

2009 Volume II



Inside this issue:	
Kids Speak Up!	2
Mardi Gras Update	2
Emerald Miles Update	3
Volunteer Opportunities	3
Community Care Days	4
Rampart	4
Talk About It!	4
Camp Dream Catcher	5
Volunteer Award	5
New Onset Clinics	6
Sand Volleyball	6
Calendar of Events	7
Clermont County Support Group Move	7

Cincinnati Kids Take it to the Streets in DC

For the second year in a row, a vanload of youth from the area attended the National Walk for Epilepsy on March 28. They were joined by 9000 other people from around the country who decided the time is now to stand up and be counted. At the march, the youth were inspired by Greg Grunberg from the TV show Hero's, along with Alan Faneca from the NY Jets and our very own, Geoffrey Pope of the Cincinnati Bengals. Together they proclaimed loud and clear, "not another moment lost to seizures!"

After the walk, the youth visited the Capitol Building, the Library of Congress, a couple of the Smithsonian's and the National Monuments. Before leaving the city, they were also able to visit Arlington Cemetery and buy a few souvenirs to take home. All and all, everyone had a great time and represented our city well.



We would like to thank Mike

Lykins from D & L Leasing for once again donating a large van for the group's travels. A special thanks also goes out to adult volunteers Ron Childs, Debi Schwartz and Dale Grillot for graciously donating their time to make this trip possible.

Ask the Expert: Is epilepsy surgery an option for me?

David M. Ficker, MD
Director, Epilepsy Monitoring Unit, Cincinnati Epilepsy Center
University of Cincinnati Medical Center



David M. Ficker, MD

For some people with epilepsy, currently available medications are unable to completely control seizures; in fact, for about 1 in 3 with epilepsy, seizures remain uncontrolled (this is called "medication resistant" or "refractory" epilepsy). Once an individual does not respond to trials of three different seizure medications, the chance for complete seizure control is less than 10 percent. Fortunately, for some patients, epilepsy surgery may be an option that may offer a good chance for seizure control.

The evaluation for surgery is performed at specialized epilepsy centers and basically involves pinpointing the location in the brain of seizure onset. There are multiple tests that are performed including video/EEG monitoring, several different brain imaging tests (MRI and PET scans) and testing of language and memory function. If a patient has temporal lobe epilepsy, then surgery may be an excellent treatment option and may offer up to a 60 to 90 percent chance of seizure freedom. The decision to offer surgery is usually made by a team of epilepsy specialists

after all testing is reviewed. Not all patients will be candidates for surgery, but sometimes vagus nerve stimulation or other treatments may then be recommended.

You can visit the following websites to learn more about epilepsy surgery:

www.mayfieldclinic.com/PE-EpilepsySurg.htm

www.epilepsyfoundation.org/about/treatment/surgery/

www.epilepsy.com/EPILEPSY/surgery



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



Mandy Valentine, Rep. Jean Schmidt and Pat Valentine

Following the National Walk for Epilepsy on the National Mall March 28, children 7-16 years of age from throughout the US along with their parents and affiliate staff descended on Washington DC for the 3rd annual Kids Speak Up! Program. This year The Epilepsy Foundation of Greater Cincinnati was proud to sponsor 2 kid's efforts to raise epilepsy awareness and learn about advocacy at the national level.

Though the Cherry Blossom Festivities were officially underway and the city was swarming with tourists eager to view the trees, the news was that due to the cool weather we would miss the blooms by just a couple of short days! No matter. The job to be done was of a more serious nature.

Allison Baker, 13, and her parents Ellen and Keith from Butler County, and Mandy Valentine, 16, and mom, Pam, of Mason, gave their time and effort to deliver a united message from the epilepsy community. The group urged members of Congress to help secure a better future for children with seizures by supporting federally funded medical research, programs that improve access to appropriate care, and public health education to reduce discrimination against people with epilepsy.



Pat & Mandy Valentine and Ellen, Allison & Keith Baker

By the end of the day, the offices of Senators Sherrod Brown and George Voinovich and Representatives John Boehner, Michael Turner and Jean Schmidt were visited by our young advocates to share their stories with our elected officials to help increase public awareness about epilepsy. There are many positive outcomes from the Kids Speak Up! Programs, including substantial local and national press. The kids make a tremendous impact on lawmakers and this has translated into greater support for epilepsy programs on Capitol Hill and can be a wonderfully positive educational experience for participants.

Mardi Gras Update

This year's Mardi Gras Gala took place on February 29th, on Fat Tuesday, with cocktails, dinner and music at the Cincinnati Hyatt Regency. This 5th Annual Fundraiser brought out the generosity of some of this city's finest. Special recognition was given to Rick Friedmann, from Health Care Accounting Services, LLC for his dedication and service to the Epilepsy Foundation.

