



# Epilepsy Connection

## SURVEY ESTIMATES 1 PERCENT OF ADULTS HAVE ACTIVE EPILEPSY

(CNN) -- An estimated one percent of adults have active epilepsy, and many of them are getting insufficient treatment, according to a 19-state survey released Thursday.

The CDC study found one in six adults with active epilepsy and had recent seizures were not taking medication.

"This is the first time that we actually have data from multiple states," said Rosemarie Kobau, lead author of the Centers for Disease Control and Prevention study, in a telephone interview. "What we learned is that, among adults with active epilepsy, more than a third of them reported not seeing a specialist for their epilepsy, and that's really unacceptable."

A follow-up survey is planned to determine why so many people with seizure disorders said they had not seen a specialist in the past year, Kobau said.

"This is a highly specialized field," said Eric Hargis, the president and CEO of the Epilepsy Foundation, which collaborated with the authors of the study. "It's not possible to get state-of-the-art care" for the disorder from primary care doc-

tors.

One in six (16.1 percent) adults with active epilepsy with recent seizures said they were not taking their medication and two-thirds (65.1 percent) said they had had more than one seizure during the prior month.

More than a fifth (20.4 percent) said cost was a barrier to seeking care from their doctor.

Access to high-quality care is key to quality of life, Kobau said. People with recurrent seizures face substantial impairments in their daily activities; many are not allowed to drive and, as a result, depend on public transportation. In some areas, particularly rural ones, that can present a barrier to full participation in life, she said.

That's not all. In addition to carrying stigma, people with epilepsy were more likely to live in households with the lowest annual incomes and to report being unemployed and unable to work.

According to the 2005 findings, 1.65 percent of the population said they had been told by a doc-

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By: Amy Nichols, EFLA Staff

**SATURDAY, SEPTEMBER 27,** gather with over 400 riders, walkers and volunteers at the Stoner Boat Launch off of the Clyde Fant Parkway and choose from 4 different courses that will take you north through our beautiful rural Louisiana countryside. Cyclists can ride for 17, 41, 52 or 60 miles. If you prefer a shorter distance, and one without wheels, you can run, walk or stroll a 4 mile distance along the winding red river. Children are invited to ride their bicycles along this shorter distance. The Caddo Parish Sheriff's department will be holding a children's bicycle safety program at 11:00 a.m. Full support will be provided with stocked

rest stops, SAG vehicles, medical support, bike mechanics and more!

Come as an individual or participate as part of a team. Forming a team is a great way to build a sense of teamwork while representing your community involvement. Want to learn more about forming a team? See online details at [www.seizetheroad.org](http://www.seizetheroad.org) or [www.sportspectrumusa.com](http://www.sportspectrumusa.com) or call the Epilepsy Foundation at (800) 960-0587 or (318) 402-6752.



## Foundation News:

### *Message From the Director*

The August 7<sup>th</sup> Epilepsy Awareness Day in New Orleans was a great success that was co-sponsored by LSU, ASET, and the Epilepsy Foundation of Louisiana. Thanks to all staff that helped with this project and a huge "thank you" to Nicole Pittman at LSU who worked tirelessly to make it happen. It is the time of year where the focus is on the "Seize The Road" Bike Tour and Walk in Shreveport that will be held September 27<sup>th</sup>. Hope all of you can participate. Also, look for a new project we are sponsoring via email for November, Epilepsy Awareness month. Holly will be working on this project which will roll out November 1<sup>st</sup>. Finally, look for the first fund raising event for greater New Orleans since the storms of 2005. On December 14<sup>th</sup>, the Foundation will sponsor the "Larry Fuslier/Epilepsy Foundation Race" with the New Orleans Track Club. This is a qualifying race for marathon runners and the last one to be held in Louisiana for the year. Don't fret though if you are not a "marathon" runner. We will have the Epilepsy Run/Walk on this day and we look forward to all of your participation.

- *Dotty Martino, LCSW*  
Executive Director

### **COMMUNITY MEETINGS 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) 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.

