



The Update

Join us for the 2013 Mason Half Marathon!

Your participation in this event helps the Epilepsy Foundation provide valuable services to the community including: Community Education, Counseling, Youth Camping Program, Support Groups, Adult Day Activity Program, Group Homes and much more! To find out more about the agency, go to: www.epilepsy-ohio.org.



Course: The race starts and finishes at Mason High School (6100 Mason Montgomery Rd., Mason, OH 45040).

Time: The race starts at 8:00 AM. Same day registration is from 6:30-7:30 AM, in the high school.

Course Closure: The course will remain open for 3½ hours.

Registration Costs:

- **5K run/walk:** adults 13 and over: \$35 if postmarked by 10/28/13 or completed online by 10/30/13 at midnight; \$45 on race day (No guarantee of shirt)
- **5K run/walk:** children 12 and under: \$20
- **Half-Marathon:** adults 13 and over: \$55 if postmarked by 10/28/13 or completed on-line by 10/30/13 at midnight; \$70 on race day (No guarantee of shirt)

Registration includes short sleeve t-shirt for 5K races and technical shirt for half-marathoners, awards and refreshments.*
*All pre-registration shirts must be picked up by 8:00 AM on race day or they will be forfeited.

Group Discount: Send in five or more registrations in one envelope and take advantage of a discount of \$5.00 off per person.

Register On-line: Go to www.epilepsy-ohio.org to register on-line.

Pre-registration Packet Pick-Up: Beat the crowd the day of the event! Pick up your shirt and race number early on Fri., 11/1/13 from 3-6 PM at the Epilepsy Foundation's office (895 Central Ave., Suite 550, Cincinnati, OH 45202) or Sat. 11/2/13 from 10 AM-2 PM at MoJo Running (8777 Cincinnati Dayton Rd., West Chester, OH 45069).

Refreshments: Enjoy food, music & drinks after the race.

Chip timing: This event will be chip timed.

Awards: First place trophies given after the event to the top male and female in the 5K walk, 5K run and half-marathon. Medals to the top 2 finishers in each age division.

Half Marathon Finishers: All runners who finish the half-marathon in 3½ hours or less will receive a special commemorative medal.

Questions? Call the Epilepsy Foundation at (513) 721-2905.

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Seize Hope
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Seize Hope Gala- Save the Date!

Friday, November 8, 2013

Call Kathy Schrag at (513) 721-2905 for more information

Have you enrolled for the Kroger Community Rewards Program yet? If you have, we thank you so much for your participation! As a reminder, participants must re-enroll every year to continue earning awards during the coming year. If you haven't enrolled yet, it is easy to participate and there are no strings attached—shop at Kroger and scan your Rewards card when you check out and a percentage of your purchase will be donated to the Epilepsy Foundation. Enroll or re-enroll at www.krogercommunityrewards.com. Our organization number is 82140.



2013, Volume III

Inside this issue:

Greetings from our Assistant Director	3
Board of Directors	3
Community Support of EFGCC	4
Chanda Gunn visits Camp!	5
Camp for Champs Wrap-Up	5
Save the Date: Fall Camp Flame Catcher	5
Entertainment Books for Sale	5
Rest In Peace Jackie Hagedorn	5
Benjamin Taylor Huth Golf Tournament Wrap-Up	6
Calendar of Events	7
Highlights from the Hill	7
Mud Volleyball Wrap-Up	8



Like us on Facebook for the latest updates!

Ask the Expert: *Seizure Dogs*

Katherine Holland, MD, PhD
Pediatric Epileptologist Cincinnati Children's Hospital
Associate Professor, UC Department of Pediatrics



Seizure dogs are service dogs with special training to respond to a person having a seizure. They have been trained to demonstrate particular behaviors (often barking) to notify caregivers that a seizure is occurring. Sometimes these dogs are also called seizure response dogs. They can be helpful in notifying parents when children have seizures when sleeping or when children are having seizures while outside or playing in a different room. Some can also be trained to respond to seizures in specific ways to limit seizure-related injuries or assist in calling for help. A small subset of dogs might also develop the ability to predict that seizures are coming (they are termed seizure alert or seizure predicting dogs).

