

New organ manifestations associated with pulmonary sarcoidosis years later in a longitudinal patient-reported cohort: real-world data from the Foundation for Sarcoidosis Research Patient Registry

Elise Hoover¹, Ethan Fechter-Leggett¹, Elliott Crouser², Logan Harper³, Taylor Harwood¹, Timothy Legenzoff¹, Mary McGowan¹, Leslie Serchuck¹, Tricha Shivas¹

¹Foundation for Sarcoidosis Research ²The Ohio State University ³Cleveland Clinic Foundation

Disclosure: The authors have no conflict of interests related to this project.

INTRODUCTION

The Foundation for Sarcoidosis Research (FSR) Patient Registry captures longitudinal data from over 7,400 patients with sarcoidosis across 70+ countries, including:

Demographics Disease Experiences Quality of Life

Our objective was to understand self-reported incidence of new organ manifestations of sarcoidosis and quality of life impacts among patients reporting pulmonary sarcoidosis at baseline.

RESULTS



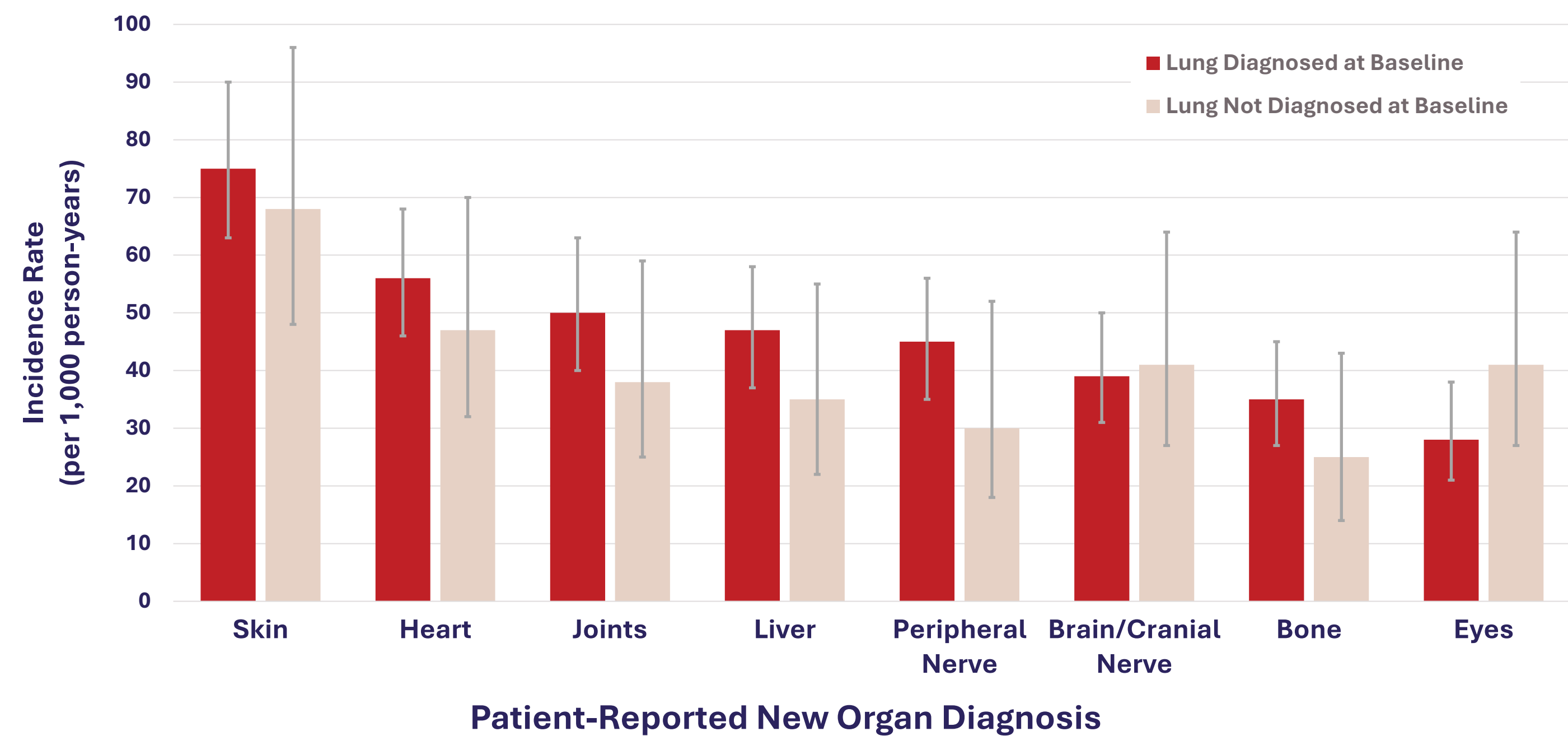
Baseline completed: Jun 2014–Sep 2024
Follow-Up completed: Dec 2020–Dec 2025

