

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

March

Collective Kitchen #3

Thursday, March 12, 12:30 - 3:00 pm EEA Office

(program registration required)

Annual General Meeting

Thursday, March 19, 5:45-8:00 pm St. John Ambulance Bldg

Fun BINGO for Prizes

Friday, March 20, 1:00 – 3:00 pm EEA Office

Easter Passion Play

Sunday, March 29; 2:15-4:30 Millwoods Assembly 2225 - 66 Street NW (pre-registration required)



April

Computer Training Program

Wednesdays, April I, 8, 15, 22; 1-2:45pm EEA Office

(program registration required)

Collective Kitchen #4

Thursday, April 9, 12:30 - 3:00 pm EEA Office

(program registration required)

Managing Your Money

Saturday, April 11; 1:00 - 3:30 pm EEA Office

(pre-registration required)

Fun BINGO for Prizes

Friday, April 24, I:00 – 3:00 pm

EEA Office

FREE MEMBER ACTIVITIES



Easter Passion Play Sunday, March 29; 2:15 - 4:30 Millwoods Assembly, 2225 - 66 Street NW

Managing Your Money Saturday, April 11; 1:00 - 3:30 pm EEA Office



Transportation to Member Activities is not provided when public transit is available. EEA Office staff would be happy to assist you with transit travel planning if needed.

2015 EEA ANNUAL GENERAL MEETING and Volunteer Recognition Event

When: Thursday, March 19th 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

be your own boss

THE CHRONIC CONDITION SELF-MANAGEMENT PROGRAM FOR YOUTH

Next "Be Your Own Boss" Program for Youth Starting Soon!

See page 3 for details.

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, March 11, 2015

Wednesday, April 8, 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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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



St. Albert's 15th

Mayor's

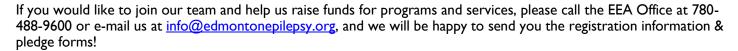
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Roy Financial

Do You Love to Run or Walk? Then Join Team EEA!

Kim Mahe, Registered Nurse of the ACDC Clinic at the Glenrose Hospital is organizing "Team EEA" to participate in St. Albert's 13th Annual Roy Financial Mayor's Walk for Charity, on Saturday, April 25, 2015.

- 100% of the pledges you collect will come back to the EEA, who will issue tax receipts to your donors.
- After the event, Team EEA participants will enjoy a free hot dog lunch and other goodies
- Team EEA members will get a specially-logo'd shirt
- Participants can walk (3km) or run (5km).
- Walk begins at 10:00 am
- The event is open to participants of all ages.
- There is no registration fee.



If you are not able to walk or run yourself, but would like to pledge towards our participation in this event, please contact the EEA Office and we will put you in touch with a registered participant who will be happy to accept your pledge.



Lighting Edmonton's High Level Bridge

We're turning the High Level Bridge purple to celebrate Purple Day 2015! March is Epilepsy Awareness Month and March 26th is Purple Day. 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.

be your own boss

THE CHRONIC CONDITION SELF-MANAGEMENT PROGRAM FOR YOUTH

If you are a youth or young adult aged 14-20 and live with one or more chronic conditions, you probably face many challenges. Alberta Health Services, in partnership with the EEA, is offering a free six-week workshop series on planning for everyday living.

April 16, 23, 30, May 7, 14, 21 Thursdays, 4:30-7:00 pm. Edmonton Epilepsy Association, 11007 - 124 Street Supper Provided for All Participants

In a supportive environment with young people like you, you will learn:

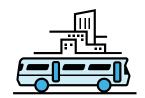
- · how to look after your condition and the various requirements associated with having a chronic condition
- · how to carry on with school, homework, activities, social life, and relationships with friends and family
- how to handle the difficult emotions and stresses that come with living with a chronic condition

Contact 780-488-9600 or info@edmontonepilepsy.org to register.

Detailed flyer available on EEA website.

