You may have noticed that the Epilepsy Foundation of Kentuckiana has gotten a fresh new look! For the last 21 years, the Epilepsy Foundation of Kentuckiana, featuring its unwavering red flame, has dared to provide the best education, advocacy, outreach, and support services for people living with epilepsy and their families in Kentucky and southern Indiana. While Epilepsy Awareness Month is every month for the Foundation, epilepsy’s official awareness month is November. This year, we joined the national office, affiliates across the nation, and Rick Harrison from the hit show Pawn Stars on History Channel, in launching our fresh new purple and red logo, as well as an awareness campaign like you have never seen before.

This campaign, #DareTo, dares the public to help break barriers blocking many people living with seizures from reaching their fullest potential, challenging the general public to better understand epilepsy, to know how to recognize seizures, and to learn proper first aid. For people living with epilepsy “#DareTo” focuses on improving understanding and management of seizures, including exploring the best available treatment options. The campaign, and the new logo, underscores the Foundation’s commitment to be bold and aggressive in accelerating change for people living with epilepsy.

Also, beginning in November, a national PSA featuring Pawn Stars Rick Harrison, who had epilepsy as a child, premiered on the A&E Networks. Rick has graciously made a PSA for each Foundation affiliate and we will be pitching our PSA to TV stations and cable companies throughout Kentucky and southern Indiana to air. If you have not yet seen the PSA, be sure to go to www.efky.org and check it out. If you have a connection to a cable company and are willing to help open the door for us, please contact Events Manager Gary Zortman at 502-634-4440 / 866-275-1078 x17 / gzortman@efky.org.

The Foundation would also like you to #DareTo become SUDEP aware. Each year, more than 1 out of 1,000 people with epilepsy die from SUDEP, or Sudden Unexpected Death in Epilepsy, which is said to occur when a person with epilepsy dies unexpectedly and was previously in their usual state of health. The death is not known to be related to an accident or seizure emergency such as status epilepticus, and when an autopsy is done, no other cause of death can be found.

Unfortunately, over the last 21 years, we have had to grieve with a number of families as they mourned the loss of a loved one to SUDEP. It is by far the most difficult thing we do as staff. We have also noticed that when asked, many family members were not aware of SUDEP, had not discussed it with their neurologist, or even realized that the possibility existed.

We know it is a difficult conversation to have, but one that cannot be ignored. We Dare You to become more aware of SUDEP and to learn the facts so that more care can be taken to prevent SUDEP from occurring to you or your loved one. We also encourage you to discuss your risk of SUDEP with your neurologist. For more information about SUDEP please go to http://www.epilepsy.com/get-help/about-sudep-institute. Also, be sure to read Client Perspectives - PAME Conference 2014 on page 4 of this newsletter to hear about what two of our clients learned at the Partners Against Mortality in Epilepsy conference in Minneapolis, Minnesota this past June.

The Epilepsy Foundation of Kentuckiana works tirelessly raise epilepsy awareness throughout Kentucky and southern Indiana to improve the quality of life for those 90,000 individuals living with epilepsy. Just think what could happen if every single person reading this newsletter #DaredTo raise epilepsy awareness in their everyday life? It could be epic! We ask that you take a minute every day to #DareTo talk about it! The Epilepsy Foundation of Kentuckiana Dares You!
It is hard to believe another year is about to pass us by! If you are like me, rather than looking to the past, I would rather look ahead to the coming year and plan how I am going to make this New Year even better! This is just my competitive nature and I think I come by this honestly with my German ancestry... This said, having a competitive spirit certainly helps when advocating for the more than 90,000 children, adults, and veterans living with and affected by epilepsy in Kentucky and southern Indiana. It is with great honor that I serve in this vitally important role - speaking up and speaking out for those whose voices have been stifled far too long from the myriad of stigmas and misconceptions surrounding epilepsy that still exist today.

In conjunction with the national Epilepsy Foundation, the Epilepsy Foundation of Kentuckiana and 47 other independent Epilepsy Foundation affiliates, we just unveiled a new logo and bold and unwavering commitment to serve the nearly 3 million men, women, and children living with epilepsy in America. Because one in 26 Americans will develop epilepsy in their lifetime, we must act now to eradicate the barriers limiting full access to care, including high costs to treat seizures. While the Affordable Care Act and Kynect have made good strides toward this, it is not enough. Persons with epilepsy should not have to settle for limited access to life-saving drugs that may or may not work to control their seizures. The “fail first” mentality is like playing Russian roulette when it comes to seizures, especially since you never know when or where the next one will strike… many times, leaving you completely defenseless to suffering a serious injury or even death. Asking persons to fail first puts them in grave danger of having a life-altering or life-ending seizure. This is no longer acceptable. I have to ask, when did the cost to provide appropriate healthcare take precedence over the person with the medical condition?

In this issue of the Illuminator, you will read about the national “#DareTo” campaign. I strongly encourage you to get behind this national campaign as well as dare your family and circle of friends, co-workers, teachers, and those in your social media outlets to join you. Rick Harrison of Pawn Stars has taken the dare, as has Coach Kill of the Minnesota Gophers, and “Mighty Mike” Simmel, Harlem Wizards star and founder of Bounce Out the Stigma. My #DareTo you is to take part in the Foundation’s Speak Up! Speak Out Kentucky Advocacy Day on February 18, 2015 and let your voice be heard in Frankfort to “Cap the Co-Pay” and remove anti-seizure drugs from specialty tiers set up by insurance providers. Your healthcare provider should not have to choose from a short list of medications to effectively treat your seizure disorder, and you should not have to settle for a medication that does not provide optimal results or are so costly that you are unable to afford them.

For more information or to get registered to attend the 2015 Speak Up! Speak Out Kentucky Advocacy Day, please visit www.efky.org or contact me (502-637-4440 / 866-275-1078 x13 / dmcgrath@efky.org) to be part of this very important day as we #DareTo urge our legislators to help the 90,000 Kentuckians with epilepsy and seizure disorders live up to their potential!

Wishing you the best this Christmas and Holiday season! – Deb

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**MISSION STATEMENT**

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

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**MISSION STATEMENT**

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

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**Speak Up! Speak Out Kentucky Advocacy Day**

You are invited to join the Epilepsy Foundation of Kentuckiana for its annual Speak Up! Speak Out Kentucky Advocacy Day at the Kentucky State Capitol in Frankfort, Kentucky on Wednesday, February 18, 2015 from 9:00 a.m. - 4:00 p.m.

Let your voice be heard as we #DareTo urge our state legislators to support the more than 90,000 children, adults, and veterans living with epilepsy in Kentucky. Register to attend at www.efky.org or contact Deb McGrath at 502-637-4440 / 866-275-1078 x13 / dmcgrath@efky.org.

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**From the Executive Director**
Epilepsy Foundation of Kentuckiana Donation

Donor’s Name ________________________________
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YOUR CONTRIBUTION WILL TRULY MAKE A DIFFERENCE!
Client Perspectives - PAME Conference 2014

Sudden Unexpected Death in Epilepsy (SUDEP) is now recognized as the leading cause of mortality associated with epilepsy excluding status epilepticus (seizures that do not stop on their own) and other underlying diseases. Despite the importance of the problem and the implications for intervention, SUDEP had not received widespread professional attention in the United States prior to the mid-2000s. The first Partners Against Mortality in Epilepsy (PAME) conference was held in 2012 for clinicians, families, and researchers to (1) promote understanding of the latest developments in SUDEP and epilepsy mortality research; (2) stimulate ideas and collaborations to advance discovery; and (3) hasten efforts to increase public awareness and education for professionals and people living with epilepsy. The Epilepsy Foundation of Kentuckiana selected two individuals impacted in different ways by epilepsy, Cortney Johnson and Laureen Vassil, to attend the second PAME conference in June 2014. Here is what they learned at the conference in their own words.

