Giving voice to people with a misunderstood disease

Shanelle Gabriel was diagnosed with lupus — a chronic autoimmune disease that mostly affects women of African American and Hispanic descent — while she was at college. Today, as a singer, poet and advocate, she uses her voice to highlight challenges faced by people living with this complex and often misunderstood condition.

Photos: Brent Stirton, Getty Images for Novartis

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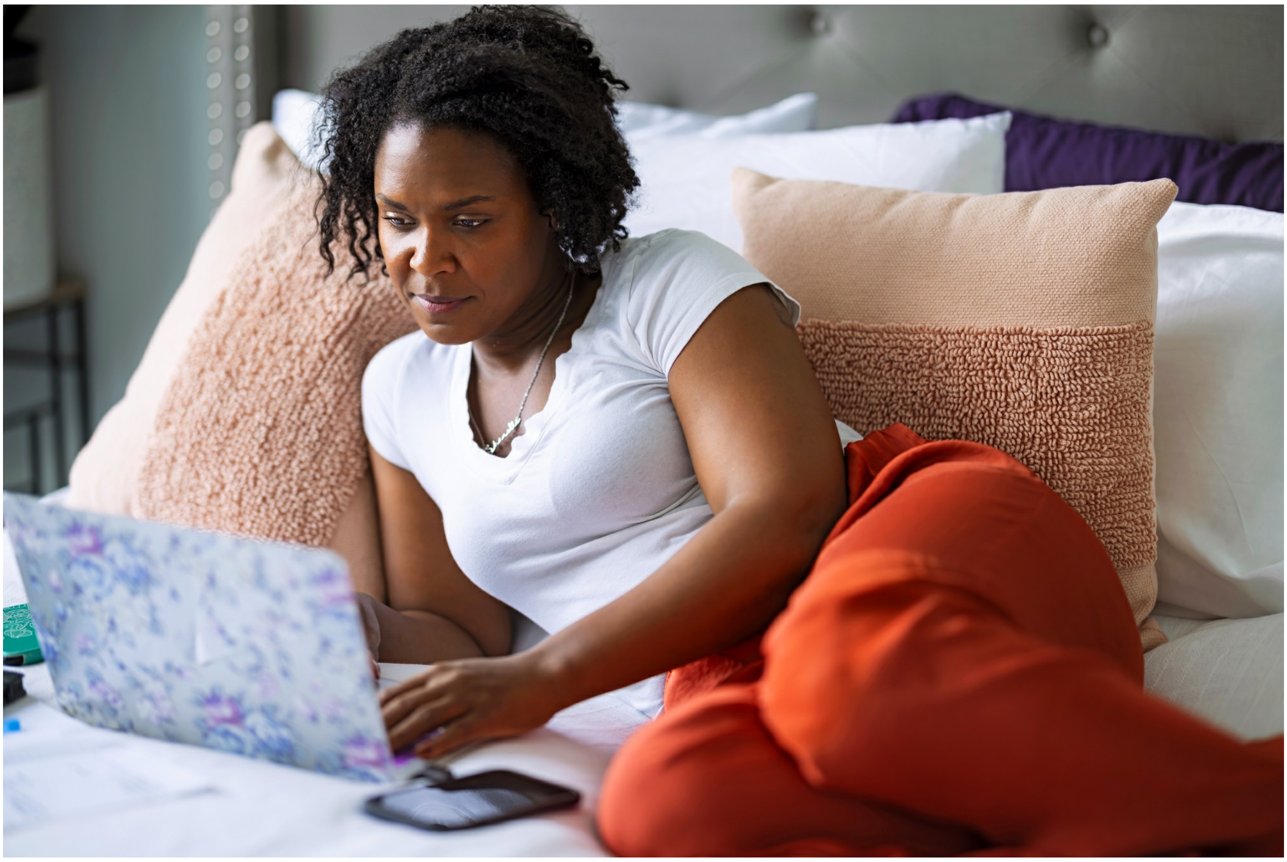
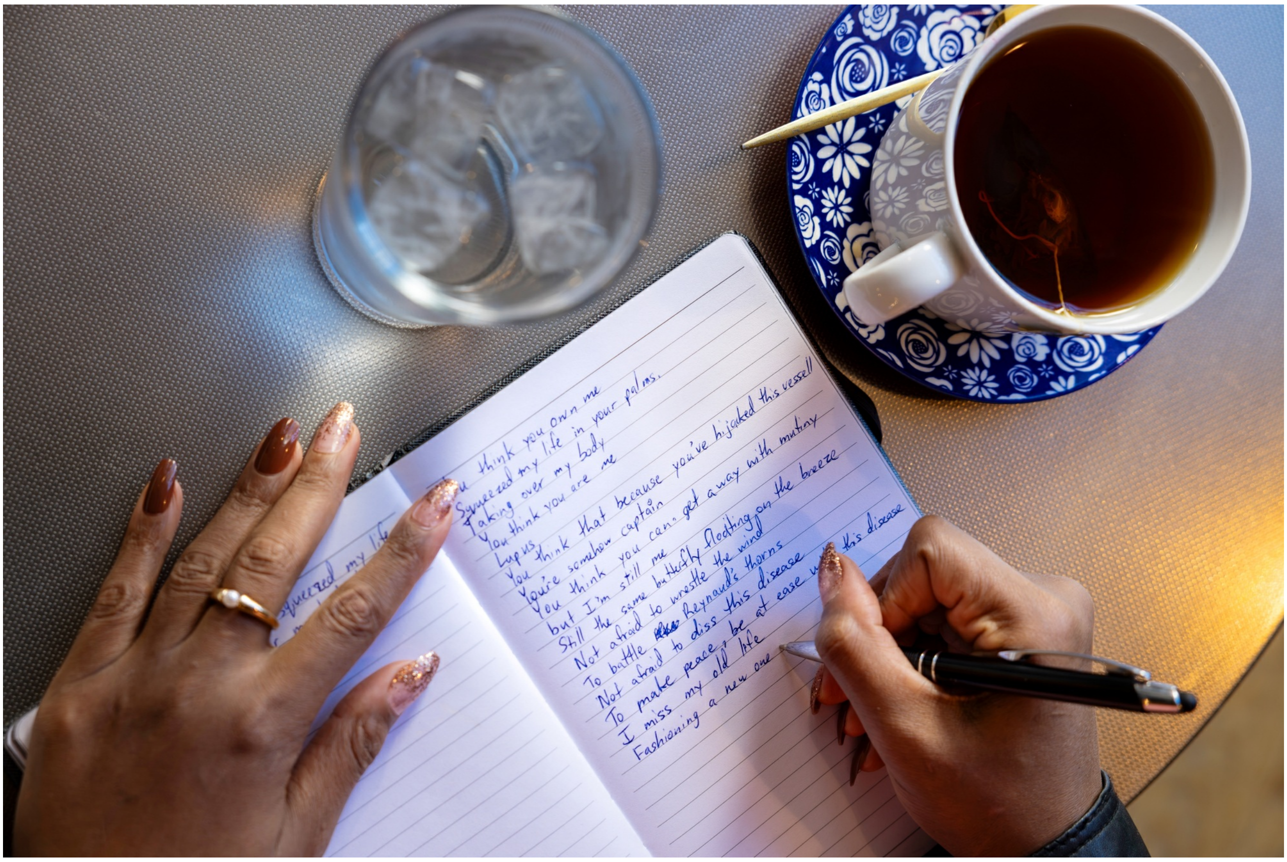
Shanelle Gabriel under the Brooklyn Bridge in New York City, close to where she grew up. Shanelle was first diagnosed with systemic lupus erythematosus when she was a junior at college. The autoimmune disease is hard to diagnose due to varying symptoms that can include pain, high blood pressure and swelling.

