



Special points of interest:

- A Friendly Hello
- A Fond Farewell
- CURE Discovery
- Myths and Misconceptions
- Covid 19 and Epilepsy
- Asked and Answered

Sorry this letter is a little late but Covid-19 delayed our date! We hope it finds you happy and well, the next newsletter will be along in a short spell!!



Spring 2020

A Friendly Hello

Hi there, I know we have had a trying few months to say the least. 2020 has not come in as the year we expected nor wanted, to date. However, better days are ahead and we have to stay positive and healthy both physically and mentally. I wanted to take a minute to introduce myself to all of the wonderful members and friends of Epilepsy NL and share that some changes have taken place here as well.

My name is Alicia Legge and I am taking over the role of Community Information Officer for Epilepsy NL from Sarah Mercer, who is leaving to pursue other opportunities.

I have come to Epilepsy NL with nearly sixteen years of experience working with the not for profit and charitable sector. I truly enjoy the work and love working with people and communities to improve their well being. In my previous life I have worked with Manuels River Natural Heritage Society, Planned Parenthood-NL and Seniors NL (formerly the Seniors Resource Centre of NL). I have a wonderful nine year old son and a husband at home. I spend my time gardening, reading, watching too much reality T.V. and enjoying the outdoors. I am hoping that my passions for advocacy, education and the pursuit of happiness and health will benefit Epilepsy NL. I look forward to working with my co workers, members and the public to raise awareness about Epilepsy in the province, and distributing important information about Epilepsy. Have a happy and healthy Spring and I look forward to serving you moving forward.—Alicia

A Fond Farewell

Goodbyes can certainly be difficult, but I would like to take this chance to say one as I transition out of my role as Information Officer. I am so extremely thankful for the connections I have made during my time at Epilepsy Newfoundland and Labrador and it has been an honour to serve you. Each and every person I have worked for and with, all of our fantastic members, clients, and many other people I have met along the way, have impacted me positively, and changed me for the better. From Epilepsy Education sessions at schools, to Awareness Campaigns, conferences, proclamations, chats and of course Purple Day, I have thoroughly enjoyed my time at ENL and will carry it with me. These are certainly different, challenging and ever changing times that we are in, however the strength and resilience I have witnessed within the epilepsy community in Newfoundland and Labrador is incredible and inspires hope. I'd like to leave you with my favorite quote:

Ring the bells that still can ring
Forget your perfect offering
There is a crack in everything
That's how the light gets in

-Leonard Cohen



You have all brought a little light into my life, and I have no doubt that we will continue to find the light within the cracks. Please know that I still stand with you and I always will. Best wishes to everyone and take care! -Sarah.

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Alicia Legge

CURE Discovery: Inhibition of an Important Brain Enzyme Attenuates the Development of Epilepsy

May 27, 2020

In his CURE-funded research, Dr. Detlev Boison and his team found that an adenosine kinase inhibitor called 5-ITU increases adenosine levels in the brain, protecting it from seizures.

Key Points

- CURE Grantee Dr. Detlev Boison and his team discovered that short-term use of a substance called 5-ITU prevents epilepsy from developing in mouse models of acquired epilepsy.
- 5-ITU inhibits a brain enzyme called adenosine kinase (ADK) that regulates a substance called adenosine (ADO), which, in turn, plays a critical role in preventing epilepsy following an injury to the brain. Dr. Boison's groundbreaking work supports the development of improved, more selective treatments which aim to cure underlying causes of epilepsy, rather than merely control seizures.

Deep Dive

One of the most common ways of developing epilepsy is through “acquired” means, such as a severe concussion, brain infection, fever-induced seizure, or stroke. A naturally occurring substance in the brain, called *adenosine (ADO)*, plays a protective role by decreasing excessive neuronal activity^{1,2} and protecting the DNA in nerve cells from changes that contribute to the development of epilepsy.³ ADO levels in the brain are regulated by an enzyme called *adenosine kinase (ADK)* and, unfortunately, brain injuries often trigger a series of events that elevate levels of ADK. In his CURE-funded research, Dr. Detlev Boison and his team found that an ADK inhibitor called 5-ITU increases ADO levels in the brain and protects it from seizures.

