

# NOVEMBER - DECEMBER 2015



## FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION  
The Epilepsy Association of Northern Alberta - Our 55<sup>th</sup> Year of Service

(This Newsletter can be viewed in full colour [on our website.](#))

### Member Outings & Activities

#### November

##### Fun BINGO for Prizes

Friday, November 27, 1:00 – 3:00 pm  
EEA Office

##### Festival of Trees

Sunday, November 29, 1:00 - 4:00 pm  
Shaw Conference Centre  
9797 Jasper Ave NW  
Meet at Festival ticket booth  
(preregistration deadline Nov. 25)



#### December

##### Gift Decorating Classes

Wednesdays, Dec. 2 & 9, 1:00-3:00 pm  
EEA Office  
(preregistration deadline Nov. 30)

##### Christmas Lunch & Social

Saturday, December 12, 12:00 - 3:00 pm  
Central Lions Seniors Centre  
11113 - 113 Street NW  
(preregistration deadline Dec. 4)

##### Fun BINGO for Prizes

Friday, December 18, 1:00 – 3:00 pm  
EEA Office

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

HANUKKAH



CHRISTMAS  
DAY

NEW YEAR'S  
EVE



### FREE MEMBER ACTIVITY

#### [Festival of Trees](#)

Sunday, November 29, 1:00 - 4:00 pm  
Shaw Conference Centre



Transportation to Member Activities is not provided when public transit is available. EEA Office staff would be happy to assist you with transit travel planning if needed.

### Free Epilepsy Education Forum:

## “When Patients with Epilepsy Also Have Other Neurological Conditions”

Thursday, November 12, 2015 6:30-9:00 p.m.  
Glenrose Hospital Auditorium

For further details and to reserve your seat see [page 5.](#)



### Annual Christmas Lunch and Social

Saturday, December 12

For more details see [page 3.](#)



### Adult Support Group Schedule

(Group meets from 1:00 - 3:00 p.m. in the EEA office.)  
Please call the Office to advise if you will be attending.

Wednesday, November 18, 2015

Wednesday, December 9, 2015

### Support for Parents of Children with Epilepsy

No formal sessions are planned. See “Free Member Activities” for EEA’s upcoming family-friendly activities. For individual questions or concerns, please contact the EEA office for support and information.





# 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 Wendy at our office or e-mail her at [info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)

## **BOARD OF DIRECTORS**

**President...**Don Risdon  
**Vice President...**Ann Gillie  
**Treasurer...**Anna Tymoszejko  
**Secretary...**Cameron Reid  
**Executive Director...**Gary Sampley

**Directors-at-Large:** Tammy Anast  
Szymon Bamburak  
Guy Doucette  
Craig Heyland  
Kim Mahe  
Cheryl Renzenbrink  
Anne Starreveld  
Brian Wilkie  
Michel Zielinski

## **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)

**Wendy Sauve...** Asst. to the Executive Director  
[info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)

## ***Edmonton Epilepsy Association***



### **EEA Partners with TD Canada Trust in Employability Program**

Through the initiative of EEA member Tim McCallen, a Branch Manager with TD Canada Trust, members who are potentially interested in part-time positions as a bank customer service representative (Teller) or full-time positions such as a Financial Service Representative have an opportunity to submit a resume directly through TD's Prairie Region Human Resources Counsellor

For Further information contact EEA Executive Director, Gary Sampley, 488-9600 or [gary@edmontonepilepsy.org](mailto:gary@edmontonepilepsy.org)

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

11215 Groat Road NW  
Edmonton, AB T5M 3K2

(780) 488-9600  
(780) 447-5486 fax  
1-866-EPILEPSY

[info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)  
[www.edmontonepilepsy.org](http://www.edmontonepilepsy.org)



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



## **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.





# News from the EEA Office



## Collective Kitchen Program Starting in January 2016

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.



The next Collective Kitchen Project runs from 12:30-3:00 pm on Friday January 22, February 19, March 11, April 22, May 20 and June 17. Interested members can phone Sharon at the EEA Office at 780-488-9600 to register. Registration is limited to **eight** participants.



## Annual Christmas Lunch and Social

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

Central Lions Seniors Centre,  
11113 113 Street, Edmonton

In keeping with our tradition of a different ethnic theme each year, this year will have a Polish theme, with entertainment by Lowicz Polish Folklore Ensemble of Edmonton.