Bus Tickets Available for Members in Reduced Circumstances

We currently have no tickets from our 2014 allotment available in the EEA Office. We expect to receive our 2015 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.







Special Lenses for Photosensitivity Available Locally



About 5% of people with epilepsy have an increased sensitivity to flickering light or quickly changing light patterns. During photic stimulation, their EEG shows a marked epileptic response. We have become familiar with epileptic seizures triggered by television, video games, and visits to venues which use strobe light effects. Some years ago, thousands of people in Japan, most of them teenagers, experienced their very first seizure when watching a commercial consisting of a rapid sequence of alternating light and dark scenes.

Some people have only photosensitive seizures; other people have more complicated types of epilepsy involving other seizure types in addition to their photosensitivity. Other than avoiding light stimulation altogether, the following simple recommendations may be useful:

- Maintain a proper distance from the TV screen and use a remote control.
- Watch TV in a well-lit room and turn the contrast down.
- Close or cover one eye when exposed to a light stimulus that may trigger a seizure.
- Watch only small screen TVs or monitors. Larger screens have a stronger light intensity, and the linear raster pattern of the picture is more likely to trigger photosensitivity.

Light stimuli caused by sunlight reflected off of water or the strobe effect that occurs when driving along a row of trees on a sunny day are more difficult to avoid. Dark polarizing sunglasses reduce the light intensity but not the flash frequency or the frequency spectrum of the light. Some photosensitive people with epilepsy require medication to avoid light induced seizures.

Valproate and Lamotrigine can prevent these seizures in 60% of people with photosensitive epilepsy. However, medications do have side effects and carry a financial burden.

A Canadian-first initiative of well-known Edmonton Epilepsy Specialist, Dr. Elout Starrveld, in 2006-2007, in concert with Spruce Grove optician Rick Pidwerbeski, saw them import Zeiss ZI blue lenses from Europe for testing in a pilot project in the EEG laboratories at the Royal Alexandra Hospital and the Hys Centre.

Individuals who suffered from Photosensitive seizures underwent proper EEG testing with Photic Stimulation in order to ascertain the benefit of these special lenses to their particular situations.

The project concluded that the ZI lens is very effective in controlling photosensitive seizures and is a valid resource in the management of patients with epilepsy. The ZI blue lenses reduce the light intensity and filter out certain light frequencies. This may, however, limit the lenses' practicality in darker environments.

These ZI lenses, in both single-vision and multi-focal lens options, are now commercially available in the Edmonton area from Spec Tacular Optical, 322 MacLeod Avenue in Spruce Grove, 780-962-9208, or

Optometrists' Clinic Inc. in Edmonton, 780-488-0944. Norm at this Optometrists' Clinic office is available to assist customers from both in and outside Edmonton.



Vancouverite Raises \$1200 for EEA



Last spring we were contacted by a young woman, Jess Smith, from Vancouver. Jess explained that her brother, Dylan, is from the Edmonton area and lives with epilepsy. Wanting to honour Dylan's determination and spirit, Jess decided to challenge herself and, in the process, raise money for the Edmonton Epilepsy Association. Jess tells her story:

"A few years ago my brother Dylan was diagnosed with epilepsy. Due to both the "illness" and the heavy medication he needs to take, he has extreme fatigue. But he has never allowed this to stop him from what he wants to do. Growing up he was an "extreme" kid. Dirt-biking, snowboarding, BMX biking, etc. were all a part of his childhood and STILL are a part of his life. He has options, he could feel "defeated" by his condition, but he instead chooses to conquer it mentally, spiritually, and physically every single day. After working 12 hours +, he still finds the strength to go to the gym every day for 1-2 hours. Dylan has found it in himself to conquer his body and mind. We all contain a insurmountable source of strength within ourselves, we just have to decide whether or not we want to use it. Dylan uses it.

