Lived Experiences with Cutaneous Sarcoidosis: Real-World Data from the Foundation for Sarcoidosis Research (FSR) Patient Registry

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INTRODUCTION

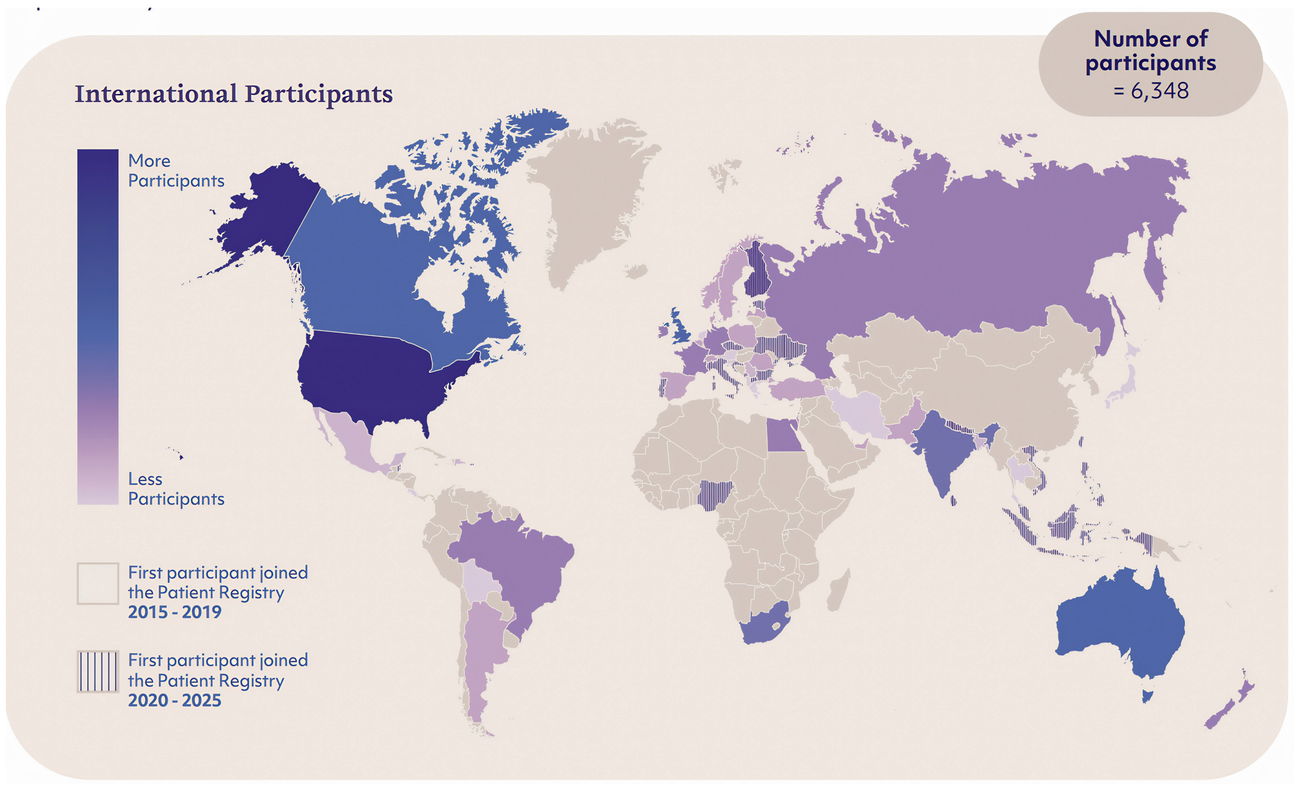
The Foundation for Sarcoidosis Research (FSR) Patient Registry serves as a comprehensive, longitudinal database capturing patient-reported experiences with sarcoidosis. Since its launch in 2014, the registry has grown to include a decade of data from nearly 7,000 participants across more than 68 countries. This analysis of the first ten years of registry data highlights key trends and identifies opportunities to inform FSR's strategic initiatives.

