FSR Data Analyst

Summary:

The Foundation for Sarcoidosis (FSR) **Data Analyst** will play a pivotal role in execution of FSR's strategic and operational plans for research development and growth. The Data Analyst will contribute directly to the interpretation and communication of the results of FSR data programs and initiatives, helping to translate the data into actionable insights for FSR and partnered researchers. The Data Analyst will also support the management of data governance plans, data access requests, and survey design to ensure studies are adequately powered. The Data Analyst will play a pivotal role in establishing and stewarding data collaborations with institutions, researchers, and patient-leaders. They will be a creative leader dedicated to advancing sarcoidosis research to improve the lives of those living with sarcoidosis. **This position has the option of being remote.**

Reporting directly to the Vice President of Research, the Data Analyst is responsible for supporting the facilitation, tracking, reporting on, and expansion of the data captured through FSR programming and will help to shape FSR future research strategies.

About the Foundation for Sarcoidosis Research (FSR):

Established in 2000, The Foundation for Sarcoidosis Research (FSR) is the leading international nonprofit organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients. FSR is based out of Chicago. Since inception, FSR has fostered nearly $8 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. FSR is committed to providing fair and equitable access to all to learn more about our efforts to address health disparities, please visit https://www.stopsarcoidosis.org/aaws-campaign/

The Data Analyst will play a pivotal role in our disease registries and larger data ecosystem programs, designed to collect, analyze, and interpret data on patients with sarcoidosis. This position will be crucial in leveraging data to improve patient care, advance research, and inform policy decisions.

Key Responsibilities:

- Design and maintain the statistical framework for our disease registries and larger data ecosystem, ensuring data quality and integrity
- Develop and implement statistical analysis plans for registry and ecosystem data, including descriptive statistics, trend analyses, and predictive modeling
- Collaborate with clinical and research teams to define relevant outcome measures and data points for collection within the registry programs
- Conduct regular analyses of ecosystem data to identify trends, patterns, and potential areas for intervention or further research
- Prepare comprehensive statistical reports and data visualizations for various stakeholders, including patients, healthcare providers, researchers, and policymakers
- Lead strategic design of program outcome assessment and analyses of return on investment for both partnership funding and program metrics

- Contribute to the development of data collection tools and processes to ensure standardization and minimize bias
- Support the organization in utilization of AI and machine learning to prepare datasets for prediction modeling in partnership with research advisors
- Perform data cleaning, validation, and quality control checks on registry data
- Assist in the preparation of manuscripts, abstracts, and presentations based on registry findings
- Build and evolve a model for evaluating research agenda success through various FSR programs and partnerships
- Support grant applications and research proposals by providing statistical expertise and preliminary data analyses
- Collaborate with IT teams to optimize data management systems and ensure data security and privacy compliance

Required Knowledge, Skills, and Abilities:
- Master's Degree in Biostatistics, Epidemiology, or a related field
- At least two years of relevant experience working with large-scale health databases or disease registries
- Advanced knowledge of biostatistical methods applicable to registry data analysis
- Strong proficiency in statistical software packages (e.g., SAS, R, STATA) and database management systems
- Expertise in epidemiological methods and longitudinal data analysis
- Excellent data management and organization skills
- 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
- Knowledge of regulatory requirements for patient registries (e.g., HIPAA, GDPR)
- Experience with REDCap or similar electronic data capture systems
- Understanding of patient, investigator, and clinician-reported registries
- 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
- Strong project management skills
- Less than 10% travel, including international, may be required

This role will be instrumental in maximizing the value of our disease registries and data ecosystem programs, providing critical insights that drive patient-centered research, improve clinical care, and inform advocacy efforts.

FOUNDATION FOR SARCOIDOSIS RESEARCH

<u>Salary and Benefits:</u>

The salary range for this position is $90,000-100,000/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@stopsarcoidosis.org