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Sarcoidosis

A decade ago, I was sick. I went to the doctor and told her “I feel really, really tired.” This was the second time I had been in her office in six months. She looked at my neck and said, “Your neck is not supposed to be that big,” to which I replied, “I’m just getting fat. It’s baby weight.” It wasn’t just baby weight. My baby was actually two years old, going on three. At that point, I knew I was really sick. They looked down my throat and saw two large growths. By the time I was on the table for the surgery, those two growths had multiplied to six. Little did I know they were granulomas. Here I was a working Black American mother with a sweet little toddler that woke up from a laryngoscopy with one less vocal cord and a Sarcoidosis diagnosis, tasked with finding out what Sarcoidosis was and what this meant for me, my life, and my motherhood.



They told me I had Sarcoidosis, but what I heard at first was that I was going to die. I knew nothing of Sarcoidosis, but I knew everything about the barriers to high quality care Black Americans faced in the health care system. They told me I had Sarcoidosis and all I could hear was that I was fighting a disease that “shape shifted” to each individual, and that I was not going to win this fight.

Sarcoidosis turned my life upside down for a long while. As a mom to a three-year-old, I was really scared. I’m whole-heartedly convinced the diagnosis was the death knell to my marriage. The diagnosis put me into a long period of fear, denial, and depression. I didn’t know where to turn for help, at first. Then, I had my first flare. It took me down for three days. First, I lost some mobility in my legs. Then, when I finally got back home with my daughter, I lost mobility in my hands. In desperation, I had to call my co-parent to come get our daughter, because I couldn’t care for her at that moment, a moment where I started to wonder how I would manage this disease. I was in Texas far away from my relatives, with a small support system, with work and parenting responsibilities, and trying to navigate this new life I had with Sarcoidosis.



No choice or knowledge of clinical trials contributed to my fears after my diagnosis. African American women may have an understandable distrust of the healthcare system and an understandable distrust of clinical trials, and this is only compounded when a patient has experienced non-equitable care empirically, when clinical trials are limited, or when providers and clinical trials do not accommodate the work logistics and financial needs of the patient. This was the case for me. They told me I had Sarcoidosis and now I had to work overtime to reclaim a new baseline with my health outcomes and my socio-emotional outlook on living with a chronic disease. I'm really glad I had many specialists and my primary care physician to help see me through.

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Over the past decade, I have educated myself about Sarcoidosis. I have worked with my healthcare providers to come up with a plan. I have moved from fear of Sarcoidosis to walking hand-in-hand with Sarcoidosis. I knew I had to fight to live every time I heard my daughter laugh, or she was excited about an achievement at school, or something brought her joy. It is in those moments I dig so very deep to stay focused on managing this disease.

I feel it is my duty to raise awareness about Sarcoidosis and its impact on Black American women. I feel it is my duty to raise awareness that encourages providers to stop using a one-size-fits all approach to treating Sarcoidosis. Black women are three times more likely to develop Sarcoidosis than white women and men, and are more likely to be hospitalized, or even die from sarcoidosis when compared to other groups. As a Black American woman living with Sarcoidosis, I want providers to see me as more than a data point. I want to be seen as a partner in a process that seeks to improve the quality of life of those living with Sarcoidosis.

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells in various organs and tissues of the body. Sarcoidosis most often affects the lungs and its hilar lymph nodes but can also involve other areas of the body including the eyes, skin, sinuses, liver, kidneys, brain and heart.

- When sarcoidosis affects the lungs (pulmonary sarcoidosis), the disease can reduce the amount of air the lungs can hold and cause abnormal stiffness, called “restriction,” of the lungs. This results in breathing problems that can interfere with daily activities.
- Since sarcoidosis can affect one or more parts of the body, the signs and symptoms depend on the tissue/organs involved. Some people with the disease do not have any symptoms and it may be noticed by chance when they are being seen for other problems. Other people may be hard to diagnose because the symptoms they have are not very specific. But certain clinical features such as the erythema nodosum, rash or eye findings may lead a healthcare provider to suspect sarcoidosis.



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