

The Update

2011, Volume 1

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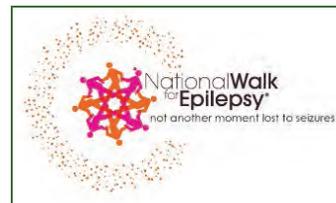
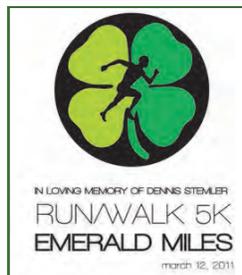
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David M. Ficker, MD

Save these dates . . .

March 12, 2011



March 27, 2011



April 16, 2011

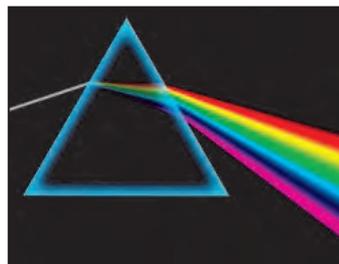
Ask the Expert: Is Epilepsy a "Spectrum" Disorder?

David M. Ficker, MD

Director, Epilepsy Monitoring Unit, Cincinnati Epilepsy Center

University of Cincinnati Academic Health Center

There is emerging evidence to suggest epilepsy is a "spectrum" disorder. A spectrum is a collection of colors that make up light. The spectra of light can be seen when sunlight is passed through a prism, comprising red, orange, yellow, green, blue, indigo, and violet.



When the term spectrum is used in epilepsy, we mean that epilepsy is more than just seizures. We now know epilepsy has other co-morbidities (or other coexisting conditions). Common co-morbidities include learning and

memory problems, depression, and anxiety. We think these co-morbidities are caused by the epilepsy.

A good example to consider is depression. We think depression in epilepsy results from abnormal function of part or parts of the brain involved with seizures. Between 20% and 50% of people with epilepsy have depression; many cases are not diagnosed.

The general treatment focus in epilepsy is seizure control. Now studies and clinical experience indicate that seizure control is only part of the treatment picture. If co-morbidities are not recognized and treated then the person may not do as well as they could. Physicians are now considering the evaluation and treatment of co-morbidities when seeing patients with epilepsy.

Greetings!

I hope everyone had a wonderful holiday season. Winter has definitely arrived and it appears as if the cold temperatures are here to stay for awhile.

The Epilepsy Foundation is working hard to improve the lives of people affected by epilepsy. We are working collaboratively with our National Office and affiliates across the country to implement the 2011-2013 Strategic Plan. As part of this plan, we have adopted a new mission statement: The Epilepsy Foundation leads the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.

In a nutshell, this new statement depicts our mission and why we work so hard on a daily basis. Additionally, we have three mission goals for this plan: Life Outcomes, Health Outcomes and Research Outcomes. We are very excited as we move forward to put these goals into action for the betterment of people with epilepsy.

In order for us to be able to implement these goals and provide the vast array of services to those affected by epilepsy, we have to rely upon fundraising efforts, grants and donations. Another way an individual can make an impact is to leave a legacy. You can do this by naming the Epilepsy Foundation of Greater Cincinnati as a beneficiary in your will. A bequest provision can be included in your will when you are creating it, or you can amend your existing will. This is very flexible and you can designate an exact amount or a percentage of the assets in your estate.

For additional information on leaving a legacy, log on to our website, or call our office to have a brochure mailed to you.

With your support, we can create a better life for those affected by epilepsy, not just today, but well into the future!

Sincerely,

Kathy Stewart, Executive Director

Online Training in Epilepsy and Seizure Response for Law Enforcement

We are happy to announce that through a partnership with our National Office, epilepsy training for law enforcement personnel is now available online. The training is free, and the user can receive a certificate of completion.

We all recognize the growing need to provide information to law enforcement about

responding to individuals with epilepsy and seizure-related calls. We also realize that these professionals need educational information in a format that is easy to access and convenient for their busy schedules.

