



EPILEPSY
 FOUNDATION®
 END EPILEPSY® TOGETHER

KENTUCKIANA

ISSUE 2 • 2021

THE
 ILLUMINATOR

The 2021 Walk to END EPILEPSY Was a Huge Success - Thank You!

The Epilepsy Foundation of Kentuckiana (EF Kentuckiana) staff was so disappointed that the **2021 Walk to END EPILEPSY** had to be held virtually again this year because of the pandemic, but while we could not be together for our largest annual awareness building and fundraising initiative, we are extremely grateful to everyone who participated in and supported this event! Through your involvement, over **\$101,500** was raised!! These funds will have a significant impact on the children, adults, and veterans living with epilepsy throughout Kentucky and southern Indiana. This nationwide initiative takes



place from coast to coast, and we are honored to be a part of this special event that strives to improve and save lives impacted by epilepsy! Every dollar raised stays right here to support the vital programs

and services that provide help and hope to those battling epilepsy and seizures in Kentucky and southern Indiana.

We were so happy to see those of you who came out to our designated drive-by locations to say hello and pick up your earned incentive prizes!



We cannot thank our fearless walkers, incredible donors, and generous sponsors enough for the support you provided to this event. It is more important than ever for the Foundation to be a voice and to serve and support those in need. While this was the second year that we have not been able to do the Walk to END EPILEPSY in person, we hope you know that your safety and well-being has been a constant priority during these difficult and challenging times. We sure do miss being together with our epilepsy warriors and their families and supporters and truly hope



that we will be able to come together for the Walks in 2022! We cannot wait to celebrate being back together to experience fun times with all of you at our Walk sites in Lexington, Owensboro, Louisville, and Paducah!

We would like to, once again, give a HUGE shoutout to all the 455 registered walkers, donors, and sponsors for your undeniable commitment to the EF Kentuckiana! We are beyond honored by your support and are eternally grateful for the impact this will have

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KENTUCKIANA

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

2021 Walk to END EPILEPSY

continued from cover

on individuals, families, and communities throughout Kentucky and southern Indiana! We would also like to give special recognition to the top teams, walkers, and our sponsors, as you all were truly instrumental in the success of this year's Walk to END EPILEPSY!

Congratulations to **Team Lifelines Neuro** who raised \$10,150! This includes a \$5,000 match that was secured from **SIDIS**, their parent company. SIDIS is a global management and investment company focused on life science solutions ranging from bioinstrumentation and smarter medical devices to strategic real estate.

Top Teams:

Team Lifelines Neuro - \$10,150
 Team Tyler (in memory of Tyler Gunterman) - \$6,082
 Team University of Kentucky Neuroscience - \$2,035
 Team Friends for Lauren - \$1,875
 Team Jennifer Spence - \$1,303
 Team Determined to END EPILEPSY - \$1,225

Top 10 Individual Fundraisers:

Denise Burks - \$6,675	Ryan Gunterman - \$5,332
David Wittmer - \$4,390	Hailey Zortman - \$3,540
Janet Lynch - \$2,535	Logan Dumitru - \$2,500
Paul Fox - \$2,000	Katie Goodin - \$1,740
Whitney Mayo - \$1,706	Savannah Roby - \$1,350

Saying thank you does not seem adequate, as we know each one of you are impacted by epilepsy in some way, but we hope you know how deeply humbled we are by your strength and resilience to continue the fight against epilepsy and SUDEP!

Thank you to our amazing sponsors for your involvement and heartfelt support to help us serve and support the more than 153,000 children, adults, and veterans with epilepsy throughout Kentucky and southern Indiana!



From the Executive Director

I hope you and your loved ones have remained well and have enjoyed a safe and fun summer with family and friends. We are starting to see some cooler temperatures, and this is definitely a welcome relief from the heat and humidity that we have had through the majority of summer.



I would like to say happy **28th anniversary** to the Epilepsy Foundation of Kentuckiana (EF Kentuckiana)! Since our humble beginning, we are so proud of how far we have come over the last 28 years. On July 1, 1993, the office officially opened to serve the seven-county area of Greater Louisville,

and then in 2001, we affiliated with the national Epilepsy Foundation. Becoming an affiliate allowed us to expand our service territory to include all counties in Kentucky, except for four counties of northern Kentucky (Boone, Campbell, Grant, and Kenton), which were already being served by the Epilepsy Foundation of Greater Cincinnati.

