EPILEPSY FOUNDATION
Greater Cincinnati and Columbus

The Update

2016, Volume II

Sand Volleyball is Back!

Get your team together and join us at Flannagan's, Dublin, Ohio, on Saturday, **July 30th, 2016**, for fun in the sun as we support the Epilepsy Foundation of Greater Cincinnati and Columbus.

EPILEPSY FOUNDATION Greater Cincinnati and Columbus
SAND VOLLEYBALL TOURNAMENT
7.30.2016

Flannagan's DUBLIN

Team Registrations:
Early Bird: On or before June 3rd — $150
June 4th to July 8th — $250
July 9th to July 29th —$ 275

Sponsorship opportunities are available. For more information visit www.Columbus-Sand.com or email Kathy at kschrag@epilepsy-ohio.org.

2016 Golf Outing Huge Success

Thanks to all our sponsors and players who supported our annual Taylor Huth Memorial Golf outing on June 11, 2016, at Elks Run Golf Course. Together they helped us raise close to $50,000 and awarded 4 scholarships to young adults with epilepsy heading off to college. A special thanks goes out to our Title Sponsor, Dentsmart and our Premium Sponsor, Window World. We would also like to thank our shirt sponsors, Gem City Tire & Dayton Freight for providing all players with an awesome Footjoy shirt. Additionally, we would like to extend a big thank you to all sponsors and donors. Together you help us make a difference in the lives of people with epilepsy.

Hats off to our first place team of Stephen Torbeck, Dave Storer, Chris Larbes & Andrew Bell. They won the event a few years ago and were happy to regain this title. Second place goes to a new team in the event consisting of Brian Smith, Constance Smith, Billy Smith & Trevor Goddall. Thanks to Neusole Glassworks for providing beautiful, one of a kind trophies.

We hope you can join us for next year's event!

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: Jack Freyvogel

Vice President: Nicole Stonitsch

Treasurer: Kevin Ricci

Secretary: Dale Dean

Member at Large: Chad Schaefer

Members

Phil Baum, Mary Broxterman, Peggy Clark, Dr. David Ficker, Craig Forrest, Dr. Emily Klatte, Dr. Diego Morita, Alyssa Rice, Erik Rickard, Matt Salyers

7 Things Everyone Needs to Know About Status Epilepticus

1. **Status Epilepticus is defined as a seizure lasting longer than 5 minutes, or two or more seizures happening without improvement in between.**
2. **Status Epilepticus is a true emergency.** Many other body systems can be involved, especially if the seizure includes generalized tonic-clonic activity. Body metabolism can be altered, heart rhythms can change, and even breathing can be effected.
3. **If a seizure lasts longer than 10 minutes it is not likely to stop on its own.** Most seizures last less than 2 or 3 minutes. Although everyone is unique, studies have shown that if a seizure lasts longer than 10 minutes, medicines are usually needed to stop the seizure.
4. **If Status Epilepticus is treated earlier, it is easier to stop.** Studies have shown that the sooner treatment of status epilepticus is started, the more likely the prolonged seizure will respond to medication.
5. **There is a well-defined treatment plan for Status Epilepticus.** In 2016, the American Epilepsy Society published guidelines on the treatment of status epilepticus.
6. **Not all Status Epilepticus is the same.** Just as everyone's seizures are unique, so is status epilepticus.
7. **Tell your doctor if you or your loved one with epilepsy has ever had Status Epilepticus, or if you are concerned that this may occur.** Creating a plan to treat breakthrough seizures or cluster seizures is an important part of epilepsy management. Things to discuss could include when to call for emergency help, when to give a rescue medication, and how to stay safe if a seizure occurs.

Action Steps

Know what type of seizures you have. Tell your health care team if you've ever had status or cluster seizures. Update your seizure response plan each year or whenever you have a change in medicines. If you don't have a seizure response plan, download a form from our Toolbox, fill out as much as you can, and take it to your next appointment with your epilepsy doctor or nurse. If you have a My Seizure Diary account, you can make one online and update it easily!

Epilepsy Foundation Unveils New **Talk About It!** Site

If you have not checked it out already, go to www.talkaboutit.org to see a great new site aimed at educating the general public about epilepsy. Put together by Greg Grunberg, Hollywood actor and parent of a child with epilepsy, he enlists the help of fellow actors to share a very informative and engaging message about epilepsy. Please share this site with your family and friends.

