

Epilepsy News



Welcome to Epilepsy News. We pride ourselves in sending you the most 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.



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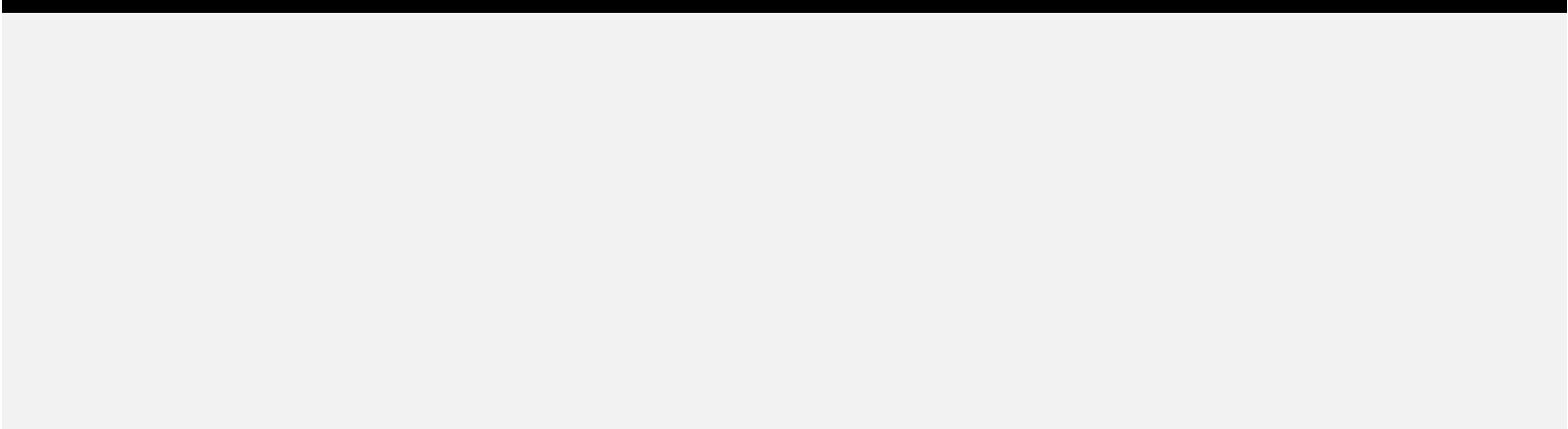
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Quick Links

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

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Enhancing Life...Through Epilepsy Education and Knowledge

A seminar on Epilepsy will be held Saturday, January 29th from 9 am - 12 noon at Jersey City Medical Center - 355 Grand Street in Jersey City. The event is free and will be offered in both English and Spanish. An overview of epilepsy, including a look at the latest treatment options, will be discussed by specialists in this area. Space for the seminar is limited. To register, or for additional information, call Beth Wiederspiel at 800.336.5843 or bwiederspiel@efnj.com.

[click here](#) for information flyer.

With a Little Help from our Friends

Debbie Wierzbicki along with daughter Olivia of Montgomery Township got the Orchard Hill Elementary School to put out a jar for student donations during November, National Epilepsy Month. Over \$1,900 was collected. Debbie's husband, who works for General Electric, was able to get the contribution matched by his company for a total of \$3,780, outstanding effort.... There were 42 class at OHES who "raced" to fill up their gallon size milk jug for epilepsy awareness month. Each staff member "118" where provided with a wrist band and a seizure smart quiz and they all paid \$2 to wear jeans and wear purple on 11/29. The 2nd grade students read books about epilepsy in health class, and attended the Helmet Safety Program. There was a bulletin board up in the foyer, and reading material available to the staff.



Also, Bella Capelli Hair Design studios of Boonton, NJ, which was selling purple hair extensions to benefit EFNJ during November, reported raising \$510 from that endeavor including from a woman who drove to Boonton from Trenton to show her support...

Thank you all for your help!!

Thinking About Epilepsy

Since 2007, EFNJ in conjunction with Anita Kaufmann Foundation has educated over 20,000 fifth grade students through the informative program Thinking About Epilepsy. This free, 40 minute presentation is made to increase awareness and to reduce stigma's about epilepsy. The 5th graders are taught how to recognize different seizure types and provide the proper first aid for each. These presentations are given statewide with the goal to inform as many students as possible.

Now that 2010-2011 school year is underway we are eager to start scheduling!

If you are interested in arranging a presentation or have a connection with any school that may benefit from this program please call Jenna Andolora at 1-800-336-5843 or jandolora@efnj.com.

