#### EPILEPSY NEWFOUNDLAND AND LABRADOR FNI.





# News

Spring 2022

#### **Special Points of**

- A Fond Farewell
- JAC Donation
- Purple Day Partnerships
- Purple Star Award Winners 2022
- Purple Sunrise Award 2022
- Purple Day Thank you
- Purple Day Ambassador
- Light The Night 2022
- Proclamation Signings
- Purple Tea Party Pictures
- HOBSCOTCH

#### A Fond Farewell

Gail Dempsey, founder of Epilepsy Newfoundland & Labrador, will be retiring from her position as Executive Director on April 30, 2022. Gail started Epilepsy Newfoundland & Labrador, in her basement, in 1983. In 1987 she was appointed to the position of Executive Director, where she has been ever since. Under her guidance we have developed all the programs and services that you see today. We have a social enterprise, Previously Loved Clothes & Things, and own a building and property on Kenmount Road. Gail says "we have come a long way from one telephone and a desk in my basement."

"I have met so many wonderful people who are working so hard to make the world a better place for

"I have met so many wonderful people who are working so hard to make the world a better place for those living with epilepsy. I am very proud of what we have accomplished, and very blessed to have been a part of it." Dempsey continues "I am thrilled with the Executive Director that the board has found to take my place. If she receives the same love and support that I did then Epilepsy Newfoundland & Labrador has a great future." "I won't be far away, so I won't say good-bye, I'll say see you all later."

Gail will be greatly missed by all of the staff, members, donors, and volunteers. There has never been an Epilepsy Newfoundland & Labrador without her, but with her passion and dedication to the cause, we have no doubt that she won't be disappearing from the epilepsy world.

"There are no goodbyes for us. Wherever you are, you will always be in my heart."

-Mahatma Gandhi



RIGHT: Gail with Purple Star Award winner Joey Callanan

LEFT: Gail with Long time Previously Loved Clothes and Things volunteer Brian Lee.





ABOVE: Gail speaking at the CLAE Conference 2018



ABOVE: Gail with other founding members of the Canadian Epilepsy Alliance

Page 2 Epilepsy News

#### JAC /Don't Fear the Purple Donation 2022

#### Faith Atkins: Don't Fear the Purple

For the last six years the JAC team have put great effort into celebrating Purple Day and raising Epilepsy Awareness with Epilepsy Newfoundland and Labrador. JAC is an award winning marketing agency providing professional web design, web development, social media, marketing and advertising services in St. John's. Team member and long time Purple Day Ambassador Faith Atkins created the campaign "Don't Fear the Purple" as a way to raise awareness of epilepsy. This amazing initiative shares epilepsy facts and information via social media, has held many special events, fundraisers and contests for Purple Day, and has donated greatly to Epilepsy NL. This year the JAC team fundraised for Epilepsy NL. For each \$5.00 donation made the donor's name would be entered to win a fabulous prize package worth over \$1500.00 as a thank you. The initiative raised \$3135.00 which was matched by JAC, making a grand total of \$6270.00! This was the most successful campaign hosted by JAC to date!



Pictured left is Ashley Slade with her prize basket from JAC.



Pictured above is Epilepsy NL Executive Director, Gail Dempsey, Graphic Designer with JAC, Faith Atkins, and JAC Owner, Patricia Atkins.



Pictured Left: John and Patricia Atkins from JAC » We Create came by the Epilepsy NL office to present Executive Director Gail Dempsey with the cheque for the amazing campaign via Don't Fear the Purple.

Thank you to everyone near and far who donated, we are eternally grateful for the support!!



#### Purple Day Partnerships 2022

We want to send a huge thank you to Volcano Bakery Icelandic for hosting a fundraiser for us during Epilepsy Awareness Month and helping to raise awareness using their delicious purple ribbon cookies! All proceeds from the sale of the cookies went to Epilepsy Newfoundland and Labrador to help continue our programming and education initiatives. The great staff raised a total of \$600.00 from cookie sales and took in an extra \$68.40 from public donations.







