

In this Issue:

- CEA 20th Anniversary
- Scholarships
- Zach Rowe Horseshoe Tournament
- Member Spotlight
- CLAE 2018 Scientific Meeting
- Asked and Answered

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

For more pictures visit
the photo gallery on our
website.

Like us on Facebook
[www.facebook.com/
EpilepsyNL](http://www.facebook.com/EpilepsyNL)

Follow us on Twitter
@epilepsynl

Get us on Instagram
@epilepsynl709

Canadian Epilepsy Alliance 20th Anniversary

Epilepsy Newfoundland and Labrador is a proud member of the Canadian Epilepsy Alliance (CEA), which consists of 28 epilepsy agencies across Canada. Members from coast to coast were present at the CLAE 2018 Scientific Meeting, where the CEA also celebrated their 20th Anniversary. Members of the CEA visited the Epilepsy Newfoundland and Labrador offices as well as Previously Loved Clothes and Things, and took in some of the sights of NL in

addition to attending the CLAE 3 day conference. Celebrations were had, including an anniversary cake, purple balloons and gift bags. Happy Anniversary to the Canadian Epilepsy Alliance!



Canadian
epilepsy
Alliance

Alliance
canadienne de
l'épilepsie



CLAE 2018 Scientific Meeting Held in St. John's

The Canadian League Against Epilepsy (CLAE) hold an annual scientific meeting which focuses on epilepsy and epilepsy research. The meeting has been held all over Canada, including in Quebec City and Vancouver. This year the CLAE Scientific Meeting was held in St. John's, Newfoundland and Labrador, spanning from Sep-

tember 21st-September 23rd. The conference was a huge success, with many informative presentations, including sessions on the impact of stress, emotions and mental health on quality of life for individuals with epilepsy, sleep and epilepsy and artificial intelligence and epilepsy.

We welcome everyone who attended the meeting from NL, and everyone who travelled to attend the meeting. It was extremely important and beneficial to our epilepsy community to have such focus on epilepsy and epilepsy research here in our province.

Board of Directors**President**

Ron Stone
(Mt. Pearl)

Vice-President

Patti Bryant
(St. John's)

Secretary

Patsy Lush
(Corner Brook)

Treasurer

Anne Marie Hagan
(St. John's)

At Large

Pauline Duffy
(Kippens)

Bernie Larkin
(Stephenville)

Edward Pilgrim-Turner
(Happy Valley-Goose Bay)

Executive Director

Gail Dempsey

Medical Consultant

Dr. A.O. Ogunyemi, M.D.,
FRCP ©

Information Officer

Sarah Mercer

Epilepsy NL 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.

Scholarship applications can be found online at: <http://epilepsynl.com/scholarships>

Now accepting applications. Contact info@epilepsynl.com / 722-0502

See below for 2017 Winners and scholarship details

Pass along to those you know who may qualify.

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.

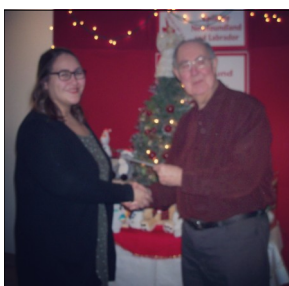
We would like to extend our thanks to Zach's family for their events and fundraising

initiatives, which support this scholarship.

The 2017 winner of the Zach Rowe Memorial Scholarship, Deidre Skinner, is studying Kinesiology at Memorial University in St. John's.



Deidre Skinner receiving her award from ENL Executive Director Gail Dempsey.

Epilepsy NL Family Scholarship

Sara George receiving her award from ENL president Ron Stone.

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.

The 2017 ENL Family Scholar-

ship Winner, Sara George, is attending her first year of studies at St. Francis Xavier University, and is working towards a Bachelor of Arts and Science in Health, with the hopes of attending medical school.

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. The scholarship honours one of ENL's incredible volunteers, Jim Hierlihy, who was a great supporter of all those living with seizures.

