

In this Issue:

- Epilepsy NL and MaxZen Racing
- Scholarships
- Epilepsy NL Member Spotlights
- Photosensitive Epilepsy
- Purple NL Photo Contest

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

Follow us on Twitter
@epilepsynl

Get us on Instagram
@epilepsynl709

Epilepsy NL and MaxZen Racing

The 2nd annual Targa Bambina competition was held during the Canada Day long weekend in 2018, and consisted of three days of driving competition, offering 16 competitive stages on the lower Burin Peninsula of NL. MaxZen Racing, a team including driver Gordon Maxwell and Navigator Mark Nofall, partnered with ENL to raise epilepsy awareness at the event, and did a fantastic job.

MaxZen spoke with many people, distributed informational material, made contacts and

held a draw for a gift basket donated by ENL. Not to mention, they won first place in their category! This was an excellent opportunity to reach a wide audience, promote awareness of epilepsy and dispel myths that still surround it.

In December of 2017 ENL Representatives Executive Director Gail Dempsey and Information Officer Sarah Mercer met up with MaxZen Racing Representatives Gordon Maxwell, Mark Nofall, Elizabeth Nofall and ENL's 2012 Purple Day Ambassador Luke Nofall at ENL's offices to discuss design concepts and awareness strategies. It is great to see the plan

to race and raise epilepsy awareness successfully come to be!



ENL Information Officer Sarah Mercer got to meet Leo up close and personal!



Gordon Maxwell and Mark Nofall bring Leo the car by ENL for a visit

The team continues to raise awareness of epilepsy at car shows, including at the Nick Coates Memorial Car Show which was held on Saturday, August 4th. If you are planning on attending future car shows, keep an eye out for the MaxZen team.

A big thank you to Gordon Maxwell, Mark Nofall, Elizabeth Nofall, Luke Nofall and the entire MaxZen Team, and congratulations on your win!

**Photos by Elizabeth Nofall.*

CLAE 2018 Scientific Meeting September 2018

Epilepsy Newfoundland and Labrador will be attending the 2018 CLAE Scientific Meeting, set to be held in St. John's, NL from September 21st-September 23rd 2018. CLAE is "an organization of medical and basic sciences professionals counting more than 125 members, including physicians,

basic scientists, nurses, neuropsychologists, neuroradiologists, students and other health professionals" (via clae-group.org). Neurologists, Researchers, Epileptologists, and Epilepsy Professionals, including Canada-wide representatives from member agencies of the Canadian Epilepsy Alli-

ance (CEA), will attend the conference in NL to participate in sessions held by registered speakers.

Epilepsy NL is a proud member of the CEA, and looks forward to this opportunity to have such focus on Epilepsy and Epilepsy research 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 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.

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

The 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.

ENL Family Scholarship

The Epilepsy Newfoundland and Labrador 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 Scholarship 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.



Sara George receiving her award from ENL president Ron Stone.

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.

*For more information, or to apply, visit www.epilepsynl.com, email info@epilepsynl.com or call 709-722-0502 / 1-866-Epilepsy.

ENL Member Spotlight: Blake Rumbolt

Blake was diagnosed with myoclonic epilepsy at just one year old. He was having multiple milder type seizures every day. As a child Blake had to avoid things that triggered his seizures such as brighter flickering lights, overexerting his tiredness level, and going on fast rides. At times this was challenging but being precautionous about triggering episodes paid off. When Blake had gone an extended period seizure free, his doctors at the Janeway decided he should be given the opportunity to come off medication. And so he did at eight years old and has been seizure free since that time.

Blake realizes that his epilepsy could return at any time and could progress to a more serious type like that of his grandfather and uncle. He focuses not on this but on living a productive life. Blake is very devoted to his studies having just completed Grade 11 with an Honours Average. He participates in extracurricular activities such as Student Council and Cross Country Running. Blake enjoys spending time with family and friends, hiking, and riding snowmobile. He is especially excited about the

prospect of getting his Drivers license this summer.