**\$15.00** per person (remainder EEA subsidized). Limited full subsidies available for those in need.

Call the EEA office 780-488-9600 to book your seats (**pre-registration by December 4th required**).

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

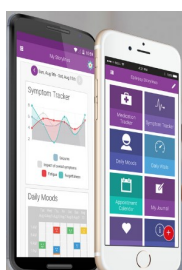
## Gift Wrapping Tips & Tricks

EEA member David Walsh has a real talent for making a gift look beautiful on a budget! We are offering two hands-on classes where David will share his tips and tricks with participants.

**Wednesdays, December 2 & 9; 1:00 - 3:00 pm**

**Please call the EEA office by November 30 to register for this activity.**

Donations of wrapping paper, ribbon, new/old ornaments, costume jewellery, beads, dried/silk flowers, etc. would be much appreciated. Items can be brought to the EEA office during business hours.



 Epilepsy Health Storylines

Successfully tracking and  
managing epilepsy is now  
at your fingertips.  
Try it today. It is 100% free.

Get it on  
Google play

Download on the  
App Store



Epilepsy Health Storylines is developed in partnership with Living Well with Epilepsy, and is powered by the Health Storylines™ platform from Self Care Catalysts Inc. [Click here](#) to find out more online.





# News from the EEA Office



## 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 2016 "Achiever of the Year" Award, please do so, in writing, to the EEA office by **March 1st, 2016**.

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](mailto:gary@edmontonepilepsy.org)

## 2016 EEA Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2016, 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, 2016**

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.



## **THE GIFTS OF WINTER**

Winter can be many things:  
a state of mind, or  
whistling winds, frosts and snow,  
while sleeping earth  
cradles gifts of spring.

The birth of the Christ-Child  
on that bleak night,  
brought new life for all  
seeking inner light  
bright as the dazzling star of old,  
guiding Wise Men  
to a place unknown.

We like them would guided be  
to inner peace and harmony.  
Knowing surely that our long night,  
like sleeping earth's,  
will bring Spring's delights.

So, come chill wind and winter weather.  
Frosts and snow  
and Christmas time  
bring treasures of the finest kind,  
to waiting hearts and willing minds.

*EEA member Jeanne Egert*



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

We have a limited number of tickets from our 2015 allotment available in the EEA Office. 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 have an AISH bus pass. Call 780-488-9600 or drop by to pick them up. (Please note new EEA Office location.)



## **Need Prescriptions Filled?**

We recommend the following Pharmacists, who support the programs of the EEA. For all your Pharmacy needs, visit their friendly, helpful staff today.

Southside: G & E Pharmacy  
7326-82nd Avenue  
780-469-7667

Central: Royal Pharmacy  
Ground Floor, 11010-101 Street  
780-426-0872







In partnership with

**The Adult Convulsive Disorder Clinic at the Glenrose Rehabilitation Hospital**

and



**Presents a Free Educational Forum:**

## ***“When Patients with Epilepsy Also Have Other Neurological Conditions”***

**Dr. Ken Makus, Glenrose Rehabilitation Hospital**

**Dr. John R. Neilson, Garneau Pediatric Associates**

**There will be a post-presentation Question & Answer panel.**

**Thursday, November 12, 2015 6:30-9 p.m.**

**Glenrose Hospital Auditorium 10230-111 Ave**

**A FREE Light Supper will be provided**

*This forum will be of interest not only to individuals who live with epilepsy and their family members, but also to health care professionals, medical and nursing students, and educators.*

For more information or to reserve your seat, please call  
780-488-9600 or toll free 1-866-374-5377 or email [info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)





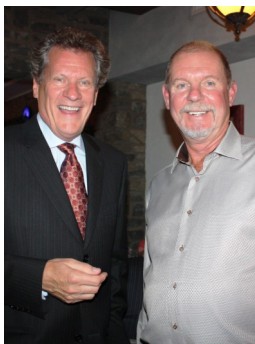
# Celebrate the Grape Fundraiser







# September 2015





## Seizures Triggered By The Fridge Made Life A Daily Struggle

INDIANAPOLIS -- When Brandy Gibson was 17 and pregnant with her daughter, Calie, something strange started happening when she opened the freezer door.

"I would just get the oddest feeling, and just would laugh and laugh," she says. It felt like she had smoked marijuana.

When she shut the freezer, the feeling would go away. But it happened again and again during her pregnancy. Sometimes she would go to the freezer and open it up for fun, just because it felt so good.

"I just thought it was part of my pregnancy. I didn't think to go to a doctor," she says.

