ISSUE 3 • 2018



## Here's what your donation can do:

THE

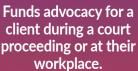
Ensures vital support & information reaches a newly diagnosed family.



Funds a much-needed consultation with our support team.







Provides a day of education training to school personnel and nurses.

Provides two seizure monitors for clients in need.

## **2018 Year End Gift Campaign -**Help Us Reach \$20,000

As we near the end of 2018 we can't thank each of you enough for being a friend of the Epilepsy Foundation of Kentuckiana. As we enter this time of giving, we hope you will consider donating today to the Foundation. Your gift will make a difference for the over 153,000 children, adults, and veterans living with epilepsy in Kentucky and southern Indiana.

**ND EPILEPS** 

Let's Use Our Brains to End Epilepsy.<sup>®</sup>

# 1 in 26 are diagnosed with epilepsy at some point in their life – please consider to help the 1.

**1 gift = 1 life changed.** Your tax-deductible donation will directly help the children, adults, veterans, and families touched by epilepsy throughout Kentucky and southern Indiana. No gift is too small and please know that 85¢ of each \$1 of your donation will directly help make a difference so not another moment or life is lost to seizures. Donations can be made online at **www.efky.org** or by mail using the donation form located on page 3 of this newsletter. (Mail to: Epilepsy Foundation of Kentuckiana, Kosair Charities Centre, 982 Eastern Parkway, Louisville, KY 40217).

Thanks to the continued generosity of our supporters we can provide education, advocacy, outreach, support services at no cost to those impacted by epilepsy and fund vital epilepsy research for individuals and families affected by epilepsy and seizures throughout Kentucky and southern Indiana. We hope you have found and continue to find comfort in knowing that you are not alone in the fight against epilepsy and remember that you have a devoted team at the Foundation who is ready and willing to offer help, hope, and support at a moment's notice.

We hope you have a healthy and happy Holiday season and are grateful for your continued support of the Epilepsy Foundation of Kentuckiana. Thank you!

**The good news is, your donation will be matched!!!!** An anonymous foundation has offered to match the first \$10,000 of contributions made by the end of 2018. We are grateful for this opportunity and with your donations, hope to turn \$10,000 into \$20,000!

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

Visit www.efky.org today and help us #EndEpilepsy in 2019.



#### MISSION STATEMENT

To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

#### **BOARD OF DIRECTORS:**

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

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#### **CONTACT INFORMATION:**

Epilepsy Foundation of Kentuckiana Kosair Charities Centre 982 Eastern Parkway | Louisville, KY 40217 Phone: (502) 637-4440 Toll Free: (866) 275-1078 | Fax: (502) 637-4442 Web: www.efkv.org | www.salutevourhealth.org

#### STAFF:

**Executive Director/Co-Founder:** Deb McGrath - dmcgrath@efky.org

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Western Kentucky Education Coordinator: David Pettit, MEd - dpettit@efky.org

**Director of Client Services:** Amy Collier, CSW - acollier@efky.org

**Director of Development:** Clifford Vatter. MBA - cvatter@efkv.org

Veterans Outreach Coordinator: Donald Bow, MS - dbow@efky.org

**Events Manager:** Gary A. Zortman - gzortman@efky.org

Administrative Assistant: 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**

I wish you seizure-free tidings of good health and a joy-filled Holiday season as you surround yourself with family and friends! It is hard to believe that we will soon be ringing in the New Year and I wish you all the best in 2019. I have a lot of exciting things to tell you about in this issue of the Illuminator, so hang tight!

It is a pleasure to announce that Cliff Vatter has joined the team at the Epilepsy Foundation of Kentuckiana (EFKY) as Director of Development. Cliff is a retired financial advisor who donated an auction item to benefit this year's Expressions of Hope Gala. After learning about the good work of EFKY, Cliff approached me to offer his service and support to help further the Foundation's mission. The EFKY has set an audacious goal of raising \$250,000 in recognition of its 25th anniversary and Cliff has accepted the challenge!

