

The Update

2011, Volume 2
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Save these dates . . .



July 17-21, 2011



August 27, 2011



July 23, 2011



November 6, 2011

Greetings!

Spring is a time for change. As we move forward through this spring season, I would like to tell you about changes that have been happening on a national level as well as on a local level.

The Epilepsy Foundation of America (EFA), of which we are a local affiliate, was very excited and pleased to announce that Rich Denness was hired as the new CEO of EFA. Rich comes with many year's experience, working as Vice President and General Manager of UCB's Central Nervous System division. He created the Epilepsy Advocates Program, which is a nationwide community of individuals and caregivers striving to achieve better seizure control.

Along with a new CEO, the EFA has adopted a new mission statement: The Epilepsy Foundation leads the fight to stop seizures, find a cure and overcome the

challenges created by seizures.

As we began planning on a national level, a strategic plan was developed with three mission goals and one organizational capacity goal. These goals are in the areas of: 1. Life Outcomes, 2. Health Outcomes and 3. Research Outcomes.

The Epilepsy Foundation of Greater Cincinnati has developed our strategic plan with staff and our Board of Directors. We are very excited about the changes to come and to be working hand-in-hand with the staff of our National Office in helping to ensure that not another moment is lost to seizures.

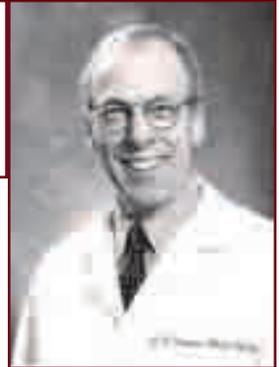
Kathy Stewart, Executive Director

Ask the Expert: Epilepsy Syndromes in Children

Ton J. deGrauw, MD, PhD

Cincinnati Children's Hospital Medical Center

Director of the Division of Child Neurology



Dr. Ton J. deGrauw

Seizures are very common in children. It is estimated that 1 in every 20 children will have at least one seizure. If a child has had two spontaneous seizures (meaning that the seizures were not caused by an acute medical problem such as infection, trauma, fever etc.), it is called epilepsy.

Although the symptoms of epileptic seizures can vary very much from one child to another, child neurologists can often determine that certain types of seizures, together with the physical examination and results of MR Imaging and EEG studies constitute a syndrome. A syndrome consists of a set of data such as seizure type (staring seizures), physical examination (normal), EEG (generalized epileptic brain waves at 3Hz), and MRI (normal). The findings with parentheses indicate a specific

syndrome in children with epilepsy: Absence Epilepsy. Recognizing a specific epilepsy syndrome is important, because it may tell us how the epilepsy and its associated problems will develop over time. Some of these syndromes have a tendency to get worse over time, some may disappear completely when the child grows up and some need to be studied more in order to find out how we can accomplish the best possible outcome. More and more epilepsy syndromes are recognized each year and some appear to have genetic causes. Much research continues into the genetic causes of pediatric epilepsy, but much work remains to be done.

At Cincinnati Children's Hospital Medical Center we are committed to improve outcomes for children with epilepsy. We study epilepsy in the

laboratory, but we also do clinical studies, such as studies of new seizure medications, specific diets and sometimes surgery that will help us to reach that goal.

Epilepsy Syndromes that we currently study at Children's Hospital include: Infantile Spasms, Lennox-Gastaut Syndrome, Dravet Syndrome, Absence Epilepsy, Benign Rolandic Epilepsy, Juvenile Myoclonic Epilepsy.

**For more information on these studies contact Dr. Tracy Glauser, Director, Comprehensive Epilepsy Center @ (513) 636-4222.

Happenings at our Nation's Capitol

► National Walk for Epilepsy - March 27, 2011

Opening Day debuted a week early this year for about 60 people from Cincinnati who traveled to Washington D.C. wearing Cincinnati Reds hats for the National Walk for Epilepsy. They joined thousands of others as together they proclaimed, "I have epilepsy, but epilepsy doesn't have me". It was great to witness that you are not alone in your struggles with seizures as you see the National Mall filled with people who support you. Thanks especially to Mike Lykins from D & L Leasing for once again providing a van for this trip. Visit www.epilepsyfoundation.org for more information and pictures from the event.



► Kids! Speak Up! - March 28-29, 2011

The *Kids Speak Up!* program provides a unique opportunity for young ambassadors with epilepsy from across the country to go to Washington, D.C., along with their families, to petition congressional leaders for aid in assuring better access to care, improved public education and more research toward a cure for epilepsy.

