Asian Americans and Pacific Islanders with Epilepsy

Plus:

Exciting advances in epilepsy medication
The cover story in this issue is about Asian Americans and Pacific Islanders (AAPI) with epilepsy. Looking at how epilepsy is viewed in a variety of cultures deepens our understanding of the disorder and the people it affects. In the AAPI community, there is superstition, stigma and, often, a profound reluctance to ask for help or to talk about the disorder at all. No culture, it seems, is immune to the negative perceptions. All too often with epilepsy, we find we are not just fighting the condition, but the perception that colors the condition.

We know that with knowledge comes understanding, which is why, as a Foundation, we are focused every day on raising awareness about epilepsy all across the country. Through our national organization and affiliate network that stretches across the entire country, we’re targeting special populations to educate—such as school nurses and first responders—in addition to reaching out to the general public. We’re casting a wide net across the country, to include all cultures, age groups, and geographic areas.

Recent stories in the news have highlighted another side of epilepsy we don’t often talk about: Death. Our In My Own Words columnist, Mary Lou Connolly, is the mother of a 24-year-old son with epilepsy. She broaches the topic gingerly, finally acknowledging the often unspoken: People do die from seizures. Again, with knowledge comes understanding. Even though we don’t want to talk about it, the public needs to understand that people can live very well with epilepsy, but there is a segment of the population that has difficulty functioning. We need to understand their challenges, make sure they can join the workforce, and be as involved in regular life activities as possible.

In May, I am stepping down as Board Chair of the Foundation and passing the baton to the Chair-Elect, Joyce Bender, a formidable presence in the disability community, who also has epilepsy. As I reflect on my two-year tenure, I am struck by the enthusiasm, commitment, and dedication of the members of our Foundation, from the National Office, to the affiliates across the country, from the staff that provide programs to the volunteers who support them, and to all who care about helping those with this condition. I’ve been involved with a lot of organizations, but I have never seen such a high level of commitment as I have here. I’d like to take this opportunity to thank everyone for the chance to be involved and to work on such a worthwhile cause. A highlight for me was definitely the passage of the Americans with Disabilities Amendments Act in 2008.

We were a great organization two years ago, and through the efforts of so many, we are a better one today. I’m grateful for that. I know we are all are aimed at one common goal, to improve the lives of all people with epilepsy, so that not another moment is lost to seizures.

Steve Sabatini
CARE & CULTURE: Body and Spirit: Asian Americans and Pacific Islanders with Epilepsy
BY ALIYAH BARUCHIN  Asian Americans and Pacific Islanders come to the U.S. bringing beliefs about epilepsy and medical care that are sometimes at odds with the U.S. health care system.

Spotlight on 2009 Summer Camps
Epilepsy Foundation affiliates are getting ready for this year’s campers.

Advances in Antiepileptic Drug Therapy
BY ANDREW N. WILNER, MD, FACP, FAAN  2008 was an exciting year for advances in epilepsy drug therapy, with two new drugs approved by the FDA and several more in the pipeline.
Mary Lou Connolly is a registered nurse with a master’s degree in community health. She is mother of two children, Meaghan and Michael, and wife of husband Barry. Michael, now 24, was diagnosed with epilepsy at age 5. She wrote a book, Missing Michael, (available in our Marketplace on page 22) sharing her family’s intensely personal story in an effort to reach even more people about epilepsy’s profound impact upon lives. She has been a board member of the Epilepsy Foundation of San Diego for 9 years.

“We constantly hear that 60–70 percent of people with epilepsy go on to lead ‘normal lives’ once a medication regimen is found to control their seizures. We just don’t showcase those individuals whose lives have been turned upside down.”

We rarely talk about it in the epilepsy community. We constantly hear that 60–70 percent of people with epilepsy go on to lead “normal lives” once a medication regimen is found to control their seizures. We just don’t showcase those individuals whose lives have been turned upside down; parents who must spend thousands of dollars and countless gut-wrenching hours caring for a debilitated child. We just don’t think about the thousands of people who die each year from epilepsy or injuries caused by a seizure. Until…it’s in the headlines. Yes, people die from seizures; people die from epilepsy. There, I said it!

When Jett Travolta died suddenly in January, the tragedy of one family was plastered across newspapers, on entertainment news, in gossip rags and even on the evening news. The Travoltas had resources. They provided their son with 24-hour caregivers, alarmed doors so they would be aware when he was in the bathroom, or left his room, and presumably did everything within their means to assure that their son led a happy, albeit, protected life. Yet, one day, all the measures failed them, and they lost their precious Jett to death from a seizure.

My mother was staying with us when the Travolta story broke. One day she asked me if I remembered a man I’d grown up with in Springfield, Mass. “Of course I remember Sean,” I said. “Why?” She said she had seen him a few weeks before she traveled to California, and, as we all do when seeing someone we haven’t spoken to in a while, she asked, “How are you?” She said he became very sad and told her he had recently lost his 29-year-old son. His son had seizures, but otherwise he was leading a pretty nice life. He enjoyed traveling and, at the time of his death, he was in Europe. He always traveled with someone, Sean said, but that person could not prevent his fatal fall from a seizure. I knew quite well why my mother hadn’t told me about Sean’s son until then. It would have meant speaking about the unthinkable—that a seizure could actually result in death.

I was asked to appear on a local morning talk show the week of Jett Travolta’s death. I suspected the request was related to the fact that I have a son with epilepsy, but the producers told me they wanted me so I could speak about my book, Missing Michael. I had more or less promised myself that I would try to avoid a conversation focusing on the tragic outcome that many still call “rare.” I was bracing for the first question after the intro to my segment, which was indeed about the Travoltas. And it came: Now we’ll speak to a local mother of a son with epilepsy…

“It [dying from a seizure] is rare,” I heard myself say. Then came, “But it is a parent’s worst nightmare,” and the interview went on in that direction. Uh-oh. Had I somehow in the space of a couple of seconds put a new face on the picture often painted of epilepsy? People go on to live normal lives.

I have a renewed passion about increasing awareness and understanding about epilepsy. I still want to stamp out the many myths, I still want to try and decrease the stigma and I still want to promote research for a cure, or at least a treatment without debilitating side effects. I still want to do all that. But I want more now—I want people to know seizures are serious. They can impair brain function and they can result in death.

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.
**IN BRIEF**

**FDA WARNS ZONEGRAN MAY CAUSE ACID IMBALANCE**

On February 23, 2009, the FDA warned that the antiseizure medication Zonegran (zonisamide) can cause metabolic acidosis in some patients. Metabolic acidosis is a disturbance in the body’s acid-base balance that results in excessive acidity of the blood. The imbalance can cause breathing difficulties, irregular heart rhythms and fatigue. Chronic metabolic acidosis can cause long-term damage to the kidneys and bones and slow growth in children.

Patients with predisposing conditions or therapies, including kidney disease, severe breathing problems, diarrhea, surgery, ketogenic diet or certain other drugs, may be at greater risk for developing metabolic acidosis following treatment with zonisamide. The risk of zonisamide-induced metabolic acidosis appears to be more frequent and severe in younger patients.

The FDA recommends that health care professionals measure patients’ serum bicarbonate levels before starting treatment with zonisamide and periodically during treatment, even in the absence of symptoms.

The FDA said it will work with the makers of zonisamide to add new warning information labels to the drug.

**SOURCE:** FDA ALERTS. FOR MORE INFORMATION, VISIT WWW.FDA.GOV

**STUDY INDICATES AN INCREASED RISK OF EPILEPSY IN CHILDREN AND YOUNG ADULTS YEARS AFTER A TRAUMATIC BRAIN INJURY**

For more than 10 years after experiencing a traumatic brain injury, children and young adults have an increased risk of developing epilepsy. Therefore, there might be a window to prevent epilepsy occurring in these patients. These are the conclusions of an upcoming article in *The Lancet*, written by Dr. Jakob Christensen, Department of Neurology, Aarhus University Hospital, Denmark, and colleagues.

The authors identified around 1.6 million young people born in Denmark from 1977–2002 from the Civil Registration System. They then obtained information on traumatic brain injury and epilepsy from the National Hospital Register and estimated relative risks.

They found that risk of epilepsy more than doubled for mild brain injury or skull fracture, and was seven times more likely in patients with serious brain injury. Even over ten years after the injury, the risk persisted—those with mild brain injury had a one-and-a-half times higher risk of epilepsy, while skull fractures doubled the risk and severe brain injury increased the risk of epilepsy by four-and-a-half times. The risk was even more pronounced in people older than 15 years—with mild injury, increasing the risk of epilepsy by three-and-a-half times, and severe injury by more than 12 times. Women also had a slightly higher risk than men.

