



**EPILEPSY
FOUNDATION
OF WESTERN OHIO**
Not another moment lost to seizures

Epilepsy Moments

Spring 2009

2009 WALK FOR EPILEPSY

Not another moment lost to seizures™



Saturday, May 30
Shelter # 3 at
1700 Delco Park Dr.
Kettering, Ohio
9:30 am Registration
10:30 am Walk begins

Join us for our annual Walk for Epilepsy & Family Picnic

Please consider joining with us this year by forming your own team to join you at the Walk for Epilepsy. This is a great way to celebrate the life of your loved one with epilepsy or to honor the memory of someone you know that lived with epilepsy. You can create your own webpage very easily by going to our Walk site and registering. Visit www.WalkForEpilepsy/kintera.org. We'll be happy to help you if you need assistance. You can add a photo and your own story of living with epilepsy, and then send it out to your email list to get supporters and recruit team members. We need you! Come join in the fun!

Walk for Epilepsy Honoree—Mrs. Joan Schreck

In honor of the 35th anniversary of the Epilepsy Foundation of Western Ohio 1974—2009 we have chosen to honor our Founder, Mrs. Joan Schreck (pronounced Joanne).

Many of you know Joan and her husband Bill, have seen them at our events, or heard her story. She is the courageous founder of the EFWO. She had epilepsy at a time when people with epilepsy were still being placed in institutions and there was a law on the books that prevented people with epilepsy from getting married. As a child she wasn't told why she was taking medication and it wasn't until she was an adult, living on her own that she found out she had epilepsy.



Thankfully, we've come a long way from those days, and we owe many thanks to Joan for being brave enough to reach out and start talking to other people with epilepsy. She, along with several other families started holding meetings for people with seizures, and their families. We owe a debt of gratitude to Joan for starting an agency that has provided important services and programs for the past thirty-five years. Please join Joan at the Walk and help to support these important programs and keep them available as we brave this challenging financial landscape. We need your help to ensure that EFWO is here another 35 years!

BANZEL (RUFINAMIDE) NEW ADD-ON TREATMENT

Banzel (rufinamide), an add-on therapy to treat seizures associated with Lennox-Gastaut syndrome (LGS) in children 4 years and older and adults, is now available in 200-mg and 400-mg tablets by medical prescription.

The FDA approved Banzel, a triazole derivative that is structurally unrelated to currently marketed antiepileptic drugs (AEDs), in November 2008. Banzel is believed to exert its effect by regulating the activity of sodium channels in the brain, which carry excessive electrical charges that may cause seizures.

A double-blind, placebo-controlled pivotal study of LGS patients treated with Banzel as adjunctive therapy showed a 42.5 percent median reduction in frequency of drop attacks, seizures that cause a person to lose consciousness and fall to the ground, compared with a 1.4 percent median increase for placebo-treated patients.

LGS is one of the most severe forms of childhood epilepsy and characterized by multiple and frequent seizures. Children usually experience the onset of LGS between the ages of 1 and 5 years old. LGS accounts for 1 to 4 percent of all childhood epilepsy cases; approximately 300,000 children under the age of 14 in the U.S. have epilepsy. The condition is difficult to treat, with patients often taking multiple AEDs in attempts to control seizures.

HELP SUPPORT EPILEPSY SERVICES



EFWO Harley Davidson Raffle!

Ever want to own your own Harley but didn't want to pay the full price? Now is your chance! Buy a raffle ticket and you may be the proud owner of this 2009 XL1200C Sportster. It's has beautiful custom colors of Black Ice and Blue Ice (purple/blue). Tickets are \$20 each and only 1,400 will be sold. We hope to draw the winning ticket by mid June. Check out the color photos on Facebook although you still can't see the real beauty of it. Call the office for tickets! 937-233-2500 or mail \$20 to EFWO and we'll send you a ticket.



