

The AFRICAN- AMERICAN EXPERIENCE of MS

B Y M A R C E L L A D U R A N D

When your life undergoes a major change, it's only natural to reach out and seek others like yourself. You need to share your questions and your answers, to compare experiences, and above all, to not feel so alone.

But African-Americans develop MS at half the rate of white Americans—one in 1,500 people, rather than one in 750. Moreover, much of the literature about MS on the Web or in print shows mostly white faces. It's all too common to hear "Where is someone who looks like me?" among non-white people with MS. Along with loneliness comes unease. If MS is popularly seen as a whites-only disease—has this affected how doctors and scientists approach it?



MILTON MORRIS

Sisters: Left, Dora Hughes, MD/MPH, has MS and works as health and education policy advisor to Senator Barack Obama, D-III. Right, Mary D. Hughes, MD, is the medical director of the Augusta MS Center in Georgia.

Outside the box: diagnosis and treatment

Kamilah Martin, founder of the Martin MS Alliance Foundation, had her first MS symptoms when she was 16. “They weren’t expecting it in a young African-American female,” she told **InsideMS**. “My doctors were testing me for everything else, from leukemia to rare blood disorders.” But despite this, Martin was diagnosed relatively quickly. “My doctors were amazing; they were very thorough.”

Two major studies seem to support Martin’s positive experience with diagnosis. Both a survey on the health-care experiences of minority populations, completed this summer by the National Opinion Research Center (NORC), and a major study at the Multiple Sclerosis Center at the University of California, San Francisco (UCSF), found little difference in diagnosis between black and white Americans with MS.

The NORC survey also found little systemic racism in MS health care cut-

ting across income and education levels. Instead, at comprehensive care centers, people of all races were getting specialist care. Moreover, the UCSF study found that African-Americans were diagnosed **faster**—one year from onset of symptoms to diagnosis, versus two years from onset to diagnosis for white Americans. “We were very surprised,” said Bruce Cree, MD, PhD, MCR. “This indicates that neurologists are able to diagnose MS regardless of whether the patient is black or white.”

Many black people would be just as surprised as Dr. Cree. It seems logical that

This summer Maryland’s Prince George’s County MS Support Group sailed to Bermuda. “We’re all in various stages of MS,” writes Yvonne Brown, “so we planned the trip six months ahead to make arrangements for individual needs. Our cabin steward even provided sharps boxes for our needles and cold storage for our medications and cooling devices.” Brown, back row, fifth from left, wears her cooling vest.



race and the law of averages would delay diagnosis. Ann Marie Johnson is a patient advocate in Brooklyn who was diagnosed in 2002 and who has written about her experiences in *Healthy Women Today* (www.4woman.gov/editor/mar06/mar06.cfm). "At neighborhood clinics that focus on community needs," Johnson said, "the doctor often looks for the ailments more prominent in that community, such as hypertension, high cholesterol, or diabetes, before going outside of the box."

Even if doctors are as color blind as these two studies suggest when it comes to diagnosing MS, what about treating it?

Should race count in treatment decisions?

Could color blindness lead to less effective treatment? Is MS the same in both races?

"We know that the approach to treating diseases can be different based on race," said Mary D. Hughes, MD, medical director of the Augusta MS Center in Georgia. "Hypertension is a classic example in which we physicians incorporate ethnicity in the decision process for planning therapy."

Some recent studies seem to indicate that MS may take a more severe course in African-Americans. The UCSF study found that "opticospinal" MS, in which symptoms affect the optic nerve and spinal cord, and attacks of "acute transverse myelitis," in which the spinal cord stops transmitting nerve impulses, resulting in paralysis, were seen more frequently in African-Americans



Right: Kamilah Martin, founder of the Martin MS Alliance Foundation; left: Dr. Michael Eric Dyson, professor of African-American and Religious Studies at the University of Pennsylvania, and honorary board member of the Alliance.

than in others. In addition, the onset of MS generally occurred later.

Dr. Hughes cited a 2003 study that found African-Americans had higher rates of relapse after 48 weeks. "This suggests that African-Americans may not be having as robust a response to interferon medication," she said.

Dr. Cree posed the obvious questions: "What is the optimal treatment for African-Americans? What is the optimal treatment for whites?"

To find out, larger studies on ethnic differences in responses to MS medications are needed. In the meantime, Dr. Hughes stresses, a treatment is still far

better than no treatment. African-Americans face the same disconnect as anyone who takes a “disease-modifying” drug. The drug acts against largely silent disease processes, while general MS symptoms, including some attacks, tend to continue.

“I wouldn’t want anyone to just stop their medication because they think their bodies aren’t responding as they should,” Dr. Hughes said.

The cost of being “outside”

“We did everything perfectly,” said Len Chatman, when his wife, Cheryl, was diagnosed in 1990. “But we still found ourselves outside many benefits. African-Americans, Hispanics, and Asians impacted by MS—we all tend to find ourselves outside. Lack of access to health care is a huge discussion.” (Len and Cheryl co-authored **The Art of Living with Multiple Sclerosis*** and now conduct couples workshops for people with MS all around the country.)

Equality of care is an equally painful issue. In an analysis of nursing home residents with MS published in **Ethnicity & Disease** in 2006, researchers at Mississippi State University found that African-American residents did not receive any more therapies or medications than white residents despite being more physically disabled and more cognitively impaired.

As for the NORC survey, which found that care was more or less equal for

***The Art of Living with Multiple Sclerosis: Six Secrets for Managing MS as a Team** by Len and Cheryl Chatman (Two Hearts Publishing, 2006, 152 pp., \$15.95)

What the gene studies show

Mixed heritage provides powerful clues

“Ethnic differences in MS populations could be genetic, or they could be environmental,” Dr. Cree pointed out. “Environmental factors are very difficult to pin down. In contrast, genetic studies may reveal something that we can actually do something about.” An ongoing genetics study at UCSF and Harvard University is closing in on why MS is comparatively rare in African-Americans, and even rarer in Africans.

“On average, 80% of the ancestry of African-Americans is West African and about 20% is European,” said Jorge Oksenberg, PhD, a researcher for the UCSF/Harvard study. “This mixed heritage is extremely valuable in studies of MS, because it allows researchers to compare groups living in similar environments who have distinctly different MS risks. It becomes

African-Americans and white Americans, study leader Claudia Schur, PhD, commented: “We had a national sample, but we didn’t have a representative sample. We knew from the onset that people answering our survey were a bit better educated and better off than the overall MS population.”

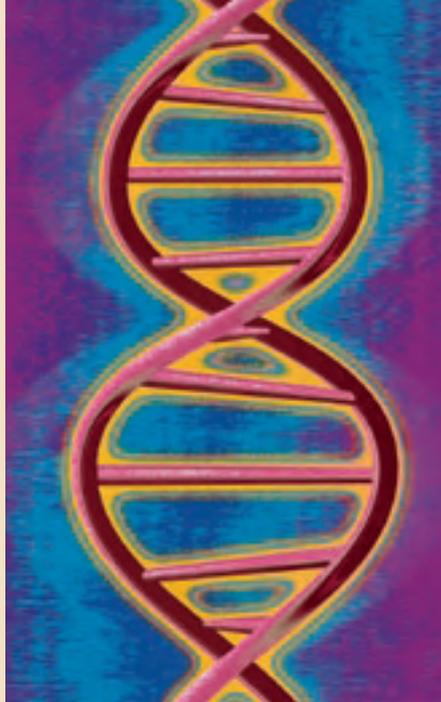
There is no question that income levels affect access to the things that make daily life with MS easier, such as adapted vehicles or home renovations, even exercise

easier to home in on the genes that influence MS susceptibility.”

According to Dr. Cree, findings already demonstrate that African-Americans who have African DNA at a certain site on chromosome number 1 are more resistant to MS. If they have Northern European DNA on that site, they have an increased susceptibility.

Michelle Witherspoon and her sister were both diagnosed with MS and are both participants in this study. “Our father is French and German and our mother African-American,” Michelle said. “My sister and I say, ‘Daddy, you gave us this disease.’”

But the mysteries of MS are not given up so easily. The UCSF researchers have also uncovered an **African** allele (variant DNA coding that produces variations in inherited characteristics) that is “a major susceptibility factor for MS in African-



Americans,” Dr. Cree said.

Moreover, environment tilts the field. When Africans move to the United States or Europe, their risk of developing MS increases. It seems that MS rates go up the farther from the equator a person lives, no matter what the individual’s race. An unknown environmental factor is involved.

According to Dr. Oksenberg, previous studies restricted to Northern Europeans failed to identify the differences between two neighboring genes; the UCSF study, using mixed-race participants, found them. “These comparative genetic studies are extremely promising,” he said. “We’re hopeful that greater understanding of the experience and the genetics of African-Americans will bring us closer to finding new treatments for all people with MS.”

classes or cooling jackets. Martin said her organization receives many requests for cooling jackets.

A legacy of distrust thwarts research and care

Sadly, there is even more to being “outside” than unequal access or economic disparities. There is a legacy of distrust.

“There is frequent concern among African-Americans about the safety of participating in research studies. People

UCSF/Harvard genetics study needs more volunteers

For more information about this and other MS genetics research projects at UCSF, visit www.ucsf.edu/msdb. For information about participating, contact the study coordinators at 866-674-3637 or e-mail msdb@ucsf.edu.

say, 'Are you experimenting on me?'" Dr. Hughes said. "There are classic examples where trust has been broken. The Tuskegee Syphilis Experiment is one. It's recent history." In this experiment, the U.S. Public Health Service allowed a group of African-American men to go without any treatment for their syphilis from 1932 to 1972, while the men believed they were receiving care in a research study. President Clinton apologized to the eight remaining survivors in 1997.

A tradition of self-help

Many African-Americans tend to depend on themselves and hide their health problems. "As a culture we don't like to seek help," Anne Marie Johnson said. "We just don't like to talk to other people about our business, whether they are therapists or doctors, or even someone else going through the same thing."

