

Epilepsy News

Winter 2020

Special points of interest:

- Purple Day 2020
- Purple Day Ambassador 2020
- Scholarship Winners
- How to Participate in Purple Day
- Friends and Family Campaign
- Living With Epilepsy
- Asked and Answered

Purple Day 2020

Purple Day 2020 is fast approaching, and we are busy preparing here at Epilepsy Newfoundland and Labrador. Purple Day, the International Day of Epilepsy Awareness, is celebrated globally each year on March 26th. People all around the world organize events, share accurate epilepsy information via social media, post purple selfies, and more, all in the name of raising Epilepsy Awareness.

Here in Newfoundland and Labrador we have a huge community of people who celebrate Purple Day, from all corners of the province. Last year we had supporters organize bake sales, facilitate t-shirt sales, arrange Epilepsy Education sessions, hold fundraisers of all kinds, and most importantly, contribute to raising awareness of epilepsy in our province of Newfoundland and Labrador.

Purple Day is an extremely special day, not only because it is the International Day of Epilepsy Awareness, but also because it gives those who live with epilepsy and those whose lives are impacted by epilepsy a way to bring awareness to their communities

in a way that is meaningful to them. It provides a chance for those who live with seizures every day to know that they are supported. It gives the more than 10,000 people living with epilepsy in Newfoundland and Labrador a voice.

We have some great things in the works for Purple Day this year, will you celebrate with us?



Epilepsy Newfoundland
and Labrador

March 26

Purple
Day

2020

Let's help raise awareness:
www.epilepsynl.com

Contact us at
info@epilepsynl.com / 722-0502
to chat about arranging a Purple Day event, request a Purple Pack (including ribbons, temporary tattoos and pamphlets) or if you have questions about epilepsy.

Purple Day Ambassador 2020: Pauline Duffy

Epilepsy Newfoundland and Labrador is proud to present our 2020 Purple Day Ambassador, Pauline Duffy. Pauline has been a tireless advocate for epilepsy awareness, and has previously served on the board of Epilepsy Newfoundland and Labrador for a grand total of 24 years! Her efforts to educate about epilepsy in Newfoundland

and Labrador have been consistent and powerful, and we are so thrilled to be working with Pauline once again as the Purple Day 2020 Ambassador.

Check out page 4 and 5 for Pauline's story.

Pauline thank you for your dedication!

INTRODUCING EPILEPSY NEWFOUNDLAND AND LABRADOR'S 2020

PURPLE DAY AMBASSADOR

WHAT IS A PURPLE DAY AMBASSADOR?

A Purple Day Ambassador is someone who helps raise Epilepsy Awareness and celebrates Purple Day in their area. A Purple Day Ambassador shares their story to let others know they are not alone. A Purple Day Ambassador inspires. Meet Epilepsy Newfoundland and Labrador's 2020 Purple Day Ambassador:



PAULINE DUFFY
STEPHENVILLE, NL.

"I MAY HAVE TO WORK A LITTLE HARDER, BUT EVERY FIGHT MAKES ME STRONGER."

Scholarship Winners 2020

Epilepsy NL Family Scholarship



Our sincerest congratulations to Kiley Hinchey, from Gander, who was awarded the \$1000 Epilepsy NL Family Scholarship at our Annual Christmas Gathering. Kiley is currently completing her first year of studies at Memorial University of Newfoundland in the hopes of pursuing a PhD in English. We wish you all the best in your endeavors!

Pictured: Kiley Hinchey receiving her award from ENL Board Member Bill Westcott.

Zach Rowe Memorial Scholarship

Epilepsy Newfoundland and Labrador was delighted to award two winners of the Zach Rowe Memorial Scholarship this year. We would like to offer a big congratulations to Christopher Edwards of Outer Cove, who was awarded a \$1000 Zach Rowe Memorial Scholarship at our Annual Christmas Gathering. This is Chris's first year attending Memorial University of Newfoundland with the goal of pursuing a Kinesiology degree.

