

Still dope



The women of WeAreILLmatic portray a powerful MS community.

by Brandie Jefferson



Victoria Reese has created a community where women living with MS can learn about the disease, ask questions, give advice and meet people who face similar challenges. Photo by Joseph Gray

Victoria Reese gets things done.

When she was diagnosed with multiple sclerosis at 25, a few months after moving to Los

Angeles, she returned home to Detroit for a week, “to deal,” she says, then headed back to California.

When working for someone else didn’t allow her to flex her creative and entrepreneurial muscles, she went into business for herself, starting her own brand management company, Victor Group LA.

“If I can’t flex my muscles,” she says, “you’re not going to see me shine.”

And when she didn’t see many people who looked like her in campaigns and organizations that support people with MS, she started her own, launching WeAreILLmatic with the blessing of the music superstar from whose album the campaign’s name is derived—legendary rapper Nas.

WeAreILLmatic has morphed into a community where young black women living with MS can learn about the disease, ask questions, give advice and meet people who face similar challenges.

“If I know about a problem,” Reese says, “maybe I can help solve it.”

A lack of research

In 2012, Reese had a problem of her own. She visited her primary care physician after experiencing numbness in her legs. “The doctor said, ‘It’s your job. You’re stressed.’” Then came the migraines and facial paralysis. Maybe it was depression, her doctor said. Reese was prescribed antidepressants. The diagnosis, however, just didn’t seem right.

She was referred to a neurologist, and later that same year Reese was diagnosed with MS.

“I started to do my own research and didn’t see many [scholarly] articles about black people with MS and the ones I found were outdated,” she says. Brochures insisted that MS was a disease found most often in young women of northern European descent, and imagery often reflected that. “I thought, ‘Am I that rare?’ I didn’t see anything specifically geared toward me.”



The rate of MS diagnosis in African-Americans is higher than once thought, says Mitzi Williams, MD, neurologist and MS specialist. Photo courtesy of Mitzi Williams, MD

Of course, MS is not a disease that only affects white women, but it turns out they might not even have the highest risk of disease, as was thought to be the case for a long time.

“Yes, the rate of diagnosis is still higher in white women, but it’s much higher in African-Americans than once thought,” says Mitzi Williams, MD, neurologist and MS specialist at the Multiple Sclerosis Center of Atlanta.

Dr. Williams cited two studies. One, published in the June 2012 issue of *Brain*, looked at nearly 2,700 U.S. veterans who served between 1990 and 2007, categorized as white, black and other (which included Hispanic). It found female veterans of all races were three times as likely as men of the same race to have MS, and that black women had the highest rate of disease: 26.3 per 100,000, followed by white women with a rate of 25.8 per 100,000.

In a smaller, more localized study in the journal *Neurology*, researchers looked at Kaiser Permanente healthcare records and found that of new diagnoses in southern California between 2008 and 2011, black patients were 47 percent more likely to have MS, and black women had the highest incidence of MS of any demographics. That study hasn’t yet been duplicated, but Dr. Williams says it resonates with her experience. “I see lots of young black women being diagnosed in my clinic.”

These are the women Reese wants to see represented and wants to support.

“I tried to represent a different type of woman,” she says, “a millennial who wanted to feel empowered.”



The rapper Nas posted Victoria Reese’s #WeAreILLmatic campaign on his social media accounts, saluting those fighting MS.

Redefining what illness looks like

“Illmatic” is the title of the 1994 debut album by rapper Nas—“ill” (like “sick”) being a slang term for almost outrageously cool. “The term illmatic just resonated with me in regards to redefining what sickness/illness looks like,” Reese says. “It felt right to find a modern, culturally fitting term to help tell our stories.”

Or, as the website notes: “We may be ill, but we are still dope.”

Reese, who works in the entertainment industry, reached out to Nas’ management and was given the rapper’s permission to use the name. On August 14, 2017, she launched WeAreILLmatic.com. That day, Nas posted Reese’s campaign video to his Instagram and Twitter accounts, commenting to his millions of followers: “Salute. I am rocking with ya’ll strong warriors. Fight MS.”

WeAreILLmatic.com provides basic information about MS, a sign-up page for a private Facebook support group with nearly 300 members, a few motivational items for sale, and videos of women sharing stories about living with MS.

But what is most striking are the images: beautiful black and white photographs of black women, all of whom are living with MS. The optics are powerful.

Reese is acutely aware of how important those optics are. When she was first diagnosed, she did what anyone would do, for better or worse: she went to the internet. “When I Googled the disease, it looked like this was a disease that only affected older white women,” she says.

Now, when someone searches for the National Multiple Sclerosis Society, there’s a good chance they’ll see a black woman. “When you Google it now,” Reese says, “I show up.”

