

Epilepsy News

Winter 2021

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Purple Day Ambassador 2021: Tim Spicer

Epilepsy Newfoundland and Labrador is proud to present our 2021 Purple Day Ambassador, Tim Spicer of Pasadena, Newfoundland and Labrador.

Tim has been a tireless advocate for epilepsy awareness, and has previously served on the board of Epilepsy Newfoundland and Labrador. His efforts to educate about epilepsy in Newfoundland and Labrador have been consistent and powerful, he even had a piece in the Western Star highlighting his efforts.

We are so thrilled to be working with Tim as the Purple Day 2021 Ambassador.

Check out page 2 and 3 for Tim's story.

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

Epilepsy Newfoundland and Labrador Purple Day Ambassador 2021

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 2021:

Tim Spicer
Pasadena, NL



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

Epilepsy Newfoundland and Labrador

March 26th 2021

Purple Day 2021



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

Purple Day 2021 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 2021: Tim Spicer

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Dr. A.O. Ogunyemi, M.D.,
FRCP ©

Information Officer

Alicia Legge

I was diagnosed with epilepsy at the age of 31. Now looking back today, I suspect that I have had epilepsy my entire life that went undiagnosed. Born in Hamilton, Ontario, I am the youngest of 5 boys. At the ages of 2 and 8, I had grand-mal seizures that my parents and doctors attributed to bladder infections. I can remember having "feelings" throughout my lifetime; however, when I mentioned it to my parents, they didn't take me seriously.

They simply shrugged off my "feelings" to being "happy" or "sad". I must have learned how to hide them, and the after-effects, well, sleepiness, confusion, difficulty talking, because no one in my family, including my brothers, noticed I was acting "weird", nor did anyone at school, or later at work. The first person to notice was my wife when we were dating. She noticed I made a chewing motion, and I often held my hand still in mid-air, or ran it along my other arm. I told her about my "feelings" but since they only lasted 1-2 minutes, we both felt there was nothing serious to worry about.

It DID become serious on October 24, 1995, when I had a grand-mal (generalized tonic clonic) seizure just before midnight when our first daughter was 17 days old. The doctors in emergency attributed it to lack of sleep due to having a newborn. I was referred to my first neurologist who subsequently diagnosed me with epilepsy. It turns out my "feelings" were actually Complex Partial Seizures now known as Focal (Onset) Impaired Awareness Seizures.

That began a long road of discovery to find the right "mix" of medications. I went through many tests including CT Scans, MRI, and EEGs which all came back normal. It wasn't until 12 years later, when I had a seizure during a Sleep EEG that I learned my seizures could actually be as long as 8-10 minutes.

In 2009, we moved from Ontario to Newfoundland and Labrador. This resulted in going over 2 years without seeing a neurologist. In 2011, my new neurologist and I finally seemed to find the right medications as my seizures dropped from a recorded high of over 65 a year to less than 15 per year.

As my seizures dropped, unfortunately, other issues began to arise. I was diagnosed with General Anxiety Disorder, Obsessive Compulsive Disorder, Social Anxiety Disorder, Major Depressive Disorder, and Dysthymia. I attempted suicide twice in 2017, and 2019.

Through treatment of depression, my psychiatrist has been able to optimize my medications by prescribing some that treat both seizure and depression disorders. It has been difficult undergoing so many medication changes, however, I am pleased to say that I have been seizure-free for over 2 years. My mental illnesses continue.

In 2011, I began actively volunteering on Purple Day for Epilepsy Awareness. Each year, I coordinate events including the declaration of Purple Day with my town mayor, reading an epilepsy story at Children's Story time at our library, handing out bookmarks, tattoos, and ribbons. I hang posters in my community and have made presentations at my church. Many community groups now wear purple on March 26th.

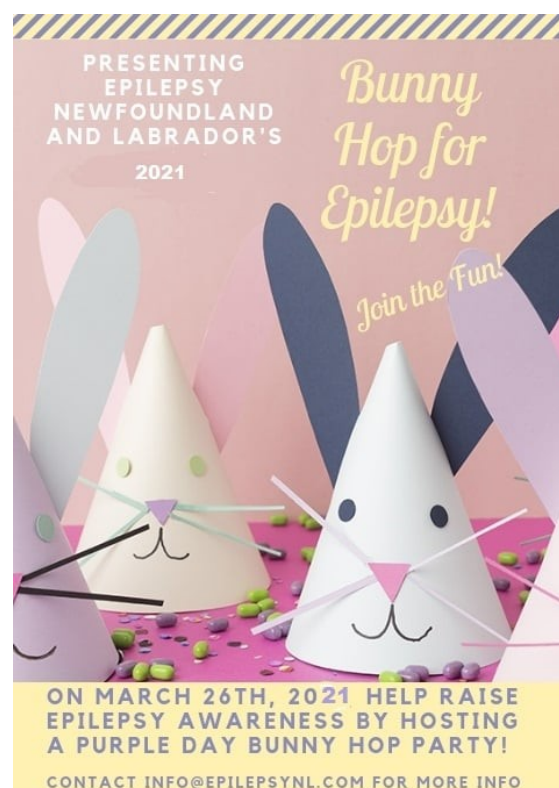
I served on the ENL Board of Directors 2015-2016. One of the highlights of my journey was when I visited Epilepsy Ireland in Dublin in 2016. We compared notes and ideas and I brought some resources back to ENL.

