

THE ILLUMINATOR

LIGHTING THE PATH FOR A BRIGHTER TOMORROW



A Publication of the
Epilepsy Foundation of Kentuckiana

ISSUE 2 - 2017

Register Now for the 2017 Not Another Moment Lost to Seizures Statewide Conference

Are you a caregiver to or person living with epilepsy? Would you like to learn more about this neurological condition? If so, we hope you and your family will join us for the 2017 annual statewide conference, Not Another Moment Lost to Seizures. This **FREE** program will kick off November as National Epilepsy Awareness Month and is designed for children and adults directly affected by epilepsy and their families. This year's program will be held on **Saturday, October 7, 2017** at the Founders Union Building at the University of Louisville ShelbyHurst Campus (450 North Whittington Parkway, Louisville, Kentucky 40222) from 8:00 a.m. – 2:00 p.m. Free breakfast and lunch will be served to conference participants. Free and secure parking is also available behind the building.



The 2017 Not Another Moment Lost to Seizures conference program 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 see the conference agenda on page 3. Also 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 get 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.

The 2017 Not Another Moment Lost to Seizures statewide conference is the Epilepsy Foundation of Kentuckiana's official kickoff event for national Epilepsy Awareness Month in November. We hope you and your family will join us!

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



Sponsorship opportunities still available.

FROM THE EXECUTIVE DIRECTOR

It is hard to believe summer has come and gone. I hope you enjoyed the cooler than normal temperatures and that you could spend time doing things you like to do, as you continued to #AimForZero seizures. I am excited to share that the national Epilepsy Foundation is continuing the #AimForZero campaign during this year's National Epilepsy Month in November and will

be carrying this throughout next year. It is crucial for everyone living with epilepsy, also known as a seizure disorder, to be mindful of the steps you can take to try to gain as much control over your seizures as possible. We understand this is not possible for 30-40% of the population living with epilepsy, but the #AimForZero campaign can be a very helpful tool in the fight against epilepsy. If you haven't already gotten on board with this campaign, we are hopeful you will take the important steps to implement the four focus areas into your daily regimen. You can find information on this campaign on our website at www.efky.org. Also, we seriously encourage those of you who struggle to gain seizure control to be evaluated by an epileptologist (epilepsy specialist). They are the experts in the field of epilepsy and would very much like to partner with you in your fight to defeat seizures.

On those lines, I would like to bring your attention to a documentary on epilepsy – SEIZED: Inside the Mystery of Epilepsy. This documentary, developed by the National Institutes of Health (NIH), has aired on PBS stations all over the country. Kentucky Education Television (KET) has aired the documentary 10 times since its release and we have requested that it be aired again this November during National Epilepsy Awareness Month. This documentary was produced to bring greater attention to one of the oldest and most mysterious ailments. Striking the organ most responsible for our very humanity — the brain — it can cause terrifying and disabling seizures that come without warning, at any time, in many different forms. SEIZED: Inside the Mystery of Epilepsy tells powerful, intimate stories of patients, families, and doctors fighting on the front lines for new treatments and new insights into this ancient disease. This very informative documentary is about an hour long. If you would like to watch it at your convenience, the link is <http://www.pbs.org/program/seized-inside-mystery-epilepsy/>. We are thankful to the NIH and to those involved in making this documentary for their efforts to show the realities of living with epilepsy, as well as also bringing hope to those who are desperately seeking treatment to control their devastating and life-threatening seizures.

To help in our mission to improve lives, the Epilepsy Foundation of Kentuckiana is thrilled and honored to have been

selected as one of six non-profit organizations to participate in and benefit from Leadership Louisville's Ignite Louisville program. The Foundation competed against nine other non-profit organizations to pitch our programs and services to six different teams of business professionals. We were hopeful that a team would choose us and embrace undertaking two key areas where we desperately need support. To our delight, The Great 8 Team adopted the Foundation and we've been working together to strategize on redesigning our website (which is in desperate need of much love and support) and moving us to a new customer relations management (CRM) database, which will help us serve you better. We are so pleased that several Great 8 team members came out to volunteer at our Louisville Walk and another member and her family participated in the Lexington Walk. Stay tuned on the new website and its launch. We will be transitioning over to the new CRM within the next couple of weeks.