Thanks to Liberty Savings Bank's commitment to the communities it serves and to charities, they have created a unique program called **Bank for a Cause**. When you open a checking account and meet the criteria of the program, Liberty will donate 1% of the debit card signature-based purchases to the Epilepsy Foundation Western Ohio for each month. As it becomes more and more difficult for non profit agencies to raise the necessary money to maintain programs, this type of program becomes more valuable. You can learn more about **Bank for a Cause** by visiting www.bankforacause.com. **Please consider opening an account today and as you purchase groceries, clothing, gasoline or make any other purchases, you'll be helping EFWO!**

Donate Your Used Vehicle to the Epilepsy Foundation

Are you thinking of selling or trading in your car, boat, or RV? Why not donate it instead? By donating your car you can earn a charitable tax deduction and you help make a difference in the lives of people with epilepsy. **Please make sure you tell them you are donating to The Epilepsy Foundation of Western Ohio.** For information, call (877) 332-2777.



The Epilepsy Foundation of America World Points Platinum MasterCard Credit Card

Every time you make a purchase, The Epilepsy Foundation will receive a contribution-at no extra cost to you! Points earned on purchases can be redeemed for car rentals, hotels stays in the US, redeemed for brand-name merchandise or gifts cards. Accepted everywhere that MasterCard is accepted. Call EFWO for an application at (937) 233-2500.

TAKE A LOOK AT OUR GROUPS!

With the addition of new part-time staff, we have been able to revamp and re-launch some of our groups. Take a look below and see what we have for you! All groups meet in the Epilepsy Foundation office located in Huber Heights.

“No Labels” Youth Group 4th Tuesday of every month from 6:00 pm -7:30 pm

Ages 12-18 meet to learn about seizures while having fun and making new friends! This group will offer an opportunity to spend time with others who understand what it's like to live with seizures. We'll decide together what type of fun activities we'd like to participate in month to month and we'll learn to give back to our community as well. This group is led by Katie Russell, part time advocate who is also living with a seizure disorder.



Parent Information Group 4th Tuesday of every month from 6:00 pm - 7:30 pm

This group meets at the same time that the “No Labels” Youth Group meets so that parents don't have to go home and come back to pick up their children. We will talk about topics such as the different types of seizures, first aid for seizures, problems in school, how to request help for your child in school, relieving stress, and other pertinent topics parents are interested in discussing. This group is lead by Betty Cornwell, part-time community educator, who has been an advocate for disabled children in the Miami Valley for 18 years and is a mother of two grown children with epilepsy.

Young Adult Group 3rd Tuesday of every month from 6:00 pm -7:30 pm



Young adults, ages 19-27, living with seizures are starting to gain their independence, enter college, find jobs, live on their own, date and form serious relationships, and manage their own lives. For some, if their seizures are uncontrolled, it can be a very disappointing and challenging time. This group will offer time to share information and resources, celebrate successes, discuss frustrations, and talk about living life with a seizure disorder. Young adults will enjoy this group that is led by Katie Russell.

Men & Epilepsy Group: 1st Thursday of every month from 6:30 pm - 8:00 pm

Men with epilepsy share their experiences, learn new resources, discuss issues of importance to all men, and make new friends. The group is led by Eric McLellan P.C.C. Eric is a professional counselor and has a sister with epilepsy. New members are always welcome.

Adult Socialization Group 3rd Thursday of every month from 10:00 am - 2:00 pm

This group is for adults with intractable seizures who enjoy getting together and socializing. Some of the activities planned for this year include, flower pot decoupage in April, a picnic and tour at Deed's Carillon Park in May, attendance at the Dragon's Baseball Game in June, and other seasonal activities.

Come and join in the fun and friendship!



Managing STUDENTS with SEIZURES

A Training for School Nurses

Saturday, April 25, 2009

9:00 am—12:30 pm

If you have a child in the local school systems, please ask your principal to make sure your school nurse attends this important annual training session. They will not only learn about epilepsy/seizures but they will also go home with professional resources that they can use to train other school personnel and students, including the latest training DVD.

