

# JANUARY - FEBRUARY 2016

## FOCUS ON EPILEPSY

THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION  
The Epilepsy Association of Northern Alberta - Our 56<sup>th</sup> Year of Service

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

### Member Outings & Activities

#### January

##### Fun BINGO for Prizes

Friday, January 29th, 1:00 – 3:00 pm  
EEA Office

##### WHL Hockey: Edmonton Oil Kings vs. Kootenay Ice

Sunday, January 31st, 3:30 - 7:30 pm  
Rexall Place  
(pre-registration required)

##### Collective Kitchen Session 1

Friday, January 25th, 12:30 - 3:00  
EEA Office  
(pre-registration required)



#### February

##### Collective Kitchen Session 2

Friday, February 19th, 12:30 - 3:00  
EEA Office  
(pre-registration required)

##### Fun BINGO for Prizes

Friday, February 26th, 1:00 – 3:00 pm  
EEA Office

##### Alberta Art Gallery Tour

Saturday, February 27th, 1:00 - 3:00 p.m.  
Alberta Art Gallery  
2 Sir Winston Churchill Square  
Meet at Art Gallery Lobby @ 12:45 pm.  
(pre-registration required)



### FREE MEMBER ACTIVITY



#### WHL Hockey: Edmonton Oil Kings vs. Kootenay Ice, Rexall Place

Sunday, January 31st, 2016, 3:30-7:30 p.m.

**Please Note:** This event would not be suitable for individuals who experience seizures from flashing lights. 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.

### 2016 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

**When:** Thursday, March 17th  
**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

### Coming Up In Our Next Newsletter

- ◆ Schedule of Member Activities for 2016
- ◆ Information on March Epilepsy Awareness Month
- ◆ Details of our March Epilepsy Awareness Forum
- ◆ Planned New Collective Gardening Program

### 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, January 13, 2016

Wednesday, February 10, 2016

### 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 Sharon 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  
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Guy Doucette	Craig Heyland
Kim Mahe	Cheryl Renzenbrink
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Michel Zielinski	

## **STAFF**

**Gary Sampley...** Executive Director & Chief Operating Officer  
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**Sharon Otto...** Program Manager & Education Coordinator  
[sharon@edmontonepilepsy.org](mailto:sharon@edmontonepilepsy.org)

**Dr. Sunny Kim...** Counsellor  
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**Cam Reid...** Volunteer Coordinator  
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## **Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta**

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



## ***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**

**We currently have no tickets** from our 2015 allotment available in the EEA Office. We expect to receive our 2016 ticket allotment in mid-April. When these are available, they 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.



## **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.





## **Ricky's All Day Grill is EEA's 2015 Employer of the Year!**

L. to R: EEA Executive Director, Gary Sampley, Goldie Hazrah of Ricky's All Day Grill and Member Kate Sauve who nominated her employer for the award.

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

Congratulations, Goldie and Ricky's All Day Grill!



## **Anna Pagliuso is EEA's 2015 Volunteer of the Year!**



R to L: EEA President Don Risdon presents the "Cameron Reid EEA Volunteer-of-the-Year Award" to award winner Anna Pagliuso. They are accompanied by EEA Executive Director, Gary Sampley.

The award is presented annually to an individual who has provided significant and substantial ongoing volunteer service to the Association over numerous years.

Thank you, Anna, for helping to make the EEA a better organization!

## **Bet You Didn't Know That Santa Is An EEA Member**

That's right! Our very own Santa is a true-blue member of the EEA who kicked off our December 12th Christmas Lunch and Social.

Our Santa is experienced and loves to make kids of all ages happy during the Holiday Season. If you would like to get in touch with Santa about a future Christmas Party where children will be present, contact the EEA Office and we can put you in touch with him.





## **MEDICATION ALERT: Divalproex Sodium (Epival)**

Canadian pharmaceutical companies are reporting shortages of divalproex sodium (Epival), also known as valproic acid. As of Thursday December 17, a total of fifteen divalproex sodium shortages were posted on [drugshortages.ca](http://drugshortages.ca) by Abbott Laboratories Limited\*, Apotex Inc., Pro Doc Limitée, Sanis Health Inc. and Teva Canada Limited. None of the pharmaceutical companies have provided an explanation for the shortages.

