

Epilepsy News

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Welcome to Epilepsy News Ezine. By updating our look and technology we can better send you the most current information about epilepsy events, conferences, and issues that are important to you.



Please visit our website for more information about our organization: www.efnj.com.

Our Administrative Office has Moved!

Our new address is 2 AAA Drive, Trenton, NJ 08691

North Jersey Office

322 US Highway 46, Ste. 220
Parsippany, NJ 07054
(973) 244-0850

Central Jersey Office

2416 Highway 35
Manasquan, NJ 08736
(732) 528-8080

South Jersey Office

216 Haddon Avenue
Suite 329
Westmont, NJ 08108
(856) 858-5900

Heads Up for Safety

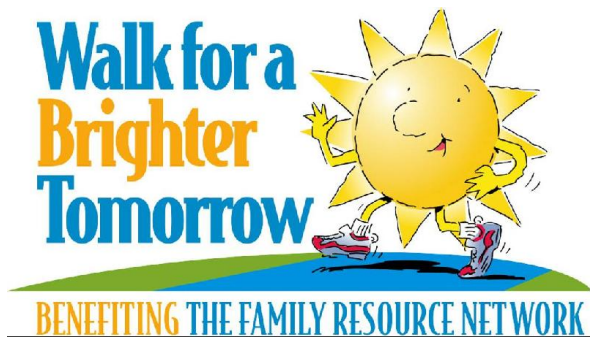
35 Beaverson Blvd.
Building 11
Brick, NJ 08723
(732) 262-8020

Quick Links

- [Epilepsy Foundation of New Jersey](#)
- [The Family Support Center of New Jersey](#)
- [The Family Resource Network](#)

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EFNJ to Hold Walk-a-thon



It seems every time you turn around there is an advertisement for a new walk-a-thon. Breast Cancer, Diabetes, Multiple Sclerosis, all great causes and each has a major walk in New Jersey. Until recently, Epilepsy has been missing from this list. With your help we can raise money and awareness for epilepsy!

Now it is time to show the media that Epilepsy deserves some much needed attention too! Join us on Sunday, October 11, 2009 as EFNJ and The Family Resource Network host a state-wide Walk-a-thon titled Walk for a Brighter Tomorrow at Roosevelt Park, in Edison, New Jersey. This will be a fun filled

day for families and friends to walk in support of their loved ones. A casual 5k Walk, entertainment and refreshments will be just a few of the day's highlights.

So call your family, friends and co-workers and start a walk team today! You can find more information and register online at www.walkforabrightertomorrow.org or via phone 1-800-FRN-2345. When registering to walk please note that you can choose to direct all of your money raised specifically to the Epilepsy Foundation of NJ. Just choose EFNJ from the drop down menu on the online registration form.

Please join us in our continuing efforts to provide low-cost quality services to New Jersey families living with developmental disabilities and chronic illness. You can make a difference!

Camp NOVA Benefits from Mardi Gras Gala

The Family Resource Network hosted its 5th Annual Mardi Gras Gala on Thursday, March 12, 2009 drawing in a crowd of 175 people to honor Joseph Fantozzi, EVP of White Rose Food. With a 180 degree view of the Manhattan skyline, the Liberty House Restaurant in Jersey City was the perfect location to bring the style of Mardi Gras to New Jersey. This enchanting location was transformed into the streets of New Orleans with a Dixieland Band, tarot card reader, stilt walkers, jugglers and more. The Gala netted over \$50,000 for the foundation and included a Camp NOVA Campership auction that raised an additional \$22,250.00 to support Camp NOVA.

Pictured (left to right): 2008 Honoree Bill Donahoe presenting award to 2009 Mardi Gras King, Joseph Fantozzi



Talk About it @ Dinner

The Epilepsy Foundation is pleased to announce the debut of new nationwide fundraiser - Talk About it @ Dinner.



Throughout the year, Epilepsy Foundation national and affiliate staff, board members and friends of the Epilepsy Foundation across the country will host "at-home" dinner parties to raise awareness and money for the Epilepsy Foundation and its mission. Talk About it @ Dinner capitalizes on the enduring popularity food oriented events and home entertaining. This initiative is both a valuable fundraiser and public awareness campaign all wrapped into one.

The Epilepsy Foundation of New Jersey has decided that we will target the month of June 2009 to launch the Talk About It @ Dinner program. We are asking that families wishing to support the project choose a date in June to host the event. Materials including invitations, foundation information, thank you cards and video are can be found by following [this link](#).

