

The Update

2010 Volume II

**INSIDE THIS
ISSUE:**

Autism & Epilepsy: An Uneasy Pair	2
National Epilepsy	2
Day of Hope Conference	3
Race for Hope	3
Kids Speak Up!	4
Community Care Day	4
Emerald Miles Results	5
House Bill 453	5
Patient Assistance	6
Medication Research	7
Calendar of Events	7



As we get ready to head into summer, our ever-growing list of outside things “to-do” continues to grow. Every year I am absolutely amazed and feel truly blessed by the many generous companies that participate in “Community Care Days” and choose the Epilepsy Foundation to support. With a 53 acre farm, a Day Activity Building, the 2 Group Homes we own, log cabins, a pond and hiking trails, there is always work that needs to be done.



With the generous support of companies like Hydrosystems, OPW Fueling Components, OPW Fluid Transfer, Ethicon Endo-Surgery, ITW Air Management, Fifth-Third Bank, Midland Company, Stockamp & Associates and Proctor & Gamble, we are able to enhance the independence of the individuals we serve. For instance, in March, over 125 employees from the Dover Corporation (including locally: Hydrosystems, OPW Fueling Components and OPW Fluid Transfer) dedicated an afternoon and completed 25 projects ranging from pouring concrete sidewalks to restoring a floor. These individuals represented 12 different states and 10 different countries. It is so amazing to me to see such generosity and willingness to serve and give-back from so many companies. Additionally, so many people are then learning about epilepsy and further enhancing our ability to continue to dispel the myths associated with epilepsy.

We are very fortunate to be a part of such a philanthropic community and are proud and very thankful to be recipients of so many generous people and the companies that afford them these wonderful opportunities.

Thank-You!

Kathy Stewart, Executive Director



'Tis the Season for Camp

A few weekends ago we hosted our annual spring weekend session of Camp Dream Catcher and welcomed 32 youth to a weekend of fun in the outdoors. Next month, we will again gather with twice as many campers for our summer camp on July 18-22; then on October 8-10, we will reconvene for our fall weekend camp. Throughout all of these camps, the kids will be singing, playing games, doing crafts, swimming, horseback riding and much more. Most important though, they will be meeting and making friends with other children who understand what they are going through. In a way, a sort of “family bond” occurs at camp and the kids can stand a little taller knowing they are not alone. We hope you will make plans to join us for this exciting and action-packed season of camping.

All of the details can be found on our website (www.cincinnati-epilepsy.org) under the “programs” tab. To enroll, simply download the “Participant Enrollment” and “Master Medical” forms. After you and your child’s doctor complete these forms, send them back ASAP and we will reserve your child’s spot at camp. Also feel free to call us at (513) 721-2905 if you have any questions or concerns. Our fundraising efforts through the year help us to provide financial assistance to those in need. If you need help, please call our office at the number above. We hope to see you at camp!





An Uneasy Pair

From: epilepsyUSA, Issue 6, 2009

A dual diagnosis of autism and epilepsy is not unusual. Dr. Sarah Spence, a clinician and researcher at the National Institutes of Mental Health in Bethesda, who studies the co-occurrence of the disorders, estimates that 20-25 % of individuals with autism or autism spectrum disorder (ASD) have seizures, though pinpointing the exact number is difficult. One problem investigators face when trying to determine the true frequency of the co-occurrence is that both disorders are very heterogeneous — and adding them together makes their presentation even more varied. “You don’t see one type of epilepsy in autism, or one age of onset, or one severity, or one type of seizure,” Spence said. “Some individuals have intractable epilepsy, while others have only two seizures in their lifetime.”

Scientists don’t understand why the two disorders occur together so frequently. A key question is whether one causes the other. In some rare situations that does appear to be the case. For example, children who have infantile spasms are very likely to develop ASD if the seizures and abnormal electrical activity in the brain are not treated effectively. Although the high frequency of seizures in individuals with ASD has been recognized by professionals since the first description of autism in the 1940s, many parents only learn of the co-occurrence when it happens to their own child. One reason that the co-occurrence of epilepsy and autism is not well known among parents and not well understood by researchers is that the two disorders have traditionally fallen under two different medical domains. Psychiatrists and behavioral specialists have carried the day in autism, while neurologists and epileptologists have focused on epilepsy and seizure activity. “Those fields have been divided for over 50 years and are only now coming together again in terms of diagnosis and treatment strategies,” says Dr. Jay Salpekar, associate professor of psychiatry and pediatrics at George Washington University School of Medicine, in Washington, D.C. and Epilepsy Foundation Professional Advisory Board member. “Very few clinicians know both.”

