



January 2005

Volume 5 Issue 1



hotline

Stopping Epilepsy Treatment Without Supervision Dangerous

People with epilepsy who stop taking their medication without medical supervision are more likely to require emergency treatment and need more visits to their doctor, according to a new survey of over 200 international epilepsy specialists.

The research showed that almost one third of people with epilepsy stop taking, or seek to stop taking, their anti-epileptic drugs (AEDs), with side effects and inadequate seizure control being blamed as the main reasons.

Dr Gunter Krämer, Medical Director of the Swiss Epilepsy Centre described the dangers of stopping AED treatment:

"[It] is frustrating for physicians and hazardous for patients because it results in uncontrolled seizures, with all the additional morbidity, mortality, emergency treatment, and increased costs, that this entails.

"When selecting an AED, physicians should consider treatments that offer long-term seizure freedom, with minimal side effects, which will encourage patients to continue their medication in the long term."

— EPILEPSY ACTION

Adult Epilepsy Support Group

*Group meets @ 6:30 PM
Second Tuesday of month at:
The Arc, 2919 W. 2nd St., Wichita*

NEXT MEETINGS:
*January 11
February 8*

Using Complimentary Epilepsy Treatments Can be Harmful

Some people who have tried various types of complementary treatment have felt that these therapies have partly or completely helped their epilepsy. However, there is, as yet, no scientific evidence to suggest that any type of complementary treatment is successful in controlling or "curing" epilepsy.

Before beginning any treatment regimen you consult with your doctor or epilepsy specialist

Most people with epilepsy are using some kind of complementary treatment, but many are not telling their doctor, which may lead to their epilepsy medication being less effective, according to research from the University of California in San Francisco.

Of the 187 people with epilepsy or their caregivers surveyed, 56% were using some kind of complementary or alternative treatment, but only 68% had reported the use of the treatment to their doctor.

Lead researcher Marie Plunkett said that many people taking epilepsy medication and using complementary treatments would probably be surprised to learn that some products might cause an increase in seizures or affect the effectiveness of seizure medication.

Almost 14% of people using complementary treatments took products containing ingredients that had the potential to increase seizure occurrence, according to the study, including ephedra, ginseng, evening primrose, and ginkgo, the researchers report.

In addition, almost a fifth of complementary treatment users took products that could interfere with the metabolism of their epilepsy medication. The researchers said that St John's Wort, echinacea, and garlic might affect liver enzymes that influence the body's response to medicine, say the researchers.

Vitamin and mineral supplements were the most popular products, with 83 users in the survey group. The researchers assured people that there were no known interactions between these supplements and anti-epileptic medication.

— EPILEPSY ACTION

Spoons Are Not First Aid Tool



49% of Americans wrongly believe that a correct first aid response to someone having a seizure is to put a spoon or something else in the person's mouth to prevent them from swallowing or biting the tongue, according to new research from the Epilepsy Foundation.

You should never put anything in the mouth of someone having a seizure. You could cause injury to the teeth or gums. It's also not true that a person can swallow his or her tongue during a seizure.

The survey of more than 1,000 people also revealed that 18% of people (including 36% of people aged 18-24), believe, incorrectly, that epilepsy is a psychological disorder.

Volunteers Needed



Epilepsy Resource Connection is seeking volunteers to help us with our outreach programs. We need volunteers in the Greater Wichita area to help us with our school alert puppet shows. The school alert program educates students about epilepsy, diversity and acceptance. The puppet shows address pre-K through grade 4 aged children. Our community events & health fairs program needs volunteers in Sedgwick County to staff our display & information table. For more information, please call 943-2453.

Glimmer Group Parent's Support Group

Sat., February 12, 10:00 AM - Noon @ The Arc

A support group for parents (and family) of children affected by seizure disorders.

The ARC of Sedgwick County
2919 W. 2nd St
Wichita, KS 67203

Phone: 316-943-2453

Fax: 316-943-3292

E-mail: ERC@arc-sedgwickcounty.org

Web: www.arc-sedgwickcounty.org/erc

School Alert Program Educates Children About Epilepsy



It's never too early to teach children about epilepsy. Appropriate for students of all ages, School Alert provides an in-depth look at seizures, first aid measures and ways to prevent epilepsy. This free program for schools in Sedgwick County, makes a great hands-on presentation for a health class or classroom where a child with epilepsy is present.

This program includes a trained speaker, and the viewing of a first-aid video as well as time for discussion. For children pre-K through grade 4, the program includes "The Kids on the Block" puppet show (pictured above). School Alert can provide emotional support for the child with epilepsy by displaying an attitude of acceptance. It can also provide basic education about an often-misunderstood disorder for the classroom that does not have a member with epilepsy. When children have seizures...**understanding** makes a difference. The School Alert Program is:



- Appropriate for students of all ages. Classroom presentations are specially tailored to the ages of the students who are in attendance.
- Provides in-depth education about seizures appropriate for health class, Epilepsy Awareness Month (November), or any classroom where a child with epilepsy is present.
- Offered free of charge.
- An excellent resource to create an atmosphere of understanding that will better enable the student with epilepsy to be accepted by other students.

For more information or to schedule a School Alert Program for a classroom in Sedgwick County, please call 943-2453.

NON-PROFIT
ORGANIZATION
U.S. POSTAGE

PAID
WICHITA KS
PERMIT #55

