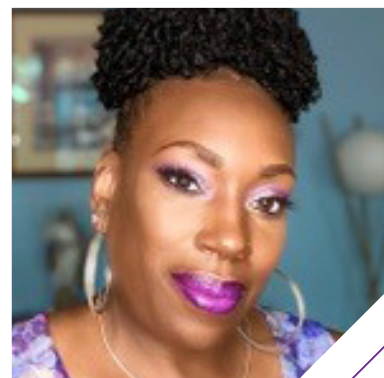


Cheryl Bradford

Cheryl Bradford is a sarcoidosis patient who struggled for years to find a healthcare provider who would take her and her illness seriously.



I grew up in Queens, the youngest of six. My block was the coolest in the neighborhood. On Saturday mornings, I would wake up to the sound of jazz music, my father's favorite, playing throughout the house.

My mom was the Big Momma of the neighborhood. She was from Bermuda, believed in the power of prayer, and always trusted in God. One of our traditions is "putting the kettle on," meaning that we never needed an excuse to make tea. In my family, tea would solve anything: whether you were sick, hurt, or sad, mommy would pray for you and give you tea and everything would be okay.

I wish life was still that easy.

I was getting ready for church one morning, and started feeling sick, like someone had peeled the skin off my entire body and was poking me with pins. I went to church anyway,

but afterward, I went to my parents' house. I always felt like that was the best place to be if you're sick, so I crawled into my mom's bed. We called the doctor, who told us to go to the hospital. I had a fever of 104 degrees and felt like I was in a daze. I was having a difficult time breathing, so the doctors took a lung biopsy, and there it was. At 30 years old, I was diagnosed with sarcoidosis. Looking back, I feel sort of lucky to have been diagnosed so quickly, because I know that sarcoidosis can be difficult to diagnose.

The doctors didn't really explain my condition to me. I had to do a lot of my own research, but it still wasn't the kind of information I know now. At the time, I was able to understand that sarcoidosis was a rare inflammatory disease. I learned that it is more common in African Americans, especially women, and that most sarcoidosis patients experience serious lung involvement. There is no cure. It really didn't hit me how sick I was,

because at first, I just had that one episode. Within a month or two, I recovered, so in my mind, I was better. I went back to work and I got on with my life.

Ten years later, I started having a chronic cough and chest pain, but had trouble getting a pulmonologist to take it seriously. I was told by one that the pain was in my head. Another asked if I thought it could be a sinus drip; he could not explain the chest pain, nor did he even check for a cause. When I could not get a specialist to help me, I tried on my own, with over-the-counter medicines. My condition was getting worse, but I had no clue. The pain eventually went away, but the chronic cough persisted.

Eventually, I found a pulmonologist to look into this further. He sent me for a chest x-ray, and asked me to come in to discuss the results. I thought I had finally found a pulmonologist who could help me. Boy, was I wrong. He showed me the x-ray of my lungs and explained to me in medical terms what was going on. I was so confused – I didn't understand anything he said. When I told him I didn't understand, he didn't clarify anything. He just asked if I was still in pain. I told him no, and he said he would not do anything if I wasn't in pain. I had no idea that I needed immediate medical attention. I had no idea that the sarcoidosis had taken over my lungs.

My life went on. I was so disappointed, I never went back to see him again. I decided to just deal with the cough, but that wasn't

as easy as I thought. Later that year, I went to North Carolina to spend Christmas with my daughter, and coughed up blood for the first time. My mother and my sister were there, and they tried to get me to go to the emergency room. I refused to go to the hospital there, so instead the three of us drove all the way back to New York. By the time I got home, the bleeding had stopped. I had already seen so many pulmonologists who didn't do anything to address my cough, I thought I was ok and went on with my life.

A few months later, I was back in the ICU after coughing up blood again. The doctors did not tell me much, or answer the questions that my family and I had asked. A surgeon told me that I might need lung surgery, but he did not explain why; that was the first and last time I saw him. I was released a week later and told to follow up with the hospital's pulmonologist.

In January of 2013, I coughed until I passed out. I woke up in a pool of blood with a split lip and a missing tooth! I looked in the mirror and it almost didn't register. I kept thinking, "I can't go to work like this. My tooth is missing!" My sister Vera rushed me to the hospital.

My condition was grave, and doctors told my family I wasn't going to make it. Through determination, prayer, support of my family and friends, I pulled through. The surgeons started suggesting a double lung transplant, as both lungs had such severe damage: there were holes throughout my lungs, as well as several fungal balls inside them. I was also

diagnosed with Interstitial Lung Disease (ILD) and scarring of the lungs, all on top of the sarcoidosis. After 45 days in the hospital, I was released.

I went to see a new pulmonologist, and he wanted to do his own biopsy. An EKG and an angiogram confirmed that sarcoidosis had also affected my heart, and the doctor diagnosed me with pulmonary hypertension, too. He addressed me very seriously, "You should have come to me a long time ago – you were not getting the right treatment and now you are in grave condition." It took us awhile, but we eventually settled on a treatment plan that was a good fit for me, and he is still my doctor today.

Applying for Disability was an emotionally difficult step for me to take, because I had always planned to work until later in my life, but in the end, I know it was the right choice for me. Now, I spend my days with my family and friends, volunteering and exercising, just caring for my body and never pushing it. I always find time to spread awareness and advocate for sarcoidosis. I am a Patient Ambassador for the Foundation for Sarcoidosis Research and a Mentor for ILD at Snow Companies. Most recently, three members of my sarcoidosis family and I started an organization called Stronger Than Sarcoidosis (STS). I'm so grateful for my life and my family, and always look forward to spending time with my biggest fans, my daughter Lynette and grandson Samir, who live in Charlotte, North Carolina. And I think my mom and dad would be proud of me. ■

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. These lumps are called granulomas. 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. Sarcoidosis varies in how active and how severe it is for each person and over time. Some signs and symptoms of Sarcoidosis are:

- Lungs: Shortness of breath, wheezing or dry cough that may lessen or go away over time in some people, but remain in others.
- Eyes: Burning, itching, tearing, redness, sensitivity to light, dryness, seeing black spots, blurred vision, reduced color vision, and, in rare cases, blindness.
- Skin: Bumps, ulcers, or rarely, flat areas of discolored skin that appear mostly near the nose or eyes or on the back, arms, legs and scalp.
- Heart: Shortness of breath with activity and swelling in the legs. One may have an irregular or fast heart beat at times, or pass out without warning.
- The Nervous System: Headaches, vision problems, numbness, weakness, or loss of movement of arms or legs, drooping of one side of the face, pain or a "pins and needles" feeling.



Learn more

ATS Patient Education Series.
"What is Sarcoidosis?" New York, NY.

<http://www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf>