

March 3, 2025

The Honorable Mitch McConnell Chairman Committee on Appropriations Subcommittee on Defense U.S. Senate Washington, D.C. 20510

The Honorable Ken Calvert Chairman Committee on Appropriations Subcommittee on Defense U.S. House of Representatives Washington, D.C. 20515 The Honorable Christopher Coons Ranking Member Committee on Appropriations Subcommittee on Defense U.S. Senate Washington, D.C. 20510

The Honorable Betty McCollum Ranking Member Committee on Appropriations Subcommittee on Defense U.S. House of Representatives Washington, D.C. 20515

Dear Chairmen McConnell and Calvert, and Ranking Members Coons, and McCollum:

Thank you for your leadership on medical research and patient care issues. I write you today on behalf of the Foundation for Sarcoidosis Research (FSR) and those in the sarcoidosis stakeholder community to <u>ask</u> that you include "sarcoidosis" on the eligible conditions list within the Committee Report accompanying the Senate's FY 2026 Defense Appropriations Bill to support ongoing research through the Department of Defense (DoD) Peer-Reviewed Medical Research Program (PRMRP).

The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Since its establishment in 2000, FSR has fostered over \$7.2 million in sarcoidosis-specific research efforts. FSR is actively working with the world leaders in sarcoidosis, investing in innovative, patient-centered research efforts and providing educational resources, support, and opportunities to accelerate research to patients worldwide. Our goals are to advance research and find a cure while educating the public and professional community and providing support to affected patients and families.

Sarcoidosis is an inflammatory disease characterized by the formation of granulomas—tiny clumps of inflammatory cells—in one or more organs of the body. When the immune system goes into overdrive and too many of these clumps form, they can interfere with an organ's structure and function. When left unchecked, chronic inflammation can lead to fibrosis, which is the permanent scarring of organ tissue. This disorder affects the lungs in approximately 90% of cases, but it can affect almost any organ in the body. Despite increasing advances in research, sarcoidosis remains difficult to diagnose with limited treatment options and no known cure. Sarcoidosis is considered chronic in people whose disease remains active for more than 2-5 years; in this population sarcoidosis can be debilitating and life-threatening. It's estimated that the prevalence of sarcoidosis in the US ranges between 150,000 and 200,000 with an estimated 1.2 million individuals with sarcoidosis worldwide.

A recent study of over 13 million veterans found an annual prevalence was about two times higher (141 vs. 60 cases/100,000 persons), and the <u>annual incidence was about four to five times higher (52 vs. 10 cases/100,000 person-years) in veterans vs. non veterans.</u> With the highest incidence in the Navy, Airforce and Army. Sarcoidosis is acknowledged as a presumed disability under the PACT ACT of



2022¹; however, many veteran risks expand well beyond just burn pit exposure. Potential toxic exposure due to airplane repairs and fuel are thought to play a significant role, as well as other exposures to the lungs, eyes, and skin. Veterans with pulmonary sarcoidosis show an increase of metal in their blood plasma. Follow-up studies that drill down to the specific external environmental exposures, internal atmosphere of work areas, and associated duties are needed to shed light on actionable risk-factor modification for military service members are essential.²

On behalf of FSR, the patients we serve, and the dedicated community of researchers working in this area, we appreciate your consideration of our request to include sarcoidosis in the eligible areas of study under the PRMRP as you consider DoD appropriations for FYFY 2026. Please consider FSR as a resource as the legislative process continues. Thank you for your time and for your consideration of this request.

Sincerely,

Mary E. McGowan, CEO

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¹ Jani, N., Christie, I.C., Wu, T.D. *et al.* Factors associated with a diagnosis of sarcoidosis among US veterans of Iraq and Afghanistan. *Sci Rep* **12**, 22045 (2022). https://doi.org/10.1038/s41598-022-24853-8

² Seedahmed MI, Baugh AD, Albirair MT, Luo Y, Chen J, McCulloch CE, et al. Epidemiology of sarcoidosis in U.S. veterans from 2003 to 2019. Ann Am Thorac Soc . 2023;20:797–806. doi: 10.1513/AnnalsATS.202206-515OC.