Epilepsy in the African-American Community: Access, Education and Advocacy

Epilepsy in the Workplace: To Disclose or Not?
message from the chair

Our cover story on epilepsy in African-American communities highlights an unfortunate reality—that epilepsy is still not being talked about enough, especially in certain demographic areas. The good news is the Epilepsy Foundation is taking the lead in educating the communities most significantly affected by epilepsy in order to raise awareness and broaden the dialogue.

Not only is the incidence of epilepsy higher in African-American communities than in others, the stigma also can be greater. We all know one of the most important ways to dispel stigma is to provide accurate information about epilepsy so everyone in the community knows what it is—from first responders, to people with epilepsy, to caregivers, to the public in general. Pertinent, reliable information will allow people in all communities to get the best access to care; ask the right questions; become active participants in their own health care; and participate in all life activities without discrimination with respect to their condition. I’m proud to be associated with an organization that knows where to focus and how to get the right information to the people who need it most.

While we are dedicated to helping individual communities, we are also actively involved in helping to ensure all Americans with disabilities are protected against discrimination. We recently played a pivotal role in an unprecedented alliance between the disability and employer communities who worked together to secure the promise of the Americans with Disabilities Act, which was signed into law 18 years ago. Just prior to the landmark legislation’s 18th anniversary, the ADA Amendments Act of 2008 passed the House of Representatives by an overwhelming margin. This bill will ensure that all people with disabilities are protected under the law. We were thrilled to see our hard work make a difference.

The momentum continued on Friday, August 1, when Senators Harkin (D-Iowa) and Hatch (R-Utah) introduced the legislation on the Senate floor with an impressive show of bipartisan support. A lot of credit goes to our national office and our affiliates around the country who mobilized their constituents and convinced Congress to support this vital legislation. It was a group effort that showcased what we can accomplish on the national stage, with the grass roots support of our affiliates, public policy institute, and others who share our passion for all people with disabilities.

It’s been a very busy summer and now it’s time to get ready for fall and back to school. My two children are grown, but I remember getting them ready for school like it was yesterday. My wife and I knew education would be a key factor in determining their future, so we always emphasized its importance. Parents of children with epilepsy have a few more steps to take into consideration to get their kids ready for school, so we have a special section devoted to seizure preparedness for back to school.

This issue is packed with information on a wide variety of topics. I hope it will make your transition from the relaxed days of summer to the busier fall season easier.

Steve Sabatini
ON THE COVER

6 Epilepsy in the African-American Community: Access, Education and Advocacy  BY ALIYAH BARUCHIN
For many African-Americans with epilepsy, access to appropriate care is the central problem around which all others seem to orbit.

15 Epilepsy in the Workplace: To Disclose or Not?  BY GARY GROSS  People with epilepsy are often confronted with the issue of whether they are required to disclose information about their health condition to their employers.

17 Getting Ready for Back to School: Seizure Management for Students  BY EILEEN FRUEH

12 / ADHD and Epilepsy  BY ANDREW WILNER, M.D., FACP, FAAN  ADHD is one of the most common mental disorders that develop in children. As many as one-third of children with epilepsy experience some trouble with ADHD.

14 / Epilepsy in Perspective  BY LISA BOYLAN  Nick McCumber, a longtime supporter of the Epilepsy Foundation, has a unique way of looking at many things, including epilepsy.

19 / Camp Provides Opportunity for Kids with Epilepsy  BY ANDRIA FARRELL

20 / Administration of Medication and Other Treatments in Schools, Daycare and Camps

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The following is adapted from a speech given by Denise Pease, Secretary of the Epilepsy Foundation Board of Directors, at the NIH Curing Epilepsy conference. Denise is the Chair of the Know the Difference campaign—an initiative to raise awareness of epilepsy in the African American community. (See article on page 5.)

My name is Denise L. Pease. I am a woman who lives every day with the challenge of having epilepsy. Thirteen years ago, on March 30th, 1995, my world came crashing down when I suffered what I first thought was a minor head injury as a result of a car accident. My doctor initially diagnosed post-traumatic shock. But in the weeks and months to follow, I lost my ability to speak effectively. Then my ability to read and write left me. Suddenly I, who dealt with the titans of industry and often discussed complex banking issues with world leaders, was unable to make change at the corner store. To be real about it—as the younger generation would say—I often could not find my way from my childhood home to the corner store and back without assistance.

Before the accident, I was recognized as one of the innovative leaders in regulatory banking. I went from being a vibrant woman with a bright future to being a candidate for an extended adult care facility. The world had once been my oyster, and the oyster just closed right up.

My neurologist never mentioned seizures or epilepsy. I told him that I would lose track of time; I was confused. It took a while for the final diagnosis of epilepsy, it took even longer—an additional five years—to find the right medication. In retrospect, some of the medications might have been more effective if I did not have the problems with my memory and cognition. There were many months, or should I say, in the middle of a month, where I could have none of one medication and the full regimen of another. Then there were side effects—the weight gain that was coupled with the lethargy, the depression and the fear.

I underwent extensive therapy to become the semblance of the woman I am today. I was not well-coiffed. I would show up at the doctor’s office looking more like someone who was homeless instead of a homeowner.

It was difficult.

When I was at my worst, to be honest, I don’t think it was as disturbing as when my skills and sense of self slowly began to return. It was then that I remembered being at the White House for a holiday celebration and the life I had led. In addition to the medical and formal therapies, I used to watch and mimic Oprah Winfrey to regain my speaking skills. I watched public television’s Learn to Read several times a day to re-learn to read. I desperately wanted to return to a fully productive life. It was then that I found the Epilepsy Foundation.

Today, I still must take antiseizure medication. I have not had a seizure in several months. Unfortunately, the more I meet people and speak about epilepsy the more I realize that my experience with the diagnosis and treatment of epilepsy is not unique. However, the opportunity to return to work still eludes so many people who struggle with seizures. I am grateful to be one of the few who has gone from a person receiving disability benefits to a proud citizen who contributes substantially to the revenue stream of my city and state and our federal government.

Still, while I am really blessed, the stigma of having epilepsy is present. With continued research into new treatment options, my blessings will be a reality for so many others. It is my hope and prayer that continued research will one day get us to our end goal—a cure. If not a cure, then the ability for the millions of us to live a life that is seizure-free, side-effects free and without stigma.

*In My Own Words* is a column featuring the voices of people affected by epilepsy.
Landmark Disability Rights Bill Passes in the House of Representatives

BY LISA BOYLAN, EDITOR, EPILEPSYUSA, AND HANS FRIEDHOFF, MANAGING EDITOR, epilepsyfoundation.org

The ADA Amendments Act of 2008 passed the House on June 25, 2008, by an overwhelming margin, 402-17, marking a historic move toward securing the promise of the original Americans with Disabilities Act, signed into law by President George H. W. Bush in 1990.

