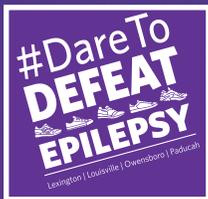




ILLUMINATOR

**EPILEPSY
FOUNDATION**
Kentuckiana

END EPILEPSY
Let's Use Our Brains to End Epilepsy.®



2019 Walk #DareTo Defeat Epilepsy Recap

The Epilepsy Foundation of Kentuckiana would like to say THANK YOU to all of you who participated in the 2019 Walk #DareTo Defeat Epilepsy in Owensboro, Louisville, Lexington, and Paducah. Thank you so very much to the over 600 walkers (both live and virtual) who laced up their shoes or greased their wheels and our amazing sponsors! Because of you and your incredible efforts, a total of \$92,000 was raised!

Those of you who participated truly are SUPER HEROES in the fight to defeat epilepsy! The funds raised through the 2019 Walk #DareTo Defeat Epilepsy will support the vital education, outreach, advocacy, and direct support services the Foundation provides to those in need. These services are designed to improve the quality of life for the over 153,000 children, adults, and veterans living with epilepsy in Kentucky and southern Indiana and their family members as we help them move closer to overcoming the many challenges and devastating consequences of epilepsy.

Please see page 5 for photos and information on next year's Walk!

Register Now for the 2019 End Epilepsy Statewide Conference

Are you living with epilepsy or a caregiver to a person living with epilepsy or seizure disorder? Would you like to learn more about this neurological condition? If so, we hope you and your family will join us for the 2019 End Epilepsy statewide conference. This **FREE** program will kick off November as National Epilepsy Awareness Month and is designed for children and adults affected by epilepsy and their families. This year's conference will be held on **Saturday, October 19, 2019** at the **Hilton Garden Inn Louisville Airport** (2735 Crittenden Drive, Louisville, Kentucky) from **8:00 a.m. – 2:00 p.m.** A free breakfast and lunch will be served to conference participants. Free parking is provided.

The 2019 End Epilepsy conference is for individuals school age and up. The program will feature a full day of educational sessions presented by experts in the field of epilepsy. These sessions are designed to help you understand more about living with seizures and how to better cope with this neurological condition. Please go to www.efky.org in the coming weeks for a complete agenda. Also, please note that if there are concurring sessions that you would like to attend. Foundation staff would like to encourage you to bring someone with you so each of you can go to a different session and then share what you learned.

A separate program for school age children will also be featured. This program provides children the opportunity to meet other kids affected by epilepsy. The children's program will include fun activities such as an art therapy session, discussion about epilepsy/seizures, games, and more.

Please contact Beth Stivers, MS, director of education, at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org for more information or to register. You may also register online at www.efky.org.



Register now for the 2019 End Epilepsy Statewide Conference or see the agenda at www.efky.org.

The Epilepsy Foundation of Kentuckiana would like to thank the following conference sponsors (at the time of printing):





MISSION STATEMENT

To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

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The Illuminator is edited by Beth Stivers.
 Design by QuantumGraphix.
 Questions and comments about the Illuminator may be directed to Beth via phone or email.



From the Executive Director

WOW! Can you believe autumn is just around the corner?! I hope you enjoyed a wonderful summer and are looking forward to everything fall will bring – cooler weather, beautiful displays of fall colors, Thanksgiving, the 2019 EFKY Fall Festival, the 2019 End Epilepsy statewide conference, the 2019 Veterans of the Year Awards Dinner, and the 10th annual Expressions of Hope Gala. You can find information on these events in this edition of the Illuminator and my staff and I hope to see you at one or all of these events!

Many of you heard about the tragic, sudden passing of Disney star Cameron Boyce due to sudden unexpected death in epilepsy (SUDEP). We are all saddened over his passing and are heartbroken for his family and friends. Death in epilepsy is not a topic that is easy to talk about, however, we cannot ignore the fact that individuals with epilepsy are at a higher risk of death due to injuries resulting from seizures and SUDEP. There are precautions that you or your loved one can take as a safeguard. Please take time to educate yourself and to stay seizure safe and always remember, we are here for you in every step of your epilepsy journey.

