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printed quarterly by:

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Epilepsy NL Research Grant

On August 15th, 2019, Epilepsy Newfoundland and Labrador presented a research grant in the amount of \$25,000.00 to Dr. Curtis French, Discipline of Genetics, MUN Faculty of Medicine. Dr. French's study involves observing zebrafish to help understand the anti-seizure properties of cannabis, and hopes to identify which molecules in cannabis plants can potentially provide the most benefit to patients with epilepsy. A summary of the research entitled *Using zebrafish to Help Understand the Anti-seizure Properties of Cannabis*, provided by Dr. French, follows:

"Cannabis has been used to treat seizures for centuries. Cannabis contains hundreds of molecules that may help manage seizures, but standardized testing for most of these molecules is lacking. While Cannabidiol (CBD) has shown promise, it is unclear whether many of the other molecules found in cannabis may also help. With this grant from EpilepsyNL, my lab

will test at least eight molecules found in cannabis plants, including CBD, for anti-epileptic properties.

For this, we will use a zebrafish model system. We can induce seizures in these animals that mimic those of patients, allowing us to test whether CBD and potentially other molecules found in cannabis can help manage seizures. Importantly, because we can house large numbers of zebrafish at low cost, we can very quickly screen compounds isolated from cannabis plants to test their potential benefits. We hope that this study will precisely identify which molecules in cannabis plants provide the most benefit in our zebrafish model system. We will subsequently work with cannabis companies in New-

foundland to identify cannabis strains that are enriched in these molecules, as such strains would likely be of most benefit to patients with epilepsy."

We are excited to support important and innovative epilepsy research happening right here in our province.

Pictured: (R-L) ENL Information Officer Sarah Mercer, ENL Executive Director Gail Dempsey, Dr. Curtis French, MUN Faculty of Medicine.



Epilepsy Research with NL Nursing Students

Epilepsy Newfoundland and Labrador is hosting 4th year nursing students for their Community Health Nursing Practice course. The goal of the course is to enable students to gain experience collaborating with groups of clients in the community. They have chosen to explore new diagnosis in the epilepsy community and have compiled a survey for those who have been diagnosed with epi-

lepsy, friends, family, loved ones and caregivers. The link is below along with their blurb, please do not hesitate to fill out the survey if you are interested!

"We are fourth-year nursing students at the Centre for Nursing Studies who are creating a resource for newly diagnosed persons with epilepsy about what to expect from, and how to navigate the healthcare system. We would appreciate

your input about the process of navigating the healthcare system in the early stages of an epilepsy diagnosis so that we can develop a resource. You can participate by completing the survey in the link below. Before you begin the survey, please know that what you share with us is anonymous and all responses will be kept confidential. Survey Link: <https://www.surveymonkey.com/r/W5H3GR5>

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Epilepsy NL Scholarships 2019

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. Applicants must be members of Epilepsy NL. Not a member? Contact info@epilepsynl.com / 709-722-0502 to register for free.

Scholarship applications can be found online at:

<http://epilepsynl.com/scholarships>

Zach Rowe Memorial Scholarship

The Zach Rowe Memorial Scholarship, valued at \$1000 is awarded to a student with epilepsy 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 his seizures in 2009. He was 21 years old.

Applicants must have diagnosed 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, extracurricular activities and financial need. Award holders must be prepared to enter or currently be enrolled in a post-secondary training institution in the academic year of application.

Epilepsy Newfoundland and Labrador

Zach Rowe Memorial Scholarship 2019

ELIGIBILITY

- STUDENT WITH EPILEPSY CURRENTLY IN, OR ABOUT TO ENTER, THEIR FIRST YEAR OF POST SECONDARY STUDIES
- MEMBER WITH EPILEPSY NL AT THE TIME OF APPLICATION

HOW TO APPLY

- DOWNLOAD THE APPLICATION FORM AT: EPILEPSYNL.COM/SCHOLARSHIPS AND EMAIL US THE COMPLETED FORM WITH ESSAY AND TRANSCRIPT AT: INFO@EPILEPSYNL.COM
- CONTACT INFO@EPILEPSYNL.COM / 722-0502 FOR FURTHER INQUIRIES

Epilepsy NL Family Scholarship

Epilepsy Newfoundland and Labrador

Family Scholarship 2019

ELIGIBILITY

- STUDENT WHO HAS A FAMILY MEMBER DIAGNOSED WITH EPILEPSY AND IS CURRENTLY IN, OR ABOUT TO ENTER, THEIR FIRST YEAR OF POST SECONDARY STUDIES
- MEMBER WITH EPILEPSY NL AT THE TIME OF APPLICATION