We would also like to thank the Canadian Mental Health Association NL— specifically Nicole Button and Grant Fitzpatrick for partnering with us to deliver a very important information session about relieving stress and how to cope with anxiety and depression. It was a new partnership for 2022 and one we hope to continue into the future. CMHA-NL is a great community resource for anyone who may be struggling with mental health issues, they are there to help. They can be reached at (709) 753-8550 and their office is located at 603 Topsail Road, St. John's, NL ATE 2ET



Association canadienne pour la santé mentale Terre-Neuve et Labrador



Finally we want to thank Purity Factories Limited for donating a package of delicious goodies to our gift basket for the Purple Tea Party for Epilepsy Awareness campaign again this year. The donation goes a long way in helping us prepare a basket for our prize winner. We hope to continue working with Purity Factories in the future!



Page 4 Epilepsy News

# **Purple Star Award Winners 2022**

**Board of Directors** 

President Ron Stone (Mt. Pearl)

Secretary
Patsy Lush
(Corner Brook)

Treasurer Anne Marie Hagan (St. John's)

At Large

Bernie Larkin (Stephenville)

Edward Pilgrim-Turner (Happy Valley-Goose Bay)

Pauline Duffy (Stephenville)

William Westcott (St. John's)

Executive Director
Gail Dempsey

Medical Consultant Dr. A.O. Ogunyemi, M.D., FRCP ©

Information Officer
Alicia Legge

2022 was the second year for the Epilepsy Newfoundland and Labrador Purple Star award. The purpose of the award is to recognize ordinary men, women, and children, who are using their own lived experience with epilepsy to educate others.

Our 2022 recipients were surprised at our office and at Gander Town Hall to receive their awards and each was broadcast on Facebook Live! There was a lot of sneaky detective work involved in keeping the news a secret! The outcomes were worth it! Each of the recipients truly are making a difference in their communities in raising epilepsy awareness and educating others about the disease. The Facebook Live of the videos is archived on our Facebook page (@EpilepsyNL). The Purple Star Award, valued at \$1000, is available to any resident of Newfoundland & Labrador who is over the age of eighteen, who has epilepsy, and is using their epilepsy to educate their family, school, workplace, and/or community.

For more information on the award criteria and how to apply please visit our website at www.epilepsynl.com/purple-star-award or call 709-722-0502 or toll free I-866-EPILEPSY

#### Joey Callanan, Mount Pearl, Newfoundland and Labrador

Joey Callanan is one of our Purple Star Award winners. He has been a Purple Day ambassador for the past nine years! He was first diagnosed with epilepsy at the age of eight. Joey is now working full time and is a member of the Newman Sound Men's Choir. Joey is a wonderful singer and enjoys sharing his talents on the local and international stage. Joey uses his voice not only to entertain but to raise awareness and to educate others about epilepsy.

Pictured right is Joey with Epilepsy NL Executive Director Gail Dempsey, at Epilepsy NL offices after receiving his award.



#### Billie Jean Colbourne Gander, Newfoundland and Labrador



Billie Jean Colbourne was one of our Purple Star award winners for 2022 and she was chosen as the Purple Day Ambassador for 2022. Billie Jean was diagnosed with epilepsy in July 2020. Since that time Billie Jean has used her voice to educated others about epilepsy and to advocate for better health care services and supports for people living with epilepsy in Newfoundland and Labrador,

Pictured left is Billie Jean, her husband, Rod Colbourne and Gander Town Councilor, Gia Brown, who presented Billie Jean with her award.

