

# EPILEPSY CONNECTION



The 6th Annual Seize the Day & Take a Walk for Epilepsy is scheduled for Saturday, April 10, 2010. The event will be held at LSU again this year on the Old Front Nine. We are looking forward to this year's event, but we need your help to make Seize the Day the best yet. Last year's event raised over \$100,000.00 for epilepsy services in Louisiana. Because of the money raised last year our important programs and services remain free to the community.

We need your help this year to keep our services in your community. Visit our race website at [www.seizethedayrace.com](http://www.seizethedayrace.com) and start a team today! Once you start your team email all of your friends and ask them to donate to your team. When your friends

*"It will take all that we have to overcome epilepsy...why not do it together? Join us today." - Willie, mother of a child with epilepsy*

*"Our team that competes in the Seize the Day and Take a Walk 5K, is our way of educating those around us about epilepsy. You can never tell too many people just how they can help. The Epilepsy Foundation of Louisiana has offered us just that...a team. A support system that reinforces the idea the we are not fighting this battle alone."*

*- Team Addie Claire Captain & Epilepsy Warrior*

donate they will receive their own donation page. Encourage friends to ask their friends to join the fight against epilepsy. Every little bit helps the cause. Imagine if you email twenty friends to join your team and they each donate \$5.00. That's \$100.00 for your team. Now imagine that each of those friends ask their friends to donate. As you see a little bit can go a long way.

Another way to support this event is to help solicit sponsorships. Do you know businesses that may want to support this event? Call our office or email us at [info@epilepsyloisiana.org](mailto:info@epilepsyloisiana.org) if you would like sponsorship packets to give to businesses.

Seize the Day has grown into the largest epilepsy awareness event in the state of Louisiana. With over 1,000 participants last year we want even more this year. Get your office, school, church, neighborhood, etc. to join us and help in the fight against epilepsy.

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Support the Epilepsy Foundation of Louisiana by purchasing your Seize the Day awareness bracelets. Order online at [www.thepurpleshop.net](http://www.thepurpleshop.net) or call us at 800-960-0587. \$2.00 each





## Foundation News:

### MESSAGE FROM THE DIRECTOR

The end of the year proved to be extremely busy for all of the staff at the Epilepsy Foundation of Louisiana. Usually by this time I have received the agency fiscal audit and have created the annual report. Unfortunately, I have not been able to get to the completion of our annual report but have it on my list for this quarter. I would like to remind you all that we have wonderful Faces of Epilepsy calendars for sale that highlights our children with epilepsy.

A new venture we have begun is the establishment of an epilepsy class conducted in Houma at Chabert Medical Center on the second Tuesday of each month. Call if you are interested in participating at 800-960-0587. This lunch and learn series will be held monthly for at least six months, and perhaps longer if the demand is there.

We are all gearing up for 6th Annual "Seize the Day Race" this April in Baton Rouge. Go to [www.seizethedayrace.org](http://www.seizethedayrace.org) to start a team or join an existing team. This event has become our largest fund raiser of the year and it helps supports services statewide. Also, "hats off" to all of the mom's of children with epilepsy and adults with epilepsy that have already begun developing their race teams for 2010. Your dedication is invaluable and I appreciate all that you do for the Foundation.

We just completed our second annual New Orleans race last weekend. It has grown a great deal in just two years since being reinitiated after 2005. Thank you to those supporters that were able to provide corporate support and/or establish a team.

We continue to grow and the statewide demand for our services is growing. We are looking to conduct one or two (this is not decided as of yet) community education days in the summer. Look for more information which is to come.

Without your help, we would not be able to accomplish the things we do. THANKS!

*Dotty Martino, LCSW*  
Dotty Martino, LCSW  
Executive Director

Stay up to date with all the epilepsy news around the state by signing up for our e alerts.

