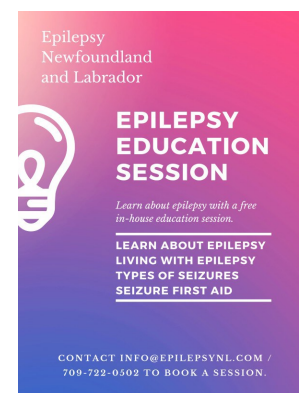


Epilepsy Summer Camp Information Sessions

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 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 high 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.

Special Points Of

Interest

- Epilepsy NL Education Sessions
- Silent Auction 2023
- Community Connect Event 2023
- Epilepsy and Summer Temperatures
- Scholarships 2023
- Photosensitive Epilepsy
- Epilepsy and Travel
- Summer Safety Tips



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



Epilepsy NL Silent Auction 2023

We asked and sponsors stepped up from all over the province.

Our silent auction kicked off on June 15! There's still time to participate and support Epilepsy Newfoundland and Labrador. We've already seen incredible bids and generous contributions from our community, but the auction is far from over! Don't miss out on the chance to win amazing items while making a difference in the lives of the individuals living with epilepsy in our province.

With a wide range of enticing items up for grabs, there's something for everyone to enjoy. Whether you're searching for unique experiences, luxury products, or exclusive services, our auction has it all. Explore the catalog and place your bids on your favorite items before it's too late!

<https://epilepsynl.com/epilepsy-newfoundland-and-labradors-online-silent-auction-2023/>

Auction ends July 14, 2023



Board of Directors

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)

William Westcott
(St. John's)

Executive Director

Gail Dempsey

Medical Consultant

Dr. A.O. Ogunyemi, M.D.,
FRCP ©

Information Officer

Alicia Legge

Community Connect Social Networking Event 2023

You asked and we listened! We are hosting our first community connect social networking event on August 19, 2023.

We have Kenmount Terrace Community Centre booked with access to the outside spaces as well. There will be food, music, special guests and fun for all ages. The event is free and family friendly.

If you plan to attend please RSVP to Alicia or if you wish to hold your own community connect event for epilepsy please contact Alicia at info@epilepsynl.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 / 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

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

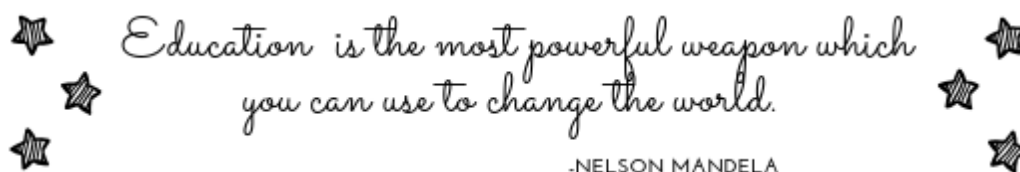
Jim Hierlihy Memorial Scholarship The Jim Hierlihy Memorial Scholarship, valued at \$1000, is awarded to a mature student with epilepsy who has taken the initiative to return to studies to advance in their present job or train for a new career. It honours one of ENL's in-credible volunteers, Jim Hierlihy, 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 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
- Three 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 programs and services
- Voting privileges at Annual General Meeting for class A members
- 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.



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.

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 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?

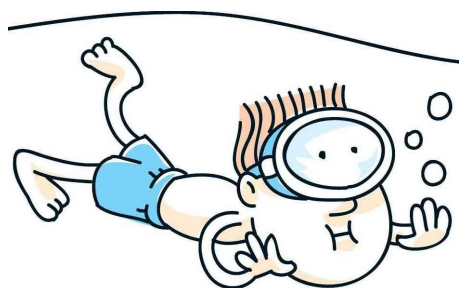
People who have photosensitive seizures may have seizures triggered by watching fireworks. Fireworks can bother people without true photosensitivity, if they are sensitive to flashing lights or patterns. If fireworks always bother you, don't watch them! Other tips to consider: Sit far back from the fireworks, 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.

- Keep the person's head out of the water
- Support the person's head
- 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 2023

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, that you will be needing during your stay, in the original bottles 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

351 Kenmount Road
St. John's, NL.
A1B 3P9

Phone: 709-722-0502
Fax: 709-722-0999

E-mail: info@epilepsynl.com

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. It may not be necessary to tell everyone about your epilepsy. It is important for friends and family to know how to help if you have a seizure.

Previously Loved ♥
Clothes & Things

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.



 @PLCAT @EPILEPSYNL  @EPILEPSYNL WWW.EPILEPSYNL.COM



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.