

FOCUS ON EPILEPSY



THE NEWSLETTER OF THE EDMONTON EPILEPSY ASSOCIATION
The Epilepsy Association of Northern Alberta - Our 56^h Year of Service

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

Member Outings & Activities

March

Collective Kitchen Session 3
Friday, March 11th, 12:30 - 3:00 pm
EEA Office
(program registration required)

Annual General Meeting Thursday, March 17th, 5:45 - 8:00 pm St. John Ambulance Building

Fun BINGO for Prizes Friday, March 18th, 1:00 – 3:00 pm EEA Office

Young Adult Bowling Activity
Wednesday, March 22nd, 6:45—9:00
p.m.
Ed's Rec Room, West Edmonton Mall

(Pre-register by March 15th)



April

Play - "Train Travel" A Private Showing Just for the EEA by the Geri-Actors Saturday, April 16th, 2:00 - 3:30 p.m.

Location: TBD

(Pre-register by April 13th)



Collective Kitchen Session 4
Friday, April 22nd, 12:30 - 3:00
EEA Office
(pre-registration required)

Fun BINGO for Prizes
Friday, April 29th, 1:00 – 3:00 pm
EEA Office

Free Epilepsy Education Forum:

"Advances in Pediatric Epilepsy Medication and Treatments"

(Includes Information on Pediatric Cannabis Treatment)

Thursday, March 10, 2016 6:30-9:00 p.m. Glenrose Hospital Auditorium

For further details and to reserve your seat see <u>page 5</u>.

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

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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, March 9, 2016

Wednesday, April 13, 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

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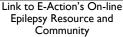
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EEA Employabilities Programs

- ⇒ 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**

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, and click on the **Canada Helps** Logo. This donation program gives you the ability to instantly print off a donation receipt.

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News from the EEA Office



Epilepsy Drug Shortage in Canada Worries Patients, Families

Valproic acid, used to control seizures, is on the World Health Organization's essential medicines list.

A widely used epilepsy drug is in critically short supply across Canada, leaving patients and their family members scrambling for alternatives.

The shortage of valproic acid, also known by the brand name Epival, began in December but has escalated recently to the point that patients are having trouble finding any. People with epilepsy and their family members say they can't get answers about the cause of the shortage or when it might be resolved from any of the nearly dozen generic drug companies licensed to sell valproic acid. More broadly, the situation highlights serious problems with drug shortages across Canada – often involving older, inexpensive generic drugs.

"It's a situation that has become quite serious and the shortage is very severe," said Suzanne Nurse, director of information and client services at Epilepsy Ontario. "The whole stability of the drug supply is our concern."

Valproic acid is used to control seizures and is on the World Health Organization's essential medicines list, which includes drugs that are "intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms." according to the WHO's website.

Carlo Berardi, chair of the Canadian Pharmacists Association and a community pharmacist in Sudbury, said valproic acid is extremely difficult to come by, presenting a major challenge to patients.

While there are other anti-convulsants on the market, switching medications can be difficult, leading to unwanted side effects and other health problems.

Shortages have become increasingly common in Canada due to a range of factors, including unavailability of raw ingredients, regulatory issues and safety problems with manufacturing plants. Some experts also speculate that money is a factor. Most of the drugs in short supply are decades-old generic drugs that don't generate much revenue, meaning there is little incentive for companies to make them.

Ms. Nurse and others want the federal government to bring in rules that would require drug companies to disclose when drugs are in short supply. The previous Conservative government proposed regulations for mandatory reporting last June, but they weren't brought into force. Instead, drug companies can voluntarily post information about shortages online at drugshortages.ca. In an e-mail, Health Canada spokesman Eric Morrissette said the department is gathering information about the valproic acid shortage and working with manufacturers to distribute the remaining supply.

He added that the government is committed to resolving the problem of drug shortages, but did not elaborate on whether that will include mandatory reporting.

The Canadian Generic Pharmaceutical Association said in an e-mail that the reasons for drug shortages are complex and that the association is committed to finding solutions to lessen the impact. Generic drug maker Apotex declined to answer questions.