This year Xavier Legault (9) of Morrow, Ohio, and Breanna Plessinger (13) of Covington, Ohio, represented the youth of Ohio as they went up The Hill to meet with Senators Brown and Portman, and Representatives Boehner and Schmidt to share their personal stories of successes and difficulties in living with epilepsy. Xavier and Breanna were educated on the importance of lobbying for funding necessary to support epilepsy research at the National Institutes of Health and critical epilepsy public health programs through the Centers for Disease Control and Prevention, and the Health Resources and Services Administration. Our young ambassadors were also there to encourage their Representatives to co-sponsor the RAISE (Raising Awareness and Insight into Seizures and Epilepsy) Act of 2011 and their Senators to be original co-sponsors of a Senate companion bill. The RAISE Act aims to increase epilepsy awareness in our communities and nationwide by targeting school nurses, educators, first responders and employers.

Well done Breanna and Xavier!



EPILEPSY & THE WORKPLACE:

WOULD YOU KNOW HOW TO SPEAK WITH YOUR SUPERVISOR ABOUT JOB ACCOMMODATIONS?

Whether you are currently employed or looking for a job, employees with epilepsy sometimes need accommodations on the job in order to perform optimally. Relatively new legislation supports your legal rights to have these accommodations. However, well before you begin to cite your ADA rights, you may need to find out exactly what your rights are and how to comfortably instigate that initial conversation with your manager or Human Resource (HR) Representative. Discussing your seizures and any accommodations you may need can be a challenging conversation. You may not be prepared to be the knowledgeable, clear, persuasive, confident negotiator you need to be to approach the topic of accommodations with your employer.

You are invited to a FREE Educational Dinner to discuss how to have effective conversations with your employer about accommodations you may need.

For your convenience, there are three dinner dates and locations to choose from:

Date	Time	Location	Registration Deadline
Thursday, June 9, 2011	5:30-7:30 pm	Brazenhead Irish Pub 5650 Tylersville Road Mason, OH 45040	6/3/11
Tuesday, July 12, 2011	6:30-8:30 pm	Eastgate Holiday Inn 4501 Eastgate Boulevard Cincinnati, OH 45245	7/7/11
Thursday, July 21, 2011	5:30-7:30 pm	Epilepsy Foundation of Greater Cincinnati 1 st Floor Conference Room 895 Central Ave., Ste. 550 Cincinnati, OH 45202	7/18/11

Space is limited so please call the Epilepsy Foundation of Greater Cincinnati at (513) 721-2905 to register by the deadlines listed above.

Post Traumatic Epilepsy in the Military. . .

How are We Helping?

Post traumatic epilepsy (PTE) is a seizure disorder that is caused by a Traumatic Brain Injury (TBI). 1.64 million soldiers have served in Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF). 320,000 of these soldiers (19.5%) will experience a TBI. Between 15-34% of TBI patients now have PTE and active duty military rates can be as high as 53%; therefore, between 48,000-169,000 soldiers serving in OIF/OEF are expected to develop PTE!

What are we doing to help? The Epilepsy Foundation of Greater Cincinnati was awarded a pilot grant funded through the Centers for Disease Control (CDC) to reach veterans and their families to teach awareness of the correlation to even the mildest TBI with seizure development sooner or later in life. Since there are so many types of

seizures, we want to educate both veterans and their families to be on the lookout for symptoms that may indicate seizure activity as well as proper first aid. We also want our veterans to know that we are here to help them and their families should the situation arise that they do in fact develop a seizure disorder. Being aware of the symptoms and knowing where to go for help empowers our veterans.

Veterans are invited to a FREE Dinner Conference at the Eastgate Holiday Inn Conference Center on Tuesday, July 12, 2011, from 5:00 pm-8:00 pm. The VA Mobile Van will be on-site from 4:30 pm-8:30 pm.

Keith Maupin, with the Yellow Ribbon Support Center, will be present to speak to the veterans. Keith's son, Matt Maupin, gained international attention as the soldier who was captured and

executed by Iraqi insurgents while serving in the Iraq War. Matt's father, Keith, has now dedicated his life to helping all veterans.

The program will also feature a local soldier's testimonial and a talk on Post Traumatic Stress Disorder (PTSD) and TBI by Dr. Kate Chard. Dr. Chard works at Cincinnati's VA Medical Center and is in charge of our nation's only TBI/PTSD inpatient residential program. Dr. Chard is the Department of Defense's go-to doctor to treat soldiers with PTSD. The VA mobile unit will be available for enrollment & information.

