

JANUARY - FEBRUARY 2017

FOCUS ON EPILEPSY

THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION
The Epilepsy Association of Northern Alberta - Our 57th Year of Service

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

Member Outings & Activities

January

Fun BINGO for Prizes

Friday, January 27th, 1:00—3:00 p.m.
(Pre-register by Noon, Jan. 26th)

Collective Kitchen Session 1

Friday, January 13th, 12:30—3:00
EEA Office
(Pre-registration required)



February

Collective Kitchen Session 2

Friday, Feb. 10th, 12:30—3:00 p.m.
(Pre-registration required)

Fun BINGO for Prizes

Friday, February 24th, 1:00—3:00 p.m.
(Pre-register by Noon, Feb. 23rd)

Annual General Meeting

Thursday, February 23rd, 4:45—8:00
p.m.
St. John Ambulance Building



FREE MEMBER ACTIVITY

2017 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

When: Thursday, February 23rd

Where: Room 113/115
St. John Ambulance Building
12304-118th Ave.



Timelines:

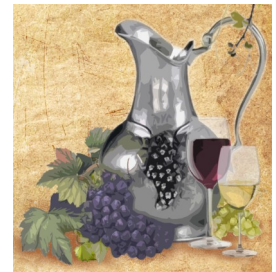
5:45 FREE Light Supper
6:15 Annual General Meeting
7:15 Volunteer recognition event
8:00 Wrap-up

“Help Seize The Day !”

Thursday, March 23rd, 2017, During
Epilepsy Awareness Month

In Support of Epilepsy Awareness,
A Celebration of Greek-Themed
Fine Food and Wine

Further Details on page 5!



A Major Donation for EEA!!!



EEA Executive Director Gary Sampley gratefully receives a \$20,000 unsolicited donation from Hank Renzenbrink of Sunrise Bakery. Sunrise has consented to their donation being deferred to future years' operating expenses to help EEA deal with the continued reduction in United Way Funding.

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.

(Support Group has been moved to Tuesdays.)

January 10th, 2017

February 14th, 2017





Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta



Focus on Epilepsy is published 6 times annually by the **Edmonton Epilepsy Association**. Articles appearing in **Focus on Epilepsy** do not necessarily reflect the opinions of the Association.

We welcome your contributions:

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

BOARD OF DIRECTORS

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Treasurer...Anna Tymoszejko
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Edmonton Epilepsy Association **The Epilepsy Association of Northern Alberta**

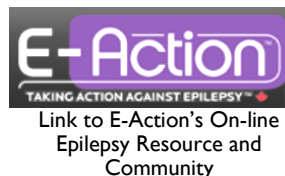
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(780) 447-5486 fax
1-866-EPILEPSY



info@edmontonepilepsy.org
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

Bus Tickets Available for Members in Reduced Circumstances

Our 2016 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 April 2017. 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 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, and click on the [Canada Helps](#) Logo. This donation program gives you the ability to instantly print off a donation receipt.





Kim Mahe is 2016 EEA Volunteer Of The Year

Kim, long-time R.N. with the Adult Convulsive Disorder Clinic of the Glenrose Hospital, former EEA Education Chair, two-term EEA Director and significant contributor to EEA Fundraising is presented with her “Keeper” plaque by EEA Executive Director Gary Sampley (L) and longest-serving EEA Volunteer Cam Reid (R), founder and funder of the award.

Spruce Grove Rotary Donates \$1000 To EEA

The EEA sincerely thanks the Spruce Grove Rotary Club for a \$1000 unsolicited donation Thank you Rotarians!



Spruce Grove

Dr. Sunny Kim on Leave of Absence

Sunny will be on Leave of Absence for the Months of January and February. Gary Sampley will be facilitating the support groups during her absence.

New Police Training Videos on Epilepsy Now Available For Download From the EEA Website

As a result of unfortunate incidents earlier this year where Edmontonians in seizures were arrested by local police, the EEA has identified two current videos designed specifically to hopefully help police better handle similar situations.

They are available through our website:

<http://www.edmontonepilepsy.org>

Or by clicking on the titles below:

[A Field Guide for Law Enforcement](#)

published by Epilepsy Foundation of America

[Police Training Video on Epilepsy and Seizures](#)

published by Epilepsy Action UK





News from the EEA Office

Collective Kitchen Program Starting in January 2017

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 13, February 10, March 17, April 14, May 12 and June 16. Interested members can phone Sharon at the EEA Office at 780-488-9600 to register. Registration is limited to **eight** participants.

