

The Update

2011, Volume 3

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Tailgating for Epilepsy

Typically people are not tailgating before football games to raise awareness about epilepsy, but an exception will be made on October 29th. To further promote services in West Virginia, and make people better aware of epilepsy in their communities, we will be joining forces with the Epilepsy Center at Cabell Huntington Hospital to do just that. Prior to the Marshall University -vs.- University of Alabama football game, we will be gathered in the parking lot to hand out purple awareness bracelets and pom-poms, letting people know about epilepsy. We will then take our cause inside the stadium to raise awareness through scoreboard advertisements and a special half-time presentation.

We are excited about this project and thank Cabell Huntington Hospital for partnering with us on this event.



Mason Half Marathon

Join us for the 2nd Annual Mason Half Marathon!

Come out on Sunday, November 6, 2011, for the Mason Half Marathon, 5K Run or 5K Walk to support those in our community who are affected by epilepsy.



Fact: Anyone with a brain can have a seizure

Fact: More than 2% of today's population is affected by epilepsy

Fact: Epilepsy is the 3rd most common neurological disorder behind Alzheimer's disease and stroke

Fact: Epilepsy is equal in prevalence to Cerebral Palsy, Multiple Sclerosis and Parkinson's Disease combined



November is Epilepsy Awareness Month

Take our interactive quiz and *Get Seizure Smart!*

The Epilepsy Foundation is asking everyone to Get Seizure Smart! By taking and distributing the Get Seizure Smart quiz, you are helping us reach our goal of getting 5 million Americans seizure smart in 2011.

You can take the quiz at: <http://www.epilepsyfoundation.org/neam/quiz/>



Greetings!

The busy summer has come to an end and there have been many different things going on at the Epilepsy Foundation.

We were awarded an Employment Grant and a Veteran's Grant by the Epilepsy Foundation of America. This summer we offered several different training sessions and had a wonderful turnout at each. "Employment and Epilepsy" is such an important topic as there are many different issues that can arise for the employee with epilepsy.

Our Veteran's Program was a two-day event in which we first participated in a motorcycle ride and an after-party; and the next day, we offered an awareness program to the Veterans that started with a nice dinner followed by an informative presentation.

We had two new fundraisers this summer. The first was the Cincy Classic WIFFLE® Ball Tournament. This was a fun, hot event that brought 35 teams together for a great day of wiffle ball. We would like to thank Rob Stewart and Evan Dearwester for approaching us with the idea and helping organize and put on this event.

The Taylor Huth Memorial Golf Tournament was a great success as we had 144 golfers attend the event at Legendary Run Golf Course. The tournament was started by Matt Salyers and Jackie Huth. This year we joined together and had a wonderful event! It was an absolutely beautiful day as we worked to raise money to offer college scholarships and help support the vital programs that we offer to the community.

The Mason Half Marathon will be the final event in 2011. November is Epilepsy Awareness month and this is the perfect time for people to come together and support epilepsy. Along with the half-marathon, the event also offers the 5K walk and run component, so everyone is able to participate at a level that is comfortable for themselves. Come join us for this great event!

Last, but certainly not least, Priscilla Thomas graciously came back to the Epilepsy Foundation as our Director of Residential Services. We are very pleased to have her back with the Epilepsy Foundation.

Kathy Schrag
Executive Director

Ask the Expert: Psychogenic Non-epileptic Seizures

David M. Ficker, MD

Director, Epilepsy Monitoring Unit, Cincinnati Epilepsy Center
University of Cincinnati Medical Center



David M. Ficker, MD

One of the greatest challenges in treating epilepsy is the many different types of seizures ranging from staring spells to convulsions. Because there are so many different seizure types a diagnosis of epilepsy can sometimes be difficult to make. One seizure type that is seen by epilepsy centers are psychogenic non-epileptic seizures. It is important to make this distinction because their treatment is much different than with epileptic seizures. Twenty to thirty percent of people seen at epilepsy centers may have psychogenic non-epileptic seizures. This diagnosis is considered when seizures do not respond to medication and the clinical description of seizures has unusual characteristics.

