HB 147 Passed
Providing Protection to Students with Seizure Disorder

The Epilepsy Foundation of Kentuckiana is excited to announce that Governor Matt Bevin has signed into law HB 147, also known as the Lyndsey Crunk Act, sponsored by Representative Mark Hart (R) of Falmouth, Kentucky, which provides support and protections to Kentucky’s students with epilepsy/seizure disorders. This legislation is the first of its kind in the United States and ensures students with epilepsy/seizure disorders will receive provisions to help them overcome the heartbreaking challenges and devastating consequences caused by potentially life-threatening seizures while in the classroom and during school activities.

Lyndsey Crunk, age 16, from Georgetown, Kentucky knows all too well the horrendous impact that seizures can have on a student’s life. She also knows how frustrating it can be when school personnel are not “Seizure Smart,” which is why she chose to champion this legislation. In 2016, she was nominated to be Kentucky’s Teens Speak Up representative and traveled to Washington, DC to attend the national Epilepsy Foundation’s Teen’s Speak Up program. In 2017, she was selected as Kentucky’s Ambassador for the Teens Speak Up program. During these programs, she met with Senators Mitch McConnell and Rand Paul and Congressman Andy Barr, urging them to increase funding for epilepsy programs and services through the Centers for Disease Control and Prevention (CDC). These programs serve to improve the lives of the over 3.4 million Americans living with epilepsy, including approximately 153,000 Kentuckians. From this empowering experience, grew an overwhelming desire to advocate for other students with epilepsy and seizure disorders to help them achieve their academic potential and Lyndsey worked diligently to see this legislation to fruition.

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It has been another very busy summer at the Epilepsy Foundation of Kentuckiana (EFKY). We hope you were able to participate in some of our activities and events and enjoyed connecting with others impacted by epilepsy and seizure disorders. We have been working hard on our fall event and hope to see you at the upcoming Fall Festival, Not Another Moment Lost to Seizures statewide conference, Veterans of the Year Awards banquet, and the Expressions of Hope Gala! Many of our clients have created lifelong friendships through the EFKY, taking comfort in the fact that they are not alone on this journey and that they have a support network to lean on during good times and bad. It is not easy to go through difficult times feeling as if no one understands or cares and the EFKY is always here to help you. Please rest assured of this!

Over the past 25 years the EFKY has fiercely advocated for the rights of individuals with epilepsy and seizure disorders and experienced some major victories while working to bring epilepsy out of the shadows in Kentucky and southern Indiana. I can honestly say that the Seizure Smart Schools legislation ranks at the top! All of us at the EFKY are extremely proud of Lyndsey Crunk and her parents, Cyndi and Tony Crunk, for their brave commitment to fight for legislation to make it required for all Kentucky schools to be Seizure Smart. Throughout this legislative session, the Crunks worked diligently on this platform, using their family’s epilepsy story to advocate for the protections and provisions of other students with epilepsy/seizure disorders. Many others joined the Crunk family in advocating for HB 147, also sharing their epilepsy stories and urging legislators to support this important bill. Together, their determined spirits were not overshadowed by those opposing HB 147, and we can all take pride in Kentucky’s General Assembly for adopting this legislation and it being signed into law by Governor Matt Bevin. The national Epilepsy Foundation has since approached us about working together to make this a national program. It would be such an incredible honor to work on this critically important advocacy initiative throughout the U.S., knowing Kentucky was first to blaze the trail in successfully advocating for Seizure Smart Schools!

The EFKY is so grateful to Representative Mark Hart (R) of Falmouth, Kentucky for sponsoring HB 147. After hearing Lyndsey’s epilepsy story, he did not think twice about sponsoring this bill as he has firsthand experience in seizure response through his many years of work as an EMT, fully understanding how devastating and potentially life-threatening some seizures can be. We are also thankful to co-sponsor of HB 147, Representative Phillip Pratt (R) of Georgetown, Kentucky, who serves the Crunk’s district, for taking up the gauntlet to ensure students with epilepsy/seizure disorders will be afforded the requirements of HB 147 to keep them safe while at school.

