

THE ILLUMINATOR

LIGHTING THE PATH FOR A BRIGHTER TOMORROW



A Publication of the
Epilepsy Foundation of Kentuckiana

ISSUE 3 - 2016

2016 Year End Gift Campaign #DareToDonate



As we near the end of 2016 we can't thank each of you enough for just being friends of the Epilepsy Foundation of Kentuckiana. As we near the end of 2016 and 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 in 26 are diagnosed with epilepsy at some point – please consider helping the 1.

1 gift = 1 life changed. Your tax-deductible donation will help the 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).

Thanks to the continued generosity of our supporters we can provide education, advocacy, outreach, support, and funds for 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 Donna Wooten, development manager at 502-637-4440 /866-275-1086 x17 / dwooten@efky.org.

We hope everyone has a healthy and happy Holiday season and thank each one of you for continuing to support the Foundation. Thank you.

\$25

Ensures vital support & information reaches a family dealing with a new diagnosis of epilepsy.



\$50

Funds a much-needed consultation with our support team.



\$100

Funds emergency medication for one client.



\$250

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



\$500

Provides two seizure monitors for clients in need.



Visit www.efky.org today and help us #AimForZero seizures in 2017.

TAKE MEDICATION AS PRESCRIBED

LIMIT ALCOHOL

AIM FOR ZERO

#AIMFORZERO

GET ENOUGH SLEEP

STRIVE TO STOP SEIZURES

FROM THE EXECUTIVE DIRECTOR

From all of us at the Epilepsy Foundation of Kentuckiana (EFKY), we wish you and your family the merriest holiday season ever! It is hard to believe 2016 will soon come to an end! It seems as if we were just beginning to plan the year's activities to help you #DareTo live as well as you possibly can with epilepsy. I do hope you were able to incorporate this national year-long

initiative into your daily or weekly activities and found it to be a helpful and empowering tool to improve your life, or the life of a loved one! This coming year, I hope you embrace the #AimForZero campaign by including the four actions people with epilepsy can take to reduce their risk of sudden unexpected death in epilepsy (SUDEP): take epilepsy medication(s) as prescribed; get enough sleep; limit alcohol; and strive to stop seizures.

school setting through a state-wide study by Kentucky's Legislative Research Committee (LRC). Understandably so, as one in 10 students will have a seizure and one in 26 will develop epilepsy. We sincerely hope you will join our advocacy efforts to speak up and speak out as we continue our work to defeat epilepsy. Register to attend by going to www.efky.org and clicking on SUSOKY.

I am also happy to report that the EFKY has been working with the Epilepsy Foundation of Indiana on an access to care issue that developed earlier this year. If you are enrolled in one of Indiana's Medicaid managed care programs and have experienced an interruption in getting your epilepsy drugs, please contact me. This issue is a direct result of a vote taken by the Drug Utilization Review Board. Since 2005, epilepsy drugs have been protected (received open access). Since this vote, these potentially life-saving drugs are now restricted and are no longer available to be prescribed at the discretion of a physician. We feel the health and well-being of affected patients could be compromised by forcing them to fail once, twice, or even more times on a drug before their neurologist or epileptologist (epilepsy specialist) is allowed to prescribe the drug they feel is better suited for the type(s) of seizures their patient experiences. Our efforts have also involved a number of neurologists who are very interested and concerned about this access to care issue and would like to have others join our advocacy efforts. Patients should not have to settle for a drug because it costs less than one that is better tailored for their seizure type or syndrome. Epilepsy is a very serious and complicated neurological condition and requires open access to find the right treatment for each person's fight against epilepsy. Please contact me at 502-637-4440 / 866-275-1078 x13 / dmcgrath@efky.org if you have experienced this issue or have a patient who has been negatively impacted. I would love to hear from you. Remember, your voice will not be heard unless you #DareTo share your epilepsy story.

If you have not signed up to receive e-mail alerts or joined us on Facebook or Twitter, please go to our website at www.efky.org to do so. We want to keep you apprised of the most current news in the fight against epilepsy, as well as the many different programs and services we offer throughout the year.

Wishing you and your loved ones a healthy and joy-filled Christmas and holiday season, and a very happy New Year!

