

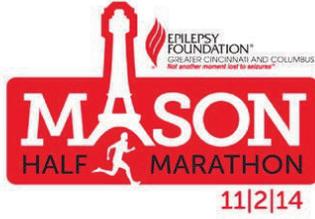
The Update

2014, Autumn Inside this issue:

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November is National Epilepsy Awareness Month!

The Epilepsy Foundation is an unwavering ally in raising awareness, providing support, and funding research to bring new treatments and therapies to market in a timeframe that matters for people with seizures.



Mason Half Marathon

- Beautiful, relatively flat course
- Great food, price and plenty of music to keep you running strong
- Finisher medals for half-marathoners, 5K runners and 5K walkers
- Start/Finish at Mason High School in Mason, OH

11|2|14



Living WITH Epilepsy

**SATURDAY
NOVEMBER 8, 2014**

8:00 AM - 3:30 PM

CEUs for Social Workers, Nurses and EEG Techs



Viva Las Vino Fundraiser

Friday, November 14, 2014
6:00 pm - 10:00 pm

Grange Insurance's Haaf Hall
671 South High Street Columbus, OH 43206

Taylor Huth Memorial Scholarship Program

A college scholarship fund set up by the family and friends of Benjamin "Taylor" Huth to remember and celebrate Taylor's zeal and love for life. Applications must be postmarked by February 27, 2015. Go our website or [here](#) for full details.



Seize Hope

November 7, 2014

A CELEBRATION OF HOPE FOR THOSE
LIVING WITH EPILEPSY

The Update is a periodic newsletter published by the Epilepsy Foundation of Greater Cincinnati and Columbus (EFGCC). The EFGCC was founded in 1953 to assist people with epilepsy, and their families, in meeting their multiple health and social needs. We provide direct services to optimize each person's understanding of epilepsy and to improve their methods of coping with epilepsy in all facets of their lives.

Executive Director: Kathy Schrag

Board of Directors

President: Tom Lockwood

Vice President: Jack Freyvogel

Treasurer: Kevin Ricci

Secretary: Shelley Davis-Parrish

Members at Large

Phil Baum, Mary Broxterman, Stephanie Cassini, Peggy Clark, Dale Dean, Edwin Dugas, Dr. David Ficker, Craig Forrest, Dr. Emily Klatte, Dr. Diego Morita, Phil Pointer, Dr. Michael Privitera, Alyssa Rice, Erik Rickard, Matt Salyers, Chad Schaefer, Dr. Bassel Shneker, Nicole Stonitsch



Greetings

November is Epilepsy Awareness Month! There are so many different upcoming activities and events to raise epilepsy awareness.

In the Cincinnati area we have had people participate in the Purple Pumpkin Project. In Columbus, the lights on top of the Lincoln LeVeque Tower will be purple for the entire month of November. We are hosting our Half Marathon, Seize Hope Event, Living Well with Epilepsy Seminar, and our Viva Las Vino event, all in the month of November! Additionally, I have been invited to attend the Ohio State vs. University of Minnesota football game on November 15th where the game is dedicated to epilepsy awareness. As some of you may know, the University of Minnesota's football coach, Jerry Kill, has epilepsy and is working hard to raise awareness. It is wonderful to see so many people coming together to help raise awareness and talk about epilepsy.

We are also very excited to introduce our brand new logo. For the past two years, our National office, the Epilepsy Foundation of America and all of the 44 affiliates across the country, have been working together on a strategic plan and the new logo that has incorporated the color purple. We will also be kicking off our new nationwide social media campaign, #DareTo. More details to come.

I would be remiss if during this month of Thanksgiving if I did not thank the many individuals, companies and foundations who have provided the Epilepsy Foundation with their tremendous supports. I would like to thank DeanHouston for hosting their International conference community work day at the Benton Center and working hard to put in new walkways, painting and more to make the home and surroundings nice for the individuals we serve. In addition to the community work day, DeanHouston provided technical supports for our website and has created several promotional videos that capture the spirit of the Epilepsy Foundation.

