



STRONGER TOGETHER

News

MARCH, 2014

AN AFFILIATE OF THE EPILEPSY FOUNDATION



Seventh Annual Gala

“A Night in Paris”

April 12, 2014

Please join us for the 7th Annual Gala, “A Dazzling Revue,” this year featuring “A Night In Paris” with Circus Kaput. The event which benefits the Epilepsy Foundation of Greater Southern Illinois will be held on Saturday, April 12th at Bellecourt Manor in Belleville, IL. Josh Routh will be your emcee for the evening, which will feature various exhibition of skills by performers, acrobatic performances, and stunt oriented artists. In addition to the entertainment, the evening will include dinner, along with oral and silent auction prizes available for bid. Tables are available and being reserved, so please reserve your table(s) today. Tickets are \$50.00 per person, with tables of (8) available for \$400.00.

WHO: The Epilepsy Foundation of Greater Southern Illinois

WHAT: “A Night In Paris” with Circus Kaput/Dinner/Auction.

WHEN: Saturday, April 12, 2014.

WHERE: Bellecourt Manor in Belleville, IL.

WHY: To help stop seizures, find a cure, and overcome the challenges created by Epilepsy.

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NEWS is the newsletter of the Epilepsy Foundation of Greater Southern Illinois, a not-for-profit organization, serving individuals with seizure disorders and/or other disabilities.

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Hours of Operation:

Monday-Friday, 8:30 am – 4:30 pm

EFGSI encourages you to submit items of interest for future publications.

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EFGSI MISSION STATEMENT

“The Epilepsy Foundation leads the fight to stop seizures, find a cure, and overcome the challenges created by epilepsy.”

SUDEP Legislation in Illinois: A Milestone in Epilepsy Support, Awareness and Research

Following New Jersey, Illinois is only the second state to pass into law, required SUDEP (Sudden and unexpected death in epilepsy) reports.

The Illinois SUDEP Act took effect January 1, 2014. The Act was inspired by Danny Stanton (Danny Did Foundation). We want to thank the efforts of Illinois State Senator Dan Kotowski, who was a staunch supporter in the passage of the act into law.

The act is named after Danny Stanton, who died from SUDEP in December, 2009, shortly before his fifth birthday. At the time of his death and before the passage of the Act, there was no state level or federal level act to document cases of SUDEP. Therefore there was not enough information including causes, incidence and risk factors to deal with SUDEP effectively.

SUDEP accounts for about 17 percent of deaths in epilepsy. The figure is higher among children. It is estimated that it is as high as 30% in children with epilepsy. According to recent research the risk of sudden death in epilepsy is sixteen times higher than in the general population. As such there was the need to take an in-depth look as to why this occurs and to take preventive measures. The Illinois SUDEP law is expected to serve as a national model in the fight against sudden and unexpected deaths in epilepsy.

Before the law was passed in August, 2013, there were not much substantial state level or federal level tools in researching issues of epilepsy and SUDEP. The Illinois law will help document evidences as well as incidences of SUDEP. The law is also expected to create more awareness in epilepsy and the debilitating effects of SUDEP.

Even though more efforts need to be done, the passage into law indicates the seriousness of the situation and need to curtail the incidence of SUDEP including prevention and the treatment of epilepsy in general. The New Jersey and the Illinois SUDEP law show that states are now taking a critical look at mitigating SUDEP and Epilepsy.

See more on our website at:

http://efgreatersil.org/news_2.html

Epilepsy Foundation Camp Roehr 2013



Camp Roehr took place from June 9th through June 15th and was held at Pere Marquette State Park in Grafton, Illinois. Camp Roehr is a week-long residential camp for children and teens with epilepsy. This year there were 73 individuals in attendance. Brittany (a seizure service dog) also attended camp this year! Camp Roehr provided campers with swimming, woodworking, visits from the Critter Professor and the KahoK Indian Dancers, tee shirts, Archery, a Rock Wall, a drive in movie, camp fires with smores, Amazing Kids Entertainment (Balloon making and magic), a Carnival day complete with face painting and cotton candy, and many other activities. This year we also had a surprise visit from Kona Ice and the Midwest Sound and Light Shows' DJ as part of the festivities.

