

# FOCUS ON EPILEPSY



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

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

# Member Outings & Activities

## May

Bowling at Bonnie Doon Lanes Sunday, May 15th, 1:00—3:30 p.m. Bonnie Doon Lanes, 8330 — 82nd Avenue (Pre-register by May 11th)

Collective Kitchen Session 5 Friday, May 20th, 12:30 - 3:00 pm EEA Office (program registration required)

Fun BINGO for Prizes Friday, May 27th, 1:00 – 3:00 pm EEA Office



## June

Visit to the Valley Zoo Saturday, June 11th, 2:00 - 5:00 p.m. Valley Zoo 13315 Buena Vista Road (Pre-register by June 8th)

Collective Kitchen Session 6
Friday, June 17th, 12:30 - 3:00
EEA Office
(pre-registration required)

**Fun BINGO for Prizes**Friday, June 24th, 1:00 – 3:00 pm
EEA Office



### FREE MEMBER ACTIVITIES



Bowling at Bonnie Doon Lanes Sunday, May 15 1:00 - 3:30 pm 8330-82nd Avenue

Visit to Edmonton Valley Zoo Saturday, June 11 2:00 - 5:00 pm

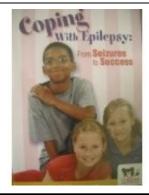


### **First Ever EEA Garage Sale**

The EEA will be having its first ever Garage Sale out of the garage behind the Office at 11215 Groat Road on Friday and Saturday, May 13th and 14th. Donations of clean, saleable goods for the sale will be much appreciated. If you wish to donate, please contact us and let us know. No clothing or books please.



Sale Hours are: Friday, May 13th, 10:00 a.m.—7:00 p.m. Saturday, May 14th, 9:00 a.m.—5:00 p.m.



# Just Received in the EEA Library

We have a new DVD titled, "Coping With Epilepsy: From Seizures to Success" for parents and children. This DVD is now available in the EEA Free Lending Library.

## **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, May 11, 2016

Wednesday, June 8, 2016



# 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**

President...Cheryl Renzenbrink Vice President...Ann Gillie Treasurer...Anna Tymoszejko Secretary...Cameron Reid

**Executive Director...**Gary Sampley

**Directors-at-Large:** 

Tammy Anast Szymon Bamburak

**Guy Doucette** Erin Duke

Doug Griffiths Craig Heyland

Tim McCallen Anne Starreveld

Brian Wilkie

#### STAFF

Gary Sampley... Executive Director & Chief Operating

gary@edmontonepilepsy.org

Sharon Otto... Program Manager & Education Coordinator

sharon@edmontonepilepsy.org

Dr. Sunny Kim...Counsellor sunnv@edmontonepilepsv.org

Cam Reid...Volunteer Coordinator cam@edmontonepilepsy.org

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

11215 Groat Road NW Edmonton, AB T5M 3K2



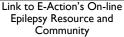
(780) 488-9600 (780) 447-5486 fax I-866-EPILEPSY



info@edmontonepilepsy.org www.edmontonepilepsy.org











#### **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**

Please note that we now have our 2016 allotment of tickets 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.



### 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**

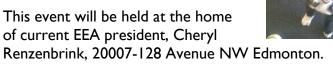




### A Well-Deserved Recognition for Gary Sampley and His Wife Sharon

On Saturday, July 9<sup>th</sup> from 1:00PM to 4:00 PM you are invited to be a part of "Gary Sampley Tribute Day" honoring the Edmonton Epilepsy Association's Executive Director, Gary Sampley. Gary's extraordinary contributions to the association have made it one of Canada's foremost and most successful providers of supports and services to individuals and families impacted by epilepsy. It is our wish to show our appreciation for his devotion, passion, vision, and the unselfish contributions and sacrifices made by Gary and his wife, Sharon, to achieve these outcomes.

Of course, this Tribute would not be complete without the attendance of Gary's faithful sidekick Gio.