Another successful Teen Speak Up (TSU)! Program took place in Washington DC from April 28 – 31, thanks to Lyndsey Crunk and Samantha Badon! These teens participated in this national Advocacy Program as Kentucky's representatives – Lyndsey as a TSU Ambassador and Samantha as a TSU Representative. This annual program serves to build courage and friendships allowing over 50 teens from all over the country to join forces to advocate to END EPILEPSY!

The last day of the program, the teens put their newly learned advocacy skills to use as they converged on Capitol Hill, where they and their family members met with their respective members of Congress and/or their staff. Collectively, their voices resonated as

they bravely shared their epilepsy stories and urged their representatives and senators to appropriate \$11.5 million to the Center for Disease Control and Prevention's Epilepsy program in Fiscal Year 2020. They also advocated for reform for step therapy protocols with health insurance companies, also known as "fail first." This practice can restrict a patient's access to the treatment method deemed best by their physician, forcing them to fail to gain seizure control with one or sometimes two or three medications before granting access to the medication their physician has prescribed. This practice can be a dangerous one for those living with refractory epilepsy and can lead to devastating consequences.



During a special TSU lunch program, I was honored to join Richard Stubblefield, father of the late Sara Stubblefield, and Phil Gattone, CEO of the national Epilepsy Foundation to present Lyndsey with the Sara Stubblefield Advocacy Award for championing Kentucky's Seizure Smart Schools

legislation (HB 147), also known as the Lyndsey Crunk Act! Lyndsey was presented this award for gallantly advocating that Kentucky educators be trained on seizure recognition and response, after having battled several negative seizure-related incidences at school. Sara worked for many years at the at the Epilepsy Foundation of Southern Illinois and, very sadly, passed away suddenly from a seizure at TSU in March of 2011. This award was dedicated in Sara's memory to recognize the good work being done to advocate on behalf of others impacted by epilepsy. With its passing in 2018, Kentucky's Seizure Smart Schools legislation has become a national Epilepsy Foundation initiative, and I am thrilled to report that Indiana, Illinois, and Texas have successfully passed similar legislation this year, to ensure that school personnel are properly educated in seizure recognition and response.

I would like to thank Lyndsey and Samantha for proudly representing the Epilepsy Foundation of Kentuckiana at TSU and for sharing their epilepsy stories to improve and save lives!

I hope you enjoy a delightful fall and please remember that the Epilepsy Foundation of Kentuckiana is committed to serving you! - Deb



This year's planning committee is working really hard to present you with an unforgettable experience. "Let's Go Crazy for a Cure!" at the 10th annual Expressions of Hope Gala! Reserve your tickets or sponsorship at www.eohgala.givesmart.com for this special evening being held at the Mellwood Art Center's Van Gogh Room on November 8.

"LET'S GO CRAZY" FOR A CURE

The Epilepsy Foundation of Kentuckiana invites you to PARTY LIKE IT'S 1999 at our 10th annual Expressions of Hope Gala!

FRIDAY, NOVEMBER 8, 2019
DOORS OPEN AT 6:30 P.M.

GALA HONORARY CHAIRS

Dr. Vinay Puri

Jim and Sara Haynes

GET YOUR TICKETS

TICKETS TO THIS YEAR'S GALA CAN BE PURCHASED ONLINE AT:

www.eohgala.givesmart.com

Tickets are \$125.00 each or save with a table of eight for \$800.00

RESERVE YOUR TICKETS/TABLES BY 10/25/19

THE NIGHT'S FESTIVITIES INCLUDE:

Open Bar

Hors d'oeuvres & Cocktails

Masterson's Catering will be serving dinner at 7:30 p.m.

Bill Menish

MC and Auctioneer Extraordinaire

Live and Silent Auctions

Music by *The Decades*

Dancing until Midnight

Bourbon and Cigar Bar

Heads or Tails Game

EXPRESSIONS OF HOPE SPONSORS

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For information on becoming a sponsor go to www.eohgala.givesmart.com

From the Director of Client Services *Amy Collier, CSW*

Welcome to the 2019-2020 School Year

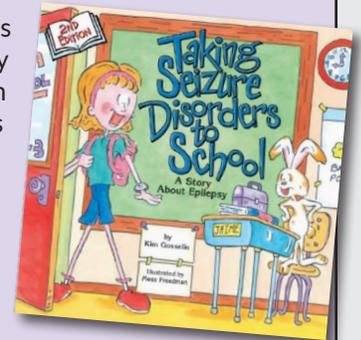
Some of you may be sending your child to school for the first time after their diagnosis of epilepsy and wondering what you might need to do to ensure your child's safety while at school. There's a good chance that many of your child's teachers and classmates won't know much about epilepsy. Educating them about the nuances of your child's epilepsy/seizures is extremely important as each person's seizures can be so different.