He sees a substantial number of patients who have both disorders and his choice of treatments for them is based on their individual symptoms and behavioral issues. “Nothing about ASD makes me pick one antiepileptic drug or another,” Dr. Salpekar says, noting that most individuals with ASD don’t require psychiatric medication. “But if I look at specific behaviors, such as impulse control problems or spontaneous aggression, those may be better treated by an antiepileptic drug that has a solid track record of treatment for mood disorders,” Dr. Salpekar said.

The impact that antiepileptic drugs might have on the symptoms of ASD is still unclear. An old theory is that controlling seizures would worsen behavior problems, as if the abnormal electrical activity that was no longer being released by seizures had to escape in some other way. More recently, some clinicians have started to suspect that controlling seizures may mitigate behavioral issues.

The full text of this article can be viewed at <http://www.epilepsyfoundation.org/epilepsyusa/magazine/Issue6-2009/AutismandEpilepsy.cfm>

Standing Tall in Capitol City



Thanks to the generosity of Mike Lykins and D & L Leasing, a group of young adults recently attended the National Walk for Epilepsy in Washington D.C. They joined with others and walked proudly with about 45 people from the Cincinnati area. They were joined by over 8,000 people from across the nation who stood up to say, “I have epilepsy, but epilepsy doesn’t have me!” The event was a powerful testimony to all who attended.

After taking part in the walk, the youth got the chance to visit a few Smithsonian Museums, tour some National Monuments and enjoy a couple of nights away from home. Thanks again to Mr. Lykins for the untiring support of our agency and those we serve!



Day of Hope Conference Raises Awareness for Epilepsy



In an effort to reach out to an underserved region, the Epilepsy Foundation of Greater Cincinnati organized a day-long Day of Hope Conference at Cabell Huntington Hospital in Huntington, West Virginia, on April 30, 2010. This free event welcomed parents and professionals, those with epilepsy and those without, and anyone affected by epilepsy to an informational conference focusing on epilepsy. With over 30 people (and one service dog) in

attendance, participants were treated to topics such as New Treatments in Epilepsy, Psychological and Spiritual Impact, Pediatric Impact, Ask the Medical Expert and more.

We would like to thank all who made this event a success, especially our presenters: Dr. Mark Stecker, Adult Neurologist at Cabell Huntington Hospital/Marshall University; Dr. Mitzi Payne, Pediatric Neurologist at Cabell Huntington Hospital/Marshall University; Mona Baran, Epilepsy Nurse Practitioner at Cabell Huntington Hospital/Marshall University; Cynthia Austin, Marshall University Clinical Psychology Doctoral Student; Terry Holley, Cabell Huntington Hospital Staff Chaplin; and Tom Koprowski, Director of Community Education for the

Epilepsy Foundation of Greater Cincinnati.

Also, deserving of thanks is Cabell Huntington Hospital, The Epilepsy Center at Cabell Huntington Hospital, and Marshall University Neuroscience.



Mitzi Payne, M.D.

Race for Hope a Huge Success



The old saying, "Many hands make light work" can be easily applied to the 1st Annual "Race for Hope" that we recently hosted in Huntington, West Virginia. Members of the local support group and the community rallied behind our cause and helped us to raise epilepsy awareness and funds for local services. Two local TV stations and the newspaper all ran in-depth interviews with people who have epilepsy and encouraged community support. The local university, Marshall, sent over enthusiastic volunteers who lined our course and cheered on our runners. The City of Huntington provided us with an army of police officers on bikes, motorcycles and in cars that made sure the course was safe while also encouraging our runners. Panera Bread provided free, delicious bagels for everyone after the race. Cabell Huntington Hospital provided us with a mirage of services from nurses working the registration and finish line to bottled water, media support contacts and much more. By the day's end, over 100 people took part in a well-executed event and the community gained a little more knowledge about epilepsy. Best of all though, funds were raised to help local people affected by seizures. We are confident that this support and enthusiasm will continue to grow.

Race Results: 5K Run - Forrest Reed, 17:13 / Skye Taylor, 20:23 5K Walk - Haley Holmquist, 23:43 / Tillis Ross, 29:30

For complete race results, visit www.tristateracer.com & follow the results tab. Find pictures at <http://www.facebook.com/pages/Epilepsy-Foundation-of-Greater-Cincinnati/82539136706>



Kids from across the country bring their stories to Capitol Hill!



The message for Congress is the same: find a cure for epilepsy and get better access to medical care that will finally end the discrimination in schools and the workplace against people with epilepsy.

This year over 40 kids representing 32 states were in Washington D.C., March 23-25, to tell Congress the

truth about what it is really like to live with epilepsy and why their voices need to be heard. Locally, Adam Sommers, age 14, from Middletown, Ohio, spent the day visiting the offices of Senators Brown and Voinovich, and Representatives Boehner, Driehaus and Schmidt to tell his story. The

ultimate goal was to urge Congress to increase funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA) and the National Institutes of Health (NIH).



Dover Days

As a non-profit agency, we frequently get the opportunity to work with very generous individuals or companies who want to give of themselves to further our mission. This may take the form of a board member, a volunteer at our run/walks or a counselor at our camp. Recently, we were blessed to be touched by over 125 individuals from around the world who made a lasting impact on Benton Center and the clients who attend this program.

On March 23, 2010, the Dover Corporation held their annual meeting with their top leaders from around the globe. The meeting was held in downtown Cincinnati over a couple of day's period. True to their mission of impacting the community where they do business, the conference included a 1/2 day of volunteering at Benton Center in Owensville, Ohio.

Arriving by large charter buses, the volunteers quickly got to work re-graveling our driveway, landscaping, installing a flagpole and installing two windows and a new floor in our Day Activity Program building. They also installed a 130' sidewalk, repaired the chicken coop, installed an automatic door opener, built bridges in the woods and made the trails more user-friendly. By the day's end, our grounds were truly transformed and the clients are benefitting daily from their hard labors.

We would like to thank the 3 local Dover Companies who spear-headed this project: Hydro Systems, OPW Fluid Transfer Group and OPW Fueling Components. In particular, we would like to thank Erik Shelton, Jeff Rowe, Junior Atkins, Tim Warning and Dave Crouse from these companies for their commitment of time and resources to make this day possible. We would also like to thank community volunteers Bob Shelton, Larry Roberts & Dave Warner from Roberts Construction, Doug Evans of Evans Landscaping & Supplies and Sardinia Concrete Company. Together, this exceptional group of people made a lasting and wonderful impact on our agency!



2010 EMERALD MILES WRAP-UP

THANK YOU TO THE 855 PARTICIPANTS WHO CAME OUT FOR THE 10TH ANNUAL EMERALD MILES RUN/WALK ON MARCH 13, 2010! EVEN WITH THE RAINY WEATHER, WE HAD A GREAT CROWD.

THANK YOU TO ALL OF OUR GENEROUS SPONSORS: FIFTH THIRD BANK, CINCINNATI BELL TECHNOLOGY SOLUTIONS, CINCINNATI BELL, HEWLETT-PACKARD, HUNT BUILDERS, AVAYA, TATA CONSULTING SERVICES, USI INSURANCE, MATRIX, KOHL'S, FOCUS ON SUCCESS, BERRY COMPANY, MARX'S HOT BAGELS, COSTCO, FLEET FEET SPORTS, NEWPORT ON THE LEVEE AND THE BAND "TEMPTED SOULS".

WE HAD A RECORD 42 TEAMS TAKING PART AND RAISING \$27,102. THE TOP 5 TEAMS WERE: TEAM B-ROX, T MONEY MILLIONAIRES, TEAM CHEESE, CALEB'S CREW AND WICKED SUPERHEROES. SO FAR, TOTAL DONATIONS AND REGISTRATIONS FROM THE RACE HAVE TOTALED \$59,137!



RACE RESULTS:

5K RUN – BLAKE JONES, PORTSMOUTH, OH, 17:42/MARLEY ROSSA, CINCINNATI, OH, 20:42
5K WALK – KEITH PRYOR, MANSFIELD, OH, 31:27/KATHY PARRISH, CINCINNATI, OH, 37:57

FOR COMPLETE RACE RESULTS, VISIT WWW.SPRUNNING.COM & FOLLOW THE REGISTER/RESULTS TAB.
TO VIEW OVER 300 PICTURES FROM THE RACE, VISIT WWW.CINCINNATIEPILEPSY.ORG & FOLLOW THE PHOTO ALBUMS TAB.



In Support of House Bill 453

For the more than 114,000 Ohioans living with epilepsy there is no cure. For the vast majority, anti-epileptic drugs (AEDs) are by far the most common and most cost effective treatment for controlling and/or reducing seizures. And until there is a cure, we need to assure them and their loved ones that they will have access to their recommended treatments as decided upon by their medical care providers.

