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Epilepsy News is
printed quarterly by:

**Epilepsy
Newfoundland &
Labrador**

351 Kenmount Rd.
St. John's, NL A1B 3P9
(709) 722-0502
Toll Free:
1-866-EPILEPSY
Fax: (709)722-0999
info@epilepsynl.com
www.epilepsynl.com

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The Importance of Summer Camp Education Sessions

Each year we offer epilepsy education sessions, including learning about living with epilepsy, types of seizures, and seizure first aid, to summer camps in St. John's and surrounding areas. The summer camp education sessions provide a valuable opportunity to educate counsellors each year, increasing awareness and knowledge surrounding epilepsy. The camp counsellors 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 or other contact Sarah at info@epilepsynl.com or 722-0502.

Epilepsy
Newfoundland
and Labrador



EPILEPSY EDUCATION SESSION

Learn about epilepsy with a free
in-house education session.

LEARN ABOUT EPILEPSY
LIVING WITH EPILEPSY
TYPES OF SEIZURES
SEIZURE FIRST AID

CONTACT INFO@EPILEPSYNL.COM /
709-722-0502 TO BOOK A SESSION.

Epilepsy NL and Rocket Bakery

A big thank you to Rocket Bakery who raised \$307.50 for Epilepsy NL by donating the proceeds of the sales of their purple macarons! Rocket has been participating in Purple Day and raising Epilepsy Awareness for many years and we are truly

thankful. If you are in the area stop by and grab a coffee and a treat-we did and they were delicious!

Pictured: Kayla Walters, Marketing and Sales at Rocket presenting a cheque to Epilepsy NL CIO Sarah Mercer.



CLAE Scientific Meeting 2019

Epilepsy Newfoundland and Labrador will be attending the CLAE Annual Scientific Meeting from September 20-22, 2019, in Winnipeg. "The CLAE Annual Scientific Meeting brings together our members to learn and apply key advances in the field of epilepsy. This meeting is

more than a scientific meeting — it is also an eventful get-together coupled with an unparalleled networking opportunity. Canadians are at the forefront of key breakthroughs, leading the world in epilepsy research". (via clae group.org)

Epilepsy NL are dedicated contributors to the funding of important epilepsy research in Newfoundland and Labrador, and are looking forward to attending and hearing the important research surrounding epilepsy that is happening throughout Canada.

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Sarah Mercer

Epilepsy Newfoundland and Labrador Scholarships

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.

The 2018 winner of the Zach Rowe Memorial Scholarship was Rachel Spicer. She has been involved with Epilepsy Newfoundland and Labrador for many years, and has been a tireless advocate for Epilepsy Awareness over the years. Rachel is currently attending the University of New Brunswick.



We wish her the best of luck in her future endeavors.

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

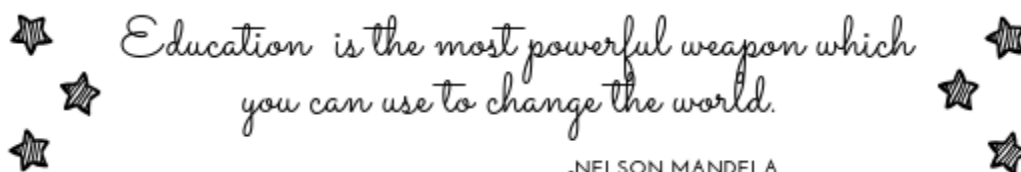
living with seizures. Applicants must have diagnosed epilepsy, be 21 years of age or older, and be a member in good standing of Epilepsy NL at the time of application.

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

Calendar Campaign

Our calendar campaign is in full swing. With a donation of \$20.00 or more we will send you a calendar featuring drawings created by grade 4 students throughout Newfoundland and Labrador as a thank you gift. We would like to offer a big thank you to all the students who submitted their artwork, and offer congratulations to the students who

have artwork in the calendar:

Kseniia Zvereva, Paradise, NL. (Cover Photo), Ava Winsor, Outer Cove, NL, Naomi Barrett, Paradise, NL, Sophie Squire, Eastport, NL, Abby Bedford, St. John's, NL, Torin Stephen, St. John's, NL, Dekin Earle, Point Leamington, NL, Emma Penney, Colliers, NL, Brooklyn Chippett, Buchans,

NL, Savannah Burden, Port Hope Simpson, NL, Noel Elliott, Mud Lake, NL, Noel Elliott, Mud Lake, NL, Ava Churchill, St. Lawrence, NL.

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.

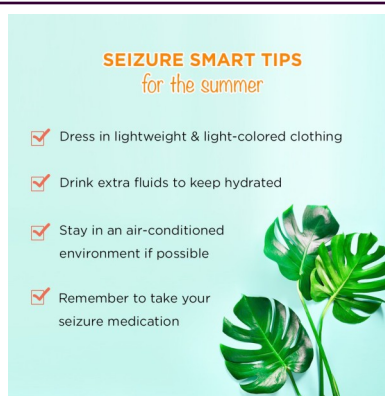


Epilepsy and Summer Heat

Although Newfoundland and Labrador is not known for it's 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.

