

Join us in Shreveport for our
2nd Annual Seize the Road Bike Tour & Walk
on
SATURDAY, SEPTEMBER 22, 2007

Choose from 4, 19, 42, or 62 mile course.

Special gifts and door prizes!

Visit our "Ask the Experts" table
Meet a National Epilepsy Advocate and Biker

TO REGISTER OR FOR MORE INFORMATION VISIT OUR WEBSITE AT:

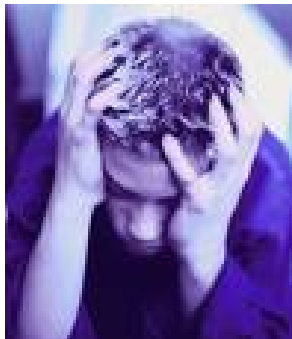
WWW.EPILEPSYLOUISIANA.ORG

In This Issue

Seize the Road Bike Tour	p1
Epilepsy May Raise Suicide Risk	p1
Foundation News	p2
Back to School	p3
Epilepsy Research	p4
Advocacy, Anti-Seizure Medication & You	p5
About Us	p6

STUDY SUGGESTS EPILEPSY MAY RAISE SUICIDE RISK

People diagnosed with epilepsy are three times more likely to commit suicide than the general population, according to an article by Danish researchers published early online and in the August 2007 edition of *The Lancet Neurology*. The study also found that women with epilepsy were more likely to commit suicide than men with the condition, and people diagnosed with epilepsy in the previous six months were at an even higher risk of committing suicide.



Researchers at the Aarhus University Hospital studied over 21,000 cases of suicide in Denmark between 1981 and 1997. They compared the data to more than 423,000 people who did not commit suicide. The researchers excluded socioeconomic factors (SEFs) such as marital status, job status, income and absence from work and still found that people with epilepsy were twice as likely to commit suicide as people without the disorder. Additionally, they found that people with both epilepsy and comorbid psychiatric disease were nearly 14 times more likely to commit suicide, adjusting for SEFs, compared with those with neither condition. Further, they found that in individuals with epilepsy, those who had been diagnosed six months ago or

(Continued on page 2)



Watch... **Saturday & Sunday** ^{#1 show on the weekend}
8 a.m.
8 a.m. on Cox 4 • 8 a.m. on Ecol 4 • 8 a.m. on Trust 55
Repeats at 9 a.m. and 11 a.m. on Mezz21

Show enquiries/
Advertisers call
225-291-9000

FOUNDATION NEWS

MESSAGE FROM THE DIRECTOR:

Summer has settled into the state and we are all busy with vacations, work and summer events. The Epilepsy Foundation had a wonderful response to its letters requesting support for summer camp which was held the week of July 8th through 14th. Thanks to UCB, Inc. and the Olivia Waddell Foundation for its donations to support this important event. We also were the beneficiaries of a wonderful donation from PACE, "Parent Against Childhood Epilepsy" in New York to help with the Foundation's work including summer camp.

- *Dotty Martino*
Executive Director

UPCOMING EVENTS:

- August 16 - Support Group Baton Rouge
- August 16 - Support Group New Orleans
- September 20 - Support Group Baton Rouge 7p-8:30p
- September 20 - Support Group New Orleans 7p-8p
- September 22 - 2nd Annual Seize the Road Bike Tour, Shreveport
- October 2 - Take Charge Glen Oaks High School
- October 18 - Support Group Baton Rouge
- October 18 - Support Group New Orleans

* Baton Rouge Support Group is held at the NeuroMedical Center, 1010 Park Rowe Circle, Baton Rouge.

* New Orleans Support Group is held at St. Frances Xavier Parish Center, 444 Metairie Road, Metairie, LA

HAVE A QUESTION FOR ONE OF OUR EXPERTS? EMAIL QUESTIONS TO HOLLY@EPILEPSYLOUISIANA.ORG.

"Suicide" (Continued from page 1)

less were more than five times more likely to commit suicide, while those diagnosed less than six months ago and with comorbid psychiatric disease were 29 times more likely to take their own lives.

Although the trend in the general population is for incidence of suicide to increase with age, the study found that the risk of suicide after epilepsy decreased with age.

The authors conclude: "Individuals with epilepsy have a higher risk of suicide, even if co-existing psychiatric disease, demographic differences and socioeconomic factors are taken into account. Our study identifies people with newly diagnosed epilepsy as a vulnerable group that require special attention."

Note: *The Epilepsy Foundation recommends that if you, or someone you know with epilepsy, appears depressed or talks about suicide, they should seek medical attention from their treating physician—or an emergency room if the symptoms appear severe or they discuss an actual suicide plan. Medical treatment is available to help. For more information, visit the [mood disorders section](#) of our Web site or the [National Institute of Mental Health's Web site on depression](#).*

Source: Adapted from a news release issued by *The Lancet Neurology*.