As of 2021, I am thrilled to report that the EF Kentuckiana has been granted approval by the national Epilepsy Foundation to include Boone, Campbell, Grant, and Kenton counties in our service territory, which is something we have been wanting to do for some time. We are so excited to now serve the men, women, and children living with epilepsy and seizures in these four counties along with their families. Since the EF Kentuckiana has always been representing these counties through our state and federal advocacy initiatives and our Seizure Smart Schools training program, we are very pleased that we will now be able to provide services in this area. We look forward to the opportunity of providing children, adults, and veterans with the same help and hope that we have been offering for many years throughout the rest of Kentucky and southern Indiana.

As we all continue to work through this pandemic, I am grateful to the EF Kentuckiana's dedicated staff and board of directors for being so committed in continuing to provide our advocacy, education, outreach, and direct client support services, as well as our youth and support group activities. I know all too well the difficult challenges of living with epilepsy and am proud of the fact that over the past 28 years, the EF Kentuckiana has been an unwavering ally to thousands of individuals and families impacted by seizures. I am so grateful for the trust that all of you have placed in us, especially during these challenging times over the past 18 months. We have been here for you and never stopped offering our programs and services, even if they have looked quite different than before the COVID-19 pandemic.

Sadly, this was the second consecutive year that the Walk to END EPILEPSY, our largest awareness building and fund-raising initiative was held virtually because of the pandemic, however we were blown away by the number of you that stepped up and answered the call to raise epilepsy awareness and funds to help make this year's event better than last year! All in all, we had more than 455 incredible registered participants who, along with our generous sponsors, raised over \$101,500! Thank YOU for your amazing support!! Be sure to read about this event in the Walk to ENDEPILEPSY article on the cover of this edition of the Illuminator.

As we move toward autumn, we are getting closer and closer to our next fundraising event, the 16th Annual Golfer's Gauntlet!

I am excited to share that we have a new title sponsor for this year's event! I would like to offer a sincere thank you to CMTA for agreeing to be the title sponsor of the Golfer's Gauntlet that will be held on **October 4th**, at the Covered Bridge Golf Club. If you're interested in playing in this event or would like information on the sponsorship levels, please go to www.efky.org/2021-golfers-gauntlet.html or reach out to me at dmcgrath@efky.org.



Deb McGrath

image credit: Business First

If you are interested in helping with this year's event, the EF Kentuckiana is always looking for volunteers to help make this event go off without a hitch and would welcome your involvement and support!

We are extremely grateful to each one of you who supported our mission during the one the most challenging times in our history. You know all too well what it is like to weather storms of uncertainty, but we draw from your strength and resilience to never let epilepsy stand in your way of accomplishing your dreams. We are so proud to be with you every step of your journey!

Wishing you all the best until we meet again!

- Deb McGrath

Golfer's Gauntlet

TITLE SPONSOR

CMTA

benefiting **EPILEPSY FOUNDATION** KENTUCKIANA

Ask for details about your chance for \$1,000,000

Covered Bridge Golf Club
Sellersburg, Indiana
Monday, October 4th, 2021

The banner features a green background with a silhouette of a golfer in mid-swing. The text "Golfer's Gauntlet" is in large, bold, red letters with a white outline. Below it, "TITLE SPONSOR" is in smaller white letters, followed by "CMTA" in large, bold, black letters. A logo for the Epilepsy Foundation of Kentuckiana is on the left. A circular graphic on the right contains the text "Ask for details about your chance for \$1,000,000". The bottom of the banner has a red and purple gradient background with white text for the event location and date.

The Epilepsy Foundation of Kentuckiana Welcomes New Staff Member, Sonya Ferguson



We are pleased to introduce you to our newest team member, Sonya Ferguson. Sonya is joining the Epilepsy Foundation of Kentuckiana as the Director of Client Services. She is looking forward to working to improve the lives of children, adults, and veterans impacted by epilepsy and seizures throughout Kentucky and southern Indiana.

