



# The Update

## 2015, Summer Inside this issue:

Greetings	2
Emerald Miles Wrap-Up	2
National Walk for Epilepsy	3
Teens Speak Up!	3
Helping Hands	3
Lemonade for Livy	4
Studio E: Art Therapy	4
Summer Camp	5
Camp for Champs	5
#Dare To	5
Fred Darling	6
My Epilepsy...	6
Common Epilepsy Myths	6
ESETT	7
Week in Paradise!	8



**Saturday August 1st 2015**

**Flannagan's**

**6835 Caine Rd  
Columbus, OH 43235**

What screams summer more than sand and pools?! Enter into our Sand Volleyball Tournament and Pool Play Tournament so you can bring your spiking skills out with a group of friends to Flannagan's! It'll be a day of fun in the sun and proceeds will benefit EFGCC.

Check out our early-bird specials and Event/Registration information at:

[Columbus-Sand.com](http://Columbus-Sand.com) or [epilepsy-ohio.org](http://epilepsy-ohio.org).



## Memorial Golf Tournament

TAYLOR HUTH SCHOLARSHIP FOUNDATION

**June 13<sup>th</sup>** marks the date of our annual golf outing at Elks Run Golf Course in Batavia, Ohio. This annual tradition raises funds for our college scholarship fund for young adults with epilepsy. Additionally it helps to fund other programs throughout our wide service area. Foursomes are still available for the event, but we anticipate filling to capacity as it did last year. To register go to our website at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org).

We would like to thank our Title Sponsor, Dentsmart for their generous support of our agency through this event. Dentsmart has been a loyal contributor from the beginning and they support our cause in many ways. Additionally, Gem City Tire and Dayton Freight have joined in as Premium Sponsors supplying golf shirts for all participants. New this year will be trophies for the first and second place teams designed by Neusole Glassworks. These one of a kind trophies will be hand-casted just for our event. Participants will also be treated to cones on the course thanks to Tri-County Skyline, along with beer from Listerman Brewing. It is taking shape to be a great event and we hope you can join us in June.



### Five Win College Scholarships



The Taylor Huth College Scholarship Program continues to grow in the applicants we receive and the amount of money we award. This year was no exception as the committee had a tough time choosing between many worthy candidates. In the end, five students were chosen and will each receive \$1500 to help them in their pursuit of a degree.

Congratulations to:

**Donald Bleasdale  
Alec Hickman  
Ben Minney  
Michael Palmisano  
Blake Wickstrom**

Thank you to Taylor Huth's family and friends for helping us start this important program!

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

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## *Greetings*

I cannot take credit for this cute poem. One of our creative staff put this poem together about our NEW Sand Volleyball Tournament being held Saturday, August 1, 2015, at Flannagans in Dublin, Ohio.

It is with a heavy heart that we are unable to host our Annual Mud Volleyball Tournament. It has been a long and difficult process in trying to find a company or individual who has 10 available acres with a source of water to allow us to use their property. Without a location, we are unable to host the event.

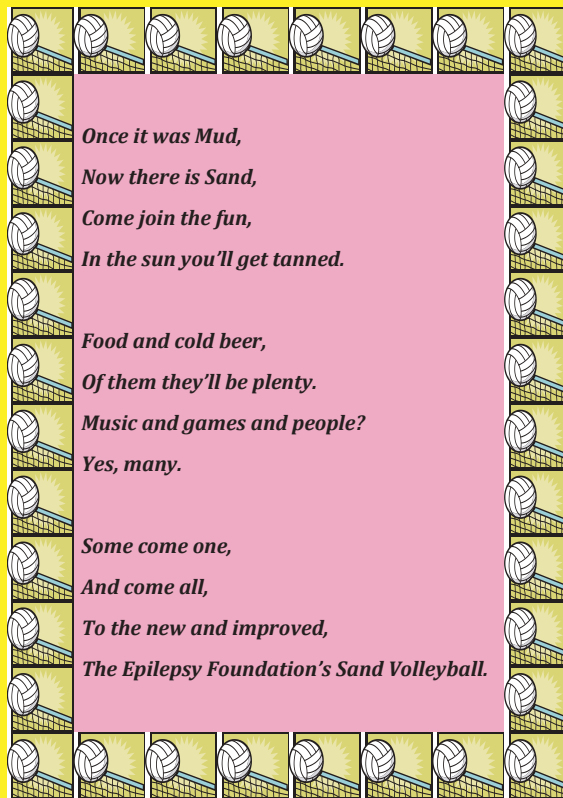
We are however very happy and proud to announce that David Straub, owner of Flannagan's, has graciously agreed to host our new Sand Volleyball Tournament. We will be able to host up to 130 teams so be sure to register early! While we are unable to host mud, we are very excited to be able to continue to host a volleyball event in the sand. We truly appreciate everyone's support of the Epilepsy Foundation of Greater Cincinnati and Columbus by participating in Mud over the years and we hope your commitment to the Epilepsy cause continues with your participation in our Sand Volleyball event.