The authors conclude: “Traumatic brain injury is a significant risk indicator for epilepsy many years after the injury. Drug treatment after brain injury with the aim of preventing post-traumatic epilepsy has been discouraging, but our data suggest a long time interval for potential, preventive treatment of increased risk patients.”

**SOURCE:** THE LANCET NEUROLOGY

**NEW RESEARCH SUGGESTS COMMON ANTISEIZURE MEDICATIONS MAY INCREASE CARDIOVASCULAR RISK**

An important clinical repercussion in the treatment of epilepsy has been discovered by a research team led by Scott Mintzer, M.D., assistant professor in the Department of Neurology at Jefferson Medical College of Thomas Jefferson University. The team has determined that two of the most commonly prescribed antiseizure medications may lead to significantly increased levels of cholesterol, C-reactive protein and other markers of cardiovascular disease risk. The finding—set to appear in the April issue of *Annals of Neurology*—may help doctors manage the care of patients with seizures more effectively by prescribing different antiseizure medications that will not adversely affect cardiovascular health.

The study involved two of the most widely-prescribed anticonvulsants—phenytoin (Dilantin®) and carbamazepine (Tegretol®, Carbatrol®)—which have potent effects on many enzymes in the body involved in different areas of metabolism. The researchers recruited 34 epilepsy patients taking either one of those two drugs who were being switched over to one of two newer anti-seizure drugs which do not widely affect enzymes—lamotrigine (Lamictal®) or levetiracetam (Keppra®). The goal was to determine if the change affected the patients’ cholesterol levels and other key markers of cardiovascular disease.

Just 6 weeks after the patients’ drugs were switched, there were significant declines in total cholesterol, non-high-density lipoprotein (commonly referred to as “bad”) cholesterol, triglycerides and C-reactive protein, suggesting the older, commonly-used drugs might substantially increase the risk of cardiovascular disease.

“The epilepsy patients in this study saw a rapid and clinically significant improvement in several markers related to cardiovascular disease, including a decrease in total cholesterol that averaged 26 points. This is almost certainly not due to some positive effect from the new drugs. It’s a consequence of being taken off the older ones, which were causing the cholesterol and other markers to be elevated in the first place,” said Dr. Mintzer. “While more investigation is needed, these results may help physicians better understand the risks of these drugs and choose the most appropriate treatment for their epilepsy patients, especially those who are already at risk for cardiovascular disease or have a family history of it.”

Dilantin is the most commonly prescribed anticonvulsant in this country, and has been since its discovery in 1938. Throughout the industrialized world, Tegretol has been the most commonly prescribed anticonvulsant for more than 20 years. The effect of older antiseizure medications (particularly Tegretol) on cholesterol has been known for 30 years. The results of this study could have far-reaching effects on how the millions of current—and future—patients are, or will be, treated.

The study was funded by the Epilepsy Foundation through the Edna Flaig Evans Trust.

**SOURCE:** THOMAS JEFFERSON UNIVERSITY NEWS RELEASE
CARE + CULTURE

BODY

and

Spirit

ASIAN AMERICANS

AND PACIFIC

ISLANDERS

WITH EPILEPSY

BY ALIYAH BARUCHIN, SPECIAL TO EPILEPSYUSA
In late 2007, Bill Stack, associate director of the Epilepsy Foundation of Northern California, began plans to host a Day of H.O.P.E. event about epilepsy in the Bay Area. Stack’s conference was designed to offer outreach and education about epilepsy to San Francisco’s Cantonese-speaking Chinese community—the Bay Area’s largest Asian population—and he recruited three Cantonese-speaking parents of children with epilepsy, all volunteers at his organization, to help develop the program.

Yet when the Day of H.O.P.E. finally arrived on April 26, 2008, the only Cantonese speakers who attended the program turned out to be the three volunteers themselves. “We viewed the Day of H.O.P.E. conference as our introduction to the Chinese community—as an opportunity to begin a relationship,” said Stack. Given the stigma about epilepsy in the community, he said, “We knew it was going to be a challenge; we would hand out our brochure in Chinatown and people would give us strange looks. In terms of how we’re going to bridge the cultural differences, we were going to have our parent volunteers that don’t share those views hopefully be the liaison to the community that does.”

Like any immigrant population, Asian Americans and Pacific Islanders come to the U.S. bringing beliefs about epilepsy and medical care from their countries of origin, and then bump into the tenets and protocols of the American health care system.

Stack is one of a cadre of people nationwide who are developing resources to offer care, outreach and education about epilepsy to the vast array of ethnic groups collectively known as Asian-Americans and Pacific Islanders (AAPI). AAPIs make up about four percent of the U.S. population, or about 12 million people, and that figure is projected to rise to 20 million by 2020. Studies estimate that about 1.5 percent of AAPIs in the United States have epilepsy, with no particular variation by country of origin or ethnic background. That figure is close to the general-population figure of about 1.3 percent, though Dr. Steve Chung, director of clinical epilepsy research at the Barrow Neurological Institute in Phoenix, Ariz., points out that because of the intense stigma surrounding epilepsy in many Asian-American communities, the condition may be under-reported.
The signature characteristic of the entire AAPI category is its incredible diversity—it draws from up to 49 different ethnicities and countries of origin in East Asia, Southeast Asia and the Indian Subcontinent and includes more than 100 different languages. To add to the complexity, some AAPI ethnicities are themselves admixtures; many Filipinos, for example, have some Chinese ancestry.

That degree of diversity makes it impossible to generalize about the experience of AAPI populations. But some information is emerging about how various AAPI communities experience epilepsy, and what kinds of tailored treatment, outreach and educational services they may need.

Like any immigrant population, AAPIs come to the United States bringing beliefs about epilepsy and medical care from their countries of origin, and then bump into the tenets and protocols of the American health care system. For providers, educators and advocates, the wild card in working with AAPIs with epilepsy is that they hail from a wide range of countries, cultures and belief systems, each of which intersects with the American system in its own way.

What seems to be universally true is that the experience of AAPIs with epilepsy has been vastly understudied; there is far too little in the way of data, literature, educational and outreach materials, and programming. Yet there are some common threads in the AAPI experience of epilepsy, and perhaps foremost among them is a powerful sense of shame and secrecy about epilepsy in many AAPI cultures.

“As a general belief in the Chinese community and other communities, it is something that is a taboo,” said Helen Dao, director of Multicultural Health Initiatives at the Epilepsy Foundation of Metropolitan New York in New York City, who has a Health Resources and Services Administration (HRSA) grant to develop culturally relevant outreach to Chinese-American and other ethnic communities about epilepsy.

Dao recalls an immigrant parent who was fighting language limitations and other barriers to try to access care for her son when he was first diagnosed with epilepsy.

“With that also came the stigma that epilepsy has—not sharing that information, not even with close relatives, because they will isolate her son and not make him part of the dynamics of the family,” Dao said. “Still nowadays when we go out in the community, with families, it is not a topic. If it is diabetes, that’s not a problem, but if it’s epilepsy, the family’s got something that cannot be shared or discussed at all... It’s not something that they’re going to talk about freely.”

Because of this stigma, Dao believes that her work in outreach and education walks a fine line. “We want to respect their personal beliefs; we don’t want to come across by disrespecting them because we’re trying to gain their trust, and at the same time to direct them to the appropriate epilepsy care, and then also to teach them that there are special ways to treat epilepsy,” she said. “How do we go about working with the Chinese-American families here—bringing the education, bringing the information, but at the same time, respecting some of their cultural beliefs?”

Easily the most famous American work on Asian-Americans and epilepsy is Anne Fadiman’s award-winning 1997 book, The Spirit Catches You and You Fall Down—a searing portrait of a Hmong child with epilepsy and her non-English-speaking family’s devastating collisions with the local medical establishment in Merced, Calif., as they tried to access care for her. [The book is available in our Marketplace on page 22.] Rather than simply portraying the Hmong as outliers, the story gave equal weight to the

Being Asian-American, you do not want to say, ‘I can’t do this.’ It took a lot for me to have to say to some people, ’I need your help.’
Hmong spiritual conception of what epilepsy is (the title of the book is the Hmong name for the condition) and to the standard American medical framework for what causes epilepsy and how it should be treated. Fadiman’s story focused on just one family, from one Asian culture. Yet the book touched a powerful nerve with many readers about the gaping need for multicultural competence among American health care providers, and it brought to light some elements of the Asian experience of epilepsy that occur not only in Hmong culture, but in many other AAPI communities as well.

