

EPILEPSY NEWFOUNDLAND AND LABRADOR ENL

Fall 2021

Special Points of

- Back to School
- Scholarships

Interest

- Fall Programming Update
- Epilepsy Research
- Signs a Student is having a
- Christmas Campaign 2020
- 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". *

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Epilepsy NL Scholarships 2021

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 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 2021

EPILEPSY NEWFOUNDLAND AND LABRADOR

Support Group.

LET US KNOW!

CONTACT Alicia AT

Virtual Support Groups 2021

We will be starting our virtual support groups again on Wednesday, September 29, 2021 at 7:00pm. We will again host one group for People Living with Epilepsy and another for Caregivers of People with Epilepsy once biweekly, for one hour per session. Schedule for all sessions will be shared via email and our social media channels before September 29, 2021.

Purple Pumpkin Project 2021

In October we will be launching our Purple Pumpkin Project for 2021. We had great success last year and a ton of entries. We will once gain 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 2021. 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 2021. 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



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Epilepsy In the News

July 7, 2021

Research is underway at Western University that can help improve antiepileptic drug delivery through optimized dosing. Existing antiepileptic drugs (AEDs) do not match the peaks and valleys of when an epileptic seizure is most likely to occur, forcing patients to consume AEDs three to four times a day.

Chemical and biochemical engineering professor Kibret Mequanint's research aims to resolve this issue by developing a single, once-a-day (or potentially once-a-week) capsule that delivers doses to match the time of seizure peaks.

Some 300,000 Canadians suffer from epilepsy, a chronic neurological disorder that affects people of all ages and characterized by frequent seizures, according to the Public Health Agency of Canada. Mequanint and his team, including Schulich Medicine & Dentistry neurology professor and co-director of Western's epilepsy program Jorge Burneo, received a 2020 Exploration award valued at \$250,000 from the New Frontiers in Research Fund (NFRF) to support their anti-epileptic drug delivery research.

The NFRF-Exploration program supports interdisciplinary research that's considered high-risk and high-reward, providing researchers with the capacity to explore new possibilities with potentially significant impact. "Most seizures are not random events, but occur in cycles," said Mequanint.

In 80 per cent of patients with epilepsy, the 24-hour body clock that regulates a person's sleep-wake cycle – known as circadian rhythm – affects the timing of seizures. The pattern of seizures varies with the location of the epileptic focus in the brain, Mequanint explained. For example, seizures originating in the temporal lobe occur more often during the day, whereas seizures arising from the frontal and parietal lobe are more frequent during sleep.

"We cannot change a person's circadian rhythm, so our goal is to harness it for chronotherapy," said Mequanint. "We adjust the dosage of drugs to match the times of highest seizure occurrence and susceptibility. For instance, with frontal lobe seizure treatment, the capsule would release lower doses during the day and higher doses during the night."

One issue with oral drugs is that, shortly after being swallowed, the capsule disintegrates and releases its contents, and the body then quickly metabolizes the drug.

"So, how can we keep the capsule in the stomach for a longer time without it disintegrating and metabolizing?" asked Mequanint.

The team's proposed oral delivery system is packaged in such a way that the small, easy-to-swallow capsule has three layers, absorbs acid from the stomach to expand, and releases the drug through pulsation for a longer period of time rather than a constant amount.

"By reimagining how patients take oral AEDs, we envision a future where seizure times are precisely matched with increased drug dosage for maximum efficacy and without toxic effects," Mequanint said. "It also greatly increases patient compliance, since confusing dosing schedules, medication mix-up, and cognitive impairment with aging are major issues when ingesting oral tablets three to four times a day." Perfecting the right timing and right dosage with the right patient has the potential to revolutionize the treatment of epilepsy.

"We are very excited about the interest and enthusiasm it has already generated among neurologists and reviewers of our proposed AED delivery technology," said Mequanint. "This work builds on my existing research and Western's excellent clinical epilepsy program."

By Natalie Ebel Souce: https://news.westernu.ca/2021/07/improving-antiepileptic-drug-delivery/

Source

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

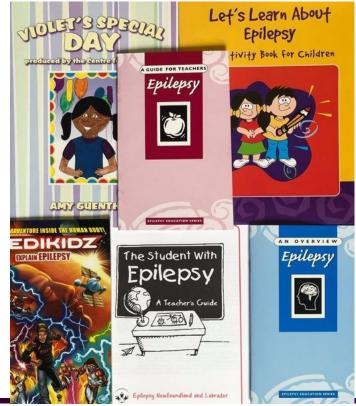
Back to School– Resources for the classroom

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.

Tips for a Productive Medical Appointment

Going to a medical appointment can be challenging. Many factors can contribute to not feeling like you are getting the most out of your appointment. Here are some tips to keep in mind before, during, and after an appointment to ensure you are getting the information you need.

- Keep a notebook with you, and before your appointment jot down questions you may have as you think of them. Bring the notebook to the appointment, this way you won't forget to ask
- Bring a pen along with your notebook to your appointment, and if comfortable bring a family member or close friend. Write down the answers to your questions, or ask your family member or friend to write them down. A large amount of information can be conveyed in a short amount of time, and writing down answers means you will have them for future reference.
- Don't hesitate to ask for clarification if you need it. Many people need further explanation of medical information, so don't be afraid to ask if you don't understand something.
- Be honest with your doctor. Try to describe your symptoms and patterns as clearly and simply as you can. An open and honest line of communication between yourself and your doctor is important in ensuring the best course of treatment. If you are taking vitamins, antidepressants, using alcohol, etc make sure you are honest about it with your doctor.
- Bring all medications with you to your appointment. Your doctor may have questions about what medications you are currently taking.
- After your appointment, take a moment to jot down things that are on your mind, either in the waiting room or in the car.



Christmas Campaign 2021

This year's Christmas Campaign is just around the corner, and 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.





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: Can I do anything to help control my seizures?

A: Sometimes people with epilepsy recognize that specific events or circumstances affect seizures. Recognizing your seizure triggers can help reduce or avoid seizures in some cases. Remembering to take your seizure medication, getting enough sleep, managing stress levels, and eating regularly and nutritiously, are all helpful in seizure control.

Some common seizure triggers are:

- Forgetting to take prescribed seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstruation/hormonal changes
- Medications other than prescribed seizure medications

*If you have further questions speak to your doctor and go from there. Via Epilepsy Education Series.



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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Disclaimer

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Attention: People with epilepsy should never discontinue anti-seizure medications or make changes in activities unless advised to do so by an attending physician.