Cortney Johnson
Daughter to a Mother with Epilepsy

The PAME conference was held in Minneapolis, Minnesota in June. This conference is truly a “meeting of the minds,” bringing people in from all over the world to discuss mortality in epilepsy. PAME does something that most organizations do not do, they include families and advocates with all of the doctors and scientists. What an amazing concept! Many of the families there had lost children from less than a year ago to 20 years ago. Some of the families were able to tell their stories to everyone at the conference. There seemed to be an underlying similarity between all of the stories, no one knew that death could occur from having a seizure without a secondary factor (i.e. drowning, accident).

One of the epileptologists said that the families telling their stories were a critical part of the conference because it gave the doctors and scientists even more motivation to find better treatments, prevention, and one day a cure. It was very therapeutic for me to meet with some of the families in the evenings and discuss their stories, as my mother died of SUDEP in 2010. I was inspired by the families at the conference to continue my family’s efforts in raising money to find a cure for epilepsy.

The advancements in research were astounding, sometimes over my head, but astounding. The research in genetics is close to a big break. They have marked a few specific genes linked to epilepsy and are continuing to search for more. Much of the advancements have been found using patients with Dravet syndrome. A great amount of the research also links patients with epilepsy with cardiac conditions unknown to the patient or the doctors. The neurologist and epileptologists encouraged the doctors at the conference to also check for cardiac abnormalities when doing the annual exam. They also discussed a link between mental illness and people living with epilepsy. Often the two are linked and can cause adverse effects on lifestyle and medication adherence.

One of the major disconnects is often the lack of open communication between doctors and patients. Doctors do not want to tell their patients that they can die from epilepsy which leads to some not understanding the seriousness of living with epilepsy. The information is not to be a scare tactic, but an informative conversation about the risks of the disease. Adherence to medication, maintaining regular sleep, and limiting alcohol consumption are all ways to help prevent having seizures that can lead to SUDEP.

The SUDEP Institute is working with a multitude of organizations to gather data and they have created a North American SUDEP Registry with NYU. The more information collected will help researchers find better treatment options, and hopefully one day a cure for epilepsy. The PAME conference occurs every 2 years and with the advancements presented this year, I foresee phenomenal results and new treatment options presented in 2016.

Laureen Vassil
Mother of a Daughter with Epilepsy

I had the privilege of representing the Epilepsy Foundation of Kentuckiana at this year’s PAME conference in Minnesota. I am also a parent of a 15 year old who suffers from uncontrolled and debilitating seizures. This bi-annual conference was amazing. There were physicians, researchers, Foundation affiliate representatives, and families all together for one purpose: to prevent SUDEP. The researchers presented some of the ideas that scientists, both nationally and internationally, are studying. This included cardiac, respiratory, and genetic links relating to SUDEP. They feel that some of these links may have a role in SUDEP and if found may help prevent further cases.

The biggest impact on me was the families that have been affected. Some of them shared their story with the group. These stories were heartbreaking. Most of them did not know that this could happen. The message from the families was that physicians need to educate families/patients about SUDEP and the risks involved. The conversations between physicians and patient/families is crucial. Medication adherence, lifestyle, and awareness all can play a role in preventing SUDEP. Knowledge is power. The research is out there, together we can make a difference.

Thanks to all of the conference planning partners for putting this conference together and thanks to the Epilepsy Foundation of Kentuckiana for allowing me to attend.

Pharmacy Delivers to Your Door—Many Affordable Anti-Seizure Medications Available

Thrifty White Pharmacy out of North Dakota is a full service pharmacy that is now stocking a large variety of generic anti-seizure medications at affordable prices. You can expect consistent access and affordably priced generic medications. Consistent manufacturers mean no therapeutic switching, which for many can be a problem. Best of all, your medications will be delivered to your door and you will receive a personal call every 27 days to make sure you are responding well to your medication and to remind you of any refills, etc. They accept Medicare, Medicaid, and most major insurance providers, as well as offer management of prior authorizations. They can also package medication in timed doses. For more information, or to get your prescriptions through Thrifty White Pharmacy, please call them toll-free at 844.432.7891.
**Veteran Views – Kentucky Veterans of the Year Program Raises Awareness of Veterans, Post Traumatic Epilepsy, and Seizures**

Colonel (ret) Pam Stevenson, the first female JAG Officer and Judge Advocate in military history, was the featured speaker at the Kentucky Veterans of the Year Banquet.