There were days when I was in a lot of pain and nobody knew. I had migraines. I had joint pain. I had hair loss. I went to the doctor, but because they're such random symptoms I didn't know how to present it. I was like: 'Fix my hair first and then let's talk about the other things.' But it was all connected.



Shanelle Gabriel at her home in New Jersey. Living with lupus as a young woman impacted her life in many ways, she says.

My friends were partying, but I couldn't join them. I was in a dance team but had to leave because of the intensity on my body. I had an internship but quit on the second day because I started having immense pain. It was very challenging and frustrating. I thought 'why me?'



Squeezed my life

u think you own me
Squeezed my life in your palms.
Taking over my body
You think you are me
Lupus
You think that because you've hijacked this vessell
You're somehow captain
You think you can get away with mutiny
but I'm still me
Still the same butterfly floating on the breeze
Not afraid to wrestle the wind
To battle Reynaud's thorns
Not afraid to diss this disease
To make peace, be at ease w this disease
I miss my old life
Fashioning a new one

Shanelle works on a poem. After discovering poetry at college — right around the time she was diagnosed — she says she fell in love with writing and spent most weekends going to New York City to perform. Over time, her experience with lupus became a major theme of her poetry.

I wrote a poem about my feeling of a lack of control over my body. One day I decided to share it in a performance. People came to me afterwards to say they have lupus or knew someone with lupus. That's when I started thinking about my poetry as something bigger: a way to communicate with people who need to know they are not alone.

Shanelle (right) at an event to raise awareness about lupus. The disease most often affects women from racial and ethnic minority groups that typically face preexisting healthcare disparities — which makes it even harder for them to get diagnosed, access treatments or participate in clinical trials. Shanelle educates pharmaceutical companies, including Novartis, on how to bridge the gap and make it easier for people with lupus to join trials to help find new treatments.

We need more therapeutics to support people living with this condition," says Shanelle. "But there's distrust — when you have bad experiences or doctors that don't listen to your concerns, are you really going to join a trial?

Shanelle with Dr. Micaela Bayard (right), a rheumatologist and lupus expert at Mount Sinai Health Systems in Queens, New York City. For women with lupus, a lack of diversity among physicians and investigators can be an obstacle to trust in clinical trials and the healthcare system more broadly. Black women make up less than 3% of the physician workforce in the US, according to the Association of American Medical Colleges.

As a physician I want to give my patients the best treatments, but when we talk about clinical trials people still have those issues of trust," says Dr. Bayard. "Whether it's through support groups, community walks, education sessions, or collaborating with lupus advocates like Shanelle, it's critical to build impactful networks that speak to the gaps in care for women and women of color living with lupus.

Shanelle in New York City.

Despite my condition, I love being a testimony to the fact you can have a chronic illness and still live a full life.

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