# **Purple Sunrise Awards 2022**

## Claire McDonald St. John's, Newfoundland and Labrador

Claire McDonald was the inaugural winner of the Purple Sunrise award for 2022 along with Janelle Martin. The award of \$100 is given to recognize children and youth from age eight to eighteen who use their lived experience with epilepsy to educate others. Claire and her family created Claire's Community a Facebook page to share her experience of living with a complex seizure disorder, PTSD, autism, cerebral palsy and photosensitivity. Pictured Right is Claire receiving her award at her School, Larkhall Academy, from Epilepsy NL executive director, Gail Dempsey.



#### Janelle Martin Charlottetown, Newfoundland and Labrador

Janelle Martin was our 2nd inaugural winner of the Purple Sunrise Award for 2022. She was the inspiration for this award along with Claire McDonald. The award of \$100 is given to recognize children and youth from age eight to eighteen who use their lived experience with epilepsy to educate others. The award will be open to public applications in 2023. She was presented with the award at her school William Gillett Academy in Charlottetown, NL by Principal Pamela Campbell.







Page 6 Epilepsy News

#### Purple Day Thank You

Epilepsy Newfoundland and Labrador is proud to report another successful Purple Day. Each year we are thrilled to see Purple Day participants all across the province, and this year was no different. The support shown on social media this year was outstanding. Many people throughout NL wore their Epilepsy NL Purple Day t-shirts and took to social media with a photo, shared their epilepsy stories and shared epilepsy facts. This contributes greatly to raising awareness and decreasing stigma.

Schools showed their support by sharing pictures of students dressed in purple, held virtual education sessions and decorated classrooms as well. Daycares across the province had children doing the "Bunny Hop" to raise awareness and some chose to also raise funds for Epilepsy NL. Businesses showed support, including Marystown Ultramar which was decorated Purple by Ann Marie Legge and Marystown Dental who had their staff dressed in purple. Many cities and towns across Newfoundland and Labrador signed proclamations in recognition of Purple Day while others lit up public buildings purple to show support.

Thanks to all those who wore purple, took to social media, held fundraisers, and raised epilepsy awareness in a way that is unique and meaningful to you. Your participation truly makes all the difference in a continuingly successful Purple Day.

If you would like to participate in Purple Day 2023 or have an idea for an event, contact Alicia at info@epilepsynl.com or 709-722-0502/I-866-EPILEPSY

Left to right: Lewisporte Collegiate Class, Marystown Ultramar and Marystown Dental









#### Purple Day Ambassador 2022

Epilepsy NL's 2022 Purple Day Ambassador Billie Jean Colbourne did an amazing job this year. She was interviewed by Bernice Hillier of CBC Radio, was a winner of a Purple Star Award, was profiled by Mothers of Avalon for Epilepsy Awareness Month and shared her personal story of living with epilepsy. Efforts such as these ensure that the topic of epilepsy remains a point of conversation and increases epilepsy awareness significantly.

Well done Billie Jean!





# **Light the Night 2022**

We had the opportunity this year to have several landmarks across the province light up purple for Purple Day 2022. These included Signal Hill, St. John's City Hall, Government House and St. John's Convention Centre to name a few. We also had several municipalities participate by lighting up public buildings or other landmarks purple. Here we have included some of the pictures.



ABOVE: Confederation Building 2022



ABOVE: St. John's Convention Centre





LEFT: Town of Northern Arm, NL 2022



ABOVE: St. John's City Hall 2022



LEFT: Town of Parker's Cove, NL 2022

Page 8 Epilepsy News

#### Ask the Doctors Event 2022

2022 marked another wonderful year for Epilepsy Newfoundland and Labrador's annual Ask the Doctors Forum, a free March Awareness event where individuals can get their epilepsy related questions answered.

Each year two amazing doctors participate, Dr. Ogunyemi (Epileptologist) and Dr. Buckley (Pediatric Neurologist). This year we celebrated the 33rd anniversary of Dr. Ogunyemi's participation and the 30th year of Dr. Buckley's participation!

The doctors held a very informative Q & A session, on our second ever virtual Facebook Live event streamed via Zoom, providing opportunity for many more participants across Newfoundland and Labrador to listen and ask questions.