Local Companies Continue to Share their Time, Talent & Resources

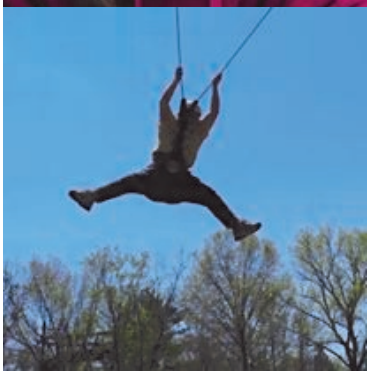
Every year we are blessed to work with a number of companies who take time out of their busy schedules to support the work of our agency. This spring we were fortunate to work with three of these companies. In May staff from UC Clermont came out to Sycamore Vista to paint, landscape and generally beautify the home. Also in May, Liberty Mutual came out for their 7th consecutive year to paint, do general construction at Benton Home and do landscaping. They left the home looking great for the springtime. In June a group of engineers from GE came out to Benton Home to lend their expertise in building a covered porch at our Day Program, excavating for a new patio and sidewalk and painting to give the home a fresh new look. This is GE's 6th year of service and we are extremely grateful for their support.

In the fall we look forward to working with GE again, along with ITW Air Management and others. If your company would like to volunteer, please call our office.

Thank You!

Camp Corner

Camping Programs Expand in 2016



We are happy to share that we have been able to touch the lives of more children, families and adults at our camps this year because of the generous support of both individuals and corporate sponsors. In addition to our traditional spring and fall weekend camps and our annual summer camp; we have hosted a family day camp in the Columbus area for children who have had surgery or are looking at this as an option for treatment. We would like to thank in a special way the neurology team at Nationwide Children's for partnering with us on this endeavor. In June we hosted a day camp in Northern Columbus at Shane Center. Here participants rode horses daily and took part in other horse related activities. This fall we look forward to hosting a weekend camp for adults with epilepsy from September 9-11. We have a few spots available for this camp to be at Lutheran Memorial Camp, north of Columbus.

Thanks again to the many people and companies who support our camp program!

To register for any of these camps or for more information call (877) 804-2241 or email mfindley@epilepsy-ohio.org.

EPILEPSY FOUNDATION
Greater Cincinnati and Dayton
2016
MASON
HALF MARATHON
5K Run/Walk

Mason Half Marathon to Move to the Mason Community Center

We are happy to share that our Mason Half Marathon and 5K on Sunday, November 6th will be held at the Mason Community Center. The Community Center has been a long time supporter of the event, but this is the first year we will be hosting the registration, start and finish at the Center. The staff has been very gracious in opening up their facilities to us and we believe this will help us expand and grow the event. Register early for the event using the form in the newsletter or online at our website at www.epilepsy-ohio.org.

Light My Fire

When you get out of the bed in the morning and brush your teeth, do you think about how easy that was for you? As you drive to work and pull an eight-hour shift, have you ever thought to yourself, "Wow I am blessed"? My name is Kayla, and I am a PCA at Cincinnati Children's. In 2013, I started volunteering at a camp for kids with Epilepsy, called Camp Flame Catcher.

The average incidence of epilepsy each year in the U. S is estimated at 150,000 or 48 for every 100,000 people.

As a child, being "different" can change your life. You learn to evaluate your surroundings to make sure people won't stare or laugh at you. You fear sleepovers with your friends because they are afraid of your condition.

As a parent to a child with Epilepsy you also fear that nobody can take care of your child when they are away from you. You want so badly for your child to feel like part of the group. To be a "normal" child.

Camp Flame Catcher allows all those things to happen. The camp is staffed with nurses, counselors, and volunteers like me. We are trained to keep the children safe, make sure they get all their medicine, but most importantly to allow them to enjoy their camp experience. The camp offers rock climbing, horse back riding, as well as many other activities these kids otherwise would not be able to participate in. The best part of camp is: everyone has Epilepsy, and for just a moment in time, these kids can let down their guards, and feel safe, loved, and carefree! And most importantly, Camp Flame Catcher offers them friendships that last a lifetime!

After volunteering at the camp I found myself humbled. I watched many kids struggle to do things you and I do every day without thought. One of the teens has multiple seizures a day, and had seven to eight seizures while trying to reach the top of the rock climbing wall. Well, guess what? She made it to the top! These kids teach you to see the world in a whole new light. They are much braver than we are; they persevere, and find strength when many of us would give up.

That first camp changed my life, and I am asking you to help me continue changing these kids' lives. These families spend countless hours at hospitals and doctors visits, they spend every penny on medicine to try to control this disorder. Some of the families can't afford to give their kids this amazing gift.

So what do you do when you have a problem? You find a solution. I started a fundraiser event called Light My Fire. This year will be our third year doing this; all the money raised goes directly to the camp to cover tuition for families unable to provide the funds.