The stigma associated with seizures and epilepsy prevents many people from talking about the disorder and from being receptive to the possibility that their symptoms could, in fact, be seizures. The idea that a person, a loved one, or a respected veteran is at risk for developing epilepsy or seizures scares people and makes them feel uncomfortable and the conversation is shut down. Yet, the conversation must be had. It is vitally important to the future health of America’s veterans. Recognizing the reluctance of people to talk about epilepsy and seizures, the Epilepsy Foundation of Kentucky’s Operation Outreach program initiated the Kentucky Veterans of the Year program.

In December of 2013, Operation Outreach met with a publisher who had retired from the newspaper industry and began his own monthly periodical. The expressed purpose of the meeting was to discuss how to get Operation Outreach’s message to the public at-large and take advantage of his years of experience in reaching the public. Many ideas were discussed, but we always kept returning to the idea of a Veteran of the Year program. We decided to do some research and found Kentucky has never had a program which honored a veteran of the year. We also discovered the United States did not have any other states that had a Veteran of the Year program. So, we decided it was time for Kentucky to take the lead. Over the course of the last year, Operation Outreach has worked diligently to raise awareness of this program to encourage nominations for the award. On Veteran’s Day eve, November 10, 2014, Operation Outreach hosted the first ever Kentucky Veterans of the Year banquet where we honored one female (Lindsay Gargotto, Louisville) and one male (Dr. James Thurman, Lexington) as Kentucky Veterans of the Year. The winners were selected from 30 nominations.

One might wonder how a Kentucky Veterans of the Year program raised awareness of veterans and their increased risk of developing epilepsy and seizures. The answer is it created three new streams of information. First, the Kentucky Veterans of the Year program attracted the attention of the media across the Commonwealth. Operation Outreach was interviewed by several television and radio stations in Louisville, Lexington, Bowling Green, and even in southern Indiana. Every interview began with Operation Outreach explaining the increased risk of epilepsy and seizures Kentucky veterans are facing.

Second, the Kentucky Veterans of the Year program opened another opportunity for internet and social media. Operation Outreach created a website in order for people to nominate their favorite Kentucky veteran (www.kentuckyveteransoftheyear.org). An information page on the website about veterans and seizures allowed people to read and watch videos about veterans and seizures as they explored the website. We also created a Kentucky Veterans of the Year Facebook page (https://www.facebook.com/pages/Kentucky-Veterans-of-the-Year/1377144505882828) where we invited people to go to our website.

Finally, the Kentucky Veterans of the Year program allowed Operation Outreach greater access to Kentucky elected officials and key stakeholders in Kentucky’s veteran population. Governor Steve Beshear sent his representative, Kentucky Department of Veteran Affairs Deputy Commissioner Margaret Plattner, to present the awards. Congressman John Yarmuth attended the banquet and made a few brief remarks, Senator Rand Paul sent his representative, Jennifer Decker, and Louisville Mayor Greg Fischer attended the banquet with his father (a veteran) and made some brief remarks. Additionally, there were eleven veteran service organizations represented at the banquet as well. KDVA Commissioner Heather French Henry also sent a special video message for our award winners and guests. Everyone there heard about veterans’ increased risk of developing epilepsy and seizures.

In the military, the phrase, “improvise, adapt, and overcome” is quite prevalent. Essentially the phrase means there is nothing…no situation, no enemy, no task…that cannot be conquered with a little determination and ingenuity. The Kentucky Veterans of the Year program is one way in which Operation Outreach is trying to break down the barriers and have a conversation about veterans and seizures.