This approximate 45 minute course aims to train law enforcement on seizure

recognition, correct response to seizures and awareness of the unique needs of people with epilepsy who might be taken into custody.

Call our office today to learn how to access this important training!



Mark Your Calendar for Camp Flame Catcher

We are happy to announce the following camp sessions for 2011. The camps will all be held at Camp Kern in Warren County and will be filled with non-stop fun that includes: swimming, horseback riding, games, crafts, canoeing, archery and much more. For a camp registration form, call our office at (513) 721-2905, or print one from our website: www.cincinnatiEpilepsy.org. (Click on "Camp" under the "Programs" menu).

- Spring camp weekend. . . April 1-3, 2011
- Summer camp. July 17-21, 2011
- Fall camp weekend. . . . September 30-October 2, 2011



College Scholarships Available



Taylor Huth Memorial Scholarship Fund

Through the generosity of the friends and family of Taylor Huth, a memorial scholarship fund has been set up to remember and celebrate Taylor's zeal and love for life. In April of 2011, the first round of three \$1,000 scholarships will be awarded to students entering college or those already in college. We encourage anyone in the area with epilepsy to apply for this scholarship. The guidelines and application can be found on our website at www.cincinnati-epilepsy.org (Follow the menu link on the right side to "Taylor Huth Memorial Scholarship Fund"). The deadline to apply is **March 30, 2011**.

2011 UCB Family Epilepsy Scholarship Program

Outstanding accomplishments deserve recognition. The UCB Family Epilepsy Scholarship Program offers financial support to people living with epilepsy, their family members and/or caregivers who demonstrate academic and personal excellence. The award is a one-time scholarship in the amount of \$5000. Forty scholarships nationally will be awarded to people living with epilepsy, family members or caregivers of people living with epilepsy, for use toward tuition at a United States-based center for higher learning (trade school, associate's, bachelor's, master's degree, etc).

Since 2004, UCB has awarded over 1 million dollars in scholarships to more than 200 deserving people! For questions regarding the 2011 Scholarship, or to apply, go to <http://www.ucbepilepsyscholarship.com/Default.aspx> Questions may also be directed to 1-866-825-1920. The deadline to apply is **May 20, 2011**.



RAMPART STUDY ENDING ENROLLMENT:

133 PATIENTS ENROLLED LOCALLY

The University of Cincinnati (UC) Department of Emergency Medicine has completed its participation in the clinical research study "Rapid Anticonvulsant Medications Prior to Arrival Trial" (RAMPART). The national trial reached its enrollment target Friday, Jan. 14, and has stopped enrolling patients across the country. Locally, fire/EMS crews enrolled 133 patients, both adults and children.

UC began enrollment in RAMPART in June 2009, working with fire/EMS departments in Cincinnati, Blue Ash, Forest Park and Green Township in Ohio & Florence and Independence in Kentucky. RAMPART was designed to study if anti-seizure medications given as a shot in the muscle were just as effective as anti-seizure medications given by intravenous injection (IV), the current protocol.

UC was one of 17 research institutions to conduct the trial, which was carried out under the Food and Drug Administration (FDA) federal regulation "exception from informed consent." Such regulations require trials to meet specific federal regulations and local Institutional Review Board's review and approval. They give the researcher the ability to enroll patients into the study when they cannot speak for themselves because of their life-threatening injury or illness.

"The UC Team would like to thank the communities and EMS agencies that participated in this important work," says UC RAMPART coordinator Irene Ewing, RN. Residents in participating communities who opted out of the trial by wearing a "RAMPART Declined" bracelet can now stop wearing this bracelet.