- Deb



MISSION STATEMENT

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

BOARD OF DIRECTORS:

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



Donna Wooten Joins Staff

The Epilepsy Foundation of Kentuckiana is thrilled to announce that Donna Wooten has joined our team as the development manager. Donna comes to us with over 15 years of fundraising experience – 12 years at the Combined Federal Campaign and three years at the Metro United Way southern Indiana office. She is eager to share her deep passion for service, strong relationship building, and successful fundraising skills to benefit the more than 153,000 children, adults, and veterans living with epilepsy and those caring for them in Kentucky and southern Indiana.

When asked about her new position, Donna said, "I am so very excited to join the Foundation team and serve those in our community that need support. We, as a family, know first-hand how beneficial that support is as my husband suffered his first seizure nearly 15 years ago and Debbie was there to provide help and support during that time. I feel blessed to get to advocate for so many who need the Foundation's services in our community and ask others to join and support so we can #AimForZero seizures and try

to prevent another moment or life lost to seizures."

Donna and her husband live in southern Indiana and have a daughter who is a senior at Floyd Central High School and a son studying to be a pharmacist at Purdue University. Donna loves spending time with her family, being outdoors, and going to arts and crafts fairs.



If you are interested in speaking with Donna to see how you can support the Epilepsy Foundation of Kentuckiana's mission, please reach out to her at 502-637-4440 / 866-275-1078 x17 / dwooten@efky.org.



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 (982 Eastern Parkway, Louisville) one Friday each month as we meet in a support setting 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.



Would you like to save paper and help the **Foundation** at the same time? Please sign up to receive the **Illuminator** in your inbox instead of your mailbox by contacting Connie Costelle, administrative assistant at 502.637.4440 / 866.275.1078 x10 / ccostelle@efky.org. If you wish to donate to the **Foundation** via credit/debit card, you may do so at www.efky.org or by calling Connie at the number above. If you would like to make a donation via check, please fill out the form below, cut it out, and mail it to us using the address on the form.

EPILEPSY FOUNDATION OF KENTUCKIANA DONATION



Kosair Charities Centre
982 Eastern Parkway
Louisville, KY 40217

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

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of the Epilepsy Foundation

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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.

YOUR CONTRIBUTION WILL TRULY MAKE A DIFFERENCE!

Thank You for Making the 2016 Walk Around Kentucky for Epilepsy a Smashing Success!!



The Epilepsy Foundation of Kentuckiana would like to thank everyone who participated in the 2016 Walk Around Kentucky for Epilepsy in Owensboro, Pikeville, Louisville, Lexington & Paducah! Thanks to our awesome walkers (both live and virtual) and our sponsors for helping us #dareto raise over \$128,000! We are so very appreciative of all the hard work and dedication exhibited by all involved and look forward to next

year. Since the Walk at Louisville Slugger Field was such a tremendous success, we have decided to reserve the ball park again in 2017!

The funds raised from the Walk Around Kentucky for Epilepsy campaign support the vital education, outreach, advocacy, and support services programs provided by the Foundation to the over 153,000 individuals living with epilepsy in Kentucky and southern Indiana and their family members. Stay tuned for exciting details of the 2017 Walk that will include a new name and logo!



2016 TOP FUNDRAISING TEAMS FOR EACH CITY

Paducah - Team Hailey - \$3,033
Pikeville - Team Whitney - \$1,335
Owensboro - Carrot Top - \$2,255
Lexington - Team Paul Fox - \$4,025
Louisville - Team Tyler - \$12,991

2017 WALK AROUND KENTUCKY FOR EPILEPSY



SAVE THE DATE

Saturday, June 10th
Owensboro & Pikeville

Saturday, June 17th
Louisville

Saturday, June 24th
Lexington & Paducah



2016 Not Another Moment Lost to Seizures – A Day of Hope and Education



On Saturday, October 15, 2016, the Epilepsy Foundation of Kentuckiana held its annual Not Another Moment Lost to Seizures statewide epilepsy conference at the Metro United Way in Louisville, Kentucky. This program was the Foundation's kickoff event for **November Epilepsy Awareness Month** and was attended by over 100 attendees, speakers, exhibitors, and volunteers.