### MARK YOUR CALENDAR!



**OCTOBER 4TH:**  
POKER RUN AT  
RACK BAR IN BATON ROUGE,  
BENEFITING THE  
EPILEPSY FOUNDATION OF LOUISIANA

**SUNDAY, DECEMBER 14TH**  
LARRY FUSLIER / EPILEPSY FOUNDATION RACE  
NEW ORLEANS, LOUISIANA



### **WE NEED VOLUNTEERS:**

The Epilepsy Foundation of Louisiana needs your help! We are looking for volunteers to assist with bulk mail four times a year (in the Baton Rouge office) as well as volunteers to assist with community education. If you are interested and available to assist the Foundation please contact us at 800-960-0587 or email us at [info@epilepsylouisiana.org](mailto:info@epilepsylouisiana.org). With your help *not another moment will be lost to seizures.*

### **REACH ANY OF OUR OFFICES AT:**

800-960-0587 or [info@epilepsylouisiana.org](mailto:info@epilepsylouisiana.org)  
11762 S. Harrell's Ferry Rd. Ste. F, Baton Rouge, LA 70816  
3701 Canal Street, Ste. H, New Orleans, LA 70119  
900 Market Street, Shreveport, LA 71101



## Ditching Epilepsy Meds is Dangerous



(Ivanhoe Newswire) – Statistics show up to 50 percent of people with epilepsy fail to take their anti-seizure medications according to doctor's orders.

That's a big mistake, report researchers who reviewed death rates among people who did and did not take their medications on a regular basis. Overall, people who took their meds less than 80 percent of the time over a three-month period were three times more likely to die.

"There are many reasons epileptic patients fail to take their seizure medications, including cost, side effects and pregnancy," study author Edward Faught, M.D., director of the University of Alabama Epilepsy Center in Birmingham, was quoted as saying.

"But this study suggests that none of those reasons overshadow the threat of death or other problems related to uncontrolled seizures. Patients need to stay on their medications and physicians need to recognize and treat issues related to people failing to take epilepsy drugs."

People in the study who didn't take their meds as prescribed had increased risk of death from car accidents and bone fractures, although no increased risk was seen for head injuries. Those who ditched their medications were also significantly more likely to require a hospitalization or go to the emergency room.

The study involved a review of insurance records from three state Medicaid programs and involved more than 33,600 people who had filled prescriptions for epilepsy drugs.

SOURCE: *Neurology*, published online June 18, 2008

### EPILEPSY 101:

#### Juvenile Myoclonic Epilepsy:



Juvenile myoclonic epilepsy (also called Janz's syndrome, impulsive petit mal, myoclonic epilepsy of adolescence and jerk epilepsy) was first described in 1956 by Dr. Dieter Janz, who called it impulsive petit mal because of the sudden jerking (myoclonic) seizures that are a prominent part of the syndrome. The syndrome is characterized by myoclonic seizures (sudden jerks of arms and legs), especially on awakening.

Juvenile myoclonic epilepsy generally appears at puberty, but may have existed prior to that time and it is usually not outgrown; it is also associated with generalized tonic-clonic seizures. Seizures may be precipitated by sleep deprivation; early awakening; alcohol and drug use; stress; strong emotion, photic stimulation, and menstruation.

SOURCE: *Epilepsy Foundation of America*®

## SEIZURE MEDICINES SAFE FOR BREASTFEEDING

(Ivanhoe Newswire) -- Though the findings are preliminary, researchers believe there's a good chance that anti-seizure medications taken by breastfeeding mothers will not harm their babies.

A study from the University of Florida in Gainesville tested the cognitive development of two year olds whose mothers were taking the epilepsy drugs lamotrigine (Lamictal), carbamazepine (Tegretol), phenytoin (Dilantin) and valproate (Depacon).

The results showed babies who were breastfed had higher cognitive test scores than those who were not breastfed, no matter which of the medications the mothers took. It is important to note that the study's author, Kimford Meador, M.D., and his team report the scores themselves were not significant after adjusting for the mother's IQ -- the higher scores for the breastfed children appear to be due to the fact that the mothers had higher IQs.

