JANUARY-FEBRUARY 2019



FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION The Epilepsy Association of Northern Alberta - Our 58th Year of Service

(This Newsletter can be viewed in full colour on our website: www.edmontonepilepsy.org)

Member Outings & Activities

January

Fun Bingo for Prizes

Friday, January 25th, 1:00—3:00 p.m. (Pre-register by Noon, January 23rd) (Registration Limited to 12)

February

Fun Bingo for Prizes

Friday, February 22nd, 1:00 – 3:00 pm (Pre-register by Noon, February 20th) (Registration Limited to 12)

Annual General Meeting and Volunteer Recognition Event

Thursday, February 28th, 5:45 St. John's Ambulance Building 12304-118th Avenue



February 18th, 2019

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MORTGAGE FREE THANKS TO THIS MAN!

On November 18th, EEA Executive Director Gary Sampley had a visit from EEA Member Terry Mahon, who had dropped in to see how EEA was doing. During the conversation, he pulled an envelope out of his pocket and handed it to Gary.

What Gary opened was a letter from Terry's Investment Company attaching an \$81,000 cheque and advising that the cheque was a Grant from Terry's Foundation in Memory of his son Terence, so that we could pay out the Mortgage on our Office property and house.



Terry Mahon

This transaction was finalized on November 22nd and our bank has advised Alberta Land Titles to clear the Lien from our title.

The unexpected early Christmas present had the additional benefit of creating a significant positive effect on the 2018 EEA fiscal year end outcome.

Words cannot properly describe how much Terry has done for us with this unexpected benevolence.

He thanked <u>us</u> for giving him this opportunity to do good because we and the services we provide for people with Epilepsy are very near and dear to his heart!!!

The EEA Board will shortly announce how we intend to recognize Terry's generosity and thoughtfulness.

2019 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

When: Thursday, February 28th, 2019

Where: Room 113/115

St. John Ambulance Building 12304-118th Ave.



Timelines: **5:45** FREE Light Supper

6:15 Annual General Meeting
7:15 Volunteer recognition event

8:00 Wrap-up

Adult Support Group Schedule

(Group meets from 10:00 a.m. —12:00 p.m. in the EEA office.) Please call the Office to advise if you will be attending.

Tuesday, Feb. 12th, 2019

March 12th, 2019





Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta



Focus on Epilepsy is published 6 times annually by the Edmonton Epilepsy Association.

Articles appearing in Focus on Epilepsy do not necessarily reflect the opinions of the Association.

We welcome your contributions:

Do you have a poem or maybe a short story (1/2 page) that you would like to share with others. Or maybe you have read a book from our library and want to share a review with others. If you would like to share your wisdom, please submit your items to Sharon at our office or e-mail her at info@edmontonepilepsy.org

BOARD OF DIRECTORS

President...Cheryl Renzenbrink
Vice President...Cameron Reid
Treasurer...Doug Griffiths
Executive Director. Gary Sample

Executive Director...Gary Sampley

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Katrina Breau Craig Heyland

Colleen Matvichuk Tim McCallen

Joe Scalzo Irene Szkambara

Anne Starreveld Katrina Van Den Berg

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gary@edmontonepilepsy.org

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sharon@edmontonepilepsy.org

Dr. Sunny Kim...Counsellor sunny@edmontonepilepsy.org

Cam Reid...Volunteer Coordinator cam@edmontonepilepsy.org

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Canadian epilepsy Alliance

Alliance canadienne de l'épilepsie



Community



EEA Employabilities Programs

- ⇒ Employment Counselling
- ⇒ Assistance with Resumes
- ⇒ In-office Skills Training
- ⇒ Referrals to Select EEA Partners In Employability

 For Further Information contact EEA Executive Director,

 Gary Sampley, 488-9600 or gary@edmontonepilepsy.org

Bus Tickets Available for Members in Reduced Circumstances

Our 2018 allotment of Donate-A-Ride bus tickets is now depleted. However, Alberta Blue Cross has very kindly donated a number of adult ticket packs to us to hopefully get us through till next April. These can be accessed by MEMBERS with limited financial resources who need help getting to medical appointments, EEA events, food shopping, etc., and who do not qualify for an ETS low-cost bus pass.

