

erocurrent

Monthly newsletter from the **epilepsy** RESOURCE CONNECTION

CDC Study: Less Than 2% Diagnosed with Epilepsy

More than 1.5% of adults in the U.S. have been diagnosed with epilepsy — a number that is likely to increase as the population ages, according to a new study published in the Center for Disease Control's *Morbidity and Mortality Weekly Report*. The study, the first of its kind, reports that 1.65% of non-institutionalized adults surveyed from across the country have been told by a doctor they have epilepsy or a history of epilepsy. The study looked at responses from 19 states and found 2,027 adults aged 18 years or older reported ever being told they had epilepsy.

Some respondents (0.84%) reported having active epilepsy, meaning they are currently taking medication for epilepsy or have had at least one seizure in the past three months. And 0.75% of people are classified as having inactive epilepsy; these people have a history of epilepsy or seizure disorder but were not taking medication or experiencing seizures in the three months before the survey. The prevalence of the disease is not substantially different based on race, gender, or home state.

The researchers found that adults with a history of epilepsy and active epilepsy are more likely to have other health problems, such as obesity, arthritis, and strokes; they are also more likely to be unemployed and live in homes with low household incomes. These people are more likely to be current smokers.

While the study, based on 2005 data, provides a baseline, the authors call for additional research. "Population-based epidemiological studies of epilepsy are important for policymakers and health-care providers to plan and provide prevention programs and appropriate care and services for those affected," the study says. The paper is based on data from The Behavioral Risk Factor Surveillance System, an ongoing, state-based, telephone survey of the non-institutionalized U.S. adult population. In 2005, 19 states included questions on epilepsy or seizure disorder. ✦WEB MD

UCB's **EpilepsyAdvocate** program presents

Do You Have Seizures or Know Someone Who Does?

The **EpilepsyAdvocate** Program invites you to learn more about epilepsy and listen to Chris, an Epilepsy Advocate, who shares his inspiring story. Includes a presentation from Dr. Kore Liow.

■ **Saturday, November 8, 2008** ■

Registration: 10:30 AM • Program: 11:00 AM

Hyatt Regency Wichita
400 West Waterman

To Reserve A Seat Call
1-866-865-7305

Light refreshments will be served.
Free Parking and admission.



Epilepsy Linked to Increased Risk of Drowning

People with epilepsy appear to have a much higher risk of drowning compared to people without epilepsy, according to a study published in an August 2008 issue of *Neurology*. Previous studies have shown a higher risk most likely due to seizures but this study is one of the first to show exactly how high the risk may be.

Researchers compiled information from 50 studies of people with epilepsy worldwide that followed the participants for a total of more than 200,000 patient-years. They also looked at population data and national registries to determine how many regular drowning deaths occur. A total of 88 people with epilepsy died by drowning. By comparison, 4.7 deaths by drowning would have been expected if the rates in the general population applied.

The study found that people with epilepsy had a 15 to 19 times higher risk of drowning compared with people in the general population. That risk was highest for people with epilepsy and a learning disability, those in institutional care and those who have had brain surgery but who were not all free of seizures. It is important that people with epilepsy and their caregivers take steps to prevent these tragedies," said study author Ley Sander, MD,

FRCP, PhD, of the University College London Institute of Neurology, Queen Square in London, UK.

"People with active epilepsy should shower instead of bathe, take medication regularly to control seizures and should have direct supervision when swimming," Sander said.

The study also found that the increased risk of drowning may not be as great in children compared with adults. Sander explains it is most likely a result of more direct supervision. The Global Burden of Disease 2000 Project estimates that nearly 450,000 people drowned in 2000 worldwide, putting the normal drowning risk at about 7 deaths per 100,000 people.

The study was supported by the UK National Society for Epilepsy and by the UCL/UCL Comprehensive Biomedical Research, with funding from the NHS National Institute for Health Research. ✦SCIENCE DAILY

Epilepsy and ADHD Linked

About 5% of children in the general population have Attention Deficit Hyperactivity Disorder (ADHD), and as many as one-third of children with epilepsy experience some trouble with ADHD.

Symptoms of ADHD present over the course of many months and include:

- **Impulsiveness:** a child who acts quickly without thinking first.
- **Hyperactivity:** a child who can't sit still, walks runs, or climbs around when others are seated, talks when others are talking.
- **Inattention:** a child who daydreams or seems to be in another world, is sidetracked by what is going on around him/her.

✦EPILEPSY FOUNDATION



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Sedgwick County...
 working for you

Sharing Your Epilepsy with Others

▪Epilepsy is Nothing to be Ashamed of or to Fear

You may feel hesitant or unsure when it comes to talking about your epilepsy and seizures. You might worry that friends will treat you differently or that coworkers may assume epilepsy will interfere with your ability to do your job. Whatever the reason for your hesitation, there may be times when trying to keep epilepsy a secret seems harder than living with the condition itself. If others don't know about your epilepsy, they won't know how to respond if you have a seizure . . . so, they may unnecessarily call 911 or make the mistake of trying to restrain you or put something in your mouth.