Concern about the effect of these drugs on breastfed babies came from animal studies that showed some anti-seizure drugs could cause cells to die in immature brains. The unborn child is protected during pregnancy by the effects of the hormone estradiol. That protection is lost after birth.

"Our early findings show breastfeeding during anti-epilepsy drug treatment doesn't appear to have a negative impact on a child's cognitive ability," Dr. Meador was quoted as saying. "However, more research is needed to confirm our findings and women should use caution due to the limitations of our study."

Dr. Meador hopes to extend the research to other anti-seizure drugs and mothers who use more than one of them.

SOURCE: Presented at the American Academy of Neurology's 60th Annual Meeting in Chicago, April 12-19, 2008



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tor that they had epilepsy or a seizure disorder, the report said. Half of that group (0.84 percent) said they had active epilepsy -- defined as having had one or more seizures during the prior three months or currently taking medication.

If the findings translate to the general population, that means a stadium filled with 60,000 people would contain 480 people with active epilepsy, Kobau noted, adding, "Epilepsy is not rare."

But that view was disputed by Dr. James King, a family physician in Selmer, Tennessee, and president of the American Association of Family Physicians.

"There are patients that can be managed fairly simply with seizure disorder," he said in a telephone interview. "In my own personal practice, I'd say that I can manage at least half, if not more, of the patients that have seizure disorder."

Many of the others are able to get by with just a one-time visit to a neurologist, said King, whose practice is 50 miles from the nearest neurologist, and 100 miles from the nearest neurologist who accepts Medicaid, the government program for the poor.

"There's only a handful of patients that are managed in my area by the neurologist." He said financial barriers -- from insurance to the cost of anti-seizure medication -- are a bigger problem.

"If you can't afford to buy it -- which is what I run into with a lot of the seizure medicine -- it doesn't really matter" if patients see a neurologist or a family physician, he said.

Many patients, forced to choose between paying their light bill or taking their anti-seizure medication, choose the former, King said.

Epilepsy is a condition in which the normal activity of the brain malfunctions, causing recurrent seizures -- electrical storms in the brain -- that can be characterized by a range of symptoms, including sudden change in awareness, movement or sensation.

Each year, about 200,000 people in the United States are diagnosed with the disease, as was Supreme Court Chief Justice John Roberts after he suffered a seizure last year at his Maine vacation home.

"Many people with epilepsy do lead normal, productive lives despite the hardship of having this disorder," Kobau said.

The study, conducted by the federal government and published in the CDC's Morbidity and Mortality Weekly Report, estimates that 2.7 million people in the United States have epilepsy, and that it costs some \$15.5 billion in medical care and lost or reduced earnings or productivity each year.

Hargis said the incidence of the disorder is expected to climb among veterans returning from Iraq or Afghanistan, where head injuries are common. "When you have a head injury, it's common for epilepsy to develop after a gestational period -- it could be a couple of months or it could be years," he said.

And the aging population is also expected to boost the incidence of epilepsy. Conditions of aging, such as stroke and Alzheimer's Disease, are also associated with a higher incidence of epilepsy.

The study was based on data from more than 120,000 adults in the Behavioral Risk Factor Surveillance System



## GETTING YOUR CHILD READY FOR SCHOOL

- By: Amy Nichols, EFLA Staff.

Every August, parents go about the business of getting their children ready for school. It may sound simple: the lists, the shopping, the appointments. But parents of children with epilepsy face a special challenge: making sure that their children can be safely treated in the event of a seizure emergency away from home.

According to the Epilepsy foundation of America, about 326,000 school children aged 14 and under have epilepsy. Most go to school and fully participate in school activities. However, if your child continues to have intermittent seizures, you'll want to prepare the school staff, especially the classroom teacher and the school nurse, to work together so that your child can grow, learn, and achieve his or her full potential.