HOW TO APPLY

- DOWNLOAD THE APPLICATION FORM AT: EPILEPSYNL.COM/SCHOLARSHIPS AND EMAIL US THE COMPLETED FORM WITH ESSAY AND TRANSCRIPT AT: INFO@EPILEPSYNL.COM
- CONTACT INFO@EPILEPSYNL.COM / 722-0502 FOR FURTHER INQUIRIES

The Epilepsy NL Family Scholarship, valued at \$1000, is awarded to a student who has a family member diagnosed with epilepsy, and is 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 of ENL at the time of application, and submit a transcript of their most recent marks with their application. Evaluations will be based on a combination of the applicant's grades, extracurricular activities and financial need.

Jim Hierlihy Memorial Scholarship

The Jim Hierlihy Memorial Scholarship, valued at \$1000, is awarded to a mature student with epilepsy who has taken 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 a great supporter of all those living with seizures.

Applicants must have diagnosed epilepsy, be 21 years of age or older, be a member with Epilepsy NL and be returning to studies. Award holders must be prepared to enter or currently be enrolled in a post-secondary training institution in the academic year of application.

Epilepsy Newfoundland and Labrador

Jim Hierlihy Memorial Scholarship 2019

ELIGIBILITY

- MATURE STUDENT WITH EPILEPSY WHO HAS TAKEN INITIATIVE TO RETURN TO STUDIES TO ADVANCE IN THEIR PRESENT JOB OR TRAIN FOR A NEW CAREER
- 21 YEARS OF AGE OR OLDER
- MEMBER WITH EPILEPSY NL AT THE TIME OF APPLICATION

HOW TO APPLY

- DOWNLOAD THE APPLICATION FORM AT: EPILEPSYNL.COM/SCHOLARSHIPS AND EMAIL US THE COMPLETED FORM WITH ESSAY AND TRANSCRIPT AT: INFO@EPILEPSYNL.COM
- CONTACT INFO@EPILEPSYNL.COM / 722-0502 FOR FURTHER INQUIRIES

Zach Rowe Horseshoe Tournament: 10 Year Anniversary



This year marked the 10th anniversary of the Zach Rowe Memorial Horseshoe Tournament, held in honour of Zach, who passed away as a result of his seizures in 2009.

The tournament is held over the Labour Day weekend and organized by Joan Parsons, grandmother of Zach Rowe, as well as family and friends. This year the tournament was a great success, raising \$1245 for the Zach Rowe Memorial

Scholarship offered by Epilepsy Newfoundland and Labrador. Zach himself was a winner of an ENL scholarship in 2006 and wrote in his scholarship application: "I have never let my disability stop me from having a normal life. All of

this just makes me even more determined."

Thank you to Joan, hosts Jim and Donna White, and all who helped organize/attended this year's tournament. Through the generosity of others we have seen the enormous impact Zach had on the people around him.

This was the final year for the Zach Rowe Horseshoe Tournament, and over the past 10 years the tourna-

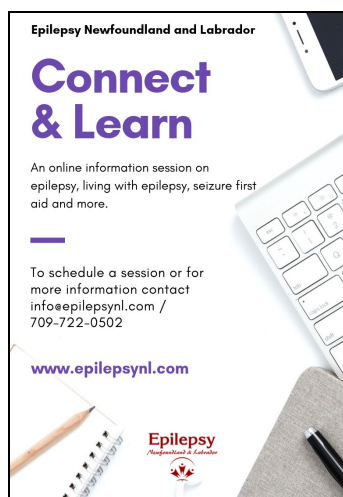
ment has raised a grand total of \$12,210.10! The grand total raised as a result of fundraisers in Zach's memory, including the Zach Rowe Hockey Tournament, Scholarship contributions and In Memoriam donations is \$22,118.29! This is truly incredible and we would like to extend our utmost thanks to Joan and all involved for your dedication to epilepsy awareness over the last 10 years and more. You have made such an incredible impact on the epilepsy community all throughout Newfoundland and Labrador.



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.



"I have never let my disability stop me from having a normal life. All of this just makes me even more determined."
-Zach Rowe



Purple Pumpkin Project: Why is Your Pumpkin Purple?

Join Epilepsy NL in our first Purple Pumpkin Project this Halloween. Purple is the international colour for Epilepsy Awareness, and what better way to raise awareness this Halloween than to showcase a purple pumpkin in a sea of orange? Participating is easy. Decorate a purple pumpkin (real or paper), snap a pic and tag us on social media answering the question "Why is your pumpkin purple?". You can even have a purple pumpkin

decorating party and/or fundraiser if you wish! This Halloween let's turn social media purple and keep awareness of epilepsy going all year round, because purple isn't just for Purple Day! Happy Halloween and let's see those purple pumpkins!



