

NOVEMBER—DECEMBER 2019



# FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION

The Epilepsy Association of Northern Alberta - Our 59<sup>th</sup> Year of Service

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

## Member Outings & Activities

### November

#### Fun Bingo for Prizes

Friday, November 29th, 1:00—3:00 p.m.  
(Pre-register by Noon, Nov. 27th)  
(Registration Limited to 12)



### December

#### Christmas Lunch & Social

Sunday, Dec. 8th, 12:00 - 3:00 pm  
Chateau Louis Hotel & Conference Centre  
11727 Kingsway Avenue  
(Pre-registration by Noon, Dec. 6th)

#### Fun Bingo for Prizes

Friday, December 21st 1:00 – 3:00 pm  
(Pre-register by Noon, December 19th)  
(Registration Limited to 12)

**Whichever Your Faith, We Wish  
Our Members and Friends Much  
Enjoyment During Your Holiday  
Celebrations!**

HANUKKAH



CHRISTMAS

NEW YEAR'S  
EVE



## MEMBER ACTIVITY



### Annual Christmas Lunch and Social

Sunday, December 8th

For more details see page 3.

### Nominate your Employer as the EEA Employer of the Year

Do you have a great and supportive Employer that recognizes and encourages the many contributions people with Epilepsy offer their fellow employees and workplace?

Nominate them for the 2019 Edmonton Epilepsy Association Employer of the Year Award. Contact us to find out how:  
780-488-9600 or [gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

Nomination Deadline is November 30th, 2019

### First Notice

### 2020 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

**When:** Thursday, February 27th, 2020

**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 - 1200 p.m. in the EEA office.)  
Please call the Office to advise if you will be attending.

November 12th, 2019

December 10th, 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](mailto:info@edmontonepilepsy.org)

## **BOARD OF DIRECTORS**

**President...**Colleen Matvichuk  
**Vice President...**Cameron Reid  
**Treasurer...**Terry Mahon  
**Secretary**—Katrina Breau  
**Past President**—Cheryl Renzenbrink  
**Executive Director...**Gary Sampley  
**Directors-at-Large:**

|                 |                 |
|-----------------|-----------------|
| Craig Heyland   | Joe Scalzo      |
| Anne Starreveld | Irene Szkambara |

## **STAFF**

**Gary Sampley...** Executive Director & Chief Operating Officer  
[gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

**Sharon Otto...** Program Manager & Education Coordinator  
[sharon@edmontonepilepsy.org](mailto:sharon@edmontonepilepsy.org)

**Dr. Sunny Kim...** Counsellor  
[sunny@edmontonepilepsy.org](mailto:sunny@edmontonepilepsy.org)

**Cam Reid...** Volunteer Coordinator  
[cam@edmontonepilepsy.org](mailto:cam@edmontonepilepsy.org)

## **Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta**

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Edmonton, AB T5M 3K2



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[www.edmontonepilepsy.org](http://www.edmontonepilepsy.org)



Canadian  
epilepsy  
Alliance

Alliance  
canadienne de  
l'épilepsie



Link to E-Action's On-line  
Epilepsy Resource and  
Community

## ***Edmonton Epilepsy Association***

### **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](mailto:gary@edmontonepilepsy.org)

## **Bus Tickets Available for Members in Reduced Circumstances**

Our 2019 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.



## **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](http://www.edmontonepilepsy.org), and click on the [Canada Helps](#) Logo. This donation program gives you the ability to instantly print off a donation receipt.





As our entertainment this year, we are very pleased to have the Edmonton Chapter of the Canadian Military Wives Choir.

## Annual Christmas Lunch and Social

Sunday, December 8<sup>th</sup>, 12 – 3 p.m.

Chateau Louis Conference Centre (Behind Chateau Louis Hotel)

11727 Kingsway Avenue, Edmonton

Bus #12 From Kingsway Mall Stops Close By/

Lots of Free Parking On Site

**\$15.00** per person (remainder EEA subsidized).

Call the EEA office 780-488-9600 to book your seats

**(Pre-registration by December 6th required).**

Everyone in attendance will get to take home a special gift.

## Volunteer Needed – Marketing/Publicist Specialist

2020 is the EEA's 60th Anniversary year and we want to make a splash! We are working hard at building better public recognition of the EEA and what we do, but we need some media-savvy help.

