

Epilepsia

Spring 2008

VOL 24, NO. 1

AN ESNI PUBLICATION

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ESNI Fundraising Drive Continues

Fundraising is an ongoing job at ESNI, as well as at any not-for-profit agency. It's difficult to succeed, especially during strained economic periods. Yes, I collected pledges and participated in Disney's Marathon Weekend in January, but we fell short of our goal. ESNI's holiday solicitation letter also underperformed, leaving the agency with a fiscal deficit that needs urgent attention. Our dilemma is not unique. I hear this lament over and over from my colleagues in the not-for-profit arena.

Another objective in recovering funds is trying to be creative and appealing to our audience. This time we've come up with a sure fire winner. A raffle that allows you to select your own prize! And do we have the prizes—everything from a Dell laptop computer, to premium seats at Chicago major league and NFC sporting events, to dinner coupons at some of Chicago's premiere dining spots!

Please take the time to read through this exciting raffle package when it arrives in your mailbox. I know your mail is inundated with pleas from organizations nationwide asking for your financial help, but ESNI is different. We don't have a national presence. We don't belong to a parent organization. We don't charge fees for our programs. We are your local epilepsy source for information and assistance. ESNI helps you, your family, and loved ones understand and cope with the impact of this curious neurological disorder. We're there when you need us, now we need you!

Don't toss this opportunity to make a difference in the "save for later" stack of mail on your countertop. Look at the array of premiums we have collected. Surely, there's something listed you'd like to win. Please be generous. All contributions are tax deductible.

Thank you!



Maureen Galassie
Executive Director

Agency Website Operational

It's been a long time in the planning and construction stages, but the wait is over. ESNI is pleased to announce our new website located at www.esniinfo.org. You'll be able to read up on ESNI's history, meet our staff and board of directors, participate in blogs/forums, and catch up on archived editions of EPILIFE. ESNI news and events will be posted as well.

Be sure to stop by. We'd love to hear from you!



Hackers Assault Epilepsy Patients via Computer

by Kevin Poulsen,
www.wired.com

Internet griefers descended on an epilepsy support message board and used JavaScript code and flashing computer animation to trigger migraine headaches and seizures in some users. The Epilepsy Foundation, which runs the forum, briefly closed the site to purge the offending messages and to boost security.

“We are seeing people affected,” says Ken Lowenberg, senior director of web and print publishing at the Epilepsy Foundation. “Fortunately, it’s only a handful. It is possible that people are just not reporting it yet – people affected by it may not be coming back to the forum so fast.”

The incident, possibly the first computer attack to inflict physical harm on the victims, began Saturday, March 22, 2008 when attackers used a script to post hundreds of messages embedded with flashing animated

graphic interchange formats.

The attackers turned to a more effective tactic on March 23, 3008, injecting JavaScript into some posts that redirected users’



Hackers Assault Epilepsy Patients via Computer

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browsers to a page with a more complex image designed to trigger seizures in both photosensitive and pattern-sensitive individuals.

RyAnne Fultz, a 33-year-old woman who has pattern-sensitive epilepsy, says she clicked on a forum post with a legitimate-sounding title on March 23, 2008. Her browser window resized to fill her screen, which was then taken over by a pattern of squares rapidly flashing in different colors. Fultz says she “locked up”.

“I don’t fall over and convulse, but it hurts,” says Fultz, an IT worker in Coeur d’Alene, Idaho. “I was on the phone when it happened, and I couldn’t move or speak.” After about 10 seconds, Fultz’s 11-year-old son came over and drew her gaze away from the computer, then killed the browser process, she says.

“It affected (to some extent) everyone who logged on, whether by causing headaches or seizures,” says Bowen Mead, a 24-year-old epilepsy patient in Maine who says she suffered a daylong migraine after examining several of the offending posts. She lingered too long on the pages trying to determine who was responsible.

Circumstantial evidence suggests the attack was the work of members of Anonymous, an informal collective of grievers best known for their recent war on the Church of Scientology. The first flurry of posts on the epilepsy forum referenced the site of EBaumsWorld, which is much hated by Anonymous. And, forum members claim they found a message board thread — since deleted — planning the attack at 7chan.org, a group stronghold.

