



The Foundation for Sarcoidosis Research is the nation's leading nonprofit organization dedicated to finding a cure for this disease and to improving care for sarcoidosis patients. Since its establishment in 2000, FSR has fostered over \$3 million in sarcoidosis-specific research efforts and has worked diligently to provide resources to thousands.

PATIENT OUTREACH & EDUCATION PROGRAMS (P.R.E.P.)

Patients are not only the reason for our mission, but are absolutely the key to achieving it. Informed, engaged patients and the support of their communities are critical to breakthroughs in disease research.

Resources for patients and loved ones include:

- **Online and Print Education Materials**
- **Online Physicians Directory** – connects patients to over 2,200 knowledgeable and experienced physicians worldwide.
- **Patient Conferences** – allows patients and loved ones the opportunity to learn about sarcoidosis and their treatment options from experts in the field.
- **Educational Webinars**
- **Online Support Group Directory** – connects patients and caregivers to online and in-person support groups throughout the world.
- **Clinical Trial Outreach** – Clinical trials fail to recruit and retain enough patients 85% of the time, which leads to fewer treatment options for sarcoidosis sufferers. To improve patient care and provide patients opportunities to advance sarcoidosis research, FSR connects interested patients to active studies.
- **FSR Patient Ambassadors** – grassroots volunteers who have been personally affected by sarcoidosis who help us educate, empower, and engage patients, especially those from under resourced areas.
- **Volunteer Opportunities** - patients and their loved ones can join our community of fighters working together to help us stop sarcoidosis.

LEARN MORE & JOIN US: WWW.STOPSARCOIDOSIS.ORG

FSR Scientific Advisory Board

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Scientific Research Agenda

The FSR Scientific Advisory Board developed an ambitious Scientific Research Agenda in 2014 that identified five specific areas of focus to help fill the gaps in the sarcoidosis field. If filled, these advancements will provide game changing results for patients.



A major limiting factor in the discovery of new insights into the pathogenesis of sarcoidosis is the lack of a viable disease model. This gap hinders new therapy development, prevents FDA-approval of off-label therapies, and has limited funding opportunities from pharmaceutical companies and government. In 2017, FSR will award \$450,000 to promising projects aimed at developing or improving disease models.

With over 3,000 patients currently registered in the FSR Patient Registry, this IRB-approved study is collecting ongoing data from patients living with sarcoidosis and changing our understanding of this mystery disease. As more patients join the registry by simply completing surveys about their experience with this disease, they are helping to guide researchers to better therapies and a cure!



FSR will host a summit in 2018 for the world-leading thought leaders in sarcoidosis, epidemiology, and other related fields to help drive consensus around patient outcome measurements. Current clinical exams do not fully represent outcomes that are meaningful to patients. In developing and distributing findings of the summit through partnerships at the NIH, FDA, WASOG, AASOG, and other medical professional groups, clinicians will learn to better treat and assess sarcoidosis.

Launched in 2015, this 8-member consortium brings together an international partnership of world-renowned medical institutes and researchers for unprecedented collaboration in studies and drug trials toward the treatment of sarcoidosis. 2016 focused on the first study, already under IRB approval, and will culminate with a published report which will help improve our understanding of this disease.