My brother's determination inspires me and because of his dedication to his health and fitness, I decided I wanted to "test" myself, in his honour. What I decided to do was train and do a sprint triathlon here in Vancouver. I planned the route myself and did it alone. (Ikm swim, 20km bike and 5km run). A triathlon was something I always wanted to do and I realized nothing needed to stop me. Sometimes we build up ideas and create barriers in our minds, "I need to sign up for a race, it will cost money, etc. etc. "but no one ever said that we cannot just DO things the way we want to. I wanted to do a triathlon, so that is what I did, still following the guidelines of a professional triathlon but on my own terms.

I was walking down the street here in Vancouver one day and overheard a woman say to her friend, "you know, people pray to God for strength, but it's not strength that we need to ask Him for, it is courage. We all have strength. We need to ask God for the courage to use our strength." This moment changed my life. My brother is my reminder that strength is an unlimited resource inside of us, courage on the other hand is something we must cultivate. Dylan cultivates courage and because of this I found it in myself to do the same, in his honour and in the hope of bringing some money to a program that can bring this awareness to others."

Thank you, Jess!

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"Beyond Epilepsy" in Africa



Thursday Evening, May 14th - Hold the Date!

EEA will be hosting a special evening event in the Ballroom of the Chateau Lacombe on Thursday, May 14th.

Last year, the Edmonton Epilepsy Association, in partnership with the International League Against Epilepsy, piloted the "Beyond Epilepsy" Education, Awareness and Advocacy Program for heathcare workers in Tanzania. This year, Beyond Epilepsy expands to Zambia.

Due to the success of the Beyond Epilepsy Program pilot, Dr. Matt Wheatley (Epilepsy Neurosurgeon here in Edmonton) and Alex Stieda (first North American to win a yellow jersey in the Tour de France) will be riding in the Cape Epic Race in Cape Town from March 15-22 to raise awareness and funding for Epilepsy in Africa. Dr. Wheatley, Alex, Beyond Epilepsy/EEA and World Bicycle Relief have partnered to continue to increase awareness and treatment of those living with Epilepsy in Africa. The goal is to provide bicycles to healthcare providers in order to educate the public, treat patients and distribute medication to those living with epilepsy in rural Africa. Anthony Zimba, VP of the International Bureau of Epilepsy Africa and a clinician in Zambia will lead the implementation in Zambia where the bicycles are built and distributed.

The Cape Epic Race in March will provide international exposure to epilepsy awareness and for the team sponsors. The race will be broadcast throughout Africa, Europe and North America as one of the premier and largest cycling races internationally.

At our May 14th event you can meet Dr. Wheatley, Alex and other members of the "Beyond Epilepsy" team in a relaxed, congenial setting, enjoy quality entertainment, relive the highlights of the race, and help contribute to the purchase of "Buffalo" bicycles for Epilepsy healthcare workers in Africa.

The cost of attendance is our cost of a Buffalo bicycle, \$134.

For further information and to book tickets, contact the EEA office, 780-488-9600 or info@edmontonepilepsy.org.





Learn more about the 2015 Cape Epic Race at: https://www.cape-epic.com/

What Matt & Alex Will Be Wearing in Africa



The \$134 Miracle Bike

200 LB.

The maximum capacity of the Buffalo's integrated rear rack. Its weighted kickstand allows easy loading of goods; fenders and a chainguard protect riders from grease, mud, and rain—especially useful on unpaved roads.

59%

Boost in academic performance among students in Zambia who received a bike. Attendance increased 27 percent.

5 X

Increase in load one can carry on a Buffalo bike compared with walking. Farmers can haul more products to market, make more deliveries, and increase their family's income.

50 LB.

Weight of each bike. The Buffalo comes with punctureresistant tires and heavy-gauge rims. Most are black with a white buffalo emblem; bikes in South Africa are yellow; a few distributed by UNICEF are blue.