We are so grateful to the group of eight professionals who make up Team Great 8!!! They are GREAT in every way and in it to win first place against the other Ignite Louisville teams! Their work with us would not be possible without the businesses they work for who have allowed them to share their awesome talents and time to benefit the Foundation. Thank you to the Archdiocese of Louisville, BB&T, Brown-Forman, Communications Electronic Design, Frost Brown Todd Law Firm, Humana, MCM CPA, and YUM.

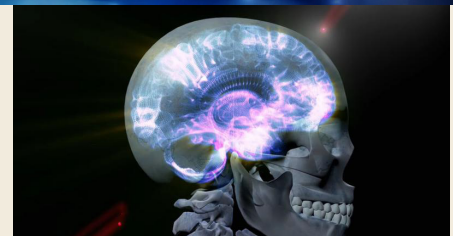
Wishing you all the best as we shift gears into this fall season and hope you will be involved in the fun activities and events we are planning.

– Deb



SEIZED

Inside the Mystery of 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:

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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.

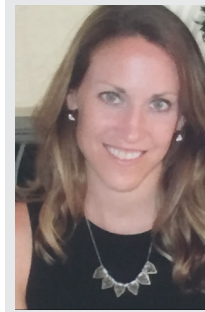


Not Another Moment Lost to Seizures

AGENDA Founders Union Building - UofL ShelbyHurst Campus (450 North Whittington Parkway, Louisville, KY 40222) October 7, 2017 | 8:00 am - 2:00 pm

TIME	ROOM 1	ROOM 2
8:00 am - 8:30 am	Registration, Breakfast, Networking	
8:30 am - 10 am	<p>KEYNOTE ADDRESS: MOOD & EPILEPSY Frank G. Gilliam, Jr., MD Epileptologist University of Kentucky HealthCare Kentucky Neuroscience Institute</p>	
10:05 am - 11:20 am	<p>LEARNING TO LET GO: HELPING TO EMPOWER YOUR LOVED ONE WITH EPILEPSY Amy McClain Chaplain Norton Healthcare</p>	<p>REFRACTORY EPILEPSY Meriem Bensalem-Owen, MD Epileptologist University of Kentucky HealthCare, Kentucky Neuroscience Institute Jordan Clay, MD Resident of Neurology University of Kentucky HealthCare, Kentucky Neuroscience Institute</p>
11:30 am - 12:15 pm LUNCH	<p>WAIVERS & RESOURCES FOR INDIVIDUALS WITH EPILEPSY Tonia Wells Senior Policy Executive, Director of Brain Injury Services - Kentucky Department of Aging & Independent Living</p>	
12:20 pm - 1:45 pm	<p>CANNABIS IN EPILEPSY – REVIEW & UPDATE Karen L. Skjei, MD Pediatric Epileptologist University of Louisville Physicians Child Neurology</p>	<p>CREATIVE AFFIRMATION Whitney Elvove Clay, ATR-BC Art Therapist</p>
1:45 pm - 2:00 pm	Evaluations & Wrap-Up	Evaluations & Wrap-Up

A MESSAGE FROM AMY COLLIER, CSW DIRECTOR OF CLIENT SERVICES



I am so happy to be here for you! I started working at the Epilepsy Foundation of Kentuckiana in April 2017 and since then, I have had the privilege of getting to know some of you and to be a part of many of the events and programs the Foundation has offered. My role at the Foundation is to help find support, services, and resources to assist individuals and families affected by epilepsy. If you have not spoken with me already, please call, email, or make an appointment to discuss your questions and concerns. Since April, I have talked to many individuals about multiple topics including epilepsy specialists in your area, vocational rehabilitation, employment issues, medication and financial assistance, school related services, SSI attorney referral, and support groups just to name a few. I will listen to your story and ideas and continue to advocate for those affected by epilepsy. I look forward to hearing from you!