We are looking for a volunteer to assist us with increasing awareness of the association so we can help and support more families impacted by epilepsy. The skills we are needing support with are:



- Use of various social media channels to connect and collaborate with influencers (celebrities, politicians, etc.)
- Use of social media to create chatter and buzz about our events and activities
- Help us increase our number of social media followers to get the word out we are here to help
- Create media pitches for TV, Print, Radio and Online media channels
- Develop impactful press releases

If you can help us or you know of someone that would be willing to help us, please contact Gary at the EEA office, 780-488-9600 or [gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org) for more information.





## Collective Kitchen Program Starting in January 2020

This is a combined support and training program to assist members living on a limited income who lack a knowledge of proper nutrition, as well of budgeting and cooking skills. Working collectively, course participants are guided into the world of nutrition and how it affects their seizures and overall health.

The course also covers issues such as low cost cooking, food preparation, budgeting skills and planning ahead. A hands-on course, it has components of active teaching. Each participant gets to take home what they have cooked, usually four to six individual portions, in freezable containers capable of fitting into a fridge freezer compartment. Dates to be determined.



Interested members can phone Sharon at the EEA Office at 780-488-9600 to register. Registration is limited to **eight** participants.

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## 2020 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 March 1st, 2020**



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



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## Life Enhancement Scholarship Program For Youths



The **Brittany Hughes 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 Arts, Music, Dance and/or Ethnic Identity Cultural Programs that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from [www.edmontonepilepsy.org](http://www.edmontonepilepsy.org), or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.

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## Does Your Child or Teen Have Upcoming Sports or Recreational Activities Costs?



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 or Recreational Activities that will enhance their development as individuals.

Scholarship criteria, eligibility details and the current Application Form can be downloaded from [www.edmontonepilepsy.org](http://www.edmontonepilepsy.org), or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.



### **Are You Interested In Being A Mentor?**

It's never easy dealing with epilepsy. The EEA is desirous of implementing a program where active caring members with epilepsy (or relatives helping members living with epilepsy) could be linked with newer members (or their relatives) having issues dealing with their epilepsy.

Sharing your own life experiences could be a great help to those who are still struggling with the condition.

**If you have such an interest, we would love to talk to you. Please contact Gary or Sharon at the EEA Office.**

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### **Free or Low Cost Food In A Tough Economy**

Many people are unaware that there are numerous sources available in the Greater Edmonton Area and indeed in most parts of Alberta where individuals and families can access no-cost or low-cost food and participate in Collective Kitchen Programs.

Members can obtain written information about these resources by contacting the EEA Office.



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### **Wanted: Volunteer Casino Workers**

The EEA is recruiting experienced Casino Worker Volunteers for our 2020 Casino whose dates were just drawn. Those dates are Friday, April 10 and Saturday, April 11th at the Century Casino on Fort Road in Edmonton.

If you have previous casino experience and are interested in helping us, please contact the EEA Office.





# Nocturnal Seizures: Everything You Need To Know



Nocturnal seizures are seizures that happen while a person is asleep. They can cause unusual nighttime behavior, such as waking for no reason or urinating while sleeping, as well as jerking and shaking of the body.

Nocturnal seizures are usually a type of seizure called a tonic-clonic seizure. Most people with nighttime seizures of this kind have epilepsy.

## **What is a nocturnal seizure?**

Nocturnal seizures may cause jerking and shaking of the body at night.

Nocturnal seizures are rare and usually mean a person has epilepsy.

Various chemicals trigger regular electrical activity that plays a role in everyday thinking, movement, and other brain functions. During a seizure, a sudden surge of unusual electrical activity causes a person to lose control of some of these functions.

There are many different types of seizures, but most nocturnal seizures are tonic-clonic.

Doctors used to call tonic-clonic seizures grand mal seizures. They typically last less than 5 minutes.

During the tonic phase, a person's muscles stiffen. This can cause them to bite their tongue or lose control of their bladder or bowels.

During the clonic phase, their muscles may twitch. Immediately after the seizure, it may be difficult to wake the person.

Lack of sleep is a common seizure trigger among people with epilepsy, so nocturnal seizures that disrupt sleep may increase the risk of further seizures.

