

# The Update

2014, Volume I

**Inside this issue:**

Greetings	2
Board of Directors	2
Foundation Grants	2
Taylor Huth Scholarship	3
Le Veque Tower	3
Mason Half Wrap Up	3
Kids! Speak Up!	4
Make A Wish	4
Camp Flame Catcher	4
Hope for Haiti	5
Vocational Training	5
Highlights from the Hill	6
FORE!	6
Calendar of Events	7
Buying a New Car?	8

Please consider joining us for two family-friendly fundraisers that are right around the corner:

## Stroll for Epilepsy

A Family Friendly Walk

On Saturday, January 25, we will be hosting our annual Stroll for Epilepsy at Polaris Fashion Place Mall in Columbus, Ohio. This event gives participants the opportunity to visit various "Treasure Hunt" stops throughout the mall to learn about epilepsy and have a chance to win \$500 in Polaris gift cards. Participants will also be able to enjoy live entertainment, a silent auction and much more in the food court area at Polaris.



**Emerald  
MILES**  
5K RUN/WALK 3.22.14  
IN LOVING MEMORY OF DENNIS STEMLER

ON SATURDAY, MARCH 22, WE WILL BE HOSTING THE 14<sup>TH</sup> ANNUAL EMERALD MILES 5K RUN / WALK AT NEWPORT ON THE LEVEE IN NORTHERN KENTUCKY. PARTICIPANTS WILL ENJOY THE SCENIC WATERFRONT COURSE THAT TAKES YOU OVER TWO BRIDGES, THROUGH SAWYER POINT AND ALONG THE OHIO RIVER. AFTER THE RUN/WALK EVERYONE IS WELCOME TO GATHER INSIDE THE LEVEE FOR FOOD, DRINKS, MUSIC AND AWARDS.

To register for both of these events go to [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org) and either print out a form and mail in or register online. Both events give you the opportunity to set up a team and email your team page to family and friends encouraging them to join. This valuable tool helps us raise much needed funds to support our many programs.

## We're Going Green!

In 2014, the Epilepsy Foundation of Greater Cincinnati and Columbus will continue to produce and distribute The Update via email and social media as well as making the publication available on our website at [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org). However, in an effort to save costs, we will be phasing out the printed version except for distribution in healthcare offices and for those who wish to receive one in the mail. If you would like to continue or begin to receive a hard copy of the newsletter we need to hear from you. Please let us know by March 1, 2014, so your distribution will not be interrupted. Please call us (877) 804-2241. We thank you for your continued support and understanding!

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.

*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, Alyssa Brown, 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, Erik  
Rickard, Matt Salyers, Chad Schaefer, Dr.  
Bassel Shneker, Nicole Stonitsch

# Greetings

A few weeks ago I had the occasion to run into a long time friend of the Foundation while giving blood. Geno is a gentleman in all aspects of the word and has been attending our Support Group for quite a while. As we were chatting, Geno shared that the holidays seemed like the perfect time to give blood as he believes we all need to give back. He then went on to tell me how ironic it is that his blood type is "B-Positive", which is also his motto through life! If you know Geno, you would realize how true this is. Despite seizures that keep him from driving and make it difficult to find work, Geno always dresses sharply, has a positive word for everyone he meets, and is constantly giving back as he helps with his aging mother and others around him. Geno's blood type and his attitude towards life is a great New Year's resolution for all of us. Whatever challenges we face, we need to B-Positive and work to make the world a better place.

Thanks to the many donors over the holiday season who responded so positively to our Annual Appeal. These extra funds will help us to continue to provide unduplicated services to the community. I encourage you to join us at our upcoming Stroll for Epilepsy in Columbus and Emerald Miles in Cincinnati. These fundraisers are essential to our agency as they provide us with the necessary funds to provide free services. And finally, on behalf of all of us at the Epilepsy Foundation, we hope you have a prosperous and seizure free year!

Mark Findley

Assistant Executive Director



Like us on Facebook for the latest updates!



Follow us on Twitter!

