

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

Elise Hoover¹, Ethan Fechter-Leggett¹, Jeffrey Gelfand², Logan Harper³, Daniel Kurz⁴, Mary McGowan¹, Sarah Sandison¹, Leslie Serchuck¹, Tricha Shivas¹

¹Foundation for Sarcoidosis Research ²University of California, San Francisco ³Cleveland Clinic Foundation ⁴University of Chicago

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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 neurosarcoidosis at baseline.

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

- Sarcoidosis Health Questionnaire (SHQ) scores at follow-up were modeled using analysis of covariance (ANCOVA), adjusting for covariates

Total (SHQ-T)

Daily Functioning (SHQ-DF)

Physical Functioning (SHQ-PF)

Emotional Functioning (SHQ-EF)

Models adjusted for:

- Age at baseline
- Sex at birth
- Race
- Years between baseline and follow-up
- Respective SHQ baseline score

RESULTS

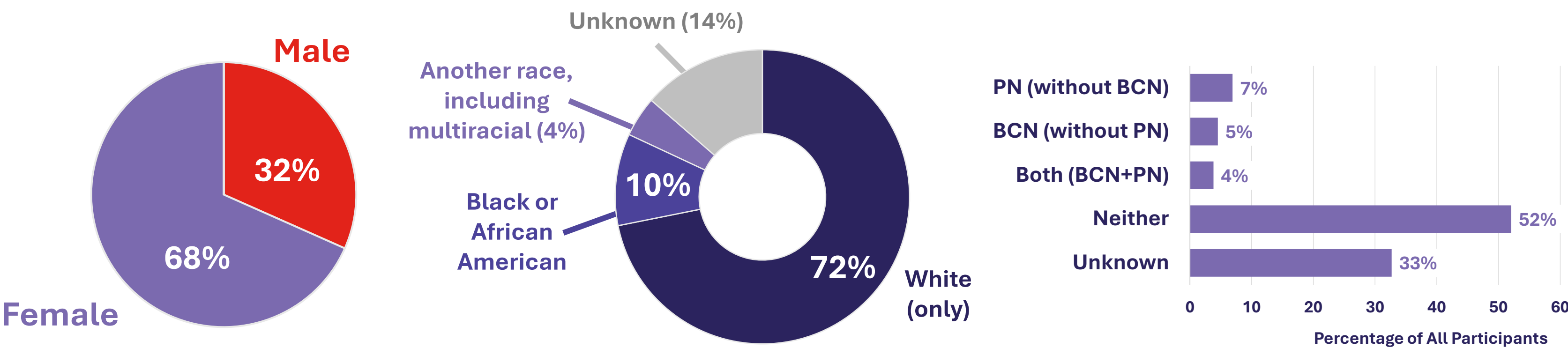


Baseline completed: Jun 2014–Sep 2024
Follow-Up completed: Dec 2020–Dec 2025

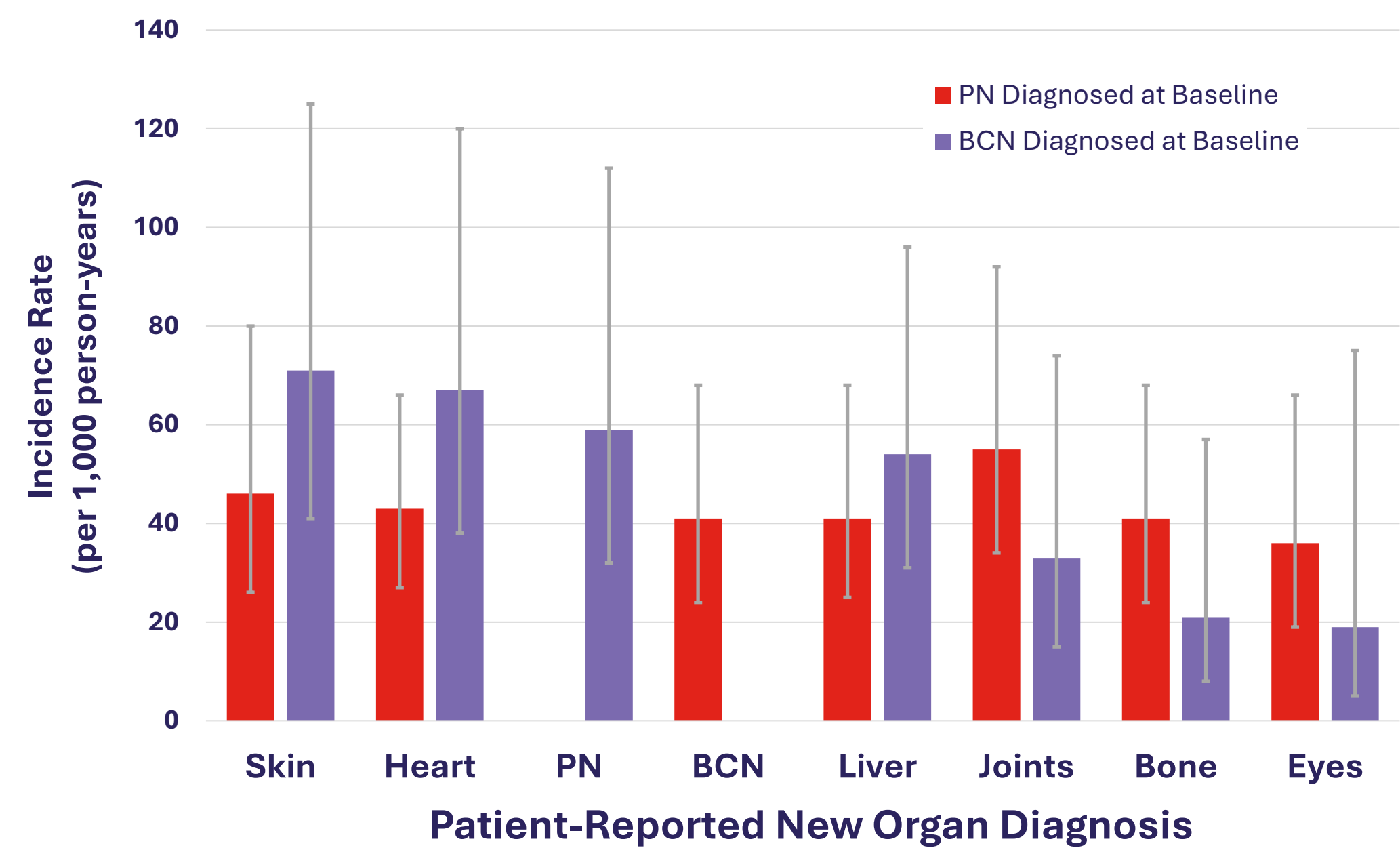
Age, disease duration, and time between Baseline and Follow-Up survey completion for included participants (N=970).

