

THE ILLUMINATOR

LIGHTING THE PATH FOR A BRIGHTER TOMORROW



A Publication of the
Epilepsy Foundation of Kentuckiana

ISSUE 3 - 2017

2017 YEAR END GIFT CAMPAIGN

As we near the end of 2017 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 makes a HUGE difference to the nearly 153,000 children, adults, and veterans living with epilepsy in Kentucky and southern Indiana.

1 GIFT = 1 LIFE CHANGED. Your tax-deductible donation will help children, adults, veterans, and families touched by epilepsy. 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. (Kosair Charities Centre, 982 Eastern Parkway, Louisville, KY 40217).

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

Thanks to the continued generosity of our supporters, we can provide education, advocacy, outreach, and support services at no cost to those impacted, and help 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 are here for you and your family.

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 x13 / dmcgrath@efky.org.

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!



\$25

Ensures vital support & information reaches a newly diagnosed family.

\$50



Funds a much-needed consultation with our support team.



\$100

Funds emergency assistance for one client.

\$350



Provides a day of education training to school personnel & nurses



\$500

Provides two seizure monitors for clients in need.

FROM THE EXECUTIVE DIRECTOR

As we close out another year, everyone at the Epilepsy Foundation of Kentuckiana (EFKY) hopes you will continue striving to #AimForZero in all you do. We are excited about this new year as it is a milestone for the EFKY. In 2018, the EFKY will be celebrating its 25th anniversary of serving

individuals battling epilepsy and seizure disorders. This grassroots organization, co-founded by Kristie Jones and myself after our young daughters were diagnosed, was created to bring help, hope, and support to others in need. It has truly been an honor to be involved in the lives of so many incredibly brave individuals and I'm thankful you trust in the EFKY as a source of strength and support. Our pledge to "Light the path for a brighter tomorrow" is as strong today as it was when we first began in 1993 as the Epilepsy Association of Greater Louisville.

involving the co-occurrence of epilepsy and intellectual or developmental disabilities. In most cases, the cause of the disease is unknown, though it is hypothesized to sometimes be due to the deterioration of the brain following uncontrollable epileptic seizures or singular genetic or environmental processes that induce seizures and brain destruction. To learn out more about this research discovery go to: <https://thevarsity.ca/2017/11/27/researchers-discover-eight-new-epilepsy-genes/>.

One of my favorite activities we do at the EFKY is our annual **Speak Up, Speak Out!** Advocacy Day where we meet with Kentucky's legislators in Frankfort. This program will be held **March 7, 2018**. I invite you to join in this great opportunity to come together with others impacted by epilepsy/seizure disorders to speak up about the myriad of issues you face resulting from seizures to your senator and representative. This program is essential in our fight to advocate for improved access to care and our Seizure Smart Schools initiative throughout Kentucky. I do hope you will join me and my team as we advocate for the 153,000 children, adults, and veterans living with epilepsy throughout Kentucky at the state capitol. **To register, please go to www.efky.org.**

Wishing you and your loved ones the very best Holiday season and a very happy and healthy New Year!

~ Deb McGrath

As you prepare for this holiday season, I hope you will take a moment to reflect on how the EFKY has impacted you or your loved one's life. As leaders in the fight against epilepsy, the EFKY staff take pride in the work we do to help you overcome the barriers that stand in your way of achieving your dreams. Until cures are found to defeat the many different seizure types and epilepsy syndromes that result in devastating challenges and heartbreaking consequences, including sudden unexpected death in epilepsy (SUDEP), the EFKY will always be in your corner as your unwavering ally in the fight to defeat epilepsy.

