

# ILLUMINATOR



**EPILEPSY  
FOUNDATION**

Kentuckiana

**END EPILEPSY**

Let's Use Our Brains to End Epilepsy.®

For the 2019 #DareTo Defeat Epilepsy Walk campaign to be successful, we need your help! Set a fundraising goal, recruit family and friends,

then use all or some of the following techniques to reach this goal:

**CREATE YOUR FUNDRAISING PAGE**  
at [www.efky.org](http://www.efky.org)

**EMPLOYER SPONSORS**  
Ask your employer if they will be a Walk sponsor or match your fundraising efforts.

**SCHOOL, WORK OR CHURCH FUNDRAISER**  
Host a pizza party, bake sale, doughnut sale, ice cream social, pancake breakfast, or car wash to raise money for the Walk.

**LETTER OR EMAIL WRITING CAMPAIGN**  
Send a letter or e-mail to all your family members, friends, neighbors, and co-workers asking them to sponsor you for the Walk.

**SOCIAL MEDIA CAMPAIGN**  
Set up an online fundraising event on social media and ask your friends to donate to the Walk.

**COLLECTIONS**  
Ask your church, synagogue, or meeting hall if you can take a collection to support the Epilepsy Foundation of Kentuckiana's Walk campaign.

## 2019 #DareTo Defeat Epilepsy Walk Registration Now Open!

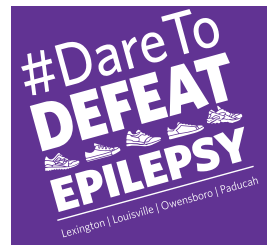
**We need you to help make this year's #DareTo Defeat Epilepsy Walk the best one ever!!** Our goal is simple...to raise epilepsy awareness and funds through this fun-filled, family oriented, non-competitive walk as we unite for the cause! This is the largest epilepsy awareness and fundraising campaign to benefit the Epilepsy Foundation of Kentuckiana (EFKY) but we cannot do it without you! Our goal is to raise \$153,000 – that's **ONLY \$1** for every child, adult, and veteran living with epilepsy and seizure disorders in Kentucky and southern Indiana. All



funds raised directly benefit the EFKY's vital education, advocacy, outreach, and direct client services. Prizes will be awarded to top fundraisers. We hope you will join us for fun, food, fellowship, and an invigorating Walk with lots of giveaways!

Here are just a few reasons raising funds for the EFKY's programs and services is so important:

- ❖ 1 in 26 individuals will develop epilepsy in their lifetime;
- ❖ Every four minutes someone is diagnosed with epilepsy;
- ❖ Epilepsy is the leading neurological disease among children;
- ❖ More people are affected by epilepsy than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's disease combined;
- ❖ It is estimated that up to 50,000 deaths occur annually in the U.S. from prolonged seizures, Sudden Unexpected Death in Epilepsy (SUDEP), and other seizure-related causes such as drowning, falls, suffocation, and other accidents. Unfortunately, SUDEP accounts for 34% of all sudden deaths in children; and
- ❖ For many soldiers who suffered a traumatic brain injury (TBI) on the battlefield, epilepsy will be a life-long consequence. Fifty-three percent of veterans who sustained a TBI in combat are estimated to develop epilepsy within 15 years.



### REGISTER FOR A WALK NEAR YOU @ EFKY.ORG

SATURDAY, JUNE 1  
OWENSBORO  
Legion Park,  
East Shelter

SATURDAY, JUNE 15  
LOUISVILLE  
Louisville  
Slugger Field

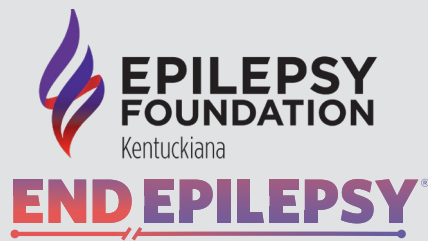
SATURDAY, JUNE 22  
LEXINGTON  
Keeneland Race  
Course, Barn 2

SATURDAY, JUNE 22  
PADUCAH  
Bob Noble Park,  
Shelter 19

Walk brochure coming soon in the mail, or go to [www.efky.org](http://www.efky.org) to download a copy.