The Epilepsy Foundation encourages your, and the Health Committee's support for HB 453 which would ensure that patients who have begun taking a prescription medication covered by their health insurance have the same, uninterrupted, continued access to that medication for as long as the medication continues to be prescribed appropriately by their physician. This is an issue of extreme importance to the patients we serve with epilepsy. Two distinguishing features of epilepsy suggest that any restriction to access to one's AEDs can be potentially very dangerous.

First, seizure control can be an

all-or-nothing proposition. Slight changes in one's medication can mean the difference between a fully controlled condition and breakthrough seizures. Critically, the patient with epilepsy exists in either of only two states: the patient is either seizure-free, or is not.

Second, the consequences of a breakthrough seizure in a well-maintained seizure-control medication regimen can be catastrophic and extreme, including: an increased likelihood of serious bodily injury and death, and, even when no physical injury occurs, seizures often result in significant social, developmental and financial consequences, including loss of one's driver's license, loss of employment, and loss of self-esteem. Consider also, if a breakthrough seizure were to occur while engaged in the various activities of daily living, such as driving. It becomes apparent that it is a matter of both individual and public safety. And finally, the consequences of a breakthrough seizure can be costly with significant expenses; ambulance, emergency room,

and doctor visits that far outweigh the monthly expense of keeping that individual on their prescribed medication. If you know anyone that lives with the uncertainty of seizures, you know how critical it is that they take their medications on time, and that they take only those prescribed by their physician.

HB 453 would provide continuity of care safeguards, giving patients the assurance that when they begin taking a drug covered by their health plan, they can complete the therapy without any disruptions by new access restrictions.

Note: This letter of support was sent to The Honorable Barbara Boyd, Chairwoman of the House of Representatives Health Committee. You can voice your support by contacting the Chairwoman or your local legislator at www.house.state.oh.us. See the entire language of the HB 453 at www.legislature.state.oh.us/bills.



Patient Assistance Programs



In these difficult times, a number of pharmaceutical manufacturers have come forward with expanded or new patient assistance programs to help individuals needing seizure medication.

Here is a list of current programs in operation for **brand name** medications:

Program/web address:	Contact Number:	Medication(s) Covered:
Abbott Patient Assistance www.abbottpatientassistancefoundation.org	(800) 222-6885	Depakene, Depakote, Depakote ER
GlaxoSmithKline Bridges to Access www.commitmenttoaccess.com	(866) 728-4368	Lamictal, Lamictal XR
Meda Pharmaceuticals Patient Assistance Program www.rxassist.org	(800) 678-4657	Felbatol
Questcor Pharmaceuticals Acthar Gel Patient Assistance Program	(888) 435-2284	Acthar Gel (ACT)
Valeant Pharmaceuticals International Patient Assistance Program www.rxhope.com	(800) 511-2120	Diastat AcuDial Rectal Gel and Mysoline
Cephalon Cares Foundation Patient Assistance Program www.cephalon.com/cephaloncares-foundation	(877) 237-4881	Gabitril
Janssen Ortho Patient Assistance Foundation www.access2wellness.com	(800) 652-6227	Topamax
Novartis Patient Assistance Foundation Program www.patientassistancenow.com	(800) 277-2254	Tegretol, Tegretol XR, Trilepta
Shire Pharmaceuticals Carbatrol Patient Assistance Program www.rxassist.org	(866) 325-8224, option 4	Carbatrol
Eisai Neurology Patient Assistance Program www.needymeds.org	(866) 694-2550	Banzel, Zonegran
Lundbeck's SHARE Call Center www.lundbeckshare.com	(888) 457-4273	Sabril
Pfizer Connection to Care www.pfizer.com	(800) 707-8990	Dilantin, Lyrica, Neurontin, Zarontin
UCB Patient Assistance Program www.rxassist.org	(866) 395-8366	Keppra, Keppra XR, Vimpat

The following programs provide **generic** medications at a discount:

Express Scripts Specialty Distribution Services Rx Outreach Medications www.rxoutreach.com	(800) 769-3880	carbamazepine, clonazepam, diazepam, divalproex, gabapentin, lorazepam, phenytoin
Xubex Pharmaceuticals Xubex Patient Assistance Program www.xubex.com	(866) 699-8239	carbamazepine, clonazepam, clorazepate potassium, diazepam, divalproex, gabapentin, lamotrigine, lorazepam, phenobarbital, topiramate, zonisamide

Vagus Nerve Stimulator assistance:

Cyberonics www.cyberonics.com	(800) 332-1375, ext. 7493	The BJ Wilder Therapy Program assists the patient with no insurance who cannot afford the VNS stimulator.
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Study Sheds Light on Which Meds Best Treat Absence Seizures in Children

Page 7

A head-to-head comparison of three popular anti-seizure drugs led by Cincinnati researchers has given doctors the first evidence-based guidelines for treating the most common form of childhood epilepsy. The findings, published in the *New England Journal of Medicine*, show that one of the oldest drugs prescribed to treat childhood absence epilepsy worked best with the fewest side effects.