This situation is a serious concern. The estimated resupply dates currently range from December 24, 2015 to April 30, 2016. These dates are estimates and could change. Drug shortages, or back-orders, at the level of the pharmaceutical companies do not always result in shortages at community and hospital pharmacies. Although the longer a shortage lasts the greater the likelihood that it could have an impact on patients.

If you or a family member have been prescribed divalproex sodium (Epival), contact your pharmacist and ask about the availability of your medication. If your pharmacist runs into any difficulty obtaining divalproex sodium they may be able to find some from a different supplier, another drug store, or another chain.

According to the Canadian Pharmacists Association's guide on drug shortages, Step 1 is for pharmacists to exhaust every avenue to supply the medication. This may require looking beyond their regular sources of supply and contacting other wholesalers or calling the manufacturers. Your pharmacist also has access to resources and information through the Ontario Pharmacists Association.

If the situation worsens and your pharmacist is not able to locate any divalproex sodium for you, it is important to work with your pharmacist and your health care provider to manage the drug shortage in the safest way possible. During a shortage, your pharmacist and health care provider may explore options that could include filling your prescription with a different strength tablet or substituting a different medication. If your dosing instructions change, ensure you understand the instructions and ask questions if it isn't clear.

When a drug is unavailable in Canada, Health Canada's Special Access Program (SAP) will consider requests from health care providers for access to the drug from outside the country. The SAP can be reached 24 hours a day, 365 days a year, and the program strives to process requests within 24 hours of receipt.

It is important to continue to take your medication as indicated. It can be frightening when an epilepsy drug is in short supply but skipping doses, taking less medication, or suddenly stopping an antiseizure drug is dangerous. This can lead to breakthrough seizures, more prolonged seizures or life-threatening events.

[Click here](#) for additional information about the Health Canada Special Access Program

\* This company may be listed on [drugshortages.ca](http://drugshortages.ca) incorrectly. Epival is no longer marketed by Abbott Laboratories Limited. According to the Health Canada drug product database, Epival is currently marketed by BGP Pharma. It appears that old drug shortage notifications from 2012 were re-used instead of creating a set of new notifications for the current Epival shortages.

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## **Dietary Fat Could Be More Effective for Epilepsy Than Current Drugs**

A specific fatty acid that results from maintaining the ketogenic diet may be more effective at controlling epilepsy than many currently used drugs, according to a new study in England. The ketogenic diet consists of food high in fat, a moderate level of protein and almost no carbohydrates. According to researchers, the diet was identified in 1971 as a treatment for refractory epilepsy.

In addition to being difficult to maintain, researchers had not been able to identify the aspect of the diet which prevented seizures in people with epilepsy. While the key factor was thought to be the production of ketones -- which the body produces to create energy in the absence of carbohydrates that can be turned into glucose -- researchers found decanoic acid actually acts to inhibit brain activity that causes seizures.

"By examining the fats provided in the diet, we have identified a specific fatty acid that outperforms drugs currently used for controlling seizures, and that may have fewer side effects," said [Robin Williams](#), a professor in from the Center for Biomedical Sciences at Royal Holloway, in a [press release](#).

Working with mice, researchers fed them the diet, investigating the effects of both decanoic acid and ketones on their brains. They found decanoic acid had significant anti-epileptic effects, while ketones had none at all.

While they acknowledge ketones may have other health benefits, the researchers suggest the potential of the ketogenic diet as treatment for some epilepsy patients future research may focus on deconoic acid.

"This discovery will enable us to develop improved formulations that are now likely to significantly improve the treatment of epilepsy. It will offer a whole new approach to the management of epilepsies in children and adults," said Matthew Walker, a professor at University College London's Institute of Neurology.

Stephen Feller  
November 25, 2015

[http://www.upi.com/Health\\_News/2015/11/25/Dietary-fat-could-be-more-effective-for-epilepsy-than-current-drugs/8171448483643/](http://www.upi.com/Health_News/2015/11/25/Dietary-fat-could-be-more-effective-for-epilepsy-than-current-drugs/8171448483643/)







# 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.

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## 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 years of age and up 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.



