

**2010 Volume III**

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**Ask the Expert: A Search for Genetic Causes for Epilepsy**

**Tracy Glauser, MD**  
Director, Comprehensive Epilepsy Center  
Cincinnati Children's Hospital Medical Center



*Dr. Tracy Glauser*

**W**hen a person is diagnosed with epilepsy, many questions arise: Why did this happen to me or my child? Which treatment is the best for me or my child? Will any of my children or relatives also be affected with seizures?

Over the past 100 years, research has indicated that genetics plays a role in why some people develop epilepsy (while others do not) and why some people with epilepsy respond to medication while others are resistant. Genes are the packets of information passed from parents to child. It appears that epilepsy is a "complex" disorder where multiple genes are involved rather than a single gene.

In order to find the genes involved with epilepsy and people's response to medications, researchers from Cincinnati Children's Hospital Medical Center partnered with colleagues from around the world to create the Epilepsy Phenome Genome Project (EPGP, [www.epgp.org](http://www.epgp.org)). The study, funded by the National Institute of Neurological Disorders and Stroke, is collecting blood samples (for genetic studies) and detailed seizure histories on adults and children with specific types of epilepsy. This information will be used to identify the multiple genes that contribute to developing epilepsy and that affect people's response to seizure medications. The hope is that this information will ultimately reveal new insights and improve diagnosis and treatment.

Worldwide, the study team plans to enroll 1,500 people with epilepsy who also have a brother, sister,



parent, or child with epilepsy. The study is also enrolling 750 participants who have seizures due to infantile spasms, Lennox-Gastaut Syndrome, polymicrogyria, or periventricular heterotopia. For this second group of people, both biological parents (without epilepsy) are required to participate. Although the results of the study will apply to many different people with epilepsy, focusing this research effort on very specific types of epilepsy will allow the genetic analysis to be completed faster.

Participating in the study involves a blood draw and interviews. The interviews can be completed over the phone and through the mail, so participation does not require travel to one of the study centers. Numerous safeguards are in place to protect the privacy of participants, and the researchers will not share personal identifying information with anyone outside of their study center. Participants may receive a small compensation for their time.

*For more information, please contact Jennifer Cassarly, Division of Neurology at Cincinnati Children's Hospital Medical Center at (513) 803-1997.*

## Camp Flame Catcher: New Name, Same Great Program

Because of issues with copyright, we changed the name of our camp to Camp Flame Catcher. We hope this new name will inspire the youth to keep the flame of hope burning brightly as they tackle the challenges associated with seizures. In spite of the name change, the camp set a record for the number of campers served this year. In the spring we welcomed 41 campers. In the summer, the cabins were full with the shouts and laughter of 62 campers. Then in autumn, 34 campers enjoyed the beautiful fall weather. Additionally, 9 youth from camp attended the National Walk for Epilepsy in Washington DC. Aside from the number of kids served, a great time was had by all and we look forward to another exciting year of camp. The 2011 dates for Camp Flame Catcher are:

- March 27, National Walk for Epilepsy
- April 1-3, Spring Weekend Camp
- July 17-21, Summer Camp
- TBD, Fall Weekend Camp

For more information or to see pictures, go to [www.cincinnatiepilepsy.org](http://www.cincinnatiepilepsy.org) or call our office at (513) 721-2905.



**Save the Date!! Emerald Miles 2011: March 12**  
Newport on the Levee • [www.cincinnatiepilepsy.org/emerald-miles.php](http://www.cincinnatiepilepsy.org/emerald-miles.php)





# Greetings!

November is Epilepsy Awareness Month. It is a perfect opportunity to talk to your friends, family and co-workers about epilepsy, epilepsy first-aid and to break down the stigma associated with epilepsy.

We have some great ways to celebrate Epilepsy Awareness Month. The Epilepsy Foundation of America has launched its "Get Seizure Smart" campaign just in time for November. We have put together some kits for students to bring to their classrooms. The kits contain "Get Seizure Smart" quizzes and some little goodies as a treat for taking the quiz and learning more about epilepsy. Please be sure to contact our office so your child/teen can take a kit to school.

We also are having our Mason Half-Marathon on November 7, 2010. Not only is this a wonderful fundraiser, it is also another way to spread epilepsy awareness. Spread the word and come join us for a morning of fun, friends and fitness.

We are happy to announce that the Epilepsy Foundation of Greater Cincinnati has recently been awarded 3 grants to provide additional services in the following areas:

1. "Sustainable Community Partnership for Families Living with Epilepsy" —serving the Huntington, WV and surrounding areas.
2. "Seizures and You: Take Charge of the Facts for Middle Schools" —serving all middle schools in our territory.
3. "Seizure Training for Daycare Personnel" —serving all day care centers in our service territory.