Mr. Thom Brennaman exceeded the Gala with his usual wit and witticisms, wowing the crowd with his live auctioneering abilities, serving up the very best seats for several Cincinnati Reds games for the 2009 season. New this year, The Hyatt donated two, Chef's Dinners for 10 guests with overnight accommodations and breakfast.

This year's guest speaker, Ms. Mandy Valentine, 16, a sophomore at Mason High School, captivated the audience with her inspirational story of her own struggles and successes in living with epilepsy.

We would like to thank Cincinnati Bell Technology Solutions and Cincinnati Bell for their generosity in co-sponsoring this year's Mardi Gras.

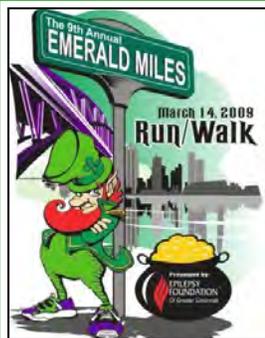
Of special note as King's Court Sponsors: Cisco, EMC², Fifth Third Bank, Hunt Builders Corporation, Microsoft, Nortel, Standard Register, and UCB Pharma.

Many thanks to the helpful people from the local community and businesses who volunteered their time and efforts to make an event



Thom Brennaman, Jim Comodeca, Jim Scott, Kathy Stewart, Mandy Valentine, John Burns & Jeff Ficke

of this size possible. We would like to acknowledge volunteers from Fifth Third Bank, Jane Stropes, Brenda Stier, Patty Szabo, Shelia Leavitt, Holy Family Home Educators Youth, Member of the St. Xavier High School Marching Band and the Cincinnati Chapter of the International Association of Administrative Professionals.



EMERALD MILES 2009

The Epilepsy Foundation of Greater Cincinnati thanks you for all your support at the 9th Annual Emerald Miles 5K Run/Walk on March 14, 2009! We had a record year raising over \$46,000 with over 920 people participating. We want to thank our wonderful sponsors:

Pfizer ♦ Health Care Services ♦ AmQuip ♦ Marx's Bagels ♦ Avon ♦ Matrix Company ♦ D & L Leasing ♦ McCabe's Granola ♦ Fleet Feet ♦ Newport on the Levee ♦ Focus on Success ♦ Oxford Physical Therapy ♦ USI Midwest

We want to give a special thanks to our 39 team captains, especially **Kathy Smith** from "Team Cheese," for being both the *Top Individual Fundraiser* and captain of the *Top Fundraising Team* generating \$3865.00 for the Epilepsy Foundation. Our other "Top Five Individual" fundraisers were: Mary Broxterman, Dennis Stemler, Staci Heiden, Allison Hughes and Aryn Morgenroth.

Our deepest gratitude to each team that raised over \$500, which includes:

Aidan's Allies ♣ Ally's Army ♣ Caleb's Crew ♣ Fab 4 (Plus More!) ♣ Joey's Joggers ♣ Lucky Charms
Meggie Moos Crew ♣ Remember Dennis ♣ Seton Supports Kasie ♣ Strides ♣ T-Money Millionaires ♣ Team B-Rox
Team Cheese ♣ Team Hooah ♣ The Never Ending Fighters ♣ University of Cincinnati Neuroscience Institute

We also give a great round of applause to the band "Tempted Souls" which provided the complimentary music after the race. Of course the event could not occur without the assistance of almost 50 volunteers that helped make the race a success!

The Top Finishers for the Emerald Miles 5K event were:

Top Female Runner : Natacha Smith 20:57 *Top Male Runner*: Ryan Woolley 17:12
Top Female Walker: Keley Smith-Keller 35:48 *Top Male Walker*: Dan Goetz 37:36

To get the entire list of finishers and their times, visit: www.sprunning.com

THANKS FOR SUPPORTING THE EPILEPSY FOUNDATION OF GREATER CINCINNATI!

Pictures of the event are available at: www.cincinnati-epilepsy.org. Follow the "Photo Albums" link on the right side of the page.



Volunteer Opportunities



Help Wanted: Openings for reliable, dedicated people!

Sand Volleyball Tournament: Saturday, August 15, 2009

Do you want to help plan our 1st Sand Volleyball Tournament to be held in August? If you have been thinking about volunteering, now is the time to get involved! We want to gather dedicated people who are passionate about helping the Epilepsy Foundation so we can build stronger ties to the community. The commitment would be 1 or 2 meetings in May, June, July and August and working the day of August 15th.