Tammy Smitham, spokeswoman for Loblaw and Shoppers Drug Mart, which sells Sanis Health private-label generic drugs, said in an e-mail that its version of valproic acid has been out of stock since October because of manufacturing issues, and that its alternative supplier has also run out of stock. New shipments are expected by mid-March, she wrote.

None of the other companies that sell valproic acid in Canada responded.

Carly Weeks
February 21st, 2016

www.theglobeandmail.com/news/national/epilepsy-drug-shortage-in-canada-worries-patients-families/article28832349/

OTHER GENERIC ANTI-SEIZURE MEDICATIONS CURRENTLY IN SHORT SUPPLY ARE:

Topirimate (Also known by the Brand Name Topamax)

Divalproex (AKA Depakote)

Lamatrogine (AKA Lamictal)

Pregabalin (AKA Lyrica)

Clobazam (AKA Frisium, Urbanol or Onfi)

Levetiracetam (AKA Keppra)



News from the EEA Office





What is Purple Day?

Purple Day is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. On March 26th annually, people in countries around the world are invited to wear purple and host events in support of epilepsy awareness. Last year, people in dozens of countries on all continents including Antarctica participated in Purple Day!

The month of March is Epilepsy Awareness Month in Edmonton, as proclaimed by Mayor Don Iveson. In addition to numerous Epilepsy Awareness events during the month, come check out our Purple Day booth at the Old Strathcona Farmers Market, 10310 - 83 Avenue, from 8 a.m. to 3 p.m on Purple Day, Saturday, March 26th.

Lighting Edmonton's High Level Bridge

As well, we're turning the High Level Bridge purple to celebrate Purple Day 2016! Thanks to an EEA initiative, the bridge will be lit up in purple, the colour representing epilepsy. Let us know about your Purple Day or Epilepsy Awareness Month activity and you could be featured in our next newsletter.





FREE MEMBER ACTIVITY FOR YOUNG ADULTS MARCH 22-YOUNG ADULTS BOWLING!

Bring a friend and make a friend ...

Join us for a fun night of 5 pin bowling with friends with epilepsy. If you are 18 -29 years old and have epilepsy, come on your own or bring a friend for some bowling fun.

No cost for bowling, but pre-registration is required by March 17th.

Call 780-488-9600 or email info@edmontonepilepsy.org

March 22, 6:45—9:00 p.m. Ed's Rec Room, West Edmonton Mall

Casino Volunteeers Needed

EEA is eligible for a Casino every second year. Our next casino is Sunday and Monday, June 5th and 6th at Casino Yellowhead. We are currently recruiting volunteers for all shifts and positions. Previous casino experience is preferred, but not absolutely necessary. Contact Gary at the EEA Office if you would like to sign up.

Like to Paint? You Can Help Us!

We are looking for Volunteers to help paint the porch and basement of our new office. All materials will be supplied. Contact Gary or Sharon if you are interested.



News from the **EEA** Office



Edmonton Epilepsy Association

The Epilepsy Association of Northern Alberta

In partnership with

The Adult Convulsive Disorder Clinic at the Glenrose Rehabilitation Hospital,

The Pediatric Epilepsy Unit of The Stollery Children's Hospital,

and



Presents a Free Educational Forum:

"Advances in Pediatric Epilepsy Medication and Treatments"
(Includes Information on Pediatric Cannabis Treatment)

Dr. Janani Kassiri, Pediatric Neurologist Laura Jurasek, Nurse Practitioner, Stollery Children's Hospital

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

Thursday, March 10, 2016 6:30-9 p.m.
Glenrose Hospital Auditorium 10230-111 Ave
A FREE Light Supper will be provided

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



The EEA gratefully acknowledges an unrestricted educational grant from Sunovion Pharmaceuticals Canada

