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SARCOIDOSIS



*“Sarcoidosis may be a snowflake disease,
but living with it hits like an avalanche.
We need your help to dig us out.”*

My first flare occurred in my last trimester, in 1990. A cough led me to an ER visit, where I was given a prescription for cough medicine. Aside from the cough, I did not have any other symptoms that indicated a cold. I gave birth, and my cough subsided and soon after dissipated. Two years later, days after giving birth to my second child, I had a repeat episode. My journey began, initially with appointments for periodic shortness of breath. I was prescribed antibiotics and several different inhalers. The diagnosis? Bronchitis, and later asthma.

In 1997, my symptoms multiplied. Having done all he knew to do, my primary doctor referred me to a host of specialists—a hematologist, rheumatologist, ophthalmologist, neurologist. I was growing impatient. Then in February 1999 my health declined almost overnight. One morning I woke up to start my day. I got out of bed to walk, and everything around was dark. I couldn't breathe, there was a burning sensation. When I stepped outside, the cold winter air felt like it was attacking my lungs. I went back inside and found myself shuffling between the bed and the couch across the room.

I scheduled the first available appointment with a pulmonologist and saw one the next day. A scheduled bronchoscopy was performed, and results came back sarcoidosis, of the right upper lobe of the lung. During a flare I was prescribed medications. Their side effects included: weight gain, sleeplessness, change in temperament, full moon face, loss of hair, acne, cotton mouth, and a metallic taste anytime I ate or drank. Two years of a misdiagnosis had taken its toll, and the lack of coordinated communication with my many health care providers complicated the diagnosis.

In 2013 I woke up to an accelerated heart rate. I drove to the ER. Immediately my heart rate dropped below 50 beats per minute, and hospice was called. According to my EKG, my heart was being affected. In two years, I was seen by three different cardiologists.

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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

In 2014 results from pulmonary function tests were persistently problematic and led me to take six weeks off from work. During this time, my HR department challenged what my specialist wrote on my medical leave documents, which stated “extrinsic, chronic severe asthma and sarcoidosis.” The date for my return to work was based on the outcome of my follow up appointment. I filed a complaint with Equal Employment Opportunity Commission and found myself battling sarcoidosis with a system that seemed to be working against me. Neither of the EEOC representatives assigned to my case had ever heard of the disease, and that added to my stress level. When I exhausted all my accrual leave, I had no choice but to be removed from the company payroll.

Every day I wake up exhausted. And with each episode I can't help but think, is this the one that is going to take my life?

There is a great need for research into the cause, cure, and treatment of sarcoidosis. Moreover, the medical profession needs better education so they can detect it earlier and diagnose it properly. Sarcoidosis may be a snowflake disease, but living with it hits like an avalanche. We need your help to dig us out.