



FSR Director of Research

Summary:

The Foundation for Sarcoidosis (FSR) **Director of Research** will play a pivotal role in execution of FSR's strategic and operational plans for research development and growth. The Director of Research will have primary responsibility for managing FSR's research grants program and Clinical Data Registry, ensuring that both programs are scientifically rigorous, patient-centered, operationally effective, and aligned with FSR's research strategy. The Director of Research will also oversee the FSR Patient Registry, a direct-to-patient database of over 10 years of data and over 7,500 individuals impacted by sarcoidosis, and oversee relevant manager and coordinator-level staff. FSR's grant funding portfolio supports research across career stages and scientific areas, while its multicenter Clinical Data Registry is designed to generate standardized, longitudinal clinical data that can strengthen understanding of sarcoidosis and accelerate scientific discovery.

Reporting directly to the Vice President of Research, the Director of Research will manage complex projects involving investigators, clinical sites, scientific advisors, patient reviewers, vendors, funders, and industry and nonprofit partners. The Director will translate FSR's strategic research priorities into well-designed programs, maintain strong governance and regulatory practices, monitor outcomes, and communicate the value and impact of FSR-supported research to diverse audiences. They will be a creative leader dedicated to advancing research to improve the lives of those living with sarcoidosis.

This position has the option of being remote.

About the Foundation for Sarcoidosis Research (FSR):

Established in 2000, the Foundation for Sarcoidosis Research (FSR), is the leading international non-profit organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. Since inception, FSR has fostered over \$11 million in sarcoidosis-specific research efforts and has worked diligently to provide resources to thousands. For more information and to join our community, visit www.stopsarcoidosis.org.

Key Responsibilities:

- Own the strategy and execution of the FSR Research Grant Program
 - Lead the administration and continuous improvement of FSR's research grant programs, from funding opportunity development through award closeout.
 - Develop and manage grant guidelines, requests for proposals, application materials, scientific peer review, conflict-of-interest processes, award recommendations, timelines, budgets, and applicant communications.
 - Engage and solicit strategic insights from the FSR Scientific Advisory Board around grant proposal requirements, review criteria, and research topic priorities.
 - Track publications, presentations, patents, partnerships, follow-on funding, career development, and other outcomes resulting from FSR support.
 - Monitor funded projects for scientific progress, milestone achievement, responsible use of funds, and compliance with award terms.
 - Build productive relationships with grantees and provide clear guidance throughout

the award period.

- Work with the research team to manage and refine patient stakeholder review to ensure funded projects align with the priorities of the patient community.
- Partner on management of the FSR Clinical Data Registry
 - Provide overall program and operational leadership for the FSR Clinical Data Registry, a longitudinal, multicenter initiative involving expert sarcoidosis clinical sites.
 - Manage registry implementation across participating institutions, including site onboarding, enrollment, data submission, and ongoing performance monitoring.
 - Serve as the primary relationship manager for principal investigators, site coordinators, data teams, vendors, consultants, and governance committees.
 - Engage and solicit strategic insights from the FSR Scientific Advisory Board around data utilization and cross-program opportunities.
 - Work in partnership with FSR's Director of Data Analysis and Strategy to oversee data governance and ensure registry activities follow approved protocols, contractual requirements, privacy and security expectations of participants, and other relevant policies.
 - Convene and support registry steering committees, working groups, investigators, coordinators, and patient advisors.
 - Manage processes for data-access requests, scientific review, data-use agreements, and tracking of resulting research products.
 - Advise strategy for utilization of the Clinical Data Registry in the larger data ecosystem and industry partnerships.
- Oversee the FSR Patient Registry
 - Manage dual enrollment and common participant identification between the Patient Registry and Clinical Data Registry
 - Assist in participant engagement efforts to maximize diverse enrollment and longitudinal data collection.
 - Manage processes for data-access requests, scientific review, data-use agreements, analytic support, and tracking of resulting research products.
 - Advise strategy for utilization of the Patient Registry in the larger data ecosystem and industry partnerships.
- Manage, mentor, and guide other manager- and coordinator-level research staff, providing guidance, training, and strategic support
 - Guide in the strategy and execution of FSR Patient Registry engagement processes and patient review panel selection, training, and feedback implementation
 - Manage and oversee all day-to-day research program budgets, contracts, vendors, consultants, and other resources.
 - Participate in discussions with leadership about potential financial support and partnerships to drive program sustainability. Collaborate with development staff on proposals, reports, donor briefings, and stewardship materials related to research programs.
 - Collaborate with communications and patient program staff to translate scientific information into accurate, accessible content for patients, clinicians, donors, and the broader scientific community.
- Research strategy and leadership

- Translate FSR's strategic priorities and research agenda into annual goals, work plans, and measurable program outcomes.
- Advise FSR leadership on research opportunities, program performance, scientific developments, operational risks, and resource needs.
- Participate in data analysis and writing of FSR research program-related abstracts, posters, publications, and white papers.
- Ensure that patient perspectives are meaningfully incorporated into research priority setting, program design, grant review, registry governance, and dissemination.
- Monitor developments in sarcoidosis research, clinical trials, data science, registry methodology, and rare-disease research infrastructure.
- Represent FSR at scientific meetings, partner convenings, investigator meetings, webinars, and community events.

Required Knowledge, Skills, and Abilities:

- Graduate Degree in Biostatistics, Epidemiology, Public Health, or a related field.
- At least five years of relevant experience working with large-scale health databases or disease registries. Proven track record of effective strategic data management and driving collaborative publications preferred.
- At least two years of relevant experience working with research grants management processes.
- Working knowledge of human-subjects research, IRB processes, informed consent, data-use agreements, research contracts, privacy, and clinical data governance.
- Strong program- and project-management skills, including the ability to manage multiple stakeholders and deadlines. Proven experience collaboratively engaging clinician or research stakeholders preferred.
- Commitment to patient-centered research and to FSR's mission of improving the lives of people affected by sarcoidosis.
- Knowledge of biostatistical methods applicable to registry data analysis.
- Strong proficiency in database management systems
- Expertise in epidemiological methods and longitudinal data analysis.
- Strong analytical and problem-solving abilities.
- Ability to communicate complex statistical concepts to diverse audiences.
- Familiarity with standardized outcome measures and quality of life assessments.
- Proficiency in creating clear and impactful data visualizations.
- Ability to work well in a team environment and independently.
- Proficiency in Microsoft Programs (i.e., Word, PowerPoint, Excel).
- Ability to communicate effectively through verbal and written communication.

This role requires frequent virtual collaboration with investigators, clinical sites, scientific advisors, patients, vendors, and partners across the United States and internationally. Periodic travel (not likely to exceed 20%) is expected for scientific conferences, investigator meetings, organizational events, and partner convenings.



Salary and Benefits:

The salary range for this position is \$85,000-95,000/year depending on experience.

FSR offers the following benefits:

- 18 Days of PTO
- 13 Holidays
- 401k with 6% Match
- Healthcare, Vision, Dental Insurance
- Life Insurance
- Short Term Disability Insurance
- Education and Professional Education Support

We are an equal opportunity employer and all qualified applicants will receive consideration for employment without regard to race, color, religion, sex, national origin, disability status, protected veteran status, gender identity, sexual orientation or any other characteristic protected by law.

To apply for this position, please provide a resume and cover letter to Elise Hoover, Vice President of Research at elise@stop sarcoidosis.org