



Fall 2020

Special points of interest:

- Back to School
- Epilepsy NL Scholarships
- Epilepsy News
- Spotlight On Katie O'Brien
- Community Resources
- Asked and Answered

Going Back to School with Epilepsy

Students with epilepsy have the same range of intelligence as other students and often epilepsy itself has no effect on intelligence or ability. However, students with epilepsy do have a higher rate of learning problems and difficulty in school as well as a lower level of achievement. Seizures can have a profound cognitive impact on a child, and this can lead to a lot of frustration for the student, their family, and teacher. The challenges can be great, however there are things that teachers can do to make things better. Some of the most prevalent challenges to learning and behaviour as well as suggestions to minimize or over-come them follow.

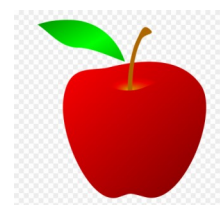
-Anxiety: The unpredictability of seizures and sensitized or overprotective relationships with parents and other care giving adults can result in anxiety in a student. This may affect initiative, interaction and independence in the classroom. If a teacher is calm, effective and understanding in dealing with seizures this may help to alleviate a great deal of the anxiety. Enabling the understanding and awareness of understanding other students and staff can also help take the pressure off and create a supportive learning and social environment.

-Absenteeism: Seizures, medical tests and treatment may result in a student missing more class time than is typical resulting in lost instruction, gaps in continuity, and less understanding of the subject by the student. Teachers can assist by assuring all missed class work is available, through the teacher directly or a classmate. Also, a willingness by the teacher to be available for additional assistance if required can be very helpful.

-Seizures: The actual process of having a seizure may affect learning significantly. For example, students experiencing absence seizures throughout the day will have their learning experience continuously disrupted. Memory can also be affected, potentially resulting in further learning challenges. Assigning a buddy to the student who can answer questions and explain what was missed will provide both emotional and academic support to the student. Providing visual and written instructions and/or repeating verbal instructions can also assist.

Teachers are one of the primary role models and influences for children as they grow up. A positive attitude and understanding that a student with epilepsy can achieve just as much as any other student is very important. The impact a teacher has can be enormous and the attitude you have will be conveyed to other teachers and students, helping to raise awareness and promote an environment of inclusion and acceptance.

"If your child has epilepsy pass this page along to their teacher or contact us at info@epilepsynl.com for a full copy of our guide: "The Student with Epilepsy: A Teacher's Guide".



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Social Media Successes

Like many charities, Epilepsy NL relies on the world of social media to reach its audience and to share information about what is happening within the organization, and to provide information to those that need it. Epilepsy NL is currently on Facebook, Instagram and Twitter and thanks to our followers and supporters we have received some wonderful feedback about our work, our team and the work that we do within the community.

We wanted to share some of the comments and feedback that we have received over the last few months via social media, to highlight why we continue to work hard and advocate for those living with epilepsy in NL. We appreciate each and every kind word that people share with us, it makes our work more enjoyable and we know we are making a difference in people's lives and that is what truly matters to us.

About Epilepsy NL:

"Thanks for sending this out and raising [#EpilepsyAwareness!](#)" - @Brainablaze via Twitter

"I was recently diagnosed with epilepsy. This group has a lot of useful info so Thank you" - Billie Jean Bull Colbourne via Facebook

"It definitely helps relaying any of this verified information! I wouldn't have known about it if it weren't for your post. So, I really do appreciate it!" - @greybruceepilepsy via Instagram

"Great post!" @seizure_soldiers on Instagram

About Previously Loved Clothes and Things:

"You guys are Number 1 in my books!!!!!" - Rhonda Brophy via Facebook

"Kudos to whoever is managing this page lately, it's great" - Rhonda Brophy via Facebook

For every like, re-tweet, shared post and follow you are helping to spread information and awareness about epilepsy and for that we thank you. It helps to know that the information, help and sometimes humor we provide makes a difference. Your support means a lot to us.

Please follow us on all our social media platforms for the latest news and information related to epilepsy in Newfoundland and Labrador.

Facebook: EpilepsyNL

Twitter: @epilepsynl

Instagram: epilepsynl709



Epilepsy NL Scholarships

Each year Epilepsy NL offers different scholarships to its members. The deadline is **November 1st** and we encourage all members to apply if they qualify.

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 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.

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.

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.

*For more information, or to apply, please visit: www.epilepsynl.com

Or contact us: (709) 722-0502

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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 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 News

Our Friends at Epilepsy Ottawa report on UPLIFT, a mindfulness-based cognitive therapy program that aims to help improve the emotional effects of living with epilepsy, including depression & anxiety.

Epilepsy Ottawa Prepares to Help UPLIFT Quality of Life with New Program

For those with epilepsy who also struggle with depression and anxiety, it can be difficult finding helpful mental health services that also consider the emotional effects of epilepsy. That is why researchers from EpLink, the epilepsy research program at the Ontario Brain Institute, have introduced UPLIFT to community epilepsy agencies in Ontario.