This will be a fun-filled day with volleyball, split-the-pots, and other fun games. There is a price difference and some previous mud rules have changed too. Please visit our new sand volleyball website at [www.columbus-sand.com](http://www.columbus-sand.com) for all event details. The first early-bird registration deadline is June 11<sup>th</sup> for a price of \$175 per team. Come join the fun while supporting those affected by epilepsy.

As always, please feel free to contact me with any questions.

Happy Spring to all!

-Kathy Schrag, Executive Director



## **Emerald Miles Breaks ALL records!!!!**

Thanks to the phenomenal support of our families and friends, we broke all records for Emerald Miles this year. A record total **1598** people took part and an amazing **\$89,097.00** was raised to support our programs and services!!!!!!!

These totals were pushed over the top by the **80 teams** who registered for the event. These teams were led by newcomer, Pacing for Payton, followed by Running for Adam and Carter's Crusaders. Thanks to everyone who made this event so successful. Your efforts will have a profound impact on our programs all year long!!!!

Stay tuned for Emerald Miles 2016 on March 19!

# National Walk for Epilepsy

Thanks to the generous support of local donor, Roger Heldman, we were able to again take a group of young adults to the National Walk for Epilepsy in Washington DC on April 11, 2015. Young men from Cincinnati, Columbus, N. Ky. and Dayton filled a 15 passenger van for an exciting weekend in DC. Besides joining 4000 others participants at the Walk, the guys visited the Smithsonians and National Monuments and had a great time. Thanks again Mr. Heldman for making this a weekend to remember!



## Teens Speak Up!

Thank you to our local teens for attending the Epilepsy Foundation's 2015 Public Policy Institute and Teens Speak Up! conference in Washington, DC! With 170 attendees, including affiliate staff, parents, teens, doctors and volunteers from across the nation, this year's event gave families and affiliates an opportunity to share their personal stories and advocate in support of the Epilepsy Foundation's legislative goals in over 200 Congressional meetings. Go to [position statements](#) for the complete list of positions and statements on epilepsy research and programs.



Kentucky Senator Rand Paul and Teen Advocate Sydney Nelson of Erlanger, Kentucky



Ohio Rep. Pat Tiberi and Teen Advocate Abby White of Newark, Ohio.

### Local Companies Lend a Helping Hand

With the advent of spring we were very happy to get a hand with spring cleaning, gardening, painting and other needed chores at our group homes as two local companies donated their time to help us out. On May 4<sup>th</sup>, 20 employees from Liberty Mutual volunteered both at Benton Center and Sycamore Vista and on May 8<sup>th</sup> employees from UC Clermont helped out at Sycamore Vista. These volunteers helped to



plant our vegetable gardens, mulch around our flowers, paint and do much needed general upkeep. Their efforts helped to make our homes a place to enjoy for our residents and staff.

Thanks Liberty Mutual and UC for making a difference!!!!





# LEMONADE FOR LIVY



We are happy to share that this summer our agency will be partnering with Lemonade for Livy to raise epilepsy awareness and fund research.

Ten year old Olivia Scheinman (Livy) is the inspiration and symbol behind the Lemonade for Livy movement. What started as one neighborhood lemonade stand to raise money in honor of Livy is expanding into a global campaign. We will help this effort grow by challenging all the kids who attend our camp to make a Stand for Epilepsy the last week of July (right after camp). At camp they will receive the "ingredients" to host a home-grown lemonade stand. Additionally, we will be hosting a lemonade stand on Fountain Square in Cincinnati during the lunch hour on July 20<sup>th</sup> and hope to have another stand at a prominent location in Columbus.

**You** can also join us in this worthwhile effort by setting up a stand in your neighborhood or at work the last week of July and talk about the need for epilepsy support and research. Please send us your pictures and donations so we can track the progress of our local efforts on our website.

Also check out [www.livyshope.com](http://www.livyshope.com) to see how one family is making a huge impact on epilepsy.