2017 EEA Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2017, 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, 2017

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



We're Looking for an Achiever!



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

If you would like to nominate someone for our 2017 "Achiever of the Year" Award, please do so, in writing, to the EEA office by **March 1st, 2017**.

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

Does Your Child or Teen Have Upcoming Sports, Arts, 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, Cultural or Recreational Activities that will enhance their development as individuals.

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





Help Seize the Day!

In support of Epilepsy Awareness,
Please Join Us In
A Celebration of Fine Food and Wine

Thursday, March 23rd, 2017, 6:00 p.m.

Yiannis Taverna Restaurant

10444 - 82 Avenue

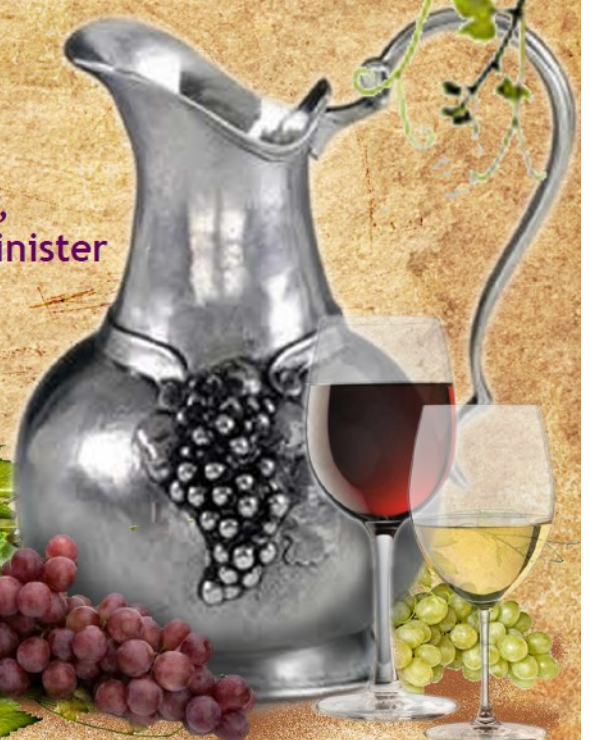
Tickets: \$125

Up-scale entertainment, numerous and diverse silent
auction items, 50/50 draw, wine-tasting contest,
mystery guests and other attractions.

Our M.C. for the evening:



Doug Griffiths
Author, EEA Director,
Former Alberta Cabinet Minister



Tickets through Yiannis, 780-433-6768 or
Edmonton Epilepsy Association,
11215 Groat Road, Edmonton, AB T5M 3K2
780-488-9600, info@edmontonepilepsy.org
Canada Revenue #119230951RR0001

In compliance with the Alberta Charitable Fundraising Act, we hope to raise \$15,000 gross
from this event, to help fund ongoing programs of the Association, at a cost of \$5,000, net \$10,000.



EEA Christmas Luncheon





EEA Christmas Luncheon





One Hurdle, Two Hurdle...

My name is Kellen Colthorp (29yrs). I have three highly inconvenient, but still mostly controllable disorders. And I do not consider myself handicapped because of either the Epilepsy, the Depression, the Borderline Personality Disorder (BPD) or any of the permanent side effects of these. I know that I am however, a person who needs a little more help a little more of the time and I accept that. Most doctors started seeing this as "Avoidant Dependency", which we would later find out about when diagnosed with BPD. These disorders increased my list of "help" resources, while also significantly decreasing my ability to create or have my own social circles. As for which one is/was more important to me? All I can say is "it depends on when you asked me".

Being that I was only 6yrs old when I was diagnosed with Grand-Mal Epilepsy, life continued as it normally would for any kid. Taking medication became like taking vitamins, not the greatest, but still routine. Any doctor visit was just an acceptable excuse to miss my "favorite" class of Math and after doctors was always lunch with mom. Unfortunately being so young nothing more than the Epilepsy could be recognized. Now beginning the cycle of more questions, less answers and a great deal of confusion we still face today.

