13 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. Further aims developed throughout the process include describing treatment patterns and outcomes related to disease course and documenting the prevalence of treatment side effects. Lessons learned from other disease registries and data elements from institution- or consortium-level programs were incorporated into program design.

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.

OBJECTIVE

Launch a program that enables better understanding of the spectrum of sarcoidosis manifestations.

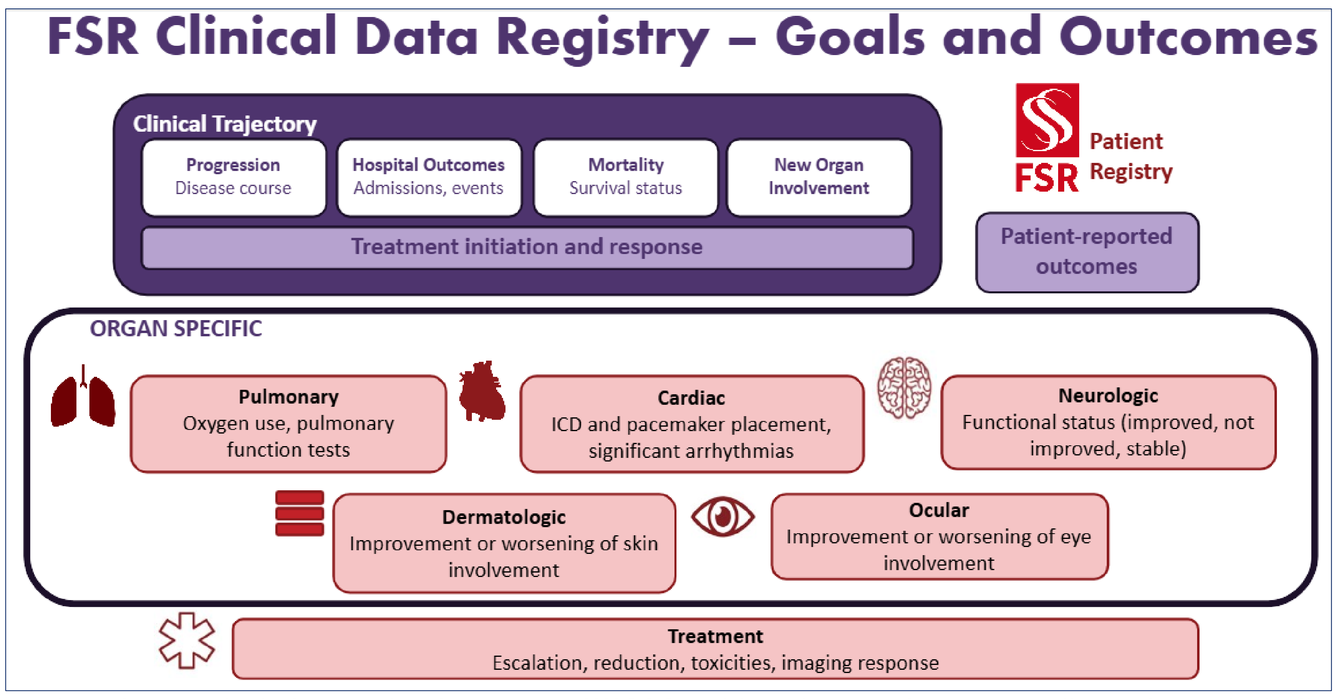
RESULTS

The Registry, planned to launch in late 2026, 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.

