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Purple Day Ambassador 2022:

Epilepsy Newfoundland and Labrador is proud to present our 2022 Purple Day Ambassador, Billie Jean Colbourne of Gander, Newfoundland and Labrador.

Billie Jean has been a tireless advocate for epilepsy awareness, and has contributed to research and advocacy. Her efforts to educate about epilepsy in Newfoundland and Labrador have been powerful, personal and persistent.

We are so thrilled to be working with Billie Jean as the Purple Day 2022 Ambassador.

Check out page 2 and 3 for Billie Jean's story.

Billie Jean, thank you for your dedication to raising epilepsy awareness in Newfoundland and Labrador.

Epilepsy Newfoundland and Labrador Purple Day Ambassador 2022

What is a Purple Day Ambassador?

A Purple Day Ambassador is someone who helps raise Epilepsy Awareness and celebrates Purple Day in their area. They share their story to let others know they are not alone. They inspire others. Meet Epilepsy Newfoundland and Labrador's Purple Day Ambassador 2022:

Billie Jean Colbourne
Gander, NL



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



Purple Day 2022 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? 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.

Epilepsy Newfoundland and Labrador's Purple Day Ambassador 2022:

Board of Directors

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Ron Stone
(Mt. Pearl)

Secretary

Patsy Lush
(Corner Brook)

Treasurer

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(St. John's)

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(Stephenville)

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(Happy Valley-Goose Bay)

Pauline Duffy
(Stephenville)

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(St. John's)

Executive Director

Gail Dempsey

Medical Consultant

Dr. A.O. Ogunyemi, M.D., FRCP ©

Information Officer

Alicia Legge

My name is Billie Jean Bull-Colbourne. I was born and raised in Happy Valley-Goose Bay, Labrador and I now reside in Gander. Growing up I had never heard of epilepsy or the term seizures. I often heard stories of my paternal Grandmother having "fits" but never knew what that was.

After I was married, I moved to the Island of Newfoundland and met my biological father. He has epilepsy and I was introduced to a whole new world.

I spent many years watching my father have seizures. Many times being called by hospital staff and summoned to the hospital because "he may not make it through the night". These were scary times. And many times I thought "Thank God I don't have to put my family through this." I still thought that Epilepsy was something you developed as a child and sometimes you grew out of it and sometimes you didn't. Little did I know how my life would change.

In May of 2020, just after the Covid Pandemic began, I was the Assistant Manager of a large retail store in Gander. My manager was leaving, and as many stores were closed, and ours was considered essential, we were even busier than normal. My stress level doubled and that's when the confusion and missing time started. I had no idea what was happening to me. My doctor thought maybe it was my heart, as I have a history of a mild heart condition, so he told me to start monitoring my heart rate during these episodes. Well, during these episodes, I would black out, making this impossible.

When I finally had a day off after working 60- 70 hours a week, pretty much every week, my husband started noticing "blank" looks on my face, and he decided to check my pulse and blood pressure. All of that was fine. When I would become aware again, I did not know what happened and I always felt very tired.

My family doctor felt it was time to send me to a neurologist. So in July 2020 off to Grand Falls I went for an appointment with the local neurologist. He sent me for an CT, MRI as well as an EEG. When he called me back to his office, he confirmed my worst fear. The EEG results showed I had abnormal activity in the left Temporal Lobe of my brain. He was also my father's neurologist and knew my family history. He started me on medication immediately and proceeded to tell me that my epilepsy would progress and I was at high risk of Grand Mal seizures and that I would most likely experience the same things I had witnessed my father go through for the past 20 years.

Next, I had to tell my grown children what was happening. They both lived on their own by this time. I knew exactly how they were going to feel and what they would have to experience. My daughter probably had the worst reaction. It took almost a year for her to admit to me how hard it was for her. She finally told me she had always considered me to be "Superwoman", and to come to terms with me being mortal was hard for her. That broke my heart.