Psychogenic non-epileptic

seizures (also called pseudo seizures) are different from an epileptic seizure in that the clinical symptoms do not result from an abnormal electrical disturbance of the brain. In general, it is thought that underlying psychological distress results in the development of physical symptoms that resemble epileptic seizures. Like epileptic seizures, non-epileptic seizures occur spontaneously and are not under one's direct control (the patient is not "faking" the seizures). The diagnosis should only be made with video/EEG monitoring to determine whether there are EEG changes with the events. Non-epileptic seizures cannot be treated with seizure medications because the medications only prevent the abnormal electrical activity in the brain that

is seen with epileptic seizures. Treatment of psychogenic non-epileptic seizures is with psychotherapy, which is designed to determine the underlying stressors that cause the unconscious development of the physical symptoms.

Additional information can be found at these websites:

<http://www.epilepsy.com/node/996271>

<http://www.epilepsyfoundation.org/aboutepilepsy/seizures/Non-epileptic-seizures.cfm>



Local Companies Continue to Lend a Helping Hand

Every year we are blessed with companies who allow their employees time off of their regular jobs to do some upkeep, maintenance and improvements at our group homes in Clermont County. This year we have welcomed more companies to our door than ever before: Hydro Systems, OPW, Dover Corp. , ITW Air Management, Cincinnati Children's Hospital Medical Center, Fifth-Third Bank, Roberts Construction, and Macy's.

These companies have beautifully landscaped our homes, painted, built a basketball court and much, much more. We thank these companies and their employees for their generosity in sharing their time and talents with us and we look forward to continuing our relationship in the years to come.

If your company would like to organize an on-site volunteer effort, please contact us at (513)721-2905.



ITW Air Management

Gifts Come in All Sizes and Shapes



Breanna Plessinger

As a non-profit agency we rely heavily on the generosity of our donors. Recently, one of our gifts came in an odd size! The Plessinger Family, who are regulars at our camp, presented us with a custom-made cornhole set complete with our camp and agency logo on the boards and bags. This gift will get many hours of use at camp and various fundraisers. We thank the Plessinger's for this unique and fun gift!



If you have a "unique" item we could use to help us to better provide services in our various programs please give us a call. Now on our wish list is: a used car, lawn tractors, a trailer, gardening/farming equipment.



The Epilepsy Foundation is now selling 2012 Entertainment Books. These books are filled with hundreds of discounts and two-for-one offers at local restaurants, venues, stores, hotels and more. Purchase a book for just \$30 from our office (\$5 off the in-store price) and begin saving today!



Emerald Miles 5K Run/Walk



On March 10, 2012, we will be hosting our annual Emerald Miles 5K Run/Walk at Newport on the Levee. Our goal this year is to raise over \$100,000 and have over 2,000 participants in the event.

March 10, 2012, is a special day for people with epilepsy and those affected by epilepsy. It is our day to raise awareness about epilepsy by forming teams and having family, friends, neighbors and co-workers come walk, run and show their support for epilepsy.

It's time to come together and show the people of Cincinnati and Northern Kentucky that although epilepsy can affect anyone, epilepsy does not stand in the way of achieving great things!

Let's SEIZE HOPE and bring awareness to this important cause.

Weekend Adventure Club

Campers who have attended our camp for a number of years are often looking for ways to continue their friendships at home between the scheduled camp days. The Weekend Adventure Club has stepped in to fill this need with previous fall trips to Washington D.C., Cedar Point Amusement Park, The Rock 'n Roll Hall of Fame Museum and most recently, the world of the underground as they visited Mammoth Cave and the surrounding area. We would like to thank Mike Lykins at D & L Leasing for his untiring support of this program. If you

are interested in future trips and are a young adult (over 18 years of age) with epilepsy, call us at (513) 721-2905.



Washington D.C.



Rock 'n Roll Hall of Fame & Museum

1st Annual Cincinnati Classic WIFFLE® Ball Tournament

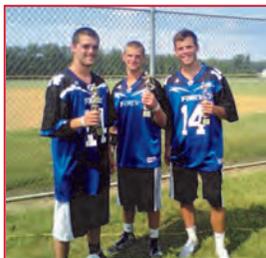
Held on Saturday, July 23, 2011

Thanks to everyone who came out in the heat to have some fun and make the 1st Annual Cincinnati Classic WIFFLE® Ball Tournament a success! We had a total of 35 teams compete for the title!