Age, disease duration, and time between Baseline and Follow-Up survey completion for included participants (N=970).

Age at Baseline completion, mean (SD), years	54.3	(10.2)
Disease duration at Baseline completion, median (IQR), years	3.9	(9.8)
Time between Baseline and Follow-Up, mean (SD), years	3.9	(2.5)
Age at Follow-Up completion, mean (SD), years	58.2	(10.2)
Disease duration at Follow-Up completion, median (IQR), years	8.3	(11.3)

26% of participants reported not taking medications for sarcoidosis at baseline. 69% of these participants later reported taking them at follow-up.

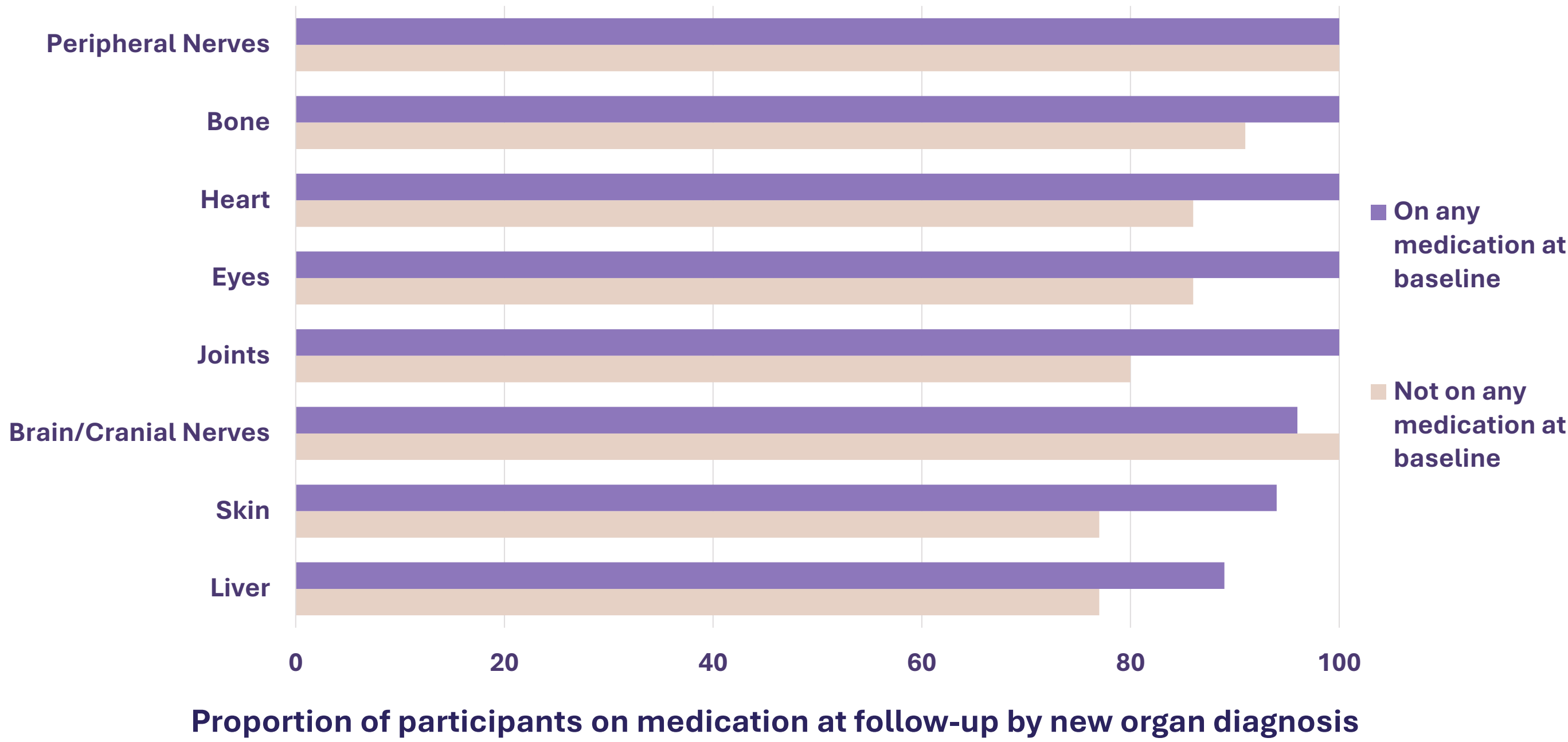
Participants who reported **lung involvement diagnosed at baseline** frequently reported new organs diagnosed with sarcoidosis at follow-up.



