The Magazine of the Epilepsy Foundation

epilepsyUSA
2011 • ISSUE 2

The 2011 Summer Camp Issue!

Make a Friend at Camp!
Our complete listing of camps for kids with epilepsy

Psychogenic Seizures
When a seizure isn’t caused by epilepsy

Plus: Meet the new leadership at the Epilepsy Foundation!

epilepsyUSA WRITER Wins Excellence in Health Care Journalism Award!

www.epilepsyfoundation.org
I am grateful for the dedication and commitment of all of our affiliates, our national office staff and all the volunteers we have, who are so intent on making sure not another moment is lost to seizures.

I am particularly pleased that the Equal Opportunity Employment Commission (EEOC) is making life easier for workers with disabilities—including epilepsy—by implementing the protections of the Americans with Disabilities Act Amendments Act (ADAAA) [page 4]. Employment for people with disabilities is my main priority and this clarified law will ensure that people with epilepsy will have an easier time getting into and staying in the workforce.

This is a great issue of the magazine and an invaluable resource for parents of kids with epilepsy who want to find summer camps [page 10]. I spend a lot of time talking to kids all over the country and I know every kid wants to fit in and experience life to its fullest. Kids with epilepsy are no different and these wonderful summer camp programs allow them to get away from home, make friends, and experience all the fun and challenging activities camp has to offer. Camp also gives parents much-needed respite from the often demanding rigors of caring for a child with epilepsy—an important consideration.

Also in this issue you will have a chance to meet the Epilepsy Foundation’s new President and CEO, Rich Denness [page 18]. We are very excited to have Rich on board and are confident he is going to lead the Foundation into a new phase of productivity and relevance among all our partnering organizations. He speaks candidly about his plans for the Foundation and also about his interests, his kids, and why working for the Foundation means so much to him. Get to know him!

This is a bittersweet time for me as I prepare to step down as Board Chair of the Foundation in May. It has truly been an honor for me to serve as Chair. I am grateful for the dedication and commitment of all of our affiliates, our national office staff and all the volunteers we have, who are so intent on making sure not another moment is lost to seizures. My good friend Brien Smith, an epileptologist who serves on our Professional Advisory Board, will be in the incoming Chair. Brien also has epilepsy and he has an incredible commitment to our community. I look forward to continuing to work with him to advance our mission.

As the magazine goes to press, we’re just coming off an incredible week of epilepsy in Washington, D.C.! The 5th annual National Walk for Epilepsy, our Public Policy Institute and Kids Speak Up! programs and our elegant annual gala. All the events were awesome! We’ll have details, photos and stories on everything in the next issue of the magazine. Watch for it!

I may be stepping down as Chair, but I will always stand up and fight for people living with epilepsy.

Joyce Bender
ON THE COVER

6 When a Seizure Isn’t Caused by Epilepsy
BY GORDY SLACK  Studies suggest that as many as one third of people with seizures that are not responsive to traditional treatments are actually suffering from psychogenic seizures, not epilepsy.

10 Spotlight on 2011 Summer Camps!
Epilepsy Foundation affiliates across the country are getting ready to welcome campers with epilepsy for an experience of a lifetime.

18 Meet the New Leadership  BY LISA BOYLAN  Get to know the Foundation’s new President and CEO Rich Denness. Find out why he’s committed to helping people with epilepsy, what he brings to the table as a leader and what he sees for the future of the Foundation.

8 / New Study Narrows Epilepsy Drug Suicide Risk
BY MIKE MARTIN  A recent study says the FDA may have overreached when it warned that all antiepileptic drugs can increase the risk of suicidal thoughts and behavior.

20 / Making a Difference
A positive update on Joey’s Song.

www.epilepsyfoundation.org
1-800-332-1000
Follow us on twitter @EpilepsyFdn
Elizabeth was born and raised in Richmond, Va. where she also attended college at the University of Richmond. Since college, she has lived in the Northern Virginia area. As a child, Elizabeth was very active in sports and acquired a passion for politics by her early teens. That passion, along with the ups and downs of epilepsy, has developed into a commitment to improving education about epilepsy and demystifying the beliefs surrounding it. She recently began working at the Epilepsy Foundation national office as part of the group tasked with Project Access.

At 17, 3 weeks before my senior year of high school and 16 years after my first seizure, I underwent a left temporal lobectomy. For several weeks earlier that summer I endured extensive tests to see if I would be a candidate for surgery. When the surgeon told me I was approved for the procedure, I was ecstatic. Whether this was because of my age or the frustration with a multitude of medicines that failed me, I am not sure. At the presurgery conference I was warned that the result could possibly lead to “paralysis, coma, or death,” but I didn’t flinch. In retrospect, my entire educational experience was peppered with long episodes of isolation and embarrassment; to me, surgery was well worth the risk.

The cumulative effect of epilepsy for me has been a gradual loss of self-dignity due to the very public places where I have had seizures and the unprofessional way they were handled. On the other hand, epilepsy has caused me to become very resilient, patient and fiercely independent. I spent so much time around doctors and hospitals; I learned quickly I would be forever frustrated if I didn’t have access to the right care. That sense of urgency made me want to help other people, either with my time, experience or by being a compassionate listener. I have found that opportunity because I now work at the national office of the Epilepsy Foundation. Specifically, I am involved in Project Access, our program that strives to improve access to education resources for youth with epilepsy. The ultimate resource, as we all know, is the nearly 3 million people currently diagnosed with epilepsy who should speak candidly and publicly about epilepsy and its impact.

Over my lifetime, I have been told more times than I can enumerate, by countless numbers of people (family, doctors, teachers, EMTs), “you’ll be fine...this is just one seizure...it will get better...you are strong...this medication will work, give it a chance.” Regardless, when the future appeared to contain only more of the same, I could not fully embrace hope. Yet one of the positives I have gained through all these ups and downs is a sense of patience.

I sincerely believe that patience is a virtue that is tested many times when you live with epilepsy. It takes time to determine if a new medicine will help, or to do all the tests to determine if you are a candidate for the latest treatment. But, most importantly, it takes patience to accept and learn to live with a chronic, incurable disorder. Additionally, I have also learned to put faith in things I cannot see, cannot comprehend and people I have only known briefly. However, as I weigh the balance of potential changes to my life—a life that has so far been medically

continued on page 20
Epilepsy Foundation Applauds EEOC for New Rules Under the ADA

The Epilepsy Foundation applauds the newly issued regulations from the Equal Employment Opportunity Commission (EEOC) for implementing Title I of the Americans with Disabilities Act Amendments Act (ADAAA). Title I protects people with disabilities, like epilepsy, from discrimination in the workplace.

“The Epilepsy Foundation is very pleased with the clear approach to implementing Title I of the Americans with Disabilities Act (ADA) is finally implemented, which is why I worked for the passage of that law originally,” said Tony Coelho, honorary lifetime board member of the Epilepsy Foundation and former U.S. congressman from California, who served as a primary author of the original ADA.

The new regulations have listed several conditions, including epilepsy, which should—almost without exception—be considered disabilities under the ADA.

The clarified law and regulations are designed to eliminate any question of whether a person with epilepsy should be protected from illegal discrimination under the law.

“These regulations are a result of a truly bipartisan effort,” said Sandy Finucane, the Foundation’s Executive Vice President. “The Foundation is very pleased with the clear approach to implementing the definition of disability that the EEOC has taken. We want, as Congress wants, to get and keep people who have epilepsy in the workforce, and the ADA and these regulations will help us do that.”


Study Shows Possible Health Risks of Energy Drinks on Young People with Seizures

Energy drinks may pose a risk for serious adverse health effects in some children, especially those with diabetes, seizures, cardiac abnormalities or mood and behavior disorders. A new study, Health Effects of Energy Drinks on Children, Adolescents, and Young Adults, in the March issue of Pediatrics, the journal of the American Academy of Pediatrics (published online Feb. 14), determined that energy drinks have no therapeutic benefit to children, and both the known and unknown properties of the ingredients, combined with reports of toxicity, may put some children at risk for adverse health events.

Youth account for half of the energy drink market, and according to surveys, 30 percent to 50 percent of adolescents report consuming energy drinks. Typically, energy drinks contain high levels of stimulants such as caffeine, taurine, and guarana, and safe consumption levels have not been established for most adolescents. Because energy drinks are frequently marketed to athletes and at-risk young adults, it is important for pediatric health care providers to screen for heavy use both alone and with alcohol, and to educate families and children at-risk for energy drink overdose, which can result in seizures, stroke and even sudden death.