BICYCLING.COM



2015 Calendar of Member Activities



Date/Time	Activity	Remarks
March 19 th Thursday, , 5:45 – 8:00	EEA Annual General Meeting	St. John's Ambulance Building 12304 – 118 Avenue NW
March 20th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
March 29th Sunday, 2:15 - 4:30	Easter Passion Play	Millwoods Assembly 2225 66 St NW
April 11th Saturday, 1 - 3:30 p.m.	"Managing Your Money" course	EEA Office
April 24th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
May 9 th Saturday, 10:00am- 12:30pm	Trip to the Royal Alberta Museum	Royal Alberta Museum 12845 102 Avenue NW
May 29th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
June 14th Sunday, 2:30 - 5:00 pm	Trip on the Edmonton Queen Riverboat	Edmonton Queen Launch Site 9734 – 98 Avenue NW
June 26th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
July 12th Sunday, 1:00-4:00 pm	Visit to Ukrainian Cultural Village	Ukrainian Cultural Village, Transportation details TBA
July 31st Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
August 15th Saturday, 11:00 - 2:00 pm	Annual Family BBQ & Social	Social Room, ACT Centre, Rundle Park
August 28th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
September 13th Sunday, 1 - 4 p.m.	Visit to the Devonian Gardens	Devonian Gardens Transportation details TBA
September 25 th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
October 23rd Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office
October 31 st Saturday, time TBA	Hallowe'en Lunch	Midnight Sun Restaurant 11003 124 Street NW
November 27th Friday, 1 - 3 p.m.	Fun BINGO	EEA Office
November 29 th Sunday, 1:00 – 3:00 pm	Visit to the Festival of Trees	Shaw Conference Centre
December 12th Sunday, 12:00 - 3:00 pm	Annual Christmas Lunch & Social (Polish ethnic theme)	Central Lions Seniors Centre
December 18th Friday, 1:00 – 3:00 pm	Fun BINGO	EEA Office

Please Note: Activities, Dates, Times, and Remarks subject to change - always check your latest newsletter for exact details. Advance registration required for many activities. If you are interested in participating in any event please contact the office to register.

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Telus World of Science - February 2015





















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



<u>Central</u> Royal Pharmacy Ground Floor, 11010-101 Street 780-426-0872



Epilepsy News From Canada



Canadian Epilepsy Alliance Welcomes Drug Shortages Announcement

Vancouver, February 10th 2015 - Canadian Epilepsy Alliance members joined Federal Health Minister Rona Ambrose today as the Minister announced that Canadian pharmaceutical manufacturers will now be required to provide notice of shortages of their drugs. Currently the drug shortage notification is voluntary.

"This is a major step forward for people living with epilepsy, and other diseases and disorders who require ongoing access to their medications," said Deirdre Floyd, President of the Canadian Epilepsy Alliance. "It's terrifying when someone living with seizures goes to the pharmacy to refill their prescription only to find out there is a shortage. It has happened too often in recent years to too many people who can't miss their medication, and hopefully this will help to address shortages in the future."

"On behalf of the 300,000 people across Canada living with epilepsy, I want to thank Minister Ambrose for implementing this change to the Federal health regulations. I also wish to thank the Members of Parliament, from every party, who have supported past efforts to ensure the safety of people who require ongoing medications."

"Today's announcement won't end drug shortages," continued Floyd. "That will require further efforts on the part of government and industry to react when a shortage is anticipated. What today's announcement does mean is that individuals and families have a real opportunity to prepare in times of anticipated crisis." Minister Ambrose's announcement comes after years of work on the part of the Canadian Epilepsy Alliance and other organizations, raising the issue of drug shortages with Federal regula-

tors and Parliamentarians. The voluntary notification system, where manufacturers may provide information on an industry administered website, has often seen shortages not reported until patients discover the shortage on their own.

This is especially dangerous for individuals living with epilepsy where an interruption in their medication can result in serious adverse effects or even death. It is hoped that with mandatory notification, individuals can work with their physicians and pharmacists to ensure an adequate supply of the medication they require.