Sonya was born and raised in Louisville, Kentucky and received her bachelor's degree in Family and Consumer Science at Western Kentucky University. Sonya then married her middle school sweetheart, had a son, and went back to school to obtain her graduate degree in social work from Spalding University. Sonya has over 15 years of experience working with children/families from disadvantaged backgrounds who struggle with different challenges and disabilities. She also has over 5 years of experience utilizing trauma informed care with clients, working with addictions, and residential services. Sonya is passionate about working with diverse populations to make a difference in others lives and feels it's her charismatic leadership style that keeps her thriving and a positive energy to be around. When Sonya isn't working, she always finds time to enjoy being a mother to her two children, Brayden and Brynlee, traveling with her husband, spending time with her church, friends/family, sorority, and having time for self-care. Sonya has a personal connection to epilepsy as her son, Brayden, was diagnosed with focal seizures in December of 2020. You can reach Sonya at sferguson@efky.org or by calling 502-907-1534.

Welcome to Sonya Ferguson

From the Veterans Outreach Coordinator *Donald Bow, MCPO, USN, Ret.*

Summer is beginning to wind down and just as COVID restrictions were beginning to be lifted, we were hit with the Delta variant. This variant has the potential to impact our friends and family as we enter fall and cooler temperatures. With the war in Afghanistan officially being ended and all our fellow service men and women brought home, there are a lot of emotions that will be stirred up. Nobody can quite understand how a combat veteran feels except for their fellow veterans, so take the time to reach out and get together to talk about what has happened and how it is affecting you. Anger, frustration, sadness, etc. are just a few of the emotions that you may be experiencing so don't isolate yourself, insulate yourself with those who care for you.

Mental health plays a vital role in how we all function on a day-to-day basis so maintaining social interaction is a necessity. Many veterans consider themselves introverts and they may feel that the isolation they have encountered during the pandemic had little to no effect on them, but all of us are human and we do crave social interaction. Without social interaction you may feel cut off from the rest of the world and this could lead to feeling down, fatigued, unmotivated, and overwhelmed. You may not like being around large groups of people, but we all have those few friends that we can call on to hang out, talk, and enjoy each other's company. There are plenty of opportunities to get out and interact with groups that are doing wonderful things throughout the state.

Below are just a few events that are free for veterans:

- Equine sessions
- HorseSensing
- Kayaking
- Coffee & Camaraderie
- Gun range
- Hunting trips/retreats for male and female veterans
- Bible study sessions
- Support group

Last year the Kentucky Veterans of the Year (KYVOY) awards dinner was cancelled due to COVID restrictions and after careful thought, this year's awards dinner will not be an in-person event. With the uptick in COVID cases due to the Delta variant, we have decided it would be best to not cancel the event but celebrate the Veterans of the Year winners a little differently. The nomination period has ended and at this time all the nominees are being ranked by a panel of judges. Over the next couple of weeks, the KYVOY award winners will be announced, and we will also determine the best possible way to recognize these outstanding veterans and their families.

For information on any of the events mentioned, reach out to me at dbow@efky.org. Be sure to "Like" and "Follow" us on Facebook, Kentucky Veterans of the Year and Operation Outreach EFKY, to stay up to date on event information.

**OPERATION
OUTREACH**



If you are a veteran experiencing seizures, are in need of assistance, or would like to learn more, please contact Donald Bow, MCPO, USN, Ret. at 502-907-1536 / dbow@efky.org.