"I would probably say that we tend to self-medicate or self-heal," Len Chatman agreed. "We treat ourselves at home and we keep our health concerns private. Sometimes we don't even let our church families know. We don't want to be identified."

Opening up can be particularly difficult for black women, who may have what Martin calls "that superwoman mental-



Ted Baker of the Prince George's County MS Support Group coordinated all the loading and unloading of luggage, scooters, and wheelchairs. After everyone was safely on board he took a power nap.

ity." Many African-American women think that they simply

don't have room for MS in a life busy with children, careers, and education. All too often, according to Martin, "they chalk their symptoms up to stress."

Alecia R. Harris is typical. She was busy working as a nurse, as a university instructor, and raising a family when her first symptoms occurred in 2001. "I thought I was experiencing postpartum fatigue; after all, my new bundle of joy was keeping me busy." After she was diagnosed, she tried to ignore MS. "I needed to continue to be a wife, mother, daughter, sister, aunt, and friend," she said.

But MS is hard to keep under the rug. "It's not something you can put to the side," Johnson said. "MS is one of those things you have to address immediately."

Faith may be a pathway

Dr. Hughes believes there are some things that must be done differently to help African-Americans overcome their distrust of the medical establishment. She suggests including "African-American" in the

names of things, in the design of research studies, events, and information packets. She also would like to see outreach through non-traditional paths. "We don't think about recruiting ministers to lead self-help groups, but there is such a high comfort level with religious leaders in this community," she said.

According to the NORC survey, 88% of blacks with MS said that their faith is very important in life with MS, while 70% of whites said the same thing.

"African-Americans as a whole are very spiritual people," said Jane Burton-Whitaker, who started an African-American support group in Alameda, California. "We pray a lot. I don't think that was understood or accepted by other self-help groups I sat in on. With our group, we felt really comfortable praying and talking about prayer."

After being diagnosed, Johnson remembers that one of the first things she did was to go to church with a young woman she had met at a conference. "Going to church with her developed my faith and current understanding of this illness. I also found many others within the church just like me. There's a culture in the African-American church that is unique," she concluded.

The connection is so strong Harris called the non-profit organization she founded after her diagnosis—"Walking with Faith, Inc." The organization raises funds at walks, luncheons, dinners, golf outings, and concerts, but it also offers educational seminars. With the help of her children, Harris founded "Kids FUN-RAISE for Multiple Sclerosis, Inc.," and

has developed fund raising events that involve kids of every race, including Kids Roller Skate for MS, Kids Bowl for MS and Kids Jump Rope for MS. "The kids work so well together," she says. "There's no color barrier. Just people working for the same cause."

Moving ahead

Many African-Americans with MS have built on their self-help traditions and taken matters into their own hands. Walking with Faith, Inc., and the Martin MS Alliance Foundation are just two of many African-American MS-focused organizations, events, support and self-help groups nationwide. As Cheryl Chatman said, "Empowerment is the key: networking, sharing, realizing you're not alone."

"When I was first diagnosed," Martin said, "I went to a support group and nobody looked like me. It made me feel worse. When you see somebody who is like you who's also living with this, it gives you a sense of community: We can all fight this."

"I thought I was the only African-American with MS anywhere until I met another woman at the National MS Society," Burton-Whitaker said. "From there, everybody we talked to knew somebody else who has MS. The group continues to grow today."

Michelle Witherspoon, who leads a self-help group for African-Americans in Raleigh, North Carolina, cited the comfort of a common social experience. "You get to talk about the same social gatherings. There's a commonality to things we all would have gone to or seen or done."

In addition, she has seen the older and younger women in her group develop almost mother-daughter relationships, by sharing life experience and advice.

In 2002, the Society's Eastern North Carolina Chapter held a conference specifically for African-Americans with MS. It was so successful that it is now held annually, featuring a variety of presentations.

Other chapters have followed North Carolina's lead and started African-American support groups and events, but more are needed, especially in urban areas. Moreover, chapters are becoming more aware of the need to be inclusive when they publicize events and programs. Pictures of mixed race groups do more to show a welcoming attitude than a line of print claiming "Everyone is invited."

The images of MS

More and more, researchers and people concerned about MS realize that every

population affected by the disease needs to be represented, whether in medical research, in conferences and meetings, or in magazines, pamphlets, and brochures. If one group is left out, it affects everyone with MS.

"If I am looking at materials and don't see people of color," Harris said, "I'm not going to think this applies to me." Celebrities don't mean as much to her as depictions from the full spectrum of ordinary African-American life. "I'm talking about seeing teachers, medical professionals, office workers, the grassroots," Martin said.

"More imagery is the absolute key," Johnson said. "Lack of it puts you in a very scary place. I need to see representations like me, a 30-something vivacious, bodacious, absolutely cute and sexy sista. If not, what kind of hope does that material give me?"

Cheryl Chatman agreed. "We need to open it up. The diversity is out there; we need to show it. We are the faces of MS." ■



"While at sea," Yvonne Brown writes, "the Prince George's County Support Group held a brief meeting to discuss what to expect when we got to Bermuda. There was something for everyone."