

SAVE THE DATES FOR THE 2020 #DareTo Defeat Epilepsy Walk

Saturday, June 6 - Owensboro

Saturday, June 6 - Paducah

Saturday, June 13 - Lexington

Saturday, June 20 - Louisville







ILLUMINATOR

2019 Year End Gift Campaign



We are rapidly approaching the end of 2019 and would like to thank each of you for being a dear friend of the Epilepsy Foundation of Kentuckiana (EFKY) throughout this year. As we enter this time of giving, we hope you will consider donating today to the Foundation. Your gift will make a difference for the nearly 153,000 children, adults, and veterans living with epilepsy in Kentucky and southern Indiana.

1 in 26 are diagnosed with epilepsy at some point in their life please donate now to help the 1.

1 gift = 1 life changed. Your taxdeductible donation will directly help the children, adults, veterans, and families affected by epilepsy throughout Kentucky and southern Indiana through the EFKY's education, advocacy, outreach, and client services. No gift is

To learn more about ways to donate and provide your time, talent, and/or treasure to the Foundation, please contact Deb McGrath, Executive Director at 502-907-1532 / 866-275-1078 / dmcgrath@efky.org.

too small and please know that 85¢ of each \$1 of your

donation will directly help make a difference so not another moment or life is lost to seizures. Donations can be made online at www.efky.org or by mail using the donation form located on page 7 of this newsletter. (Mail to: Epilepsy Foundation of Kentuckiana, Kosair Charities Centre, 982 Eastern Parkway, Louisville, KY 40217).

We are so grateful for the continued generosity of our supporters and because of you, we are able to provide our vital programs and services at no cost to those impacted by epilepsy throughout Kentucky and southern Indiana, as well as fund vital epilepsy research. If you are affected by epilepsy, we hope you have found and continue to find comfort in knowing that you are not alone in the fight to End Epilepsy and remember that you have a devoted team at the Foundation who is ready and willing to offer help, hope, and support at a moment's notice.

We hope you have a healthy and happy Holiday season! We offer a sincere thank you for your continued support of the Epilepsy Foundation of Kentuckiana.

HERE'S WHAT YOUR DONATION WILL DO!

Ensures vital support & information reaches a family dealing with a new

diagnosis.

Kentuckiana

\$25

Funds a much-needed consultation with our support team.

\$50

\$100 **Funds** emergency medication for one client.

an individual or a family

\$250 Funds advocacy services for

in need.

of education training to school personnel. school nurses, and students.

\$350

Provides a day

\$500

Provides two seizure monitors for clients in need.

Visit www.efky.org today and help us #EndEpilepsy in 2020

EPILEPSY° FOUNDATION



Let's Use Our Brains to End Epilepsy.®



END EPILEPSY

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.

BOARD OF DIRECTORS:

President: Mike Wallace Vice President: Linda O'Bryan Secretary: John Taylor Treasurer: Mindy Heck, CPA Past President: Jeff Davis

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CONTACT INFORMATION:

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The Illuminator is edited by Beth Stivers.

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Questions and comments about the Illuminator may be directed to Beth via phone or email.



From the Executive Director

It is hard to believe another holiday season is once again upon us and we will soon be ringing in 2020. I don't know about you, but for me, this year was a blur. How could it already be 2020?! It doesn't seem all that long ago when we were worried about our computers crashing with Y2K in 2000, but here we are 20 years later. So much of our world has changed since then with the development of incredibly amazing technology (I'm looking at you iPhone) and the medical advancements in the treatment of epilepsy over the last 20 years is astounding. There are so many more treatments for reducing or controlling seizure activity through brain surgeries, neurostimulation devices, and new epilepsy drugs.

For some, these advancements have been a tremendous blessing, but unfortunately, 1 in 3 individuals still battle relentless seizures. Researchers and clinicians are dedicated to finding cures and saving lives and work tirelessly to unlock the mysteries of epilepsy to eliminate all types of seizures. Until that day comes, the Epilepsy Foundation of Kentuckiana will continue to be your unwavering ally in your fight to overcome the challenges you bravely face in your quest to live life to the fullest.

This coming year will be as busy as ever at the Foundation and I invite you to join in on as many activities as you possibly can. Please check out our website at www.efky.org and like our Facebook page @EpilepsyFoundationOfKentuckiana to keep up to date on all that is being planned for you. We are especially excited about our upcoming Epilepsy Advocacy Day at the Capitol in Frankfort on February 25.