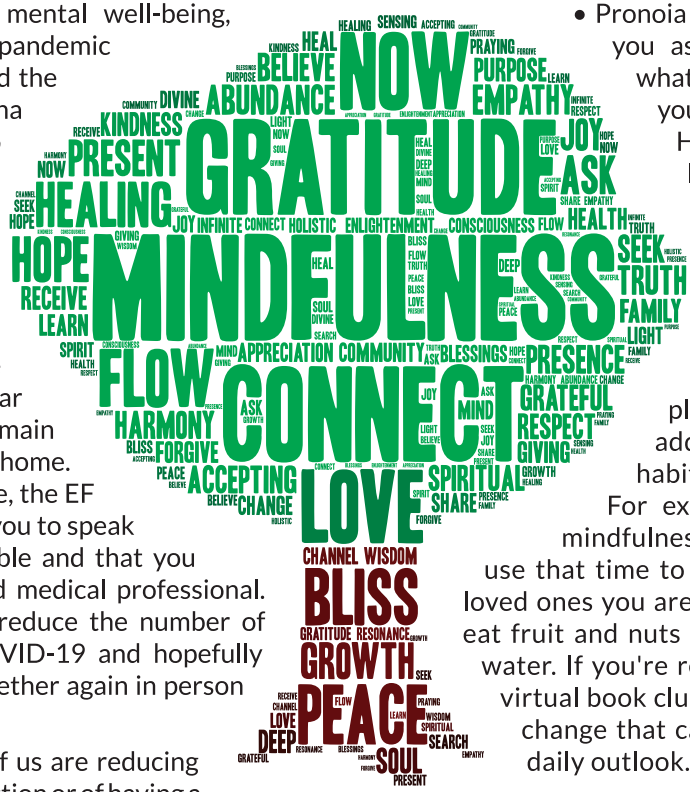
Here We Go Again... We've Got Tips for Self-Care

Self-care is so important for your mental well-being, especially these days. The COVID-19 pandemic has been a roller coaster for many and the Epilepsy Foundation of Kentuckiana staff are certainly disappointed to see the current surge of cases in Kentucky, Indiana, and the rest of the country. We ask that you please be sure to do your part to help slow the transmission and prevent further mutations of this virus. Regardless of your vaccination status, please take care to wash your hands frequently, wear a mask indoors when in public, and remain 6-feet from others when outside your home. If you have not yet gotten your vaccine, the EF Kentuckiana would like to encourage you to speak with your physician as soon as possible and that you please take the advice of this trusted medical professional. By doing these things, we can help reduce the number of individuals getting infected with COVID-19 and hopefully get to a place where we can all be together again in person sooner than later.

With the recent rise of cases, many of us are reducing our contacts to prevent spreading infection or of having a breakthrough infection, which means we may become more isolated. While some of you may relish social isolation, we know that for others, it might be more and more difficult to deal with this return to isolation. For those of you who are experiencing negative thoughts and feelings about these uncertain times, we would like to give you some ideas that may help you re-frame negative thoughts, as well as provide some insightful tips for self-care. You may even find it useful to keep this list on hand to refer to when you feel any negativity creeping back in!

Tips for Self-Care:

- We are living during an alternate state, one most of us never even considered a possibility. Please remember that although this has gone on for a long time, this is a TEMPORARY state. While we have been at this for what feels like too long, we will be back to normal before we know it. Remind yourself of this when it feels like this time may be indefinite.
- Take some time to reflect on what you can learn from this. How do you think things will change and/or stay the same? What benefits do you see from this time? Look at this time as a chance to restore, relax, renew, and reflect rather than be consumed with the negative aspects of what we are all going through.



- Pronoia is looking at what is working FOR you as opposed to paranoia, which is what is working against you. What can you be grateful for during this time? Having a mindset of gratitude, at least for part of the day, can help shift your perspective and help you feel more support and encouragement.

- Take some time to think about the healthy and positive habits you already have in place. Take it one step further and add just one more positive/healthy habit to an already established one. For example, if you take a walk, add mindfulness or meditation to your walk, or use that time to call and check in on friends and loved ones you are not able to see right now. If you eat fruit and nuts for a snack, add an 8-oz glass of water. If you're reading a book, find or organize a virtual book club. It doesn't even have to be a big change that can make a HUGE impact on your daily outlook.

- Take time each day to do something you enjoy. Read a book or scripture, meditate, rest, sit outside, go for a walk, take a drive, ride your bike, call a friend or family member, pray, watch a movie, or learn that new hobby you've been wanting to try. If you like to read, check out what free app your local public library provides for reading electronic books. For example, "Libby" with the Louisville Free Public Library.