In a show of bipartisan unity, congressional leaders and key members of the disability and employer communities held a press conference in support of the bill shortly before it went to the House floor for a vote.

The bill clarifies for the courts that people with disabilities should not lose civil rights protections because their condition is treatable with medication or can be addressed with the help of assistive technology. The bill also clarifies the definition of disability to include all individuals whose impairment substantially limits a major life activity.

House Majority Leader Steny Hoyer (D-Md.), who introduced the original ADA, recalled the ADA’s pledge to protect all people with disabilities from discrimination but acknowledged that the doors Congress intended to open, “still aren’t open all the way.” He cited recent Supreme Court rulings, which have eroded the ADA, leaving people with disabilities including epilepsy, diabetestes, cancer and mental illness, without the protections Congress envisioned when the ADA was originally enacted. He said, to a chorus of cheers, “We’re here today to burst the doors open once and for all!”

Rep. Jim Sensenbrenner (R-Wisc.) said, “As a result of the ADA Amendments Act, a person with a disability will no longer have to do what no other person who claims discrimination under the civil rights act has to do, and that is to first prove their qualifications and then prove discrimination.”

Rep. Jerry Nadler, (D-N.Y.) said the bill “strikes the right balance between the needs of the employers and the needs of those with disabilities.”

Elizabeth Goldberg, founder of the Epilepsy Foundation’s Youth Council, speaking on behalf of people living with a disability, recalled fears in job interviews over disclosing her disability and the prospect of being denied employment for something she could not control. She said, after the press conference, “I’m here to speak for those who can’t speak for themselves but, more importantly, I’m here for those who are afraid to speak for themselves, people who feel stigmatized and fear discrimination.”

Rep. Rob Andrews (D-N.J.) argued the bill would help stimulate the country’s economy. By opening the doors of employment to all Americans, the new legislation would “once again put our best team on the field” and “make America grow.”

Eric Hargis, president and CEO of the Epilepsy Foundation, said the ADA was passed originally with overwhelming bipartisan support and believed this new legislation required the same sort of collaboration to craft language that reflected the common goals of the employer and disability communities. Noting the current legislation’s broad base of support he said, “That is why this bill is going to sail through the House today.”

Editor’s note: On August 1, 2008, Senators Harkin (D-Iowa) and Hatch (R-Utah) introduced the ADA Amendments Act on the Senate floor with a large showing of bipartisan support. Contact your senator to help ensure the bill’s passage, in order to secure the promise of the ADA, as it was originally envisioned. For more information, visit epilepsyfoundation.org/advocacy.

2008 • ISSUE 4 EpilepsyUSA 4

STUDY EXAMINES DRIVING HABITS OF PEOPLE WITH EPILEPSY

Research shows that people with epilepsy continue to drive despite medical restrictions. In a study from the Ohio State University Medical Center, 26 percent of patients with epilepsy reported having an accident due to a seizure and 19 percent said they were dishonest about seizures in order to drive.

The study, published in the journal Epilepsy and Behavior, found that prior attitudes and behavior are difficult to change and participants’ main reason for driving was due to their occupation.

“Instead of focusing on the dangers of driving for patients, it is important to discuss with patients how to overcome perceived and actual barriers to transportation,” says Lucretia Long, author of the study and assistant professor of neurology at The Ohio State University Medical Center. “Addressing health behaviors while counseling persons with epilepsy is also crucial.”

The study also suggests that persons with epilepsy would benefit from employers’ assistance with workplace programs and legislation supporting transportation resources. Allowing people with epilepsy to work from home and providing adequate public assistance are a few options.

The study found that 35 percent of patients said they were not confident to use public transportation. Some feared the possibility of having a seizure, which increases the risk for injury while walking to public bus stations. In addition, a large percentage felt that family and friends were not available to assist with transportation needs.

John Elliot is the co-author and clinical research data manager in the Department of Neurology at The Ohio State University Medical Center.

The study included a total of 213 participants who were asked to complete a 46-item questionnaire with all responses submitted anonymously.

SOURCE: THE OHIO STATE UNIVERSITY MEDICAL CENTER

Editor’s note: For people with frequent seizures, it may be dangerous to wait for regular bus or rail services at busy intersections or on open railway platforms, where they may encounter danger during a seizure. Paratransit is a transportation service, required under the Americans with Disabilities Act, available to assist eligible individuals who cannot use the regular public transportation services independently. The services transport the individuals to and from their destinations. Paratransit services can be available if you meet specified requirements. For instance, eligibility can be established by showing that limitations associated with epilepsy prevent the individual from traveling to or from a bus stop or train station some or all of the time. To inquire about paratransit services, contact your local transit authority. For more information on driving and epilepsy, visit epilepsyfoundation.org/answerplace.

IN BRIEF

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Lance Curtis greets a visitor to his family’s New Jersey home with a calm smile and a confident handshake. At 17, an age when many teens seem awkward or at odds with the world, Lance carries himself with a composure that belies his age. Diagnosed with epilepsy at the age of 7, he spent several years running the gamut of medications and finally landed on the right combination: he has now been seizure-free for three years. “Actually, I’m doing very well,” he says happily. He loves school, has his learner’s permit, and is looking forward to college. He describes his future in one ready word: “Bright.”

The only problem is that Lance Curtis may be an anomaly. As an African-American with epilepsy, he is part of a group that often faces some of the most serious challenges in epilepsy treatment. According to the Epilepsy Foundation, more than 350,000 of the over 3 million Americans with epilepsy, or some 12 percent, are African-American. African-Americans are more likely to be diagnosed with epilepsy than Caucasians; they more often experience status epilepticus, a medical emergency in which a seizure continues for 10 minutes or more without stopping; and they are at an increased risk for Sudden Unexpected Death from Epilepsy (SUDEP).

In a 2006 review of racial and ethnic disparities in epilepsy treatment, a team from the University of Cincinnati found that African-American patients frequently had limited access to both epilepsy specialists and antiepileptic drugs, and they cited, among many others, a 1996 study which found that head trauma, substance abuse, and noncompliance with treatment plans all contributed to poor outcomes for an inner-city African-American population with epilepsy.

In that kind of a racial/medical landscape, what makes the difference for someone like Lance Curtis? First and foremost, as Lance and his family will tell you, he is getting the right care. For many African-Americans with epilepsy, access to appropriate care continues on page 7.
care is the central problem around which all others seem to orbit.