As the early stages of teen life came, so came Junior High. I eased through gr.7, not with many friends, but still enough to keep my spirits up and grades steady. Grades 8 & 9 however were not so easy. The schoolwork became like trying to keep water in a strainer, no matter what I tried... it just wasn't going to happen. Any friends I thought I had were now too cool to be seen with me. Once I lost them, making new friends became about as easy as winning the lottery and for me it really was. Soon, what everyone else assumed were regular teen issues began to overwhelm me on what seemed like a much deeper/ larger scale. Many different options were explored to try and overcome these hurdles... Councillors, Tutors and the infamous "you are grounded till your grades improve!" None of which were helpful for very long because if you got nowhere to go, grounded is just another day at home. Being the "expert" on Epilepsy that I was, it became my belief that I knew better than my parents and the doctors too. So it began... "Kellen, did you take your meds?", to which I usually answered one of two ways. "No, I forgot" or "I'll do it later (but not really)". At this point me not caring for medication meant I willfully began creating large, unseen and very much avoidable problems for the doctors. The biggest one of all being the half-truths I would answer to all their questions. Consumed by the fear that someone might find out about the other half of those truths, I began to spiral down. Blaming everyone helping or trying to help me for any of the negative outcomes was all I could do. As would be expected, it brought the loss of a lot of good things and the trust I managed to earn from those people. It was just "NEVER" my fault. During my gr.9 year many people started noticing me focusing only on my "short comings" (to which the list had no end) and the unusual trait of... If I wasn't an expert the first try, it wasn't worth continuing (ever again). These new traits brought the doctors some clarity to the long fuzzy list of possibilities for us and so we were filled in on disorder #2 (Depression). This now added to the list of medications to "not take". Although I made some friends in school again, that's all they really were, "In-School/class friends" only. This held true for boys as well; even the thought of a real boyfriend seemed out of my reach. During those years making friends and being cool was just way more important than those silly doctors were, I mean its not like I had to see those guys everyday, all day. Schoolwork took a further backseat in my not so busy schedule and my low grades gave me one more thing to try and blame on somebody other than myself. That thing was a redo of "the gr.9 Experience" and an increase in the dislike of being told what to do. Not that re-doing gr.9 made it any better; the only change was... this time I passed. As unpopular as I already was, adding the embarrassment of watching what little friends I had advance into High School without me just seemed...Cruel.

Finally getting to begin High School I continued to sink lower, with only one thought on my mind... "If I just quit school, everything would be fixed and all will be well again". Hurdle #1- telling my parents, taking the news with less fuss and anger than expected. Hurdle #2- "The Deal" finish the year and then you can quit (but why try anymore?). Hurdle #3- Get a job, it was work or school (NO exceptions). At first finding a job wasn't really that hard, I had work experience through years of volunteering and that seemed to be enough. Keeping a job however, seemed a lot harder than I realized. My medication/ medical things now took the same backseat that school used to hold, which again caused a whole new set of problems. Seizures came, work was missed and with it a lot of the unsunk information from earlier days. Managers got tired of having to repeat themselves, neither of us really understanding why they had to. I hid my Epilepsy from most employers (if I could) because my fright of being the "Handicapped" one in the group or being treated different. With most jobs this brought on the miscommunication of "you need to start trying" and me saying "I swear, I WAS trying." After the first few jobs were lost, my parents began to watch me a little closer, trying to verify the intricate web of lies I spun to hide the current/ future job losses. This got me more frustrated than upset, bouncing from job to job. I guess I was just destined to fail, somebody up there hated me or.... Maybe it was both. This only thought clouded my judgments and hid my want to push for anything.

Eventually the adult world caught up with me, with it bringing it's harsh realities, new doctors and more questions. One of the harshest realities I learned came from a former neurologist. As was done with previous doctors' questions, the half-truths came leaking out, resetting the old worry/fear of being found out. Lucky or unlucky for me (I haven't decided), I was seeing the one doctor that could hear right through all my answers. Strikes 1-100 came, eventually pushing the doctor over the edge. We both knew I didn't want to be there, we both knew I didn't like him (only for lack of trying) and that I was not really listening to most of the needed advice. The one piece of advice I did listen to was the best and last piece I got before we parted ways. "When you're ready to accept people's help, then you can ask for it", but as usual... It couldn't be my fault; it was the doctor's fault, right? Slowly, in time I would learn to recognize that help wouldn't just come to me and fix things. I would have to ask and I would have to be willing to take the help, whether I liked the type of help or not. A lesson that continues even today.