The proceeds from this event will benefit the numerous free programs and services offered by the Epilepsy Foundation of Greater Cincinnati.



Congratulations to our winners:



Adult Division Winners:
The Force



Home Run Champion:
Dan Niehaus



Youth Division Winners:
The Hurricanes



Memorial

Golf Tournament Benjamin Taylor Huth Memorial Golf Outing a Huge Success

TAYLOR HUTH SCHOLARSHIP FOUNDATION

2011 marks the first year that the Epilepsy Foundation partnered with the family and friends of Taylor Huth as they hosted their 3rd annual memorial golf outing. The outing was held at Legendary Run on August 27 and drew wide support from the community. Joe Stonitsch and his company, Dentsmart, impacted the event in many ways—they were our dinner sponsor, co-beverage sponsor (along with Hydro Systems and OPW) and his foursome won the tournament.

Behind them were 140 other golfers who came out to support the cause of funding the Benjamin Taylor Huth Scholarship Foundation for young adults with epilepsy who are pursuing a college education. We would like to thank Matt Salyers, Jackie Huth, Erik Shelton, Tim Huth and a host of volunteers who made this event possible. Thanks to our many supportive sponsors and participants—together we are empowering our youth for a brighter tomorrow!

Dinner Sponsor: Dentsmart (Dentsmart, Inc. & Dentsmart of Midwest, LLC-Joe Stonitsch)

Beverage Sponsors: Dentsmart, OPW Fueling Components (Erik Shelton), Hydro Systems (Jeff Rowe)

Hole-in-one Sponsor: David Taybi

Shirt Sponsors: Len Riegler Blacktop, Inc. (Ryan Riegler); Newman Tractor, LLC (Adam Brown); Legacy Financial Advisors (Brad Zapp); Miami Valley International Trucks, Inc. (Joe Heimbrock); Professional Sealants, Inc. (Joe Redman) & N-Stock Box, Inc. (Jed Brubaker)

Hole Sponsors: The Taybi Family; Len Riegler Blacktop, Inc.; Nancy Boosveld, Scentsy Wickless consultant; John Frey; Salcher Properties, LLC (Matt Salyers); Jackie Huth; The Epilepsy Center at UC Neuroscience Institute; Rick Friedman; Health Care Services (Chris Seger); Travelers Insurance (Bob Cook); Enquirer Media (Chad Schaefer); Polk Insight (Bob Sherman); Dave Von Derau and the Wright Patt Credit Union; Excellence by Nature Granite (Sara Hoff); DHT Property Services LLC, (Michael Frey) & TheraPilates Fitness (Sheri Burdick)



Please join us for the Mason Half Marathon on Sunday November 6!

Course: The race starts and finishes at Mason High School. Check out our website (www.masonhalf.com) for more details on the 5K and half-marathon courses.

Time: The race starts at 8:00 AM. Same day registration is from 6:30-7:30 AM.

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

Fees:

- **5K run/walk:** \$30.00 if postmarked by 10/31/11 or completed on-line by 11/3/11 at midnight; \$35.00 on race day (No guarantee of shirt); \$20.00 for children 12 and under
- **Half-Marathon:** \$55.00 if postmarked by 10/31/11 or completed on-line by 11/3/11 at midnight; \$60.00 on race day (No guarantee of shirt)

Pre-registration includes short sleeve t-shirt* for 5K races and technical shirt* for half-marathoners, awards, music 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 \$5.00 discount per person.

Early Packet Pick-Up: Beat the crowd the day of the event and pick up your shirt and race number early at Fleet Feet Sports (9525 Kenwood Rd., Cincinnati, OH 45242) on Saturday, November 5, from 10:00 AM-2:00 PM.

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

Refreshments: Enjoy a pancake breakfast, music & drinks after the race.

Register on-line: Go to www.masonhalf.com to register on-line.