Is your school scheduled???? We are coming to the following schools before years end.

Alexander Sullivan School-Jersey City
PS 29-Jersey City
Marlboro Elem. School-Marlboro
Thomas Jefferson-Tunersville
Nicolaus Copernicus School-Jersey City
Hoover School-Begenfield
All Saints Regional Catholic-Manahawkin
Robert Waters School-Union City
Richard Butler School-Butler
Harmony Township School-Phillipsburg
East Dover Elem School-Toms River
Nicholas S. LaCorte #3-Elizabeth
Nehausey MS-Gibbstown
Garfield School-Kearny
Netcong Elem. School-Netcong
Cherry Street School-Bridgetown
Soehl M.S-Linden
Gibbsboro School-Gibbsboro
Immaculate Conception-Annandale
Lakeview School-Denville
Upper Pittsgrove-Monroeville
Washington School-N.Arlington
East Dover-Dover
Walter M. Schirra- Old Bridge
Birches Elem School- Turnersville
Brookside Elem. School-Westwood
Academy School-Dover

Kids Speak Up

The Epilepsy Foundation is pleased to announce that Samantha Magda Grade 6, 11 years old from Annandale, NJ has been accepted as an official participant of the 2011 Kids Speak Up! program.

What is Kids Speak Up!

Kids Speak Up! is an opportunity for young people with epilepsy between the ages of 7-16 to come to Washington, D.C., with their families to learn about advocacy and to tell Congress about what it's like to live with epilepsy. The kids will bring their message to Capitol Hill and then take it back home, where they will advocate locally throughout the year. This event takes place in conjunction with the Epilepsy Foundation's annual Public Policy Institute.

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.

What is the message of the program?

The group will be urging 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.

Last year, the main message taken to Congress were increased funding for research and programs. On Day Three of the conference, all the participants fanned out across Capitol Hill to the House and Senate office buildings armed with well-honed talking points and honest testimonials

Devils Fundraiser for FRN-Great Holiday Gift Idea

When the NJ Devils take on the Philadelphia Flyers at Prudential Center in Newark on January 6th, it will be for more than a shot in the playoffs. It will be The Family Resource Network's annual Night at the Devils. Tickets are \$45 each (well below face value). Go to www.newjerseydevils.com/frn to access the offer put in the special code FRN. We look forward to seeing you in January.

Epilepsy's Big, Fat Miracle- From the New York Times

Once every three or four months my son, Sam, grabs a cookie or a piece of candy and, wideeyed, holds it inches from his mouth, ready to devour it. He knows he's not allowed to eat these things, but like any 9 year old, he hopes that somehow, this once, my wife Evelyn, or I will make an exception.

We never make exceptions when it come to Sam and food, though, which means that when temptation takes hold of Sam and he is denied, things can get pretty hairy. Confronted with a gingerbread house at a friends party last December, he went scorched earth, grabbing parts of the structure and smashing it to bits. Reason rarely works. Usually one of us has to pry the food out of his hands. Sometimes he ends up in tears.

Its not just cookies and candy that we forbid Same to eat. Cake, ice cream, pizza, tortilla chips and soda aren't allowed either. There is no crusade against unhealthful food in our house. Some might argue that unhealthful food is all we let Sam eat. His breakfast eggs are mixed with heavy cream and served with bacon. A typical lunch is full-fat Greek yogurt mixed with coconut oil. Dinner is hot dogs, bacon, macadamia nuts and cheese. Sam's diet is 90 percent fat.

Sam has Epilepsy and the food he eats is controlling most of his seizures (he used to have 130 a day). The diet, which drastically reduces the amount of carbohydrates he takes in, tricks his body into a starvation state in which it burns fat, and not carbs, for fuel. Remarkably, and for reasons that are still unclear, this process-called ketosis-has an antiepileptic effect. He has been eating this way for almost two years. [continue reading](#)

The Family Support Center of NJ presents....Sibshops!

Sibshops are for kids between the ages of 8-12 years old who have a sibling with special needs. FSCNJ will host Sibshop meetings once a month on a Saturday from 10:00 a.m. to 2:00 p.m.
Each session costs \$25.00 per child.

2011 Meeting Schedule

January 15, 2011

February 19, 2011

March 19, 2011

April 16, 2011

May 21, 2011

June 18, 2011

July 16, 2011

August 20, 2011

September 17, 2011

October 15, 2011

November 19, 2011

December 17, 2011

Sibshops will take place at
The Family Resource Network - Shore Office
Lions Head Office Park
35 Beaverson Blvd. Bldg. 11
Brick, NJ 08723

Please Call the Family Support Center of NJ to Register: 1-800-372-6510. Click [here](#) to download a registration form and follow instructions to ensure proper registration.

