

FOCUS ON EPILEPSY



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

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

Member Outings & Activities

January

Live Play at Shadow Theatre Sunday, January 25; 1:45 - 3:45 pm EEA Office staff would be happy to assist

you with planning travel by public transit.

(pre-registration required)

Collective Kitchen

Friday, January 16, 12:30 - 3:00 pm EEA Office

(program registration required)

Fun BINGO for Prizes

Friday, January 30, 1:00 – 3:00 pm EEA Office



February

Telus World of Science

Saturday, February 21; 1:00 - 4:00 pm EEA Office staff would be happy to assist you with planning travel by public transit. (pre-registration required)

Collective Kitchen

Friday, February 13, 12:30 - 3:00 pm EEA Office

(program registration required)

Fun BINGO for Prizes

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

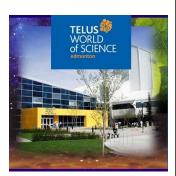


FREE MEMBER ACTIVITIES



Live Play "Circle Mirror Transformation" Sunday, January 25, 2015 Meet in lobby of Varscona Theatre - 1:45 pm 10329 - 83 Avenue, Edmonton

Telus World of Science Saturday, February 21, 2015, 1:00 - 4:00 pm Meet inside lobby 11211 142 Street, Edmonton



Watch for Updates on the Following Upcoming Events:

- March Epilepsy Awareness Month
- March EEA Annual General Meeting
- Spring "Be Your Own Boss" Course for Teens and Young Adults
- Member Activities for 2015

Adult Support Group Schedule

(Group meets from 4:00 - 6:00 p.m. in the EEA office.) Please call the Office to advise if you will be attending.

Wednesday, January 14, 2015

Wednesday, February 11, 2015

Support for Parents of Children with Epilepsy

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





Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta



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

We welcome your contributions:

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

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sharon@edmontonepilepsy.org

Dr. Sunny Kim...Counsellor sunny@edmontonepilepsy.org

Wendy Sauve... Asst. to the Executive Director info@edmontonepilepsy.org

Edmonton Epilepsy Association



EEA Partners with TD Canada Trust in Employability Program

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

For Further information contact EEA Executive Director, Gary Sampley. 488-9600 or gary@edmontonepilepsy.org

Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta

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



Now you can Donate to the EEA online!

If you would like to make either a lump sum Donation or a monthly donation contribution to the Association by credit card, please visit our website, www.edmontonepilepsy.org, 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

The following is an excerpt from an information bulletin sent by Pfizer Canada to healthcare professionals regarding the supply of Dilantin in Canada. If this shortage may affect you we suggest contacting your healthcare professional to clarify your personal circumstances.

"Pfizer Canada is currently experiencing national supply challenges for Prollantino (phenytoin oral suspension) 30mg/mL (6mg/mL) 250mL. Please note that we are currently making short dated product available for sale (lot expiring February 2015) and will continue selling the aforementioned lot until the end of December 2014. We anticipate that we will be able to normalize supply on this product with a new lot by mid to late-January 2015. Unfortunately, we cannot confirm a more precise date at this time.

Pfizer Canada is aware of the burden this situation may create and is committed to providing a constant supply of quality medication to our patients. We would like to assure you that we are doing our utmost to resolve the situation as quickly as possible. We will advise you as soon as the supply situation stabilizes."

For full text of manufacturer's information release on EEA website click here.

2015 EEA Scholarship Awards

The Edmonton Epilepsy Association will fund two \$1000 Scholarships in 2015, 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, 2015

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.



Epilepsy

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 2015 Award, please do so, in writing, to the EEA office by **March 1st, 2015.**

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

Need Prescriptions Filled?

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

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



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



More News from the EEA Office



Igloo Building Supplies Group is EEA's 2014 Employer of the Year!

L. to R: EEA Member Dale Pasin, who nominated his employer for the award, Barry Stewart of Igloo Building Supplies Group, winner of the 2014 EEA Employer-of-the-Year Award, and EEA Executive Director, Gary Sampley.

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, Igloo Building Supplies Group!



Laura Jurasek is EEA's 2014 Volunteer of the Year!



L to R: EEA Executive Gary Sampley holds the main award trophy for the "Cameron Reid EEA Volunteer-of-the-Year Award", while award winner Laura Jurasek holds the presentation plaque, accompanied by Trophy donor Cam Reid.

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, Laura, for helping to make the EEA a better organization!

Collective Kitchen Program Starting in January 2015

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 on January 16, February 13, March 13, April 17, May 15 and June 12, 2015. Interested members can phone Sharon at the EEA Office at 780-488-9600 to register. Registration is limited to **eight** participants.



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.edmontonepilepy.org, or a hard-copy Application can be mailed to you on request to the EEA Office, 780-488-9600.

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News from the EEA Office



EEA Fundraising Benefits from our Christmas Gift Wrapping Venture

From December 1st through 24th, 2014, numerous EEA volunteers manned a gift wrapping station at the downtown Edmonton City Centre Mall. Shoppers made a donation of their choice for our volunteers' wrapping of their gifts.

Through the efforts of our volunteers, for which we sincerely thank all of them, we raised \$7122.35 for EEA Programs and Services.



We would like to also express our appreciation to Oxford Properties for giving us this fundraising opportunity.



EEA 2014 Casino Results

Every second year, the Edmonton Epilepsy Association is eligible for a two-day casino.

We held our 2014 casino on August 7th-8th at Casino Yellowhead in Edmonton. Under Alberta Gaming regulations, all organization workers at a casino must be volunteers. Over the two 14-hour days of the casino, thirty-seven EEA volunteers provided services as either General Managers, Bankers, Cashiers, Chip Runners or Count Room Staff.

To all of them, we offer our sincere thanks.

In mid-November, Alberta Gaming released our share of the casino pool to us. The total amount we earned, to be utilized for EEA Programs over the next two years, was \$80,904.30!!!

Jonathan's Legacy

Nineteen year old Jonathan Langille, an aspiring musician and actor who also lived with epilepsy, passed away in February 2014.

On September 20th, his family hosted a fundraising event and banquet in his memory in Jonathan's home town of Bashaw, Alberta. The proceeds of this fundraiser were divided between the Bashaw School Music and Drama programs, the Majestic Theatre and the Edmonton Epilepsy Association.

The EEA gratefully acknowledges a 2014 donation from the Legacy of \$2200.

In addition, the Legacy has donated a high-quality specially commissioned electric guitar, in Epilepsy colours of purple and lavender, which will figure prominently in 2015 EEA fundraising. Stay tuned for further details.



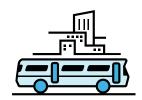
It is the family's intention that this fundraiser become an annual event.

For more information, contact Jonathan's family at 587-991-0700 or jonathanslegacy@hotmail.com



Bus Tickets Available for Members in Reduced Circumstances

We have a very limited number of tickets from our 2014 allotment available in the EEA Office. These can be accessed by MEMBERS with limited financial resources who need help getting to medical appointments, EEA events, food shopping, etc., and who do not have an AISH bus pass. Call 780-488-9600 or drop by to pick them up. Please note that when these tickets are gone, we will not have a replenishment until mid-April, 2015.







Christmas Lunch & Social



























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Italian Meal and Entertainment































A Wish that made all things possible...Joy really is a wonder drug

When we were granted a wish trip by the Children's Wish Foundation for Blake little did we know the change in our life this wish would bring, and boy, are we grateful!

We were stuck. Truly. As a family we were stuck in the daily grind of being tired from being up with our boy through nights full of seizures, dealing with seizures during the day, managing his diet, his appointments, his sister's school, work, etc.

We felt frustrated that he couldn't just tell us what his wish would be. What if I guess and I am wrong and we've wished away his one chance to do something he REALLY would want?

And then we heard about this magical place called, Give Kids the World (GKTW). It was the shimmer of light in the darkness that we needed to make the decision to just go. To jump and trust we would be ok. Knowing that GKTW was designed with families like ours in mind – that they had access to medical equipment, would help stock our cottage's fridge with Blake's keto ingredients prior to our arrival, that they had a magical accessible playground with parachute shades! I could just picture us there, heat and all, and Blake able to play! Imagine! Pools and carousels and trains. If there wasn't something there he would love, then we were in trouble. So we signed up. To Florida we would go. To hot Florida. To potentially over-stimulating places full of fun and adventure and every kind of potential seizure trigger imaginable. Ready and.....jump.

Blake's sister has been constantly asking, when, oh when would the day come when we could go somewhere? Well, that day arrived – we could say, "yes – we are going! rather than the, "someday" response she was used to. What a gift! It didn't hit me until there we were, sitting on a plane, as a family. We were doing something 'normal' families do. We were going to just be together, to have fun, to be away! This was the gift of travel we had dreamed of giving our children that we had not yet been able to achieve. Fear had held us back.

Quickly, our unrealistic hope of a seizure-free week was dashed. When seizures hit we re-adjusted and carried on. What else could we do? It is so hard to put into words what we and our children experienced that week. Nothing gave him greater joy than riding the carousel for hours! We did Disney and Seaworld and Blakey touched the ocean for the first time (yes, he seized but he loved it before that). We swam and played and discovered he LOVES princesses, probably more than his sister. We slept in a new place and the kids rode horses for an entire morning. Mr. Larry, who brought the horses, fell in love with Blake, who signed, "horse" and "please" and "thank you" over

and over.

I am in tears just thinking about it. Magical moments. We took risks, and it always felt like everything, for once, was on our side. I have absolute and abundant gratitude for being cared for. Waking up in our villa and opening the shutters to the magical world of GKTW transported us out of our funk – our medicalized, difficult life. We experienced more JOY than we had in so long. And it woke up a part of our son that had never yet been stimulated

The blissful sounds of our exhausted children, laughing together in the rental van after a full day of Disney, is something I will never forget. The trip gave us hope. It gave us a lifeline that we needed. It seems to have brought our son to life. Everyone who has seen him since cannot help but mention the change in him. He's adventuresome. He's social. And boy, is he trying hard to be talkative. Our son. Our Blake!

At bedtime, our sleepy Blake, just before falling asleep, would try his hardest to retell us about his day. Of all the new sights and sounds and experiences. He would use sounds and signs and motions to tell us of the different animals he rode on, on the carousel and of the characters he had met. HE WAS TELLING STORIES! He signed "fish" and "throw" and motioned with his mouth eating – yes, we had fed the dolphins! His little brain was working so hard to process it all and it was magical to see our son start to change. He suddenly started feeding himself! Using the spatula like a pro. Bringing us his clothes or shoes or whatever we needed just so we could go do more! Our baby was suddenly growing up with all these new experiences. For every day of activity, he need a day or so of rest. We did what we could and that was more than we ever could have thought possible!

We are so grateful to everyone, including strangers, who made this gift possible! We, with all our hearts, thank you!!







Excerpted with permission of the author. The full text can be read at <u>dravet-momma.wordpress.com</u> a blog written by Edmonton Epilepsy Association member Joelle Fawcett-Arsenault.

Stereoscopic 3D 'can enhance analysis of brain images'

Epilepsy scientists studying brain imagery could benefit from the advent of visualisation techniques that take advantage of stereoscopic 3D technology.

A collaborative study between researchers in Chile, the US and Germany has examined the benefits of stereoscopic visualisation of clinical data, in comparison with traditional 3D

rendering technique.

Effective visualisation is a core element in exploring and comprehending brain imaging data. Despite MRI data being acquired in three-dimensional space, current methods for visualising this

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Stereoscopic 3D....

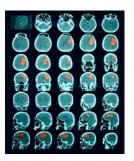
(Continued from page 8)

...information rarely takes advantage of 3D stereoscopic technologies.

However, this new study suggested such innovations can aid the intuitive description of exact locations and relative sizes of various brain landmarks, structures and lesions, and even facilitates comprehension of the anatomical position of complex large-scale functional connectivity patterns in some cases.

The researchers concluded: "Stereoscopic visualisation improves the intuitive visual comprehension of image contents and brings increased dimensionality to visualisation of traditional MRI data, as well as patterns of functional connectivity."

Brain imaging is a vital element of epilepsy research and diagnosis, due to the need to determine the exact part of the brain that is causing the patient's seizures where possible.



Posted Nov 27 2014 http://www.epilepsyresearch.org.uk/ stereoscopic-3d-can-enhance-analysis-ofbrain-images/

What Factors Have the Greatest Effect on Quality of Life in Children with Epilepsy?

During a platform session at the 43rd Annual Child Neurology Society Meeting, held in Columbus, OH, October 22-25, Nora Fayed, PhD, et al. presented "Quality of Life in Children with Epilepsy From the Kids' Point of View," featuring results from a study that focused exclusively on self-reported quality of life (QoL) among children diagnosed with epilepsy. The study used a conceptual approach to explore the relationships among seizure and medication variables, co-morbidities, and child and social factors, relative to QoL and relative to each other.

The authors noted that "the effects of epilepsy can influence biological, psychological and social life in children and youth, and later when people with epilepsy become adults. There is conflicting evidence in children with epilepsy as to what degree seizures have an impact on quality of life (QoL) from the child's point of view."

Acknowledging that QoL means different things to different people, the authors used a definition that is consistent with the World Health Organization's position that QoL is "an individual's perception of [his/her] position in life... in relation to their goals, expectations, standards and concerns."

For the study, researchers used data from the QUALITE longitudinal study of patient reported outcomes in children with epilepsy. To participate in the study, patients had to be 8-14 years old at baseline, possess the ability to self-report information about their condition (estimated verbal IQ>70), have active or medication-managed epilepsy, and understand English or French.

The researchers measured a range of variables, including seizure and medication status, verbal IQ, mental health indicators (overall mood, depression, anxiety, attention, maladaptive conduct, and adaptive conduct), parental support, peer support and attitudes, and epilepsy-specific QoL.

The study enrolled 480 children (248 males, 232 females) who presented with a range of seizure types (16% simple partial, 38% complex partial, 37% tonic clonic, 31% absence, 5% myoclonic). Fifty-seven percent had had at least one seizure in the last 12 months, 17% had a seizure within the last 24 months, 19% were inactive but on medications. Two-thirds of the children were in regular classes, 28% were in special needs classes at least part of the time, and5% were in "fully modified" classes.

Seventy-one percent of the children were taking one seizure medication, 17% were taking 2 medications, and 5% were on more than 2. More than half of the children (54%) had not previously failed treatment with seizure medication, 21% had failed one prior form of treatment, and 23% had failed more than one. The two most common medications prescribed for this cohort were carbamazepine and oxcarbamazepine (30%) and valproate (29%).

Three-quarters of the children lived with their nuclear family, 8% had parents who were divorced or separated, 8% lived with "reconstituted" families, and 9% lived with a single parent. Maternal education level was high, with 70% having graduated from a college or university. More than 60% of children lived in households with annual income of \$60,000 or more. Three-quarters of the children spoke English at home, 20% spoke French, and 5% spoke some other language.

Analysis of these data found that peer support, parental support, and mental health had the greatest effect on QoL, with seizure status exerting "a weak, indirect effect on QoL only through the child's mental health."

In their conclusions, the authors wrote "There are many potential gains from understanding the children's own perspective of their QOL including the fact that epilepsy-specific QOL is strongly related to psychosocial factors and is unrelated to actual seizure status." In children and with epilepsy, "psychosocial factors such as parental and peer support as well as child mental health should be an area of focus in their assessment."

The potential targets for intervention "need to reflect the children's own perspectives rather than relying solely on parental reports." Targets for improving the child's perception of life "can occur by improving mental health through supportive parents and peer acceptance but these causal relationships need to further be tested among subgroups and longitudinally."

ByHPCLive Staff October 31,2014

http://www.hcplive.com/conferences/cns-2014/What-Factors-Havethe-Greatest-Effect-on-Quality-of-Life-in-Children-with-Epilepsy





Women With Epilepsy Can Have a Healthy Baby

The impact of the neurological disorder epilepsy is on the minds of thousands of women and girls who are living with it. Those who want to get pregnant worry about a number of things, such as, will their seizures or the drugs they are taking keep them from having a healthy baby. The answer is yes, it is indeed possible.

A healthy pregnancy weighed heavily on Sandy Caldwell's mind when she wanted to have a second child.

"I had never been diagnosed with epilepsy, so I never had seizures prior," said Caldwell.

There was also the risk of birth defects due to anti-seizure medications, but after consulting extensively with neurologist Dr. Erica Schuyler at Hartford Hospital, Caldwell overcame her fears.

"I was told the medication I was on was basically two-percent chance, roughly, of having a birth defect, and in any normal human being there is a two-percent risk at least of having a birth defect," said Caldwell.

Planning ahead led to a healthy pregnancy and a second son, Luke.