- Keeping sleep and medication(s) on schedule is very important. It can be easy to slip out of your normal routine when you spend more time at home, however, sleep clears toxins from the body and can directly impact your physical and mental health. Set an alarm on your phone to remind you to take your medication(s) or even go to bed on time!

We are all more resilient than we think and are going to experience some level of growth during this time. Reflect on this time and what you have learned about yourself. Give yourself credit! You are doing a great job getting through something none of us has experienced before. Also think about the positive things you are learning about your family, friends, business, community, state, and country. We hope you find these tips useful and that you and your loved ones stay safe, get vaccinated (if you can), and that you each take some time each day to do something that brings you comfort.

NOVEMBER '21

Virtual END EPILEPSY Conference

**save
the date**

November is National Epilepsy Awareness Month!

Since we are not going to be able to get together in person for our END EPILEPSY statewide conference due to the surge in COVID-19 cases, the Epilepsy Foundation of Kentuckiana will be hosting several virtual sessions throughout November on Zoom. There will be a variety of topics for parents of children with epilepsy, young adults living with epilepsy, and adults and veterans affected by epilepsy. Please go to www.efky.org for more information and to register.

From the Director of Education *Beth Stivers, MS*

Are **YOU** seizure smart? Be it on-demand or live programming via Zoom, we have the options you need to ensure you receive the training you need to properly recognize various seizure types and know how to provide first aid for someone having a seizure. Both programs provide the following objectives, however one is tailored to educators and the other one is designed for everyone.

Program Objectives:

- Define seizures and epilepsy.
- Identify correct and incorrect steps for helping a person having a seizure.
- Identify when you should call for emergency help (911) in the event of a seizure.
- Increase confidence to help a person during a seizure.

Seizure Training for Educators

Since 2018, when **HB 147** (Lyndsey Crunk Act) was signed into law, the schools are required to do the following: (1) principals, guidance counselors, and teachers to complete a one-hour seizure recognition and first aid response training; (2) a "Seizure Action Plan," signed by the treating physician to be part of the student's file and made available to school personnel and volunteers responsible for the students; and (3) any FDA approved medication to be administered to the student with epilepsy/seizure disorder as prescribed by the treating physician.

David Pettit, MEd (EF Kentuckiana's western Kentucky education coordinator) and I are the Foundation staff responsible for providing training programs to educators, we knew we had our work cut out for us to train the over 50,000 educators throughout Kentucky. We realized very quickly that we needed a solution to train a lot of educators in a short amount of time, and thanks to a generous education grant from UCB, Inc., we created Seizure Training for Educators, an on-demand training course that is available from our website (<https://www.efky.org/education--training.html>).

Since it went live in April of 2019, the EF Kentuckiana is proud to say that this program has trained **over 65,000** educators/participants

to date and 11 other states have followed our lead and passed similar legislation, which has become a national model. If you are a school administrator and you are looking for a comprehensive epilepsy training program for your staff to fulfill the training requirement of HB 147, we hope you will utilize this free resource! For questions about this program, please contact me at bstivers@efky.org.



Seizure Recognition and First Aid Certification Program

The Seizure Recognition and First Aid Certification training program was developed by the national Epilepsy Foundation and the Centers for Disease Control and Prevention (CDC) and provides information and skills to recognize seizures and safely help someone during a seizure. Participants who successfully complete the course will receive a two-year certification, much like CPR certification.

We currently host **two** virtual Seizure Recognition and First Aid Certification training sessions each month **via Zoom**. These programs are free-of-charge, but registration is required to participate. To register, go to <https://www.efky.org/first-aid-training-form.html> and once you do, you will receive an e-mail containing the information you will need to access the course and receive your certification. We are also available to provide private virtual programs if your business, organization, club, or any other group would like to participate. For questions about this program, or to schedule a private session, please contact David Pettit, MEd at dpettit@efky.org.