During my early adult years we knew that full independence in my outside life was probably not going to be an option. With the lack of ability to create a personal life outside of my family, I became way too dependent on my family for way too much. So at that time the best and what seemed to be the only option was to stay where I was... with my parents. To which people my age (early 20's) would look at only as shameful and the sign of a freeloader. With their lack of information, my reclusive nature and my record of job losses, who could blame them? As the years went by I started to feel an increased want to be out of their house and on my own. Not to mention an even bigger want to show my parents that I could be on my own. After some brainstorming we all agreed that it was time to try, coincidentally also giving us a win-win idea of moving into the basement suite of my brother's new house. I would help out by paying a reasonable amount of rent and be able to start getting back some much-wanted freedoms. Hopefully also increasing my "real world" skills, be on my own, take care of myself and still be close to the safety of family. But would this help my unusual dependency on others (those close to me) or soon set it into overdrive?

Although I was happier with my new living arrangements it didn't change anything medically. I was still the same old depressed, over emotional Epileptic I was before. For some reason, I really thought a change in houses might magically fix all that. With doctors help we realized that maybe going to see a therapist (instead of councillors) might be the best help for the time being. This started with Anger Management classes for disrespectful and aggressive social behaviors (yet to know the cause), as well as a referral to what was said to be an experienced therapist for the depression and emotional outbursts. Unfortunately all this brought was a diagnosis of Bi-Polar Disorder, more medications, extremely unexpected side effects and big problems. The most extreme of these side effects was what my mother calls "the straw that broke the camel's back". A hurdle we are still trying to jump today, but have come very far with. Combining the many years of uncontrolled seizures, emotional stress and sudden mix of new medications my mind began to fail me and the more I tried to hold onto or remember the more things slipped away. All the old stuff fell out like previous vacations, family events and most of the past, to make room for new information, which unknowingly was also leaking through an unseen "hole" in my head. With little to no verified reason for this the doctors tried to help it by taking me out of the stress of the working world and hope something might change or come back. As inconvenient as this sounds it brought me to the one place that turned my life around, the bright side to my story.

During my year off I was able to volunteer at an organization that brought some of the most significant changes to my life that my family had seen in a long time. Their knowledge of Epilepsy was remarkable (as well as helpful), the generosity I saw with the sudden feeling of true acceptance was uplifting and that's something I don't remember feeling a lot of in the past. This made it hard to be depressed when, now, no one cared about what's wrong with you, only what's great. In 1yr of volunteering I made more friends (real ones) and had more fun learning "work" skills than I had done in a lifetime. Soon socializing wasn't that hard, the side effect causing it all was decreasing in severity and my overall health seemed to get better with every passing day. This amazing organization is The Edmonton Epilepsy Association (EEA). With the amount they have done for me and what things I did see of their efforts, I would not have reached where I am without them. The list of resources for helping is long and diverse, which allowed them to introduce me to my current and best neurologist yet. Life courses became available through them that I would never have done or found out about on my own. From as small as cooking classes and more knowledge of my disorders to Money Management and creating balance between work and life skills. Most of what I learned there was learned through the "doing" aspects of volunteering. Like usual with any office, things needed to get done and as an "employee" I needed to do them. Instead of watching me like a hawk with every job I did, they showed a trust that I could and I would do it on my own. I gained an unseen confidence that helped break down the wall preventing me from trusting in myself. I found out that more people than I knew were just like me in most ways. And we all just wanted the acceptance of a society that just wasn't quite ready to accept us, yet. As new people came into the EEA I began to step up taking a more forward roll in welcoming, showing them the ropes and helping them get the same acceptance I did. During my time at the EEA, I have been asked to speak about the hurdles I was encountering. And I knew in the back of my mind, these people listening would not be judging me as hard as I was judging myself, but I still couldn't bring myself to open up about the personal side of those hurdles. The feeling of confidence, self worth and friendship was still too new to be letting people that far in. While the EEA helped me better understand that I wasn't afraid, ashamed or embarrassed of these disorders... I was more afraid of what would happen when society finds out. I was getting scared of the thoughts people tend to associate with them. Any personality disorders meant "She must be crazy", Epilepsy, like cooties, meant "Beware/stay away" and Depression meant "You're just a downer". For the most part this fear has been overcome by using a new found point of view from my friends in the EEA. Anything that I thought was wrong with me or thought people were seeing was on the inside. Which in turn meant "if you don't tell anyone, than nobody would know or ever see it", I am always going to be harder on myself about things than anyone could be. Funny how I couldn't see that before, about I wish I had a lot earlier.