### BEFORE SCHOOL STARTS

- ü Schedule a visit to your child's health care provider to ensure that your child's current medication dosages are appropriate for his or her growth since the last doctor's visit.

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## Randomized Trial Confirms Efficacy of Ketogenic Diet in Preventing Epileptic Seizures in Children

A randomized controlled trial has confirmed the efficacy of the ketogenic diet in helping control and prevent epileptic seizures in children with drug-resistant epilepsy. These are the conclusions of authors of an article published early online and in the June edition of *The Lancet Neurology*.

The ketogenic diet has been used widely and successfully to treat children with drug-resistant epilepsy since the 1920s. It is a diet very high in fat, low in carbohydrate, and with controlled protein. Although the exact mechanism of action is still unclear, the high fat and restricted carbohydrate content of the diet is thought to mimic the biochemical response to starvation, when ketone bodies\*, rather than sugars, become the main fuel for the

brain's energy demands. While there have been many observational studies of this diet, Professor J. Helen Cross of the Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust at the University College in London and colleagues have done the first randomized controlled trial to test its efficacy.

The trial assessed 145 children aged between 2 and 16 years who had at least daily seizures (or more than seven seizures per week), had failed to respond to at least to antiepileptic drugs, and had not been treated previously with the ketogenic diet. Seventy three children were put on the diet immediately while 72 were assigned to the diet after a

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## Epilepsy Research<sup>1</sup>

### 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 19 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 LSUHSC 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.

### 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](mailto:epicenter@lsuhsc.edu). Please provide your name, e-mail address or telephone number and the study in which you are interested.

### Lennox-Gastaut Syndrome (LGS) Clinical Trial

A new clinical research study is being conducted in your area to determine the effects of a potential new treatment, clobazam, in children and adults with LGS or those who experience LGS symptoms. Participation in a clinical study can help researchers learn more about the disease and can allow patients to gain access to medical care directly related to the study. Enrollment is currently underway in the United States at more than 30 centers with neurologists who specialize in the treatment of LGS patients. Individuals may be able to join the clobazam study if they currently have LGS, had LGS when they were young or have drop seizures but were never officially diagnosed with LGS. Among other requirements, participants:

- Must be between 2 and 60 years of age
- Must have been younger than 11 years of age at the onset of LGS
- Must be on one, but no more than three, antiepileptic drugs (AED)
- Willing to undergo study procedures, such as EEG recordings and routine blood draws.

Individuals meeting study requirements will be asked to participate in the study over a 23-week period. All medical care directly related to the study will be provided at no cost to participants. Call 800-976-4496 or email [LGSstudy@edelman.com](mailto:LGSstudy@edelman.com). For more information and study site locations nearest you please visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov) (Identifier NCT00518713).

<sup>1</sup>The Epilepsy Foundation of Louisiana does not promote or encourage any consumer to participate in research. Any decision to do so should always be made with the consultation of your neurologist. For a complete listing of current clinical trials that are available, please see [clinicaltrials.gov](http://clinicaltrials.gov) or [centerwatch.com](http://centerwatch.com).



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- o If your child uses medication to treat emergency seizures, consider asking the doctor for an extra supply to keep at school
- ü Meet with your child's teacher to discuss:
  - o The types of seizures your child might have
  - o How to distinguish different types of seizures and respond to them
  - o How to discuss them with other children so that they accept your child
- ü Create an emergency backpack with a small blanket to place under the child's head, a change of clothes, first-aid instructions, and rescue medications, if prescribed
  - o Some parents create a laminated card with important information for use by a substitute teacher or other school staffers
- ü Meet with the school nurse. If your child takes regular medication during the day, the school nurse is responsible for giving it in most school systems.
  - o In most schools, nurses also administer emergency medications. If this is not the case for your child's school, find out who could do this if your child has a seizure emergency
- ü The Epilepsy Foundation ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)) provides many sample forms for parents, teachers, and school nurses
  - o A questionnaire for you to complete before meeting with the school
  - o A student interview form for the school nurse
  - o A seizure information sheet to help you tell teachers about your child's seizures and medication
  - o A record form teachers can use to report a seizure and/or medication side effects.

