IT'S TIME FOR BACK TO SCHOOL!

The Magazine of the Epilepsy Foundation

epilepsyUSA

2008 • ISSUE 4

Epilepsy in the African-American Community:

Access, Education and Advocacy

Epilepsy in the Workplace: To Disclose or Not?

www.epilepsyfoundation.org

PHOTO CREDIT: ISTOCKPHOTO/DANIEL RODRIGUEZ

EPILEPSY IN THE AFRICAN-AMERICAN COMMUNITY:

Access, Education and Advocacy

BY ALIYAH BARUCHIN, SPECIAL TO *EPILEPSYUSA*

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

continued on page 7

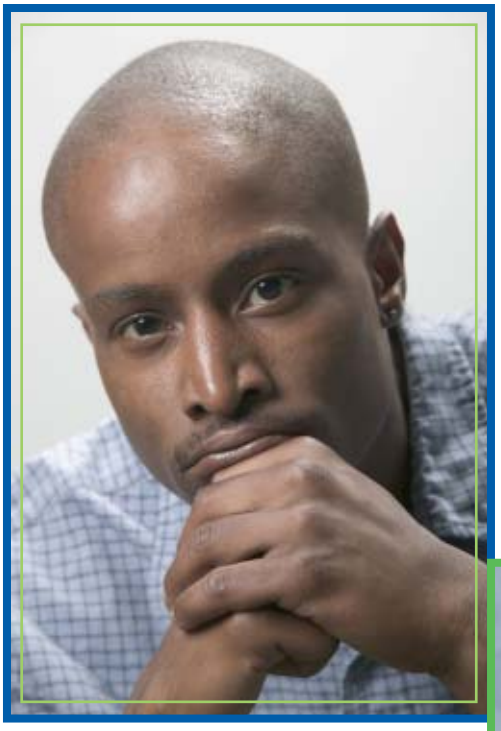
African-Americans are more likely to be diagnosed with epilepsy than Caucasians; they more often experience status epilepticus, a medical emergency in which a seizure continues for 10 minutes or more without stopping; and they are at an increased risk for Sudden Unexpected Death from Epilepsy (SUDEP).

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

Continued from page 6

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.

Both economics and proximity factor into this. Geographic access to comprehensive epilepsy centers is an issue for many Americans who live far from major urban areas. Yet in New York City, home to several epilepsy centers, the problem of access for African-Americans is more complicated. "Comprehensive Epilepsy Centers don't really see people of color. They have to be referred, and they don't get referred, for a whole series of reasons," says Dr. W. Allen Hauser, professor of neurology and epidemiology at Columbia University's Mailman School of Public Health in New York. "In the Washington Heights and Inwood neighborhoods of northern Manhattan, Hauser says, "the primary source of medical care for the black population seems to be the Emergency Room. A lower proportion than whites or Hispanics are connected into either the clinics or to private-practice physicians, and few of them have ever even seen a neurologist. And you don't usually get to a Comprehensive Epilepsy Center until you've seen a neurologist. It really is a problem of access to care."

Dr. LaJoie is putting together a study of where African-Americans in New York City receive care for epilepsy, but locating that care is turning out to be much harder than she'd expected. NYU's Comprehensive Epilepsy Center has a fairly small African-American patient population; Harlem Hospital doesn't have a center of its own; and major centers like Columbia Presbyterian or Bellevue that serve lower-income communities have a majority of

> "Because epilepsy treatment can be so expensive, families without good insurance can easily find themselves out in the cold."