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**Operation Outreach Coordinator and Chairman of the Kentucky Veterans of the Year John Mustain is joined by Kentucky’s Female and Male Veterans of the Year, Lindsay Gargotto and Dr. James Thurman following the Banquet.**

Sue Peney is recognized at the Kentucky Veterans of the Year Banquet for being a Gold Star Mom. Sue became a Gold Star Mom when her son was killed in Afghanistan in 2010.

Congressman John Yarmuth congratulates the Kentucky Veterans of the Year.

Plattner, to present the awards. Congressman John Yarmuth attended the banquet and made a few brief remarks, Senator Rand Paul sent his representative, Jennifer Decker, and Louisville Mayor Greg Fischer attended the banquet with his father (a veteran) and made some brief remarks. Additionally, there were eleven veteran service organizations represented at the banquet as well. KDVA Commissioner Heather French Henry also sent a special video message for our award winners and guests. Everyone there heard about veterans’ increased risk of developing epilepsy and seizures.

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**Operation Outreach**

Helping Veterans Open Doors of Hope...

www.kdva.org

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.
A separate program was also offered to children and siblings affected by epilepsy. A highlight of the children’s program was the expressive art program led by a licensed professional clinical counselor. The children had fun creating, while talking about how epilepsy affects their lives.

In addition to the programming, participants enjoyed delicious bagels and boxed lunches from Panera, thanks to our sponsors. They also received the opportunity to meet representatives from our sponsoring organizations and most importantly, other people who are also living with and affected by epilepsy, reaffirming that they are not alone in their journey with this neurological condition.

The Epilepsy Foundation of Kentuckiana staff would like to thank all who attended and hope you had a wonderful educational experience and that you will all join us again next year!

### Thank You to the Following Presenters, Facilitators, Exhibitors, and Volunteers

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### 2014 Peggy Sherrell Memorial Scholarship Recipient - Isabella Jordon McGlone

Isabella Jordon McGlone

The Epilepsy Foundation of Kentuckiana is excited that Isabella Jordon McGlone of Grayson, Kentucky was selected as the 2014 recipient of the Peggy Sherrell Memorial Scholarship. Isabella is a 2014 graduate of East Carter High School in Grayson. She began her college career this semester at the University of Kentucky (UK) to pursue a Bachelor’s degree in Japanese language and literature with plans of becoming a translator. In her free time, she enjoys writing novels (unpublished, of course), playing video games, and studying psychology. She has an interest in people, personalities, and human interaction, which assists her interest in video games and writing.

Isabella’s seizures began in the 5th grade, but she was not officially diagnosed with epilepsy until the 7th grade. Since then, her life has been complicated by multiple seizure types that have forced her to plan many days around her intense seizure activity. On bad days, she draws strength from faith and laughter and refuses to let her seizures rule her mentally and physically. She chooses to live in the moment and keep believing in her ability to move forward and feel that laughter helps keep her positive. Her motto is, “you have only lost hope when the only thing you can see is negativity.”

The Foundation is so proud of Isabella and all that she has accomplished despite the challenges she has and continues to face with her epilepsy. We hope you are able to return to school very soon and that you always keep fighting to achieve your dreams!

I’m happy to able to use this opportunity to be an example to others with similar struggles. It’s easy to think no one understands what it’s like and I’m glad to have been given the opportunity to let people know they aren’t the only ones struggling with epilepsy.”

The Peggy Sherrell Memorial Scholarship is administered by the Epilepsy Foundation of Kentuckiana in honor of Peggy Sherrell, who died of Sudden Unexpected Death in Epilepsy (SUDEP) in 2010. Peggy felt that education was extremely important and her family determined that a scholarship would be the perfect way to carry on her legacy.
The Epilepsy Foundation of Kentuckiana congratulates Alexander Story for being awarded the 2014 Shannon O’Daniel Memorial Scholarship. Alexander is a 2014 graduate of Paducah Tilghman High School in Paducah, Kentucky and is now attending his first semester at Texas A&M University in College Station, Texas. He is focusing his studies on nuclear engineering.