We are excited to offer *Studio E: The Epilepsy Art Therapy Program* to people with epilepsy again in the Cincinnati and NEW to the Columbus area!

*Studio E* offers group art therapy sessions for adults, teens and kids with epilepsy, allowing them to explore their creativity, meet others with epilepsy and express themselves in an open, accepting and safe group setting. Art is a natural way to communicate, relieve tension and express emotions. According to research presented at the 2014 annual meeting of the American Epilepsy Society, people living with epilepsy reported increased self-esteem after participating in *Studio E*.

During the program, participants work with licensed art therapists using a variety of artistic media, including painting, sketching and sculpting. Because some things are easier to "say" through art, *Studio E* provides people impacted by epilepsy a unique opportunity to express themselves and open up about their experiences with the condition.

#### CINCINNATI (Adults, Teens, Kids):

This year's program will be taking place on Saturdays at 9:00 AM, May 30, June 6, 13, 20, 27, and July 11 at our offices located at 895 Central Avenue, Suite 550, Cincinnati, Ohio 45202. For more information about the *Studio E* program, or to enroll in this year's sessions, contact Doug Simmons at [dsimmons@epilepsy-ohio.org](mailto:dsimmons@epilepsy-ohio.org) or call (513) 721-2905 or toll free 877-804-2241.

#### COLUMBUS (Adults):

The program will be taking place on Saturdays at 9:00 AM, June 6, 13, 20, 27, and July 11 (+ one more to be added) at St. John's Episcopal Church located at 1003 West Town Street, Columbus, Ohio 43222. For more information about the *Studio E* program, or to enroll in this year's sessions, contact Doug Simmons at [dsimmons@epilepsy-ohio.org](mailto:dsimmons@epilepsy-ohio.org) or call (513) 721-2905 or toll free 877-804-2241.

*Studio E* is made possible through an ongoing partnership between Lundbeck, a pharmaceutical company committed to helping people with epilepsy, and the Epilepsy Foundation. To learn more about the *Studio E* program or see artwork generated during previous programs, visit [YourPartnerInEpilepsy.com](http://YourPartnerInEpilepsy.com).



## Summer Camp Taking Shape

Our annual Summer Camp for kids with epilepsy will take place **July 12 -16, 2015** at Camp Kern. On the schedule are many traditional favorites such as: horseback riding, GAGA, canoeing, crafts, games, zip line, singing and much more. We will also take the kids on a rafting trip down the Little Miami River and host the Adventure Challenge. This summer we hope to fill the camp with close to 80 campers and 40 counselors. Many of our older campers are moving up the ranks into a counselor role and we thank them for their willingness to give back. There is still time to register for camp for you have not already done so. Please call our office at 877-804-2241.

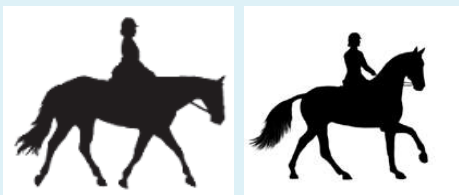


Thanks to our special events and generous donors, we never turn a child away from camp because of finances.



### Camp for Champs filled to Capacity!

We are happy to share that our annual day camp in the Columbus area is filled to capacity. Participants are anxiously looking forward to a week of horseback riding and activities at Shane Center. Camp will take place June 22-25. If you would like to come out and visit this program to get on the waiting list for next year, please contact our office.



**#DARE TO**

..... WE #DARE TO CONQUER EPILEPSY. WHAT DO YOU #DARE TO DO? .....

Please join us and other post-epilepsy surgery superheroes for a day of family education, entertainment, and recreation!

**JUNE 13, 2015** : 8:30-AM-4:30 PM  
: CAMP KERN :  
: OREGONIA, OHIO

This exciting day of camp will give parents the opportunity to network with other parents, learn what's new in the world of epilepsy, and gain valuable support from our Comprehensive Team of Epilepsy Superheroes. Both kids and adults are invited to participate in a variety of games and activities as we collectively celebrate life beyond seizures!

REGISTRATION REQUIRED. BREAKFAST AND LUNCH INCLUDED.

PLEASE RSVP TO MEGAN NO LATER THAN MAY 4, 2015 513.803.9057  
epilepsysurgery@cchmc.org

**\*NOTE\*** This special program is hosted by the doctors and nurses of Cincinnati Children's Hospital Medical Center and is open to children who have had their surgeries at Cincinnati Children's.





