STEP IT UP at the #DareToDefeat Epilepsy Walk

Join us as we STEP IT UP at the 2018 #DareTo Defeat Epilepsy Walk. Our goal is simple...to raise epilepsy awareness and funds through this fun-filled, family oriented, non-competitive walk, and to unite for the cause. This is the largest epilepsy awareness and fundraising event to benefit the Epilepsy Foundation of Kentuckiana and this year, we are walking to raise $153,000. That is only $1 for each of the 153,000 children, adults, and veterans living with epilepsy and seizures in Kentuckiana and southern Indiana. All funds raised will directly benefit the Foundation’s vital education, outreach, advocacy, and direct client services. Prizes will be awarded to top fundraisers. We hope you will join us for fun, food, fellowship, and an invigorating Walk with lots of giveaways!

- **School, Work, or Church Fundraiser** – Host a pizza party, bake sale, doughnut sale, ice cream social, pancake breakfast, or car wash to raise money for the Walk.
- **Letter or Email Writing Campaign** – Send a letter or e-mail to all your family members, friends, neighbors, and co-workers asking them to sponsor you for the Walk.
- **Collections** – Ask your church, synagogue, or meeting hall if you can take a collection to support the Epilepsy Foundation of Kentuckiana’s Walk campaign.
- **Social Media Campaign** – Set up an online fundraising event on social media and ask your friends to donate to the Walk.

Register Now at www.EFKY.org/walk

For the 2018 #DareTo Defeat Epilepsy Walk fundraising campaign to be successful, we need your help! Set a fundraising goal and then use all or some of the following techniques to reach this goal:

- **Employer Sponsors** – Ask your employer if they will be a Walk sponsor or match your fundraising efforts.

**HEY KIDS!**

Raising money for the 2018 #DareTo Defeat Epilepsy Walk is not just for grown-ups! You can raise lots of money too! All you have to do is ASK! Think about all of your family members and friends, and even invite your school to support you for the Walk. Pennies and dollars add up very quickly, and who knows, you might just raise the most money on your team!

**SAVE THE DATE - ORGANIZE YOUR TEAM**

- **Saturday, June 9th**
  - Owensboro
  - Legion Park, West Shelter

- **Saturday, June 9th**
  - Pikeville
  - Bob Amos Park

- **Saturday, June 16th**
  - Louisville
  - Louisville Slugger Field

- **Saturday, June 23rd**
  - Lexington
  - Keeneland Race Course, Barn 2

- **Saturday, June 23rd**
  - Paducah
  - Bob Noble Park, Shelter 19
Kentucky and southern Indiana just experienced the worst flooding in over 20 years. Everyone at the Epilepsy Foundation of Kentuckiana hopes you and your family were not immediately impacted by this historical flooding. The news reports were frightening to watch, especially seeing homes, businesses, schools, and entire towns under water. Thousands of lives and businesses were displaced and there was nothing any of us could do to stop the rivers and streams from overflowing their banks. Thankfully, forecasters predicted the flooding, which gave folks living in flood prone areas the necessary time to prepare and evacuate. This also helped save lives as people heeded warnings of imminent danger from flash flooding.

Using the same analogy - seizures flood the brain with too much electrical current. In many cases there is no warning sign a seizure is going to happen, or the warning (also known as an aura or simple partial seizure) happens so quickly that the person has no time to prepare. In some cases there is no impact to the brain or the impact might be temporary. However, prolonged and reoccurring seizures can cause permanent brain damage, and, unfortunately, seizures can also cause death.

Equipping yourself with the best care possible is crucial when seizures are a part of your or a loved one’s life. This includes having access to a neurologist specializing in epilepsy/seizure disorders and seizure medications to treat your seizures. This could make a world of difference as you fight to defeat this neurological disease. You and your physician should also have the decision-making power to determine the medication(s) that might work best for you. Epilepsy is very individualized. There is no “one size fits all” with epilepsy/seizure disorder treatment(s) like with other chronic health conditions.