Source: The American Academy of Pediatrics

“The Epilepsy Foundation concurs with the American Academy of Pediatrics in that we believe that physicians should review the risks of energy drinks with their patients and we encourage further research on the topic.” - Joseph Sirven, M.D., Chair, Elect of the Epilepsy Foundation’s Professional Advisory Board

EpilepsyUSA Journalist Wins Journalism Award for Article on Native Americans and Epilepsy

Journalist Aliyah Baruchin won a prestigious Award for Excellence in Health Care Journalism for an article that ran in epilepsyUSA. The article, Closing the Distance: Native Americans and Epilepsy was one in a series of four articles on minorities with epilepsy and access to care broke ground in health care journalism and casts a light on a deserving and underreported subject.

Lisa Boylan said, “Aliyah Baruchin never forgets the human aspect of the topics she covers. Her award-winning series on minorities with epilepsy and access to care broke ground in health care journalism and casts a light on a deserving and underreported subject.”

continued on page 5
**In Brief**

**Continued from page 4**

>> FDA WARNS OF INCREASED RISK OF ORAL BIRTH DEFECTS IN CHILDREN BORN TO MOTHERS TAKING TOPIRAMATE

New data suggest that the drug Topamax (topiramate) and its generic versions increase the risk for the birth defects cleft lip and cleft palate in babies born to women who use the medication during pregnancy, the U.S. Food and Drug Administration said today.

Before prescribing topiramate, approved to treat certain types of seizures in people who have epilepsy, health care professionals should warn patients of childbearing age about the potential harm to the fetus if a woman becomes pregnant while using the drug. Topiramate also is approved to prevent migraine headaches, but not to relieve the pain of migraines.

“Health care professionals should carefully consider the benefits and risks of topiramate when prescribing it to women of childbearing age,” said Russell Katz, M.D., director of the Division of Neurology Products in the FDA's Center for Drug Evaluation and Research. “Alternative medications that have a lower risk of birth defects should be considered.”

Cleft lip and cleft palate, collectively called oral clefts, are birth defects that occur when parts of the lip or palate do not completely fuse together early in the first trimester of pregnancy, a time when many women do not know they are pregnant. The defects range from a small notch in the lip to a groove that runs into the roof of the mouth and nose, possibly leading to problems with eating, talking, and to ear infections. Surgery often is performed to close the lip and palate and most children do well after treatment.

Data from the North American Antiepileptic Drug (AED) Pregnancy Registry indicate an increased risk of oral clefts in infants exposed to topiramate during the first trimester of pregnancy. Infants exposed to topiramate as a single therapy experienced a 1.4 percent prevalence of oral clefts, compared with a prevalence of 0.38 percent – 0.55 percent in infants exposed to other antiepileptic drugs.

Infants of mothers who did not have epilepsy and were not being treated with other antiepileptic drugs had a prevalence of 0.07 percent. Similar data from the United Kingdom Epilepsy and Pregnancy Register supported the North American AED Pregnancy Registry data.

Based on the data, topiramate will have a stronger warning in its prescribing information (labeling). The pregnancy category will be changed to Pregnancy Category D. This means that there is positive evidence of human fetal risk based on human data, but the potential benefits of the drug in pregnant women may outweigh the risks in certain situations. The FDA previously designated the drug as Pregnancy Category C because of the lack of human data.

**HEALTH CARE DISPARITIES SEEN IN EPILEPSY PATIENTS WITH LOW SOCIOECONOMIC STATUS**

More uncontrolled seizures and drug-related side effects found in this patient group

A newly-published report reveals patients with epilepsy and low socioeconomic status (SES) are more likely to have uncontrolled seizures, drug-related side effects, and a lower overall quality of life. The study also indicates that low SES patients used the hospital emergency room more often and had more visits to a general practitioner than epileptic patients at higher socioeconomic levels. Full findings are now available in the journal Epilepsia.

The Centers for Disease Control and Prevention (CDC) estimates that two million Americans have epilepsy and roughly 140,000 new cases are diagnosed each year. Prior studies in epilepsy literature provide evidence of disparities in health care use between individuals of different SES. One study found that patients who have epilepsy with incomes below the poverty level in California were 50 percent less likely than those with higher income (not in poverty) to report taking epilepsy medication.

“Current medical evidence is based on point-in-time comparisons across population and suggests that disparities in health care may be due to access difficulties,” explains lead study author Dr. Charles E. Begley, Professor of Management & Health Sciences at the University of Texas Health Science Center in Houston. “Our study investigates disparities in health care over time, examining the impact of SES in patients with epilepsy who have access to regular care.”

Researchers enrolled 566 adult patients with epilepsy from three clinics in Houston and New York City serving a low-SES population, and one in Houston serving high-SES patients. Participants were interviewed at baseline regarding health care use, seizure frequency and type, antiepileptic drug (AED) side effects and outcomes during the prior three-month and one-year periods. The survey was repeated several times during the year-long study period.

Indicators of SES include income, education, employment and insurance. Patients at the low-SES sites had consistently higher emergency room use and visits to the general practitioner. Throughout the one-year study period low-SES patients had significantly higher likelihoods of poor outcomes—2.2 to 3.9 times more likely to have uncontrolled seizures and 4.9 to 16.3 times more likely to have AED side effects—compared with higher-SES patients.

The authors determined that significant disparities in patterns of care and outcomes of low and high-SES patients receiving regular care for epilepsy were persistent over the one-year study period. “Future research needs to examine specific site-related factors that may be associated with these disparities in care for individuals with epilepsy,” concluded Dr. Begley.
Danielle began having seizures 6 years ago when she was 24 years old. Her doctors prescribed one antiseizure medication after another. None helped, though, and her condition worsened. She lost the veterinary technician job she loved and she had to stop horseback riding, the focus of her social and active life and her biggest source of happiness. She became depressed and exhausted. Her doctors were flummoxed.

After 2 years of ineffective treatments, Danielle was referred to an epileptologist at Brigham and Women’s Hospital in Massachusetts who hooked her up to an EEG and turned on a blinking strobe light. To Danielle’s surprise, the seizure-inducing technique worked and she began to seize. An even bigger surprise came in her post-EEG meeting with the neurologist. While her seizures were real, the doctor said, they were not caused by malfunctions in her brain. In fact, they were not epileptic seizures at all. “Their roots were,” the doctor said, "psychological or emotional stress into physical symptoms."

Their problems are not neurological. They come to us because they look like they are having seizures. But really they are suffering from what is called ‘conversion disorder,’ or the transformation of psychological or emotional stress into physical symptoms.

SELIM BENBADIS
DIRECTOR, COMPREHENSIVE EPILEPSY PROGRAM
AT THE UNIVERSITY OF SOUTH FLORIDA AND TAMPA GENERAL HOSPITAL

continued on page 7
"psychological. They were the unconscious mind's way of processing stress." The epileptologist referred Danielle to Curt LaFrance, a renowned specialist in psychogenic non-epileptic seizures, also known as PNES.

"Non-epileptic seizures are under-studied and under-treated. They are common, but are also commonly misdiagnosed, like Danielle's," says LaFrance, who is both a psychiatrist and neurologist, and so especially attuned to PNES patients, who often slip between the cracks separating the two specialties.

Neurologists don't know how to treat these patients, says Selim Benbadis, a neurologist and the Director of the Comprehensive Epilepsy Program at the University of South Florida and Tampa General Hospital. "Their problems are not neurological. They come to us because they look like they are having seizures," he says. "But really they are suffering from what is called 'conversion disorder,' or the transformation of psychological or emotional stress into physical symptoms."

Physical or sexual abuse is often at the root of PNES. But not always. Other kinds of trauma can cause PNES, too. Psychogenic non-epileptic seizures are surprisingly common among combat veterans, says Karen Parko, a neurologist and Director of the San Francisco VA Epilepsy Center of Excellence. Like Benbadis, Parko also sees patients who have not responded well to other treatments, so they are not representative of epilepsy patients at large. Nonetheless, it is very impressive, she says, that "many of the patients who come to me thinking they have refractory epilepsy actually have PNES."

"It's just my opinion, but I think that [PNES] is a more acceptable form of post traumatic stress disorder," says Parko. "A lot of these vets have seen trauma and experienced horrifying things, and their form of PTSD doesn't resemble the PTSD I am used to seeing in the Vietnam vets. They aren't jumpy, or distrustful, or angry. They have this very somaticized expression of PTSD: seizures."