BACK TO SCHOOL & EPILEPSY

GETTING OFF TO THE RIGHT START



*Written by Holly Guess,
EFLA Staff*

The start of a new school year can be a stressful and anxious time of year for both parents and students especially when your child suffers from epilepsy. Starting off the year on the right foot is very important to insure your child has a successful school year. The first step in preparing for school is to have a Sei-

zure Plan in place. Having a Seizure Plan insures that parents and school personnel agree on the steps to be taken when your child has a seizure. If you are uncertain on how to write a Seizure Plan the Epilepsy Foundation can provide you with a form to complete with your child's physician. There are numerous ways the Foundation can help you communicate with schools. We can aid you in IEP meetings, as well as educating your child's

school on epilepsy and proper management of seizures. This may include educating your child's teachers, classmates, or school nurse. Below you will find a list of steps that you can take with your child's school personnel to establish a good relationship and insure your child has a great year. Contact the Epilepsy Foundation at 800-960-0587 or visit our website for more information or assistance with your child's school.

STEPS TO STARTING THE YEAR OFF RIGHT WITH YOUR CHILD'S TEACHER:

1. Get your child a medical ID bracelet (these can be ordered through the Foundation for \$8.50)
2. Meet your child's teacher and communicate the following:
 - Seizure Plan (the Epilepsy Foundation can provide you with a seizure plan form) A seizure plan provides school personnel the appropriate information to assist your child when a seizure occurs.
 - What is epilepsy
 - Describe what your child's seizures are like (daydreaming, stomach ache, etc)
 - Discuss first aid for seizures
 - Steps to take incase of an emergency
 - Discuss & name the different medications your child takes
3. Try to schedule an in service for school staff (the Epilepsy Foundation can educate school staff at no cost).
4. Try to schedule a training to educate the students in your child's class (the Epilepsy Foundation can also provide this at no cost).



PARTICIPATE IN EPILEPSY RESEARCH

Lamictal Extended Release Study for Partial Seizures

GlaxoSmithKline is sponsoring a clinical trial at the LSU Epilepsy Center in New Orleans for persons 13 years and older experiencing partial epileptic seizures. Persons who meet the study criteria and are willing to participate will receive Lamictal extended release for 23 weeks with a potential option for an additional 24 weeks. Study visits and study medication costs will be covered by the Sponsor. Persons interested in getting more detailed study information should e-mail the study coordinator at epicenter@lsuhsc.edu. Please provide your name, e-mail address or telephone number and the study in which you are interested.

Lexapro Study for Depression in Persons with Temporal Lobe Epilepsy

Forest Pharmaceuticals is sponsoring a clinical trial at the LSU Behavioral Sciences Clinic in New Orleans for persons who are 18 to 65 years of age with temporal lobe epilepsy and suffer from depression. Persons who meet the study criteria and are willing to participate will receive Lexapro for 10 weeks. Study visits and study medication costs will be covered by the Sponsor. Persons interested in getting more detailed study information should e-mail the study coordinator at epicenter@lsuhsc.edu. Please provide your name, e-mail address or telephone number and the study in which you are interested.

Open Label Study of Flexible Dose of Brivaracetam in Subjects 16 Years or Older Suffering From Epilepsy

The purpose of this study is to evaluate the long-term safety and tolerability of brivaracetam. Inclusion Criteria: Male/female subjects from 16 years or older. Subjects with epilepsy who participated in previous brivaracetam trials. Subjects from whom the investigator believes a reasonable benefit from the long-term administration of brivaracetam may be expected. Exclusion Criteria: Severe medical, neurological and psychiatric disorders or laboratory values which may have an impact on the safety of the subject. Poor compliance with the visit schedule or medication intake in the previous brivaracetam trial. Contact: UCB Clinical Trial Call Center Located in: St. Ruston, LA Telephone: 1-877-822-9493

NEW GENES IDENTIFIED IN CHILDHOOD FEVER-RELATED SEIZURES

Researchers have localized two new genes that are associated with fever-related seizures that occur in infancy and childhood, according to a study published in the April 24, 2007, issue of *Neurology*.

“Identifying the genes responsible for febrile seizures could improve the understanding, treatment and even prevention of this disorder,” said study author Rima Nabhout, MD, PhD, of the French Institute for Medical Research (INSERM) in Paris.

Fever-related (febrile) seizures are the most common seizure disorder in children and affect two to five percent of children by age six in the United States. For most children, the seizures do not cause permanent brain injury and occur only once or a few times. A small percentage of children go on to develop other seizure disorders such as epilepsy later in life.