RIGHT: Dr. Buckley and Dr. Ogunyemi at the 2019 Ask the Doctors event held at Epilepsy NL office.





## **Purple Day Proclamation Signings 2022**

Each year it is so inspiring to see cities and towns all around the province sign the Purple Day Proclamation, declaring March 26<sup>th</sup> as Purple Day.

Although many in person signings did not take place this year due to the Covid -19 pandemic, the municipalities across the province showed their support by sending signed proclamations back to ENL via email or sending in pictures taken during the signings. Many also shared their proclamations to their own city or town social media pages. Signing the proclamation is an excellent opportunity to show support for those living with epilepsy in your area, raise awareness of epilepsy, and fight against stigma.

We would like to thank all municipalities across the province for taking the time to sign a proclamation for Purple Day 2022 including Grand Falls, Windsor, Parker's Cove, Mount Pearl, Fox Harbour, Englee, Placentia, Torbay, Rocky Harbour, Ferryland, Winterland, Lark Harbour, St. Lawrence, Northern Arm, Heart's Desire, Wabush, Victoria, St. Anthony, Flatrock, Fortune, Marystown, and Heart's Delight-Islington.

# **Purple Day Proclamation Pictures 2022**



ABOVE: Mayor Paulette Pelley and Deputy Mayor Linda Buckey, Town of Northern Arm, NL



ABOVE: Councillor Gia Brown with Billie Jean Colbourne, Town of Gander, March 2022



RIGHT: Mayor Jason Cullihall of Rocky Harbour signing the Purple Day proclamation March 2022





ABOVE: Mayor Darren Gardner of Pasadena , NL and Tim Spicer at the signing of the Purple Day 2022 proclamation.



LEFT: Mayor David Aker and Councillors from City of Mount Pearl, March 2022

ABOVE: Proclamation signed by Minister John Haggie March 2022

#### **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 Epileps Newfoundard & Labor 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.

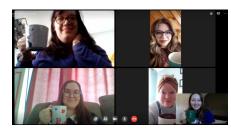
#### **Purple Tea Party for Epilepsy Awareness 2022**

This year we offered the opportunity for people to get involved with Purple Day in a Covid safe way. We asked people to host a "Purple Tea Party" for epilepsy awareness between March 1st and 31st and to enter into a draw for a prize basket filled with goodies from Tetley Tea and Purity Factories Ltd. People were asked to dress in purple and host a party either in their own Covid "bubble" or virtually. As always the people of Newfoundland and Labrador accepted the challenge.

Here are some of the pictures we received from coast to coast.































# EPILEPSY NL

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

PHONE: 709-722-0502 or Toll Free I-866-EPILEPSY

EMAIL: info@epilepsynl.com





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.





@EPILEPSYNL WWW.EPILEPSYNL.COM



#### **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

#### **HOBSCOTCH:**

HOme-Based Self-management and COgnitive Training CHanges lives

HOBSCOTCH is a behavioral program designed to address memory and attention problems in adults with epilepsy. The program is designed to help adults with seizures find ways to manage and cope with memory problems in order to lead happier, more productive lives.

The program consists of 8 sessions delivered by a certified HOBSCOTCH Memory Coach. The sessions occur weekly and last 45-60 minutes. The first session is conducted either in-person, in a private office setting, or virtually while the participant is at home using a computer or tablet and a webcam. It is up to the Memory Coach and participant to decide if an in-person or virtual approach is more appropriate.

HOBSCOTCH has been shown to be effective for adults with epilepsy who are experiencing memory problems. The program is appropriate for those with controlled and uncontrolled seizures.

If you are interested in learning more about HOBSCOTCH or entering the program please reach out to Alicia at info@epilepsynl.com or by phone at 709-722-0502 or toll free I-866-EPILEPSY There is no cost to register or participate in HOBSCOTCH.