Call 780-488-9600 or drop by to pick them up.



Now you can Donate to the EEA online!

If you would like to make either a lump sum Donation or a monthly donation contribution to the Association by credit card, please visit our website, www.edmontonepilepsy.org, and click on the Canada Helps Logo. This donation program gives you the ability to instantly print off a donation receipt.

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News from the **EEA** Office



IKEA Canada is EEA's 2018 Employer Of The Year



Vannie Campagnolo successfully nominated his employer, IKEA Canada for the EEA Employer of the Year Award.

The Employer of the Year Award is presented annually to a deserving employer who shows exceptional ongoing support and encouragement of employees who live with epilepsy.

Pictured here is Viola Mah, IKEA Canada, Vannie Campagnolo and EEA Executive Director Gary Sampley.



Jace Desaulniers is the Garry Hannigan Youth Scholarship Winner



Jace Desaulniers is the recipient of the Garry Hannigan Memorial Life Enhancement Scholarship for Youth. Jace will be using his scholarship to play hockey. This scholarship is available for Youths of any age, up to the age of 18 to assist them in participating in Sports, Cultural or Recreational Activities that will enhance their development as individuals.



News from the EEA Office



Edmonton Epilepsy Association

Hosts a Free Educational Forum:

"When the Meds Don't Work—Alternative Options for Seizure Control"

Information for both Adult and Juvenile Patients

There will be a post-presentation Question & Answer period.

Thursday, March 7th, 2019, 6:30-9 p.m. Central Lions Seniors Centre Auditorium IIII3—II3 Street, Edmonton

A FREE Light Supper will be provided

For more information or to reserve your seat, please call 780-488-9600 or toll free 1-866-374-5377 or by email at info@edmontonepilepsy.org

Psychotherapy Helps Those Suffering From Non-epileptic Seizures

A new Yale study has shown that psychotherapy improves the quality of life for those suffering from non-epileptic seizures. Also known as PNES, non-epileptic seizures result from a psychiatric disorder rather than a neurological one. For those with PNES, Yale researchers linked the continued use of psychotherapy with reduction in seizure frequency, improved quality of life and reduction in emergency department utilization. The study was published in the American Academy of Neurology on Jan. 4. "The real takeaway is that neurologists, psychiatrists and psychologists need to collaborate to help patients both get into psychotherapy and get through the regimen," said Benjamin Tolchin, neurologist, epileptologist and professor at Yale, who led the study. The study followed 105 patients who received psychotherapy either at Brigham and Women's Hospital or with a local therapist. In the following months, detailed follow-up data was collected for 89 percent of the participants to inform the results of the study. To treat PNES, the study used cognitive behavioral therapy, which involves teaching patients both cognitive and behavioral skills. Cognitive skills help those suffering with PNES identify thought patterns leading to seizures and learn how to modify them. Behavioral skills use techniques such as meditation, deep breathing or total body relaxation after the onset of negative symptoms. "The inspiration for the study is the enormous number of PNES patients we see here at Yale, at Brigham and Women's Hospital and really at every epilepsy center across the country," Tolchin said. "It's really painful to see the patients' lives torn a part by the condition."

Despite the evidence for the success of psychotherapy, 60 percent of patients who have access to this treatment are non-adherent, failing to complete the regimen. Adherence to psychotherapy was defined as attending at least eight sessions within a 16-week period starting at the time of referral.

"The immediate direction for research is developing interventions that can address non-adherence," said Tolchin. Indeed, the research team recently submitted a second manuscript that looks at biological and technological interventions to address non-adherence as well as improvements in the availability of psychotherapy to those suffering from PNES. Tolchin added that researchers have also begun to investigate the causes of PNES.

"There is some interesting research that is starting to develop but we don't really have any definite answers yet," he said. Tolchin highlighted that at this stage, it is clear that there are certain risk factors for developing PNES. Significant risk factors include psychologically traumatic events such as physical, sexual and emotional abuse and certain psychological characteristics, including an inability to consciously recognize and communicate emotions.

What is yet to be discovered is why some patients who have been subjected to these risk factors develop PNES, while others do not.