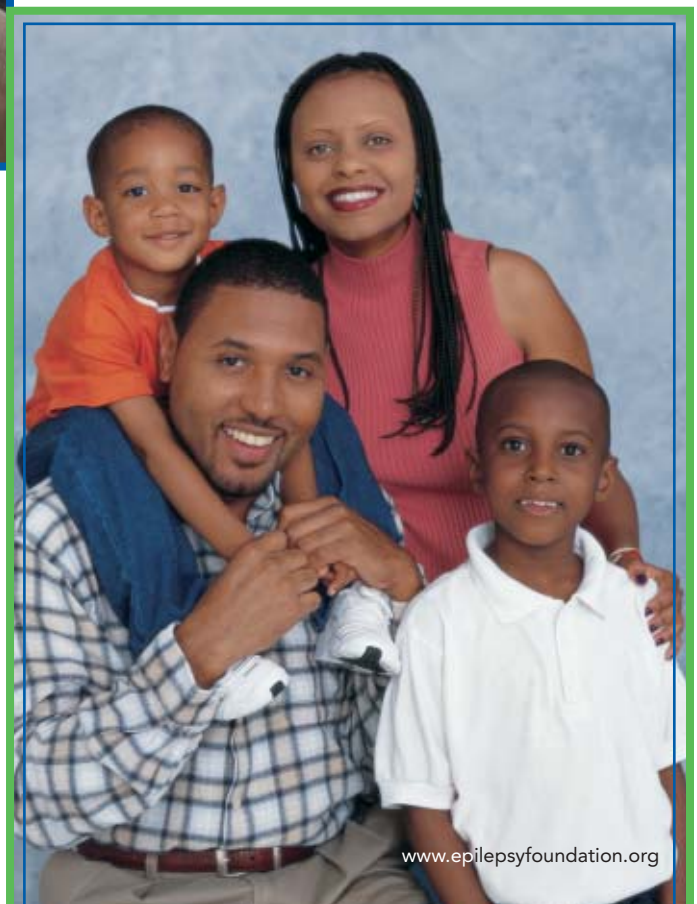


PHOTO CREDITS: LIQUID LIBRARY

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.

Yet alongside access and economics come questions of trust and racial disparities in health care for African-Americans that transcend epilepsy alone. A 2005 study at the University of Alabama by a team led by Dr. Jorge Burneo showed that African-American patients with temporal-lobe epilepsy—classic candidates for surgery—were nearly 60 percent less likely than non-Hispanic white patients to receive surgery in the course of their treatment, though they were treated at the same center, and by the same staff, as their white counterparts. 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.

"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."

"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

continued on page 9

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

Continued from page 8

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."

> "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."

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."

PHOTO CREDIT: LIQUID LIBRARY

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,

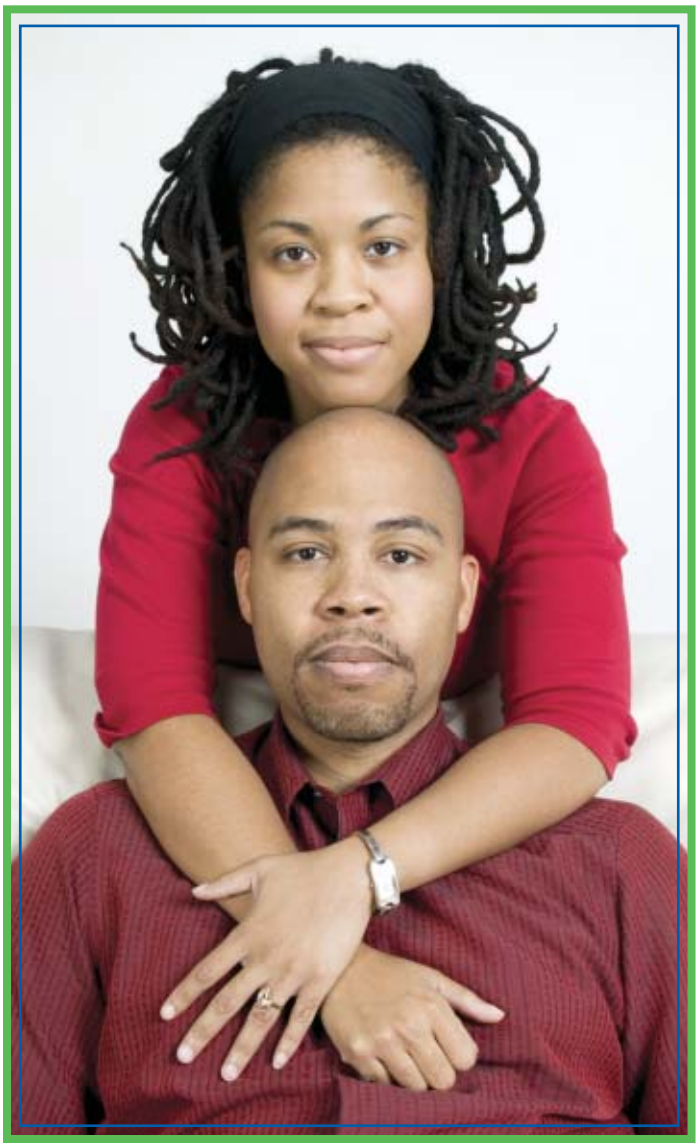
continued on page 11

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

Continued from page 9

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***

PHOTO CREDITS: LIQUID LIBRARY