Blake really enjoys volunteering. He holds Bingos regularly, has played Santa Claus, completed landscaping work, and been involved with special events at the Harbourview Manor, an assisted living facility in his community. Blake has a passion for computers and has videotaped community events. As a member of his student council at St. Mary's All-Grade, he has helped organize Spirit Days, special events for kids, dances, awareness campaigns, etc. Blake helps out with shopping for and carrying the groceries to the school for the Kids Eat Smart program. Blake has been involved in fundraising for the Janeway, participated in Shave for the Brave, operated game booths at the Annual Crab Festival, fundraised for a community playground, participated in two Relay for Life events, donated birthday money to Daffodil Place, and helped raise funds for a missionary trip to drill wells in Cambodia.

When he was younger Blake saw his mom collect door to door during the month of March for Epilepsy



Blake Rumbolt



Blake with mom Bonnie Rumbolt and dad Craig Rumbolt.

and sometimes went along to help.

For the past three years he has canvassed himself, both his own community and the neighboring community as well. Blake is especially proud of his volunteering with Epilepsy NL as he realizes every dollar raised goes to help with research, programs and services.

**Submitted by Bonnie Rumbolt*

“Blake is especially proud of his volunteering with Epilepsy NL”

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:

-Ayden O'Toole, Hazelwood Elementary, St. John's, NL.

-Aaliyah Magalona, J.R. Wabush Middle School, Wabush, NL.

-Alayna Young, Carbonear Academy, Carbonear, NL.

-Kayden Strickland, Hillside Elementary, La Scie, NL.

-Alexander Tucker, St. Thomas Aquinas, Port au Port East, NL.

-Jayden Walters, French Shore Academy, Port Saunders, NL.

-Cameron Thompson, Memorial Academy, Botwood, NL.

-Kaylee Pardy, Fortune Bay

Academy, St. Bernard's-Jacques Fontaine, NL.

-Catherine Mercer, Whibourne Elementary, Whitbourne, NL.

-Declan Kenny, Hazelwood Elementary, St. John's, NL.

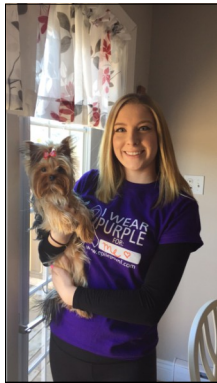
-Joey Canning, Random Island Academy, Hickman's Harbour, NL.

-Noah Pope, Memorial Academy, Botwood, NL.

-Georgia Holloway, Glovertown Academy, Glovertown, NL.



Cover of the 2019 Epilepsy Newfoundland and Labrador Calendar.



Lisa and Sailor

**“Epilepsy has
never, and will
never, own my
life”**

Epilepsy NL Member Lisa Pack Shares Her Story

Unlike many people, I wasn't born with epilepsy, and I didn't develop it at a young age. The first 18 years of my life were spent happy & healthy. In October of 2016, however, all that changed. One evening, I went to bed like any other night, but woke up around 6 am and knew something was wrong. I started vomiting and having multiple seizures. My family brought me to the hospital where I was then transported via ambulance to another hospital a few hours away. From there on I underwent a CT scan, an MRI, EKG'S, EEGS, sleep deprived EEGS, and had a few needles.

I was finally diagnosed a few weeks after all of the testing. It was a weird moment. I knew my life was about to change completely. I was put on anti-seizure medication right away and was taught about how to avoid the things that triggered my seizures. For me, it was not getting enough sleep, being stressed out, or being under the influence of alcohol. So I had to learn how to start taking care of myself, which didn't come easy. Along with that I had also lost my license. This was all happening in the middle of mid-term week in my first year of university. Battling my health and school work and all these changes took quite a toll on me.

I've always had really bad anxiety growing up but it worsened and I was also eventually diagnosed with depression alongside it. I was put on anti-depressants to try and improve my mood and quality of life. It was a hard time. I spent countless days not getting out of bed because I saw no point, and I was too sad and anxious to leave my room most of the time. Having my license gone, I know it may seem like no big deal, but it made me have to rely on others. Having to ask family or friends to take me places or to help me out bothered me. I wanted to be able to do things by myself, so I felt like my independence was gone. All of my friends were out enjoying themselves and enjoying university, and I felt like (and sometimes still do) I was missing out on that part of my life.

I think one of the main things that helped along the way was the amazing support system I had. My family and friends always went above and beyond to help me anyway they could and I'm forever grateful for them. When I was in one of the lowest points of my journey my parents decided to finally buy me a dog (I had been begging for one for years!). I named her Sailor, and she is completely the light of my life. She came into my life at a time when I really needed her, and her love and energetic spirit is what continues to make me happier each day.

In no way was my journey easy but I wouldn't change anything because it's made me a stronger person. I am thankful for everything and everyone I have in this life and I never take anything for granted anymore. You get one life, and even though it's been rough, I'm blessed this is the one I get to live.

Epilepsy has never, and will never, own my life.

**Submitted by Lisa Pack*



Lisa with Dad, Mom and Sailor

We Want to Hear Your Story!

Epilepsy NL is a proud member of the Canadian Epilepsy Alliance (CEA), and as part of the CEA's 20th Anniversary, we would like to highlight individual stories of epilepsy this year.

Sharing stories lets us know we are not alone and can inspire others.

Do you have a story that you would like to share? We would love to help you get it out there. Email info@epilepsynl.com or call 709-722-0502 to talk about submitting your story to Epilepsy Newfoundland and Labrador and for consideration to be placed on the CEA website.

There are many faces of epilepsy-let's show some from Newfoundland and Labrador!

Epilepsy
Newfoundland & Labrador



Canadian
epilepsy
Alliance

Alliance
canadienne de
l'épilepsie

Statement Regarding the Film “The Incredibles 2”

On June 19, 2018 Walt Disney Pictures issued a warning for the animated Movie “The Incredibles 2”. The movie contains scenes that may be triggering for those living with photosensitive epilepsy. The Canadian Epilepsy Alliance/Alliance Canadienne de l’épilepsie (CEA/ACE) believes this is a positive move for individuals that may have flashing lights as a trigger for their seizure disorder. *“The CEA/ACE agrees with the Epilepsy Foundation of America that any steps to help provide warnings of imagery or flashing lights, that could be potential triggers in relation to movies or video games would be helpful for those living with seizure disorders”* says Deirdre Floyd, President of the CEA/ACE. (Via www.canadianepilepsyalliance.org)

Those living with photosensitive epilepsy may want to practice caution if viewing this film.

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

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.

Family and Friends Campaign – 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.

We would like to give recognition to Belanger Memorial School in Doyles, NL. this year. Belanger Memorial have been dedicated volunteers for the past three years, and over the span of those three years has collected \$1000 for the programs and services offered by Epilepsy Newfoundland and Labrador!

Last year Belanger Memorial collected \$584.10! Thank you for all 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.

Purple NL Photo Contest

Do you see purple in your part of the province? Why not enter Epilepsy Newfoundland and Labrador's Project Purple NL photo contest? Entering is easy—simply spot or wear something purple, snap a selfie with it, and submit by posting to Epilepsy Newfoundland and Labrador's Facebook page (@EpilepsyNL) using

#PurpleNL.

See a field of lupins? A shiny purple car? Have purple balloons or a purple shirt? Go ahead and Spot, Snap, Submit! Let's raise epilepsy awareness around the province by painting Facebook purple, the colour for epilepsy.

For more information contact Sarah: info@epilepsynl.com / 709-722-0502.

*Contest open from August 6th, 2018-August 20th 2018. Winner will be contacted via Facebook—you could win a purple prize pack.



PROJECT PURPLE NL

SPOT, SNAP, SUBMIT.

**SEE PURPLE IN YOUR CORNER OF THE PROVINCE?
SNAP A PURPLE SELFIE BETWEEN AUGUST 6TH
AND AUGUST 20TH, AND POST IT ON THE ENL
FACEBOOK PAGE USING #PURPLENL.
YOU COULD WIN A PURPLE PRIZE PACK!**

Epilepsy
Newfoundland & Labrador

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.

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*

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



Seizure Medication Tips

- Always take your seizure medication as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus. Any changes in taking seizure medication should be discussed with your doctor.
- Discuss the use of any other medications or vitamins with your doctor or pharmacist. Decongestants, acetylsalicylic acid products (ASA) such as Aspirin, herbal medications, diet pills and birth control pills can all interact with seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with your seizure medication. To learn more, ask your doctor or pharmacist.
- Don't change from a brand name drug to a generic drug without first consulting your doctor. The use of different fillers, dyes, etc., can result in differences in processing by the body.
- A timer and a weekly pillbox are helpful in reminding you to take seizure medication at the right time.
- Keep a one to two week supply of your seizure medication to ensure that you don't run out.