Multiorgan Involvement and Disease Burden in Sarcoidosis: Real-World Data from the Foundation for Sarcoidosis Research (FSR) Patient Registry

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FSR Foundation for Sarcoidosis Research

Introduction

- The Foundation for Sarcoidosis Research (FSR) Patient Registry is a robust longitudinal resource of patient-reported data on the variety of sarcoidosis experiences, disease impacts, treatments, and quality of care.
- Launched in 2014, the program now hosts over 10 years of data from nearly 7,000 participants in over 68 countries.
- We analyzed the first decade of registry data to identify trends and assess opportunities for FSR strategic programs.

Methods

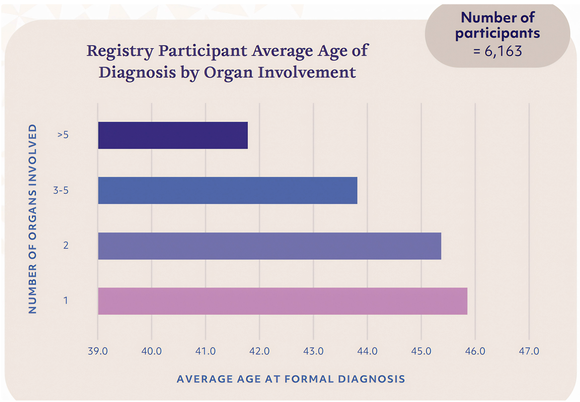
- The registry captured data on demographics, diagnosis, organ involvement, medications, symptoms, employment and disability status, and the validated measures such as the Sarcoidosis Health Questionnaire.
- Participants completed the Baseline Questionnaire through the online Patient Registry platform and self-identified demographic, geographic, and disease-related characteristics.
- Participant data collected through March 2025 were included in descriptive analyses.

Conclusions

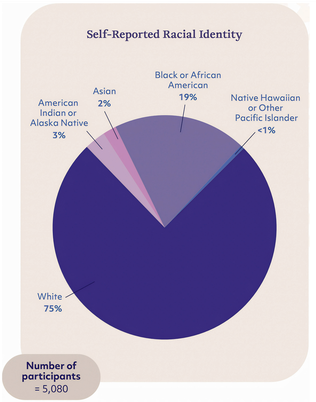
- FSR's Patient Registry is one of the richest sources of real-world sarcoidosis data in the world.
- The registry provides critical real-world insights into the lived experience of sarcoidosis patients, such as fatigue and depression remaining significant burdens, multi-organ involvement might indicate a need for earlier intervention, and substantial impacts on employment.
- Differences in participant enrollment and engagement by gender may highlight differences in disease manifestations/severity or engagement barriers.
- Though reporting bias may limit generalizability, these insights highlight the need to improve representation, validate self-reported data, and enhance longitudinal tracking.
- The registry continues to guide research priorities, strengthen advocacy, and promote equitable care for all patients with sarcoidosis.

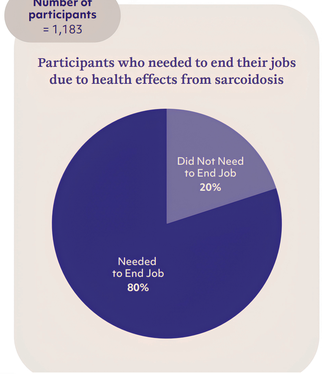
Results

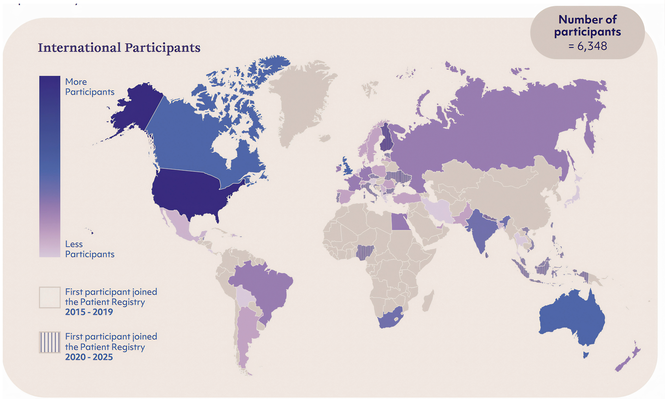
During the first 10 years of the Patient Registry, 6,348 participants completed the Baseline Questionnaire. Respondents represented a wide range of ages (range: <18–>80 years), geographies, and disease manifestations.

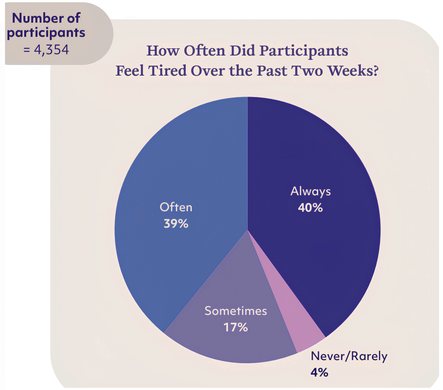


Compared with those with less organ involvement, respondents with 5 or more organ systems involved experienced their first sarcoidosis symptoms nearly 4 years earlier and were diagnosed on average almost 3 years earlier.









Acknowledgements and Resources

Registry Report
Registry Data
Registry Website

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FSR Website