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News From the EEA Office



Date/Time	Activity
March 17 th	-
Thursday, 5:45 – 8:00	EEA Annual General Meeting Volunteer Recognition Event
March 18th Friday, 1:00 – 3:00 pm	Fun BINGO
April 16 th Saturday, 2:00 – 3:30 pm	Play - "Train Travel"
April 29th Friday, 1:00 – 3:00 pm	Fun BINGO
May 15th Sunday, 12:00 - 3:00pm	Bowling at Bonnie Doon Lanes
May 27th Friday, 1:00 – 3:00 pm	Fun BINGO
June 11th Saturday, 2:00 - 5:00 pm	Visit to the Valley Zoo
June 24th Friday, 1:00 – 3:00 pm	Fun BINGO
July 17th Sunday, 1:00-3:00 pm	Historic Tram Trip
July 29th Friday, 1:00 – 3:00 pm	Fun BINGO
August 13th Sat., 11:00 - 2:00 pm	Annual Family BBQ & Social
August 26th Friday, 1:00 – 3:00 pm	Fun BINGO
September TBD	Painting Class
September 30th Friday, 1:00 – 3:00 pm	Fun BINGO
October 21st Friday, 1:00 – 3:00 pm	Fun BINGO
October 30th Sunday, 11:00-2:00	Hallowe'en Potluck Lunch
November 25 th Friday, 1 - 3 p.m.	Fun BINGO
November TBD	Weekend Movie Afternoon
December 10th Sunday, 12:00 - 3:00 pm	Annual Christmas Lunch & Social (Portuguese ethnic theme)
December 23rd Friday, 1:00 – 3:00 pm	Fun BINGO

New EEA Program Begins In May



Beginning in May, the EEA will implement a Collective Gardening Program for members.

Interested members will be allotted their own raised plot for vegetable planting, ongoing maintenance and harvest-

ing and will keep the vegetables they harvest to augment their food needs.

The EEA will provide the raised plots, seeds or plant stock and gardening tools. There will be 6 plots available on a first-come, first-registered basis. To register for a plot, please contact Sharon at the EEA Office.



The EEA will be having a Fundraising Garage Sale out of the garage behind the Office at 11215 Groat Road on Friday and Saturday, May 13th and 14th. Donations of saleable goods for the sale will be much appreciated.

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Epilepsy News From Around Alberta



Young EEA Member Looking For Support

My daughter, Tianna Lizotte, is a 13 year old Metis girl from the small northern town, Fort Vermilion, one of the oldest towns in Alberta. She is currently fundraising to compete in the teen category of Miss Canada Globe 2016. In this pageant, Tianna will speak to an audience about a charity of her choosing. For Tianna, it was easy to choose a charity to raise awareness for and to fundraise for. Tianna does not suffer from epilepsy and has only had one seizure in her life due to a high fever. However, she is very familiar with the condition.

I met Tianna's step dad, Riley, in 2005. He quickly fell in love with Tianna, and took her as his own. Riley always encouraged Tianna not to be shy and to have fun in everything she did. To Tianna, Riley was the best dad ever! They would go quadding, skating, and fishing, amongst many other things. Riley taught Tianna how to solve math problems, bake, color and even taught her how to ride a bike. Tianna looked up to this new father figure in her life and loved him like any daughter loves their father. Riley spoiled Tianna as much as any father does.

Over the years, Riley, Tianna & I would travel the 8 hours from our hometown of Fort Vermilion, to Edmonton, to visit numerous doctors and specialists because Riley suffered from multiple seizures. Tianna witnessed Riley's seizures on a weekly basis. She was very familiar with what they were and how to handle a person having a seizure. Although she was still young, she was educated by experience. Riley was prescribed medication to help lessen his seizures but he was not seizure free. Riley's seizures never stopped him from being himself, loving his family and taking jumps with his quad or dirt bikes. Tianna tagged along on many of these quadding/dirt bike adventures. He purchased Tianna her very own quad so she could ride alongside him. He was a huge part of her life.

In 2008, Tianna's brother Ryder was born. It was around this time that we were all sitting around watching the Victoria's Secret Fashion Show. Tianna was only 6 years old at the time. She'd seen the Victoria's Secret Angels come out and after staring at the TV for a few moments, she said to Riley "Daddy I want those wings, can you buy me them?". I laughed but Riley replied "You will get those wings my baby, you are more pretty than all those girls". It was sweet, something any parent would tell their child. Tianna was proud and smiled as she watched the rest of the show. Every year after that, it was a must watch.