"There is some early research being done with MRI looking at the neurobiological differences between patients who do develop psychogenic seizures and those who don't," Tolchin explained.

According to the Epilepsy Foundation, approximately 25 percent of people who have been diagnosed with epilepsy and are not responding to drug therapy have been misdiagnosed.

Sophie Oestergaard, January 15, 2019

https://yaledailynews.com/blog/2019/01/15/psychotherapy-helps-those-suffering-from-non-epileptic-seizures/



EEA Christmas Luncheon



















December 9th, 2018



























The Epilepsy Association of Northern Alberta

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OUR FIFTY-NINTH YEAR OF SERVICE

NOTICE OF 2019 EEA ANNUAL GENERAL MEETING and Volunteer Appreciation Dinner/Event

- 1. This is to advise all EEA Members that the 2019 Annual General Meeting of the Association will be held on Thursday, February 28th, 2019 in Rooms 113/115 of the St. John's Ambulance Building, 12304 118th Avenue, Edmonton, commencing at 6:15 p.m. The St. John's Ambulance Building is close to the #3, #12, and #132 bus. There is ample parking behind the building, which is off 123rd Street.
- 2. From 5:45 p.m. to the start of the A.G.M., there will be a buffet-style no-cost light meal. Members are advised to arrive by 5:45 so that they have the opportunity to avail themselves of the meal.
- 3. A Member's Annual Membership Fee must still be currently valid in order for that Member to vote at the AGM;
- 4. A Member who is not able to attend in person should complete the attached Instrument of Proxy and either deliver it, mail it or fax it to the EEA Office no later than two days prior to the AGM;
- 5. Any Member who plans to attend the AGM/ Volunteer Appreciation Dinner Event in person, and who requires transportation to/from the EEA Office to the Meeting location, will have such transportation provided at no expense to the Member;
- 6. The Agenda for the Meeting is attached. It will also be posted on the EEA website, and will be available at the AGM itself;
- 7. Any Member in good standing over the age of 18 who meets the eligibility criteria (below) and wishes to stand for election to the Association's Board of Directors may do so as follows: A written nomination with the signature of two supporters (who are current EEA Members in good standing), and the written consent of the Nominee, must be filed with the Secretary of the Association, c/o the EEA Office, at least fourteen (14) days prior to the Annual General Meeting. (Interested individuals may contact the Executive Director for assistance with the logistics of this process, if desired);

- 8. Other items of Business at the AGM will include Approval of the Minutes of the February 22nd, 2018 AGM, Approval of the Report to Members on 2018 EEA Activities and Membership Review and Acceptance of the 2018 EEA Financial Statements;
- 9. After the Business of the AGM has been concluded, the Association will recognize its valued volunteers with tangible keepsakes and enjoyable entertainment.

Eligibility Requirements to be a Member of the Board

Essential Requirements:

- Be, or become, a Member in good standing of the Association
- Good knowledge of the neurological condition of Epilepsy
- Interest in, and willingness to support, the Objectives of the Association;
- A commitment to contribute the necessary time for active monthly participation in Board business;
- The ability to work as a member of a team;
- Willingness to serve on at least one Committee of the Association;
- The successful clearance of a CPIC security check, the cost of such clearance check to be paid by the EEA; and
- The willingness and ability to provide two Letters of Reference, on request.

Desirable Requirements:

- Previous Board or Committee experience; and
- Knowledge and skills in one or more of the following key areas: Health care, Education, Financial Management, Legal, Fundraising, Advocacy/Lobbying, Media/Public Relations, Administration/Governance/Policy.



The Epilepsy Association of Northern Alberta

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OUR FIFTY-NINTH YEAR OF SERVICE

AGENDA

2019 Edmonton Epilepsy Association Annual General Meeting
Thursday February 28th, 2019
St. John's Ambulance Building
Rooms 113/115, 12304-118 Ave Edmonton

(Immediately preceding the Meeting, and starting at 5:45 p.m., there will be a No-Cost light supper meal for Members.)