I will always have to live with these things, but... With the help of the EEA, some good people and a little trust I am now becoming part of a working class society that I believed I couldn't before. Though my life isn't fully on track (no ones ever is), I feel like I have come farther in the last couple years than any point in my life so far. I am working at and holding down a respectable job with TD Bank, to which I owe a special thanks to both The EEA and TD Bank for the help and continued support that was given. Help to which now will create more opportunities for advancement later on. Most social interactions are still a mystery to me and may always be, but slowly this may come to pass. I think now it's more shyness and lack of practice than fear of the other person. As for the independent side of things I have began to take steps that further me from the former dependency on my family, without leaving behind the safety of their love. I have also brought my confidence to where I am in a happy relationship with someone who accepts my past and looks to help enhance my future.





World-First Epilepsy Treatment Delivers Promising Trial Results in Victoria

A Victorian woman becomes the first person in the world to trial a revolutionary treatment for epilepsy which involves implanting a pump in a patient's abdomen that sends medication directly to the brain.

A Victorian woman has become the first person in the world to trial a new implant treatment for people with neurological conditions, which is producing promising results. Natalie Kellalea, from Numurkah, in northern Victoria, suffered numerous daily seizures from epilepsy, leaving her sleepy and often stuck at home. Recently doctors at St Vincent's Hospital implanted a pump in her abdomen with a small tube under the skin that sent medication directly into a cavity in the brain.

That medication appeared to work quickly and Ms Kellalea did not have to endure unwanted side effects of taking tablets.

The head of neurology at St Vincent's, Professor Mark Cook, said although it was early days, there had already been an improvement in the 27-year-old's symptoms. "Natalie had the pump put in nearly two weeks ago now and we put medication in it only a week ago but so far things are going very well," he said. "At the moment [her seizures] have reduced very dramatically. "We do need to wait and check we're getting the right doses and it's not affecting her in any other way but so far we're really pleased with the results." The benefit of a pump was that it was able to deliver the medication directly to the brain. "We have the opportunity perhaps to give better doses than we do currently and also to avoid the side effects that come about because you have to swallow it and the whole body has to take a dose of the medication," Professor Cook said. Professor Cook said doctors hoped to soon try the treatment on another eight patients, but noted it would probably be up to five years before such treatments were commercially available. "This is a very early phase trial. So we expect with this we will determine if it's possible and then in the years ahead we'll determine what drugs are the most effective ones to give in this way," he said. "It may be that some drugs that previously could not be used because they could not be absorbed by the body can now be used in this way."

Doctors paid tribute to patients like Ms Kellalea who participated in the trial and said there was scope to use the treatment for other conditions. "Potentially treatments for tumours affecting the nervous system, Parkinson's disease, other conditions like that might be treated in the same way," Professor Cook said. "It's a really big thing to step out into the unknown [with treatments] like this. "It's because people are so desperately, badly affected by these conditions.

"We really do rely entirely on these really brave patients who do help us with this work."

December 15th, 2016

Australian Broadcasting Corporation

<http://home.nzcity.co.nz/news/article.aspx?id=239127&fm=newsarticle+--+Rural%2Cnrhl%20WFLQdwlP1gU.email>

New Definition of Epilepsy May Improve Treatment

The definition of epilepsy has recently changed to help physicians and healthcare professionals treating patients with suspected epilepsy to improve the timeliness of diagnostic and treatment options. Speaker Jacqueline French, MD, discussed the new definition of epilepsy at the *Annual Fundamentals Symposium: The New Definition and Classification of Epilepsy* at the American Epilepsy Society conference on Friday, December 2, 2016. Before the revision, the guideline was for physicians to wait until 2 spontaneous seizures occurred before treating a patient with suspected epilepsy. However, this raises questions such as "Is it necessary or appropriate to put off treatment until 2 seizures have been experienced?" and "If it is known that epilepsy has developed, should physicians still wait to initiate treatment?" The revised definition removes any burden on physicians to determine the risk of a second seizure for each patient. Physicians are now trying to diagnose epilepsy after the first seizure, as long as the necessary evidence is present, Dr French said. In the article "A Practical Clinical Definition of Epilepsy," which updated the definition of the disease, epilepsy is considered to be present if there are 2 unprovoked seizures within 24 hours or if the probability of additional seizures after the first is similar to the general recurrence risk of 60%. In addition, the new definition says that if there is enough information to diagnose an epilepsy syndrome without the presence of seizures, a patient can be given a diagnosis of epilepsy. For example, Dr French said that a diagnosis can be made if a patient had a single seizure plus an electroencephalogram (EEG) that shows centrotemporal spikes.