Fultz says the attack spawned an uncommonly bad seizure. “It was a spike of pain in my head,” she says. “And the lockup only happens with really bad ones. I don’t think I’ve had a seizure like that in about a year.”

She’s satisfied with the Epilepsy Foundation’s relatively fast response to the attack, about 12 hours after it began on Easter weekend. “We all really appreciate them for giving us this forum and giving us this place to find each other,” she says.

Epilepsy affects an estimated 50 million people worldwide, about 3% of whom are photosensitive, meaning flashing lights and colors trigger seizures.



Osteoporosis & Antiepileptic Drugs

By Janet Yagoda Shagam
EpilepsyUSA

Many patients and their doctors are not aware that accelerated bone loss and osteoporosis are long term side effects of taking certain antiepilepsy drugs (AEDs).

This makes it especially important that older men and women who take medication to control seizures discuss bone health with their neurologists and primary care physicians.

Research shows that people who have epilepsy are 2-3 times more likely to break a bone sometime during their life than people who do not have this condition. These findings, according to Mayo Clinic epilepsy specialist, Jerry Shik, MD, also imply that elderly epilepsy patients have a higher incidence of broken bones than other people of the same age. While these findings may seem worrisome, it is important to remember there are ways to lower your risk for

osteoporosis and bone fractures even though you are taking medication to control seizures.

Risk factors for osteoporosis involve a combination of issues that range from gender to dietary habits. Some, such as gender and age, you cannot control. However, you can reduce your risk for osteoporosis by eating a well-balanced diet, refraining from smoking, limiting alcohol consumption and engaging in bone-bearing exercise such as walking.

According to the World Health Organization, having osteoporosis is the number one risk factor associated with bone fractures and spinal column changes that cause reduction in height and chronic back pain.

A recent study published in *Neurology* shows that sodium valproate (Depakote) and other non-enzyme inducing AEDs also decrease bone mineral density. With this

evidence in mind, many investigators believe that even the newer AEDs may also adversely affect bone strength.

According to Michael Lewiecki, MD, of the Clinical Research and Osteoporosis Center located in Albuquerque, New Mexico, not enough doctors understand the importance of referring patients who take AEDs for vitamin D blood level and bone density screening tests.

Protecting patients who take AEDs to prevent seizures may require expertise and input from many specialists. In addition to working closely with your neurologist and primary care physician, an osteoporosis specialist may be helpful if you have experienced broken bones or if monitoring shows you are not responding to medication. Taking these important steps will reduce your overall risk for bone loss.

RESEARCH

FDA Warns Antiepileptic Medications May Increase Risk of Suicide

EpilepsyUSA, 2008

The U.S. Food and Drug Administration (FDA) issued new information to health care professionals on January 31, 2008, to alert them about an increased risk of suicidal thoughts and behaviors

(suicidality) in patients who take antiepileptic drugs to treat epilepsy, bipolar disorder, migraine headaches and other conditions.


The FDA analyzed 199 studies comparing 11 antiepileptic drugs to placebos and found that patients taking the drugs increase the risk of suicidal thoughts and behaviors (43%) compared with patients receiving placebo (22%). The analysis included 27,863

patients in drug treatment groups and 16,029 patients in placebo groups. While the risk in patients receiving the medications appeared double to those who did not receive the drug, the overall risks appear to be small.

The FDA has monitored the drugs since 2005, following a preliminary analysis of data from several antiepileptic drugs that suggested an increased risk of suicidality.

Antiepileptic drugs in the analysis included the following: Carbamazepine (marketed as Carbatrol, Equetro, Tegretol, Tegretol XR), Felbamate (marketed as Felbatol), Gabapentin (marketed as Neurontin), Lamotrigine (marketed as Lamictal), Levetiracetam (marketed as Keppra), Oxcarbazepine (marketed as Trileptal), Pregabalin (marketed





as Lyrica), Tiagabine (marketed as Gabitril), Topiramate (marketed as Topamax), Valproate (marketed as Depakote, Depakote ER, Depakene, Depacon) and Zonisamide (marketed as Zonegran). Some of these drugs are also available in generic form.

The FDA will discuss these data with a panel of experts who will be able to further clarify the true risk associated with these drugs. The agency will also work with manufacturers of antiepileptic drugs to include the new information on the labeling of these products.