Another victory for the epilepsy community happened on June 25 when the U.S. Food and Drug Administration (FDA) approved Epidiolex (cannabidiol) oral solution in the treatment of Lennox Gastaut Syndrome and Dravet Syndrome, two rare and catastrophic types of epilepsy that are drug resistant, in patients two years of age or older. For those living with intractable (also known as drug resistant) seizures caused by Lennox-Gastaut and Dravet syndromes, Epidiolex could represent a true medical advancement. Clinical development for these rare and severe conditions is essential, and this news brings hope for these patients and their families that a new treatment option may have the potential to help better control their seizures. The FDA approval of Epidiolex will soon bring to market the first ever drug derived from the cannabis plant in the U.S. The Drug Enforcement Administration (DEA) has until September 25th to reschedule Epidiolex before it can be available to patients. The EFKY worked diligently to ensure patients in Kentucky and Indiana would have access to this drug, once approved and rescheduled by the DEA. To learn more about Epidiolex, please go to www.epilepsy.com.

Advocating for children and adults with epilepsy has been a passion of mine since the inception of the Epilepsy Foundation of Kentuckiana 25 years ago. I couldn’t expect my daughter to advocate for herself at the age of 5 and had to learn quickly to defend her and her rights. I am overwhelmed to see how much the EFKY has grown over the years and how much we have accomplished by working together with all of you! I hope you feel the EFKY is a place you can turn to in times of need and the Board of Directors, my staff, and I are truly honored that the EFKY is here to serve you and your loved ones.

– Deb
HB 147 will require:

- Principals, guidance counselors, and teachers to complete at least a one-hour seizure recognition and first aid response training by July 1, 2019.
- 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 student.
- Any FDA approved medication to be administered to the student with epilepsy/seizure disorder as prescribed by the treating physician.

This legislation has the potential to truly improve the lives of thousands of Kentucky’s students battling seizures - by ensuring that life-saving FDA approved medications are administered as prescribed, that school personnel are trained in seizure recognition and first aid, and that each student has a written, tailored seizure response plan for school personnel to follow should a seizure occur while at school or at a school activity.

As a leader in the fight against epilepsy, the Epilepsy Foundation of Kentuckiana is dedicated to serving children, adults, and veterans living with and impacted by epilepsy/seizures in Kentucky and southern Indiana. The Foundation was honored to work with Representative Mark Hart and Lyndsey Crunk on HB 147, and is extremely pleased that Governor Matt Bevin has signed it into law.

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

Donor’s Name ___________________________________________________________
Address ___________________________________________________________________
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E-mail address ___________________________________________________________
__ In Honor of ___________________________________________________________
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__ Shannon O’Daniel Memorial Scholarship Fund
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__ 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!
Let’s Talk About It! – Cortney Sherrell Johnson

I was honored to attend the fourth PAME (Partners Against Mortality in Epilepsy) Conference held in Alexandria, Virginia in early June. The PAME Conference stands alone in its format, with scientists, doctors, advocates, and families from all over the world who come together to collaborate and work toward finding better treatments and raising awareness for those living with epilepsy. Ultimately, the goal is to end all types of mortality linked with epilepsy and ultimately find a cure to end the disease that has taken too many lives. Thank you to the Epilepsy Foundation of Kentuckiana for allowing me the chance to participate in this conference.

The conference opened with a family session. Each person in the room introduced themselves and explained why they were there. The number of families that have lost a loved one to Sudden Unexplained Death in Epilepsy (SUDEP) or other seizure related death is heartbreaking. Families came to find answers, to learn how to prevent other families from suffering the same experience, and to find a group of people that genuinely understood their heartache.

One of the unfortunate, but common themes in these introductions was the lack of information on the possibilities of death from epilepsy discussed by doctors. This is a topic that has come up in each of the previous conferences I have attended. This is not to say that doctors are not doing their job, but too many patients and families are leaving doctor appointments not well enough informed. There are different strategies to help doctors have difficult conversations with patients, such as the SPIKES strategy. You can read more information about this strategy at www.childneurologyfoundation.org/programs/SUDEP.

Preventing SUDEP was a large focus at the conference. This is a very personal topic because I lost my mother, Peggy Sherrell, to SUDEP in 2010. Attending my third PAME Conference gives me hope that the future will lead to less mortality in epilepsy. While there is still much work to do, the epilepsy community is moving in the right direction.

Many of the new detection devices on the market now are more accurate and can send alerts to family members faster. The wearable devices are getting help for those living alone faster when they need it, where they may not have received it soon enough prior. Other devices such as monitors are also more accurate and help parents be more aware of children with nocturnal seizures. These devices are not without errors and cannot detect all seizures or all types of seizures but are continually improving.

There was a great amount of conversation about the link between seizures and cardiovascular or pulmonary malfunction. There are currently not enough conclusive studies to determine one, the other, or both as a cause of SUDEP. Genetic testing is also becoming more common in patients with epilepsy. Unfortunately, there is not just one genetic anomaly that causes all epilepsies.

