

Epilepsy News

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Welcome to the new version of the Epilepsy News Ezine. We are hoping that by updating our look and technology we can better send you up-to-date information about epilepsy events, conferences, and issues that are important to you.



Please consult our website for further information: 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

Camp Counselors Wanted

The Epilepsy Foundation of New Jersey's Camp Nova is celebrating its 21st year in operation. This year camp will be being held from August 16th-22nd at the Linwood MacDonald YMCA camp facility in Branchville, NJ. While camp starts on August 16th for the campers, counselors are required to arrive beginning on August 15th for mandatory training.

Camp NOVA is a wonderful opportunity for children and young adults living with epilepsy and other developmental disabilities to enjoy summer camp. Camp NOVA, which provides an exciting and independent camping experience in an environment filled with fun experiences and memories that last a lifetime, is a one-week overnight camp for young people ages 12-28. Camp activities include acting, arts and crafts, boating, fishing, karate, swimming and yoga.

We are currently seeking camp counselors for the week. If you are above the age of 18, have a background of working with individuals with Epilepsy or other developmental disabilities, and are looking to have fun, apply! All counselors are required to have a criminal background check and be certified in CPR and first aid. For an application, please call or email Amirah Harmon at 800.336.5843 or aharmon@njcaregivers.org.

Register with "Register Ready"

New Jersey's Office of Emergency Management has developed "Register Ready", a special needs registry for disasters that helps first responders identify where there are individuals in the state with special healthcare, medical, or transportation needs in the event of an emergency. The Office of Emergency Management reminds members of the public that they can find additional information about how to prepare for a hurricane or other emergency on their website, www.Ready.NJ.gov. They also noted that there is a "Register Ready" icon on the NJOEM home page that can be clicked on to sign up for the special needs registry for disasters.

3 Simple Tips from Colonel Rick Fuentes, Superintendent of the New Jersey State Police and Director of the New Jersey Office of Emergency Management:

1. Get a kit of emergency supplies - the items that will help you stay self-sufficient for up to three days.
2. Make a plan for what you and your family will do during an emergency - including knowing how to evacuate and shelter-in-place.
3. Stay informed of possible threats.

Become a Member of EFNJ

For a number of years now, the Epilepsy Foundation of NJ has sponsored a membership program for the purpose of fostering unity in the epilepsy movement and to bring together those people with a common interest in the condition of epilepsy. The membership dues are \$25 a year and includes a subscription to *EpilepsyUSA*, the award-winning publication designed to keep you abreast of the latest advances in controlling, treating, and preventing epilepsy. In addition to this national publication, you will be kept up to date about local events and information.

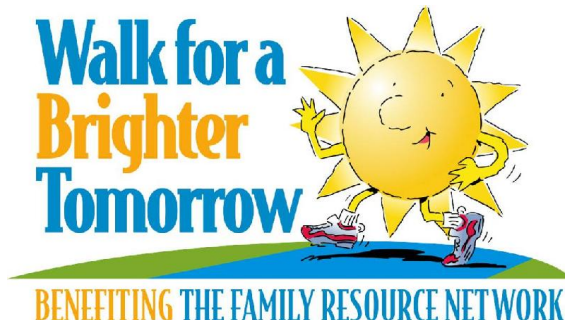
If you are interested in becoming a member, please send a check payable to "Epilepsy Foundation of NJ" to 1 AAA Drive, Ste. 203, Trenton, NJ 08691. Or simply, [click here](#) to view our donation page. Please scroll down, select the option for \$25 and indicate "membership" in the "dedication" field.

Epilepsy Foundation of NJ Volunteer

Since early March, the Epilepsy Foundation of New Jersey has been fortunate enough to have a volunteer on staff. Mary Beth Valenzona, Point Pleasant, has been working two days a week at our Manasquan office. Mary Beth has been a great addition to our team. She has been working on many projects, including tabulating pre and post surveys from our S.H.A.R.E. program. On May 19th, Mary Beth will be attending a Parent Focus Group at our National Office in Landover, MD. The group will be reviewing the National Epilepsy Foundation's new parent website.