I would also like to thank Window World of Cincinnati for donating all new window and their installation to the Benton Center Home. This incredible act of kindness not only allows us to finally open all the windows, but is helping to cut down on the utilities costs to heat and cool this old house. General Electric and ITW Air Management have continued to support the Epilepsy foundation by holding their community work days on our properties building such things as a raised rock fire pit, raised gardens, and the clearing of old trees and brush.

Lastly, I would like to thank all of the local foundations who have been so generous in awarding us grants to help ensure we can continue to provide our free programs and services and to help provide items such as a new accessible van.

We wish you a very Happy Thanksgiving!

- Kathy Schrag, Executive Director

Why is your Pumpkin Purple?

This question is being asked around the community as kids from our camp and many others paint their pumpkins purple to raise awareness for epilepsy. The **Purple Pumpkin Project** was started in Connecticut and has taken off around the country and continues to help to promote epilepsy awareness, one pumpkin at a time. At our fall camp the kids not only decorated their pumpkin, but learned how to educate the public about this often misunderstood condition. They were told they are the best advocates for the cause and can be a living example that they may have epilepsy, but epilepsy does not have them.

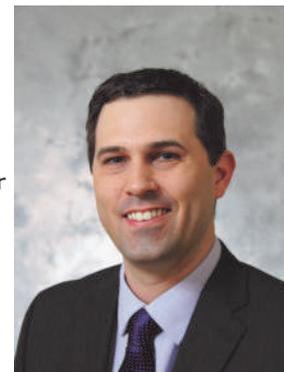
Check out more of about the **Purple Pumpkin Project** on Facebook [here](#).



Jacob Bolling

Ask The Expert: Update on New Anti-Seizure Medications

Dr. Jason Bisping, MD, ABPN
Adult Epileptologist, OhioHealth Comprehensive Epilepsy Center
Riverside Hospital, Columbus, Ohio



In the past few years, there has been a steady stream of new Anti-Epileptic Drugs (AED's) approved for use in patients with epilepsy. With doctors and patients always looking for new ways to better control seizures, these medications have been a welcome addition to our growing arsenal of AED's. Many of them carry significant advantages, such as fewer side effects or once-per-day dosing. With a total now of about 20 drugs to choose from, the need for patient education about the benefits and risks of these individual drugs is more important than ever.

Onfi® (Clobazam) is a fairly new AED that was released in 2011. Onfi, is FDA approved for use as add-on therapy in Lennox-Gastaut Syndrome, although it is being used widely in treating partial epilepsy as well. Onfi is a Benzodiazepine drug that has a similar chemical structure to drugs like Ativan and Valium – medications usually used to stop seizures in emergency situations. Studies show that, although Onfi is chemically similar to Ativan and Valium, there is much less "tolerance" effect over time, meaning that the drug can be used permanently without as much fear that its effect will wear off over time. Onfi is dosed twice daily at either 10 or 20 milligrams, and the most common side effect is sedation.

Aptiom® (Eslcicarbazepine) is the newest approved AED on the market, approved by the FDA in late 2013. It works on a common target site for anti-seizure medications, the neuronal Sodium Channel. Familiar drugs like Dilantin, Tegretol, Trileptal, and others all target the sodium channel. However, Aptiom is unique in that it has much higher affinity for the channel's inactivated state, which may promote less frequent abnormal firing of neurons. It also has the advantage of being a once-a-day medication, with a simple one step titration to the target dosing of 800mg. The most common side effects are dizziness and nausea.

Fycompa® (Perampanel) was discussed individually in a prior EF newsletter, but is another important newer AED in our arsenal. It has a unique mechanism of action in targeting neuronal AMPA receptors to be less prone to abnormal firing. Fycompa also has convenient once-a-day dosing, and a common dosing range between 4 and 12 mg. It does carry a warning from the FDA for side effects of psychosis or hostility in a very small minority of patients.

There are also significant recent developments in some other established AED's. Vimpat® (Lacosamide) was just given approval from the FDA for use in initial monotherapy (may be used alone). As a reminder, all other agents described above are approved for use as add-on therapy. There are also new delivery methods for older drugs like topiramate (now with once-daily forms in Trokendi and Qudexy) and oxcarbazepine (Oxtellar).