Pictured: Chris Edwards receiving his award from ENL Board Member Bill Westcott.



Congratulations to Blake Rumbolt, winner of a 2019 Zach Rowe Memorial Scholarship! Blake has volunteered for Epilepsy NL in his community of Mary's Harbour, and has done fantastic work as an epilepsy advocate. Blake is currently attending Memorial University of Newfoundland with the goal of pursuing Chemical Process Engineering.

Pictured: Blake Rumbolt receiving his award from Information Officer Sarah Mercer.

Jim Hierlihy Memorial Scholarship

Congratulations to Jodi Loder, winner of the one thousand dollar 2019 Jim Hierlihy Scholarship. Jodi is studying at the College of the North Atlantic Happy Valley—Goose Bay campus in the Personal Care Attendant program. We wish you all the best in your future endeavors.

Pictured: Jodi receiving her award from Craig Baker, Senior Campus Director, CNA



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Sarah Mercer

Purple Day 2020: Get Involved!

Wondering how you can get involved in Purple Day 2020? Check it out!

Get your school involved: Are you or your family members attending school? Talk to a teacher, guidance counselor or principal about making your school a Purple Day School on March 26th. Once your school is on board contact us and we will send along some supplies. Primary, elementary, secondary, post-secondary, all schools are welcome to participate!

Join the Purple Day Bunny Hop: Day Cares across the province celebrate Purple Day by learning about epilepsy, dressing in Purple and bunny hopping throughout the day. Ask your child's centre about joining the fun on March 26th. We will send Bunny Hop packages to registered children's centres, including temporary tattoos, epilepsy story book and colouring sheets.

Get your work involved: Organize a Purple Day event or fundraiser that speaks to you to join in raising Epilepsy Awareness at work. Ideas include a Purple Bake Sale, Wacky Purple Accessory Day or Purple Sock Party (everyone donates a loonie or toonie to wear purple socks-be sure to get a photo!) We will post pictures online and on Social Media throughout the week.

Attend 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. This session will be broadcast live on Facebook Live or you can attend in person. The session will be at our offices @ 351 Kenmount Road on March 24 from 7pm—9 pm. Call us for more details 709-722-0502. Don't miss out on this amazing opportunity to get your questions answered.

Buy a T-Shirt or Pen: We have Purple Day Pens for \$2 and Purple Day T-Shirts for \$12.00. Show your Purple colours this March with a pen or t-shirt with all proceeds going to ENL! *shipping costs will apply



Volunteer: Want to participate in Purple Day in another way? Contact Sarah at info@epilepsynl.com / 709-722-0502 to chat about it! Great options are volunteering to share Epilepsy NL's Epilepsy Awareness posts on Twitter and/or Facebook, volunteering to host a bake sale at your school/workplace, volunteering to help distribute Epilepsy Awareness packages in the St. John's and surrounding areas, or another idea that speaks to you!

Purple Day Proclamation: Cities and towns all around the province also participate in Purple Day by signing the Purple Day Proclamation. Pictured left is The Honourable John Haggie, Minister of Health and Community Services, signing the 2020 Purple Day Proclamation with Previously Loved Clothes and Things long time volunteer Brian Lee. Brian has been volunteering with us for 17 years! Thank you Minister

Haggie for your ongoing support of Epilepsy Awareness in Newfoundland and Labrador, and thank you Brian for your dedication to the team! Keep an eye out on our social media for towns and cities that have signed the Purple Day Proclamation this year.

Friends and Family Campaign 2020

Our Friends and Family Campaign is in full swing! Epilepsy Newfoundland and Labrador would like to take this opportunity to thank all of our past and present participants of this campaign for your dedication and support. This campaign would not be a success without our volunteers generously donating their time and energy. Thank you for all of your hard work! Canvassing kits are available now, and

our campaign is an excellent way for high school students to gain career and volunteer hours. 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, or would like more information, please contact our Fundraising Coordinator Elaine (Pictured right) at 709-722-0502 or 1-866-EPILEPSY.