Riley suffered with seizures, but you could never tell. He never stopped his high risk life style of quadding & riding his dirt bike at high speeds. He was dubbed "wild one" and rambunctious. He was known to never give up or back down. Riley was a patient of the Adult Epilepsy program at the University of Alberta Hospital and although sometimes tired & reluctant, he would drive 8 hours and made every appointment. In November 2012, Riley was scheduled to begin a program for surgery on his frontal lobe to help lessen or stop the seizures. However, in May 2012, Riley succumbed to his illness.

It was hard on our family and on people that knew him personally. Fort Vermilion is a small town, so everyone knew Riley in some way or other. Riley enjoyed life regardless of his seizures and it taught Tianna & Ryder to also enjoy life. He is forever in our hearts.

I don't think Tianna ever forgot what her daddy said to her that day as we watched Victoria's Secret. It has been over 3 years since Riley left us. Tianna is now 13 years old and although still too young for Victoria's Secret, she wishes to pursue her dream by starting small and working her way up. She still wants those wings. This is the beginning and a small step in her journey to getting them. Tianna needs to raise \$3000.00 plus flight & wardrobe expenses to enter Miss Teen Canada Globe. We feel that this pageant will be a great experience for her and may open doors for her. Along the way she wishes to raise Epilepsy awareness & fundraise for the Edmonton Epilepsy Association in memory of Riley. If you would like to donate, you can find her page on Facebook for upcoming events. Search: Tianna Paris Leigh Lizotte for Miss Teen Canada Globe.

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Mozart's Music 'May Help Reduce Cognitive Impact of Epilepsy'

A new study has shown that music by Mozart could be useful in helping to reduce the cognitive impact of epilepsy.

The University of Electronic Science and Technology of China led a study that analysed the effect of playing music by Mozart to rodents with temporal lobe epilepsy. Researchers were looking to see whether the music would affect the animals' awareness, understanding and response to their spatial environment.

According to results published in the medical journal Cognitive Neurodynamics, the animals experienced persistent cognitive impairment as a result of their epilepsy, but exposure to Mozart's music significantly enhanced their cognitive abilities.

It was also suggested that music intervention may be more effective for improving cognitive function during the early stages after an incident of status epilepticus.

"These findings strongly suggest that Mozart's music may help to promote the recovery of cognitive damage due to seizure activities, which provides a novel intervention strategy to diminish cognitive deficits in temporal lobe epilepsy patients," the study concluded. This is a potentially useful study as many current therapeutic interventions for epilepsy are focused on seizure reduction, rather than protecting or recovering cognitive functions.

In 1781 Wolfgang Mozart wrote his Sonata for Two Pianos in D Major. It is this composition that has been the focus of the most research around the "Mozart effect". The piece has been shown to have a positive impact on brain activity, inducing short-term improvements to certain cognitive abilities, as well as a decrease in epileptic brain activity.

Olga Rzadkiewicz February 5th, 2016

www.epilepsysociety.org.uk/News/Mozarts-music-may-help-reduce-cognitive-impact-of-epilepsy-05-02-2016#.Vs4h1jf2aM8

ADHD More Prevalent in Children With Epilepsy, Says Review

A paper published by Indiana University, reviewing multiple studies, says that ADHD (attention deficit hyperactivity disorder) is more prevalent in children with epilepsy than in their peers without epilepsy.

Some children with ADHD may be diagnosed as predominantly inattentive, while others are predominantly hyper-active or impulsive. Some are diagnosed with a combination of both.

Researchers have found that children with epilepsy are more likely to be diagnosed as inattentive.

The study found that some aspects of epilepsy and its treatment could contribute to ADHD symptoms. For example, children with complicated epilepsy may be at greater risk for ADHD, and some antiepileptic medications are known to contribute to ADHD symptoms.

However, scientists concluded that, because ADHD symptoms may be seen before the diagnosis of epilepsy, seizures are not likely to be the sole cause of increased prevalence of ADHD.