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. 2013 Grants that were received and the programs they were designated to:

**Camp Flame Catcher:**

Louis & Melba Schott Foundation... \$10,000  
Marge & Charles J. Schott Foundation... \$5,000  
Greater Cincinnati Foundation Summertime Kids Grant... \$1,000

**Residential Group Home Improvements:**

The Sutphin Family Foundation... \$15,000

**Counseling Program:**

FOCUS Pilot Grant... \$7,500  
E-Studio Art Therapy Lundbeck... \$10,000  
W. H. Albers Foundation... \$1,500

**Community Education Program:**

Epilepsy Foundation of America, "African American & Hispanic Outreach" ... \$10,000  
Epilepsy Foundation of America, "Asian American Outreach"... \$16,000  
Epilepsy Foundation of America, "Peer Youth Education"... \$2,500  
Epilepsy Foundation of America, "School Nurse Training"... \$16,000  
Epilepsy Foundation of America, "Seniors and Seizures Training"... \$4,000

# Thank you!

**ARE YOU HEADING TO COLLEGE IN THE FALL?**

**Do you have epilepsy?**

**If so, be sure to apply for the Epilepsy Foundation of Greater Cincinnati and Columbus' Taylor Huth Memorial Scholarship. You can also apply if you are presently enrolled in college. Details can be found on our website. Please note the deadline for applications is February 28, 2014.**



*The Lincoln LeVeque Tower in downtown Columbus Ohio, lit up in purple through November, in recognition of Epilepsy Awareness Month, thanks to the support of Ohio Health, Nationwide Children's, and OSU Medical Center.*



**Thanks for coming out and making our Mason Half Marathon a great success in 2013!**

**Special thanks to our gracious sponsors!**



*The Sibsy Cline Group*

# Kids! SPEAK UP!



**WASHINGTON DC OR BUST! WE ARE HAPPY TO ANNOUNCE THAT TWO YOUNG LADIES, ONE FROM CINCINNATI AND ONE FROM COLUMBUS, HAVE BEEN CHOSEN BY THE NATIONAL EPILEPSY FOUNDATION TO ATTEND THE Kids! Speak Up / Public Policy INSTITUTE MARCH 23-25, 2014.**

**CATHERINE REDDEN, A SENIOR AT ST URSULA HIGH SCHOOL IN CINCINNATI, AND MEREDITH HANS, IN 8<sup>TH</sup> GRADE AT BLESSED SACRAMENT IN NEWARK, OHIO, WILL BE ATTENDING THE 2014 EVENT TO LEARN ABOUT ADVOCATING FOR PEOPLE AFFECTED BY EPILEPSY FOLLOWED BY VISITS WITH OUR ELECTED OFFICIALS TO SHARE WITH THEM THE NEEDS OF PEOPLE WITH SEIZURES. WE ARE HOPEFUL THESE CONGRESSIONAL MEETINGS WILL LEAD TO GREATER FUNDING FOR EPILEPSY RESEARCH AND ULTIMATELY A CURE! GOOD LUCK CATHERINE AND MEREDITH!**

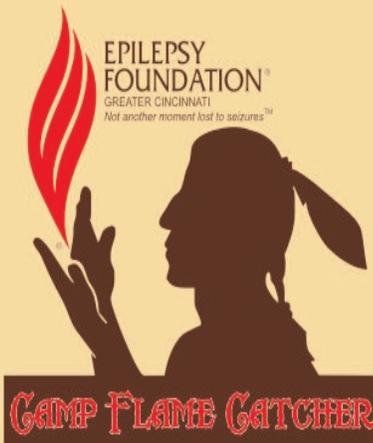
## Make A Wish



*Recently we were contacted by the Make A Wish Foundation to let us know they are granting wishes for kids who have intractable or difficult to control seizures. They realize the profound effect that seizures can have on a child and their family. If you would like your child to be considered for Make A Wish contact them at:*

*(877) 206-9474 (x3736) or visit:*

*[www.oki.wish.org](http://www.oki.wish.org)*



### ***DON'T FORGET ABOUT OUR AWESOME CAMP FLAME CATCHER!***

March 28-30, 2014  
Spring Camp

July 13-17, 2014  
Summer Camp

October 3-5, 2014  
Fall Camp

We are looking forward to another great year of camp for kids with epilepsy and we hope your son or daughter will consider joining us for the fun. The dates of our overnight camp have been confirmed and we are working to firm up the dates for our day camp. Both camps offer many chances for fun and fellowship, as well as opportunities to learn valuable skills to help campers overcome the many challenges which seizures may present. If you are interested in attending camp, email Mark Findley at:

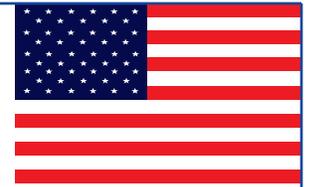
[mfindley@epilepsy-ohio.org](mailto:mfindley@epilepsy-ohio.org) or call 877-804-2241.

Camp for Champs— Day camp in Columbus: Dates to be determined.

For more information, visit us at <http://www.epilepsy-ohio.org/programs/camp-flame-catcher/camp-flame-catcher/>



# Hope for Haiti



**A team of experts in the field of neurology from Cincinnati Children’s Hospital Medical Center are not only making a huge impact on the lives of children with seizures in Cincinnati, but they have also been providing hope for children with seizures in Haiti. Gail McMonigle, a nurse in the Neurology Department recently made her 22<sup>nd</sup> trip to Miriam Center, a special needs orphanage in Haiti where 49 children live. Thanks to the care of Dr. David N. Franz, Carol Stone, RN, Cornelia Gonsalves, CNP and Gail, these children from the orphanage and 109 children in the outpatient program have been receiving the quality medical attention they need to control their seizures. They provide the children with medications and treatments that are otherwise not available in Haiti, and offer them hope for a seizure free life. Dr. Franz and his team travel to Haiti three times a year to check on their patients. As Gail McMonigle shares, “the response of the patients to good medical care is amazing. It has been wonderful to work with the Haitian staff as they learn new ways to care for the children. The love that is shared and developed between these kids is contagious.”**

**In February the team will again be packing their bags for another trip to Haiti. If you would like to learn more about this great work, google “Miriam Center in Haiti,” or contact them at: [www.miriam.center.medical@gmail.com](mailto:www.miriam.center.medical@gmail.com).**



*Carol & Dr. Franz*



*Cornelia with a new friend*



## Special Needs Vocational Training

Kimberly Buechner Fouse and sister Julie Bodette Verhelst, through their company, All Things Alpaca, LLC, provide employment to individuals with developmental disabilities who might otherwise have a difficult time finding a job. All Things Alpaca, LLC works with clients of the Epilepsy Foundation of Greater Cincinnati and the Epilepsy Center of Northwest Ohio in their therapeutic day programs. Their signature product, the Alpaca Fleece-filled Bird Nesting Ball,™ provides the clients with a vocational activity that fosters fine motor skill



development, focus and attention, and creativity. Kimberly notes, “The clients work at a pace that is appropriate for their abilities. Staff provide supervision and assistance to ensure quality. All of our artisans are paid [per completed ball] as contractors. “The ball is interactive – the birds play with the fiber before flying off to build their nests. It is also a functional gift, and an exceptional nesting material for wild birds due to its natural properties.”



# Highlights from the Hill

... the latest in advocacy news

## CRPD Hearing Highlights Support for Ratification

The Senate Foreign Relations Committee held two hearings on the Convention on the Rights of Persons with Disabilities (CRPD), an international disabilities treaty modeled after the Americans with Disabilities Act. These hearings are a big step for moving the treaty towards ratification. Attendance by supporters of ratification was strong with overflow rooms set up for both hearings. Secretary John Kerry spoke at the second hearing and urged the committee to support the CRPD. Secretary Kerry noted that by ratifying the CRPD, the United States will have more leverage to influence other nations to improve the rights of those living with disabilities. Testimony by other witnesses highlighted the benefits of ratification and stressed the need for the United States to reclaim its position as a world leader for disability rights. We urge you to contact your Senators to support ratification of the CRPD at: <http://capwiz.com/efa/callalert/index.tt?alertid=62988666>

## Epilepsy Foundation Seeks Update to Medicare Guidelines for Prescription Drug Coverage

The Epilepsy Foundation submitted public comments to United States Pharmacopeia (USP), which proposed an update to the Medicare Model Guidelines. USP is charged by Congress with maintaining the Medicare Model Guidelines that guide formulary coverage in Medicare Part D plans, which provide access to prescription drugs for Medicare beneficiaries. Part D plans must cover at least two drugs in each USP class. The Epilepsy Foundation asked USP to update the current classes under the Anticonvulsant category to reflect anti-epilepsy drugs' methods of action. Updates to the USP classes within the Anticonvulsant category would improve access to prescription medications to Medicare beneficiaries living with epilepsy by requiring Medicare Part D plans to cover a greater number of anti-epilepsy drugs. To read the letter, go to: <http://www.epilepsyfoundation.org/getinvolved/advocacy/positionstatements/upload/EF-Letter-to-USP-on-MMG-v6-Final.pdf>

## Healthcare Reform Resources

The healthcare access page at the Epilepsy Foundation has updated to a new layout and with more resources to help you navigate the Marketplace. Most importantly, there is a checklist that you can fill out for each plan you are considering. It can be an important tool for working through the plans that are out there. The Access to Care & Treatment page can be located at: <http://www.epilepsyfoundation.org/getinvolved/advocacy/advocacypriorities/Healthcare.cfm>

**FORE!!**  
as

Although it is a bit cold for golf, we wanted to share the latest about our 2014 Taylor Huth Memorial Golf Tournament. This year we will be teeing off Saturday, June 14, 2014, at Elks Run Golf Course in Batavia, Ohio, at 9:00am. Elks Run is a beautiful Greg Norman Course Design that has been Ranked #10 Best of Ohio. Do not delay in registering this event is sure to sell out. Go to [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org) for registration details.



**January 25, 2014 8:30 AM– 11:30 AM**

Stroll for Epilepsy  
Polaris Fashion Place 1500 Polaris Parkway  
Columbus, OH 43240

**January 30, 2014**

Seminar “Methods and Models in Practice: A Creative Approach”: The Health Foundation of Greater Cincinnati; \$50

**February 05, 2014 6:15-8 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

**February 11, 2014 6-7:30 PM**

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

**February 12, 2014 5:30-7 PM**

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

**February 19, 2014 6-7:30 PM**

Northern Kentucky Epilepsy Support Group: St. Elizabeth-Florence, Emergency Department Conference Room (lower level) (4900 Houston Rd., Florence, KY 41042) \*3rd Wednesday

**February 19, 2014 6-8 PM**

Cyberonics “Epilepsy + VNS”(Bing Cancer Center at Riverside Methodist Hospital, (500 Thomas Ln., Columbus, OH 43215). Park in the purple parking garage!

**February 20, 2014 6-7:30 PM**

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

**February 25, 2014 6:30-8**

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

**February 27, 2014**

Seminar “The Physical and Psychosocial Effects of Hearing and Balance Disorders in the Elderly: What You Should Know”: The Health Foundation of Greater Cincinnati; \$50

**March 05, 2014 6:15-8 PM**

Columbus Adult Support Group

**March 06, 2014**

Seminar “Emotional Intelligence”: The Health Foundation of Greater Cincinnati; \$50

**March 11, 2014 6-7:30 PM**

Clinton County Support Group

**March 12, 2014 5:30-7 PM**

Warren County Support Group

**March 19, 2014 6– 7:30 PM**

Northern Kentucky Epilepsy Support Group

**March 19, 2014 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

**March 20, 2014**

Seminar “Nutritional Approaches to Manage Anxiety”: The Health Foundation of Greater Cincinnati; \$50

**March 20, 2014 6-7:30 PM**

Hamilton County Support Group

**March 25, 2014 6:30-8 PM**

Columbus Parent Support Group and Teen Support Group

**March 28-30, 2014**

Spring Camp Weekend

**April 02, 2014 6:15-8 PM**

Columbus Adult Support Group

**April 08, 2014 6-7:30 PM**

Clinton County Support Group

**April 09, 2014 5:30– 7 PM**

Warren County Support Group

**April 16, 2014 6-7:30 PM**

Northern Kentucky Epilepsy Support Group

**April 17, 2014 6-7:30 PM**

Hamilton County Support Group

**April 24, 2014**

Seminar “Understanding Substance Abuse and Helping Your Clients Cope”: The Health Foundation of Greater Cincinnati; \$50