New discoveries in the fight against epilepsy were just unveiled by a research team at the University of Montreal. Their work has discovered eight new epilepsy genes. Until now, targeting the genetic mutations involved in epilepsy has been a challenge for researchers. Epileptic encephalopathy is a disease



MISSION STATEMENT

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

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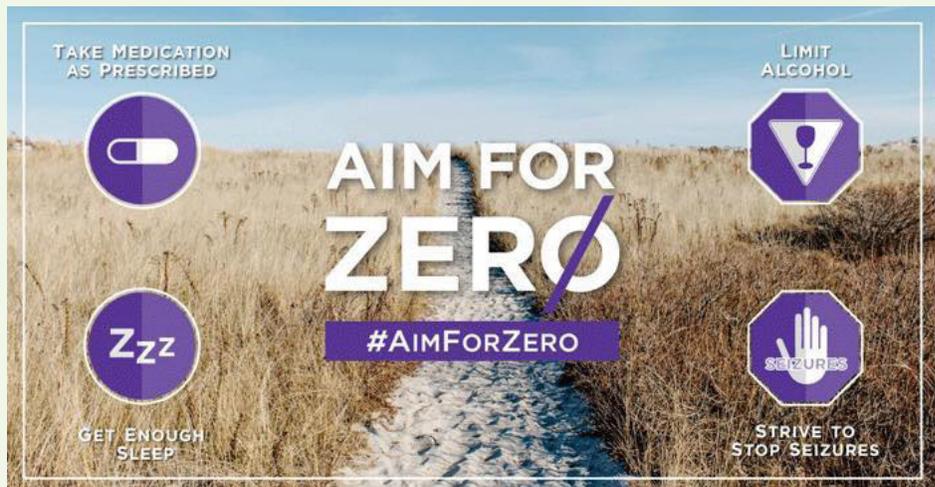
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The Illuminator is edited by Beth Stivers. Design by QuantumGraphix.
Questions and comments about the Illuminator may be directed to Beth via phone or email.



Fun and Fellowship at the Farm

A wonderful afternoon and evening was had by all at the Central Kentucky Epilepsy Support Network's (CKESN) annual gathering at Bonnie Reid and David Wittmer's farm in Woodford County on October 14. The food was delicious, but the company was even better! Thank you to Bonnie and David for hosting us and providing such a beautiful setting for us to have this annual event.



The Epilepsy Foundation of Kentuckiana partners with the UK HealthCare Kentucky Neuroscience Institute to offer the CKESN's support group and activities. If you live in the central Kentucky area and are affected by epilepsy and would like to be a part of the CKESN, please join us for support group on the first Tuesday of each month at the Don and Cathy Jacobs Education Center at the University of Kentucky from 6:30 p.m. – 8:00 p.m., or for more information, please contact CKESN at gotpurplecentralky@gmail.com.



A MESSAGE FROM AMY COLLIER, CSW DIRECTOR OF CLIENT SERVICES



Hello! It has been a privilege talking with and meeting many of you as well as learning more and more about the epilepsy community. The Epilepsy Foundation of Kentuckiana (EFKY) staff are all here to support you and those affected by epilepsy, but I wanted to make sure you knew that my role with the EFKY is specifically to provide services and assist in finding the resources

you need in regard to your epilepsy. Since I came on board in April, I have been busy advocating for and supporting clients regarding job discrimination, court involvement, school related services, access to care, and affording medication, just to name a few. Please contact me at 502-907-1534 / 866-275-1078 x15 / acollier@efky.org with any questions.

Are you wondering what support services are out there? Here's a few to look into...

Find help with the cost of medicine:

Needy Meds: needymeds.org; 1-800-503-6897

RxOutreach: rxoutreach.org; 1-888-796-1234

Health KY: healthkentucky.org; 1-800-633-8100

Managing anxiety: anxietycoach.com

Community services and Waiver programs:

Contact your local Aging and Disability Resource Center: <http://chfs.ky.gov/dail/AreaAgenciesonAging.htm>

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 502-907-1532 / 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

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Toll-Free 866-275-1078
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In Honor of _____

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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.

YOUR CONTRIBUTION WILL TRULY MAKE A DIFFERENCE!

2017 Expressions of Hope Gala Recap

The 8th annual Expressions of Hope Gala was a smashing success! Over \$100,000 was raised through sponsorships and the 320 guests in attendance. The 2017 Expressions of Hope Gala theme was the "Disco Ball" and many arrived dressed in their finest disco attire at the Mellwood Arts Center on November 3, 2017. The event was held on November 3, 2017 at the Mellwood



Arts Center. Guests were treated to a collection of spectacular silent and live auction items, a delicious prime-rib dinner prepared by Masterson's Catering, and open bar, bourbon bar, and cigar bar, disco music by Sounds Unlimited Productions, 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.



For nearly 25 years, the EFKY, has been steadfast in providing help and hope 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 to work at the 2017 Expressions of Hope. We would like to give a HUGE thank you to Kosair Charities for donating \$26,877 during our live auction and our appeal! Also thank you to our Expressions of Hope planning committee co-chairs: Linda O'Bryan, Beth O'Daniel, Val Speth, and Lisa Wallace; and committee members: Meriem Bensalem-Owen, MD, Angela Bishop, ARNP, Missy Lawless, Bill Menish, and Tim Morris.

The Foundation would like to thank all who planned, sponsored, donated auction items, attended, and/or volunteered to work at the 2017 Expressions of Hope. We would like to give a HUGE thank you to Kosair Charities for donating \$26,877 during our live auction and our appeal! Also thank you to our Expressions of Hope planning committee co-chairs: Linda O'Bryan, Beth O'Daniel, Val Speth, and Lisa Wallace; and committee members: Meriem Bensalem-Owen, MD, Angela Bishop, ARNP, Missy Lawless, Bill Menish, and Tim Morris.



THANK YOU SPONSORS!



2017 Not Another Moment Lost to Seizures – A Day of Education and Hope

On Saturday, October 4, 2017 the Epilepsy Foundation of Kentuckiana held its annual Not Another Moment Lost to Seizures statewide epilepsy conference at the Founders Union at the University of Louisville ShelbyHurst campus in Louisville, Kentucky. This program was the Foundation's kickoff event for November Epilepsy Awareness Month and was attended by over 70 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: Mood Dysfunction in Epilepsy, Learning to Let Go: Helping to Empower Your Loved One with Epilepsy, Refractory Epilepsy, Kentucky Waiver Overview, Cannabis in Epilepsy – Review & Update, and Creative Affirmation. A separate program was also offered to children with the day spent playing games, learning more about 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 2018!



Frank G. Gilliam, Jr., MD



Karen Skjei, MD

Thank You to the Following Presenters, Facilitators, and Volunteers

Meriem Bensalem-Owen, MD
Whitney Clay, ATR-BC
Amy Collier, CSW
Clara Collier
Frank G. Gilliam, Jr., MD
Amy Stephens McClain, MAMFT, MDiv
Deb McGrath
John Mustain, MSSW
Karen Skjei, MD
Beth Stivers, MS
Madison Trachsel
David Pettit, MEd
Tonia A. Wells, MSW, CSW, CBIS



Monthly Remote Access Journaling Workshop



Join us on the first Thursday of each month from 12:00 p.m. - 1:00 p.m. EST from your home or office for a remote access journaling workshop for anyone affected by epilepsy. If you need a little extra support managing your epilepsy, this would be a wonderful opportunity for you.

Be guided through journal writing for management of anxiety and depression with the help of Robert Slocum, PhD from UK Healthcare Narrative Medicine. Connect from home or wherever you are! It's easy! Download Zoom onto your laptop for free. According to Kevin Kays, a participant in the remote access journaling workshop, "The online

support group is very helpful because you are able live video chat with medical staff at UK hospital, someone at the Epilepsy Foundation of Kentuckiana, other people affected by epilepsy. It's great to ask questions in real time to everyone, listen to them, and see them, as it makes it more personal. Most of these people, I would never get to meet and learn from otherwise. I encourage everyone to join in on these great meetings."

Grab a few pieces of paper and a writing instrument, find a quiet place to connect and follow this link: <https://uky.zoom.us/j/5335125591>.

We hope to "see" you there!

