

erocurrent

Monthly newsletter from the **epilepsy** RESOURCE CONNECTION

ERC Presents Annual Awards

Epilepsy Resource Connection presented awards at The Arc of Sedgwick County's Annual Evening of Awards on Thursday, May 8th.

Colette Deeds-Conner was honored as ERC's Volunteer of the Year. She has been instrumental on ERC's *Brain Storms: Bringing Epilepsy Stigma Out of the Shadows* Conference Planning & Advisory Committees since its inception in 1995. Colette has a strong history with ERC as she helped with the support group that eventually grew into an agency serving an entire spectrum of support needs. She has been a great advocate for persons affected by seizures. She is an asset to other Arc programming as well, by serving on The Arc Board and Arc Ladies' Luncheon Committee.

Bryan Griffin received ERC's Advocate of the Year Award. Bryan does not allow epilepsy to define him. One of the most critical actions one can take to counteract epilepsy stigma is personal contact. Telling people you have epilepsy eliminates stigma. By humanizing epilepsy a person is seen as an individual not as an "epileptic." Bryan supports the epilepsy cause everyday by sharing his story openly with others. He speaks nationally to groups as part of the EpilepsyAdvocate® program sponsored by UCB Pharma. He has also spoken as an advocate at ERC's Brain Storms Conferences.



Bryan Griffin

Bob Hamilton was selected to receive the ERC Professional of the Year Award. Without Bob, ERC might never have materialized. He had the vision seeing the need for a resource like the Epilepsy Resource Connection and worked on the original committee to establish the program and served as the chair of the ERC Advisory Board.

Bob has a special passion to help people that have epilepsy. He has been an integral part of our Brain Storms Conference since its inception. He has served on the planning committee and last year co-presented a workshop on employment & epilepsy.

Heidi Brandenberger and **Becky Smith** were honored with ERC Community Ambassador Awards. When ERC needed some help hosting our second annual Brain Storms Conference, we turned to **Heidi Brandenberger**. She helped ERC plan and coordinate the conference held at Wichita State's Hughes Metroplex. She also opened the door so that ERC could present workshops at WVSU's annual Recovery Conference in 2007 & 2008 serving the mental illness community.



Heidi Brandenberger

Becky Smith has a passion for helping people find successful employment. She has inspired many people to overcome disability as a barrier to employment. In 2008 she helped ERC by hosting *Work Success!*—two workshops on employment strategies for persons with epilepsy. She also co-hosted an employment workshop at our 2007 Brain Storms Conference.



Becky Smith

Congratulations to all 2008 award recipients!

Ketogenic Diet Efficacy Confirmed

A randomized controlled trial has confirmed the efficacy of the ketogenic diet in helping control and prevent epileptic seizures in children with drug-resistant epilepsy. These are the conclusions of authors of an article published early online and in the June edition of *The Lancet Neurology*.

The ketogenic diet has been used widely and successfully to treat children with drug-resistant epilepsy since the 1920s. It is a diet very high in fat, low in carbohydrate, and with controlled protein. Although the exact mechanism of action is still unclear, the high fat and restricted carbohydrate content of the diet is thought to mimic the biochemical response to starvation, when ketone bodies*, rather than sugars, become the main fuel for the brain's energy demands. While there have been many observational studies of this diet, Professor J. Helen Cross of the Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust at the University College in London and colleagues have done the first randomized controlled trial to test its efficacy.

The trial assessed 145 children aged between 2 and 16 years who had at least daily seizures (or more than seven seizures per week), had failed to respond to at least 2 antiepileptic drugs, and had not been treated previously with the ketogenic diet. Seventy three children were put on the diet immediately while 72 were assigned to the diet after a delay of three months. The delay group acted as the control group during the three-month delay. Using the baseline figures as 100%, they found that the number of seizures in the diet group dropped by more than a third (62% of seizures recorded compared with baseline), while the control group saw their seizures rise by more than a third. Twenty-eight of the 54 children who completed the three months in the diet group had greater than 50% seizure reduction compared with just four of 49 children in the control group. Five children in the diet group saw a seizure reduction of above 90% percent, compared to none in the control group. The most frequent side-effects reported at three months were constipation, vomiting, lack of energy and hunger.

The authors said, "We have shown that the diet has efficacy and should be included in the management of children who have drug-resistant epilepsy. However, the diet is not without possible side-effects, which should be considered alongside the risk benefit of other treatments when planning the management of such children." They added, "We stress this is a diet which should only be undertaken on medical advice and under medical and dietetic supervision."

