

EPILEPSY NEWFOUNDLAND AND LABRADOR ENL



Summer 2020

Special points of interest:

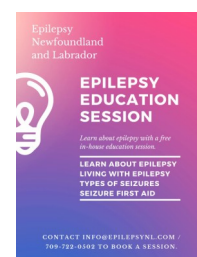
- Epilepsy Information Sessions
- Epilepsy and Summer Heat
- Epilepsy and Travel Safety
- Epilepsy and Music
- Epilepsy and Water Safety
- Asked and Answered



Epilepsy Summer Camp Information Sessions

Each year we offer epilepsy education sessions to summer camps in St. John's and surrounding areas which include learning about living with epilepsy; types of seizures; and seizure first aid. The summer camp education sessions provide a valuable opportunity to educate counselors each year, increasing awareness and knowledge surrounding epilepsy. The camp counselors are then in turn, able, to pass this knowledge along to their campers and are better able to offer a fully inclusive environment for the participants who are living with epilepsy. It is great to see this commitment to epilepsy awareness in our province, and the opportunity to educate a young population who can bring their education forward is truly priceless. Special shout out to Torbay, Bay Bulls and Portugal Cove-St. Philips who book every year!

To book an epilepsy education session for your work, school, community centre, daycare etc. contact Alicia at info@epilepsynl.com or 722-0502.



Epilepsy and High Temperatures

Although Newfoundland and Labrador is not known for its extreme high temperatures, this summer in particular has had some very hot and humid days. Some people with epilepsy may be sensitive to heat, and for some it can be important to stay cool to avoid triggering a seizure. www.epilepsy.com has some tips for beating the heat if you have epilepsy and are sensitive to higher temperatures.

Considerations for staying cool in warm weather include:

- Limit sun and heat exposure. Plan activities in the early morning or late afternoon and evening. This helps you avoid the warmest temperatures in the middle of the day.
- Dress in lightweight and light-colored clothing.
- Drink water before, during, and after physical activity to help keep your body temperature cool.
- When temperatures are high, spend time in buildings with air conditioning, such as museums, indoor playgrounds, libraries, or shopping centers.
- If a person has extreme heat intolerance, wearing a cooling vest may be helpful.

Listen to your body. If you feel weak, dizzy, or thirsty, find a place to rest in the shade. Drink water, tell someone (family member, lifeguard, camp counselor, coach, or friend) how you are feeling and take a break. Ask them to stay by your side until you feel better.

SEIZURE SMART TIPS for the summer

- ☒ Dress in lightweight & light-colored clothing
- ☒ Drink extra fluids to keep hydrated
- ☒ Stay in an air-conditioned environment if possible
- ☒ Remember to take your seizure medication



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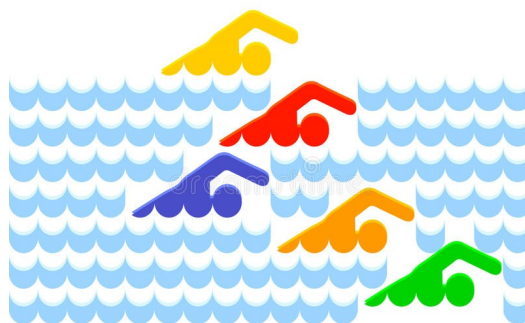
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Alicia Legge

Epilepsy and Water Safety

Would you know what to do if a seizure occurred when someone was in the water? With summer now here, more people will be hitting up pools, lakes, ponds, rivers and beaches to swim and enjoy outdoor recreation. Anyone who participates in water activities should be aware of the safety hazards and potential dangers. For those living with epilepsy a seizure can be an ongoing concern while swimming or doing other water related activities. Here are some safety tips if a seizure occurs in the water.

- Support the person's head
- Keep the person's head out of the water
- Tilt the head back to keep the airway clear
- Get the person to the side of the pool or to the shoreline
- Check the airway for obstruction
- If the person is NOT breathing begin resuscitation
- Call for emergency assistance. Immediate medical attention treatment is required even if the person seems to have recovered. Inhaling water can cause heart or lung damage.



Research-Epilepsy and Music Therapy

The results of the research study, "The Rhyme and Rhythm of Music in Epilepsy," was recently published in the international journal *Epilepsia Open*. It looks at the effects of the Mozart melody, "Sonata for Two Pianos in D Major, K. 448" on reducing seizures, as compared to another auditory stimulus -- a scrambled version of the original Mozart composition, with similar mathematical features, but shuffled randomly and lacking any rhythmicity.

"In the past 15 to 20 years, we have learned a lot about how listening to one of Mozart's compositions in individuals with epilepsy appears to demonstrate a reduction in seizure frequency," says Dr. Marjan Rafiee, lead author on the study. "But, one of the questions that still needed to be answered was whether individuals would show a similar reduction in seizure frequency by listening to another auditory stimulus -- a control piece -- as compared to Mozart."