Veterans Views: The 2017 Kentucky and Indiana Veterans of the Year Programs

our years ago, the Epilepsy Foundation of Kentuckiana's signature veterans program, Operation Outreach, began the Kentucky Veterans of the Year program to attract the media to our message concerning veterans and seizures, as well as celebrate the various contributions veterans are making across the Commonwealth. We did not know what to expect in terms of reception, attendance, and interest, but we were certainly optimistic. Our optimism, however, pales in comparison to the actual success of the Kentucky Veterans of the Year program. We have told our story of veterans and post traumatic epilepsy/seizures on numerous television and radio stations, in a number of newspapers and magazines, while at the same time, spotlighting how our Kentucky Heroes are "Still serving..." their country by serving their communities and neighbors.

On November 6, 2017, over 200 people attended the 4th annual Kentucky Veterans of the Year Banquet - A Tribute to WWII Veterans at the Brown and Williamson Club. We were honored to have in attendance: Major General (Ret.) Robert Silverthorn, Kentucky Department of Veterans Affairs Commissioner BG (Ret.) Norman Arflack, representatives from the office of Senator Rand Paul, and many others. We were especially pleased to have in attendance, Woody Williams, the last surviving Medal of Honor recipient from the Battle of Iwo Jima and the Master of Ceremonies for the evening George Patton "Pat" Waters, the grandson of General George S. Patton, Jr. The featured speaker was WWII Veteran Dr. E. Bruce Heilman and entertainment was provided by the Ladies for Liberty. We were proud to honor the 2017 nominees for the Kentucky Veterans of the Year awards as well as recognize our 2017 Friends of Veterans awardees Jamie Burton and Rick Wright. It was an amazing night that ended with our awarding Sherry Whitehouse as the Female Kentucky Veteran of the Year and Gregory Bethards as the Male Kentucky Veteran of the Year.



KYVOTY Sherry Whitehouse



KYVOTY Gregory Bethards



INVOTY Winners Stephanie Redd and Michael Kennedy

We also held our second annual Indiana Veterans of the Year banquet using the same format as the Kentucky Veterans of the Year, and are grateful to Mike Mustain, a Clarksville, Indiana businessman, for his commitment to honor Hoosier veterans through the Epilepsy Foundation of Kentuckiana, just as our Operation Outreach program has been doing in Kentucky.

On November 9, 2017, Mike and his committee along with the Foundation presented the second annual Indiana Veterans of the Year banquet at the The Grand, a beautifully renovated historic movie theater, in New Albany, Indiana. We were honored to have in attendance Indiana State Representatives Karen Engleman and Steve Stemler, as well as the Honorable Judge Maria Granger, and many others. The featured speaker was CSM (Ret.) James Brown, Director of Indiana Department of Veterans Affairs. It was a marvelous night that ended with our recognizing all the nominees and introducing Stephanie Redd as the Female Indiana Veteran of the Year and Michael Kennedy as the Male Indiana Veteran of the Year.

The EFKY would like to thank the following sponsors for the Kentucky banquet: Campbellsville University, Karl Truman Law, First Command, Oldham County History Center, Middleton Reutlinger, BBMC Mortgage, L&N Federal Credit Union, Paralyzed Veterans of America Kentucky-Indiana Chapter, and Riches and Glory Photography. For the Indiana banquet, thanks to: Karl Truman Law, Stemler Corporation, and IBI.



The Ladies for Liberty with Woody Williams



KYVOTY Friend of Veterans
Jamie Burton



KYVOTY Friend of Veterans
Rick Wright



2017 Nominees for & Winners of the Kentucky Veterans of the Year Award



2017 Peggy Sherrell Memorial Scholarship Award



Charles Davis Eckmann

The Epilepsy Foundation of Kentuckiana is proud to announce that Charles Davis Eckmann of Lexington, Kentucky was selected as the 2017 recipient of the Peggy Sherrell Memorial Scholarship. Charles is a 2017 graduate of Tates Creek High School in Lexington, Kentucky and is currently attending the University of Kentucky with plans to pursue a career in ecology or environmental conservation. His interest in these areas stem from his experience with his family's animal rescue efforts and his passion for recycling and sustainability.

