

# erocurrent

Monthly newsletter from the **epilepsy** RESOURCE CONNECTION

## Epilepsy Research Trials

Do you have epilepsy and are you having a hard time controlling your seizures? Exciting research studies are currently being conducted at the Via Christi Comprehensive Epilepsy Center.

The center, which is located at 848 N. St. Francis, Wichita, Kan., is part of the Via Christi Wichita Health Network. It provides care for individuals throughout Kansas and the Mid-West. Aside from epilepsy care, the center is also involved in a number of different research studies.

Several of these studies work with new drugs or medications that are not yet available to the general public. Some of these drugs will come to market and may one day be prescribed by your doctor.

So, how do these new medications become available? Through clinical trials conducted at multiple clinics around the nation and some overseas. "Clinical trial" is the scientific term for a test or study of a drug or medical device in people. These tests are done to see if the product is safe and effective for people to use. Doctors and other health professionals run the tests according to strict rules set by the Food and Drug Administration (FDA). FDA sets the rules to make sure that people who agree to be in the studies are treated as safely as possible.

Why should you volunteer? By taking part in a clinical trial, you can try a new treatment for epilepsy that may or may not be better than those that already exist. You can also help others better understand how the treatment works.

The Via Christi Comprehensive Epilepsy Center is involved in ongoing research for new treatments for epilepsy. They have multiple studies available now for people with uncontrolled seizures. These studies are being done at their site and many other clinics across the country. Currently Via Christi is looking for volunteers:

- who are at least 12 years of age
- having 2 or more seizures a month
- taking 1, 2, or 3 epilepsy medications

These studies involve brand new medications or different versions of medications already used to control seizures. There is also a study especially for people over 65 years of age. Study visits to the clinic and any study activities are at no cost to you. Money to assist with transportation may be available.

If you are interested or for more information, please contact Toni or Ann at the Via Christi Comprehensive Epilepsy Center (316) 268-8500 or toll-free 1-800-362-0070, Ext. 88500.

For general information about clinical trials, call FDA's Office of Special Health Issues at 301-827-4460 or visit [www.fda.gov/oashi/home.html](http://www.fda.gov/oashi/home.html) For other clinical trials, visit [www.clinicaltrials.gov](http://www.clinicaltrials.gov)

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**Via Christi**  
Comprehensive Epilepsy Center

## Heflin to Advocate on Capitol Hill

Libby Heflin has been chosen to participate in The Epilepsy Foundation's Kids Speak Up! Program in Washington, D.C., March 30 thru April 1. Kids Speak Up! provides a unique opportunity for children aged 7 - 16 to meet with their elected officials to advocate on behalf of children with epilepsy and discuss the importance of funding.

Libby said, "This is a great opportunity to learn how government works and to get the word out about the difficulties of living with epilepsy."

Libby is in the 7th grade; she is home schooled by her mother, Lena. Libby loves animals and volunteers at the Humane Society each week. She also loves to read and is on the Teen Board at the Wichita Public Library. She enjoys soccer, the flute and loves to be outdoors.



Libby was diagnosed at the age of 5 with epilepsy. She has small seizures most of the time, even with her medication. The seizures, which you cannot see, come in small bursts and can be in almost any area of her brain. The seizures sometimes make it difficult to learn and can make it hard for her to remember things. She copes extremely well despite this handicap. We are very proud of Libby!

The Heflin's are longtime supporters of ERC and the epilepsy community we serve. Libby is a regular at our Family Camp Day and Lena is an advocate in her own right and recently spoke to families at a workshop during our Brain Storms 2007 conference. The Heflin's live in Haysville, KS.

We are very excited that Libby will attend and represent other Kansas youth with epilepsy. Parents, children, doctors and volunteers come from all over the country to receive advocacy training and to bring the epilepsy message to their legislators on Capitol Hill

The Kids Speak Up! program is sponsored through an educational grant from Abbott Laboratories.

Our April issue will highlight their experience and outcomes of their lobbying efforts!

*NOTE: If you would like to attend Kids Speak Up! 2009, you need to apply with the Epilepsy Foundation. Applications are usually due in November. Contact ERC and we can direct you to more information as it becomes available.*

## ...Epilepsy Answers

ERC is unveiling a new monthly Q&A feature with the help of Wichita epileptologist Dr. Kore Liow in the *CURRENT*. This is your opportunity to ask an epilepsy question that will be answered and printed anonymously. Now we just need to receive your questions!

**To submit a question:**

email to: [erc@arc-sedgwickcounty.org](mailto:erc@arc-sedgwickcounty.org)

mail to:

Epilepsy Resource Connection  
2919 W. Second Street  
Wichita, KS 67203

## Q&A



Kore Liow, MD is Medical Director of the Via Christi Comprehensive Epilepsy Center in Wichita, KS.



Sedgwick County...  
working for you

## Breakthrough Seizures

A breakthrough seizure is a seizure that occurs in a person who otherwise experiences good seizure control with their medication.

Sudden unexpected "breakthrough seizures" in someone who previously had achieved reliable control may result from forgetting to take medication, taking less than prescribed over a period of time (producing a slowly falling blood level that permits a seizure once it reaches a sub-therapeutic range); withdrawal from excessive use of alcohol; or illness. Many times, however, such causes cannot be identified.



Illness can produce seizures in a number of ways. There may be a sudden drop in medication blood levels because of inability to retain medication due to illness-related vomiting; or fever may lower the seizure threshold; or there may be interaction with illness-related medication. During a fever-related illness, for example, phenytoin (Dilantin) levels can decrease by approximately 50%, but Phenobarbital levels appear to be unaffected. Among children taking antiepileptic

drugs, a recent study reported 21% had significant changes in blood levels during illness with fever. Four of 14 children studied had increased carbamazepine concentrations caused by co-medication with the antibiotic erythromycin. Three of the children with fever had lower phenobarbital levels, and one developed phenytoin toxicity.

In children, medication is usually calculated by body weight and if the child has a growth spurt a breakthrough seizure may occur. This doesn't mean the medication is not working or the seizures are getting worse. It may simply mean a medication review is needed and possibly an increase in dose.

It is important to identify your seizure triggers and what is likely to cause you to have a breakthrough seizure. By tracking your seizures with a seizure diary you can provide your physician important information in helping you control breakthrough seizures.

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## Looking For Advocates to Share Stories at Brain Storms Conference



Applications are now being accepted for Advocate Presenters at the 2008 **Brain Storms: Bringing Epilepsy Stigma Out of the Shadows Conference** (Nov. 8, 2008 in Wichita).

Advocate Presenters are persons affected by epilepsy who wish to present their (or their loved one's) story at the conference. By sharing insights on living with epilepsy and how they found support, advocates help to widen the circle of support for everyone.

Applications are due by May 1, 2008.

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[erc@arc-sedgwickcounty.org](mailto:erc@arc-sedgwickcounty.org)

Hurdle the barriers to successful employment in

## ...GETTING THE JOB

### A FREE Employment & Epilepsy Workshop

Friday, April 4, 2008

9:00 AM — NOON

@ Office This (4031 E. Harry, Wichita)



This workshop is cosponsored by **Job Force Employment Solutions** and **Epilepsy Resource Connection**.

Role-playing and discussion will focus on the process of getting a job and the issues and misconceptions of epilepsy in the workplace. This is not a job fair; NO jobs will be offered. There is no cost to attend.

**Who should attend:** Anyone with epilepsy interested in gaining employment, who has questions how to get a job, and/or feels epilepsy is a barrier to getting/keeping a job. Caregivers and family members are welcome to attend.

#### Get help with these common questions:

What do I say in an interview about my epilepsy?

How do I get a job despite my epilepsy?

What is my next step in trying to get a job?

#### \*TO ATTEND THIS FREE WORKSHOP:

Please reserve a seat by calling  
**(316) 943-2453**

Workshop is accessible using Wichita Transit's East Harry bus which passes in front of *Office This* on-the-hour.

## Adult Epilepsy Support Group

Meets Second Tuesday of Month,  
5:00 PM ■ 2919 W. 2nd Street, Wichita

March 11th: "Recognizing Seizure Triggers"  
April 8th: "Group Choice"