Lance is a patient at the Comprehensive Epilepsy Center at St. Barnabas Medical Center in Livingston, N.J., where he sees Dr. Orrin Devinsky, a renowned neurologist who also directs the NYU/Mt. Sinai Comprehensive Epilepsy Center in New York City. The Curtises adore Dr. Devinsky and his team, whom they found after trying two other neurologists. “Everybody loves that man. You can’t say anything bad about him,” says Lance’s father, Leroy. Lance’s mother, Valarie, is authoritative and unhesitating in talking about the path that she, Lance and their family have traveled since his diagnosis, and about how easily his care, and their lives, could have gone another way. “The first doctor we went to, I think that [race] would’ve been an issue; I think I was treated differently,” says Valarie. “Race matters, and I think it matters who you go to. I don’t think race will matter if it’s a doctor like Dr. Devinsky.”

Apart from Dr. Devinsky’s expertise, the more general fact that Lance is being treated at a comprehensive epilepsy center is also key, according to Dr. Josiane LaJoie, a pediatric epileptologist at the NYU Comprehensive Epilepsy Center. “I think one of the problems is African-Americans, regardless of their descent”—African-American, African, or West Indian—“having access to tertiary centers where epileptologists are available,” she says.

Because epilepsy treatment can be so expensive, families without good insurance can easily find themselves out in the cold. “Epilepsy treatment is so expensive, families without good insurance can easily find themselves out in the cold.”
patients who are Hispanic—all of which makes many African-American patients with epilepsy in New York City seem invisible.

Dr. LaJoie’s initial conclusion is that many African-Americans are likely being treated simply by local neurologists in their communities rather than taking advantage of the city’s tertiary care centers. And she believes that many others—even those with tonic-clonic seizures—may not be receiving treatment at all, for purely monetary reasons. Because epilepsy treatment can be so expensive, families without good insurance can easily find themselves out in the cold. “I think, number one, it’s access to care,” Dr. LaJoie says. “If they don’t have insurance, where are they going? How are they going to pay for medication?”

The Curtises are a middle-class family—Leroy is a longshoreman, and Valarie runs a financial services business from home—but at one point they found themselves without insurance at a time when Lance’s medications totaled some $2,000 a month. They received financial assistance from family and friends and a nonprofit. “I was like, ‘How can we repay it?’” Valarie remembers. “And they said, ‘The only thing we want you to do is make sure Lance can be all that he can be.’ I’ll remember them always for what they did.”

Yet alongside access and economics come questions of trust and racial disparities in health care for African-Americans that transcend epilepsy alone. Those types of drastic, seemingly ingrained disparities dovetail with a historic mistrust of physicians by many African-Americans, producing a kind of perfect storm of inadequate care.

Some African-Americans with epilepsy are also reluctant to seek emergency care, given notorious precedents such as patients with sickle-cell disease being labeled drug-seekers when they arrive at emergency rooms requiring pain medication. Yet emergency physicians from a variety of urban hospitals feel strongly that in emergency epilepsy care, race is actually not a factor.

“Post-ictal states can result in altered mental status that mimics [alcohol] or other overdose situations,” says Ed Dickinson, M.D., medical editor of the Journal of Emergency Medical Services. “EMT and EMT-P textbooks routinely teach the importance of never assuming that altered mental status is the simple result of intoxication/drug effect. This is a race neutral issue.” And African-American emergency physician Toni Wright, M.D., who has worked at New York’s Harlem Hospital for 14 years, agrees. “Law enforcement, firefighters and EMS in New York City generally are able to differentiate seizures from various intoxications and mental illness,” she says. “I cannot recall any cases where the lack of recognition of a seizure has caused any problems.”

But even more impactful than issues of medical care are questions about the powerful layers of stigma surrounding epilepsy in communities of color. Many African and West Indian cultures believe that epilepsy is a spiritual, rather than medical, condition, or that only certain...
types of episodes are actually epilepsy. “There have been studies that look at perceptions of epilepsy, and some people in that culture only recognize grand mal seizures as epilepsy,” says Dr. LaJoie, “as opposed to partial seizures, which may be taken as spells, or a nervous condition. So it might be lack of awareness that this also is a seizure.” Dr. LaJoie also recalls an African family, settled in the U.S. for a few years already, in which one daughter with epilepsy had been given her own set of cups, plates and cutlery by her parents, to keep other family members from being “exposed” to the disorder. “We were able to talk about it, but I’m not sure things have really changed; I think that takes time,” says Dr. LaJoie. “They’ve heard it their whole lives, and now they’re hearing something contrary from me for the first time.”

That type of stigma persists in African-American communities—a fear of people with epilepsy, a lack of knowledge about the condition or about how to help someone having a seizure, even a sense that epilepsy is used as an excuse for other personal problems or a way of avoiding work. Valarie Curtis remembers an incident with a cousin that still raises her blood pressure. “My cousin said, ‘Oh, yeah, doesn’t Lance have fits or something?’” she recalls. “And I was hot. But I found out from my mom that back in the day, if you had epilepsy, you were put in a mental home, like you were crazy. A lot of people aren’t educated about it.”

Dr. LaJoie agrees that the stigma about epilepsy may be more intense among African-Americans than in some other groups. “There are some studies that show that there’s more stigma in African-American communities, because I think they’re dealing with issues of discrimination already, as far as employment and things like that, and this is just an added factor involved,” she says.

Like most parents of children with epilepsy, Valarie and Leroy have taken direct hits from the stigma that still surrounds the condition, including hearing other parents say that they didn’t want Lance at their homes for sleepovers or even playdates. Lance feels that race has definitely played a role in his experience of having epilepsy. “Peer comments are different depending on who you’re dealing with,” he says. Valarie isn’t as sure how much of a role race has played in the encounters she’s had. “I would tell people straight up, ‘My son has epilepsy.’ So I ran into people who were ignorant, and I don’t know if it was because we were black, or because he has epilepsy, or because he was black and has epilepsy,” she says. “Because you never know. And there’s those people that are ignorant that want to stay ignorant, and then there’s those that want to learn.”

Among African-Americans, as in any community, education about the disorder is key to changing attitudes. This summer the Epilepsy Foundation began Know the Difference, an outreach and education campaign to African-Americans that follows its 2004 campaign, Get the Word Out, which launched in 15 major cities. Get the Word Out operated through barbershops, beauty salons and houses of worship, long used as avenues for disseminating information about a variety of health problems that affect African-Americans. According to Ava DuVernay of DuVernay Public Relations, whose Urban Beauty Collective partnered with the barbershop and salon arms of the program, Get the Word Out was “definitely a success—well received by member shop owners who reported strong interest among their customers.”

