



Special points of interest:

- Announcing Purple Day Ambassador 2023
- Purple Community Awards 2023
- Scholarship Winners
- Meet our new Executive Director
- Asked and Answered
- How to Participate in Purple Day 2023
- Purple Day Ambassador Story

## Purple Day Ambassador 2023:

Epilepsy Newfoundland and Labrador is proud to present our 2023 Purple Day Ambassador, Christina Keough of Plate Cove East. Christina has been a tireless advocate for epilepsy awareness, and has contributed to fundraising and community support.

Her efforts to educate about epilepsy in Newfoundland and Labrador have been powerful, personal and persistent. We are so thrilled to be working with Christina as the Purple Day 2023 Ambassador. Check out page 10 for Christina's story. Thank you, Christina or your dedication to raising epilepsy awareness.



## Purple Day Ambassador 2023

### What is a Purple Day Ambassador?

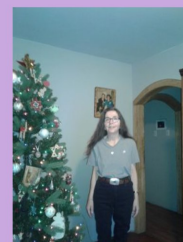
A Purple Day Ambassador is someone who helps raise epilepsy awareness and celebrates Purple Day in their area.

They share their story to let others know they are not alone.

They inspire others.

Meet Epilepsy Newfoundland and Labrador's Purple Day Ambassador for 2023:

Christina Keough of Plate Cove East, NL.



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Purple Day 2023 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 26<sup>th</sup>. 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. 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](mailto: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 Star Award 2023

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.

### Board of Directors

#### President

Ron Stone  
(Mt. Pearl)

#### Secretary

Patsy Lush  
(Corner Brook)

#### Treasurer

Anne Marie Hagan  
(St. John's)

#### At Large

Bernie Larkin  
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Edward Pilgrim-Turner  
(Happy Valley-Goose Bay)

Pauline Duffy  
(Stephenville)

William Westcott  
(St. John's)

### Executive Director

Andrea MacDonald

### Medical Consultant

Dr. A.O. Ogunyemi, M.D.,  
FRCP ©

### Information Officer

Alicia Legge

#### 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](mailto:info@epilepsynl.com) [www.epilepsynl.com](http://www.epilepsynl.com)



## Ron E.G. Stone President's Award 2023-BRAND NEW

The Ron E.G. Stone President's Award is awarded to a person living with epilepsy who has shown perseverance in overcoming the obstacles epilepsy may present. Valued at \$1000, it honors Ron Stone on the 25<sup>th</sup> anniversary of his volunteerism on the board of Epilepsy Newfoundland & Labrador. Ron has served on the board in varied capacities and has been President of the board since 1997. Ron has no personal connection to epilepsy other than his love of helping people. His loyalty and dedication have inspired us to present this award to a person who demonstrates those same qualities.

**Purpose of Award:** To recognize a person with epilepsy, over the age of 18, who has achieved a personal goal through perseverance, while navigating obstacles presented by epilepsy.

**Value of Award:** One time award of One thousand dollars (\$1,000.00)

**Qualifications:** Applicants must:

- be 18 or older
- have been diagnosed with epilepsy,
- be a resident of Newfoundland & Labrador
- demonstrate successful accomplishment of goal

**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/ron-e-g-stone-presidents-award-2023/>***

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](mailto:info@epilepsynl.com) [www.epilepsynl.com](http://www.epilepsynl.com)



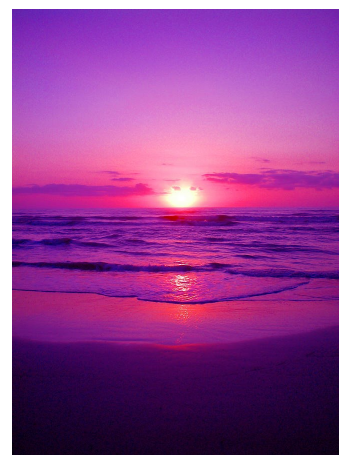
## Purple Sunrise Award 2023– BRAND NEW

The Epilepsy Newfoundland & Labrador Purple Sunrise Award, valued at \$100.00, is available to any resident of Newfoundland & Labrador, between the ages of 8 to 18, who has epilepsy and is using their epilepsy to educate their family, school, workplace, and/or community.