"Summer can bring extreme temperatures. Some people with epilepsy may be sensitive to heat. Staying cool is important. 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.



"Some people with epilepsy may be sensitive to heat. Staying cool is important."

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, or canvass door to door in your area, please contact Elaine at 709-722-0502 or 1-866- EPILEPSY.



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 Research in Ireland May Help Predict Seizures

Researchers in Ireland have found a signal that appears in the blood before an epileptic seizure happens. This discovery may lead to the development of an early warning system, which would enable people with epilepsy to know when they are at risk of having a seizure.

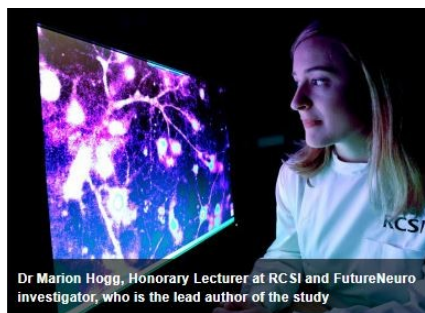
Researchers at FutureNeuro, hosted at the Royal College of Surgeons in Ireland (RCSI) led the study, which is published in the current edition of the *Journal of Clinical Investigation* (JCI). The researchers have discovered molecules in the blood that are higher in people with epilepsy before a seizure happens. These molecules are fragments of transfer RNAs (tRNAs), a chemical closely related to DNA that performs an important role in building proteins within the cell.

When cells are stressed, tRNAs are cut into fragments. Higher levels of the fragments

in the blood could reflect that brain cells are under stress in the build up to a seizure event. Using blood samples from people with epilepsy at Beaumont Hospital, Dublin and in a similar specialist centre in Marburg, Germany, the group found that fragment levels of three tRNAs "spike" in the blood many hours before a seizure.

"People with epilepsy often report that one of the most difficult aspects of living with the disease is never knowing when a seizure will occur," said Dr Marion Hogg, the study's lead author said. Around 40,000 people in Ireland have epilepsy and one third of those don't respond to current treatments, meaning they continue experiencing seizures.

"New technologies to remove the unpredictability of uncon-



Dr Marion Hogg, Honorary Lecturer at RCSI and FutureNeuro investigator, who is the lead author of the study

Image: Maxwell Photography

trolled seizures for people with epilepsy are a very real possibility," said Professor David Henshall, a co-author on the paper, said. "Building on this research we in FutureNeuro hope to develop a test prototype, similar to a blood sugar monitor that can potentially predict when a seizure might occur."

Via thejournal.ie

"New technologies to remove the unpredictability of uncontrolled seizures for people with epilepsy are a very real possibility."

-Professor David Henshall,

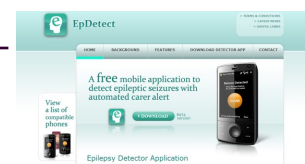
EpDetect

EpDetect is an accelerometer based mobile phone app that uses advanced signal processing to detect epileptic seizures. It runs on most mobile phones that support SMS messaging, movement detection and GPS position location. EpDetect monitors the

wearers movements, distinguishing between normal movement and movement associated with a Tonic-clonic seizure. If a seizure is detected, EpDetect will contact and alert your carer with your status and GPS position. EpDetect has been designed to work



with most Android or Windows Mobile 6.1 equipped phones that support accelerometer applications. EpDetect is not currently compatible with the apple iPhone or Windows Phone 7. For more info visit epdetect.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.

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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

Epilepsy
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Asked and Answered

Q: Will my epilepsy medication have side effects?

A: All drugs, including anti-epileptic medications, have the potential to cause side effects. Many people take anti-epileptic medication for years without difficulty. It is important that you talk to your physician about any possible side effects from prescribed medication. Side effects, which tend to be more common when a drug is just started, or when dosage is increased, may go away after a few days/weeks.

Side effects can be categorized as follows:

Dose Related: Some side effects are related to the level of the drug in the blood. In other words, the effect will not be present at low doses and low blood levels, but virtually everyone will have the side effect at very high doses and high blood levels. The most common side effects include drowsiness, fatigue, dizziness and loss of co-ordination.

Allergic side effects: these side effects are not directly related to the blood level and are much less common than the dose related effects. Allergic side effects are unpredictable. Examples of this type of side effect include a skin rash or liver trouble. Ask your physician which "allergic" responses you might encounter with your specific medication.

Although the overwhelming majority of medication side effects are not dangerous or permanent, some people with chronic epilepsy worry about the possibility of long term side effects. Long term side effects vary from drug to drug and *can* involve cognitive, renal and liver function. Long term use of some anti-epileptic medications can also affect vitamin D and calcium metabolism, with possible effects on bone density (bone thinning). Talk to your physician about ways you can avoid possible long term side effects.

Previously Loved ♥
Clothes & Things

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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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@EPILEPSYNL

WWW.EPILEPSYNL.COM



Interested in a Support Group?

Let Us Know!

Contact Sarah at info@epilepsynl.com / 722-0502