Although the definition has changed and may speed up diagnosis, treatment may not be an immediate decision, according to the session. Time to treatment varies depending on the uncertainty present after 1 seizure because there is no concrete diagnostic test for determining the risk of another seizure. Dr French also discussed the American Academy of Neurology's guideline called *Management of an Unprovoked First Seizure of Adults*, which aligns with the updated definition of epilepsy. This evidence-based review allows physicians to review certain factors prior to treating a patient who may have epilepsy. According to the American Academy of Neurology review, patients who experienced an unprovoked first seizure should be informed that recurrence is most likely to occur within 2 years. Other factors that increase the risk for seizure recurrence include a prior seizure, an epileptiform EEG, an abnormal computed tomography scan or magnetic resonance image, and a nocturnal seizure, according to the session. The presence of these additional factors may impact a physician's decision to treat. The guideline also states that immediate treatment with antiepileptic drugs may help to reduce the occurrence of a second seizure within 2 years. By treating patients more rapidly, they are less likely to experience poor health outcomes and healthcare costs associated with seizures. However, the final decision about whether to initiate treatment should be based on a physician's assessment of the risks of adverse events from antiepileptic drugs, the potential risk of seizure recurrence, and input from the patient. Dr French concluded that the new definition of epilepsy will better align with treatment strategies implemented by physicians, as well as allow them to have more involved conversations with their patients. Perhaps in the future, these guidelines could also help create an additional marker for the disease.

December 3, 2016, Laurie Toich

<http://www.pharmacytimes.com/conferences/aes-2016/new-definition-of-epilepsy-may-improve-treatment>





Women on Epilepsy Drug Say They Weren't Warned of Birth Defect Risk

A drug commonly used to treat epilepsy has been linked to serious birth defects -- a side-effect that some Canadian mothers say they weren't properly warned about while pregnant. Nicole Vahle of St. Catharines, Ont., was prescribed a medication containing valproic acid while she was pregnant. When her daughter Savannah was born, she was diagnosed with fetal valproate syndrome, a condition that delayed her ability to walk, talk and smile. "She didn't really move much, she couldn't even move most of one side of her body," Vahle told CTV News. Countries such as France and the U.K. have recently issued strong warnings about pregnant women taking valproic acid. But Vahle says that she was given no such forewarning from her doctor.

"I was very depressed about it. It was upsetting, not having your daughter smile while everybody else's kids around that age are smiling," she said. Health Canada issued a public advisory about valproic acid five years ago, saying that birth defects are "a rare but well known risk associated with their use." The agency also referenced studies that found children whose mothers took a valproate drug generally scored lower on cognitive tests.

While that information can be easily found online, some mothers say the Canadian government and doctors aren't doing enough to directly communicate the serious risk. Noreen Spagnol took valproic acid for her epilepsy, and both her daughters, now aged nine and seven, were born with birth defects. "He didn't tell me, you know, 'Do you want to try another medication? Do you want to look more into what the side-effects are?' He didn't give me any of those options," Spagnol said. But the decision to discontinue the treatment for expectant mothers is fraught. Going off the drug can be a difficult choice, as substitute medications may not work as well -- if at all -- and a seizure during pregnancy can carry a risk of death for both mother and baby. Spagnol said she should've been told of the "true risks" of being on the medication. "I had so many other options I didn't know about and all my neurologist made me think was, you have to stay on this medication, because if you're off, you'll have a seizure and that's too big a risk. That's not the only option," she said. Regardless, women taking the drug should have all the necessary information before they become pregnant, according to one Canadian patient advocate. "So it is a significant concern that not just neurologists but also all doctors who are prescribing these medications do need to be aware of this," said Dr. Esther Bui, a neurologist with Toronto Western Hospital. Spagnol said she hopes that by sharing her story, she'll be able to reach women who aren't aware of the birth defect link.

"I would like to let other women know that it is very important to fully educate yourself as much as you can," she said. "I thought I had, to be honest."

(The drug is also known by the brand names Epilim, Convulex, Episenta and Epival.)

November 23, 2016
Avis Favaro and Elizabeth St. Philip

<http://www.ctvnews.ca/health/women-on-epilepsy-drug-say-they-weren-t-warned-of-birth-defect-risk-1.3174345>

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
780-426-0872





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, 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...*