The stigma that epilepsy carries in many AAPI cultures often has to do with a belief in epilepsy as a spiritual malady—a form of possession, for example, or a punishment for a parent’s sins. Dr. Alan Stein, director of epilepsy and neurophysiology at the Queen’s Medical Center in Honolulu and president of the Epilepsy Foundation of Hawaii, has encountered these types of beliefs in his practice. “I have a patient who was born and raised in Laos, and he was convinced that the reason he had epilepsy is because somebody in Laos put a spell on him,” he said. “He thought the way that he needed to get rid of it was to go back to Laos and find that person and either kill them or put a different spell on them.”

Yet Dr. Stein sees generational differences in patients’ beliefs about what causes epilepsy. “In Hawaii there’s a fair number of new immigrants, but a lot of our populations are second, third, fourth generations,” he said. “My guess is that you would be seeing more of that philosophy of the spiritual causality primarily in people who were actually born in another country and moved here, or maybe the first generation.”

Bill Stack agrees, citing his three parent-volunteers as examples. “Probably the first thing is the amount of time that they have been in America, and their view of the Western approach,” he said. “All three are well-educated, and their children receive care from UCSF [the University of California at San Francisco], which is a top-of-the-line epilepsy center, so perhaps the results have been shown for them.”

Mary Wong, an Epilepsy Foundation board member who is the president of the Office Depot Foundation, believes that for many AAPIs, part of the stigma surrounding epilepsy has to do, paradoxically, with cultural pride. Wong, whose father’s ancestry is Chinese, has had one of the most severe forms of epilepsy since the age of 14; she has no identifiable seizure focus and no auras, and she often has clusters of 15 seizures at a time. “Asian-American culture is very, very proud—a very reserved proud,” Wong said. “Being Asian-American, you do not want to say, ‘I can’t do this.’ It took a lot for me to have to say to some people, ‘I need your help.’ But you have to be able to learn to let people help you. You don’t get through these things alone.”

There are also health-disparity issues confronting the AAPI population, including language barriers, problems with access to epilepsy care and mistrust of U.S. health care systems. For AAPIs, language and interpretation are another formidable set of barriers to care. Logistically, few hospitals have the resources to meet the interpreting needs of a community as massively diverse as AAPIs. Dr. Anuradha Singh, director of the Epilepsy Center at New York’s Bellevue Hospital Center, says that the hospital offers phone interpreting in a broad array of languages for her AAPI patients, who are often from China, India or Taiwan. “It’s a three-way phone system where an interpreter is there, the doctor is there, and the patient is on the phone,” she said. As an attending physician, she added, she gets the services of a face-to-face interpreter.

continued on page 9
At UCSF, which has a Comprehensive Epilepsy Center, Bill Stack says, “Several of their physicians may be bilingual, but certainly there is such a large Chinese-speaking population, so they have interpreters for Cantonese and Mandarin. But that’s only for the people that have gotten to UCSF; we would say that that would be a very small percentage of the overall population. Certainly in general, language barriers are a huge problem.”

A third major barrier to epilepsy care is basic access. Helen Dao stresses that AAPIs confront the same problems with access that plague many other groups, yet in this regard, she finds her corner of the AAPI community exceptionally proactive. “Chinese families, they take action,” she said. “We’re targeting medically under-served areas and most of the Chinese families that we’re serving are new immigrants to this area. They are very resourceful; they do seek health insurance for their child, and they make sure that the child is covered. But they’re also very resourceful in finding other ways—by working or selling everything they have to pay for medical care. They will do anything to access services for their child; the key is for them to know where to go and what those services are.”

Dr. Singh sees problems with financial access to medication—especially second-generation antiepileptic drugs (AEDs), those developed after 1990. “These people are immigrants, so they are struggling to find some base in our country, and some of them are probably not insured,” she said. “They cannot afford [the newer drugs], even if they tolerate it better, they were better controlled; they go back to the first generation, because it’s just too expensive for their pockets.”

Besides insurance, geography presents the other primary barrier to access. In San Francisco, Bill Stack notes, the Chinese patient community is in a very good position because of the existence of the city’s Chinese Hospital, which, though it doesn’t house a Comprehensive Epilepsy Center, has neurologists on staff. But the situation is vastly different in rural areas, where Americans of every background have trouble accessing any specialized epilepsy care at all—never mind care that includes a trained interpreter and a physician sensitive to AAPI cultures.

Some AAPI communities also present specific epilepsy treatment challenges. In many AAPI cultures, herbal remedies are used along with Western antiepileptic drugs. “The problem with that is, as Western doctors, we don’t know anything about herbs. I can’t even pronounce most of the herbs they use,” said the Barrow Institute’s Dr. Chung, who is Korean. “When we prescribe our own Western medication, interactions between these two medications are unknown, and sometimes that gets into trouble—not only in terms of side effects, but also in terms of efficacy of the medication. For example, if the herb they’re taking for whatever reason increases the level of seizure medication, then it could be toxic to the patient unknowingly. On the other hand, if they increase the clearance of Western medicine for seizures, then the level would be very low and then they may have more seizures. So the interaction is very important, and it’s very difficult to suspect which way they’re going to turn.”

As part of her work, Helen Dao is creating a medication-list tool to encourage Chinese patients to name any and all remedies—Western or traditional—that they are using to treat epilepsy. “We hope to catch any other over-the-counter medication that a child with epilepsy is taking,” she said. “The education that comes for families, which is very, very crucial, is that there can be a counteraction in epilepsy medication and natural remedies. With the specialists that we work with, we see that they also try to educate families in understanding that.”

Epilepsy surgery is another treatment challenge for some AAPI populations. Although opting to undergo brain surgery isn’t an easy choice for anyone, Dr. Chung says that receptiveness to surgery can vary widely among AAPIs by country of origin. “There are certain Asian countries where surgery is still considered as something they should avoid,” he said. “Epilepsy surgery is very well-received in East Asia, Japan and South Korea. If you go to Tibet and some parts of China, they perceive it as kind of an escaping of spirit if you make a hole in the brain or skull... I have some patients from the aforementioned
areas, and no matter how I tried to persuade them, they would not go through with surgery.” At Bellevue, Dr. Singh finds many of her Chinese patients unwilling even to undergo a video EEG—a non-invasive inpatient procedure in which patients are monitored for several days through external leads placed on the scalp.

Dr. Singh also sees a sharp socioeconomic difference in AAPI patients’ willingness to consider surgery. “I see patients who are either uninsured or low-income, and then [other patients in] my private office. There is such a contrast. In the office they will be reading about the latest medicines which are out, or whether the gamma knife surgery is available or not. ‘Is that good for my epilepsy surgery? Is that an option?’ Versus [the lower income] population, who would be very, very loyal patients otherwise, but you utter the word ‘surgery’ and they think that you’re crazy.”

And in the burgeoning world of personalized medicine and pharmacogenetics, another treatment issue arose in 2007: the FDA issued a warning about the use of carbamazepine formulations, such as Carbatrol and Tegretol, by patients with a gene mutation found almost exclusively in some people of Asian ancestry. In these patients, the drugs can cause potentially life-threatening skin reactions. The warning included people from several AAPI countries of origin—India, China, Malaysia, Taiwan, the Philippines, Indonesia, Thailand, Japan, and Korea.

With so many factors influencing AAPI epilepsy care and outreach, and with so few resources already in place, just finding a starting point for research, advocacy and education may seem daunting, especially in terms of diversity. “What’s really challenging for our affiliate is the fact that, okay, yes, the Chinese community is the largest of the Asian populations, but they speak two languages, and that’s different than Vietnamese, which is different than Hmong, and all of these groups need services,” said Bill Stack. “We just had to identify the largest population. So many people say ‘Oh, Asian outreach,’ but there’s so many nationalities and languages encompassed in that that it can be overwhelming.”

Perhaps the first goal of any epilepsy outreach effort to AAPI communities has to be helping families begin to come out from under the burden of stigma and shame.

In New York, Helen Dao is targeting parents of children with epilepsy directly, not only as her audience, but as potential recruits. “We want to have a partnership with the Chinese parents in increasing the health care access for their children and youth with epilepsy here in New York City,” she said. “We want parents to become partners in this goal that we have as an organization.”

To accomplish this, many epilepsy advocates are also seeking out broader alliances with partner organizations in AAPI communities. Dao has partnered with the Charles B. Wang Community Health Center, a facility that functions as a medical home for the Chinese community in Manhattan. “A medical home is a physician or health care center who truly provides comprehensive, culturally competent health care services to their patients, being sensitive to their cultures and their needs,” she said. “This center can be identified as one of those—as a true medical home for the Chinese community.”

