



The Update

2016, Volume I



Join us on Saturday, March 19th as we celebrate our 16th annual Emerald Miles 5K Run/Walk at Newport on the Levee. This event has grown to become our largest fundraiser of the year because of the support we receive from our teams and runners. In order to meet our goal of \$95,000 and provide funding for our host of services, we need you!!! Please consider setting up a team at www.epilepsy-ohio.org and walking or running for epilepsy. Additionally, we ask you to encourage family and friends to support our cause. This event is a powerful way to stand up for people living with epilepsy and show them they are not alone! We hope to see you on March 19th.

Running the 26th Mile for the "1 in 26"

The Epilepsy Foundation of Greater Cincinnati and Columbus is an Associate Charity Partner for the 2016 Flying Pig Marathon and gives you a couple of ways to support our organization and raise awareness about epilepsy.

If you are planning to run the full, half, or 4-person relay, please register under the Epilepsy Foundation's team, *Run For Epilepsy*, at:

<http://getmeregistered.com/homepage.php?id=123360>. Runners can register and share this link and ask family, friends and co-workers to donate to the Run For Epilepsy Team. Another option for runners/walkers is to start your own team as a sub-group of the Epilepsy Foundation's team. All participant's registration fees go to the Flying Pig. Any

donations made to the Epilepsy Foundation come directly to our organization. Finally, if you would prefer to register on the Flying Pig's website, you can select the Epilepsy Foundation as a Charity in the drop-down to make an additional donation.

Please feel free to **share** with any runners you may know.

Additionally, we are encouraging kids to join us for the Flying Pig Kids' 26th Mile Marathon. This fantastic opportunity allows kids ages 5-12 walk or run 25 miles, one mile at a time, prior to the race on April 30th. Then on the 30th, they will join other kids who are running for epilepsy as they run their final mile finishing at the official finish line. They will receive shirts, medals and many other goodies. This is a great way to get in shape and run for epilepsy!

For information on these and other Flying Pig related questions, call Kathy or Mark at 513-721-2905.



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.

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Greetings

As we welcome in the new year, we generally set goals for ourselves to work on and improve on over the next year. We are no different at the Epilepsy Foundation of Greater Cincinnati and Columbus. The management team, over a span of two days, had lively discussions about our programs and services, and set goals and objectives on how to make improvements over the next year. We put measurements in place to help us monitor our successes. We all agree that it is very important to hear from you, our consumers, on your thoughts of our programs and services and if they have been beneficial to you and your family.

Additionally, we would love to hear your suggestions on what new services you could use and how we could improve on what we currently provide to our community. If you live in our service territory: Central and Southern Ohio; Boone, Campbell, Grant and Kenton counties in Kentucky; Dearborn and Ohio counties in Indiana; or in the Huntington, West Virginia area, we want to hear from you! We will be sending out surveys and kindly ask that you take the time to respond. We look forward to serving you and helping to meet your needs as well as the needs of our entire community.

Best Regards,
-Kathy Schrag, Executive Director



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.

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.



Flannagan's
DUBLIN

Camp Corner

Camp 2016

Again this year, we are offering many traditional camp programs, but we are also branching out to offer some exciting new programs. Please see the highlighted camp programs below and let us know if you would like to take part. Many of them have limits on the amount of people who can take part and are sure to fill up, so don't delay. As always, we offer financial assistance if needed, so don't let finances stand in the way of coming to camp.

Spring Camp – April 22-24 at Camp Kern. Join us as we enjoy some beautiful spring weather while hiking, fishing, playing games and more. Campers will stay at Elk Lodge on Friday night and have the option of staying in tree houses on Saturday night if they like. It will be a weekend to remember, so don't delay in registering. Cost is \$175.00

Camp for Champs Day Camp – June 27-30 at Shane Center in Centerburg, OH. Join us for this day camp that runs from 9:00 a.m. to noon, Monday through Thursday. Parents will need to stay during the program which centers around horseback riding is led by qualified staff at the Shane Center. Limited to only 10 campers. Cost is \$50.00.

Summer Residential Camp – July 10-14 at Camp Kern. The tradition continues as we host our annual summer camp that includes swimming, games, rafting, zip lines and more. A good time is guaranteed for all. Cost is \$375.00

Fall Adult Weekend Camp – September 9-11 at Lutheran Memorial Camp in Northern Columbus. For the first time ever, we are hosting a weekend adult camp that will include time to relax, enjoy the great outdoor and gain mutual support. Limited to 18 adults, this camp is sure to sell out. Cost is \$125.00.

Fall Kids Camp – September 23-25 at Camp Kern. Join us at Elk Lodge as we get together for a weekend of fun during the beautiful fall season. Kids will hike, make crafts, play games and much more. Cost is \$175.00.

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



Ask the Expert: Who are the right patients for epilepsy surgery?