If your child attends a public school in Kentucky, thanks to the passage of HB 147, also known as the Lyndsey Crunk Act, in April of 2018, you can rest assured that your child's educators were required to take a one-hour training program about seizure recognition and response prior to the start of the 2019-2020 school year. Before HB 147 was passed, the Epilepsy Foundation of Kentuckiana provided an onsite school training as requested by a parent and/or school. The Lyndsey Crunk Act has been incredibly instrumental in providing Kentucky's public school educators with the knowledge needed to properly recognize and respond to a child experiencing a seizure. To date, over 24,000 educators have participated in the Epilepsy Foundation of Kentuckiana's online training program.

However, if you feel your child's educators are not properly trained, the Epilepsy Foundation of Kentuckiana can assist you in educating their school about epilepsy as well as provide guidance and support in accessing needed services in the classroom. To request a training program please contact Beth Stivers, MS, director of education at 502-907-1533 / 866-275-1078 / bstivers@efky.org. We can also provide materials such as seizure action plan and seizure first aid information. Your child should have their own personalized seizure action plan on file at the school that was signed by their treating physician. Also, if your child requires a rescue medication to treat their prolonged seizures, please make sure to talk to the nurse and teachers at your child's school, to ensure they are trained on how to properly use this potentially life-saving medication.

BACK TO SCHOOL TIPS...

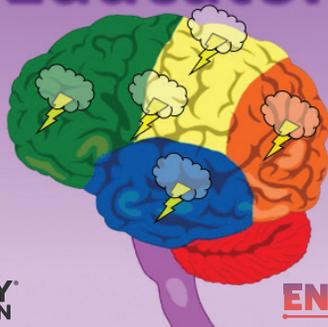
- ✓ Schedule an appointment with your child's teacher(s), school nurse, coaches, etc. to make them aware of your child's epilepsy and the role each of them will have to ensure proper management;
- ✓ Complete a Seizure Action Plan with your child's physician;
- ✓ Discuss the need for close observation regarding medication side effects and/or learning/behavioral problems;
- ✓ If your child has a learning disorder, work with the teachers to develop a 504 plan or Individual Education Plan (IEP);
- ✓ Follow-up with your child's teacher and school staff regularly to monitor progress;
- ✓ Ask that your child's classmates become educated about epilepsy and seizures. The Foundation provides training programs for K-12 students and can also provide resources, such as the book "Taking Seizure Disorders to School: A Story About Epilepsy" by Kim Gosselin.



If you need help getting your child with epilepsy off to the right start this school year or would like resources such as a seizure action plan, first aid sheets, or a copy of this book, please let me know. You can contact me at 502-907-1534 / 866-275-1078 / acollier@efky.org.

Calling all Educators!

Seizure Training for Educators



END EPILEPSY

Online training course now available for educators.
Go to www.efky.org and take the course now!

Join us for the 9th Annual Fall Festival

You and your family are invited to join the Epilepsy Foundation of Kentuckiana on Saturday, September 28, 2019 for our 9th annual Fall Festival from 11:00 a.m. - 2:00 p.m. on the great lawn at the Kosair Charities Centre (982 Eastern Parkway, Louisville, KY 40217). Lots of fun will be had with inflatables, pony rides, games, balloon creations, crafts, and food! Also joining us for the day is The Dream Express!

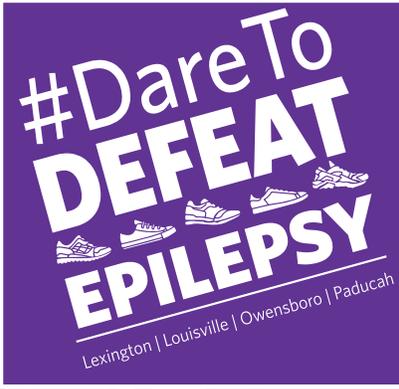
The Fall Festival is free of charge for those living with epilepsy/seizures and their family members thanks to a grant from Kosair Charities.



2019 Walk #DareTo Defeat Epilepsy THANK YOU!!!!



See the front cover for a recap of the 2019 Walk! Check out some of the photos from across the state here.



