



Serving Persons
Affected by Epilepsy

June 2006

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hotline

Epilepsy Is More Than Just Having Seizures

Symposium Examines Epilepsy & Quality of Life Issues

The Via Christi Comprehensive Epilepsy Center (VCCEC) and KU School of Medicine partnered to present a symposium titled “Epilepsy is More Than Just Having Seizures” at Roberts Amphitheater at the KU Wichita Campus on May 19th.

An audience of over 100 physicians, physician assistants, nurse practitioners, medical students and other healthcare professionals attended the event focused on comprehensive care of the epilepsy patient. 75% of the neurologists in Wichita were in attendance along with neurologists from other parts of the state. In all, there were attendees from 5 different states.

Keynote speakers were Martha J. Morrell, MD, a clinical professor in neurology from Stanford University, and Patricia A. Gibson, MSSW, Associate Director of Wake Forest University’s Comp. Epilepsy Program.

Dr. Morrell’s clinical work has focused on reproductive health risks associated with epilepsy and worked to bring the concerns of women with epilepsy to the attention of the medical community. Ms. Gibson is an expert in the area of the psychosocial issues in epilepsy.

Topics discussed at the symposium included epilepsy as a public health concern, epilepsy in relation to pregnancy, bone health and other women’s issues; optimizing treatment; and depression and epilepsy.

ERC appreciates the work of Dr. Kore Liow, VCCEC, and the event planning committee from KU to bring this event to Wichita. Attendees were exposed to the important, some often unforeseen, issues of persons living with seizures. *Epilepsy is more than just having seizures* and this event increased the epilepsy awareness of our medical community. ✨

Herbs As An Epilepsy Treatment ?

Herbs Not Proven as Deterrent to Seizures & May Be Dangerous

Herbal products have been taken for centuries for a variety of reasons. Over the past 15 years, more and more people have taken herbal products for their general health.

Popular herbal products in America include: ginkgo biloba, echinacea, garlic, ginseng, soy, saw palmetto, St. John’s wort, valerian and cranberry. Likewise, studies show that people with chronic medical conditions increasingly take herbal products, too. Nearly 1-in-3 people with epilepsy use some form of complementary and alternative medicine. The most common herbs include: ginseng, St. John’s wort, melatonin, ginkgo biloba, garlic and black cohosh.



But are herbs safe for people with epilepsy? Do they work? After all, if most prescription drugs originally come from plants, herbal products must be good for a person’s health, right?

At this time, research studies of people with epilepsy have not conclusively shown that any herbal product effectively and safely treat

seizures. And despite being “natural,” **some herbs have the potential for making seizures worse and weakening the effects of seizure medicines.**

Herbs are not regulated like prescription drugs. Herbal products are classified by the government as dietary supplements, not prescription drugs. No government agency, including the Food and Drug Administration, independently reviews and verifies the claims, supporting evidence, quality and safety of herbal products.

Active ingredients of herbal products are often unknown, and this is a major limitation to taking herbal products. For example, it is generally assumed that the active ingredient in St. John’s wort is hypericin, and St. John’s wort products are generally made to be 0.3 percent hypericin. However, hypericin has never been confirmed as the active ingredient of St. John’s wort.



If you don’t know the active ingredient of an herbal product, the quality control of that herbal product is not independently verified. Therefore, you can’t measure the active ingredient in the blood stream and you can’t be certain of how much of the herbal product to take.

Herbal products can interfere with seizure medicines. Not enough research has been done in this area. We do know, for example, that taking St. John’s wort for more than a couple weeks can lower the blood level of a person taking carbamazepine. Long-term use of St. John’s wort can also potentially lower the effectiveness of birth control pills. These are only a couple reasons why **it’s very important to tell your doctor if you are taking any herbal products or dietary supplements.**

Research studies of people with epilepsy have not conclusively shown that any herbal product effectively and safely treats seizures or other medical conditions commonly experienced by people with epilepsy. Clinical trials of herbal products are not generally monitored by the FDA, and the results of these trials are often difficult to interpret because of the quality control issues discussed earlier. Some herbs and aromatic oils have actually been reported to provoke seizures.

Just because something is natural does not mean it is safe, (e.g., poison ivy).

Epilepsy researchers increasingly recognize that herbal products have a centuries-old tradition of being used to treat the condition in many countries. So, scientists are beginning to study herbal products more carefully, trying to identify the active ingredients that could then be further tested under the FDA’s supervision as possible new treatments for epilepsy. And this year, for the first time, herbal products were discussed at the American Epilepsy Society’s annual meeting in Washington, D.C. ✨EPILEPSYFOUNDATION

The Scoop on Epilepsy Surgery

Epilepsy Surgery is Underutilized Treatment Option

Epilepsy surgery has been used for more than a century, but its use dramatically increased in the 1980s and '90s, reflecting its effectiveness as an alternative to seizure medicines.

Approximately 100,000 to 200,000 U.S. epilepsy patients with intractable seizures (i.e., individuals whose epilepsy cannot be treated satisfactorily with any of the commonly available medications) are eligible for surgery. Yet only 2,000 to 3,000 surgical procedures are performed a year.

While epilepsy surgery has become a more accepted treatment for individuals with epilepsy, it typically takes a seizure patient 18 – 22 years after the onset of intractable epilepsy to get to a treatment center for epilepsy surgery.

Not long ago, brain surgery was a last resort for the 30 to 40 % of people who had seizures despite anti-seizure drugs. Improved imaging technology now allows doctors to more precisely locate the section of the brain involved in seizures, making surgery a viable treatment.

Seizures that begin in the temporal lobe, the part of your brain that runs along each side of your head, are the most common type of seizure and the most difficult to suppress with drugs. Fortunately, temporal lobe seizures respond to surgical treatment more often than do other seizure types.

