



Serving Persons
Affected by Epilepsy

March 2006

Volume 6 Issue 3



hotline

Epilepsy and Type 1 Diabetes Link Suggested Diabetes May Cause Epilepsy in Some Persons

Young adults with generalized epilepsy whose seizures have no known cause (idiopathic) are 4x more likely to develop type 1 diabetes, according to a new study published in the journal *Annals of Neurology*. Researchers, led by Dr. Dougal McCorry from the Walton Centre for Neurology and Neurosurgery in Liverpool, UK investigated clinical experiences that people having both epilepsy and diabetes were more common than would be expected.

The study looked at 518 people with idiopathic generalized epilepsy aged 15 to 30 and found that seven of them had type 1 diabetes (one person in 74). The figures were then compared to 150,000 members of the general population, of whom 465 had type 1 diabetes (one person in 322).

In six of the seven cases of people who had both conditions, the diabetes was diagnosed before the epilepsy. The researchers say that this may be because diabetes causes idiopathic generalized epilepsy or because diabetes, in general, develops at an earlier age than epilepsy. The team also suggests that some people with type 1 diabetes may develop epilepsy due to low blood sugar. ↵ EPILEPSY ACTION

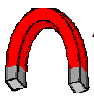
Chemical Markers Could Help Diagnose Epilepsy Chemical Tests May Also Indicate Effectiveness of Seizure Meds

Researchers from Advanced Neuroprotective Systems in Israel have found chemicals in blood and urine that they can measure in order to find out whether someone is likely to develop epilepsy or has it already.

Tests in a hospital laboratory have shown that the amounts of the chemicals present can also show how well anti-epileptic drugs (AEDs) are working.


At the moment, there are no commercially available chemical tests to find out who is at risk from epilepsy, or how well AEDs are working. The researchers are seeking a company to help them sell diagnostic kits based on their tests. ↵ EPILEPSY ACTION

MRI Offers New Hope to Persons With Epilepsy New MRI Technique May Lead To Wider Epilepsy Surgery

 A new method of detecting tiny brain lesions in people with severe epilepsy has been developed, which may lead to more people being able to have epilepsy surgery.

Researchers have now found a way to use magnetic resonance imaging (MRI) to detect minute brain lesions in people with severe epilepsy, making surgical treatment potentially available to many more patients. The Canadian Institutes of Health Research supported study, led by Dr. Andrea Bernasconi at McGill University in Montreal, used new automated techniques for improving the detection of brain lesions that had been overlooked by conventional radiological inspection. The findings, published in the January 27, 2006 issue of *Epilepsia*, could reduce the complexity and cost of pre-surgical evaluation, and improve understanding of the cause of epilepsy. ↵ CIHR

Medicaid PDL Committee Rules to Limit AEDs Restrictions May Reduce Quality of Care for Epilepsy Patients

 In February 28th, the State of Kansas Medicaid Program held a public hearing of the Medicaid Preferred Drug List (PDL) Advisory Committee. The committee, composed of practicing physicians and pharmacists, evaluated removing some of the newer or "second-generation" anti-epileptic drugs (AEDs) from the PDL.

A PDL is a listing of prescription products selected as efficacious, safe, and cost effective choices when prescribing for Medicaid patients.

The PDL hearing committee's agenda was to decide if some or all of the AEDs were clinically equivalent. When the committee removes an FDA approved drug from the listing, the drug may be available with prior authorization (PA) from a physician.

Several individuals attended the meeting in Topeka to advocate on the behalf of epilepsy patients throughout Kansas. Among those addressing the committee were: Dr. Kore Liow, MD, Director of the Via Christi Comprehensive Epilepsy Center; Matthew Fullerton, Coordinator of Epilepsy Resource Connection; Colleen Stack, Board President of Epilepsy Foundation of KS & Western MO; and Carol Vaughn, mother of an adult epilepsy Medicaid patient.



These advocates presented compelling testimony as to our belief that a restrictive PDL can prevent individuals with epilepsy from following an optimal treatment regimen. This, in turn, could result in breakthrough seizures. Such events often result in emergency room visits and hospital admissions, and can be devastating to the individual's health as well as costly to society.