Veterans, don't miss this free educational dinner! Space is limited so call (513) 721-2905 by July 7, 2011 to reserve your spot!





Recommendations for Care

Getting the best treatment from the right doctor at the right time is key for people with epilepsy. The Epilepsy Foundation's Professional Advisory Board has developed two new booklets with this goal in mind: "Recommendations for Care of Children with Epilepsy" and "Recommendations for Care of Adults with Epilepsy". The booklets help people know when to seek treatment for seizures and contains information about new onset seizures, patients already taking epilepsy medications, uncontrolled seizures and making the most of your office visit. Find these booklets on our home page at www.cincinnati-epilepsy.org.



Donations come in all sizes and FLAVORS!! Thanks to Lori Embry, scout leader; Judy Stein, "cookie mom" and all of the scouts of Girl Scout Troop 30938 in Centerville, Ohio, for donating 174 boxes of Girl Scout Cookies to our organization. This unique (and delicious) donation will be sold to the community to raise additional funds for our many programs. We thank them for their generosity and willingness to partner with us to make a difference in the community!



Camp Flame Catcher – The Tradition Continues!

All youth with epilepsy are invited to join us July 17 – 21 as together we celebrate another week of camping fun at Camp Flame Catcher. Over 60 Campers and 30 volunteers will gather for non-stop fun that will include swimming, games, zip lines,

canoeing, crafts, horseback riding and much more. Because of the generosity of our donors we will again welcome any camper who would like to attend, regardless of their ability to pay. If you would like to take part as a camper or volunteer, call our office at (513) 721-2905. Space is limited, so register early!
P.S. Save the date for the Fall Weekend Camp—September 30-October 2.

West Virginia Connections

The staff at the Epilepsy Foundation have gotten to know the route to and from Huntington, West Virginia, over the past few months as we have shared important information and services related to epilepsy. We have visited many Junior High and High Schools in the area sharing the "Take Charge of the Facts" program. This educational tool has been invaluable in dispelling myths and empowering local youth with up-to-date information on seizures.

We were happy to present the Foundation's new First Responder Program for EMT's in West Virginia. In February we presented this information to paramedics at the state conference in Beckley, West

Virginia, and in April, we presented the program to the paramedics from Cabell-Huntington Hospital. We would like to thank Dr. Stecker for contributing his valuable knowledge and expertise to this training.

We will be touching an important segment of the population in June as we present an overview of epilepsy at the state school nurse conference. Like the paramedics, these nurses are on the front line in dealing with seizures in the schools across the state and their support of people with epilepsy is invaluable.

Finally, we were pleased to host the 2nd annual Race for Hope on April 16, in downtown Huntington. Despite some rainy

weather, a nice group of people came out to support the cause. In particular, we would like to thank Sherry Bartley and Ross Williams who drove from Charlotte, North Carolina to run the 5K in support of a friend who passed away recently from a seizure. We want to thank the friends of the Deller family from Three Gables Surgery Center and Dixon Electrical for supporting our race. And finally, we would like to thank Cabell-Huntington Hospital for supplying water and Jolly Pirate Donuts for the delicious treats!



Cincinnati Classic WIFFLE® Ball Tournament



Looking for something fun to do this summer? Then we're looking for you! Join us at Miami Meadows Park in Milford on July 23 at 9:00 AM for our first ever Cincinnati Classic WIFFLE® Ball Tournament!

Teams of 3-5 members (any gender mix) will compete to be crowned winners of the tournament. Also featured: a Home Run Derby!

Cost: \$65.00 per team – youth division: 13 years and under

\$80.00 per team – adult division: 14 years and over

Visit www.cincinnati-epilepsy.org for complete rules and registration information.



Taylor Huth Memorial Scholarships

We are very excited this year to partner with the family and friends of Taylor Huth who provided three \$1,000 college scholarships to area youth with epilepsy. This has been a dream of the Foundation to set up a scholarship fund and we thank Taylor's family & friends for making this happen.

We would also like to thank our Board of Directors, who amongst themselves donated another \$1,000 to provide one more scholarship.

We had many applications for the scholarships, but could only give out four. This year's recipients are:

» **Neal Eckstein** «

» **Meghan Frey** «

» **Alex Marksberry** «

» **Stephen Wood** «

We wish them the best as they pursue a degree in higher education and we are confident they will use this knowledge to positively impact our community.