The feeling went away completely after her daughter was born. But when she got pregnant again a couple years later, it came back. This time, things changed. It was triggered by the refrigerator now. And instead of the high feeling, she would black out, sometimes for a few seconds, sometimes for several minutes. "It was as if your body had a power button, and someone was pressing it and your batteries were just going dead," she says. "Then all of a sudden, you're just gone."

Brandy finally saw a doctor about her symptoms. She was diagnosed with epilepsy, and found out her strange feelings were actually seizures.

From there, Brandy started a medical journey that finally led her to letting a team of doctors operate on her brain in an effort to solve the problem. Along the way she struggled—as many people with epilepsy do—to maintain her normal life in the face of her increasingly disruptive symptoms.

**Episodes of Electrical Activity** The typical image of someone having seizure on TV — violent shaking or convulsing on the floor — doesn't apply to everyone with epilepsy. A seizure is an episode of increased electrical activity in the brain and those dramatic TV examples, known as tonic-clonic seizures, involve the whole brain.

But seizures can also involve just one part of the brain. These are known as partial seizures and they can be subtle, a momentary loss of consciousness or feeling of confusion, explains Meredith Runke, one of Brandy's neurologists at the IU Health Neuroscience Center in Indianapolis.

"Usually there's something there structurally — scar tissue, a developmental abnormality, a vascular malformation — something there that's triggering the seizure disorder," says Runke.

People having partial seizures, she says, may be unresponsive but their hands can be fidgeting or they can have unusual movements of the mouth.

That's what they were like for Brandy. She usually didn't fall to the floor, and in fact, most of the time when she lost consciousness, her body would keep moving, even talking. Sometimes she would smack her lips.

The doctors didn't know this for sure at the time, but Brandy's seizures were coming from her left temporal lobe, the part of the brain around the temple.

Temporal lobe epilepsy is the most common kind of partial seizure epilepsy, but Brandy's case was unusual because her seizures were also reflex seizures, meaning they had a trigger: her fridge.

No one knows exactly why a fridge could trigger Brandy's seizures, but one of the theories involved specific neurons in the temporal lobe called place cells, which are activated by a location.

The doctors think whenever she saw a refrigerator or even an image of one, it would remind Brandy of a location in her house, where her fridge is. In effect, she was recalling that place, even if she wasn't actually there. Somehow this started a chain reaction in her temporal lobe that would lead to a seizure.

About 60 to 70 percent of people are able to control their seizures with medications. Brandy's doctors put her on medication, and again, the seizures went away after the pregnancy. But a couple years later, Brandy was driving her truck into town when she felt that familiar sensation again, like she was going to black out.

She pulled over. "And my mind shut off and I hit the gas and floored my truck into a dumpster," she says.

Given what happened, she says she just knew she was pregnant again. Pregnancy, it turns out, was not the cause of her problems—she doesn't have gestational epilepsy—but it seemed to make them worse.

This time they got a lot worse. She started having memory problems and she was even more sensitive to her trigger: the seizures would come if she just walked by the kitchen and glanced at the fridge. And after her son was born, the seizures didn't stop.

**A hidden disability** The trigger for Brandy's seizures is really unusual, but the way epilepsy affected the rest of her life is not. For the 3 million Americans living with epilepsy, daily life can be hard to navigate. All kinds of every day activities are a danger if you might lose consciousness, says Runke. Driving, holding down a job, even taking care of your kids can become problems.

"I think what's really hard about it is how unpredictable seizures are," Runke says.

In many states, people diagnosed with epilepsy lose the right to drive and have to be seizure-free for a long period of time before they can legally drive again. Runke says many of her patients have a hard time maintaining steady jobs, or are afraid to take care of their kids on their own. She said that her team loses about one patient a year due to drowning in a bathtub.

For a lot of people with epilepsy, this unpredictability can make them more vulnerable to stigma and economic hardship.

In the last several years several federal agencies have begun acknowledging this and are taking action. The Institutes of Medicine published a major 450-page report in 2012 pushing for increased data collection, better health care access for those with epilepsy, and improved education surrounding the condition. According to a 2014 report, the U.S. Department of Health ...







... and Human Services is trying to heed the IOM's many recommendations.

The CDC has announced a round of funding coming in January 2016 for initiatives that improve the situation of epileptics: to increase the number of people with epilepsy getting appropriate medical care, to decrease stigma, and to improve their chances of holding down a job and completing school.