For the most part, the Curtises have been happy to find that among their extended family and friends, continued on page 11
The know the difference campaign was created to respond to the growing number of African-Americans who are living with epilepsy. Epilepsy awareness is lower among African-Americans because of misinformation, lack of access to health care and stigma associated with the condition. An estimated 350,000 African-Americans have epilepsy, and nearly 24,000 new cases are diagnosed each year. For more information about the campaign, visit www.epilepsyfoundation.org/knowthedifference.
stigma hasn’t been an issue. People who know and love Lance have been extremely supportive, willing to help in any way they can and eager to learn what Lance might need from them if he should have a seizure in their company. “Actually, the older family members are better at making sure he does things he’s supposed to,” says Leroy. “You’re supposed to take this? You take this now. You’re supposed to eat? You eat.” And that’s good.” Lance agrees that his grandparents have been anchors for him. “They were there to help and educate, and see what’s going on,” he says.

For Valarie, one of the biggest questions about epilepsy and race comes down to the ability to advocate for one’s child, as she has done so forcefully and so successfully for Lance. “You have to speak up, you have to ask questions, and you have to go and be hands-on. If it’s not there, then make it; if you need a support group, start one. Whatever it is that you need, you’ve got to be an advocate for your child. If you don’t agree, don’t accept anything: your child deserves the best,” she says. “And that’s when I think race becomes an issue, because I don’t think African-Americans know how to advocate as much for themselves—it’s harder. If you’re of a lower economic status or lower educational status, you don’t know what to ask a doctor; whatever the doctor says, you just take. And he might tell you very minute things; he might not explain everything to you. That’s where money matters, and race matters.”

At the moment, Lance Curtis is keeping busy—incredibly busy. He works on plays and the school paper; he bowls and holds down two part-time jobs. He volunteers with a community organization called United For Service, and August 2007 was his first stint as a counselor at Camp EAGR in Warsaw, New York, a camp sponsored by the Epilepsy Foundation of Rochester-Syracuse-Binghamton that Lance and Leroy have attended together for the last several years. Because he believes that he expresses himself well, that he dresses well and that his personality puts people at ease—all of which are true—Lance plans to make a career in public relations. It seems like a natural fit for him.

Based on their experience over the last nine years, the Curtises have straightforward advice for any African-American family that finds itself dealing with epilepsy. Leroy says that volunteering at Lance’s camp has taught him an enormous amount about what people with epilepsy are capable of. “The worst thing the children can do with me is tell me they can’t do anything. I don’t believe that,” he says. “Yes, you have epilepsy, but that doesn’t mean you can’t function; it doesn’t mean you can’t do what others do. You just have to try a little harder, and do little things to help yourself.” Valarie is equally positive, and equally determined. “I encourage husbands and wives to learn together, advocate together, and support each other. Find the best doctor you can find. And talk to the family; make sure you get your children involved,” she says. “Epilepsy is not a death sentence. It’s something you can live with—and you can achieve anything you want with it.”

“I encourage husbands and wives to learn together, advocate together, and support each other. Find the best doctor you can find. And talk to the family; make sure you get your children involved.”

Valarie Curtis
ADHD and Epilepsy

BY ANDREW N. WILNER, MD, FACP, FAAN

ADHD and Epilepsy—A Common Combination

Children with attention deficit hyperactivity disorder (ADHD) and their parents are frequent visitors to the offices of pediatric neurologists. About 5 percent of children in the general population have ADHD, and as many as one-third of children with epilepsy experience some trouble with ADHD (Dunn et al 2003). EpilepsyUSA spoke with three pediatric neurologists who care for children with epilepsy and ADHD.

"If you think a child has ADHD, he might actually have epilepsy. This possibility has to remain in the back of your mind, especially for the kids who are the ‘daydreamers.’ For the children who are hyperactive, epilepsy is less likely to be the explanation."

L. Matthew Frank, M.D., Associate Professor of Neurology and Pediatrics, Eastern Virginia Medical School, Norfolk, Virginia, told me about a young boy he recently saw in clinic:

"Jacob* is a perfectly healthy 7-year-old who did fine in first grade, but when he began second grade he started having problems in school. He couldn’t complete assignments, had trouble following directions, made mistakes in his work and sometimes didn’t even go outside for recess. One day when the teacher was reprimanding him for not getting up for lunch, she realized that he was staring and blinking his eyes. When she touched him, he didn’t respond. Over the next few days, the teacher noticed multiple periods during the day when Jacob was inattentively staring off into the distance, constantly blinking his eyes and making subtle mouth movements. When she discussed these events with Jacob’s parents, they acknowledged that they had seen similar behaviors at the dinner table. A few days later, they visited their pediatrician who asked Jacob to hyperventilate. When he did, he had a staring spell. When I saw Jacob in the office, the EEG showed bursts of 3 Hertz spike and wave, confirming the diagnosis of childhood absence epilepsy."

Dr. Frank enrolled Jacob in a clinical trial that is comparing three drugs, ethosuximide, lamotrigine, and

What is Attention Deficit Hyperactivity Disorder?

Attention Deficit Hyperactivity Disorder, ADHD, is one of the most common mental disorders that develop in children. Children with ADHD have impaired functioning in multiple settings, including home, school and in relationships with peers. If untreated, the disorder can have long-term adverse effects into adolescence and adulthood.

Signs & Symptoms

Symptoms of ADHD will appear over the course of many months, and include:

• Impulsiveness: a child who acts quickly without thinking first.
• Hyperactivity: a child who can’t sit still, walks, runs, or climbs around when others are seated, talks when others are talking.
• Inattention: a child who daydreams or seems to be in another world, is sidetracked by what is going on around him or her.

How is it diagnosed?

If ADHD is suspected, the diagnosis should be made by a professional with training in ADHD. This includes child psychiatrists, psychologists, developmental/behavioral pediatricians, behavioral neurologists and clinical social workers. After ruling out other possible reasons for the child’s behavior, the specialist checks the child’s school and medical records and talks to teachers and parents who have filled out a behavior rating scale for the child. A diagnosis is made only after all this information has been considered.

Treatment

Effective treatments for ADHD are available, and include behavioral therapy and medications.

Getting Help: Locate Services

Locate mental health services in your area, affordable health care and listings of professionals and organizations.

*All the names have been changed to protect the privacy of the individuals.
valproate, for the treatment of childhood absence epilepsy. Because the trial is ongoing, Dr. Frank doesn’t know yet which drug Jacob is taking, but it seems to be working. He has had no more staring spells and his grades are back up.

Paul Knowles, M.D., Director of Pediatric Neurology, T.C. Thompson Children’s Hospital, Chattanooga, Tenn., said, “If you think a child has ADHD, he might actually have epilepsy. This possibility has to remain in the back of your mind, especially for the kids who are the ‘daydreamers.’ For the children who are hyperactive, epilepsy is less likely to be the explanation.”