**JUST FOR KIDS!** Raising money for the 2019 #DareTo Defeat Epilepsy Walk is not just for grown-ups! Kids can raise lots of money too! All you have to do is ASK! Think about all of your family members and friends, and even invite your school to support you for the Walk. Pennies and dollars add up very quickly, and who knows, you might just raise the most money on your team!



## 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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### CONTACT INFORMATION:

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Web: www.efky.org | www.saluteyourhealth.org

### STAFF:

#### Executive Director/Co-Founder:

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#### Director of Client Services:

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Connie Costelle - ccostelle@efky.org



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

Spring has finally arrived! I love this time of year when the flowers and trees begin to bloom and people begin to venture outdoors to embrace this new season and all the fun activities this time of year offers. I hope you get out to enjoy some fresh air and soak up some sunshine!

It has been another busy legislative session and I sincerely want to thank those of you who responded to our "calls to action" by contacting your legislators and asking them to support the proposed bills the Epilepsy Foundation of Kentuckiana has been involved in supporting. I also want to recognize the amazing group of advocates who participated in our annual Epilepsy Advocacy Day in Frankfort on February 26! Together, we bravely raised our voices to talk about epilepsy, increase awareness, and request support for legislation to improve and save lives impacted by seizures. I am excited to report that your advocacy efforts were instrumental in the passing of Senate Bill 54, also known as Prior Authorization legislation, and Senate Bill 16, the Rare Disease Advisory Council Act! Both bills passed the Senate and House chambers and were signed in to law by Governor Bevin.

SB 54, sponsored by Senator Ralph Alvarado, will streamline the prior authorization (PA) process in Kentucky. Your healthcare provider knows the best treatment for you, however they are unfortunately not always the ones making the final decision. Once this law goes into effect, (1) maintenance drugs will require an annual PA; (2) emergency services, screening and stabilization services will be deemed medically necessary; (3) when possible, require the use of licensed physicians, of the same specialty or subspecialty, to review prior authorization requests; and (4) 24-hour response required for urgent healthcare services and five-day response required for non-urgent. I've been told that epilepsy will fall under the urgent healthcare services and a PA should be responded to within the required 24-hour timeframe.

The Rare Disease Advisory Council Act, SB 16, was sponsored by Senator Julie Raque Adams and is needed to improve state policy for the rare disease community. With over 7,000 known rare diseases, including over 30 rare forms of epilepsy, it is incredibly difficult for anyone - let alone state policymakers - to have an in-depth understanding of rare diseases. Consequently, this lack of awareness contributes to some common difficulties that rare disease patients must face every day, such as delays in diagnosis, misdiagnosis, difficulty paying for treatment, and lack of access to medical specialists. What's more, research into rare diseases continues to advance and produce new breakthrough treatments for patients - including epilepsy

research being done at UK and UofL. However, state policies affecting patient access to these breakthroughs is often determined without consulting individual disease communities. Without greater representation in state government, Kentucky legislators and other officials cannot adequately address this and other barriers to better care for constituents with rare diseases. This legislation will allow for greater representation of rare diseases in state government so that issues faced by those with rare diseases can be better addressed.

The Epilepsy Foundation of Indiana has been diligently working on their Seizure Safe Schools legislation, as have other Epilepsy Foundation affiliates and chapters across the country. The Epilepsy Foundation of Kentuckiana is keeping a watchful eye on their progress, offering support as needed, and cheering them on every step of the way. To be the first in the country to pass legislation that has such a profound impact on students with epilepsy has been tremendously humbling, especially when we can also offer support to our colleagues as they work to achieve the same goal! We are forever grateful to Lyndsey Crunk for her courage to make Seizure Smart Schools her advocacy platform in Kentucky - and now a national campaign!

