



# Epilepsy Connection

## Think Twice Before Switching Medications



By Amy Nichols, EFLA Staff

On Thursday, May 7, the National Epilepsy Foundation will launch an outreach campaign to raise awareness about the possible dangers of medication switching. Tactics will include:

- The Foundation's survey results documenting links between switching and the increased risk of seizures and the side effects. The distribution of a pharmacy alert to thousands of pharmacists and a newly-revised Web site for consumers about medication switching: <http://www.epilepsyfoundation.org/medicationswitching/>

A concentrated satellite media tour of 13 or more interviews fea-

turing Dr. Brien Smith and Eric Hargis

An interactive news release that will be distributed to health, Science, and life style reporters and editors and

Video postings on YouTube, Soapbox, Imeem, Daily Motion, Mochila, Clip Syndicate, KIT-digital, Voxant, as well as 80-100 TV Web sites.

Our message is a simple one. We strongly urge the FDA to inform patients and their doctors about the possible dangers of medication switching. We are calling on the FDA to do more research into this

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## 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."



## Foundation News:

By: Kassie Campbell, EFLA Staff

It was a perfect day to seize the day! The 5<sup>th</sup> Annual Seize the Day and Take a Walk for Epilepsy was held on April 25, 2009. Our new location on the LSU campus was the backdrop for this year's event and everybody was fired up.

We welcomed over 1000 people to Seize the Day, our biggest turnout-until next year of course. Both runners and non-runners enjoyed food, drink, music, door prizes and awards. Like last year, N2N band played great music and kept the energy level high while emcee Scott Rogers kept everybody laughing. Sponsors such as Community Coffee, Krispy Kreme Donuts, Coke, Jambalaya Shoppe and Hot Diggity Dog kept everybody wanting more.



Race teams took off this year! There were 50 teams and more than 700 team members. Team Gabrielle Reece raised the most money, raising over \$27,000.00 for epilepsy services and the SCMA Running Tigers scored with the most team members (90 team members). HATS OFF TO ALL

### TEAMS!

A balloon release to remember those who have lost their lives to epilepsy touched everyone. It also reminded us why it is important to create awareness and understanding of epilepsy and to seize the day, everyday.

Thanks to all who came out and had a great time. Thanks to those who supported us but couldn't attend the event. Thanks to everyone who helped the event happen. See ya next year!

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)

### **EPILEPSY SUPPORT GROUPS AROUND THE STATE:**

- **Baton Rouge:** 3rd Thursday of every month. (10101 Park Rowe) 7:00-8:30 pm
- **New Orleans:** 3rd Thursday of every month. (St. Francis Xavier Parish Center, Metairie) 444 Metairie Road, 7:00-8:00 pm
- **Shreveport:** 2nd Tuesday, every other month (Christus Schumpert) 6:00pm
- **Lafayette:** 1st Wednesday of every month. (Southwest Medical Center) 6:30pm.



Camp Shining Stars for kids with epilepsy is scheduled for July 5th—10th.

For more information or to register for camp visit our website  
[www.epilepsylouisiana.org](http://www.epilepsylouisiana.org)



## Message From the Director

### "People Don't Understand Epilepsy" - Abby's Story



Abby's parents said they felt something was going on with Abby, 11, but they weren't sure what was happening. Abby's sister learned about epilepsy at school when a local epilepsy educator spoke at her health class.

Abby's sister told her mother that she thought Abby was having seizures. A pediatric neurologist confirmed that Abby has epilepsy. She is now being treated for her seizures.

Abby has absence seizures. "I blank out & can't hear anything. I just kind of stare off and my lips move. After the seizure, I realize that I just had one".

Children with absence seizures are often misdiagnosed with attention problems. This type of seizure lasts only a few seconds.

Abby says the hardest thing about living with epilepsy is "People don't understand Epilepsy"

Dear Friend of the Foundation:

5/4/09

Nationwide three million adults and children are diagnosed with epilepsy which is more people than have multiple sclerosis, cerebral palsy and Parkinson's combined. Approximately, 10% of Alzheimer's and 22% of stroke patients are affected with epilepsy.

The Epilepsy Foundation of Louisiana's mission is **"to ensure that people with seizures are able to participate in all life experiences; and will prevent, control and cure epilepsy through services, education, advocacy and research"**.

The Foundation combats myths & fears about epilepsy through education. We also provide medication assistance, education and seizure first aid, counseling and support for patients, families and communities in Louisiana in addition to the youth programs including summer camp, "Take Charge of the Facts" a youth education program, and November's youth outreach for epilepsy. All services are free even in this financially challenging environment.

The Foundation is the only agency in Louisiana providing social services to individuals with epilepsy and we are asking for your help to support these efforts including its youth programs.

This year, our national office has developed a program called, "Talk About It", the brainchild of Greg Gumbert of NBC's Hero's program. His son has epilepsy. The idea is that if we all just "talk about it" we will reduce the mystery of epilepsy. People are sponsoring local dinner parties in their homes so that we can "talk about it". Instead of bringing the host a gift, dinner participants are asked to make a donation to the Epilepsy Foundation. The amount is not as important as is the opportunity to "talk about it". You can help us by sponsoring a dinner in your home or by making a direct donation to support youth programming. Either effort will help.

