

h otline

Senator McCain Calls for Epilepsy Awareness

Senator John McCain (R-AZ) is lending his support to the more than Three million Americans living with epilepsy, a neurological condition that produces sudden bursts of electrical energy and disrupts certain brain functions.



McCain will star in a series of radio and television public service announcements to promote awareness and eliminate stigma about the widely misunderstood condition during National Epilepsy Awareness Month in November. The senator has a personal understanding of epilepsy because his father, the late Admiral John S. McCain Jr., was diagnosed with the condition.

Epilepsy is the third most common neurological disorder after Alzheimer's disease and stroke. According to a 2000 study, Epilepsy costs the nation more than \$16.26 billion a year in medical costs and lost productivity. Despite the fact that epilepsy is the oldest condition known to humanity, it is still surrounded by mystery, ignorance and fear.

"We are committed to bringing epilepsy out of the shadows so that the legacy of stigma and discrimination ends with this generation," explained Eric Hargis, president and CEO of the Epilepsy Foundation. "We hope Senator's McCain's commitment to raising awareness will help make more people with epilepsy comfortable and willing to openly discuss their condition with family, friends, teachers, colleagues and employers." The PSAs can be viewed at www.epilepsyfoundation.org. ☞EF

Ketogenic Diet May Inspire New Epilepsy Drugs

The "ketogenic diet" might be the springboard for a new type of epilepsy drug.

The ketogenic diet strictly limits carbohydrates and may help control seizures in some people. That's nothing new. The ketogenic diet has been around since the 1920s (and shouldn't be tried without medical supervision). But the science behind the ketogenic diet and epilepsy seizures hasn't been understood. Now, researchers have a new clue about how the ketogenic diet works, and they say that clue may eventually lead to new epilepsy drugs.



The finding comes from researchers including Avtar Roopra, PhD, of the neurology department of the University of Wisconsin-Madison. Their study appears in *Nature Neuroscience's* advance online edition.

More than 50 million people worldwide have epilepsy, 20 million of whom "continue to have seizures despite treatment with current antiepileptic drugs or surgery," Roopra's team writes. The researchers reasoned that ketogenic diets, being low in carbohydrates, result in very little glycolysis (carbohydrate breakdown). So the scientists tested a glycolysis-blocking chemical in a rat model of epilepsy. The chemical, called 2DG (2-deoxy-D-glucose), reduced the number and severity of seizures in the rats.

"Our results show that 2DG has anticonvulsant and antiepileptic properties, suggesting that antiglycolytic compounds may represent a new class of drugs for treating epilepsy," write Roopra and colleagues.

The scientists haven't tested 2DG on people. ☞WEBMD

Patients Have Gripes; So Do Docs

Most patients are satisfied with their doctors, but the majority cite long waits in the waiting room as their top pet peeve. Nearly one in four patients (24%) said they waited 30 minutes or longer.

This according to a new survey by *Consumer Reports* conducted of its subscribers. The survey of about 39,000 patients and 335 primary care doctors appears in the February edition of *Consumer Reports*.

Doctors have their gripes about patients too. Doctors' major annoyance with patients was about not following prescribed treatment. Almost six in 10 doctors (59%) voiced that complaint.

Doctors' other complaints about patients were: Waiting too long before making an appointment (41%); reluctance to discuss their symptoms (32%); requesting unnecessary tests (31%); and requesting unnecessary prescriptions (28%).

8 Tips for Patients

These tips from *Consumer Reports* might get you better care:

Research carefully. When gathering health information, consider the quality of the source.

Make an agenda. Before your appointment, set priorities about what you want to discuss with your doctor.

Ask about email. If you don't have time to cover everything in your appointment, ask if you can follow up by email.

Bring someone with you. A friend or relative can help you get your questions answered and remember what the doctor tells you.

Tell it like it is. Be frank, honest; and don't be shy. Bring up any conditions bothering you.

Follow your doctor's advice. For example, don't stop taking medications without talking with your doctor.

Be persistent. Work with your doctor to find the right treatment.

Switch doctors, if necessary. Not happy with your doctor? There are others out there.