It is worth remembering that in patients with hard-to-treat epilepsy, the addition or substitution of medications is less effective than we would hope. The effectiveness of adding a 3rd anti-seizure medication is 4% or less, as shown by Dr. Brodie's pivotal study. This underscores the idea that every patient with refractory seizures deserves the opportunity to be considered for resective Epilepsy Surgery or use of a device for epilepsy, such as VNS or RNS, if they are interested. Be sure to continue to actively engage with your treating doctors to see how new medications or devices can help better control your epilepsy.

Epilepsy Awareness in West Virginia

An art and essay contest is highlighting the efforts of an Epilepsy Awareness event set to take place on Tuesday, November 18th in Huntington, West Virginia. This event will take place in the Atrium of Cabell Huntington Hospital and will feature booths set up by various organizations, including the Epilepsy Foundation that serve people with epilepsy. Participants will be able to gather information on the latest trends and treatments in epilepsy and celebrate the artistic talents of people with seizures. Awards, food and drinks will be provided by Sunovion and Cyberonics. For more information call 877-804-2241.



Fall 2014 Campers



Camp for Champs Finds New Home

Our day camp program, Camp for Champs, in the Columbus area has found a new home. After many years in operation, Rail Fence Farm has closed. We are indebted to Belinda Harting for her guidance in starting and growing this program over the years and are happy we can continue serving children with a therapeutic riding experience. Shane Center, in Centerburg, Ohio, will be our new home and we are anxious to work with Karen Sanchez and her staff in creating a magical camp experience for all involved. The camp will take place the week of June 23 – 26 and run from 9:00 a.m. to noon each day. While at camp the campers will receive instruction in horse care and riding while also taking part in fun and educational games and activities. Space is limited for this special camp so call our office at 877-804-2241 if you are interested.



Camp Flame Catcher Round-Up



It is hard to believe, but another season of camping has come and gone for Camp Flame Catcher. We continue to grow our number of children served and welcome new kids to the magic of camp. This year we were especially happy to have many of our long-time campers move up into the role of counselor. They did an awesome job and bring a unique perspective to the job that is very beneficial for the kids. Camp continues to be a place where the children feel safe, meet others with a similar diagnosis and reach beyond their epilepsy to attain new heights.



The pictures on our website and FB pages highlight just some of the fun.



News from the Group Home

As many of you are aware, the Epilepsy Foundation is blessed to operate four group homes in Clermont County that serve people with epilepsy and developmental delays. The residents in the homes live with us 24/7 and our staff provides excellent care.

This past year we were saddened by the loss of two of our long time residents; Anna Boyles and Brian Rope who both passed away after bouts of illnesses. We were all saddened by their passing, but felt very blessed to be part of their lives for the past twenty plus years. With their passing we were able to welcome two new residents into our homes. Michael Ott moved into Benton Center and Kelly Parker moved into Sycamore Vista.

Additionally, Dara Brigalli moved into Arborview earlier in the year. These three individuals bring a spirit of joy that is appreciated by all. We look forward to getting to know these clients more and sharing many good times.

Stroll for
Epilepsy
A Family Friendly Walk

January 31, 2015, 9:30 AM - Polaris Mall,
Columbus, Ohio

**MARCH 21, 2015, 9:00 AM -
NEWPORT ON THE LEVEE,
NEWPORT, KENTUCKY**


Emerald
MILES
5K RUN/WALK
IN LOVING MEMORY OF DENNIS STEMLER

Young Adult Group

This is just a reminder that on the 3rd Wednesday of every month, a group of young adults with and without epilepsy meet at Lookout Joe Coffee Roaster in Mt. Lookout for an evening of fellowship, fun and support. They gather at 7:00 p.m. and hang out until the conversation dies down. If you would like to join this group simply go to Lookout Joe's on the 3rd Wednesday or call our office at 513-721-2905.

An Open Letter to My Epilepsy



Hello, old friend,

We're coming up on our 11th year together and I have a few things to say to you.