Throughout the day, individuals affected by epilepsy and their family members were joined by regional experts in the field of epilepsy who presented a number of educational sessions on a variety of topics including: Living Well with Epilepsy, #DareToSaySUDEP, Expressive Therapy for Adults: Creating Art to Cope with Epilepsy, Important 2016 Changes to Social Security's Evaluation of Epilepsy, Pediatric Epilepsy, and Epilepsy Surgery for the Adult Patient. 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 delicious bagels and boxed lunches from Panera, thanks to our 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 2017!

Thank You to the Following Presenters, Facilitators, and Volunteers

Meriem Bensalem-Owen, MD
Kaitlin Blessitt, BSN, RN
Whitney Clay, ATR-BC
Calista Craddock
Deb McGrath
John Mustain, MSSW
Debra O'Donnell, MD
Adriana Palade, MD
Kendra Parker
Kelvon Redmon
Samuel L. Schad
Beth Stivers, MS
David Sun, PhD, MD
Donna Wooten



Thank You to the Following Sponsors:



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NEUROPACE

ucb

Attention Educators and Parents: Seizure Education Program Now Available for Students K - 5

The Epilepsy Foundation of Kentuckiana has received a grant from the national Epilepsy Foundation and the Centers for Disease Control and Prevention to provide free 40 – 45-minute epilepsy awareness programs for elementary school aged children (grades K – 5) throughout Kentucky and southern Indiana. Students who complete this training will: (1) Demonstrate a basic understanding of epilepsy as a medical condition; (2) Identify and learn about different types of seizures; and (3) Know what to do and what not to do when someone is having a seizure.

We will be scheduling the lessons on a first-come, first-served basis. If you are a teacher interested in this program, or would like this program to be implemented at your child's school, please contact Beth Stivers, MS, director of education at 502-637-4440 / 866-275-1078 x14 / bstivers@efky.org.

Activities are made possible by a grant from the Epilepsy Foundation and the Centers for Disease Control and Prevention (CDC) under grant number 1U58DP00382-05. Its contents do not necessarily represent the official views of CDC.

Veterans Views: The 2016 Kentucky and Indiana Veterans of the Year Programs

by John Mustain, MSSW, Director of Veterans Outreach



EFKY Executive Director, Deb McGrath, and Mayor Greg Fischer greet one another at the 2016 Kentucky Veterans of the Year Banquet.



Major General (Ret.) Robert Silverthorn concludes his excellent remarks concerning the strength, resiliency, and contributions of veterans.



MG (Ret.) Silverthorn receives a special gift from the Kentucky Veterans of the Year program: a Commemorative Box and Bottle of Patton Bourbon that Medal of Honor recipient, Woody Williams signed. (L to R) Lt. Col. (Ret.) Karl Truman, MG (Ret.) Robert Silverthorn, Medal of Honor recipient Woody Williams, and John Mustain, Director of Veterans Outreach at EFKY.



Stormey Vanover was awarded the 2016 Female Kentucky Veteran of the Year. John Mustain assists Lt. Gov. Jenean Hampton with presenting the award.



Marion "Joe" Carter was awarded the 2016 Male Kentucky Veteran of the Year. He was unable to attend due to being hospitalized for pneumonia. Joe's son, Steve Carter, accepts the Award from Lt. Gov. Jenean Hampton assisted by John Mustain.

Three years ago, we 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 were certainly optimistic. Our optimism, however, pales in comparison to how huge the Veterans of the Year has become. We have told our story of veterans and post traumatic epilepsy/seizures on numerous television and radio stations, as well as a respectable 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 7, 2016, over 300 people poured into the Brown & Williamson Club for the 3rd annual Kentucky Veterans of the Year banquet. This is the second year in a row we have completely sold out the event, but this year definitely represents the largest attendance since the program's inception. We were honored to have in attendance: Lieutenant Governor Jenean Hampton, Major General



(Ret.) Robert Silverthorn, Kentucky Department of Veterans Affairs Commissioner Norman Arflack, representatives from the offices of Senator Rand Paul, Congressman John Yarmuth, and Senator Mitch McConnell, Metro Louisville Mayor Greg Fischer, 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. It was an amazing night that ended with our awarding Stormey Vanover as the Female Kentucky Veteran of the Year, and WWII veteran

Marion "Joe" Carter as the Male Kentucky Veteran of the Year.