Purpose of Award:	To recognize children and youth, from 8 to 18 who are making a difference in Newfoundland & Labrador by using their lived experience with epilepsy to educate others.
Value of Award:	One hundred dollars (\$100.00) non-renewable Because the Purple Sunrise Award is a once in a lifetime award, the award may be won only once in a lifetime.
Qualifications:	Applicants must: <ul style="list-style-type: none"> <li>- be between the ages of 8 &amp; 18</li> <li>- have been diagnosed with epilepsy,</li> <li>- be a resident of Newfoundland &amp; Labrador</li> <li>- use their epilepsy to educate others</li> </ul>
Closing Date:	Applications must be received by Epilepsy Newfoundland and Labrador no later than <b>March 1st</b> .
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-sunrise-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](mailto:info@epilepsynl.com) [www.epilepsynl.com](http://www.epilepsynl.com)



## Purple Teddy Award 2023– BRAND NEW

The Epilepsy Newfoundland & Labrador Purple TEDDY Award, is available to any resident of Newfoundland & Labrador, under the age of eight (8) who has epilepsy and is using their epilepsy to educate their family, school, workplace, and/or community.

**Purpose of Award:** To recognize children under the age of eight (8) who are making a difference in Newfoundland & Labrador by using their lived experience with epilepsy to educate others.

**Value of Award:** A Purple Teddy.  
Because the Purple Teddy Award is a once in a lifetime award, the award may be won only once in a lifetime.

**Qualifications:** Applicants must:

- be under the age of 8
- 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:** The Teddy will be presented 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-teddy-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](mailto:info@epilepsynl.com) [www.epilepsynl.com](http://www.epilepsynl.com)





## Scholarship Winners 2022

### Jim Hierlihy Memorial Scholarship 2022

The Jim Hierlihy Memorial Scholarship, valued at \$1000, is awarded to a mature student with epilepsy who has taken the initiative to return to studies to advance in their present job or train for a new career.

Courtney Russell was the recipient of the Jim Hierlihy Memorial Scholarship and was presented with her award at the College of the North Atlantic campus in Gander. This was significant as Jim was originally from the town of Gander. Pictured (left) is Courtney receiving the cheque from CNA employee Celena Alcock (right) who is the Student Development Officer.



### Epilepsy NL Family Scholarship 2022

The Epilepsy NL Family Scholarship, valued at \$1000 is awarded to a student who has a family member (spouse, parent, child, legal guardian, grandparent, grandchild or sibling) diagnosed with epilepsy, and currently in, or about to enter, their first year of Post Secondary studies.

Christopher Swyer was the recipient of the Epilepsy NL Family Scholarship. Pictured (right) is Christopher with Epilepsy NL Executive Director Gail Dempsey. (left)



### Ben Basha Memorial Scholarship 2022

The Ben Basha Memorial Scholarship is awarded to a student with epilepsy studying at a post-secondary institution. Valued at \$1000, it honours Ben, who passed away suddenly at the age of 19.

Christopher Edwards was the recipient of the Ben Basha Memorial scholarship. Here Ben is pictured (middle) with members of Bens family; mom Holly (left) and stepfather Michael (right).



## Welcome our New Executive Director Andrea MacDonald



Hello Everyone,

It has been my pleasure to work with Gail, the Staff and Board at Epilepsy Newfoundland and Labrador this past month and to learn about the important ways our Association supports those living with Epilepsy. I have learned that funding for programs and services are made possible through generous donations gathered in exciting and creative ways by caring individuals and groups in this province. Funds are also provided through a thriving retail operation, Previously Loved Clothes and Things, which employs staff, offers affordable products for purchase, and saves items from destruction by allowing them to be repurposed or reused.

A big thank you to the Board of Directors of Epilepsy Newfoundland and Labrador for their faith that my education and experience in non-profit and social enterprise management was the right combination to fill the role of Executive Director. I hope that my Master of Business Administration degree, twelve years as Executive Director of the Historic Sites Association of Newfoundland and Labrador, and the invaluable training and support from Gail Dempsey will prepare me for this new career and the important role that has been entrusted to me. I am excited to learn how I can help support people living with Epilepsy in this province and to work with the team, stakeholders and supporters of Epilepsy Newfoundland and Labrador.

Sincerely,

Andrea

## Asked and Answered

**Q:** Do medications work for everyone with epilepsy?

**A:** Unfortunately no. The good news is that 70% of people who are prescribed medications to control their seizures will see a reduction or elimination of seizures over a period of time. This does not mean they are cured of epilepsy but that they have responded well to treatment.

About 30% of people who live with epilepsy have what is called “drug resistant epilepsy.” There are additional treatments for people with drug-resistant epilepsy that can improve seizure control or stop seizures altogether. Some treatment options are the Ketogenic diet, Vagus Nerve Stimulation and brain surgery.