Arthur Pancioli, MD, principal investigator for RAMPART and chair of the UC Department of Emergency Medicine, says the trial could help first responders better treat seizures. "Prolonged seizures are dangerous, and may be life threatening," says Pancioli, "it's imperative that these patients receive medical intervention as quickly as possible. If RAMPART demonstrates that the auto injector method is as effective as starting an IV and delivering medication by that method, then we will be able to offer a wonderful new method to routinely treat prolonged seizures." He says results from the study should be released to the local public this spring and will also be available on the RAMPART website after the data has been analyzed.

For more information, contact Irene Ewing at (513) 558-0095.



Mason Half Marathon Results

On November 7, 2010, we hosted our first “half-marathon” along with our 5K run/walk in Mason. We were ecstatic at the great response from the community! The event fell just shy of 950 participants ranging in age from 2 to 77 years old and traveling from Mason itself to as far away as California! The cold weather did not deter runners, walkers or volunteers from gathering together for a great cause!

Congratulations to the top finishers!

- | | |
|------------------------------------|--|
| ▶ Half-marathon (494 participants) | ● 1 st place male: Andy Johnson from Dayton, OH (1:20:03) |
| | ● 1 st place female: Kerry Lee from Cincinnati, OH (1:24:59) |
| ▶ 5K run (251 participants) | ● 1 st place male: Peter Curnutte from College Hill, OH (17:31) |
| | ● 1 st place female: Gena Bishop from Mason, OH (20:19) |
| ▶ 5K walk (198 participants) | ● 1 st place male: Akhilesh Menon from Mason, OH (42:42) |
| | ● 1 st place female: Monica Merkel from Worthington, OH (36:26) |

Thank you! to all of our sponsors: AmQuip, Balconi Gear, the Berry Company, Brazenhead Irish Pub, Cincinnati Bell Directory, Cincinnati Tan Company, Fleet Feet Sports, the Golf Center at Kings Island, La Quinta Inn & Suites, Mason Bowl, Oxford Physical Therapy Centers, Road ID, United Health Care, Upper Cervical Health Centers of America and Willie’s Sports Café; and all of our volunteers: Sysco Corporation, Green B.E.A.N. Delivery, Fifth-Third Bank, King’s soccer team, Mason High School student volunteers and everyone else who pulled together to make this event such a success!

The 5th Annual National Walk for Epilepsy—Sunday March 27, 2011

The National Walk for Epilepsy® is a family oriented, noncompetitive walk in our nation's capital to raise funds for research, education, advocacy, and services for people with epilepsy and their caregivers. It also serves to raise awareness of the magnitude of epilepsy in the USA. In the past 4 years, the event has raised over 4 million dollars and welcomed over 25,000 participants.

The walk will take place on the National Mall in Washington, D.C. on Sunday March 27. The course is slightly over 2 miles.

Registration is \$35 for adult participants and \$20 for children 12 and under. This fee includes a white event t-shirt, or if you have epilepsy, you can choose a purple t-shirt. When you register, either as a walker

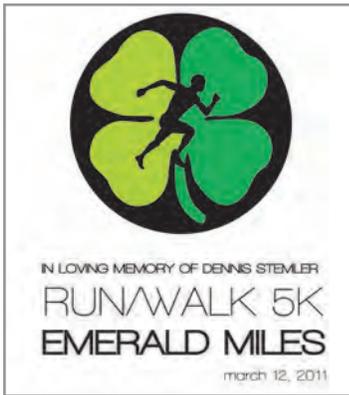
or a donor, please join our crew: *Team Cincinnati Epilepsy Foundation*. 100% of the money raised through “Team Cincinnati” stays in Cincinnati! For more information about the walk, call 1-866-433-9255 or visit www.walkforepilepsy.org.



The 2nd Annual Race for Hope – Huntington, West Virginia

Last year was such a success in bringing epilepsy awareness to the attention of the Huntington Area that we want to once again encourage you, your family, neighbors, friends, and the supporting community to come out Saturday, April 16, 2011, for the 2nd Annual Race for Hope. This race helps to support much needed services in and around Huntington, including epilepsy education in schools, for police, fire and EMT personnel; counseling in the local epilepsy clinics and information and referral services for those affected by epilepsy. The Race for Hope starts and ends at Pullman Square and includes both a 5K run and 5K walk. For more information and to register, visit: www.cincinnatiEpilepsy.org.