"If we properly diagnose PNES patients, we neurologists refer to psychiatrists," says Benbadis. "But psychiatrists often don't know what to do with them...they aren't typically responsive to drugs, they can take up a lot of time...can be very difficult to treat, so psychiatrists often send them back to us."

PNES is shockingly common. Studies suggest that as many as one third of the patients with intractable seizures (seizures not responsive to traditional treatments) are actually suffering from PNES, not epilepsy. "PNES is as common in the U.S. as multiple sclerosis or Parkinson's disease," says LaFrance, "but most of it is never properly diagnosed. And when it is diagnosed, it is typically after 7 or 8 years of treatment for epilepsy."

One very common scenario, says Benbadis, is that when first diagnosing a patient a neurologist "over-reads a normal EEG as indicating seizures." Because there is no mandatory training in EEG analysis during neurology training, the level of "EEG reading in the [neurology] community is pathetic," he says. And once a patient is classified as having both seizures and an epileptiform EEG, it is very hard to get the diagnosis changed.

"Without a definitive diagnosis, a patient may suffer for years from the side-effects of unhelpful drugs and the uncertainty, frustration and depression that can result from persistent and unresponsive seizures."
The Food and Drug Administration (FDA) vastly over-reached when in 2008 it warned that all antiepilepsy drugs (AEDs) increase the risk of suicidal thoughts or behavior, says a new study published in the journal Neurology.

The study found that only certain drugs—levetiracetam, topiramate and vigabatrin among them—increase the risk. Other drugs such as lamotrigine, gabapentin, carbamazepine, valproate and phenytoin had either a low risk or no risk of suicidal ideation.

The findings don’t surprise Loyola University Chicago Health System neurologist Jorge Ascanapé, M.D., an expert on antiepilepsy drugs. What did surprise Ascanapé was “that FDA had put such a broad, class-action label on each and every drug. Their study was inadequate to say conclusively which drugs should be so labeled, and their warnings created a lot of unnecessary anxiety. Parents with children who had benign forms of epilepsy were suddenly worried about suicide.”

In the FDA’s AED warnings—and the Neurology study’s contradictory results—Eric Braverman, M.D., a clinical assistant professor of Integrative Medicine in Neurological Surgery at New York Presbyterian Hospital/Weill-Cornell Medical Center in New York City, sees history repeating.

“Antidepressant and antipsychotic medications were given the same black-box warning—risk for suicidal behavior,” Braverman said. “But later studies showed there wasn’t an increase in suicide risk after all.”

Seizures and suicide

After analyzing some 200 studies of 11 AEDs, the FDA concluded that, compared to placebos, antiseizure drugs nearly doubled the risk of suicidal behavior.

But the analysis was flawed because FDA grouped all the drugs together, explained Neurology study co-author Frank Andersohn, M.D., of Charité University Medical Center in Berlin, Germany. “It did not address the question of whether there were differences among the various classes of epilepsy drugs,” he said.

Armed with data from the United Kingdom General Practice Research Database, Andersohn and colleagues René Schade, M.D., Stefan N. Willich, M.P.H., and Edeltraut Garbe, Ph.D. looked at 44,300 patients with epilepsy who had at least one prescription for an AED from 1989 through 2005.

They classified antiepilepsy drugs into four categories: barbiturates; conventional AEDs; newer AEDs with low potential of causing depression; and newer AEDs with high potential of causing depression.

Based on reported drug usage, suicide attempts, and successful suicides, Andersohn and colleagues concluded that only newer AEDs with a high potential of causing depression were associated with an increased risk—3-fold—continued on page 9
of self-harm or suicidal behavior.

The most commonly-used AEDs—barbiturates, conventional AEDs and low-risk newer AEDs—showed no increased suicide risk.

Weighing the risks

Epileptologists say they are pleased Andersohn and colleagues narrowed the scope of potentially problematic drugs. But the study’s findings are troublesome nonetheless.

“This new study is interesting because it does not blacklist an entire class of drugs,” said Jefferson Medical College neurology professor Michael Sperling, M.D., who directs the Jefferson Comprehensive Epilepsy Center in Philadelphia. “That said, it still poses problems because some of the drugs classified as ‘high-risk’ are commonly used.”

Those “high-risk” drugs are safe for most patients, Sperling explained.

Based on varying degrees of risk, Eric Braverman said he is reluctant to do away with any effective antiepilepsy drug. Balancing the short-term risk of “self harm behavior” with the long-term risk of seizure and mood destabilization is a critical component of AED therapy, he said.

Seizure risk versus suicide risk addresses a “critical fact” FDA neglected, Sperling said. “The risk of not taking antiepileptic medications nearly always outweighs the risk of taking those medications.”

FDA blunders?

Just as all AEDs are not the same, neither are all forms of epilepsy or all patients, more reasons the FDA recommendation may have been too broad.

“The risk of increased suicidal behavior among epilepsy patients on AEDs has been known to neurologists for decades,” Asconapé explained. “But the risk is much more patient-specific than the FDA warning suggested. It’s also relatively miniscule—maybe 1 in 1,000.”

In fact, the FDA study lacked specificity on several fronts. The patients it included “were not representative enough of the population who take these drugs,” said Michael Sperling. “Less than 10 percent of people with epilepsy would even qualify for inclusion in an FDA analysis of this type.”

Lumping the term “suicide,” with “self harm” is also problematic, Braverman noted. “Self harm behavior is much different than suicide risk,” he said. “It is more like a cry for help,” and can occur “when there is no suicidal intent.”

But even correcting for FDA’s flawed definitions and wide-reaching conclusions, “we will probably never be able to properly understand whether or to what extent these drugs truly cause suicidal behavior,” Sperling explained. “Therefore, it remains critical that physicians and other health care providers proactively discuss potential alterations in mood and the possibility of depression with patients and their families.”

Seizure risk versus suicide risk addresses a “critical fact” FDA neglected. The risk of not taking antiepileptic medications nearly always outweighs the risk of taking those medications.

MICHAEL SPERLING, M.D.
NEUROLOGY PROFESSOR, JEFFERSON MEDICAL COLLEGE; DIRECTOR, JEFFERSON COMPREHENSIVE EPILEPSY CENTER

The risk of increased suicidal behavior among epilepsy patients on AEDs has been known to neurologists for decades. But the risk is much more patient-specific than the FDA warning suggested. It’s also relatively miniscule—maybe 1 in 1,000.

JORGE ASCONAPÉ, M.D.
NEUROLOGIST, LOYOLA UNIVERSITY CHICAGO HEALTH SYSTEM
Spotlight on 2011 Summer Camps

ALABAMA
Epilepsy Foundation of Alabama
Camp Evoked Potential @ Camp ASCCA
July 3–8
Opened in 1976, Camp ASCCA, located on Lake Martin off Highway 280 between Dadeville and Alexander City, is the world’s largest year-round, barrier free camp for people with disabilities. Camp Evoked Potential @ Camp ASCCA is designed to be accessible and adapted to campers’ individual needs and abilities, all in a safe, medically monitored setting. The cost is $695. Scholarships are available for qualified individuals, based on availability and financial need. Contact David Toenes at 800-626-1582, or dtoenes@efala.org.

ALASKA
Epilepsy Foundation Northwest
Camp Discovery
August 21–24
(See Washington listing on page 16)

ARIZONA
Epilepsy Foundation of Arizona
Camp Candlelight
June 5–10
Camp Candlelight is a week-long sleep-over camp featuring summer activities such as: arts and crafts, archery, horseback riding, rock climbing, zip line, low and high ropes, campfires and hiking. This program allows campers the opportunity to participate in outdoor activities while developing a sense of self-worth, independence and personal responsibility. To be eligible, the camper must have a primary diagnosis of epilepsy and be between the ages of 8–15. The fee is $375 ($350 if completed application is received by April 1st). To ensure no child is turned away for financial hardships, camp scholarships are available based upon need. Visit www.epilepsyfoundation.org/arizona to download an application or contact Kate Burns at 602-406-3581 or efaz@chw.edu.