If you have a computer, please register or RSVP by using this link. <a href="https://sampleytribute.eventbrite.ca">https://sampleytribute.eventbrite.ca</a> If you do not have access to a computer, please call Cheryl directly @780-909-4006.

# Critical Shortage of Epilepsy Drug, Divalproex, ends Drug Used in the Treatment of Epilepsy and Mood Disorders

Apotex, Canada's largest manufacturer of Divalproex Sodium, reportedly restarts shipments of the essential epilepsy drug after encountering problems with manufacturing 10 months ago. The drug is used in the treatment of seizures and mood disorders.

The company reported on the <u>Canadian Drug Shortage Database</u> that the 500-milligram formulation of the drug, known by its brand name as Apo-Divalproex, was on its way to wholesalers and could be available for use in early May.

Lower dose tablets will reportedly take more time to restock. Apotex's problems with Apo-Divalproex, also known as Epival, had a ripple effect on other makers of the drug, causing a national shortage. The drug is used to treat epileptic convulsions and off-label use includes psychiatric conditions such as bipolar disorder. So many people need it, it's on the World Health Organization's list of essential medicines, meaning it's meant to be "available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms."

April 22nd, 2016 CBC News

http://www.cbc.ca/news/health/critical-shortage-of-epilepsy-drug-divalproex-ends-1.3547526

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# **News from the EEA Office**



#### Yvonne Leonardis - Long Time Member of Board and EEA Passes Away



On April 2, 2016, Yvonne Leonardis passed away peacefully at the age of 63. Left to cherish her memory are her loving husband Dominic of 46 years, children Nina and Dean (Kat), grandchildren Quinn, Sophia and Hanna, her 2 brothers and numerous relatives and close friends.

Yvonne's Accounting background led to her serving as the Treasurer of the EEA for several years. During this time, she was a member of the EEA Executive, Audit, Personnel and Budget Preparation Committees.

Yvonne was honoured as EEA's Achiever Of The Year in 2015, as an individual living with epilepsy achieving significant success in life, inspiring others in the process. Yvonne, you will be missed!

### Annual Members' BBQ, Games & Social



Saturday, August 13th, 11–2 p.m.

"Social Room" in the ACT Centre, Rundle Park

Call the Office to register! 780-488-9600

More details to follow in the July/August Newsletter.

## One Spot Still Available In Our NEW Collective Garden



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 harvesting 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 the <u>last plot</u>, please contact Sharon at the EEA Office.

# Nominate your Employer as the EEA Employer of the Year



## Do You Have Epilepsy???

Do you have a great and supportive Employer that recognizes and encourages the many contributions people with Epilepsy offer their fellow employees and workplace?

Nominate them for the 2015 Edmonton Epilepsy Association Employer of the Year Award. Contact us to find out how: 780-488-9600 or gary@edmontonepilepsy.org

Nomination Deadline is September 1st, 2016





# **Epilepsy News From Around Alberta**



# This is a Story Update From Our March-April Newsletter Fort Vermilion Girl Supports City Charity in Pageant



Tianna Lizotte, a 14-year-old girl from Fort Vermilion, stands behind her birthday cake at a jamboree on Saturday, March 26. She raised money from community members to cover the costs of her participation in the 2016 Miss Teen Canada Globe pageant in Toronto this summer.

A 14-year-old Metis girl from Fort Vermilion, hoping to compete at the Miss Teen Canada Globe pageant in Toronto this summer, got one step closer to her dream on Saturday. To raise money for hefty pageant entrance fees, plane tickets and clothing costs, she and her family held a jamboree with dancing, singing and food for more than 100 people. In total they raised about \$8,000 from friends, family, teachers and other community members. The amount will easily cover all of her expenses for the pageant.