The use of seizure dogs has not been rigorously studied and most of what is known comes from patient and family reports describing their dog's capabilities. Families and people with seizure dogs consistently report an improved quality of life. This may come from the increased sense of independence and security that people feel with having with a seizure dog in the family. Some also perceived a reduction in seizure frequency. The ability of dogs to predict seizures is more controversial, is reported only a subset of trained dogs, and has not been demonstrated scientifically.

Although some people with dogs describe seizure detection and predicting behaviors in their own family pets, this is unusual. True seizure dogs undergo rigorous training which can be very costly (\$10,000-\$25,000) and lengthy. These dogs are service animals and the laws for these dogs are no different than for other service dogs; a person has the right to use the dog in any public place.

For more information about seizure dogs contact:

- » 4 Paws for Ability (937) 374-0385, www.4pawsforability.org
- » Canine Assistants (800) 771-7221, www.canineassistants.org
- » Circle Tail, Inc (513) 877-3325, www.circletail.org
- » Paws with a Cause (800) 253-7297, www.pawswithacause.org

F.O.C.U.S. ON EPILEPSY

WE ARE STILL SEEKING A FEW INDIVIDUALS WITH EPILEPSY WHO WOULD LIKE TO TAKE PART IN A SPECIAL SELF MANAGEMENT STUDY. PARTICIPANTS WILL BE ASKED TO TAKE PART IN A FEW PHONE INTERVIEWS, WILL BE GIVEN VALUABLE INFORMATION TO HELP THEM DEAL MORE EFFECTIVELY WITH THEIR SEIZURES AND HALF OF THE STUDY GROUP WILL BE INVITED TO A SEMINAR ON OCTOBER 5, 2013. TO TAKE PART IN THE STUDY, CONTACT PATTY TROTTA AT (513) 721-2905.

LIVING WITH EPILEPSY CONFERENCE

Presented by: Riverside Methodist Hospital, OhioHealth and the Epilepsy Foundation of Greater Cincinnati and Columbus

Saturday, November 9, 2013

Riverside Methodist Hospital • Bing Cancer Center • 500 Thomas Ln. • Columbus, OH 43214

November is National Epilepsy Awareness Month and highlights the advances made in the management and treatment of epilepsy throughout one's lifespan. Leading medical practitioners will present current and new treatments, the latest research in the effort to find a cure and strategies for dealing with the challenges that epilepsy presents to persons of all ages.

Two general presentations and nine breakout sessions are designed to meet the needs of parents of children with epilepsy, adults living with epilepsy and the professionals & families providing care. Speakers include: epileptologists, social workers and pharmacists who will address

Frontline Seizure Care; Epilepsy & Its Impact on Memory; Autism, Developmental Delay & Epilepsy; The Negative Effects of Stress on Seizures; Social Media & Epilepsy; Medicines for Epilepsy; Clinical Trials; Spirituality, Religion & Epilepsy; and How Does Social Security Disability Work?

The seminar offers a broad range of topics to ensure that all participants, both professional and public, will have the opportunity to choose the subjects that best meet their educational needs. In addition, a panel of epilepsy practitioners will respond to questions from the audience to address individual concerns.

The cost is \$10 per person and \$40 for professionals seeking Contact Hours or CEUs. All registrations include presentations, exhibits, complementary parking, continental breakfast, box lunch and beverages. Scholarships are available for those who may require one by calling (614)315-0437.

Please mark your calendars and plan to join us in Columbus for an outstanding conference. For further information, please contact the Epilepsy Foundation of Greater Cincinnati and Columbus at (513) 721-2905 or (877) 804-2241 and visit the website: www.epilepsy-ohio.org.

Please join us for a most rewarding day!!

Greetings!

Recently I heard a golfer express why he enjoyed the game of golf so much. He said golf is a game of HOPE: there is always the hope that on the next swing or the next hole you will improve your putt or hit that coveted hole-in-one. That analogy is similar to what we do. In the world of epilepsy there is always the hope that the next medication will help, the seizures will stop, or the person can get their drivers license or finish school. This hope keeps us working harder every day to make sure not another moment is lost to seizures.

We just hosted two events that bring this theme of hope close to home. At our recent golf outing four young adults were awarded college scholarships through the Taylor Huth Scholarship Fund to help them pursue their dreams and keep their hopes alive. I cannot express in words what a joy it is to meet and work with these young adults. They have overcome great obstacles with their seizures, kept their heads held high and continue to focus straight ahead. Thanks for helping us provide this hope for these individuals.

This summer we also hosted our largest group ever at camp as our Columbus and Cincinnati youth came together for a great week of fun. The week was filled with shouts of joy and laughter as the kids swam, hiked, canoed, played games and much more. In all that they do, these kids live out the message of hope as they show the world that, "I may have epilepsy, but epilepsy does not have me". I hope you are able to visit our website and see the many pictures we have posted that share this message of hope. In order to make our camp possible, I would like to thank two very special groups that make it all possible: our counselors and our donors.

Making sure 73 kids with epilepsy have a fun and safe time at camp can seem like a daunting task, but our camp counselors make it look easy. Our 35 camp counselors run the gamut from having epilepsy to not having seizures, from a young college student to the adult who has lived with epilepsy for years. What they all share in common though is a great love and dedication for "our kids". They take a week of vacation from work, they wake up at all hours of the night dealing with seizures, they run with the kids from 7:00 a.m. to 10:00 p.m., they have kids climb on them in the pool and throw whip cream pies at them in a carnival - and they do all of this with a smile on their face and joy in their hearts. Our counselors are amazing and we could not serve all the kids without them. Thanks to our camp volunteers for all you do!

The other key ingredient to our camp is often unseen, but very much appreciated. Since we have started our camp we have never had to turn a child away from camp because they cannot pay. Often the cost of raising a child with special needs is very expensive given the cost of medication, doctor visits, time away from work, etc. Camp is often a luxury that parents cannot afford. Thanks to a quiet, but committed group of donors, we can make camp available for everyone. We have had nurses from Cincinnati Children's Hospital forego the typical Holiday Gift Exchange to sponsor a needy child, one family we serve asked that instead of Christmas gifts the family members sponsor a child at camp (they actually donated enough for two kids!). Other individuals give annually in memory of a loved one who passed away. The reasons are endless, but the results are the same—a child can enjoy and grow at camp because someone cared. Thanks to all our donors for making this possible!

And so it is with a grateful heart that I say thanks to all of you for helping us provide hope for people with epilepsy. Your support and generosity allows us to have a far reaching impact from the kids at our camp, to students at college and adults looking for assistance. Together we are making sure that **not another moment is lost to seizures!**

Thank you for your continued support!
Mark Findley, Assistant Director

The Update is a quarterly 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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To learn how what we can do for you, visit our website at www.dentsmart.net or call us at 1-866-960-8029.

Our Community Gives Back. . .

Although we are months away from the holidays, it feels a little like Christmas here at the Epilepsy Foundation as companies are stepping forward to help us at our group homes and with our special events. Over the summer Liberty Mutual spent three days at Benton Center painting, landscaping and doing many other projects. Kohl's employees have also stepped up to the plate and helped us with our recent fundraisers. Presently we have employees from ITW Air Management, Children's Hospital, Park National, and students from Seton High School to help us with various projects at our group homes. These volunteers help us accomplish tasks that brighten up the homes and touch the lives of our residents. If your company would like to volunteer at one of our group homes or at a special event please call our office at 877-804-2241 or visit the volunteer section of our website at www.epilepsy-ohio.org.



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Olympic Hockey Goalie Visits Camp

This summer, camp received a very special visitor as Chanda Gunn, the goalie for Team USA, spent two days at our camp. Thanks to the support of our national office, Chanda flew in from the Boston area with her daughter, Sofie, to spend the final two days at camp. While at camp, Chanda shared her story of growing up with seizures and overcoming the obstacles which they present. She shared

how hard work, determination and a positive attitude brought her to the Olympics three times where she won a coveted bronze medal and set records for most saves by a goalie. Chanda has also played at the World Games winning a gold medal. Besides all of her achievements on the ice, Chanda showed all at camp that compassion and caring are virtues far more valuable than an Olympic medal.



Chanda Gunn

She encouraged, motivated and challenged all at camp to live life to the fullest.



Camp for Champs at Rail Fence Farms

Each and every one of our campers showed his or her courage in mounting and going through the paces upon a very large, yet gentle creature whose patience and discipline aided in increasing their rider's posture, body control, confidence and, not to mention their pleasure astride their own personal 1,000 pound horse. Friendships made between riders and steeds are apparent as each morning campers call out their favorite horse's name as they don their safety helmets. Undoubtedly a little scary at first, the experience becomes a favorite one as many campers come back each summer hoping to renew their friendship with a four, very long-legged friend.



Watching the riders is most enjoyable, but in some respect pales in comparison to watching the parents, whose delight in seeing their children do something that even the parent may have some qualms in attempting, is sheer satisfaction.



Horses as therapy animals is not new, but certainly gaining favor as more youth are given the opportunity to find their means to greater independence, personal accomplishment and exhilaration from a saddle seat five feet off the ground. Come test your mettle next year!



Fall Camp

Mark your calendar for October 4-6, 2013, as we host our annual fall camp at Camp Kern. We will be hiking, canoeing, playing games and much more. To take part in the fun call our office today to register as space is limited.



We are happy to announce that the 2014 Entertainment Book is available for sale for the reduced price of \$25.00. This is 5.00 less than last year's price and each book is filled with hundreds of savings coupons. We have both Columbus and Cincinnati books available. To purchase your book call (877) 804-2241 or stop in our office from 8:00 AM-4:00 PM at 895 Central Ave., Ste. 550, Cincinnati, OH 45202. To mail the books out, there is an additional \$5.00 fee.



Jackie Hagedorn 4/1/55 to 8/12/13

Jackie Hagedorn passed away suddenly on August 12th, 2013. We were blessed to have Jackie as a part of this agency for over 20 years and she will forever remain in our hearts. Jackie was born on April fool's day and loved a good joke. She also enjoyed Reds baseball, the color red, comfy slippers, and m & m's. We will miss her feisty spirit, quick wit, and corrections (she preferred the word supper over dinner and would not hesitate to correct the unfortunate speaker!) Rest in peace, Jackie.



Memorial Golf Tournament

TAYLOR HUTH SCHOLARSHIP FUND

Thank you to all of those who participated in the Taylor Huth Memorial Golf Tournament on August 10 at Glenview Golf Course! Event proceeds are used to provide young adults with epilepsy college scholarships!

A Special Thanks to the Golf Committee: Matt Salyers, Chad Schaefer, Joe Stonitsch and Jack Freyvogel and the Huth Family for all of your support in making this event successful again this year!

Visit our website and/or Facebook page to see some of the greatest shots of the day and to stay informed of next year's tournament information!



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September 10, 2013; 6:00-7:30 PM

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

September 11, 2013; 5:30-7:00 PM

Warren County Epilepsy Support Group: Kidd Coffee (322 Reading Rd., Mason, OH 45040)

September 18, 2013; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group: St. Elizabeth-Florence, Emergency Department Conference Room (lower level) (4900 Houston Rd., Florence, KY 41042)

September 18, 2013; 6:15-8:00 PM

Columbus Adult Support Group: Riverside Health Center (500 Thomas Ln., Columbus, OH 43215). Park in the purple parking garage!