Visit our website for more information:

[www.epilepsylouisiana.org](http://www.epilepsylouisiana.org)

### Upcoming Events



**Saturday, April 10, 2010:** 6th Annual Seize the Day & Take Walk for Epilepsy  
[www.seizethedayrace.org](http://www.seizethedayrace.org) for more information.

#### **Support Groups in Your Area:**

- **Baton Rouge:** 3rd Thursday of every month. (10101 Park Rowe) 7:00-8:30 pm
- **New Orleans:** 3rd Thursday of every month. (East Jefferson General Hospital, 4200 Houma Blvd., Foundation Board Room, Metairie)
- **Shreveport:** 2nd Tuesday, every other month (Christus Schumpert) 6:00pm
- **Lafayette:** 1st Wednesday of every month. (Southwest Medical Center, 4212 W. Congress, meeting room 1) 6:30pm



# Epilepsy Research

## Adjunctive Therapy Study with Oxcarbazepine XR for Partial Seizures

Supernus is sponsoring a clinical trial at the LSUHSC Epilepsy Center in New Orleans where eligible candidates will be 18 to 65 years and experiencing partial epileptic seizures. Those meeting the study criteria who are willing to participate will receive either one of two strengths of the study drug or placebo for up to 23 weeks as adjunctive treatment (in addition to their other antiepileptic medications) for their partial seizures. Study visits and study medication costs will be covered by the Sponsor. At the end of the study, there may be an option to extend treatment with the study drug. Anyone interested in getting more detailed study information should e-mail the study coordinator at [epicenter@lsuhsc.edu](mailto:epicenter@lsuhsc.edu). Please provide your name, e-mail address or telephone number and the study in which you are interested.

*"This listing of epilepsy clinical trials is for information purposes only; and the reader assumes full responsibility and risk for the appropriate use of the information provided. The information concerning the trial has been provided by the investigator; the Epilepsy Foundation, its affiliates, officers, directors, employees and agents do not warrant or guarantee the accuracy or completeness of this information and specifically disclaims any liability therefore."*

## Injectable Rescue Medication Study for Acute Repetitive Seizures

King Pharmaceuticals is sponsoring a clinical trial at the LSUHSC Epilepsy Center in New Orleans under the direction of Dr. Piotr Olejniczak where eligible candidates will be aged 18 years or older and experiencing episodes of acute repetitive seizures, also known as seizure clusters. Individuals meeting the study criteria who are willing to participate will receive either study drug or placebo in the first phase of the study and then study drug in the second phase of the study. Study visits and study medication costs will be covered by the Sponsor. Anyone interested in getting more detailed study information should e-mail [epicenter@lsuhsc.edu](mailto:epicenter@lsuhsc.edu). Please provide your name, e-mail address or telephone number and the study in which you are interested.



## EATING RIGHT

A new year brings to mind personal health issues and how to address them, not just through medication, but also through diet and exercise. Since triggers do exist for epilepsy, it's important to avoid behaviors that put an individual at risk for a seizure. A healthy consistent diet and exercise make a difference. This article offers suggestions for easily incorporating healthy foods into our daily diet.

Food, Nutrition and Health Tips from the American Dietetic Association. **20 Ways to Enjoy More Fruits, Vegetables, Whole Grains and Dairy** To get the most nutrition out of your calories, choose

foods packed with vitamins, minerals, fiber and other nutrients-and lower in calories. Pick fruits, vegetables, whole grains and fat-free or low-fat dairy more often. Be aware of portion sizes. Even low-calorie foods can add up when portions are larger than you need.

*Kassie Campbell, EFLA Staff*

- 1.Variety abounds when using vegetables as pizza topping. Try broccoli, spinach, green peppers, tomatoes, mushrooms and zucchini.
- 2.Get saucy with fruit: Puree berries, apples, peaches or pears for a thick, sweet sauce on grilled or broiled seafood or poultry, or on pancakes, French toast or waffles.
- 3.Mix up a breakfast smoothie made with low-fat milk, frozen strawberries and a banana.
- 4.Heat leftover whole-grain rice with chopped apple, nuts and cinnamon.
- 5.Make a veggie wrap with roasted vegetables and low-fat cheese rolled in a whole-wheat tortilla.
- 6.Try crunchy vegetables instead of chips with your favorite dip or low-fat salad dressing.