The costs to society for epilepsy involves far more than the acquisition costs of the drugs. Patients who do not have seizure control or develop drug toxicity are not able to work or attend school, require more physician visits, and require more costly blood work than patients who are seizure free and have no side effects. Restricting AED access to our patients will ultimately be detrimental not only to our patients but the taxpayers in the state of Kansas.

Unfortunately, the state has decided to proceed with the action to remove the 5 new AEDs (Lyrica, Neurontin, Keppra, Tiagabine and Zonisamide) from the state Medicaid PDL, thus requiring Prior Authorization (PA) for these AEDs to be used starting this summer.

The Kansas Medical Assistance Program created the PDL to promote clinically appropriate utilization of pharmaceuticals in a cost-effective manner without compromising the quality of care. ERC is concerned the PDL committee's decision has put that very quality of care in jeopardy for some Kansas Medicaid patients with epilepsy.

Although the outcome was not what we wanted, we have made our voices heard and advocated on behalf of the more than 40,000 epilepsy patients in our state. ↵ ERC & EPILEPSY FOUNDATION

Overcoming Epilepsy's Stigma

Public Misperception Tied to Lack of Education

As if epilepsy itself were not enough to deal with, there are also the social and psychological challenges that come with it. In some social situations, including school and the workplace, a lack of information and understanding can make for some awkward moments, which can affect how you feel about yourself. Even concealing the condition doesn't make a person with epilepsy immune from awkward social moments: coworkers may take a reluctance to have a drink after work or join in a group event the wrong way; fellow students can be quick to judge and slow to understand.

Educate others when you can. For the most part, any remaining negative feeling surrounding epilepsy comes from lack of knowledge, confusion about what epilepsy is, and outdated ideas. The good news is, epilepsy is going the way of many other conditions that had biases attached to them a generation or two ago.

Educating yourself about your condition is one key to managing it. Educating others—as gently as possible, where and when appropriate—can also help. Think of it as another way of taking control.

ERC offers several programs to help educate the community about epilepsy.

The **SCHOOL ALERT PROGRAM** targets elementary school children aged pre-K through grade 3. Children are taught about seizures, appropriate first aid, and diversity & acceptance of others. This program is free to all schools in Sedgwick County. To learn more, please inquire at 943-2453.

IN-SERVICE EDUCATION PRESENTATIONS are available for businesses, schools, organizations, aging providers & retirement centers, and civic groups. The program offers general education about epilepsy, and first-aid. If you have concerns about an employee or member with seizures, this program provides the training and education you need to best accommodate and accept individuals with seizures. Most people still believe the epilepsy myths they learned growing up, this program brings you out of the shadows and stigma. ERC can tailor the program to best meet your group's needs.

For information on any of the epilepsy education programs, call 943-2453 or visit www.arc-sedgwickcounty.org/erc.html

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FACTOIDS

- Up to 50 or 60% of patients with chronic epilepsy have various mood disorders including depression and anxiety. Whereas the relationship between epilepsy and depression has received much attention, less is known about anxiety disorders. It is now recognized that anxiety can have a profound influence on the quality of life of patients with epilepsy.
- Epilepsy affects more people than muscular dystrophy, multiple sclerosis, and cerebral palsy combined.
- Between 60-80 % of people with epilepsy will become seizure-free within two (2) years using antiepileptic drugs.
- A person having a convulsive seizure will NOT swallow their tongue. You should NEVER put anything in the mouth of someone having a seizure. It is impossible to swallow your tongue.

Adult Epilepsy Support Group

Meets Second Tuesday of Month at 6:30 PM

2919 W. 2nd Street, Wichita (943-2453)

Upcoming Meetings:

March 14th: Depression & Epilepsy: A Common Link

April 11th: Epilepsy in the Workplace

Do you have a group that could benefit from epilepsy education?

Work, School, Church, Clubs,
Civic Groups, etc.

943-2453