The Epilepsy Foundation of Kentuckiana is committed to advocating for improved access to care for persons battling seizures through state and federal legislation. We believe you and your physician should have the decision-making power on which medication(s) are best in treating your seizures and will continue fighting for this through our advocacy efforts. The brain controls everything our body does. If flooded with too much electrical current, the brain will short-circuit. As one of our clients, who works in the computer science field, has illustrated to us, the brain is the “motherboard” of our bodies and when it misfires with seizure activity, this can cause our brains to do things we would normally not do or behave completely out of character. Epilepsy does not receive anywhere near the attention or funding it desperately needs to fund research, develop, and maintain essential programs and support services, and eliminate stigmas and misperceptions that, unfortunately, still exist today. Epilepsy directly affects over 3.4 million Americans, including over 153,000 children, adults, and veterans in Kentucky and southern Indiana. As many of you already know - seizures can result in heartbreaking challenges and devastating consequences. It is more than past time to break down the barriers that stand in the way of defeating epilepsy and seizure disorders.

Will you help in this fight to raise much needed funds to support the ongoing advocacy efforts of the Epilepsy Foundation of Kentuckiana? One way is to register to attend an Epilepsy Walk near you and invite your family and friends to join your team, set your fundraising goals, and start working to achieve your goals! We are in this fight together and your support can make a tremendous difference and impact! Thank you!

– Deb
Join us on Saturday, April 28 from 9:00 a.m. - 2:00 p.m. at the W.T. Young Library (401 Hilltop Avenue, Lexington, Kentucky) for a day of networking and education for anyone affected by epilepsy. A program for school age children will be provided. This event is free, but registration is required. Breakfast and lunch will be provided.

Please register by contacting 859-218-5053 / gopurplecentralky@gmail.com. Please be sure to provide a call back number and number of individuals wanting to attend.

Epilepsy Education Day in Lexington on April 28

Would you like to save paper and help the Foundation at the same time? Please sign up to receive the Illuminator in your inbox instead of your mailbox by contacting Connie Costelle, administrative assistant at 502.637.4440 / 866.275.1078 x10 / ccostelle@efky.org. If you wish to donate to the Foundation via credit/debit card, you may do so at www.efky.org or by calling Connie at the number above. If you would like to make a donation via check, please fill out the form below, cut it out, and mail it to us using the address on the form.

Epilepsy Foundation of Kentuckiana Donation

Donor’s Name ________________________________
Address _____________________________________
City, State, Zip ______________________________
Phone number ________________________________
E-mail address ________________________________
__ In Honor of ________________________________
__ In Memory of ________________________________
__ Shannon O’Daniel Memorial Scholarship Fund
__ Peggy Sherrell Memorial Scholarship Fund
__ Epilepsy Research Project Fund
__ My employer has a matching gift program. Enclosed is the required form.
__ Please contact me/us about including the Foundation in my estate plans.

Your contribution will truly make a difference!
From the Director of Client Services - Amy Collier, CSW

Are you wondering if a seizure alert device is right for you? While there are no devices available that have been proven to prevent sudden unexpected death in epilepsy (SUDEP), we do know that SUDEP most often occurs during sleep, and some people with seizures may be helped by having a way to let a loved one know if a seizure occurs. Seizure alert devices are useful in letting family members know if a seizure is occurring, even if the person is asleep or living independently. The Epilepsy Foundation of Kentuckiana has received funding through the Kentucky Colonels and Kosair Charities to purchase a limited supply of the following seizure detection devices:

- **Embrace Watch**: an FDA approved Smartband for seizure alert, seizure tracking, and epilepsy management. Embrace uses advanced machine learning to identify convulsive seizures and send alerts to caregivers. It also provides sleep, rest, and physical activity analysis. (www.empatica.com)

- **Emfit MM**: a movement monitor consisting of a bed sensor placed under the mattress and a bed-side monitor that detects abnormal muscle movements that continue 10 seconds or longer. If activated, it emits a quick, high-frequency alert to allow a caregiver or family member ample time to respond to the seizure.

- **SAMi Sleep Activity Monitor**: a camera/monitor that detects unusual movement and then sounds an alarm to alert caregivers. It also records live audio and video from the SAMi network camera. (www.samialert.com)

Consult with your doctor to see if a seizure alert device is right for you, then contact me at 502-907-1534 / 866-257-1078 x15 to see if you are eligible to receive one of these devices at no charge to you. Please understand that we cannot guarantee that you will receive one of these devices as there is a limited supply and only those with certain seizure types can benefit from these devices. I look forward to talking to you and discussing with you whether you or your loved one is eligible.

Funding for these seizure alert devices was provided to the Epilepsy Foundation of Kentuckiana by the Kentucky Colonels through a Good Works Program grant and Kosair Charities through grant #774C. The Foundation is grateful to these organizations for helping protect the children, adults, and veterans living with epilepsy that we serve by providing the opportunity for us to provide these potentially life-saving devices at no charge to eligible clients.