That's because Reese is now an MS ambassador with the Society. She also sits on the Society's newly formed Emerging Leaders Board for the Southern California and Nevada areas to raise awareness for those living with MS among younger people.

Joining the conversation

When Reese started participating in events in her local area, she noted a lack of representation. So, again, she decided to do something about it.

"I raised my hand. I wanted to play a part, not the 'black girl' part, but the part of a changemaker." Her work as an ambassador complemented her personal outreach work, creating a synergy that has helped bring more people of color into the conversation around MS.

"I was talking about outreach and going to the communities where people of color are," she says, "because we don't typically go seek help. We don't raise our hands for therapy or support. That's just not part of our culture."

#WEAREILLMATIC

Define

ILLMATIC [IL-'MADIK]

adjective

Meaning "beyond ill," "the ultimate," "supreme ill," "as ill as it gets," and the title of rapper Nas' 1994 debut album.

Reese uses her influence through WeAreILLmatic to direct women to the Society and to encourage them to sign up for clinical trials to make sure that they are represented in the medical literature.

"Maybe that's my lane," she says. "I'll be the one with my ear to the street," continuing to direct people to services and to connect them to a like-minded community.

"That's huge," Dr. Williams says. "One of the things I think is very important with a chronic disease is to have a sense of community and support. You can get a certain level from family and friends, but it's not the same as from people who understand what you're going through, and people that you can identify with on this other level."

That sense of community can be so important that it drives some people, like Dawnia Baynes, to ask total strangers for their phone numbers.

"Honestly, when I see other African-Americans at MS events, I get their info because you

don't see that a lot, and I like to stay in touch," says Baynes, who also lives in L.A. "Back in the day, it was 'African-Americans don't get MS.'"

Baynes, herself a Society ambassador, met Reese last year on a flight to Sacramento for the Society's State Action Day.

"She told me about the campaign, and I said, 'I would love to be involved.'" So when it came time to shoot those photos for the website and record women for video spots, Baynes headed straight to her phone to contact some of the people she'd met at previous events.

Making connections everywhere

WeAreILLmatic has, in turn, encouraged strangers to reach out to Reese. "They join the group, they call me on the phone, we ask questions about shampoo," she says. "Now we're connected and we're good."



The WeAreILLmatic Facebook group helped Lauren Clayborne feel more comfortable talking about her MS. Photo courtesy of Lauren Clayborne

Reese has connected with all types of people like Lauren Clayborne, who took months to tell her best friend that she was diagnosed with MS and still hasn't told many people.

But she did tell a second friend. "[My friend] went on Instagram and found Victoria," Clayborne says. "She reached out to her, basically said, 'Hey, my friend has been diagnosed with MS.'" Clayborne didn't know what her friend was up to until Reese reached out.

Now Clayborne, who lives in Michigan, is a member of the WeAreILLmatic Facebook group. And she's still reserved when it comes to her diagnosis. "I still haven't told many friends to this day, and here's Victoria, all 'MS ambassador,'" she says with a laugh.

"But every time I talk to her she says, 'It's going to get easier.' Now I'm at the point where I

randomly told somebody that I had MS in conversation last week,” she says. “I was like, ‘Oh my god, I can’t believe I just did that!’”

“I’m so proud of Victoria, I would do whatever she needs,” Clayborne says, adding through laughter, “Including talking to you for this interview.”

That’s the power of the community Reese is creating.

“It’s been very comforting knowing others who have been diagnosed,” Clayborne says. “I look at it as my secret society.”

A growing community

The secret may be out, though. WeAreILLmatic has been featured in Vibe and Essence magazines as well as in the Washington Post and other traditional media. And, of course, on social media.

“People say, ‘Hey, I read about you on Essence and found you on Facebook,’” Reese says. Just like that, the community continues to grow, as do Reese’s aspirations.

“I want to stay in the conversation,” she says. “I’d love to do more public speaking. And I’d love to continue to advocate.”

Whatever she does next, Reese will continue amplifying that single voice that doesn’t always get heard and solving those little problems that, to a person with MS, can present big challenges, like getting your hair done.

A woman posted on the WeAreILLmatic Facebook page that because of her MS symptoms, it had become harder for her to get her hair done. She uses a wheelchair and couldn’t find anyone to help her get to the salon.

“Not only did it require a lot of work to get her there, but no one wanted to help,” Reese says. “It can be hard to get someone to pick you up, drop you off, then do that all over again once you’re done.”

Reese enlisted the help of some friends and reached out to a hairdresser in her hometown: “Wouldn’t that be a cool idea? A mobile hairdresser who styles sick people’s hair in their home?”

Reese did what she always did. She solved the problem.

“I found someone to do that for her,” Reese says. “Just because you have MS, that doesn’t mean you can’t get your hair done.”

Brandie Jefferson is a freelance writer in St. Louis, Missouri. She was diagnosed with MS in 2005.

Winter 2018-19

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