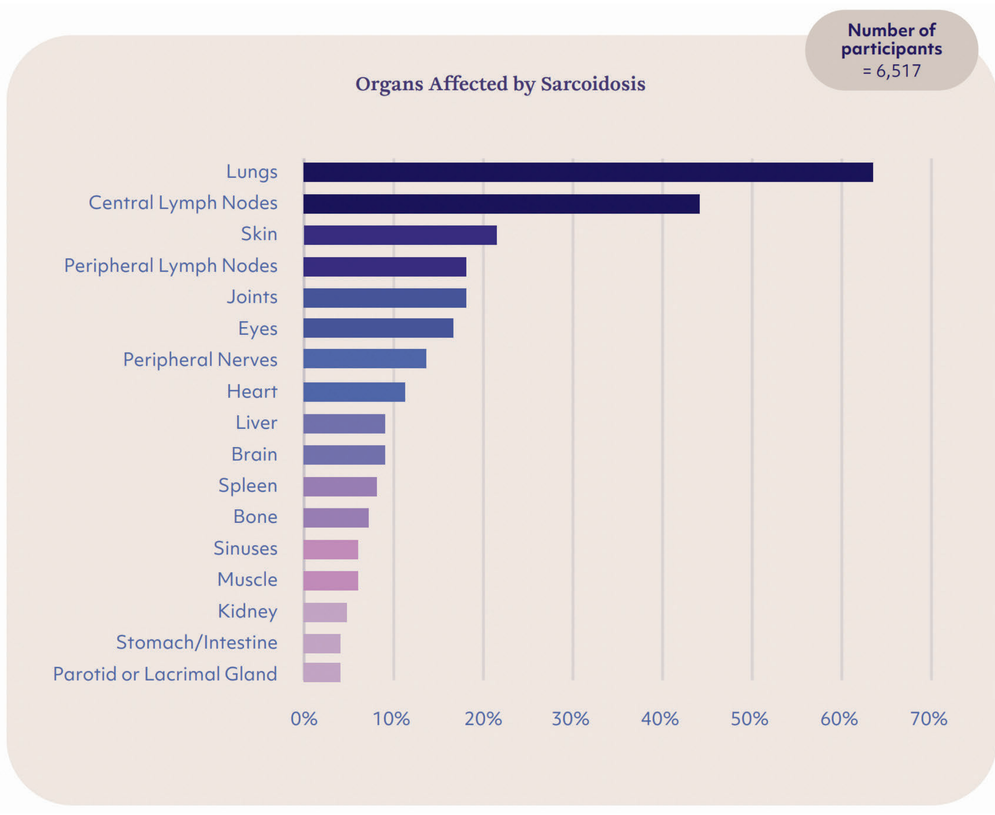
MATERIALS & METHODS

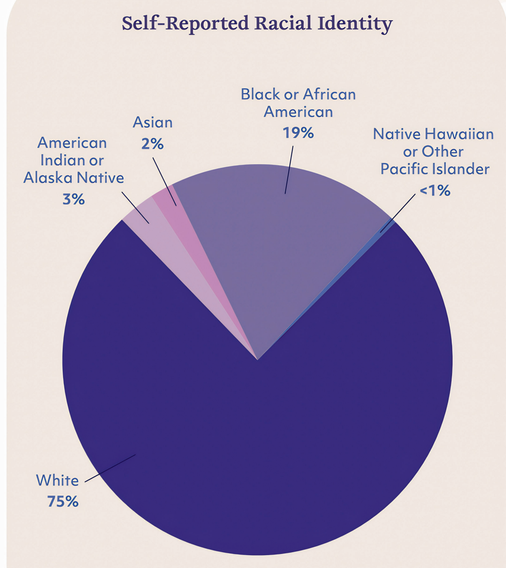
The registry captures data on diagnosis, organ involvement, medications, symptoms, and quality of life. Participants completed the Baseline Questionnaire through the online Patient Registry platform and self-identified demographic, geographic, and disease-related characteristics. These were included in the descriptive analyses along with cutaneous sarcoidosis-specific insights.