- 1. Call to order at 6:15 p.m.;
- 2. Review of Minutes of the February 22nd, 2018 Annual G.M.; (Section 1);
- 3. Business Arising;
- 4. Review of Report to Members on 2018 Activities; (Section 2)
- 5. Review of 2018 EEA Fiscal Year Financial Statements; (Section 3)
- 6. Election of Directors; (Section 4)
- 7. New business;
- 8. Adjournment

IMMEDIATELY FOLLOWING, THERE WILL AN ENTERTAINING VOLUNTEER RECOGNITION EVENT.

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The Epilepsy Association of Northern Alberta

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OUR FIFTY-NINTH YEAR OF SERVICE

Edmonton Epilepsy Association Bylaw Articles 2.03 and 2.04 outline the process for Proxy Voting at the Edmonton Epilepsy Association Annual General Meeting if a Member is unable to attend in person.

If you will not be able to attend the February 28th, 2019 meeting in person, we would respectfully request that you complete and sign the following Proxy form and either deliver or mail it to the EEA office at 11215 Groat Road NW, Edmonton, AB T5M 3K2, or fax it to 780-447-5486.

Thank you for your cooperation.

Instrument of Proxy

Edmonton Epilepsy Association

I hereby appoint **Cheryl Renzenbrink** or failing her then **Cameron Reid** as my proxy to vote for and on my behalf at the **ANNUAL GENERAL MEETING** of the members of the Edmonton Epilepsy Association to be held on February 28th, 2019 (or such other date that it may be adjourned to), in respect to all matters which may come before the meeting.

Dated theday of	, 2019	
Member Name- please print	Member Signature	
Witness Name- please print	Witness Signature	

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News from the EEA Office

The Edmonton Epilepsy Association offers educational services that help to dispel assumptions and stereotypes as well as providing first aid and seizure-response information:

Kids on the Block (KOB) offers an entertaining, unforgettable educational puppet troupe that teaches children about epilepsy & seizures. Each performance consists of informative scripts followed by an interactive Q & A period with the puppets.

Epilepsy in-services are tailored to fit the needs of staff meetings, meetings with staff and families, and/or individual classrooms, including Health, Biology, Science and C.A.L.M. classes. Presentations are interactive and include footage of seizures, resource materials and scenarios.

To book these no-cost services, contact sharon@edmontonepilepsy.org or call the EEA office 780-488-9600.

2019 Diary & Seizure Record Book

We have recently received our stock of 2019 Diary & Seizure

Record Books, which can be picked up at the EEA Office or mailed to you on request.

2019 EEA Continuing Education Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2019, for the purpose of assisting students to advance to or continue with College or University studies. Application for these Scholarships is open to Greater-Edmonton area students aged 17-29 years of age who are currently under a Canadian physician's care for epilepsy and are Canadian Citizens or who have permanent resident status.



Visa students are not eligible for this award.

Deadline for applications is February 15th, 2019

To download an application, visit our website: www.edmontonepilepsy.org, or call our Office at 780-488-9600 if you wish to receive one by mail.



We're Looking for an Achiever!

Do you know someone living with Epilepsy who has accomplished significant success in life, inspiring others in the process?

If you would like to nominate someone for our 2019 "Achiever of the Year" Award, please do so, in writing, to the EEA office by **March 1st, 2019.**

If you have any questions about the criteria for the award, please contact EEA Executive Director Gary Sampley at 780-488-9600 or gary@edmontonepilepsy.org





The Garry Hannigan Memorial Life Enhancement Scholarships for Youth, to a maximum of \$500 each, are available for Youths of any age, up to the age of 18, to assist them in participating in Sports, Cultural or Recreational Activities that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from www.edmontonepilepy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.

Focus on Epilepsy Page 11



Epilepsy News From Around The World



The High-Tech Armband That Could Prevent Night-Time Epilepsy Deaths

A high-tech armband that detects night-time seizures before they start could help thousands of people with epilepsy. The device, worn on the upper part of either arm, works by tracking the patient's heart rate while they sleep. Every year, hundreds of people in the UK die suddenly as a result of having an epileptic seizure, typically at night, often because the patient suffocates in bed while having a seizure lying face down, or because they vomited during a fit and choked. In more than half of epilepsy patients, it has been shown that there is a sudden increase in heart rate in the minute or so before a seizure strikes.