If you have not participated in this program before or would like to join us again, we would be delighted to have you. Sharing your epilepsy story with your elected officials can be an empowering experience and will help your senator and representative understand the

impact that epilepsy has had on you, your child, and/or your family. You very well know that epilepsy is not only about seizures – it can also cause anxiety, depression, isolation, rejection, memory and cognition issues, and psychosocial issues. Many have deep wounds from being bullied or discriminated against. While this is a difficult subject to talk about, we can no longer sweep under the rug the fact that there are risks to seizures that include injury and death and ignoring this will not make these risks go away. Being mindful and doing what you can to protect yourself from injury or death is paramount, as is ensuring that you are being provided the best care available and that barriers to access epilepsy treatments and specialists are removed. We ALL need to be in this together to make our voices heard and have a real impact.

One of my favorite quotes is:



"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

- Margaret Mead

I love seeing individuals impacted by seizures come together at our Epilepsy Advocacy Day as they become empowered to speak up about the struggles they have faced because of epilepsy. It is truly a rewarding experience and I do hope you will make it a commitment to attend. Come let your light shine and bring epilepsy out of the shadows! To register, please go to www.efky.org.

On behalf of the Epilepsy Foundation of Kentuckiana, cheers to you and your loved ones!

May you have the merriest of Holidays and a healthy and happy New Year! - Deb



The EFKY extends our sincere appreciation to Mayor Linda Gorton of Lexington for Proclaiming November as National Epilepsy Awareness Month. On hand to receive the Proclamation was Dr. Meriem Bensalem Owen, a member of the EFKY Board of Directors, as well as other healthcare professionals from the UK Kentucky Neuroscience Institute and members from Central Kentucky Epilepsy Support Network. A special thank you to Laureen Vassil, our Volunteer Advocacy Coordinator for requesting the Proclamation.

2019 Expressions of Hope Gala Recap

The 10th annual Expressions of Hope Gala presented by Blue Grass MOTORSPORT was a tremendous success with over \$113,000 raised through sponsorships and the over 350 guests in attendance. The 2019 Expressions of Hope Gala theme was "Let's Go Crazy for a Cure" and many arrived dressed in their finest purple and/or Prince-themed attire on November 8, 2019 at the Mellwood Arts Center. Guests were treated to an amazing collection of spectacular silent and live auction items, a delicious dinner prepared by Masterson's Catering, an open bar, bourbon and cigar bar, live music by The Decades, Heads or Tails game, and a photo booth. Above all, we were overwhelmed by the funds raised to directly benefit the vital programs and services of the Epilepsy Foundation of Kentuckiana (EFKY).

Over the past 26 years, the EFKY has been steadfast in providing help, hope, and support 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 client support service programs available at no cost to them, because of fundraising events like the Expressions of Hope Gala.

The Foundation would like to thank all who planned, sponsored, donated auction items, attended, and/or volunteered at the 2019 Expressions of Hope Gala. Also thank you to our Honorary Chairs, Vinay Puri, MD and Jim and Sara Haynes. We are also grateful to the Expressions of Hope planning committee: Linda O'Bryan, Co-Chair, Beth O'Daniel, Co-Chair, Val Speth, Co-Chair, Lisa Wallace, Co-Chair, Meriem Bensalem-Owen, MD, Mary Beth Dwyer, Olivia McBee, Bill Menish, and Tim Morris.



From the Director of Client Services Amy Collier, CSW

Grant Provides Embrace2 Seizure Detection Devices

The Epilepsy Foundation of Kentuckiana has received a Good Works Program grant from the Honorable Order of Kentucky Colonels to provide 10 Embrace2 seizure detection watches to clients in need. The Embrace2, manufactured by Empatica, is the latest generation of seizure detection watches. This FDA-approved device is designed for adults and children (ages 6 and up) and uses

advanced machine learning to detect possible generalized tonic-clonic seizures and immediately notify caregivers. This device is ideal for those who have convulsive seizures that last longer than 20 seconds. Unfortunately, other non-convulsive seizure types currently cannot be detected by the Embrace2.

When the Embrace 2 detects a possible generalized tonic-clonic seizure, it communicates with a companion app empatica on a paired mobile device to alert your caregivers with a phone call and text

message. It is important to note that the Embrace2 does not predict seizures, but instead is designed to expedite assistance when a seizure occurs.

The person wearing the Embrace2 will need two things: a compatible mobile device with a stable internet connection and the Alert App with an active subscription plan. It is also important that the person wearing the Embrace2 always be within a 30-foot radius of the connected mobile device to send an alert, but alerts

caregivers from any understand you love.