## **Symptoms**

During a nocturnal seizure, a person may:

- cry out or make unusual noises, especially right before the muscles tense
- suddenly appear very rigid
- wet the bed
- twitch or jerk
- bite their tongue
- fall out of the bed
- be difficult to wake after the seizure
- be confused or display other unusual behaviors after a seizure
- wake suddenly for no apparent reason

Not all people with nocturnal seizures know they have them. Sometimes, the only symptom is a headache or a bruise upon waking.

Following a seizure, a person may feel exhausted or sleep deprived. This can cause them to be sleepy or irritable during the day.

Nocturnal seizures usually occur right after a person falls asleep, right before they awake, or right after they awake.

## **Causes**

Genetics are a possible cause of epilepsy.

Epilepsy can cause nighttime seizures. Epilepsy is an umbrella term that refers to many different types of seizure disorders.

Knowing a person has epilepsy does not explain why they have seizures. Doctors diagnose a person with epilepsy if they have two or more seizures that are not clearly due to something else, such as a fever or alcohol withdrawal.

Some potential causes of epilepsy include:

- Genetics
- Head trauma
- A Brain Infection
- Strokes, blood vessel malformations and tumors

Certain types of epilepsy are more likely to cause nocturnal seizures. They include:

- awakening tonic-clonic seizures
- childhood benign rolandic epilepsy
- Landau-Kleffner syndrome
- frontal lobe epilepsy
- Juvenile myoclonic epilepsy







## **Diagnosis**

Distinguishing nocturnal seizures from other sleep behavior, such as sleepwalking or night terrors, can be challenging. People who live alone may wake up tired, but not know that they have seizures. If a person does not experience daytime seizures, they may be unaware they are at risk for nighttime seizures.

A person who has unusual nighttime behavior, headaches in the morning, or unexplained mood changes should see a doctor.

Doctors usually diagnose epilepsy with an electroencephalogram (EEG), which is a test that measures electrical activity in the brain. In some cases, a doctor may recommend MRI or CT scans to see if there is an area of brain injury or a tumor in the brain.

When a person only experiences nighttime seizures or is not sure whether their nighttime experiences are seizures, a doctor may recommend a sleep study. Sleep studies can rule out other issues, such as sleep apnea.

## **Nocturnal seizures in children**

Several types of childhood epilepsy can cause nocturnal seizures.

Benign rolandic epilepsy, the most common form of childhood epilepsy, usually disappears in adulthood. The primary symptom is nighttime seizures.

Children with this form of epilepsy may also have migraines or behavioral issues. Most children with this form of epilepsy have a family history of seizures.

Juvenile myoclonic epilepsy, sometimes called Janz syndrome, typically begins in adolescence, and the seizures may be short at first. Doctors do not know what causes this type of epilepsy, but it may be genetic.

Not all nighttime seizures in children mean the child has epilepsy. Between 2% and 5% of children under 5 years of age in the United States experience febrile seizures, which happen when they have a fever. Febrile seizures are usually harmless, and they typically resolve once the fever subsides. However, it is essential to see a doctor to rule out other causes, such as a brain injury or infection.

## **Treatment and prevention**

Antiseizure medication may help prevent nocturnal seizures.

Nocturnal seizures are potentially dangerous and increase the risk of dying from epilepsy. Having a seizure while sleeping can also make a person prone to injuries.

People who experience nighttime seizures are more likely to suffer low blood oxygen during and after the seizure. They are also more likely to continue to experience unusual brain activity after the seizure.

While this can be frightening, epilepsy is usually treatable. Controlling the seizures greatly reduces a person's risk of complications.

The right treatment depends on the type of seizure a person has, the cause, and other health factors. Possible treatments include:

- antiseizure medication, such as phenytoin
- Avoiding seizure triggers, such as sleep deprivation
- A high fat, low carbohydrate diet, or ketogenic diet
- a vagus nerve stimulator, or surgical implant that sends electrical impulses to the brain

Tracking symptoms and triggers can help with identifying any patterns in the symptoms and whether the treatment plan is working.

People who have nocturnal seizures may also wish to take measures to prevent injuries. These can include:

- choosing a low bed frame or placing the mattress on the floor
- putting a safety mat, such as those for gymnastics, on the floor next to the bed
- using wall mounted lamps rather than table lamps
- keeping furniture away from the bed
- Using a nocturnal seizure monitor that alerts a loved one when a person has a seizure

## **Summary**

Nocturnal seizures are potentially dangerous. For people with no previous history of seizures, they may be the first sign of epilepsy. No matter how many nighttime seizures a person has or what medication they take, it is vital to see a doctor for any symptoms of nighttime seizures promptly.