We would like to thank Mary Beth for her generosity and help.

Epilepsy Foundation of NJ to Host 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 EFNJ. 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!

Prince Reveals He Had Epilepsy as a Child

April 28, 2009 - Legendary and often reclusive rock star, Prince, revealed he had epilepsy on PBS's Tavis Smiley show last night. The Grammy and Oscar award-winning musician said, "I used to have seizures when I was young and my mother and father didn't know what to do and how to handle it, but they did the best they could with what little they had."

Prince said he had to deal with a lot of things in life and attributed his past extravagant behavior to being teased as a kid. "Early in my career I tried to compensate for that by being as flashy as I could and as noisy as I could." He said he had never spoken publicly about his epilepsy before, but he is enjoying this time in his life when he can reflect on his experiences and talk about them openly.

To get past the teasing from his peers, Prince said, "I went into self and taught myself music." He stayed with it, practicing constantly, and soon the neighborhood kids were talking about him-this time with admiration instead of derision. He said, "Once I got that support from people, then I believed I could do anything."



Researchers Identify New Drug to Prevent Seizure Progression in Model of Epilepsy

PITTSBURGH, May 5, 2009-Carnegie Mellon University researchers have identified a new anticonvulsant compound that has the potential to stop the development of epilepsy. The findings are published in the current issue of the journal *Epilepsia*.

The research discovery builds on previous work identifying a specific molecular target whose increased activity is associated with seizure disorders, a potassium channel known as the BK channel.

"We have found a new anticonvulsant compound that eliminates seizures in a model of epilepsy," said Alison Barth, associate professor of biological sciences at Carnegie Mellon's Mellon College of Science. "The drug works by inhibiting ion channels whose role in epilepsy was only recently discovered. Understanding how these channels work in seizure disorders, and being able to target them with a simple treatment, represents a significant advance in our ability to understand and treat epilepsy."

In the current study, Barth tested this theory by blocking the ion channels using a BK-channel antagonist called paxilline. Using an experimental model for epilepsy, Barth asked whether paxilline could reduce or prevent experimentally induced seizures, as it could normalize aberrant brain activity induced by previous seizures. Remarkably, Barth and colleagues Jesse Sheehan and Brett Benedetti discovered that the compound was effective at completely blocking subsequent seizures.

"The drug is orally available, and works in the low nanomolar range," said Barth, noting that these characteristics, which mean the drug is effective in low concentrations and can be taken as a pill, make it an especially promising compound for treatment in epilepsy patients. While most anticonvulsants currently used to treat epilepsy work to directly modulate the activity of ion channels or neurotransmitters, few compounds interact specifically with potassium channels. The researchers believe that targeting the BK channels and the abnormal brain activity that they induce might one day be used as a way to prevent the progression of seizure disorders over time, thus attacking the root cause of epilepsy.

According to Barth, the next steps will be to further investigate paxilline to see whether it is an effective anticonvulsant treatment for multiple types of seizures. The investigators continue to look at how BK channels are regulated by seizures to better understand the development of epilepsy.

Co-authors of the study include Sheehan and Benedetti, doctoral students in the Department of Biological Sciences and Center for the Neural Basis of Cognition at Carnegie Mellon. The study was funded by the Milken Family Foundation for Translational Research, through the support of the Epilepsy Research Foundation, the National Institutes of Health and the Alfred P. Sloan Foundation.

Source: Carnegie Mellon University press release. Reviewed by Epilepsy Foundation Professional Advisory Board member, Brian Alldredge, PharmD.

Thank you for reading Epilepsy News! If you have any information you would like included in our e-zine, or know of anyone that would like to be added to our listserv, please email me at aracioppi@efnj.com or click the "Join Our Mailing List" button on the top right side of the newsletter.

Sincerely,

Andrea Racioppi
Associate Director
Epilepsy Foundation of NJ

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