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Donald Bow Joins Staff

The Epilepsy Foundation of Kentuckiana is thrilled to announce that Donald Bow, MS has joined our team as the Veterans Outreach Coordinator. Donald recently retired from a 20 ½ year career in the United States Navy where he spent 17 years in the healthcare field and closed out his career as a Command Master Chief. Donald earned his Master of Health Sciences at Trident University in between operational assignments. He is looking forward to serving veterans through our signature program, Operation Outreach, and building relationships throughout the Commonwealth that focuses on raising awareness and providing our veterans education and resources that contribute to healthy lifestyles.

Donald lives in Mount Washington with his wife Hayley and their two sons, Donald and Harrison. Donald enjoys all activities that allows the family to spend time together. He is excited to continue to learn and become a part of all the events at the Epilepsy Foundation of Kentuckiana. Please feel free to contact Donald at 502-907-1536 / 866-275-1078 x17 / dbow@efky.org. All veterans are encouraged to reach out for assistance.

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From the Veterans Outreach Coordinator – Donald Bow, MS

I am very excited that I was given the opportunity to join the Epilepsy Foundation of Kentuckiana as the Veterans Outreach Coordinator. In October 2017 I made the decision that I would retire from the United States Navy after 20 ½ years and I had three and a half months to figure out what my next step would be. Throughout my career I have always received the most joy by helping my fellow service men and women. As I began the transition from the military to the civilian sector, my hope was I would find a position that enabled me to continue to be an advocate for military personnel and improve their lives in any way I could. A friend of a friend mentioned the Veterans Outreach Coordinator position to me and I knew this would be an awesome position to be able to step into.

I enlisted in the Navy out of Louisville in September of 1997 and was assigned to be a Hospital Corpsman. Initially, the only thing I was told about the job of a Hospital Corpsman was “you could work in a hospital or you could serve alongside the Marines.” I lucked out with my first duty station and was sent to Hawaii from 1998–2001 and began working alongside the Marines as a Fleet Marine Force corpsman. I deployed to Okinawa, Japan and from there we went to South Korea and Australia. I was stationed at Naval Medical Center Portsmouth when we were attacked on 9/11 and I knew it would only be a matter of time before I would be deployed to Iraq. Luckily, a little bit of time passed before that happened and I was lucky enough to meet my wife Hayley, who was also serving as a Hospital Corpsman.

continued on page 6
Register Now for the 2018 Studio E Art Therapy Program

If you are an adult living with epilepsy, we hope you will join us for one of our 2018 Studio E: The Epilepsy Art Therapy programs. This year, the Foundation will host our seventh program in Louisville at the Epilepsy Foundation of Kentuckiana office every Saturday from July 7 – August 11 from 10:00 a.m. – 1:00 p.m. We will also offer our third program in Lexington at the University of Kentucky (Charles T. Wethington, Jr. Building Commons Room) every Saturday from July 14 – August 4.

The Studio E program allows participants the opportunity to work with an art therapist and other people with epilepsy age 18 and older in a group setting to create artistic pieces using a variety of mediums. Participation does not require previous art making or artistic talent, in fact, many past participants have discovered new talents because of this program! Additionally, with your consent, the artwork you create may help raise awareness about the realities of life with epilepsy on a national level.

There are a limited number of slots available and registration will be on a first-come-first-served basis. A light lunch and drinks will also be provided each week. If you would like to register to participate in the Studio E program or would like more information, please contact Beth Stivers, MS, director of education at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org by July 6.

KAREN RICCI - I Feel Brave When

As long as I live you will love.
As long as I live you will be remembered.
As long as I live you will be loved.

Each year, a number of pieces are selected by the Studio E program administrators at the national Epilepsy Foundation to be displayed on a national level at the American Epilepsy Society (AES) conference. This year, Karen’s piece was selected from the Kentuckiana affiliate’s art therapy program to be displayed.

Congratulations, Karen!

Chris Holland - Untitled

Join Us for Our Monthly Art Group Gathering

If you have epilepsy/seizures and are 18 or older, we hope you will consider joining us at the Foundation office (982 Eastern Parkway, Louisville) one Friday each month as we meet in a support setting (without an art therapist) to create art, eat lunch, and enjoy fellowship with other people living with epilepsy. If you are interested in joining us please contact Beth Stivers, MS, director of education at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org.

