FSR
FOUNDATION FOR
SARCOIDOSIS RESEARCH

January 29, 2025

Dear Member of Congress,

Congratulations on your election to the 119th Congress. On behalf of the Foundation for Sarcoidosis Research (FSR) and the thousands of researchers and patients we serve, I encourage your support of medical research, public health, and patient care programs. I write to offer FSR as a resource on important local and national issues related to sarcoidosis and patient care. As you work to address key priorities for the coming year, we encourage you to continue advancing initiatives that support research, improve access to clinical trials and medical care, and enhance healthcare for the patient community.

FSR is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for those affected by the disease through research, education, and support. Since its founding in 2000, FSR has raised over $6 million for sarcoidosis-specific research efforts and is actively collaborating with the world's leading researchers to accelerate breakthroughs. FSR's mission is not only to advance research but also to provide patients and their families with educational resources and critical support.

Sarcoidosis is a rare, chronic inflammatory disease that can affect any organ in the body, though it most commonly impacts the lungs. It is characterized by the formation of granulomas—small clumps of inflammatory cells—that can interfere with the normal function of affected organs. When left untreated, the disease can cause chronic inflammation, leading to permanent tissue damage and fibrosis. This debilitating condition affects between 150,000 to 200,000 people in the United States and is a serious challenge to both patients and healthcare providers due to its difficulty in diagnosis, limited treatment options, and the lack of a known cure.

FSR's work is focused on advancing research, increasing awareness, and improving patient care. We hope to work with you to support the following priorities for the sarcoidosis community:

- Increased funding for the National Institutes of Health (NIH) to foster additional research in sarcoidosis and other rare diseases.
- Expanded support through legislation for and access to clinical trials and medical research programs to bring innovative therapies and diagnostic tools to those affected by sarcoidosis.
- Increased funding to the Centers for Disease Control and Prevention (CDC) to strengthen public health efforts to improve the early detection and diagnosis of sarcoidosis, ultimately improving patient outcomes.

We also urge you to support legislation that seeks to restore access to supplemental oxygen by providing adequate reimbursement and correcting market failures in competitive bidding for DME (which has previously been included in the *Supplemental Oxygen Access Reform Act*). Additionally, we urge you to support legislation focused on medication access, coverage, and out-of-pocket costs. Both issues are critical to our patient community being able to access key treatments and quality therapies.

Thank you for your time and consideration of these issues. We are excited to work with you and your colleagues to advance these priorities and make meaningful progress for sarcoidosis patients and their families.

Sincerely,

Mary E. McGowan

Mary E. McGowan, CEO