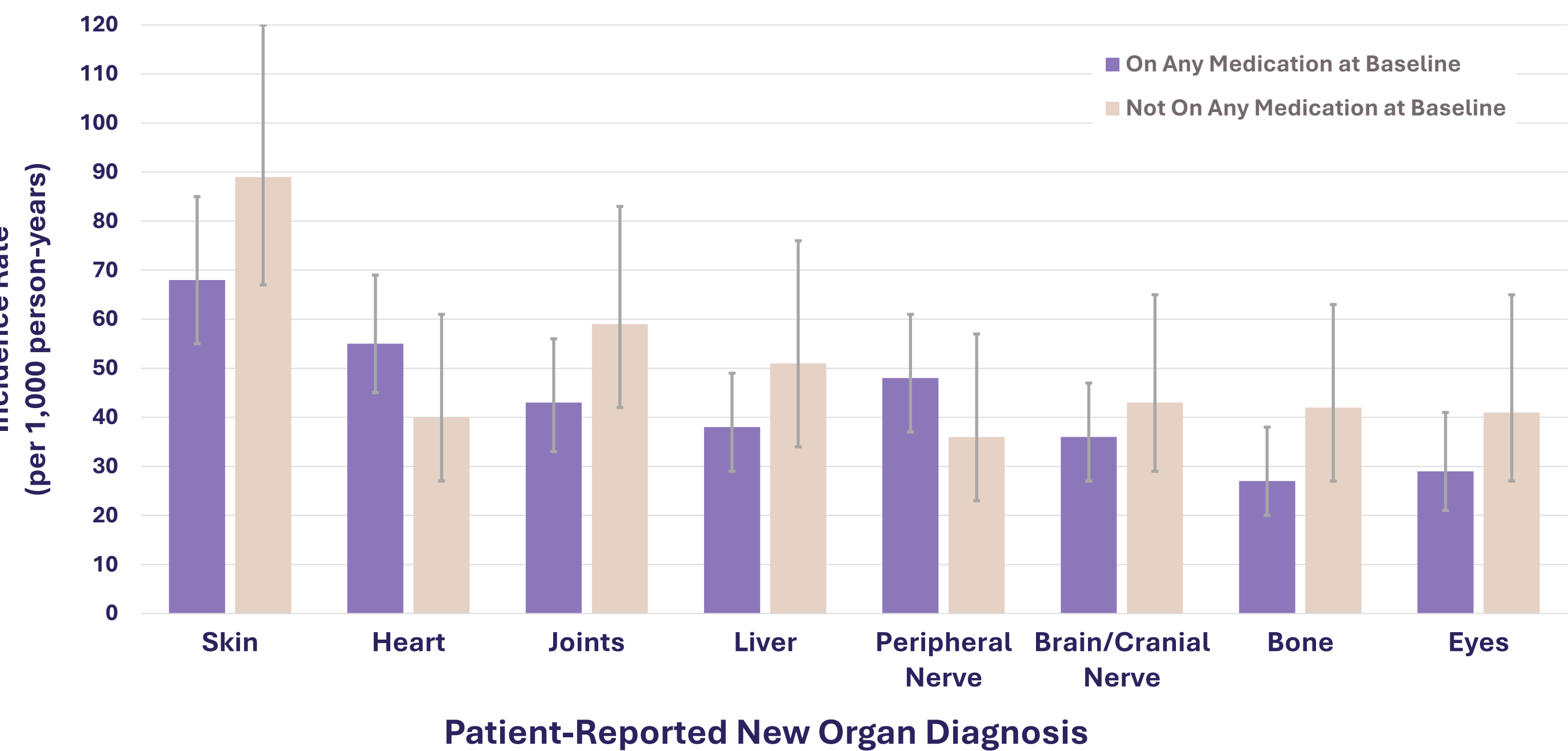
DESIGN/METHODS

- Participants with completed Baseline and Annual Follow-Up surveys through December 2025 were included
- Incidence rates (IR), with 95% confidence intervals, for new organ manifestations were calculated using modified Poisson regression with robust error variance and accounting for person-time between surveys

Medication use at follow-up was high across many new organ manifestations, regardless of medication status at baseline.

