

MY EXPERIENCE WITH SARCOIDOSIS

BY

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There was a nodule on my forehead that I had recognized from a similar experience 10 years before. Things were different this time, though. There were lumps all down my legs and arms, visible lumps. They appeared on my face, eyes, and nose. I had a rash in a localized area on my back. It was July, 2006, and I was in Houston visiting my sister. While discussing my symptoms with my little sister, she told me her mother-in-law had lumps on her legs and arms and had been diagnosed with sarcoidosis.

Upon returning home, a dermatologist did a biopsy of the rash on my back that confirmed sarcoidosis. I lost my appetite and lost weight. I was tired all the time. I was lethargic. There were joint pains. That was the beginning of a series of specialists: an intern specialist, a cardiologist, and oncologist. Of course, the drug of choice was prednisone, which meant accepting the good/bad/and the ugly. Felt good, had lots of energy, ate like a pig, gained lots of weight. Nodules went down, the rash on my face and back disappeared. But then, there was the fear of diabetes.

The doctor took me off prednisone. In my determination to stay off of it, I got really sick. I went to the doctor asking for prednisone. Unfortunately for me, the doctor prescribed too much for the amount of weight I had lost. Within two weeks, I landed in the hospital for three days with a medically induced psychosis. That period of time was unbelievable. Thank God, things got better.

Needless to say, I changed doctors. I have a new intern and a rheumatologist. I have since been diagnosed with neurosarcoidosis, which I am told is the most dangerous form of sarcoidosis. I experience left-side numbness. I have had a series of MRIs, CAT scans, and sonograms. The medicines of choice this time were prednisone and metrotrexate. After a short period of time, my doctor took me off metrotrexate because my white blood cell count dropped too low. My weight ballooned to 203 lbs. I had to come off prednisone because my sugar count went up. So, I am in what I call limbo. I am losing weight again, and my white blood cell count has improved. I take blood tests every two weeks. The nodules in my legs are back, but under the skin. There are a few nodules on my face. My joint pains have increased. I experience left-side numbness which is a major concern for me. I anticipate having new medication once the white blood cell count gets better. My doctor, too, is concerned with the numbness.

But through it all, God is good. He has taken care of me through this. There are times when I fear the medicines more than I fear the disease. At any rate, I am blessed to be as well as I am. I am thankful to the Sarcoidosis Foundation for the information and support I have received. Rachella Parks-Washington has been such a blessing, and I thank her for always being there, ready to talk whenever I call. I have friends to call upon who are experiencing the same thing. That support is comforting and their prayers are so welcomed.