This has been another busy year at the EFKY. Over the past 25 years, it has been a complete honor and joy for me to be of service to you and your loved ones. It has been my privilege to work to help you overcome the myriad of challenges and heartbreaking consequences caused by epilepsy and seizure disorders in Kentucky and southern Indiana. As the leader in the fight against epilepsy, my staff and I are committed to being your ally in the fight to end epilepsy.

In November, the national Epilepsy Foundation launched the "Use Your Brain to End Epilepsy" marketing campaign to increase awareness and change the conversation around epilepsy - to improve and save lives through care, advocacy, research, therapies, and education - mobilizing everyone to take action. I am so proud of the action Lyndsey Crunk took to use her brain and share her epilepsy story to advocate for other students who have been negatively impacted by having seizures in the school setting. She made it her mission to make



Kentucky schools "seizure smart" through her work to get HB 147 (Lyndsey Crunk Act) passed in Kentucky earlier this year. The EFKY is excited that Kentucky is the first state to pass legislation of this kind requiring (1) all public school administrators, school nurses, counselors, and teachers to participate in a one-hour seizure recognition and response training; (2) all students with epilepsy to have a seizure action plan; and (3) the administration of any FDA approved seizure medication

prescribed by the treating physician.

I am excited to share that Lyndsey's actions caught the attention of the national Epilepsy Foundation (EF) and she was invited to be involved in the "End Epilepsy" marketing campaign! Lyndsey and her mom, Cyndi, traveled to New York City for a photo shoot and videotaping of their epilepsy story. Through this campaign, the EF is engaging other affiliates and chapters to advocate for their state to adopt legislation requiring their public schools to be "seizure smart." The EFKY is honored to lead this charge and we are looking forward to seeing similar legislation adopted throughout the country to bring epilepsy out of the shadows through education and empowerment!

We are already at work for the 2019 legislative session and I am excited to announce that our annual Epilepsy Advocacy Day at the Capitol in Frankfort has been set for February 26, 2019. This is a great opportunity to come together with others to talk with your elected officials about the impact epilepsy has on you and your family. I will never forget the first time I had the opportunity to do this - sure, I was nervous, but I knew there was no one better to tell my daughter's epilepsy story than me. It was so empowering. I knew right then that our epilepsy story mattered. Your epilepsy story matters too, and it can help make a difference for you and the over 153,000 children and adults living with epilepsy in Kentuckiana. The EFKY will take care of setting up appointments with your legislators, help you get to your scheduled meetings, and attend meetings with you. You will have the opportunity to sit in on committee hearings. where proposed legislation will be discussed and see laws being passed by lawmakers in their respective chambers, just like we did with the Seizure Smart Schools legislation last year! Your voice is vitally important in helping us improve the lives of those battling this potentially lifecontinued on page 3

# **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.



The Epilepsy Foundation of Kentuckiana is

excited to announce that Cliff Vatter joined the staff in October as the Director of Development after a successful career as a financial advisor. During the years, he was active on non-profit boards, but is excited to become involved in a more meaningful way at the Foundation. Cliff says, "As a retired financial advisor, my goal was to join a non-profit agency where I could

make a difference. I am so pleased to have landed at the Epilepsy Foundation of Kentuckiana and look forward to raising funds for those

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 Form**

Donor's Name:	
Address:	
<b>T</b>	
In Honor of:	
In Memory of:	
Shannon O'Daniel Memorial Scholarship Fund	
Peggy Sherrell Memorial Scholarship Fund	
Epilepsy Research Project	ct Fund
My employer has a matching gift program. Enclosed is the required form	
Please contact me/us abo	out including the Foundation in my estate plans.
	KOSAIR CHARITIES CENTRE 982 Eastern Parkway • Louisville, KY 40217
Kentuckiana An independently incorporated affiliate	Web: www.efky.org • Phone: 502.637.4440 Toll-Free 866.275.1078 • Fax 502.637.4442

Your Contribution Will Truly Make a Difference!