#### **USEFUL LINK:**

**[WWW.EPILEPSYCLASSROOM.COM](http://WWW.EPILEPSYCLASSROOM.COM)**

Created for parents and teachers, Epilepsy Classroom is here to provide advice, insight, and tools that can make handling epilepsy just another part of the school day.

More tools for your epilepsy plan are available at [www.epilepsyplan.com](http://www.epilepsyplan.com) and [www.diastat.com](http://www.diastat.com).

#### **SCHOOL SAFETY TIPS**

As a parent, you are your child's best advocate. Here are some factors to discuss with your child's teachers:

- Ask if your child can sit at the front of the classroom. This will limit distractions and help the teacher be more aware of any seizures
- Ask for someone to escort your child to the restroom
- If your child participates in activities on risers (choir, for example) ask if he or she can stand on the lowest riser
- Can your child have extra test time or untimed test?
- Ask the PE teacher to monitor your child closely during PE activities
- Get permission for your child to wear a hat if needed to dim classroom lights

#### **DO YOU HAVE A PLAN?**

A seizure preparedness plan can help your child avoid serious health problems and expensive emergency room visits. Create a plan today:

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### Be prepared for seizure emergencies

If you care for someone who has epilepsy, seizure emergencies can be an ongoing concern. Seizure emergencies can occur anytime and anywhere. When a seizure emergency happens, you need quick and effective action.

### Give your child the security of a seizure preparedness plan

A seizure preparedness plan contains written information and step-by-step instructions. It will prepare family and caregivers, friends and teachers, and health care professionals to help a person having a breakthrough seizure quickly and effectively, wherever he or she may be.

It starts with communication among the health care professionals, parents, the person with epilepsy, and other people who might help during a seizure. You can find online resources to help you put together a plan for your child at [www.diastat.com](http://www.diastat.com) or [www.epilepsyplan.com](http://www.epilepsyplan.com). Visit these websites today to discover valuable planning resources.

Be sure to educate everyone who might respond to a breakthrough seizure about his or her specific role in the plan. This helps ensure that everyone will know what to do when needed.

By working together, you, your child's teachers, school administrators, nurses, and your child's health care professionals help your child achieve success in school and in life.

*Information for this article was provided by Kasey Douglas with DIASTAT AcuDial (diazepam rectal gel)*

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delay of three months. The delay group acted as the control group during the three-month delay. Using the baseline figures as 100 percent, they found that the number of seizures in the diet group dropped by more than a third (62 percent of seizures recorded compared with baseline), while the control group saw their seizures rise by more than a third. Twenty-eight of the 54 children who completed the three months in the diet group had greater than 50 percent seizure reduction compared with just four of 49 children in the control group. Five children in the diet group saw a seizure reduction of above 90 percent, compared to none in the control group. The most frequent side-effects reported at three months were constipation, vomiting, lack of energy and hunger.

The authors said, "We have shown that the diet has efficacy and should be included in the management of children who have drug-resistant epilepsy. However, the diet is not without possible side-effects, which should be considered alongside the risk benefit of

other treatments when planning the management of such children." They added, "We stress this is a diet which should only be undertaken on medical advice and under medical and dietetic supervision."

Dr. Max Wiznitzer of Rainbow Babies and Children's Hospital in Cleveland said more information is needed about the long-term effects of the ketogenic diet, including changes in blood fat concentrations and persistent ketosis. He added, "Better identification of epilepsies that benefit from starting early on the ketogenic diet and comparisons between the choices of ketogenic diet are needed."

\*Ketone bodies are water soluble compounds that are produced as by-products when fatty acids are broken down for energy in the liver and kidneys. They are used as a source of energy in the heart and brain. In the brain, they are a vital source of energy during fasting.

*Source: Adapted from a press release from The Lancet Neurology.*



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FOUNDATION®**  
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