Camp Roehr is an annual event with new adventures each year! Applications are available now for 2014. Space is limited so apply early to reserve your fun filled week at Camp Roehr. For more information, contact Trudy L. Baxter, Camp Director, at (618) 236-2181 ext. 104, or visit our website at www.efgreatersil.org.

A Special Thanks to all who contributed to Camp Roehr 2013!

National Epilepsy Foundation-St. Clair County Mental Health Board-Madison County Mental Health Board-Boeing Foundation-Lundbeck, Inc.-St. Clair County Health Dept.-St. Luke's Hospital-St. Clair County Junior Service Club-Delta Theta Tau/Gamma Chi Chapter- Cambridge Dental-NE PA CIL (Access)-Lowe's-Cabelas-Don's Hardware-Curt Smith Sporting Goods-Complete Cleaning-Wal Mart-Casey's General Stores-Quality Vending and Distributors, Inc.-Landshire Sandwiches-Shop N Save-KFC Restaurants-Captain D's-Wells Fargo (Sara Baxter, Christine Henderson, and Pam Deck)-Tom Aubuchon-Jean Bedwell-Erin Gotto-Dr. Rosenfeld and staff-Dr. Lippmann-Kayla Portwood-Tatonya Roberts-Pat Beaty.

Residential News

The Epilepsy Foundation of Greater Southern Illinois residential consumers have kept themselves busy throughout 2013. Consumers have had the opportunity to attend several Grizzlies baseball games, a Cardinal's baseball game, Sharon's Run/Walk/Ride/Swim for Epilepsy, many dances, an agency Halloween party, Bingo with the Director of Programs and Services, jewelry making with the CILA QIPD, and many day trips with the DSP Supervisor such as car races, yard sales, flea markets, and BBQ's. In 2014, the consumers are looking forward to taking the day off work for their Birthdays and having lunch with office staff! The consumers are looking forward to a day- long adventure to the Casino Queen, a trip to the zoo when the weather breaks, and a Red- Hot Valentines Celebration!

Special Olympics continue to be a big event for consumers. The consumers participate in swimming, basketball, track/field and bowling. Everybody at EFGSI continues to support our athletes and will be cheering them on.



Last September the agency opened a new home on Wendy Way in Belleville. KM moved right in and then a few days later JMM moved in as well. Everybody loves the "man cave". The house has been a great addition to the growing residential program. All the residential homes have received everything from new couches to deep freezes this year.

During the cold winter months the kitchens were warm and smell so good while the consumers were cooking with the DSP supervisor. The consumers enjoyed baking cookies over the holidays which they graciously shared with office staff. Looking ahead, it is rumored that the individuals will be going on vacation this summer. The destination has not been chosen as yet. Any ideas?

Ask The Doctor



"Hi my name is Janice." I found out a couple of months ago that I have epilepsy. I am concerned that this means I can't have any more children. I already have a 2 year old boy. I had a seizure while baking cookies with my friends. When I woke up I was in the hospital. My doctor started me on medication right away, but I had another one a month later. I am worried!

Dear Janice: It is scary finding out you have a seizure disorder. If you have told the doctor your fears he will prescribe a drug that will have the least side effects while controlling your seizures. It may take a few months to adjust the medication so that is the most effective for you. He probably has already prescribed vitamin supplements, as well as calcium and vitamin D to maximize long-term bone health.

For more information to your frequently asked questions, please visit the national web site at www.epilepsyfoundation.org

If you would like to Ask the Doctor a question, please e-mail your question to trudyeepilepsy@sbcglobal.net or mail to EFGSI, 140 Iowa Avenue, Suite A, Belleville, IL 62220.

Medical Marijuana: A Miracle For Epilepsy?

Illinois has formally joined several other states in legalizing medical marijuana for patients with certain debilitating medical conditions. Illinois' new law does not include epilepsy as one of the medical conditions covered for medical marijuana use. But, its use for seizures is spreading across the United States. Certainly people with epilepsy are eager to understand their treatment options under the Medical Marijuana Act. This article will throw some light about medical marijuana and review the Illinois' Medical Marijuana Act.