*(Eating Right Continued on page 5)*



# Calling All Kids!

By: Amy Nicols, EFLA Staff

**It's time to come to Washington, D. C. to  
SPEAK UP! SPEAK OUT!**

The Epilepsy Foundation's PUBLIC POLICY INSTITUTE is the Foundation's centerpiece advocacy initiative, during which Epilepsy Foundation affiliate staff, parents, children, doctors and volunteers come from all over the country to receive advocacy training and to discuss the needs of people with epilepsy. KID'S SPEAK UP! Is a program that provides an opportunity for children with epilepsy and their parents to visit the nation's capital, to meet with their legislators, and tell their personal stories.

The message of this program is to urge 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.

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. The program is a positive educational experience for participants. It is a chance for young people and parents to share their stories with elected officials and to help increase public awareness about epilepsy.

Children are nominated by their state affiliates by submitting an application to the National office. To be eligible, the child must be between seven and sixteen years of age and must have been diagnosed with epilepsy or a seizure disorder and currently receiving treatment. Selections are made through a national selection committee. The committee is dedicated to ensuring that a diverse group of children that represent the entire spectrum of children with seizure disorders are selected.

Samuel Johnson, IV, a fourteen-year-old from Clinton, Louisiana will travel with his parents, Samuel and Shaneka Johnson, along with myself to Washington, D. C. on Tuesday, March 23 through Thursday, March 25<sup>th</sup>. Together, we will learn to make our voices heard on Capitol Hill and with state policymakers back home.

Amy Nichols, Educator





*(Eating Right Continued from page 3)*

7. Grill colorful vegetable kabobs packed with tomatoes, green and red peppers, mushrooms and onions.
8. Banana split: Top a sliced banana with a scoop of low-fat frozen yogurt. Sprinkle with a tablespoon of chopped nuts.
9. Add color to salads with baby carrots, grape tomatoes, spinach leaves or mandarin oranges.
10. Prepare instant oatmeal with low-fat or fat-free milk in place of water. Top with dried cranberries and almonds.
11. Stuff an omelet with vegetables. Turn any omelet into a heavy meal with broccoli, squash, carrots, peppers, tomatoes or onions with low-fat cheddar cheese.
12. "Sandwich" in fruits and vegetables. Add pizzazz to sandwiches with sliced pineapple, apple, peppers, cucumbers and tomato as fillings.
13. Wake up to fruit. Make a habit of adding fruit to your morning oatmeal, ready-to-eat cereal, yogurt or toasted waffle.
14. Stock-up. Fill your fridge with raw vegetables and fruits—"nature's fast food"—cleaned, fresh and ready to eat.
15. Top a baked potato with beans and salsa or broccoli and low-fat cheese.
16. Microwave a cup of tomato or vegetable soup for a quick afternoon snack.
17. "Grate" complement: Add grated, shredded or chopped vegetables such as zucchini, spinach and carrots to lasagna, meat loaf, mashed potatoes, pasta sauce and rice dishes.
18. Stuff a whole grain pita with ricotta cheese and Granny Smith apple slices. Add a dash of cinnamon.
19. Make your main dish a salad of dark, leafy greens and other colorful vegetables. Add chickpeas or edamame (fresh soybeans). Top with low-fat dressing.
20. Try this recipe for an easy, healthy snack. Surprise! Popcorn is a whole grain.