"It was really nice for everybody to get to know her and for her to realize how much support she has," her mother, Jolene Lizotte, said on Monday. Tianna is not your typical pageant participant. She is shy and struggles to speak in front of big groups. But she wants to raise money for the Edmonton Epilepsy Association in honour of her stepdad, who had the disorder and passed away in May of 2012. From the time she was three years old until she was nine, Tianna watched her stepdad, Riley, have seizures and would ride with him in the car during long trips to and from doctors appointments in Edmonton.

In 2008, while the family was watching the Victoria's Secret Fashion Show, Tianna asked Riley if he might buy her a pair of the wings worn by the Victoria's Secret Angels. Riley told her she would get her wings and that she was prettier than all of the models on screen. Since then, the family has watched the fashion show religiously and Tianna has had an interest in modelling.

To raise awareness for the Edmonton Epilepsy Association, Tianna distributed brochures at the jamboree and asked guests to wear purple. By coincidence the event fell on March 26, which is World Epilepsy Day.

Miss Teen Canada Globe will take place in Toronto over 10 days in August. The top five girls advance to represent Canada at an international competition and the overall winner gets \$5,000.

Since the pageant isn't for a while, Tianna plans to host a walkathon or running race of some kind to raise money for the Edmonton Epilepsy Association. To learn more about Tianna or follow her route to the pageant in August, search for "Tianna Paris Leigh Lizotte For Miss Teen Canada Globe" on Facebook.

Madeline Cummings March 30, 2016

www.edmontonexaminer.com/2016/03/30/fort-vermilion-girl-supports-city-charity-in-pageant

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# **News from the EEA Office**



#### Congratulations to Our 2016 Continuing Education Scholarship Recipients







Susan Kirk and Garrett Henrickson are the happy recipients of \$1000 EEA Continuing Education Scholarships.

Presenting Susan and Garrett with their scholarships are EEA President Don Risdon

Thank you to the Epilepsy Trust, sponsor of this award.

EEA Continuing Education Scholarships are presented each year at our March AGM. Scholarship applications are accepted year-round. For details please contact the EEA office. The application deadline for next year is March 1, 2017.

### Retiring Board Members Thanked for Service to EEA





On behalf of EEA's Members and Board of Directors, EEA President Don Risdon made a presentation to outgoing Board Member Michel Zielinski. EEA Executive Director, Gary Sampley also presented Don Risdon with a similar plaque. Kim Mahe was not able to be with us, but Gary had previously presented her with her plaque. Kim and Don served a full six years of service on the Board. All were warmly thanked for their years of service.



#### **Casino Volunteers 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.



# 2016 Annual General Meeting



























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### **Even Controlled, Epilepsy May Still Cause Problems For Kids**

Even when their seizures are well-controlled, children with epilepsy can still have learning and behavioral disorders that lead to social and educational problems when they're young adults, a new study finds. "Frequency and intensity of seizures remain important predictors of how well a child does into adulthood. But, somewhat to our surprise we also found seizures are by no means the sole influencers of social and educational outcomes among adults with childhood epilepsy," said study lead author Anne Berg. Berg is a scientist with the Ann and Robert H. Lurie Children's Hospital of Chicago, and professor of pediatrics and neurology at Northwestern University Feinberg School of Medicine.

The research included 241 children and teens in Connecticut who were diagnosed with uncomplicated epilepsy from 1993 to 1997. They were followed for an average of 12 years. Thirty-nine percent of the participants had excellent seizure control, with no seizures one year after diagnosis, the study showed. About 23 percent had good seizure control, with no seizures up to five years after diagnosis. Nearly 30 percent had seizures that came and went but generally responded to medication, and 8 percent had recurrent, drug-resistant seizures, the study found. As young adults, more than 90 percent of the participants with excellent seizure control were either pursuing a college degree or had full-time or part-time jobs, compared with 60 percent of those with poor seizure control. More than 90 percent of those with good or excellent seizure control had a driver's license, compared with 60 percent of those with poor seizure control, researchers said.