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## 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 the 2016 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)

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## 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



### Central

Royal Pharmacy  
Ground Floor, 11010-101 Street











# Christmas Lunch & Social







## **Alberta Health Service has Now Approved APTIOM(TM) (Eslicarbazepine acetate) as a Once-Daily Adjunctive Treatment for Partial-Onset Seizures in Patients with Epilepsy**

APTIOM™ (eslicarbazepine acetate) is a once-daily adjunctive therapy for the treatment of partial-onset seizures in patients with epilepsy who are not satisfactorily controlled with conventional therapy. APTIOM™ is not indicated for use in patients under 18 years of age.

Partial-onset seizures are the most prevalent seizure type, accounting for 60% of new epilepsy diagnoses and approximately one third of patients do not have adequate seizure control.

The Health Canada approval of APTIOM™ is based on three Phase 3 randomized, double-blind, placebo-controlled, safety and efficacy trials (Studies BIA-2093-301, BIA-2093-302 and BIA-2093-304), which included more than 1,400 people living with partial-onset seizures inadequately controlled by one to three concomitant AEDs (including carbamazepine, lamotrigine, valproic acid and levetiracetam). In these global studies, treatment with APTIOM™ demonstrated statistically significant reductions in standardized seizure frequency versus placebo, and significantly more APTIOM™ treated patients experienced seizure frequency reduction of 50% or more from baseline (41% compared to 22% for placebo-treated patients).

The most frequently reported adverse reactions in patients taking APTIOM™ were dizziness, somnolence, headache, nausea, diplopia, vomiting, fatigue, ataxia, vision blurred, and vertigo.

### **About Partial-Onset Seizures**

Epilepsy is a chronic neurological condition characterized by recurrent seizures resulting from abnormal firing of impulses from nerve cells in the brain<sup>2</sup>. In partial-onset seizures, these bursts of electrical activity are initially focused in specific areas of the brain, but may become more widespread, with symptoms varying according to the affected areas.

### **About APTIOM™**

APTIOM™, a voltage-gated sodium channel inhibitor, is a prescription medicine approved for use as adjunctive treatment of partial-onset seizures. Treatment with APTIOM™ should be initiated at 400 mg once daily. After one week, dosage may be increased to the recommended maintenance dosage of 800 mg once daily. Some patients may benefit from the maximum recommended maintenance dosage of 1,200 mg once daily, although this dosage is associated with an increase in adverse reactions. The maximum dose of 1,200 mg daily should only be initiated after the patient has tolerated 800 mg daily for at least a week. For some patients, treatment may be initiated at 800 mg once daily if the need for additional seizure reduction outweighs an increased risk of adverse reactions during initiation. The initial research and development of eslicarbazepine acetate was performed by BIAL, a privately held Portuguese research-based pharmaceutical company. Subsequently, Sunovion acquired the rights under an exclusive license to further develop and commercialize eslicarbazepine acetate in the U.S. and Canadian markets from BIAL. Eslicarbazepine acetate was approved on November 8, 2013, by the U.S. FDA as adjunctive treatment of partial-onset seizures.

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## **New study highlights factors affecting web searches for epilepsy information**

A new study has shed light on the factors that prompt people to search the internet to find out more information about epilepsy.

The international research project – involving the University of Verona in Italy, University Medical Center Utrecht in the Netherlands and Paracelsus Medical University in Austria among others – aimed to examine information-seeking behaviour of English-speaking internet users seeking to educate themselves about epilepsy and epileptic seizures.

Given its status as an increasingly widely-used source of health information for millions of people worldwide, the researchers chose to focus their attention on the use of the online encyclopaedia Wikipedia.

Using Wiki Trends, which provides quantitative information on daily viewing of articles, data on global search queries for Wikipedia articles related to epilepsy and seizures were analysed over a period running from January 2008 to December 2014.

Wikipedia article views on syncope, psychogenic nonepileptic seizures, migraine and multiple sclerosis used as comparative data, with results [published in the medical journal \*Epileptic Disorders\*](#).

Overall, it was shown the Wikipedia article on epilepsy and driving was more frequently visited than the articles on epilepsy and employment or epilepsy in children, while the page on multiple sclerosis was more often visited than the articles on epilepsy, syncope, psychogenic nonepileptic seizures or migraine.