Nathalie Jette, President of the Canadian League Against Epilepsy, was also encouraged by the announcement and congratulated members of the Canadian Epilepsy Alliance for their efforts in bringing this important healthcare issue to government. "Mandatory reporting of drug shortages is critical for those with epilepsy as it is unsafe to stop antiseizure medications abruptly. This new policy will enhance the likelihood of ongoing safe care for those with epilepsy who already have to deal with so much uncertainty related to their conditions."

Said Floyd, "This is an important decision for Canada's epilepsy community."

Watch Minister Ambrose's announcement: <a href="http://www.ctvnews.ca/video?clipId=548376&playlistId=1.2229532&binId=1.810401&playlistPageNum=18binPageNum=1.810401&playlistPageNum=1.810401&playlis

The EEA is a member of the Canadian Epilepsy Alliance

Epilepsy News From Around the World

New Study Highlights Benefits of Depression Screening in Paediatric Epilepsy

Paediatric epilepsy patients could receive better mental health care and experience quality of life benefits through the more widespread use of depression screening services, according to a new study.

Carried out by the Cincinnati Children's Hospital Medical Center in the US, the study examined whether or not proactive behavioural medicine screening processes could facilitate the identification of depressive symptoms and necessary interventions among children in this category, thereby helping to optimise behavioural health and health-related quality of life.

For this study, children with epilepsy between the ages of seven and 17 years of age and their parents were asked to fill out questionnaires as part of their routine clinic care over a 24-month period. A chart review was conducted to ascertain demographics, medical variables and behavioural medicine visits and recommendations.

Of the 311 study subjects, elevated depression was observed in 23 per cent of cases, with the severity of the mental health issues affected by factors such as antiepileptic drug usage and age.

According to results published in the journal Epilepsy & Behavior,

health-related quality of life was shown to be worse among those with depression, even when differences in seizure status were taken into account.

However, it was also revealed that depression scores tended to decrease over time, particularly among those referred for behavioural medicine services, suggesting that proactive diagnosis and treatment of mental health issues is important to the overall wellbeing of young patients.

The researchers concluded: "Systematic assessment and early detection of depression and/or suicidal ideation in youth with epilepsy can improve health-related quality of life and decrease depression. Depression screening can be implemented through clinic-based behavioral medicine services."

Although epilepsy can be diagnosed at any age, it most frequently presents itself for the first time during childhood. It can be a challenging condition for young people and their families to cope with, meaning that efforts to look after their mental as well as their physical health should be considered a priority.

Feb 4 2015

http://www.epilepsyresearch.org.uk/new-study-highlights-benefits-of-depressionscreening-in-paediatric-epilepsy/

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Epilepsy News From Around the World



World Health Organisation in New Global Commitment to Tackle Epilepsy

commitment to tackle epilepsy on a world-wide basis. A new resolution to prioritise epilepsy care in a coordinated way around the world was approved by the Executive Board of the World Health Organisation (WHO).

The resolution received strong support and calls on member states of WHO to take action to tackle epilepsy care. It places equal importance on both medical care and the social aspects of living with epilepsy. It also focuses on everyone epilepsy impacts on including people with epilepsy and those who care for them.

As part of the resolution, it has been suggested that WHO should put together plans and documents which member states can use to implement the actions set out in the resolution.

The Executive Board, which approved the resolution, is made up of 34 health professionals from each member state. Given members' specialist knowledge it is able to give direction to the priorities, decisions and policies of WHO. Its recommendation for the resolution will be submitted to a meeting of WHO's General Assembly in May.

Yesterday marked a huge step forward in getting an international Twenty-eight countries spoke in support of the resolution and suggestions were put forward to strengthen the resolution. Some of the statements from members states were extremely strong and supported the need for improved healthcare services and measures to reduce stigma and discrimination.

> Philip Lee, chief executive of Epilepsy Action, said: "This new resolution is excellent news for people with epilepsy across the world. It will highlight the impact of epilepsy and the action needed at a country level to tackle the health and social problems associated with the condition.