"...there are certain seizure conditions that are more likely to experience nocturnal seizures."

A seizure is caused by unusual electrical activity in the brain. This usually causes to muscles of the body to tighten or weaken temporarily. Nocturnal seizures happen when a person is sleeping. They are most common right after falling asleep, just before waking up, or soon after waking up.

Any seizure can occur during sleep. However, there are certain seizure conditions that are more likely to experience nocturnal seizures, including juvenile myoclonic epilepsy, tonic-clonic, Benign Rolandic, Landau-Kleffner syndrome and frontal lobe epilepsy.

Nocturnal seizures are often unnoticed because the patient is asleep when they happen. However,

there are signs that may suggest the patient's is experiencing these seizures, including loss of bladder control, biting their tongue, difficulty concentrating, awakening suddenly for an unknown reason, and/or feeling drowsy.

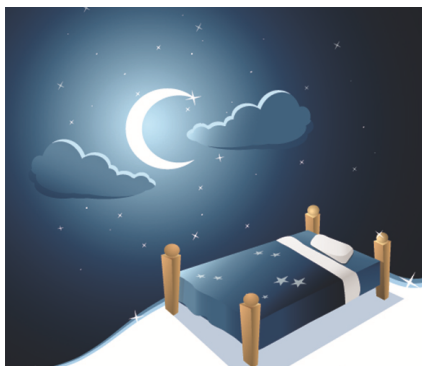
The cause of seizures is often unknown. However, there are certain seizure conditions as listed above that are more likely to experience nocturnal seizures.

When a patient is experiencing nocturnal seizures, a sleep study is often needed to diagnose the condition. The sleep study will require the patient to stay overnight at the hospital where their brain activity can be monitored during their sleep. For many patients, correct diagnosis and treatment can lower or prevent seizures. In some cases, patients may not have any more seizures for the rest of their life. Treatment is based on the

type of seizure, any underlying conditions, how often seizures happen, the patient's medical history, and other factors. Anti-seizure (or anti-epileptic) medications can be very helpful. It may take a few tries to get the right medicine and dose. The doctor will watch for side effects to find the best treatment. Surgery may be an option if medication can't control the seizures. A vagus nerve stimulator (VNS) is sometimes implanted and used with anti-epileptic medication to lower seizures. The VNS is a tool placed under the skin of the chest. It sends electrical energy through the vagus nerve into the neck and up to the brain.

If you have concerns about nocturnal seizures speak to your physician.

Via www.cedars-sinai.edu



Back to School: Is Your Child's School 'Seizure Ready?'

Getting ready for a new school year means more than new school supplies and shoes for kids with epilepsy. For these kids and their caregivers, it also means making sure school staff are ready if a child has a seizure while at school.

Making a school “seizure ready” can entail a number of steps and it is important to get started on these as soon as possible. M. Scott Perry, M.D., medical director of Neurology and an epileptologist at Cook Children's, offers the following advice.

Step 1: Does your child have a seizure action plan? One of the most important components of being prepared for the school year is having a plan in place should a seizure occur. A seizure action plan is a form provided by your medical team which describes the types of seizures a child has and what to do if one occurs. The plan covers the key components of seizure first aid, as well as for instructions on how and when to use rescue medications for the child's seizures.

Step 2: Is your child's rescue medication appropriate for their current age and weight?

Rescue medications are commonly prescribed to patients with epilepsy and are most often used for seizures that are prolonged or occur in clusters. Each patient will have unique circumstances for which a rescue medication may be ap-

propriate. Some patients may not have a rescue medication as part of their Seizure Action Plan – for example, if their seizures are rare, well-controlled, and typically very brief. It is very important that parents and their providers make sure the rescue medication prescribed for the child is appropriate for their age and weight. As a child grows, the dosing of medications will change. For those patients that have rare seizures and rarely require rescue medications, it is possible that the dose prescribed years ago may no longer be appropriate and therefore, may be less likely to work if the dose is too low.