CALIFORNIA
Epilepsy Foundation of Northern California, Epilepsy Foundation of Greater Los Angeles and Epilepsy Foundation of San Diego County
Camp Coelho
August 7–12
The three Epilepsy Foundation affiliates of California are proud to announce that we will be joining together to have one amazing camp this year! Camp Coelho is a 5-night, 6-day adventure held in the Yosemite Valley for children, ages 9–15, with a primary diagnosis of epilepsy. The camp is staffed by doctors, nurses and Epilepsy Foundation staff and volunteers. Activities include arts and crafts, horseback riding, swimming, archery, ropes course, climbing wall and more. Camp Coelho gives children the opportunity to learn more about epilepsy and develop self-confidence and independence in a safe environment. The cost is $750 and a limited number of full and partial scholarships are available. For more information, please contact the camp representative in your region:

For Northern California, contact John Haupert at 925-224-7760, or johnh@epilepsynorcal.org or visit our Web site at www.epilepsynorcal.org.
For Greater Los Angeles, contact Patricia Leyva at 800-564-0445, or pleyva@epilepsyFoundationGla.org.
For San Diego, call 619-296-0162, or write info@epilepsysandiego.org.

Epilepsy Foundation of San Diego County
Camp Quest
July 17–22
Camp Quest is held in partnership with the YMCA of San Diego County’s Camp Marston. Children with epilepsy ages 8–12 are integrated into the regular YMCA camping program with other campers, staying in cabins with children their own age and doing all the camping activities provided, such as hiking, sports, swimming, boating, crafts, drama, and campfires. Camp Marston is located in the high mountain district of Julian, Calif., in an area of pines and oaks with miles of hiking trails. Facilities include a swimming pool, lake Jessop, soccer and volleyball fields, basketball court, archery and air-rifle ranges, an outdoor crafts area and rock climbing tower. EFSDC provides a registered nurse and volunteers whose responsibility is to provide medical oversight and support to our campers with epilepsy. The only cost to families is the $25 registration fee, all camp fees are paid by EFSDC. Financial aid is available for those that cannot afford the registration fee. For more information please contact Heal Vigderson at 619-296-0161, or info@epilepsysandiego.org.

Contd...
**COLORADO**

**Epilepsy Foundation of Colorado**

**Jason Fleishman Summer Camp**

**June 19–23**

The Jason Fleishman Summer Camp is located at the YMCA of the Rockies in beautiful Estes Park, Colo. It is a 5-day overnight camp for youth ages 10–17 living with epilepsy. The camp provides an opportunity for youth to participate in fun and exciting activities like rock climbing, zip line, horseback riding, arts and crafts and more. We provide a safe, medically monitored setting. The cost is $300. Scholarships are available. Contact Marcee Peterson at 303-377-9774 or toll-free at 888-378-9779, or marcee@epilepsycolorado.org. Or register online at www.epilepsycolorado.org.

**CONNECTICUT**

**Epilepsy Foundation of Connecticut**

**Camp Courage**

**July 24–29**

Camp Courage is held at Easter Seals Camp Hemlocks in Hebron, Conn., for kids and teens ages 8–18. Just 25 miles east of Hartford, the camp is surrounded by 160 acres of unspoiled woodland and includes a dining hall, health center, auditorium, indoor heated pool, greenhouse, cabins, an arts and crafts center and much more. Campers enjoy the same activities as all campers do, including swimming, drama, sports and many other exciting activities. The cost is $270 with a $25 non-refundable application fee. Contact Allison Gamber at 800-899-3745, or agamber.efct@sbcglobal.net.

**GEORGIA**

**Epilepsy Foundation of Georgia**

**Camp Big Heart**

**Session I: June 12–17**

**Session II: June 19–24**

Camp Big Heart is located in Winder, Ga. within Ft. Yargo State Park. The camp is a partnership between the Epilepsy Foundation of Georgia, Camp Twin Lakes and the Civitan Clubs of Georgia. The camp accepts children and adults with epilepsy, but they must also have a diagnosis of a developmental disability. Two sessions are held: Session I is for children ages 7–25 and Session II is for adults, ages 26 or older. The camp will offer traditional camp activities, with the safety net of full-time medical staff, low camper to counselor ratios and counselors trained in seizure recognition and first aid. All camp applications, medical forms, etc. are available online at www.epilepsyga.org. Contact Lloyd Brown at 800-527-7105, or lloyd@epilepsyga.org.

**ILLINOIS**

**Epilepsy Foundation of Greater Chicago**

**Camp Blackhawk**

**July 17–22**

The Epilepsy Foundation of Greater Chicago's popular camp for kids ages 6–18 returns. Camp Blackhawk, which is conducted at Red Leaf Village located on the grounds of Camp Henry Horner in Ingleside, Ill., is a week-long overnight camp for children and teenagers with epilepsy. It's a great opportunity for kids to experience the fun of camp activities—swimming, fishing, hiking, crafts, and more—all designed to be accessible and adapted to individual needs and abilities, and all in a safe, medically-monitored setting. Camp Blackhawk is offered free of charge, however donations are accepted and welcomed. Priority acceptance will be given to children residing within the Epilepsy Foundation of Greater Chicago's 43-county service area. See a complete county listing and download camp applications at www.epilepsychicago.org. For more information, contact Meredith Taylor at 800-273-6027 ext. 202 or mtaylor@epilepsychicago.org.

**Epilepsy Foundation of Greater Southern Illinois**

**Camp Roehr (Ruling Over Epilepsy Helps Realize Dreams)**

**June 12–18**

Camp Roehr 2011, located at Pere Marquette State Park in Grafton, Ill., is a weeklong overnight camp for children and teenagers, ages 6–17, with epilepsy. It's a great opportunity for children to make new friends and have a great time in a safe, supportive environment. Camp activities include swimming, balloon art, a build-n-fly event, sports, hiking, wildlife exploration, entertainment and much more.
more. We do everything at Camp Roehr that other camps do! We just do it with more supervision and medical support personnel. The cost is $500. Scholarships are available for qualified individuals, based on availability and financial need. For more information, please go to our website at www.efgreaterils.org or contact Trudy Baxter at 618-236-2181 ext. 104 or trudyepilepsy@sbcglobal.net.

INDIANA
Epilepsy Foundation of Greater Southern Illinois
Camp Roehr
June 12–18
(See Illinois listing on page 11)

Epilepsy Foundation of Greater Cincinnati
Camp Flame Catcher
June 19–24, September 30–October 2
(See Ohio listing on page 14)

Epilepsy Foundation of Kentucky
Center for Courageous Kids
July 19–24
(See Kentucky listing on this page)

IDAHO
Epilepsy Foundation of Idaho
Camp Spirit-Family Camp
July 29–31
Camp Spirit is located in McCall, Idaho and is a 2-day, 2-night camp offering families an opportunity to meet each other and get away from everyday stressors. Whether you are a parent or child with epilepsy, the whole family is invited. The facilities are camper-friendly with dorm-style living and planned meals. Families will have opportunities to enjoy lake activities, arts and crafts, sports, hiking and much more. The camper with epilepsy will receive a camp T-shirt, water bottle and backpack. Please call Diane Foote at the Epilepsy Foundation of Idaho for more information at 208-344-4340, or dfoote@epilepsyidaho.org.

KENTUCKY
Epilepsy Foundation of Kentucky
Center for Courageous Kids
July 19–24
The Center for Courageous Kids, located in Scottsville, Ky., is a world-class overnight medical camp for children ages 7–15 with epilepsy and other chronic conditions. Our campus, situated on 168 acres, includes our medical center, equestrian center, bowling alley, indoor swimming complex, gymnasium, climbing wall and so much more! The camp is free for campers whose applications are approved. For an application or additional information, visit www.courageouskids.org, or call Judy Snoody at 270-618-2900.

Epilepsy Foundation of Greater Southern Illinois
Camp Roehr
June 12–18
(See Illinois listing on page 11)

Epilepsy Foundation of Greater Cincinnati
Camp Flame Catcher
June 19–24, September 30–October 2
(See Ohio listing on page 14)

LOUISIANA
Epilepsy Foundation of Louisiana
Camp Shining Stars (hosted by MedCamps of Louisiana, Inc.)
July 24–29
Camp Shining Stars is designed specifically for children ages 6–16 living with epilepsy and seizure disorders. Hosted by MedCamps of Louisiana, Camp Shining Stars is held at Camp Alabama located in the rolling hills of North Louisiana just east of Ruston, La. This is a weeklong overnight summer camping experience that allows children with epilepsy to participate in various activities including swimming, hiking, arts and crafts, games, etc. Camp Shining Stars is free of charge for campers. Contact Caleb Seney at info@medcamps.com, or 877-282-0802.