The supposed medicinal benefits of marijuana are not new. However modern research in the recent past has confirmed the medicinal value. The March Issue of 1999 of the National Academy of Sciences Institute carried an article which narrated the powerful medicinal benefits of marijuana. As with any other drug, there were potential risk factors.

Since the report by the National Institute of Medicine about the medicinal benefits of marijuana, the substance's therapeutic powers continue to unfold. Several individuals are reported to have experienced the benefits of using medical marijuana to treat or reduce the incidence of certain ailments such as multiple sclerosis, HIV/AIDS, cancer and other ailments that do not respond well with conventional medicine. Those with seizures are also hopeful for help.

Most recently some patients have reported a huge reduction in the episodes of seizures. For example, Charlotte Figi (born October 18, 2006) is reported to have had her seizures reduced from as high as 300 episodes of Generalized Seizures a week to just 2 or 3 times a month on medical marijuana. She is said to be greatly improved just after two years on medical marijuana.

The story of Charlotte and others on Medical Marijuana has inspired a new breed of marijuana called "Charlotte Web". Charlotte Web contains high-CBD, low-THC pot strains.

The Tetrahydrocannabinol (THC) is the chemical component in marijuana responsible for making users "high". It creates the euphoria feeling that users are looking for. Users may experience a perceptual alteration and intensification of the senses.

The THC is not without its side effects. The short term impacts range from an impairment of motor skills and reaction time to short term memory loss. Anxiety, panic reactions, and depressive feelings are also among the common side effects said to be experienced by users. The long term effects are not clearly known due to inadequate research. Long term users are said to have an increased risk of developing schizophrenia, especially among those who are vulnerable. Vulnerable people are those with pre-existing mental illness or people highly susceptible to mental illness.

The other component of Marijuana, called Cannibidiol (CBD), is said to be the chemical responsible for the *wide range of therapeutic benefits*. It does not get users "high" and it is non-psychoactive.

The Charlotte Web medical marijuana was developed by extracting out THC component of the marijuana to produce a high CBD content. The CBD content is turned into Alepsia or Real Oil. This oil is then given to the patient, which is hoped to work well on seizures.

Even though marijuana has gained significant momentum in the medical field over the past few years, *the long term risk factors are still largely unknown*.

As a result of the fact that the long term risk factor is still not clear, States and organizations observe cautionary measures on issues of medical marijuana.

Colorado law currently permits the use of medical marijuana for the following conditions: cancer, glaucoma, HIV/AIDS, muscle spasms, seizures, severe pain, severe nausea, cachexia or dramatic weight loss, and muscle atrophy.

See more on our website at:
http://efgreatersil.org/news_1.html

Sharon's Ride-Run-Swim-Walk Triathlon 2013

Sharon's Ride- Run-Swim-Walk Triathlon for Epilepsy was held on Saturday, October 12th, 2013, at Southern Illinois University-Edwardsville for the benefit of the Epilepsy Foundation of Greater Southern Illinois. The event is done each year to honor the memory of Sharon Rosenfeld, a nurse and teacher who was killed on a cross country bicycle ride in 1993. The event, established in her memory by Dr. William Rosenfeld and his wife Dr. Susan Lippmann, helps to make individuals aware of epilepsy and to educate individuals about helmet safety.

The event raised nearly \$17,000.00 for the Foundation. Adding the triathlon to the event brought in registrants from Chicago, Iowa, Missouri and many other areas to participate for a great cause.

The foundation wishes to express their thanks to our wonderful sponsors, who along with the participants made this event a success.

UCB Pharma, Lundbeck, Dr(s). William Rosenfeld and Susan Lippmann, Joe Pott (The Voice of the SIU-E Cougars), Alie Stach, Metro East Park & Recreation District, Visionary Production, Helmets First, Paul Baillargeon (Photographer), Jimmy John's, Bike Surgeon, St. Louis Baseball Cardinals, Kemoll's Restaurant, Gateway Grizzlies, All-Star Distributing, Casual Tees, Big River Running Management Co., and Heimos Produce.