Step 3: Can your child's school administer the rescue medications provided? It is important to know what medications your school is able and willing to give. While rectal diazepam is commonly used in schools, there are some school districts that only allow the medication to be given by a school nurse or similar medical personnel, even though the drug was designed to be administered by laypeople. If your school does not have a full-time nurse, there may be times when the medication cannot be given and an alternative rescue plan may be needed. Likewise, some school districts will not administer nasal midazolam because this formulation of the drug is not FDA approved to be utilized in this manner, though in the medical pro-

fession, we've used it this way for many years. Talk to your school about the seizure action plan recommended by your medical team. If they are unable to give rescue medications suggested, talk to your team to see if there are alternatives or if training can be provided to the school to ensure the rescue plan is followed

Step 4: Is your child's school “seizure ready”?

Probably the most important step in making sure your child is safe at school is making sure the people caring for them during the day are prepared to recognize and treat seizures. Despite how common epilepsy is, many people are only familiar with one type of seizure – tonic clonic. It is important that teachers and staff understand what seizures look like for each child with epilepsy, so they can recognize when rescue treatments may be needed, but also to keep parents informed if seizures are occurring frequently and may require a visit to the doctor to discuss treatment changes. Via: <https://www.checkupnewsroom.com/is-your-childs-school-seizure-ready/>

We can help ensure teachers, students and staff are aware of epilepsy! Contact us at info@epilepsynl.com / 722-0502 to schedule an epilepsy education session for your child's school, free of charge.

Epilepsy
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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.



“One of the most important components of being prepared for the school year is having a plan in place should a seizure occur.”



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.



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.

“Rescue Inhaler” Could Benefit Photosensitive Epilepsy Patients

A rescue “inhaler could potentially provide relief for people experiencing seizures in the same way that an inhaler benefits people who experience asthma attacks, the findings of a very small proof-of-concept study suggest.

The new study found inhaled alprazolam quickly suppressed epileptiform activity in five photosensitive epilepsy patients in a laboratory setting, in which participants were exposed to flashes of light.

It will take much more research to determine if the approach could actually stop seizures in real life, the researchers, led by Jacqueline A. French, MD, FAAN, professor of neurology at the NYU Comprehensive Epilepsy Center, said.

They are encouraged enough by the early results to begin testing the rescue inhaler in a hospital monitoring unit with a group of patients who experience long or repetitive seizures: “We think of it as an asthma inhaler for epilepsy. When you feel a seizure coming on, you take it out of your pocket and take a breath,” Dr. French said. “I think it

could make people feel more secure.”

When patients experience an aura or other symptoms that may precede seizure onset, they, or a family member or friend if necessary, could use the inhaler to deliver a dose of aerosolized alprazolam into the lungs.

The researchers reported in the July 3 online edition of *Epilepsia* that the drug rapidly got to the bloodstream and into the brain, as demonstrated by electroencephalography (EEG), which showed that the drug seemed able to suppress the brain's photoparoxysmal response (PPR).

“It is a very interesting study and it is the type of work we need in the field of epilepsy because we do not have sufficient options for rescue interventions,” said Sheryl R. Haut, MD, professor of neurology and director of adult epilepsy at Montefiore Einstein, who was not involved with the study.

Dr. Haut said photosensitivity provides a good model for testing epilepsy drugs because epileptic-like activity can be triggered in a lab by using light stimulation, as

was done in the current study. But she cautioned, “You can't extrapolate that suppressing the photoparoxysmal response is the equivalent to suppressing seizures. It is a marker. The ability of the drug to suppress seizures has to be studied in a clinical trial that measures seizure as the outcome.”

“There is a need for acute treatment options for seizure clusters (defined as acute repetitive seizures), as well as other seizure emergencies,” the study authors wrote.

Speed of action is key for rescue medicines for epilepsy since “significant seizure activity may occur in the first 10 minutes after seizure or cluster onset is recognized—for example, a cluster of myoclonus preceding a generalized tonic-clonic seizure, a prolonged focal aware seizure preceding impaired awareness of bilateral tonic seizure,” the paper noted. “The development of fast-onset treatment options that can easily be administered in the outpatient setting is vital.”

Via: journals.lww.com/neurotodayonline



Staccato alprazolam inhaler.

“There is a need for acute treatment options for seizure clusters.”



Dr. Jacqueline French, professor of neurology at the NYU Comprehensive Epilepsy Center.

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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Asked and Answered

Q: Does taking seizure medication affect a person?

A: All medication has the potential for side effects, and some seizure medication may produce side effects. The most common side effects are those related to the level of the drug in the blood and can include drowsiness, loss of coordination, fatigue, headache, decreased appetite, nausea, drooling, tremor, weight gain or loss, double or blurred vision, dizziness, and even impaired attention and memory. Sometimes dose-related side effects are cosmetic and include overgrowth of the gums, hair loss, or excessive hair growth. *Via Epilepsy Education Series, Edmonton Epilepsy Association.*

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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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