Michael Chez, M.D., Director of Pediatric Neurology at Sutter Neuroscience Institute, Sacramento, Calif., and Associate Professor of Neurology at the University of California, Davis, Davis, Calif., cautioned that all children who are inattentive at school don’t have absence epilepsy. He said, “If a child has lapses of attention both at school and at home, the diagnosis is often absence epilepsy. But if the staring spells just occur at school, it is probably attention deficit hyperactivity disorder. An EEG can be helpful to confirm the diagnosis of epilepsy.”

Dr. Knowles offered another clinical observation, “If a child is inattentive and doesn’t respond when you call him, it may be ADHD or a seizure. But if you touch the child and he still doesn’t respond, that is more suggestive of a seizure. Children with ADHD will respond when you touch them. It’s really easy to turn off your ears, but it’s much harder to tune out touch.”

Dr. Chez told me about one of his patients, Susan*, a 6-year-old who has had partial complex seizures since the age of 7 months. She was taking one antiepileptic drug and had occasional breakthrough seizures. Susan’s parents had noticed significant hyperactivity and impulse control problems at home. Dr. Chez gave forms to her teachers to fill out to confirm that the hyperactivity was happening at school and asked her parents to fill out the forms as well. Dr. Chez commonly uses two screening instruments for ADHD—the Connors ADHD Rating Scale and the Vanderbilt ADHD Rating Scale. Several other scales exist for measuring ADHD symptoms.

The results from the teachers and parents confirmed Susan’s hyperactive and impulsive behavior. This is important because the diagnosis of ADHD depends upon abnormal functioning in two or more settings, in this case, both home and school.

Dr. Chez made sure that the dose of Susan’s seizure medication was appropriate, and that the seizure control was as good as he could get it, and then added stimulant medication for ADHD. Susan became less hyperactive and started doing better in school.

Dr. Chez said, “ADHD and seizure medication can be taken together. Usually seizure control is not adversely affected by stimulants.” Though stimulants are safe in children with epilepsy, it is still important to monitor seizure control and to be aware of potential drug interactions. If the child has side effects from stimulants, then atomoxetine (Strattera) has been used in children with epilepsy with improvement in attention and reduction of hyperactivity.

Dr. Chez offered some advice regarding the treatment of ADHD, “Parents should not be afraid to address the attention and learning issues that sometimes accompany epilepsy. I would estimate that about 40 percent of children with epilepsy may have ADHD or attention problems as a comorbidity. I think that a lot of parents often have guilt about putting their children on medication for behavior issues, because they think they should be better parents, or they have heard horror stories about medication side effects. But parents need to talk to a well informed physician about how to treat these conditions and make a sound decision based on facts and not some of the misinformation that is out there. Parents should realize that treating the symptoms of ADHD in children with epilepsy will help their children function at a higher level, and the children will have a higher level of self esteem.”

References

Andrew Wilner is the author of EPILEPSY: 199 ANSWERS.
Nick McCumber, a longtime supporter of the Epilepsy Foundation, was diagnosed with epilepsy when he was around 7 years old. Nick is active with the Foundation because he strongly believes in protecting the rights of people with epilepsy through initiatives such as the Jeanne A. Carpenter Epilepsy Legal Defense Fund, which works to advance the rights of people with epilepsy by changing discriminatory practices, policies and laws.

Nick lives in Boulder, Colo. and is a photographer. His photographs are mystical montages—double-exposed images with enigmatic titles that don’t seem to match their subjects. Nick has a unique point of view. He is reluctant to use the word “abstract” to describe his photographs and is similarly hesitant to accept many people’s common perception that living with epilepsy must be a terrible thing. He says, “I just don’t find it to be that way.”

Nick’s seizures are fairly well under control, but he still can’t drive, a fact that does not deter him. He takes taxis everywhere, however the frequent comings and goings of the taxis to his house ended up taking a toll on the lamppost he had at the end of his circular driveway. Taxi drivers kept hitting the lamppost as they backed out, until one night a driver knocked the lamppost flat.

Nick said, “I went to the manager of the cab company and asked him, ‘Could I have two doors off the cab you guys use for parts?’” The manager didn’t bat an eye and asked if he wanted them delivered. Nick said, “Yes.”

He bought a new lamppost and had the taxicab doors welded to the post, creating an unconventional landmark for police cars and other service vehicles trying to make their way in his neighborhood. He effectively fashioned a barricade made up of salvaged parts of taxis—the unwitting perpetrators of damage to his property—to protect the replacement for his hard-hit lamppost.

It is this elasticity of vision and resourcefulness that his older brother, John McCumber, a professor of philosophy at UCLA, came to appreciate in his younger brother. John was in boarding school when Nick was young and was not familiar with his brother’s seizures and the impact epilepsy had on his life. He knew his brother had a positive attitude and did not complain about his epilepsy, and that was about the extent of it. John realizes, however, that Nick’s seizures have taken him to places—not altogether negative—he could never envision. He said Nick’s seizures seem to have a “mystical dimension to them,” which has taught John “a certain amount of humility as a philosopher.” He explained that philosophers tend to assume they know what knowledge is, but his brother’s experiences with seizures have taught him otherwise. John also said he initially didn’t get his brother’s complex photographic images, but now he sees “he’s really on to things that take me quite a while to figure out.” He said, “If you’re the big brother, you’re supposed to be the teacher, but that has not been the case.”

Clearly Nick’s way of looking at things—from epilepsy, to images in front of his camera, to a damaged lamppost—provides him with a unique angle that helps topple conventional viewpoints and preconceived notions. He says, “People with epilepsy have a different perspective.” This must be true since he has even taught his older brother, a professor trained in the logic-seeking discipline of philosophy, that there are some realities we can never define.
People with epilepsy are often confronted with the issue of whether they are required to disclose information about their health condition to their employers. Prior to the passage of the Americans with Disabilities Act (ADA) in 1990, employers often used disability-related inquiries or medical examinations to exclude or otherwise discriminate against individuals with disabilities—particularly “invisible” disabilities such as epilepsy—without determining if the individual was capable of doing the job. In passing the ADA, Congress was careful to address this concern by including provisions restricting this practice. These provisions reflect Congress’ intent to both protect the rights of workers to be judged on merit alone, while also protecting the rights of employers to make reasonable inquiries about workers’ qualifications. Here are some guidelines on disclosing your condition to an employer. Some of the information is based on guidance issued by the Equal Employment Opportunity Commission (EEOC), which enforces the employment provisions of the ADA. For more information, visit eeoc.gov.

“Job applicants with epilepsy should know that medical inquiries are permissible only after a conditional offer of employment has been made.”