## Community Training Programs

The Epilepsy Foundation offers many training programs to the community. All programs are free of charge and are great to not only teach people about proper seizure management and seizure first aid, but to raise awareness of a often misunderstood condition. If you are interested in having any of the following programs presented to your community, church, school, etc. please contact us through email at [info@epilepsylouisiana.org](mailto:info@epilepsylouisiana.org) or by calling 800-960-0587. Also, let us know if you are interested in being trained on presenting any of the programs.

### AVAILABLE TRAINING PROGRAMS

- Seizure Recognition & First Aid: General Audiences
- Seizure Recognition & First Aid: School Personnel
- Managing Students with Seizures: A training for school nurses
- Seizures after Sixty
- Women & Epilepsy
- Take Charge of the Facts—Epilepsy Awareness Program for Teens
- Kids on the Block Epilepsy Program
- H.O.P.E. Mentoring Program
- Take Another Look: Police Response to Seizures & Epilepsy
- First Responders: Emergency Medical Services Personnel Training

## Ginkgo Herbal Medicines May Increase Seizures In People With Epilepsy



Restrictions should be placed on the use of Ginkgo biloba (*G. biloba*) - a top-selling herbal remedy - because of growing scientific evidence that Ginkgo may increase the risk of seizures in people with [epilepsy](#) and could reduce the effectiveness of anti-seizure drugs, a new report concludes. The article appears in ACS' monthly *Journal of Natural Products*. It also suggests that Ginkgo may have harmful effects in other people after eating raw or roasted Ginkgo seed or drinking tea

prepared from Ginkgo leaves.

Eckhard Leistner and Christel Drewke note that consumers use pills, teas, and other products prepared from leaves of the Ginkgo tree to treat a wide array of health problems. Those include [Alzheimer's disease](#) and other memory loss, clinical [depression](#), [headache](#), irritable bladder, alcohol abuse, blockages in blood vessels, poor concentration, and dizziness. Scientific concern focuses mainly

*(Ginkgo, Continued on page 6)*

# Ask the Expert

Have a questions for one of epilepsy experts or a question for our staff?

Simply email your question to [info@epilepsylouisiana.org](mailto:info@epilepsylouisiana.org) or visit our website and fill out the information request. Your question and answer may be featured in our next newsletter.

*(Ginkgo, Continued from page 5)*

on one chemical compound in the herb. It is a potentially toxic material known as ginkgotoxin.

They reviewed scientific research on Ginkgo, and found 10 reports indicating that patients with epilepsy who take Ginkgo products face an increased risk of seizures. They note that laboratory studies explain how Ginkgo could have that unwanted effect. Ginkgotoxin seems to alter a chemical signaling pathway in ways that may trigger epileptic seizures. Further evidence showed that Ginkgo can interact with anti-seizure medications and reduce their effectiveness. "Contrary to our own previous assumption, we are now convinced, however, that G. biloba medications and other products can have a detrimental effect on a person's health condition," the report concludes. "It is therefore important that the large number of G. biloba product users and their health care providers be made aware of these risks, in order to enable them to make informed decisions about the use of these preparations."

Source: Michael Bernstein  
American Chemical Society



## **Mission:**

- To end epilepsy-related discrimination and injustice through education and increased access to legal services for individuals with epilepsy -- through a system of managed referrals and legal support to a nationwide network of attorneys committed to this cause.
- To advance the rights of people with epilepsy by changing discriminatory practices, policies and laws.

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The Jeanne A. Carpenter Epilepsy Legal Defense Fund has been created to help people with epilepsy fight this discrimination.

**Information, including access to a national database of legal and scientific articles about epilepsy and related legal issues are available. If you are interested in a literature search in a specific area of interest, please submit a request to [legalrights@efa.org](mailto:legalrights@efa.org) or**



**Disclaimer:** *The information in this newsletter is for informational purposes only, and should NOT be construed as any type of medical or legal advice or treatment. The Epilepsy Foundation of Louisiana does not recommend any one product, treatment, or trial. All cases of epilepsy are different and only a certified physician can properly treat any given individual.*