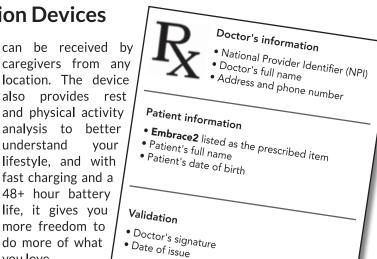
location. The device also provides rest and physical activity analysis to better your lifestyle, and with fast charging and a 48+ hour battery life, it gives you more freedom to do more of what

Our supply of Embrace2 watches will

be available on a first-come-first-served

basis for those who suffer from convulsive seizures only. It is recommended that you consult your physician to see if this device is right for you and please note that a signed prescription from your healthcare provider is required. Please see the requirements below and make sure all necessary information is on your prescription. If you are interested in receiving an Embrace2 seizure detection watch,

please contact me at 502-907-1534 / 866-275-1078 x15 / acollier@efky.org and if you qualify, I can work with you.



Colonels.

Calling all Educators!

Seizure Training for Educators

> Online training course now available for educators.

END EPILEPSY

Go to www.efky.org and take the course now!

2020 Golfer's Gauntlet





Presenting Sponsor

MAKE A DIFFERENCE by becoming a sponsor, registering your team, or playing individually in the 15th Annual Golfer's Gauntlet presented by Meiners Electric on Monday, April 20, 2020. All participants will enjoy a fun-filled day at Fuzzy Zoeller's Covered Bridge Golf Club in Sellersburg, Indiana, a hearty lunch by Aspen Creek, 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 be a sponsor, register your foursome, or for more information, please go to www.efky.org.



Thank You, Kosair Charities!

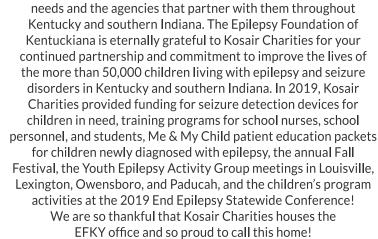




Supported Organization







Kosair Charities is a tremendous blessing to children with special







Thank you, Kosair Charities!





























From the Veterans Outreach Coordinator Donald Bow, MS

The holiday season is fast approaching and this can be a difficult time for veterans, especially veterans who have been impacted by posttraumatic stress disorder (PTSD) and/or traumatic brain injury (TBI) from combat and other times throughout their military service.

It can be a common occurrence for a veteran who is struggling to have times throughout the year where they feel the "weight of the world" is on their shoulders and they cannot continue on, and at times like these, veteran programs like Operation Outreach can be extremely beneficial. The best person a veteran can talk to may be that other veteran who has similar experiences. Operation Outreach was started to educate veterans on their increased susceptibility of developing post-traumatic epilepsy (PTE) and psychogenic nonepileptic seizures (PNES) but other key components are outreach and support. There are quite a few veteran organizations around Kentucky that are doing great things for the veteran community and I will do whatever I can to get a veteran connected with the right organization that can be the most beneficial for them.

Karen Weaver, 2019 Female Kentucky Veteran of the Year with friends and family



Karen Weaver and **KDVA Commissioner BGEN Adams**



Fred and Laura Johnson

The 6th annual **Kentucky Veterans of the Year Awards Dinner** was held on **November 4. 2019** at The Jeffersonian. We had a great turnout for this wonderful event designed to honor veterans "Still Serving" their communities. Fred Johnson from Louisville and Karen Weaver from Lexington were recognized as the Kentucky Veterans of the Year. KDVA Commissioner, BGEN Adams was on hand to recognize all our veteran nominees and our two winners. Fred and Karen were both presented with an American Flag designed and made by Cruise Customs, a veteran owned business that repurposes Kentucky bourbon barrels into patriotic American Flags. The Kentucky Veterans of the Year Awards Dinner was 100% funded by the generosity of our sponsors, Campbellsville University, the Karl Truman Law Office, Volunteers of America Mid-States, and Fort Knox Federal Credit Union. Nominations for the 2020 Kentucky Veterans of the Year are currently being accepted at www.kentuckyveteransoftheyear.org.

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.

Have a Happy Holiday season!



Fred Johnson and KDVA Commissioner BGEN Adams



John Miles presenting proclamations to Karen Weaver and Fred Johnson from Mayor Fischer

Thank you to the following sponsors:









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 End Epilepsy Statewide Conference - A Day of Education and to #DareTo Say SUDEP

On Saturday, October 19, 2019 the Epilepsy Foundation of Kentuckiana (EFKY) held its annual End Epilepsy Statewide Conference at the Hilton Garden Inn Louisville Airport in Louisville, Kentucky. This program was the Foundation's kickoff event for **November Epilepsy Awareness Month** and was attended by over 50 participants, speakers, exhibitors, volunteers, and Foundation staff.