In order to participate, you simply need to fill out the registration form found online and fax it to 609-392-5621 or email it to Heather Comstock at hcomstock@efnj.com. Please do not hesitate to call 800-336-5843 with any questions.

3 New Jersey Teams Stand Out at National Walk for Epilepsy

On March 28, 2009, approximately 9,000 individuals gathered on the National Mall in Washington, D.C. to help raise awareness and funding for Epilepsy at the Third Annual Walk for Epilepsy. Undaunted by spring showers, muddy walk conditions and cool temperatures, walkers gathered from all over the country to help people with epilepsy, their loved ones, caregivers and health care professionals.

Money raised from the Walk helps create essential programs for people with epilepsy and aid in the search for a cure. At the walk there were three New Jersey teams that designated the money that they raised to help people in New Jersey specifically. The teams included Jack is Strong, Murphy's Law, and TeaMeehan. The Epilepsy Foundation of New Jersey would like to thank these teams for their support.



Walk Chair, Greg Grunberg, star of NBC's hit series Heroes, whose son Jake has epilepsy, joined Jets offensive lineman and eight-time Pro Bowler, Alan Faneca, Atlanta Falcons running back, Jason Snelling, and Cincinnati Bengals cornerback, Geoffrey Pope. Also attending the walk was Harlem Wizards player and New Jersey resident, Mighty Mike Simmel. Simmel wowed the crowd with his phenomenal basketball-well-wizardry.

Faneca led his own Walk team of family, friends and fans. "We were really proud to be part of the Walk again and bring our families and friends together to support the epilepsy community," said Faneca. "It provides a great opportunity to let other people with epilepsy know that they should be advocates for themselves, find the highest quality care and move forward with accomplishing their dreams."

Pictured (left to right): Jack Dau, New York Jet Alan Faneca

Rachel Beck Represents EFNJ at Kids Speak Up, Speak Out!



Rachel Beck of Morganville, N.J., traveled to Washington, D.C., Sunday, March 29 through Tuesday, March 31, 2009 to meet with congressional leaders and gain their support for epilepsy public health programs and more research toward a cure for epilepsy.

Beck, 10, was one of 37 young people from across the country participating in Kids Speak Up!, a national program coordinated by the Epilepsy Foundation and funded by Abbott Laboratories. The program rallies young ambassadors with epilepsy between the ages of 7 and 16 to personally petition congressional leaders for aid in assuring better access to care, improved public education and more research toward a cure for

epilepsy.

The Public Policy Institute (PPI) and Kids Speak Up!(KSU) programs provide participants with a crash course in advocacy, epilepsy and current Epilepsy Foundation priorities to focus on in order to improve the lives of all people with epilepsy.

This year, the main messages to take to Congress were increased funding for research, health care reform to ensure access to the very best treatment available, and ending discrimination against people with disabilities, including people with epilepsy. While the adults learned about these priorities in a series of excellent presentations by experts in the field, the kids focused on probably the most compelling legislative tool: Telling their own stories about life with epilepsy.

On Day Three of the conference, Tuesday, March 31, all the participants fanned out across Capitol Hill to the House and Senate office buildings armed with well-honed talking points and honest testimonials. Rachel and her family, David, Tracy, and Matthew, were able to meet with Senator Robert Menendez and staff for Congressman Frank Pallone, Congressman Rush Holt, and Senator Frank Lautenberg.

Pictured: Back Row - Tracy Beck, Senator Robert Menendez, David Beck; Bottom Row: Matthew Beck, Rachel Beck

New Keppra XR(TM) Dosage Strength Offers Simplified Treatment Option for People Living with Partial-Onset Seizures

Once-daily Keppra XR(TM) (levetiracetam) extended-release tablets are now available in a new dosage strength--750 mg--enabling doctors to simplify patients' treatment plans by decreasing the number of tablets they take each day.

According to studies published in *Epilepsy & Behavior* and *Neurology*, patients are more likely to adhere to their medication regimen when it is taken once daily, and therefore may be more likely to reach the goal of epilepsy therapy--seizure freedom with minimal side effects.

Keppra XR(TM), from UCB, The Epilepsy Company(TM), was approved last year as an add-on therapy for partial-onset seizures in patients who are 16 years of age and older with epilepsy. Keppra XR(TM) is the only extended-release formulation of levetiracetam and cannot be substituted with generic levetiracetam, immediate-release levetiracetam or any other antiepileptic medication at the pharmacy counter.