Dr. Satya Gedela

Medical Director of Epilepsy Surgery, Director of Epilepsy Monitoring Unit - Nationwide Children's Hospital
Associate Professor of Pediatrics - Ohio State University

Epilepsy is a very common neurological condition affecting 1% of the population. In the US, there are more than 3 million people with epilepsy. In 66% of these patients, epilepsy is well controlled with one or two anti-seizure medications and some of these patients will grow out of this condition. The remaining 33% of these patients will continue to have seizures despite using several anti-seizure medications. When patients continue to have seizures even being on two or more medications we call this condition by different names such as drug resistant epilepsy, treatment resistant epilepsy or medically intractable epilepsy. At this stage the chances to become seizure free with further trials of medications is less than 5%. These patients will need different treatment options to increase their likelihood of seizure freedom. The nonmedical treatments currently available are epilepsy surgery, palliative epilepsy surgery, Vagus Nerve Stimulator (VNS) and dietary treatments. Usually these patients are referred to an epileptologist, a neurologist who specializes in taking care of patients with epilepsy.

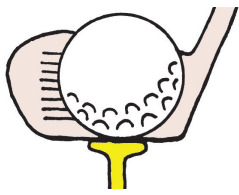


Epilepsy surgery may be the best option and the only cure available in certain patients with epilepsy. It used to be a last resort but now it has become a standard and common practice to offer epilepsy surgery after failing 2 or 3 medications. Unfortunately, in certain areas the time gap from the diagnosis of drug resistant epilepsy to work-up for epilepsy surgery is still longer than 15 years in adult populations. This gap is slowly getting better with increasing awareness about epilepsy surgery among the patients and referring physicians.

Once seen by an epileptologist in a tertiary hospital center equipped with a comprehensive epilepsy center, patients will have detailed history, examination and extensive testing to determine their eligibility for epilepsy surgery. These tests are collectively called Phase 1 or pre-surgical work up. These include admitting the patient in the epilepsy center (usually level 3 or 4 centers) to get prolonged video EEG to capture 3 or more typical habitual seizures. The patients will also get a very special MRI scan of the brain which will help to diagnose even small abnormal brain tissue. They may also need special functional brain scans to identify the seizure-making abnormal part of the brain especially when the MRI is normal. One of these scans is called PET scan which identifies the glucose utilization of the brain. The other special scan is called SPECT scan which identifies the blood circulation of the brain. Patients also will need neuropsychological testing. All these tests will help to locate the seizure making part of the brain.

This Phase 1 data will be discussed among several specialists from different specialties like neurology/epilepsy, neurosurgery, neuroradiology, and neuropsychology. As a group they will decide whether a particular patient is good epilepsy surgery candidate or not. The best patient for epilepsy surgery is one who had failed two or three appropriately used anti-seizure medications, all the seizures come from one side of the brain and the seizure making area is far from parts of the brain which are involved in other very important functions like speech and movement. Epilepsy surgery is possible even in patients with a normal MRI scan of the brain.

Epilepsy surgery can not only give the patient with epilepsy higher chances of seizure freedom but can also make the quality of life and the ability to learn better.



Taylor Huth Golf Outing

Save the date for our annual Taylor Huth Memorial Golf Outing on Saturday, June 11 at 9:00 a.m. at Elks Run Golf Course in Batavia, OH. This event has sold out the past two years and we anticipate it will do the same this year. It is a beautiful course and participants get many perks including golf shirts, golf balls, food, drinks and much more. Don't delay in signing up. Contact our office if you would like to become a sponsor. Sponsorships are available from the \$100 level up to \$5000. Proceeds benefit all our programs, including our college scholarship program.



College Scholarship Applications Due Soon

Do you have epilepsy? Are you heading off to college? Or are already enrolled in college? Then consider applying for the Taylor Huth College Scholarship. Applications are **due by February 26, 2016.**

See all the details on our website at www.epilepsy-ohio.org.



Local Student Takes Action for Epilepsy!

Julia Rice of Verona, Kentucky, is working to raise epilepsy awareness for her Cadette Girl Scout Silver Award (2nd highest award in scouting). A former Girl Scout troop member and current classmate with epilepsy is the reason behind Julia's Take Action project. An awareness event is scheduled at Walton-Verona Middle School for Thursday, March 24. This event will include epilepsy educational programs for all the students as well as encouraging the students to wear purple that day to show support. The school's Jr. Beta Club will also be volunteering at this year's Emerald Miles 5K in Newport, KY on March 19. If you wish to keep up with Julia's project you may do so at <http://silverforepilepsy.weebly.com/>.



Thanks, Julia, for raising awareness about epilepsy and supporting a friend!



10th Anniversary National Walk For Epilepsy



This spring we will make our presence known in our nation's capitol as we take part in both the National Walk for Epilepsy and the Teens Speak Up Advocacy Program in Washington, DC.

On April 16, families and individuals from our area will join over 5,000 other people from across the nation as we take part in the National Walk for Epilepsy. This event helps people see that they are not alone in their struggles with seizures as teams from across the nation take part in this event. If you would like to head to DC for this event, please sign up under our affiliate team at www.walkforepilepsy.org.