Look for the event next year in October of 2014, at SIU-E for the benefit of The Epilepsy Foundation of Greater Southern Illinois... and thanks for your great support this year!

Sara's Walk-Run 2014

Sara's Walk-Run will be held on Saturday, June 28th, 2014, at Southern Illinois University-Carbondale in memory of Sara Elizabeth Stubblefield. The event will consist of a 5K run and a walk to benefit the Epilepsy Foundation of Greater Southern Illinois-Southern Illinois Region.

The Chair for the event is Terri Bryant, Dietary Director for the Department of Corrections. Entry fee for those participating in the event is \$20.00, and ALL participants will receive refreshments, lunch, t-shirts, and more! Midwest Sound and Light will entertain at the event.

Awards will be distributed for the 5K run for the top ten (10) runners who finish first.

For more information, please contact Jan M. Conder at jan.epilepsy@gmail.com or call (618)236-2181 Ext. 110.

Participants can follow our links and register online- www.efgreatersil.org

Support a great cause, in memory of a great person- Sara Stubblefield. Sara was dedicated to helping those with epilepsy. She died suddenly in March, 2011 while attending the National Speak Up Conference in Washington, D.C. while working for the Epilepsy Foundation.

See you on June 28th in Carbondale!



Seizure Tracker

Seizure Tracker has the largest collection of patient entered seizure event and treatment information in the world. The data collected through the tools available to everyone's user base could have a great impact on the understanding of seizures and epilepsy.

<http://www.SeizureTracker.com/ResearchUserSurvey/>

What's New...

The capability to export your seizure data to EXCEL, JSON and XML formats is now available on SeizureTracker.com.

<http://www.seizuretracker.com/STH/Seizure-Tracker-Help-Topics.php?T=26&M=3&LOC=>

Ask...

What rescue medication do you use to stop prolonged seizures?

<http://seizuretracker.com/News-Tracks/Seizure-Tracker-News-Ask.php?PV=>

Seizure Clusters

On March 3, 2014, [Upsher-Smith Laboratories, Inc.](#) announced a new educational program created for patients living with seizure clusters, as well as their families and friends. The initiative—called Seizure Clusters Connect™—uses traditional and social media to offer patients and their caregivers a community for learning and support. The program launched online with the debut of the [Seizure Clusters Connect Facebook](#) page and the [Seizure Clusters Connect YouTube](#) channel.

Seizure clusters are seizures that happen one after the other over a short period of time. There is a recovery period between each seizure and a pattern that is different from the usual seizure pattern. Anyone who has epilepsy can have seizure clusters—at any age, at any time—even when taking antiepileptic medicine as directed.

“We created these new social media venues to provide a community of support for patients and caregivers affected by seizure clusters,” said Matthew A. Fox, Sr. Vice President, Corporate Strategy, Upsher-Smith.

“Seizure clusters can be particularly challenging for patients and their caregivers,” added Sheryl Haut, M.D., Professor of Clinical Neurology, Montefiore Medical Center/Albert Einstein College of Medicine. “The new Seizure Clusters Connect online community offers an array of valuable information and support to patients and caregivers living with seizure clusters.”

Epilepsy Support Group News

The Epilepsy Foundation of Greater Southern Illinois offers monthly support groups with a wide variety of activities and social outings. Our support groups are designed to encourage friendships and networks among people who are dealing with seizures. Over the course of 2013, the Epilepsy Foundation of Greater Southern Illinois has offered support groups that cover a wide range of interests.

2013 Support Group Activities:

- Bamboo Valley Restaurant/St. Clair 10 Cinema
- Golden Corral
- Cahokia Mounds
- Schmidt Art Center
- Cardinals Baseball Game
- Stock Car Races at the Belle-Clair Fairgrounds
- Grizzlies Baseball Game
- St. Louis Botanical Gardens
- Bel-Air Bowl
- Relleke Farm
- Bingo
- The Way of Lights at the National Shrine of Our Lady of Snows

Upcoming Activities:

- Movie Day – March, 2014

The Epilepsy Foundation of Greater Southern Illinois is planning a tremendous year filled with many exciting new activities for individuals participating in monthly support groups! New ideas from our participants are always welcome. For more information on upcoming support groups or to join our mailing list, please call 236-2181 to contact Mary (ext. 109) or Samantha (ext. 106).

