



FOUNDATION FOR  
SARCOIDOSIS RESEARCH

To Whom It May Concern,

A diagnosis of sarcoidosis can be life changing for patients and their loved ones. As the world's leading nonprofit organization dedicated to finding a cure for this disease and to improving care for sarcoidosis patients, we strongly advocate for the recognition of the burden of chronic manifestations of sarcoidosis. This potentially debilitating and deadly multi-organ, inflammatory disease has no known cause or cure. It can affect people of any age, race, or gender, however, many patients are diagnosed in the prime of their lives, between the ages of 20 and 40.<sup>1</sup>

Quality of life is often diminished in patients with chronic inflammation associated with sarcoidosis. Severe complications may include, but are not limited to unmanageable pain syndromes resembling fibromyalgia and those stemming from small-fiber neuropathy, and debilitating fatigue which affects an estimated 50-70% of sarcoidosis sufferers.<sup>2</sup>

"Uncommon manifestations include neurologic, cardiac, bone marrow, renal, exocrine gland, sinonasal, and bone disease. Clinically relevant presence of these uncommon manifestations is often associated with chronic or progressive sarcoidosis. When they are discovered as incidental findings on imaging studies or biopsies, they do not usually portend significant organ dysfunction."<sup>1</sup>

For patients who experience chronic disease, the chances of remission are low. Therapy is generally aimed at maintaining stability and preventing organ failure since there are few reliable therapies to slow or halt the progression of chronic cases.<sup>1</sup>

While FSR does not advocate for all sarcoidosis sufferers to receive disability benefits, it should be considered in patients with chronic and progressive cases of sarcoidosis. While more research is needed to understand this mystery disease, there exists a great deal of literature which can aid in decisions for each unique case.

Sincerely,

Ginger Spitzer  
Executive Director

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References

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2. Drent, Marjolein. "Sarcoidosis-associated Fatigue" *PubMed*. National Center for Biotechnology Information, U.S. Library of Medicine, July 2012. Web. 20 Apr. 2017.