By letting others know about your epilepsy, you're creating a wider support network that you can depend on. You'll no longer need to be as worried about having a seizure when you're at work or out with friends. And, as an added bonus, you'll have the opportunity to help others get past their worries and misconceptions and learn the real facts about epilepsy. Remember, whether it's in the workplace or on the softball field, epilepsy shouldn't be a secret; an open dialogue can be helpful to everyone.

So how do you talk about epilepsy? Often a matter-of-fact approach works best. Explain that epilepsy is a medical condition, just like diabetes or high blood pressure, and that in most cases, it can be controlled with medication. Describe what sort of seizures you experience, how often you have them, and how they are being controlled. Most people think of tonic-clonic (convulsive) seizures when they think of epilepsy; they may not realize that there are other types of seizures. Explain what to do in case you have a seizure. Some seizures can be intimidating when you don't know what to expect. People are relieved to know that the best thing to do in most cases is just stay with you and make sure you're safe. Stay positive. Remind friends and family of the many people who have epilepsy. And brush up your trivia . . . they may be surprised to find out that Alexander the Great, *Alice in Wonderland* author Lewis Carroll, the military general Napoleon, Charles Dickens, and Beethoven all had seizures. Fill out an Identification & Emergency Card and keep it in your wallet. Let others know where the card can be found. ✨EPILEPSYADVOCATE



Temporal Lobe Epilepsy

Research Volunteers Needed

Ph.D. candidate writing dissertation is searching for volunteers. Research will document how temporal lobe epilepsy (TLE) affects the whole person psychologically, socially, spiritually, creatively, and intellectually focusing on the positive strengths and attributes that are sometimes unique to persons with epilepsy.

If you have TLE or have had a temporal lobectomy for TLE and have an interest in contributing to this project per the premise that TLE can contribute to heightened creativity, complexity of thought, and/or the evolution of deeper intellectual insight, please contact:

Teri Strong at tkstrong@earthlink.net or call ERC at (316) 943-2453

www.arc-sedgwickcounty.org/ERC.html

Epilepsy & Driving

Research shows that people with epilepsy continue to drive despite medical restrictions. In a study from the Ohio State University Medical Center, 26% of patients with epilepsy reported having an accident due to a seizure and 19% said they were dishonest about seizures in order to drive.

The study, published in the journal *Epilepsy and Behavior*, found that prior attitudes and behavior are difficult to change and participants' main reason for driving was due to their occupation.

"Instead of focusing on the dangers of driving for patients, it is important to discuss with patients how to overcome perceived and actual barriers to transportation," says Lucretia Long, author of the study and assistant professor of neurology at The Ohio State University Medical Center. "Addressing health behaviors while counseling persons with epilepsy is also crucial." The study also suggests that persons with epilepsy would benefit from employers' assistance with workplace programs and legislation supporting transportation resources. Allowing people with epilepsy to work from home and providing adequate public assistance are a few options.



The study found that 35% of patients said that they were not confident to use public transportation. Some feared the possibility of having a seizure, which increases the risk for injury while walking to public bus stations. In addition, a large percentage felt that family and friends were not available to assist with transportation needs. John Elliott is the co-author and clinical research data manager in the Department of Neurology at the Ohio State University Medical Center. The study included a total of 213 participants who were asked to complete a 46-item questionnaire with all responses submitted anonymously. ✨EPILEPSY FOUNDATION

For people with frequent seizures, it may be dangerous to wait for a bus at busy intersections, where they may encounter danger during a seizure. **Paratransit** is a transportation service, required under the ADA, available to assist eligible individuals who cannot use the regular public transportation services independently.



Paratransit services are available if you meet specified requirements. For instance, eligibility can be established by showing that limitations associated with epilepsy prevent the individual from traveling to or from a bus stop some or all of the time. To inquire about paratransit services, contact your local transit authority. ✨

Adult Epilepsy Support Group

Group Meets Second Tuesday of the month.

LOCATION: 2919 W. Second Street in Wichita • TIME: 5:00 PM

Sept. 9: Patient & Family Concerns

Oct 14: Employment & Epilepsy



SAVE the DATE
Sept. 18, 2008 at 8 PM



Epilepsy Advocate L.I.V.E. Webcast

More Practical Tips for Living with Epilepsy

September 18, 2008 at 8 PM

You can register today to watch this discussion about the aspects of epilepsy that touch your life.

To register:

<http://tx3.epilepsyadvocate-mail.com/track.aspx1275133.8673.2034127575.2182.157822>

This Webcast is a great opportunity for you to be a part of an enlightening conversation:

What's in this Webcast:

- Advocate Greg Grunberg, star of TV's *Heroes*, and three other Advocates share tips about how they make living with epilepsy a success.
- Why it's important to talk to everybody—from doctors to friends—and how it can pay off in terms of diagnoses and treatments.
- The difference seeing an epileptologist can make.
- Facts, figures, and personal stories—Just part of what makes our Webcasts so great.

epilepsyadvocate.com

**Register today
and be sure to watch the
Webcast on September 18.**