The challenges of living with epilepsy are made worse, Runke says, because epilepsy is also associated with other impairments, such as depression, anxiety, memory problems, and other cognitive problems that can make it hard to sustain good jobs.

**Life put on hold** For Brandy, these seizures triggered by such a common, everyday object made normal life nearly impossible. Sometimes, a seizure would start just from feeling the breeze in the refrigerated section at the grocery store.

"I could not help it," she recalls. "My mind [was] thinking about a refrigerator." To prepare for a seizure, she only had one trick. "The safest thing to do is lay down, even if it's on the floor," she says.

After she had a seizure at work, Brandy actually lost a factory job. She says the management considered her a liability, and rumors circulated that she was faking her condition or addicted to drugs.

Brandy's biggest worry was taking care of her kids. Preparing food was one of the hardest things she had to do. "Being a single mother, you still have to open that fridge, and being alone with your children and going into a seizure, you don't know what's going to happen," she says.

So it often meant going out to eat, often to a nearby Chinese restaurant. "They love my daughter," she says. "They know why I always went there."

She knew it wasn't the healthiest choice, but it was the safe option. She felt she could be a danger to her kids every time she opened the fridge.

There was a particular reason Brandy was extra sensitive to the risks to her kids, even more than other parents might be. Though it had nothing to do with her seizures, Brandy had already lost her elder son, Bryson.

He passed away while sleeping, most likely from asphyxiation, from spitting up and inhaling. "I just went and checked on him and knew he was gone," she says. "He just was sleeping and passed away."

She had her youngest son, Vallis, about two years ago. Since her seizures kept happening after her pregnancy with him, she worried she'd fall into a seizure and hurt him somehow. So she sent him to live with his grandmother, and visited him there.

"I wasn't losing a child from something I do during a seizure. I had already lost a child," she says.

Throughout this time, she was dealing with a lot of fear and grief and her friends just didn't really seem to get how hard epilepsy was for her, and gradually fell out of touch. "A lot of people just didn't see what I truly went through," she says.

**A bold surgery** Since medications were not doing much to stop her seizures, Brandy came to Indianapolis and saw Dr.

Nicholas Barbaro, a neurosurgeon at the IU Health Neuroscience Center, and the rest of his team. After several tests and brain scans, Barbaro decided she was likely a good candidate for a type of brain surgery known as a temporary lobectomy.

But they had to do an initial procedure to pinpoint exactly where the seizures were starting: "We open a flap of skin, and then open a window in the bone to expose the brain," Barbaro says.

They put electrodes on the surface of Brandy's brain so they could observe her brain while she was seizing. To speed things up, Brandy Googled images of freezers on a tablet. Within moments she lost consciousness. Over the next few days, still with an opening in her skull, her medical team triggered seizure after seizure, caught it on video, and pinpointed their source.

The team recommended her for surgery, planning to cut out a piece of her temporal lobe a few centimeters in size. "A temporal lobe operation for epilepsy is the most common kind of epilepsy surgery," says Barbaro. "So through a lot of experience, we understand what part is safe to remove."

It was at this point that Brandy had to make a choice. She really wanted to stop the seizures. But she was scared—not about the actual surgery, but about something the doctors told her about the side effects: They said she might have problems with her memory afterwards.

Brandy feared that meant she would lose memories of her family. She thought she could rebuild relationships with her family members that were still alive, but worried especially about her memories of her son Bryson, who she couldn't get to know again.

"Right then and there is when I wanted to change my mind," she says. "I almost decided I didn't want the surgery, because there's the one person that wouldn't be there for me to talk to and to remember."

Lying in that hospital bed, she had to make a choice, and she kept going back and forth. But then her daughter called her. "It was just right then that I realized, 'I need to do this for my kids that I have now,'" she says.

The doctors went back in and worked for a few hours to cut out that part of her brain. When she woke up she was relieved that her worst fears had not come true: "One of the things that made me the happiest when I woke up from the surgery was Bryson was the first thing I thought of," she says.

That was in January and today, things still aren't totally back to normal. Brandy had some short term memory issues before, and she says it's worse since the surgery. But the seizures that came from her refrigerator are completely gone. She can prepare food for her kids again. And sometimes she stands in front of the open refrigerator, just because she can. "I do love the fridge now," she says with a laugh.

Brandy had been living with her mother, but now she's ready to move out. She's looking for a new place with her boyfriend and both of her kids.

"My life is a lot better now," Brandy says.

