



## **OPIOID EPIDEMIC Impacts Patients suffering from Orphan Disease of Sarcoidosis**

CHICAGO, IL, December 19, 2017. Effective and appropriate management of chronic pain is a nationwide priority, especially given the current US opioid crisis. The Foundation for Sarcoidosis Research, in collaboration with the Cleveland Clinic and Araim Pharmaceuticals, conducted a survey in patients suffering from the often-debilitating orphan disease of sarcoidosis to better understand the degree and severity of pain and other symptoms experienced by them, and effectiveness of their treatment. Over 2,700 patients responded to the survey. Notable top-line results demonstrate that a majority of patients diagnosed with sarcoidosis self-report having chronic moderate to severe pain despite the heavy utilization of opioids and other pain therapies.

“We felt it was important to understand how sarcoidosis affects the lives of patients, and these new data add to the available evidence regarding the magnitude of the health-related problems that sarcoidosis patients face on a daily basis,” remarked Ginger Spitzer, Executive Director at FSR. “Once our data analyses have been completed, we will present the results to the broader health care community such that both patients and providers share in the important new information this sarcoidosis outreach effort has uncovered.”

In addition to assessing the prevalence, severity and treatment of pain, the questionnaire also evaluated the impact of pain on activities of daily living, and on overall quality of life. A consistent finding was the considerable (“quite a lot”, “very much”) toll that chronic pain took on walking ability, sleep, or enjoyment of life. “Given these findings, we hope that patients suffering from rare and orphan diseases like sarcoidosis will be prioritized as part of the national conversation on how to address chronic pain, and the underlying disease that causes it, without relying on medicines with the potential for addiction and harm to patients,” added Ms. Spitzer.

Prevalence of sarcoidosis is approximately 60 per 100,000 persons in the US, depending on ethnicity, the recent increase in prevalence attributed to improved detection.<sup>i,ii</sup> The number of persons with sarcoidosis who have neuropathy has not been well-established, given differences in diagnostic approaches across care providers. In the FSR survey nearly one-third of responders report having been diagnosed with neuropathy. “Given the pathophysiology of the condition, and the large number of patients in chronic pain despite treatment, a sizeable number of patients with sarcoidosis may have undiagnosed neuropathy”, said Dr. Dan Culver, a specialist in sarcoidosis at The Cleveland Clinic. “The survey revealed a large number of patients with a pattern of debilitating symptoms associated with small fiber neuropathy, such as vision and gastrointestinal problems, muscle weakness, sexual dysfunction, and temperature swings. I’m very eager to conduct additional analysis on this dataset as these findings are important in helping to understand the scope and severity of the problem. There are no currently approved treatments for sarcoidosis, with physicians prescribing a variety of symptom-directed treatments off-label in an attempt to improve patient quality of life, often with significant side effects. These new data underscore the high degree of pain and disability present in sarcoidosis patients, and hopefully will help expedite solutions for this extreme unmet medical need.”



## **About the Foundation for Sarcoidosis Research**

FSR is an organization dedicated to helping patients with sarcoidosis lead better lives. As such, one of FSR's primary priorities is to accelerate sarcoidosis research which will lead to treatments and possibly a cure. FSR provides funding and collaborations for research and initiatives which focus on the understanding of sarcoidosis, addresses the causes of the disease, counters the suffering of patients, and advances the potential for a cure. FSR educates and connects patients with opportunities to become involved by becoming knowledgeable about sarcoidosis research, including participation in clinical trials, tissue donation programs, patient registries and shared data for research. They also offer annual conferences, webinars and comprehensive educational materials for people across the globe living with sarcoidosis, and connect patients to each other for support and enabling a larger impact.

## **About Sarcoidosis**

Sarcoidosis<sup>ii,iii,iv,v,vi</sup> is a chronic systemic granulomatous disease of unknown etiology. This uncommon multisystem disorder is characterized by clinically significant organ impairment, including small nerve fiber loss, and disabling neuropathic symptoms, with pain as the most common complaint. While variable for each patient, the symptoms can cause a major loss in quality of life and inability to participate in the economic work force. Morbidity in sarcoidosis is significant and multifactorial. Mortality is infrequent, but may be increasing over the years. Sarcoidosis is an orphan disease with significant unmet need, with no approved treatments for the disease itself or to modify the disease of neuropathy that many patients suffer from.

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The Foundation for Sarcoidosis Research

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<sup>i</sup> Erdal BS et al. Unexpectedly high prevalence of sarcoidosis in a representative US Metropolitan population. *Respiratory Medicine* 2012;106:893-899.

<sup>ii</sup> Baughman RP et al. Sarcoidosis in America: Analysis Based on Health Care Use. *Ann Am Thorac Soc* 2016;13(8):1244-1252.

<sup>iii</sup> Ianuzzi MC, Rybicki BA, Teirstein AS. Sarcoidosis. *N Engl J Med* 2007;357:2153-65.

<sup>iv</sup> Tavee J, Culver D. Sarcoidosis and Small-fiber Neuropathy. *Curr Pain Headache Rep* 2011;15:201-206.

<sup>v</sup> Gerke AK. Morbidity and Mortality in Sarcoidosis. *Curr Opin Pulm Med* 2014;20(5):472-478.