Keppra XR(TM) was approved by the U.S. Food and Drug Administration (FDA) based on data from an international clinical study of 158 epilepsy patients with partial-onset seizures who added 1,000 mg of Keppra XR(TM) or placebo to their other epilepsy medications once daily. The study consisted of an 8-week baseline period followed by a 12-week treatment period.

The study showed that 10.1 percent of Keppra XR(TM) patients experienced complete partial-onset seizure freedom vs. 1.3 percent in the placebo group over the treatment period.

Keppra XR(TM) patients experienced a 46.1 median percent reduction in weekly partial-onset seizure frequency versus 33.4

percent in the placebo group.

Keppra XR(TM) is also available in 500 mg tablet strength. Data presented at last year's American Epilepsy Society meeting demonstrated that taking two 750 mg levetiracetam extended-release tablets is the same as taking three 500 mg extended-release tablets.

Treatment with Keppra XR(TM) should be initiated with a dose of 1,000 mg once daily. The daily dosage may be adjusted in increments of 1,000 mg every two weeks, to a maximum recommended dose of 3,000 mg per day.

For full prescribing information, please see www.KeppraXR.com.

In order to ensure patient access to this valuable medication in the U.S., UCB is initiating a co-pay support program. For more information, contact U.S. UCB Medical Information at 1-866-822-0068 (press 9).

FDA Approves Generic Topamax to Prevent Seizures

The U.S. Food and Drug Administration has approved the first generic versions 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 ingredient 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., CIPLA Ltd., Glenmark Generics Ltd., Cobalt Laboratories, Apotex Inc., Zydus Pharmaceuticals USA, Aurobindo Pharma Ltd., Torrent Pharmaceuticals Ltd., Invagen Pharmaceuticals Inc., Unichem Laboratories 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 professionals should perform a blood test to monitor the level of a patient's serum bicarbonate.

The use of topiramate 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-name drugs.

Source: FDA press release. For more information, visit www.fda.gov. Reviewed by Epilepsy Foundation Professional Advisory Board member Brian Alldredge, PharmD.

Researchers Identify Cause for Severe Epilepsy Disorder

Researchers at the University of California, San Diego School of Medicine have discovered that convulsive seizures in a form of severe epilepsy are generated, not on the brain's surface as expected, but from within the memory-forming hippocampus. The scientists hope that their findings - based on a mouse model of severe epilepsy - may someday pave the way for improved treatments of childhood epilepsy, which affects more than two percent of children worldwide. Their study was published online by the Proceedings of the National Academy of Science (PNAS) on March 16.

"A parent of an epileptic child will tell you that they think their child is going to die during their attacks," said senior author Joseph Gleeson, MD, director of the Neurogenetics Laboratory at the UC San Diego School of Medicine, professor in the department of neurosciences and Howard Hughes Medical Institute Investigator. "Parents of children with epilepsy, especially the most severe types of epilepsy, are desperate for a deeper understanding of the causes of the problems and for the development of new treatments."

One of the major causes of epilepsy in children is an alteration in the development of the cerebral cortex. The cerebral cortex is the main folded part of the brain, containing a large percentage of brain cells, and is integral to purposeful actions and thoughts. However, this complex structure is subject to all kinds of defects in development, many of them due to defective genes and many associated with epilepsy.

Cortical dysplasia, meaning disordered development of the cerebral cortex, is identified in 25 to 40 percent of children with the most severe and difficult-to-treat forms of epilepsy. These children often come to the attention of specialists due to stagnation in the acquisition of language and balance skills and accompanying epilepsy. The symptoms displayed by these children can range from very subtle - such as small muscle jerks or eyelid fluttering - to dramatic whole body, tonic-clonic spasms (a series of contractions and relaxations of the muscle) that can affect basic bodily function.

The study was funded in part by the National Institutes of Health, the Burroughs Wellcome Fund, the Howard Hughes Medical Institute and the Epilepsy Foundation.

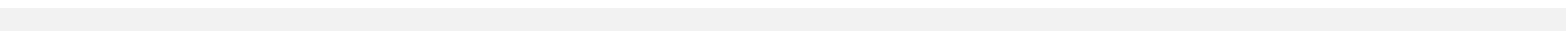
Source: University of California at San Diego news release. Reviewed by Epilepsy Foundation Professional Advisory Board member Tallie Z. Baram, M.D., Ph.D.



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Sincerely,

Andrea Racioppi
Associate Director
Epilepsy Foundation of NJ



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