The main epilepsy article ranked at 3,779th in traffic on Wikipedia and was less frequently visited than the multiple sclerosis page, which was ranked in 571st. The highest peak in search volume for the epilepsy article coincided with the news of a celebrity experiencing seizures.

The study concluded: "Fears and worries about epileptic seizures, their impact on driving and employment, and news about celebrities with epilepsy might be major determinants in searching Wikipedia for information."

Anne Brown

November 25, 2015

<http://www.epilepsyresearch.org.uk/new-study-highlights-factors-affecting-web-searches-for-epilepsy-information/>







## Whooping Cough in Infants Tied to Epilepsy Risk

Whooping cough in infancy is associated with an increased risk for epilepsy, a new study has found. The findings underscore the importance of vaccination for whooping cough, also known as pertussis, in childhood.

Danish researchers used government registries to find 4,700 children born between 1978 and 2011 who were diagnosed with whooping cough; about half were diagnosed when they were less than 6 months old. Each child was matched with 10 healthy control individuals from the general population.

Among the 4,700 children who had had pertussis, 1.7 percent later developed epilepsy, compared with 0.9 percent among the 47,000 controls. After adjustment for gestational age, congenital malformations, maternal history of epilepsy and other health variables, the researchers calculated that the risk of developing epilepsy by age 10 in a child who had had whooping cough was 70 percent higher than for an uninfected child. The [study was published in the Journal of the American Medical Association](#).

"We can't say that if a child has epilepsy it was because of a pertussis infection," said the lead author, Dr. Morten Olsen, an associate professor in the department of clinical epidemiology at Aarhus University Hospital. "And in any case, the absolute risk for epilepsy is very small — about 2 in 100. So we don't want anyone to panic."

But, he said, "This is another argument to have your child vaccinated, another study showing that pertussis is a serious disease." Pertussis is known to be associated with seizures and brain damage, but this is the first study to find an association with epilepsy. The mechanism is not clear, but the authors suggest that the severe coughing of pertussis may reduce the flow of oxygen to the brain.

Nicholas Bakalar  
November 17, 2015

<http://well.blogs.nytimes.com/2015/11/17/whooping-cough-in-infants-tied-to-epilepsy-risk/>

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## CU-Boulder Study Links Combination of Pre-natal Stress and Terbutaline to Autism and Epilepsy in Lab Rats

Researchers at the University of Colorado Boulder have discovered that a combination of pre-natal stress and an unapproved pre-term labor medication called terbutaline may create a higher risk for the co-development of autism and epilepsy based on test results involving laboratory rats.

The new study, which was published today in *The Journal of Neuroscience*, indicates that the use of terbutaline, a drug sometimes used to delay labor by up to 72 hours, may increase the risk of a fetus developing both autism and epilepsy, but only when combined with elevated stress levels on the part of the pregnant mother.

The findings may open up new avenues of clinical investigation for autism and epilepsy research, with potential applications for humans further down the line.

"With this new animal-based research model in place, we can start looking at neurological mechanisms that we haven't been able to in the past and explore why there is a connection between epilepsy and autism and how to decrease risk for both disorders," said Daniel Barth, a professor in the Department of Psychology and Neuroscience at CU-Boulder and a co-author of the study.

Autism and epilepsy commonly manifest together, with about 30 percent of autistic patients exhibiting epileptic symptoms such as seizures. Previous research has suggested that genetics can play a role in the development of both syndromes, but the impact of pre-natal environmental, non-genetic factors has received less attention.

Terbutaline is a drug that prevents the constriction of airways and is approved for treating asthma, bronchitis and emphysema. The U.S. Food and Drug Administration has cautioned against the use of terbutaline to delay pre-term labor.

Premature births affect roughly one in six pregnancies and premature labor often results from maternal stress. Since terbutaline can be used to arrest preterm labor, maternal stress followed by terbutaline administration becomes more likely.

The CU-Boulder researchers found that although pre-natal stress or terbutaline alone can increase the risk of autism in newborn rats, the more severe neurological syndrome of combined autism and epilepsy manifested only when both factors were in play simultaneously.