September 29, 2015

<http://www.wfyi.org/news/articles/seizures-triggered-by-the-fridge-made-life-a-daily-struggle>





## What's in Store 5 Decades Following Childhood-onset Epilepsy?

A 45-year study of 179 individuals with childhood-onset epilepsy indicates that patients' long-term health is excellent, with most attaining 10-year remission off medications, which is the definition of resolved epilepsy.

Despite having excellent seizure outcomes, individuals often have abnormal neurologic signs including markers of cerebrovascular disease that may be a risk factor for future stroke and cognitive impairment.

"The cohort was studied in-depth with detailed neuropsychological assessments and multimodality imaging techniques, all of which will provide very unique insights into the aging process of persons with 'uncomplicated' childhood onset epilepsies," said Dr. Matti Sillanpaa, lead author of the *Epilepsia* study.

October 5, 2015

<http://www.sciencenewsline.com/news/2015/10/05/19160054.html>

### Related article with additional in-depth information:

<http://www.epilepsyresearch.org.uk/long-term-seizure-outcomes-excellent-for-childhood-onset-epilepsy/>

## Epilepsy and Migraine: A Common Ground?

Migraine and epilepsy have several things in common: they often co-occur and share similar symptoms, each is generally under-treated, one is often misdiagnosed as the other,<sup>1</sup> and various medications are effective in treating both disorders.<sup>2</sup> Recent research may help elucidate the relationship between the two and shed light on more appropriate diagnosis and treatment options.

"Patients with migraine are more likely to have epilepsy, and patients with epilepsy are more likely to experience migraine," Pavel Klein, MD, director of the Mid-Atlantic Epilepsy and Sleep Center, told *Neurology Advisor*. In fact, people with seizure disorders are twice as likely to experience migraines which can often lead to misdiagnosis.

There are commonalities between the two disorders "in clinical symptomatology, particularly with regard to visual and other sensory disturbances, pain, and alterations of consciousness." For instance, if a patient has a migraine that causes focal neurological symptoms — numbness in the arm or face, for example — it can appear to be a seizure. It is also known that stress can trigger seizures, and in a less common scenario, "in someone with very severe migraine, it is possible that the stress of the pain could trigger a seizure," Klein explained.

The potential reasons for the close relationship between the two disorders are just as varied. "There could be common substrates that cause both headaches and seizures," said Klein. For example, a condition called benign epilepsy of childhood is commonly associated with migraine and is often misdiagnosed as such, while another possibility is that migraine could lead to mild forms of brain damage that increase the risk of epilepsy. Studies have found that MRI of some patients with migraine show small areas of abnormal lesions or scarring. Researchers are not yet sure of the cause, but it is possible that the scarring is a result of a stroke that is otherwise asymptomatic, and the "scarring leads to reorganization of the local network that could lead to seizures," said Klein.

### What Role Do Genetics Play?

Research published in *Epilepsia* in 2013 was the first to investigate the role of genetics in the co-occurrence of migraine and epilepsy. After testing 730 participants with epilepsy, researchers divided them into two non-overlapping groups — one with mi-

graine with aura and one with migraine without aura — and interviewed participants about their family history of seizure disorders. The results showed that a history of migraine with aura was "significantly increased in enrolled participants with two or more additional affected first-degree relatives," supporting the researchers' hypothesis of a shared genetic susceptibility to migraine and epilepsy.

"The hope of scientists, caregivers, and families with epilepsy is that genetics will offer a novel and wider understanding of the causes and the pathophysiology of epilepsy," study co-author Melodie R. Winawer, MD, MS, an associate professor of neurology at Columbia University, told *Neurology Advisor*.

Approximately two thirds of epilepsy cases have no known cause, and genetic factors may play a critical role in that subset of cases. A ground-breaking aspect of these findings is in regards to reconceptualizing disease boundaries.

"A disorder does not stand alone but can be seen as part of a network of intersecting disorders — in fact, there have been intersecting bidirectional relationships identified for epilepsy, migraine, anxiety, depression, suicidality, and psychosis," she said. "As we start to understand that some of these disorders are occurring in a network or a cluster rather than standing by themselves, I think it is going to completely transform treatment strategies" and potentially affect preventive efforts.

Ultimately, the knowledge of a shared pathophysiology could lead to the development of new treatment options, as well as recognition of accompanying disorders beyond seizures that can severely impact a patient's quality of life.