Even so, in 2009, epilepsy remains a misunderstood condition. As Abby points out, "People don't understand epilepsy." Unfortunately, she is correct but with your support, we may be able to improve outcomes for all people in our state with epilepsy.

*Dorothy Martino, LCSW*

**Dorothy Martino, LCSW  
Executive Director**



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Epilepsy is marked by abnormal electrical activity in the brain that leads to recurring seizures. A person who has a first seizure is statistically much more likely

to have a second, and with each subsequent seizure, the chance of having another seizure grows. A person is often diagnosed with epilepsy after having two or more unprovoked seizures.

In prior studies, Barth and colleagues were the first to link BK channels, ion channels that allow electrically charged potassium ions to move out of cells, to sporadic epilepsy. Previous studies had shown that these channels were genetically altered in a few rare individuals who suffer from the disorder, but Barth and colleagues demonstrated that seizures themselves could lead to the same alterations in BK channel function.

Potassium ions move through the channels, starting and stopping the electrical impulses that allow neurons to communicate with one another. The Carnegie Mellon researchers found that after a first seizure, BK channel function was markedly enhanced. As a result, the neurons became overly excitable and were firing with more speed, intensity and spontaneity, leading Barth to believe that the abnormal increased activity of the channels might play a role in causing subsequent seizures and the emergence of 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.



## Epilepsy Research

### Lacosamide Monotherapy Trial for Partial Seizures

Schwarz Biosciences is sponsoring a multi-site clinical trial for persons 16 to 70 years with a diagnosis of partial seizures. Persons who meet the study criteria and are willing to participate will receive either 300 mg per day or 400 mg per day of Lacosamide for up to 20 weeks with a potential option to enter an open-label trial. Study visits and study medication costs will be covered by the Sponsor (Schwarz). Persons interested in getting more detailed study information should e-mail the study coordinator for the LSU Epilepsy Center of Excellence in New Orleans 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.

### Monotherapy Study with Lyrica for Partial Seizures

Pfizer is sponsoring a clinical trial at the LSUHSC Epilepsy Center in New Orleans where eligible candidates will be 18 years or older and experiencing partial epileptic seizures. Those meeting the additional study criteria and willing to participate will receive one of two doses of the study drug for 20 weeks as treatment 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 for about 6 months. 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."*



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matter and to develop a standard that ensures equivalency and safety for all patients.

Here are some quick answers to the most frequently asked questions.

**Q: What is the issue of medication switching?**

**A:** People with epilepsy are experiencing seizures and other harmful side effects after switching from one version of an antiepileptic drug (AED) to another, whether the switch is brand-to-generic, generic-to-brand, or generic-to-generic. While the Food and Drug Administration (FDA) requires these medications to have the same active ingredient, they allow some variability in the concentration of the active ingredient; they also allow different processing techniques and different fillers. While this variability does not harm most people with epilepsy, for some these variations can mean the difference between controlled epilepsy and breakthrough seizures (sudden unexpected seizures in someone who previously had achieved reliable control), toxic side-effects, or in some cases even death.

**Q: Wouldn't cheaper drugs be beneficial to patients?**

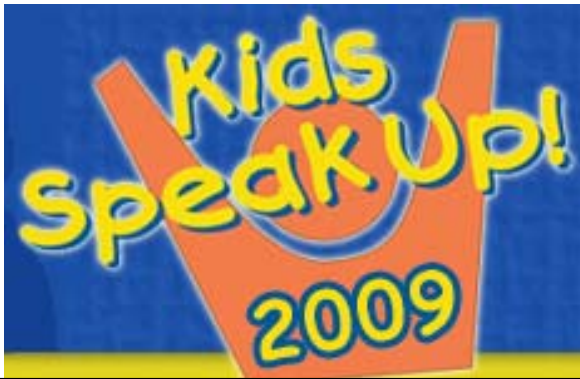
**A:** Absolutely! The cost of medications is an issue for us all and particularly for people with epilepsy who frequently will take medications throughout their life-time. People with epilepsy just need to be sure it is safe for them to switch by talking to their doctor before making any changes in their medication. People with epilepsy need to know what their medications look like, and alert their pharmacist and doctor if it looks different. A recent study documents that the cost of emergency room trips and other treatments from a breakthrough seizure far exceed any savings from medications; and no one should put a price tag on the human cost of a seizure.