Thank you to our sponsors



SAVE THE DATES FOR THE 2020 #DareTo Defeat Epilepsy Walk

SATURDAY, JUNE 6 OWENSBORO
SATURDAY, JUNE 13 LOUISVILLE
SATURDAY, JUNE 20 LEXINGTON
SATURDAY, JUNE 20 PADUCAH

From the Veterans Outreach Coordinator *Donald Bow, MS*

As summer comes to an end, I'm happy to say that I have been out and about throughout the state spreading the word about the Epilepsy Foundation of Kentuckiana and our veterans program, Operation Outreach. Throughout my travels to Bowling Green, Radcliff, Shelbyville, Frankfort, and southern Indiana over the last three months, it makes me proud to see various organizations and communities embracing the military and veteran population. For all veterans, please know there are organizations and groups out there that can not only provide aid to you and/or your families, but also be there just to listen.

Please look in the box to the right to see just a few of the events that are being held in September and October. If you are in the area, come out with your friends and family to socialize and make lifelong connections.

The 2019 Kentucky Veterans of the Year Awards Dinner is right around the corner. This program serves to honor a female and male veteran that are doing great things in their community and will be held at The Jeffersonian in Jeffersontown, KY from 6:30 – 8:30 p.m. Be sure to "Like" and "Follow" us on Facebook, Kentucky Veterans of the Year & Operation Outreach EFKY, to stay up to date on event information.

I am truly honored and fortunate to be able to work with veterans and expand the Operation Outreach network across the state. Please share with friends and family!

UPCOMING
VETERAN EVENTS

September 20 Korean War Recognition Ceremony at the Boone National Guard Base

September 25 VA Suicide Prevention Training Seminar in Lexington

September 28 Women's Veteran Open House at Robley Rex VAMC

September 29 Veteran's Appreciation Day at Red Mile Race Track

October 5 Bowman Fest (Military Heritage Festival) at Bowman Field

October 17 Veteran's Breakfast in Elizabethtown

October 31 6th Annual veteran's Appreciation Lunch at Jenny Wiley State Resort Park

**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 x 17 / dbow@efky.org.

2019 Kentucky Veterans of the Year Awards Dinner

Tickets for this year's event will be free thanks to the wonderful support of our sponsors. However, seats are limited. Please reserve your tickets at www.AwardVets.givesmart.com.

The **2019 Kentucky Veterans of the Year Awards Dinner** will be held on **Monday, November 4** at **The Jeffersonian** (10617 Taylorsville Road, Jeffersontown, Kentucky) from **6:30 p.m. – 8:30 p.m.** A delicious meal will be served, catered by Victoria's Catering. We hope you will join us for this event as we honor one male and one female veteran in Kentucky who continues to serve their community. Our guest speaker will be Jeremy Harrell, Founder and President of Veteran's Club – Kentucky and Co-Chair of the Veterans Community Alliance of Louisville and the event's emcee will be Lt. Col. (ret) Fred Johnson. Get your tickets now!



Thank you to the following sponsors:



From the Western Kentucky Educ. Coordinator

David Pettit, MEd

This is not the article I had planned to write, and it is certainly not the story I wanted to tell. I was supposed to write an article celebrating my milestone of being seizure-free for ten years. It was January 25th, 2009, the night of the ice storm. We were without electricity, trying to ride it out with a fire in the fireplace. Suddenly, I started tasting aluminum foil, which had always been my warning sign. That progressed to a creepy-crawly feeling up the back of my neck and I felt the familiar pounding of my heart in my chest and in my head. My arms started convulsing, which was a new twist for me, and I went into what I call the "Twilight Zone." After several minutes, just as I thought things were calming down, it started all over again. I ended up having two complex partial seizures back to back and they just would not stop. We both knew the danger of prolonged seizure activity, so my wife called 911 and I took a slow, icy ambulance ride to the emergency room.

Since that night I had not had another seizure. Not for over ten years. Then, one night a few weeks ago, my wife and I were having dinner with her family. I made what now seems like a reckless statement. "I haven't had a seizure in over ten years!" A few minutes later, as I was talking to my mother-in-law, I suddenly realized I didn't understand what she was saying. It's nearly impossible to describe the aura I felt, but it wasn't the weird metallic taste that I was used to. I felt like someone had a squirt gun filled with confusion and they were squirting it at my head. Swish! Swish! Swish! I've always felt lucky that I have at least two or three minutes of warning before I start to lose awareness, and it was the same this time. I stood up, got my wife's attention and let her know what was going on. We went into the living room and sat on the couch until the seizure passed. A seizure is a terrifying experience. It's knowing that you're giving up control of your body and your brain. It's a pervading fear that – despite knowing it's unlikely – you might die.