Alexander knew what he wanted to do when he began high school. Inspired by his grandfather, a Korean War veteran, he dreamed of attending the United States Naval Academy to obtain a career in engineering and to serve his country. To achieve this goal, he focused on academics, extracurricular activities, and the JROTC program at his high school. He worked hard and it paid off. At the end of his freshman year, Alexander was celebrating great grades, had been elected to student council, and even received an award of merit from the Surface Navy Association for an outstanding first year cadet in his JROTC unit. Just as he felt like he was getting his career plans on track, he learned the hard way that the storms of life can force you to change direction quickly.

At the end of his freshman year, Alexander began experiencing some strange symptoms. He felt like he was “freezing during homework, like if you were hitting the pause button” followed by an inability to concentrate. After some time, he eventually received the diagnosis of epilepsy and at first, he could not even say the word. The reality soon hit that he could no longer attend the U.S. Naval Academy, sinking him into a deep depression. During this time, he withdrew from family and friends and could not eat for days on end. During his sophomore year, the seizures, effects of his medication, and his depression soon damaged his GPA and caused him to drop out of his extracurricular activities. After a while, he started to feel better and found himself considering other options for college. He began the slow process of rebuilding his severely damaged GPA and relearned missed coursework. After his school work was back on track, he rejoined many of his extracurricular activities, including running and his church youth group.

Slowly, Alexander began to re-chart his course. He began to see that service to his country and community could come in a different form, perhaps by him working at one of the national laboratories. He persevered although the side effects from his medications affected his concentration and memory and at times he felt he would never get back on course. Alexander also struggled as his teachers lacked understanding of his condition and felt that he just needed to concentrate harder to learn the material. Throughout it all, he held on to one piece of advice that kept him steady through the difficult times: “God laughs at our plans. While I may have the best plan in the world that I can come up with, it pales in comparison with the plans that God has for my life.”

The Foundation would like to congratulate Alexander for his epic comeback and for learning to make the best out of the complications that epilepsy can present. Good luck and best wishes in your future endeavors!

Shannon O’Daniel was a senior in college and just credits away from graduating when she died from 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 death, this scholarship was created to honor Shannon and her achievements.

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Epilepsy Foundation of Kentuckiana

As we look back at the over 21 years of service the Epilepsy Foundation of Kentuckiana has been serving children, adults, and veterans with epilepsy, we are truly honored by the generous spirit of giving our donors have provided to the Foundation. Year after year, your generosity has allowed us to continue to provide support through education, advocacy, outreach, and research for individuals and families affected with epilepsy and seizures throughout Kentucky and southern Indiana. We hope you have found and continue to find comfort in knowing that you are not alone in the fight against epilepsy, and remember that you have a devoted team who is ready and willing to offer help, hope, and support at a moment’s notice. We are here for you and your family.

We strive to improve the quality of life of those living with this very misunderstood and many times feared neurological condition by providing all services at no charge. However, we could not do this without your generous support and ask that you please help the Foundation continue its mission by making a tax deductible donation before the end of 2014. We appreciate any gift, big or small, and please know that your donation will help make a difference so not another moment or life is lost to seizures. Donations can be made online at www.epky.org or by mail (Epilepsy Foundation of Kentuckiana, 982 Eastern Parkway, Louisville, KY 40217).

We hope you and your family have a healthy and happy Holiday season and thank each one of you for continuing to support the Foundation.
Join the Foundation’s Young Adult Group

Are you a young adult and affected by epilepsy? Do you feel like you are the only person your age that is living with epilepsy? Do you want to speak up and speak out about epilepsy in your community, but do not know where to get started? We have got you covered! The Foundation understands that life with epilepsy can be different from that of your peers and knows that it can be isolating at times.

We want young adults with epilepsy to know they are not alone so in 2015, we are starting a group just for you, led by volunteer Taylor Wallace, also a young adult living with epilepsy. We will get together and have fun, but also learn about how to advocate for yourself and others with epilepsy.

Our first meeting will be in January. If you are interested in coming to this meeting or joining the group, please contact Executive Director Deb McGrath at 502-637-4440 / 866-275-1078 x13 / dmcgrath@efky.org, or sign up at www.efky.org.