> "Epilepsy Action is a member of the International Bureau of Epilepsy (IBE) and collectively we have supported the need for this resolution to ensure that the voice of epilepsy is heard across the globe."

> > February 3, 2015

https://www.epilepsy.org.uk/news/news/world-health-organisation-new-globalcommitment-tackle-epilepsy-64447



Medical Pot for Children's Epilepsy Still Remains Unproven

For parents hoping that medical marijuana extracts would be the One of the problems with this study is that it relied on parents' magic bullet for their children's epilepsy, the jury is still out. The first study results were announced in Seattle Monday, with mixed findings.

For most of his life, Jace Bratten had seizures like this every night.

Doctors tried 17 different drugs, but the side effects were often worse than the symptoms.

"One drug when Jace was a little guy it caused him so much rage and anger that he ground his baby teeth to the gums. To the gums," said Mike Bratton, Jace's father.

Then the family heard about a medical marijuana extract called CBD. It's doesn't produce a high and within two and a half months his dad says Jace went from nightly seizures to one every three weeks.

"It's not like a light switch. It's a gradual reawakening," said Mike Bratten.

Now the first study results about CBD are in from the state with the most experience, Colorado, but findings are mixed. Families who moved there for the sole purpose of getting the extract for their kids were three more times to believe it was working.

"That was surprising to us that all of these families that we didn't have much of an interaction with previously were reporting these great results. Whereas the families that we had been following for quite a while and had good relationships with weren't reporting that same benefit," said Dr. Kevin Chapman, University of Colorado.

reporting and no standardized dose of the extract.

"I often times tell families it's often liked different strains of grape in making wines, so there's a wide amount of CBD in these different preparations," said Dr. Chapman.

That's why doctors like Kevin Chapman are reluctant to recommend CBD until more rigorous randomized trials can be conducted.

Dr. Orrin Devinsky is working with a purer form called cannabidiol, which will soon begin human clinical trials.

He believes there is a place for oral medical marijuana in the most severe cases of epilepsy, but wants parents to be cautious.

"They need to at the same time demand scientific evidence whether we are helping children, whether we are harming children and probably to what degree we're doing both," said Dr. Devinsky.

One recommendation researchers do have for parents who choose to go ahead with this therapy is to be open about it with their child's doctor.

These study results were reported Monday afternoon at the American Epilepsy Society's annual meeting in Seattle. The first rigorous clinical trial will start in January for children with Dravet Syndrome, a rare and one of the most severe forms of epilepsy.

> December 8, 2014 Link to video report:

http://www.king5.com/story/news/health/body/2014/12/08/medicalpot-for-childrens-epilepsy-still-remain-unproven/20119553/

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Epilepsy News From Around the World





Omega-3 Fish Oil 'could reduce seizure frequency for epilepsy patients'



Aproximately 2.3 million adults and around 470,000 children in the US have epilepsy, a lifelong neurological condition characterized by recurrent seizures. Now, a new study claims epilepsy patients could reduce seizure frequency by consuming low doses of omega-3 fish oil every day.

The research team, led by Prof. Christopher DeGiorgio of the Department of Neurology at the University of California-Los Angeles (UCLA) School of Medicine, says their findings may be particularly useful to epilepsy patients who no longer respond to medication.

They publish their findings in the Journal of Neurology, Neurosurgery & Psychiatry.

Omega-3 fatty acids can be obtained through consumption of oily fish - such as a trout, mackerel, tuna, herring, sardines and salmon - and fish oil supplements.

Past studies have indicated omega-3 can stabilize heart rhythm and prevent heart attacks. Prof. DeGiorgio says this is important for individuals with epilepsy, since they are at higher risk of heart attack than those who do not have the condition. Furthermore, the team notes that omega-3 has been linked to reduced brain cell excitability among epileptics, which may curb seizures.

However, they point out that previous studies looking at such associations using high-dose fish oil have been inconclusive. As such, the team set out to determine the effects of high-dose and low-dose fish oil on the cardiovascular health and seizure frequency of epileptic patients.

Low-dose fish oil supplementation 'reduced seizures by more than 30%'

For their study, the researchers enrolled 24 participants with epilepsy who had stopped responding to antiepileptic medication

Each patient was subject to three different supplementation regimes, each of which lasted for 10 weeks and were divided by a 6-week period. These were:

- Low-dose fish oil supplementation: three fish oil supplements daily - the equivalent of 1,080 mg of omega-3 - plus three placebo supplements (corn oil)
- High-dose fish oil supplementation: six fish oil supplements daily - the equivalent of 2,160 mg of omega-3

• Three placebo supplements twice a day.

The researchers found that the fewest number of seizures occurred - 12 a month - when participants were following the low-dose fish oil regime, compared with 17 a month on the high-dose regime and around 18 a month for the placebo regime.

This means the low-dose regime represented a 33.6% reduction in seizures.

The team also found that two of the patients following the low-dose fish oil regime had no seizures at all during the 10-week trial, while none of the patients taking high-dose fish oil or placebos were seizure-free.

Furthermore, blood pressure fell by 1.95 mm/Hg among patients following the low-dose fish oil regime, while high-dose fish oil was linked to an increase of 1.84 mm/Hg in blood pressure. The team notes, however, that they found no link between fish oil and severity of seizures, changes in heart rate or blood lipid levels.

Commenting on their findings, the researchers say: "The primary finding is that low-dose fish oil was associated with a reduction in seizure frequency of 33.6% compared with placebo. Though the size of the trial will require confirmation, the magnitude of the effect on seizure frequency is similar to many randomized trials of antiepileptic drugs.

The reduction in blood pressure indicates that low-dose fish oil may exert a positive cardiovascular benefit in this cohort with drug-resistant epilepsy, a finding of some importance, given the recent data that the risk of death due to myocardial infarction is significantly higher in people with epilepsy."

Prof. DeGiorgio and his team admit, however, that their study is subject to some limitations. For example, they note that exposure to each of the supplementation regimes was relatively short, therefore it is unknown as to whether low-dose fish oil sustained reduced seizure frequency.

They conclude that a large, randomized controlled trial of the effects of fish oil on epilepsy is warranted in order to confirm their findings.

September 9, 2014 Written by Honor Whiteman http://www.medicalnewstoday.com/articles/282192.php

US Scientists Discover Novel Compound That Curtails Temporal Lobe Epilepsy

Scientists in the US have discovered a novel compound that curtails temporal lobe epilepsy, a form of the condition traditionally thought to respond only to neurosurgery.

Researchers at Louisiana State University studied the onset of temporal lobe seizures in mice, noting that small 'microseizures' often occured in the run-up to an epileptic episode.

Published in PLOS ONE, their report described the effects of systematically administering Neuroprotectin D-I, or NPDI, as a means of regulating this anomolous electrical activity in the brain.

The scientists found that the compound – derived from an essential omega 3 fatty acid found in fish oil – effectively reduced

both the aforementioned microseizures and spontaneous recurrent seizures.

"These observations will contribute to our ability to predict epileptic events, define key modulators of brain circuits ... and therapeutic approaches for epileptogenesis," commented coauthor Dr Nicolas Bazan.

According to the Epilepsy Foundation, temporal lobe epilepsy accounts for approximately 60 per cent of all patients with the condition.

Jan 30 201.

http://www.epilepsyresearch.org.uk/us-scientists-discover-novel-compound-thatcurtails-temporal-lobe-epilepsy/

Page 10 Focus on Epilepsy



Epilepsy News From Around the World



Prone Position Linked to Epilepsy Sudden Death Risk

Around three-quarters of patients who have a sudden unexpected death in epilepsy (SUDEP) are found lying in the prone position, show meta-analysis findings.