Over the next couple of weeks, I had what can best be described as "aftershocks" – simple partial seizures that didn't develop into anything more serious. A friend of mine has described them as "twingy" feelings, and that seems like an apt description. I was able to get in to see a neurologist right away and he ordered a sleep-deprived EEG and an MRI – tests that I had long assumed I would never need again. My brain seems to have calmed down now and I am feeling back to normal. But a lot of the old fears and feelings have returned.

The experience has left me confused about how and why the seizure happened after so long a time. Is it a normal part of the aging process for someone with epilepsy? I wasn't under any stress at the time. No flashing lights or other common triggers. I have a follow-up appointment scheduled with my neurologist and hopefully, I will get some answers. In my training sessions, I always make the comment that there's an awful lot that people don't understand about seizures and those of us who have them. As it turns out, I guess there's a lot we don't understand ourselves.

I share this information with you because I want our readers to know that I understand what it is like to have a seizure. I understand the fear that many of you live with daily. While this experience has been scary, I want to let you know that it has only strengthened my resolve to educate individuals in western Kentucky about seizures and epilepsy. Beth is also working diligently to educate those throughout the rest of the state, and we have the same goal, to ensure that those living with epilepsy in Kentucky and southern Indiana are safe and understood in their communities, wherever they are.

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 502-907-1530 / 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 Form

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.



KOSAIR CHARITIES CENTRE
982 Eastern Parkway • Louisville, KY 40217
Web: www.efky.org • Phone: 502-637-4440
Toll-Free 866-275-1078 • Fax 502-637-4442

Your Contribution Will Truly Make a Difference!

Feel Alone? Would it help you to talk to someone that understands?

Please 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 (Kosair Charities Centre, 982 Eastern Parkway, Louisville) one Friday each month as we meet in a support setting (without an art therapist) to create art, eat a free lunch, and enjoy fellowship with other people living with epilepsy. We provide art making supplies or you can bring your own!

If you feel like no one understands what it is like to live with epilepsy/seizures, this group is the right place for you. Join us by contacting Beth Stivers, MS, director of education at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org.





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- From the Veterans Outreach Coordinator
- 2019 Veterans of the Year Awards Dinner
- From the Western Kentucky Education Coordinator

Get your tickets for the EOH Gala at eohgala.givesmart.com

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LEARN ABOUT EPILEPSY

INFORMATION • KNOWLEDGE • EMPOWERMENT

Exploring Epilepsy



VISIT

ExploringEpilepsyToday.com

Exploring Epilepsy provides the opportunity to:

- Learn more about epilepsy
- Gain knowledge about medication and non-medication management
- Feel empowered to manage epilepsy

There's a lot that you can do to better manage your or your loved one's seizures.

Log on today to find education, tools and resources to help you better understand and manage epilepsy.



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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 KENTUCKIANA'S YOUTH EPILEPSY ALLIANCE! IS SUPPORTED BY A GRANT (#774C) FROM KOSAIR CHARITIES.



UPCOMING YOUTH EPILEPSY ALLIANCE! EVENTS

SEPTEMBER

Saturday, Sept. 28
11:00 a.m. – 2:00 p.m.
2019 Annual Fall Festival
Kosair Charities Campus
982 Eastern Pkwy,
Louisville



OCTOBER

Lexington: Sat., Oct. 12
10:00 a.m. – 11:30 a.m.
Newton's Attic
4974 Old Versailles Rd, Lexington

Louisville: Saturday, October 19
8:00 a.m. - 2:00 p.m. 2019 End Epilepsy Statewide Conference Children's Program (See page 1.)



NOVEMBER

Saturday, Nov. 2
9:00 a.m. – 11:30 a.m.
Fire Studio and Gallery
170 Carter Avenue,
Louisville



DECEMBER

Saturday, Dec. 14
12:00 p.m. – 1:30 p.m.
Captain's Quarters
5700 Captain's Quarters Rd,
Prospect



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