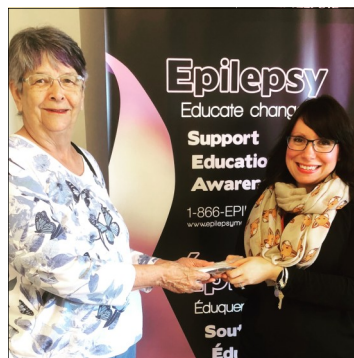
Zach Rowe Horseshoe Tournament

This year marked the 9th 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 \$1000 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, Jim and Donna, 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.



Pictured: (L) Joan Parsons presenting funds raised to CIO Sarah Mercer.

"I have never let my disability stop me from having a normal life..."

***-Zach Rowe
(1988-2009)***

ENL Member Kim Picco Shares Her Story

Hi, my name is Kim. I am writing today to share my experience with epilepsy. As most of us know, yet a lot don't, epilepsy is not the same for all of us. Some people have more seizures, some have less, and many have different experiences. Here is my story.

Back in February of 1994, at the age of 15, was the first time I ever experienced a seizure. Not being familiar with or understanding what was happening made it scary. My teacher and parents had been watching me for quite some time before this happened, as to them I was off-things weren't right. I was doing things that made no sense yet were simple things, like putting the milk in the cupboard, or going to pick up take-out and instead going to a store to buy things for my hair.

Upon having my first seizure, coming to and having paramedics over me, I was confused. I did not know what happened or what they were trying to do to me, so I began to fight. I

spent two weeks in the Jane-way not remembering anything that had happened. Finally, I did remember, it all slowly came back. The doctors worked with me as it was my first seizure and there was no reason for it. They chose not to medicate me until I had my third one in 2000.

I do have epilepsy, and it comes with a lot of things. I found in high school a lot of people didn't understand epilepsy. I couldn't really concentrate, and my grades slipped. My family was always worried about where I was and what I was doing.

Throughout the years I have changed many medications to get control of my seizures to the best that they could. However, while they control my seizures, I still have the side effects. I had a problem with weight gain, I would lose weight and it would all come back. I developed depression and anxiety. I did go on to college anyway. I was determined to be the person who I always

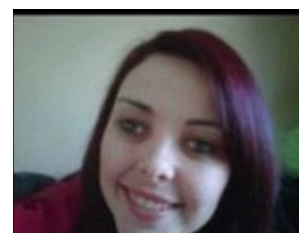
was, now I just have a medical condition. I was denied entry to college, I wasn't sure why. I sat outside the administration office for the whole day right up until 4:30 pm to meet the administration to explain why I wanted in. That's how I got in college- not by an acceptance letter.

I found it hard getting jobs once they knew about my medical condition; they would try and get rid of me. One job I had they actually took a vote while I was on break. But I refuse to give up. My medical conditions do not show if you look at the picture I posted to show you. I'm just like everyone else. The support you get from friends and family really does help.

I try not to let my epilepsy define me. I'm simply Kim, with a medical condition that is called epilepsy.

"I try not to let my epilepsy define me. I'm simply Kim, with a medical condition that is called epilepsy."

-Kim Picco





Research Funded by ENL Presented at CLAE 2018

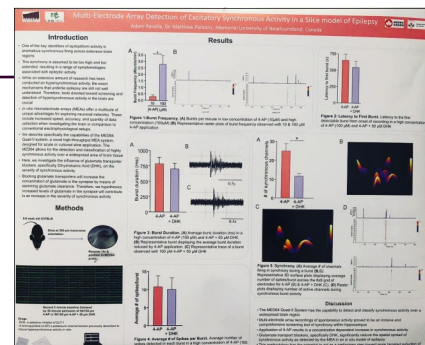
The CLAE 2018 Scientific Meeting featured research presentations from exceptional students, in a segment entitled "Top Trainee Abstract Presentations". Crystal Wilkie, a student at Memorial University, was selected and presented her ENL funded research which was very well received. Student Adam Ravalia and Dr. Matthew Parsons of Memorial University also showcased their research via a poster featured in the CLAE 2018 Poster Tour.