First and foremost, I'm glad that we've reached somewhat of an understanding and that my medicine is keeping you under control. Hooray for 7 months seizure free!

Secondly, I won't lie. There are days when I REALLY don't like you. At all. Between the phone tag with the doctors, the mental health issues, the medicine fiascos with pharmacies, etc, you can get incredibly annoying. I want to be able to donate blood, but I don't want to share my toxic blood with those who need it. I want to have a "typical" 21st birthday, but that is so unbelievably out of the question. (And a big part of that is my 21st birthday is the first day of finals...). There are days when I wonder how much of my personality and the way I am is a medication side effect. I wonder if I would still be the way I am if I wasn't on medication. I've wondered what my life would be like if you hadn't so rudely interrupted my near 10 years of vaguely normal health.

Thirdly, and this is the most important part, I want to say something that not a lot of people say to you. I want to say thank you. Thank you for throwing my world out of whack. Thank you for my bad days. Thank you for all those sleepless nights in the hospital. Thank you for the failed medications and the countless tests and EEGs. I'm not being sarcastic, I'm genuinely grateful for you. If we'd never met, I don't know if I'd still be pursuing a career as an ASL interpreter or Child-Life specialist. Who knows? Without you, I wouldn't know what it means to be strong and to persevere. I would never have met some of the most important people in my world. I wouldn't know my hero, Brady. I wouldn't know some of my best friends. I would have never gone to camp and I would not have half the amazing support system that I'm so blessed to have. I would be missing a second family that I love more than anything.

So, thank you. Thank you for every disoriented ambulance ride. It helped me understand true fear. Thank you for the scary morning of over 150 seizures. Thank you for every well-meaning, hushed, "How ya doing?". They remind me that I am loved and cared for. Thank you for every minute I lost, because now I don't want to lose another. Thank you for so rudely throwing my world out of whack. Now I understand that I can't always be as busy as I want to be. Thank you for my camp family. Thank you for every door you have opened for me. Thank you for helping discover my life's purpose. Thank you for teaching me to be strong. Thank you for every single person you have introduced me to. Thank you for reminding me that I have it so much better than some, even if I might have it worse than others. Life's not fair. You move on and make the walk a little easier for someone else.

Epilepsy, you have become a huge part of who I am, but you will never define who I am. You have changed parts of my life, but I will never let you wholly change me. If I was to be totally honest with myself, I wouldn't change having you in my life. I truly wouldn't. You shook me up and you sent me on the roller coaster ride of my life (one that I'm still riding!) and I find myself finally able to enjoy the ride.

So, until next month,

Erin Louise Grasty

Facebook post by Faith Rummel

Dear Epilepsy,

You might control my brain and actions but I will not let you win. You make people think bad about themselves when there is nothing wrong with them. You allow people to make jokes about having seizures. For example a popular joke at my school is, "Look! I'm having a seizure and I'm swallowing my tongue." They don't understand it's impossible to swallow your tongue. People think they should treat us differently. Epilepsy you came into my life early when I was 15 months old. You can come at anytime in a person's life. Now I am twelve and in the 7th grade. I have many friends. I go to Camp Flame Catcher. I love going to camp. It changed the way I look at the world. I learned many things about my epilepsy. Epilepsy is not a mental illness, it is a medical condition. Everyone is fighting their own fight.

Faith, age 12



For the third consecutive year, the Epilepsy Foundation of Greater Cincinnati and Columbus has participated in StudioE: The Epilepsy Art Therapy Project through a partnership with Lundbeck. In



2014, the Studio E program was expanded to 20 additional markets for a total of 33 affiliates nationwide. Locally, seven people (adults and kids) spent six sessions with our returning Art Therapists, Christy Wolfram and Natalie Carpenter, to express themselves through a variety of mediums. Their artwork, currently available for viewing on [Photobucket](#), will be on display at some of the various events through the month of November in recognition of National Epilepsy Awareness Month. Thanks to all who participated!