Epilepsy Newfoundland and Labrador

**PURPLE DAY
AMBASSADOR 2020**

Pauline Duffy

I always had seizures, but I was not aware of them until they generalized. I would have strange “feelings” moving from the pit of my stomach to my head. I asked about it as a child, and was reassured that all had these feelings. I could still speak, so I believed it. When I turned 15, these “feelings” in the pit of my stomach intensified at times. I was still aware through most of them, but now they could generalize. I would often end up on the floor or wandering around like a sleepwalker.

I didn’t understand what was happening and neither did doctors. Epilepsy was suspected, but no irregular brain activity showed on EEGs. Another neurologist overheard my case and wanted to prove they were seizures with a sleep-deprived EEG. I seized on the table that day. It would be another decade before specialists would be able to connect my hormones to seizures (Catamenial epilepsy).

When I went to university, the seizures changed again. I noticed that about 5 days before my cycle, I would have a bout of these episodes at once that would often generalize. The number of generalized seizures increased and I began to grow scared. Although I finished my French/Linguistics degrees, I stopped there. I was trying to get better understanding of my body/seizures before doing more.

My epileptologist asked my boyfriend and I if we'd ever considered having children. I was shocked because I didn't think I 'could' have children. I was taking multiple seizure medications.

I discovered I was expecting shortly afterward. I still was unsure if I could have the child. Epilepsy NL helped support me by sending me to a conference in Toronto concerning Women and Epilepsy. I learned more about motherhood from other mothers with Epilepsy. I gained a lot of strength.

I needed a respite worker when my husband was away working. I also learned about the importance of family support when social workers in Clarendville refused to meet with me. I moved our family to Stephenville where my family was in case I needed any support. Social workers in Stephenville did meet with me there and I was able to get needed respite assistance. I still took care of my infants on the floor in case I did have an unexpected seizure.

My youngest is getting ready to graduate from High School this year. My oldest is living in St. John's. They're very informed about various types of seizures because they've lived with me.

One of my goals will always be to educate myself and others about seizures and how different they are. The more I have learned about seizures and my own body, the better I've been able to control them.

Seizures can always change, and people should know that. Mine have gradually improved. I did do an Education certificate about ten years ago, but I am still tempted to complete the degree.

Something Epilepsy has taught me is that I may have to work a little harder, but every fight makes me stronger.

Epilepsy NL Membership

We invite you to become a member of Epilepsy Newfoundland and Labrador. **Membership is free of charge.** 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 epilepsy is important to you and you want to make it important to others, please apply for membership by emailing info@epilepsynl.com, calling (709) 722-0502/ 1-866-Epilepsy, or mailing in the form found below.

**Your
Membership
Matters**



I Would Like to Become a Member with ENL

Name:	Email:
Address:	
Phone:	Would you prefer email or postage?
Do you or a loved one have epilepsy?	What type of seizure/seizures are present?
Additional Comments and Suggestions: Are there any issues regarding epilepsy you would be interested in learning more about?	

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). If you would like to make a donation you can donate through our website by visiting epilepsynl.com and clicking the DONATE button.

Living with Intractable Epilepsy

Living with epilepsy is like a dream. A surreal dream. Each new day, I can't help but wonder if everything that's happened to me is all true. I have refractory epilepsy (also known as uncontrolled or intractable epilepsy). It is difficult to control this form of epilepsy with medication. Each person with refractory epilepsy goes through their own unique ordeal. For me, every day, I experience absence seizures, which last a few seconds and cause a lack of awareness that looks like I'm "blanking out," and complex partial seizures (also called focal impaired awareness seizures), which cause involuntary movements in addition to the lack of awareness. My seizures are usually accompanied by blurred vision, and other times there are also problems with speech, sometimes preventing me from performing ordinary tasks such as walking or speaking properly.

Occasionally, I experience seizures that causes an aura such as an awkward odor like burning wires or soap; other times, I will black out and awaken to a massive headache and have to be told what happened. These types of seizures tend to be an exhausting occurrence and it takes me an entire day or two of recovery to fully recharge.

