Join us as we step it up at the Walk 2017 #DareToDefeatEpilepsy!

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 beat the amount raised last year ($130,000). That’s less than $1 for each person living with epilepsy and seizures in Kentucky and southern Indiana! 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!

Here are just a few reasons raising funds for the Foundation’s programs and services is so important:

- 1 in 26 individuals will develop epilepsy in their lifetime;
- Epilepsy is the leading neurological disease among children;
- More people are affected by epilepsy than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson’s disease combined;
- It is estimated that up to 50,000 deaths occur annually in the U.S. from prolonged seizures, Sudden Unexpected Death in Epilepsy (SUDEP), and other seizure-related causes such as drowning, falls, suffocation, and other accidents. Unfortunately, SUDEP accounts for 34% of all sudden deaths in children; and
- For many soldiers who suffered a traumatic brain injury (TBI) on the battlefield, epilepsy will be a life-long consequence. Fifty-three percent of veterans who sustained a TBI in combat are estimated to develop epilepsy within 15 years.

For the Walk 2017 #DareToDefeatEpilepsy 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.
- 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 of your family members, friends, neighbors, and co-workers asking them to sponsor you for the Walk 2017 #DareToDefeatEpilepsy
- Collections – Ask your church, synagogue, or meeting hall if you can take a collection to support the Epilepsy Foundation of Kentuckiana’s Walk campaign.


JUST FOR KIDS!

Raising money for the Walk 2017 #DareToDefeat Epilepsy is not just for grown-ups! Kids can raise lots of money too! All you have to do is ASK! Think about all of your family members and friends and simply ask them 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!
Happy spring! I hope you are as glad to see the arrival of spring as I am!

Last December, I was excited to attend the 70th annual American Epilepsy Society (AES) Annual Meeting in Houston, TX. This conference hosted over 4,000 clinical and research specialists from all over the world, along with representatives from the national Epilepsy Foundation and its affiliates. AES is the largest annual epilepsy conference in the world and sessions provided the most extensive education on everything epilepsy. Everyone in attendance had the same goal of working toward a world without epilepsy.

During the meeting, the national Epilepsy Foundation’s (EF) Board of Directors and Management and Operations Team also held meetings and I was in attendance as business was conducted. Dr. Jacqueline French, Chief Scientific Officer of the EF, shared that the AES had just accepted recommendations by the International League Against Epilepsy (ILAE) to revise the current classification of various seizure types. These revisions involve partial and generalized seizures and were accepted by the ILAE the week prior. Our current classification system has been in place since 1981, however current research and treatment options have led epilepsy specialists and researchers from all over the world to feel these revisions would be advantageous to make diagnosing and classifying seizures more accurate and easier. You will see these revisions reflected in our materials as they are updated, but in the meantime please go to http://www.epilepsy.com/article/2016/12/2017-revised-classification-seizures to read more about this new seizure classification system.

I would like to offer a most sincere THANK YOU to those who participated in the annual Speak Up Speak Out Kentucky Epilepsy Day at the Capitol in Frankfort on February 23rd. I hope you felt empowered by your advocacy efforts and that you know how much your support in helping to raise epilepsy awareness among Kentucky’s legislators meant to all of us at the Epilepsy Foundation of Kentuckiana.

Your epilepsy story matters and is what helps drive our efforts as we advocate to improve access to care for everyone living with epilepsy in Kentucky. We believe every tool in the toolbox should be available in the fight against epilepsy. This includes products derived from cannabidiol – whether it comes from hemp or marijuana. Together, we worked diligently to get language in House Bill 333 passed by the General Assembly that would allow Epidiolex, a European product derived from marijuana to be prescribed by Kentucky physicians once the FDA approves it and it is scheduled by the DEA. This medication is intended for those living with devastating and severe forms of epilepsy. Thanks to your efforts, we are pleased to announce that HB 333 is on its way to Governor Bevin to be signed into law.