Linking up with an established organization, Dao feels, is crucial. “The key will be for us to have a partnership with a community center—not necessarily just a health center, but any other center that is part of the Chinese community where they have built trust and they have a sort of open-door policy where the community members feel comfortable and safe coming in. Then, in our way, we will become integrated into that culture in order for us to provide effective education and outreach.”

continued on page 11
Body and Spirit

Continued from page 10

Churches and Eastern houses of worship, and their clergy, can also be deployed to help AAPI patients with epilepsy feel safer navigating the halls of Western neurology. "I've got one Japanese patient who actually comes with her minister," said Dr. Stein. "I think it's a non-Christian denomination, a Buddhist temple. He comes with her to our visits, and he is definitely advocating for appropriate uses of medications and other interventions.

Blaï Meng Vang plays a similar, if expanded, role in his Hmong community in Wisconsin. Vang, 58, is a shaman, or healer, who himself has had epilepsy since his adolescence in Laos, and his seizures have only recently abated. Having been treated with what he considers success by shamans and Western doctors throughout his life, he sees a role for both spiritual and physical healing in epilepsy, and encourages the people he treats to take advantage of both. "If something is causing pain due to the physical, then doctors can be very helpful. If it is caused by something spiritual, it has to be a spiritual doctor who goes to that world to get that spirit better," he said through a translator. "Culturally, we believe that epilepsy comes from the spirit; but the reality is, it may not be the spirit. My focus is to encourage people to see a doctor plus shaman—do both things to help the person get well."

Clergy have the added benefit of being able to function not just as religious advisors, but also as cultural brokers. In a 1992 study of managing epilepsy in a Korean-American family, Dr. Soo-Young Chin writes, "In negotiating the Western medical system in the United States, first-generation immigrants need a cultural interpreter, not just a translator." Considering the enormous difficulty of teaching cultural competence about even a few AAPI ethnicities to non-AAPI health care providers, cultural brokers who can support AAPI patients in getting the right epilepsy care occupy a crucial role.

Even in the early stages of her work, Helen Dao (who, despite her passion for Chinese-American issues and her husband’s Vietnamese last name, is herself from El Salvador) recognizes that she will need to recruit insiders from the Chinese community to do outreach. "Once we start doing the one-on-one education, working full speed, we need to have parents or someone they can identify with," she said. "Because building that trust, it’s going to be a challenge; they’re very close, this community."

For the Chinese-Americans she serves, Dao’s ultimate mission is all about education. "One of the things that is very, very important for Chinese families is to get the information that they need about epilepsy, get the facts," she said. "Sometimes we hear a neighbor might have heard of someone with epilepsy, and they would tell the parent, ‘Oh, don’t give him the medication.’ That can really confuse the parents. My message will be, Get the facts about epilepsy and seek appropriate health care services. Epilepsy doesn’t make the person; it’s just what they have. And don’t limit their child or their sibling, because they’re limiting their potential to fully integrate into society and live normal lives."

Bill Stack is focusing on multiple ways to encourage AAPI communities to bring epilepsy out in the open.

"The first thing is to reduce stigma, and the second would be to potentially diagnose more people so that they are not needlessly having seizures," he said. "We think that there’s probably a lot of people out there that are suffering that don’t need to be, so we’ve just got to reduce the stigma and educate them. It’s a simultaneous approach."

Rather than being discouraged by the fact that information about —and outreach to — AAPIs with epilepsy is still in its infancy, Helen Dao is now busy moving forward. "We know that we have a ton more to learn, because we’re just starting the research and getting ready to truly go full speed in working with the Chinese community," she said. "I would think around this time next year, it will be a whole different volume of information."

And Mary Wong hopes to send a message to other AAPIs by focusing on what it has ultimately, and surprisingly, meant to her to have epilepsy. Wong is sometimes asked whether, if she could have wished the condition away, she would have — and she says, definitively, no. "This is not a handicap,” she said. “It’s helped me. It has given me the greatest inner strength, and it has taught me, truly, what’s important.”

For more information on improving access to care for children and youth with epilepsy, please visit www.acessforepilepsy.org.
**ALABAMA**

**Epilepsy Foundation of Alabama**

**Camp Evoked Potential @ Camp ASCCA**

**June 28–July 3**

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 at Camp ASCCA is for children and teenagers, ages 6–18, 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. The cost is $675. Full and partial scholarships are available for qualified individuals, based on availability and financial need. Contact David Toenes at 1-800-626-1582, or e-mail dtoenes@efala.org.

**ARIZONA**

**Epilepsy Foundation Arizona**

**Camp Candlelight**

**June 21–27**

In 2009, Camp Candlelight celebrates its 21st year of delivering a well-rounded quality program offering a climbing wall, horses, archery, hiking, outdoor sports, overnight campout, arts and crafts and more. It also allows children the opportunity to have small group meetings on dealing with their disorder with a doctor available for questions. Camp is for children ages 8–15. Cost is $375. Financial aid is available. For more information contact Tom Walsh at 602-406-3581 or twalsh002@chw.edu.

**CALIFORNIA**

**Epilepsy Foundation of Northern California**

**Camp Coelho**

**June 14–19**

The Epilepsy Foundation of Northern California is excited to sponsor the 4th annual Camp Coelho to be held this June 14–19. Camp Coelho is a 5-night, 6-day adventure in the Yosemite Valley for children ages 9–15 with a primary diagnosis of epilepsy. The camp is staffed by doctors, nurses, Epilepsy Foundation staff and volunteers. Activities include arts and crafts, swimming, archery, a ropes course and more. Camp Coelho gives children the opportunity to learn more about their epilepsy and develop self-confidence and independence in a safe environment. Cost is $750. Full scholarships are awarded to all accepted campers. For more information please contact Stephanie Eistetter at stephaniee@epilepsynorcal.org, 925-224-7760, or visit our Web site at www.epilepsynorcal.org.

**Epilepsy Foundation of San Diego County**

**Camp Quest**

**July 12–17**

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 the cabins with children their own age and doing all the camping activities provided, such as hiking, sports, swimming, boating, crafts, drama, campfires and other fun camping activities. Camp Marston is located in the high mountain district of Julian, Calif., in an area of pines and oaks with miles of hiking trails. The 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. Cost is a $25 registration fee. Financial aid is available. For more information please contact Sasha Clifton, program director at 619-296-0162 or sasha@epilepsysandiego.org.

**Epilepsy Foundation of Greater Los Angeles**

**Epilepsy Teen Retreat**

**June 21–26**

Our annual Epilepsy Teen Retreat is held at Camp Arrowhead Ranch in Lake Arrowhead, Calif. This is a week-long residential camp for teens and pre-teens with epilepsy between the ages of 12–20 years. It’s a great opportunity for teens to experience exciting recreational activities such as swimming, volleyball, ice skating, hiking, challenge courses, plus social activities including parties, picnics and bowling. All activities are safe and monitored by professional staff. Activities are designed to fit campers’ individual needs and abilities. The cost is $500 per person. Scholarships are available for those who qualify. Please contact Patricia Leyva at 1-800-564-0445 or pleyva@epilepsy-socalif.org for more information.

Continued on page 13
Epilepsy Family Camp  
**Camp Family Fun and Friendship**  
**September 4–6**

Our annual Epilepsy Family Camp is held at Camp Mt. Craggs in the Santa Monica/Malibu Mountains. This is a weekend camp for children with epilepsy and their immediate family members. It’s a great opportunity for families to interact with one another and experience many fun camp activities such as swimming, sports, hiking, arts and crafts, a carnival for children, a family night social, a teen party and much more. All activities are safe and monitored by professional staff. The cost depends on family size but ranges from $140-$200. Scholarships are available for those who qualify. Please contact Patricia Leyva at 1-800-564-0445 or pleyva@epilepsy-socalif.org for more information.

**COLORADO**

**Epilepsy Foundation of Colorado**  
**Jason Fleishman Summer Camp**  
**July 12–16**

The Jason Fleishman Summer Camp is located at Covenant Heights Camp and Retreat Center in beautiful Estes Park, Colo. It is a 5-day overnight camp for youth ages 10–17 years old living with epilepsy. It provides the opportunity for youth to participate in fun and exciting activities like rock climbing, zip lining, canoeing, horseback riding and more. We provide a safe, medically monitored setting and the camp has shown to increase self-esteem and confidence. The cost is $300. Scholarships are available. Contact Marcee Peterson at 303-377-9774 or toll-free at 888-378-9779 or e-mail at marcee@epilepsycolorado.org.

**CONNECTICUT**

**Epilepsy Foundation of Connecticut, Inc.**  
**Camp Courage**  
**July 19–24**

Camp Courage, located at the Easter Seals Camp Hemlocks in Hebron, Conn., is a week-long overnight camp for children and teens, ages 8–18. Former campers and individuals, ages 15–21 can also participate in a new Camper Assistant Program. All of our campers experience a safe, comfortable environment to go fishing, swimming, boating, rock climbing, hiking and more. The staff of Camp Hemlocks receive extensive epilepsy training and medical personnel is onsite 24 hours a day. The cost is $245 and scholarships are available based on financial need. Please contact Patrick Danis at 1-800-889-3745 or e-mail at pdanis.efct@sbcglobal.net.

**FLORIDA**

**Epilepsy Foundation of Florida**  
**Camp Boggy Creek**  
**August 6–11**

Located in Eustis, Fla., Camp Boggy Creek is a permanent, year-round facility, on 232 acres of tall pines, majestic oaks and nature trails. Boggy Campers enjoy a week-long summer session of fun, adventure and independence, meeting new friends and sharing their challenges while enjoying swimming, boating, fishing, arts and crafts, horseback riding, theater, archery, singing and dancing. Laughter and friendships abound where children between the ages 7–16 with chronic or life-threatening illnesses can come at no charge to them or their families. Camp Boggy Creek’s staff and volunteers are professionals from the fields of medicine, administration and therapeutic camping.

The camp is free to campers ages 7–16. For a camper application or more information visit www.BoggyCreek.org or www.epilepsyfla.org.

**GEORGIA**

**Epilepsy Foundation of Georgia**  
**Camp Lakewood** (Soddy Daisy, Tenn.)  
**June 14–20**  
**Camp Big Heart** (Winder, Ga.)  
**June 14–19**

Camp Lakewood is in Soddy Daisy, Tenn. (near Chattanooga). It is appropriate for children and teenagers ages 6–16 with well-controlled seizures and no overlying medical problems. Lakewood offers the typical camp activities—swimming, arts and crafts, sports, fishing, etc. Camp Big Heart is in Winder, Ga. (near Athens). It is appropriate for children and young adults ages 7–25 with less-controlled seizures and those with developmental disabilities. Big Heart also offers typical camp activities. Both camps offer full-time onsite medical staff. All counselors are trained in seizure recognition/first aid. Both camps cost $400. Partial and full camp scholarships are available on a limited basis. For more information please contact Lloyd Brown, Epilepsy Foundation of Georgia, 1-800-527-7105 or lloyd@epilepsyga.org.

**ILLINOIS**

**Epilepsy Foundation of Greater Chicago**  
**Camp Blackhawk**  
**July 19–24**

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. The cost is $600; however camperships are available for qualified individuals, based on availability and financial need. Priority acceptance into Camp Blackhawk 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 1-800-273-6027 x202 or mtaylor@epilepsychicago.org.

**Epilepsy Foundation of Greater Southern Illinois**  
**Camp Roehr**  
**June 7–12**

Located at Hickory Shores Resort on Carlyle Lake, children ages 6–18 with epilepsy will participate in activities such as swimming, fishing, miniature golf, paddle boats, tennis, basketball, horse-
shoes and arts and crafts. The cost is $450 per child. Limited scholarships are available for those who qualify. Visit our Web site for camper applications at www.efgreateril.org or contact Trudy Baxter at 618-236-2181 x104 or e-mail trudyepilepsy@sbcglobal.net for further information.

**Epilepsy Foundation North/ Central Illinois Iowa & Nebraska**

Partnerships with a variety of different organizations so kids can find the camp that’s “Just right!”

*Dates of camp: variable throughout summer*

Children and teens with epilepsy have the opportunity to participate in a variety of programs, depending on their needs and interests. We partner with the YMCA of the Rock River Valley’s Camp Winnebago program. This is a week-long day camp with the option of one overnight. It runs throughout the summer. We also partner with the Rockford Park District Therapeutic Recreation program to offer recreational opportunities for children and teens with epilepsy who have more involved needs. These programs, for children pre-K–21, depending on the camp, also run throughout the summer. The cost depends on the program, and financial assistance is available. Please contact Shea Godwin at 815-964-2689, x25, sgodwin@efncil.org.

**IOWA**

Epilepsy Foundation North/ Central Illinois Iowa & Nebraska

Partnerships with a variety of different organizations so kids can find the camp that’s “Just right!”

*Dates of camp: variable throughout summer*

(See above Illinois listing)

**KANSAS**

Epilepsy Foundation of Kansas and Western Missouri

Camp Shing

June 5–7

Camp Shing is located at the Tall Oaks Conference Center in Linwood, Kan. It’s a weekend camp for children and teenagers, ages 6–17, with epilepsy. Camp Shing provides the kids with great opportunities to build new friendships and participate in swimming, archery, sand volleyball, horseback riding, camp fires and astronomy, and more! They will also be able to enjoy a magician, karaoke and zoo animals! The cost is $80 for the first person and $30 for every person after that. Scholarships are available upon request for those who qualify. Contact Sean Taylor or Dominique Thomas at 816-444-2800, or epilepsy2@efha.org.

Jason Fleishman Summer Camp

July 12–16

(See Colorado listing on page 13)

**KENTUCKY**

Epilepsy Foundation of Kentuckiana

The Center for Courageous Kids*

June 22–25

The Center for Courageous Kids is a medical camping facility open to children between the developmental and chronological ages of 7–15 with specific medical needs. Children from any city, state or country will enjoy total access to every feature and program of the camp, including horseback riding, bowling, swimming, woodworking, arts and crafts, basketball, climbing wall, campfire singalongs, archery and more! The onsite medical support structure provides the kids with great opportunities to build new friendships and participate in swimming, archery, sand volleyball, horseback riding, camp fires and astronomy, and more! They will also be able to enjoy a magician, karaoke and zoo animals! The cost is $80 for the first person and $30 for every person after that. Scholarships are available upon request for those who qualify. Contact Sean Taylor or Dominique Thomas at 816-444-2800, or epilepsy2@efha.org.

*Camp has no geographic guidelines*

allows the child with special medical needs to fully participate in the camping experience. Parents can be confident their child will receive the special care they need in a safe, specially designed and professionally staffed facility where the medical presence is purposely kept in the background. There is no charge to children or their families, but The Center for Courageous Kids expects the referring agency/affiliate to provide $300 per camper they refer to them to assist in subsidizing the cost of their camp. For more information contact Judy Snoddy, Camper Recruiter, at 270-618-2900 or jsnoddy@couragouskids.org or visit www.courageouskids.org.

**LOUISIANA**

Med-Camps of Louisiana, Inc.

Camp Shining Stars (For Children Living with Epilepsy & Seizure Disorder)

July 5–10

Med-Camps of Louisiana holds a series of one-week, fun-filled camps each summer free of charge for children living in Louisiana and facing the challenges of a variety of physical and mental disabilities. The camp is free of charge for children who qualify. Ages of children: 6–16. Located at Camp Alabama, at the intersection of Highways 145 and 821, about 4 miles north of Interstate 20. Take the Choudrant-Sibley Exit 93. For more information, visit our Web site www.medcamps.com, e-mail info@medcamps.com or call 318-329-8405.

**MASSACHUSETTS AND RHODE ISLAND**

Epilepsy Foundation of Massachusetts and Rhode Island

Camp Wee Kan Tu

June 19–24

The camp was founded for children with epilepsy in the Massachusetts and Rhode Island area, to provide them with a safe place to participate in a welcoming camp environment. The camp offers children and teens ages 8–17 with epilepsy an overnight program full of traditional camp fun and adventure. It provides them with the personal and medical supervision that gives parents peace of mind with our dedicated team of counselors and volunteers. For children ages 8–17. The cost is $1,200 less scholarship monies raised by the EFMRI, with the total cost per child $425.

Continued on page 15
Financial aid is available. For more information please contact Sarajune Dagen, RN, at sdagen@partners.org.

**MICHIGAN**

**Epilepsy Foundation of Michigan**

**Camp Discovery**

**June 28–July 2**

Camp Discovery 2009, held at Sherman Lake YMCA Outdoor Center in Augusta, Mich., is a 5-day and 4-night camp for youth with epilepsy, ages 8–17. Campers enjoy all the activities such as swimming, rock-wall climbing, horseback riding, arts and crafts, canoeing and more. Camp Discovery is staffed with Epilepsy Foundation staff, experienced camp counselors and a fully staffed medical team including a pediatric neurologist and at least 8 registered nurses and residents experienced in the treatment of epilepsy. The cost is $800. Financial assistance is available. Contact Sheryl Darroch at 1-800-377-6226 option 1, ext. 231 or sdarroch@epilepsymichigan.org.