“Using Practice and Learning to Increase Favourable Thoughts,” or “UPLIFT,” is a mindfulness-based cognitive therapy program. Developed by Dr. Nancy J. Thompson at Emory University, the UPLIFT program was designed to help adults with epilepsy experiencing mood challenges.

Mindfulness-based cognitive therapy programs can be helpful for anyone with mood disorders. However, what makes the UPLIFT program different is how it caters to adults with epilepsy. Since it’s delivered over the telephone or videoconferencing, the program addresses issues like transportation, wait time, and cost barriers that traditional therapy may create in addition to the effects of epilepsy on mental health.

Recognizing these barriers, Dr. Kathryn M. Hum from EpLink explains, “we wanted to find a program that would allow folks to participate from the comfort of their own home, so it’s convenient for them.”

The UPLIFT program includes 8 semi-structured sessions that can be done over the phone or online. The sessions go over different ways living with epilepsy can affect mental health and teaches valuable coping strategies. Some topics focused on in the program include coping and relaxing, monitoring thoughts, and preventing future low moods.

Researchers at EpLink found that at six months and one year after participants completed the program, their depression and psychological quality of life scores remained improved.

“This was a finding we were happy with because we wanted to ensure that there were long-lasting effects. There is no point bringing a program to folks if it only helps them for a week after they finish,” says Hum.

In comparison to other epilepsy agency programs such as Clinic to Community, UPLIFT focuses more on mindfulness-based cognitive therapy and relating it to epilepsy. Still very useful, Clinic to Community focuses more on epilepsy education and is usually introduced earlier on in someone’s involvement with an agency.

“If someone is further along in their epilepsy journey, maybe they have been struggling with epilepsy for 10, 20, 30 years, they may know a lot about epilepsy already and already learned some strategies to deal with their mood. This is where UPLIFT could be more helpful,” explains Hum. “It focuses less on epilepsy education and focuses more on very specific strategies that can hopefully add to their toolbox in terms of helping them alleviate symptoms of depression they may be feeling.”

Funds raised by Epilepsy Ottawa’s Fitness Challenge Fundraiser and this year’s Ottawa Fire Truck Pull will help the agency bring UPLIFT to Ottawa. Epilepsy Ottawa would like to launch the program by the end of this year.

My name is Katie and the first thing you should know about me is that I love sarcasm. I'll likely insert a lot into this little story- just a warning. I love nerdy science stuff- when I was about seven, I used my birthday money to buy myself a little microscope. I love music: playing, singing, listening (not that I'm very good at the first two, but still. . .) I love mountains; I tend to be a fairly anxious person and mountains are the stable and calm brought to my life. I like sports. I like to do speedy things; I was a bobsledder for about five years, then a track cyclist (I even got to compete at the Rio 2016 Olympics!) Oh right, I also have epilepsy. But that doesn't make me me. I'll tell you a bit of my story, but I'll try to keep it short- I don't want to make you read too many of my ramblings! A little background: I am a Calgarian; I went to university there and while I was working on my master's degree I started competing in bobsleigh. I competed in that for about five years and then was recruited to track cycling. I ended up getting to compete in the Rio 2016 Olympics, an experience for which I am very grateful. Anyway, moving along, I went through the 2016/2017 season. We trained in Pennsylvania in June of 2017 and then headed home for a couple of weeks in July. During a training session on the track in Calgary, I crashed. I've crashed before with nothing other than a few scrapes. This just happened to be the "perfect" (not really in a good way. . .) crash. I broke a few bones, but the main thing was that I hit my noggin; I had a traumatic brain injury (TBI). I was very fortunate in that I was able to recover a fair amount from this and begin training again, but about a year later I had my first seizure. After a few more seizures, it was deemed that I have post-traumatic epilepsy. I was in the hospital with the TBI for about three months. I had brain surgery. I was told I would never ride a bike again, that I might never speak properly again, that I might never walk again, but I got to work with amazing people and had so much support that I was able to go back to training and racing. Even though I had gotten through these crumbly things, having "epilepsy" made me the most unhappy I have been, perhaps in my life. I refused to accept it. I refused to see doctors for it. I refused to go onto medication. I denied it. I saw it as such an untrue, shameful thing to have. I would be shunned. I could not be the girl who survived this and then had a new, embarrassing thing like EPILEPSY. Ew. No way. I fought it for a long time, but eventually, I did go onto anti-seizure medication. I don't know what enticed me to start medication, but I did. Even on medication, which has had a huge positive impact, I still worry. At the start of taking it, I was terrified. I wouldn't train. I was terrified I would have a seizure while I was asleep, so I didn't sleep (not the greatest for anyone, but especially people with epilepsy). I didn't want to have a seizure on the bus, so I would stay home... All. The. Time. But then, after a few weeks, then months of not having seizures, I grew more confident. I was going out, I was allowed to drive, I was training, my epilepsy was controlled. I didn't have any more seizures after I started the medication. . . until I had a breakthrough seizure just past the one year mark. I was devastated and terrified. Things went back to how they were. I wasn't driving, I wasn't going out, I wasn't training. I had moved past having epilepsy. It was gone, but now it was back. WHAT THE HECK?! I would love to end this story by saying that I moved past it and got better and everything is totally back to how it was before I hit my head. Before I was diagnosed with epilepsy. The truth is, stuff isn't back to normal. But over the last couple of years, I've realized that "normal" is just a word. My life will never be the same as it was, but that's not a bad thing-things don't need to stay the same all the time. I've realized that change is a part of life, good, bad or ugly, but that's one of the great things about being human. I will always have epilepsy. I will likely have more seizures in my life. But what I've realized (or am trying to realize) is that that's okay. Even though I have epilepsy, I am still the same Katie as I always was, the sarcastic rambling, speed-loving, music-loving, mountain-loving (and candy-loving ha!) human. I have been able to go back to training and competing; in fact, I won World Championships in 2020 and set two world records! I can do all of the things that I used to, to the same extent as I always have. My path to get there was different, but I am so grateful for it. Epilepsy is caused by brains doing things a little bit differently, but it's still the same brain, the brain that makes me, me. I have epilepsy, epilepsy doesn't have me. Thanks for reading the ramblings my brain has to offer! For more on Katie you can visit her Youtube page <https://www.youtube.com/watch?v=2CZ-Fzt7gZE&feature=youtu.be>