Mason Mini Marathon: Sunday, November 8, 2009

If you can't help out with Sand Volleyball or you live in the Mason area and would like to be on the Mason Mini Committee we are now forming a team to make this an area wide Mason event and we need your help! We have ambitious goals of attracting over 1000 participants to this event and we can't do it alone. Time commitment is 1 meeting per month May-August and 2 meetings per month September-November.

To be a part of one or both of these events, contact the office at (513) 721-2905.

Community Care Days 2009

Every year the Epilepsy Foundation benefits from the hard work of hundreds of people who donate their labors to our agency to paint, mulch, pave sidewalks, build decks and

much more. We are beginning to plan for our Community Care Days 2009. If you and your fellow employees would like to donate a day to our agency to help in this

worthwhile project please call us at (513) 721-2905. We would be happy to meet with your company representatives to plan a great day of service!



RAMPART-Rapid Anticonvulsant Medication Prior to Arrival Trial

The University of Cincinnati, Department of Emergency Medicine is happy to announce that the RAMPART Seizure study is set to begin. We want to remind everyone that this study involves Status Epilepticus. Treatment will begin prior to arrival at the hospital. Patients, determined by paramedics to be in status epilepticus, will receive either Midazolam IM (with an auto injector) or Lorazepam IV. Both of these medications are currently used for treatment of seizures in the emergency setting. The EMS departments locally that will be participating are: Blue Ash, Forest Park, Green Township, Cincinnati Fire, Covington, Independence and Florence, KY.

The past year was spent on community consultation and public disclosure efforts and our goal has been to inform as many people as possible about this study. For more information the local RAMPART phone line is 513-558-0095. The national number is 1-866-929-NETT. The local rampart website is: <http://sitemaker.umich.edu/uc/home> and the national website is: <http://sitemaker.umich.edu/nett/welcome>.



****Remember****

The gift of your gently used car, truck or **minivan** is tax deductible and will be used in our residential program!

The Epilepsy Foundation of Greater Cincinnati is pleased to announce a new fundraiser in affiliation with our national office called "Talk About It! @ Dinner." This new initiative debuted with a short video on www.talkaboutit.org with actor, Greg Grunberg, TV star from the show *Hero's*. "TalkAboutIt.org is a

new star-studded web site created to educate the world about seizures and epilepsy on behalf of the 50 million people around the globe, who are coping with the condition, including his oldest son." The goal of the event is to raise awareness and money for the Epilepsy Foundation and our mission of epilepsy through hosting

"at-home" dinner parties. This event is both a valuable fundraiser, public awareness campaign and a cultivation opportunity all wrapped into one event. All money raised will stay locally in our community. If you would like to be included in this exciting program please contact our office at (513) 721-2905.





New Family Camp



All families who have a child with epilepsy are invited to our first-ever Family Camp on June 19 and 20, 2009. This exciting new program will give the entire family the opportunity to attend our camp, stay in a cabin as a family, enjoy fun activities like swimming, canoeing and more, and have the chance to meet other families who share similar challenges. We are also working with professionals in the field of neurology to offer educational sessions about epilepsy-related topics.

Families will arrive in time for dinner on the 19th and stay until dinner on the 20th. If your family is not able to spend Friday night, you may register to join us just for the day on Saturday. Cost is \$50 per person for the overnight or \$20 for Saturday and includes meals. Space is limited so register for the Family Camp now at (513) 721-2905.



Summer Camp Dream Catcher 2009



Parents, send your child to the nationally recognized camp designated for children with epilepsy for 5 days in the midst of trained counselors. Allow your child to establish friendships while developing a lasting support system in their lives. We create a wonderful atmosphere so all the kids have a GREAT time at camp. They take part in such activities as: hiking, arts & crafts, swimming, archery, horseback riding,

fishing, boating, shooting BB guns, canoeing, kayaking, hay rides, singing, scaling a climbing wall and much, much more. Camp Dream Catcher creates memories to last a lifetime!

When: Sunday, July 12 -Thursday, July 16
Where: Camp Kern in Oregonia, Ohio
Cost: \$350.00
Contact: (513) 721-2905

If needed, there is financial assistance available through PACE (Parents Against Childhood Epilepsy, Inc.), Family Resources, and the Epilepsy Foundation of Greater Cincinnati.

Mason Associate Named "Volunteer of the Year" by Warren County United Way

Ron Childs III, enrollment and billing representative, was recently honored by the United Way of Warren County, Ohio, for his work with the Epilepsy Foundation of Greater Cincinnati. Ron began volunteering with the Epilepsy Foundation four years ago, spending his time helping children with epilepsy through camps and fundraisers.

