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Monthly newsletter from the **epilepsy** RESOURCE CONNECTION



Transcending Spells and Social Stigmas ...

An Empowerment Retreat for Teens with EPILEPSY JUNE 13

FOR: Teens with epilepsy and their parents
ON: June 13, 2009
AT: Strong Retreat Center (2309 NW Prairie Creek
Road, Benton, Kansas)

The adolescent years are a time of many changes, conflicts and growing independence. Teens living with seizures face challenges that require good working relationships and communication between parents, health care providers and teens.

The Think Strong Retreat will facilitate this relationship and help families and caregivers organize their needs, implement plans, and teach teens how to manage their epilepsy.

DUAL TRACKS

Since parents also struggle with how to parent a child with epilepsy and how to prepare for their child's future, the retreat features a workshop track just for parents that will address issues including employment, college, and a parents' networking lounge.

Retreat will:

- educate teens with seizures and their parents, providing them a working knowledge of epilepsy and ways to improve their quality of life;
- increase the self-esteem of each teenager with epilepsy empowering them to advocate for their needs and educate their peers;
- arm teenagers with seizures with the tools to fight stigma and support the challenges of living with epilepsy

REGISTRATION: call (316) 943-2453 or register online at epilepsybrainstorms.org

Transportation to the retreat may be available, please let us know if lack of transportation will prevent you from attending.



ANITA KAUFMANN
FOUNDATION

New Drug to Prevent Seizure Progression in Model of Epilepsy Identified

Carnegie Mellon University researchers have identified a new anticonvulsant compound that has the potential to stop the development of epilepsy. The findings are published in the current issue of the journal *Epilepsia*. The research discovery builds on previous work identifying a specific molecular target whose increased activity is associated with seizure disorders, a potassium channel known as the BK channel.

"We have found a new anticonvulsant compound that eliminates seizures in a model of epilepsy," said Alison Barth, associate professor of biological sciences at Carnegie Mellon's Mellon College of Science. "The drug works by inhibiting ion channels whose role in epilepsy was only recently discovered. Understanding how these channels work in seizure disorders, and being able to target them with a simple treatment, represents a significant advance in our ability to understand and treat epilepsy."

Epilepsy is a neurological disorder marked by abnormal electrical activity in the brain that leads to recurring seizures. A person who has a first seizure is statistically much more likely to have a second, and with each subsequent seizure, the chance of having another seizure grows. A person is often diagnosed with epilepsy after having two or more seizures that have no other apparent cause.

In prior studies, Barth and colleagues were the first to link BK channels, ion channels that allow electrically charged potassium ions to move out of cells, to sporadic epilepsy. Previous studies had shown that these channels were genetically altered in a few rare individuals who suffer from the disease, but Barth and colleagues demonstrated that seizures themselves could lead to the same alterations in BK channel function.

Potassium ions move through the channels, starting and stopping the electrical impulses that allow neurons to communicate with one another. The Carnegie Mellon researchers found that after a first seizure, BK channel function was markedly enhanced. As a result, the neurons became overly excitable and were firing with more speed, intensity and spontaneity, leading Barth to believe that the abnormal increased activity of the channels might play a role in causing subsequent seizures and the emergence of epilepsy.

In the current study, Barth tested this theory by blocking the ion channels using a BK-channel antagonist called paxilline. Using an experimental model for epilepsy, Barth asked whether paxilline could reduce or prevent experimentally induced seizures, as it could normalize aberrant brain activity induced by previous seizures. Remarkably, Barth and colleagues Jesse Sheehan and Brett Benedetti discovered that the compound was effective at completely blocking subsequent seizures.

"The drug is orally available, and works in the low nanomolar range," said Barth, noting that these characteristics, which mean the drug is effective in low concentrations and can be taken as a pill, make it an especially promising compound for treatment in epilepsy patients. While most anticonvulsants currently used to treat epilepsy work to directly inhibit the activity of neurotransmitters that causes seizures, few compounds interact with specific ion channels, especially potassium channels. The researchers believe that targeting the BK channels and the abnormal brain activity that they induce might one day be used as a way to prevent the progression of seizure disorders over time, thus attacking the root cause of epilepsy. EMNT



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An Empowerment
Retreat for Teens
with EPILEPSY
JUNE 13

High, Often Overlooked Costs Associated With Epilepsy Revealed By Study

Employees with epilepsy cost healthcare insurers and employers significantly more than those without the condition, according to findings from two studies presented here today at the American Academy of Neurology (AAN) Annual Meeting.

"These findings suggest that the true cost of epilepsy to third-party payors may often be underestimated when looking only at costs directly related to epilepsy," said Susan Caleo, Director of Health Economics and Neurology at Johnson & Johnson Pharmaceutical Services, Inc. (JJPSI). JJPSI sponsored the study in collaboration with Ortho-McNeil Neurologics®, Division of Ortho-McNeil-Janssen Pharmaceuticals, Inc.

"In particular, the studies suggest that perhaps most overlooked among those with epilepsy are the costs associated with comorbidities, particularly mental health disorders," Caleo noted. "These findings underscore the need for physicians to treat the whole patient, beyond seizure control."

The first study was a 12-month retrospective analysis of the total cost of epilepsy to third-party payors, including insurers and employers. The study found that compared to those without the condition, people with epilepsy reported higher rates of mental disorders, substance abuse and other neurological and physical disorders.

Findings also noted that in people with epilepsy, the costs to third-party payors of these comorbidities, coupled with the condition itself, can be significant. The study compared the direct cost for the insurers among people with and without epilepsy, and found that on average, direct annual costs for third-party payors, such as medical and pharmaceutical costs, were nearly three times higher in people with epilepsy than those without the condition.

The second study analyzed indirect third-party payor epilepsy costs, such as disability and medically-related absenteeism. These expenses were more than three times higher in employees with the condition than those without epilepsy.

Expenses related to other health issues, excluding epilepsy, in patients with epilepsy accounted for 80% of insurers' total annual costs for epilepsy patients. Of that, 13% were attributable to mental health-related expenditures. Insurers' direct annual medical costs were nearly \$6,400 higher on average per epilepsy patient than for those without the condition.

Outpatient services accounted for 34%, inpatient services for 28% and drug costs for 27% of epilepsy patients' annual direct costs to insurers. CONTINUED in NEXT COLUMN

CONTINUED FROM COLUMN 1

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Employees with epilepsy had six times the number of annual disability days compared to those without the condition.

The data were presented as two abstracts: one that looked at the direct costs of people with epilepsy, and one that analyzed the indirect costs of those with epilepsy.

The study looked at 1,866 people with epilepsy in 2004, ages 18-64 years, selected from a privately insured claims database containing disability data from 17 US companies, and compared with a similar age/gender control group without epilepsy. All were required to have continuous health coverage during 2004 (baseline) and 2005 (study period). The baseline differences between the groups were controlled in the analysis using appropriate statistical techniques.

4,323 epilepsy patients, ages 16-64 years, were selected from a privately insured claims database with more than six million beneficiaries. The control group was an age and gender matched cohort of randomly chosen beneficiaries without epilepsy. All were required to have continuous health coverage during 2004 (baseline) and 2005 (study period). The baseline differences between the groups were controlled in the analysis using appropriate statistical techniques. ©MEDICAL NEWS TODAY

Adult Epilepsy Support Group

*A Group for Adults with Epilepsy to Share Common Experience
Meets on Second Tuesday of the month @ 5:00 PM.*

LOCATION: 2919 W. Second Street* in Wichita
*2nd and St. Paul St. between West Street and Meridian Ave.