This report represents FOUNDATION FOR SARCOIDOSIS RESEARCH’s responses to Charting Impact, a joint project of BBB Wise Giving Alliance, GuideStar USA Inc, and Independent Sector. Charting Impact uses five simple yet powerful questions to encourage strategic thinking and help organizations share concise information about their plans and progress toward impact.
1. What are we aiming to accomplish?
Finding a Cure FSR provides funding and collaborations for research and initiatives which focus on the understanding of sarcoidosis, addresses the causes of the disease, counters the suffering of patients, and advances the potential for a cure. Educating and Resourcing Patients and the Public We are committed to informing the public about the disease and the dire need for increased funding, as this will in turn advance research and an understanding of the disease. FSR believes in the power of many to join forces for true game-changing results in sarcoidosis research. The quality of life – and life itself – of thousands of patients depends on a true collaborative process. Only then will we see true results.

2. What are our strategies for making this happen?
Finding a Cure: Through collaborations and partnerships with the pharmaceutical industry, biotech companies, medical institutes and professionals, academic institutes, researchers, and patients from across the globe, FSR is producing game-changing initiatives toward a cure. To date, FSR has fostered more than $1.5 million in sarcoidosis-specific research. In the years ahead, the Foundation looks forward to increasing our investment to find innovative breakthroughs which will provide treatments, therapies and a cure for the disease. Educating and Resourcing Patients and the Public: Patients can be KEY elements in progress toward better treatments and a cure! FSR educates and connects patients with opportunities to become involved by becoming knowledgeable about sarcoidosis research. This includes participating in clinical trials, tissue donation programs, patient registries and shared data for research. FSR also offers annual conferences, webinars and comprehensive educational materials for people across the globe living with sarcoidosis, and connects patients to each other for support and enabling a larger impact. More than 20,000 members from all 50 states and nearly 80 countries have joined our free Stop Sarcoidosis Online Support Community. Thousands more are helped through in-person support groups under the umbrella of FSR.

3. What are our organization's capabilities for doing this?
FSR provides funding and collaborations for research and initiatives which focus on the understanding of sarcoidosis, addresses the causes of the disease, counters the suffering of patients, and advances the potential for a cure. Through collaborations and partnerships with the pharmaceutical industry, biotech companies, medical institutes and professionals, academic institutes, researchers, and patients from across the globe, FSR is producing game-changing initiatives toward a cure.

4. How will we know if we're making progress?
FSR has continued to grow while focusing on our mission to find a cure while providing resources and education for patients and the public. FSR’s refined approach is to develop a specific research agenda that identifying and addressing the major gaps in sarcoidosis research. These are key components missing in the field, which, if produced, would be transformational toward advancing research to help patients. The huge voids that exist in sarcoidosis research include a patient registry, an animal model, consensus on endpoints, biomarkers, diagnosis tools, and other critical essentials for research. The lack of these greatly impedes research in sarcoidosis. FSR will facilitate game-changing advances in sarcoidosis research, resulting in promising therapies that can move quickly from the laboratory to the patient. The advancement of research in any of these areas will point to true progress, and the eventual development of new therapies for sarcoidosis is our ultimate goal.
5. What have and haven't we accomplished so far?

FSR has fostered over $1.5 million in direct grants to sarcoidosis-specific research. In addition, the FSR Scientific Advisory Board developed an ambitious Scientific Research Agenda in 2014 that identifies five specific areas of focus to help fill the gaps that exist in the sarcoidosis field. Our goal is to have promising therapies move quickly from the laboratory to the patient, and we do so through collaborations and strategic funding. Here is a much abbreviated snapshot of the Scientific Research Agenda and the progress made to date since its initial inception in 2014:

• Animal Model – Major outreach in place to secure funding for this critical discovery.
• Patient Registry – Currently over 2,000 patients registered. We are enrolling thousands of patients represented worldwide to inform researchers on various elements of the disease.
• End Point Development – Discussions with NIH, FDA, WASOG, and AASOG members and key players underway; full plan for FSR investment and input to be completed in 2015.
• Clinical Studies Network – 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.
• Patient Resource & Education Program – Expanded resources and tools including: a new suite of patient conferences, a treatment protocol, a physicians outreach program, a physicians directory, a new sarcoidosis brochure, a sarcoidosis online community, social media initiatives, and more.