If the armband detects a sudden increase in heart rate, it sounds an alarm to wake the patient before the seizure occurs and also sends an alert via smartphone to a carer or family member. The gadget, called NightWatch, could reduce the number of lives lost to Sudden Unexpected Death in Epilepsy (SUDEP), the majority of which occur during the night.

Around 600,000 people in the UK have epilepsy — that's around 1 in 103 people. Seizures are the most common symptom of the condition and occur when electrical impulses that ferry messages between cells in the brain get disrupted. Some people experience seizure as a 'trance-like' state for a few seconds or minutes; others can lose consciousness and suffer convulsions. A wide range of drugs are available, but up to 30 per cent of patients do not respond to these and may require more invasive treatment, such as surgery to remove the part of the brain affected by the seizures.

Night-time seizures claim the lives of around 600 people a year in the UK. Some patients use sensors under the mattress to detect seizures during sleep. These alert carers, usually by sounding an alarm, once they detect jerky limb movements that occur when a seizure is happening. But they are only triggered once a seizure is already under way and, research shows, miss up to three out of four attacks. By contrast, the armband predicts the onset of a fit, sounding an alarm to wake the patient and giving carers vital time to reach them.

Pat Hagan December 10th, 2018

https://www.dailymail.co.uk/health/article-6481301/Would-wear-arm-band-prevent-night-time-epilepsy-deaths.html

A 19-Year-Old Sang Through Her Surgery To Preserve Her Musical Talents And Her Doctor Called It 'The Performance Of A Lifetime'

When 19-year-old Kira laconetti went tone deaf and began slurring song lyrics, she knew something was wrong. A talented singer since the age of six, laconetti began having episodes four years ago where she, "couldn't process the words in time with the music" and "couldn't sing," she told Teen Vogue.

It turns out, laconetti had musicogenic epilepsy – a form of epilepsy where listening and singing music can trigger seizures, according to the Epilepsy Society – and she needed surgery to remove a brain tumour and stop the seizures. In an effort to help laconetti without harming the parts of her brain where her musicality stems from, Dr. Jason Hauptman and his team performed an awake surgery at Seattle Children's Hospital.

"In the short time I got to know Kira, I learned her passion was in singing and acting and I thought the worst thing I can do is take that away from her," Hauptman told INSIDER.

The risks of awake brain surgery aren't much different than the risks of regular brain surgery

According to Teen Vogue, Iaconetti was initially put to sleep, then woken up when it was time to remove her tumour. Once awake, Iaconetti was asked to sing and perform other musical tasks so Hauptman could determine what parts of her brain to touch and which were off-limits.

"One advantage of doing surgery while a patient is awake is that it's very reassuring that function is being preserved," Hauptman told INSIDER. He also noted this type of surgery can be useful for people with epilepsy who need to preserve their speech or other brain functions, not just music-related ones.

An awake surgery sounds scary, but Hauptman said the procedure has similar risks as a regular brain surgery. "In a small percentage of patients, [awake brain surgery] could cause transient seizures, but we can fix it immediately if necessary," he told INSIDER. According to the Mayo Clinic, other risk factors include changes to your vision, impaired coordination and balance, impaired speech, and memory loss.

laconetti's procedure was a team effort and the "performance of a lifetime"

Brain surgery is a complex procedure that requires teamwork, and Hauptman said his team rose to the challenge. From the anesthesiologists who were in charge of keeping laconetti awake and comfortable to the neurosurgeons performing

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Epilepsy News From Around The World



the procedure and all of the hospital staff in between, Hauptman said it was a fulfilling experience to watch his team flawlessly complete the surgery. Hauptman hopes this procedure and laconetti's story give others going through similar experiences hope in the modest of scary uncertain times in their lives.

As for laconetti, "it was a performance of lifetime," Hauptman told INSIDER of her work in the operating room. "She was performing for her health and did it incredibly well. I couldn't think of a better patient to do this surgery on."

Hauptman hopes this procedure and laconetti's story give others going through similar experiences hope in the midst of scary, uncertain times in their lives.