On the federal level, the Epilepsy Foundation of Kentuckiana has been advocating along with the national Epilepsy Foundation for protection of the 6 protected classes, which includes epilepsy, under Medicare. There is a nationwide movement by several national health organizations expressing concern over the implications any changes to the protected classes would have on patients receiving benefits through Medicare. Letters have been sent to Secretary Azar urging him to stop proposed changes that would delay access to life saving medications to the Medicare drug prescription benefit, as this will create barriers for patients with epilepsy to access their epilepsy medications. We will keep you apprised as we learn more about this issue.

The Epilepsy Foundation of Kentuckiana is grateful to the legislators and congressmen who have or are still working to support the over 153,000 children, adults, and veterans living with epilepsy in Kentucky and southern Indiana. Working together will bring us closer to our goal to end epilepsy!

As your unwavering ally in the fight against epilepsy, the Epilepsy Foundation of Kentuckiana proudly stands with YOU in your quest to defeat epilepsy!

Enjoy a happy and healthy spring! - Deb

# From the Director of Education *Beth Stivers, MS*

## Online Training Course for Educators Available in Late-April

When HB 147 (Lyndsey Crunk Act) was signed into law, the Epilepsy Foundation of Kentuckiana (EFKY) was relieved to know that students with seizures would be safe during the school day. HB 147 requires: (1) principals, guidance counselors, and teachers to complete a one-hour seizure recognition and first aid response training by July 1, 2019; (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.

With David Pettit, MEd (the EFKY's western Kentucky education coordinator) and I being the only Foundation staff responsible for providing training programs to educators, and over 50,000 educators to train throughout Kentucky, we realized very quickly we needed a solution to train a lot of educators in a short amount of time. That solution was to create an online training course.



Thanks to a generous education grant from UCB, Inc., we have been diligently working to create the Seizure Training for Educators online training course. We have also been working with Chronicle Cinema to create

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](http://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  
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Toll-Free 866-275-1078 • Fax 502-637-4442

**Your Contribution Will Truly Make a Difference!**



our own training video, starring Vinay Puri, MD, Michele Whitlock, MEd, and Lyndsey and Cyndi Crunk. This training program will fulfill the training requirement of HB 147 and will ensure that educators in Kentucky are properly trained to recognize and respond to multiple seizure types, as well as emotionally support a student with epilepsy while at school. We anticipate the course will be available by late-April 2019. We are so excited to be able to provide this resource to Kentucky's educators!

If you have any questions or would like more information, please contact me at 502-907-1533 / 866-275-1078, x14 / bstivers@efky.org.

## Join Us for Epilepsy Education Day in Lexington on June 8

Join us on **Saturday, June 8, 2019** from 12:30 p.m. – 4:00 p.m. at the Hilary J. Boone Center (500 Rose Street, Lexington, Kentucky) for a day of networking and education for anyone affected by epilepsy. A program for school age children will be provided. This event is free, but registration is required by May 31, 2019. Please register by contacting 859-218-5053. Also be sure to provide a call back number and number of individuals wanting to attend.

## 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 lunch, and enjoy fellowship with others living with epilepsy. 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.



# 2018 Not Another Moment Lost to Seizures Statewide Conference - A Day of Hope and Education

On Saturday, October 20, 2018 the Epilepsy Foundation of Kentuckiana held its annual Not Another Moment Lost to Seizures statewide epilepsy conference at the Hilton Garden Inn Louisville Airport in Louisville, Kentucky. The program was the Foundation's kickoff event for **November Epilepsy Awareness Month** and was attended by over 70 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 including: STABLE Kentucky - Kentucky's Able Plan, Quality of Life: Advancements in the Treatment of Epilepsy, Talk About It! - Raising SUDEP Awareness, Psychogenic Non-Epileptic Seizures, Social Security Update 2018, Pediatric Epilepsy, and Surgery for Epilepsy. A separate program was also offered to children with the day spent playing games, talking with other kids affected by epilepsy, and exploring their feelings about epilepsy through an expressive art program led by an art therapist.