My mission: To shine light on Epilepsy and provide a way to see children smile through their fight! With your help we can change the way a child experiences life, even for a day. With your donation you can help me achieve this.

Come enjoy food, drinks, music, dancing, a silent auction, a photo booth and more at the third annual

Light My Fire Benefit!

Proceeds provide camp scholarships to help parents send their children with epilepsy to Camp Flame Catcher.

When? Saturday, August 13, 2016 from 7:00 pm-12:30 am

Where? Orchard Hills Clubhouse (5927 Orchard Hills Lane , Cincinnati, OH 45252-2617)

Tickets are $25 per adult (18 and over) or $40 per couple, $15 per child (3-17 years old) or $20 for 2 children. Children under 3 are free. Tickets may be purchased at the door.

The theme this year is ***Neon Lights*** and ***Glow in the Dark*** (no strobe lights will be used). Bring your friends, young and old!

Please consider this opportunity to help these kids!

Email Kayla Conroy at kc.fundraiser@yahoo.com for any questions or to purchase tickets.

Hope is like a neon light, glowing in the dark! Hope to see you all there!!

You are cordially invited. . .

A Celebration of Hope for Those Living with Epilepsy

- Friday, November 4, 2016 7:00 pm—11:00 pm
- American Sign Museum
- 1130 Monmouth St., Cincinnati, OH 45225

Enjoy a night out meeting and celebrating with those who have *Seized Hope* and attained success through their accomplishments. This event is to honor all of the individuals living with epilepsy who do not allow their epilepsy to stop them from achieving their goals and reaching great success. The American Sign Museum is a unique one-of-a kind venue with a century of signage on display that is sure to trigger past memories. The night will be filled with fun, great company, full bar service, hors d'oeuvres, raffles and a silent auction.

Put this on your schedule now! Registration opens soon!

Teens Speak Up!

The Epilepsy Foundation's annual Public Policy Institute and Teens Speak Up! Conference was held April 17-19 in Washington DC. Brought together were 46 teens with epilepsy, their parents, and affiliates from across the county who united for a day and half of learning and advocacy training that culminated with a Hill day on April 19. Families and affiliates shared their personal stories and advocated in support of the Epilepsy Foundation's legislative goals in more than 220 Congressional visits.

This year we focused on federal epilepsy program funding, improving access to cannabis for research and individuals in states with medical cannabis programs, and creating a nationwide system to gather data on neurological conditions and diseases.

Our local representatives to DC this year included Andrew Goodell (Athens, Ohio), Mason Hicks (Letart, West Virginia), and Jack Simone (Pickerington, Ohio).

Gentlemen! Well done!

Andrew Goodell and Jack Simone on the Capitol step with Ohio Senator Rob Portman

Suzette Hicks, Mason Hicks, West Virginia Senator Shelly Moore Capito, and Dr. Mitzi Payne

Calendar of Events

July 19, 2016 6:00 PM
Huntington, WV Epilepsy Support Group (Enslow Presbyterian Church 1338 Enslow Blvd Huntington, WV 25701) *3rd Tuesday

July 20, 2016 6:00-7:30
Hamilton County Epilepsy Support Group: Epilepsy Foundation's Main Office (895 Central Ave., Suite 550, Cincinnati, OH 45202) *3rd Wednesday

July 20, 2016 6:00-8:00 PM
Licking County Support Group: Licking Memorial Hospital (Mound View Room, 1320 West Main St., Newark, Ohio 43055) *3rd Wednesday

July 20, 2016 7:00-8:00 PM
Cincinnati Young Adult Group: Lookout Joe Coffee Roaster (2901 Robertson Ave, Cincinnati, OH 45209) *3rd Wednesday

July 26, 2016 6:30-8:00 PM
Columbus Parent Support Group and Teen Support Group: Dempsey Family Education and Resource Center (Silver Tower area of Riverside Methodist Hospital located at 3535 Olentangy River Road, Columbus, Ohio 43214) *Last Tuesday

July 20, 2016 8:00 AM
Sand Volleyball Tournament Flannagan's—Dublin, Ohio

August 3, 2016 6:00-8:00 PM
Columbus Adult Support Group: Dempsey Family Education and Resource Center (Silver Tower area of Riverside Methodist Hospital located at 3535 Olentangy River Road, Columbus, Ohio 43214) * First Wednesday

August 10, 2016 5:30-7:00 PM
Warren County Support Group: Kidd Coffee (653 Reading Rd., Mason, OH, 45040) *2nd Wednesday

