

The Update

Our Camp Family Continues to Grow!

Over the years as we have hosted our camps for children with epilepsy, a common theme that has been shared by campers and counselors is that of FAMILY. The kids and counselors watch over and protect one another as family and share a special bond. They quickly support and help one another as an unexpected seizure comes on and they also support one another outside of camp via Facebook, phone conversations and occasional get togethers. This year we are happy to see our "camp family" grow as we welcome kids from the Columbus area and beyond.

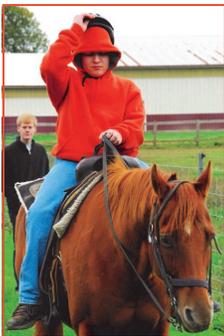
To help this growth go smoothly, we are welcoming many new families at our first annual Family Day Camp on June 1st. Here families will have the chance to enjoy camp with their child who has seizures

and other siblings. We want everyone to see and understand what a special place camp can be. They will hike, canoe, do crafts and much more; all the while meeting other families who share the common bond of epilepsy.

This spring our camp family took to the road as they attended the National Walk for Epilepsy in Washington DC. Thanks to D & L Leasing, we were able to take a vanload of kids and adults from camp to the National Walk. We visited such sites as the Capitol, Mt. Vernon and the Smithsonian's and joined over 5000 other people at the Walk as we let the nation know that we may have epilepsy, but epilepsy does not have us. Gary Campbell, from Columbus joined us in our van and performed at the Walk. He is a professional musician with epilepsy who

has the gift of sharing his story through song. He motivated, encouraged and helped us see that we all have many gifts to share.

If you would like to be a part of our "camp family" join us at camp as a camper or volunteer, or support us financially. Because of the generous support of our donors we have never had to turn a kid away from camp who cannot afford the cost. If you are one of these donors, we thank you for making camp possible. If you would like to become one of these donors we encourage you to contact our office. To see the impact you as a donor have on our kids, we encourage you to join us at camp for lunch or dinner. If you really want to see our camp family in action, join us for our annual camp dance as we joyfully dance to "We Are Family"!



Did you know that camp is offered in the spring, summer and fall?



Your support of \$350.00 will send a child to camp this summer.



Our teenagers from camp gather throughout the year for social activities that include sled riding, bowling, visiting the zoo and much more.



This summer we hope to welcome 80 kids and 35 counselors to our camp.



Camp gives kids a world of good! We create memories that last a lifetime!



2013, Volume II

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Like us on Facebook for the latest updates!

Greetings

Spring has arrived and with it new growth at the Epilepsy Foundation of Greater Cincinnati and Columbus (EFGCC). With the merger becoming effective January 1, 2013, there have been many changes at the Foundation.

We combined websites and launched the new EFGCC site at the end of March and kept the Epilepsy Foundation of Central Ohio (EFCO) web address (www.epilepsy-ohio.org) and email addresses (efgcc@epilepsy-ohio.org). We hope that you are enjoying the new look and all of the information that is on the website.

I would like to welcome Amy Merritt to the EFGCC staff. Amy is our new Director of Development and started her current position on April 2, 2013. Amy is in the process of evaluating and implementing our development plan and is very excited about the growth potential in our large service territory. Amy came to us with 9 years of experience in all facets of development. We are very excited to have Amy join our team!

I am so very pleased that we have joined together with EFCO to ensure that all those affected by epilepsy in the Columbus area are still able to receive the services that we provide to those in our service territory. Patty Trotta, our Director of Counseling, also writes and submits all of the grant proposals for EFGCC. Patty has already secured four new grants for new programs in the Central Ohio area. New grants help enhance the programs and services already provided. We look forward to the additional grant opportunities that Patty is seeking in the Greater Cincinnati and Columbus areas.

It has been and continues to be my pleasure in meeting the many people in the Central Ohio region who are dedicated to helping the Epilepsy Foundation in many different ways. Thank you for attending our events, volunteering in many different capacities and helping raise awareness about epilepsy and the EFGCC.

Please mark your calendars for our next two major events. Mud Volleyball will take place on Saturday, July 27 at Beulah Park in Grove City, OH. The Taylor Huth Golf Tournament is being held on Saturday, August 10 at Glenview Golf Course in Cincinnati. We look forward to seeing you there!

Thank you for your continued support.

Kathy Schrag, Executive 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.

Executive Director: Kathy Schrag

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Emerald Miles a Success Once Again!

Thank you to all those who supported our 2013 Emerald Miles 5K! More than 1,300 people participated in raising more than \$75,000 in support of the Epilepsy Foundation's various programs and services! We can't wait to do it again in March of 2014!

Special Thanks to our Sponsors: Cincinnati Bell Technology Solutions, Vantiv, Green BEAN Delivery, Newport on the Levee, B-105, Bob Roncker's Running Spot, Power Bar and Rewind 94.9!



Ask the Expert: Stress and Seizures
Michael Privitera, MD

Professor of Neurology; Director, Epilepsy Center, UC Neuroscience Institute



Many people believe that stress can trigger seizures. When we physicians at the University of Cincinnati Epilepsy Center surveyed our patients, more than 50 percent told us that stress can trigger their seizures. What is it about stress that can trigger seizures and what can people with epilepsy do to block this effect?

Stress triggers the body to release certain "stress hormones" that may help in the short run, for example, allowing you to run faster to escape danger, but these same hormones can lead to long term problems for the body and brain. Epilepsy specialists have often believed that stress caused sleep problems, and it was the poor sleep that triggered seizures, but new studies indicate that stress itself is the trigger. In a recent study from UC Epilepsy Center, we found that if a person with epilepsy has anxiety or depression, stress may be even more likely to trigger seizures. Both anxiety and depression are common in people with epilepsy, so we at the UC Epilepsy Center screen every patient at every visit for anxiety and depression.

It's clear that more research is needed. At the UC Epilepsy Center, we hope to answer questions about stress by conducting research with the help of the Charles L. Shor Foundation for Epilepsy Research. Our multicenter stress

management study aims to 1) better understand the possible link between stress and seizures; and 2) block the effects of stress on seizures. In our groundbreaking study patients use smart phones to keep daily diaries of how relaxed, nervous or anxious they feel each day. In addition patients learn a standard stress reduction technique that they perform 2-3 times per day. You can learn more by visiting our website www.ucepilepsycenter.com or contact Adrienne Fleck, RN Adrienne.fleck@uc.edu; 513-558-3726.

What can a person with epilepsy do to help block the harmful effect of stress on seizures? Here are a few tips:

- Try to identify factors in your life that you find stressful and try eliminating or reducing them.
- Ask your doctor to screen you for anxiety and depression and try counseling or medication if indicated.
- Try using stress reduction programs like yoga, exercise, meditation, or relaxation exercises.
- Take medication as prescribed, get adequate sleep and avoid alcohol to help control seizures.

Public Policy Institute & Kids Speak Up!



Owen Justice (7th from left) at the US Capitol

The Epilepsy Foundation's annual Public Policy Institute and Kids Speak Up! Conference was held April 21-23 in Washington, DC. Representatives from 28 states and 35 affiliates participated in the conference and Hill day, which brought together 154 teens, parents, affiliates and volunteers for a day and a half of learning

and advocacy training that culminated with a Hill day on April 23rd. Families and affiliates shared their personal stories and advocated in support of the Epilepsy Foundation's legislative goals through more than 140 Congressional meetings. This year we focused on federal epilepsy program funding, FDA epilepsy initiatives, and the Convention on the Rights of Persons with Disabilities. Read the entire 2013 legislative message at www.epilepsyfoundation.org/get_involved/advocacy/public/index.cfm

Ohio was proudly represented by Owen Justice, a 15 year old freshman advocate and his mother, Hillary. They,

along with Cincinnati and Columbus affiliate representatives, visited the respective offices of Ohio Senators Rob Portman and Sherrod Brown, and Congressmen John Boehner (OH 8th), David Joyce (OH 14th), and Brad Wenstrup (OH 2nd). Way to go, Owen!



Owen Justice (center) with Jill and Phil Catone, President and CEO of the Epilepsy Foundation

Point Pleasant, West Virginia's Inaugural Epilepsy Awareness Walk

The First Annual Epilepsy Awareness Walk was held April 6, 2013 on the shores of the Ohio River in beautiful Point Pleasant, West Virginia. Over \$4000 was raised through the efforts of Becky Hut and the local 4-H to be used to increase epilepsy awareness and education in the area. Ezekiel Hut led the crowd of 200+ in what is sure to be a growing annual event. Way to go, Point Pleasant!





Memorial Golf Tournament

TAYLOR HUTH SCHOLARSHIP FOUNDATION

Saturday, August 10, 2013; 1:30 PM
 Glenview Golf Course
 (10965 Springfield Pike, Cincinnati, OH 45246)

The Taylor Huth Memorial Golf tournament is an annual event that benefits the Epilepsy Foundation of Greater Cincinnati and Columbus and remembers the fun-loving spirit of Taylor Huth, who began having seizures in high school and died at an early age. In spite of being challenged with epilepsy, Taylor was a good-natured young man who would do anything for anyone and was committed to life.

Join Taylor's family and friends and special guest Mo Egger in helping those who have epilepsy continue to live each moment to the fullest and celebrate Taylor's joy for life, friends and golf.

SPACE IS LIMITED SO REGISTER TODAY!

Itinerary

12:30- 1:30 p.m. Registration
 1:30 pm Shot Gun Start
 6:30 pm Dinner, Raffle, Prizes, Awards

Cash prizes

Longest Drive-Male	\$100
Longest Drive-Female	\$100
Longest Drive over 50	\$100
Closest to the pin-Male	\$100
Closest to the pin-Female	\$100

Fee

\$100 per player includes: green fees, golf cart, shirt, dinner, drink tickets and much more!
 \$20.00 for dinner and drink tickets only

Sponsorship Opportunities Available

\$5,000 Title Sponsor
 \$3,000 Presenting Sponsor
 \$2,000 Tournament Sponsor
 \$1,500 Leadership Sponsor
 \$1,000 Community Sponsor
 \$300 Cart Sponsor
 \$200 Hole Sponsor

For more information on how you can partner with the Epilepsy Foundation in sponsoring this event, please call Amy Merritt at (513) 721-2905 or send an email to amerritt@epilepsy-ohio.org.



REGISTRATION INFORMATION

1. Name _____ Address _____ City _____ State _____ Zip _____ Phone(_____) _____ Shirt Size _____ Email _____	3. Name _____ Address _____ City _____ State _____ Zip _____ Phone(_____) _____ Shirt Size _____ Email _____
2. Name _____ Address _____ City _____ State _____ Zip _____ Phone(_____) _____ Shirt Size _____ Email _____	4. Name _____ Address _____ City _____ State _____ Zip _____ Phone(_____) _____ Shirt Size _____ Email _____

Make payment payable and mail to:
 Epilepsy Foundation of Greater Cincinnati and Columbus, Golf Tournament
 895 Central Ave., Suite 550
 Cincinnati, OH 45202

To register on-line, visit www.epilepsy-ohio.org



BENEFITTING THE Epilepsy Foundation of Greater Cincinnati and Columbus

Still Muddy After All These Years!!!

Join us, and more than 2,500 of our closest friends, for our 28th Annual MUD Volleyball Tournament on July 27, 2013 at Beulah Park! Whether you choose to play, volunteer or just come to cheer everyone on, there is something for everyone and you are sure to have a great time while truly impacting the lives of those affected with epilepsy!

Registration Information

Fees:

- \$300.00 for a team of 8- 12 players
~Once we receive your registration form, we will send you a participant waiver form and team roster
Each member of a team must submit a completed participant waiver form to be eligible to play!
- \$5.00 per vehicle to park—Carpooling is encouraged!
- Entrance fee for spectators is \$5.00; children under 6 are free.
- \$10.00 for event shirts up to size XL; \$12.00 for event shirts XXL-XXXL



Tournament Rules:

- 8 people (minimum of 3 females) on a court. Roster can include 4 subs, for a total of 12 on a team. Players must be 16 years old. Refs must be 18 years old.
- Morning pool play determines standings; all teams play afternoon championship round(s).
- All participants MUST wear shoes. It is advisable to duct tape shoes to your feet.

JOIN US AT OUR PRE-REGISTRATION EVENTS!!!

<p>Tuesday, July 23 The VolleyPark and Izze's Barefoot Bar 5501 Sandalwood Boulevard Columbus, OH 43212 5:30 – 7:30 p.m.</p>	<p>Wednesday, July 24 Red Rock Grille & Pub 6959 East Broad Street Columbus, OH 43213 5:30 – 7:30 p.m.</p>	<p>Thursday, July 25 Roosters Restaurant 1650 Stringtown Road Grove City, OH 43123 5:30 – 7:30 p.m.</p>
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VOLUNTEER OPPORTUNITIES

Volunteers are always needed. We have many positions available including: set-up, concessions, beer service, ticket sales, registration, clean-up, parking, tear-down and more. All volunteers get a free 2013 Mud Volleyball t-shirt.

Mud Volleyball Team Registration Form

Registrations must be post marked on or before July 22, 2013 ~ Each team requires a \$300.00 registration fee.

Team Name: _____ Captain's Name: _____

Phone: _____ E-mail: _____

Address: _____ City, State, Zip: _____

I would like to order t-shirts: (Please write in the quantity next to the size. T-shirts are \$10 each, Adult 2XL & 3XL are \$12 each.)

___YS ___YM ___YL ___YXL ___S ___M ___L ___XL ___XXL ___XXXL

Do you want to order spectator tickets at \$5.00 each? If yes, how many? _____ **Total Owed:** _____

Mail check payable to: Epilepsy Foundation of Greater Cincinnati & Columbus; 895 Central Ave., Ste. 550; Cincinnati, OH 45202.

Register online at: www.epilepsy-ohio.org/events

To sign-up to volunteer or for additional information please contact Amy Merritt

Phone: (513) 721-2905 Toll free: 877-804-2241 Email: amerritt@epilepsy-ohio.org.

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

Want to Improve Something in Your Life Affected by Epilepsy?

Consider participating in a research study sponsored by the researchers at the University of Michigan to test the effectiveness of a self-management program for adults with epilepsy, called *FOCUS on Epilepsy*.

This study will provide:

- » The latest research findings on quality of life and epilepsy.
- » Tools and a simple step-wise way to tackle problems related to epilepsy.
- » One-on-one support in choosing and working on a problem that you select.
- » Time to share and socialize with other people living with epilepsy.

To Participate, You Must be an Adult Who:

- » Is at least 21 years old.
- » Has had a diagnosis of epilepsy for at least one year.
- » Is mentally able to participate.
- » Takes medicine for seizures at least daily.
- » Can find one close friend or family member to participate in the research program with you.

Participants completing the study and providing their feedback will receive a gift card worth \$40.

For More Information Contact:
Patty Trotta, Director of Counseling
(513) 721-2905 or (877) 804-2241
ptrotta@epilepsy-ohio.org
www.epilepsy-ohio.org



Viva Las Vino



...great wines. great company.
great cause.

Thank you to all those who joined us on May 4, 2013 at our annual Viva Las Vino Wine Tasting Event! The evening was full of great wines and food, lots of fun with the prize wheel and auction items and concluded

with announcing the winner of the Napa Dreams Raffle! Be sure to Save-the-Date for our 2014 event on May 2!

Special Thanks to our Sponsors: AEP, Fifth Third Bank, The Ohio State University and Nationwide Children's Hospital.



Highlights from the Hill

... the latest in advocacy news

The Epilepsy Foundation of Cincinnati and Columbus is presently engaged with the State of Ohio in continuing certain protections for patients with epilepsy. Of specific concern is the proposed changes to Ohio's Medicaid formulary for anticonvulsant drugs in the drug class Central Nervous System (CNS) Agents: Anticonvulsants, that are currently considered "preferred drugs" for this program. These proposed changes and related policies would require patients to "fail first" or yet, fail two, or three or more times before a drug that has been recommended by a physician will be made available. Although the proposed changes include language to exempt patients who have a claim for a non-preferred drug in the previous 120 days, as well as patients who have taken the drug in the previous 120 days but do not have a claims history, we remain concerned about the impact that new barriers to adequate treatment will have on patients. Changing the preferred drug formulary could result in harmful changes to patient therapies mid-stream. These changes have the very real possibility in the interruption of a person's hard-fought independencies in driving/transportation, living, education, relationships, employment/income and others. As we believe the proposed changes to Ohio's Medicaid formulary as it relates to AEDs is unnecessary and may not be in the best interest of patients suffering from epilepsy, we have asked Ohio's Office of Medical Assistance, Pharmacy and Therapeutics Committee to reject any changes to Ohio's Medicaid preferred drug formulary for AEDs. For more information, please contact us at (877) 804-2241.

June 1, 2013

Family Camp Day; Camp Kern

June 5, 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!

June 11, 2013; 6:00-7:30 PM

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

June 12, 2013; 5:30-7:00 PM

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

June 15, 2013

Scoutin' for Epilepsy; Mill Dam Corner Grille in Hebron OH

June 19, 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)

June 19, 2013; 6:30-8:00 PM

Columbus Adult Support Group

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

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

June 25, 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)

June 25, 2013; 6:30-8:00 PM

Columbus Parent Support Group and TASSELS (Teens and Students with Seizures/Epilepsy Living Socially): Riverside Health Center (500 Thomas Ln., Columbus, OH 43215). Park in the purple parking garage!

June 27, 2013; 9:00 AM-12:30 PM

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

July 3, 2013; 6:15-8:00 PM

Columbus Adult Support Group

July 9, 2013; 6:00-7:30 PM

Clinton County Epilepsy Support Group

July 10, 2013; 5:30-7:00 PM

Warren County Epilepsy Support Group

July 14-18, 2013

Summer session of Camp Flame Catcher

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

Northern Kentucky Epilepsy Support Group

July 17, 2013; 6:15-8:00 PM

Columbus Adult Support Group

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

Hamilton County Epilepsy Support Group

July 27, 2013

Mud Volleyball Tournament; Beulah Park

July 30, 2013; 5:30 PM

Huntington, WV Epilepsy Support Group

July 30, 2013; 6:30-8:00 PM

Columbus Parent Support Group and TASSELS

August 7, 2013; 6:15-8:00 PM

Columbus Adult Support Group

August 10, 2013

Taylor Huth Memorial Golf Tournament

August 13, 2013; 6:00-7:30 PM

Clinton County Epilepsy Support Group

August 14, 2013; 5:30-7:00 PM

Warren County Epilepsy Support Group

August 15, 2013; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

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

Northern Kentucky Epilepsy Support Group

August 21, 2013; 6:15-8:00 PM

Columbus Adult Support Group

August 27, 2013; 5:30 PM

Huntington, WV Support Group

August 27, 2013; 6:30-8:00 PM

Columbus Parent Support Group and TASSELS



WE WILL ALWAYS REMEMBER

We are sad to report the passing of a beloved member of the Epilepsy Foundation Family. Anna Sue Boyles was born July 15th, 1940 and began her transition to life in heaven on May 10th, 2013. Anna has resided with the Foundation for over 22 years. During this time we were blessed to experience her sassy spirit and vibrant personality. She enjoyed keeping up with the latest Hollywood gossip, working to earn a paycheck, and good, hot food especially hamburgers. Her presence will be greatly missed, but our memories of her will last forever.