By August 2020 I was sent home by my new manager due to my seizures, as they were progressively getting worse. Staff members had found me having seizures on the stairs, on ladders and they once caught me as I was about to fall out through the receiving bay doors. This was getting scary and the medications weren't working. So back to Grand Falls I went. The neurologist increased my medication and took me off work for a while. He even told my husband maybe he should take me on a trip to relax and get a change of scenery. So we went to Halifax to visit our son and meet his new girlfriend.

When we got home, things had not improved. I was still having multiple seizures a day and taking several falls. I had injuries to my back, knees and hips. My family doctor had decided that it was not safe for me to return to work, contacted my neurologist who once again increased my meds, and sent me to physiotherapy and massage therapy. I have not been able to return to work since.

Medications have decreased my seizure activity, but I am still having anywhere from 3 -10 seizures a day. I have had to come to terms with not working anymore which has been very hard for me. I feel like I have lost all of my independence and have become a burden to my husband. I need someone with me 24 hours a day, as my seizures can happen at any time. My husband is my main caregiver and only gets a break when a respite worker comes 14 hours a week. He gets very little sleep and is always on his toes. My husband is my rock and without him I am not sure what I would do.

The way I have been coping is by learning more about epilepsy and trying to help myself and others like me.

I found the Epilepsy NL Facebook group and it has changed my life. I have been able to participate in the HOBSCOTCH program which has taught me tools to cope with memory and how to manage my anxiety. I have had the opportunity to take part in a survey via the Ontario Brain Institute and a UK based company which led to me being part of a panel of patients and professionals. The panel was selected to develop a list of questions people with epilepsy would like researchers to focus on to get answers.

I obtained the final report and reached out and shared it with as many people as would listen to me. I sent copies to a contact with CBC's Here and Now, our Minister of Health, Dr. John Haggie, and even a Neurologist resident I happened to meet at one of my husbands' appointments in St. John's.

As a person with epilepsy, I have come to realize that our little province of Newfoundland and Labrador needs support when it comes to epilepsy research, funding and education. There are still many in our province that know nothing about epilepsy or still label us as a result of lingering stigma. I have even had a family member tell me they will not go to a store with me because I "embarrass" them when I have a seizure!

I am determined to use my time to fight for more for our epilepsy community. We deserve better. Epilepsy has been around for so many generations that one would think there would be much more education available about it. Sadly, it seems it has been put on the back burner for way too long. It is now time for us to fight the stigma and fight for change.

I am asking you to join with me in talking about Epilepsy and doing your part to help Epilepsy Newfoundland and Labrador bring awareness to our province.

Purple Day 2022 How to Get Involved!

Wondering how you can get involved in Purple Day 2022? 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! If you are online learning you can still get involved with Purple Day 2022!

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 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. The session will be a Facebook live event on Wednesday, March 23 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 T-Shirts for \$12.00 to \$14.50 (depending on size) Show your Purple this March with a t-shirt with all proceeds going to ENL! *shipping costs will apply* Pens are \$2.00 each!

Purple Day Proclamation: Cities and towns all around the province also participate in Purple Day by signing the Purple Day Proclamation. Keep an eye out on our social media for towns and cities that have signed the Purple Day Proclamation this year.

Light it up Purple: Municipalities across Newfoundland and Labrador will be lighting up their town halls and other venues to celebrate Purple day. Keep an eye out on our social media for towns and cities that have lit up for Purple Day this year. Send us your pictures from your town or city so we can share how you are celebrating Purple Day!



Scholarship Winners 2021

Jim Hierlihy Memorial Scholarships 2021

Pictured Right- Bradley Perry was awarded the Jim Hierlihy Memorial Scholarship. Here Brad is pictured with Epilepsy NL Board President, Ron Stone.



Pictured Left- Mark Hickey was awarded the Jim Hierlihy Memorial Scholarship. Here Mark is pictured with Epilepsy NL Board President, Ron Stone.

Pictured Right- Mona Earle was awarded the Jim Hierlihy Memorial Scholarship. Here Mona is pictured with Epilepsy NL Board President, Ron Stone.



