

## Special Points Of

### Interest

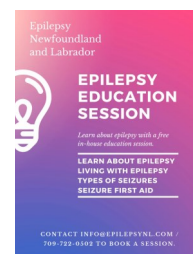
- Epilepsy NL Education Sessions
- Epilepsy and Summer Temperatures
- Donations 2022
- Scholarships 2022
- Photosensitive Epilepsy
- Epilepsy and Travel
- Summer Safety Tips



## 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 in a position to pass this knowledge along to their campers and are better equipped 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](mailto: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](http://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



## Hebron Donation 2022

Epilepsy NL was delighted to receive a donation from Hebron Offshore Workforce (ExxonMobil). The offshore workers from the Hebron Platform participate in a Nobody Gets Hurt (NGH) Safety Program. This program encourages workers to look out for each other and record both safe & unsafe acts while on and off duty. The observations are captured on NGH Cards and submitted to the Safety Department for trending.

For each card submitted ExxonMobil Canada (EMC) donates \$0.50. Each Quarter workers will vote from a list of potential charities and the charity with the most votes will be presented the donation. The Hebron Platform workforce voted Epilepsy Newfoundland and Labrador as this last quarter's charity recipient. The donation was inspired by Jacob, who lives with epilepsy and is the son of Wallace England who works for Hebron.

The Hebron co-venturers (ExxonMobil Canada - operator, Chevron Canada, Suncor Energy, Statoil Canada, Nalcor Energy) provided Epilepsy Newfoundland and Labrador with a one time donation of \$7,202.00 as part of the Hebron Platform Nobody Gets Hurt Charity Program. This money will help Epilepsy Newfoundland and Labrador continue their important work in the community; we are honored and grateful to accept this donation from Hebron.



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## Best Kind Productions Looking to Support Epilepsy NL

Best Kind Productions is planning to donate one dollar from every admission to their summer children's musical at the Bowring Park Amphitheatre to Epilepsy Newfoundland and Labrador. It is their ninth summer production, and in the summer of 2022 they're producing "Disney's Descendants". A well known actor from Disney movies, Cameron Boyce, passed away suddenly from epilepsy, (SUDEP) in 2019 so they thought it would be appropriate to donate to Epilepsy NL. A friend of the company, Emma MacDonald, who's boyfriend passed away from SUDEP will be helping to promote the production.

For more information on dates for the event please visit  
[www.bestkindproductions.com](http://www.bestkindproductions.com)



Each year, Epilepsy Newfoundland and Labrador offers four 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](mailto: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: [epilepsynl.com/scholarships](http://epilepsynl.com/scholarships)

## Zach Rowe Memorial Scholarship

**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

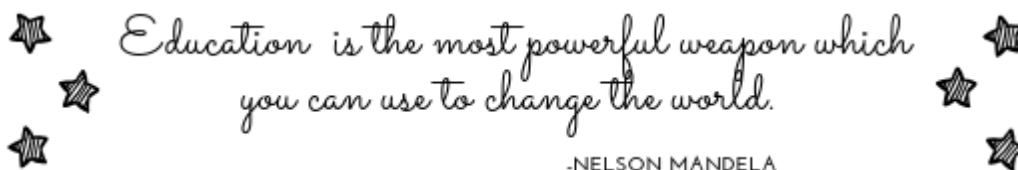
**Jim Hierlihy Memorial Scholarship** The Jim Hierlihy Memorial Scholarship, valued at \$1000, is awarded to a mature student with epilepsy who has taken the initiative to return to studies to advance in their present job or train for a new career. It honours one of ENL's in-credible volunteers, Jim Hierlihy, who was on the Executive of the ENL support group in Gander and a great supporter of all those living with seizures.

## Epilepsy NL Family Scholarship

**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.

## Ben Basha Memorial Scholarship

**Ben Basha Memorial Scholarship** The Ben Basha Memorial Scholarship is awarded to a student with epilepsy studying at a post-secondary institution. Valued at \$1000, it honours Ben, who passed away suddenly at the age of 19 in 2019.



## Asked and Answered

**Q: My pharmacy has substituted the brand name medication I am used to taking with the generic brand. Is there a difference?**

**A:** Anti-epileptic medications come in two forms. "Brand name" or "generic". Brand name medications are made by a research based pharmaceutical company which has a patent on the drug for a certain length of time. When the patent expires, other manufacturers can then produce the drug under a generic name. The active ingredient that helps to control your seizures is the same in both brand and generic names, but there are also components of the medication known as fillers, dyes or binders. These can sometimes differ between brand and generic names. This can occasionally make a difference in how quickly they are absorbed from your stomach, or processed by your body. The difference in fillers, binders or dyes that may be found between generic and brand name medications may affect how much medicine you need. You should at all times be aware of exactly what medications you are receiving.