Charles is diagnosed with partial epilepsy caused by a stroke he sustained on the day he was born. He has persevered through years of occupational, speech, and physical therapy but still struggles with lingering neurological problems. He works hard to succeed despite his limitations. Despite his challenges in life, he was a member of the National Honor Society and Beta Club and graduated from high school with a 3.9 GPA. At present, his seizures are controlled and his hopes and dreams are on track. He is honored to represent Peggy through this scholarship opportunity and hopes to carry on her legacy through his educational endeavors.

The Foundation is so proud of Charles and hopes he keeps fighting to reach his goals!

2017 Shannon O'Daniel Memorial Scholarship Award



Makayla True Stock

The Epilepsy Foundation of Kentuckiana congratulates Makayla True Stock for being awarded the 2017 Shannon O'Daniel Memorial Scholarship. Makayla, is a 2017 graduate of Stock Academy Home School in Mayfield, Kentucky and is currently enrolled at Pensacola Christian College.

Makayla had her first seizure at the age of 10 months and has a father with epilepsy. Her father's diagnosis allowed her family to quickly recognize her seizure activity and to know what to do if she had a seizure. Elementary and middle school were difficult for her because of her frequent seizures in the classroom or on the bus. Together, she and her family decided that she would be home schooled for high school and her mom left her job as a registered nurse to make this possible. She is most appreciative to her mother for making this sacrifice that allowed her to thrive in high school and graduate with a 3.68 GPA. While studying at home, she went on to become the president of the local chapter of the Future Business Leaders of America and even the FBLA Region One Parliamentarian for Kentucky. Before her last seizure in December 2015 exercise and heat caused her to have seizures. Since then, she has gained control of her seizures and was even able to play center for a girls' basketball team her senior year.

Her current plans are to pursue a career in pharmacy so that she can serve her community and help people. The Foundation would like to congratulate Makayla on receiving this scholarship. Good luck and best wishes in your future endeavors!



The Peggy Sherrell Memorial Scholarship is administered by the Epilepsy Foundation of Kentuckiana in honor of Peggy Sherrell, who died of Sudden Unexpected Death in Epilepsy

(SUDEP) in 2010. Peggy felt that education was extremely important and 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 close to \$125,000 to the Epilepsy Foundation of Kentuckiana since its inception in 2010.



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.



MAKE A DIFFERENCE by becoming a sponsor, registering your team, or playing individually in the 13th Annual Golfer's Gauntlet on Monday, April 23, 2018. 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 for individuals affected by epilepsy living in Kentucky and southern Indiana. To be a sponsor, register your foursome, or for more information, please go to www.efky.org.



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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

Happy Holidays from the Epilepsy Foundation of Kentuckiana

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.

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JOIN US FOR OUR MONTHLY ART GROUP GATHERING

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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 other people living with epilepsy. If you are interested in joining us please contact Beth Stivers, MS, director of education at 502-637-4440 / 866-275-1078 x14 / bstivers@efky.org.

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UPCOMING YOUTH EPILEPSY ALLIANCE! EVENTS

Saturday, January 6

Arts and Crafts at Cut & Paste Craft Studio
220 Ruccio Way, Ste 180, Lexington
10:30 a.m. – 12:00 p.m.



Saturday, January 20

Watching Paddington 2 at Xscape Theatres
12450 Sycamore Station Place, Louisville
10:00 a.m. – 11:30 p.m.



Saturday, February 24

Ice Cream at Gr8ter Good Ice & Gifts Shop
858 KY-44, Shepherdsville
10:00 a.m. – 11:30 a.m.



Saturday, March 23

Fun and Games at Main Event Entertainment
12500 Sycamore Station Place, Louisville
10:00 a.m. – 11:30 p.m.



Saturday, April 14

Pizza and Games at Gatti's Pizza
4200 Outer Loop, Louisville
11:30 a.m. – 1:00 p.m.