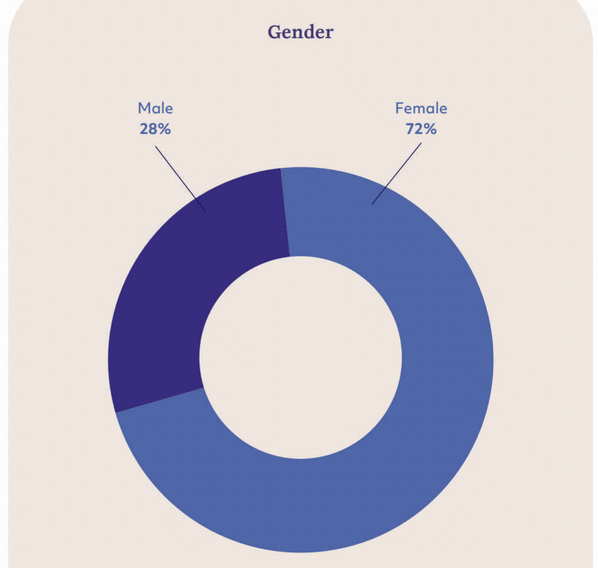
RESULTS

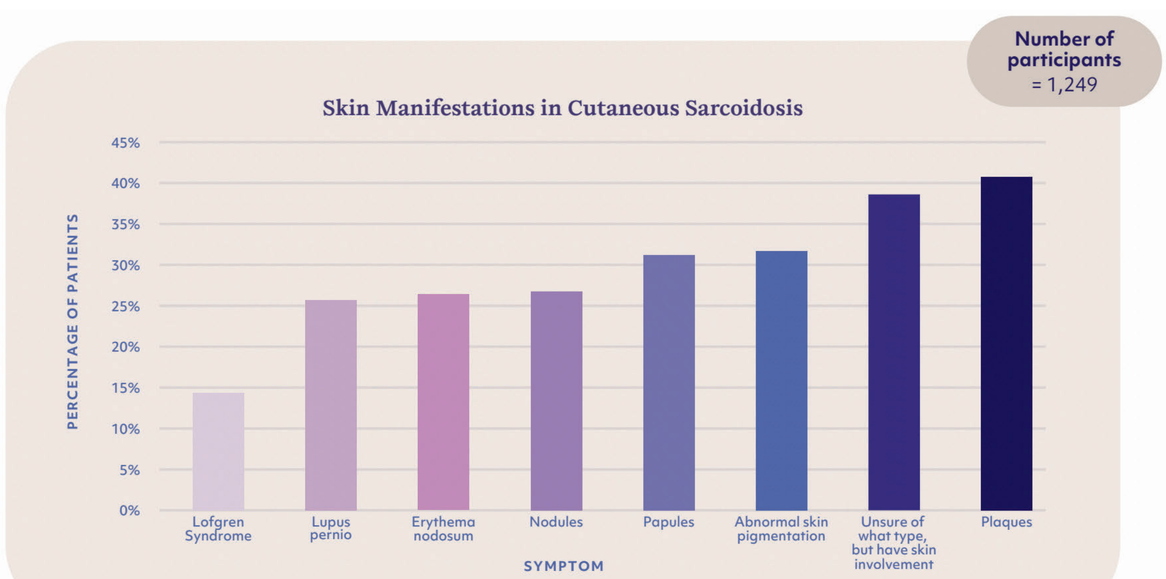
6,348 participants completed the Baseline Questionnaire through March 2025, 1,396 (22%) of which reported a diagnosis of cutaneous sarcoidosis. Among those with cutaneous sarcoidosis were 78% female, 79% White, and 20% Black/African American, with an average age of 59 years old and 86% residing in the United States. The most common reported skin manifestations were plaques (41%), abnormal skin pigmentation (32%), and papules (31%). Nearly 60% reported ever being treated with conventional disease-modifying antirheumatic drugs (Hydroxychloroquine 24%, Methotrexate 16%, Tacrolimus 4%, Cyclosporine 4%, Azathioprine 3%, Leflunomide 3%, Mycophenolate Mofetil 3%), while 15% reported treatment with biologic agents (Infliximab 11%, and Etanercept, Adalimumab, Ustekinumab 4%)." Most participants with cutaneous disease also have multi-organ involvement—most commonly lung (76%), central lymph nodes (44%), and heart (12%).











CONCLUSION

Cutaneous sarcoidosis patients are most often female, but all racial groups are affected. Disease manifestations in this cohort often warranted systemic immune modulating treatments, which may reflect a reporting bias. The FSR Patient Registry features valuable data crucial to better understanding the demographics, organ involvement, and treatment patterns in a large US cutaneous sarcoidosis cohort.The FSR Patient Registry features valuable data crucial to better understanding the demographics, organ involvement, and treatment patterns. Continued expansion of the registry will help to better understand cutaneous sarcoidosis internationally.

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FSR Website

RESOURCES

Registry Report Registry Data Registry Website