

Rodney K. Reese SARCOIDOSIS

"My pulmonologist is very active in our support group. It has opened his eyes and changed the way he handles his patients." In 1997, we experienced a massive explosion at a chemical plant where I worked as a process operator in Baton Rouge, La. The ceiling collapsed in the control room and pushed a huge dust cloud of ceiling tile, fiberglass insulation, and aluminum sheeting through the building. Outside, we discovered a sump overflowing and emitting toxic vapors of formaldehyde, methanol, propanol, butanol, propargyl, sodium hydroxide (caustic soda), acetylene gas, hydrogen gas, copper acetylide catalyst, and nickel catalyst.

Two hours later, my symptoms started with a dry cough. When I went to bed, I couldn't breathe while lying flat on my back. My cough continued with dyspnea and fatigue.

The next day, I reported to the plant doctor. After chest x-rays and a breathing test, I was diagnosed with an irritated airway and given two inhalers. I was told I would be fine in a couple of weeks. This did not happen.

I went to my pulmonologist. After chest x-rays and pulmonary function tests, I was diagnosed with early stages of pneumonia. I was given meds and told it would clear up in a couple of weeks. This did not happen.

About six months later, I returned to my pulmonologist and received the same diagnosis, but I started having frequent and severe nosebleeds.

Eventually, my primary care physician referred me to an ear, nose, and throat specialist. A CT scan revealed that I didn't have a normal sinus, and surgery was performed. An allergist who read the biopsy report found non-caseating granulomas and told the physician and specialist that I possibly had sarcoidosis.

SARCOIDOSIS

- Sarcoidosis is a potentially fatal inflammatory disease that can appear in almost any organ in the body. Although the lungs are affected in more than 90 percent of patients, the disease often attacks the heart, eyes, central nervous system, liver and kidneys.
- In the United States, Sarcoidosis is most common in African Americans and people of European—particularly Scandinavian—descent.
- In the United States, Sarcoidosis frequently occurs more often and more severely among African Americans than among Caucasians.
- Among African Americans, the estimated lifetime risk of developing Sarcoidosis might be as high as 3 percent.

Source: Foundation for Sarcoidosis
Research—http://www.stopsarcoidosis.org

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After tests for TB and Wegners Granuloma came back negative, I was diagnosed with sarcoidosis. By that time, I had lost about 40 percent of my lung capacity.

I was given two inhalers and placed on 80 milligrams of prednisone per day, which continued for three-and-a-half years. The side effects of these high dosages wreaked havoc on my body. Along with being diagnosed with glaucoma and severe muscle and bone pain, I had to have both hips replaced by the age of 48.

The effects of sarcoidosis on my work and family life have been devastating. I had to retire at the age of 49 because I could no longer perform the duties of my job. Because of my breathing difficulties, fatigue, and orthopedic problems, I can't be as active in my son's and daughter's personal, academic, and athletic lives.

After trying just about every drug listed to use for sarcoidosis, the drug Remicade been a godsend. I feel better than I've felt since being diagnosed. I'm not as fatigued, my breathing tests are significantly better, and the aches and pains are not as severe.

I urge doctors to listen to their sarcoid patients' complaints and to become involved in support groups. My pulmonologist is very active in our support group. It has opened his eyes and changed the way he handles his patients.

Rodney Reese was a patient speaker at the ATS 2010 International Conference in New Orleans, La.

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