Victoria Rookard - Untitled
From the Veterans Outreach Coordinator - continued

We were married in January 2003 and a couple months later I was deployed to Nasiriyah, Iraq with 2nd Marines during the initial invasion of Iraq. I would deploy again to Iraq for seven months in the summer of 2005 and the following year we welcomed our first son Donald to our family. From there I served as a Survival, Evasion, Resistance, and Escape (SERE) Instructor for a little over three years and in 2011 I deployed to Afghanistan for seven months. During this deployment I witnessed numerous Marines and Sailors suffer from IED blast injuries and began to see the drastic impact it had on their lives. After completing that deployment I was stationed at the United States Naval Academy and Hayley and I welcomed our second son Harrison to the family. My last duty station was a F-35C squadron based out of Edwards Air Force Base, California where I served as the Command Master Chief.

As the Veterans Outreach Coordinator, I believe I bring a unique military background that directly relates to the Epilepsy Foundation of Kentuckiana. My three combat deployments have allowed me to witness the devastating effects that combat can have on military personnel. I have seen firsthand from those who I have served with and from friends how the diagnosis of TBI and PTSD can impact their lives. My goal will be to build on the current Operation Outreach program and educate as many veterans, family members, and clinicians on TBIs and PTSD and how these conditions correlate to post traumatic epilepsy (PTE) and psychogenic non-epileptic seizures (PNES).

Education is a vital piece to this position because throughout my time in the service and throughout my deployments I never received any medical briefs that broached the subject of PTE and/or PNES and I know this is the same for many veterans, not only in Kentucky, but throughout the United States.

My plan is also to get out and meet as many veterans, veteran’s organizations, and clinicians as I can and build relationships throughout the state and to help remove the stigma about reaching out for assistance that can be common throughout the military community.

I am truly honored and fortunate to be able to serve veterans. As we grow the Operation Outreach network, I ask that you follow us on social media at https://www.facebook.com/EFKYvets/ and https://www.linkedin.com/groups/13578700 and share with friends and family!

Bounce Out the Stigma Basketball Camps

In July, the Epilepsy Foundation of Kentuckiana will host its fifth annual Bounce Out the Stigma basketball camp in both Lexington and Louisville. This FREE two-day basketball camp is specifically tailored for youth ages 8 – 20 with epilepsy/seizure disorders and autism spectrum disorders to help them learn that limits do not define them, but they define their limits through skills, drills, thrills, and fun. To make this camp experience even better, participants are encouraged to bring a sibling or friend between ages 8 - 20 to join in the fun. Camp goers will receive a Bounce Out the Stigma t-shirt and basketball. Space is limited and required for all youth wishing to attend, so register early to ensure you get a spot! We are also looking for sponsors and volunteers. If you are interested in either, please contact Deb McGrath, executive director at the phone number/e-mail address listed below.

Bounce Out the Stigma is a basketball camp, founded and directed by “Mighty Mike” Simmel, a retired 13-year professional entertainment basketball player of the world-famous Harlem Wizards. These days, Mike is a top-notch camp clinician, event performer, and motivational speaker. He knows what it is like to be treated differently, as he has lived with epilepsy since age 2. In fact, when “Mighty Mike” was 16 years old, he was asked to leave a basketball camp after suffering a seizure. He decided then that if he ever was in a position to do so, he would develop a basketball program for unique kids….and he did just that! To learn more about this program, go to bounceoutthestigma.org.

Registration is now open at www.efky.org.

To get more information or to register via phone/e-mail, please contact Deb McGrath, executive director, at 502-907-1532 / 866-275-1078 x13/ dmgrath@efky.org.

This camp is proudly partnered with and associated with:

**Operation Outreach**

If you are a veteran experiencing seizures, are in need of assistance, or would like to learn more, please contact Donald Bow, MS at 502-907-1536 / 866-275-1078 / dbow@efky.org.
2018 Peggy Sherrell Memorial Scholarship Award

The Epilepsy Foundation of Kentuckiana is now accepting applications for the 2018 **Peggy Sherrell Memorial Scholarship Award**. The one-year, $1,000 scholarship is awarded to a deserving degree/certificate seeking student who meets the following criteria:

- Is currently under a physician’s care for epilepsy/seizures (i.e. neurological seizures);
- Is currently undergoing treatment and/or taking anticonvulsant medication(s);
- Can demonstrate their struggle to overcome adversity because of their epilepsy/seizures;
- Is a degree or certificate-seeking student (graduating senior, first time adult learner, or those returning to complete their degree or certificate);
- Lives in Kentucky (excluding Boone, Campbell, Grant, & Kenton counties) or lives in Clark, Floyd, or Harrison Counties in Indiana.

