

EPILEPSY NEWFOUNDLAND AND LABRADOR ENL

Fall 2022

# Special Points of

- Back to School
- Scholarships

Interest

- Fall Programming Update
- Epilepsy Research
- School Resources
- Christmas Campaigns 2022
- Ask and Answered

## Back to School for Students with Epilepsy

Students with epilepsy have the same range of intelligence as other students and often epilepsy itself has no effect on intelligence or ability. However, students with epilepsy do have a higher rate of learning problems and difficulty in school as well as a lower level of achievement.

Seizures can have a profound cognitive impact on a child, and this can lead to a lot of frustration for the student, their family, and teacher. The challenges can be great, however there are things that teachers can do to make things better. Some of the most prevalent challenges to learning and behaviour as well as suggestions to minimize or overcome them follow.



- -Anxiety: The unpredictability of seizures and sensitized or overprotective relationships with parents and other care giving adults can result in anxiety in a student. This may affect initiative, interaction and independence in the classroom. If a teacher is calm, effective and understanding in dealing with seizures this may help to alleviate a great deal of the anxiety. Enabling the understanding and awareness of other students and staff can also help take the pressure off and create a supportive learning and social environment.
- -Absenteeism: Seizures, medical tests and treatment may result in a student missing more class time than is typical resulting in lost instruction, gaps in continuity, and less understanding of the subject by the student. Teachers can assist by assuring all missed class work is available, through the teacher directly or a classmate. Also, a willingness by the teacher to be available for additional assistance if required can be very helpful.
- **Seizures:** The actual process of having a seizure may affect learning significantly. For example, students experiencing absence seizures throughout the day will have their learning experience continuously disrupted. Memory can also be affected, potentially resulting in further learning challenges. Assigning a buddy to the student who can answer questions and explain what was missed will provide both emotional and academic support to the student. Providing visual and written instructions and/or repeating verbal instructions can also assist.

Teachers are one of the primary role models and influences for children as they grow up. A positive attitude and understanding that a student with epilepsy can achieve just as much as any other student is very important. The impact a teacher has can be enormous and the attitude you have will be conveyed to other teachers and students, helping to raise awareness and promote an environment of inclusion and acceptance.

• If your child has epilepsy pass this page along to their teacher or contact us at info@epilepsynl.com for a full copy of our guide: "The Student with Epilepsy: A Teacher's Guide". \*

#### **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)

Vice President
William Westcott
(St. John's)

# **Executive Director**Gail Dempsey

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

**Information Officer**Alicia Legge

# **Epilepsy NL Scholarships 2022**

Each year, Epilepsy Newfoundland and Labrador offers three different scholarships to its members. The deadline for applications is November 1st, and we encourage all members to apply if they qualify. Not a member? Contact info@epilepsynl.com / 709-722-0502 to register for free. Applicants must be members of Epilepsy NL themselves.

Scholarship applications can be found online at:

#### **Zach Rowe Memorial Scholarship**

The Zach Rowe Memorial Scholarship, valued at \$1000, is awarded to a student with epilepsy who is currently in, or about to enter, their first year of Post Secondary studies. It honours Zach Rowe, recipient of an ENL scholarship in 2006, who passed away as a result of a seizure in 2009. He was 21 years old.

## Jim Hierlihy Memorial Scholarship

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. It honours one of ENL's in-credible volunteers, Jim Hierlihy, who was on the Executive of the ENL support group in Gander and a great supporter of all those living with seizures. Applicants must have diagnosed epilepsy, be 21 years of age or older, and be a member in good standing of Epilepsy NL at the time of application.

## **Epilepsy NL Family Scholarship**

The Epilepsy NL Family Scholarship, valued at \$1000 is awarded to a student who has a family member (spouse, parent, child, legal guardian, grand-parent, grand-child, or sibling) diagnosed with epilepsy, and currently in, or about to enter, their first year of Post Secondary studies. Applicants must have a family member diagnosed with epilepsy, be a member in good standing of Epilepsy NL at the time of application, and submit a copy of their most recent transcript or marks with their application. Evaluations will be based on a combination of the applicant's grades, extra-curricular activities, and financial need.

# Ben Basha Memorial Scholarship

The Ben Basha Memorial Scholarship is awarded to a student with epilepsy who is attending a post secondary institution and who is involved in activism, volunteering and demonstrates a love for community. Valued at \$1000 it honours Ben who passed away suddenly at age 19. Ben was many things to many people: night owl, practical joker, Raven fan, ace tennis player, terrible driver, enthusiastic chair dancer, a committed university student, fiercely loyal son, stepson, brother and friend. He went out of his way to offer help and comfort to anyone in need of it. His love for life was infectious, and enriched the lives of anyone ho knew him. Financial means are not disqualifying in any way but will be considered when evaluating applications.



