

Traci Waters

SARCOIDOSIS



I was diagnosed with sarcoidosis at the age of 31. At the time of diagnosis I had no symptoms, I was athletic and completely healthy.

I had no idea the impact it would come to have on my life. As the years went on I began to have flair-ups. These flair-ups forced me to make many physical and psychosocial adjustments.

I began to feel isolated and ostracized because of the cough. I was embarrassed by the shortness of breath. I was irritable and suffered from insomnia because of the Prednisone that I was on to control my symptoms, and I was depressed about the weight it caused me to gain. The pain and distressing fatigue made it difficult to exercise, as well, which led to decreased function and more weight gain. I felt trapped in a distressing cycle of illness.

In 2008 I contracted a fungal infection that caused so much damage to my lungs that I later had a lobe of my right lung removed. Fortunately, I had enough reserve lung function remaining that I didn't need to be on supplemental oxygen after the surgery.

Traci Waters was a patient speaker at the ATS 2018 International Conference in San Diego, California.

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The damage to my lungs from the sarcoidosis has left me with many limitations but I try not to allow these limitations to stop me from living my best life. I work full-time, I travel, I exercise and interact with my friends and family. There are occasions when I can't participate in events because I'm too fatigued and I've learned that it's important to pay attention to my body when it's telling me to rest.

Through the years I have remained prayerful and had the benefit of family and friends who prayed for me. I am determined not to let this disease steal my life. I have shortness of breath and a chronic cough and I'm not able to walk as fast or as far as I used to, but that's okay because I'm grateful to be here to share my story. ■

Sarcoidosis

Sarcoidosis is a disease of unknown cause in which inflammatory cells clump together and form tiny lumps of cells, called granulomas, 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. Sarcoidosis varies in how active and how severe it is for each person and over time. The granulomas, when active, can cause short term and/or long-term damage to the organ involved. Some signs and symptoms of Sarcoidosis are:

- Lungs: Shortness of breath, wheezing or dry cough.
- Lymph nodes: Enlarged and sometimes tender lymph nodes, most often in the neck and chest.
- 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. Painful and tender reddened bumps called *erythema nodosum* can suddenly appear on the ankles and shins.
- Bones and Joints: Bone lumps (nodules), causing pain in the hands and feet, and/or swelling of ankles or other joints.
- Spleen and Liver: There can be pain in the upper abdomen, under the ribs on the right (liver) or left (spleen).
- Heart: Shortness of breath with activity, leg swelling, irregular or fast heart beat, or passing 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.
- Fatigue is a common problem, seen in more than half of patients.

Learn more: *ATS Patient Education Series What is Sarcoidosis?* New York, NY. www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf.