



erc
epilepsy RESOURCE CONNECTION

arc-sedgwickcounty.org/erc.html

hotline

Epilepsy and Your Changing Hormones

Women who have epilepsy know that there are issues that affect them -- but not men with epilepsy. For some women, their pattern of epileptic seizures is directly affected by the normal hormonal cycles they experience throughout life.

Two primary sex hormones, estrogen and progesterone, flow through women's bodies. Most of the time, a woman's body has about the same amount of each.

Doctors have learned that both of these hormones interact with brain cells. Estrogen is an "excitatory" hormone, which means that it makes brain cells give off more of an electrical discharge. Progesterone, on the other hand, is an "inhibitory" hormone, which means that it calms those cells down.

When the body is making more estrogen than progesterone, it can make the nervous system "excitable." In other words, you could be at greater risk for seizures. The hormones aren't actually causing the seizures, but they can influence when they happen.

Some women with epilepsy have more seizures at times when their hormones are changing. For example, some young women have their first seizures at puberty. Other women have more seizures around the time of their menstrual periods. This doesn't happen to all women, so doctors are still learning about how hormones and epilepsy interact.

Some women have a form of epilepsy called *catamenial epilepsy*. This refers to seizures that are affected by a woman's menstrual cycle. Doctors aren't completely sure how many women with epilepsy have this, but they think it's about 10% to 12%.

The exact cause of these seizures is unknown. However, some women have most of their seizures when there is a lot of estrogen in their body, such as during ovulation. Other women have seizures when progesterone levels tend to drop, such as right before or during their period.

If you have seizures that start around the last half of your menstrual cycle and continue through the whole second half of your cycle, then you might have another type of catamenial epilepsy. This is when a woman has menstrual cycles that do not release an egg. These are called "anovulatory" cycles.

Women with epilepsy have more anovulatory cycles than other women do. Some doctors think that as many as 40% of menstrual cycles in women with epilepsy do not release an egg. It depends on the woman, and it is not always the same every month. Some months a woman will release an egg, and some months she will not. In general, though, women with epilepsy do not ovulate as regularly as women without epilepsy.

Why is that? Doctors do not know for certain. But, some seizures start in the temporal lobes of the brain. This is an area that is very closely connected to the areas regulating hormones. Women who have seizures that start in the temporal lobes may have their hormone production affected by their seizures.

If you can identify the role hormones play in your seizure patterns, it can help with your treatment. Try keeping a calendar of your menstrual cycle, and the days that you have seizures. Include notes about other factors that might be important, such as missed medication, sleep loss, stress, or illness. By sharing these records with your doctor, you can work together to manage your epilepsy more effectively.

[Continued] see Hormones on back



New On-line Seizure Resource Launched

Epilepsy.com has launched a new first-of-its-kind Seizure Preparedness on-line resource that introduces practical skills, tools and essential information for seizure management.

The new comprehensive epilepsy management resource is freely available to the public and healthcare professionals by visiting the *epilepsy.com* website.



Designed to prepare people with epilepsy and their families or caregivers with the ability to address seizure emergencies – at home, in the office, at children's summer sessions, in school – the site provides vital information to help patients and families develop a seizure preparedness plan, with the goal of maximizing faster response and safety.

For the first time, people living with epilepsy will have access to a broad array of physician-and parent-reviewed information addressing the "how-to's" on issues ranging from managing seizures to choosing a summer camp for children with epilepsy.

✦ EPILEPSY THERAPY DEVELOPMENT PROJECT

erc family camp day

Sunday, August 5, 2007 ☆ 12:30 - 5:30 PM

Camp Hiawatha

1605 W. 51st Street N., Wichita

Meet other families living beyond the diagnosis of epilepsy.

Family Fun for all!!

Games, Inflatables, Swimming, Horseback Riding, Crafts, Prizes, Frog Hop, BBQ Dinner, & More

Guest Speaker : Kore Liow, MD

Epileptologist, Via Christi Comprehensive Epilepsy Center

Registration: Individual \$5 Family \$15

To Register or for more info: (316) 943-2453

REGISTRATION FORM ATTACHED

Note: Please pre-register; Registrations received day of camp: Individual \$8, Family \$18.

Hormones [continued from front]

Many people develop their first seizures when they enter puberty. This happens to both men and women. Doctors think this is because before puberty we don't have many sex hormones circulating in our body. After puberty there are many more hormones in the body. Hormones do have a direct effect on the cells of the brain.

Some women's seizures may go away when they reach menopause. This usually happens in women who have catamenial epilepsy. For other women, menopause doesn't seem to make a difference in their seizures. And still other women have worse seizures during menopause.

Most of the time, though, doctors say that seizures become easier to control as you get older. They are not sure if that's because the seizures themselves are decreasing, or because newer medications are now available that control epilepsy better than in the past.

Keep in mind that some types of antiseizure medications can cause bone loss when taken over a long period of time. Since osteoporosis is a particular problem for women who have reached menopause, it is never too soon to talk with your doctor about your medication and what you can do to help prevent osteoporosis. On the whole, it's best to build strong bones early in life - in your 20s and 30s - and not wait till you're close to menopause when some of your bone strength may have already been lost. ✍WEB MD

Pacemaker May Help Avoid Seizures

Researchers at M.I.T. have developed a 'neurological pacemaker' that they claim can treat seizures before they happen.

Using electrodes attached to a cap, the system monitors brain activity and can determine when a seizure is likely. A signal is sent to a vagus nerve stimulation device implanted in the body which then sends a specific impulse to the brain, preventing the seizure, instead of the series of impulses currently used.