To make this discovery, the team evaluated if short-term treatment of 5-ITU following an injury to the brain could halt the development of epilepsy over the long-term.⁴ To do so, they used a mouse model of acquired epilepsy that reliably develops seizures two weeks after an injury. The team first had to determine the appropriate time points to administer 5-ITU following a head injury. Over a two-week period, the team monitored the progression of brain tissue damage in their mouse model, along with ADK levels and changes in EEG, analyzing samples at different days post-injury compared to controls. The team found that by the third day, ADK levels had started to increase and continued to increase over the two-week time period, accompanied by a loss of neurons in an area of the brain called the hippocampus and changes in EEG patterns by the fourteenth day post-injury. Reasoning that 5-ITU should first be administered when ADK levels initially rise, the team gave their mouse model the substance for a limited time – for only five days starting on day 3 post-injury – and continued to monitor the mice closely. After six weeks, the team found that the 5-ITU-treated mice had little brain tissue damage, significantly decreased ADK levels, and fewer seizures compared to the control group. Importantly, these changes were sustained even after nine weeks.

Discovering that short-term inhibition of ADK leads to a long-lasting antiepileptogenic effect makes this a promising therapy, especially since it could avoid any potential toxicities and intolerable side effects from long-term use of ADK inhibitors. Such a treatment would represent a true cure for epilepsy. Dr. Boison's groundbreaking research supports the development of improved, more selective compounds which can one day be tested in clinical trials and, hopefully, approved for clinical use.

*taken from <https://www.cureepilepsy.org/news/#news-featured> *

MYTHS AND MISCONCEPTIONS

Epilepsy comes from a Greek word meaning 'possession.' The Greeks believed seizures were caused by demons, and regarded them as a supernatural phenomenon. The true nature of epilepsy has long been distorted by myth and fear, and people continue to hold mistaken notions about the disorder. Here are twelve common myths and misconceptions about epilepsy.

- 1. You can swallow your tongue during a seizure.** *It's physically impossible to swallow your tongue.*
- 2. You should force something into the mouth of someone having a seizure.** *Absolutely not! That's a good way to chip teeth, puncture gums, or even break someone's jaw. The correct first aid is simple. Just gently roll the person on one side and put something soft under his head to protect him from getting injured.*
- 3. You should restrain someone having a seizure.** *Never use restraint! The seizure will run its course and you can not stop it.*
- 4. Epilepsy is contagious.** *About as contagious as a gunshot wound! You simply can't catch epilepsy from another person.*
- 5. Only kids get epilepsy.** *Epilepsy happens to people over age 65 almost as often as it does to children aged ten and under. Seizures in the elderly are often the after effect of other health problems like stroke and heart disease.*
- 6. People with epilepsy are disabled and can't work.** *People with the condition have the same range of abilities and intelligence as the rest of us. Some have severe seizures and cannot work; others are successful and productive in challenging careers.*
- 7. People with epilepsy shouldn't be in jobs of responsibility and stress.** *People with seizure disorders are found in all walks of life and at all levels in business, government, the arts and the professions. We aren't always aware of them because many people, even today, do not talk about having epilepsy for fear of what others might think.*
- 8. With today's medication, epilepsy is largely a solved problem.** *Epilepsy is a chronic medical problem that for many people can be successfully treated. Unfortunately, treatment doesn't work for everyone and there's a critical need for more research.*
- 9. Epilepsy is rare and there aren't many people who have it.** *There are more than twice as many people with epilepsy in Canada as the number of people with cerebral palsy (55,000), muscular dystrophy (28,000), multiple sclerosis (39,000), and cystic fibrosis (3,400) combined. Epilepsy can occur as a single condition, or may accompany other conditions affecting the brain, such as cerebral palsy, mental impairment, autism, Alzheimer's, and traumatic brain injury.*
- 10. You can't die from epilepsy.** *Epilepsy still can be a very serious condition and individuals do die of it. Experts estimate that prolonged seizures (status epilepticus) are the cause of many deaths in Canada each year.*
- 11. You can't tell what a person might do during a seizure.** *Seizures commonly take a characteristic form and the individual will do much the same thing during each episode. His behaviour may be inappropriate for the time and place, but it is unlikely to cause harm to anyone.*
- 12. People with epilepsy are physically limited in what they can do.** *In most cases, epilepsy isn't a barrier to physical achievement, although some individuals are more severely affected and may be limited in what they can do.*

