Rebecca Stanfel

Sarcoidosis

Getting diagnosed with sarcoidosis when I was 34 years old—and a brand-new mother—left me reeling. An urgent care doctor in my small Montana city told me I probably had lymphoma after seeing my abnormal CT scan. It was a very long two weeks until I got an appointment with a pulmonologist across the state. Still, when I learned that I had some immune disease instead of lymphoma, I felt hopeful.

A few weeks later, while I was out for a neighborhood walk pushing baby Andrew in his stroller, I passed out. I had no idea how long I had lain in the street, out cold, with my child unattended.

My pulmonologist referred me to a research hospital a couple of states away. I had a battery of tests: a cardiac MRI, a signal average EKG, an echocardiogram. The electrophysiologist (EP) told me I had cardiac sarcoidosis and that I could

“drop dead at any moment.” I still get gooseflesh and a pain deep in my gut when I even think of his words now, 18 years later, and picture Andrew waiting for me back at the hotel with my parents.

The question that my medical team wanted to address was whether I should have a defibrillator implanted immediately and be started on high-dose steroids, or just start on steroids. At the time, the protocol was to use a right heart catheterization to help decide. If the EP could stimulate (potentially fatal) ventricular tachycardia while I was safely being monitored in the surgical lab, they would implant the defibrillator then and there. If not, I was judged not to be at any real risk and wouldn’t need a defibrillator. I passed my cath lab test that day and began a years’ long course of high-dose steroids (80 mg. and above).

However, my heart didn’t get the message that all was well. I spent the next few years passing out without warning. Each of these episodes of syncope required I return to the cath lab that was a long day’s drive from my home.

I began what felt like an increasingly absurd and surreal roster of tests. A different EP theorized that perhaps exertion combined with my underlying cardiac sarcoidosis caused my issues so, I went into my fourth right heart cath unmedicated, and was handed light dumbbells midway through the procedure and instructed to carefully do some chest pressed and biceps curls while they tried to stimulate v-tach. As usual, my heart behaved itself in the lab.

I hadn't yet learned the most important question any patient should ask when being scheduled for a test. Will the results of this test change my treatment or prognosis? I had good insurance and wanted to be a good patient. I believed that if I followed all the doctors' instructions, I would get to live to see my son grow up.

What followed were tilt table tests, blood gas tests, EMGs, more heart caths, PET scans, MRIs. I gained 100 pounds on prednisone, and none of these tests provided a definitive answer. More than one doctor blithely suggested I get a heart biopsy. By then I'd learned enough to ask questions and discovered that even such an extreme procedure wouldn't provide definitive results.

I changed doctors. Early in my first appointment he asked how my defibrillator was managing my cardiac sarcoidosis.

Defibrillator?

I had been caught between protocols. Newer research showed that all my hours in the cath lab without getting v-tach were just that—hours. He told me I was lucky not to have died.

A week later, I had an AICD implanted in my chest, and I've grown accustomed to it pacing and occasionally shocking my heart back into normal rhythms. It saved my life.

I don't blame those doctors who had me lifting weights while in surgery. With so few cardiac sarcoidosis patients, they did the best they could with the limited data they had. I'm extremely fortunate not to have ended up a data point disproving their theory.

But I am left with strong feelings about all the testing I endured. The irony is that in all my cath lab exams, in being flipped around on a tilt table and spun around in a chair with flashing lights until I vomited is that I was both over and under treated. In my doctors' quest for surety, my life ended up at stake.

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Testing and then re-testing patients with diseases like mine often don’t bring surety, only more questions (that require more tests). My goal isn’t to appear, anonymous, in a medical journal. Now I am a patient advocate for the Foundation of Sarcoidosis Research. I want to live as fully as I can with sarcoidosis. For this to happen, I need my doctor to ask herself how the test will improve the patient’s treatment and quality of life before ordering the test.

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. Other people 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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