If you feel your child's school or daycare could benefit from such training, please feel free to contact our office. As always, we are here to provide support and assistance to all who are affected by epilepsy.

As Epilepsy Awareness Month approaches, remember to **TALK ABOUT IT!**

Kathy Stewart, Executive Director



## In the Spotlight: "A Seizure" by Nathan Jones

Writer/Producer/Actor Nathan Jones has epilepsy. He grew up in the Lexington, KY area with an interest in making it big in the film industry. His move to Los Angeles provided for this opportunity when he completed his work "A Seizure" which he shared as a volunteer of the Epilepsy Foundation of Greater Los Angeles with the assembly of Epilepsy Foundation Affiliates and National Office at this year's Leadership Skill Building Institute.

"A Seizure" is an eight minute film drawn from his memories and seen through his eyes. Though a short film, it captures the raw energy and emotions those experiencing a seizure may face through visual and audio imagery.

The Epilepsy Foundation has put the eight minute film in the spotlight in time for November and National Epilepsy Awareness Month. The complete version will be available



soon at [www.a-seizure.com](http://www.a-seizure.com). The trailer is available now through <http://www.epilepsyfoundation.org>.

# EpilepsyAdvocate™

Strength in numbers™

You're invited to a FREE program where an Epilepsy Advocate will share her inspiring personal story of living with epilepsy. Epilepsy Advocates are people who have taken control of their epilepsy and refuse to be defined by it.

Bring your friends, your family and your questions. Take home a connection to others in your community and the inspiration to LIVE on your terms!

**Date/Time:** Wednesday, October 20, 2010 at 6:30pm

**Location:** Mason Public Library (200 Reading Rd., Mason, OH 45040)

**Speakers:** Dr. David Ficker and Heather O., Epilepsy Advocate

**RSVP:** • E-mail [Julie.Donahue@ucb.com](mailto:Julie.Donahue@ucb.com) with your full name and the number of guests attending with you; or  
• Phone (800) 477-7877, press 8, enter 32220303#  
and then follow the instructions



THE EPILEPSYCOMPANY™



## Weekend Adventures: New Program Serving Young Adults with Epilepsy!

Over the years we have proudly offered our camp for youth with epilepsy, but as campers “graduated” from camp we wanted to offer them the opportunity to continue to connect with their friends.

Beginning in the fall of 2010,

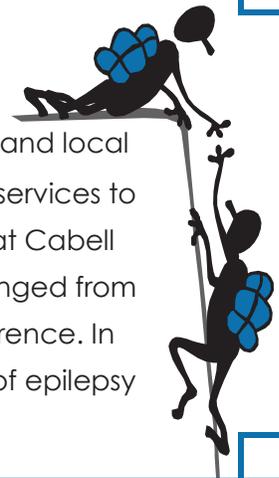
we will be offering weekend trips for young adults with epilepsy. These trips will cost around \$150.00 and include food, lodging and travel. The first trip will kick off Friday, October 22, as we travel to northern Ohio where the group will visit Cedar Point on beautiful Lake Erie Saturday and then head

over to Cleveland to visit the Rock & Roll Hall of Fame on Sunday, returning to Cincinnati Sunday evening.

If you would be interested in taking part in future trips, call our office at (513) 721-2905.

## Outreach to West Virginia Continues

Thanks to support from our national office, the Center For Disease Control (CDC) and local fundraising efforts in Huntington, we are pleased to continue to provide epilepsy services to West Virginia. For the past year, we have been working with the Epilepsy Center at Cabell Huntington Hospital to provide needed services in the community. These have ranged from epilepsy education in the schools to a run/walk fundraiser and an epilepsy conference. In the past year we have met some wonderful people dedicated to the cause of epilepsy and are happy to partner with them to continue to make a difference!





November is National Epilepsy Awareness Month (NEAM) and the Epilepsy Foundation is asking everyone to Get Seizure Smart about seizure first aid, recognition and types. Epilepsy affects people of all ages and races, and represents 1% of the population in this country—nearly 3 million people.

It is our goal to energize and motivate the entire epilepsy community and share with the general public and individuals who are living with epilepsy about what seizures are and what to do if someone is having one. The entire month will be an opportunity to spread the word about seizures and how to help if someone is having a seizure. NEAM will focus on educating and encouraging communities of all sizes to Get Seizure Smart together. You can use the tools at [www.GetSeizureSmart.org](http://www.GetSeizureSmart.org) to get the word out and encourage everyone to Get Seizure Smart!

