of you all dressed up. Share your pictures on your social media and tag us, or email your pictures to us to share. You can make the event a fundraiser by asking everyone wearing Purple to bring in a dollar, having a Purple Bake Sale, or in many other creative ways unique to you. If you would like a Purple Day package for your festivities contact us at 709-722-0502 or info@epilepsynl.com

Check us out on Facebook: EpilepsyNL

Follow us on Twitter: [@epilepsynl](https://twitter.com/epilepsynl)

Purple Day T-Shirts and Pens

Get your one of a kind T-shirt, unique to Epilepsy Newfoundland and Labrador! Locally made with all proceeds going directly to our organization, ordering helps spread Epilepsy Awareness, and allows us to better serve the 10,000 people living with epilepsy in this province.

Shirt prices and sizing are as follows: Youth XS - Adult XL: \$12.00, Adult XXL: \$14.50, Adult 3XL - 5XL: \$16.00.

We offer pickup at our office or shipping, at a cost of \$5/shirt. To guarantee delivery by March 26th Purple Day, shipped orders must be placed by Feb. 28th.

One of a kind Purple Pens will be available to order for \$3 each, without a time limit.

T-shirts and pens can be ordered through email transfer or credit card, to order or for further information contact Sarah: info@epilepsynl.com or (709) 722-0502.

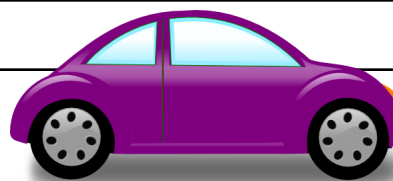
While quantities last!



Driving and Epilepsy

Article contributed to ENL by: by: Kelly Aminian, MSc and medical student at Memorial University of Newfoundland.

This research was conducted by: Kelly Aminian, MSc and medical student at Memorial University of Newfoundland; Jeanie Coombs, Medical Review Officer at Service NL; and Dr. Abayomi Ogunyemi, neurologist and epileptologist at the Faculty of Medicine, Memorial University of Newfoundland.



Driving is not for everyone, and people can lose their licenses for various reasons. For people with illnesses that cause persistent disability, like stroke or dementia, driving ability can be determined by a medical assessment. In the case of seizures or epilepsy however, this is not such an easy task because seizures occur episodically, with the person functioning normally between events. Estimation of driving safety relies on trying to predict the likelihood of a seizure happening again.

Studies have shown that the inability to drive can stigmatize people with epilepsy, limit job opportunities, and make people feel burdensome to family members. Nevertheless, regulation of drivers' licences in people experiencing seizures is important because there must be a balance between the driver's freedom and safety the of both the driver and the general public.

Driving restrictions vary widely between jurisdictions; however, a 6-month seizure-free interval is required in most Canadian provinces. Research surrounding driving safety in people with epilepsy is limited, and data from Newfoundland and Labrador were not previously analyzed. The Department of Motor Vehicles and Registration, a branch of Service NL, maintains health records for drivers with active licences who are reported to have seizures. In NL, doctors are required to report seizures to the Department of Motor Vehicles and Registration. We received ethics approval to look at data on seizures among drivers from 2010-2014 inclusively. We examined two age groups: drivers aged 16-24 years and those aged 75 and older.

5.4% of drivers had a motor vehicle collision attributed to a seizure during the 5-year study period. This number may be higher, however, since unwitnessed events are hard to attribute to seizures. The overall collision rate among drivers for that period is not known, but it would be interesting to compare to our study group, and may be studied in the future.

36.1% of the people in our study did not have a mandatory report filed after a first seizure. This is a measure of something referred to as 'driving disobedience'. Our rates of driving disobedience are among the highest reported in published studies. There are several reasons that might explain this. Whereas most studies rely on self-report data from patients who may be hesitant to admit driving disobedience, our study instead did a review of Service NL documents. Patients and doctors may be unaware of the laws surrounding seizures and driving. Patients can also be unaware that they had a seizure, leading to decreased reporting.

We looked at seizure type as well. This was broadly classified into focal-onset seizures which start in a specific part of the brain, and general-onset seizures which affect multiple areas at once. We thought that patients would be more likely to recognize general-onset seizures, and expected that these would be reported more frequently. However, there was no difference between reporting of these two seizure types, and there was also no difference in collision rates.

We wanted to do this research to help understand driving safety in people with epilepsy, rates of driving disobedience, and how laws around mandatory reporting might affect the two. Future research could explore other age groups and surveys to understand patient and physician awareness of current legislation.

Individualized Funding

During the week of October 23rd 2017, Epilepsy Newfoundland and Labrador participated in a series of workshops, information sessions and seminars offered by the NLACL and the COD-NL. The sessions featured guest speaker Dr. Leighton Jay, a global disability expert and advocate for the rights of persons living with disabilities.

The sessions included a workshop on Individualized Funding, a change in the distribution of disability support funds slated to come into effect in NL in 2018. As proposed, an individual would have the option of applying for individualized funding, a method of distributing funds that is intended to offer more choice to a person with regards to which services they receive and whom is providing the services.

An individualized plan would be set up with a designated planner, preferably independent of the program funder. The benefits highlighted during the seminar were that in the case of individualized funding an individual receiving disability supports would now have one point of contact, the ability to choose who is providing them with services, including highly personal services and care, and the ability to receive services that will support them in living the life they choose. The Individualized Funding plan aims towards a goal of available supports fitting an individual person, not the person fitting into what supports they qualify for.