**April 29, 2014 6:30-8 PM**

Columbus Parent Support Group and Teen Support Group

**May 07, 2014 6:15-8 PM**

Columbus Adult Support Group

**May 13, 2014 6-7:30 PM**

Clinton County Support Group

**May 14, 2014 5:30-7 PM**

Warren County Support Group

**May 15, 2014 6-7:30 PM**

Hamilton County Support Group

**May 21, 2014 6:00 PM**

Huntington, WV Support Group

**May 21, 2014 6-7:30 PM**

Northern Kentucky Epilepsy Support Group

**May 27, 2014 6:30-8 PM**

Columbus Parents Support Group and Teen Support Group

**May 29, 2014**

Seminar “Understanding the Role of Assistance and Therapy Animals in Society”: The Health Foundation of Greater Cincinnati; \$50

**June 04, 2014 6:15-8 PM**

Columbus Adult Support Group

**June 10, 2014 6-7:30 PM**

Clinton County Support Group

**June 11, 2014 5:30-7 PM**

Warren County Support Group

**June 14, 2014 9AM**

Taylor Huth Memorial Golf Tournament

**June 18, 2014 6-7:30 PM**

Northern Kentucky Epilepsy Support Group

**June 18, 2014 6:15-8 PM**

Columbus Adult Support Group

**June 19, 2014 6-7:30 PM**

Hamilton County Support Group

**June 24, 2014 6:30-8 PM**

Columbus Parents Support Group and TASSELS

**June 24, 2014 6:30-8 PM**

Columbus Support Group and Teens Support Group

**June 26, 2014**

Seminar: “Motivational Interviewing: Introduction and Basic Skills: Part 1”: The Health Foundation of Greater Cincinnati; \$50

**July 2, 2014 6:15-8 PM**

Columbus Adult Support Group

**July 8, 2014 6-7:30 PM**

Clinton County Support Group

**July 9, 2014 5:30-7 PM**

Warren County Support Group

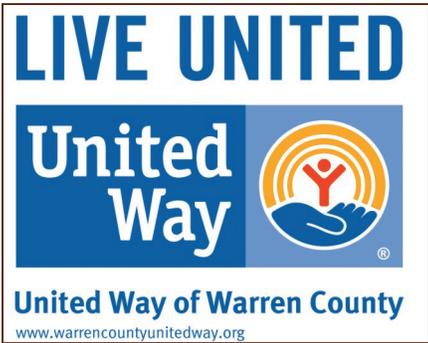
**July 13-17, 2014**

Summer Camp



Return Service Requested

Non-Profit Org.  
U.S. Postage  
PAID  
Permit No. 2532  
Cincinnati, OH



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.

**BUYING A NEW CAR? CONSIDER HELPING THE EPILEPSY FOUNDATION WHILE RECEIVING A TAX DEDUCTION**

**OUR GROUP HOMES FOR ADULTS WITH DISABILITIES ARE IN NEED OF GOOD USED CARS THAT THE STAFF CAN USE TO DRIVE OUR RESIDENTS TO DOCTOR APPOINTMENTS AND COMMUNITY OUTINGS. EACH OF OUR FOUR GROUP HOMES ALREADY HAS A LARGE ACCESSIBLE VAN THAT CAN CARRY EVERYONE IN THE HOME, BUT OFTEN WE NEED TO TRAVEL TO MULTIPLE LOCATIONS WITH ONLY A FEW PEOPLE AND COULD USE A SMALLER VEHICLE TO HELP ON COST SAVINGS. IF YOU WOULD BE INTERESTED IN DONATING YOUR GENTLY USED VEHICLE, PLEASE CALL US AT 877-804-2241. WE WOULD BE HAPPY TO PROVIDE YOU WITH A TAX DEDUCTION AND GIVE YOUR CAR A SECOND LIFE.**



**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](mailto:efgcc@epilepsy-ohio.org) ♦ Web address: [www.epilepsy-ohio.org](http://www.epilepsy-ohio.org)