# **Programming Update Fall 2022**

#### **Halloween BINGO 2022**

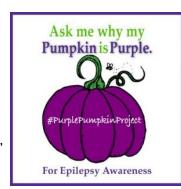
Thursday, October 27th, 2022 at 6pm. Come join us **online** for some spooky fun and a chance to win a prize or two. If you feel inspired to wear a costume on camera please do! Feel free to have the kids join too! More details to follow by October 1st.

#### 12 Days of Crafting 2022

A mix of in person and online crafting activities to help you through the longer autumn nights! We will tell you what supplies you need and make some videos along the way! Pre-registration will be required for in person events as we have limited space! Supplies will be provided for in person events. More details to follow by November 1st.

#### **Purple Pumpkin Project 2022**

In October we will be launching our Purple Pumpkin Project for 2022. We had great success last year and a ton of entries. We will once again be distributing prizes for first, second and third place for the pumpkins. This is a great way to show your pride, creative talents and spread epilepsy awareness while having some fun. So now is the time to start planning your design for 2022. More information will be released via email and social media by the end of September.



#### 10,000 Steps NL 2021

In October we will be launching our 10,00 Steps for Epilepsy Awareness Campaign 2022. We had great success last year and a ton of people participate from across the province. We will once again use this opportunity to raise awareness for the 10,000 people living with epilepsy in Newfoundland and Labrador and provide an opportunity for people to get active during the fall season. This event is not a fundraiser but if people wish to raise money for Epilepsy NL they may do so. More details will be announced in September.

There are over 10,000 people living with epilepsy in Newfoundland and Labrador.

WWW.EPILEPSYNL.COM



Page 4 Epilepsy News

# **Epilepsy In the News**

August/September 2022

New AI Algorithm Could Lead to an Epilepsy Cure.

The AI algorithm detects brain abnormalities that cause epileptic seizures. International researchers working under the direction of University College London have created an artificial intelligence (AI) algorithm that can identify subtle brain abnormalities that cause epileptic seizures. In order to create the algorithm that reveals where abnormalities occur in instances with drug-resistant focal cortical dysplasia (FCD), a major cause of epilepsy, the Multicentre Epilepsy Lesion Detection project (MELD) analyzed more than 1,000 patient MRI images from 22 international epilepsy centers. FCDs are brain regions that have developed abnormally and often cause drug-resistant epilepsy. Surgery is typically used to treat it, however, finding the lesions on an MRI is an ongoing problem for physicians since MRI scans for FCDs can appear normal. The scientists utilized about 300,000 locations throughout the brain to develop the algorithm, which measured cortical features using MRI scans, such as how thick or folded the cortex/brain surface was. After that, based on patterns and characteristics, professional radiologists classified examples as either having FCD or having a healthy brain, which served as the algorithm's training data.

According to the results, which were published in the journal "*Brain*", the algorithm was successful in identifying the FCD in 67% of cases in the cohort (538 participants). Previously, 178 of the individuals were declared MRI negative, which signifies that radiologists were unable to detect the abnormality; however, the MELD algorithm was able to detect the FCD in 63% of these instances.

This is particularly crucial because, if medical professionals can identify the abnormality in the brain scan, surgery to remove it may provide a cure. Co-first author, Mathilde Ripart (UCL Great Ormond Street Institute of Child Health) said: "We put an emphasis on creating an AI algorithm that was interpretable and could help doctors make decisions. Showing doctors how the MELD algorithm made its predictions was an essential part of that process."

Co-senior author, Dr. Konrad Wagstyl (UCL Queen Square Institute of Neurology) added: "This algorithm could help to find more of these hidden lesions in children and adults with epilepsy, and enable more patients with epilepsy to be considered for brain surgery that could cure epilepsy and improve their cognitive development. Roughly 440 children per year could benefit from epilepsy surgery in England." Around 1% of the world's population has the serious neurological condition epilepsy, which is characterized by frequent seizures. In the UK some 600,000 people are affected. While drug treatments are available for the majority of people with epilepsy, 20-30% do not respond to medications. In children who have had surgery to control their epilepsy, FCD is the most common cause, and in adults, it is the third most common cause. Additionally, of patients who have epilepsy that have an abnormality in the brain that cannot be found on MRI scans, FCD is the most common cause. Co-first author, Dr. Hannah Spitzer (Helmholtz Munich) said: "Our algorithm automatically learns to detect lesions from thousands of MRI scans of patients. It can reliably detect lesions of different types, shapes and sizes, and even many of those lesions that were previously missed by radiologists."