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

Your participation in this event helps the Epilepsy Foundation provide valuable services to the community including: counseling, support groups, community education, group homes, youth camping program, day activity program and much more! To find out more about the agency, please visit: www.cincinnati-epilepsy.org

Sponsored by:



Mason Half-Marathon Pre-Registration
Must be postmarked by 10/31/11 for pre-registration

Send completed registration form & payment to:
 Epilepsy Foundation of Greater Cincinnati
 895 Central Avenue, Suite 550
 Cincinnati, OH 45202

Please type or print clearly and fill the form out completely. Thank you!

Name: _____

Age on day of race: _____ Gender: M ___ F ___

Address: _____

E-mail: _____

City, State & Zip: _____

Phone: _____

5K participants: T-shirt size: (Please circle one) Youth: M L Adult (Unisex): S M L XL XXL

Half-Marathon runners: Technical shirt size: (Please circle one) Youth: M L Adult: Men's: S M L XL XXL
Women's: S M L XL XXL

Category: 5K walk 5K run Half Marathon Registering with a team/company? Name: _____

Pricing: \$20 Youth (12 and under) pre-registration for 5K walk or 5K run (includes entry fee and short sleeve t-shirt)
 \$30 Adult pre-registration for the 5K walk or 5K run if postmarked by 10/31/11 (includes entry fee and short sleeve t-shirt)
 \$55 Adult pre-registration for the half-marathon if postmarked by 10/31/11 (includes entry fee and technical shirt)

WAIVER: In consideration of the acceptance of my entry, I hereby waive on behalf of my heirs, executors and assigns, all claims of any nature arising from my participation in the Mason Half Marathon, and do hereby release the Epilepsy Foundation of Greater Cincinnati, Steve Prescott, Mason City Schools, all sponsors, workers, officials and volunteers from any claim whatsoever arising from my participation in this event. I agree to abide by all the rules of participation, and acknowledge that the Race Committee may refuse or return my entry at its discretion. I understand the risks for such a run, and have trained adequately in preparation for the run. I HAVE NOTED ANY MEDICAL CONDITION on this entry form next to my signature. I will permit the use of my name and picture participating in this event for publicity.

Signature: _____ Date: _____ Parent/Guardian Signature (if under 18): _____

Be on the Lookout. . .

Annual Campaign Letters are being sent out in the month of November. We would greatly appreciate any support you can provide. Without the support our generous people like yourself, we would not be able to provide our quality services, such as our Counseling and Community Education Programs to people with epilepsy and their families free of charge. Any amount of generosity is fully appreciated.



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Highlights from the Hill:

Advocacy Update from the Epilepsy Foundation of America

House Resolution 298 aims to coordinate efforts within our government to get more information about epilepsy and what to do when someone has a seizure into the hands of people nationwide who live with, work with, teach or provide services to people with epilepsy—and it does not require any federal funding! To gain co-sponsors for this important resolution, the Epilepsy Foundation of America (EFA) is stressing two new outlets:

1. A “Letter to the Editor”, which can be sent to local media along with your personal story about why epilepsy awareness is important to you. This serves to educate the public while at the same time asking for support for House Resolution 298.
2. For students & families, a “sign-on” letter take to school and distribute to friends, teachers, principals to sign and send to your Member of Congress.

To find samples of both of these letters, visit: www.epilepsyfoundation.org and then follow the “get involved” and “advocacy” tabs.

Federal Funding for Epilepsy Research & Programs: For the upcoming 2012 Fiscal Year (FY), beginning 10/1/12, the EFA encourages Congress to continue programs that are important to ensuring the safety and health of people with epilepsy; we have supported maintaining funding for the CDC Epilepsy Program (\$7.9 million) and the Project Access Epilepsy Program at HRSA (\$3.7 million). There is good news from the Senate appropriations subcommittee -- the CDC Epilepsy Program and HRSA programs received level funding for FY 2012. However, the full Congress must pass the appropriations bill, and there is a possibility that all outstanding appropriations could be combined in one large continuing resolution (CR) for FY 2012. This could result in support for the level funding or some across the board cuts. A new continuing resolution (HR 2608) passed the House, but has dim prospects in the Senate. With few days remaining in the fiscal year, there is pressure on Congress to act before an anticipated early recess. The House spending bill would fund the government through 11/18/11. Whether through large CR or individual appropriations legislation, funding could be in danger for the next fiscal year (and that budget process will begin soon in early winter). The EFA's Government Affairs Department will continue to monitor this and work to support full funding of these important programs and research.