– Amy Collier, CSW / 502-907-1534
866-275-1078 x15 / acollier@efky.org

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 502.637.4440 / 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



Kosair Charities Centre
982 Eastern Parkway
Louisville, KY 40217

Phone 502.637.4440
Toll-Free 866.275.1078
Fax 502.637.4442
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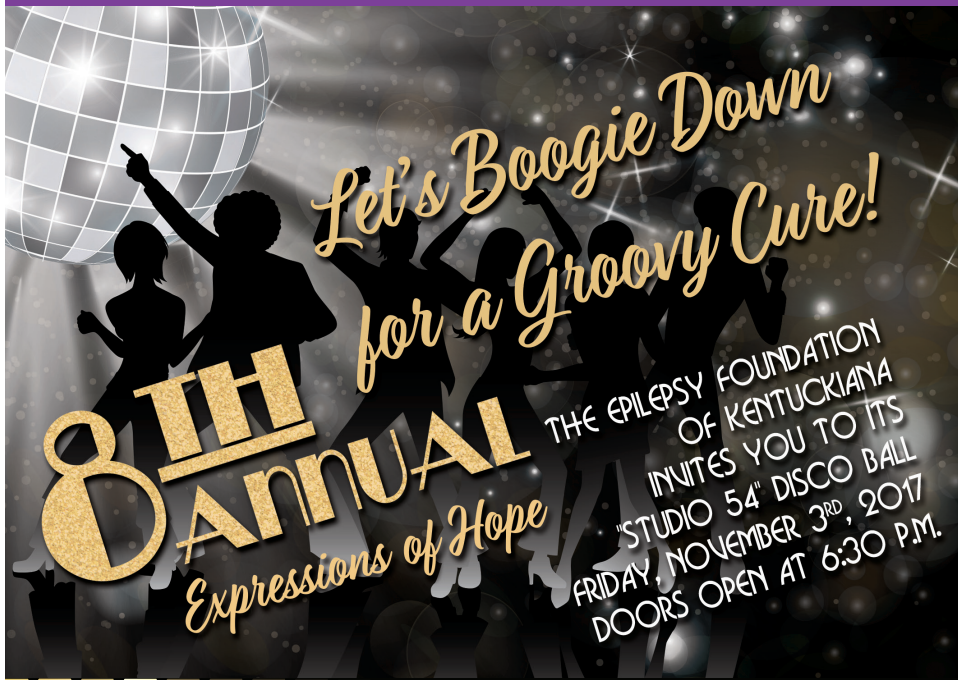
Epilepsy Research Project Fund

My employer has a matching gift program. Enclosed is the required form.

Please contact me/us about including the *Foundation* in my estate plans.

YOUR CONTRIBUTION WILL TRULY MAKE A DIFFERENCE!

Epilepsy Awareness Month – November 2017



EXPRESSIONS OF HOPE DISCO BALL

Dress to Impress – Disco Style

Friday, November 3, 2017

Doors open at 6:30 p.m.

Mellwood Arts Center (Van Gogh Room)
1860 Mellwood Avenue • Louisville, KY 40206

Open bar

Hors d'oeuvres and cocktails served before dinner

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

EVENING'S FESTIVITIES INCLUDE:

"Studio 54" Music and Dancing until Midnight

Auctioneer Extraordinaire - Bill Menish

Live and Silent Auctions

Bourbon & Cigar Bar • Heads or Tails Game

DISCO BALL TICKETS

\$100 each -or- \$800 for a table of eight (8)

Sponsorship opportunities available,
go to www.efky.org for details.

Reserve your ticket(s) by 10/24/17
online at <http://DiscoBall.gesture.com>



While Epilepsy Awareness Month is every month for us, we hope you are already planning awareness activities of your own and putting together all of your purple outfits in honor of yourself or someone you love who is living with epilepsy and seizures. This year we plan to continue the theme of #AimForZero and challenge you to do the same!

There are approximately 153,000 individuals living with epilepsy in Kentucky and southern Indiana that need to know about the potential deadly impact of a single seizure. Every year, 1 in 150 people who has uncontrolled seizures dies from sudden unexpected death in epilepsy, known as SUDEP. When people with epilepsy and their caregivers are empowered with information to understand SUDEP, they can take action to reduce the risk of harm. This November, we will respond to this urgency, raise awareness, and promote steps you can use to help prevent SUDEP. We will continue to focus on how YOU can #AimForZero seizures by adopting four behaviors: (1) Take medication as prescribed; (2) Get enough sleep; (3) Limit alcohol; and (4) Strive to stop seizures. We also know that putting these behaviors into action can be challenging for people with epilepsy, and so we ask that their efforts please be supported by their caregivers and healthcare team members.