Those with a history of learning problems were nearly 50 percent more likely to be unemployed, the study revealed. Regardless of seizure control, participants with a history of emotional, behavioral or psychiatric conditions such as anxiety, depression, bipolar disorder or attention-deficit/hyperactivity disorder (ADHD) were 60 percent less likely to complete college and 50 percent less likely to be living independently. Level of seizure control didn't affect the chances of trouble with the law. Participants with disruptive behavioral disorders, such as oppositional defiant disorder, had a nearly three-times increased risk of trouble with the law, regardless of seizure control. The findings show the need to screen all children with epilepsy for learning problems, regardless of how well their seizures are controlled, the researchers said. Doing so could help prevent problems later in life. "Physicians caring for those patients should not assume kids are doing fine just because their seizures are under control. Seizures really don't tell the whole story," Berg said in a hospital news release. The findings were published online recently in the journal Pediatrics.

March 31, 2016

 $\underline{http://consumer.healthday.com/cognitive-health-information-26/epilepsy-news-235/even-controlled-epilepsy-may-still-cause-problems-for-kids-709554.html$ 

### Children Often Have A Good Understanding Of Their Epilepsy

A new study has revealed that children with epilepsy often have a high level of understanding about their condition. Led by Leipzig University and University Hospital Heidelberg in Germany, the research involved 84 children with epilepsy between the ages of six and 18 years and their parents, and investigated how the children perceived their own condition and health status. It is understood that children with epilepsy often face difficulties in daily life, but self-assessment data among these individuals remain rare. To address this, the current study invited children with epilepsy to take part in a structured interview and draw a picture depicting their own view of their condition.

The results, published in the medical journal Epilepsy & Behavior, revealed that 75% of the children were able to name their condition correctly, whilst 96% were able to say whether they had to take medication and 52% of those taking long-term medication correctly named the drugs they had been prescribed. In addition, 54% of the children named specific precautions to prevent harm from seizures, with 7% of these believing that non-adherence to safety precautions would cause new seizures, and 27% perceived themselves to be worse off than healthy children. The survey also highlighted a few misconceptions that exist among young people with epilepsy, with 12% believing that their medication would cure their condition and 10% believing that their epilepsy might be contagious.

With respect to the illustrations, 80% of the children drew a picture entitled "This is how I feel when I have a seizure", as requested. Specific symptoms and the interaction between the child and their environment were the most common subjects depicted in the drawings. The research concludes: "Most children with epilepsy had rather good knowledge about medication; half of the children knew specific safety precautions. The children were often able to describe their seizures well. Pictures drawn by patients can give an insight into their experiences. "Teaching programmes should, among others, address the fear of contagiousness of epilepsy in some children and the fact that children with epilepsy might feel disadvantaged."

April 26, 2016

https://www.epilepsyresearch.org.uk/children-often-have-a-good-understanding-of-their-epilepsy/



**Focus on Epilepsy** Page 8

Epilepsy Research UK





#### Medical Pot Activists Fear Epilepsy Drug Could Undercut Them

COLUMBUS, Ohio -- An experimental epilepsy drug made from cannabis plants grown in England is complicating the medical marijuana debate in U.S. hospitals and statehouses. Epidiolex is a nearly pure extract of cannabidiol, or CBD, with little of the tetrahydrocannabinol, or THC, that gets traditional pot users high. CBD products are the current rage in medicinal pot products, and activists fear that if the maker of Epidiolex manages to get FDA approval it could undercut the political momentum of the medical marijuana movement.

Anup Patel, a pediatric neurologist who oversees Epidiolex clinical trials at Nationwide Children's Hospital in Columbus, insists the drug contains the optimal known marijuana compound for treating seizures. He cited a study that found children can be hurt by using the whole plant. Patel laments that children with epilepsy are being used -- including during an unsuccessful Ohio ballot campaign last year -- to push for medical marijuana legalization."People are mixing terms, mixing ideas," he said. "I'm not sure if that's just because of confusion, lack of knowledge or on purpose."