Job Seekers: Job applicants with epilepsy should know that medical inquiries are permissible only after a conditional offer of employment has been made. Prior to a job offer, an employer may not inquire about whether you have a disability or about its severity; the employer also cannot make any inquiry that is likely to elicit information about a disability. An employer may not ask an applicant questions about epilepsy or seizures, prescription drugs, or missed work due to a health condition. Applicants are not required to disclose their health condition during the job application process, unless there is a need for an accommodation in that process. If an applicant voluntarily discloses that he has epilepsy, the employer can only ask if an accommodation is needed and if so, what type. Learning that an applicant has epilepsy is not a sufficient reason for a potential employer to withdraw a job offer if the individual can perform the essential duties of the job, with or without reasonable accommodations (see below for information on reasonable accommodation).

After an Offer Has Been Made: An employer may require that the individual respond to a medical inquiry or undergo a medical examination, as long as all applicants in that job class or category are required to undergo such an exam or inquiry. An employer may ask the applicant questions about his epilepsy, regarding the use of medication, the type and frequency of seizures and the need for assistance if he has a seizure at work. The employer also could send the applicant for a follow-up medical examination or ask him to submit documentation from his doctor answering questions specifically designed to assess the applicant’s ability to safely perform the job’s functions.
**After Employment Begins:** A person may experience a seizure in the workplace or an employer may begin to notice that the person’s medical condition might be affecting his ability to perform the job or do it safely. In these instances, an employer may make a medical inquiry or ask the employee to submit to a medical examination. However, such inquiry or examination must be job-related and consistent with business necessity. This means there must be a valid reason to believe that an employee’s ability to perform the job is impaired by epilepsy (or some other medical condition), or that the condition poses a significant risk of substantial harm to himself or others. In addition, an employer may ask an employee with epilepsy to justify the use of sick leave by providing a doctor’s note or other explanation, as long as it requires all employees to do so. If an employer requires an employee to go to a health care professional of the employer’s choice, the employer must pay all costs associated with the visit(s).

**Safety Concerns:** Prior to denying a job opportunity to an employee or applicant whom the employer believes poses a threat to health or safety, the employer must conduct an individualized assessment of the person’s ability to safely do the essential functions of the job. The assessment must be based on “reasonable medical judgment that relies on the most current medical knowledge and/or the best objective evidence.” To meet this burden, in the case of an applicant or employee with epilepsy, the individual should be examined by a neurologist, preferably one with expertise in epilepsy. Any medical examination must be limited to determining whether the individual can perform his job without posing a significant threat to health or safety, with or without reasonable accommodation. Accordingly, in most situations, an employer cannot request an employee’s complete medical records because they are likely to contain information unrelated to whether the employee can perform the essential functions of the position without posing such a direct risk.

**Voluntary Disclosure Related to Reasonable Accommodation:** Where an employee with epilepsy requests an accommodation, he may be required to substantiate that his condition is a disability covered under the ADA or the state’s antidiscrimination law, and that he needs a reasonable accommodation. (Note, however, that based on decisions of the Supreme Court, people with conditions controlled with medication or other “mitigating” measures, may not be protected from employment discrimination under the ADA.* This may include persons with epilepsy whose seizures are controlled with medication. For more information on these issues, see the Foundation’s Web site at epilepsyfoundation.org/advocacy.) Job accommodations include alterations in duties, the work environment, or the way job functions are performed that enable a qualified individual with a disability to perform the essential functions of the position. For a discussion of possible accommodations for persons with epilepsy, see the Job Accommodation Network publication at www.jan.wvu.edu/media/epilepsy.html.

The documentation to be provided, such as a letter from the physician, should describe the individual’s seizures and their severity and frequency, along with any side effects of anti-seizure medication; indicate the extent to which the epilepsy limits the employee’s ability to perform the job duties; and justify why the requested reasonable accommodation is needed. The employer may require the employee go to an appropriate health care professional of the employer’s choice if the employee provides insufficient documentation from his treating physician (or other health care professional). In this case, the employer should explain why the documentation is insufficient and allow the employee an opportunity to provide the missing information in a timely manner. The employer also should consider consulting with the employee’s doctor (with the employee’s consent) before requiring the employee to go to a health care professional of its choice.

The EEOC’s guidance on epilepsy in the workplace notes that:

> Although many individuals who have seizures do not require any first aid or assistance, an employee who might need assistance may want to work with his employer to create a plan of action that

*continued on page 21*

> The decision to disclose is a personal one that should be based on a weighing of the potential costs and benefits.”

*The Epilepsy Foundation is working diligently to secure the promise of the ADA by supporting the ADA Amendments Act of 2008 (see article on page 4).*
As many as 325,000 school-age children, ages 5–14, have epilepsy. Thankfully, with medication, surgery, a special diet, or vagus nerve stimulation, most go to school and fully participate in school activities.

It is important for parents and schools to work together to create a safe and supportive environment for students with seizures to grow, learn and achieve their full academic potential.

Meeting the Teacher

Parents should take the time to meet with their child’s teacher before the beginning of each school year to discuss what type(s) of seizures their child has, how to recognize them, how the teacher should respond to them, and how the teacher can prepare the other students so that they understand and accept the child. The Epilepsy Foundation offers several sample forms that can aid in this process. (For more information on these forms, see sidebar.)

Working with Your School Nurse

Many children with epilepsy control their seizures with antiseizure medications that must be taken from one to four times a day. In many states, the school nurse has the primary responsibility for administering these medications during school hours.

School nurses also work with the parents to develop seizure action plans, a tool that organizes and communicates the student’s health care and educational needs. A seizure action plan helps ensure a safe environment for the student, while maximizing opportunities for learning and development.

The plan should be specific for each student and should include instructions for both basic first aid as well as appropriate emergency responses to ensure the child’s safety in the event of an acute seizure emergency. Many action plans include the following instructions for what do do if someone is having a seizure (see box at right).

For all seizures:
- Keep calm
- Remain with the student until he or she is fully alert
- Do not offer food or drink
- Reassure the student after the seizure is over

For absence seizures:
- Make sure the student has not missed key parts of the lesson

For simple partial seizures:
- Ensure the student is fully oriented to person, place and time before resuming activities
- Comfort and reassure the student if he/she seems confused or frightened

For complex partial seizures:
- Speak to the student softly and calmly
- Reassure the student that he/she is safe
- Move harmful obstacles to ensure safety
- Allow wandering student to walk in a contained area
- Stay with the student until complete awareness of environment is regained
- Help reorient the student if he/she seems confused afterwards

For generalized tonic clonic seizures:
- Stay calm and reassure the student that he/she is safe
- Reassure the other children that the student will be fine shortly
- Ease the student gently to the floor and clear the area around him/her
- Cushion the student’s head
- Turn the student gently on one side
- Do NOT put anything in the student’s mouth
- Do NOT hold the student down
- Let the student rest until full consciousness returns
Of course, each child is unique and parents should work with the school to create an individualized seizure action plan that outlines the specific needs of their particular child. Here are just some of the accommodations that parents may include in their children’s seizure action plans, depending on the child’s unique needs:

- The child should be seated at the front of the classroom so that the teacher can be more aware of his or her seizures and to diminish distractions
- The child should be escorted to the restroom and lunchroom
- When the child participates in activities on rises (e.g. choir), the child should stand on the lowest riser
- The child should have extra test time or untimed tests
- The child should be closely monitored during PE activities
- The child should stay indoors during recess on hot days
- The child should be allowed to wear a hat if needed to dim classroom lights

School nurses also play a key role in helping train teachers and staff to respond appropriately to seizures and in creating a positive environment among teachers, staff, and fellow students with respect to a child with epilepsy. This helps to minimize stigmatizing beliefs, reinforce the need for compassion, and support the student’s positive self-image.