In addition to the educational sessions, participants enjoyed a continental breakfast and buffet lunch, thanks to our amazing sponsors. They also received 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. The Epilepsy Foundation of Kentuckiana staff would like to thank all who attended and hope you had a wonderful educational experience and that you will all join us again in 2019!



**Mark Your Calendar!**  
**2019 END EPILEPSY STATEWIDE CONFERENCE**  
**OCTOBER 19, 2019**  
**HILTON GARDEN INN LOUISVILLE AIRPORT**  
**8 :00 A.M. - 2 :00 P.M.**

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

Sydney Badon	Max Mieth
Donald Bow, MS	Debra M. O'Donnell, MD
Whitney Clay, ATR-BC	Saghi Tasori Partovi
Amy Collier, CSW	Abigail J. Rao, MD
Matthew Collier	Sam Schad
Mary Beth Dwyer	Beth Stivers, MS
Cortney Sherrell Johnson	Jayan Thomas, LSCW, LMFT
Siddharth Kapoor, MD, FAES, FANA, FAHS	Clifford Vatter, MBA
Deb McGrath	Lauren Vassil, RN
	Eric Wheeler

## Thank You to the Following Sponsors



## Epilepsy Research Update at the University of Kentucky

Epilepsy is a complex set of disorders, and research into their causes, mechanisms, treatments, and cures is a priority for the people of the Commonwealth of Kentucky. As partners with the Epilepsy Foundation of Kentuckiana, the scientists and clinicians in the Epilepsy Research Center (EpiC) at the University of Kentucky are driven to understand the mechanisms underlying seizures and epilepsy, with the ultimate goal of developing better treatments and, eventually, a cure.

In the past few months, EpiC researchers at the University of Kentucky have been awarded new grants from the NIH, Department of Veterans Affairs, and the Epilepsy Foundation to support research aimed at preventing or slowing epilepsy development, as well as to identify new ways to treat seizures, with fewer side effects. A **4** group of EpiC members have also formed the Epilepsy and Brain

Metabolism Alliance (EpiMet Alliance), directed by Drs. Matthew S. Gentry, Frank G. Gilliam, and Bret N. Smith and funded by the UK College of Medicine. EpiMet Alliance investigators are elucidating how perturbations in brain metabolism contribute to disease, including epilepsy.

Dr. Gentry, a Professor at the University of Kentucky College of Medicine and EpiMet Co-Director, was recently awarded one of just two grants nationally from the Epilepsy Foundation to advance the development of new treatments for patients living with refractory epilepsy (i.e. those not controlled by medication). The award is through the Foundation's New Therapy Commercialization Grants Program and is part of the Foundation's Epilepsy Therapy Project, which has invested more than \$8.3 million in innovative therapeutic

*continued on page 7*

# 2018 Expressions of Hope Gala Recap

The 9th annual Expressions of Hope Gala was a smashing success! Over \$100,000 was raised through sponsorships and the over 350 guests in attendance. The 2018 Expressions of Hope Gala theme was the “Win, Place, & Show for a Cure” and many arrived dressed in their finest Derby-themed attire. The event was held on November 2, 2018 at the Mellwood Arts Center. Guests were treated to a 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 Barnstable Brown Band, Heads or Tails game, and a photo booth. Above all, we were exceptionally proud of the funds that were raised to directly benefit the programs and services of the Epilepsy Foundation of Kentuckiana.

Over the past 25 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 support service programs available at no cost to them, because of 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 2018 Expressions of Hope Gala. Also thank you to our Expressions of Hope planning committee: Co-Chair Linda O’Byran, Co-Chair, Beth O’Daniel, Co-Chair, Val Speth, Co-Chair, Lisa Wallace, Co-Chair, Meriem Bensalem-Owen, MD, Bill Menish, Tim Morris, Trey Morris, Cliff Vatter, and Lauren Wallace.