# FRED DARLING

Fred Darling was born on December 21<sup>st</sup>, 1934 and passed away on March 31<sup>st</sup>, 2015. He was a long time resident of The Epilepsy Foundation and always had a smile on his face, loved a good joke, singing, and listening to Bluegrass music. Fred was also a diehard Red's fan. He loved watching and listening to the games. He passed away quietly at home surrounded by loved ones. Even though Fred is no longer with us, he will always have a special place in our hearts.

## My Epilepsy... by Elizabeth "Liz" Winter

I was diagnosed with juvenile myoclonic epilepsy when I was 18 years old. I was diagnosed the weekend after attending my orientation at Ohio State, and I started treatment with medication just three weeks before I was due to move from Michigan to Columbus, to begin my freshman year. You can practically hear my mother's worry in that sentence.

I had my first generalized tonic-clonic seizure in February of my senior year in high school. It happened on a Monday morning

in the hallway of my school right in front of all of my friends, just before classes were starting for the day. That was one of the scariest days of my life. I am fortunate that my seizures have been almost entirely controlled by medication since my diagnosis. I am now 21 years old and as of April 13<sup>th</sup>, 2015, I am one year seizure-free and counting!

While I mostly have had the typical college experiences, this diagnosis has absolutely changed the course of my life. I have been studying psychology and neuroscience at OSU and I have an enormous passion for research and education. Somewhat ironically, I chose to study these fields before I was diagnosed with a neurological condition of my own. Originally, my plans were to pursue a PhD in cognitive science research. This year, I began volunteering with the Epilepsy Foundation of Greater Cincinnati and Columbus. Through them I have met a lot of lovely people living with epilepsy and I have learned so much about my own diagnosis, what others go through, and the strength of our community. It gives me an appreciation for how lucky I am to have controlled seizures. It is also educative because I am able to meet other individuals and families that are affected by all kinds of epilepsy. I have also had the opportunity to meet many social workers, medical professionals, educators, and advocates who all help our cause; I have been inspired by many of these people. Largely because of the work I have done with this organization and my own personal experiences with epilepsy, I have decided to pursue a Master of Public Health after I graduate. With this degree, I will be able to use my passions to make a real, practical difference.

I am motivated to make changes in society. Before I was diagnosed with epilepsy, I had no idea of the scope of this condition or what it really means. I have been shocked by how little the public really knows about seizures and epilepsy. Public health is such a diverse and interesting field and I am excited to be a part of it. Public health research and education is what I want to do with my life and I am thankful for all of the experiences that have led me to this path.

**Liz is a junior at The Ohio State University. Liz created these infographics as part of a class project to combat stigma surrounding epilepsy.**

### The Truth About

## Common Epilepsy Myths

**#1** "You can swallow your tongue during a seizure"

It's physically impossible to swallow your tongue.

**#2** "You should force something into the mouth of someone having a seizure"

Absolutely not! That's a good way to chip teeth, puncture gums, or even break someone's jaw.

**#3** "You should restrain someone having a seizure"

Never use restraint! The seizure will run its course, and you cannot stop it.

**#4** "People with Epilepsy are disabled and can't work"

People with Epilepsy have the same range of abilities and intelligence as the rest of us.

## The FACTS

Epilepsy is not a mental illness. "Epilepsy" is an umbrella term covering about twenty different types of seizure disorders.

People with epilepsy don't look different! Unless someone with epilepsy is actually having a seizure there is no way that their condition can be detected.

People with seizure disorders are found in all walks of life and at all levels in business, government, the arts and other professions. We aren't always aware of them because many people, even today, do not talk about having Epilepsy for fear of what others might think.

Epilepsy is a chronic medical problem that for many people can be successfully treated. Unfortunately, treatment doesn't work for everyone and there's a critical need for more research.

Source of Information: [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org) and [www.epilepsy.com](http://www.epilepsy.com)

powered by



**May 6, 2015 6:00–8:00 PM**

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

**May 13, 2015 5:30–7:00 PM**

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

**May 20, 2015 6:00-7:00 ESETT**

The Ohio State University Wexner Medical Center Graves Hall 333 W 10th Ave, Rm 1069, Columbus, OH 43210.