Please note: Patients who are currently taking antiepileptic medicines should not make any changes without first talking to their health care provider. Health care providers should notify patients, their families and caregivers of the potential for an increase in the risk of suicidal thoughts or behaviors so that patients may be closely observed for notable changes in behavior.

Epilepsy Foundation Responds to the Recent Announcement from the FDA on Antiepileptic Drugs

The Epilepsy Foundation feels that the recent announcement linking suicidal thoughts with antiepileptic drugs should not cause anyone to become frightened about taking their medications. Reacting to this FDA warning by abruptly stopping an antiepileptic medication could be very dangerous and is better handled by contacting your doctor to discuss any concerns.

Individuals taking antiepileptic medications can feel reassured by a number of factors. Since depression is very common in epilepsy, it is not known for sure if some individuals had suicidal thoughts that were not in fact caused by medications. Much more information is needed about how these statistics were derived. Even if medications do raise the risk, this risk is very low. The risk of developing this problem after long-term use of a drug is probably especially low if a person has been feeling fine up until now.

The Epilepsy Foundation has always supported the idea that health care providers need to spend time looking for and talking about depression with epilepsy patients.

Recent Survey Results Demonstrate Patients' Need to Communicate More Effectively

EpilepsyUSA, 2008

The American Epilepsy Society and the Epilepsy Foundation announced results from a jointly sponsored patient survey underscoring the need for enhanced patient knowledge of treatment objectives and improved patient-physician dialogue for better epilepsy care. The two organizations are raising awareness of the survey results to empower patients to seek more from their treatment to improve epilepsy control. The survey was supported through a sponsorship by Pfizer, Incorporated.

- Only about half of the people surveyed said that their doctors ever discussed with them other treatment options or what to expect from their treatment.

Recommendation: Individuals with epilepsy should empower

themselves by becoming more informed health care consumers. This is achieved by seeking information from reliable sources and then bringing questions based on their information to the health care provider. A key question to pose is "Are there any other medication or non-medication options available?" Another reasonable question is "Would there be value in receiving a consultation from a specialty epilepsy center?" Writing a list of questions before seeing the health care provider, and taking notes during the office visit, also facilitates a comprehensive discussion with the health care provider.

- One in four said they did not know what their doctor would consider to be a significant improvement in seizure control.

Recommendation: Having a treatment goal is key to stay-

ing motivated and managing epilepsy. Patients should discuss and come to an agreement with their doctor on what would be a significant improvement in control. However, if you feel the doctor is not being sufficiently aggressive in trying to control the seizures, it is reasonable to get a second opinion.

- About half of those surveyed also said their doctors did not discuss epilepsy's impact on such things as day-to-day activities, mood and difficulty sleeping.

Recommendation: Many people may not realize that achieving control of seizures is only one part of the proper care of the patients with epilepsy. There are many other very important issues that deserve to be addressed, including commonly-associated depression, medication side effects and the impact of epilepsy and its

treatments upon a person's quality of life. During the typically rushed doctor-patient interaction, it is important for the patients to take a proactive stance on voicing these kinds of issues.

- *About one in five feels they are more concerned than their doctor about medication side effects.*

Recommendation: Reasonable questions to ask your doctor include: How does the drug work? What are the risks and what are the benefits? Are there alternatives that carry the same benefits with fewer side effects? Why was this particular treatment selected? What are the potential short-term and long-term side effects? What kinds of problems warrant notifying the doctor? Are there any potential drug interactions with my other medication or even herbal agents I am taking?

- *One in ten said they underestimate the number of seizures*

when talking to their doctors, either because they fail to record their seizures, are unable to recall, or even to know when a seizure happens.

Recommendation: It is very helpful to maintain a seizure diary. This helps keep an accurate record of the number and nature of the seizures that have occurred. Providing your doctor a more accurate listing of seizures is important in

guiding changes in treatment. It is also essential to tell the doctor if you believe a seizure may have occurred because of forgetting to take your medications.

- *A small number of those surveyed said they reported fewer seizures than they experienced because they did not want their doctor to know how many seizures they were actually having.*

Recommendation: Patients who under-report seizures deprive themselves of their best chance for reducing seizures and improving their condition.

