



Epilepsy Association Newsletter

October 2013

Epilepsy Association of Oklahoma
711 Stanton L. Young Blvd. Suite 550
OKC, OK. 73104
Phone: 405-271-3232
Fax: 405-271-3366
Email: epilepsy-ok@prodigy.net
Website: www.okepilepsy.org

SUDDEN UNEXPECTED DEATH IN EPILEPSY

Talking About Sudden Unexpected Death in Epilepsy (SUDEP), nobody really wants to talk about this process. It is a really hard subject to talk about for anyone. Especially for people with epilepsy or loved one that suffers from epilepsy. However, it is important to learn about it because that is the first step to understanding it. Once we understand it, it can be less scary. In June 2012, Partners Against Mortality in Epilepsy (PAME) held its first three-day conference devoted predominantly to Sudden Unexpected Death In Epilepsy (SUDEP), where clinical, basic science and patient/family attendees came together to understand and support each other was a great success. This was a joint effort of SUDEP Coalition

production by the American Epilepsy Society. The next conference is planned for June 19-22, 2014 in Minneapolis, MN. Blue Sky Broadcast teamed up with this conference in putting together a web seminar or webinar as they are called. A webinar is a live interactive presentation over the Internet. All you need is a computer with high speed Internet access and speakers. If you don't have speakers, you can access the audio through a toll-free number provided in the email. This webinar is going to make it so all of us can understand what sudden unexpected death in epilepsy is. During the webinar the presenters will discuss when and how nurses and doctors should ideally talk about SUDEP with a patient and their family. They will also discuss what people with epilepsy and their families should be asking their doctors, the important questions. Also included will be a review of what research studies say those living with epilepsy and their families want to hear from doctors about sudden unexpected death in epilepsy. A review the ethics of SUDEP disclosure will also be included. The presenters will also explore the perspective of those who are bereaved by the loss of a loved one to epilepsy and what information they believe should be disclosed. This will be the hardest part of the seminar but it is needed for learning. Participants will leave with a basic understanding of SUDEP and the knowledge about how and when to discuss SUDEP appropriately. Plenty of time will be left to answer your questions and the end of the webinar. The webinar will host:

Nancy Collins, MD
Associate Professor of Neurology
Chicago Medical School
Clinical Ethicist

Elizabeth Donner, MD, FRCPC
Faculty of Medicine University
Toronto Pediatric Neurologist
Hospital for Sick Children
Co-Founder, SUDEP Aware

Date: October 23, 2013

Time:

Eastern: 3:00 PM

Central: 2:00 PM

Mountain: 1:00 PM

Pacific: 12:00 PM

For more information on this webinars and other webinars go to:

<http://www.aesnet.org/pame/>

For SUDEP FAQs go to: <http://www.aesnet.org/pame/Documents/SUDEPFAQs.pdf>

EAO WALK!

Come join us for the first ever Epilepsy Walk in Oklahoma!

Located at Bluff Creek Park

North of Lake Hefner at Hefner Rd. & Meridian

November 2, 2013

11:00AM - 2:30PM

1.5 Mile Walk

1st 300 people receive a goodie bag

Bring your dogs!

Bring your kids for this family event
and Support Epilepsy Awareness!

For more information visit:

<http://www.okepilepsy.org/index.htm>

We look forward to seeing you there!

http://okepilepsy.org/pdf/EAO_Charity_Walk_2013_11_17.pdf

THANK YOU!

I would like to personally thank the State of Oklahoma.

From the kind hearts of Oklahoman's to Madison's special need of a seizure dog...they raised over \$13,000.

Here are the results of your kindness.

Stella is a 18 m/o Long Haired German Shepard,

She has had her for 1 week and is all ready hitting on her seizure activity at night.

God Bless You All!

MADISON AND STELLA



MUSIC FOR A GOOD CAUSE

What if the time you spent practicing your instrument could be turned into money for a good cause??

At Ivory 'N Ovation, that's what we are doing. Beginning September 9, each piano student will be asking friends and family to sponsor them per day of practice. The students will keep track of their practice and keep a record each week of the amount of practice and money earned from their sponsors. Not only will the students improve their piano skills, but they will also be raising money for a good cause. What is our cause? The Epilepsy Association of Oklahoma. Since 1978, the Epilepsy Association of Oklahoma has been incorporated as a nonprofit health agency with the mission of helping Oklahomans who have epilepsy and their families. Epilepsy affects over 3 million Americans of all ages-more than Multiple Sclerosis, Cerebral Palsy, Muscular Dystrophy and Parkinson's Disease. Epilepsy has also affected a student in this piano studio. Historically, epilepsy research has been under-funded. Each year NIH spends \$30 billion on medical research, but just 1/2 of 1% is spent on epilepsy. This piano practice fund-raiser will continue from September 23 to December 9. If you do not know my students personally, but would like to give toward this

EPILEPSY STUDY

ADEPT CONSUMER TESTING

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Adept Consumer Testing, a National Market Research Firm, is looking for **Caregivers of individuals and Patients who have been diagnosed with EPILEPSY** to participate in a paid market research study.