"It's really important that we get the seizures under good control beforehand and make sure she is on a medication that has a lower risk of causing birth defects or problems with the pregnancy," said Dr. Schuyler. Caldwell was monitored closely with frequent office visits.

"There were times during the pregnancy when I would feel off and I would get what they called auras," said Caldwell. "It would be a funny sensation in my nose or just something not seeming right."

"The metabolism changes somewhat as the pregnancy goes on, so we do monitor levels, blood levels, of the medication in her system, and we did notice that they were declining, so we did need to increase her medication," said Dr. Schuyler.

The priority was controlling the seizures.

"I needed to be on medication for well over a year to make sure everything was copacetic," said Caldwell.

"I think that it's more likely for someone to decide not to have children if their seizures are not well controlled," said Dr. Schuyler.

Caldwell says every calculated step was well worth taking. "Definitely, I would do it again," said Caldwell. "He is adorable, he is sweet."

Good regular prenatal care also made the pregnancy possible.

Caldwell was able to breast feed her infant son as well.

By Jocelyn Maminta, Medical/Health Reporter, Hartford, Conn.
December 2, 2014
http://wtnh.com/2014/12/02/women-with-epilepsy-can-have-a-healthy-baby/

Embrace Medical-Quality Smartwatch Predicts Seizures

The Embrace is the first medical-quality smartwatch that helps predict epileptic seizures, and measure stress, activity and sleep. Designed to improve the lives of people with epilepsy, the sleek-looking device can also be worn purely as a stylish watch.

According to the Institute of Medicine, one in 26 people in the US will suffer from epilepsy at some point in their life. Approximately 65 million people worldwide suffer from the brain disorder. The Embrace wearable works in conjunction with the wearer's smartphone to monitor physiological stress, sleep and physical activity and alerts people with epilepsy when an unusual event like a convulsive seizure happens.

One of the benefits of today's smart technology is the ability to also alert other people when a loved one experiences a health issue, or forgets to take their medication as with the Memo pillbox. The Embrace can send an alert to nominated family members or friends via the system's Empatica Alert iOS/Android app, who can then bring help.

Family, friends or caregivers can also wear a "companion" Embrace. When the two Embraces are within range, the companion device will vibrate to alert them that another wearer may need assistance.

Embrace will also launch with the Empatica Mate app which can be used by anyone to track stress, sleep quality and physical activity. For example, you can set the Embrace to vibrate gently when your stress level starts rising, giving you the opportunity to take action before it gets too high, or when you reach activity targets during the day or during your workout.

If you push yourself too hard, the Embrace will gently remind you with a vibration that you need some time to recover. You can also track changes in your stress levels during different daily activities, like commuting by car versus bike, meeting with your boss or a friend, and taking exercise, giving you customized insights into your behavior.

Embrace measures movement and physiological signals to detect potentially life-threatening seizures via a range of sensors that gauge electrodermal activity (EDA) or skin conductance (arousal, excitement), movement or activity (accelerometers) and activity (temperature). The sensors and algorithms were originally developed at the MIT Media Lab where researchers discovered that combining stress data from the wrist with activity data led to the most accurate seizure detection.

EDA is activated by areas of the brain involved in emotions such as fear, anxiety, and excitement, and is strongly activated during the kinds of seizures that can shut down breathing. These emotions generate skin conductance which varies depending on the amount of sweat-induced moisture on the skin.

Although the algorithm has currently only been validated for convulsive seizure detection, research is being conducted into the detection of nonconvulsive seizures. Empatica notes that as

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Embrace Medical-Quality...

(continued from page 10)

biofeedback using skin conductance can cut seizure frequency almost in half for many people, the Embrace may be able to help those with complex partial or other nonconvulsive seizures. The sleep and stress pattern data collected by the Embrace may also help people with epilepsy work out whether changing these patterns reduces seizure frequency.

The Embrace is water resistant, uses Bluetooth Low Energy, and provides USB connectivity for charging. Simply snap it on and it tightens with a magnet for a perfect fit. It's also aesthetically pleasing with an ultra thin design, Italian leather band available in a range of colors, and a polished metal case.