Poster title: "Multi-Electrode Array Detection of Excitatory Synchronous Activity in a Slice Model of Epilepsy". Excellent work!

Pictured: (Right) ENL Executive Director Gail Dempsey, Crystal Wilkie, Adam Ravalia, Dr. Matthew Parsons. Bottom Left: Crystal Wilkie presenting her research. Bottom Right: Poster featuring research conducted by Adam Ravalia and Dr. Matthew Parsons.



Research Title:
"Multi-Electrode Array Detection of Excitatory Synchronous Activity in a Slice Model of Epilepsy".



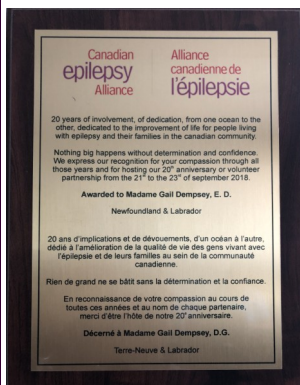
Award Presented to ENL Executive Director Gail Dempsey

Epilepsy Newfoundland and Labrador was particularly proud to be the hosting city for the CLAE 2018 Scientific Meeting, as this year marks the 20th anniversary of the Canadian Epilepsy Alliance, of whom Epilepsy Newfoundland and Labrador is a founding member. During the opening remarks of the conference fellow founding member Pierrette Cloutier, Directrice Générale of Épilepsie Mauricie Centre-du-

Quebec presented Gail Dempsey, Executive Director of Epilepsy Newfoundland and Labrador with an award in recognition of Gail's continuous dedication to the improvement of life for people living with epilepsy and their families in the Canadian community. Congratulations Gail from all of us at Epilepsy NL!!



Pictured: Gail Dempsey receiving her award from Pierrette Cloutier.



Congratulations!

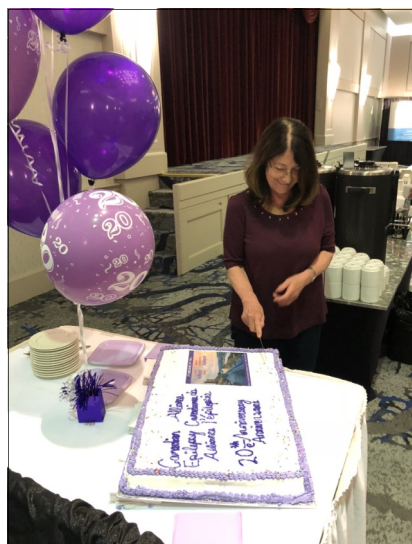
CLAE 2018 Scientific Meeting Photos



CEA 20th Anniversary Cake.



Catherine Saurwine of Epilepsie Montreal Metropolitan speaking at the Gala Dinner.



Aurore Therrien previously of Epilepsie Montreal Metropolitan cutting the cake. Aurore is now retired.



Aurore Therrien, CEA President Deirdre Floyd and ENL Executive Director Gail Dempsey.



Rhonda Latendresse, Executive Director of the Seizure and Brain Injury Centre and ENL Executive Director Gail Dempsey at the CEA booth.



CEA President Deirdre Floyd chairing a CEA meeting.



Members from coast to coast attended.

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

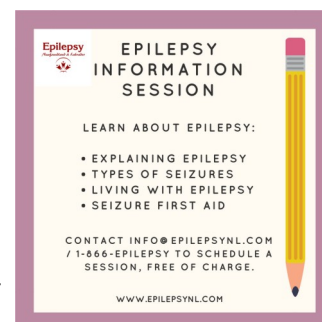
Name:	Email:
Address:	
Phone:	Would you prefer email or postage?
Do you or a loved one have epilepsy?	What type of seizure/seizures are present?
Additional Comments and Suggestions: Are there any issues regarding epilepsy you would be interested in learning more about?	

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.

Tips for a Productive Medical Appointment

Going to a medical appointment can be challenging. Many factors can contribute to not feeling like you are getting the most out of your appointment. Here are some tips to keep in mind before, during, and after an appointment to ensure you are getting the information you need.