## Taylor Huth Memorial Scholarship

For years the Epilepsy Foundation has hoped to set up a local college scholarship fund to assist youth with epilepsy. Recently this dream became a reality as the friends and family of Taylor Huth decided to fund such a venture with the proceeds from the annual Taylor Huth Memorial Golf Outing. Now a handful of young adults will get the help they need to pursue their dreams at college.

To apply for this scholarship, simply go to our website at [www.cincinnatiepilepsy.org](http://www.cincinnatiepilepsy.org) and click on the Taylor Huth Scholarship link on the right. From there you will be directed on how to apply for this scholarship. If you have any questions, please call our office at (513) 721-2905.

Thanks again to the Huth family and their friends for graciously providing the funds for this

scholarship. This will be a wonderful way to remember and celebrate the beautiful life of their son, Taylor Huth who struggled with seizures. We appreciate their desire to positively impact others who live with epilepsy.



## 2011 Kids Speak Up! - Recruitment

We are now accepting applications from interested families for the 2011 Kids Speak Up! event. The selected child and accompanying parent will be flown to Washington D.C. March 27-29 to participate in the National Walk for Epilepsy, train on epilepsy advocacy and network with other participating families. The event will culminate in a Day on the Hill lobbying your district legislators for their support in necessary epilepsy research and services. All expenses are paid.

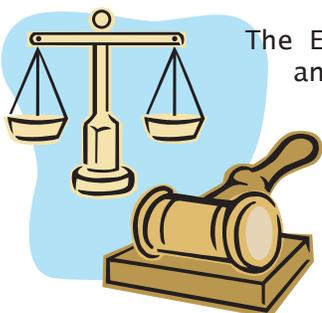
Children of all abilities and ethnic backgrounds are encouraged to apply, but to be eligible the child must have been diagnosed with epilepsy or a seizure disorder and be receiving treatment. Several other factors will be considered: residence in a key congressional district; advocacy experience and affiliate involvement; age (emphasis on preteen through 17 years, though ages 8 and up are welcome); children reflecting the entire spectrum of epilepsy and types of

seizures; diversity in race, nationality and geographic location.

Interested families should contact Doug Simmons at (513) 721-2905, or email at [doug.simmons@cincinnatiepilepsy.org](mailto:doug.simmons@cincinnatiepilepsy.org)



## Make Epilepsy an Election Year Issue



The Epilepsy Foundation is asking all candidates for Congress to complete and return a questionnaire about epilepsy. By sending an email to the candidates in your community, you can help raise awareness, secure more funding for programs and improve access and treatment to care. Please take action by visiting the Foundation's online action center at <http://capwiz.com/efa/issues>. Share this alert and information with your friends, family and everyone you know affected by epilepsy!



# Please join us for the Mason Half-Marathon on November 7!

**Course:** The race starts and finishes at Mason High School. Check out our website ([www.masonhalf.com](http://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 6:30-7:45 AM.

**Course Closure:** The course will remain open for 3 1/2 hours.

**Fees:**

- **5K run/walk:** \$30.00 if postmarked by 11/2/10 or completed on-line by 11/4/10 at midnight; \$35.00 on race day (No guarantee of shirt); \$20.00 for children 12 and under
- **Half-Marathon:** \$45.00 if postmarked by 11/2/10 or completed on-line by 11/4/10 at midnight; \$50.00 on race day (No guarantee of shirt)

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.cincinnatiEpilepsy.org](http://www.cincinnatiEpilepsy.org)

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.

**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 6, 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 3 hours or less will receive a special commemorative medal.

**Refreshments:** Enjoy food and drinks after the race.

**Register on-line:** Go to [www.masonhalf.com](http://www.masonhalf.com) to register on-line.

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

Sponsored by:



## Mason Half-Marathon Pre-Registration

**Must be postmarked by 11/2/10 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 received between 9/26/10 and 11/2/10 (includes entry fee and short sleeve t-shirt)

\$45 Adult pre-registration for the half-marathon received between 9/26/10 and 11/2/10 (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, Greg McCormick, 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): \_\_\_\_\_



Most people with epilepsy are able to work in the full range of jobs. Neither the condition itself or the treatments for it will affect their ability to work. There are people with epilepsy serving successfully in every walk of life. Unfortunately, epilepsy is often still stigmatized and people often face discrimination. Sometimes people are reluctant to tell their employers they have epilepsy or seizures because they learn through bitter experiences that it can be used against them.