"We've learned that this combination of risk factors is far greater than either one alone," said Barth. "This is the first research in this area to show how environmental factors can operate in tandem rather than individually."

December 1, 2015

<http://www.colorado.edu/news/releases/2015/12/01/cu-boulder-study-links-combination-pre-natal-stress-and-terbutaline-autism-and-epilepsy-in-lab-rats>





## Miss Scotland Mhairi Fergusson on Living With Epilepsy: It Could Have Held Me Back But It's Made Me Stronger

MHAIRI's family had no history of illness, but when she had her first seizure, they had friends at the Muir Maxwell Trust to turn to. Now the beauty queen is an ambassador for the charity. IT was a morning like any other in the Fergusson household, with three girls getting ready for school.

Then, from the bathroom, came an almighty crash.

"As I was running towards the bathroom - I thought someone had broken in and was attacking Mhairi," her mother Elaine recalled. "In the split second, I just couldn't make sense of the huge noise."

But it wasn't an intruder. It was Mhairi, who was just about to turn 13, having an epileptic seizure. There was no family history of the disease and nothing like it had happened to her before.

"I got the fright of my life," Elaine said. "We all did. I just put my hands under her head and called to my oldest, Julie, to call an ambulance."

While Mhairi was en route to Stirling Royal Infirmary, her dad Tommy was on the phone to family friend Ann Maxwell. Ann's son Muir has epilepsy and she runs the Muir Maxwell Trust. Tommy had run a marathon to raise funds for the charity five days earlier.

Now he and his family needed their practical help.

"Mhairi was kept in for observation," said Elaine. "But we were told it would be six weeks before she could see a consultant."

"I now know uncontrolled epilepsy can be fatal. You have to have diagnosis and medication fairly quickly."

This is where Ann's experience and advice were invaluable.

"She was fabulous," said Elaine. "She told me exactly what to say and do. It could have been a lifesaver."

"There was another girl in the papers at the time. She was 13, had her first seizure and couldn't see a consultant for weeks. She died."

It's hard to imagine today's Mhairi helpless. At 22, she is Miss Scotland and is on her way to the Miss World contest in China later this month.

But it's not all about wearing sashes. She is an ambassador for the Muir Maxwell Trust and is using her reign to talk about epilepsy at every possible opportunity.

"I've spoken at events for the charity since I was 14," she said. "The Muir Maxwell Trust has helped me so much, I always want to give back to them."

"If I can change one person's views of their life, how they feel about their condition, I will sit down and speak to them for as long as I have to. That's what I needed when I was younger and there was no one there for me."

Being a teen with epilepsy is tough. There's still a lot of stigma around the condition, as the Fergussons found out.

It turned out that there were several pupils at her school, Dollar Academy, who were epileptic. But no one ever talked about it.

"I didn't speak too much about it," Mhairi admitted. "I had so many questions. It was always, 'Why me, because I'm just the same as everyone else? Why did it have to happen to me, what have I done, is there something I could have stopped?'"

Elaine made sure sleepovers took place at their house, so Mhairi could take her meds. As her daughter and her friends grew up, she briefed them on what to do if Mhairi had a fit.

She has not had another seizure - drugs she will take twice a day for the rest of her life control her condition.

Some young people grow out of her type of epilepsy and when Mhairi was 16 she stopped taking the drugs to see if she was one of them. She was not.

She said. "I've never cried over epilepsy except for the day I was told I'll have it for the rest of my life. That's what I had to come to terms with."

Sixteen is not the ideal age to have a chronic condition that calls for early nights and a healthy lifestyle. "Everyone's going out, being teenagers," she said. "I had to be a lot more careful."

And if Mhairi found it hard work, her mother Elaine had to sit on her hands to avoid wrapping her youngest daughter up in cotton wool.







When the family went on holiday, she was there in the pool beside her. Riding lessons were an hour of knuckle-biting. "At first, during the night, I would wake up two or three times and go through and check that she was OK," Elaine said. "A lot of parents can't relax, can't sleep, can't get any peace whatsoever."

With her condition under control, Mhairi headed off to study at Glasgow Caledonian University. And, without telling a soul, she entered Miss Scotland.

