

EPILEPSY NEWFOUNDLAND AND LABRADOR ENL

Fall 2023

Special Points of

- Back to School
- Scholarships

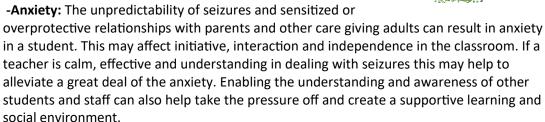
Interest

- Fall Programming Update
- Community Connect
 Event 2023
- Epilepsy Research
- School Resources
- Christmas Campaigns
 2023

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 as well as suggestions to minimize or overcome challenges.



-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 support the student 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". *



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Epilepsy NL Scholarships 2023

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 2023

Purple Pumpkin Project 2023

In October we will be launching our Purple Pumpkin Project for 2023. 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 2023. More information will be released via email and social media by the beginning of October. We are working on some spooky partnerships for this year's event! Stay tuned!



Epilepsy Awareness Walk 2023

On September 23, 2023 Epilepsy NL will be holding it's first Epilepsy Awareness Walk. Registration is now open to the public. The event will tale place on Saturday, September 23 from 11am to 1pm at Quidi Vidi Lake. Rain date will be Sunday September 24, from 11am to 1pm.

We encourage everyone to wear purple for the event and to meet at the bandstand by 10:45am To register for the walk please see the link below: https://form.jotform.com/232123762493253

Community Connect Event 2023

On Saturday August 19 we held our first Community Connect event. The event was held at Kenmount Terrace Community Centre with entertainment provided by Les Fluers Duo (Melody and Claire), Alex Taylor Music and Sci Fi on the Rock. There were approximate 40 people in attendance. Our guests enjoyed some music, food, pictures and fun time outside. We want to send out a huge thank you to all our volunteers who held make this day a success. We look forward to planning another event in 2024!











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Epilepsy In the News

September 2023

Is the cause of epilepsy genetic? New DNA study offers clues via Medical News Today.

- A new study identified 26 areas of DNA involved in the development of epilepsy.
- The research is the largest genetic study of its kind and involved more than 150 researchers across the world.
- Experts say being able to better understand the genetic underpinnings of epilepsy could lead to more targeted treatments.

Specific changes in DNA may increase the risk of developing epilepsy, according to research published in the journal <u>Nature</u>

<u>GeneticsTrusted Source</u>. In the study, researchers identified 26 areas of DNA involved in the development of epilepsy and 29 genes that are likely contributing to epilepsy within those areas.

Largest genetic study to identify DNA changes associated with epilepsy

The new research is the largest genetic study of its kind and involved more than 150 researchers in North America, South America, Europe, Australia and Asia.

As part of the study, the researchers compared DNA from nearly 30,000 people living with epilepsy alongside DNA from more than 52,500 people without the condition. The scientists were able to identify 26 distinct changes to the DNA in people living with epilepsy. They were also able to identify 19 changes in DNA that are specific to a type of epilepsy called genetic generalized epilepsy (GGE).

As part of the study, the researchers said they were able to demonstrate that many medications currently used in the treatment of epilepsy work by targeting the genes they identified as increasing the risk of epilepsy.

They were also able to use their data to suggest alternative drugs that are currently used for other conditions but are also known to target some of the genes identified in the study.

Understanding the genetics of epilepsy could lead to improved therapies

Epilepsy is a brain disorder in which neurons, a type of nerve cell located in the brain, can sometimes send the wrong signals. This causes seizures. When a seizure occurs, there is an increase in excessive electrical activity in the brain. This may cause involuntary sensations, movements and behavior.

Experts say the study represents an important step forward in understanding epilepsy.

"We don't really understand clearly what are the causes of epilepsy and how it comes about," Dr. Jean-Philippe Langevin, a neurosurgeon and director of Restorative Neurosurgery and Deep Brain Stimulation Program for Pacific Neuroscience Institute at Providence Saint John's Health Center in California, told MNT.Individualized treatment for epilepsy

According to the Centers for Disease Control and Prevention (CDC)Trusted Source, about 3.4 million people in the United States live with epilepsy, and no single treatment works for every person with the condition. Experts say the new research is another step toward precision medicine, an approach in which treatments are tailored to the individual based on their genetics, lifestyle, and environment.

To read more about this study please visit:

Epilepsy: DNA study reveals potential causes and treatments (medicalnewstoday.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

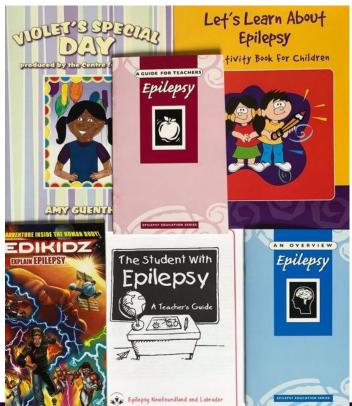
We have many classroom resources for students as well as for teachers, guidance counselors, principles and more. These resources are used to increase the awareness and understanding of epilepsy in the

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.







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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 2023

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

LED Sign Campaign 2023

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.

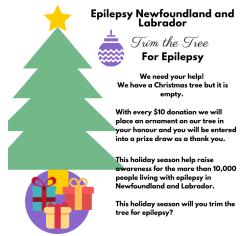
*To reserve a spot, or to learn more, please contact us by November 31st by emailing info@epilepsynl.com. Space is limited and will be reserved on a first come first served basis.



Trim the Tree for Epilepsy 2023

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 **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.





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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 advised to do so by an attending physician.