After all, failing to treat co-occurring disorders is a disservice to patients, said Winawer. Treatment of any condition — including migraine and epilepsy — should consider potential comorbidities that could worsen or improve depending on the chosen treatment. "We really need to understand epilepsy in its context," said Winawer. "There is a huge move in the last few years to do that and I think this work is part of that larger question."

Toni Rodrigues, MA, LPC

October 5, 2015

<http://www.neurologyadvisor.com/epilepsy/epilepsy-migraine-disorder-similarities/article/443017/>







## Researchers Identify Genetic Links Between Epilepsy and Sudden Death

Scientists have made a breakthrough in understanding premature death in people with epilepsy.

A group of researchers, led by those from Epilepsy Society and University College London, have discovered that an individual's genetic make-up may contribute to the risk of sudden unexpected death in epilepsy (SUDEP).

SUDEP is a devastating outcome of epilepsy that tragically takes the lives of 600 people each year in the UK. This latest breakthrough brings us a step closer to determining risk in individual people, with the eventual aim of preventing deaths through personalised diagnosis and treatment.

By analysing a person with epilepsy's genes, medical professionals may, in the future, be able to identify the heightened risk of SUDEP in advance, contributing towards the quest for prevention.

Genetic sequencing is playing an increasingly important role in healthcare, as it may help patients receive more tailored treatment for their conditions. Epilepsy affects more than half a million people in the UK and a greater genetic understanding will help identify precision treatments, as well as pinpointing the causes and risk factors.

This study is the largest of its kind so far, analysing sequences of 1,479 non-epilepsy disease controls, 18 people who died of SUDEP and 87 living people with epilepsy. This research was funded by the charity Dravet Syndrome UK with contributions from other bodies. SUDEP can occur in any epilepsy, and is more common in some, such as Dravet Syndrome.

Sanjay Sisodiya, Professor of Neurology at University College London and Head of Genetics at Epilepsy Society, commented: "This discovery is an important step in understanding the causes of sudden death in epilepsy. It gives the scientific community a further hint at how the genetic make-up of a person with epilepsy might contribute to the risk of this devastating outcome in epilepsy. As we look towards more accurate estimation of individual risk, more personalised treatment and perhaps prevention of SUDEP in the future, we need to test our findings further and we would welcome further collaboration in this area."

July 14, 2015

<http://www.epilepsysociety.org.uk/researchers-identify-genetic-links-between-epilepsy-and-sudden-death#.Vh1y99-FOM8>

For more information about SUDEP  
please visit [SUDEP Aware Canada](#)



## Teachers 'need more education on epilepsy'

Awareness and understanding of epilepsy could be improved by providing teachers with more information and education on the condition, according to new research.

The Italian study, led by the University of Salerno and published in the *Italian Journal of Pediatrics*, aimed to examine the level of knowledge of epilepsy among teachers, as well as assessing their perceptions of quality of life for children with epilepsy, and of interpersonal relationships between students with epilepsy and their classmates.

A sample group of 113 female teachers with a mean age of 44.4 were given a questionnaire with 33 multiple-choice answers to gather information on their work seniority and experience with students with epilepsy.

It was indicated that teachers with more than 11 years of experience generally showed a more than adequate knowledge of information about epilepsy, though in other respects the understanding of the condition was shown to be limited.

In the case of a seizure occurring in the classroom, the most common first aid approach would be to call an ambulance, rather than administering rescue drugs; meanwhile, teachers who had experience with teaching students with epilepsy, perceived them to be limited in the possibilities of getting married, having children, finding a job and practising a sport.

The study also indicated that teachers had inadequate knowledge of the educational strategies needed to integrate students with epilepsy with his or her classmates.

The researchers concluded: "Teachers demonstrate inaccurate information about epilepsy, its impact in educational contexts and management of seizures in the classroom. Also, critical areas have emerged, indicating efforts should focus on education, sharing the role of teachers, awareness and integration in the class group."

It was added that challenging stereotypes and common assumptions about epilepsy among teachers is an important step in changing attitudes to the condition more widely.

Posted by Anne Brown

Oct. 7, 2015

<http://www.epilepsyresearch.org.uk/teachers-need-more-education-on-epilepsy/>

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](mailto:sharon@edmontonepilepsy.org) or call the EEA office 780-488-9600.





# 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)
- ◆ Twice-yearly no-cost Epilepsy Educational Forums, and a bi-annual weekend specialized Educational Conference, all 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 and annual in-house Computer Training Programs 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...*