Both of my daughters have been Purple Day champions for raising epilepsy awareness at their schools. They actively fundraised each year during awareness events. Our collective efforts were recognized in an article in the Western Star in 2013. Both were recipients of ENL's Family Scholarship, one in 2013 and the other in 2018.

Because of the many challenges I have faced, I am open to discussing my disorders and hope that my story will inspire others. I would like them to know you can't stop striving to be seizure-free without finding the right medications, being open to testing, and gaining new knowledge.

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.

Epilepsy Awareness Month/Purple Day 2021 Events!



Scholarship Winners 2020

Epilepsy NL Family Scholarship

Epilepsy NL was delighted to award Stephanie Russell, of Stephenville, a two thousand dollar 2020 Epilepsy NL Family Scholarship. Stephanie is in her first year of studies at Memorial University.

Pictured left: Stephanie Russell (and her parents Pauline Duffy and Owen Russell) receiving her award at the Epilepsy NL office.



Zach Rowe Memorial Scholarship

Epilepsy Newfoundland and Labrador was delighted to award two winners of the Zach Rowe Memorial Scholarship for 2020.

We would like to offer a big congratulations to Christian Simms of Corner Brook, who was awarded a two thousand dollar Zach Rowe Memorial Scholarship. This is Christian's first year attending Memorial University of Newfoundland, Grenfell Campus where he is pursuing a Bachelor of Science with the goal of Physiotherapy program in the future.

Pictured right: Christian Simms with his letter and award.



Epilepsy NL was delighted to award Carson Ryan, of St. Mary's a two thousand dollar 2020 Zach Rowe Memorial Scholarship! Carson is attending his first year at the Carpenter's Millwright College where he is studying to become an Industrial Mechanic.

Pictured right: Carson Ryan at the Carpenter's Millwright College



Jim Hierlihy Memorial Scholarship

Congratulations to Lisa Pack, of Mount Pearl, winner of the two thousand dollar 2020 Jim Hierlihy Scholarship. Lisa is studying at the Centre For Nursing Studies, in the Practical Nursing program. We wish you all the best in your future endeavors.

Pictured left: Lisa Pack receiving her award at Epilepsy NL Office.



Purple Day 2021 How to Get Involved!

Wondering how you can get involved in Purple Day 2021? 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 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 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 Alicia at info@epilepsynl.com / 709-722-0502 to chat about it! Great options are volunteering to share Epilepsy NL's Epilepsy Awareness posts on Instagram, Twitter and/or Facebook, volunteering to host an event 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. 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.

Trim the Tree Campaign and Christmas LED Sign Campaign

We want to thank everyone who participated in our two campaigns in 2020.

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 Marilyn MacDonald.

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!



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 2021

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, 2021. 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

Home Based Self-management and Cognitive Training Changes Lives (HOBSCOTCH)

People with seizures have a lot of difficulties with day-to-day memory, which may affect their job and their social lives.

HOBSCOTCH (HOMe-Based Self-management and COgnitive Training CHanges lives) is a program developed at Dartmouth specifically for people with epilepsy, which may improve memory performance in people who suffer from seizures.

We offer this free, eight-week program to our members who may have difficulty with memory issues and cognitive problems.

If you are interested in this program please email us at info@epilepsynl.com or call 709-722-0502 or toll free 1-866-EPILEPSY.



**EPILEPSY
NEWFOUNDLAND
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E-mail: info@epilepsynl.com

www.epilepsynl.com



Previously Loved ♥
Clothes & Things

LOCATION: 351 KENMOUNT ROAD, ST. JOHN'S, NL.
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HAVE SOMETHING TO DONATE? (709) 722-5571

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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

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Upcoming Events!

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 24, 2021

7:00pm to 9:00pm

**Call 709-722-0502 or 1-8666-EPILEPSY for more
information on this event**

WWW.EPILEPSYNL.COM