The training offers 3.2 Continuing education credits for nursing. All training materials were created in partnership by the Epilepsy Foundation affiliate network with the National Association of School Nurses and The Epilepsy Foundation of America. To register please send contact information along with a check for \$10.00 to EFWO, 7523 Brandt Pike, Huber Heights, OH 45424.

“This training is made possible through a grant from the Center’s for Disease Control and Prevention (Grant # U58/CCU322072). Its contents are solely the responsibility of the authors and do not necessarily represent the views of the CDC.”



What is Pfizer’s Epilepsy Scholarship Award?

Who Can Apply?

How to Apply:

A 1-year \$3,000 scholarship honoring 25 outstanding students who have:

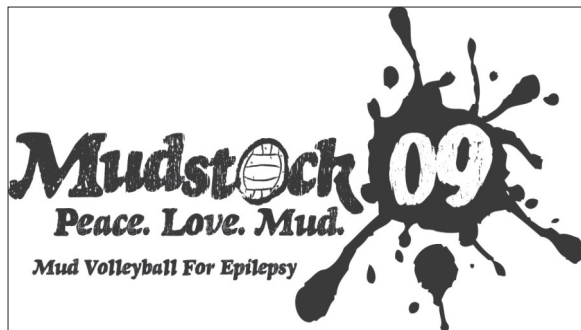
- Overcome the challenges of epilepsy
- Been successful in school
- Done well in activities outside the classroom or in the community
- Shown a desire to make the most out of college or graduate school

You may apply for Pfizer’s Epilepsy Scholarship Award if you are:

1. Under a doctor’s care for epilepsy
2. In school as:
 - A high school senior who has applied to college
 - A freshman, sophomore, or junior in college
 - A college senior who has applied to graduate school

- Ask your doctor or guidance counselor for an application.
- Download the application from www.epilepsy-scholarship.com.
- **Submit all of your materials via mail by the May 1, 2009 deadline**

CHECK OUT THESE EVENTS!



MUD Volleyball, the premier event for the Epilepsy Foundation will take place on Saturday, July 11 at 1301 E. Siebenthaler Avenue, Dayton, OH. This year's tournament features competitive and non-competitive tournaments; the choice is yours. New this year, **all registration** will be done online at www.daytonmud.com. We expect to sell out quickly, so gather your team, register online and join us for a day of sun, fun and **MUD!** Volunteers needed!

GOLF SCRAMBLE FOR EPILEPSY—Sponsors Needed!

Planning for the 11th Annual Golf Scramble for Epilepsy has started. Unfortunately, we received the news that two of our major sponsors cannot return, as they too, are victims of the recession. Corporate sponsorship is the only way that we actually profit from this event. It helps to pay event expenses. If you know a company that might be willing to step in and become a Title sponsor of this event, please contact our office.

If we can replace our sponsors, the event will be held on Monday, September 28 at the Heatherwoode Golf Club located at 88 Heatherwoode Blvd., Springboro, OH. By supporting the Golf Scramble, you will assist the Foundation in providing vital services and programs for residents of 11 western Ohio counties, including Auglaize, Champaign, Clark, Darke, Greene, Logan, Mercer, Miami, Montgomery, Preble, and Shelby.

Sponsorship opportunities are available; for more information, please contact Janine Poppa at (937) 233-2500 or jpoppa@ohioepilepsy.org.



MEET OUR NEW STAFF



Betty Cornwell is a native Daytonian, who graduated from Patterson Coop High School in the medical technologies field. She received a Bachelor of Science Degree in Rehabilitation Education in 1979 from Wright State University. Since then, she has raised two children with epilepsy, ADHD, and many learning disabilities; both are now college graduates. Betty volunteered at EFWO many years ago as a Community Educator and is now back to do the same in a part-time position. She has represented parents and children in school districts as a lay advocate for the past 18 years. Betty leads the **Parent Information Group** and is excited to meet new families and help them empower their children.