Julia Naftulin November 22nd, 2018

https://www.businessinsider.com.au/brain-surgery-kira-iaconetti-awake-preserve-musical-talent-2018-11

Colchester Boy, 8, Steers Car To Safety After Mum Has Seizure



Ben and his Mom were on their way home from school.

An eight-year-old boy took control of a car at 60mph and steered it to safety across a busy dual carriageway when his mother blacked out at the wheel.

Ben Hedger was on his way home from school with mum Lauren Smith when she had a seizure on the A120 near Colchester, in Essex, England.

The Ford Ka hit the central reservation and realising the danger, Ben put on the hazard lights and guided the vehicle across the lanes to the hard shoulder.

His mum said she was "so proud".

Miss Smith, 27, who lives in Colchester, lost consciousness at about 15.45 GMT on Monday.

"When I started having the seizure at first I grabbed the wheel and was steering erratically so because of that we moved from the left lane into the central reservation and crashed into that," she said.

"We were scraping along and that is when Ben realised he needed to do something.

"He put the hazards on, grabbed the steering wheel and steered us to the hard shoulder where we continued along until the car stalled."

pair were on the school run home

Miss Smith said Ben had not realised how serious his actions had been.

"He realised something was wrong with me but he didn't realise he had done this amazing thing.

"He said he just did what he had to do otherwise we would have died."

After pulling the car over, Ben tried to use his mother's phone to call the emergency services before another car stopped and helped them.

Miss Smith, who came around after five to 10 minutes, said she had never had a seizure before and had to be told about what had happened by Ben, the emergency services and a fellow driver.

December 7th, 2018

https://www.bbc.com/news/uk-england-essex-46484849?platform=hootsuite





Epilepsy News From Around North America



9-Year-old Girl First Child in Canada To Undergo Deep Brain Stimulation For Epilepsy

It started when Andi Dreher was only three years old. Her head slumped over, her face went blank. It was the first of many epileptic seizures that the Ontario child would endure. At the beginning, Andi would have a couple of seizures a year, but the condition slowly progressed. By the time she turned seven, she was having up to 150 seizures a day.

Her family has come to call them "glitches." "The other day at school, she had 27 glitches in less than an hour," said her mom, Lori Dreher. The seizures make it difficult for Andi to do even the simplest tasks, such as walking, talking and eating. "She knows she used to play soccer and she used to do cheerleading — that she used to do these things and now she can't. That's hard." her mom said.

Among serious neurological conditions in children, epilepsy is the most common. For most, the condition can be controlled by medications. "But about one-third of children



Andi Dreher, 9, and her mom Lori spend time together in a play room at the Hospital for Sick Children in Toronto. Andi, who has epilepsy, underwent deep brain stimulation, a rarity for a child, as a way to deal with her seizures.

who have epilepsy don't respond to medication. A subset of them can potentially be helped by a variety of surgical treatment," said Dr. George Ibrahim, the pediatric neurosurgeon at the Hospital for Sick Children who operated on Andi.

When Andi and her family came from Kitchener to meet him last year, Ibrahim said he was struck by the severity of her case. "Her brain is developed in a very unique way," he said. "She has a brain malformation that resulted in the seizures, and because the seizures had been going on for so long — and they were so frequent — other areas beyond the area that was abnormal, were generating seizures. Before meeting Ibrahim, Andi and her family had already tried countless medications, had two surgical procedures, and even tested out the ketogenic diet — a high-fat, mid-protein, low-carbohydrate way of eating that's sometimes used to try to control seizures in children with epilepsy. "Everything helps in little bits and pieces, but not one thing has been able to fix her," Lori Dreher said.

