

Sheron Williams

Sheron Williams is a sarcoidosis patient who went misdiagnosed for many years as having kidney and bladder infections or as having been poisoned.



I was diagnosed with sarcoidosis Dec. 15, 1992. I was symptomatic for about two years prior to that, but doctors just simply didn't know what was wrong with me. I went from doctor to doctor. I was told it was a bladder infection, a kidney infection, and I should drink more water, drink more cranberry juice. One doctor told me I had been poisoned! I was very active, I was in my mid- to late-20s, and I just couldn't understand why I was so exhausted. I would have rashes one day that weren't there the next day, my eyes would be blurry.

Finally, a friend suggested I go to the hospital. The doctor pretty much examined me for five minutes and told me I either had tuberculosis or sarcoidosis. I thought to myself "Oh my goodness, I've been going to doctor after doctor for two years and this man just walked in the room and knew what was wrong with me." After a couple of tests came back, he confirmed I had sarcoidosis, but he believed at that

time that I was perhaps at the end of a flare up.

I don't remember if he put me on medication, but after the new year a whole new reel of symptoms started to occur. The taste of food started to really turn me off. I could not eat. It was hard for me to swallow. It got to the point where I was carrying a bottle because I couldn't even swallow my own saliva, so I would spit in the bottle. It got to the point where I was sleeping the entire day, my speech started getting slurred, and my mouth would be moving but only every other word would come out. I didn't realize that the back of my throat was actually closing. I didn't know because I wasn't in pain. Eventually I went back to the hospital, and they found that my sarcoidosis was traveling through my spine, and affecting my nervous system, which is why I didn't have any pain. They worked on me around the clock from that afternoon until two or three in the morning. I was so small that even

though I was 27 years old, they thought I was a teenager, and they asked my aunt to contact my parents to have them sign the consent forms! It had knocked out the uvula in the back of my throat, and that was why I couldn't swallow. It was also affecting my brain and liver.

I spent a month in the hospital with a feeding tube. I went to the library there at the hospital and found everything I could on sarcoidosis.

I went home at the end of January and I still had the feeding tube for two weeks. I was on an extremely high dosage of steroids. For a couple of years, I didn't work. My life as I knew it had completely changed. I went from full-time student on the Dean's List, working two jobs, and being in a play to absolutely nothing. It wasn't until close to four years went by before it went into remission again.

Twelve years ago, it started to really manifest again. By this time, I was supervisor in a bank managing several branches. I went to my primary doctor, who was not involved with my pulmonologist. He did blood work, and I remember getting a call at work. The doctor asked, "Ms. Williams, is there something that you want to tell me? I'm looking at your bloodwork here. Is there something you want to tell me?" And I remember being at work and trying to be quiet so people won't know what's going on, and I said, "No, what are you talking about?" and he says "Are you having



a drinking problem?" I was like, "You idiot, my sarcoidosis affects my liver! I am not an alcoholic." That day I knew he wouldn't be my primary doctor anymore. How can you call someone at work and ask them if they are an alcoholic without even really looking at their tests or their medical records? I was so livid.

A few weeks later, I was driving to work, and I felt something dripping and I looked, and I was having a nosebleed. I drove myself straight to the hospital and to my pulmonologist. He told me the sarcoidosis was affecting my liver very badly, my kidneys and part of my brain again. He wanted to do some really heavy doses of steroids. However, they could not do that high a dosage because of my liver and the kidneys. We started using trial and error, with constant blood work. I was in the hospital for a couple of weeks and the doctor told me that when I left, I couldn't go back to work again.

In 2010, they put me on oxygen. As long as I'm sitting or I'm calm, I'm ok but any time I have to exert myself, or I go out I have to have my oxygen. I have two inhalers and I sleep with a CPAP machine so I can constantly breathe properly when I'm sleeping. We also found a medication that works.

Then, in July of 2018, I was diagnosed with triple negative breast cancer. I thought to myself, "You gotta be kidding me!" but because I go every year to get my mammogram, it was caught in time, but I still required a surgery to remove it.

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However, in order for me to have my surgery, and then do chemo and radiation, they had to take me off my sarcoidosis medication and risk my sarcoidosis hitting me harder.

I started chemotherapy within a month of the surgery and my first day of chemo I almost died in front of my mother. I was allergic to the medication that was chosen for my chemotherapy. I was doing fine on my pre-meds but as soon as they started the chemotherapy medication, I seized. I remember falling back, and my insides were on fire. I heard them saying "Miss Williams, we got you. You're having an allergic reaction." I remembered my meditation strategies, so I thought to myself, "Listen to their voices, they're coaching you through this. It's going to be ok," as my body calmed down. Two days later I went back, and we started a new chemotherapy, and six months after that, I went through radiation. I finished everything on March 30, 2019 and went back on my sarcoidosis medication again.

The entire time, I was still doing my activist work. I helped in getting three bills introduced to the Michigan Legislature. I don't care what side of the table you stand on. Illness is illness, a sickness is a sickness, a disease could care less when it grabs hold of the body. It's just looking for a host. It could care less your political views. I also continued to run the support group I had started – because I wanted a group based on empowerment – and hosted our third annual walk to raise money for the Foundation on Sarcoidosis Research one month after my cancer treatment. This year would have been the fourth year, but it was canceled because of COVID-19. I had it scheduled for a park, and I had all these sponsors and everything, and then the pandemic hit, but I'm not even worried. I know next year will be even better. ■



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>