For a copy of the application, please contact Beth Stivers, MS, director of education, at 502-637-4440 / 866-275-1078 x14 / bstivers@efky.org or download a copy at www.efky.org.

**Mailed Application Submission Deadline:** MUST be post-marked by June 8, 2018.

Peggy Sherrell was a 46 year-old wife and mother of two adult children who died suddenly on August 28, 2010 from what was attributed to sudden unexpected death in epilepsy (SUDEP). Peggy believed that education was extremely important and therefore, her family determined that a scholarship would be the perfect way to carry on her legacy. Her family strives to assist the Foundation in educating people about SUDEP and raises funds through the Peggy Sherrell Memorial Golf Scramble each year around the anniversary of her death.

2018 Shannon O’Daniel Memorial Scholarship Award

The Epilepsy Foundation of Kentuckiana is now accepting applications for the 2018 **Shannon O’Daniel Memorial Scholarship Award**. The one-year, $1,000 scholarship is awarded to a deserving student who meets the following criteria:

- Is currently under a physician’s care for epilepsy/seizures (i.e. neurological seizures);
- Is currently undergoing treatment and/or taking anticonvulsant medication(s);
- Can demonstrate their struggle to overcome adversity because of their epilepsy/seizures;
- Is a college-bound high school senior;
- Lives in Kentucky (excluding Boone, Campbell, Grant, & Kenton counties) or lives in Clark, Floyd, or Harrison Counties in Indiana.

For a copy of the application, please contact Beth Stivers, MS, director of education, at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org or download a copy at www.efky.org.

**Mailed Application Submission Deadline:** MUST be post-marked by June 7, 2018.

Shannon O’Daniel was a senior in college and just credits away from graduating when she died from what was attributed to SUDEP (Sudden Unexpected Death in Epilepsy). Shannon struggled to overcome the seizures that frequently disrupted her life. She did so with a determination to achieve her dreams, one of which was to receive her college diploma. In the aftermath of her tragic death, this scholarship was created to honor Shannon and her achievements.

**MAKE A DIFFERENCE** by registering your team to play in the 13th Annual Golfer’s Gauntlet on Monday, April 23, 2018. All participants will enjoy a fun-filled day at Fuzzy Zoeller’s Covered Bridge Golf Club in Sellersburg, Indiana, a hearty lunch, raffle, a cookout, cash bar, and awards presentation. All proceeds from this event will benefit the vital services and programs provided by the Epilepsy Foundation of Kentuckiana for individuals affected by epilepsy living in Kentucky and southern Indiana. To be a sponsor, register your foursome, or for more information, please go to 18Gauntlet.gesture.com.
what’s inside

Register Now for 2018 #DareToDefeat Epilepsy Walk
From the Executive Director
Epilepsy Education Day in Lexington
From the Director of Client Services
From the Veterans Outreach Coordinator
Register Now for 2018 Studio E Program
2018 Bounce Out the Stigma Basketball Camps
2018 Peggy Sherrell Memorial Scholarship
2018 Shannan O’Daniel Memorial Scholarship
2018 Golfer’s Gauntlet

Phone 502.637.4440 • Toll-Free 866.275.1078 • Fax 502.637.4442 • Web www.efky.org

An independently incorporated affiliate of the Epilepsy Foundation

YOUTH EPILEPSY ALLIANCE!

WHO: School age & affected by epilepsy...maybe you have epilepsy, or your brother, sister, or parent does. If so, we’re just the group for you!!!

WHEN: Monthly

WHERE: Changes each month, so call for details, or to be added to the email/mailing list!!

WHY: To have fun, make friends, and talk & hang out with those who understand!

COST: Free to youth, thanks to Kosair Charities!

EPILEPSY FOUNDATION KENTUCKY’S YOUTH EPILEPSY ALLIANCE!

UPCOMING YOUTH EPILEPSY ALLIANCE! EVENTS

Saturday, May 5th
Family Photo Session by Faith, Love Photography
Location and Time TBD

June Activity
2018 Walk #DareToDefeat Epilepsy
Walk Nearest You! (See cover article)

July Activity
Bounce Out the Stigma Basketball Camp (See page 6)

For more info or to attend, visit www.efky.org or contact Gary Zortman, events manager at gzortman@efky.org.