



# Garrie Farrow

Sarcoidosis

I came to sarcoidosis through swollen feet and ankles. I now know this is a benign sarcoidosis symptom. It took four years and three different primary care physicians to learn this isn't normal. That a Black woman in her early 30s, even with extra weight, shouldn't have swollen feet and ankles. A chest x-ray resulted in an appointment with a pulmonologist. After a mediastinoscopy with biopsy, I had my diagnosis of sarcoidosis of the lungs – Stage 1.

When I was first diagnosed, I was more concerned about survivability and got a little depressed because there wasn't much research about that aspect that I could find, or that was easily accessible. I wasn't quite sure what to expect – what was I supposed to be doing to deal with this rare disease?

I was initially told that with Stage 1 sarcoidosis, there was nothing for me to worry about and sarcoidosis would have very little impact on my lungs; just to watch for long term coughing or trouble breathing. Reading through some of the medical journals looking for information on sarcoidosis, I realized that the information that I was finding was not written for a patient, I stopped researching and went back to my regular life.

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I already had thrombotic thrombocytopenia purpura (TTP), which I’ve since learned can be a symptom of splenic sarcoidosis. It was a tough pill to swallow; that I could be lucky – or unlucky – enough to have not one, but two rare diseases.

As I was undergoing my sarcoidosis journey, my sister Sharon – sadly – joined me on the trip. She had had breathing issues for years, so after my initial appointments with my sarcoidosis specialist, I'd call her and encourage her to talk to her primary care physician about her symptoms. Unfortunately, Sharon was diagnosed with sarcoidosis after a biopsy. She lived far away and was financially disadvantaged, which meant that she could not make the trip from her hometown to see my specialist.

I gave her the best help I could. We talked about my medication regimen, and Sharon let me know she was on prednisone. I let her know I was on methotrexate and suggested she discuss steroid alternatives with her physician. I don't know if her doctor didn't think medications other than steroids were an option for her or if she didn't tell them about the medication, but she died in January 2019 from pulmonary sarcoidosis. Her lungs filled up with fluid and they couldn't drain it from her fast enough.

After my sister died, I became very angry and felt guilty. She was only 18 months older than me – why was my sarcoidosis experience so drastically different? I decided that I was going to find anything I could on sarcoidosis and dug through the scientific journals again. I found the Foundation for Sarcoidosis Research, and joined their Patient Advisory Committee. My hope is that all clinicians, not just sarcoidosis specialists, become

educated on sarcoidosis and its impact on the entire body. Despite being an introvert, I felt the need to add my voice to others and joined their Speaker's Bureau. I wanted to get the word out about sarcoidosis.

Helping others helps me to deal with the emotions I've been compartmentalizing all these years. When something impacts your physical well-being, your emotions and mental health are also impacted. A lot of those feelings I just put in a nice little box and just didn't address. But it does accumulate over the years. Opening myself up and the experiences I have been through with this disease empowers me and I hope the experiences I have been through with this disease uplifts others.

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What I hope to highlight is that this disease isn't centered on just one organ, and so having a central point of sarcoidosis care is important. Most patients experience one specialist at a time, and some may not find that one sarcoidosis specialist who helps them put it all together. I think it is urgent to establish a paradigm for multidisciplinary care in sarcoidosis.

I've been fortunate to have a team of doctors actively working together on my health. I would meet with my rheumatologist and sarcoidosis specialist, usually within an hour or two of each other. They collaborate on my treatment and speak with each other immediately before or after my appointments. That's the level of care I hope all sarcoidosis patients can access; that I wish my sister would have been able to receive. ●

## 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. For other people it 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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