

March 7, 2025

Outside Witness Testimony Request from Mary McGowan, CEO of the Foundation for Sarcoidosis Research (FSR). This testimony request is in support of funding for the full spectrum of biomedical research and access to clinical trial participation, particularly for patients from underserved populations. Point of Contact: Kira Flaherty, FSR Washington Representative, flaherty@hmcw.org

The Honorable Robert Aderholt Chairman, Subcommittee on Labor, Health and Human Services, Education and Related Agencies Committee on Appropriations U.S. House of Representatives Washington, DC 20515

Dear Chairman Aderholt,

I write today on behalf of the Foundation for Sarcoidosis Research (FSR) to request the opportunity to appear before your subcommittee during the public witness hearings for Fiscal Year (FY) 2026 Labor, Health and Human Services, Education and Related Agencies Appropriations. FSR is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support.

FSR would like to testify regarding the critical need for legislative action and funding to advance research, improve access to treatment and clinical trials, and support the sarcoidosis and larger chronic and rare disease community. Specifically, we would like to address the need for meaningful NIH and biomedical research funding, the passage of key bipartisan legislation addressing access to critical treatments and clinical trials, as well as efforts to improve awareness of clinical trial participation being a permissible use of leave under the Family and Medical Leave Act (FMLA).

We believe these efforts are vital in ensuring that individuals with rare and chronic diseases like sarcoidosis receive the care and research support they urgently need. If selected to testify our witness would be FSR CEO, Mary McGowan.

Please advise FSR's Washington Representative, Dane Christiansen and Kira Flaherty, at the Health and Medicine Counsel, 50 F Street, NW, Suite 340, Washington, DC 20001, (202) 544-7499, <a href="mailto:christiansen@hmcw.org">christiansen@hmcw.org</a> and <a href="mailto:flaherty@hmcw.org">flaherty@hmcw.org</a>, regarding our opportunity to testify. On behalf of the stakeholder community, thank you for your consideration of this request.

Sincerely,

Mary E. McGowan, CEO

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