Usually to be considered for surgery, you must have tried at least two anti-seizure drugs without success. If two drugs have failed, it is highly unlikely that any other antiepileptic drug will help you. People whose seizures always start in the same area in the brain benefit most from surgery for epilepsy. Surgery is rarely considered for people whose seizures start in several areas of the brain. ✚ MAYOCLINIC

Adult Epilepsy Support Group

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

June 13th: "Stress & Seizures" July 11th: "Knowledge is Power"

Cyberonics® & Via Christi Epilepsy Center

Host a monthly seminar on VNS Therapy®

THIRD WEDNESDAY of the month 11:30 -12:30
Lunch is served, but **you must RSVP to attend.**
Note: The meetings are subject to cancellation.

For more info or to RSVP call: 617-9795

 Learn more about the treatment; time for Q&A

The Arc of Sedgwick County
2919 West Second Street
Wichita, Kansas 67203

Phone: 316-943-2453
Fax: 316-943-3292
E-mail: erc@arc-sedgwickcounty.org
Web: www.arc-sedgwickcounty.org/erc.html

August 6, 2006

 family camp day

▣ REGISTRATION FORM ENCLOSED ▣

Employment & Epilepsy Surgery

Job Experience Important Before Epilepsy Surgery

A recent study revealed that most patients succeed in getting a job after temporal lobe surgery. But the most important predictor wasn't seizure freedom, it was whether they were employed before the operation.

Andres Kanner, M.D., Professor of Neurological Sciences, Rush Medical College, Chicago, Illinois, and his colleagues presented the results of their study at the 58th Annual Meeting of the American Academy of Neurology in San Diego, CA, this past April.

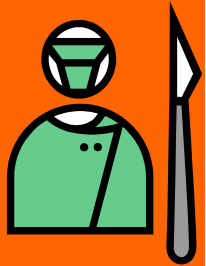
Kanner's group reviewed the charts of 88 patients who had temporal lobe surgery. 52 of the patients had mesial temporal sclerosis, 18 had another type of lesion in the temporal lobe and 18 had idiopathic temporal lobe epilepsy. Most of the patients (66) were working before their epilepsy surgery.

The results of the study indicated that the best predictor for employment after epilepsy surgery was presurgical employment, followed by seizure freedom and lack of severe psychiatric problems.

In addition, prior to surgery, many patients had psychiatric problems as well as epilepsy; 22 patients had depressive disorder, 21 had depressive and anxiety disorders, and 8 had other psychiatric problems. Kanner explained that the most important predictor of psychiatric problems after surgery was the presence of depression before surgery.

"Our interest in this research grew out of our experience with postsurgical epilepsy patients. We wanted to get a better understanding of which factors contribute to gainful postsurgical employment and ultimately what we could do better to prepare patients to seek and obtain such employment", said Frey. She further noted that, "This research has important implications for patients and their caregivers as it shows that seizure freedom does not necessarily lead to postsurgical employment. Rather, lack of employment following successful seizure surgery may be related to numerous issues, such as lack of experience in the work force, lack of adequate support system in the home and community, and reaction to psychological stress associated with seizures and their treatment. Such issues are rarely addressed in studies of postsurgery employment because they are often considered to be secondary to seizure."

Kanner encourages patients with epilepsy who are unemployed to either seek out or ask for a referral from their doctor for vocational evaluation and rehabilitation to ensure gainful employment as soon as they are diagnosed with epilepsy. In addition, he believes that vocational and psychiatric evaluations should be included in all presurgical evaluations. ✚ EPILEPSY.COM



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helps save us money in
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family camp day

August 6, 2006 • 12:30 - 5:30 PM

@ Camp Hiawatha

1605 W. 51st Street North*, Wichita

For more information:
(316) 943-2453

*If you live outside Wichita and need directions, give us a call

Camp is accessible: west on 51st St. from Meridian Ave. /OR/
south on Legion St. from 53rd St. N. (look for big Camp Hiawatha sign)

Keynote Speaker: Kore Liow, MD

Medical Director of the Via Christi Comprehensive Epilepsy Center in Wichita, Dr. Liow will give a brief educational presentation about epilepsy and answer your questions. An invited speaker at national and international epilepsy/EEG meetings, Dr. Liow is an advocate for epilepsy patients' quality of life and often speaks to leaders, politicians, congress and other officials on behalf of the epilepsy community.

We are **pleased** to have Dr. Liow at our camp as he will be a tremendous resource for our campers.



Camp Fun!!

—Network and meet other families that are living beyond the diagnosis of epilepsy—

Swimming!

Moonwalks!

Horseback riding!

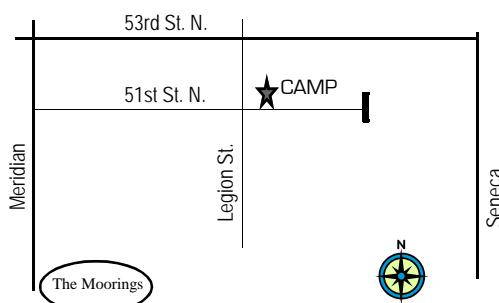
Crafts!

Games!

Prizes!

Medallion Hunt!

BBQ Dinner!



2006 ERC Family Camp Day Registration Form

Please Complete & Return by August 1st

Register yourself or family::

- Individual \$3.00
- Family \$6.00

Do NOT send cash.
Please enclose check payable to: ERC

Name(s) and age of children attending:

Name _____

Address _____

City & Zip _____

Phone _____

email _____

Return by August 1, 2006 to:

ERC Family Camp Day
2919 W. 2nd Street
Wichita, KS 67203-5319

* Please list any special accommodations you will need (e.g., dietary restrictions) on back.