Getting a job, safety-sensitive jobs, and changing jobs are just a few of the difficulties in employment. But your rights are protected. While many people with epilepsy are able to maintain regular employment without interruption, others may need to miss work because of seizures, changes in medication, or to visit a doctor for regular monitoring. The federal laws that protect employees are known as the Family and Medical Leave Act and the Americans with Disabilities Act (ADA). The ADA prohibits employment discrimination against qualified individuals with disabilities who are able to perform the essential functions of the job, with or without reasonable accommodation(s).

Prior to the offer of a job, an employer may not ask whether an applicant has a disability, inquire about the severity of a disability, or make any inquiry that is likely to elicit information about a disability. Once employment begins, an employer may make disability-related inquiries and require medical examinations only if they are "job-related and consistent with business necessity."

Finally, many courts have recognized epilepsy as a disability and that many people with a history of epilepsy are considered disabled because of the varied nature of seizures though filing for disability can be a slow process, often taking one to two years to complete.

To learn more from others with employment issues connect with **eCommunities** in the [Epilepsy & Employment forum](http://www.epilepsyfoundation.ning.com) at [www.epilepsyfoundation.ning.com](http://www.epilepsyfoundation.ning.com).

# Camp Flame Catcher



# October 2010

# Calendar of Events

**October 20, 2010; 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)

**October 20, 2010; 6:30 PM**

Epilepsy Advocate Program (see pg. 3)

**October 21, 2010; 6:00-7:30 PM**

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

**October 22-24, 2010**

Weekend Adventures: Cedar Point/Rock & Roll Hall of Fame (see pg. 3)

**October 28, 2010; 9:00 AM-12:30 PM**

Seminar "Cultural Diversity: What Does It Mean To You—Melting Pot or Tossed Salad?": The Health Foundation of Greater Cincinnati

**October 28, 2010; 6:00-7:30 PM**

Butler County Epilepsy Support Group: Janet Clemmons Center (282 N. Fair Ave., Hamilton, OH 45011)

**November 7, 2010; 8:00 AM**

Mason Half Marathon: Mason High School

**November 9, 2010; 6:00-7:30 PM**

Clermont County Epilepsy Support Group: Miami Township Civic Center Conference Room (6101 Meijer Dr., Miami Township, OH 45150)

**November 10, 2010; 5:30-7:00 PM**

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

**November 13, 2010; 2:00-3:30 PM**

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

**November 17, 2010; 6:00-7:30 PM**

Northern Kentucky Epilepsy Support Group

**November 18, 2010; 6:00-7:30 PM**

Hamilton County Epilepsy Support Group

**November 18, 2010; 6:00-7:30 PM\*\***

Butler County Epilepsy Support Group  
**\*\*Note Date Change**

**December 2, 2010; 9:00 AM-12:30 PM**

Seminar "Update on New Treatments and Devices for Epilepsy": The Health Foundation of Greater Cincinnati

**\*\*No Support Groups in December\*\***

**Enjoy your holidays!!**

**January 8, 2011; 2:00-3:30 PM**

Clinton County Epilepsy Support Group

**January 11, 2011; 6:00-7:30 PM**

Clermont County Epilepsy Support Group

**January 12, 2011; 5:30-7:00 PM**

Warren County Epilepsy Support Group

**January 19, 2011; 6:00-7:30 PM**

Northern Kentucky Epilepsy Support Group

**January 20, 2011; 6:00-7:30 PM**

Hamilton County Epilepsy Support Group

**January 27, 2011; 6:00-7:30 PM**

Butler County Epilepsy Support Group



**Thank you to all of our 2010 Camp Counselors and Volunteers—**

**Camp Flame Catcher wouldn't be possible without you!**

- |                 |                |                 |
|-----------------|----------------|-----------------|
| Cameron Auer    | Chad Auer      |                 |
| Lindsey Beasley | Kari Childs    |                 |
| Ron Childs      | Jan Cremens    |                 |
| Molly Cremens   | Angelle Cupit  |                 |
| Alex Day        | Joe Findley    |                 |
| Ben Findley     | Katie Magee    |                 |
| Josh Findley    | Olivia Preston |                 |
| Alex Marksberry | Gus Misleh     | Nicholas Misleh |
| Joe Schroth     | Tony Schroth   | Nick Siegel     |
| Sydney Stewart  | Julie Teets    | Nick Teets      |
|                 |                | Katie Turner    |
|                 |                | Adam VanAtta    |
|                 |                | Sam VanAtta     |



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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.

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Dr. Michael Privitera, Dr. Marvin Rorick, Erik Shelton

**Mission statement:**  
The Epilepsy Foundation of Greater Cincinnati will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through services, education, advocacy and research.

**Epilepsy Foundation of Greater Cincinnati**

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