Ten Clinical Sites Across the United States to Collaborate to Collect Data on Patients with Multisystem Sarcoidosis

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INTRODUCTION

The Foundation for Sarcoidosis Research (FSR) is spearheading a clinical data registry program to enable comparative outcomes and other sarcoidosis natural history research.

OBJECTIVES

Launch a program that enables better understanding of the spectrum of sarcoidosis manifestations. Further aims developed throughout the process include describing treatment patterns and outcomes related to disease course and documenting the prevalence of treatment side effects.

MATERIALS AND METHODS

FSR convened multidisciplinary experts in 2025 to define the overall aims of the program and develop related core data elements to be obtained by research personnel from site specific chart abstraction. They then identified opportunities to maximize feasibility and efficiency of data collection in addition to protocol design and site selection criteria. Clinical site applications were solicited in early 2026.

RESULTS

The Registry will enroll geographically diverse patients from multiple sites to ensure adequate representation of high-risk phenotypes, with a sarcoidosis diagnosis established by consensus criteria and confirmed by biopsy. Participants will be new to the clinic within the past 2–4 years, aged 18–85 years, and willing to participate in the FSR Patient Registry. Patients with diagnoses that limit the interpretability of the analysis of sarcoidosis (i.e., severe comorbidities and/or overlapping diagnoses that are primary drivers of clinical course/therapy) will be excluded. Common data elements include organ involvement per WASOG tool focusing on pulmonary, cardiac and neurologic disease, concomitant diseases and co-morbidities, and medication side effects, to be collected at enrollment and annually. Overall and site-specific cohort characteristic enrollment goals will be discussed at investigator meetings to ensure analyses are powered to address key outcomes (Figure).

CONCLUSION

The FSR Clinical Data Registry will systematically collect and analyze health data on at least 2,000 sarcoidosis patients across 10 clinical sites in the U.S. to improve understanding, management, and outcomes of the disease. The program will encourage dual enrollment with FSR's Patient Registry, a direct-to-patient program collecting patient-reported outcomes.

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Figure: FSR Clinical Data Registry Key Outcomes