Running out of options, Ibrahim and his team decided they needed to try something different. Believing deep brain stimulation (DBS) may be the answer, Ibrahim recruited colleague Dr. Suneil Kalia, a neurosurgeon at Toronto Western Hospital, to assist with the surgery. Toronto Western performs the most deep brain stimulation procedures in Canada. The procedure is commonly done on adults to treat movement disorders such as Parkinson's, as well as epilepsy and chronic pain. It works by sending electrical impulses to targeted areas deep in the brain to relieve symptoms without harming the surrounding tissue. Performing the procedure on a child, however, is rare — with only 40 known cases — and none in Canada. That all changed on Oct. 1 this year when Andi made her way into the operating room, emerging about eight hours later with electrodes placed deep in her brain. "The idea is that with electrical current flowing through those electrodes, we can alter the neural circuits — dial certain circuits up and dial certain circuits down. In Andi's case, we wanted to decrease her seizure frequency, to decrease the excitability of the brain," Ibrahim said. For that to happen, the electrodes have to be connected to a battery-operated implant in Andi's chest.

On Nov. 15, the implant was turned on. Lori Dreher now has control of it, adjusting the levels on her programmed device to try to figure out what works best in minimizing her daughter's seizures. "For instance, last week we were on Level D and she was a zombie — no muscle control, no words ... We changed back to Level B, and she was immediately able to say a few words and tell a sentence or two about her day. So based on that, we have hopes that this will work, once we tighten it in," Dreher said. Ibrahim said it will take time, but he, too, is hopeful. "The true effects of the deep brain stimulation can only be known once the device has been turned on for several months. But when we turned it on as a test during surgery, it completely silenced the electrical activity that's causing Andi's seizures, which is what we were hoping to target."

As for Andi, Lori said her daughter was actually excited going into surgery, because she knew it may be the answer to stopping her "glitches." "She has such perseverance and determination to be like everybody else. "She has such perseverance and determination to be like everybody else and to do what her brothers and sisters are doing," she said. Ibrahim agrees. "She's an extremely resilient young girl. She has a very severe form of epilepsy and despite that, she loves life."

Kelda Yuen, December 13th, 2018

https://www.cbc.ca/news/canada/toronto/9-year-old-girl-first-child-in-canada-to-undergo-deep-brain-stimulation-for-epilepsy-1.4943923?

cmp=rss&fbclid=lwAR2JKMNq 73nRPHB5XeeG5i0xFjpPh06f QS6QOXFYI0VrD9NCxdKM-6iqU

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Epilepsy News From Around North America



Stem Cells Implanted Into The Brain Stop Epilepsy Seizures In Rats

For people with severe epilepsy, no medication is effective – but a radical approach of implanting stem cells into the brain could stop seizures at their source. The technique, which has so far shown promise in rats, would involve taking some of a patient's own skin cells and turning them into embryonic-like stem cells in the lab. These can then be directed to become a kind of brain cell that damps down seizures.

Epilepsy arises when there is an imbalance between two different kinds of nerve cell in the brain; excitatory ones, which cause other cells to fire, and inhibitory ones, which block firing. Seizures result when excitation swamps inhibition. For some people with epilepsy, the surge of excitation starts in one part of the brain, called the hippocampus, before spreading elsewhere. So Ashok Shetty at Texas A&M University and his colleagues tried boosting inhibition at that site to see what would happen.

First, Shetty's team injected 38 rats with a chemical that triggers a long seizure. The resulting brain damage causes the animals to have spontaneous seizures, starting from the hippocampus, over the next few months. A week after the initial damage, the team implanted inhibitory brain cells in the hippocampi of about half the rats. Five months later, those given implanted cells had 70 per cent fewer seizures than those without implants.

To check it was really the inhibitory cells working, five of the animals were given inhibitory cells that were genetically modified to stop firing when the animal was dosed with a drug. When under the drug's influence, these rats had seizures nearly as often as rats primed for seizure that hadn't had any inhibitory cells implanted. Dissections also showed that the implanted cells survived in the hippocampus.

Shetty says the treatment could be suitable for people whose seizures originate in a small part of their hippocampus, and whose only other option is surgery to remove that part. They could try a cell implant instead, and if something went wrong, they could have all the graft removed along with the epileptic brain tissue. And if the therapeutic cells were made from a patient's own skin, they wouldn't need medicines to stop rejection.

The study isn't proof this approach will work, though, says Bruno Frenguelli at the University of Warwick, UK. The rats were given implants soon after their brain damage, and it isn't clear if the technique would help people with seizures stemming from a head injury in the past, which is a common cause of epilepsy.