The following account about Ron's volunteerism was shared by Mark Findley, assistant director of the Epilepsy Foundation, who nominated Ron for the award:

"We offer camps for children with epilepsy at Camp Kern four times a year. Ron schedules his vacation around these programs so he can spend the entire week or weekend at camp with the kids. He sleeps in the cabin and is often up through the night caring for children who have seizures. Then during the day he is constantly with the kids: swimming, playing games, horseback riding, etc. In between sessions, Ron researches and brings materials for various crafts and activities for the kids to enjoy. He has also enlisted the help of his wife in leading "beading sessions" for the kids. During the camps, Ron is always ready to help, never shying away from helping the "needy" campers or being extremely caring and patient.

Last spring, Ron volunteered to go on a weekend trip with 10 young men as they attended the National Walk for Epilepsy in Washington, DC. Again Ron took time off work and was very helpful on this long, but exciting trip. The youth were empowered to stand up and tell the world that they have epilepsy, but epilepsy does not have them. One of the reasons they were able to do this is because they have seen Ron live this message out in his service to our agency. Despite his diagnosis of epilepsy, Ron has finished school, become successful in his career and most of all, given back to the community. He is an excellent role model!

Besides Ron's volunteerism at camp, he has been a faithful volunteer at our fundraisers. Recently at our 1st annual Mason Mini Marathon, Ron and his wife worked throughout the event to see that it all went smoothly and, as is Ron's style, he was there early and stayed until the end to lend a hand where needed. Our agency has truly been blessed by Ron's commitment to service and his willingness to give back to the community."



Congratulations, Ron, for this honor!

New Onset Clinic

The Epilepsy Foundation of Greater Cincinnati in conjunction with The Neuroscience Institute and Cincinnati Children's Hospital Medical Center is now offering on-site counseling during each office's new onset clinic, currently once a month. This is an opportunity for newly diagnosed patients or their parents and caregivers to discuss the non-medical issues faced by those affected by epilepsy. These counseling services are free and are done following regularly scheduled office visits. To find out more about these and other services offered by the Epilepsy Foundation of Greater Cincinnati call us at (513) 721-2905.

1ST ANNUAL CO-ED SAND VOLLEYBALL TOURNAMENT

SATURDAY, AUGUST 15, 2009

THE SANDBAR ON KELLOGG AVENUE

JOIN US FOR A DAY OF FUN IN THE SAND! THIS IS A GREAT OPPORTUNITY TO GET YOUR COWORKERS, FRIENDS OR FAMILY TOGETHER FOR A GREAT TIME WHILE SUPPORTING A GREAT CAUSE. THERE WILL BE MUSIC, SAND AND PLENTY OF GREAT VOLLEYBALL. FOOD AND DRINKS WILL BE SOLD AT THE EVENT.

- **REGISTRATION AT 12:30 PM; PLAY BEGINS AT 2:00 PM**
- **TEAMS OF 8 PLAYERS WITH 6 ON THE COURT INCLUDING 2 FEMALES PLAYING AT ALL TIMES.**
- **POOL PLAY TOURNAMENT WITH TOP 2 TEAMS FROM EACH POOL ADVANCING TO A SINGLE ELIMINATION GAME..**
- **RALLY SCORING WILL BE USED.**
- **PRIZES WILL BE AWARDED TO THE 1ST AND 2ND PLACE OVERALL TEAMS.**
- **REGISTER EARLY FOR THE BEST PRICES! REGISTRATION COST PER TEAM:**
 - ☀ **\$200 IF POSTMARKED BY 6/30/09**
 - ☀ **\$225 IF POSTMARKED BY 7/31/09**
 - ☀ **\$250 AFTER 8/1/09**

TO REGISTER AS A TEAM CAPTAIN, FILL OUT THE FORM BELOW AND SEND IN WITH YOUR PAYMENT OR GO TO WWW.CINCYSAND.COM TO REGISTER ON-LINE. AT THE EVENT, ALL TEAM MEMBERS WILL NEED TO SIGN AN "ACCIDENT WAIVER & RELEASE OF LIABILITY" FORM. TO EXPEDITE YOUR CHECK IN AT THE EVENT, YOU MAY DOWNLOAD AND COMPLETE ALL NECESSARY FORMS BEFORE ARRIVING. (AVAILABLE AT: WWW.CINCYSAND.COM)