For those living with epilepsy, self-awareness and care are critical. Learning what triggers seizures, taking medication regularly without skipping doses, getting plenty of sleep, and minimal consumption of alcohol are all ways that a person can help prevent seizures. If there are questions that arise, ask the doctor. Do not be afraid to ask difficult questions and tell the doctors your concerns. It is important to have an open line of communication with your medical provider.

Life comes with a great amount of challenges on different levels for those with epilepsy and family members. Continue to have the difficult and honest conversations. Support one another and help raise awareness that will allow others to become educated on epilepsy and the risk of mortality. The PAME Conference demonstrates that there is an incredible, supportive community working toward ending mortality in epilepsy and finding better treatments for those living with epilepsy. Know that however epilepsy has impacted your life, you are not alone. Let’s talk about it!

“Make a difference today for someone fighting for their tomorrow.”
– Jim Kelly

Join us for the 8th Annual Fall Festival
You and your family are invited to join the Epilepsy Foundation of Kentuckiana on Saturday, September 15, 2018 for our 8th annual Fall Festival from 11:00 a.m. – 3:00 p.m. on the great lawn at the Kosair Charities Centre (982 Eastern Parkway, Louisville, KY 40217). Lots of fun will be had with inflatables, pony rides, games, and food! Also joining us for the day are Metro Air 60, The Dream Express (from 11:00 a.m. – 1:00 p.m.) and The Bubble Bug (from 11:00 a.m. – 1:00 p.m.).

The Fall Festival is free of charge for those living with epilepsy/seizures and their family members thanks to a grant (#774C) from Kosair Charities. Please register online by September, 10, 2018 at www.efky.org.
Feel Alone? Would it help to talk to someone that understands? 
Please Join Us for Our Monthly Art Group Gathering!

If you have epilepsy/seizures and are 18 or older, we hope you will consider joining us at the Foundation office (Kosair Charities Centre, 982 Eastern Parkway, Louisville) one Friday each month as we meet in a support setting (without an art therapist) to create art, eat a free lunch, and enjoy fellowship with other people living with epilepsy. We provide art making supplies or you can bring your own!

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

Register Now for the 2018 Not Another Moment Lost to Seizures Statewide Conference

Are you living with epilepsy or are you a caregiver to a person living with epilepsy or seizure disorder? Would you like to learn more about this neurological condition? If so, we hope you and your family will join us for the 2018 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 affected by epilepsy and their families. This year’s conference will be held on Saturday, October 20, 2018 at the Hilton Garden Inn Louisville Airport (2735 Crittenden Drive, Louisville, Kentucky) from 8:00 a.m. – 2:00 p.m. Free breakfast and lunch will be served to conference participants. Free parking is also provided.

The 2018 Not Another Moment Lost to Seizures conference is for individuals school age and up. The program will feature a full day of educational sessions presented by experts in the field of epilepsy. These sessions are designed to help you understand more about living with seizures and how to better cope with this neurological condition. Please go to www.efky.org/conference in the coming weeks for a complete agenda. 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/conference.

Epilepsy Foundation of Kentuckiana Awarded Grant to Provide Seizure Awareness and Response Training to Law Enforcement Officials

Most law enforcement personnel do an outstanding job recognizing and handling individuals experiencing seizures, however in limited cases, they may respond with inappropriate force to behaviors associated with seizures, interpreting undirected, involuntary, unorganized movements, and reflex reactions to being restrained as aggression. The results can be harmful or fatal for the person with epilepsy, especially when dangerous restraint practices are used.

Education staff are excited to announce that the Epilepsy Foundation of Kentuckiana has received a grant from the national Epilepsy Foundation and the Centers for Disease Control and Prevention (CDC)* to provide the It Could Be Epilepsy: Epilepsy and Seizure Response for Law Enforcement Personnel training program to law enforcement agencies throughout western Kentucky. This program seeks to provide law enforcement personnel with tools as they need to assess the situation when seconds matter, to provide the proper responses to various types of seizures, and to avoid taking someone having a seizure into custody. This 60-minute program is free of charge to law enforcement agencies. Through this educational outreach program, we hope to raise awareness of epilepsy among law enforcement officials in western Kentucky to increase the safety of individuals living with epilepsy. The Foundation also aims to improve negative attitudes regarding epilepsy among those working in this profession.

To schedule a program or to request a training for law enforcement personnel in your western Kentucky area, please contact David Pettit, western Kentucky education coordinator at 270-316-3945 / dpettit@efky.org.

