

Brenda Clark

SARCOIDOSIS



“The news nearly knocked me out of my chair. I read it over and over again and several times aloud to myself. I was very scared and also angry. I would have appreciated a phone call or in-person consultation.”



Like many patients diagnosed with sarcoidosis, I sought to find out as much as I could about the disease, scouring the Internet and reading a great deal of literature from my health care providers. It was disappointing to find out the cause was unknown and that there was no cure—yet.

I was age 44 at the time, in June 2008. My ophthalmologist was the first to make the diagnosis. I needed treatment for inflammation, which I had in one eye, and that quickly progressed to pain and blurred vision. On the day we reviewed my chest X-rays, I received a second diagnosis of iritis. I jokingly asked my doctor if this was arthritis of the eye.

I began a treatment of steroid drops to relieve the inflammation and return to normal eye sight. The iritis flared up roughly six months later in the other eye. So far I have not had another recurrence.

I learned that symptoms could appear and disappear throughout my lifetime and what really stuck was that the microscopic lumps in my lungs could appear in almost any body organ. In four years this happened.

When presented to the emergency room late one Sunday evening in excruciating pain I assumed I had a ruptured appendix or kidney stone. The ER physician sent me for abdomen and pelvis CTs without contrast, and those later revealed I was suffering from bilateral kidney stones. This was a first for him—he said he never had a patient appear with bilateral kidney stones. The nurse who came with an injection for the pain asked if I had any children. When I asked her why she said that this pain was comparable to childbirth. My partner, who was with me in the ER, reminded me of a quote from the comedian Carol Burnett who once said giving birth is like taking your lower lip and pulling it over your head. Things would not end so lightheartedly.

Sarcoidosis is an inflammatory disease that most commonly involves the lungs but can impact any organ in the body including the eyes, nervous system, liver and heart. For some patients, the disease is mild and for others it may be progressive and devastating. The cause of sarcoidosis remains unknown. However, experts suspect that sarcoidosis develops when a patient's immune system overreacts to some type of exposure—occupational, environmental or infectious—and small clumps of inflammatory cells called granulomas are formed and deposited in affected organs.

Learn more from ATS Public Advisory Roundtable member the Foundation for Sarcoidosis Research. stopsarcoidosis.org

The next business day, I received the following email from my primary care physician:

“Dear Ms. Clark, I reviewed your recent CT abdomen scan with the radiologist and it shows abnormally increased lymph nodes in your abdomen which needs further evaluation by another scan and a biopsy to rule out other abnormalities such as cancer. I have sent the referral to surgery and radiology for these studies.”

The news nearly knocked me out of my chair. I read it over and over again and several times aloud to myself. I was very scared and also angry. I would have appreciated a phone call or in-person consultation.

That August I went in for my surgical consult visit and was fortunate to have a compassionate physician, who must have read the anxiety on my face the moment we met. She went over my options and in the 45 minutes she spent with me, she was extremely thorough. She believed it was best to get an MRI with contrast as soon as possible because the previous CT previously was without contrast, and she said this would help with surgical planning. It wasn't until years later when I went back and read my medical record for the first time, that I recognized the significance of this visit with my surgeon. Abnormal lymph nodes were everywhere, and there were varying sizes from two to four centimeters in my upper abdomen, intestine, diaphragm, chest, and esophagus. Thankfully, the biopsy came back negative. No cancer. Conditions and findings were found to be consistent with the history of sarcoidosis.

While this entire process took over five weeks to determine, it felt more like five months. Today I suffer from fatigue, skin rashes, and other various conditions likely related to the disease. Though it helps to stay active with organizations like the Foundation for Sarcoidosis Research, and I appreciate being able to share my personal and medical history with you.