**May 20, 2015 6:30-7:30 ESETT**

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

**May 20, 2015 7:00– 8:00 PM**

Young Adult Group: Lookout Joe Coffee Roaster (2901 Robertson Ave, Cincinnati, OH 45209) \*3rd Wednesday

**May 26, 2015 7:00 PM**

Huntington, WV Epilepsy Support Group (Enslow Presbyterian Church 1338 Enslow Blvd Huntington, WV 25701) \*\*NOTE\*\* Normally 3rd Tuesday

**May 26, 2015 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

**May 28, 2015 9:00 AM–12:30 PM**

Seminar: "When Nothing Else Seems to Work: The Promise of Neurofeedback" The Heath Foundation of Greater Cincinnati, \$55

**May 30, 2015 9:00 AM–12:00 PM**

Studio E — Cincinnati Begins

**June 3, 2015**

Columbus Adult Support Group and Teen Support Group

**June 6, 2015 9:00 AM–12:00 PM**

Studio E — Columbus Begins

**June 10, 2015 5:20– 7:00 PM**

Warren County Support Group

**June 13, 2015 8:00 AM**

Taylor Huth Memorial Golf Outing (Elk Run Golf Course, 2000 Ellick Rd., Batavia, OH 45103)

**June 13, 2015 8:30 AM–4:30 PM**

#Dare To, Day Camp for Parents, See page 5.

**June 16, 2015 6:00 PM**

Huntington, WV Support Group

**June 17, 2015 6:00 7:30 PM**

Hamilton County Support Group

**June 17, 2015 7:00–8:00 PM**

Young Adult Group: Lookout Joe

**June 18, 2015 9:00 AM–12:30 PM**

Seminar: "Depression: It's More than just the Blues" The Health Foundation of Greater Cincinnati; \$55

**July 22-25, 2015 9:00–noon daily**

Camp for Champs Day Camp

**June 30, 2015 6:30-8:00 PM**

Columbus Parent Support Group and teen Support Group

**July 1, 2015 6:00– 8:00 PM**

Columbus Adult Support Group

**July 8, 2015 5:30-7:00 PM**

Warren County Support Group

**July 12-16, 2015**

Camp Flame Catcher

**July 15, 2015 6:00– 7:30 PM**

Hamilton County Support Group

**July 15, 2015 7:00– 8:00 PM**

Young Adult Group: Look Out Joe

**July 21, 2015 6 PM**

Huntington, WV Support Group

**July 28, 2015 6: 30–8:00 PM**

Columbus Parent Support Group & Teen Support Group

**August 1, 2015 7:00 AM**

Sand Volleyball Tournament (Flannagan's, 6835 Caine Rd)



**What is the ESETT?**

ESETT is an emergency medicine study designed to try to save and improve the lives of people who experience a seizure that will not stop on its own (status epilepticus) or that has not responded to adequate doses of benzodiazepine medications. Emergency department care of these patients in the US is not the same everywhere.

Because it is not known which drug best treats this type of seizure, different doctors use different medicines. This study plans to look at three commonly used medicines given in the emergency departments for a seizure not stopping: fosphenytoin (fPHT), valproic acid (VPA), and levetiracetam (LVT) to learn which treatment is best at stopping a seizure quickly.

For more information about the study, visit [Synopsis](#) or attend an informational seminar below.

**Cincinnati: May 20, 6:30–7:30**  
895 Central Ave, Suite 550, Cincinnati, OH 45202. This study is between University of Cincinnati Hospital and Nationwide Children's Hospital

**Columbus: May 20, 6:00–7:00**  
The Ohio State University Wexner Medical Center Graves Hall 333 W 10th Ave, Rm 1069, Columbus, OH 43210. This study is between Ohio State University Hospital and Nationwide Children's Hospital

Please call (877) 804-2241/(513) 721-2905 for more information or to RSVP to attend the meeting.







## *Win a Week in Paradise!*



Here is an awesome way to support the Epilepsy Foundation and have great odds at a Palace Resort in Mexico.

Limited tickets are being sold for a special raffle to take place on June 13th at our Taylor Huth Memorial Golf Outing. You do not need to be present to win. Winner will walk away with an all-inclusive one week stay for 2 (to be used 6/14/15-12/22/15) at your choice of four beautiful resorts in Mexico. All food, accommodations, drinks, activities and entertainment are provided, you just need to provide the plane ticket.

Call our office at 877-802-2241 to buy a ticket or on our website at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org)

Thanks:



Joe & Nicole Stonitsch  
for this package

### **Epilepsy Foundation of Greater Cincinnati and Columbus**

895 Central Ave., Suite 550 ◇ Cincinnati, OH 45202 ◇ Phone: (513) 721-2905 / (877) 804-2241  
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E-mail: [efgcc@epilepsy-ohio.org](mailto:efgcc@epilepsy-ohio.org) ◇ Web address: [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org)