## **Cliff Vatter Joins the EFKY Staff**

affected by epilepsy." Cliff has a BA from the University of Denver, and both a BS and MBA from the University of Louisville.

Cliff lives in Prospect with his wife of 45 years, Bonnie. They have a daughter, Crissy, and two grandsons. In his free time, he enjoys sailing, tennis, and mountain biking. He wishes all of you a Happy Holidays and hopes to meet many of the Foundation's supporters in the near future.

If you would like to make a donation or discuss giving, please feel free to contact Cliff at 502-907-1535 / 866-275-1078 x16 / cvatter@efky.org.

**From the Executive Director** (cont. from pg.2) threatening neurological disease. For more information and to register to attend our Epilepsy Advocacy Day on Feb. 26, please go to www. efky.org/epilepsy-advocacy-day. Remember, your voice WILL make a difference as we work together to End Epilepsy!

Gary Zortman and I are already working on the 2019 Epilepsy Walk campaign. We look forward to coming together with you and your Walk team as we make strides in raising epilepsy awareness and support for the EFKY's vital programs and services. We are looking at moving the Louisville Walk to a different location and are in discussions with the Louisville Zoo. Many of you have expressed your interest in returning the Walk to the Zoo, where it originated over 15 years ago. While we loved holding the Walk at the Louisville Zoo, price increases in parking and venue rental over the last few years made it cost prohibitive and we felt it decreased the amount raised overall for EFKY programs and services. This said, we are considering all options and are currently in search of a sponsor to offset the cost of returning to the Zoo. As soon as a decision is made, we will send an announcement through our social media outlets, so be sure to "Like/Follow" our Facebook page (www.facebook.com/EpilepsyFoundationOfKentuckiana) and stav tuned for more information!

I thank you for your support in 2018. I know the Holidays can be a difficult time, especially when seizures derail your plans, which is why the EFKY's work is so very important. Until we END EPILEPSY, you can count on us to be there for you and your loved ones.

May your Holidays be filled with many blessings!

**a** 



















Kosair Charities is a tremendous blessing to children with special needs and the agencies that partner with them. The Epilepsy Foundation of Kentuckiana cannot begin to express how grateful we are to Kosair Charities for our continued partnership and commitment to improve the lives of the more than 50,000 children living with epilepsy and seizure disorders in Kentucky and southern Indiana. Kosair Charities provides funding (through grant #774C) for training programs for school nurses, school personnel, and students, seizure detection devices for children in need, patient education packets for children newly diagnosed with epilepsy, the annual Fall Festival, and the Youth Epilepsy Activity Group meetings in Louisville, Lexington, Owensboro, and Paducah! In addition to these, Kosair Charities campus is also home to the EFKY office and we are so proud to call this home!













## **2019 Golfer's Gauntlet**



MAKE A DIFFERENCE by becoming a sponsor, registering your team, or playing individually in the 13th Annual Golfer's Gauntlet on Monday, April 15, 2019. All participants will enjoy a fun-filled day at Fuzzy Zoeller's Covered Bridge Golf Club in Sellersburg, Indiana, a hearty lunch, raffle, a cookout, cash bar,

and awards presentation. All proceeds from this event will benefit the vital services and programs provided by the Epilepsy Foundation of Kentuckiana to individuals affected by epilepsy living in Kentucky and southern Indiana. To be sponsor, register your foursome, or for more information, please go to www.efky.org.



**Presenting Sponsor** 

## **2019 Walk Save the Dates**





June 15 Louisville

Stay tuned for information about times and locations at www.efky.org.