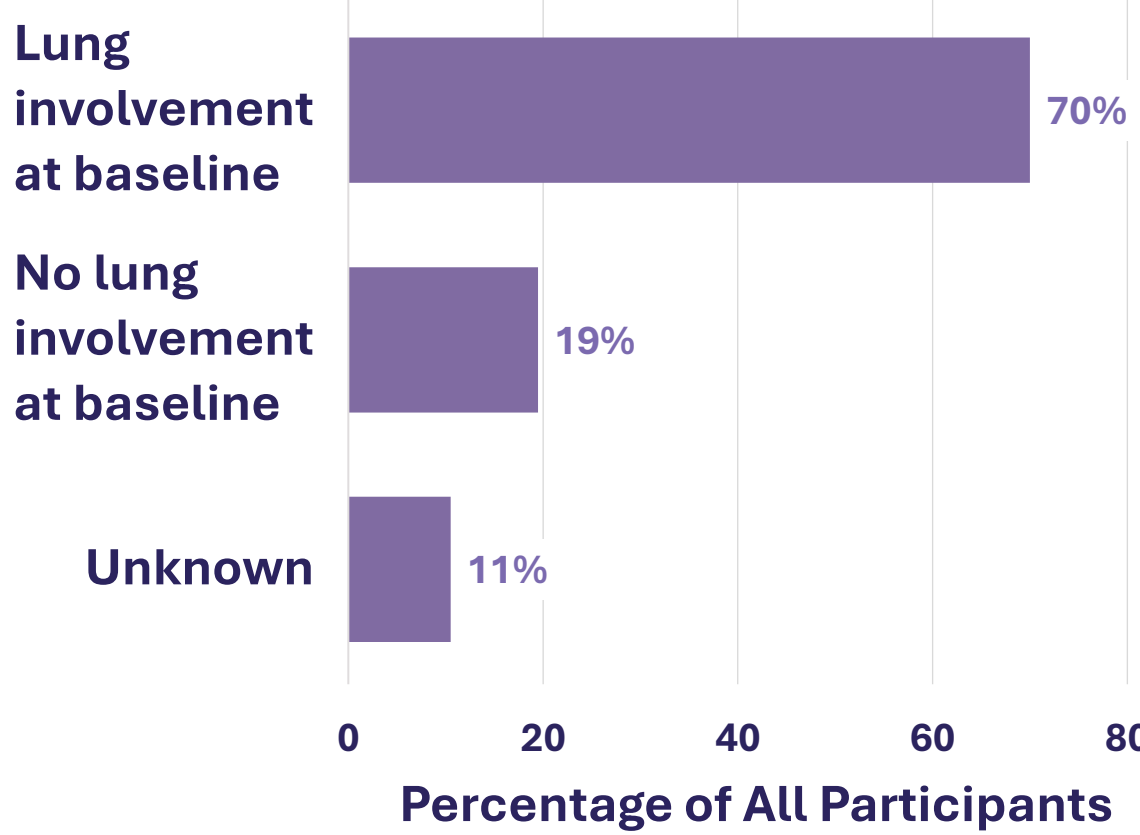
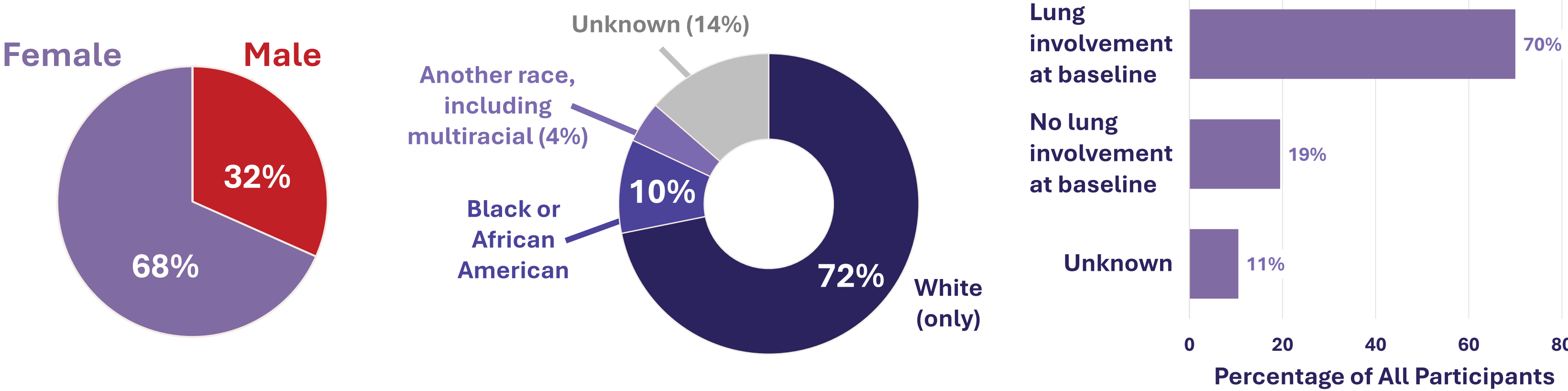


Participants who reported **being on any medication at baseline** also frequently reported new organs diagnosed with sarcoidosis at follow-up.



PARTICIPANTS

Among all 970 included participants, most were female and self-identified as white. About 70% reported lung involvement at baseline.



CONCLUSIONS

Individuals in the FSR Patient Registry frequently report development of additional organ involvement years after initial diagnosis.

These findings underscore the multisystem nature of sarcoidosis and the importance of ongoing, long-term monitoring.

It is likely that the FSR Patient Registry represents patients with more complex disease than the average patient seen in the clinic. The cohort may also represent the characteristics of those most likely to engage in research. Clinical trial eligibility criteria should consider these characteristics in study design to ensure therapies address more complex disease.



FSR-SARC 10-Year
Registry Report



FSR-SARC Patient
Registry Data



FSR-SARC Patient
Registry Website



Digital Poster

Corresponding Author

Elise Hoover, MPH
elise@stop sarcoidosis.org