This year, we also successfully launched the Indiana Veterans of the Year banquet using the same format as the

Kentucky Veterans of the Year. Mike Mustain, my brother and Clarksville, Indiana businessman, wanted to honor Hoosier veterans like the Epilepsy Foundation of Kentuckiana's Operation Outreach has been doing in Kentucky, as well as help spread the word about veterans and post traumatic epilepsy/seizures in Indiana. Thus, the Indiana Veterans of the Year was born.

On November 10, 2016, more than two-hundred people filled The Grand, a beautifully renovated movie theater, in New Albany, Indiana for the first ever Indiana Veterans of the Year banquet. We were honored to have in attendance Indiana Representatives Ed Clere and Steve Stemler, the Mayor of New Albany, Jeff M. Gahan, and former Marine Aviator, Silouan Green, as well as many others. It was a marvelous night that ended with our awarding Carrie Bridgewater as the Female Indiana Veteran of the Year, and Edward Parero as the Male Indiana Veteran of the Year.

We are so proud of our Kentucky and Hoosier heroes here at Epilepsy Foundation of Kentuckiana's Operation Outreach, and we are proud of your support in helping to spread the message of how seizures affect the lives of so many...even veterans.



Indiana Representative Steve Stemler presents Edward Parero with the 2016 Male Indiana Veterans of the Year Award assisted by Mike Mustain.



Indiana Representative Steve Stemler presents Carrie Bridgewater (and family) with the 2016 Female Indiana Veterans of the Year Award assisted by Mike Mustain.

OPERATION OUTREACH



If you are a veteran experiencing seizures, are in need of assistance, or would like to learn more, please contact John Mustain, MSSW at 502-637-4440 / 866-275-1078 x16 / jmustain@efky.org.

Happy Holidays from the Epilepsy Foundation of Kentuckiana

The Holidays are almost here and Foundation staff is celebrating by sharing recipes for their favorite must-have holiday dishes with you! We hope these dishes will grace your family's table this season and that you and your family enjoy them much as we do. We wish you and yours a fantastic and seizure-free holiday season!

Connie's Marbled Peanut Butter Fudge

Ingredients:

- 4 cups sugar • 1 can (12oz) evaporated milk
- 1 cup butter or margarine
- 3 packages (6oz) semi-sweet chocolate chips, 18 oz total or about 3 cups
- 1 tablespoon vanilla • 1 cup peanut butter

Directions:

Combine sugar, milk, and butter in a heavy saucepan. Bring to a boil and cook for 8 minutes, stirring constantly. Add marshmallow cream, chocolate chips and vanilla and stir to blend. Pour half of the mixture into a buttered 13 x 9 x 2-inch pan and dollop with spoonfuls of peanut butter. Spoon the remaining chocolate mixture over the peanut butter and gently swirl the mixture with a knife to create a marble effect. Chill until firm, then cut into 1-inch pieces and store in an airtight container in the refrigerator.

let's make Deb's Orange Juice Cake
from Deb McGrath

what you need:

CAKE INGREDIENTS:

- 1 package Duncan Hines® butter flavor cake mix
- 1 small pkg vanilla instant pudding
- 1 cup orange juice
- ½ cup oil
- 4 eggs

GLAZE INGREDIENTS:

- 1 cup sugar
- 1/4 cup orange juice
- 1/4 stick butter

what to do:

CAKE: Grease and flour a Bundt cake pan. Mix cake mix, eggs and oil. Add vanilla pudding and orange juice and mix to combine. Pour into pan and bake at 325° F for 50 – 60 minutes, or until toothpick inserted in center comes out clean. About five minutes before the cake is to come out of the oven, prepare glaze.

GLAZE: Put all ingredients together in small pan and bring to a boil. Carefully pour glaze over hot cake, let cool 30 minutes then remove from pan.

other stuff to know:

NOTE: It is suggested that after the cake has been glazed, cooled and taken out of pan, wrap in plastic wrap and freeze overnight to ensure an extremely moist cake.

Beth's Grandmother's Chocolate Cake

Ingredients:

- 1 cup granulated sugar • 4 Tbsp cocoa powder
- 1 cup mayonnaise • 2 cups flour • 2 tsp baking soda
- 1 cup water • 1 Tbsp vanilla extract

Directions: Mix granulated sugar, cocoa powder, and mayonnaise (trust me, it is good!). In another bowl, sift together flour and baking soda. Add to wet ingredients. Add water and vanilla and mix until combined. Pour into greased and floured 9-inch pan. Bake at 350° F for 30 minutes or until toothpick inserted in the center comes out clean. While cake is baking, make the caramel icing.