June 22 Lexington Paducah



# From the Director of Client Services Amy Collier, CSW



If you don't wear some form of medical identification (ID), we would like to urge you to get one and wear it every time you leave the house. A medical ID bracelet or necklace can help others know that you have a medical condition that may need attention and in the event 911 is called, it will alert first responders to a history of seizures and allow them to respond to your needs more readily, leading to better understanding and more efficient treatment.





the better you will be able to fight stigma and discrimination. Combatting stigma is essential in order to raise awareness and improve quality of life for all individuals living with epilepsy and seizures.

There are many different types of medical alert options. Some are just pieces of jewelry that can be engraved with your key medical conditions or health information. Others look like a simple bracelet or necklace. You can purchase one from various sources online, however if you are unable to afford a medical ID bracelet, please contact me at 502-907-1534 / 866-275-1078 x15 / acollier@efky.org to assist you in getting one. We have a limited supply of medical ID bracelets available on an as needed basis. Keep in mind, getting a medical ID for yourself or your loved one is more than a piece of jewelry, it's peace of mind.

### **2018 Peggy Sherrell Memorial Scholarship Recipient**

The Epilepsy Foundation of Kentuckiana is proud to announce that Keith Peirce of Floyds Knobs, Indiana was selected as the 2018 recipient of the Peggy Sherrell Memorial Scholarship. Keith is a 1983 graduate of Jeffersonville High School in Indiana and went on to pursue a B.A. in biology at Indiana University Southeast. Unfortunately, he was in a head on collision at the fault of a young, distracted Keith Pierce driver while traveling home from campus,



changing his live forever. About two weeks later, Keith started experiencing tonic seizures and eventually had a generalized tonicclonic seizure before being diagnosed with epilepsy.

Keith has struggled with employment and is currently unable to work because of his seizures, however, he is using this time as an opportunity to return to Indiana University Southeast to continue working on his degree. Using this degree, he plans to overcome his seizures and become employed in an office environment. Keith wants to become an inspiration for others living with epilepsy and other chronic diseases by showing them that there is life after a diagnosis that disrupts their life and their ability to achieve their goals. He hopes he can also volunteer with tax preparation services for those in need.

Keith 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 Keith 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. Peggy's family developed the Peggy Sherrell Memorial Golf Scramble and have donated over to \$140,000 to the Epilepsy Foundation of Kentuckiana since its inception in 2010.

## **2018 Shannon O'Daniel Memorial Scholarship Recipient**

The Epilepsy Foundation of Kentuckiana congratulates Nina Piazza for being awarded the 2018 Shannon O'Daniel Memorial Scholarship. Nina is a 2018 graduate of Sacred Heart Academy in Louisville, Kentucky. She is currently attending the University of New Hampshire, majoring in biology with plans to become a surgeon.



Nina has been seizure free for over two years, but during her first years in high school suffered generalized tonic-clonic seizures. After having two seizures in school, she realized it was much easier to share her story and move forward with her life. striving to make people see epilepsy more as "something a person has to deal with" than "something a person needs to be afraid of."

Knowing how to deal with Nina's seizures allowed her classmates to want to look out for her rather than not hang out with her. She encourages those living with epilepsy to speak up and share their story and to educate people about epilepsy. Even though Nina is now in college, she works to continue to change people's views on how they see others with disabilities. Nina is honored to represent Shannon O'Daniel through this scholarship and hopes to carry on her legacy through her educational endeavors.



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 Operations Outreach Coordinator Donald Bow, MS



the Mellwood Arts Center and it was a wonderful evening to honor veterans. The Epilepsy Foundation of Kentuckiana's Operation Outreach program was honored to name Jeremy Harrell (Veteran's Club Founder) and Megan Karr (Team Red, White, and Blue) as the Kentucky Veterans of the Year and Jim Garigen (Invisible Vets)

(L-R) Jeremy Harrell, Megan Karr, Jim Garigen

as the Indiana Veteran of the Year. The Traveling Kentucky Vietnam Memorial Wall was also showcased at the event as well as keynote speaker, Alex Ramirez. Entertainment was provided by DJ Wesley Howland and the banquet was catered by Victoria's Catering. We would also like to thank special guests emcee Colonel Fred Johnson (US Army Retired), Commissioner of the Kentucky Department of Veterans Affairs Brigadier General Benjamin Adams, and Lieutenant Governor Jenean Hampton for presenting. We would also like to thank our sponsors Campbellsville University, Volunteers of America, and Karl Truman Law Office. If you missed out on this year's event, don't fret, as we will begin taking nominations for the 2019 Veteran of the Year very soon and continue to build on our annual awards dinner for veterans and celebrate again next November.

