



Summer 2021

Special points of interest:

- Epilepsy NL Program update
- Epilepsy Research New Updates
- Seizure First Aid– Water Safety
- Staying Safe in the Heat
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- Asked and Answered



Epilepsy NL-Programming Update and Thank You

Hello folks and welcome to spring 2021. It has been an exciting year to date with much more to come. I am now celebrating one year with Epilepsy NL and I wanted to say a sincere thank you for all the support and kindness that has been shown to me over the last year. I have met and worked with some wonderful people and I look forward to much more in the future. So after a very successful year including our Purple Day Campaign and other activities and programs here at Epilepsy NL, I think it is time for an update on what has been happening since March.

In April 2021 we started two support groups, via zoom, for people in NL living with Epilepsy. One group is for those who live with epilepsy as a diagnosis, the other is for their caregivers and support persons. We have had a handful attend each session and despite some bumps in the road I think we are getting there. This new zoom format was a first initiative of its kind for Epilepsy NL so I am proud to say we have started offering that support service. Right now the groups are offered to our membership but I hope to expand that in September 2021 to the general public. So we can continue to help more people across the province.

Since we started offering the HOBSCOTCH (Home Based Self Management and Cognitive Training Changes Lives) program in the fall of 2020 we have had four people complete the program with great success. The program has shown to make a difference in the lives of people with epilepsy who experience memory loss or other cognitive issues. It has been a privilege to offer the program and see the successes made by the graduates thus far. I hope to be able to help more people going forward.

Now that we are into the spring season we have started to offer education sessions for the public once again and we are offering sessions to local camps for new staff for training purposes. Our first sessions are booked for the end of June 2021.

As you may know by now I love to offer contests and prizes! So to kick off spring/summer 2021 I have launched the project Purple 2021 contest. I am asking people to show us pictures of purple inspiration in their community and share it with us in order to spread awareness and have some fun while doing so. We have already received several entries and I think this will be a lot of fun for everyone. The contest is open until June 30, 2021. Prize winners will be announced after that date.

In summary it has been a whirlwind of a year with lots of growth and learning along the way. I look forward to the rest of 2021 and beyond and look forward to serving you further.

Thank you,

Alicia

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Epilepsy Research—Artificial neurons recognize biosignals in real time

May 27, 2021

Researchers have developed a compact, energy-efficient device made from artificial neurons that is capable of decoding brainwaves. The chip uses data recorded from the brainwaves of epilepsy patients to identify which regions of the brain cause epileptic seizures. This opens up new perspectives for treatment.

Current neural network algorithms produce impressive results that help solve an incredible number of problems. However, the electronic devices used to run these algorithms still require too much processing power. These artificial intelligence (AI) systems simply cannot compete with an actual brain when it comes to processing sensory information or interactions with the environment in real time.

Neuromorphic chip detects high-frequency oscillations

Neuromorphic engineering is a promising new approach that bridges the gap between artificial and natural intelligence. An interdisciplinary research team at the University of Zurich, the ETH Zurich, and the University Hospital Zurich has used this approach to develop a chip based on neuromorphic

Complex, compact and energy efficient

The researchers first designed an algorithm that detects HFOs by simulating the brain's natural neural network: a tiny so-called spiking neural network (SNN). The second step involved implementing the SNN in a fingernail-sized piece of hardware that receives neural signals by means of electrodes and which, unlike conventional computers, is massively energy efficient. This makes calculations with a very high temporal resolution possible, without relying on the internet or cloud computing. "Our design allows us to recognize spatiotemporal patterns in biological signals in real time," says Giacomo Indiveri, professor at the Institute for Neuroinformatics of UZH and ETH Zurich.

Measuring HFOs in operating theaters and outside of hospitals

The researchers are now planning to use their findings to create an electronic system that reliably recognizes and monitors HFOs in real time. When used as an additional diagnostic tool in operating theaters, the system could improve the outcome of neurosurgical interventions.

However, this is not the only field where HFO recognition can play an important role. The team's long-term target is to develop a device for monitoring epilepsy that could be used outside of the hospital and that would make it possible to analyze signals from a large number of electrodes over several weeks or months. "We want to integrate low-energy, wireless data communications in the design -- to connect it to a cell phone, for example," says Indiveri. Johannes Sarnthein, a neurophysiologist at University Hospital Zurich, elaborates: "A portable or implantable chip such as this could identify periods with a higher or lower rate of incidence of seizures, which would enable us to deliver personalized medicine." This research on epilepsy is being conducted at the Zurich Center of Epileptology and Epilepsy Surgery, which is run as part of a partnership between University Hospital Zurich, the Swiss Epilepsy Clinic and the University Children's Hospital Zurich.

Story Source:

<https://www.sciencedaily.com/releases/2021/05/210527112501.htm>

Materials provided by University of Zurich. *Note: Content may be edited for style and length.*

Epilepsy Research- New research could lead to better treatment for Epilepsy

May 20, 2021

Scientists have discovered that the way in which neurons are connected within regions of the brain, can be a better indicator of disease progression and treatment outcomes for people with brain disorders such as epilepsy.

Many brain diseases lead to cell death and the removal of connections within the brain. In a new study, published in *Human Brain Mapping*, a group of scientists, led by Dr Marcus Kaiser from the School of Medicine at the University of Nottingham, looked at epilepsy patients undergoing surgery. They found that changes in the local network within brain regions can be a better predictor of disease progression, and also whether surgery will be successful or not.