The day after the event, three young men from Ohio and West Virginia will represent our agency and take part in the Teens Speak Up program. This program teaches them how to be advocates for epilepsy and empowers them to stand up for issues near and dear to our hearts. We are happy to announce that **Andrew Goodell, Mason Hicks, and Jack Simone** were chosen to take part in this program. We wish them the best of luck as they head off to DC!

New Year, New Support Groups, New Locations

Epilepsy can be a very challenging diagnosis and sometimes you could use a little extra support. We are here to help with that. We have a number of support groups to give you a chance to meet with others who have epilepsy as well as their family members. It is a great opportunity to share your frustrations, questions, successes, and resources as well as be a support to others new to the diagnosis.

We are excited to announce a **new support group starting in the Newark, Ohio** area. We will meet on the third Wednesday of each month from 6pm to 8pm. The group will be held at Licking Memorial Hospital in the Mound View Room, located by the cafeteria. The address is 1320 W. Main Street, Newark, Ohio 43055.

New Locations: All of the Columbus area groups have moved their location. They will now meet in the Dempsey Family Education and Resource Center located in the Silver Tower area of Riverside Methodist Hospital located at 3535 Olentangy River Road Columbus Ohio 43214. Parking passes provided for these groups and parking is located in the Emergency (RED) parking lot or the Main Entrance (BLUE) parking lot.

Adult Support group meets the first Wednesday of each month from 6pm to 8pm. Parent support group and TASSELS(for teens), meets the last Tuesday of every month from 6:30pm to 8pm.

We hope to see you there!!

February 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

February 10, 2016 5:30—7:00 PM

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

February 16 2016 6:00 PM

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

February 17, 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

February 17, 2016 7:00– 8:00 PM

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

February 18, 2016 9:00 AM—

12:30 PM Seminar: "Practical
Approaches to Solving Ethical
Dilemmas" The Health Foundation: \$55

February 23, 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 **Except month of May

March 2, 2016 6:00-8:00 PM

Columbus Adult Support Group

March 9, 2016 5:30– 7:00 PM

Warren County Support Group

March 15, 2016 6:00 PM

Huntington, WV Support Group

March 16, 2016 6:00-7:30 PM

Hamilton County Support Group

March 16, 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

March 16, 2016 7:00—8:00 PM

Cincy Young Adult Group: Lookout Joe

March 19, 2016 9:00 AM

Emerald Miles: Newport on the Levy

March 29, 2015 6:30-8:00 PM

Columbus Parent Support Group and
teen Support Group

March 31, 2016 9:00 AM— 12:30 PM

Seminar: "SBIRT: Screening, Brief
Intervention & Referral to Treatment"
The Health Foundation: \$55

April 6, 2016 6:00– 8:00 PM

Columbus Adult Support Group

April 13, 2016 5:30-7:00 PM

Warren County Support Group

April 16, 2016

National Walk for Epilepsy,
Washington DC

April 19, 2016 6:00 PM

Huntington, WV Support Group

April 20, 2016 6:00– 7:30 PM

Hamilton County Support Group

April 20, 2016 6:00—8:00 PM

Licking County Support Group

April 20, 2016 7:00– 8:00 PM

Cincy Young Adult Group: Look Out Joe

April 26, 2016 6:30—8:00 PM

Columbus Parent Support Group & Teen
Support Group

April 28, 2016 9:00 AM—12:30 PM

Seminar: "Creative Approaches for the
Treatment of Childhood Abuse" The
Health Foundation: \$55

April 30, 2016

Flying Pig: 26th Mile

May 4, 2016 6:00– 8:00 PM

Columbus Adult Support Group

May 11, 2016 5:30-7:00 PM

Warren County Support Group

May 17, 2016 6:00 PM

Huntington, WV Support Group

May 18, 2016 6:00– 7:30 PM

Hamilton County Support Group

May 18, 2016 6:00—8:00 PM

Licking County Support Group

May 18, 2016 7:00– 8:00 PM

Young Adult Group: Look Out Joe

May 26, 2016 9:00 AM—12:30 PM

Seminar: "Integrative Medicine: The
New Sister to Allopathic Medicine" The
Health Foundation: \$55

May 31, 2016 6:30—8:00 PM

Columbus Parent Support Group & Teen
Support Group

June 1, 2016 6:00– 8:00 PM

Columbus Adult Support Group

June 8, 2016 5:30-7:00 PM

Warren County Support Group

June 15, 2016 6:00– 7:30 PM

Hamilton County Support Group

June 15, 2016 6:00—8:00 PM

Licking County Support Group

June 15, 2016 7:00– 8:00 PM

Young Adult Group: Look Out Joe

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





By popular demand Studio E: The Epilepsy Art Therapy Program is back. We will once again offer this innovative therapy program in the Cincinnati and Columbus areas in 2016. The dates and times and places are yet to be determined in both locations so while you wait, enjoy the link for more information about Studio E.



Epilepsy Foundation of Greater Cincinnati and Columbus

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