# Sandra Detter

SARCOIDOSIS

Living with sarcoidosis is like living by traffic light.

When I am "green," life is great! I am alert and productive at work. I have no limits when it comes to exercise. I can do anything I want.

"Red" is when the symptoms are so severe that I can't work full-time or do any exercise. It is obvious to everyone that I am not well, and I've never managed to get out of a red state without medical intervention.

At "yellow," fear and uncertainty cause me to be anxious. I am functioning, but I feel sick. I can only meet the minimum requirements of my life. I force myself to exercise because it is the only thing that makes me feel better.

I do my best to hide this because I cannot afford to show a doctor too much anxiety because, if I do, that ends up being the diagnosis. You've heard of people carrying baggage from old relationships? I still have baggage from my doctors/patient experiences during the years when I was sick with sarcoidosis and misdiagnosed. So when I do slide into "yellow," I give it two weeks to go away, or improve. If it doesn't, I need to see a doctor. But which one?

*Sandra Detter was a patient speaker at the ATS 2019 International Conference in Dallas, TX.*

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If I start with my primary care physician, she will help me figure out the specialist I need to see, though she can’t treat me herself. That will delay the process by two weeks and cost a half day of work when I am already struggling to keep up. Another option is my pulmonologist, who is sarcoidosis-proficient, but sometimes my lungs are fine.

No matter what I do, I am still far from treatment. It will take several weeks to see a specialist, and then medical tests will take another few weeks. That’s a long time when I am not feeling well, and my batteries are draining. I often think I should just give up, but again, if I show a doctor too much hopelessness, depression ends up being the diagnosis.

Physicians, if I sense that you are taking me seriously, you will be my hero and I will trust you. You will be my hero even if you do not know what is wrong with me. I will appreciate your support in ruling out possible causes and pointing me in the right direction. ■

## 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. 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.
- 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.
- Bones and joints: Bone lumps (nodules), and/or swelling of ankles or other joints.
- Spleen and liver: There can be pain in the upper abdomen.
- 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.
- 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.* ***www.thoracic.org/patients/patient-resources/resources/sarcoidosis-pt-1.pdf.***