Congratulations!!!

United Way Community Care Days

As a United Way agency, we benefit from the financial contributions that many people make to the campaign on an annual basis. These funds help us reach out and serve the community with innovative, unduplicated and life-changing services. Many people do not realize that these same companies who give financially also impact our agency in a more "hands-on" way.

Through the United Way Community Care Program, we partner with over 300 people annually to make a huge impact on the clients we serve. These volunteers paint our group homes, plant flowers, dig and pour new accessible sidewalks, build beautiful outdoor gathering spaces and more. They have truly left their mark on our agency for years to come.

Recently, we had the opportunity to partner again with Dover Corporation as part of their annual Leadership Conference. Over 80 employees took an afternoon off from their meetings to work at Benton Center. As the buses drove away at the end of the day, the property was transformed! There were new gardens, sidewalks, picnic tables a hay wagon and much more. We are indebted to these and other volunteers who generously impact our agency through this initiative.

If your company would like to take part in a Community Care Day project, call our office at (513) 721-2905.



For more pictures of the day,
visit us on



Epilepsy Advocate

UCB Pharma and the Epilepsy Foundation of Greater Cincinnati invite you to a FREE program where an Epilepsy Advocate will share their 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.



Tuesday, August 9, 2011; 6:00 – 8:00 PM

Crowne Plaza Hotel, 5901 Pfeiffer Rd., Blue Ash, Ohio 45242

Speakers to include Michele Turner, CNP Specializing in Epilepsy, University of Cincinnati Neurology

Snacks will be available. Space is limited, so please RSVP to Julie Donahue at julie.donahue@ucb.com or call the Epilepsy Foundation at 513-721-2905 by 8/2/2011.

****Note: This event replaces select August Support Groups****

Emerald Miles 2011 Wrap

Thank you to all of our participants and sponsors for an outstanding event on March 12, 2011. It was a beautiful day as over a thousand people converged upon Newport on the Levee to support and stand with people who have epilepsy. They truly felt they were not alone in their struggles with seizures! Thanks to our volunteers from D & G and LaSalle High School who helped us put on a very successful event. We could not have done it without them. Thanks to Channel 19 for airing a special feature on the race—the awareness they raised was invaluable.



Caleb's Crew

A giant thanks to all the team members who came out in full force to support their loved ones with epilepsy. They accounted for 85% of the funds that were raised! A big thank you to the 139 team members of Emily & Co. from Rising Sun, Indiana, who raised over \$6,000! Their support of Emily is a beautiful witness of love. To date, Emerald Miles 2011 has raised a record \$65,585.93!!! Congratulations to our top male and female runners Jeffrey Schroer and Heather Clark; and walkers Keith Dryor and Patricia Schmidt! To view the race results, visit www.sprunning.com and follow the registration/results link to Emerald Miles '11. To view race pictures, visit www.cincinnati-epilepsy.org and choose the photo album for Emerald Miles '11.



Emily & Co.

Thanks to the following sponsors:

AK Steel ~ Am Quip ~ Berry Company ~ Cincinnati Bell Yellow Pages
Cincinnati Bell Technology Solutions ~ D & L Leasing ~ Fleet Feet Sports ~ Franz CPAs
Green Bean Delivery ~ Health Care Solutions ~ Hydro Systems
Marx Hot Bagels ~ Newport on the Levee ~ OPW

Mark your calendar for Saturday, March 10, 2012, as we gather again for this annual event!

Calling All Golfers!

Wondering where the finances come from to support the Taylor Huth Memorial Scholarship (featured on p. 5)? Well, this event is where the biggest portion of the funding comes from and you can help! Join us for the Memorial Golf Tournament that supports the Taylor Huth Scholarship Foundation. By taking part in this tournament, you will be touching the lives of young adults who have epilepsy as 100% of the proceeds from this event provide college scholarships for these individuals. We encourage you to come out, play some golf on an excellent course, duff one in the water (as Taylor would have done), maybe win a prize or two and support the work of the Epilepsy Foundation in honor of Taylor's memory.



Taylor Huth Memorial Golf Tournament
Saturday, August 27, 2011 at 1:00 pm
Legendary Run Golf Course
915 East Legendary Run
Cincinnati, OH 45245



Fee: \$75 per player, includes: green fees, cart, event shirt, dinner, drinks and more. Featuring a \$20,000 hole-in-one contest!
Visit www.cincinnati-epilepsy.org for registration, sponsorship and volunteer information.