- Keep a notebook with you, and before your appointment jot down questions you may have as you think of them. Bring the notebook to the appointment, this way you won't forget to ask.
- Bring a pen along with your notebook to your appointment, and if comfortable bring a family member or close friend. Write down the answers to your questions, or ask your family member or friend to write them down. A large amount of information can be conveyed in a short amount of time, and writing down answers means you will have them for future reference.
- Don't hesitate to ask for clarification if you need it. Many people need further explanation of medical information, so don't be afraid to ask if you don't understand something.
- Be honest with your doctor. Try to describe your symptoms and patterns as clearly and simply as you can. An open and honest line of communication between yourself and your doctor is important in ensuring the best course of treatment. If you are taking vitamins, antidepressants, using alcohol, etc make sure you are honest about it with your doctor.
- Bring all medications with you to your appointment. Your doctor may have questions about what medications you are currently taking.
- After your appointment, take a moment to jot down things that are on your mind, either in the waiting room or in the car.



Classical Music-A Potential New Therapy for People with Epilepsy

Music therapy has been used as a tool to treat individuals with a variety of medical conditions including those with acquired brain injury, autism, and developmental disabilities. It may also have the potential to help those living with epilepsy. About 30% of individuals with epilepsy are resistant to conventional epilepsy drugs, which is why it is particularly important to research alternative therapies. Epilepsy Ontario has joined forces with the Krembil

Neuroscience Centre (at Toronto Western Hospital) to conduct Canada's first clinical research study looking at the potential link between music therapy and seizure reduction. Entitled "The Rhyme and Rhythm of the Music of Epilepsy" and led by epilepsy neurosurgeon Dr. Taufik Valiante and post-doctoral fellow Dr. Marjon Rafiee, this 2 year clinical study hopes to build on the work on previous international studies that found a link be-

tween music (specifically Mozart's K. 448 Sonata) and seizure reduction in people with intractable epilepsy. With increasing technological advances, exploring the potential therapeutic benefits of music therapy is a promising and exciting field of epilepsy research.

**It is important to remember that music therapy affects everyone differently.*

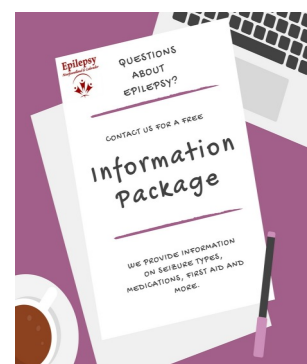
**Reference: E-Action Magazine*

**"The Rhyme
and the Rhythm
of the Music of
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 NEWFOUNDLAND AND LABRADOR ENL

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: Can I do anything to help control my seizures?

A: Sometimes people with epilepsy recognize that specific events or circumstances affect seizures. Recognizing your seizure triggers can help reduce or avoid seizures in some cases. Remembering to take your seizure medication, getting enough sleep, managing stress levels, and eating regularly and nutritiously, are all helpful in seizure control.

Some common seizure triggers are:

- Forgetting to take prescribed seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstruation/hormonal changes
- Medications other than prescribed seizure medications

**If you have further questions speak to your doctor and go from there. Via Epilepsy Education Series.*

Previously Loved ♥
Clothes & Things

LOCATION: 351 KENMOUNT ROAD, ST. JOHN'S, NL.
OPEN SEVEN DAYS A WEEK 9:30 AM - 9:30 PM
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.

Epilepsy
Newfoundland & Labrador



@PLCAT @EPILEPSYNL



@EPILEPSYNL

WWW.EPILEPSYNL.COM



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 from grade four students throughout Newfoundland and Labrador as a thank you gift. If you would like to donate to the campaign you can do so online at www.epilepsynl.com. Make sure you indicate

"Calendar Campaign" on your donation and include your address so we can send out your thank you gift. You can also give our fundraising coordinator a call at 709-722-0502 to donate. Thank you for your support and thanks to all the students who submitted artwork!