Seizures and School Work

Many children with epilepsy do well in school, but seizures can affect school performance in subtle ways. Seizures can affect a child’s memory and processing skills. After a seizure, some children are unable to remember anything that happened the previous day or immediately afterwards. Medications can also affect a child’s attention span and ability to concentrate.

The care of children with epilepsy is a mutual concern of parents, teachers, school administrators, nurses, and the child’s health care providers. By working together, they can help the child achieve success in school life.

School Forms to Aid in Seizure Management

The Epilepsy Foundation offers several sample forms that can aid in educational planning for students with epilepsy. The free boilerplate forms can be adapted to meet individual and institutional needs. Copies are available for downloading on the Epilepsy Foundation Web site or can be obtained through your local affiliate.

The forms include:

■ **Questionnaire for Parents**

This form is to be completed by the student’s parent(s) to assist school personnel in recognizing a student’s seizure(s) and responding appropriately. It includes space for parents to provide details about the student’s seizure patterns, medications and how they are to be administered, precautions that should be taken during physical education and recess, and other issues. The parents’ questionnaire should be updated annually or when any changes occur.

■ **Student Interview Form**

A student can provide valuable information about his or her epilepsy that is helpful in health management planning. This form is to be completed by the school nurse through an interview with the student. It should be updated every six months or when changes occur.

■ **Seizure Information Sheet**

This form was designed to provide classroom teachers with basic information about a student’s seizures and medication. It should be signed by the school nurse and given to the teachers at the beginning of a school year, when a diagnosis is made, or when changes occur.

■ **Teacher’s Anecdotal Record**

This form is to be completed by the student’s teacher or other school personnel when reporting a seizure(s) and/or medication side effects. It includes space for teachers to record a description of the seizure or behavior observed, what behavior immediately preceded and followed the seizure, what procedures were followed by the teacher/observer, and other details.

To download these forms, visit:
A summer camp experience can be a life-changing event in a child’s life, but for many years, children living with epilepsy did not have that experience.

On June 20, Camp Wee Kan Tu at Camp Wing in Duxbury, Mass. celebrated its 10th anniversary with another summer season of approximately 50 campers, all living with epilepsy. For one week, these children have the opportunity to just be a child among children just like them.

“There are 3 million Americans living with epilepsy,” said Rebecca Oliver, communications coordinator for the Epilepsy Foundation of Massachusetts and Rhode Island. “A child could go his or her whole life without ever seeing a camp; this brings the kids together and sets the stage for a life that can be lived without the stigma they are different. Everyone knows how to take care of them and five minutes later they are back to arts and crafts.”

Camp Wee Kan Tu is made possible through grants and donations, as well as volunteers, Oliver said. Through the Epilepsy Foundation of Massachusetts and Rhode Island, children with epilepsy from Massachusetts, Rhode Island, New Hampshire and Maine have the opportunity to spend a week of fun at camp with children just like them, she said.

Doctors and nurses like Sarajune Dagen and Barbara Dworetzky, doctor of neurology at Brigham and Women’s Hospital, donate their time to provide a safe and healthy camp for the children. Dagen—or Nurse Sara, as she is known—has been a nurse at the camp for eight years. She said she came out one day and never left.

“It is a magical experience,” she said.

With a 2-1 staff-to-child ratio and a full-time nurse and doctor on staff at all times, children with epilepsy can have a normal camp experience without the fear of being looked at weird or made fun if they have a seizure, camp Wee Kan Tu co-founder Jeff Robins said. Robins said he and co-founder Eileen Salmanson heard about an epilepsy camp in Virginia while attending a conference for the American Epilepsy Society in Washington, D.C. The two thought it was a great idea and wanted to begin a camp in New England.

“Here seizures are about as significant of an event as scraping a knee when they fall,” he said. “After a child has a seizure, they get up and return to the activity they were involved in.”

Epilepsy Foundation of Massachusetts and Rhode Island board member Janet Rich said the camp has given her daughter Amanda the opportunity to become a part of a community and see first-hand that there are other children and adults just like her.

“It gives the experience of camp where she would never be able to go to a normal camp because no camp takes on that liability,” she said. “A person with epilepsy in the water is very dangerous; they go on boats, and swimming. It is all supervised to make it a safe environment. They climb a big wall; she would never have that experience. It is a neat place to go and experience what these kids experience. They have top doctors, top nurses, all who volunteer their time. It is an absolutely incredible situation they have created.”

Rich said not only does the camp give Amanda a chance to be kid, it also gives families a chance to relax without the constant worry that their child is in the other room having a seizure.

Amanda, who is now a counselor in training (CIT) at the camp, has been going to camp for nine years. She said she really enjoys all the people at the camp and doing all the activities. She enjoyed the fun of camp so much she wishes she wasn’t a CIT, because she has more work to do and it is more exhausting.

Children can only attend camp until they are 18, after that some of the children have the opportunity to become a CIT or even a counselor.

“It has been very rewarding on all counts,” Rich said. “She (Amanda) can have a normal camp experience where she can’t anywhere else.”

Another unique part of the camp is that several of the counselors have epilepsy, including Deb Mayo, who is also the administrative assistant at the Epilepsy Foundation of Massachusetts and Rhode Island. Mayo’s condition cannot be controlled by medication, and has tonic-clonic or grand mal seizures approximately every three to four months. At 54, she said she wishes they had a camp like this when she was a child; she always wanted to go to camp but never was allowed.

“This place is so exciting, so unbelievable. It’s my love, besides my grandson,” she said.

Lisa Volkening, the woman’s camp leader, had her first continued on page 21
Administration of Medication and Other Treatments in Schools, Daycare and Camps

There are multiple situations in which people with epilepsy who are prescribed FDA-approved treatments, such as rectally administered diazepam (Diastat®) or the VNS (vagus nerve stimulator), have been denied access to school, daycare or school-related activities, or have incurred unnecessary medical risks because educators and child care service providers refuse to make the medications readily available on-site.