These web-assisted telephone interviews will last approximately 60 minutes, between **Wednesday, October 9th and Friday, October 18th.**

A generous honorarium will be provided to all those that qualify and participate.

If you or someone you know is interested, please call us so we can ask the remaining **qualifying questions.**

We thank you for your interest!

Please call Nakia @ 800-233-7895 extension 379

All information will be kept confidential and will not be used or sold for any other purpose. Adept will always abide by HIPAA laws and will never share personal identifiable information

Market Research Focus Groups

If you would like to participate in this survey please contact

Nakia @ 800-233-7895 ext. 379

If you're accepted for this survey you'll receive a \$100 donation and you can donate it to the Epilepsy Association.

You'll receive a Thank You Letter and our Tax ID for your records.

Thank you for your help, much appreciated.

Sincerely,

Jenniafer Walters

SUPPORT GROUPS

Lawton OK-- contact: Christy Parker 580-351-0711 for more information

Norman OK--contact: Julie Rios (405) 590-3373 or Pat Sharp (405) 527-9886 located at Norman Regional Hospital at 901 North Porter - 3rd. Floor Conference Room 3rd Thursday of each month from 7-8 pm

Edmond/NW OKC--contact: Olivia Kavanaugh 405-919-4968 for more information

Tulsa OK--contact: Paul Elliot 480-321-5106 for more information

Ponca City OK--contact: Shirley Bracken 580-765-0003 for more information

Stigler OK-- contact: Kim Harvey 918-967-3902

For more information

<http://www.okepilepsy.org/supportgroups.htm>

EPILEPSY ACROSS THE SPECTRUM

While researching for books I came across one that really caught my eye. The book is titled "Epilepsy Across the Spectrum." It is seemingly a text book. I went and attempted to buy it and it was relatively pricey so I had to walk away from the purchase. I kept thinking about this book and how badly I wanted to read it. It contains in-depth information on epilepsy and how it can affect parents, children, and even the future of my own epilepsy. It seemed so fascinating that this book was able to have all of these answers for me. I ended up stumbling across a website that had most of the synopsis or overlay for the book. It was in-depth and gave me the answers I was looking for without even having to pick the book up. This website has statistics and science behind epilepsy that anyone can understand. I recommend you check it out. You might find the answer you have been looking for.

Website: <http://www.ncbi.nlm.nih.gov/books/NBK100608/>

If you would like purchase this book go to: http://www.nap.edu/catalog.php?record_id=13379 OR
<http://www.amazon.com/Epilepsy-Across-Spectrum-Promoting-Understanding/dp/0309259533>

SCAN MED QR

Please visit our website at [http:// www.okepilepsy.org](http://www.okepilepsy.org) for the latest technology and all the info. It's about SPEED, LIVES, and TIME for all ages. By going through our website and using our promo code your cost will be \$19.99. Pre-orders are going on now and shipments start second week of July. Promo Code is "EPILEPSYOK" don't forget to add it at checkout. For each profile made a donation will be given to Epilepsy Association of Oklahoma. Thank you for your support and Thank You Scan Med QR!

"REMEMBER CODE AT CHECK OUT"

"EPILEPSYOK"

It will save you \$10

SUGGESTIONS

If there is something you would like to see added to the monthly newsletter, email Olivia Kavanaugh at oliviakavanaugh@yahoo.com.

VOLUNTEER OPPORTUNITIES

Ever thought about volunteering? The Epilepsy Association of Oklahoma welcomes anyone looking for an opportunity to volunteer their time and services. You will be among a great group of people all working toward a great cause!

If you are interested, contact Jenniafer Walters by phone at (405) 271-3232 or by email: epilepsy-ok@prodigy.net.

UPCOMING EVENTS

November2:

10:00am 1st Epilepsy Walk Bluff Creek Park

And for More Information Visit Our Website/Events Calendar:

<http://www.okepilepsy.org/events.htm>

ALSO CHECK OUT OR FACEBOOK PAGE!

<https://www.facebook.com/OkEpilepsy>

Newsletter Contributors

Olivia Kavanaugh

Jenniafer Walters, President - Epilepsy Association of Oklahoma

and as always much help from Kevin Hill!

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Epilepsy Association of Oklahoma

711 Stanton L Young Blvd.

Suite 550

Oklahoma City, OK 73104

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