Its creators, say they are still a long way from making the device available to the public. There will be some serious development work to make it small and portable - not in the sense of needing a scientific breakthrough, but lots of hard engineering. ✍EPILEPSY ACTION



Don't forget to register for ERC FAMILY CAMP DAY

Adult Epilepsy Support Group

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

July 10th: "Quality of Life & Recreation"

August 14th: "Stress of Living in Seizure Fear"

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



Phone: 316-943-2453
Fax: 316-943-3292
erc@arc-sedgwickcounty.org

New Epilepsy Treatment Discovered

A new treatment that holds enormous potential for people whose epilepsy does not respond to anti-epileptic drugs has been discovered by a doctor in Australia.

Dr Phil Robinson, of the Children's Medical Research Institute, Paramatta, has found a way to prevent communication between brain cells, using a protein called dynamin, which he first discovered 27 years ago.

Robinson said that as many as 30% of people with epilepsy do not respond to medication.

"Through a series of discoveries we now have a new understanding of the brain and the basis of epilepsy," he said.

His team and their partners at the University of Newcastle have been working on developing a new treatment for epilepsy that differs from existing methods.

Most current treatments cause people to slow down, but the new treatment did not affect rapid nerve communication.

Robinson said the treatment was still being tested in the United States and he expected to receive the results in the coming months.

"Our hope and our aim is that the new treatment will have an effect on people who don't respond to anti-epileptic drugs," he said.

"We haven't got to the final stages yet, but we are on the way."

✍ EPILEPSY ACTION

Anti-dandruff Compound may Treat Epilepsy

Researchers at Johns Hopkins University, have discovered that an ingredient used in anti-dandruff shampoos can also calm over-excited nerve cells in the brain, making it a potential treatment for epilepsy. The results of the study have been published in Nature Chemical Biology.

Epilepsy and other seizure disorders result when nerves excessively or inappropriately "fire" in the brain. The brain's 'off' switches fail partly because of protein defects that prevent potassium from exiting nerve cells and calming them.

Min Li, PhD, professor of neuroscience at Johns Hopkins, said, "Channels that carry potassium must open on cue to make sure nerve cells only fire for defined periods of time."

Li and his colleagues developed a new way of testing molecules to find any that could turn the potassium switch on or off. They chemically shaved off all the potassium channels on the cell surface and forced the cells to make new channels. By measuring the activity of the new channels, the researchers could identify the molecules that accelerated the recovery.

One chemical that proved quite effective in improving channel recovery was zinc pyrithione, the active ingredient in many dandruff shampoos.

"Most drug discoveries uncover chemicals that stop things from working - it's a lot easier to close or block a door than open it," Li says. "But here we found a chemical that makes a defective protein work better. So now we have a chance to actually try to fix the causes of epilepsy, rather than traditionally circumventing them. Plus, this study really shows that we don't fully appreciate the biological roles of many familiar chemicals that surround us."

✍ CHEMICAL BIOLOGY



NON-PROFIT
ORGANIZATION
U.S. POSTAGE

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PERMIT #55



2007 FAMILY CAMP DAY



Sunday, August 5, 2007 • 12:30 - 5:30 PM
 Camp Hiawatha • 1605 W. 51st N.

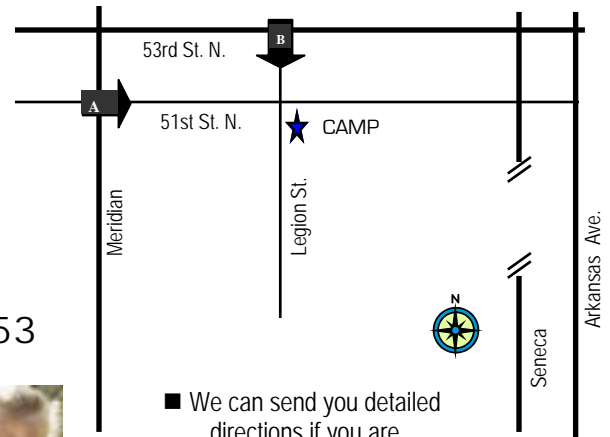
Camp is intended for persons of all ages with epilepsy & their families.
 Camp gives those affected by seizures an opportunity to meet others facing similar challenges in living with epilepsy.



DIRECTIONS

Camp Hiawatha is accessible :

- A) from Meridian → Go west on 51st St. /OR/
- B) from 53rd St. N. → Go south on Legion St. (LOOK FOR CAMP HIAWATHA SIGN ON 53RD)



■ We can send you detailed directions if you are coming from outside Wichita, call us at 316.943.2453

Please note: Lunch is NOT provided.

Keynote Speaker @ 1:00 PM

Dr. Kore Liow, MD

Medical Director of the Via Christi Comprehensive Epilepsy Center

Dr. Liow will give a brief presentation about epilepsy and answer your questions.

Fun Activities

Swimming (bring your suit) ★

Horseback Riding ★

Inflatables to bounce in

Games & Crafts

BBQ Dinner @ 5:00 PM

For More Information:

(316) 943-2453



i Please list any diet restrictions/ food allergies on back of this registration form (e.g., ketogenic diet).

Registration for yourself or family[†]

- Individual \$ 5.00
- Family \$ 15.00

[†] Please pre-register.

Registration on Day of Event: \$8.00 Individual; \$18.00 Family

Do NOT send cash. Make check payable to:
 ERC Family Camp Day

Return to:

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

* Please list NAMES of persons attending in box below, please include AGE for children:

1
2
3
4
5

*

Name _____

Address _____

City & Zip _____

Phone _____

email _____