The research demonstrated the importance of ADHD medication treatment both in healthy children and those with epilepsy, as ADHD is linked with worse long-term academic outcome. While the study found there may be an increased risk of seizures in patients treated for ADHD, the benefits were found to outweigh the risks.

The paper concluded that research into the subject should continue, especially testing the efficacy and seizure effects of drugs used to treat ADHD.

Olga Rzadkiewicz February 10th, 2016

www.epilepsysociety.org.uk/News/ADHD-more-prevalent-in-children-with-epilepsy-says-review-10-02-2016#.VrtvSk3SmUk#main-content







Recovery Position 'Can Help Children Who Lose Consciousness To Avoid Hospital'

According to a recent study, children who lose consciousness during events such as seizures could avoid the need to be sent to hospital if they are properly placed in the recovery position.

The research, led by the Paris Diderot University, aimed to closely examine the typical responses of caregivers to the loss of consciousness in children. The results are published in the *Archives of Disease in Childhood*.

Part of the reason for this investigation was the fact that many potential caregivers – including parents and teachers – have a poor knowledge of the recovery position, the position in which an unconscious person should be ideally placed in order to protect the airway.

The study recruited a total of 553 children up to the age of 18, who had received a diagnosis of loss of consciousness, from 11 paediatric emergency departments across six European countries. The enrolment period was three months and data was obtained from parental interviews, hospital reports and clinical examinations.

Seizures were shown to be the most common reason for loss of consciousness in this group, accounting for 50.3% of all cases. Vasovagal syncope was the second most common factor, causing 22.4% of the blackouts.

Caregivers were shown to have put the child in the recovery position in 145 cases, or 26.2% of the total sample. Importantly, the recovery position was linked to a significant decrease in hospital admission rates.

The study concluded: "Our study demonstrates for the first time that the recovery position may reduce the admission rate of infants with loss of consciousness. Caregivers often perform inadequate manoeuvres when a child becomes unconscious. Campaigns aiming at increasing knowledge of the recovery position should be promoted."

Bob Jones January 29th, 2016

www.epilepsyresearch.org.uk/recovery-position-can-help-children-who-lose-consciousness-to-avoid-hospital/#secondary

Watching Movies During Brain Scans 'Can Help Children With Epilepsy'

The results of a recent study suggest that brain scans performed on children with epilepsy can be carried out more effectively if the child is given a 'movie' to watch.

The research, led by University College London and the epilepsy unit at Great Ormond Street Hospital, sought ways to improve the results of tests in children that combine EEG and functional magnetic resonance imaging (fMRI), in order to encourage more specialists to use them.

These so called EEG-fMRI scans are used to analyse the brains of people with epilepsy and assess the different patterns of electrical activity that are occurring. Used appropriately they can help doctors to identify the regions that are responsible for specific functions, and pinpoint the area(s) in which seizures originate (the seizure focus (plural foci)).

This mapping of brain activity is a vital part of epilepsy surgery planning, and it requires the person to be very still. In adult patients, the scans are typically carried out while the individual lies motionless with their eyes closed. Children typically find this a lot more difficult and are often given mild sedation; however this is not a perfect solution as it requires more medical supervision and carries low risks, and sedation itself can impact upon the test results. Early surgical intervention has been linked to better outcomes in eligible children with epilepsy, hence the need to optimise pre-surgical assessments.

For this study, 46 children with focal epilepsy and 20 healthy controls aged between the ages six and 18 underwent EEG-fMRI imaging. For two ten-minute sessions, all subjects were simply told to lie at rest during scanning, and for a further two sessions they were given a cartoon to watch inside the scanner.

(IEDs – activity that resembles epilepsy in between seizures) in the brain of each child. Tracking IEDs effectively is important in locating seizure foci.

According to results <u>published in the scientific journal PLoS One</u>, viewing the cartoons did not alter the children's brain activity, so (importantly) it didn't affect the interpretation of scans; however having something to watch helped them to be less restless.

Although movement increased with scan duration, watching the cartoon reduced movement by around 40% when played within the first 20 minutes.