The researchers recruited 13 patients to participate in the novel, year-long study. After three months of a baseline period, half of the patients listened to Mozart's Sonata once daily for three months, then switched to the scrambled version for three months. The others started the intervention by listening to the scrambled version for three months, then switched to daily listening of Mozart.

Patients kept "seizure diaries" to document their seizure frequency during the intervention. Their medications were kept unchanged during the course of the study.

"Our results showed daily listening to the first movement of Mozart K.448 was associated with reducing seizure frequency in adult individuals with epilepsy," says Dr. Rafiee. "This suggests that daily Mozart listening may be considered as a supplemental therapeutic option to reduce seizures in individuals with epilepsy."

Epilepsy is the most common serious neurological disorder in the world, affecting approximately 300,000 Canadians and 50 million people worldwide.

Many experience debilitating seizures. The treatment is often one or more anti-seizure medications. But for 30 per cent of patients, the medications are not effective in controlling their seizures.

"As a surgeon, I have the pleasure of seeing individuals benefit from surgery, however I also know well those individuals for whom surgery is not an option, or those who have not benefitted from surgery, so, we are always looking for ways to improve symptom control, and improve quality of life for those with epilepsy," says Dr. Taufik Valiante, senior author of the study and the Director of the Surgical Epilepsy Program at Krembil Brain Institute at UHN and co-Director of CRANIA.

"Like all research, ours raises a lot of questions that we are excited to continue to answer with further research and support from the epilepsy community."

While these results are promising, the next step is to conduct larger studies with more patients, over a longer period of time.

Source: sciencedaily.com Materials provided by Universal Health Network.



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.

Epilepsy and Travel

While our bubble continues to expand and more people are on the move it is important for people with epilepsy to remain safe while traveling. This article is intended to pass along some important safety tips while you travel at home or abroad.

- There are restrictions to driving if your seizures are not controlled. Driving is generally not allowed until you have been seizure free for at least 6 to 12 months, and you are under a doctor's care.
- Carry a copy of important medical information, phone numbers,, and a list of your seizure medication with you.
- Assure that you stand away from platforms if using a train, subway or bus while travelling.
- Use elevators rather than escalators or stairs.
- Have someone accompany you if you are going to be outdoors during extremely hot or extremely low temperatures.
- If travelling by air, consider whether to inform the airline officials of your condition in advance to allow for preparation in case of a seizure
- Carry some seizure medication on your person in the event of lost luggage
- Take all seizure medication in the original bottles that you will be needing during your stay in case of unavailability. Extra medication should also be taken in the event that some is lost or your stay is extended.
- If crossing time zones, assure that you maintain your seizure medication schedules as prescribed
- Before having a vaccination, ask your doctor about any medication interactions or concerns
- Find out if travel agencies offer discounted transportation for an escort that is capable of giving the required assistance if medically necessary
- Wear a medical identification bracelet



Calendar Campaign

Our calendar campaign is in full swing. Although things look different this year due to Covid-19, and we do not have physical calendars on hand, we still need your support. If you wish you can donate to our calendar campaign online via our website epilepsynl.com or you can call our office at 709-722-0502.

Friends and Family Thank You

Epilepsy Newfoundland and Labrador would like to take this opportunity to thank all of our past participants of this campaign for your dedication and support. This campaign would not be a success without our volunteers generously donating their time and energy. Thank you for all of your hard work! If you would like to pick up a kit and collect donations from your Friends and Family, please contact Elaine at 709-722-0502 or 1-866—EPILEPSY.



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.