I would also like to provide an update regarding our joint advocacy efforts with the national Epilepsy Foundation and Epilepsy Foundation of Indiana. As I reported before, a change was made in early 2016 to Indiana Medicaid’s fee for service and managed care programs that limited access to FDA approved epilepsy drugs used to treat children and adults. As a result, these changes put many individuals living with epilepsy in Indiana at risk of not being able to receive the potentially life-saving medications their physician felt would be best to combat their seizures. I am happy to report that an agreement has been reached by Indiana’s Family and Social Services Administration (FSSA), who oversees Indiana Medicaid, the Epilepsy Foundation, and Epilepsy Foundations of Indiana and Kentuckiana, along with other stakeholders. This agreement allows neurologists and epileptologists who sign up with Indiana’s Gold Card Program full access to the arsenal of FDA approved drugs to treat pediatric and adult patients. We feel this was a major victory since many enrolled in the Medicaid program are patients who suffer from debilitating and life threatening seizures and should be under the care of a neurologist or epileptologist.

In closing, our advocacy work continues. Rest assured that the Foundation will always fight for you and the many others living with epilepsy in Kentucky and southern Indiana.

Happy Spring!

– Deb
Amy Collier Joins Staff

The Epilepsy Foundation of Kentuckiana is thrilled to announce that Amy Collier has joined our team as a social worker. Amy has over 15 years of experience in the field of social work, working with children, adults, and families in the community, school, and various settings. Amy earned her Masters of Social Work at Spalding University and is a Certified Social Worker (CSW) in Kentucky. Amy is looking forward to serving our clients and help support, advocate, and partner with others to get individual needs met and bring the community together.

Amy lives in Louisville with her husband and two elementary-age children. Amy enjoys being active and spending time with her family. Amy is excited to join the team and is eager to learn and be a part of the many valuable events and activities at the Epilepsy Foundation of Kentuckiana. Please feel free to contact Amy at 502-637-4440 / 866-275-1078 x15 / acollier@efky.org with your questions and she will work diligently to support you and help you find solutions. You are not alone, and together, she can work with you to improve knowledge, find acceptance, and move forward to reach a positive and hopeful outlook.

Join Us for Epilepsy Education Day in Lexington on April 29

Join us on Saturday, April 29, 2017 from 9:00 a.m. – 2:00 p.m. at the Hilary J. Boone Center (500 Rose Street, Lexington, Kentucky) for a day of Derby-themed 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 by April 22. 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 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!
The 7th annual Expressions of Hope Gala was a smashing success! Over $106,000 was raised through sponsorships and the 320 guests in attendance and we were exceptionally proud to have raised this amount to directly benefit the programs and services of the Epilepsy Foundation of Kentuckiana. The 2016 Expressions of Hope theme was “007” and many arrived dressed in their James Bond finest. The event was held on November 4, 2016 at the Mellwood Arts Center. Guests were treated to a collection of spectacular live and silent auction items, a delicious sit-down dinner prepared by Masterson’s Catering, and array of spirits and wines, an open bar and bourbon bar, entertainment by the band, No Problem, Wine Cork Pull, Heads or Tails game, Roulette Wheel, and a photo booth.

Courtney Sherrell-Johnson gave a moving testimonial about her mother Peggy, who hid in the shadows of epilepsy. It was not until attending the Louisville Walk that she realized she was not alone in her journey. Unfortunately, Peggy lost her life to sudden unexpected death in epilepsy (SUDEP) in 2010, leaving her family in shock because they were not aware of SUDEP. After suffering this tragic loss, Peggy’s family decided to do something to help educate others about the consequences of epilepsy and created the Peggy Sherrell Memorial Golf Scramble and Peggy Sherrell Memorial Scholarship programs. To date, they have raised over $95,000 for the Epilepsy Foundation of Kentuckiana.

The Foundation also presented four #DareToChangeLives Awards. These awards were presented to Kosair Charities, Lauren Vassil, Senator Dan Seum, and Quantum Graphix.