For most people, conventional medications that can be taken orally are effective in controlling seizures. A number of children, however, are susceptible to prolonged, cluster or status seizures, which may last longer than 10 minutes and can cause serious injury and even death. For these people, the doctor may prescribe Diastat® to be administered on an emergency basis, or some other similar treatment. Following standard procedures, as prescribed by the treating physician, caretakers such as parents, school nurses, teachers or daycare providers can administer these therapies onsite when a prolonged seizure or cluster of seizures occurs.

The Epilepsy Foundation’s Position

Federal and state laws guarantee every child the right to participate in free, appropriate public education in the least restrictive setting. Schools, camps and day care providers are also required to provide many health-related services, including administering medicine—if needed—to students with disabilities, as either a reasonable accommodation or a related service. The purpose of these laws is to ensure that children with chronic health conditions such as epilepsy can be educated in the least restrictive environment and participate in recreational activities, camp and daycare programs with their peers. Because medicines, including rectally administered diazepam, can be administered by nonmedical personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason to refuse to administer the medication on-site or to deny a child or student access to the program.

Schools and service providers should, along with the child’s parents and as appropriate, the treating physician, develop a plan for ensuring that adequate measures are taken to administer the treatment and that the appropriate staff is properly trained to do so. Such a plan may legally be a part of a Section 504 plan, an IHP, an IEP or simply a plan required to ensure compliance with the ADA; the critical point is that a mutually satisfactory approach that allows the child or student complete access to educational opportunities can and should be developed to cover the potential need, usually remote, for administration of Diastat. The Epilepsy Foundation believes that this approach is not only more desirable than exclusion from a program but also that federal law requires such instruction as either a reasonable accommodation or a related service. Proper planning and adequate instruction will ensure that children with seizures who require these services will be able to participate in school and other activities as the federal law requires.

Editor’s note: For more information on your rights as a parent of a child with epilepsy, visit the Epilepsy Foundation’s Jeanne A. Carpenter Epilepsy Legal Defense Fund at epilepsyfoundation.org/epilepsylegal
includes such information as: who to contact in an emergency; warning signs of a possible seizure; how and when to provide assistance; when to call an ambulance, etc. The employee and employer also should discuss who in the workplace should know this information. Some individuals also might want to ask their employers for an opportunity to educate their co-workers about epilepsy to dispel any misperceptions or unsubstantiated fears they may have about the condition.

Of course, an important consideration in deciding to disclose relates to whether the employer is legally obligated to provide the desired accommodation. If there are questions on this issue, the Foundation’s Jeanne A. Carpenter Epilepsy Legal Defense Fund can provide guidance or make a referral to an attorney who can provide legal help (for information on this program, visit epilepsylegal.org).

If epilepsy is not affecting job performance or relationships in the workplace, it is generally inadvisable to disclose the condition—because discrimination, unfortunately, remains a real possibility. The decision to disclose is a personal one that should be based on a weighing of the potential costs and benefits, including:

- Need for accommodation to perform the job
- Need for accommodation to avoid discipline or termination
- Need for accommodation to protect health and safety
- Whether modification may be obtained without disclosing disability
- Risk of stigma and harassment
- Risk of loss of privacy
- Potential for more successful and supportive employment experience

Gary Gross is the director of the Epilepsy Foundation’s Jeanne A. Carpenter Epilepsy Legal Defense Fund.

For More Information:
Equal Opportunity Employment Commission  
[eeoc.gov](http://eeoc.gov)
Epilepsy Foundation’s advocacy site  
[epilepsyfoundation.org/advocacy](http://epilepsyfoundation.org/advocacy)
The Job Accommodation Network  
[jan.wvu.edu](http://jan.wvu.edu)
Epilepsy Foundation’s Jeanne A. Carpenter Epilepsy Legal Defense Fund  
[epilepsylegal.org](http://epilepsylegal.org)

Dear Editor:

My husband, Tony, is 50 years old and has had epilepsy all of his life. He takes medication to control his seizures. I make sure he takes his medication so his seizures are under control. Tony and I have been married eleven years. When I read the articles in *Epilepsy USA*, we don’t feel so alone in this world.

Sincerely,
Delores Vargas
Concord, Calif.

**letter to the editor**

**We want to hear from you!**

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

**e-mail:** editor@efa.org

**mail:** EpilepsyUSA, 8301 Professional Place, Landover, MD 20785-2238

All letters to *Epilepsy USA* must include your full name and home address.
## MARKETPLACE

### Epilepsy and Pregnancy

*By Stacey Chillemi and Blanca Vasquez, M.D.*

This book gives readers the basic facts they need to help them make medical decisions throughout preconception, pregnancy, labor, delivery, and the early days after childbirth. It includes guidelines for the use of antiepileptic drugs during pregnancy, recommendations and questions to ask their neurologist, recommended daily allowances by age group, glossary, and much more. It’s an essential guide for any woman who has epilepsy and desires to have a child.

*Item Number: 137567  $16.95*

### Koko The Service Dog

*By Lisa Mink, M.S.*

Koko shares his story as a seizure dog in a fun and engaging manner that teaches children important lessons about people with disabilities—that it’s not about what they can’t do, but what they can. This full color true story explains Koko’s role as a seizure response dog and how important service dogs can be in the lives of people with disabilities.

*Item Number: 137569  $14.95*

### Epilepsy: Information for You and Those Who Care About You

*By Elaine Wyllie, M.D.*

This easy-to-understand book provides thoughtful information for people with epilepsy and their parents, friends, teachers and co-workers, as well as for others who want to understand this disorder. Dr. Elaine Wyllie guides you through all aspects of epilepsy, from a definition of seizures and their underlying causes through treatment with medicine or surgery. In this book you will also learn: the myths about epilepsy; what to do when you witness a seizure; the long-term health prospects; whether someone with epilepsy can drive; the psychological side of dealing with epilepsy and how to help children with epilepsy.

*Item Number: 137565  $14.95*

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To place an order for products from the Epilepsy Foundation Marketplace or to subscribe to *EpilepsyUSA*:

Go to [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) and click on ‘STORE’ or call (866) 330-2718 or fax the order to (877) 687-4878

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### ORDER FORM

**PLEASE USE THE ENCLOSED ENVELOPE WITH YOUR ORDER**

**CATMAG**  DM913

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**SUBTOTAL**

| MD residents add 6% sales tax |

**SHIPPING & HANDLING** *(see below)*

**TOTAL**

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(Appplies to all orders. On foreign orders, call for charges.)

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**PLEASE USE THE ENCLOSED ENVELOPE WITH YOUR ORDER**

CATMAG  DM913
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
Attn: Daniell Griffin, Sr. Director Individual Giving
Phone: 301-918-3741   Fax: 301-577-9056   E-mail: dgriffin@efa.org