Caramel Icing - Ingredients

- 1 cup brown sugar (firmly packed) • 3 Tbsp vegetable shortening
- 2 Tbsp butter • ¼ tsp salt • ¼ cup milk
- 1 ½ cups confectioner's sugar

Caramel Icing Directions: In a pan, bring brown sugar, shortening, butter, and salt to a boil, stirring constantly. Add milk and cook for three minutes. Cool and then add confectioner's sugar and beat until ready to spread.

David's Mom's No-Bake Fruitcake

Ingredients:

- 1 lb chopped pecans • 1 (15-oz) box raisins
- 1 (14-oz) package of sweetened flaked coconut • 1 lb graham crackers
- 1 (4-oz) jar maraschino cherries • 1 (14-oz) can Eagle Brand® milk

Directions: Smash the graham crackers with a rolling pin. In a mixing bowl, combine pecans, raisins, coconut, graham cracker crumbs, and cherries. Stir in Eagle Brand® milk then press the mix into a greased loaf pan. Cover with plastic wrap and refrigerate for 24-hours.

John's Wife's Corn Pudding

Ingredients: 5 eggs • ½ cup butter, melted • ¼ cup granulated sugar
¼ cup heavy cream • 4 Tbsp cornstarch • 1 (15.25-oz) can whole kernel corn (with about ¼ - ½ of liquid drained, but keeping the rest)
2 (14.75-oz) cans cream-style corn

Directions: Pre-heat oven to 400° F and grease a 2-qt casserole dish. In a small bowl, combine sugar and cornstarch. In a large bowl, lightly beat eggs, then add the sugar/cornstarch mixture to the eggs, stirring to incorporate. Add milk to mixture and combine well, then add in melted butter. Stir in whole kernel and cream-style corn and pour into prepared casserole dish. Bake for one hour or until gold brown and not jiggly in the center.

Donna's Squash Casserole

Ingredients:

- 8 medium yellow squash • 1 cup sour cream
- 2 large eggs • 1 (16-oz) package shredded cheddar cheese
- 2 tsp Wyler's® chicken bouillon powder • 2 tsp garlic salt

Directions: Pre-heat oven to 350° F and grease an 8 x 8-inch casserole dish. Cut and quarter the yellow squash, then boil for approximately 20 minutes, or until softened. Drain the squash and smash so that all excess water is removed. Place in a bowl and mix with all other ingredients. Pour into casserole dish and top with additional cheese, if desired. Bake for 30 minutes.

Gary's Sugared Pecans

Ingredients:

- ½ cup (1 stick) butter, melted • 3 large egg whites • 1 cup sugar
- 1 teaspoon ground cinnamon • 4 cups pecan halves

Directions: Preheat Oven 350° F. Line a large baking sheet with sides with aluminum foil. Pour the butter onto the lined sheet. In a large bowl, mix the egg whites, sugar, and cinnamon. Add the pecan halves and toss until they are fully coated. Spread the pecans onto the baking sheet. Bake for 25 minutes, stirring the pecans every 10 minutes. Cool on the baking sheet for 10 to 15 minutes before serving.



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2016 Year End Gift Campaign

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

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Golfer's Gauntlet

MAKE A DIFFERENCE by becoming a sponsor, registering your team, or playing individually in the 12th Annual Golfer's Gauntlet on Monday, April 24, 2017. All participants will enjoy a fun-filled day at Fuzzy Zoeller's Covered Bridge Golf Club in Sellersburg, Indiana, a hearty breakfast, 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 register or for more information, please go to www.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

Saturday, January 7

Creating Epilepsy Awareness T-Shirts
at A+ Sign and Screen Printing
1795 KY-44 | Shepherdsville, KY
9:00 a.m. - 11:00 a.m.



Saturday, February 4

Painting at Miss Priss Creations
11604 Main Street | Middletown, KY
10:00 a.m. - 12:30 p.m.



Saturday, March TBD

Family Photo Sessions at
Bluegrass Bebe
1201 Story Avenue, Suite 299 | Louisville, KY
10:00 a.m. - 12:00 p.m.



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