## 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
- Four Scholarships exclusively available to members
- 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](mailto:info@epilepsynl.com), calling (709) 722-0502/ 1-866-Epilepsy, or mailing in the form found below.



### 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](mailto:info@epilepsynl.com) to save on postage. You can also submit your form online ([www.epilepsynl.com](http://www.epilepsynl.com)). If you would like to make a donation you can donate through our website by visiting [epilepsynl.com](http://epilepsynl.com) and clicking the DONATE button.



# Purple Day 2023: How to Get Involved!

Wondering how you can get involved in Purple Day 2023? 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 2023!

**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 22 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.

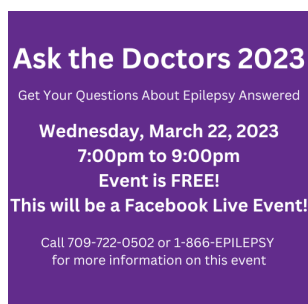
**Light it up Purple:** Municipalities across Newfoundland and Labrador will be lighting up their town halls and other venues to celebrate Purple day.

**NEW! Purple Pets Contest:** Dress your Pets in Purple and be entered for a prize pack!

**Purple Tea Party:** host a tea party for epilepsy awareness and be entered for a prize pack!

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!



# Purple Day Ambassador Story 2023

My name is Christina Keough, I was diagnosed with epilepsy at 3 days old. When I had my first seizure the doctors knew something was wrong. As it turned out, I had a blood clot on the brain; I developed tonic clonic seizures. I had one hundred and five tonic clonic seizures and was told by doctors that I would never walk, read, or write again because of the area of my brain that was affected. I endured two open heart surgeries and at the age of ten I had to have half my left lung removed due to having pneumonia over twenty times. After nineteen months of sheer determination, I learned how to walk, read, and write again. After my lung surgery my lungs seemed to be doing ok again and at the age of eighteen my seizures seemed to ease off over time.

My family was not supportive of my diagnosis. For years I hid my seizures because my mother and sister were ashamed of me if I had one in public. It took me a long time to come out from the shadows and live the life I wanted. It seems that even today, epilepsy is rarely talked about publicly and it seems like the slogan “out of the shadows and into the light” applies to this devastating disease.

Today, I only have the small seizures, but over the years, it feels like I have prescribed every seizure drug on the market; today I am on two medications that seem to work for me. I only have seizures now if my INR (International Normalized Ratio) is to high or low or if I get an infection. My seizures may never truly be under control but I'm glad that the medication I'm taking is working for me and that I can lead a normal life and do the things I enjoy doing. I enjoy doing crafts and even though they may not be perfect, crafting brings me joy.

For me the most important part of this journey is the little things I do and being there to help others when I can. I can look back at my life and see how far I have come; from a child who had a bad heart who wasn't expected to live to be this old to someone who has overcome so many challenges. I look back at life, I see how far I have come, it shows me that if we hang in there we can overcome anything.

Christina's message: “My husband and I believe that epilepsy should not be hidden, and we are all equal no matter what the sickness, we are all one.”

Pictured right are some of the many crafts that Christina makes to help raise epilepsy awareness.



Pictured left are Christina and her husband Eugene.

## EPILEPSY NEWFOUNDLAND AND LABRADOR

351 Kenmount Road  
St. John's, NL.  
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Phone: 709-722-0502  
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E-mail: [info@epilepsynl.com](mailto:info@epilepsynl.com)

[www.epilepsynl.com](http://www.epilepsynl.com)

## Trim the Tree Campaign and Christmas LED Sign Campaign



We want to thank everyone who participated in our 2022 campaigns.

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

Those who donated \$10 or more for a purple bulb during this Campaign, received were entered to win a prize pack. The winner was Holly Warford.

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 in 2023.



*Previously Loved*   
**Clothes & Things**

LOCATION: 351 KENMOUNT ROAD, ST. JOHN'S, NL.  
OPEN SEVEN DAYS A WEEK 10:00AM to 9:00PM  
HAVE SOMETHING TO DONATE? (709) 722-5571

**Where You'll Find Hundreds of Treasures With Experience!**

**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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[WWW.EPILEPSYNL.COM](http://WWW.EPILEPSYNL.COM)

**Epilepsy**  
Newfoundland & Labrador



### 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.

**Epilepsy**  
Newfoundland & Labrador