Seizure Smart For People of all Ages!

The Epilepsy Foundation of Greater Southern Illinois has Signature programs in many areas, **there is one for you!**

- “Law Enforcement Training Guide”.
- “First Responders: EMS personnel Training”.
- “Seizures after Sixty”, for older individuals and nursing homes.
- “Managing Students with Seizures” and “Take Charge of the Facts” for families and teenagers with seizure disorder.
- “Chart Your Course”, job seeking and skills training.

(More on next page)

Epilepsy Foundation of Greater Southern Illinois News

Listed below are the presentations that the agency provided throughout 2013. We have shared information with 9,482 people in Madison and St. Clair Counties in the metro east area:

1/23/13 Lindenwood College, Belleville, IL	6/14/13 Southwestern Illinois College. Family Fun Night, Belleville, IL
2/15/13 Civic Memorial High School, Bethalto, IL	7/23-28/13 Madison County Fair, Highland, IL
3/05/13 Center for Autism, Maryville, IL	7/31/13 Southwestern Illinois Police Academy, Belleville, IL
3/28/13 Meadowbrook Elementary School, Moro, IL	8/13/13 Transitional Center, Centerville, IL
3/19/13 Collinsville Middle School, Collinsville, IL	8/22/13 First Assembly of God Church Hope Summit, Collinsville, IL
4/05/13 Albert Cassen Elementary School, Glen Carbon, IL	9/07/13 Our Lords, Lutheran Church, Maryville, IL
4/10/13 Southwestern Illinois College, Red Bud, IL	9/19/13 Cahokia School District, Parents Night, Cahokia, IL
4/13/13 Madison County Child Advocacy Center Health Fair, Alton, IL	10/8/13 Goshen Elementary School District 19, Edwardsville, IL
4/17/13 Bernard Long Elementary School, Madison, IL	10/9-10/13 Webster University Camp Expo, Webster Groves, MO
4/17/13 Southwestern Illinois College, Volunteer Health Fair, Belleville, IL	10/29-30/13 University of Missouri Camp Expo, St. Louis, MO
4/17/13 Southwestern Illinois College Police Academy, Belleville, IL	11/25/13 Boy Scouts of America, Highland, IL
4/25/13 Southwestern Illinois College Job Fair, Belleville, IL	11/7/13 Veterans Affairs Job Fair, Belleville, IL
5/04/13 Cahokia High School, Project Success, Cahokia, IL	12/4/14 Southwestern Illinois College Police Academy, Belleville, IL
6/01/13 Greater St. Mark's COGIC, East Louis, IL	
6/13/13 Vintage Support Systems, Belleville, IL	

Presentations already scheduled in 2014 are:

3/13/14 Collinsville Middle School, Collinsville, IL
4/04/14 Albert Cassens Elementary School, Glen Carbon, IL
5/03/14 Disability Awareness Day, Moody Park, Fairview Heights, IL

The Epilepsy Foundation of Greater Southern Illinois offers assistance to any person (regardless of age) or community group requesting training, information, or assistance with seizures throughout the 34 counties of Greater Southern Illinois. EFGSI has a wide variety of presentations designed specifically to meet your needs! EFGSI has an extensive library available to the general public for anyone needing information about seizures.

If you or a loved one has experienced bereavement due to SUDEP (Sudden Unexplained Death due to Epilepsy) please contact us for assistance and support.

Transportation assistance is available for various needs including physician appointments, medical testing, various government agencies, Social Security, Human Services, and housing assistance programs.

Call soon to schedule a presentation or to speak to one of our agency staff at (618) 236-2181 ext. 104 or email trudypilepsy@sbcglobal.net.

News from the Southern Region Office

Epilepsy Foundation of Greater Southern Illinois - Southern Illinois Region

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FUNDING:

The Epilepsy Foundation of Southern Illinois is able to provide free services due to the funding from the Illinois Department of Human Services Title XX Grant, the United Way of South Central Illinois, the United Way of Southern Illinois, and Jefferson County 708 Mental Health Board.