****SPACE IS LIMITED. PLEASE REGISTER AS SOON AS POSSIBLE****

Sponsors Announce Major National Study of Public Health Dimensions of the Epilepsies

San Antonio - On December 6 representatives for government, professional and family organizations concerned with epilepsy announced their sponsorship of an independent national review of the public health dimensions of this common neurological disorder. Epilepsy comprises a broad constellation of seizure syndromes, collectively known as the epilepsies, which affect nearly 3 million Americans. Families with members affected by these syndromes, and the health care professionals and service providers who give specialized epilepsy care and support, are concerned that the prevalence and consequences of the disorder are inadequately recognized.

The national review of the burden of epilepsy is being conducted by the Institute of Medicine (IOM) at the request of 21 sponsoring organizations, including the U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, the National Institutes of Health, and Vision 20/20, an informal coalition of non-government professional and lay organizations concerned with the disorder, including the Epilepsy Foundation. The IOM is now in the process of convening an ad hoc committee of individuals with a range of expertise in epilepsy and other relevant fields for its analysis, according to an announcement at a media briefing during the American Epilepsy Society's annual meeting and scientific conference on December 6.

Speakers at the briefing were Story C. Landis, Ph.D., Director, National Institute for Neurological Diseases and Stroke (NINDS); Carmita Vaughan, CEO, Citizens United for Research in Epilepsy (CURE), who represented the Vision 20/20 group of epilepsy organizations; and Frances E. Jensen, M.D., a neuroscientist and professor of neurology at Children's Hospital Boston and Harvard Medical School, who spoke on behalf of the American Epilepsy Society (AES), where she serves as its first vice president. According to Dr. Jensen, "Traditional approaches to epilepsy do not fully take into account the broad range of seizure disorders or syndromes that vary in their onset, severity, progression, and impact on health and disability. The special needs of affected infants, children, adults and the elderly, as well as the special needs of people with disabilities and people with intractable seizures, are also poorly understood and inadequately addressed in the national response to epilepsy."

The IOM committee has been asked to suggest priorities and propose strategies for dealing with the barriers and gaps in knowledge that diminish quality of life for people with epilepsy and their families. Epilepsy is one of the most common neurologic conditions in the United States, affecting at least 1 in 100 adults and 1 in 20 children. There are more than 40 types of epilepsy-referred to collectively as the epilepsies-that cause recurrent seizures and that can be responsible for brain damage; neurological, cognitive, or psychiatric impairment; and death. Advances in research are improving our understanding of the scope of epilepsy and its public health impact. However, current approaches do not fully take into account either the broad range of epilepsy disorders and their comorbidities or their consequences for health and quality of life.

The IOM is undertaking a new study that will consider the public health dimensions of the epilepsies in the United States-including health care and human services, health literacy, and education. The IOM will recommend priorities in these areas in order to better understand the public health impact of the epilepsies and to meet the needs of people with epilepsy and their caregivers.

Specifically, the IOM will focus on the following questions:

- How can the public health burden of epilepsy for patients and families be more accurately assessed?
- What priorities for future population health studies could inform treatment and prevention?
- How can the access to health and human services and the quality of care for people with epilepsy be improved?
- How can the education and training of professionals who work with people with epilepsy be improved?
- How can the understanding of epilepsy in patients and the general public be improved to create supportive communities?

The IOM ad hoc committee on the public health dimensions of the epilepsies will meet in January to hear presentations by the sponsors and begin its work. For more information on the study, visit: <http://iom.edu/Activities/Disease/Epilepsy.aspx>.

Donate your car to EFNJ!

Are you thinking of selling or trading in an old car? Why not donate it instead? As a charitable contribution your vehicle donation could make a big difference. Our process is simple, quick, and convenient and we will provide free and timely pick-up of your vehicle donation. Our program is simple... The better the car, the greater your tax deduction.

To inquire about a donation please call Michelle Smith 732-262-8020

EFNJ is on Facebook!!

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a blue rectangular background.

Epilepsy Foundation of New Jersey and The Family Resource Network have joined cyber space and we want to connect with you! Click on [Facebook](#) to become our "fan" to receive bulletins and messages. Our goal is to keep people updated on news, legislation, and other activities important to the community we serve.

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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