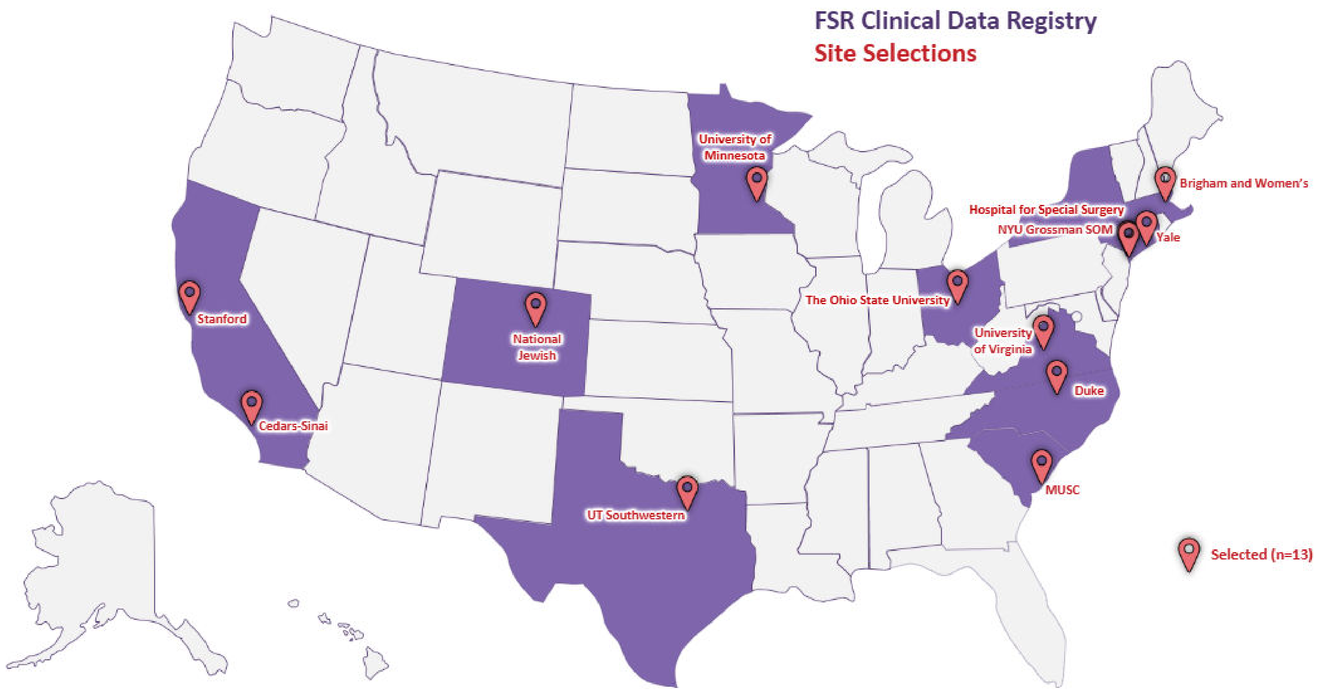
Participants will be new to the clinic within the past 2–4 years, aged 18–85 years, and willing to participate in the FSR-SARC Patient Registry.

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.

Overall and site-specific cohort characteristic enrollment goals utilizing stratified sampling strategies will be discussed at investigator meetings to ensure analyses are powered to address key outcomes.



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.



Institution*	Site PI	PI Specialty
Brigham and Women's Hospital, Inc.	Sotonye Imadojemu, MD	Dermatology
Cedars-Sinai Medical Center	Paula Barreras, MD	Neurology
Duke University School of Medicine	Ravi Karra, MD	Cardiology
Hospital for Special Surgery	Arthur Yee, MD	Rheumatology
Medical University of South Carolina	Ennis James, MD	Pulmonology
NYU Grossman School of Medicine	Kerry Hena, MD	Pulmonology
National Jewish Health	Lisa Maier, MD	Pulmonology
Stanford University	Matthew Baker, MD	Rheumatology
The Ohio State University	Maneesh Bhargava, MD	Pulmonology
UT Southwestern	Connie Hsia, MD	Pulmonology
University of Minnesota - Twin Cities	David Perlman, MD	Pulmonology
University of Virginia	Bonham Catherine, MD	Pulmonology
Yale University	Wonnie Ryu, MD	Pulmonology

**Pending contracting*

CONCLUSIONS

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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RESOURCES

FSR Homepage

FSR Global Sarcoidosis Clinic Alliance

FSR Research Grants