Days of Caring for Epilepsy

Every year we are the recipients of an incredible amount of hours donated on behalf of the Epilepsy Foundation from various companies in our community. These companies help at our fundraisers and do much needed work at our group homes. This year various Kohl's stores around the community brought employees to our special events to help things run smoothly. Additionally, employees from ITW Air Management, GE, DeanHouston, Park National Bank and Liberty Mutual donated 100's of hours to improve our facilities in Clermont County. They poured new sidewalks, making the area more accessible for our clients in wheelchairs. They also painted, built raised garden beds, put up fence, landscaped the yard, built a fire pit and much more. This year we were also the recipient of Jack Smith's and his Boy Scouts generosity as he did his Eagle Scout project at Benton Center by putting in a fountain, planting flowers, staining our table and erecting bird feeders. These projects all help to brighten the lives of the clients we serve.



Window World has Huge Impact on Epilepsy Foundation in 2014

John Oslica, the owner of Window World has a passion for helping those in need and in 2014 the Epilepsy Foundation was blessed abundantly by John's generosity.

John has been a long time supporter of our golf outing and gala, but this year John became aware of other needs and responded in a very generous way. Benton Home, which is over 100 years old, has been in need of new windows for quite some time. The old rambling farm house has a hard time keeping out the cold in the winter and staying cool in the summer because of the many un-insulated windows. John heard of this problem and responded by replacing all 46 windows with the highest quality windows on the market. These new windows not only make the home more efficient, which will save us money, but look great and allow the staff to open windows to let in the fresh air.

As if the windows were not enough, John also decided to hold a fundraiser in the fall to benefit three agencies close to his heart, one being the Epilepsy Foundation. On October 11, Window World sponsored, "Laughter is the Best Medicine". This evening of entertainment featured a delicious meal from Magianno's, an array of live and silent auction items and four comedians that had the audience in tears. Not only was it a fun night, but under John's leadership, over \$24,000 was raised for the Epilepsy Foundation.

Thank you John and his staff at Window World for making a difference at our agency!



November 02, 2014 8:00 AM

Mason Half Marathon and 5K Run / Walk, Mason High School, Mason, Ohio 45040

November 05, 2014 6:15 -8:00 PM

Columbus Adult Support Group: Bing Cancer Center at Riverside Methodist Hospital (500 Thomas Ln., Columbus, OH 43215). Park in the purple parking garage! *First Wednesday

November 07, 2014 7:00 - 11:00 PM

Seize Hope Gala, American Sign Museum, 1330 Monmouth St, Cinti, Ohio 45225

November 08, 2014 8:30 AM - 3:30 PM

Living With Epilepsy, OhioHealth Riverside Methodist Hospital, Bing Cancer Center, 500 Thomas Lane, Columbus, Ohio 43214

November 11, 2014 6:00 - 7:30 PM

Clinton County Epilepsy Support Group: Books 'N More Conference Room (28 W Main St., Wilmington, OH 45177) *2nd Tuesday

November 12, 2014 5:30 - 7:00 PM

Warren County Support Group: Kidd Coffee (653 Reading Rd., Mason, OH, 45040) *2nd Wednesday

November 14, 2014 6:00 - 10:00 PM

Viva Las Vino, Grange Insurance's Haaf Hall, 671 South High Street, Columbus, Ohio 43206

November 19, 2014 7:00 PM—?

Young Adult Group: Lookout Joe Coffee Roaster (2901 Robertson Ave, Cincinnati, OH 45209)

November 20, 2014 9:00 AM - 12:30 PM

Seminar "Don't Panic, It's Just an Attack: Dealing with Panic Disorders & Other Related Anxiety Disorders": The Health Foundation of Greater Cincinnati; \$50

November 20, 2014 6:00 - 7:30 PM

Hamilton County Epilepsy Support Group: Epilepsy Foundation's Main Office (895 Central Ave., Suite 550, Cincinnati, OH 45202) *3rd Thursday

November 25, 2014 6:30 - 8:00 PM

Columbus Parent Support Group and Teen Support Group: Bing Cancer Center at Riverside Methodist Hospital (500 Thomas Ln., Columbus, OH 43215). Park in the purple parking garage! *Last Tuesday

****There will not be any Support Groups in the Month of December****

December 11, 2014 9:00 AM - 12:30 PM

Seminar "Crisis Intervention / Suicide Prevention": The Health Foundation of Greater Cincinnati; \$50

January 07, 2015 6:15-8 PM

Columbus Adult Support Group

January 13, 2015 6:00 - 7:30 PM

Clinton County Support Group

January 14, 2015 5:30-7 PM

Warren County Support Group

January 15, 2015 6:00 - 7:30 PM

Hamilton County Support Group

January 21, 2015 7:00 PM—?

Young Adult Group: Lookout Joe

January 21, 2015 6:00 PM

Huntington, WV Epilepsy Support Group: Cabell Huntington Hospital, in PDR 1&2 (behind the Cafeteria) 1340 Hal Greer Blvd., Huntington, WV 25701 *3rd Wednesday, every other month

January 27, 2015 6:30-8 PM

Columbus Parent Support Group and Teen Support Group

January 31, 2015 9:30 AM

"Stroll for Epilepsy" Polaris Mall, Columbus, OH

February 04, 2015 6:15-8 PM

Columbus Adult Support Group

February 10, 2015 6:00 - 7:30 PM

Clinton County Support Group

February 11, 2015 5:30-7 PM

Warren County Support Group

February 18, 2015 7:00 PM—?

Young Adult Group: Lookout Joe

February 19, 2015 6:00 - 7:30 PM

Hamilton County Support Group

February 24, 2015 6:30-8 PM

Columbus Parent Support Group and Teen Support Group

February 27, 2015

Taylor Huth Memorial Scholarship Program Applications Due

March 04, 2015 6:15-8 PM

Columbus Adult Support Group

March 10, 2015 6:00 - 7:30 PM

Clinton County Support Group

March 11, 2015 5:30-7 PM

Warren County Support Group

March 18, 2015 7:00 PM—?

Young Adult Group: Lookout Joe

March 18, 2015 6:00 PM

Huntington, WV Epilepsy Support Group

March 19, 2015 6:00 - 7:30 PM

Hamilton County Support Group

March 21, 2015 9:00 AM

Emerald Miles, Newport on the Levee

March 31, 2015 6:30-8 PM

Columbus Parent Support Group and Teen Support Group

April 01, 2015 6:15-8 PM

Columbus Adult Support Group

April 08, 2015 5:30-7 PM

Warren County Support Group

April 14, 2015 6:00 - 7:30 PM

Clinton County Support Group

April 15, 2015 7:00 PM—?

Young Adult Group: Lookout Joe

April 16, 2015 6:00 - 7:30 PM

Hamilton County Support Group

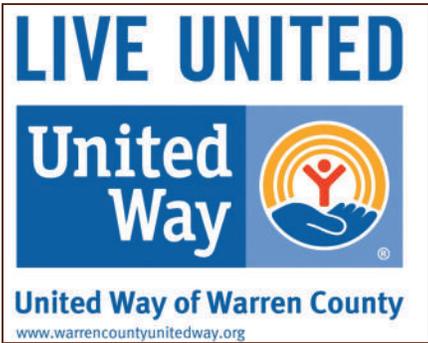
April 28, 2015 6:30-8 PM

Columbus Parent Support Group and Teen Support Group



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Did you know that the Epilepsy Foundation offers FREE support at your child's IEP meeting? Call if you would like us to

University of Cincinnati Neuroscience Institute
UC EPILEPSY CENTER

Strategies for Managing Your Epilepsy

Ask the experts at this free symposium for patients, families and caregivers

Saturday, November 22 | 8:30 a.m. - 12:30 p.m.

AGENDA

- Diagnosis and treatment of epilepsy – What's new?
- Stress management as a treatment for epilepsy
- Medical marijuana for epilepsy? Fact vs. fiction
- Working and driving with epilepsy
- Strategies for living with epilepsy
- What to do when medications don't work – Surgery, devices and diets
- Physician panel question and answer session



Mission statement:

The Epilepsy Foundation leads the fight to stop seizures, find a cure and overcome the challenges created by seizures.

Epilepsy Foundation of Greater Cincinnati and Columbus

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