



Serving Persons  
Affected by Epilepsy

October 2006  
Volume 6 Issue 10



# hotline

## Epilepsy Awareness Focuses on Stigma

November is National Epilepsy Awareness Month. There are nearly 2.5 million Americans—over 41,000 in Kansas alone—with epilepsy. For many, the biggest problem they face, besides seizures, is society's negative attitudes about the condition. Epilepsy Resource Connection and Via Christi Comprehensive Epilepsy Center have partnered to sponsor a patient education conference and public awareness campaign.

Epilepsy accounts for 1% of the world's burden of disease, the same as for breast cancer in women or lung cancer in men. Yet, while society has rallied to support those diagnosed with these cancers, individuals with epilepsy have often been shunned. Historically, epilepsy has been considered a curse of the gods, 'demonic possession,' and a form of madness, consequently epilepsy is a condition that has been feared and rejected. Misconceptions have led to social isolation for the individual with epilepsy and in many cases, for his or her family also. The myths and prejudice that have surrounded epilepsy has resulted in the stigmatization of people with the disorder. A psychosocial burden has been uncovered which suggests that people with epilepsy suffer as much from a social disease as a neurological disorder

Epilepsy remains a hidden disease associated with discrimination in the work place, school, and home. As such, many people with epilepsy fear sharing the knowledge of their condition with friends and family. In this sense, they are indeed living in the shadows hiding from society.

The *Out of the Shadows* campaign focuses on creating conditions for people with epilepsy to step *Out of the Shadows* of ignorance and social stigma, and for the disorder to be drawn *Out of the Shadows* of public health priorities.

The number-one problem for people with epilepsy in the United States – other than their medical care – is society's reaction to the disorder. The focus of *Out of the Shadows* is on improving public acceptance and understanding of people with the condition.

We strive to enlighten people about the condition and erase their fears about reacting when someone has a seizure.

### Epilepsy Stigma : It Was Not So Long Ago...

- 1940s Thousands of people with epilepsy were still confined in mental institutions and psychiatric facilities.
- 1960s North Carolina strikes laws barring all people with epilepsy from driving
- 1970s One in two Americans surveyed said they would not want their child to marry an epileptic.
- 1980s Missouri repeals ban against performing marriage of someone with epilepsy.  
Delaware repeals sterilization law for people with epilepsy.
- 1990s Red Cross changes policy to now allow people with epilepsy to donate blood. For decades, the Red Cross forbid people with epilepsy to donate blood for fear of adverse reactions that would increase the risk of seizures.



## BRAIN STORMS:

Bringing Epilepsy Stigma out of the Shadows

A patient education conference

**Saturday, November 4, 2006**

11:30 a.m. – 3:00 p.m.

Via Christi Regional Medical Center–  
St. Francis Campus  
929 N. St. Francis, Wichita, Kansas  
2nd Floor, Room 2306

This free conference welcomes epilepsy patient-survivors, caregivers and family members. Conference includes program, lunch and access to the vendor exhibits in our epilepsy resources area.

**Please help us by registering prior to the event.** Early registration helps to ensure we will be able to serve lunch to everyone attending the conference. Lunch is intended only for those individuals attending the conference. You must pre-register to be eligible to win the prizes to be awarded during the conference.

**For more information, call (316) 943-1191 or visit [www.arc-sedgwickcounty.org/erc.html](http://www.arc-sedgwickcounty.org/erc.html)**

*We gratefully acknowledge partial support through an educational grant from: Cyberonics, Inc. — VNS Therapy*



**BRAIN STORMS:**

Bringing Epilepsy Stigma out of the Shadows



**Via Christi**  
Comprehensive Epilepsy Center

## Epilepsy and the Family

Most children who have a seizure don't have another one.

Most children who have epilepsy -- which by definition means that they've had more than one seizure -- will outgrow the condition.

Most children with epilepsy are perfectly healthy and normal in other ways.

70% to 80% of children with epilepsy can control the condition completely with medication.

"We don't have a cure for epilepsy, and unfortunately treating seizures is just about controlling them," says William R. Turk, MD, Chief of the Neurology Division at the Nemours Children's Clinic in Jacksonville, Florida. "But in children, that may be all you need. If you can buy them some time with medication, the seizures may very well go away on their own."

About 400,000 children in the U.S. have epilepsy, and most of them are able to control their seizures and lead normal lives.

That's not to say that dealing with epilepsy is easy, and it will almost certainly change your family. As a parent of a child with epilepsy, you'll have new responsibilities. Obviously, you'll need to make sure that your child is getting good medical care, but there's more to it than that.

You'll have to make sure that your child takes medications, and learns how to avoid triggers of seizures. You may also have to become an advocate for your child, explaining epilepsy to family, friends, and teachers who may not understand the condition or be frightened by it.

So while it may be tough being the parent of a child with epilepsy sometimes, just remember that treatment works. Epilepsy is not nearly as scary as it sounds.

"With treatment, a child with epilepsy should have a pretty normal life with very few limitations," says Solomon L. Moshe, MD, Director of Clinical Neurophysiology and Child Neurology at the Albert Einstein College of Medicine in New York City. ✚ WEB MD

*In terms of productive life-years lost to disability and premature death, epilepsy ranks with breast cancer in women and lung cancer in men.*

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erc@arc-sedgwickcounty.org

## Adult Epilepsy Support Group

Meets Second Tuesday of Month, 6:30 PM • 2919 W. 2nd Street, Wichita

Oct. 10th: "Coping with Stigma"  
Nov. 8th: "Stress & Seizure Triggers"

## Epilepsy medication may become less effective over time

A critical review by Dr Wolfgang Loscher and Dr Dieter Schmidt suggests that anti-epileptic drug (AED) therapy may become less effective at preventing a patient's seizures over time. The review, published in the current issue of *Epilepsia*, suggests the body's ability to adapt to the presence of foreign bodies is responsible, rather than patients being naturally resistant to certain medications. The risk of developing a tolerance to AEDs was previously thought to be small, but Loscher and Schmidt conclude that although it's not a risk for most people with epilepsy, it could be a significant factor in some people's treatment.

The findings conflict with the treatment method many doctors currently use: increasing AED dosages until the patient's seizures are under control. Despite spending decades investigating the effects of AEDs, Loscher believes that AED tolerance is a topic that has yet to be fully explored. ✚ EPILEPSY ACTION

## Avoiding Stereotyping & Stigma

**"Epileptic"** Like all individuals with a disability, persons with epilepsy dislike labels, such as in "He's an epileptic." These feelings can be summed up by the statement, "epilepsy is what I have, not what I am." The preferred terminology is "person with epilepsy" or "child with epilepsy" rather than "epileptic." Use of "epileptic" as an adjective, as in "epileptic seizures" is appropriate.

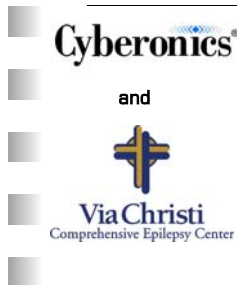
Perception plays an important role in the quality of life for individuals with epilepsy. A survey mailed to a sample of epilepsy patients in Kansas, revealed these beliefs:

89%: the general public was not well informed about epilepsy

86%: the general public does not know how to react to a seizure

71%: educating the public about epilepsy would help to decrease stress or problems they experience because of epilepsy

41%: felt stigma affected the way they view themselves



host a monthly info session on  
**VNS Therapy®**

11:30 - 12:30

**Third Wednesday** of the month

Lunch is served. **RSVP is required to attend.**  
**(316) 268-8562**

848 N. St. Francis, Wichita

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distributing this  
newsletter! Thank You!!