The Kosair Charities award was accepted by Jerry Ward, chairman of the Kosair Charities board of directors. Kosair Charities does so much to protect thousands of children living with epilepsy and other medical conditions in Kentucky and southern Indiana. Lauren Vassil, a long-time Foundation volunteer, a NICU nurse at the University of Kentucky, and mother of daughter with severe epilepsy. Lauren has spent countless hours assisting Foundation staff with walks, education programs, Studio e art therapy programs, and is the coordinator for the Kentuckiana affiliate for the Public Policy Institute/Teens Speak Up program in Washington, DC. Senator Dan Seum is a fierce advocate for the Epilepsy Foundation of Kentuckiana’s signature veterans program, Operation Outreach, in Frankfort. He works diligently to ensure that we continue to receive state funds for this program. Quantum Graphix has provided the Foundation with hours of donated graphic design work, printing services, and cash donations that have been vital to our programs and services for many years. We would like to congratulate Kosair Charities, Lauren Vassil, Senator Dan Seum, and Quantum Graphix and extend a huge thank you for all they do to support the work of the Epilepsy Foundation of Kentuckiana.

Over the past 24 years, the EFKY has been steadfast in providing help and hope to the more than 153,000 children, adults, and veterans with epilepsy and seizure disorders in Kentucky and southern Indiana. Those living with and affected by this very misunderstood and many times feared neurological condition can rely on an array of advocacy, education, outreach, and support service programs available at no cost to them, because of events like the Expressions of Hope Gala.

The Foundation would like to thank all who planned, sponsored, donated auction items, attended, and/or volunteered to work at the 2016 Expressions of Hope Gala.

We would like to give a HUGE thank you to Kosair Charities for giving a $20,000 match to our appeal; Co-Chairs: Linda O’Bryan, Liz Sapata, Valerie Speth, and Lisa Wallace; and committee members: Kristen Bremer, Barry Elliott, Missy Lawless, Bill Menish, Beth O’Daniel, and Dee Dee Taylor for making this year’s event the best and biggest yet!

Thank you to our sponsors!
2017 Studio e: The Epilepsy Art Therapy Program

If you are an adult living with epilepsy, we hope you will join us for one of our 2017 Studio E: The Epilepsy Art Therapy programs. This year, the Foundation will host our sixth program in Louisville at the Epilepsy Foundation of Kentuckiana office every Saturday from July 8 – August 12 from 10:00 a.m. – 1:00 p.m. We will also offer our second program in Lexington at the University of Kentucky Albert B. Chandler Hospital every Saturday from July 15 – August 5 from 10:00 a.m. - 1:00 p.m.

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 502-637-4440 / 866-275-1078 x14 / bstivers@efky.org by July 6.

Studio e: The Epilepsy Art Therapy Program is sponsored by Lundbeck.

Tina Thompson - ZentangleQuilt

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 502-637-4440 / 866-275-1078 x14 / bstivers@efky.org.
Veterans Views: Serving the Military Culture
by John Mustain, MSSW, Director of Veterans Outreach

Spring is here! It is time to enjoy the outdoors and all its beauty.

My family and friends are often heard asking me, “What is it like working with veterans?”

For me, and perhaps other veterans, the above question seems on the surface completely illogical. Veterans are humans. We have bodies and brains. We have hopes, dreams, and desires like anyone else. We have spouses, children, and grandchildren that we care about. There isn’t a difference between veterans and everyone else.

Or is there?

While there may be no biological differences between veterans, there is a huge difference in terms of culture. Webster dictionary defines “culture” as “the set of shared attitudes, values, goals, and practices that characterizes an institution, organization, or a corporate culture focused on the bottom line.” Indoctrination of military culture begins on the first day of boot camp, and it never ends. Our “shared attitudes, values, goals, and practices” are drilled into our heads and psyche…loyalty, honor, and absolute commitment to our sisters- and brothers-in-arms. Many professional providers struggle trying to administer services to veterans. These providers cannot imagine what the veterans they are working with have been through, they don’t understand their motivations, and often don’t even understand their language.

Operation Outreach is trying to narrow the distance between the veteran and the provider by joining with Kentucky’s varied mental health associations and a few of the Kentucky governmental offices to develop criteria for designating clinicians in Kentucky as “Military Qualified.” Our work is still very early in its development, but Operation Outreach is excited to be a part of this effort. Soon Kentucky’s veterans will be cared for with a greater sense of accuracy and competence. All veterans deserve great care, but especially veterans who are living with post traumatic epilepsy. We work diligently to raise awareness of this condition among veterans, but we hope you will also remember to share this information with your friends, families, and co-workers. Thank you for helping us advocate for Kentucky’s veterans with epilepsy. For more information regarding our programs for veterans, please visit www.SaluteYourHealth.org / www.KentuckyVeteransoftheYear.org.