Katie Russell is a native of Centerville, Ohio. She graduated from Alter High School in 2003 and attended Miami University in Oxford, Ohio and Sinclair Community College in Dayton, where she majored in Sociology and Communications. Katie was diagnosed with epilepsy in 2002.

Katie is the leader of both the **Young Adults Group** and the **"No Labels" Youth Group** and is working to keep our Facebook page updated and active. She is very excited to be with others that share a common bond with her!

2009 SPRING/SUMMER CALENDAR

APRIL

2nd	Men & Epilepsy Group	6:30 PM-8 PM
16th	Adult Socialization Group	10 AM-2PM
21st	Young Adult Group	6 PM-7:30PM
23rd	EFWO Board Meeting	
25th	School Nurse Training	9 AM-12:30 PM
	Treasure Hunt Road Rally	5:45PM-11PM
28th	"No Labels" Youth Group & Parents Group	6 PM-7:30 PM

MAY

7th	Men & Epilepsy Group	6:30 PM
19th	Young Adult Group	6 PM-7:30 PM
21st	Adult Socialization Group	10 AM-2 PM
28th	EFWO Board Meeting	6pm
25th	Memorial Day- Office Closed	
26th	"No Labels" Youth Group & Parents Group	6 PM-7:30 PM
30th	Walk for Epilepsy, Delco Park	9:30 AM

JUNE

4th	Men & Epilepsy Group	6:30 PM
16th	Young Adult Group	6 PM-7:30 PM
18th	Adult Socialization Group	10 AM-2 PM
23rd	"No Labels" Youth Group & Parents Group	6 PM-7:30 PM
25th	EFWO Board Meeting	6 PM

JULY

2nd	Men & Epilepsy Group	6:30 PM
11th	MUD Volleyball for Epilepsy	7 AM-8:00 PM
16th	Adult Socialization Group	10 AM-2 PM
21st	Young Adult Group	6 PM-7:30 PM
	EFWO Board Meeting Cancelled	
28th	"No Labels" Youth Group & Parents Group	6 PM-7:30 PM

AUGUST

6th	Men & Epilepsy Group	6:30 PM
18th	Young Adult Group	6 PM-7:30 PM
20th	Adult Socialization Group	10 AM-2 PM
25th	"No Labels" Youth Group & Parents Group	6 PM-7:30 PM
27th	EFWO Board Meeting	6 PM

Epilepsy Foundation on Facebook

Check out our new Facebook page! Posted here we have our events, discussion boards, notes and much more! It is a great way to connect with other people in the Dayton area that are living with epilepsy. Simply go to www.facebook.com and search for Epilepsy Foundation of Western Ohio.

Website Update

We hope you will be pleased with the updates to our website. New resources, outside links and even the newsletter can now be accessed. Take a peek at www.ohioepilepsy.org.

FDA Approved Generic Topamax to Prevent Seizures

The U.S. Food and Drug Administration has approved the first generic version of Topamax tablets (topiramate) to prevent seizures

"Generic drugs undergo a rigorous scientific review to ensure they will provide patients with the same dose of high quality, safe and effective active ingredients as the name brand product," said Gary Buehler, director of the Office of Generic Drugs in the Center for Drug Evaluation and Research. "The FDA is committed to providing access to safe and effective generic drugs as soon as the law permits when a brand name drug's patents and exclusivities expire."

Topiramate tablets in several different strengths have been approved to be marketed by the following firms: Roxane Laboratories Inc., Par Pharmaceuticals Inc., Mylan Pharmaceuticals Inc., Barr Laboratories Inc., TEVA Pharmaceuticals USA, Ranbaxy Laboratories Ltd., CIRLA Ltd., Glenmark Generics Ltd., Cobalt Laboratories, Apotex Inc., Zydus Pharmaceuticals USA., Aurobindo Pharma Ltd., Torrent Pharmaceuticals Ltd., Invagen Pharmaceuticals Inc., Unichem Ltd., Sun Pharmaceuticals Ltd., and Pliva Hrvatska.