Controlling nighttime seizures can significantly reduce the risk of epilepsy complications. A full diagnosis can also rule out other causes of troubling symptoms at night.

<https://www.medicalnewstoday.com/articles/326864.php#summary>





## The "Maternal Effect" On Epilepsy Risk: Analysis Of Familial Epilepsies And Reassessment Of Prior Evidence.

[Ann Neurol](#). 2019 Oct 21. doi: 10.1002/ana.25625. [Epub ahead of print]

Ellis CA<sup>1</sup>, Berkovic SF<sup>2,3</sup>, Epstein MP<sup>4</sup>, Ottman R<sup>5</sup>, Epi4K Consortium (Epi4K is an international collaboration for epilepsy genomics).

### Abstract

#### OBJECTIVE:

Previous studies have observed that epilepsy risk is higher among offspring of affected women than offspring of affected men. We tested whether this "maternal effect" was present in familial epilepsies, which are enriched for genetic factors that contribute to epilepsy risk.

#### METHODS:

We assessed evidence of a maternal effect in a cohort of families containing  $\geq 3$  persons with epilepsy using three methods: (1) "downward-looking" analysis, comparing the rate of epilepsy in offspring of affected women versus men; (2) "upward-looking" analysis, comparing the rate of the epilepsy among mothers versus fathers of affected individuals; (3) lineage analysis, comparing the proportion of affected individuals with family history of epilepsy on the maternal versus paternal side.

#### RESULTS:

Downward-looking analysis revealed no difference in epilepsy rates among offspring of affected mothers versus fathers (prevalence ratio 1.0, 95% CI 0.8, 1.2). Upward-looking analysis revealed more affected mothers than affected fathers; this effect was similar for affected and unaffected sibships (odds ratio 0.8, 95% CI 0.5, 1.2) and was explained by a combination of differential fertility and participation rates. Lineage analysis revealed no significant difference in the likelihood of maternal versus paternal family history of epilepsy.

#### INTERPRETATION:

We found no evidence of a maternal effect on epilepsy risk in this familial epilepsy cohort. Confounding sex imbalances can create the appearance of a maternal effect in upward-looking analyses and may have impacted prior studies. We discuss possible explanations for the lack of evidence, in familial epilepsies, of the maternal effect observed in population-based studies. This article is protected by copyright. All rights reserved.

<https://www.ncbi.nlm.nih.gov/pubmed/31637767>

## Have Your Say On Epilepsy Research

The [Ontario Brain Institute's](#) (OBI) epilepsy research program ([EpLink](#)) is looking to better understand the questions Canadians have about epilepsy and seizures. These questions could be about causes or diagnosis, treatment, managing day-to-day life or managing co-existing conditions related to epilepsy.

Co-existing conditions related to epilepsy include:

- Rett Syndrome
- Cerebral Palsy
- Down Syndrome
- Tuberous Sclerosis
- Depression, anxiety, or other mood disorders
- Neurodevelopmental disorders

If you have epilepsy or experience seizures, or if you care for or work with someone who does, we want your help in setting the priorities for epilepsy research. Your answers to this survey will help researchers and research funding organizations better identify what is important to people living with epilepsy and/or seizures and incorporate their priorities when planning future projects.

This priority setting process follows the methods of the [James Lind Alliance \(UK\)](#) and is being funded by [OBI](#). It is led by a steering committee that includes patient advocates, patient advocacy group representatives, clinicians, and healthcare professionals working with persons who have epilepsy and/or seizures.

This is an opportunity for you to lend your expertise from your own personal/professional experience, and have your say in setting epilepsy research priorities.

Please complete this short questionnaire at: <http://www.braininstitute.ca/epilepsy-psp>

This survey is open from October 2019 to January 2020— contribute your voice today!







## Kids' Fever-Related Convulsions Tied to Greater Risk of Epilepsy, Schizophrenia



A new Danish study shows a link between repeated febrile (fever-related) convulsions and the risk of epilepsy and psychiatric disorders such as [schizophrenia](#) and [depression](#).