Throughout the day, individuals affected by epilepsy and their family members were joined by regional experts in the field of epilepsy who presented educational sessions on a variety of topics. The keynote address was SUDEP: Talk About It, Take Action, & Don't Let it Get You Down! delivered by SUDEP Ambassador Cortney Sherrell Johnson. With the recent news of the sudden passing of Disney star, Cameron Boyce, Foundation staff chose to highlight this topic to better educate participants about their risk of SUDEP (Sudden Unexpected Death in Epilepsy) and what measures can be taken to help prevent it. Foundation staff are so grateful to Cortney for sharing her story, as she knows all too well the tragic consequences of epilepsy, having lost her mother to SUDEP in 2010. If you would like to learn more about SUDEP and how you can take steps to reduce the risk of SUDEP, we encourage you to go to www.epilepsy.com/learn/early-death-and-sudep/sudep. It is important that we ALL #DareTo Say SUDEP so that those living with epilepsy can do all they can to stay healthy and live life to the fullest.

Other topics throughout the day included: Surgery for Epilepsy, Epilepsy in Women, Relieving Anxiety & Depression Through Art Therapy, and Pediatric Epilepsy presented by David Sun, MD, PhD, Meriem Bensalem-

Owen, MD, Whitney Elvove Clay, ATR-BC, and Samir R. Karia, MD, respectively. The EFKY would like to thank all these speakers who donated their time to share their expertise with our participants and hope all who attended gained knowledge about epilepsy and seizures.

In addition to the educational sessions, participants enjoyed a continental breakfast and buffet lunch, thanks to our amazing sponsors, as well as the opportunity to meet representatives from our sponsoring organizations. Most importantly, participants received the opportunity to meet other people who are also living with and affected by epilepsy, reaffirming that they are not alone in their journey with this neurological disease. A separate program was also offered to children who spent the day playing games, talking with other kids affected by epilepsy, and exploring their feelings about epilepsy through art with an expressive therapist.

The Epilepsy Foundation of Kentuckiana staff would like to thank all who attended and hope you had a wonderful educational experience. We hope that you will all join us again in 2020!

Thank You to the Following Presenters, Facilitators, and Volunteers

Sydney Badon Isabelle Beckham Meriem Bensalem-Owen, MD Donald Bow, MCPO, USN, Ret. Whitney Clay, ATR-BC Amy Collier, CSW Clara Collier Rebecca Goldman Cortney Sherrell Johnson Samir R. Karia, MD Deb McGrath Beth Stivers, MS David Sun, MD, PhD

Physicians

NEUROSURGERY

Thank You to the Following Sponsors





HealthCare







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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 $502-907-1530 / 866-275-1078 \times 10 / ccostelle@efky.org$.

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

__ Hope for Hadley Jo Project 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.



of the Epilepsy Foundation

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.





END EPILEPS

Kosair Charities Centre 982 Eastern Parkway

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what's inside

- 2019 Year End Giving Campaign
- 2020 Walk Save the Dates

Louisville, KY 40217

- From the Executive Director
- 2019 Expressions of Hope Gala Recap
- From the Director of Client Services
- 2020 Golfer's Gauntlet
- Thank You, Kosair Charities
- From the Veterans Outreach Coordinator
- 2019 End Epilepsy Statewide Conference Recap
- Monthly Art Group Gathering

THE EPILEPSY FOUNDATION OF KENTUCKIANA WISHES YOU A



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



We have partnered with Bluegrass Distillers to raise money through their private select barrel program. For every \$53 bottle sold from our selected barrel, Bluegrass Distillers will donate \$20 to the Foundation. The barrel is expected to yield approximately 220 - 250 bottles and the Epilepsy Foundation of Kentuckiana could receive upwards of \$5,000 from the sales of these signature bottles.

You will want to get your own bottle or two (or six!) which are available for prepurchase on the Bluegrass Distillers' website at www.bluegrassdistillers.com/store1/ efky. Please note that these bottles are only being sold by Bluegrass Distillers, buyers must be 21 years of age, and there is a limit of 6 bottles per person. Bottle pickup will be from 10:00 a.m. - 5:00 p.m. on February 8 and must be picked up at the distillery located at 501 West 6th Street, Lexington, Kentucky. If you cannot make it for pickup, please let us know and we can make other arrangements with you. Bluegrass Distillers has also agreed to donate 10% of all other sales generated at the distillery on February 8, so we hope to see you at the release party! The deadline for bottle pick-up is February 16, 2020.

Youth Epilepsy Alliance!

 $\overline{\mathsf{WHO}}$: 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

KOSAIR CHARITIES Supported Organization



Saturday, January 11

Louisville Aikikai 1860 Mellwood Avenue, Louisville

11:45 a.m. - 1:15 p.m.

Saturday, January 18 Mellow Mushroom 3121 Broadway Street, **Paducah**

10:30 a.m. - 12:00 p.m.



LEXINGTON

Saturday, February 15 Cut & Paste 220 Ruccio Way, Lexinaton 10:30 a.m. - 12:00 p.m.

LOUISVILLE Saturday, March 7

Paint Spot 4600 Shelbyville Road, Louisville 10:30 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.