*This program is made possible with funding from the Centers for Disease Control and Prevention (CDC) under cooperative agreement number 1U58DP0026256-02-00, CFDA 93.850. Its contents are solely the responsibility of the authors and do not necessarily represent the views of the CDC.
I hope everyone has had a wonderful and happy summer! Over the last five months, I have spent time talking with veterans and their families at various Resource & Veteran fairs (Shelbyville, Glasgow, & Frankfort), attended a Honor Flight return trip for our World War II veterans, and have continued to reach out and build relationships with veteran groups to not only educate about post traumatic epilepsy (PTE) and psychogenic non-epileptic seizures (PNES), but also to continue to build on the “Operation Outreach” following. I dedicated time to linking up with Post 9/11 veterans and educating these veterans on the debilitating conditions that both traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD) can lead to. One of the first comments that I always hear is, “I never knew TBI/PTSD could lead to seizures.” I know this is a common thought across the veteran community because before I took this position, I never knew veterans were 53% more likely to develop seizures if they had been diagnosed with a TBI and/or PTSD.

Recently, after sharing some information with a veterans group on social media, I received a phone call from a veteran who believed he may be experiencing PNES. Had he not read the information I provided, he would have continued having episodes without knowing what was happening to him. This eye-opening experience prompted him to make an appointment to be evaluated by a physician.

The Epilepsy Foundation of Kentuckiana was recently awarded a grant that will allow them to host the Upcoming HOBSCOTCH Program. This is a great resource for veterans who suffer from seizures.

Do You Have Memory and Attention Problems? Our Upcoming HOBSCOTCH Program is for YOU!

Persons with seizures have a lot of difficulties with day to day memory, which may affect their job and their social lives. HOBSCOTCH (HOMe Based Self-management and COgnitive TChanges CHanges) is a program developed at Dartmouth, specifically for people with epilepsy, which may improve memory performance in patients who suffer from seizures.

Every person experiences memory lapses at some point in their life. We have all had moments where we have forgotten someone’s name or telephone number, forgotten to take our medication, or forgotten something that was told to us in conversation. Some memory problems can be part of the normal experience of being a human. However, approximately half of persons with seizures report more than average memory difficulties. Those living with seizures or epilepsy have many additional reasons to have memory and concentration problems.

The Epilepsy Foundation of Kentuckiana was recently awarded a grant opportunity to offer the HOBSCOTCH program to our clients living throughout Kentucky and southern Indiana. This is good news for you if you are suffering with memory and attention problems and would like to improve in these areas! We want you to learn ways to manage and cope with these problems so that you can lead a happier, more productive life!

Here’s how the program will work:

• You will participate in 8 sessions delivered by a certified HOBSCOTCH Memory Coach;
• These sessions will be delivered weekly and last 45 – 60 minutes each;
• Your first and last sessions will be conducted either in-person or via computer/phone/tablet with an audio/visual connection. All other sessions are conducted over the telephone; and
• Once you complete the program, you will have learned new skills to help improve your memory AND you will receive a $25 gift card to the retailer of your choice!

HOBSCOTCH is a win-win for you! In September, I will travel to Dartmouth in New Hampshire to be trained as a certified HOBSCOTCH memory coach. I am very excited to bring this program to the Kentuckiana area and look very forward to working with YOU! I am estimating that we will kick off the program in late September or early October, but you can register NOW!

Please keep in mind that all participants must commit to one hour per week for HOBSCOTCH sessions during the program period and must complete the program to receive the gift card. To register for the program, or for more information, you can reach me at 502-907-1534 / 888-275-1078 x 15 / acollier@efky.org.

*This program is made possible with funding from the Centers for Disease Control and Prevention (CDC) under the cooperative agreement number 1U58DP0026256-02-00, CFDA 93.850. Its contents are solely the responsibility of the authors and do not necessarily represent the views of the CDC.
From the Director of Client Resources, food, and fun activities! To raise awareness of the prevalence of epilepsy in the African American community by providing free seizure awareness and response programs, the Foundation’s education and client resources, food, and fun activities! To raise awareness of the prevalence of epilepsy in the African American community by providing free seizure awareness and response programs, the Foundation’s education and client resources, food, and fun activities!