The register-based study involved two million Danish children born between 1977 and 2011. Researchers from the Department of Clinical Medicine at Aarhus University and Aarhus University Hospital in Denmark identified approximately 17,000 children with more than a single febrile convulsion.

This makes the register-based study the most comprehensive thus far to look at the long-term consequences of repeated febrile convulsions. The study is published in the journal *JAMA Pediatrics*.

"Though previous research has documented an increased occurrence of epilepsy among children with febrile convulsions, this is still

one of the first studies to demonstrate such a convincing correlation between febrile convulsions and psychiatric disorders," says the study's lead author postdoc Julie Werenberg Dreyer from the National Centre for Register-based Research.

"Not least due to the size of the study, the long period of time that the study covers and the valid Danish data."

Werenberg Dreyer emphasizes that although the study demonstrates a clear link, this is not the same as concluding that febrile convulsions in themselves cause epilepsy or psychiatric disorders.

"A statistical correlation does not necessarily mean that one thing causes the other and that it is the febrile convulsions themselves which have a damaging effect on the brain. But the study's results are so significant that looking into this more closely is more than relevant when it comes to possibly being able to provide the best possible prevention and treatment," said Werenberg Dreier.

She says that a future study could look into the significance of genetics for the child's risk of suffering febrile convulsions and subsequent epilepsy or psychiatric disorders.

"There are still many unknown factors that we don't know enough about. As we learn more about the importance of genes for health and disease, it may be that it is here we will find an explanation for why some children suffer repeated febrile convulsions and then later in life also develop epilepsy and psychiatric disorders," she says.

The results show that among children who have three or more attacks of febrile convulsions, the risk of developing epilepsy within 30 years is approximately 15 percent, while the risk of a psychiatric disorder that requires treatment is approximately 30 percent.

In comparison, children with no history of febrile convulsions have a 2 percent risk of developing epilepsy and a 17 percent risk of developing a psychiatric disorder.

"Both epilepsy and psychiatric disorder can be extremely serious and associated with high morbidity and mortality — so in this way the diseases have major consequences for both the individual patient, their family and society," says Jakob Christensen, a clinical associate professor at Aarhus University and consultant at the Department of Neurology at Aarhus University Hospital. He has conducted intensive research into epilepsy over many years.

The team hopes the results will encourage more research to clarify the link between febrile convulsions and the long-term consequences.

"Our results may be frightening reading for parents who have a child that suffers from repeated attacks of febrile convulsions. But these are families who are already deeply concerned about their children. The new knowledge can help them and healthcare professionals to be extra aware of these children's health and development," said Werenberg Dreier.

Traci Pederson  
November 1st, 2019

<https://psychcentral.com/news/2019/11/01/kids-fever-related-convulsions-tied-to-greater-risk-of-epilepsy-schizophrenia/151179.html>





## Better Seizure Control With Ketogenic Diet In Infants

Young children with epilepsy due to genetic causes respond better to ketogenic diet treatment compared to people with other types of epilepsy. This is according to a review of cases across 10 years at a Chicago hospital in the US. The results were published in Scientific Reports in June 2019.

The study author is John Millichap, Associate Professor of Pediatrics at Northwestern University Feinberg School of Medicine, US. He said: "Overall, we observed that the ketogenic diet continues to be a safe, effective and well-tolerated treatment for patients under three years of age with drug-resistant epilepsy." "Clinicians could consider offering the ketogenic diet earlier to infants diagnosed with genetic epilepsy, perhaps even before it becomes clear that the patient is not responding to anticonvulsant medication."

The ketogenic diet is a high fat, low carbohydrate and protein restricted diet that has to be closely overseen by specialist doctors, nurses and dieticians.

"The ketogenic diet helps control seizures by reducing fluctuations of blood sugar, which reduces hyper-excitability in the brain," explains Dr Millichap.

Generally, it is only recently that US epilepsy specialists have been offering a ketogenic diet to younger children. This latest research looks at the ketogenic diet in 109 young patients with various types of epilepsy that began in infancy. In the study, the youngest patient to start on the diet was three weeks old. Of the children in the study, nearly 20% achieved complete seizure control after three months on the diet and nearly 40% had significant seizure reduction. In children with genetic causes of epilepsy, the results were even better. Nearly half reported to have more than 50% fewer seizures.