Please join us for the Emerald Miles 5K Run/Walk on March 12

♣Course: The race starts at Newport on the Levee, crosses over the Ohio River, loops through Sawyer Point, into Cincinnati, then back to the Levee.

♣Time: The race starts at 9:00 AM. Same day registration is from 7:30-8:30 AM.

♣Fees: Pre-registration is \$25.00 (non-refundable). The registration fee is \$15.00 for children 12 and under. This fee includes the race and a long sleeve race t-shirt. To pre-register, your registration form must be **postmarked** by March 7, completed on-line by noon on March 8, or done in person at the Fleet Feet Sports "early packet pick-up" on March 10 (4:00-8:00pm).

Same Day Registration is \$25.00 for the race only or \$30.00 with a long sleeve race t-shirt (while supplies last).

♣All shirts must be picked up by 9:00 a.m. on race day or they will be forfeited.♣

♣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 Thursday, March 10 from 4:00-8:00 pm.

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

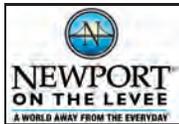
♣Refreshments: Enjoy food and drinks after the race.

♣Register on-line: Go to <http://emeraldmiles2011.kintera.org> 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.cincinnatiEpilepsy.org

Sponsored by:



Emerald Miles Run/Walk Pre-Registration **Must be postmarked by 3/7/11 for pre-registration**

Send completed registration form & payment to:
Epilepsy Foundation of Greater Cincinnati
Emerald Miles
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: _____

How did you hear about the race? _____

Are you part of a team? Team Name: _____

For more information on teams, go to: www.cincinnatiEpilepsy.org, then Emerald Miles

Category: 5 K Walk 5 K Run **Circle T-shirt Size:** Youth Sizes: S M L Adult Sizes: S M L XL XXL

Pricing: \$25 Adult Pre-registration (13 and over) (includes entry fee and long sleeve race T-shirt)

\$15 Registration for children (12 and under) (includes entry fee and long sleeve race T-shirt)

*Registration fees are non-refundable.

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 Emerald Miles run/walk, and do hereby release the Epilepsy Foundation of Greater Cincinnati, Steve Prescott, 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): _____

Emergency Contact Name: _____ Phone: _____



United Way – Community Care Days 2010

As many of our loyal readers know, the Epilepsy Foundation of Greater Cincinnati operates 4 group homes in Clermont County providing services and care to 32 adults with disabilities. We also manage 2 Day Programs for these adults and others from the surrounding communities relying exclusively on our well-trained and dedicated staff to provide basic care and programming. In addition to routine maintenance, these homes and grounds often need larger undertakings that require more hands. This is where the United Way comes in.

Throughout 2010, the United

Way of Greater Cincinnati has provided the manpower (and womanpower) to the Epilepsy Foundation of Greater Cincinnati allowing us to host 268 volunteers from area companies who gave of their time to complete 29 projects—painting, repairing, building, shoveling, hauling, hammering, planting, and otherwise getting messy to make a difference in the lives of those we serve.

The following companies deserve our recognition and gratitude for their efforts in 2010:

- ▶ Dover Corporation - 120 volunteers

- ▶ Proctor & Gamble - 65 volunteers
- ▶ ITW Air Management/Vortec - 22 volunteers
- ▶ Fifth Third Bank Processing (1st group) - 35 volunteers
- ▶ Fifth Third Bank Processing (2nd group) - 26 volunteers

If you would like more information on how your company can become part of a Community Care Day Event, call us at (513) 721-2905.

For more pictures of these groups and their efforts, follow the “photo albums” link on our website to “Community Care Days”.