Because they were subscribers to *Consumer Reports*, the patients included in the survey may not be typical patients, the magazine notes. ☞WEBMD

Adult Epilepsy Support Group

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

Feb. 13th: "Epilepsy in the Work Place"

☞ Mar. 13th: No Group * * *Note: March group will meet on Friday, March 9th at 1:00 PM* * *

Mar. 9th, *1:00PM* "Seizure Triggers & Strategies"

Fear of stigma causes unemployment among people with epilepsy

A new study by the University of Florida (USA) has revealed that the unemployment rate among people with epilepsy in the U.S. is much higher than the national rate due to fear of discrimination at work.



Researchers interviewed nearly 300 people with epilepsy in northeast Florida and southeast Georgia during September 2005. Only about a third of patients in the study were employed.

Principal author Dr. Ramon Bautista said the study, published in the journal *Epilepsy & Behavior*, described a complex problem. Dr. Bautista is an assistant professor of neurology and director of the Comprehensive Epilepsy Program at the UF College of Medicine-Jacksonville.

"The problem encompasses employers and companies who hire these people as well as the patients themselves, who may or may not want to work in the first place," Bautista said. "Even though the Americans with Disabilities Act makes it illegal to discriminate on the basis of one's disability, there are still employers who may think twice about hiring someone with epilepsy."

"It very well may be only perceived rather than actual discrimination, but if epilepsy patients believe that they have less of a chance in the workplace, then they're less likely to even want to try to work."

☞EPILEPSY ACTION

New drug may work as anti-epileptic medication

The drug manufacturer Schwarz Pharma has presented data suggesting that it may be possible to treat epilepsy using their drug lacosamide.

Phase III trials investigated the safety and oral usage of lacosamide as an add-on therapy for adults with uncontrolled partial seizures.

Seizures were reduced by 15% in people that took 400mg per day. During the trial, lacosamide was generally well tolerated, with dizziness, headache and double vision being the most commonly reported side-effects.

"Lacosamide is a promising new compound with a novel mode of action, and it has the potential to play an important role in the management of epilepsy," said Iris Loew-Friedrich, member of the Executive Board of Schwarz Pharma.

Unlike traditional anti-epileptic drugs, lacosamide is believed to reduce neuron transmissions in the brain. The trial will be submitted to the regulatory agencies in both the European Union and the US.

☞EPILEPSY ACTION

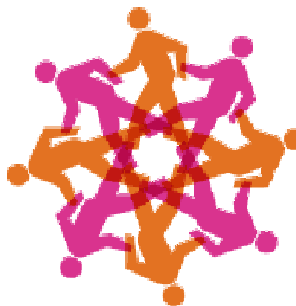
The Arc of Sedgwick County
2919 West Second Street
Wichita, Kansas 67203

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



NationalWalk
for **Epilepsy**
March 31, 2007

Misunderstood for more than 5,000 years...
Help us reveal the truth.
Help us pace toward a brighter future.
Help people with epilepsy.



NationalWalk
for **Epilepsy**

not another moment lost to seizures

www.walkforepilepsy.org

The National Walk for Epilepsy is a 5K family oriented, noncompetitive walk to raise funds for research, treatment, and education programs for people with epilepsy and their caregivers.

Saturday, March 31, 2007
On the National Mall in Washington, DC and
Online Throughout the Nation

Winter fun & games

Sat. Feb 3, 2007

10:00 a.m. - 1:30 p.m.

@ ERC (2919 W. 2nd Street)

Fun, lunch and connect with other families facing similar challenges of living with a seizure disorder. Includes free lunch (*donations are accepted to help defray costs.*)

Pull the kids away from the cartoons... And join other families affected by epilepsy for a morning of indoor fun for all ages! We will have Inflatables for the kids to bounce in.

Adults will enjoy a challenging game of Cranium!! If you haven't played it, imagine combining charades and a trivia game. Everyone can contribute giving their team a moment to shine.

To attend, please RSVP at (316) 943 - 2453

NON-PROFIT
ORGANIZATION
U.S. POSTAGE

PAID
WICHITA KS
PERMIT #55