The research concludes: 'A child-friendly natural stimulus improves the tolerability of EEG-fMRI and reduces in-scanner movement, without having an effect on IED occurrence and quality of EEG-fMRI maps. This allowed us to scan children as young as six and obtain localising information without sedation.' The authors acknowledge several limitations to their study, but it is clear that it gives a good foundation for further research.

Steven Long February 16th, 2016

www.epilepsyresearch.org.uk/watching-movies-during-brain-scans-can-help-children-with-epilepsy/







Migraine With Aura and Epilepsy Share Genetic Link

Migraine with aura and epilepsy have been found to share a genetic link. The findings, published in *Epilepsia*, found that a strong family history of seizures was associated with higher incidences of migraines with aura. There is much evidence that supports a coexistence of migraine and epilepsy, and previous findings revealed that epilepsy patients are at a higher risk of suffering from migraines, but a shared genetic cause was never established previously.

Lead author Dr. Melodie Winawer said, "Epilepsy and migraine are each individually influenced by genetic factors. Our study is the first to confirm a shared genetic susceptibility to epilepsy and migraine in a large population of patients with common forms of epilepsy." The researchers analyzed data from participants of the Epilepsy Phenome/Genome Project (EPGP), consisting of 27 clinics across the U.S., Canada, Argentina, Australia, and New Zealand. The study focused on sibling and parent-child pairs with focal epilepsy or generalized epilepsy with an unknown cause. Many patients with epilepsy do not have a family history of the condition, but the researchers aimed to focus on the rare cases where epilepsy appears to run in the family.

They analyzed 730 participants with epilepsy and 501 families with a prevalence of migraines with aura. They found that migraines with aura were substantially higher in families with epilepsy and seizure disorders. Patients with epilepsy were found to have three or more relatives with seizure disorders and were twice as likely to have sufferers of migraines with aura in the family. Essentially, the more relatives there were with seizure disorders or epilepsy, the more members experienced migraine with aura.

Dr. Winawer concluded, "Our study demonstrates a strong genetic basis for migraine and epilepsy, because the rate of migraine is increased only in people who have close (rather than distant) relatives with epilepsy and only when three or more family members are affected. Further investigation of the genetics of groups of comorbid disorders and epilepsy will help to improve the diagnosis and treatment of these comorbidities, and enhance the quality of life for those with epilepsy."

Migraine and epilepsy may occur simultaneously

Migraines are generally divided into two groups: less than 15 headache days a month and over 15 headache days a month. Comorbidities differ between each group, with migraines of over 15 headache days a month negatively impacting quality of life and leading to other health complications.

It has been found that epilepsy patients have a twice as high risk of experiencing migraines, and children with epilepsy are three to four times more likely to be at a greater risk for migraines.

Research suggests that epilepsy combined with migraine with aura can lead to worsened outcomes for patients. Epilepsy patients with migraines are less likely to have a remission from epilepsy, compared to epilepsy patients without migraines. Furthermore, epilepsy patients with migraine have higher rates of depression and suicide as well. Due to their overlap, both epilepsy and migraines do respond well to some of the same treatments, which makes handling both conditions a bit easier. Speaking with your doctor can narrow down the best form of treatment for both conditions in order to reduce complications.

Dr. Victor Marchione, February 5th, 2016

www.belmarrahealth.com/migraine-with-aura-and-epilepsy-share-genetic-link/

B.C. Woman With Epilepsy Calls For Better Disability Signage on Public Transport

Tavia Marlatt from Surrey, British Columbia, experiences major seizures, causing her to black out and fall to the ground. She uses the seats marked for people with disabilities to prevent getting injured. "I get the nastiest looks from everybody because I'm 19 and just by looking at me, you can't tell that I have a disability," Ms Marlatt said. "There's not enough room in the back to have a grand mal seizure without getting hurt."

Ms Marlatt relies on public transport to get around every day; drivers must not be seizure-free in Canada for at least a year to get behind the wheel, but she has a major seizure about every two weeks. To accommodate the needs of people like her, Ms Marlatt is asking TransLink to put up signs with the international medical symbol — a mark she has tattooed on her arm — alongside the wheel-chair symbol. She says the current sign implies a person must have a physical disability to use the priority seating.