**MISSISSIPPI**

**Epilepsy Foundation of Mississippi**

**Alvin P. Flannes Summer Camp**

**June 2–6**

The Alvin P. Flannes Summer Camp, an overnight camp for kids ages 8–16 with epilepsy, will be held at Camp Wesley Pines in Gallman, Miss. This full camp experience that includes canoeing, swimming, arts and crafts, rope course, horseback riding, water slide and team games is staffed by Epilepsy Foundation personnel and medical professionals. The camp is offered free of charge to any child in Mississippi with a primary diagnosis of epilepsy. Contact Kristin Lape at 601-936-5222 or e-mail kristinmsepilepsy@bellsouth.net for more information.

**NEBRASKA**

**Epilepsy Foundation North/Central Illinois Iowa & Nebraska**

**Permissions with a variety of different organizations so kids can find the camp that’s “Just right!”**

**Dates of camp:** variable throughout summer

(See Illinois listing on page 14)

**NEW JERSEY**

**Epilepsy Foundation of New Jersey**

**Camp NOVA**

**August 16–22**

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 $875 (3:1 and 2:1 ratio) or $1,075 (1:1 ratio) plus a $50 non-refundable application fee. Financial aid is available. For more information, contact Liza Gundell at 1-800-336-5843 or lgefnj@aol.com.

**Mighty Mike’s Bounce Out the Stigma™ Basketball Camp**

**July 27–31, August 3–7, August 10–14, August 17–21**

Mighty Mike’s Bounce Out the Stigma™ Basketball Camp are 4 separate week-long basketball day camps located throughout the state of New Jersey for children with emotional, learning and motor disabilities. It is a great opportunity for children ages 8–18 to have fun, interact with other children and learn in a safe environment with excellent supervision and positive peer support. Guest speakers and parent workshops will highlight camp and we will have a full-time nurse on staff. The camp costs $300 for 1 week, $500 for 2 weeks, $800 for 3 weeks and $1,000 for 4 weeks. All applicants will be contacted and screened accordingly. Scholarships are available for qualified individuals, based on availability and financial need. Please contact Patrick Connelly at the Epilepsy Foundation of New Jersey at 973-244-0850 or pconnelly@efnj.com.

**NEW MEXICO**

**Jason Fleishman Summer Camp**

**July 12–16**

(See Colorado listing on page 13)

**NEW YORK**

**Epilepsy Foundation Rochester-Syracuse-Binghamton**

**Camp EAGR**

**August 16–22**

Camp EAGR is the Epilepsy Foundation of Rochester-Syracuse-Binghamton’s week-long 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, wall climbing, canoeing and arts and crafts. Along with approximately 35 qualified counselors, Camp EAGR has a neurologist and registered nurses who remain at camp the entire week. The cost is $400 and scholarships are available. For more information, please contact Camp Director Mike Radell at 1-800-724-7930 ext. 2702 or 585-442-4430 ext. 2702 or mradell@epilepsy-uny.org.
Epilepsy Foundation of Northeastern New York, Inc.
Camp scholarships (of up to $250 to the camps 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. Contact Deborah Bain, program coordinator, at 518-456-7501 or dbain@epilepsyeny.com.

NORTH CAROLINA
Epilepsy Foundation of North Carolina
Camp Carefree
Epilepsy week: June 28–July 4
Siblings week: June 21–27 (for well siblings who live with chronically ill children)
Camp Carefree provides a free, one-week camping 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 disabled or seriously ill parent. Contact Michelle Richardson at 336-427-6099 or visit www.campcarefree.org.

NORTH DAKOTA
Epilepsy Foundation of Minnesota
Camp Oz
June 21–26
(See Minnesota listing on page 15)

OHIO
Epilepsy Foundation of Central Ohio
Camp Firebird
July 5–July 9
Camp Firebird 2009, located at Recreation Unlimited in Ashley, Ohio, is a week-long overnight camp for children and teenagers, ages 7–17, with a diagnosis of epilepsy. It’s 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 $170 plus a $35 application fee. Financial aid is based upon availability. Please contact Rachel Sweatte at 614-315-0572 or rsweatte@epilepsy-ohio.org for more information.

OREGON
Epilepsy Foundation Northwest
Camp Discovery
August 27–30
Camp Discovery 2009, located at Camp Colman near Gig Harbor, Wash., is a 3-night/4-day overnight camp for children and teenagers, ages 7–17 with epilepsy and their siblings. It’s a great opportunity for kids to experience the fun of camp activities—archery, rock climbing, huge swing, canoeing and waterfront activities, hiking, arts and crafts, campfire games, and more—all designed to be accessible and adapted to campers’ individual needs and abilities, all in a safe, medically moni- tored setting. The cost is free to kids with epilepsy, $200 for siblings and $125 for one-on-one aides. Scholarships are available for qualified individuals, based on availability and financial need. For more information, please contact Alta Hancock at 503-228-7651, or ahancock@epilepsynw.org.

PENNSYLVANIA
Epilepsy Foundation Western/Central Pennsylvania
Camp Frog
July 5–11, at Camp Fitch
June 21–27, at Camp Conrad Weiser
Camp Frog is a week-long residential program that places extra supportive 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, Penn., and Camp Conrad Weiser in Wernersville, Penn. 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 $445–$625. Financial assistance is available through the Steve “Froggy” Morris/G. Peter Rockwell Endowment Fund. Contact Jordan Hinds at 1-800-361-5885 or jhinds@efwp.org or Gretchen Knaub at 1-800-336-0301 or gknaub@efwp.org.

Epilepsy Foundation Eastern Pennsylvania
Camp Achieve at Camp Green Lane
August 23–28
Camp Achieve at Camp Green Lane, Green Lane, Penn., is a 6-day overnight camp for children, preteens and teens 8–17 with a primary diagnosis of epilepsy/seizure disorder. Camp Achieve provides a unique opportunity for campers to meet others who are living with the same 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, EFPEA staff and Camp Green Lane counselors. The camp is one of the 22 counties of New York served by this affiliate. Contact Deborah Bain, program coordinator, at 518-456-7501 or dbain@epilepsyeny.com.
The cost is $250. Scholarships are available for qualified individuals. For more information, please contact Jean Gardyne, at 215-629-5003 x110, PA toll-free 1-800-887-7165, x110 or camp@efepa.org.

**Camp Chameleon**
**June 5–7**
Camp Chameleon, located at Camp Victory in Millville, Penn., is a week-long overnight camp for children and teenagers, ages 6–18, with a seizure disorder. It is our mission for children with seizure disorders to meet their peers who may have similar challenges while having fun. Our camp activities include swimming, fishing, rope course, paddle boats, art and crafts—all under the watchful eye of a full medical staff and trained personal. The cost is $50 and financial aid is available. For more information call Barbara Branda at 570-523-7748 or e-mail bbranda@ptd.net or visit http://campchameleon.org/ (Please note the date on the Web site is currently wrong.)

**RHODE ISLAND**
**Epilepsy Foundation of Massachusetts and Rhode Island**
**Camp Wee Kan Tu**
**June 19–24**
(See Massachusetts listing on page 14)

**SOUTH CAROLINA**
**Epilepsy Foundation of South Carolina**
**Camp River Run**
For information, contact Erin Stone at 803-798-8502, 866-616-4866 or erin@epilepsysc.org.

**TENNESSEE**
**Epilepsy Foundation of East Tennessee**
**Camp Discovery**
**July 5–10**
For young people ages 7–19 (adults with epilepsy over age 19 can attend camp on a different week). The cost is $350 per camper. Financial assistance is available. Applications are due to the Foundation office by May 31st. Contact Pam Hughes at 1-800-951-4991 or 865-522-4991.

**Epilepsy Foundation of Middle and West Tennessee**
**Camp Courageous Kids**
**June 22–27**
For children and teens ages 7–15. Campers will enjoy fishing, swimming, archery, arts and crafts, horseback riding and much more. There is no cost to attend. Contact Joyce Whitmer at 1-800-244-0768 or jwhitmer@epilepsyttn.org for more information or to register.

**TEXAS**
**Epilepsy Foundation of Southeast Texas**
**Camp for All**
**Open all year**
Camp for All was founded by a group that realized there was a need to an accessible recreational and camping facility for southeast Texas’s special needs population. The camp was designed and built in collaboration with 19 different area health organizations and serves people with a wide variety of disabilities. Facilities include two large lakes, a main lodge, 18 cabins, covered gym/pavilion, equestrian center, small animal farm, nature center, tree house and crafts barn as well as a fishing pier, canoe dock, aquatics center, ROPEs course, archery range, baseball field, and nature trails. All areas are wheelchair accessible and barrier free. Visit our Web site for upcoming events, a calendar and more information: www.campforall.org, or call 979-289-3752.

**Epilepsy Foundation Texas**
**Kamp Kaleidoscope**
**July 12–18**
Kamp Kaleidoscope, located at YMCA Collin County Adventure Camp in Anna, Texas, is a week-long overnight camp for teenagers, ages 15–19, with epilepsy. Our campers are given the chance to flourish through challenging new experiences and relationships with others who share the commonality seizure disorders bring. Activities include fishing, archery, field sports, a dance, swimming, canoeing and much more! Our camper to counselor ratio is 4:1, a pediatric neurologist, neurology nurses and staff from the Epilepsy Foundation of Texas are also onsite at all times. CAMP IS FREE to all campers, although donations are greatly appreciated. Contact Kristin Schkade at 1-888-548-9716 or kschkade@eftx.org for more information and an application.

**Camp Spike ‘n’ Wave®**
**June 14–20**
Located at Camp for All in Burton, Texas, Camp Spike ‘n’ Wave® is a week-long overnight camp for children ages 8–14 with epilepsy. All activities, including horseback riding, rock climbing, challenge course, art and crafts, canoeing, archery, and biking, to name a few, are designed to allow ALL campers to participate and be challenged to their own highest ability. Our camper to counselor ratio is 3:1, and a pediatric neurologist, neurology nurses and staff from the Epilepsy Foundation of Texas are also onsite at all times. CAMP IS FREE to all campers, although donations are greatly appreciated. Contact Kristin Schkade at 1-888-548-9716 or kschkade@eftx.org for more information and an application.

**Epilepsy Foundation**
**West Texas**
**Camp EFWT**
**July 24–27**
Camp EFWT 2009, located at Ceta Canyon in Happy, Texas, is a weekend overnight camp for children ages and teenagers, ages 8–16 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 cost is free but space is limited to the first 60 campers. Contact Laura Bullard or Lee Ann Shaw at 877-706-2345, or e-mail laura@efwt.org or leeann@efwt.org.

UTAH
Jason Fleishman Summer Camp
July 12–16
(See Colorado listing on page 13)

VIRGINIA
Epilepsy Foundation of Virginia
4H and Family Camp
July 20–24 and August 2–7
The Epilepsy Foundation is partnering with two camps to help kids with epilepsy have a fabulous time: 1) Near Williamsburg, eastern Virginia on the James River, with rafting, swimming and history. July 20–24 for children ages 9–13, and 2) Family Camp week with mountains (Blue Ridge Mountains) and of course Thomas Jefferson, August 2–7 in Charlottesville for children of all ages. Cost is $150–$1,000 depending on the camp. All people who sign up via srb3m@virginia.edu will receive an EFVA stipend. Full aid available when need shown. For more information contact Suzanne Bischoff at 434-924-8660 or srb3m@virginia.edu.

WASHINGTON
Epilepsy Foundation Northwest
Camp Discovery
August 27–30
(See Oregon listing on page 16)

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 Va. For more information, please contact Melissa Stallings at 301-918-2121 or mstallings@efa.org.

WISCONSIN
Epilepsy Foundations of Wisconsin
Camp Phoenix
July 19–24
Camp Phoenix 2009, located at the Wisconsin Lions Camp in Rosholt, Wisc., is a week-long overnight camp for children and teenagers ages 8–17 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 cost is $600. Scholarships are available for qualified individuals, based on availability and financial need. For more information, please contact your local affiliate (see below).

Adult Retreat at Wisconsin Lions Camp
August 21–23
The Adult Retreat, located at the Wisconsin Lions Camp in Rosholt, Wisc., is a 3-day, 2-night camp for adults with epilepsy. It’s a great opportunity for adults to experience the fun of camp activities—like swimming, fishing, sports, hiking and more—all in a safe setting designed to be accessible and adapted to campers’ individual needs and abilities. The cost is $150. Scholarships may be available for qualified individuals, based on availability and financial need. Contact your local affiliate (see below).

Epilepsy Foundation
Central and Northeast Wisconsin
1-800-924-9932
Ann Hubbard, 715-341-5811 or annhubbard@efcnw.com

Epilepsy Foundation
South Central Wisconsin
1-800-657-4929
Jane Meyer, 608-442-5555 or janemeyer@wisc.edu

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

Epilepsy Foundation
Southern Wisconsin
1-800-693-2287
Jeanne Lee or Carolyn Parker at 608-755-1821 or efsw@choiceone-mail.com

Epilepsy Foundation of Western Wisconsin
1-800-924-2105
Lou Kelsey 715-834-4455 or lkelseyefww@sbcglobal.net

PUERTO RICO
Sociedad Puertorriqueña de Epilepsia
Encuentro Recreativo y Educacional 2009
June 8–12
Our agency celebrates annually a summer camp called Encuentro Recreativo y Recreativo para Niños y Jovenes con Epilepsia. This year we expect about 100 children and adolescents between the ages of 5 and 16 who have epilepsy, along with children and adolescents who have epilepsy and other special conditions. Participants come from families with few economic resources. The purpose of this summer camp is to show participating children and adolescents that epilepsy is not a barrier, that you can have epilepsy and still live a wonderful life. Many activities focus on promotion of talents, strengths and capacities using a diverse array of activities that involve art, education, sports and interaction among participants. For more information please contact Alex Ramirez Torres, 787-782-6200, or aramirez@sociedadepilepsiarpr.org

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.
The epilepsy community received very good news in 2008: The Food and Drug Administration approved not one, but two new antiepileptic drugs, lacosamide (Vimpat) and rufinamide (Banzel). Even though more than 10 antiepileptic drugs are in common use for the treatment of epilepsy (see Table 1), new drugs are needed because, according to a 2004 study, as many as 40 percent of people with epilepsy still have uncontrolled seizures or unacceptable side effects. Because many drugs have different mechanisms of action, seizures may respond to a new drug even though one or more other drugs have already been tried. Consequently, the more medication choices that are available, the better the chances for seizure control and fewer or less severe side effects.

Two New Antiepileptic Drugs

Lacosamide was approved for the adjunctive (add-on) treatment of partial onset seizures in people with epilepsy 17 years of age or older (see Table 2). Partial seizures are the most common type of seizure. Lacosamide appears to have two unique mechanisms of action, which may increase its likelihood of effectiveness; it increases sodium channel slow inactivation and modulates CRMP-2 (collapsin response mediator protein-2). Lacosamide was tested in more than 1,000 people with epilepsy and received FDA approval in October 2008.

Rufinamide was approved for the adjunctive treatment of seizures in Lennox-Gastaut syndrome in children 4 years and older (Table 2). Lennox-Gastaut syndrome affects only a small percentage of people with epilepsy, but it is one of the most difficult epilepsies to control. Rufinamide works by prolonging sodium channel inactivation. Rufinamide was tested in more than 100 patients with Lennox-Gastaut syndrome and received FDA approval in November 2008. It was especially effective in

<table>
<thead>
<tr>
<th>TABLE 1. ANTIEPILEPTIC DRUGS IN COMMON USE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brand Name</td>
</tr>
<tr>
<td>-------------</td>
</tr>
<tr>
<td>Dilantin</td>
</tr>
<tr>
<td>Depakote</td>
</tr>
<tr>
<td>Felbatol</td>
</tr>
<tr>
<td>Gabitril</td>
</tr>
<tr>
<td>Keppra</td>
</tr>
<tr>
<td>Lamictal</td>
</tr>
<tr>
<td>Lyrica</td>
</tr>
<tr>
<td>Neurontin</td>
</tr>
<tr>
<td>Tegretol</td>
</tr>
<tr>
<td>Trileptal</td>
</tr>
<tr>
<td>Zonegran</td>
</tr>
</tbody>
</table>

| Others      |              |                        |           |                     |            |               |              |

<table>
<thead>
<tr>
<th>TABLE 2. RECENTLY APPROVED ANTIEPILEPTIC DRUGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brand Name</td>
</tr>
<tr>
<td>-------------</td>
</tr>
<tr>
<td>Banzel</td>
</tr>
<tr>
<td>Vimpat</td>
</tr>
</tbody>
</table>

*CRMP-2 (collapsin response mediated protein-2)
**PR interval (time from the P wave to the R wave on the electrocardiogram (EKG))
drop attacks, reducing them by 42.5 percent. More studies are underway to determine whether rufinamide may also be effective in controlling partial seizures. People with uncontrolled seizures interested in participating in these or other clinical trials should contact their neurologist, a nearby epilepsy center or visit www.clinicaltrials.gov.