Karmen Hanson, the expert on marijuana policy for the nonpartisan National Conference of State Legislatures, said the two sides are at odds."The argument for traditional (whole-plant) medical marijuana is that people know what works for them - whether they're going to make their own concentrates or vape or combust, use flowered products, oils, you name it - so they want to protect their ability to do that," she said. "The other camp wants to see the head-to-head science, to give it more scientific validity, to elevate the products that are produced in terms of reliability and consistency."

Patel is in Camp 2. He personally lobbied to get U.S. patients access to Epidiolex, which he said is effective, consistent and doesn't get users high. About two years ago, Patel persuaded London-based GW Pharmaceuticals to give him enough of the medicine for a single patient, and his hospital's study was born. Last month, the company released positive results of late-stage testing. It plans to take Epidiolex to the U.S. Food and Drug Administration later this year.

The FDA has not yet found any botanical form of marijuana to be safe or effective to treat any disease or condition, spokesman Michael Felberbaum said. If approved, Epidiolex would be the first. Two synthetic cannabinoids - Marinol and Cesamet - are available. FDA approval would allow any doctor to prescribe Epidiolex to any patient, and it would be covered by insurance. No law or ballot issue would be required. Many medical marijuana activists fear Epidiolex approval will mark the beginning of Big Pharma's takeover of the marijuana plant, undercutting patients' ability to treat themselves as they see fit.

"We are not concerned with the pill (actually oil) form of a natural plant," said Wendy Johnson, who represents the Cannabis Safety Association in Ohio, where medical marijuana legislation was introduced last week. "In fact, it is looked upon very unfavorably and as a stumbling block on our way to whole plant."

Twenty-three states now have comprehensive medical marijuana and cannabis programs - but 17 others have chosen only to permit use of "low THC, high cannabidiol" products, mostly mom-and-pop cannabis oils or hemp extracts. Since marijuana can't be legally grown in those 17 states, the narrower bills aren't much more than legal protections for people who are able to access the products, Hanson said. A low-THC, high-CBD strain of medical marijuana called Charlotte's web is grown in Colorado, for example, where marijuana is legal.

"They're worried about political pushback. That's it in the end," said John Hudak, a senior fellow at the Brookings Institution who studies marijuana law. "They're worried about an ad being run against them."

Tara Cordle, of Wheelersburg, Ohio, has a 10-year-old son, Waylon, who suffers from a severe form of epilepsy and is part of Epidiolex clinical trials at Nationwide Children's Hospital in Columbus. She said she also wants Waylon to have access to the whole marijuana plant, even if it has risks. Cordle said it's difficult as a parent not to hope for a miracle cure - like the widely circulated story of 6-year-old Charlotte Figi seeing her seizures drop from 300 a week to three, giving her name to Charlotte's web. She said Waylon takes 47 pills a day, pills that make him sweat, that give him diarrhea, that put him at risk of kidney stones or that promote early onset osteoporosis. "I'm not afraid of doing a trial and error," she said, "because every seizure medication you put your child on is a trial and error."

April 18, 2016

Julie Carry Smyth, The Associated Press

http://www.ctvnews.ca/health/medical-pot-activists-fear-epilepsy-drug-could-undercut-them-1.2863573

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### IBM Teams With Australian Researchers for Smart Brain System for Epilepsy

Scientists are looking for smarter ways to stop and prevent seizures, and now, IBM is joining the effort. The company is working with neurologists in Australia to develop a computing system that can analyze brain waves to stave off epilepsy. IBM researcher Stefan Harrer and a team at the University of Melbourne are building a system with a neural network, or computer software that mirrors the web of neurons in the human brain, Wired reports. The network, which works similarly to those used by Facebook to identify photos and Androids to recognize commands, reads brainwaves to learn how to flag epilepsy.

"We're trying to extract all the meaningful information from all the background noise. We want to be able to detect a specific seizure for a specific patient," Harrer told the magazine. Harrer and the team run the neural network on an experimental IBM chip called TrueNorth. Unlike other neural networks, which usually run across many machines in large computer data centers, TrueNorth is flexible. It doesn't require much power and could eventually run on a laptop, tablet or phone.

Eventually, the chip could lead to a device that works with a brain implant to monitor for seizures 24/7 and notify patients before they happen. "That's the only way this technology will have an impact beyond cool research papers," Harrer said, as quoted by Wired. The system grew out of research from a previous study at the University of Melbourne. Scientists there collected data from a less complex implant that took EEG readings from epilepsy patients over three years. Now, Harrer and his team are using the data to train their neural network.

Even though a seizure warning system is still years in the making, Harrer and University of Melbourne researchers are optimistic about its prospects. In the future, the system could even prevent seizures entirely by detecting them at onset and sending out electrical impulses to stop them.

"Our aim is to replace broken neural systems with machines--machines that can interact with the brain in a very natural way," Dean Robert Freestone, a senior research fellow at the University of Melbourne, told Wired.

April 11, 2016 Emily Wasserman

http://www.fiercemedicaldevices.com/story/ibm-teams-australian-researchers-smart-brain-system-epilepsy/2016-04-11

### Harrison Ford's Han Solo Jacket Sold For \$191,000 In Aid of Epilepsy Charity

The leather jacket worn by Harrison Ford's character Han Solo in the Star Wars films has been sold at auction for \$191,000 to benefit an epilepsy charity.

Ford, who made his final appearance as Han Solo in "The Force Awakens" last December, autographed the jacket he wore in the film and put it up for auction.

The jacket was listed as a 'custom-made, one-of-a-kind leather jacket worn by Han Solo in "Star Wars: The Force Awakens" and signed by Harrison Ford'. The Indiana Jones star recently revealed his daughter, 26 year-old Georgia Ford, has epilepsy. He said: "When you have a loved one who suffers from this disease, it can be devastating. You know how it affects their lives, their future, their opportunities and you want desperately to find mitigation. You want to find a way that they can live a comfortable and effective life."



April 12, 2016 Olivia Rzadkiewicz

https://www.epilepsysociety.org.uk/News/Harrison-Fords-Han-Solo-jacket-sold-for-%24191%2C000-in-aid-of-epilepsy-charity-13-04-2016#.VyD3Bjf2aM8

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#### Epilepsy Patients Sleeping on Stomach Face Sudden Death Risk

Epilepsy patients who sleep on stomach face sudden death risk similar to SIDS (sudden infant death risk), according to research. Study author Dr. James Tao said, "Sudden unexpected death is the main cause of death in uncontrolled epilepsy and usually occurs unwitnessed during sleep."

Among epileptics, the risk of death while asleep is highest among patients with tonic clonic seizures. The researchers reviewed 25 studies, which included 253 sudden deaths. Body position during sleep was recorded. The researchers found that 73 percent of sudden deaths occurred in individuals sleeping on their stomach, and the remaining 27 percent accounted for other sleep positions.

Looking at a subgroup of 88 study subjects, the researchers found that individuals under 40 were four times more likely to sleep on their stomachs at the time of sudden death. Tao added, "We're not sure why this was more common in younger people. It may be that they are more likely to be single and not have anyone with them during a seizure while sleeping."

"Similar to infant SIDS cases, adults often have an impaired ability to wake up after a seizure, especially a general seizure. Our findings highlight an important strategy for preventing sudden unexpected death in epilepsy — that 'back is best'. Using wrist watches and bed alarms designed to detect seizures during sleep may also help prevent these deaths," Tao concluded.

#### Change in heart activity may reveal epilepsy

Epilepsy has long been known as a brain disorder, but researchers at Case Western Reserve University also found that changes in heart activity can reveal seizures, too. Senior author Roberto Fernández Galán said, "All the findings of our study on heart rate variability in epilepsy point to increased activity in the parasympathetic nervous system during sleep. But we don't know if this abnormality compensates for epilepsy, coincides with the disease, or is part of the etiology."

The researchers found that children who were deemed neurologically normal but had strong breathing modulations (similar to those seen in epileptic children) and low heart rates were later diagnosed with epilepsy. The researchers looked at 91 children and adolescents with generalized epilepsy and 25 neurologically normal children during 30 minutes of light sleep. The researchers uncovered that respiratory sinus arrhythmia – the increase in heart rate when breathing in and decrease when breathing out – was more pronounced in epileptics, and that their heart rate also was significantly lower. There was also no difference in blood pressure between the two groups of children, which indicates that the part of the nervous system responsible for fight-or-flight response was not involved.

The researchers discuss the possibility of using medications to control the autonomic nervous system as a means of treating epilepsy. Undergraduate researcher Siddharth Sivakumar added, "This may be a key contributing factor. The heart rate and breathing decline dramatically after a seizure. If they are already low, and are then lowered further, that may cause a child to go a minute or more without a breath or pulse." Adult treatment for epilepsy involves the implantation of an electrode to stimulate the vagus nerve, which stimulates the brain. Galán cautions that this method should not yet be used on children despite his findings.

April 8, 2016 Devon Andre

http://www.belmarrahealth.com/epilepsy-patients-sleeping-on-stomach-face-sudden-death-risk-study/

### **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



# **Our Programs and Services**



- ◆ Free "Kids on the Block" puppet presentations that educate children (and their teachers, administrators, caregivers, and group leaders) about kids with Epilepsy in an entertaining manner;
- ♦ Free specially-tailored In-services about Epilepsy to schools, businesses, group homes, Public Service bodies, Colleges, etc. (includes annual training for NAIT EMT students and ETS Supervisors and Security Personnel, and on-line information about Epilepsy on the EPS Training System)
- ♦ Twice-yearly no-cost Epilepsy Educational Forums, both of interest to Health Care Professionals as well as the General Public;
- ♦ Free provision of our series of 12 Epilepsy Education Information booklets to Members, Hospitals, Clinics, Neurologists' Offices and Pharmacies;
- ♦ Website, print and video information about Epilepsy, and a free lending library for members;
- ♦ Bi-monthly newsletter for Members that includes the latest current medical information available about Epilepsy, as well as current news about the Association and our services and events;
- ◆ Scholarship Program for Post-secondary Students with Epilepsy (minimum two scholarships a year);
- ♦ Garry Hannigan Memorial Life Enhancement Scholarships for Youth, to assist young people (up to the age of 18) to participate in sports, arts, cultural or recreational activities that will enhance their development as individuals;
- ♦ No-cost Counselling on Epilepsy-related problems for people with Epilepsy and families of people with Epilepsy, with referrals to other supporting Agencies as needed;
- ◆ Monthly group sessions geared toward Adults with Epilepsy and concerned family members;
- ♦ Information and support for Parents/Caregivers of Children with Epilepsy;
- ♦ No-cost provision of assistance/advice on diverse matters, including, but not limited to, finding employment, driving and Epilepsy, potential side-effects of medication, and dealing with the complexities of Government forms and applications (AISH, Disability, housing subsidy, etc);
- No-cost advocacy on behalf of people with Epilepsy experiencing discrimination or other problems;
- ♦ No-cost social and recreational activities for Members that help reduce social isolation, free ETS Bus Training, and free "Donate-a-Ride" Program bus tickets for Members in need;
- ♦ An annual no-cost in-house Collective Kitchen Cooking Training Program and annual in-house Computer Training Programs for Members;
- ♦ Ongoing recruitment and screening of quality Volunteers, annual recognition of all Volunteers, and annual award of Member-nominated Volunteer-, Achiever-, and Employer-of-the-Year Awards.



Edmonton Epilepsy Association 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...