For 3 out of 10 people living with epilepsy, we know that a life without seizures is not within reach at this time. However, by adopting the four actionable behaviors recommended above, and working toward the best seizure control possible, your risk of SUDEP may be reduced.

We will also be challenging you to #ShareMySeizure. This awareness campaign is a bold initiative designed to raise awareness of the different types of seizures through audio and video messages on social media. We know that this is not something that everyone will be comfortable doing, but we would like you to please consider sharing your story through the #ShareMySeizure campaign. You can also follow the hashtag #ShareMySeizure and share, re-tweet, and comment on social media. Be sure to share the message with your friends and followers and to talk about epilepsy and seizures with your friends, co-workers, neighbors, and community.

How do you #AimForZero? What is your #ShareMySeizure story? We challenge you to share how you plan to incorporate the four behaviors for seizure management on social media with the #AimForZero hashtag. We challenge you to consider sharing a video/audio of your seizure with the #ShareMySeizure hashtag. For more information about how to #AimForZero and #ShareMySeizure, please go to: www.epilepsy.com.

#ShareMySeizure

Bounce Out the Stigma Basketball Camps



Who knew that basketball camp could be so much fun?!? We do! In July, the Epilepsy Foundation of Kentuckiana hosted Kentucky's fourth Bounce Out the Stigma basketball camps for youth with epilepsy and autism spectrum disorders in Lexington and

Louisville. Through these camps, 50 youth ages 8 – 20 learned that limits do not define them, but they define their limits through skills, drills, thrills, and fun.

Bounce Out the Stigma is a basketball camp, founded and directed by "Mighty Mike" Simmel, a retired 13-year professional entertainment basketball player of the world-famous Harlem Wizards. These days, Mike is a top-notch camp clinician, event performer, and motivational speaker. He knows what it is like to be treated differently, as he has lived with epilepsy since age 2. In fact, when "Mighty Mike" was 16 years old, he was asked to leave a basketball camp after suffering a seizure. He decided at once that if he ever was able to do so, he would develop a basketball



program for unique kids... and he did just that! To learn more about this program, go to bounceoutthestigma.org.

Too often, children receive "the label" – a child with autism, epilepsy, attention

deficit disorder, hyperactive, and even disabled. Too often, it is that "label" that creates a deep emotional scar and a childhood of sitting on the sidelines in life watching others have fun. It may be called stigma, but the Epilepsy Foundation of Kentuckiana and "Mighty Mike" call it "unfair" and "seriously wrong." The Bounce Out the Stigma program strives to create the "I CAN TOO!" attitude with kids. When met with challenge, peer support, and nurturing adults, kids achieve more, empower themselves, and discover... "my will can define my limits."



We would like to recognize the awesome volunteers that served as "BOTS Staff" during the four-day camp experience. Without your support, these kids would not have had this unique and rewarding opportunity.

Thank you "Mighty Mike" for making Kentucky one of the states where you held your Bounce Out The Stigma basketball camps this year!

Thank You to Our Sponsors

This camp would not have been possible without the generous support from Kosair Charities, St. Paul United Methodist Church, Immanuel Baptist Church, and UK HealthCare Kentucky Neuroscience Institute.



Kentuckiana's Studio e: The Epilepsy Art Therapy Program and Monthly Art Group Gathering



The Epilepsy Foundation of Kentuckiana was excited to host its sixth annual Studio e: The Epilepsy Art Therapy Program this summer

in Louisville, as well as its second program in Lexington. In Louisville, participants worked with expressive therapist Kate Dennis, MSSW, MED, and in Lexington, participants worked with expressive therapist Whitney Clay, ATR-BC.

A total of 16 individuals with epilepsy gathered for these two programs to express themselves through art. Different mediums were explored and artistic voices were discovered while creating pieces that will help raise awareness about the realities of life with epilepsy. These pieces will be photographed and displayed on a regional and national level. Prints will also be available to purchase and proceeds will support the Foundation's vital programs and services.



The Epilepsy Foundation of Kentuckiana would like to thank Lundbeck and the national Epilepsy Foundation for the opportunity to provide this invaluable program for the past six years, as well as the UK Healthcare Kentucky Neuroscience Institute for the additional support for the Lexington program for the last two years. We would also like to thank Kate, Whitney, and our group participants, who made it a fabulous program! We look forward to next year's Studio e programs!