Tracy Glauser, director of the Comprehensive Epilepsy Center at Cincinnati Children's Hospital Medical Center, headed up the study, which included 453 children and 32 hospitals. The study found that ethosuximide, marketed as Zarontin, was most effective as an initial treatment for preventing seizures with the fewest intolerable side effects in children newly diagnosed with childhood absence epilepsy. The medications valproic acid (Depakene) and lamotrigine (Lamictal) were also studied.

It is not uncommon for children to try two or three different drugs before they gain control over their seizures. Until Dr. Glauser's study, doctors didn't have any data-backed guidelines for which anti-seizure medication worked the best and the decision as to which drug to try first usually came down to the doctor's personal preference.

This study was funded by the National Institutes of Health (NIH). Please join us in urging Congress to increase funding for critical epilepsy public health programs at the Centers for Disease Control and Prevention (CDC), the Health Resources and Services Administration (HRSA) and the NIH. Make a difference at <http://capwiz.com/efa/home>.

Calendar of Events

June 8, 2010; 6:00-7:30 PM

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

June 9, 2010; 5:30-7:00 PM

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

June 12, 2010; 2:00-3:30 PM

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

June 16, 2010; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group:
St. Luke Hospital West, Lower Level
Conference Room (7380 Turfway Rd.,
Florence, KY 41042)



June 17, 2010; 9:00 AM-12:30 PM

Seminar "Understanding ADHD": The Health
Foundation of Greater Cincinnati

June 17, 2010; 6:00-7:30 PM

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

June 24, 2010; 6:00-7:30 PM

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

July 10, 2010; 2:00-3:30 PM

Clinton County Epilepsy Support Group

July 13, 2010; 6:00-7:30 PM

Clermont County Epilepsy Support Group

July 14, 2010; 5:30-7:00 PM

Warren County Epilepsy Support Group

July 15, 2010; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

July 18-22, 2010

Camp Dream Catcher Summer Session

July 21, 2010; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

July 22, 2010; 6:00-7:30 PM

Butler County Epilepsy Support Group

August 10, 2010; 6:00-7:30 PM

Clermont County Epilepsy Support Group

August 11, 2010; 5:30-7:00 PM

Warren County Epilepsy Support Group

August 14, 2010; 2:00-3:30 PM

Clinton County Epilepsy Support Group

August 18, 2010; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

August 19, 2010; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

August 26, 2010; 6:00-7:30 PM

Butler County Epilepsy Support Group

September 8, 2010; 5:30-7:00 PM

Warren County Epilepsy Support Group

September 11, 2010; 2:00-3:30 PM

Clinton County Epilepsy Support Group

September 14, 2010; 6:00-7:30 PM

Clermont County Epilepsy Support Group

September 15, 2010; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

September 16, 2010; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

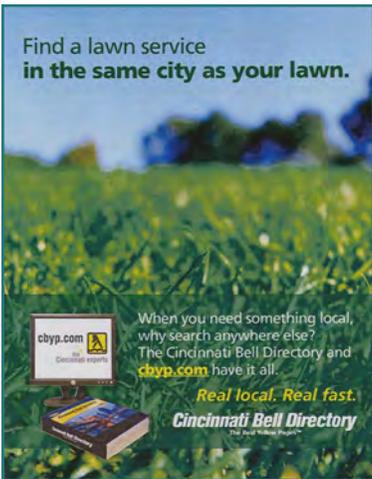
September 23, 2010; 6:00-7:30 PM

Butler County Epilepsy Support Group



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Save the Date!
Mason Mini Marathon
Sunday, November 7, 2010
5K walk/ 5K run &
New this Year—Half Marathon!!
(13.1 miles)

Do you wear a Medic Warning necklace? Do you need one?
We have a limited number of ACU-LIFE Medic Warning ID Adult Necklaces for pick-up for just \$5.00 or mailed for \$6.22. Each necklace is mounted on a 24" chain and engraved with "EPILEPSY" on the back. Act now!

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 Stewart
President of the Board of Directors: James Comodeca

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.

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