May 18, 2011; 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)

May 19, 2011; 6:00-7:30 PM

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

May 26, 2011; 6:00-7:30 PM

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

June 8, 2011; 5:30-7:00 PM

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

June 9, 2011; 5:30-7:30 PM

"Epilepsy & the Workplace" dinner (see p. 3): Brazenhead Irish Pub

June 14, 2011; 6:00-7:30 PM

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

June 15, 2011; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

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

Hamilton County Epilepsy Support Group

June 23, 2011; 6:00-7:30 PM

Butler County Epilepsy Support Group

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

Seminar "Learning the Common Triggers to Anxiety and Reducing It's Grip on Your Life": The Health Foundation of Greater Cincinnati

~~**July 12, 2011; 6:00-7:30 PM** CANCELLED~~

Clermont County Epilepsy Support Group

July 12, 2011; 5:00-8:00 PM

"Veterans Outreach" dinner (see p. 3): Eastgate Holiday Inn

July 12, 2011; 6:30-8:30 PM

"Epilepsy & the Workplace" dinner (see p. 3): Eastgate Holiday Inn

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

Warren County Epilepsy Support Group

July 17-21, 2011

Camp Flame Catcher Summer Session (see p. 4)

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

Northern Kentucky Epilepsy Support Group

July 21, 2011; 5:30-7:30 PM

"Epilepsy & the Workplace" dinner (see p. 3):

Epilepsy Foundation's Main Office

~~**July 21, 2011; 6:00-7:30 PM** CANCELLED~~

Hamilton County Epilepsy Support Group

July 23, 2011; 9:00 AM

WIFFLE® Ball Tournament: Miami Meadow Park (see p. 5)

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

Butler County Epilepsy Support Group

August 9, 2011; 6:00 PM

Epilepsy Advocate (see p. 6): Crowne Plaza Hotel

~~**August 9, 2011; 6:00-7:30 PM** CANCELLED~~

Clermont County Epilepsy Support Group

~~**August 10, 2011; 5:30-7:00 PM** CANCELLED~~

Warren County Epilepsy Support Group

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

Northern Kentucky Epilepsy Support Group

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

Hamilton County Epilepsy Support Group

August 25, 2011; 6:00-7:30 PM

Butler County Epilepsy Support Group

August 27, 2011; 1:00 PM

Taylor Huth Memorial Golf Tournament: Legendary Run Golf Course (see p. 6)

Online Training For Emergency Medical Service Professionals

Accredited online training in Epilepsy and Seizure Response for EMS personnel is now available. The online training is **free**, and the user can receive **free** continuing education hours from CECBEMS. We all recognize the growing need to provide information to EMS personnel 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 EMS personnel on seizure recognition, correct response to seizures, and awareness of the unique needs of people with epilepsy who they may encounter.

For more information, go to our home page at www.cincinnati-epilepsy.org

and follow the link to "Access Trainings"; register with a user name and password and then enter promotion code "04".



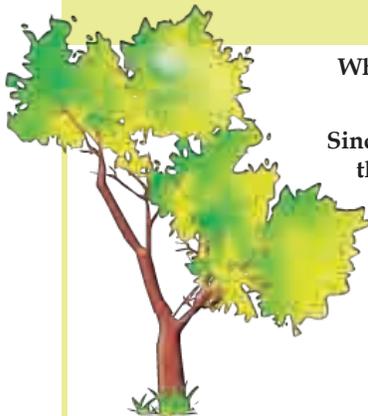
Leave a Legacy – Your Gift is a Lasting Tribute

When you leave a legacy to the Epilepsy Foundation of Greater Cincinnati, you make sure that the agency's programs continue to help those who need it!

Since 1953, the Epilepsy Foundation of Greater Cincinnati has played an important role in the lives of thousands of individuals with seizures by offering unique programs to counter the often devastating effects of epilepsy. From a therapeutic camping program and school support for children to education, job training, support groups, counseling, group homes for adults with epilepsy, advocacy and public awareness initiatives, the Foundation helps people with epilepsy and their families enjoy an enhanced quality of life.

In order to continue these vital programs, the Epilepsy Foundation needs financial assistance from you. When you leave a legacy to the Epilepsy Foundation of Greater Cincinnati, you make sure that the vitality of these programs remains uncompromised for generations to come!

To learn more, call us at (513) 721-2905, or visit www.cincinnati-epilepsy.org and click on "Leave a Legacy"





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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.

Epilepsy Foundation of Greater Cincinnati

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