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



Your Partner in Epilepsy

The Lexington Studio e: The Epilepsy Art Therapy Program was additionally sponsored by UK Healthcare Kentucky Neuroscience Institute.



If you were not able to be a part of the summer program or are just reading about our art therapy program, we hope you will consider joining us in Louisville one Friday each month as we continue meeting in a support setting (without an art therapist) to create art, eat lunch, and enjoy fellowship with other people living with epilepsy. The group is open to anyone with epilepsy age 18 and up. If you are interested in joining us, please contact Beth Stivers, MS, director of education at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org.

Veterans Views: Battle Brain fx Symposium

by John Mustain, MSSW, Director of Veterans Outreach



The first **Battle Brain fx Symposium** was held on July 14, 2017 at the American Red Cross in Louisville, Kentucky. This event, which was open to the public, hosted approximately 50 participants. Attendees were

university professors, students, professional mental health clinicians, nurses, state government officials, traumatic brain injury (TBI) clients, post traumatic epilepsy (PTE) clients, and several veterans from all over the Commonwealth and Indiana. The symposium was a great success!

A few months ago, Alex Nauert, the military outreach coordinator at the Brain Injury Alliance of Kentucky, and I talked about our mutual desire to work together on a project that would raise awareness of TBI and PTE in both the public and health services sectors. We spent hours talking about what kind of event we could have and what kind of event would be best to help people understand the nature of TBIs and PTE. From these discussions came the idea for the Battle Brain fx Symposium. "Battle Brain" refers to the traumatic brain injuries that veterans sustain while deployed. The "fx" is the Hollywood symbol for special effects and represents all the physical and emotional effects that can develop after a TBI.

We (Alex and I) assembled a stellar line-up of speakers. William D. Watson, MD, a veteran and a neurologist at the University of Kentucky HealthCare Kentucky Neuroscience Institute, discussed chronic traumatic encephalopathy (CTE). This degenerative condition was popularized in the 2015 movie *Concussion*, starring Will Smith. John T. Slevin, MD, from the University of Kentucky Albert B. Chandler Hospital and the Lexington VA Medical Center, presented about post traumatic epilepsy. This presentation discussed why PTE develops after a TBI and the many ways in which it manifests itself, particularly in veterans. Stephen Bliss, PsyD, a clinical psychologist at the Louisville VA Medical Center, gave an extremely interesting presentation on how TBI and PTE effects veterans with addiction issues, like alcohol and illicit drug use.

Also included in the speaker lineup was John Taylor, a veteran, a member of the board of directors for the Epilepsy Foundation of Kentuckiana, and the owner of Commonwealth Extracts. He discussed products manufactured with cannabidiol (CBD) oil from hemp, as well as the truths and controversies of using hemp as medicine. The symposium ended with a panel of five people living with TBI and/or PTE with four out of the five panelists being veterans. The questions from the audience were excellent and the panel's responses were honest and insightful.

Mark your calendar! The next **Battle Brain fx Symposium** will be held on October 13, 2017 in Lexington, KY. The program will be free of charge and the location has yet to be determined. Be sure to check out www.efky.org/www.saluteyourhealth.org and the Operation Outreach Facebook page for more information



If you are a veteran experiencing seizures, are in need of assistance, or would like to learn more, please contact John Mustain, MSSW at 502-907-1535 / 866-275-1078 x16 / jmustain@efky.org.

Epilepsy Nights at the Ballpark

Fun times were had by all attending our Epilepsy Nights at Louisville Slugger Field on August 18th and at Whitaker Ball Park on August 19th. Over 100 children and adults of all ages were treated to an all-you-can-eat buffet of ball park food and enjoyed rooting on the Louisville Bats and the Lexington Legends. They came from all over Kentuckiana to enjoy time together with others impacted by epilepsy at these fun-filled activities. We are sure are glad you did!



These two nights of fun would not have been possible without the generous support of our sponsors - Norton Neuroscience Institute and the UK HealthCare Kentucky Neuroscience Institute.