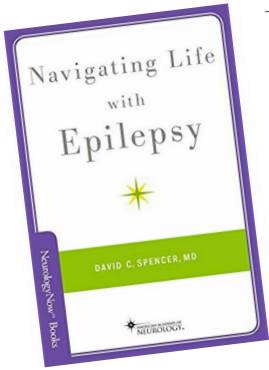
**Thank You to the Following Sponsors**



**Stay Tuned for More Information  
2019 Expressions of Hope Gala  
Friday, November 8, 2019**



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



The Epilepsy Foundation of Kentuckiana provides a variety of educational materials for those affected by epilepsy and thanks to a Good Works Grant from the Honorable Order of Kentucky Colonels, we have limited supply of the book "Navigating Life with Epilepsy" by David C. Spencer, MD. This book provides reliable information about epilepsy and translates current medical knowledge to the average person. The book discusses current approaches to diagnosis and treatment and shares patient experiences and advice on navigating psychosocial challenges including driving, work, and relationships. The book is relevant for adolescents and adults with epilepsy, as well as families and caregivers of a loved one with epilepsy.

We have heard some great feedback from clients who have received a copy and hope that it can be a great resource for others.

We are happy to share that 4 participants have successfully completed the HOBSCOTCH program, that works to improve memory and attention for adults with epilepsy. All four participants reported an improved quality of life after participating in the program. We would like to invite YOU to participate in this program if improving your memory is a priority for you.



We also still have medical ID bracelets and seizure detection devices available, thanks to a Good Works Grant from the Honorable Order of Kentucky Colonels and Kosair Charities (grant #774C). Devices include the Embrace Watch, EMFIT Mattress Monitor, and SAMi Video monitor.

If you are interested in receiving a copy of "Navigating Life with Epilepsy," participating in the HOBSCOTCH program, or receiving a medical ID bracelet or seizure detection device, please contact me at 502-907-1534 / 866-275-1078 x15 / acollier@efky.org.



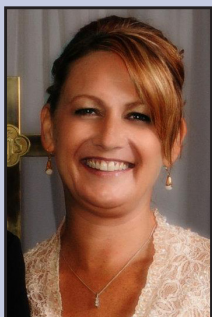
## 2019 Peggy Sherrell Memorial Scholarship Award

The Epilepsy Foundation of Kentuckiana is now accepting applications for the 2019 Peggy Sherrell Memorial Scholarship Award. This one-year, \$1,000 scholarship will be awarded to the finalist selected who meets the following criteria:

- Is currently under a physician's care for epilepsy/seizures (i.e. neurological seizures);
- Is currently undergoing treatment and/or taking anticonvulsant medication(s);
- Can demonstrate their struggle to overcome adversity because of their epilepsy/seizures;
- Is a degree or certificate-seeking student (graduating senior, first time adult learner, or those returning to complete their degree or certificate);
- Lives in Kentucky or in Clark, Floyd, or Harrison counties in Indiana.

For a copy of the application, please contact Beth Stivers, MS, director of education, at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org or download a copy at [www.efky.org](http://www.efky.org).

**Mailed Application Submission Deadline: MUST be post-marked by June 10, 2019.**



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.

## 2019 Shannon O'Daniel Memorial Scholarship Award

The Epilepsy Foundation of Kentuckiana is now accepting applications for the 2019 Shannon O'Daniel Memorial Scholarship Award. This one-year, \$1,000 scholarship will be awarded to the finalist selected who meets the following criteria:

- Is currently under a physician's care for epilepsy/seizures (i.e. neurological seizures);
- Is currently undergoing treatment and/or taking anticonvulsant medication(s);
- Can demonstrate their struggle to overcome adversity because of their epilepsy/seizures;
- Is a college-bound high school senior;
- Lives in Kentucky or in Clark, Floyd, or Harrison counties in Indiana.

For a copy of the application, please contact Beth Stivers, MS, director of education, at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org or download a copy at [www.efky.org](http://www.efky.org).

**Mailed Application Submission Deadline: MUST be post-marked by June 10, 2019.**



Shannon O'Daniel was a senior in college and just credits away from graduating when she died from what was attributed to SUDEP (Sudden Unexpected 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.