The team found that looking at connectivity within regions of the brain, showed superior results to the current approach of only observing fibre tract connectivity between brain regions. Dividing the surface of the brain into 50,000 network nodes of comparable size, each brain region could be studied as a local network with 100-500 nodes. These local networks showed distinct changes compared to a control group not suffering from epileptic seizures.

Using a non-invasive technique called diffusion tensor imaging -- a special measurement protocol for Magnetic Resonance Imaging (MRI) scanners -- the team of scientists demonstrated that fibres within and between brain regions are removed for patients.

However, they found that connectivity within regions was a better predictor of whether surgical removal of brain tissue was successful in preventing future seizures. Explaining the work, Dr Kaiser, Professor of Neuroinformatics at the University of Nottingham, says: "When someone has an epileptic seizure, it 'spreads' through the brain. We found that local network changes occurred for regions along the main spreading pathways for seizures. Importantly, regions far away from the starting point of the seizure, for example in the opposite brain hemisphere, were involved.

"This indicates that the increased brain activity during seizures leads to changes in a wide range of brain regions. Furthermore, the longer patients suffered, the more regions showed local changes and the more severe were these changes."

The researchers at Nottingham, Newcastle, Qingdao, Shanghai, and Munich Universities, along with the company Biomax, evaluated the scans of 33 temporal lobe epilepsy patients and 36 control subjects.

Project partners used the NeuroXM™ knowledge management platform to develop a knowledge model for high-resolution connectivity with more than 50,000 cortical nodes and several millions of connections and corresponding automated processing pipelines accessible through Biomax's neuroimaging product NICARA™.

Project manager Dr Markus Butz-Ostendorf from Biomax: "Our software can be easily employed at hospitals and can also be combined with other kinds of data from genetics or from other imaging approaches such as PET, CT, or EEG."

Commenting on the fact that local changes were more informative of surgery outcome, Professor Yanjiang Wang, who is one of the corresponding authors, and Ms Xue Chen, both from China University of Petroleum (East China), explained: "Local connectivity was not only better in overall predictions but particularly successful in identifying patients where surgery did not lead to any improvement, identifying 95% of such cases compared to 90% when used connectivity between regions."

Story Source:

<https://www.sciencedaily.com/releases/2021/05/210520133728.htm>

Materials provided by University of Nottingham. Note: Content may be edited for style and length.

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
- Purple Star Award offered to members and residents of NL
- 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,

**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.

Seizure First Aid– Water safety

If you are enjoying time outside in the warmer temperatures this summer it is important to remember some safety tips if a seizure occurs in the water. If a person with epilepsy is swimming it is recommended that the person take extra precautions to stay safe. Swimming with a companion, preferably an experienced swimmer is recommended for anyone who has seizures. Swimming in a pool is safer than open water for people with epilepsy as lifeguards are usually on duty at regulated pool sites.

If a seizure does occur in water here is what you should do:

1. Support the persons head and keep it above the water line
2. Keep the persons face out of the water
3. Tilt their head back to keep the airway open
4. Get the person to the shoreline or poolside as quickly as possible
4. Roll the person on to their side so they can spit up water and not choke on it
5. Check their airway and see if it is clear and if they are breathing
6. If the person is not breathing roll the person on to their back and begin CPR (resuscitation)
7. Call for emergency assistance. Immediate medical treatment is required even if the person seems to have recovered. The inhalation of water can cause heart or lung damage.
8. Stay with the person and make sure they are attended to by medical professionals in a timely matter. Escort them to the hospital if needed.

Participation in sports and recreational activities should be discussed with your doctor/neurologist or epileptologist. It is also important to use the appropriate safety gear (helmets, lifejackets, floatation devices etc.) and to avoid related problems such as low blood sugar, dehydration, or overexertion which could increase the risk of seizures.



Staying Safe in the Summer Heat

Some people living with epilepsy can have seizure activity triggered by warm temperatures. It is important to keep yourself safe while enjoying the summer heat and sunshine.

High temperatures and humid conditions can make seizures more likely to happen. When a person is exposed to heat for a long period of time and does not stay well hydrated, they can be more at risk of a seizure. It is also important to note that increased perspiration can cause medication to be secreted from the body which can lower a person's seizure threshold.

Here are some things you can do to keep yourself safe in the summer heat:

1. Stay well hydrated, drink plenty of water and stay away from drinks that can lead to dehydration such as caffeinated drinks and alcoholic beverages in large quantities (if you do consume these types of drinks)
2. Stay inside when temperatures are at their peak which is usually between 12:00pm each day and 2:00pm each day. This can decrease the likelihood of a seizure.
3. Keep your house at a cool temperature which is still comfortable. Using a air conditioner, a fan or keeping a window open to increase air flow may help.
4. If you do want to sit in the sun, do it for brief periods of time with breaks in between in the cooler shaded areas.
5. Try to avoid high velocity sports or recreational activities in the direct sun if possible as they can lead to quicker dehydration and increased perspiration.
6. Always wear sunscreen and a hat if outside in the sun. This will help to decrease sunburn and sunstroke or heat stroke.

We all have a part to play in staying safe while still enjoying our summer sunshine. Please take care out there!



Project Purple 2021 SPOT, SNAP, SUBMIT



PROJECT PURPLE NL

SPOT, SNAP, SUBMIT.

SEE PURPLE IN YOUR CORNER OF THE PROVINCE?

Snap a picture of the purple in your community and enter to win a prize! Submit photos via social media or email info@epilepsynl.com by June 30, 2021.

Epilepsy
Newfoundland & Labrador



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 paid work, 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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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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