School Nurse Training Seminars

The Epilepsy Foundation of Greater Southern Illinois- Southern Illinois Region will be hosting a number of school nurse training seminars in 2014. These are geared toward educating school nurses in epilepsy and training school personnel at the schools where they serve students. We will also be hosting a number of in services on seizure education in 2014 and continue to look forward to educating people with epilepsy, their friends and families.

New Location



In case you missed it, we have moved locations. Our new office is located at the Mt. Vernon Outland Airport in the main terminal. Airport manager Chris Collins welcomed us into his airport family in August. Every year his office manager puts together a compilation calendar of the various businesses and events that take place at the airport. We

were chosen to be the May calendar and provided this picture for the month.

New Partner

The Epilepsy Foundation of Greater Southern Illinois-Southern Illinois Region is proud to partner with St. Mary's Good Samaritan Medical Group and Dr. Elizabeth Horton. Dr. Horton is providing neurological services for the area and the Epilepsy Foundation is providing seizure education during her neurological clinic, which Good Samaritan Hospital and she host once a month.



In Picture: Dr. Elizabeth Horton, Erin Gale (Epilepsy Educator), Sharon Mower (Office Coordinator)

Welcome Jan!

The Epilepsy Foundation of Greater Southern Illinois-Southern Illinois Region is proud to welcome Jan Conder as a part of our Sara's Walk for Epilepsy team. Jan is instrumental in making sure that each event that she plans is a huge success.

Kids Speak Up

The Epilepsy Foundation Mount Vernon office would also like to announce that this year's Greater Southern Illinois ambassador for our Kids Speak Up/Public Policy Institute in Washington, D.C. is Reese Abigail Johnson and her mother Connie Bates of Benton, IL. They will be attending the conference in Washington D.C. on March 23-25 with Epilepsy Foundation staff. The conference allows young people the opportunity to get a front row seat of how Congress works as well as becoming educated on advocacy for seizures and people with epilepsy. Each person who attends the Public Policy Institute returns home with a new sense of independence and a host of new knowledge concerning their condition.

Sara Elizabeth Stubblefield Memorial Scholarship Awarded

The Sara Elizabeth Stubblefield Foundation announced that Mr. John Shearer of Gurnee, Illinois, was awarded the SARA ELIZABETH STUBBLEFIELD MEMORIAL SCHOLARSHIP for Persons with Epilepsy for 2013. This \$2,000 scholarship award will be paid \$1,000 per semester for the 2013-2014 academic year. Mr. Shearer will attend Carthage College in Kenosha, Wisconsin, where he will double major in biology and business administration, after which he plans to attend medical school.

The Foundation also renewed the scholarship award of the 2012 winner, Ms. Jenna Pedersen of St. Charles, Illinois. Ms. Pedersen will continue her education at Illinois State University, where she is majoring in special education. The assets of the scholarship fund permitted funding Ms. Pedersen for a second year, and it is hoped that in addition to selecting an academic winner each year, the scholarship fund will be able to continue funding previous years' winners until they complete their 4 years of undergraduate education.

The Sara Elizabeth Stubblefield Memorial Scholarship Foundation awards a \$2,000 scholarship every year to a deserving Illinois student who is living with epilepsy. Students should consult their local guidance counselors. This year's applications are due no later than April 30, 2014. Please click on the following link to directly fill out this year's application. <http://efgreatersil.org/scholarships.html>



STRONGER TOGETHER

Not another moment lost to seizures™

140 Iowa Avenue, Suite A
Belleville, Illinois 62220



UPCOMING EVENTS

www.efgreatersil.org

- April 12** **7th Annual Gala, A Dazzling Revue, “A Night in Paris”, 6:00 p.m., Bellecourt Manor in Belleville, Illinois**
For more information, please contact Jan Conder at (618) 236-2181, ext. 110.
- June 8 -14** **Camp Roehr, Pere Marquette State Park**
For more information, please contact Trudy Baxter at (618) 236-2181, ext. 104.
- June 28** **Sara’s Walk-Run, SIU-Carbondale**
For more information, please contact Jan Conder at (618) 236-2181, ext. 110.