# From the Veterans Outreach Coordinator *Donald Bow, MS*

Happy New Year! As we wrap up the first few months of 2019 and are working toward accomplishing New Year's resolutions, one important thing that all of us veterans need to keep in mind is, just because we leave active duty does not mean we need to completely disconnect from our former lives. Interacting with veterans throughout the community is a great way to maintain that sense of camaraderie that you may be seeking.

For veterans suffering with post-traumatic epilepsy (PTE) and/or psychogenic non-epileptic seizures (PNES), maintaining that connection with not only the military community but also those veterans that have been impacted by seizures is a valuable resource that has the potential to improve your daily quality of life.

For local events throughout the state, be sure to Like and Follow our Facebook page at: <https://www.facebook.com/EFKYvets/>. On this page you will see posts from various veteran organizations that all have the same intent...to do what's best for the veteran community. Along with these camaraderie events, there are various veteran resource events that are happening over the next few months. If you are in the area during one of these events, take some time out of your day and stop by to gain valuable information designed to improve daily life and/or to share in the company of your fellow veterans.

I am truly honored and fortunate to be able to work with veterans and expand the Operation Outreach network across the state. Like/Follow us on Facebook at <https://www.facebook.com/EFKYvets/> and on Instagram at [efkyoperationoutreach](#) and [kentuckyveteransoftheyear](#). Please share this information with friends and family!

## UPCOMING VETERAN EVENTS

**March 28th** (10 am – 2 pm) Veterans Resource Fair, 3300 Tamarack Road, Owensboro, KY

**April 11th** (10 am – 2 pm) Veterans Resource Fair, 410 Cavalry Drive, Glasgow, KY

**April 14th** (2 – 4 pm) Camaraderie and Coffee, 1475 Veterans Pkwy, Jeffersonville, IN

**April 24th** (10 am – 2 pm) Veterans Education Expo, 1938 Stanton Way, Lexington, KY

**April 28th** (7:30 – 9:30 pm) Honor Flight Return, Bluegrass Airport, Lexington, KY

**April 29th** (12 – 3 pm) Military Child Appreciation Event, American Legion Post 244, Louisville, KY

# 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](mailto:dbow@efky.org).

# From the Director of Development *Cliff Vatter, MBA*

Thanks to your generosity and the matching grant of \$10,000 from an anonymous donor, we received a record amount of \$26,000 for our Year End Fundraising Campaign, compared to \$6,000 in 2017. Your support was needed and very much appreciated. Fundraising, no matter how worthy the mission, is challenging in our community and having a previous relationship at a foundation, company, or with an individual who is charitably minded is helpful, if not required. If you have such a relationship, please share it with Deb or me and we will proceed in a very thoughtful and sensitive way. 2019 will be a very eventful year for which we need your continued support:

- 1 Development and implementation of the Seizure Smart Schools training program for all educators in Kentucky's public schools;
- 2 Supporting research at the national level to find new treatments and someday a cure for epilepsy and seizure disorders;

- 3 Expansion of the Studio E: Epilepsy Art Therapy Program;
- 4 Monitoring the Kentucky Industrial Hemp Research Pilot program for future approval of CBD related products;
- 5 Continuing our lobbying efforts at the state capital, which produced results like HB 147 (Lyndsey Crunk Act), SB 54 (prior authorization bill), and SB 16 (Rare Disease Advisory Council Act).

There are many worthy causes out there but if you have a personal connection with epilepsy, then our mission is the most important: to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

Thanks again for your support and have a good 2019!

# Epilepsy Research Update at the University of Kentucky *(cont. from pg. 4)*

ideas since 2006. Dr. Gentry will also receive matching funds from a commercial partner, Valerion Therapeutics.