MAINE
Epilepsy Foundation of Massachusetts, Rhode Island, New Hampshire & Maine
Camp Wee Kan Tu
August 9–13
(See Massachusetts listing on page 13)

MARYLAND
Epilepsy Foundation Chesapeake Region
Camp Great Rock
July 17–23
The Epilepsy Foundation Chesapeake Region refers people to Camp Great Rock in Harrisonburg, Va. The camp is run by Brainy Camps, a subsidiary of the Children’s National Medical Center. Camp Great Rock is a weeklong overnight camp for children and teens with epilepsy, ages 7–16. For 16 years, it has provided campers with epilepsy a safe environment where they can have fun while building confidence, independence, and self-esteem. For more information, visit www.brainycamps.com.

Continued on page 13
Massachusetts
Epilepsy Foundation of Massachusetts, Rhode Island, New Hampshire & Maine
Camp Wee Kan Tu
August 9–13
Camp Wee Kan Tu has a new home at the Frank A. Day Camp in East Brookfield, Mass. The camp offers children and teenagers 8–17 with epilepsy an overnight program full of traditional camp fun and adventure, while providing them with the personal and medical supervision that gives parents peace of mind. The camp experience strives to enhance a child’s self-esteem, confidence and independence by encouraging social relationships, respect, understanding, and a sense of community. The medical staff is comprised of volunteers from Harvard teaching hospitals in and around the Boston and central Massachusetts area and Dartmouth Hitchcock Medical Center. The counselors provide close supervision of all campers and are well trained. The cost is $425. Scholarships are available for qualified individuals based on availability and financial need. Contact Susan Welby at swelby@efmarinhme.org.

Michigan
Epilepsy Foundation of Michigan
Camp Discovery
June 26–30
Camp Discovery has proven to be a life-changing event for campers and volunteers alike. Youth ages 8-17 with epilepsy spend 5 days and 4 nights enjoying all the activities that camp has to offer, including rock wall climbing, canoeing, horseback riding, swimming in a lake and an Olympic-sized swimming pool, arts and crafts, forming life-long friendships and much more. For more information call 800-377-6226, or visit www.epilepsymichigan.org/campdiscovery.

Minnesota
Epilepsy Foundation of Minnesota
Camp Oz
June 19–24
Camp Oz is located at YMCA Camp St. Croix in Hudson, Wisc. We offer a week-long overnight camp for youth and teens, ages 9–17, whose primary condition is epilepsy. It’s a great opportunity for youth to experience a safe yet fun camping experience that includes swimming, horseback riding, campfires, games, sports, nature and meeting new friends. Our camping program is equipped with a full onsite medical staff and volunteers. The cost is $200 for residential camp. Financial assistance is available. Contact Nikki Baker at 800-779-0777 ext. 2308, or nbaker@efmn.org.

Mississippi
Epilepsy Foundation of Mississippi
Alvin P. Flannes Summer Camp
June 7–11
Alvin P. Flannes Summer Camp, located at Camp Wesley Pines, Gallman, Miss., is a weeklong overnight camp for children and teenagers, ages 8–16, with epilepsy. It’s a great opportunity for kids to experience the fun of camp activities—swimming, canoeing, horseback riding, crafts and more—all designed to be accessible and adapted to campers’ individual needs and abilities, all in a safe, medically monitored setting. The camp is free for children in Mississippi. Contact Tres Townsend at 601-936-5222, or tresmsepilepsy@bellsouth.net.

Missouri
Epilepsy Foundation of Missouri and Kansas
Camp Shing
June 3–5
Camp Shing, located at the Tall Oaks Conference Center in Linwood, Kan., is a weekend camp for children and teens with epilepsy, ages 6–17. Parents are encouraged to accompany their children. Children and parents participate in swimming, archery, sand volleyball, horseback riding, crafts, astronomy and a variety of games. Time is set aside for parent education while the children are participating in camp activities. Evening entertainment may include a magician, karaoke, songs around a campfire and watching zoo animals. The cost is $150 for the first camper and $75 for each additional family member. Contact Danielle Walk at 816-444-2800, or dwalk@efha.org.

Montana
Epilepsy Foundation Northwest
Camp Discovery
August 21–24
(See Washington listing on page 16)

New Hampshire
Epilepsy Foundation of Massachusetts, Rhode Island, New Hampshire & Maine
Camp Wee Kan Tu
August 9–13
(See Massachusetts listing on this page)

New Jersey
Epilepsy Foundation of New Jersey
Camp Nova
August 14–20
Camp NOVA is a wonderful opportunity for children and young adults living with epilepsy and other developmental disabilities to enjoy summer camp. Camp NOVA, which provides an exciting and independent camping experience in an environment filled with fun experiences and memories that last a lifetime, is a one-week overnight camp for young people ages 12–28.
Camp activities include acting, arts and crafts, boating, fishing, karate, swimming and yoga. The cost is $962.50 (3:1 and 2:1 ratio) or $1,182.50 (1:1 ratio) plus a $50 non-refundable application fee. Contact Liza Gundell at 800-336-5843, or lgefnj@aol.com.

**NEW MEXICO**
Epilepsy Foundation of Colorado
**Jason Fleishman Summer Camp**
June 19–23
(See Colorado listing on page 11)

**NEW YORK**
Epilepsy Foundation of Rochester-Syracuse-Binghamton
**Camp EAGR**
August 14–20
Celebrating 20 years of helping kids with epilepsy be just kids, Camp EAGR is the Epilepsy Foundation of Rochester-Syracuse-Binghamton's weeklong overnight camp for children and teenagers, ages 8–17, with epilepsy. It is located at the YMCA's Camp Weona, just outside of Warsaw, N.Y. It's a great opportunity for children to participate in activities such as swimming, horseback riding, canoeing and arts and crafts. Along with approximately 30 qualified counselors, Camp EAGR also has a neurologist and 2–3 registered nurses who remain at camp the entire week. The cost is $400 and financial aid is available for those in need. Contact Mike Radell at 800-724-7930 or 585-442-4430 ext. 2702, or mradell@epilepsy-uny.org.

**Epilepsy Foundation of Northeastern New York**
Camp scholarships (up to $250 to camp of choice) are available for children with epilepsy ages 5–18 who reside in one of the 22 counties of New York served by this affiliate. Scholarships for qualified individuals are based on availability and financial need. Contact Deborah Bain at 518-456-7501, or dbain@epilepsyneny.com.

**Epilepsy Foundation of Massachusetts, Rhode Island, New Hampshire & Maine**
**Camp Wee Kan Tu**
August 9–13
(See Massachusetts listing on page 13)

**NORTHERN CAROLINA**
Epilepsy Foundation of North Carolina
**Victory Junction Gang Camp**
July 5–8
Victory Junction is a year-round camping environment for children, ages 6–16, with chronic medical conditions or serious illnesses. Founded by Kyle and Pattie Petty in honor of their son, Adam, the camp is located in Randleman, N.C., and offers programs for 24 disease groups and maintains strong relationships with 30 partner hospitals. Victory Junction's mission is to provide life-changing camping experiences that are exciting, fun and empowering, in a safe and medically-sound environment. As a not-for-profit organization, the camp operates solely through the support of generous donors to provide this experience at no charge to children and their families. For more information, visit www.victoryjunction.org, or call 877-854-2267 or 336-498-9055.

**Camp Carefree**
**Epilepsy week: June 26–July 2**
**Siblings week: June 19–25 (for well siblings who live with a chronically ill child)**
Camp Carefree provides a free one week camp experience for youngsters with specific health problems and disabilities from North Carolina and neighboring states. The program also includes camps for well siblings of chronically ill or disabled children and a week for those with a seriously disabled parent. Contact Ann Jones at 336-427-6099, or visit www.campcarefree.org.

**NORTH DAKOTA**
Epilepsy Foundation of Minnesota
**Camp Oz**
June 19–24
(See Minnesota listing on page 13)

**OHIO**
Epilepsy Foundation of Greater Cincinnati
**Camp Flame Catcher**
June 19–24, September 30–October 2
Camp Flame Catcher offers both weekend and weeklong opportunities for kids with seizures. While at camp the kids get to meet others who share a similar diagnosis, while also learning about epilepsy and having fun in the outdoors. Campers swim daily, hike, play games, horseback ride, canoe and much more. Memories and friendships are made to last a lifetime! The cost is $125 for a weekend and $350 for a week. Financial assistance is available. For more information on registrations or scholarships contact Mark Findley at 877-804-2241, or mark.findley@cincinnatiepilepsy.org.