Her mum was a runner-up in 1981 and represented Scotland in Miss International. "I knew she was Miss Scotland," Mhairi said. "At school, all the kids would talk about it."

So when she saw the competition on Facebook, she gave it a shot. "I applied seven minutes before the deadline. I didn't want anybody to know," she said.

Aged 19, with no modelling or pageant experience, she was runner-up.

Two years later, after spending a year in the US, she was not only ready to try again, she was determined to use it to raise awareness of epilepsy.

Elaine was all for it. She thought it would be good for Mhairi's knocked confidence.

"Growing up I felt singled out," Mhairi said. "Being older and coming to terms with it, I'm realising it's not a negative at all. I've turned it into a positive."

"For a part of my life, I didn't want to know anything about epilepsy. I had to grow up faster, I had to take my medication morning and night, I had to be careful. Some teenagers are reckless. That wasn't an option for me."

"I've had to work a little bit harder. I know it could have held me back, I could have made excuses. It's made me a stronger person."

Anna Burnside

November 6, 2015

<http://www.dailyrecord.co.uk/news/real-life/miss-scotland-mhairi-fergusson-living-6784845>

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## Eisai Receives Health Canada Approval for Antiepileptic Agent FYCOMPA® as Adjunctive Treatment for Patients with Primary Generalized Tonic-Clonic Seizures

Eisai Limited announced today that it has received approval from Health Canada for a new indication regarding the use of its antiepileptic agent FYCOMPA® (perampanel) as an adjunctive treatment for adults with primary generalized tonic-clonic (PGTC) seizures.

"New treatment options are important for people living with this type of seizure, which can be disabling and cause injuries and even death (SUDEP)," says Dr Jean-Francois Clément, Hôpital Charles-Lemoyne, Neuro Rive-Sud clinic, Université de Sherbrooke. "For clinicians dealing with PGTC, treatment options could rapidly be exhausted. Since approved in Canada three years ago, Fycompa has demonstrated good seizure control in patients with partial onset seizures and this new indication provides hope for patients with uncontrolled PGTC seizures. For people living with epilepsy, seizure freedom is vital to help people lead a more normal life."

The indication expansion was based on a placebo-controlled clinical phase III study (Study 332) of FYCOMPA in 164 patients with PGTC seizures. In the study, a statistically significant reduction in PGTC seizure frequency was observed in the FYCOMPA group compared with placebo (FYCOMPA: -76.5%, placebo: -38.4%,  $p < 0.0001$ ). Additionally, the responder rate for Fycompa was 64.2%, which was a statistically significant improvement over the responder rate for placebo of 39.5% ( $p = 0.0019$ ). The most common adverse events for FYCOMPA were dizziness, fatigue, headache, somnolence and irritability.

Generalized tonic-clonic seizures can cause significant injury to patients from falling down suddenly and are the most important risk factor associated with sudden unexpected death in epilepsy (SUDEP)<sup>1</sup>, making them one of the most severe forms of epileptic seizures. Through this indication expansion, FYCOMPA can now be used as an adjunctive treatment for primary, in addition to, secondarily generalized tonic-clonic seizures.

"The expanded indication of FYCOMPA is positive news for the epilepsy community, specifically for people living with Primarily Generalized Tonic-clonic seizures in Canada. Patients now have a new treatment option that is proven to significantly reduce seizure frequency," says Deirdre Floyd, President, Canadian Epilepsy Alliance.

FYCOMPA is an oral medication taken once-daily and is a first-in-class antiepileptic drug (AED) discovered and developed by Eisai. The agent is a highly selective, noncompetitive AMPA receptor antagonist that reduces neuronal hyperexcitation associated with seizures by targeting glutamate activity at postsynaptic AMPA receptors. Fycompa was approved in 2013 as an adjunctive treatment for partial-onset seizures (this type of seizure may be associated with secondarily generalized seizures) in patients with epilepsy 18 years of age and older in Canada.

December 3, 2015

<http://www.newswire.ca/news-releases/eisai-receives-health-canada-approval-for-antiepileptic-agent-fycompa-as-adjunctive-treatment-for-patients-with-primary-generalized-tonic-clonic-seizures-560416311.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)
- ◆ Twice-yearly no-cost 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 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...*