

erocurrent

Monthly newsletter from the **epilepsy** RESOURCE CONNECTION

Getting the Most from Your Doctor's Appointment

Doctors spend on average only a few minutes with each patient they see for routine examinations. (Of course, there is often time out of the exam room that is spent reviewing the chart and records.) The experience can be both confusing and frustrating when communication on one or both sides is lacking, particularly if you're presented with new information to process or new instructions to follow.

While a visit to the clinic can be intimidating for anyone, you can lessen the stress and worry associated with doctor's appointments by taking steps to be sure that you're provided with all the information you need at the appointment. There are also ways you can improve the quality of your care by helping your doctor develop the best understanding possible of your symptoms and condition.

Before the appointment, write down a list of things you need to tell the doctor. Note any concerns or questions you may have. Also write down the names and dosages of any prescription, over-the-counter medications, or supplements you are taking. It is very important to take this list with you to the appointment – don't count on remembering every single item. Before you leave the office, go over the list to be sure you've covered everything. This simple step benefits both you and your doctor by keeping the discussion focused and ensuring that all your concerns are addressed.

Don't hesitate to use the words "I don't understand." Doctors are only human and may not always know when they haven't explained something well or in terms you can understand. Never feel embarrassed or shy about asking for clarification about something your doctor says. When in doubt, repeat back what your doctor has told you and ask if you've got it right. You can also ask if he or she recommends any specific reading materials about your condition.

If your doctor asks questions that sound embarrassing or overly personal, remember that the information you provide enables him or her to better establish a diagnosis, or to determine which treatment is most appropriate for you. Never fib in response to questions about alcohol or drug use, sexual history, or other lifestyle matters. Be honest about the extent to which you are taking your prescriptions or following a treatment plan. Withholding the truth can affect the quality of your care and can even lead to a wrong diagnosis.

Finally, the office medical assistants and nurses can be an additional resource of information. Do not hesitate to ask them questions about your concerns as well.

Advance preparation for your doctor's visit is a vital step toward becoming a partner in your own health care and an advocate for your health and well-being. A good doctor will always encourage your desire to understand as much as possible about your condition and will welcome your active participation in your care. ❖WEB MD



BioLink Wins Three Patents for Epilepsy Treatment

The U.S. Patent Office has awarded three patents to BioLink Life Sciences Inc. for four novel epilepsy drugs. BioLink is based in Cary, North Carolina.

"Most epileptic patients take valproate drugs like Depakote to treat their disease," BioLink's president Deanna Nelson noted.

"Current valproate drugs cause nausea, lethargy, weight gain, and other more serious side effects. In contrast, each of BioLink's four new valproates is formulated to cause fewer side effects while providing the valproate drug that the patient needs."

Valproates are used for the treatment of epilepsy, bipolar disorders, and migraines.

New uses of valproates as treatments for Alzheimer's disease and cancer are being evaluated in clinical trials. BioLink says it will work with strategic partners to gain FDA approval for each of its new valproate drugs.

BioLink "repairs" drugs to reduce side effects and improve their safety, a strategy that significantly reduces the time and cost of development for FDA approval.

BioLink Life Sciences Inc. works with pharmaceutical partners to commercialize, market, and distribute its drug candidates. In the U.S., the sale of new drugs requires approval by the FDA. BioLink's "repaired" drugs are currently undergoing testing to establish the efficacy and safety that are required for FDA approval.

BioLink's new valproates are NOT available for sale nor have they yet been shown as useful for the treatment of epilepsy.

❖TECH JOURNAL SOUTH



Tips for Seizure Observation

Before you can track seizures, you need to know what to look for. Seizures can be broken down into 4 phases: **Prodrome**: behaviors or feelings that occur hours to days before a seizure; **Aura**: the actual start of a seizure and may be thought of as a "warning;" **Ictus**: the seizure event; **Postictal**: the recovery period after the seizure.

When watching a seizure, try to note what happens in each phase of the seizure – before, during and after the event. Write down what happens as soon as you can – it's easy to forget details when you don't write them down. Reporting accurately what occurs during your seizures, gives your physician better data to use towards controlling your seizures.

If you lose consciousness during your seizures ask your friends, family or coworkers to help watch for these changes/phases and write down the information for you. For more on these tips, visit www.epilepsy.com/epilepsy/tips_seizure_observation.

Is it Seizures or Epilepsy?

Seizures are a symptom of epilepsy. Epilepsy is the underlying tendency of the brain to produce sudden bursts of electrical energy that disrupt other brain functions. Having a single seizure does not necessarily mean a person has epilepsy. High fever, severe head injury, lack of oxygen — a number of factors can affect the brain enough to cause a single seizure.

Epilepsy, on the other hand, is an underlying condition (or permanent brain injury) that affects the delicate systems which govern how electrical energy behaves in the brain, **making the brain susceptible to recurring seizures.** ❖EPILEPSY FOUNDATION

Adult Epilepsy Support Group

Group Meets Second Tuesday of the month.