In a written response, TransLink said Ms Marlatt's request serves as a reminder to all passengers that many disabilities are invisible. "We urge all our customers to be kind and considerate to their fellow passengers," said TransLink. It also said it has increased the number of priority seating signs but did not, however, specifically address whether it would accept Ms Marlatt's request.

Ms Marlatt says her ultimate goal is to create a better understanding of invisible disabilities among transit users and the general public. "I would just really hope that people put more of an effort into learning about non-physical disabilities," she said. She said her last experience having a seizure on the bus came as a shock — she woke up lying on the floor with the door repeatedly closing on her head. "Literally nobody tried to help me. They just stood there and watched," she said. "I was very upset with our society for not helping a youth having a medical issue." She has sat in the priority seating area ever since then, despite the dirty looks.

Olga Rzadkiewicz February 10th, 2016

www.epilepsysociety.org.uk/News/Canadian-woman-with-epilepsy-calls-for-better-disability-signage-on-public-transport-25-02-2016#.VtCDOPkrKM8







Lie Detector 'Game' That Helps Reduce Epileptic Fits: Subjects are Hooked up to a Polygraph Machine and Make a Computer Character Move with Just Their Minds

- Lie detectors use electrodes attached to person's finger to measure stress
- New test uses same technology, asking people to focus on on-screen man
- · Electrodes detect activity and man moves faster as they concentrate more
- 40 per cent of 21 patients in tests had fewer seizures after 12 sessions

Technology used in lie- detector tests has had dramatic results in controlling seizures in epileptics taking part in a UK clinical study. Lie detectors use electrodermal activity sensors – electrodes that are attached to the index and middle fingers – to measure tiny changes in stress via the skin's sweating response. The more stress a person feels, the greater the electrical conductivity of the skin. A sudden increase in conductivity indicates a lie.

Now Dr Yoko Nagai, a Wellcome Research Trust Fellow working at the Brighton and Sussex Medical School, has modified a lie detector machine so that a user's electric activity can make a computer character on a screen move. Patients are encouraged to focus on the character and will it to move. The more they focus their minds on the task, the faster 'she' moves. 'We found that training people to increase their level of alertness actually helped to calm their brain and reduce the number of seizures they were having,' Dr Nagai said.

'In essence, it is a visual way of teaching people to willingly lower their stress levels, by increasing alertness and focus on one thing.' An initial clinical trial of the technique, called autonomic cognitive rehabituation training (ACRT), involved 21 patients, and on average over 40 per cent had fewer seizures after 12 sessions.

A current trial of 40 patients is expected to show better results and Dr Nagai hopes it will offer another choice to the 30 per cent of sufferers who do not respond to drug treatments, and whose only other option is risky brain surgery. It is not believed stress alone causes epilepsy. However, it can cause seizures in those who already have epilepsy.

One patient on the first trial, Terry Murphy, a former stockbroker who was diagnosed with epilepsy in 1995, is now almost fit-free He said: 'Before this I was put on medication, but reached the maximum dose. My neurologist referred me to Dr Nagai, who got me to look at a fish on a screen. 'It turned into a woman who started walking on the beach, and my goal was to get her up a hill and through some ruins, using only my mind. It took eight or nine sessions until I finally worked it out – then the game told me I was a champion. I then learnt techniques like rubbing my hands or legs while remembering how I operated the game, which helps to calm me down, and from 130 fits a month I have gone down to 15 or fewer.'

Carpenter Michael Meredith says he has been fit-free for the first time in six years since mastering the technique in 2014. 'I am now going to reapply for my driver's licence,' he said.

Dr Nagai hopes to create an online version for home use. Until then, the treatment will be available for about £1,000 later this year at her clinic in Brighton. Dr Nagai is crowdfunding her research. To contribute, visit indiegogo.com and search 'epilepsy'.

Anthea Gerrie
January 30th, 2016

www.dailymail.co.uk/health/article-3424625/Lie-detector-game-helps-reduce-epileptic-fits-Subjects-hooked-polygraph-machine-make-computer-character-just-minds.html

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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.



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