Prescribing information, or labeling, for generic topiramate will differ from the innovator drug, Topamax, because some uses of Topamax continue to be protected by patents and exclusivity.

The labeling for Topamax and generic topiramate contains an important safety warning about metabolic acidosis, a condition associated with excessive acid in the blood, which can cause symptoms such as tiredness, loss of appetite, irregular heartbeat, and impaired consciousness. Health care professional should perform a blood test to monitor the level of a patient's serum bicarbonate.

The use of tapiramate has been associated with serious eye problems, such as a sudden decrease in vision and a blockage of fluid in the eye causing increased pressure in the eye. Patients taking topiramate should contact their health care professional immediately if they have a loss in vision or experience eye pain. These problems can lead to blindness if not treated right away.

Note: The Epilepsy Foundation recommends that you talk to your doctor before making any medication switch from brand-name drugs to generic, between different manufacturers of the same generic, or from generic to brand.

2008 HOLIDAY OPEN HOUSE MEMORIES

2008 AWARD RECIPIENTS



Joan Schreck Inspiration Award
Mario A. Suzman III
Janine, Joan Schreck, Mario



Distinguished Volunteer
Steve Mangen



Advocate of the Year
Betty Cornwell



Family of the Year
The Nolan Family
(l to r) Janine, Amanda, Sally, & Bob



Director's Award
Jim Hausfeld
"King of MUD"



Community Spirit Award
Mike Kurtz
UD Media Production Group



Ric Ayres Award
David Bowman
Debbie Noorani, David, Janine



Distinguished Volunteer
Joe Erickson
Mud Volleyball

Not pictured: Personal Achievement Award— Walter Latino



Holiday Party Photos by Thomas Sheibenberger, TwoToms.Com Inc.

MEDWATCH REPORTING BY CONSUMERS

MedWatch is the Food and Drug Administration's (FDA) program for reporting serious reactions, product quality problems and product use errors, with human medical products such as drugs and medical devices.

If you think someone in your family has experienced a serious reaction to a medical product, you are encouraged to take a reporting form to your doctor. Your health care provider can provide clinical information based on your medical record that can help the FDA evaluate your report.

If you prefer not to have your health care provider complete the form, you can simply complete the Online Reporting Form via the Internet. You will receive an acknowledgement from the FDA after they receive your report. You will personally be contacted only if they need more information.

To make a report to the FDA by phone, call 1-800-FDA-1088. The FDA prefers an online report (www.fda.gov/medwatch). You also have the option of downloading, printing and then filling out the form to be mailed to **MedWatch**, The FDA Safety Information and Adverse Event Reporting Program Food and Drug Administration, 5600 Fishers Lane, Rockville, MD 20852-9787.



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www.ohioepilepsy.org

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Mission Statement

The Epilepsy Foundation of Western Ohio will ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through research, education, advocacy and services.

SERVICE AREA

Serving the residents and communities of eleven western Ohio counties including Auglaize, Champaign, Clark, Darke, Greene, Logan, Mercer, Miami, Montgomery, Preble & Shelby.

2009 BOARD OF TRUSTEES

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Katie Russell, Advocate, PT
katie@ohioepilepsy.org



2009 WISH LIST

We would appreciate it if you can provide any of the following items. All donations are tax-deductible as allowable by law.

Office Equipment

- L or U shaped Reception Desk
- Cases of bottled water for events & groups
- Padded folding metal chairs
- High resolution digital camera
- Office supplies & paper
- Microsoft Office Software

Skills and Services

- Graphic Design and professional printing services
- Grant Writing
- Clerical Volunteer

Volunteers

- Event committee members
- Event Volunteers
- Board of Trustees Members
- Driver to presentations

MUD VOLLEYBALL

We need a shed built on the Mud Volleyball site so that we can store all of our event equipment on site. This will save us money on storage costs. We need materials donated and volunteers to construct.



An Independently
Incorporated
affiliate of the
Epilepsy Foundation



Partner Agency

