

Black women with MS speak up



Three Black women with multiple sclerosis offer their personal insights about healthcare.

by Kimberly Kishpaugh

Disparities in healthcare — diagnosis, treatment and access — are among the top issues that affect people of color, including black women with MS.

What did your healthcare professional initially believe was causing your symptoms?

“MS never came up,” says Antoinette Pick-Jones, an attorney who was diagnosed with MS in 2019. Although she provided doctors with spreadsheets of symptoms and test results, which included the presence of multiple lesions, one neurologist even told her, “This is kind of concerning, but there is probably nothing wrong with you.” Another neurologist said bluntly: “You just don’t have MS.” Instead, she was asked repeatedly about HIV, lupus and sickle cell anemia. “The majority of people who are diagnosed with those illnesses are Black,” Pick-Jones says. “And that was really problematic.”

Robin Carr McClure first experienced vision problems in 2011. After the symptoms didn’t go away, she made an appointment with an ophthalmologist. When the ophthalmologist couldn’t find anything wrong with McClure’s eyes, she looked for answers elsewhere. “She decided I needed to get lab tests, as what I was describing was a symptom that was common in syphilis or AIDS,” McClure recalls. “That was an unexpected thing to hear when you just wake up, and you have a vision problem. Everyone I know who has MS is Black. It seems like the

first test everyone gets is for STDs. I'm not sure if that's across the board, but everyone I've talked to who's Black has had that experience."

Did you feel as black women with MS that your feelings and symptoms were taken seriously?

"Many MS symptoms can be invisible," says Lawaunda Stephens, who was diagnosed with MS in 2000. "I had to fight to have medical professionals take my symptoms seriously. The MRI sometimes doesn't match what's really going on."

"There is just a 'Black woman thing' where people don't take us seriously," Pick-Jones says. "When I told my current neurologist, who's great, about my symptoms [the first time], he said, 'It's just shocking that someone didn't flag this years ago.'"

What do you think are the barriers to staying on a disease-modifying therapy (DMT)?

"I ended up spending \$15,000 out of pocket to get this diagnosis. And thankfully, I had the resources to do that," Pick-Jones says. "But if I didn't ... Some people don't even have the resources to pay for a co-pay."

"If you really want a patient to stay on a DMT, listen to what they say," Stephens says. "If they say they're having trouble with a DMT, don't blow them off. Because once you blow them off, they're going to stop taking it, and that could lead to more progression."

What is your greatest hope for research?

"[I hope for] research into diagnosis, or lack of diagnosis of women — Black women — with MS. I think that would be really interesting," Pick-Jones says. "The most pressing populations are poor and working-class Black people."

"When research is done, it would be nice to know if any Black women were included in the study. That way, maybe when a Black woman comes to the doctor, the first thing they're thinking is not HIV. Maybe they're thinking MS a little sooner."

Do you believe MS is uncommon in Black people?

"It's interesting to me in that a lot of what you see online or anything related says this is uncommon in Black people," McClure says. "And I think now people are more aware of history some of us have been aware of our whole lives. Me being Black doesn't mean there wasn't somebody white in the bloodline as well. And in my case, it's true. There were some, not by choice, white ancestors in the line [who had raped my ancestors, who were slaves], which led to me. And so, I do have a Scottish ancestor. And nobody by marriage and nobody by choice, but it's part of my genetic makeup. So, if [physical characteristics are being used to determine race], it's a very narrow view about what race is."

McClure says her neurologist told her, “People in your community don’t have this disease.” But genetically speaking, I did an ancestry DNA test a while ago, and I’m 53% white,” Pick-Jones says. “So technically, if we’re talking about race as being a risk factor, it’s more likely with someone who’s like me. I said there’s no real research about mixed-race people and how the statistics pan out for people who are mixed race.”

Do you think being black women with MS affected your diagnosis or treatment?

“Diagnosis, definitely. I don’t think anyone was looking for MS, so it took a long time,” McClure says. “And wondering if you have HIV or syphilis or anything that could have been prevented. That was pretty agonizing. When I talk to some people about their diagnosis — and again, I only know Black women who have MS — we’ve all thought being diagnosed was a relief instead of a sad moment. ‘Ok, I’m not crazy. And these doctors who’ve said there’s nothing wrong with me, I’m not crazy. There really is a medical issue.’ I think it takes longer to get to that point for a lot of Black women.”

“A lot of medical professionals don’t take Black women’s concerns or pain as seriously as they would other people’s. There are a lot of medical professionals who literally do not believe that Black people feel pain in the same way,” McClure says. “I went to Brown University for grad school. My dad also attended Columbia for law school and he always wore a Columbia T-shirt when he went to the doctor.

I never paid any attention because most of his T-shirts have schools on them. But when I started to talk to him about my treatment by professionals, he would say, ‘Make sure you have your law school shirt on’ or ‘Do you have your Brown shirt on?’ And I did. And I noticed that the times that I wore regular clothes it was OK. But if I wear a shirt that says Brown University on it, there is a discussion around that. They talk to me at a much higher level.”

Do you think you experienced any injustices or discrimination in the healthcare system?

“I think the hard thing is, you only know by comparison sometimes. You only know what you’re not getting when you see what someone else is getting,” McClure says. “I never had any outright discrimination. I know that my experience being diagnosed is different than what I’ve seen from white women, not all, obviously.”

“Oh, I could write a book on it,” Stephens says. “I could hear [the doctors] in the other room with the other patient and hear how [they] address the other patient. But then when [the doctors] look at me ... because when you have especially ethnic, African features, you’re going to get judged off the top.”

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