August 13, 2016 7:00 PM—12:30 AM
Light My Fire Benefit—Cincinnati, Ohio

August 19, 2016 6:00 PM
Huntington, WV Support Group

August 17, 2016 6:00-7:30 PM
Hamilton County Support Group

August 17, 2016 6:00-8:00 PM
Licking County Support Group

August 17, 2016 7:00-8:00 PM Cincy Young Adult Group: Lookout Joe

August 25, 2016 9:00 AM-12:15 PM
Seminar: "Methods and Models in Practice: A Creative Approach" The Health Foundation: $55

August 30, 2015 6:30-8:00 PM
Columbus Parent Support Group and Teen Support Group

September 7, 2016 6:00-8:00 PM
Columbus Adult Support Group

September 9-11, 2016
Fall Adult Weekend Camp - Lutheran Memorial Camp, Columbus, Ohio

September 14, 2016 5:30-7:00 PM
Warren County Support Group

September 20, 2016 9:00 AM - 12:15 PM Seminar: "ADHD Through the Age Spectrum" The Health Foundation: $55

September 20, 2016 6:00 PM
Huntington, WV Support Group

September 21, 2016 6:00-7:30 PM
Hamilton County Support Group

September 21, 2016 6:00-8:00 PM
Licking County Support Group

September 21, 2016 7:00-8:00 PM
Cincy Young Adult Group: Look Out Joe

September 23-25, 2016
Fall Kids Camp - Camp Kern, Oregonia, Ohio

September 27, 2016 6:30-8:00 PM
Columbus Parent Support Group & Teen Support Group

October 5, 2016 6:00-8:00 PM
Columbus Adult Support Group

October 17, 2016 5:30-7:00 PM
Warren County Support Group

October 18, 2016 6:00 PM
Huntington, WV Support Group

October 19, 2016 6:00-7:30 PM
Hamilton County Support Group

October 19, 2016 6:00-8:00 PM
Licking County Support Group

October 19, 2016 7:00-8:00 PM
Young Adult Group: Look Out Joe

October 22, 2016 6: 30-8:00 PM
Columbus

October 25, 2016 8:00 AM-3:30 PM
Living Well With Epilepsy Conference, Bing Cancer Center, Columbus, Ohio

October 27, 2016 9:00 AM -12:15 PM Seminar: "When Nothing Else Seems to Work: The Promise of Neurofeedback" The Health Foundation: $55

November 2, 2016 6:00-8:00 PM
Columbus Adult Support Group

November 4, 2016 7:00-11:00 PM
Seize Hope—Cincinnati, Ohio

November 6, 2016
Mason Half Marathon—Mason, Ohio

November 9, 2016 5:30-7:00 PM
Warren County Support Group

November 15, 2016 6:00 PM
Huntington, WV Support Group

November 16, 2016 6:00-7:30 PM
Hamilton County Support Group

November 16, 2016 6:00-8:00 PM
Licking County Support Group

November 16, 2016 7:00-8:00 PM
Cincy Young Adult Group: Look Out Joe

November 17, 2016 9:00 AM—12:15 PM Seminar: "Managing the Stress of Behavior Change" The Health Foundation: $55

November 29, 2016 6:30-8:00 PM
Columbus Parent Support Group & Teen Support Group

Like us on Facebook to keep up with all of our events!

EPILEPSY FOUNDATION
Greater Cincinnati and Columbus

Thank You

We would like to extend our warmest thanks to the following foundations for their generous support by awarding the Epilepsy Foundation grants for our many services. Thanks to their generosity we are able to continue to serve those with epilepsy and their families. 2015 Grants that were received and the programs to which they were designated include:

Camp Flame Catcher:

Summertime Kids Greater Cincinnati Foundation… $1,000

United Way of Warren County… $1,820

Counseling Program:

The Spaulding Foundation… $17,500

Charles H Dater Foundation… $10,000

Jack J. Smith, Jr Charitable Trust… $12,500

Annonomous… $10,000

StudioE Art Therapy Lundbeck… $10,000

United Way of Warren County… $1,820

Community Education Program:

The Wohlgemuth Herschede Foundation… $4,000

The Epilepsy Foundation of America, "School Nurse Training"…$8,000

The Epilepsy Foundation of America, "African American Outreach"… $5,000

The Epilepsy Foundation of America, " Seniors and Seizures Training"…$5,000

The Epilepsy Foundation of America, "Peer Youth Education"...$4,000

The Epilepsy Foundation of America, "Asian American Outreach"… $10,000

United Way of Warren County… $5,749

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

895 Central Ave., Suite 550 ◇ Cincinnati, OH 45202 ◇ Phone: (513) 721-2905 /(877) 804-2241 ◇ Fax: (513) 721-0799

E-mail: efgcc@epilepsy-ohio.org ◇ Web address: www.epilepsy-ohio.org