Bounce Out the Stigma Basketball Camps

In July, the Epilepsy Foundation of Kentuckiana will host Kentucky’s fourth 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 registration is 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 Donna Wooten, development manager 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 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 and there 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 www.bounceoutthestigma.org.

Registration is now open at www.efky.org. To get more information or to register via phone/e-mail, please contact Donna Wooten, development manager, at 502-637-4440 / 866-275-1078 x17/ dwooten@efky.org.

This camp is proudly partnered with and associated with:

Lexington
July 25 & 26
9:00 a.m. – 2:00 p.m.
Immanuel Baptist Church
3100 Tates Creek Road

Louisville
July 27 & 28
9:00 a.m. – 2:00 p.m.
St. Paul United Methodist Church
2000 Douglas Boulevard

OPERATION OUTREACH

If you are a veteran experiencing seizures, are in need of assistance, or would like to learn more, please contact John Mustain, MSSW at 502-637-4440 / 866-275-1078 x16 / jmustain@efky.org.

Stigma is NOT a Physical Limitation, Nor an Illness. It is a ‘LABEL’ Applied BY OTHERS, Based on THEIR Perception, That Says ‘YOU Can’t’ – “Mighty Mike” Simmel
2017 Peggy Sherrell Memorial Scholarship Award

The Epilepsy Foundation of Kentuckiana is now accepting applications for the 2017 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 postmarked by June 7, 2017.

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.

2017 Shannon O’Daniel Memorial Scholarship Award

The Epilepsy Foundation of Kentuckiana is now accepting applications for the 2017 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 502-637-4440 / 866-275-1078 x14 / bstivers@efky.org or download a copy at www.efky.org.

Mailed Application Submission Deadline:
MUST be postmarked by June 7, 2017.

Shannon O’Daniel was a senior in college and just credits away from graduating when she died from what was attributed to SUDEP (Sudden Unexplained 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.

Thank You, Kosair Charities!

Kosair Charities is a tremendous blessing to children with special needs and the agencies that partner with them. Their Making Seasons Bright Luncheon was evidence of this when 50 partnering agencies were invited to attend this very special Luncheon with members of Kosair Charities dedicated Board of Directors, amazing staff, and Santa Claus himself. Each agency was surprised with a beautiful red gift box with explicit directions to not open until told. Jerry Ward, Chairman of the Board, then instructed all to open their box and the room was immediately filled with cheers of joy and utter surprise as Kosair Charities presented each agency with a check, in total giving over $1.6 million dollars. The Epilepsy Foundation of Kentuckiana cannot begin to express how grateful we are to Kosair Charities for our continued partnership and commitment to improve the lives of the more than 50,000 children living with epilepsy and seizure disorders in Kentucky and southern Indiana. Thank you, Kosair Charities!

Deb McGrath and Randy Cox, President of Kosair Charities

Santa, Donna Weather, Jerry Ward, and Deb McGrath
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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. It 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 KENTUCKIANA’S YOUTH EPILEPSY ALLIANCE IS SUPPORTED BY A GRANT (Y74C) FROM KOSAIR CHARITIES.

UPCOMING YOUTH EPILEPSY ALLIANCE! EVENTS

Saturday, April 15
Making pizzas at Wick’s Pizza Middletown
12717 Shelbyville Rd., Louisville
11:00 a.m. - 12:30 p.m.

Saturday, May 13
Learning a dance routine at Dreamz Dance Company
8603 Citadel Way, Suite 108, Louisville
10:00 a.m. - 12:00 p.m.

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

MAKE A DIFFERENCE by becoming a sponsor, registering your team, or playing individually in the 12th Annual Golfer’s Gauntlet on Monday, April 24, 2017. All participants will enjoy a fun-filled day at Fuzzy Zoeller’s Covered Bridge Golf Club in Sellersburg, Indiana, a hearty breakfast, 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 to individuals affected by epilepsy living in Kentucky and southern Indiana. To register or for more information, please go to www.efky.org.