Dr Millichap said: "The ketogenic diet and parents need extensive support. Genetic testing should be performed as early as possible so that we can provide the most precise treatments right away," said Dr Millichap. "Large studies are needed to explore which genetic epilepsies respond best to the ketogenic diet so that we can add it to our toolkit"

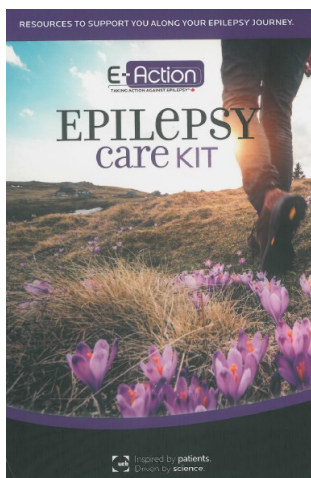
October 31st, 2019

<https://www.epilepsy.org.uk/news/news/better-seizure-control-ketogenic-diet-infants-72490>

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## Seizure Record Book

Pre-order your 2020 pocket or purse sized calendar/seizure record book with pen by contacting the EEA Office. We will either hold it for your pick-up or mail it out to you (your choice) when our shipment comes in.



### Epilepsy Care Kit

The Epilepsy Care Kit was designed by UCB to provide further information, access to resources and support, and guidance on taking an active role in monitoring your seizures.

To obtain your Care Kit, contact the EEA to either pick one up or to have one mailed to you.





## Toronto Girl, 5, Becomes First Person In Canada To Receive Newest Version Of Epilepsy Implant



Since her diagnosis with a rare seizure disorder at seven months old, Emma Greco, now five, has come a long way. There is still a lot to learn about infantile spasms (IS) though, and as long as there is, her family has work to do.

So on Nov. 29, her parents, Monica Diaz-Greco and Daniel Greco, will host the second annual Emma IS event to raise awareness about IS and fund research into treatments for the disorder.

Emma's parents realized something was wrong when Emma was seven months old. At the time, Emma suffered from spasms every two weeks or so. The Grecos' observations led to her diagnosis with IS at an early age, giving doctors an opportunity to treat Emma for the epileptic disorder before it could cause permanent developmental damage.

Not all families are so fortunate. The subtle signs of IS can go undetected long enough to lead to cognitive delay in children. IS can also progress into other forms of epilepsy as a child ages, so having an early diagnosis can prepare parents for addressing new challenges as they arise.

This is why the Weston couple is so passionate about raising awareness of IS, helping parents understand the disorder and funding research into treatments for it.

"We wanted to raise money for infantile spasm research," said

Diaz-Greco, "and coincidentally, Emma's doctor is doing a study on first-line treatments in the defense against infantile spasms, so the money we raise goes directly to her research."

Dr. Cristina Go, Emma's neurology specialist at Toronto's Sick Kids hospital, is studying ways to better triage patients from the time symptoms first appear so they can receive the most appropriate treatment in the shortest length of time.

"My goal is to try to get them diagnosed as soon as they present, and part of it is education of other physicians who refer these patients to us," Go said. "Also, once they are in our program, it's about looking at patients that might potentially benefit from epilepsy surgery."

Epilepsy surgery, also known as vagus nerve stimulation (VNS) surgery, involves implanting a device similar to a pacemaker under a patient's skin. The implant stimulates the vagus nerve, helping control seizure activity to make epilepsy more manageable.

Emma, whose infantile seizures have developed into epilepsy, became the first person in Canada to undergo the newest version of VNS therapy on Sept. 6.

Diaz-Greco said the family and Emma's doctors are monitoring how her seizures respond to the device in order to fine-tune its settings to her disorder. Otherwise Emma, who is now in senior kindergarten, is doing well.

"It's remarkable. We've been really lucky in that we've had really good professionals working with Emma,"

Diaz-Greco said. She explained that Emma, who experiences delayed speech due to her condition, is enjoying progress with a speech pathologist.

"She's doing a lot of things better than she could. Her progress is always going to be slower, and we accept that, but she's making great strides."

Megan DeLaire  
October 24th, 2019

<https://www.thestar.com/news/gta/2019/10/24/toronto-girl-5-becomes-first-person-in-canada-to-receive-newest-version-of-epilepsy-implant.html>





# 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*

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...*