Back to School with epilepsy cont'd

Asked and Answered

Q: *Will Having Epilepsy Affect My Schoolwork?*

A: Talking to your teachers about epilepsy is important. Let them know the type of seizures you experience, how your condition and/or seizure medication might affect your schoolwork, and what the proper procedure is should you have a seizure in school. Your school should also have a medical record on file with information regarding your doctors, medications, allergies, other medical conditions, and a description of your seizures and instructions on what to do if you have a seizure. People with epilepsy have the same range of intelligence as other people, but students with epilepsy do have a slightly higher rate of difficulty in school and learning problems than those without the condition.

This could be influenced by many factors including:

- the side effects of seizure medicine (e.g. some seizure medications interfere with concentration and memory).
- the student's anxiety (e.g. the anxiety over having a seizure could affect initiative and independence in the classroom).
- teachers' attitudes (e.g. teachers may misunderstand the condition and incorrectly view a student with epilepsy as having less potential than another student).
- an underlying neurological cause of the epilepsy. • the seizures themselves (e.g. absence seizures could result in an interruption in learning, or memory could be affected following a complex partial or tonic clonic seizure).

If you have concerns over any of these school-related issues, you and your family should discuss these with your teachers, school administrators, and doctor. If people understand some of the challenges you are facing, they will be better able to support and assist you in meeting those challenges. If you would like your peers and teachers to better understand epilepsy, most epilepsy associations offer in-services to schools in order to educate others

Asked and Answered

Q: *Why do I feel so depressed?*

A: There is an increased risk of depression in people with epilepsy. Depression may be a side effect of medication, or it may occur just before, just after, or between seizures. Depression could also be a reaction to the insensitivity of others or the anxiety caused by not knowing when or if another seizure will occur. If you find that you are not sleeping or eating properly, or are feeling hopeless and have no energy, you should talk about these feelings with people who care about you AND with your doctor. They may be able to help.

Q: *Who Can I Talk To?*

A: Consider talking to a parent, a teacher, or a family friend. They may offer support and could be able to help you in making decisions. They may also be able to help you find useful information.



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Community Resources

Empower

Empower, the Disability Resource Centre, is a consumer-controlled organization committed to providing supports, resources, and opportunities for empowerment, which enables persons with disabilities to make informed choices about their lives. For more information visit their site: <http://www.empowernl.ca/>



Channel Peer Support Warm Line

Consumers' Health Awareness Network Newfoundland And Labrador (CHANNAL) is the only consumer-led mental health organization in the province. CHANNAL's aim is to combat isolation for those living with mental illness, to provide a forum for mental health consumers' concerns, to educate the public on issues relevant to mental health consumers and to offer advocacy, social and emotional support to mental health consumers.



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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.



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Previously Loved Clothes and Things

Located at 351 Kenmount Road in St. John's, Previously Loved Clothes and Things is a thrift store owned and operated by Epilepsy Newfoundland and Labrador. With clothing, footwear, furniture, books, cookware, collector's items and more there is something for everyone, and shopping at Previously Loved Clothes and Things helps provide services and resources to the more than 10,000 people living with epilepsy in Newfoundland and Labrador. Did we mention that because we are a charity you never pay tax, and 100% of the proceeds go directly back into ENL? Unique items, great prices and giving back to your community? It's a win-win! Do you have a donation to make? Drop it off to our store Monday to Friday 9:00am to 4:00pm.

**Donations
are Greatly
Appreciated!**