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)

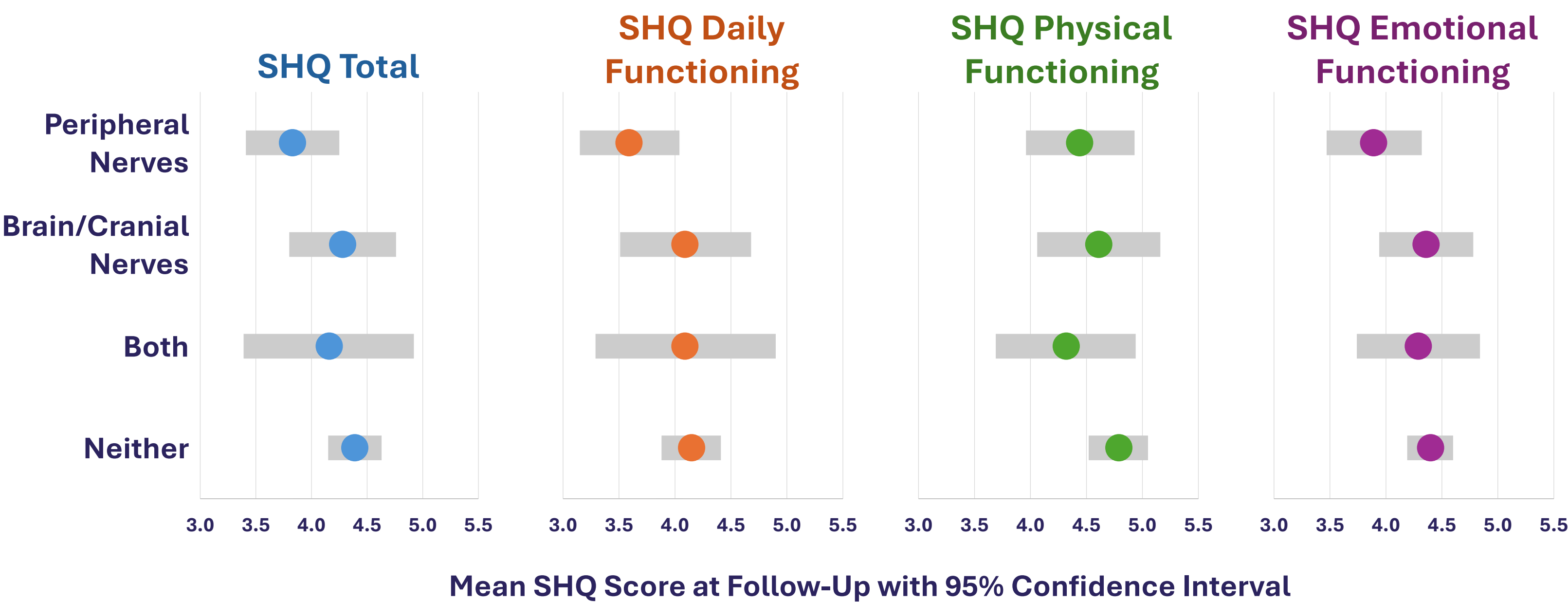
Among all participants, most were female and self-identified as white. About half self-reported neither peripheral nerve (PN) nor brain/cranial nerve (BCN) involvement at baseline.



Participants who reported peripheral nerves (PN) or brain/cranial nerves (BCN) diagnosed at baseline frequently reported new organs diagnosed with sarcoidosis at follow-up.



Patients who reported peripheral nerve sarcoidosis at baseline had lower SHQ scores at follow-up, overall and for each of the 3 SHQ subdomains.



CONCLUSIONS

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

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

The FSR Global Sarcoidosis Clinic Alliance (FSR-GSCA) is uniquely positioned to meet this need through its collaborative, multidisciplinary network of 50 clinics, hospitals, and providers.



The FSR-GSCA strives to meet the needs of clinicians to drive better patient outcomes, including strategies to ensure continuity of care as a patient's sarcoidosis evolves, a focus on sharing best practices that help sarcoidosis specialists recognize new manifestations, and a shared commitment to evidence-based, patient-centered care.

Corresponding Author

Sarah Sandison, MSc, MA
sarah@stop sarcoidosis.org