Editor's note: If you need any assistance in formulating questions for your health care provider or understanding the many ramifications of your diagnosis, please contact ESNI at 847-433-8960. We understand the complexities of this condition and have 30 years of experience. We are here to help you achieve an improved quality of life.



Brain Study May Lead to Improved Epilepsy Treatments

Using a rodent model of epilepsy, researchers found one of the body's own neurotransmitters released during seizures, glutamate, turns on a signaling pathway in the brain that increases production of a protein that could reduce medication entry into the brain. Researchers say this may explain why approximately 30% of patients with epilepsy do not respond to antiepileptic medications.

The study was conducted by researchers at the National Institute of Environmental Health Sciences (NIEHS), part of the National Institutes of Health, and the University of Minnesota College of Pharmacy and Medical School, in collaboration with the Ludwig-Maximilians-

University in Munich, Germany.

"Our work identifies the mechanism by which seizures increase production of a drug transport protein in the blood brain barrier, known as P-glycoprotein, and suggests new therapeutic targets that could reduce resistance," said David Miller, Ph.D., a principal investigator in the NIEHS Laboratory of Pharmacology and co-author of the paper.

The blood-brain barrier (BBB) which resides in brain capillaries, is a limiting factor in treatment of many central nervous system disorders. It is altered in epilepsy so that it no longer permits free passage of administered

antiepileptic drugs into the brain. Miller explained that P-glycoprotein forms a functional barrier in the BBB that protects the brain by limiting access of foreign chemicals.

"The problem is that the protein does not distinguish well between neurotoxicants and therapeutic drugs, so it can often be an obstacle to the treatment of a number of diseases, including brain cancer," Miller said. Increased levels of P-glycoprotein in the BBB has been suggested as one probable cause of drug resistance in epilepsy.

Using isolated brain capillaries from mice and rats and an animal model of epilepsy, the researchers found that glutamate, a neurotransmit-

“Findings provide insight into one mechanism that underlies drug resistance in epilepsy and possibly other central nervous system disorders.”

Bjoern Bauer, Ph.D

ter released when neurons fire during seizures, turns on a signaling pathway that activates cyclooxygenase-2 (COX-2), causing increased synthesis of P-glycoprotein in these experiments. It has yet to be shown in animals or patients that targeting COX-2 will reduce seizure frequency or increase the effectiveness of antiepileptic drugs.

“These findings provide insight into one mechanism that underlies drug resistance in epilepsy and possibly other central nervous system disorders,” said Bjoern Bauer, Ph.D, lead author of the publication. “Targeting blood-brain barrier signals that increase P-glycoprotein expression rather than the transporter itself suggests a

promising way to improve the effectiveness of drugs that are used to treat epilepsy, though

more research is needed before new therapies can be developed.”



Atkins-like Diet Cuts Seizures

U.S. National Library of Medicine,
January, 2008

Adults with epilepsy who have failed other treatments may be able to dramatically reduce their number of seizures by following a modified Atkins-like diet, Johns Hopkins researchers report.

The high-protein, low-carbohydrate diet has already been shown to be valuable in controlling seizures in children, and now results from a small study suggest that the diet also works for adults.

“There are a lot of adults with very bad seizures. There are a lot of adults who have failed medicines and are not candidates for other treatments,” said lead researcher Dr. Eric. H. Kossoff, an assistant professor of neurology and pediatrics at John Hopkins School of Medicine.

For the study, Kossoff’s team gave the diet to 30 adults who had unsuccessfully tried at least two anticonvulsant drugs and had an average of 10 seizures per week. The eating plan restricts patients to 15 grams of carbohydrates per day. Most of the calories come from fats such as eggs, meats, oils and heavy

cream. In addition, patients are free to eat as much protein and noncarb drinks as they want.

“There was good news and bad news,” Kossoff said. “The good news was it worked. The bad news was it was tough. About 30% of the patients stopped the diet. This happened even in patients who had good seizure control who thought the diet was still too tough to follow.”

After a month on the diet, half the patients reported 50% fewer seizures. The diet’s side effects, such as increases in cholesterol or triglycerides, were mild, Kossoff noted.

After six months on the diet, 14 patients continued with it even though the study was over. The findings are published in the February issue of the journal *Epilepsia*.