WELCOME

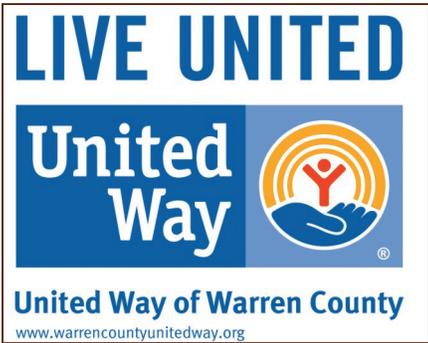
Huntington West Virginia Welcomes New Neurologist

We are happy to announce that Dr. Samrina Hanif, MD has begun seeing patients with epilepsy at Cabell-Huntington Hospital in WV. Dr. Hanif is a fellowship-trained neurologist who specializes in the diagnosis and treatment of epilepsy. She has a special interest in refractory epilepsy and treating children with autism and epilepsy. Dr. Hanif will be attending our June Epilepsy Support Group meeting in Huntington on June 25th at 4:00 p.m. If you would like more information about this program please call 877-804-2241.

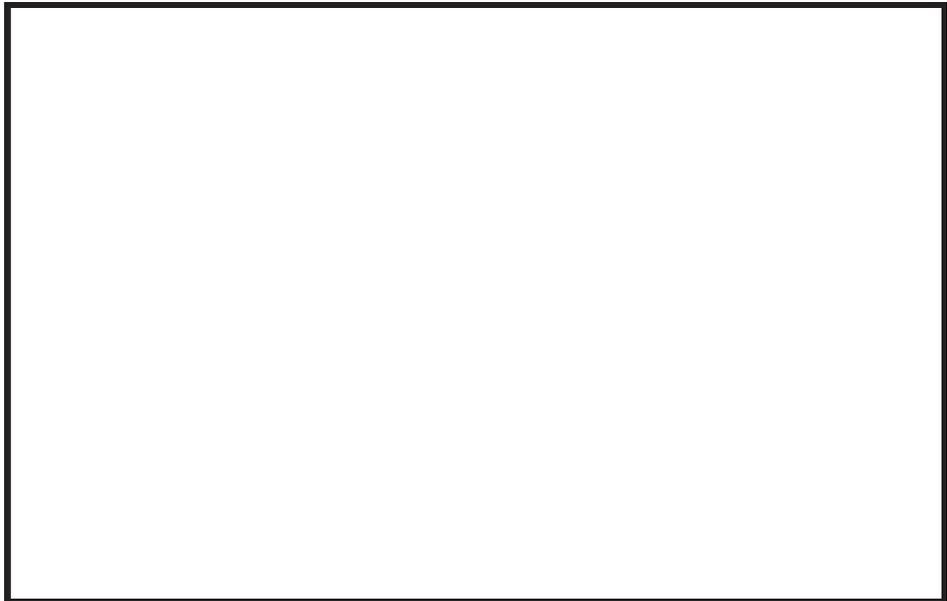


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Cincinnati, OH



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.



Tri-Valley Ruri-Teen Club Helps out Camp!

Recently, Karen Brown, Social Worker with the Epilepsy Foundation of Greater Cincinnati and Columbus, had the opportunity to speak to a group of students at Tri-Valley High School who are members of the Tri-Valley Ruri-Teen Club. This group is a community service organization and has been in existence since 1996. Each year, this group averages over 4,000 volunteer hours and donates over \$6,000 to the community. Karen was able to educate the group about epilepsy and seizure first aid.

During the presentation, Karen also informed the group about the many services we provide and about our camping programs. The students were very excited to hear about our camp programs and truly felt that this was an area that they could help some children/teens have the ability to attend camp.



The Tri-Valley Ruri-Teen group applied to the Muskingum County Youth Foundation for a \$200 grant to assist with our camps. When they received their grant award notification, they were actually awarded \$625!

We are very thankful and truly appreciate the Tri-Valley Ruri-Teen Club's support of the Epilepsy Foundation and our camps. Thank you so much for giving your time and talents to help our camping programs!

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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