Drugs in Development

Progress in the development of a variety of new drugs for epilepsy was presented in December 2008 at the American Epilepsy Society meeting in Seattle. Three of these, carisbamate, eslicarbazepine and retigabine, are in Phase III testing for the add-on treatment of partial seizures and may soon seek approval from the FDA. A fourth drug, vigabatrin (Sabril), was recently recommended for approval by an FDA advisory committee for the add-on treatment of refractory partial seizures in adults and monotherapy treatment of infantile spasms. A fifth drug, ganaxolone, is in an earlier phase of testing (Phase II) for partial seizures and infantile spasms. Information on these five investigational drugs is summarized in the Table 3.

In 1998, the FDA did not approve vigabatrin for partial seizures because of concerns about visual side effects. The most recent application to the FDA for partial seizures included more research on visual side effects, as well as an indication for monotherapy treatment of infantile spasms. A decision from the FDA regarding the approval of vigabatrin for these two indications is expected in the very near future. For more information, visit www.fda.gov.

Ganaxolone,* a synthetic neurosteroid, modulates gamma aminobutyric acid (GABA) A receptors in the brain. It is being developed as add-on therapy for infantile spasms and partial seizures in adults. Currently, there are no FDA–approved antiepileptic drugs for the treatment of infantile spasms. Phase III studies of ganaxolone, with larger numbers of patients, are expected to begin later in 2010.

John Krayacich, CEO of Marinus Pharmaceuticals, the company developing ganaxolone, said, “Ganaxolone is the only neurosteroid in development for epilepsy and one of the more novel mechanisms in quite some time. We anticipate initiating Phase 2b and discussing the results with the FDA.”

In addition to the recent progress in the approval of new antiepileptic drugs, there have been many patient-friendly advances in terms of new and improved drug formulations. For example, extended-release preparations

“...

New Formulations

In addition to the recent progress in the approval of new antiepileptic drugs, there have been many patient-friendly advances in terms of new and improved drug formulations. For example, extended-release preparations

continued on page 21

TABLE 3. SELECTED ANTIEPILEPTIC DRUGS IN DEVELOPMENT*

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Average Dosage (mg/day)</th>
<th>Frequency</th>
<th>Mechanism of Action</th>
<th>Indication</th>
<th>Adverse Events</th>
<th>Phase**</th>
<th>Manufacturer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carisbamate</td>
<td>200 400</td>
<td>Twice a day</td>
<td>Modulates sodium and calcium channels</td>
<td>Partial seizures</td>
<td>Dizziness Somnolence</td>
<td>III</td>
<td>Ortho-McNeil</td>
</tr>
<tr>
<td>Eslicarbazepine acetate</td>
<td>400 800 1200 1500</td>
<td>Once a day</td>
<td>Sodium channel blocker</td>
<td>Partial seizures</td>
<td>Dizziness Somnolence Headache</td>
<td>III</td>
<td>Bial-Portela and Co</td>
</tr>
<tr>
<td>Ganaxolone</td>
<td>Not yet determined</td>
<td>Two or three times a day, liquid or capsule</td>
<td>Enhances GABA mediated neurotransmission</td>
<td>1. Infantile spasms 2. Partial seizures 3. Catamenial seizures</td>
<td>Dizziness Somnolence Headache</td>
<td>II</td>
<td>Marinus</td>
</tr>
<tr>
<td>Retigabine</td>
<td>600 900 1200</td>
<td>Three times a day</td>
<td>Opens neuron specific potassium channels and increases M-current***</td>
<td>Partial seizures</td>
<td>Dizziness Somnolence Fatigue</td>
<td>III</td>
<td>GSK and Valeant</td>
</tr>
<tr>
<td>Vigabatrin</td>
<td>1000-3000</td>
<td>Twice a day</td>
<td>Irreversible inhibitor GABA transaminase</td>
<td>1. Partial seizures 2. Infantile spasms</td>
<td>Visual field defect Fatigue Somnolence</td>
<td>III</td>
<td>Ovation</td>
</tr>
</tbody>
</table>

*These drugs are not FDA approved and the information in the table may change when and if the drugs are approved

**Phase II drugs are early in clinical development and Phase III have had more extensive clinical trials

GABA-gamma-aminobutyric acid

***M-current is a noninactivating potassium current found in many neurons

2009 • ISSUE 2 epilepsyUSA 20
are now available for Depakote (Depakote ER), Keppra (Keppra XR) and Tegretol (Tegretol XR). An extended release preparation may soon be available for Lamictal (Lamictal XR). Extended release formulations need be taken only once or twice a day and may have fewer and less severe side effects than the parent compound. However, these preparations are often more expensive than non-extended-release formulations.

Intravenous (IV) preparations are available for Depakote, Keppra and a potentially less toxic IV form is available for Dilantin (Cerebyx). The availability of an IV form allows patients to receive the medication when they cannot take oral medication, such as around the time of surgery or when sick with the flu or other illness. Intravenous formulations may also be useful for seizure emergencies such as status epilepticus, however the formulations mentioned above are not FDA approved for this use. Oral solutions and chewable tablets are also available for some drugs, which provide additional options for patients who have difficulty swallowing pills.

The Good News

Two new drugs have been approved for epilepsy, lacosamide for partial seizures, and rufinamide for Lennox-Gastaut syndrome. Many other antiepileptic drugs are under development. Three of these, carisbamate, eslicarbazepine, and retigabine, have been tested in Phase III trials for partial seizures and may receive FDA approval in the near future. A fourth drug, ganaxolone, is being tested for partial seizures and infantile spasms. Modifications of existing drugs, such as extended release, IV, liquid and chewable forms, have made these antiepileptic drugs more user-friendly. As treatment options increase, there is good reason to believe that more and more people will achieve seizure control without suffering side effects.

For more information about lacosamide and rufinamide, consult each company’s Web site: www.vimpat.com (lacosamide) and www.banzel.com (rufinamide). Both drugs are now available by prescription.

*The author participated in early clinical trials of ganaxolone.

Dr. Wilner is the author of Epilepsy: 199 Answers, Demos Publications. The book is available through our online store at epilepsyfoundation.org.

We want to hear from you!

Give us your feedback. Share a personal story. Ask a question.

e-mail: editor@efa.org

g: epilepsyUSA, 8301 Professional Place, Landover, MD 20785-2238

All letters to epilepsyUSA must include your full name and home address.

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: Accounting/Jeanne A. Carpenter Epilepsy Legal Defense Fund
8301 Professional Place
Landover, MD 20785-2238

Jeanne A. Carpenter
Epilepsy Legal Defense Fund
National Walk for Epilepsy Kit
This special kit of memories from the historic third National Walk for Epilepsy on March 28 includes a DVD with extensive footage from the Walk, a one-year subscription to EpilepsyUSA, a full-color commemorative poster and the official song called “The Walk.” Ready 6-8 weeks after the Walk.
Item Number: 137497    $29.95 (includes shipping & handling)

Missing Michael
A Mother’s Story of Love, Epilepsy, and Perseverance
By Mary Lou Connolly
A mother’s moving account of her son’s struggle with epilepsy, its complications and the effect of drugs used to treat it. Connolly writes of societal indifference and the harm that can result from a lack of compassion and tolerance toward people with disabilities.
Item Number: 137256    $15.50

The Spirit Catches You and You Fall Down
By Anne Fadiman
When a Laotian child with epilepsy and her parents encounter the American health care system, cultural differences lead to treatment crises, misunderstandings and sadness. A compelling tale of how cultural beliefs can profoundly affect thoughts about illness and response to treatment.
Item Number: 137729    $15.00

Show Your Support in Style!
*Available Only Online!*
Thirty products from hats to bags to shirts available in many colors and sizes and embroidered with the Epilepsy Foundation logo. Hurry and order yours today!

To order these products from the Epilepsy Foundation Marketplace:
Go to www.epilepsyfoundation.org
Click on ‘STORE’
Then on ‘Epilepsy Foundation Logo Apparel’
Or call (866) 330-2718
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 towards 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
Attention: Daniell Griffin, Sr. Director Individual Giving
Phone: 301-918-3741   Fax: 301-577-9056   E-mail: dgriffin@efa.org