September 19, 2013; 9:00 AM-12:30 PM

Seminar "Anger Management: Prevention of Bitterness and Rage": The Health Foundation of Greater Cincinnati; \$50

September 19, 2013; 6:00-7:30 PM

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

September 24, 2013; 5:30 PM

Huntington, WV Epilepsy Support Group: Cabell Huntington Hospital, Room G403, near the Atrium Entrance. (1340 Hal Greer Blvd., Huntington, WV 25701)

September 24, 2013; 6:30-8:00 PM

Columbus Parent Support Group and TASSELS

(Teens and Students with Seizures/Epilepsy Living Socially): Riverside Health Center

October 2, 2013; 6:15-8:00 PM

Columbus Adult Support Group

October 4-6, 2013

Fall Camp Session of Camp Flame Catcher

October 8, 2013; 6:00-7:30 PM

Clinton County Epilepsy Support Group

*****October 9, 2013; 5:30-7:00 PM*****

Warren County Epilepsy Support Group, *****New Location*****
Kidd Coffee (653 Reading Rd., Mason, OH 45040)

October 16, 2013; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

October 16, 2013; 6:15-8:00 PM

Columbus Adult Support Group

October 17, 2013; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

October 23, 2013; 9:00 AM-12:30 PM

Seminar "Utilizing Cognitive Behavioral Therapy to Help Clients Improve Symptom Management": The Health Foundation of Greater Cincinnati; \$50

October 29, 2013; 5:30 PM

Huntington, WV Epilepsy Support Group

October 29, 2013; 6:30-8:00 PM

Columbus Parent Support Group and TASSELS

November 3, 2013; 8:00 AM

Mason Half Marathon; Mason High School

November 6, 2013; 6:15-8:00 PM

Columbus Adult Support Group

November 8, 2013

Seize Hope Gala

November 9, 2013

Living Well With Epilepsy Symposium

November 12, 2013; 6:00-7:30 PM

Clinton County Epilepsy Support Group

November 13, 2013; 5:30-7:00 PM

Warren County Epilepsy Support Group

November 20, 2013; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

November 20, 2013; 6:15-8:00 PM

Columbus Adult Support Group

November 21, 2013; 9:00 AM-12:30 PM

Seminar "Cognitive Behavioral Therapy Applications to Diverse Problems (Alcohol and Drug Abuse, Insomnia, Depression)": The Health Foundation of Greater Cincinnati; \$50

November 21, 2013; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

November 26, 2013; 5:30 PM

Huntington, WV Support Group

November 26, 2013; 6:30-8:00 PM

Columbus Parent Support Group and TASSELS

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

Highlights from the Hill

... the latest in advocacy news

In June of 2013, the Epilepsy Foundation of Greater Cincinnati and Columbus took part in a Pharmacy and Therapeutics (P & T) Committee Meeting at the Ohio State Capitol, to express concern on behalf of those affected by epilepsy with the proposed changes to Ohio's Medicaid formulary for anticonvulsant drugs in the drug class Central Nervous System (CNS) Agents: Anticonvulsants. Specifically, that the currently considered "preferred drugs" for this program would cease to be protected resulting in the possibility of people whose seizures are currently under control to be required to change medications and fail one, two, or even three medication before going to the medication of their doctor's choosing. We urged the state to continue these protections for people with epilepsy.

The ruling of the Committee was not favorable. Drug formularies and related policies that require people with epilepsy to "fail first" or worse yet, fail two, three or more times before a drug that has been recommended by a physician will be made available are, in our opinion, morally wrong and ineffective in controlling costs. People who have intractable epilepsy – seizures that cannot be controlled using medications available to the person – are placed at a dangerous disadvantage when they are not provided with access to all possible treatments. When people with epilepsy continue to have seizures despite treatment, they are most often also being treated in emergency room departments, making additional visits to their physician's offices and undergoing far more lab tests than a person with epilepsy who has achieved seizure control.