Super Committee & FY 2013 Budget: The "Joint Special Committee on Deficit Reduction" or "Super Committee" held its first meeting on 9/22/11. This committee is tasked with finding ways to reduce the deficit by \$1.5 trillion by 11/23/11, and is made up of 12 Members from both the Senate and the House (equal number of Republicans and Democrats). If the Super Committee or Congress fails to act by 12/23/11, there would be automatic across-the-board cuts, split 50-50 between defense and non-defense spending (including Medicare). Social Security and Medicaid would be excluded from the cuts. The EFA works to advocate for open dialogue on proposed policy changes and budget cuts, attention to the health care needs of special populations (epilepsy, etc.), and foresight into what a budget cut today will mean to health care costs tomorrow.

Combating Autism Reauthorization Act: Approximately 25% of individuals with autism develop epilepsy. This is why the EFA supports legislation to increase treatment and evidence-based interventions for individuals on the autism spectrum. The Combating Autism Reauthorization Act (S 1094/HR 2005) seeks to reauthorize a program that was signed into law and will expire if Congress does not act by 9/30/11. The legislation would reauthorize and allow programs to continue through 2014. The EFA supports this Act because it contains: (1) the surveillance and research program for autism spectrum disorder and other developmental disabilities; (2) the education, early detection, and intervention program for autism spectrum disorder and other developmental disabilities; and (3) the Interagency Autism Coordinating Committee. Congressional committees in the Senate and the House have approved the bill, now the full Congress must act.

Lifespan Respite: The EFA joined in support of the National Respite Coalition's statement to the Senate Health, Education, Labor, & Pensions Committee on the Lifespan Respite Program. Epilepsy Advocates have long advocated for this program that was authorized by Congress in 2006, though no funding was given until 2009. The program is authorized at \$94.8 million for FY 2011, but has never received more than \$2.5 million in any of the fiscal years 2009-2011. For FY 2012, the President has recommended \$10 million as part of the Administration's Caregiver Initiative.

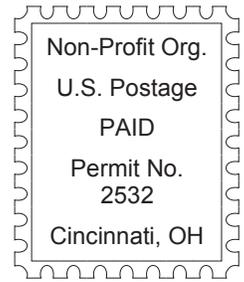
Health Care Reform: Recently a federal appeals court has issued conflicting decisions on health reform's constitutionality — one dismissing a challenge to the law and another opening the door to future challenges once the law takes effect. The issue of this and many other challenges is the individual mandate to purchase health insurance or face a tax burden (there are financial supports if affordable coverage is not available). Ultimately, the US Supreme Court is expected to decide the issue of the law's constitutionality; the only question now is whether this will happen next year or after the 2012 elections. You can follow issues related to health care reform implementation at: <http://www.healthcare.gov/>.

Visit the EFA's “Speak Up Speak Out” advocacy network for more information, to find the local contact information for your Senators and Representative, and to learn more about our advocacy efforts in Congress and in your state at: <http://capwiz.com/efa/home/>

Like us on [Facebook](#) for up-to-date Highlights from the Hill!



Return Service Requested



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.

The Update is a quarterly newsletter published by the Epilepsy Foundation of Greater Cincinnati. The Epilepsy Foundation of Greater Cincinnati is a United Way Agency founded in 1953 to assist people with epilepsy and their families in meeting their multiple health and social needs.

Executive Director: Kathy Schrag

Board of Directors

President: James Comodeca

Treasurer: Tom Lockwood

Secretary: Mark Calkin

Members at Large:

Peggy Clark, Jack Freyvogel, Dr. David Ficker, Dr. Diego Morita,
Dr. Michael Privitera, Dr. Marvin Rorick, Chad Schaefer, Erik Shelton

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

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