Zach Rowe Memorial Scholarships 2021

Pictured Right- Holly Morgan was awarded the Zach Rowe Memorial Scholarship. Here Holly is pictured with Epilepsy NL Board President, Ron Stone.



Pictured Left- Lauren Hinchey came was awrdded the Zach Rowe Memorial Scholarship. Here Lauren is pictured with Epilepsy NL Board President, Ron Stone.

Pictured Right- James Day was awarded the Zach Rowe Memorial Scholarship. Here James is pictured with Epilepsy NL Board President, Ron Stone.



Epilepsy NL Family Scholarship 2021

Pictured Left- Madison Healey was awarded the Epilepsy NL Family Scholarship. Here Madison is pictured with Epilepsy NL Executive Director, Gail Dempsey.

Ben Basha Memorial Scholarship 2021

Pictured Right- Katie Currie was awarded the Ben Basha Memorial Scholarship. Pictured here is Katie with members of Ben's family: Ben's father, Mike, Ben's mother Holly and Ben's stepfather, Michael.



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.

Purple Star Award 2022

The Epilepsy Newfoundland & Labrador Purple Star Award, valued at \$1000, is available to any resident of Newfoundland & Labrador who has epilepsy and is using their epilepsy to educate their family, school, workplace, and/or community.

Purpose of Award: To recognize ordinary men, women, and children, making a difference in Newfoundland & Labrador by using their lived experience with epilepsy to educate others.

Value of Award: One thousand dollars (\$1,000.00) non-renewable

Qualifications: Applicants must:
- have been diagnosed with epilepsy,
- be a resident of Newfoundland & Labrador
- use their epilepsy to educate others

Closing Date: Applications must be received by Epilepsy Newfoundland and Labrador no later than March 1st.

Award: This award will be paid directly to the successful applicant. Notification of award will be made no later than March 26th. The successful applicant should be available in person to receive their award at a formal presentation.

Deadline is March 1, 2022. For application please visit our website:
<http://epilepsynl.com/purple-star-award/>

Please forward application, by fax, email, or post to:

Epilepsy Newfoundland and Labrador, 351 Kenmount Road, St. John's, NL A1B 3P9
Phone: (709) 722-0502 or 1-866-EPILEPSY Fax (709) 722-0999
info@epilepsynl.com www.epilepsynl.com

Purple Day 2022 Events!

Pro Active Wellness Presentation

In Partnership with Canadian
Mental Health Association -NL

Tools, Tips and Tricks on Dealing with Stress,
Anxiety and Depression



Event is FREE! A Facebook Live Event
Monday, March 21, 2022
7:00pm to 8:00pm

Call 709-722-0502 or 1-866-EPILEPSY for more
information on this event
WWW.EPILEPSYNL.COM

Ask the Doctors

Dr. A. Ogunyemi, Epileptologist

Dr. D. Buckley, Pediatric
Neurologist

Answer Your Questions on Epilepsy

Event is FREE! A Facebook Live Event
Wednesday, March 23, 2022
7:00pm to 9:00pm

Call 709-722-0502 or 1-866-EPILEPSY for more
information on this event

WWW.EPILEPSYNL.COM

**EPILEPSY
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www.epilepsynl.com



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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.



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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

Trim the Tree Campaign and Christmas LED Sign Campaign

We want to thank everyone who participated in our two campaigns in 2021.

The Trim the Tree for Epilepsy campaign was a great success. We want to thank all of our supporters who thought of us during the holiday season.

Those who donated \$10 or more during this Campaign, received were entered to win a prize pack. The winner was Lisa Coady

The Christmas Campaign takes advantage of our LED sign located on Kenmount Road. The City of St. John's tells us that 37,000 cars drive past our sign everyday! Our location gives the public a great opportunity to spread a Christmas message to all your friends and family. This year many businesses donated to ENL and as a thank you, we displayed their Christmas message on our huge sign for all to see.

We want to thank all of the businesses who participated in the Christmas Campaign. We look forward to working with everyone again next year and appreciate everyone's support!