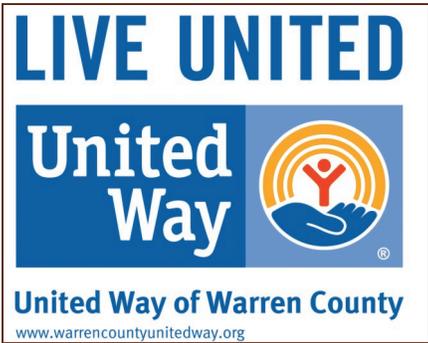
Although proposed changes include language to exempt people with epilepsy who have a claim for a non-preferred drug in the previous 120 days, as well as people with epilepsy who have taken the drug in the previous 120 days but do not have claims history, we remain concerned about the impact that new barriers to adequate treatment will have on people with epilepsy. Changing the preferred drug formulary could result in harmful changes to patient therapies mid-stream. While an automated prior authorization process may alleviate access challenges for people with epilepsy currently on a non-preferred drug, people with epilepsy without a history beyond 120 days would still need to secure prior authorization. Moreover, if the person with epilepsy with an established prior authorization were to require a reevaluation of their treatment, they may need to meet the onerous criteria of failing on two preferred drugs, like all new people with epilepsy.

The next P&T Committee Meeting is in October and we will be there to advocate for your rights!

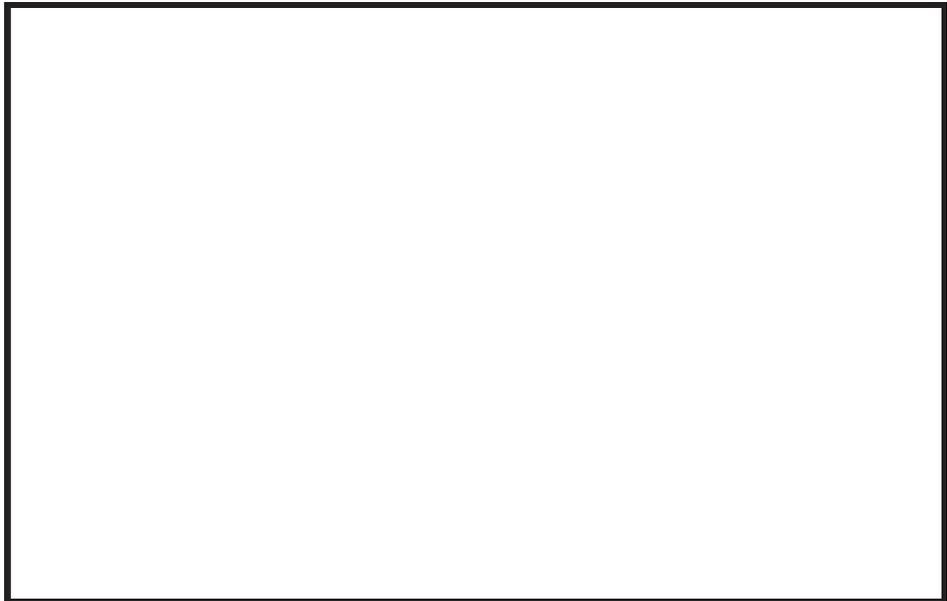


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Did you know that the Epilepsy Foundation offers FREE support at your child's IEP meeting? Call if you would like us to attend your next meeting with you.



MUD Volleyball...A GREAT Success!

We had great time at our annual MUD Volleyball Tournament on July 27! Thank you to all the teams who participated as well as our sponsors and volunteers for making the day a great success! Like our Facebook Page to see all the action and stay tuned for information on our 2014 Tournament!

Thank You Again to Our Sponsors!



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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