Clare Wilson December 19, 2018

https://www.newscientist.com/article/2188510-stem-cells-implanted-into-the-brain-stop-epilepsy-seizures-in-rats/

Drug Approval A First For Alberta

Effective December 1st, 2018, Alberta became the first province in Canada to approve the new UCB Canada drug Brivlera.

New Drug Product(s) Available by Special Authorization only, as detailed below:

Trade Name / Strength / Form Generic	Description	<u>DIN</u>	MFR
BRIVLERA 10 MG TABLET	BRIVARACETAM	00002452936	UCB
BRIVLERA 25 MG TABLET	BRIVARACETAM	00002452944	UCB
BRIVLERA 50 MG TABLET	BRIVARACETAM	00002452952	UCB
BRIVLERA 75 MG TABLET	BRIVARACETAM	00002452960	UCB
BRIVLERA 100 MG TABLET	BRIVARACETAM	00002452979	UCB

BRIVARACETAM

"For adjunctive therapy in patients with refractory partial-onset seizures who meet all of the following criteria: - Are currently receiving two or more antiepileptic medications, AND - Have failed or demonstrated intolerance to three other antiepileptic medications, AND - Patients are not receiving concurrent therapy with levetiracetam, AND, - Therapy must be initiated by a Neurologist. For the purpose of administering these criteria failure is defined as inability to achieve satisfactory seizure control. Special authorization may be granted for six months. Coverage cannot be provided for brivaracetam, eslicarbazepine, lacosamide or perampanel when these medications are intended for use in combination." Each of these products is eligible for auto-renewal.





Our Programs and Services



- ♦ Free "Kids on the Block" puppet presentations that educate children (and their teachers, administrators, caregivers, and group leaders) about kids with Epilepsy in an entertaining manner;
- ♦ Free specially-tailored In-services about Epilepsy to schools, businesses, group homes, Public Service bodies, Colleges, etc. (includes annual training for NAIT EMT students and ETS Supervisors and Security Personnel, and on-line information about Epilepsy on the EPS Training System)
- ♦ Annual Epilepsy Educational Forums, both of interest to Health Care Professionals as well as the General Public;
- ◆ Free provision of our series of 12 Epilepsy Education Information booklets to Members, Hospitals, Clinics, Neurologists' Offices and Pharmacies;
- Website, print and video information about Epilepsy, and a free lending library for members;
- ♦ Bi-monthly newsletter for Members that includes the latest current medical information available about Epilepsy, as well as current news about the Association and our services and events;
- ◆ Scholarship Program for Post-secondary Students with Epilepsy (minimum two scholarships a year);
- ♦ Garry Hannigan Memorial Life Enhancement Scholarships for Youth, to assist young people (up to the age of 18) to participate in sports, arts, cultural or recreational activities that will enhance their development as individuals;
- ♦ No-cost Counselling on Epilepsy-related problems for people with Epilepsy and families of people with Epilepsy, with referrals to other supporting Agencies as needed;
- ◆ Monthly group sessions geared toward Adults with Epilepsy and concerned family members;
- ♦ Information and support for Parents/Caregivers of Children with Epilepsy;
- ♦ No-cost provision of assistance/advice on diverse matters, including, but not limited to, finding employment, driving and Epilepsy, potential side-effects of medication, and dealing with the complexities of Government forms and applications (AISH, Disability, housing subsidy, etc);
- ♦ No-cost advocacy on behalf of people with Epilepsy experiencing discrimination or other problems;
- ♦ No-cost social and recreational activities for Members that help reduce social isolation, free ETS Bus Training, and free "Donate-a-Ride" Program bus tickets for Members in need;
- ♦ An annual no-cost in-house Collective Kitchen Cooking Training Program, An Annual Collective Gardening Program and an annual in-house Computer Training Program for Members;
- ♦ Ongoing recruitment and screening of quality Volunteers, annual recognition of all Volunteers, and annual award of Member-nominated Volunteer-, Achiever-, and Employer-of-the-Year Awards.



Edmonton Epilepsy Association 11215 Groat Road NW Edmonton, AB T5M 3K2

Place address label here

If you are planning to move in the near future please inform our office so that we can continue to ensure that you get your newsletter...