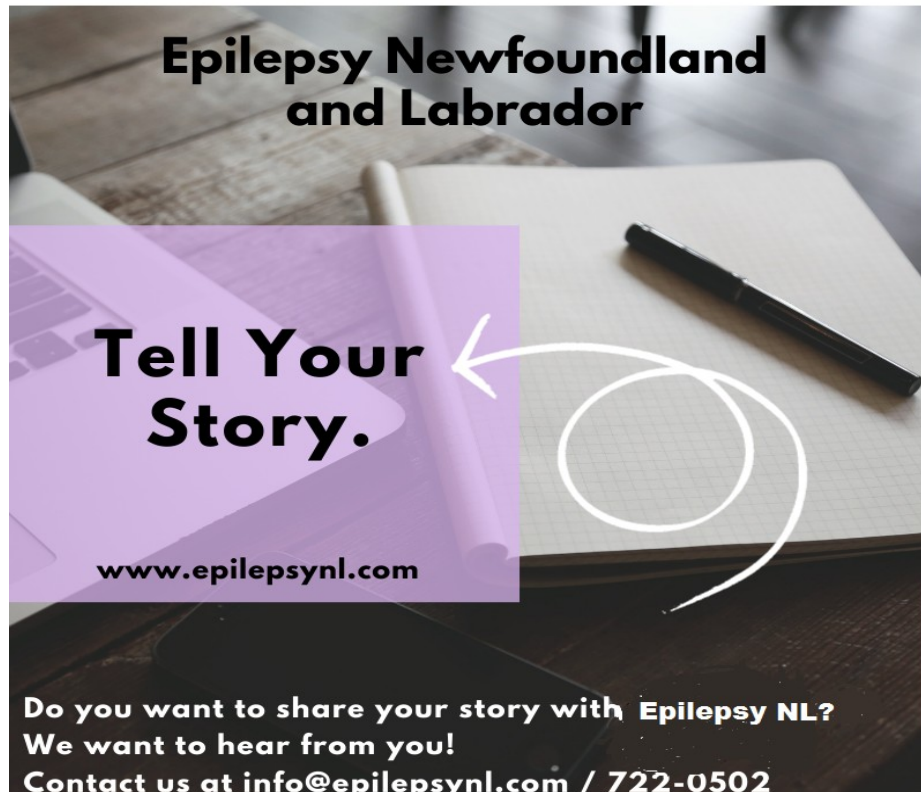
Epilepsy Education Session: Now Online with Connect & Learn

Awareness of epilepsy and seizure first aid is essential in protecting the safety of a person who lives with epilepsy and seizures. Our mission is to share information, and educate the public on the subject of epilepsy, and to adopt any measures necessary to improve the health, strength, and well being of those with epilepsy, wherever possible, in the province of Newfoundland and Labrador. With our new Connect & Learn Online Epilepsy Education Program we will be able to reach more of Newfoundland and Labrador by offering Information Sessions online.

Schedule an info session for your school, workplace, community centre or other and learn about epilepsy, living with epilepsy, seizure first aid and more anywhere in NL with Internet access. Contact us at: info@epilepsynl.com / 722-0502 to schedule a session or for further information.

Share your Story with us!

Do you want to share your story with Epilepsy NL? We want to hear from you! Sharing experiences reminds us that we are not alone. Contact us at info@epilepsynl.com / 722-0502 if you'd like to share your story in our newsletter!



Epilepsy News –Epilepsy NL Scholarship Program

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

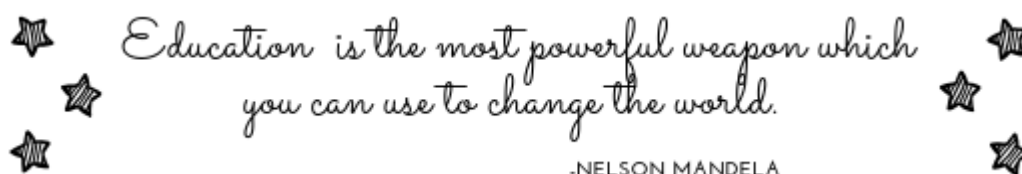
The Zach Rowe Memorial Scholarship, valued at \$1000, is awarded to a student with epilepsy who is currently in, or about to enter, their first year of Post Secondary studies. It honours Zach Rowe, recipient of an ENL scholarship in 2006, who passed away as a result of a seizure in 2009. He was 21 years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



-NELSON MANDELA

Asked and Answered

Q: *What is photosensitive epilepsy?*

A: In one type of epilepsy known as photosensitive epilepsy, lights flickering at certain speeds and brightness (e.g. From televisions, computer screens, strobe lights video games, movies) can trigger a seizure. Sometimes natural light patterns such as sunlight reflecting off water can trigger seizures. Seizures are most often tonic clonic. Treatment includes avoiding the stimulation, or if the epilepsy is severe, medication may be prescribed. Photosensitive epilepsy is often outgrown in adulthood (late 20's or early 30's). It is estimated that fewer than 5% of people with epilepsy are photosensitive according to the Canadian Epilepsy Alliance.



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Epilepsy
Newfoundland & Labrador



Asked and Answered



Q: What about pregnancy and epilepsy?

A: Some types of seizure medications can also interfere with the effectiveness of birth control pills and or could involve the risk of causing harm to a fetus. Most women with epilepsy have healthy babies but there is a slightly higher risk that having epilepsy or taking seizure medication will affect the fetus. **If you are planning to use or are taking birth control pills, are planning to become pregnant, or are pregnant, it is essential that you talk with your doctor.** Changes in medication levels or prescribed drugs may be required. Your doctor may recommend taking folic acid as it is thought to prevent birth defects and is recommended for all women of child bearing age.

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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.

Epilepsy
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Tips to keep mentally healthy during COVID-19

1. **PAUSE.** Breath. Reflect
2. **KEEP** a healthy routine
3. **CONNECT** with others
4. **BE KIND** to yourself and others
5. **REACH OUT** for help if you need it

Taken from the World Health Organization