An estimated 375,000 African Americans are currently living with epilepsy in the United States, and more than 24,000 African American patients are newly diagnosed each year. African Americans are also more likely to be diagnosed with epilepsy than Caucasians; to experience status epilepticus, a medical emergency in which a seizure continues for 10 minutes or more without stopping; and are at an increased risk for Sudden Unexpected Death in Epilepsy (SUDEP). Despite this, epilepsy awareness is low among African Americans, due to lack of access to health care and health information, misinformation, and stigma associated with the condition.

If you would like your predominantly African American church or faith-based organization to participate in this program, please contact Beth Stivers, MS, director of education at 502-907-1533 / 866-275-1078 x14 / bstivers@efky.org.

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EFKY Awarded Grant to Provide Epilepsy Education to Predominantly African American Faith-Based Organizations

The Foundation recently received a grant from the national Epilepsy Foundation and the Centers for Disease Control and Prevention (CDC)* to provide epilepsy education to predominantly African American faith-based organizations. For this program, we are targeting churches and other faith-based organizations in Louisville, Lexington, and Frankfort to train staff and provide Epilepsy Education Day events for these churches/organizations. The Foundation’s education and client services staff are very excited to work with these churches/organizations to raise awareness of the prevalence of epilepsy in the African American community by providing free seizure awareness and response programs, resources, food, and fun activities!

The annual Teens Speak Up! program provides a special opportunity just for teens with epilepsy and their parents to visit the nation’s capital, receive advocacy training, meet with their legislators, and tell their personal stories. Teens from across the country are nominated by their respective affiliates and selected by the Foundation to participate in the program. After receiving training at TSU, each teen is asked to turn that training into action in their respective home districts through the national Foundation’s Year of Service program. This year’s program was held April 15 – 17, 2018.

The Epilepsy Foundation of Kentuckiana was honored to have Jackson Sturgeon of Paris, Kentucky represent children and youth with epilepsy throughout Kentucky as the 2018 Teen Speak Up! representative. Jackson was joined by Charles Wilson, last year’s Teen Speak Up representative as an Ambassador for this year’s program. These young men did an excellent job, making us all proud as they shared their epilepsy stories with Kentucky’s congressional leaders. Jackson and Charles also shared an important message with these leaders, urging them to fund $175 million in epilepsy research at the National Institutes of Health (NIH), to continue investing $9.5 million in critical epilepsy public health programs through the Center of Disease Control and Prevention (CDC) to help build safer communities, to end stigma associated with epilepsy, to educate community leaders, and to build epilepsy awareness to benefit everyone with epilepsy and other chronic health conditions and disabilities throughout the nation. Congratulations to both Jackson and Charles for their incredible strength representing Kentucky on a national level!

I was honored to be 1 of 40 different kids with epilepsy in the United States to be invited to Washington, DC for the 2018 Teens Speak Up! conference to represent the Epilepsy Foundation of Kentuckiana. It made me feel very good about myself to be chosen to inform our representatives in the Senate and Congress about why it is necessary to devote time, money, and resources to epilepsy research and education. It was very fun to socialize with other kids that have epilepsy from all around the country. We got to compare how epilepsy affects us and when and how we have our seizures. Everything the speakers talked to me and the rest of the kids about was engaging.

The party at the end of the conference was incredibly fun. The hotel was very nice and convenient. The monuments in Washington, DC were fun to visit, and I was happy to participate in the National Epilepsy Walk. Lastly, the food was delicious. I look forward to serving the people of Kentucky and southern Indiana in my Year of Service.

2018 Kentuckiana’s Teens Speak Up! Representative

~ Jackson Sturgeon

2018 Teens Speak Up! in Washington DC

From L - R: Clay Sturgeon, Deb McGrath, Michele Sturgeon, Kathryn Sturgeon, U.S. Congressman Thomas Massie, Charles Wilson, Christy Wilson, Laureen Vassil, and Jackson Sturgeon

U.S. Congressman Andy Barr and Jackson Sturgeon

2018 Kentuckiana's Teens Speak Up! in Washington DC
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-2018 Not Another Moment Lost to Seizures Conference
-Low Enforcement Training Grant Awarded for Western Kentucky Area
-From the Veterans Outreach Coordinator
-Program to Improve Memory Skills Coming to Kentuckiana
-2018 Teens Speak Up! in Washington, DC
-EFKY to Provide Programs at Predominantly African American Faith Based Organizations

Friday, November 2 will mark the 9th Annual Expressions of Hope Gala. This year’s theme is Win, Place, and Show for a Cure (just in time for the Breeders Cup)! Watch online for more information. This is definitely one race you won’t want to miss.

Go to www.foracure.givesmart.com for tickets or sponsorship opportunities.