Co-senior author, Dr. Sophie Adler (UCL Great Ormond Street Institute of Child Health) added: "We hope that this technology will help to identify epilepsy-causing abnormalities that are currently being missed. Ultimately it could enable more people with epilepsy to have potentially curative brain surgery."

This study on FCD detection uses the largest MRI cohort of FCDs to date, meaning it is able to detect all types of FCD.

The MELD FCD classifier tool can be run on any patient with a suspicion of having an FCD who is over the age of 3 years and has an MRI scan.

Study limitations

Different MRI scanners were used at the 22 hospitals involved in the study around the globe, which enables the algorithm to be more robust but might also affect algorithm sensitivity and specificity.

Source: New AI Algorithm Could Lead to an Epilepsy Cure (scitechdaily.com)

## Back to School-Signs a student may be having a seizure

Seizure activity can present in many different ways, depending on the type of seizure(s) a person experiences. Therefore it is important to recognize signs that may indicate a student is having a seizure while attending school.

Signs that may indicate a student is having a seizure include:

- A sudden loss of awareness that may appear like daydreaming
- A brief lack of response
- Memory gaps
- Rhythmic head nodding
- Rapid eye blinking
- Repeated movements that appear unnatural
- Repeated jerking movements of the body, arms or legs
- Sudden falls without apparent reason
- Sudden stomach pain followed by sleepiness and confusion
- Frequent complaints that things taste, sounds, smell, look or feel strange
- Sudden fear, panic or anger without apparent reason

#### Back to School– Resources for the classroom

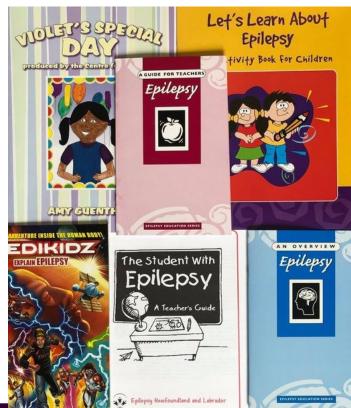
We have many classroom resources for students as well as for teachers, guidance counselors, principles and more. These resources are used to increase the awareness and understanding of epilepsy in the

school environment.

Do you need classroom resources or know someone who could avail of such? Contact us today to arrange a time to pick up or to have a package sent by mail. Our email is info@epilepsynl.com or call 709-722-0502 within the metro region or 1-866-EPILEPSY outside the metro region.







Page 6 Epilepsy News

# **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.

# **Christmas Campaigns 2022**

This year's Christmas Campaigns are just around the corner, and there are two to choose from.

# LED Sign Campaign 2022

For a \$50.00 tax deductible donation to Epilepsy Newfoundland and Labrador we would like to thank you publicly, over 50 times, on our full colour digital display. Thirty-seven thousand vehicles drive past our LED sign every 24 hours and your greeting will run a minimum of 50 times over Christmas and Boxing Day. Your donation will be used to provide programs and services on behalf of the more than 10,000 men, women and children living with epilepsy in Newfoundland and Labrador.

\*To reserve a spot, or to learn more, please contact us by November 31st by emailing info@epilepsynl.com. Space is limited and will be reserved on a first come first served basis.



# **Trim the Tree for Epilepsy 2022**

We have a Christmas tree in need of some purple decorations, would you like to help? With every \$10 donation made to the campaign a bulb is hung on our tree in your honour and your name is entered to win a prize just in time for Christmas!

Epilepsy Newfoundland and Labrador

Trim the Tree
For Epilepsy

We need your help!
We have a Christmas tree but it is empty.

With every \$10 donation we will place an ornament on our tree in your honour and you will be entered into a prize draw as a thank you.

This holiday season help raise awareness for the more than 10,000 people living with epilepsy in Newfoundland and Labrador.

This holiday season will you trim the tree for epilepsy?

#### **EPILEPSY NEWFOUNDLAND** AND LABRADOR **ENL**

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

Phone: 709-722-0502 Fax: 709-722-0999 E-mail: info@epilepsynl.com

#### Asked and Answered

#### Q: What does accommodation mean?

A: Accommodation is the process through which a worksite/place is modified to remove barriers for a person with a disability. Under the Canadian Human Rights Act and under some provincial codes, it is the duty of the employer to make *reasonable* efforts to accommodate individuals with epilepsy in the workplace unless such an accommodation would cause undue hardship. Accommodation can be as simple as moving furniture in an office or allowing a person to trade work with another employee.

More details can be found through local organizations offering employee assistance for persons with disabilities or through the Canadian Council on Rehabilitation and Work (CCRW).





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 Will 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.







#### 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.