**RETURN FORM TO: EPILEPSY FOUNDATION OF GREATER CINCINNATI
895 CENTRAL AVE., SUITE 550
CINCINNATI, OH 45202**

2009 REGISTRATION FORM

TEAM CAPTAIN: _____ **TEAM NAME:** _____
ADDRESS: _____ **PHONE:** _____
CITY, STATE, ZIP: _____ **E-MAIL:** _____

AS TEAM CAPTAIN, I UNDERSTAND THAT I AM RESPONSIBLE FOR COMMUNICATING ALL "RULES OF PLAY" AND "GUIDELINES" TO MY TEAM (AVAILABLE AT: WWW.CINCYSAND.COM). I ASSURE THAT ALL TEAM MEMBERS WILL FOLLOW RULES AS STATED. MY TEAM WILL BE READY TO PLAY AT 1:45 PM. I WILL CHECK MY TEAM IN AT THE REGISTRATION TABLE ONCE THEY ARE ASSEMBLED.

I UNDERSTAND THAT TOURNAMENT PLAY MAY BE POSTPONED OR CANCELLED IN CASE OF SEVERE WEATHER (THUNDER/LIGHTNING), BUT RAIN WILL NOT STOP PLAY.

I UNDERSTAND THAT THE TEAM REGISTRATION FEE IS NON-REFUNDABLE FOR ANY REASON.

CAPTAIN SIGNATURE: _____ **DATE:** _____

Calendar of Events

May 12, 2009; 6:00-7:30 PM

Clermont County Epilepsy Support Group: Miami Township Civic Center Conference Room (6101 Meijer Dr., Miami Township, OH 45150)****PLEASE NOTE NEW LOCATION!!!****

May 13, 2009; 6:00-7:30 PM

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

May 20, 2009; 6:00-7:30 PM

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

May 21, 2009; 6:00-7:30 PM

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

May 28, 2009; 9:00 AM

Seminar "Professional Ethics": The

Health Foundation of Greater Cincinnati

May 28, 2009; 6:00-7:30 PM

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

June 9, 2009; 6:00-7:30 PM

Clermont County Epilepsy Support Group

June 10, 2009; 6:00-7:30 PM

Warren County Epilepsy Support Group

June 17, 2009; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

June 18, 2009; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

June 19-20, 2009

Camp Dream Catcher Family Camp Session: Camp Kern

June 25, 2009; 9:00 AM

Seminar "Social Work Supervision: A Two-Way Process": The Health Foundation of

Greater Cincinnati

June 25, 2009; 6:00-7:30 PM

Butler County Epilepsy Support Group

July 8, 2009; 6:00-7:30 PM

Warren County Epilepsy Support Group

July 12-16, 2009

Camp Dream Catcher Summer Session

July 14, 2009; 6:00-7:30 PM

Clermont County Epilepsy Support Group

July 15, 2009; 6:00-7:30 PM

Northern Kentucky Epilepsy Support Group

July 16, 2009; 6:00-7:30 PM

Hamilton County Epilepsy Support Group

July 23, 2009; 6:00-7:30 PM

Butler County Epilepsy Support Group

July 30, 2009; 9:00 AM

Seminar—Topic TBA: The Health Foundation of Greater Cincinnati



***Clermont County Epilepsy Support Group
Moves to Milford***

Tuesday, May 12, 2009 from 6:00 PM - 7:30 PM, and every 2nd Tuesday of the month, the Clermont County Epilepsy Support Group will be meeting at the Miami Township Civic Center located at 6101 Meijer Drive, Milford, Ohio 45150. This support group will meet in the conference room and is free and open to friends, family, caregivers and those with epilepsy to discuss the challenges in overcoming the obstacles epilepsy presents. Groups are facilitated by a licensed social worker. Call 513-721-2905 for more info.

Please Note: This Support Group replaces the Epilepsy Support Group previously held at Mercy Hospital Clermont.

Save the Date!!

Celebrate Epilepsy Month with us in Warren County! Lace up your running (or walking) shoes and begin training for our 2nd Annual Mason Mini Marathon on Sunday, November 8, 2009. The event will be held at Mason High School and will feature a 15K run as well as a 5K run and walk. The race will start at 9:00am and wind its way through two local parks and surrounding communities in beautiful Warren County.





**EPILEPSY FOUNDATION
OF GREATER CINCINNATI**

895 Central Avenue, Suite 550
Cincinnati, OH 45202

Phone: 513-721-2905/877-804-2241
Fax: 513-721-0799
E-mail: efgc@cincinnatiepilepsy.org

We're on the web!
www.cincinnatiepilepsy.org

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

Would you like to receive The Update at your home or office? Just call, mail or e-mail the Epilepsy Foundation (at the above address) your mailing information to request your free subscription!



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.



Non-Profit Org.
U.S. Postage
PAID
Permit No. 2532
Cincinnati, OH