Thank You



Calendar of Events

February 8, 2011; 6:00-7:30 PM

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

February 9, 2011; 5:30-7:00 PM

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

February 12, 2011; 2:00-3:30 PM

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

February 16, 2011; 6:00-7:30 PM

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

February 17, 2011; 6:00-7:30 PM

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

February 24, 2011; 9:00 AM-12:30 PM

Seminar "When Nothing Else Seems to
Work: The Promise of Neurofeedback" The
Health Foundation of Greater Cincinnati

February 24, 2011; 6:00-7:30 PM

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

March 4, 2011; 9:00 AM-4:00 PM

Ohio Respite Summit: Columbus, Ohio

March 8, 2011; 6:00-7:30 PM

Clermont County Epilepsy Support Group

March 9, 2011; 5:30-7:00 PM

Warren County Epilepsy Support Group

March 12, 2011; 9:00 AM

Emerald Miles 5K Run/Walk: Newport on the
Levee

March 12, 2011; 2:00-3:30 PM

Clinton County Epilepsy Support Group

March 16, 2011; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

March 17, 2011; 9:00 AM-12:30 PM

Seminar "Understanding Substance Abuse
and Helping Your Clients Cope": The Health
Foundation of Greater Cincinnati

March 17, 2011; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

March 24, 2011; 6:00-7:30 PM

Butler County Epilepsy Support Group

March 27, 2011

National Walk for Epilepsy: Washington DC

April 1-3, 2011

Spring Camp Flame Catcher Weekend:
Camp Kern

April 9, 2011; 2:00-3:30 PM

Clinton County Epilepsy Support Group

April 12, 2011; 6:00-7:30 PM

Clermont County Epilepsy Support Group

April 13, 2011; 5:30-7:00 PM

Warren County Epilepsy Support Group

April 16, 2011; 9:00 AM

Race for Hope: Huntington, WV

April 20, 2011; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

April 21, 2011; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

April 28, 2011; 9:00 AM-12:30 PM

Seminar "Overview of the Ohio Nurse Prac-
tice Act": The Health Foundation of Greater
Cincinnati

April 28, 2011; 6:00-7:30 PM

Butler County Epilepsy Support Group

May 10, 2011; 6:00-7:30 PM

Clermont County Epilepsy Support Group

May 11, 2011; 5:30-7:00 PM

Warren County Epilepsy Support Group

May 12, 2011; 9:00 AM-12:30 PM

Seminar "Professional Ethics": The Health
Foundation of Greater Cincinnati

May 14, 2011; 2:00-3:30 PM

Clinton County Epilepsy Support Group

May 18, 2011; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group



Kids Speak Up!

At the end of March, two local kids, Breanna Plessinger (from Covington, OH) and Xavier Legault (from Morrow, OH) and their parents will be packing their bags and heading to Washington D.C. to take part in the Kids Speak Up! Public Policy Institute. Breanna and Xavier will learn how to advocate on behalf of all people with epilepsy as they meet with their local representatives and congressional staff. Topics will include: ensuring coverage and access to essential services for all people with epilepsy, protecting the rights of individuals with disabilities and promoting research into treatments and, ultimately, cures for all the epilepsies.

Congratulations and best of luck Breanna and Xavier!

Ohio Respite Summit: March 4, 2011

For parents, caregivers, respite providers, community groups and agencies who serve people impacted by developmental disabilities, other disabilities, mental health issues, aging, chronic illness, abuse, etc..

The summit goal is to help expand, enhance and coordinate respite services in Ohio. This is a free, working meeting to be held at the Ohio Rehabilitation Services Commission in Columbus, Ohio from

9:00am-4:00pm on
March 4. Find more
information and
registration details on our website:
www.cincinnatiPILEPSY.org.





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



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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Mission statement:
The Epilepsy Foundation leads the fight to stop seizures, find a cure and overcome the challenges created by seizures.

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