Gentry works on Lafora disease (LD), a catastrophic epilepsy that strikes healthy teenagers and leads to constant, ever-worsening seizures until it results in death approximately 10 years after onset. Currently, there is no therapy or cure for LD, but thankfully LD is very rare. Like many rare diseases, LD offers a unique glimpse into how alterations in normal cellular function can cause disease. Gentry's work on LD has defined an emerging link between brain metabolism and epilepsy. In collaboration with Valerion Therapeutics, Gentry and

colleagues are exploiting and targeting these links to treat LD with the hope of extending the work to more generalized epilepsies. They have developed a unique pre-clinical therapeutic that successfully treats LD in mouse models. Moving forward, this novel approach may have potential impacts beyond LD. The discoveries from this research may establish a paradigm with broader applicability for the treatment of other refractory epilepsies.

For more information about epilepsy research at the University of Kentucky, please contact Bret N. Smith, PhD at [bret.smith@uky.edu](mailto:bret.smith@uky.edu).



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## Don't forget to register for the 2019 #DareTo Defeat Epilepsy Walk

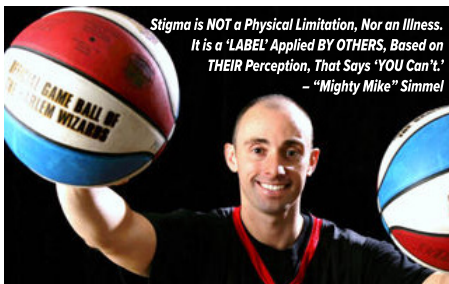
Phone 502.637.4440 • Toll-Free 866.275.1078 • Fax 502.637.4442 • Web [www.efky.org](http://www.efky.org)

An independently incorporated affiliate of the Epilepsy Foundation

DESIGNED TO EMPOWER KIDS

# BASKETBALL CAMP

FOR CHILDREN WITH EPILEPSY/SEIZURE DISORDERS AND AUTISM SPECTRUM DISORDERS



*Stigma is NOT a Physical Limitation, Nor an Illness. It is a 'LABEL' Applied BY OTHERS, Based on THEIR Perception, That Says 'YOU Can't.'*  
- "Mighty Mike" Simmel

### LEXINGTON

July 23 - 24, 2019  
Immanuel Baptist Church  
3100 Tates Creek Road  
Lexington, KY 40502

### LOUISVILLE

July 25 - 26, 2019  
St. Paul United Methodist Church  
2000 Douglas Boulevard  
Louisville, KY 40205

This basketball camp is proudly partnered with and associated with:



**END EPILEPSY**



To register your child, go to  
[www.efky.org](http://www.efky.org).

For more information,  
please contact the Epilepsy  
Foundation of Kentuckiana at  
**866-275-1078 / 502-907-1532 /**  
[dmcgrath.efky.org](http://dmcgrath.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:** 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!



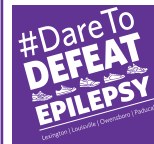
EPILEPSY FOUNDATION KENTUCKIANA'S YOUTH EPILEPSY ALLIANCE! IS SUPPORTED BY A GRANT (#774C) FROM KOSAIR CHARITIES.

### UPCOMING YOUTH EPILEPSY ALLIANCE! EVENTS



### APRIL

**Saturday, April 27**  
**10:00 a.m. - 1:00 p.m.**  
Me Memories Photography  
Family Photo Session at  
Papa John's Park - 2002 Papa  
John's Boulevard • Louisville



### JUNE

**2019 #DareTo Defeat Epilepsy Walks**  
We need you to help make this year's Walk the best one ever!! See times and locations on front cover.



### MAY

**Saturday, May 11**  
**10:00 a.m. - 12:30 p.m.**  
Main Event Entertainment  
Pizza, Bowling, and Video  
Games at 12500 Sycamore  
Station Place • Louisville



### JULY

**July 23-24**  
**July 25-26**  
Bounce Out the Stigma  
Basketball Camps  
(see ad to left)

For more info or to attend, visit [www.efky.org](http://www.efky.org) or contact Gary Zortman, events manager at [gzortman@efky.org](mailto:gzortman@efky.org).