The meta-analysis confirms results from previous case series and suggests that SUDEP may have similar mechanisms to sudden infant death syndrome (SIDS), say James Tao and study coauthors, from The University of Chicago in Illinois, USA.

From 25 publications, the team identified 253 cases of SUDEP where the body position was recorded. Among these, 73.3% of patients died in a prone position and 26.7% in a non-prone position, they report in *Neurology*.

In an accompanying editorial, Barbara Dworetzky (Harvard Medical School, Boston, Massachusetts, USA) and Stephan Schuele (Feinberg School of Medicine, Chicago, Illinois, USA) say: "Discovering a possible modifiable risk factor for SUDEP, such as sleeping in the prone position, is clearly important because it implies the possibility of preventing a substantial number of deaths by having patients sleep on their back".

In a subanalysis of patients with available demographic data, dying in the prone position was most likely among patients aged 40 years or younger, at 85.7% compared with 60.0% in older patients. The likelihood of being found in the prone position did not vary according to gender and whether patients were asleep or awake at the time of death.

Of note, the researchers identified II cases of SUDEP that occurred during video-electroencephalography (EEG) monitoring.

All of these patients died in the prone position, and all had generalised tonic-clonic seizures and postictal generalised EEG suppression (PGES).

"Given that these monitored SUDEP cases have been randomly reported over a period of 25 years, these commonalities cannot be simply a matter of chance", write Tao et al. "Instead, they likely reflect a common mechanism."

They add that PGES is likely to be an EEG marker of impaired arousal, strengthening the similarities to SIDS.

In their editorial, Dworetzky and Schuele note the limitations of the research, including not knowing the predominant final body position of patients after surviving a generalised tonic–clonic seizure, and whether SUDEP patients frequently sleep in a prone position or move into one during a seizure.

"However, the study underlines that simple measures may have a substantial effect on SUDEP risk and that our efforts to attend to patients and bring them out of a prone position are worthwhile", they conclude.

Ianuary 29, 2015

http://www.medwirenews.com/44/106132/General neurology/Prone position linked to epilepsy sudden death risk.html



Proxy Reports 'more accurate for assessing cognitive function in epilepsy patients'

Asking epilepsy patients to evaluate their own cognitive functioning may be a less accurate method of assessment than seeking proxy reports provided by relatives.

This is according to a new study from Germany's Technische Universitat Dresden, which aimed to address the problem that self-reporting of cognitive deficits by patients with epilepsy is often poorly correlated with objective test performances, but highly related to mood and personality.

As such, the researchers asked 34 patients and 29 close relatives to fill in a questionnaire about everyday cognitive deficits of the patient, to see whether or not information obtained by family members showed a higher correlation with the subjects' actual test scores, thus making them a useful complementary measure for ensuring a reliable basis for diagnostic decision-making.

In addition to the questionnaires, patients were also asked to complete a neuropsychological test battery to help build an accurate picture of their memory, attention and executive functioning, while the subjects were also asked to fill out surveys on their levels of anxiety, depression and neuroticism.

According to results published in the medical journal Epilepsy & Behavior, the self-reports generated from patients showed no

significant correlation with any neuropsychological measures of memory and only a small subset of the objective measures of attention and executive functioning.

Further regression analyses revealed that patients' self-assessment was heavily influenced by their levels of depression, anxiety and neuroticism, suggesting this could be a reason why their perceptions are often skewed.

By contrast, the correlations between relatives' reports and patients' actual test performances were highly significant across all examined domains.

The researchers concluded: "These results point out the risk of self-reports distorting reality and additionally recommend consulting a close relative of the patient to ensure reliable information about the patient's everyday cognitive functioning."

This study offers further evidence that any effective approach to managing and treating people with epilepsy needs to take into account and fully involve the support that family members can provide.

Feb 5 2015

http://www.epilepsyresearch.org.uk/proxy-reports-more-accurate-forassessing-cognitive-function-in-epilepsy-patients/



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.



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