

RARE VIEWS

Sarcoidosis

Sarcoidosis, a complex inflammatory disease affecting multiple organs, reveals stark inequities in diagnosis, treatment, and outcomes among the Black American community. This Rare Views from **Mary McGowan, CEO of Foundation for Sarcoidosis Research (FSR)** highlights their *Ignore No More* campaign. By examining the disparities faced by patients with sarcoidosis, FSR hopes to shed light on the challenges faced by patients and advocate for strategies to promote equity in care for this rare disease.



Q. What Are the health disparities in sarcoidosis?

A. The estimated prevalence of sarcoidosis in the US ranges between 150,000 and 200,000¹, with an estimated 1.2 million individuals with sarcoidosis worldwide. Sarcoidosis can impact any race, ethnicity, and gender. Sarcoidosis patients who are Black, female or of low socioeconomic status experience more severe disease and health-related challenges, including worse dyspnea (shortness of breath), lower health-related quality of life, and higher rates of mortality, morbidity, and hospitalization.² Black Americans with sarcoidosis have the highest prevalence and mortality rates in the US. Black Americans are 2x more likely to have sarcoidosis, 9x more likely to be hospitalized, and die at a rate 12x higher than that of White Americans.

In general, women of all races have a slightly higher prevalence of the disease compared to their male counterparts, yet for Black American women, not only do they have the highest prevalence of all groups, they are almost twice as likely to have the disease than their male counterparts, who experience the second highest prevalence of all groups.³ In addition to having the highest prevalence, Black American women bear the greatest burden when compared to all other groups impacted by sarcoidosis in the United States. Statistics show that socioeconomic barriers further exacerbate these disparities, leading to reduced access to healthcare, specialists, and medications. Additionally, insufficient insurance coverage, unhealthy living conditions, and challenges in scheduling appointments and adhering to

¹ Baughman, R., Field, S., Costabel, U., Crystal, R., Culver, D. A., Drent, M., Judson, F., & Wolff, G. (2016). Sarcoidosis in America: Analysis Based on Health Care Use. *Annals of the American Thoracic Society*, 13(8), 1244-1252. <https://doi.org/10.1513/AnnalsATS.201511-760OC>

² Sharp, M., Eakin, M. N., & Drent, M. (2020). Socioeconomic determinants and disparities in sarcoidosis. *Current Opinion in Pulmonary Medicine*, 26(5), 568-573. <https://doi.org/10.1097/MCP.0000000000000704>

³ Hena, K. M. (2020). Sarcoidosis epidemiology: Race matters. *Frontiers in Immunology*, 11.

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medications due to work and transportation constraints further compound the issue, leading to worse health outcomes.^{4 5}

Q. Tell us about the Ignore No More campaign?

A. The *Ignore No More* Initiative is a series of campaigns focused on improving health outcomes for Black and African American sarcoidosis patients, who have the highest incidence of sarcoidosis and experience the poorest health outcomes among all groups. We are grateful to Mallinckrodt Pharmaceuticals for their support in these efforts.

The *FSR Ignore No More* Initiative aims to empower Black patients through advocacy, education, community, and transparency. It is a call to action for patients and providers to partner to reduce health disparities by confronting the factors contributing to disparate health outcomes for Black Americans. It is a call to action for patients to listen to their bodies and be proactive participatory agents in their healthcare journeys. It is also a call for health care providers to listen to Black Americans, acknowledge the massive health disparities that impact their care, and take active steps to address the interpersonal and systemic barriers that fuel mistrust and lead to poorer outcomes.

The first campaign, [Ignore No More: African American Women & Sarcoidosis](#), was launched to raise awareness of sarcoidosis among the group experiencing the highest prevalence and worst outcomes – Black and African American women. Building on the successful foundation laid by the first campaign, FSR launched Phase II: [Ignore No More: ACTe Now! \(Advancing Clinical Trial for Equity in Sarcoidosis\) Campaign](#). This campaign focused on a specific pathway patients can take to improve care and treatment for Black Americans – clinical trial participation. Through this campaign, FSR launched a national patient survey for Black individuals with sarcoidosis to identify challenges and barriers that contribute to lower participation by Black Americans in clinical trials. FSR further explored the findings and recommendations were presented at a Congressional Briefing featuring Representatives Eleanor Holmes Norton (DC) and Danny Davis (IL) and can be found in [FSR's White Paper: Advancing Clinical Trial Equity for Black Patients with Sarcoidosis](#). Our most recent [Ignore No More campaign: ACTe Now!: Roadmap 2 Progress](#) is using these recommendations to develop a blueprint to increase clinical trial diversity by addressing barriers experienced by Black patients.

⁴ Rabin, D. L., Judson, M. A., et al. (2004). Title of the article. *European Respiratory Journal*, 24(4), 601–608.

⁵ Judson, F., et al. (2003). Title of the article. *Sarcoidosis, Vasculitis, and Diffuse Lung Diseases*, 20(3), 204-211.

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Q. What do you hope people learn from the campaign?

A. *Ignore No More* is a rally cry – one we plan to continue to elevate, not just in our community, but across all chronic conditions. We hope people learn the critical importance of addressing health disparities in diseases like sarcoidosis. Visit FSR’s website, www.stopsarcoidosis.org, to learn more about our programs, resources, and opportunities to get involved.

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