No one knows how the diet works to reduce seizures, Kossoff said. And, most people find it too hard to follow, so it’s probably not a long-term solution for most people with epilepsy, he added. He also noted that patients who go on the diet need to continue with it, perhaps for

years to keep seizures under control.

Kossoff thinks the diet can be simplified to make it easier to follow. “We are looking at less time in the clinic, fewer restrictions and without a dietician,” he said.

Dr. Gholam Motamedi, Director of Epilepsy Services at Georgetown University Hospital, thinks the diet can be useful for patients who have no other options. “The study is promising, especially given that patients with refractory epilepsy in particular – those who are not surgical candidates – are left without much hope,” he said.

Normally, the plan for these patients is to try a combination of different drugs or to use vagus nerve stimulation, but none of these options offers much hope of seizure control, Motamedi said. “Therefore, having another modality available is always welcomed by neurologists,” he said. “It also encourages basic research looking for insight to the underlying reasons for epilepsy.”

Walgreens Embraces Employees WITH Disabilities

Exceptional Parent, Fall, 2007

Editor's note: Walgreens has long been one of ESNI's most supportive contributors. The Corporation's history with ESNI has enabled us to maintain high quality programs and services to those affected by epilepsy. The following article demonstrates how Walgreens' commitment to people with disabilities makes a difference.

Thank you Walgreens!

Tucked away in the rolling hills of South Carolina, the small town of Anderson, population 25,500, splashed onto

the national scene. All the news coming out of Anderson is good on the disabilities front.

Randy Lewis, senior vice president of Distribution and Logistics, and other officials of Walgreens, were searching for a home for the first in a new generation of Walgreens' distribution centers. Anderson had all the right stuff; it was geographically close to the stores it would service and the town offered a quality work force.

Presently, over 42% of the work force of the Walgreens'

Anderson, South Carolina distribution center is made up of people challenged with disabilities! The company has committed to hiring 1,000 people with disabilities across 12 Walgreens distribution centers.

The Anderson center currently employs 275 employees with disabilities and plans to hire approximately 350 more over the next four years. A similar initiative in Windsor, CT is scheduled for 2009 with the goal of filling at least 1/3 of jobs with people with disabilities.



EPILIFE

Vol. 23, No. 2, Fall, 2007

Published by

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This issue of
EPILIFE
is generously
underwritten by
the Daniel F.
and Ada L. Rice
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Epilepsy can be a difficult road to travel... *...It need not be traveled alone*

Counseling

ESNI offers psychological counseling to all persons whose lives are touched by epilepsy. ESNI clients come to understand that epilepsy is not a disease, but rather a brain disorder. They learn why seizures occur, how medical treatment acts to control them, and to what extent this disorder will affect their lives. **All ESNI counselors are cross-trained in standard counseling techniques and are skilled in addressing the special psychosocial problems associated with epilepsy.**

Support & Discussion Groups

Shared experiences are a great source of strength and encouragement. In peer, parent support and discussion groups led by ESNI counselors, the participants come to understand that the prejudices and other epilepsy-related problems they encounter in everyday life are neither new nor unique to them alone. They learn that, for thousands of years,

these same problems have been experienced by countless others with epilepsy. More importantly, they learn how to cope and successfully resolve them.

Community Education

ESNI provides a full range of informational and educational literature on epilepsy. It is available, without charge, to individuals, school nurses, teachers, libraries, or any interested person.

ESNI maintains pamphlet files on epilepsy at all public libraries in its service area.

Community education programs featuring neurologists speaking on medical aspects of epilepsy are presented to the public without charge at area hospitals. Professional in-services on epilepsy are provided to school staffs, teachers, employers and staff of other human services agencies by skilled ESNI counselors. ESNI serves as an exhibitor at health fairs and similar events.

Vocational Assistance

Persons with epilepsy often encounter unexpected obstacles in the job market. ESNI provides counseling and, when necessary, referral to special community resources such as sheltered workshops, the Department of Rehabilitation Services, the Private Industry Council, etc. Through ongoing support, clients are able to maximize their potential, and achieve realistic employment goals.

Advocacy

ESNI is prepared to vigorously intercede on behalf of clients whenever and wherever needed. This includes employers, HMO organizations, schools, insurance providers, as well as national, state, county and community government agencies.

**Call ESNI at
847-433-8960**

**Visit our Website at
www.esniinfo.org**

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