Embrace has been developed by affective computing company Empatica in partnership with the Epilepsy Foundation and private donors. Empatica has strong credentials in developing medical-

quality wearable devices for hospitals and universities around the world. Its work has been published in journals such as Epilepsia, Neurology and Nature and the company is in the process of applying both for CE Medical (Europe) and FDA clearance (USA) for the Embrace.

By Karen Sprey December 4, 2014

http://www.gizmag.com/embrace-smartwatch-epilepsy-seizuredetection/35037/

Watch a video: https://www.youtube.com/watch?v=mN14CuXkHm4







Study Sheds Light on Epilepsy and Stress

It's been well documented that stress is the most common seizure precipitant for people with epilepsy. But little is known about the specific stressors, the timing of the stressors and other associated factors for stress-precipitated seizures. If investigators could have such information, says Michael Privitera, MD, it could help in the design of large-scale randomized controlled trials of stress reduction interventions for epilepsy.

Privitera, a professor in the UC Department of Neurology and Rehabilitation Medicine and director of the Epilepsy Center at the UC Neuroscience Institute (UCNI), and colleagues at UC and Albert Einstein College of Medicine in New York surveyed a study population drawn from the Epilepsy Center at UCNI to identify patients who felt that their seizures were sometimes precipitated by stress and determined whether other epilepsy or mood factors were associated with stress-related seizures. They also asked participants if they had used stress reduction methods in the past and what effect stress reduction had on their seizures.

The research appears online in *Epilepsy & Behavior*, an international journal focusing on peer-reviewed articles based on laboratory and clinical research. Portions of the work were supported by a gift from the Shor Foundation for Epilepsy Research.

"Our goal was to determine mood and epilepsy characteristics of people who report stress-precipitated seizures," says Privitera. "We are also interested in anxiety—is it a trait related to the tendency to report stress-induced seizures, or is anxiety itself a seizure precipitant?"

The study population was drawn the Epilepsy Center of the UC Neuroscience Institute, with outpatient clinics at two sites (Clifton and West Chester). Patients who agreed to participate filled out a questionnaire that included questions such as:

- "Do you believe that stress, especially emotional stress, makes a seizure more likely?"
- "Do you think that reducing your stress will reduce the number of seizures you experience?"

- "Have you ever tried any methods of stress reduction?"
- "Do you believe that any of the stress reduction methods you have tried helped reduce the number of seizures you experienced?"

Of the 266 subjects in the study, 219 (82.3 percent) endorsed stress as a seizure precipitant. Those who endorsed stress as a seizure precipitant were more likely (51.8 percent vs. 14.3 percent) to believe that they could at least occasionally predict seizures.

Among those who endorsed stress as a seizure precipitant, 85 percent endorsed chronic stress, and 68 percent endorsed acute stress (there was some overlap). Some type of relaxation or stress reduction treatment was used by 57 percent of the subjects who endorsed stress as a seizure precipitant, and 88 percent thought that it improved (i.e., reduced) seizures.

"Interestingly," Privitera says, "of those who did *not* endorse stress as a seizure precipitant, 25 percent had tried relaxation or stress reduction, and 71 percent thought their seizures improved."

The most common stress reduction methods, according to the study, were yoga, exercise and meditation, with more than one method used by most respondents.

As for the role of anxiety, Privitera notes that the ongoing SMILE (Stress Management Intervention for Living with Epilepsy) study, of which he is principal investigator for the Cincinnati site, uses daily electronic diaries to record subjects' moods. Results are expected to be published in early 2015.

"This will provide additional data that may help in deciphering the complex relationship between stress, anxiety, depression and seizure frequency," Privitera says.

November 2, 2014

http://www.healthcanal.com/mental-health-behavior/56941-studysheds-light-on-epilepsy-and-stress.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, and a bi-annual weekend specialized Educational Conference, all of interest to Health Care Professionals as well as the General Public;
- ◆ Free provision of our series of 12 Epilepsy Education Information booklets to Members, Hospitals, Clinics, Neurologists' Offices and Pharmacies;
- ♦ Website, print and video information about Epilepsy, and a free lending library for members;
- ♦ A 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;
- ◆ A 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;
- ♦ Two group sessions a month, one geared toward Adults with Epilepsy and concerned family members, and one 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 Membernominated Volunteer-, Achiever-, and Employer-of-the-Year Awards.



Edmonton Epilepsy Association 11007-124th Street NW Edmonton, AB T5M 015

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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...