Kentucky is a great state for veterans and there always seems to be a dbow@efky.org. different event honoring the veteran community. I attended several veteran events over the last few months including a Veteran's Stand-I am truly honored and fortunate to be able to work with veterans down and Purple Heart pinning ceremony at Humana, the Charles and expand the Operation Outreach network across the state. Young Veteran Memorial unveiling at the Kentucky Center for African Please Like/Follow us on Facebook at www.facebook.com/ American Heritage, and the Patriot's Peace Memorial ceremony for EFKYvets/ and on Instagram at efkyoperationoutreach and the 241 Americans who were killed on October 23. 1983 in the **kentuckyveteransoftheyear.org**. I ask that you please share this barracks bombing in Beirut, Lebanon. All these events were a sight important information with your friends and family, especially veterans, and have a wonderful and safe Holiday season! to see and I encourage everyone to get out

and see these jewels throughout Kentucky.

Now that the summer has come and gone, and we have entered the Holiday season I would like to remind you that even with all the joy that this season brings, it can be a trigger for depression and suicidal thoughts in veterans and others. For veterans suffering with PTSD and/or TBIs, the stress of the Holidays has the potential to exacerbate these conditions and veterans may find themselves at a higher risk of committing



**OPERATION OUTREACH** 



have had a busy summer/ fall leading up to all of the Veterans Dav events. The 5th annual Veterans of the Year Awards Banquet was held on November 5th at



Traveling Kentucky Vietnam Memorial Wall

suicide. For all veterans, know there are many organizations available to assist you in your time of need. If you are in crisis and need to talk to someone, I urge you to please reach out to the Veterans Crisis Line at www.veteranscrisisline.net or 1-800-273-8255 (then, press 1). Operators are available 24/7 and provide you with the option to talk or text. Please know that all calls are confidential and can save your life.

Another option available to veterans is to join the Veteran's Club-Kentucky Facebook group. Through this page, vou can interact with other veterans throughout Kentucky, as well as learn about ways veterans are helping other veterans. Resources are available, so never hesitate to



reach out for help. For information about resources to meet your needs, please contact me at 502-907-1536 / 866-275-1078 x17 /

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.



Kosair Charities Centre 982 Eastern Parkway Louisville, KY 40217

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# Happy Holidays from the Epilepsy Foundation of Kentuckiana

END EPILEPS

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Web www.efky.org

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# **Come Join Us!**





Summer Camp Sessions provide the opportunity for children to partake in a week of fun, adventure and independence. CCK IS PROUD PARTNERS WITH





To apply online visit **www.courageouskids.org.** For more information and questions, call Camper Admissions office at 270-618-2912.

# 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! WH To have fun, make friends, and talk & hang out with those who understand! COSE: Free to youth, thanks to Kosair Charities!



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

#### COMING YOUTH EPILEPSY ALLIAN EVENTS

Saturday, January 12 Louisville Slugger Museum 800 West Main Street, Louisville 9:30 a.m. - 11:00 a.m.

Saturday, February 16 Malibu Jack's 12101 Sycamore Station Place, Louisville 10:30 a.m. - 12:00 p.m.

> Saturday, March 2 Malibu Jack's 2520 Nicholasville Road, Lexington 10:30 a.m. - 12:00 p.m.

#### **MARCH - LOUISVILLE - TBD**

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



Return Service Requested