**Epilepsy Foundation of Central Ohio**
**Camp Firebird**
July 11–15
Camp Firebird, located at Recreation Unlimited in Ashley, Ohio is a weeklong overnight camp for children and teenagers ages 7–17, with a diagnosis of epilepsy. It is a wonderful opportunity for campers to experience the fun of camp activities such as crafts, swimming, boating, hiking, indoor/outdoor sports, along with learning about their epilepsy. All activities and experiences are designed to be accessible and adapted to campers’ individual needs and abilities in a safe, medically monitored setting. The camp costs $100 for individuals in our service area and $225 for individuals outside the service area. There is a $35 nonrefundable application fee. Please contact Karen Brown at 614-315-0572 or kbrown@epilepsy-ohio.org.

**Camp for Champs**
July 25, August 1, 8 and 15
Camp for Champs is a day program for children ages 4–12, that offers a world of horses and green fields on the Rail Fence Farm located near Centerburg in Knox County, Ohio. Here, campers not only participate in hippotherapy (occupational therapy on horseback), but are given the opportunity to take part in many crafts, water play, fishing and other farm related activities. An occupational therapist and certified equine instructor provide for a safe and confidence-building atmosphere with a three staff to one camper ratio. The cost is $50 and financial aid is available. Parental transportation is required to and from camp. Contact Carol Johnson at 614-315-0437, or cjohnson@epilepsy-ohio.org.

Continued on page 15
SCHOLARSHIPS AVAILABLE

Epilepsy Foundation of Pennsylvania

Scholarships are available for qualified individuals, based on availability and financial need. Contact Gretchen Knaub at 800-336-0301 or gknaub@efwp.org.

Camp Achieve at Camp Green Lane

August 21–26

Camp Achieve at Camp Green Lane, Green Lane, Pa., is a 6-day overnight camp for children, ages 8-12 and teens 13-17, with a primary diagnosis of epilepsy/seizure disorder. Camp Achieve provides a unique opportunity for campers to meet others who are living with similar challenges. Camp activities are designed to increase self-esteem, independence, enhance personal growth, build friendships and create unforgettable memories. A fun, secure, safe and healthy environment is ensured by our medical professionals, trained volunteers, staff and Camp Green Lane counselors. Pennsylvania residents have priority; other states are given consideration depending upon availability. The cost is $300 and there is a $25 non-refundable application fee. Scholarships are available for qualified individuals. Contact Jean Gardyne, at 215-629-5003 ext. 110 or contact Jean Gardyne, at 215-629-5003 ext. 110 or 800-887-7165 ext. 110, or contact Jean Gardyne, at 215-629-5003 ext. 110 or contact Jean Gardyne, at 215-629-5003 ext. 110, or 800-887-7165 ext. 110, or camp@efepa.org.

Epilepsy Foundation

Western/Central Pennsylvania

Camp Frog

June 19–25, at Camp Conrad Weiser

Camp Frog, located in Spring Hill, Pa., is a weeklong residential program that places extra support and medical services into existing YMCA summer camp programs, allowing children who have a primary diagnosis of epilepsy to enjoy summer camp just like their peers. It is offered at two different locations: Camp Fitch in North Springfield, Pa., and Camp Conrad Weiser in Wernersville, Pa. Both camps offer a wide range of activities for children and teens ages 8-17, including archery, horseback riding, climbing towers, arts and crafts, fishing, outdoor games, swimming and camp fires. A pediatric neurologist and nurse, along with trained counselors, are onsite during the entire week of camp. The cost is $470–$685. Financial assistance is available through the Steve “Froggy” Morris/G. Peter Rockwell Endowment Fund. Contact Gretchen Knaub at 800-336-0301 or gknaub@efwp.org.

PUERTO RICO

Sociedad Puertorriqueña de Epilepsia

Bayamón, Puerto Rico

June 6–10

The Sociedad Puertorriqueña de Epilepsia is a popular camp for kids, ages 5–16. Kids have the opportunity to share learning experiences and integrated recreational activities. Among the activities are tours, educational and motivational talks, sports and recreational activities. It’s a great opportunity for children to make new friends and have a great time in a safe, supportive environment. The Puerto Rican Society for Epilepsy is a private, nonprofit founded in 1963. It has come to offer free medical, psychosocial and educational services to people diagnosed with epilepsy across the island. For more information please contact Alex Ramirez at info@sociedadepilepsiapr.org, 787-782-6200, or visit our Web site at www.sociedadepilepsiapr.org.

RHODE ISLAND

Epilepsy Foundation of Massachusetts, Rhode Island, New Hampshire & Maine

Camp Wee Kan Tu

August 9–13

(See Massachusetts listing on page 13)

SOUTH CAROLINA

Epilepsy Foundation of North Carolina

Victory Junction

July 5–8

(See North Carolina listing on page 14)

TENNESSEE

Epilepsy Foundation of East Tennessee

Camp Discovery

July 10–15

Camp Discovery 2011, located in Gainsboro, Tenn., is a weeklong overnight camp that provides opportunities for children such as crafts, swimming, horseback riding, fishing, and a talent show. It also allows them to meet with successful adults and peers with epilepsy. More importantly, it provides the chance for our children to feel like they fit in, while being provided the safety of a medically monitored setting. Many of these children often say that this is the best week of their life. The cost is $395. Scholarships are available for qualified individuals, based on availability and financial need. Contact Pam Hughes at 800-951-4991 or pam@efeasttn.org.

Epilepsy Foundation Middle & West Tennessee

Center for Courageous Kids

July 20–24

The Center for Courageous Kids (located in Scottsville, Ky) is a world-class medical camp designed specifically for children, ages 7–15, living with medical challenges that might otherwise not be able to attend a traditional camp. CCK is dedicated to uplifting children living with chronic or life-threatening illnesses. The campus includes a medical center, equestrian center, bowling alley, indoor swimming complex, gymnasium, climbing wall and so much more. Contact Georgia Sims at 615-269-7091, or gsims@epilepsytn.org.

Epilepsy Foundation of Kentuckiana

Center for Courageous Kids

July 20–24

(See Kentucky listing on page 12)

TEXAS

Epilepsy Foundation Texas – Houston/Dallas-Fort Worth/ West Texas

Camp Spike ‘n’ Wave

June 12–18

Camp Spike ‘n’ Wave, located at beautiful, handicap accessible Camp For All in Burton, Texas, is a weeklong overnight camp for children, ages 8–14, with the
primary diagnosis of epilepsy. Built on happiness, love, friendship, respect and admiration, Spike ‘n’ Wave is proud of its role model counselors (camper to counselor ratio is 3:1). An outstanding team of medical professionals, led by a pediatric neurologist, are present during the entire week of camp. Camp is provided at no cost. Contact Kristin Schkade at 888-548-9716, 713-789-6295, or kschkade@eftx.org.

Kamp Kaleidoscope
July 10–16
Kamp Kaleidoscope is a weeklong overnight camp for teenagers, ages 15–19, with epilepsy, located at YMCA Collin County Adventure Camp in Anna, Texas, just outside Dallas. It provides a safe, enjoyable experience while promoting independence, self-confidence, competency and social interaction. The camper to counselor ratio is 4:1. Counselors are selected for their experience and enthusiasm for working with teenagers. A dedicated medical staff is present during the entire week of camp. There is no cost to attend. Contact Kristin Schkade at 888-548-9716, or 713-789-6295, or kschkade@eftx.org.

Camp Neuron
July 22–24
Camp Neuron, located at Ceta Canyon in Happy, Texas, just south of Amarillo, is a weekend overnight camp for children and teenagers, ages 7–14, with epilepsy. It’s a great opportunity for kids to experience the fun of camp activities—swimming, fishing, sports, hiking and more—all designed to be accessible and adapted to campers’ individual needs and abilities, in a safe, medically monitored setting. There is no cost to attend. Contact Kristin Schkade at 888-548-9716, or 713-789-6295, or kschkade@eftx.org.

VERMONT
Epilepsy Foundation of Vermont
The Epilepsy Foundation of Vermont offers camp scholarships to families in Vermont who can select the camp of their choice for their child for one week. Please contact Audrey Butler, executive director at 802-775-1686, or epilepsy@sover.net.

VIRGINIA
Epilepsy Foundation of Virginia
Victory Junction
July 5–8
(See North Carolina listing on page 14)

WASHINGTON
Epilepsy Foundation Northwest
Camp Discovery
August 21–24
The Epilepsy Foundation Northwest’s Camp Discovery, located at Camp Fire USA’s Camp Killoqua in Stanwood, Wash. (Snohomish County), is a 4-day, 3-night camp for children and teenagers, ages 7–17, with epilepsy. It’s a great opportunity for kids to experience the fun of camp activities—swimming, fishing, sports, hiking and more—all designed to be accessible and adapted to campers’ individual needs and abilities, all in a safe, medically monitored setting. The camp is free to kids with epilepsy and one sibling. Parents are welcome to attend as camp counselors/volunteers. Contact Brent Herrmann at 206-547-4551, or register at www.epilepsynw.org.