**Q: Why are generic drug cheaper?**

**A:** Generic drugs are less expensive because generic manufacturers don't have the investment costs of the developer of a new drug. New drugs are developed under patent protection. The

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**Share your story of living with epilepsy**  
**Become a Face of Epilepsy**  
**[www.facesofepilepsy.org](http://www.facesofepilepsy.org)**



# Lafayette Teen goes to Capital Hill for Epilepsy

By: Amy Nichols, EFLA Staff

Friday, March 27<sup>th</sup> started with sunny skies in Louisiana and moved to pouring rain and thunderstorms all over the south. Those thunderstorms delayed flights in Texas, rerouted other flights and left us over an hour late arriving in Washington D. C. to represent the Epilepsy Foundation of Louisiana at the 2009 Public Policy Institute and Kids Speak Up! Conference. We were instructed to bring raingear and umbrellas and we're glad we did. It proceeded to be cold and rainy most of the time.



April Torres and Emily Barnes (Lafayette), Amy Nichols (Shreveport) in front of the Capitol in Washington, DC



Jamie Baker, Legislative Correspondent to Senator Mary Landrieu, April Torres and Emily Barnes (Lafayette) and Amy Nichols (Shreveport) meeting in Senator Mary Landrieu's office

Thousands of supporters gathered on the National Mall Saturday, March 28<sup>th</sup> to make a difference in the lives of people living with epilepsy, to raise awareness and to increase funds for research in the quest for a cure. The raindrops fell, the gray clouds gathered but the band still played signaling the start of the walk as everyone took off in the rain. Later that day April Torres and Emily Barnes of Lafayette, our Louisiana family attending the Kids Speak Up! Conference, and I toured the Mall area and visited the famous Smithsonian Museums. But that was the only day of leisure.....

The conference packed a week's worth of information into two solid days of meetings that began at 8 a.m. and lasted until 8 p.m. We heard from informed, educated, experienced people on subjects of advocacy, research and empowerment. We heard from parents of children with epilepsy as they told




Amy Nichols (Shreveport), Mike Thompson, Legislative Assistant to Cong. Charles Boustany 7th District, Emily Barnes and April Torres (Lafayette) meeting in Charles Boustany's office

their stories inspiring us to dig in, stay the course and not let go of the fact that “we” are our children’s best advocate. The “Kid’s” side of the conference began on Sunday night with a Welcome Ceremony hosted by Joyce Bender. Ms. Bender began the “Kid’s” Conference with heartening, empowering words calling them tomorrow’s leaders and today’s conquerors. The children were entertained during their dinner by a magician and later listened to an encouraging message from Mike Simmel or better known as “Mighty Mike of the Harlem Wizards”.

Finally, Tuesday arrived and it was time to put our training into action. Our task at hand was to put a personal face of epilepsy in front of our local congress people. We met with Senator’s Mary Landrieu and David Vitter and Representative’s John Fleming, from my district and Charles Boustany, from Emily and April’s district. Emily did a great job telling them about her condition and answering their questions directly and sincerely. April also expressed how epilepsy affects everyone in the family and that epilepsy is a “disorder of anticipation”. I left behind information with our state agenda.

Our last day was a fun day filled with things we had never done before. The day was bright and sunny and we enjoyed seeing Washington in full bloom. We walked from the Senate offices to the Representative offices and strolled outside the White House. We went inside the Library of Congress and passed the Supreme Court Building. We ate lunch in the Senator’s cafeteria, went inside the capitol and we took pictures all along the way like the “tourist” we seemed to be. But all in all, we met new friends, learned a lot, listened a lot more and discovered when a few people gather together for the same cause, we can make a difference.



**DID YOU KNOW?**

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



Amy Nichols (Shreveport), April Torres and Emily Barnes (Lafayette), Meghan Marino, Legislative Correspondent for Congress. John C. Fleming 4th District, meeting in Congress. John Flemings' office



Amy Nichols (Shreveport), Amanda Walsh, the Legislative Coordinator for Senator Vitter, Emily Barnes and April Torres (Lafayette) meeting in Senator Vitter's office

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patent protects the investment – including the research, development, marketing and promotion – by giving the company the sole right to sell the drug while it is in effect. As patents near expiration, other manufacturers can apply to the FDA to sell generic versions. Because these manufacturers don't have the same development costs, they can sell their product at substantial discounts. Also, once generic drugs are approved, there is greater competition, which keeps the price down.

**Q: Can an epilepsy patient's medication be switched without their knowledge?**

A: Yes! Many different companies make the same AED and pharmacies purchase from different companies based on price. As such, it is common that your pharmacy will have a different generic AED, in some cases from month to month. People with epilepsy have reported getting three different colored pills in the same prescription.

**Q: What advice can you give to people who have epilepsy or have someone they care about who has epilepsy?**

A: First talk to your doctor and also visit [www.EpilepsyFoundation.org](http://www.EpilepsyFoundation.org) Get more informed, and in particular, if you have a problem with medication switching, or your medication was switched without you or your doctor knowing, let the FDA or your local Epilepsy Foundation know about your experience.

This is one of our top state issues for the Epilepsy Foundation of Louisiana. If you or your loved one has experienced medication switching without your consent or your doctor's direct written consent, or have experienced breakthrough seizures due to generic switching, please let me know at [amy@epilepsylouisiana.org](mailto:amy@epilepsylouisiana.org) .



**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.