KY and IN Veterans of the Year Banquets



The 2017 Kentucky Veterans of the Year Banquet

will be November 6, 2017 at the Brown & Williamson Club (inside Papa John's Stadium). This year's theme is A Tribute to WWII Veterans. Dr. E. Bruce Heilman, a WWII veteran who fought in Iwo Jima and Okinawa, will be our featured speaker. Gen. George S. Patton's grandson, Pat Waters, will be our emcee. Woody Williams, the last surviving Medal of Honor recipient from the Battle of Iwo Jima will be there to recognize all WWII veterans in attendance. Tickets are \$35 each and can be purchased only at www.KentuckyVeteransoftheYear.org. Sponsorship opportunities are still available.



The 2017 Indiana Veterans of the Year Banquet

will be on November 9, 2017 at The Grand, 138 E. Market Street, New Albany, Indiana. This year we are pleased to have as our featured speaker CSM (Ret.) James M. Brown. Mr. Brown is the Director of the Indiana Department of Veterans Affairs. Brown's dynamic speaking style will hold your attention, inform you, and entertain you. Tickets are \$35 each and can be purchased only at www.IndianaVeteransoftheYear.org. Sponsorship opportunities are still available.

2017 Walk #DareTo Defeat Epilepsy

THANK YOU!!!!

The Epilepsy Foundation of Kentuckiana would like to say THANK YOU to all of you who participated in the 2017 Walk #DareTo Defeat Epilepsy in Owensboro, Pikeville, Louisville, Lexington, and Paducah. Thanks to the over 650 walkers (both live and virtual) that laced up their shoes or greased their wheels and our sponsors, we raised a total of \$104,000!

Those of you that participated truly are SUPER HEROS in the fight against epilepsy! The funds raised through the 2017 Walk #DareTo Defeat Epilepsy will be used to support the vital education, outreach, advocacy, and support services the Foundation provides for those in need. These services are designed to improve the quality of life for the over 153,000 individuals living with epilepsy in Kentucky and southern Indiana and their family members to help them move closer to overcoming the many challenges and devastating consequences of epilepsy.



THANK YOU!!!!

Thank You to Our Sponsors



SAVE THE DATE

2018 Walk #DareTo Defeat Epilepsy

June 9 – Owensboro & Pikeville

June 16 – Louisville

June 23 – Lexington & Paducah



#DARETO DEFEAT EPILEPSY!

LEXINGTON | LOUISVILLE | OWENSBORO | PADUCAH | PIKEVILLE



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982 Eastern Parkway
Louisville, KY 40217

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Phone 502.637.4440 • Toll-Free 866.275.1078 • Fax 502.637.4442 • Web www.efky.org

An independently incorporated affiliate of the Epilepsy Foundation

YOUTH EPILEPSY ALLIANCE!

- WHO:** School age & affected by epilepsy...maybe you have epilepsy, or your brother, sister, or parent does. 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.

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

Help the Foundation Raise Funds through Kroger Community Rewards

Kroger Community Rewards® makes fundraising easy...and your participation will benefit the Epilepsy Foundation of Kentuckiana! All you have to do is set up your online account at <https://www.kroger.com/communityrewards> and designate the Epilepsy Foundation of Kentuckiana, or enter our ID number (12661) as your organization of choice, then anytime you shop at Kroger, just swipe your Plus Card and the Foundation will receive credit!

For more information, please go to www.efky.org/ways-to-help.html. Thank you for your support!



UPCOMING YOUTH EPILEPSY ALLIANCE! EVENTS

Saturday, October 7

Trampolines and Games at Vertical Jump Park
5101 Old Hinkleville Road, #610 | Paducah
10:00 a.m. – 12:00 p.m.



Saturday, October 14

Trampolines and Games at Get Air Trampoline Park
400 East Brannon Road | Nicholasville
10:00 a.m. – 12:00 p.m.



Saturday, October 21

Liquid Nitrogen Ice Cream Demonstration at Arctic Scoop and Picking out a Book at Barnes & Noble
841 South Hurstbourne Pkwy | Louisville
1:00 p.m. – 2:00 p.m.



Saturday, November 11

Pottery Painting at Paint Spot
4600 Shelbyville Road | Louisville
10:30 a.m. – 12:00 p.m.



Saturday, December 9

Basketball, Swinging, Foam Pits, and Trampolines at House of Boom
100 Urton Lane, #101 | Louisville
10:30 a.m. – 12:30 p.m.