Dr. Max Wiznitzer of Rainbow Babies and Children's Hospital in Cleveland said more information is needed about the long-term effects of the ketogenic diet, including changes in blood fat concentrations and persistent ketosis. He added, "Better identification of epilepsies that benefit from starting early on the ketogenic diet and comparisons between the choices of ketogenic diet are needed."

*Ketone bodies are water soluble compounds that are produced as by-products when fatty acids are broken down for energy in the liver and kidneys. They are used as a source of energy in the heart and brain. In the brain, they are a vital source of energy during fasting.

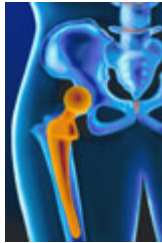
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Editor's Note: The Ketogenic Diet is a treatment that could be dangerous and should only be used when under a physician's recommendation & supervision.



Epilepsy Drug Causes Bone Loss in Young Women

Young women who took the commonly used epilepsy drug phenytoin for one year showed significant bone loss compared to women taking other epilepsy drugs, according to a study published in the April 29, 2008, issue of *Neurology*, the medical journal of the American Academy of Neurology.



Researchers tested the bone health of 93 women with epilepsy who were between the ages of 18 and 40 and were taking the epilepsy drugs phenytoin, carbamazepine, lamotrigine or valproate. Bone mineral density was measured at the spine and two areas of the hip, (the femoral neck and total hip) at the beginning of the study and one year later. Researchers also evaluated each woman's nutrition and physical activity, along with other factors that affect bone health.

The study found women taking phenytoin for one year lost 2.6% of the bone density in the femoral neck of the hip. Women taking the other epilepsy drugs did not lose any bone density in the femoral neck. There was no bone loss at the spine or the total hip in any group.

"This is a significant amount of bone loss and raises serious concerns about the long-term effects of taking phenytoin in young women with epilepsy," said study author Alison M. Pack, MD, with Columbia University in New York, and member of the American Academy of Neurology. "This is one of the first prospective studies to examine the long-term effects of common epilepsy drugs on rates of bone loss in young women."

"This amount of bone loss, especially if it continues over the long term, could put these women at increased risk of fractures after menopause," Pack said. Femoral neck fractures are tied to a higher risk of death in elderly people.

AMERICAN ACADEMY OF NEUROLOGY

Epilepsy Drug Use Heightens Risk of Bone Disease

Literature going back to the 1940s, indicates that women and men with epilepsy are at higher risk for bone disease. Most of this literature suggests that the likelihood of having bone disease is related to the burden of exposure of the skeleton to antiepileptic drugs -- whether that is taking antiepileptic drugs for a longer period of time, taking multiple antiepileptic drugs, or taking higher doses. The data also suggest that the risk for bone disease is highest in individuals taking enzyme-inducing antiepileptic drugs.

Persons taking anti-epileptic drugs are 4 times more likely to have a hip fracture and 2 times more likely to have a fracture at any location in the skeleton.

Osteoporosis (brittle bone disease) and osteomalacia (softening of the bones) are possible side effects of enzyme-inducing anti-epileptic drugs (AEDs) like carbamazepine, phenobarbital, phenytoin and sodium valproate. These AEDs may reduce the body's vitamin D level, which can, in some cases, cause a loss of bone mass. Therefore, using these AEDs over a long period of time may be a risk factor for bone loss and fractures.

A bone density scan is advisable for people who have been taking these AEDs long term. Changes in bone density easily are detectable by dual X-ray absorptiometry (DXA) scan. Ultrasound, a less precise measure of bone density, also has been used to pick up this bone loss.

While certainly a concern for women with epilepsy, even a recent prospective study has shown that young men are similarly affected. In epidemiologic studies identifying variables predicting risk for bone disease in the general population, individuals with epilepsy who are receiving AEDs always emerge as a population at risk. Persons taking AEDs are 4 times more likely to have a hip fracture and 2 times more likely to have a fracture at any location in the skeleton.

If you are concerned about bone loss, you should address this with your physician. MEDSCAPE



Adult Epilepsy Support Group

Group Meets Second Tuesday of the month.
LOCATION: 2919 W. Second Street (Wichita) • TIME: 5:00 PM

June 10: Safety & Seizures

July 8: Dealing with Medication Side Effects

GLIMMER GROUP

a quarterly support group for parents and caregivers

Living Well With Epilepsy Parents Luncheon
Saturday, June 28 ♦ 11:30 AM @ ERC*

June offers a wonderful opportunity for parents of children with epilepsy to share their experiences. Lunch is on us!

To REGISTER CALL: 943-2453

*2919 W. Second Street (Wichita)



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“Living Well With Epilepsy” Parents Luncheon



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11:30 AM
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Join us for lunch and an opportunity to share with other parents of children with epilepsy. **Lunch is on us!**

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