If you notice any changes in your seizure pattern talk to your physician or pharmacist. \*Via Epilepsy Education Series \*If you have a question you would like answered email [info@epilepsynl.com](mailto:info@epilepsynl.com) or call 709-722-0502

## 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
- Purple Star Award, Purple Teddy and Purple Sunrise Awards offered to members and residents of NL who have epilepsy
- 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](mailto: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](mailto:info@epilepsynl.com) to save on postage. You can also submit your form online ([www.epilepsynl.com](http://www.epilepsynl.com)). If you would like to make a donation you can donate through our website by visiting [epilepsynl.com](http://epilepsynl.com) and clicking the DONATE button.

## What is Photosensitive Epilepsy?

Photosensitivity describes a sensitivity to flashing or flickering lights, usually of high intensity, which are pulsating in a regular pattern. Many people are uncomfortable when exposed to such lights, but people with photosensitive epilepsy can be triggered into seizures by them. When given an electroencephalogram (EEG test), the majority of such patients will show epileptiform brain discharges when exposed to flashing lights.

Photosensitive epilepsy most commonly affects children, and usually appears between the ages of 8 and 20 years. The incidence is highest around ages 12 and 13, suggesting a link with early puberty, and girls are affected more often than boys. There is some evidence to suggest that photosensitivity can disappear with age. It is estimated that fewer than 5% of people with epilepsy are photosensitive.

In addition, there is an unknown number of photosensitive persons who have as yet not had a seizure. Photosensitive epilepsy is largely a genetically determined, although its inheritance is complex. Not all flashing lights or visual patterns will trigger a seizure, even in individuals who are photosensitive. The rate of the flashing light, the duration of the flashing, and the intensity of the light all play a part. A flash at a frequency of between 15 and 20 flashes per second is most likely to cause a seizure, whereas very few people are sensitive to a rate of 3 flashes per second. The seizures that are produced may take various forms, usually tonic clonic (grand mal), absence, myoclonic, or, less often, simple or complex partial seizures.

## Safety for Those with Photosensitive Epilepsy

Lights flickering at a certain speed and brightness can trigger a seizure in people with photosensitive epilepsy. "Safety and Epilepsy" via the Epilepsy Education Series lists some tips and suggestions.

- Limit situations that expose you to flickering light
- Do not sit too close to the television • Watch television in a room that is well lit
- Take breaks from using the computer
- Monitor which video and computer games could trigger seizures
- Wear polarized sunglasses outdoors to diminish the effect of flicker from natural light.

## Summer Fun Safety Tips

Do fireworks bother people with seizures? What other triggers should I watch *out for*?

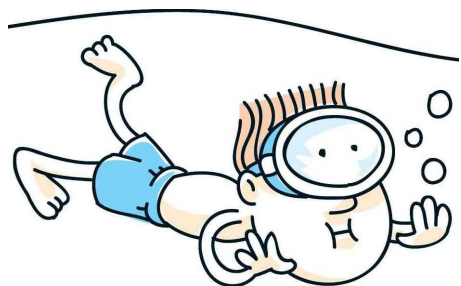
*People who have photosensitive seizures may have seizures triggered by watching fireworks.* Fireworks can bother people without true photosensitivity, if they are sensitive to flashing lights or patterns. If fireworks always bother you, don't watch them! Other tips to consider: Sit far back from the fireworks, look away frequently, and wear head phones if noise bothers you too. Try to avoid lots of triggers happening at the same time. Consider your high risk times. Being sleep deprived, over-tired, sick, or in midst of other physical or emotional stress can make a person more likely to have a seizure too.



## 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.





## Epilepsy and Travel 2022

Since the world is getting back to a new way of “normal” more people are starting to travel again. 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

### Seizure First Aid for People Who use a Wheelchair

Put the brakes on, to stop the chair from moving

Allow the person to remain seated in the chair during the seizure (unless they have a care plan which says to move them).

If the person has a seatbelt or harness on, leave it fastened

If the person doesn't have a seatbelt or harness, support them gently, so they don't fall out of the chair

Cushion the person's head and support it gently.

Do not restrain

Afterward, talk gently to the person, be comforting and reassuring and stay with them until they become re-oriented.



## EPILEPSY NL

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[www.epilepsynl.com](http://www.epilepsynl.com)



## Asked and Answered



**Q: Who should I tell about my epilepsy?**

**A:** Consider carefully with whom you share personal information. The decision may depend on the type and frequency of your seizures. Sometimes it may be based on how close you feel to the person or whether a person would know what to do to help you if you had a seizure while in their company. Although it may not be necessary to tell everyone about your epilepsy it is important for those you are with often to know how to help if you have a seizure.

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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.**

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