When I was diagnosed with epilepsy, I had no idea the extent it would impact my life. In order to ensure my safety, I could no longer

drive myself to and from where I wanted and needed to go. Due to the amount of seizures I continued to have, I could no longer work a job outside the home. I discovered that caffeinated foods and beverages aggravated my seizure activity so I had to refrain. To sum it all up, I had to restructure my life for the betterment of my health.

One example of how I've done this is accepting that I now need assistance to do the simplest of tasks, for example driving, cooking, or at times showering, since it is not uncommon for a seizure to occur even then. I need my husband, a family member or friend to be there with me, and sometimes take over for me as I complete these tasks in order to protect me from harm if I have a seizure. Holding sharp objects like knives when I cook dinner is a risk. And I need to be a passenger rather than a driver, which took me a while to emotionally come to terms with because I felt as though a chunk of my independence had been stolen away. There are good days and bad days — some days I have more seizures, some days I have less, some days I can get away with no seizures at all; however, I chose not to take any chances and allowed help into my life.

Rather than shut down and give up, I decided to fight back. I visited websites, reached out to others who are affected by epilepsy

(patients, family members, friends and caregivers) on social media, and had extensive conversations with my doctor. This motivated me to research my epilepsy and learn how to live the best life I could with this condition. Though determined, I also felt somewhat like a hindrance to my spouse and family, who so lovingly stood by my side and went out of their way to help me throughout the tireless process to halt my seizures. I was comforted to hear them say that being a hindrance to them was absolutely not true and they would go to the ends of the Earth to help me rid this "unwelcome guest" from my life.

Still, to this day, after undergoing several tests, medication changes and adjustments, my seizures persist. Every single day. Epilepsy may be difficult to control. Some people with this form of epilepsy do indeed find the right combination of medication that works for them. Some find the right therapy, such as brain surgery, vagus nerve stimulation, responsive neurostimulation, medical cannabis, the ketogenic diet, etc. I am not a candidate for brain surgery; however, I do have the other options listed above that I can try. There is hope yet. I hope that this helps other people living with epilepsy. Give it all that you've got and don't ever give up.

Via themighty.com

"I hope that this helps other people living with epilepsy. Give it all that you've got."

"When I was diagnosed with epilepsy, I had no idea the extent it would impact my life."

**EPILEPSY
NEWFOUNDLAND
AND LABRADOR**

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Fax: 709-722-0999
E-mail: info@epilepsynl.com

www.epilepsynl.com



Asked and Answered

Question: Can a person with epilepsy drive?

Answer: If a person's seizures are uncontrolled, then driving is restricted. If epilepsy has been diagnosed, driving is generally not allowed until a person has been seizure free for at least 6-12 months and the person is under a doctor's care. There are provincial and territorial differences in regulations. Drivers are also required by law to report any health problems such as epilepsy that would interfere with driving to the appropriate provincial or territorial regulatory agency.

Via Epilepsy Education Series

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At Previously Loved Clothes and Things thrift store you never pay sales tax. Because we are a charity, 100% of the proceeds from the sales at our store stay right here in the province and go directly back into the community through the programs and services of Epilepsy Newfoundland and Labrador.

Previously Loved Clothes & Things is a social enterprise owned and operated by Epilepsy Newfoundland and Labrador, and has been successfully contributing to our community since 1998.



 @PLCAT @EPILEPSYNL  @EPILEPSYNL WWW.EPILEPSYNL.COM

Ask the Doctors

Dr. A. Ogunyemi, Epileptologist
Dr. D. Buckley, Pediatric Neurologist

ANSWER YOUR QUESTIONS ON EPILEPSY.

Epilepsy Newfoundland and Labrador Offices
351 Kenmount Road

Event is free, space is limited!

RSVP by March 20 to info@epilepsynl.com / 722-0502

Tuesday
March 24
7 pm - 9 pm