METROPOLITAN WASHINGTON, D.C. AREA
The Epilepsy Foundation Metropolitan Washington has a limited number of camp scholarships for children and youth with epilepsy who reside in Washington, D.C. and Northern Virginia. For more information, please contact Dr. Vera Jackson at 301-918-2117, or vjackson@efa.org.

WISCONSIN
Epilepsy Foundations of Wisconsin
Camp Phoenix
July 24–29
Located at the Wisconsin Lions Camp in Rosholton, Wisc., Camp Phoenix is a weeklong overnight camp for children and teenagers, ages 8–17, with a primary diagnosis of epilepsy. Over 400 acres of woods and trails surround the private Lions Lake. Plenty of well-trained staff, nurses and counselors provide a safe, medically monitored setting. Kids experience the fun of camp activities like swimming, fishing, sports, hiking and more. The cost is $600 and scholarships are available based on need and availability.

Epilepsy Foundation Central and Northeast Wisconsin
Ann Hubbard, 715-341-5811 or annhubbard@efcnw.com

Epilepsy Foundation Western Wisconsin
Lou Kelsey, 715-834-4455 or lkelseyefww@sbcglobal.net

Epilepsy Foundation Southern Wisconsin
Jane Meyer, 608-442-5555 or janemeyer@wisc.edu

Epilepsy Foundation Southeast Wisconsin
Kristin Deuchars, 414-271-0110 or kdeuchars@epilepsyfoundationsewi.org

WYOMING
Epilepsy Foundation of Colorado
Jason Fleishman Summer Camp
June 19–23
(See Colorado listing on page 11)

Editor’s note: These listings are for information purposes only and are accurate as of press date. The Epilepsy Foundation national office does not directly run, evaluate, guarantee or endorse camp programs. For more information, please contact your local affiliate.
When you first introduced yourself to staff, you said you were from the Midwest. How has that shaped who you are today?

**Rich Denness:** I think my parents shaped who I am more than where I am from. I was raised in a very supportive middle-class household in St. Louis, Missouri. My parents basically pushed for us to be the best we could possibly be, for ourselves and for others.

That resonated very well with me, both in sports and in school, and ultimately in terms of my career. If I was going to do something, I was going to do it right, and I was going to work hard at it. That’s basically what molded me into who I am today.

When you began your career at UCB you said you didn’t know much about epilepsy. What did you learn about it that surprised you?

**Rich Denness:** You’re right, when I came to UCB I had no background or experience at all. My view of a seizure was probably no different at that time than anybody else out on the street. The first thing I remember learning about epilepsy was how complicated it is.

I had studied oncology issues, hepatitis issues, respiratory topics all in different sectors of the pharmaceutical industry. I was taken aback at how complicated understanding epilepsy can be, with the brain and the various seizure types and the impact that it has on people with epilepsy.

Then I gained an understanding of the impact epilepsy has on the lives of the people it affects, both the people themselves and their caregivers, friends and families. The more my team started doing the right things for patients and developing programs—partnering with the Epilepsy Foundation—the more we got to know these people very closely. I now know a countless number of people impacted by epilepsy who are very good friends of mine that I communicate with regularly.

How has getting to know people with epilepsy and also epileptologists informed your work?

**Rich Denness:** The traditional business model is to sell as many of your units of product as you possibly can, and that changed when I got involved with epilepsy. Epileptologists are the most special segment of health care providers I have ever met in my life. These are some of the most amazing people who will go anywhere, anytime to help somebody impacted by epilepsy.

When I got to know people impacted by epilepsy—moms, dads, patients, children, sometimes the sons and daughters of people with epilepsy—you realize that it impacts the entire family.

It’s not just the person who has epilepsy. Siblings are also impacted by it. Moms and dads can’t necessarily do all the things that they want to do in their career or pursue all of their personal interests. It’s a very serious topic and if the Epilepsy Foundation and all other

Even when I left the industry, I stayed involved. I’m here at the Epilepsy Foundation because I didn’t want to walk away from epilepsy.
organizations that are focused on helping people with epilepsy all work together, I think we can achieve something great.

**epilepsyUSA:** Do you have a strong commitment to people with epilepsy?

**Rich Denness:** Yes. My children do not have epilepsy, nobody in my family has epilepsy, but spending so many years with folks that are impacted by epilepsy, I realize nobody deserves to have a seizure. Nobody deserves the anxiety and the uncertainty about when their next seizure is going to come.

It’s completely unfair, especially when I sit and talk with children. It’s something I refuse to walk away from. Even when I left the industry, I stayed involved. I’m here at the Epilepsy Foundation because I didn’t want to walk away from epilepsy.

**epilepsyUSA:** You’ve worked in the for-profit part of the industry, and this has to be a big change for you. What strikes you most as being one of the main differences?

**Rich Denness:** There are more similarities than differences at the end of the day, especially in this current state of the economy. I think the biggest difference is at a nonprofit the ability to fund programs and services comes from raising money, or securing grants, versus selling products.

However, the similarity is if you’re not constantly executing a very focused, strategic plan; if you’re not evolving based on an ever-changing world and trying to stay ahead of the pace; if you’re not building very talented teams that are completely engaged and really looking beyond the horizon—you’re going to fail whether you’re a for-profit or nonprofit.

**epilepsyUSA:** Why do you think raising awareness about epilepsy is so important?

**Rich Denness:** A lack of understanding of epilepsy and the lack of an ability to recognize a seizure has resulted in some very catastrophic situations. Just understanding what a seizure is and how to respond to one is important for the general well-being and safety of people with epilepsy.

The more epilepsy is understood, the less epilepsy will be discriminated against. I’m not just talking about employment, which is a huge issue. I’m talking about the ability to interact in society, whether you’re an adult or a child. Raising awareness helps people understand what epilepsy is.

**epilepsyUSA:** As president and CEO of the Epilepsy Foundation, what do you want your most significant contribution to be for people living with epilepsy?

**Rich Denness:** I would like the Epilepsy Foundation to be recognized as a true, positive force—a much more positive force than perhaps we are today throughout the epilepsy community. I want people to see us as a foundation that is doing greater and greater things to make the lives of people impacted by epilepsy better. More specifically, the more we deliver research, programs, services and education in a unified and effective manner, the more highly regarded the Epilepsy Foundation is going to be.

I also want us to strive for better unity among all of the stakeholders and interested parties dealing with epilepsy.

continued on page 19

“Epileptologists are the most special segment of health care providers I have ever met in my life. These are some of the most amazing people who will go anywhere, anytime to help somebody impacted by epilepsy.
epilepsyUSA: Are you optimistic?

Rich Denness: Yes. If I didn’t believe that I could have a positive impact and try to make the Epilepsy Foundation a better place, I wouldn’t have come here.

epilepsyUSA: On a more personal level, can you tell us about your kids?

Rich Denness: I’ve got an 18-year-old son, Michael, who is a freshman in college and I have a 16-year-old daughter named Claire. Michael is a musician. Claire is a straight-A student and a tremendous athlete. They’re both good students.

epilepsyUSA: You mentioned your kids have also been involved with epilepsy.

Rich Denness: My kids have had an opportunity to meet several people whose lives have been positively impacted in one way or another by Canine Assistants, an organization that matches people with seizure response dogs. My kids are very proud that I’m in this role at the Epilepsy Foundation. Not because of the role itself, but because it makes an impact on people’s lives. I think that speaks volumes for the quality of my two children.

epilepsyUSA: What interests do you have?

Rich Denness: I grew up a hockey player and I just stopped playing a few years ago. And I’m a diehard sports fan. I grew up playing hockey and baseball and a little bit of football, but hockey was my world. Now my favorite thing in the world to do is snow ski.

epilepsyUSA: One final question: Beatles or Rolling Stones?

Rich Denness: Foo Fighters!

In the next issue you’ll meet Sandy Finucane, our new Executive Vice President!

No one should be fired from a job simply because of a medical condition, but it happens all the time.

When people are fired or discriminated against because they have epilepsy, the Epilepsy Foundation is the first place they turn. The Epilepsy Foundation created the Jeanne A. Carpenter Epilepsy Legal Defense Fund to seek justice and help protect the civil rights of people with epilepsy.