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**

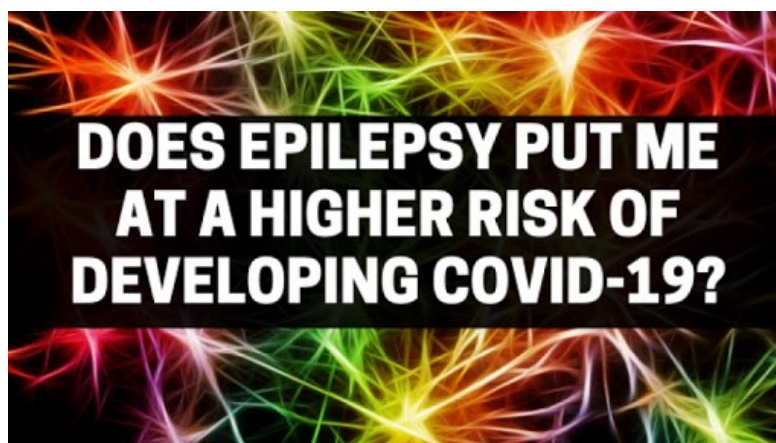


I Would Like to Become a Member with ENL

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.

COVID 19 and Epilepsy News



Epilepsy is a “family” of many different disorders that lead to seizures. Some people will have easily controlled seizures, have no other health problems, and become seizure-free on medications. Or they may have epilepsy with occasional seizures but no other health problems. For these people, the available data suggests that just having epilepsy alone

-Does not increase the risk of getting COVID-19 AND

-Does not increase the severity of COVID-19

There is no evidence that people with epilepsy alone have a weakened immune system. They should not be considered “immunocompromised” and would not have an “immune deficiency” from having seizures. People with different types of epilepsy, certain causes of epilepsy or other health conditions may have factors affecting their immune system.

What factors may increase the risk from COVID-19 for a person with epilepsy?

Some people with epilepsy regardless of seizure control have other health conditions that put them at higher risk from COVID-19.

They may be taking medicines to control seizures that also affect their immune system (for example, ACTH, steroids, everolimus, immunotherapies). It is important to note that most seizure medications do not affect the immune system.

- Some people may have other neurological or developmental issues that affect their immunity. People in these situations are at greater risk of developing more severe symptoms with viral illnesses.
- People with epilepsy may have other medical problems that could place them at higher risk of developing more severe symptoms with COVID-19.
- For example, people who have problems swallowing or frequently inhale food or liquids into their lungs (aspiration) are at higher risk for pneumonia.
- People with diabetes or underlying heart or lung problems also appear to be at higher risk for severe COVID-19.

Regardless of your situation, it is important for anyone with epilepsy to talk to their treating health care provider about their individual risks and specific medical precautions are needed. Take precautions to avoid getting sick too.

COVID 19 and Epilepsy News –Continued

What is autoimmune epilepsy and does it increase my risk for severe COVID-19?