LOCATION: 2919 W. Second Street (Wichita) • TIME: 5:00 PM

August 12: Dealing with Epilepsy Confusion
Sept. 9: Concerns by the Patient & the Family





Sedgwick County...
working for you



Study: Stroke Victims With Seizures More Likely To Die

Seizures may be a sign of significant brain injury, and may occur in patients that experience any type of stroke. A new study finds that stroke patients with ensuing seizures are more likely to die in the 30 days following stroke than patients without seizures. The findings show a mortality rate of over 30% at thirty days after stroke.



The study, published in the June issue of *Epilepsia*, finds that the overall incidence of seizures within 24 hours of an acute stroke is 3.1%. Patients with intracranial hemorrhages (bleeding within the brain), have a higher incidence (8.4%) of seizures – in the first 24 hours after stroke.

Cerebrovascular diseases (disease of blood vessels supplying the brain), including strokes, have long been recognized as a risk factor for the development of epilepsy, particularly in elderly populations. However, the incidence of seizures within 24 hours of stroke has not been studied extensively.

The authors also aimed to establish any racial differences in the incidence of these post-stroke seizures. They found that, despite the fact that blacks are known to have higher prevalence rates of both seizures and strokes (especially in younger age groups), there were no racial differences in seizure incidence or mortality rates in the studied population.

"Patients with seizures in the setting of an acute stroke may constitute a target population for the development of drugs that may prevent seizures," says Dr. Jerzy P. Szaflarski, M.D., Ph.D. Professor of Neurology at Cincinnati Epilepsy Center and lead author of the study. "Because patients with stroke have high incidence of immediate and long-term seizures and epilepsy, they constitute a population where seizure prevention with anti-epileptic drugs can be studied." ❖SCIENCE DAILY

Temporal Lobe Epilepsy Research Volunteers Needed

Ph.D. candidate writing dissertation on neuroplasticity and epilepsy is searching for volunteers for her research. Research will document how temporal lobe epilepsy (TLE) affects the whole person psychologically, socially, spiritually, creatively, and intellectually focusing on the positive strengths and attributes that are sometimes unique to persons with epilepsy.



If you have TLE or have had a temporal lobectomy for TLE and have an interest in contributing to this project per the premise that TLE can contribute to heightened creativity, complexity of thought, and/or the evolution of deeper intellectual insight, please contact:

Teri Strong at tkstrong@earthlink.net
or call ERC at (316) 943-2453. ❖

FDA OKs Generic Depakote ER

In July, FDA approved the first generic version of Depakote (divalproex sodium) delayed-release tablets. Depakote is approved by the FDA to treat seizures, bipolar disorder, and migraine headaches.



"Generic drugs undergo a rigorous scientific review to ensure that they will provide the patient the same amount of high-quality, safe, and effective drug as the name-brand product," Gary J. Buehler, RPh, director of the FDA's Office of Generic Drugs, says in an FDA news release. "This approval provides an additional treatment option for patients who suffer from epilepsy, bipolar disorder, and migraines."

Generic divalproex sodium will have the same safety warnings as Depakote, including a "black box" warning -- the FDA's sternest warning -- that cautions about the risk of liver damage (hepatotoxicity) and inflamed pancreas (pancreatitis), including fatal cases of both. The boxed warning also highlights the risk of birth defects, including neural tube defects.

The FDA has approved companies with facilities in the US, Canada, and India to market divalproex sodium delayed-release tablets. ❖WEB MD

ADA Amendments Act Enters Senate

On July 31, the Senate introduced the ADA Amendments Act of 2008 (S. 3406). This is a critical step for the ADA legislation and builds on the strong bipartisan momentum of the House vote of 402 to 17 on its version of the legislation (H.R. 3195). Both Kansas Senators are co-sponsors of the bill.



The proposed Amendments Act would secure the promise of the ADA, which has been eroded by recent Supreme Court decisions that left people with disabilities—including epilepsy, diabetes, cancer and mental illness—without the protections Congress originally envisioned.

Only YOU can make sure the bill becomes law! Contact Senators Sam

Brownback and Pat Roberts today! Thank them for their support as cosponsors of the ADA Amendments Act of 2008 (S. 3406) and encourage them to follow through in supporting a floor vote in the Senate on S. 3406 when they return from the August recess. You should also express your desire for them to support future bills that directly affect persons with epilepsy.

Call your Senators today. As they will be in Kansas for the August recess, you can call and find out if they will be doing any public meetings, forums, open office hours, or town hall meetings in your area. These opportunities to meet directly with your Senator are incredibly helpful to our advocacy efforts!

To contact Senator Roberts in his Wichita office call (316) 263-0416. Senator Brownback's Wichita office is (316) 264-8066. You can email the senators from their on-line forms; visit www.senate.gov to access the forms. ❖EPILEPSY FOUNDATION