If you agree that a person should not be discriminated against and you desire to help people with epilepsy live full, productive lives at home and at work, consider making a gift to support the Jeanne A. Carpenter Epilepsy Legal Defense Fund. You can use the envelope located in the center of the magazine, or mail your contributions to:

Epilepsy Foundation
Attn: Jeanne A. Carpenter Epilepsy Legal Defense Fund
8301 Professional Place
Landover, MD 20785-2353

Scan this Smart Tag with your smartphone and instantly go to the Legal Defense Fund donation page. iPhone, Droids, Blackberry and HTC can all accept this barcode technology. Visit http://gettag.mobi to download the application for free. If you do not have a smartphone please go to www.epilepsyfoundation.org/epilepsylegal/and make a donation through our Web site.
In My Own Words
Continued from page 3

uncontrollable—I am willing to take that risk. The desire to be better and suffer less embarrassment is worth the risk.

I have been told that when I talk about my epilepsy people are surprised about how candid I am, discussing details they consider personal, while I seem to appear unaffected. Epilepsy is very different for each person who lives with it. I have chosen to speak up with the hope that we can continue to make significant progress on policy, education and research fronts that will increase awareness about the condition.

Epilepsy has defined my life, for better or worse. It made an impact on basic life decisions, like how I could get from point A to point B, my career path and personal relationships. I have been upset that I couldn’t learn to scuba dive or skydive or snow ski because there is a “chance of seizure.” Trying to live your life to the fullest is often in conflict with reality. Such reality strikes you in the face when you must surrender your driver’s license for 6 months and have to keep handing it over. Driving is something many people take for granted. They assume that after age 16 they will always be driving. I have given up my license a handful of times, each with its own emotional toll because it means I must rely on others to get everywhere, take all forms of public transportation, calculate twice as much time for travel, and lose my sense of independence, which may or may not return in 6 months. It is these kinds of things that make living with epilepsy tremendously complicated and life-altering.

Working at the Epilepsy Foundation gives me the chance of a lifetime. It puts my individual experiences in the context of the nearly 3 million of us who are diagnosed, which is both humbling and helpful at the same time.

The In My Own Words column gives people whose lives are affected by epilepsy the chance to share experiences and solutions to their problems. These are real stories by real people that show strength, resilience, optimism and courage. We hope they will inspire others.

Making a Difference

Every day, all across the country people are thinking of creative ways to raise funds for the Epilepsy Foundation so we can educate the public about epilepsy and fund research that will one day lead to a cure. We want to highlight their contributions.

AN UPDATE ON JOEY’S SONG

In just a little over 2 weeks after the CD release party of Joey’s Song, the Joseph Gomoll Foundation presented the Epilepsy Foundation with a check for $5,000! And as you are reading this, the number of CDs sold and distributed has surpassed the 1,000 mark! The CD, produced in memory of Joey, a 4-year old who had a rare form of epilepsy, is a compilation of never-before released songs by music legends, Grammy nominees and singer/songwriters from around the world. To order your copy, go to www.epilepsyfoundation.org/store. All proceeds will go to the Epilepsy Foundation and will be used to support research and raise awareness for epilepsy.

Epilepsy Foundation Director of Major Gifts Tanya Sweeney and Kevin Baird, Executive Director of the Joseph Gomoll Foundation.
Every week, several such misdiagnosed patients come through Benbadis’s clinic’s doors, and they are lucky when they do. To get a clear diagnosis, a neurologist must witness a seizure at the same time as he is watching the patient’s EEG. “Video-monitored EEG provides the gold standard for diagnosing PNES, because you can see the seizure and the brain activity side by side. You can say, ‘Here’s your seizure and there’s no signature of epilepsy associated with the event,’” says Benbadis. And video-EEG monitoring units are generally only available at major epilepsy centers. Without a definitive diagnosis, a patient may suffer for years from the side-effects of unhelpful drugs and the uncertainty, frustration and depression that can result from persistent and unresponsive seizures. These patients also suffer from the untreated psychological cause of the psychogenic seizures, too.

“It’s tragic—influriating actually—that these patients aren’t recognized and treated sooner, and that many of them never get properly treated at all,” says Benbadis. “The system is failing them.”

Danielle was lucky. As part of a treatment study, LaFrance treated her and 20 other patients with 12 weeks of cognitive behavioral therapy for PNES in which they “focused more on strategies for managing stress and paying attention to and responding positively to distress signals coming from my body,” she says. She hasn’t had a seizure since 2007.

“Sometimes your body has to really scream at you before you listen,” Danielle says. “Maybe that’s what these seizures are. And maybe something is wired funny in me to give me the tendency to respond like this, when other people might have a panic attack or not be able to sleep.”

Other reportedly effective treatments include hypnosis and traditional psychotherapy. LaFrance is conducting an American Epilepsy Society and Epilepsy Foundation-funded multi-site pilot randomized controlled trial, comparing the effectiveness of treatments for PNES. Danielle’s seizures have stopped and her life is slowly returning to normal. She is working part time again and is able, from time to time, to get back on a horse. But there are tens of thousands of Americans, and millions of patients worldwide, who continue to be treated for epilepsy they do not have and to go untreated for the debilitating illness they do have.
Subscribe to epilepsyUSA!
Our magazine epilepsyUSA is a great resource for people affected by seizure disorders: articles on new treatments and medicines, ground-breaking research, personal stories, advice for parents and much, much more—all delivered right to your door! You'll receive six, full-color, 24-page issues for only $15.00.

Mommy, I Feel Funny!
By Danielle M. Rocheford
This colorfully illustrated book describes how a little girl named Nel and her family deal with the discovery that she has epilepsy. Nel describes how she experiences a seizure and her first doctor appointments to diagnose her epilepsy.
Item Number: 459MFF $12.95

Epilepsy Awareness Bracelets
Raise awareness of epilepsy and make a fashion statement! The Epilepsy Foundation name and logo are on one side and the words “Not another moment lost to seizures” are on the other side. Made of silicone. Pack of 10 or 100.
Item Number: 125EAB-10 $12.50
Item Number: 125EAB-100 $75.00

Piece of Mind
My Journey to Peace Amid Seizures, a Tumor, and Brain Surgery
By Deanna M. Brady
This story is a fascinating journey with epilepsy—part mystery, part comedy, part love story and part self-help. She gives readers the confidence to trust their gut—and proves that when it comes to losing a “piece” of your mind it’s best to keep your wits about you.
Item Number: 602POM $15.95

Make your wardrobe blossom!
We have a whole garden worth of styles, colors, and fashions for the whole family for spring—each complimented with the Epilepsy Foundation’s logo. Go online, choose your size and order today! Make everyone green with envy!

To order these products from the Epilepsy Foundation Marketplace:
Go to www.epilepsyfoundation.org
Click on ‘STORE’
Then on ‘Apparel’
Or call (866) 330-2718

Scan this tag with your smartphone and instantly go to the Epilepsy Foundation Marketplace Store page. iPhone, Droids, Blackberry and HTC can all accept this barcode technology. Visit http://gettag.mobi to download the application for free.

Get the free mobile app at http://gettag.mobi
Will our children and grandchildren inherit a future free of seizures and stigma?

That depends on you and me, people who understand the challenge, and still dream of a future where not another moment is lost to seizures.

The Candle of Light Society is our community of committed individuals and families who invest in transforming life for people with epilepsy. By remembering the Epilepsy Foundation in our wills and estate plans, we leverage gifts of cash, life insurance, stocks, and other assets toward our shared vision of a future free of seizures and stigma. In addition to certain tax advantages, we receive insider progress reports, invitations to exclusive phone briefings, a complimentary subscription to epilepsyUSA, recognition in the Annual Report (optional), and personalized visits with senior Foundation staff at your convenience. Will you join us?

Our investments transform lives so that not another moment is lost to seizures.

Join us by signing up below and learn more about the advantages you can enjoy as a member of the Candle of Light Society.

- Please enroll me in the Epilepsy Foundation Candle of Light Society.
- The Epilepsy Foundation is included in my will.
- Amount of bequest (optional) $____________
- I plan to include the Epilepsy Foundation in my will.
- Please send me a free will planning kit.

Name ___________________________________________________________________________________________
Address __________________________________________________________________________________________
City, State, Zip ______________________________________________________________________________________
Daytime Telephone ___________________________ E-mail ________________________________________________

Send this form to: Epilepsy Foundation, Gift Planning Office, 8301 Professional Place, Landover, MD, 20785
Attn: Daniell Griffin, Sr. Director Individual Giving
Phone: 301-918-3741 Fax: 301-577-9056 E-mail: dgriffin@efa.org