2021 Peggy Sherrell Memorial Scholarship Recipient



Jaden Little

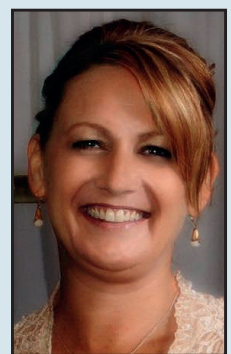
The Epilepsy Foundation of Kentuckiana is proud to announce that Jaden Little of Drift, Kentucky was selected as the 2021 recipient of the Peggy Sherrell Memorial Scholarship. He is a 2021 graduate of The Piarist School and is pursuing a degree in Culinary Arts at Sullivan University. Jaden's inspiration for cooking is Cajun Chef Isaac Toups and his dream is to move to New Orleans after school to learn to cook authentic Cajun food and then bring the cuisine back to Kentucky.

Jaden is living with generalized tonic clonic epilepsy that is controlled. He also struggles with depression, kidney disease, and social anxiety and feels that all these things in addition to having epilepsy has made it difficult to find the will to want to get an education and to follow his passion of cooking. He does believe that while epilepsy and

his other diseases have taken a toll on him, they have ultimately led to him to become a stronger person. When asked what advice he has for other young people living with epilepsy, he states, "To keep pushing and never give into despair."

Jaden is excited to represent Peggy through this scholarship and looks forward to carrying on her legacy with his future career. The Foundation is proud of him and hopes he keeps fighting to reach his goals!

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. To date, her family has raised over \$200,000 through their annual Peggy Sherrell Memorial Golf Scramble to support the EF Kentuckiana's programs and services. The EF Kentuckiana would like to extend a heartfelt thank you for this generous support.



2021 Shannon O'Daniel Memorial Scholarship Recipient

The Epilepsy Foundation of Kentuckiana congratulates Laura Tinnell for being awarded the 2021 Shannon O'Daniel Memorial Scholarship. Laura is a 2021 graduate of Presentation Academy in Louisville, Kentucky and is currently attending the Eastern Kentucky University with plans to major in history. Before her diagnosis of generalized tonic-clonic seizures at age 13, Laura had dreams of joining the Air Force and possibly working for NASA. Once she started having seizures, she had to figure out a career path that would allow her to be around others to ensure her safety should a seizure occur. She eventually settled on history because it was a subject that has always interested her and she believes that learning about history can help us understand life in the present. After graduation, she hopes to become a history teacher/professor or a historian.

Laura's last seizure was seven months ago, and freedom of seizures is a new development for her. Prior to then, she had two to four seizures a month and it prevented her from getting her driver's license until August of this year. When asked who is the biggest inspiration in her life, Laura said it is her mom, Kristen. Although they used to fight a lot when she was younger, she has realized how much her mother has done for her over the years saying, "She is the strongest woman I've ever known."



Laura Tinnell



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.

Laura went on to say, "I love her more than anything, and as I grow older, I will always remember the things she has done for me and the guidance she has given me."

When asked what advice she has for other young people living with epilepsy, Laura says, "Having epilepsy really stinks, but that doesn't mean that life stinks. Every day is a reason to get up and kick epilepsy's butt by being with your family and friends, eating your favorite food, watching your favorite show, or even playing with your pet. Having a great day every day will help you feel better and might even help you forget about it, even for just one second." Laura is honored to represent Shannon O'Daniel through this scholarship and hopes to carry on her legacy through her educational endeavors.

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
 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.



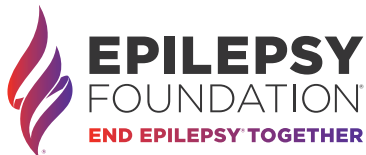
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GALA UPDATE

While we look forward each year to this festive evening, the Epilepsy Foundation of Kentuckiana has decided to hold its annual Expressions of Hope Gala in the Spring of 2022.

Watch the Illuminator for more updates and information in future issues. Thank you for your continued support of the Epilepsy Foundation of Kentuckiana.

Your Contribution Will Truly Make a Difference!



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An independently incorporated affiliate of the Epilepsy Foundation



COMMUNITY

Join Us for our Virtual Monthly Support Group Gathering

If you have epilepsy/seizures and are 18 or older, we hope you will consider joining us on Zoom on the third Friday of each month as we meet in a support setting to chat and catch up 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.

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:** All events are currently virtual!

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

All Youth Epilepsy Alliance activities are meeting virtually via Zoom.



Contact Gary Zortman at gzortman@efky.com for details.