The study examined four generations of a French family. Of the 51 people in the family, 13 had

“Gene” (Continued on page 6)

Advocacy, Anti-seizure Medications and You

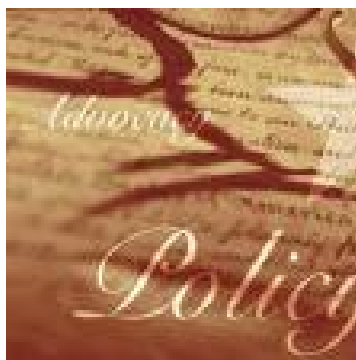
By: Kelly April, EFLA Staff

This year marked the first attempt by the Epilepsy Foundation of Louisiana to support the passing of a House bill designed to protect the rights of Louisiana Residents with epilepsy. The Patient Protection Act was designed to re-

quire that all persons taking anti-epileptic medications and their doctors be fully informed before any change is made to the formulation of their medications. We at the Epilepsy Foundation

strongly supported this legislation because many people have reported a change in their seizure status when the formulation of their medication has been changed. People from across the state were sought out to begin a grass roots advocacy initiative designed to support this legislation and an advocacy training session this past March. Unfortunately, the Patient Protection Act did not make it out of the Senate Health & Welfare committee this session. We are saddened by this turn of events but we are not giving up the fight. Our efforts to support such legislation and to encourage grass roots advocacy for the rights of individuals with epilepsy in Louisiana will continue in the future.

In order to continue toward our goal of enacting patient protection legislation we are asking for your help. Many people with epilepsy have reported changes in their seizure patterns when they have been switched from a brand name medication to a generic, from a generic to a brand name or when switched from one generic formulation to another. Break through seizures and changes in seizure patterns are of serious concern to individuals with seizure disorders and these issues need to be reported so that they may be formally catalogued. We are strongly encouraging anyone who has experienced any negative outcomes as a result of a change in the formulation of their anti-seizure



medication to report these outcomes to their physician, the Epilepsy Foundation, the Louisiana Board of Pharmacy and the FDA.

While we are quite familiar with the issues surrounding the switching of medication formulations for people with epilepsy, the FDA and the Louisiana Board of Pharmacy tell us that they have had very few reports about such issues. Without formal reporting, it is difficult to argue for strong patient protection legislation. If you have experienced any problems when your anti-seizure medication was switched from a brand name to a generic, from a generic to a brand name, or from one generic formulation to another, please report these issues to your doctor and ask your doctor to formally report these issues to both the FDA and the Louisiana Board of Pharmacy. We also ask that you personally report these issues to the Epilepsy Foundation of Louisiana, the FDA and the Louisiana Board of Pharmacy. The FDA encourages physicians and people with epilepsy to report any breakthrough seizures that occur after a change from one medication formulation to another to the FDA's MedWatch Program. For reporting information call 1-800-FDA-1088 or go to <http://www.fda.gov/medwatch>. The Louisiana Board of Pharmacy can be reached at www.labp.com or by calling 1-225-925-6496. The Epilepsy Foundation of Louisiana can be reached at (800) 960-0587.

It is crucial that the rights of individuals with epilepsy be protected in our state. The Epilepsy Foundation of Louisiana wants to ensure that anti-seizure medications are not substituted without the prior informed consent of both the patient and their physician, but in order to do this we need more information. By formally reporting your experiences with medication formulation changes, you are providing that vital information. Your reports to all of the above listed agencies will help us to demonstrate the need for patient protection legislation in the state of Louisiana.

“Gene” (Continued from page 4)

childhood febrile seizures. The febrile seizures stopped by the age of seven for all 13 children. However, six of the children developed epilepsy later in life. The 13 affected by the disorder and 13 additional family members not affected by the disorder took part in the genetic study. The researchers used a technique called genetic linkage to determine which segments along chromosomes were shared by all family members who had febrile seizures. All of those affected shared a portion of chromosome 3. Chromosome 3 has not previously been reported to be associated with febrile seizures. The researchers also found that the family members who developed epilepsy shared another common segment on chromosome 18, providing evidence that the gene on chromosome 18 might act as a modifier gene. The gene on chromosome 18 may also be associated with febrile seizures.
Source: The American Academy of Neurology

OUR LOCATIONS:

Reach any of our offices at: **800-960-0587**

New Orleans Office

3701 Canal Street Ste. H
New Orleans, LA 70119
504-486-6326
neworleans@epilepsylouisiana.org

Baton Rouge Office

11762 S. Harrell's Ferry Rd. Ste. F
Baton Rouge, LA 70816
225-298-5499
batonrouge@epilepsylouisiana.org

Shreveport Office

900 Market Street
Shreveport, LA 71101
800-960-0587
shreveport@epilepsylouisiana.org

Visit Us Online at:

www.epilepsylouisiana.org

Thanks to the Huey & Angelina Wilson Foundation
for their continued financial support of the Baton Rouge office.



Our Mission

The mission of the Epilepsy Foundation of Louisiana is to enhance the quality of life of individuals and families living with epilepsy and seizure disorders by addressing their individual needs and increasing public awareness. The Epilepsy Foundation is a not-for-profit, volunteer health agency and an affiliate of the national Epilepsy Foundation.