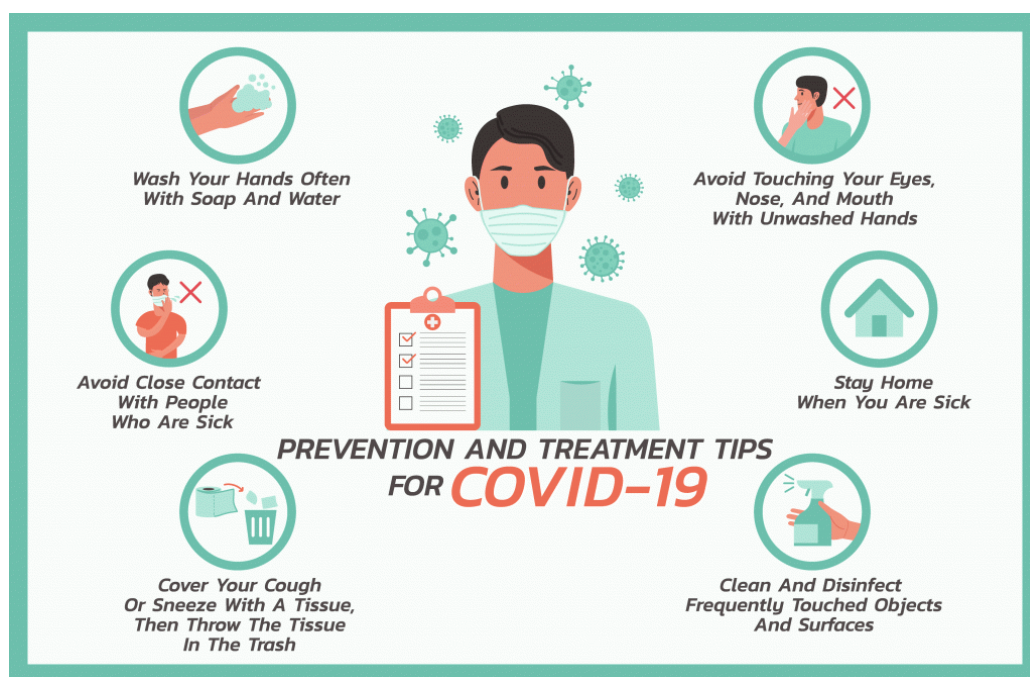
Some types of epilepsy may be caused by a change in the body's immune function. These are called autoimmune epilepsies. The immune system is a critical part of the body that helps us fight infections and inflammation in the body and brain.

- Autoimmune epilepsy may be treated with immunotherapy. Examples of these include steroids or immunoglobulin.

A person taking any of these medicines may be at higher risk of developing a serious form of COVID-19.

Information provided from www.epilepsy.com

Overall it is important to follow health guidelines laid out by healthcare professionals and decrease risk factors of contracting Covid-19 for yourself and others.



Covid 19 and Epilepsy News –Announcements



The Federal government is providing a special one-time-tax payment to individuals who are certificate holders of the Disability Tax Credit (DTC) as of June 1, 2020, as follows:

\$600 for Canadians with a valid DTC certificate.

\$300 for Canadians with a valid DTC certificate and who are eligible for the Old Age Security (OAS) pension.

\$100 for Canadians with a valid DTC certificate and who are eligible for the OAS pension and the Guaranteed Income Supplement (GIS).

People who are eligible for this special payment will receive it automatically via direct deposit or by cheque in the mail.

Information provided by <https://www.canada.ca/en/departement-finance/economic-response-plan.html>

Asked and Answered

Q: Can a person with epilepsy work?

A: Most people with epilepsy can work and can have rewarding careers. Physical disabilities are protected grounds under human rights legislation and the Canadian Human Rights Act does not allow discrimination by an employer due to a disability such as epilepsy. If seizures do prevent a person from working, there are many ways to use skills including volunteering, developing a hobby or pursuing an artistic talent.



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Asked and Answered

Q: Can a person with epilepsy drink alcohol?



A: While excessive use of alcohol and subsequent withdrawal can trigger seizures, modest occasional alcohol consumption does not seem to increase seizure activity in individuals who are not alcoholics or who are not sensitive to alcohol. Alcohol use can, however, lower the metabolism which results in lower blood levels of the seizure medication that is also metabolized by the liver. Drinking alcohol can also lower the seizure threshold. A seizure threshold is the level at which the brain will have a seizure. Some doctors recommend that individuals with uncontrolled seizures abstain from alcohol consumption. If a person with epilepsy chooses to consume alcohol, it is essential that he or she continues to take seizure medication as prescribed.

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Tips to keep mentally healthy during COVID-19

1. **PAUSE.** Breath. Reflect
2. **KEEP** a healthy routine
3. **CONNECT** with others
4. **BE KIND** to yourself and others
5. **REACH OUT** for help if you need it

Taken from the World Health Organization