



## FSR Sarcoidosis Patient Engagement Coordinator

### **Job description**

Foundation for Sarcoidosis Research (FSR) is seeking a full-time Patient Engagement Coordinator to coordinate and manage the Foundation's Sarcoidosis Patient Registry FSR-SARC and the Patient Ambassador Program. For the right candidate, this is an extraordinary opportunity to help build an organization that improves the lives of those who suffer from sarcoidosis. This role will support FSR's registry and ambassador programs' recruitment, collaborations, and projects that resource patients within the sarcoidosis disease space.

The Foundation for Sarcoidosis Research (FSR) works to support research and awareness in sarcoidosis, and ultimately to find a cure. We do this by empowering and educating patients, funding cutting-edge research, building strategic collaborations, and raising public awareness.

The Patient Engagement Coordinator will report to the Director of Patient Outreach and Education, and will be responsible for working with FSR leadership to help build and grow the FSR Sarcoidosis Patient Registry

The Patient Engagement Coordinator helps facilitate the activities and functions of the FSR Sarcoidosis Patient Registry with the long-term goal to bring together data from patients and cutting-edge researchers all working to improve care and develop new and better therapies for individuals suffering from lung cancer.

This position will also be responsible for the following, but not limited to:

- Manages and facilitates the national and international recruitment and patient engagement elements of the FSR Sarcoidosis Patient Registry.
- Develops and facilitates a registry recruitment strategy that specifically targets demographics specific to sarcoidosis, especially African Americans
- Fully leads the ongoing recruiting program, ensuring demographic representation of all patients; executes in-person, as well as online and phone educational endeavors, utilizing appropriate promotional or marketing methods, such as individual letters, brochures, board member outreach, medical relationships, and presentations at meetings.
- Supports the FSR Sarcoidosis Patient Registry educational and marketing efforts, assisting in the development of communications and promotional literature for distribution.
- Leads and manages the FSR Patient Ambassador program including all ambassador communications, reporting, tracking, recruitment.
- Builds FSR's volunteer opportunities to guide patients in full engagement with FSR initiatives.
- Efficiently and independently plans time, meets deadlines, initiates and follows through on tasks to ensure that goals and objectives specified for various projects.

- Provides support with compiling and fulfilling data requests from internal staff, partner organizations, researchers, and industry.
- Prepares monthly reports, mapping graphics, and records on Registry and Ambassador activities, progress, and recruitment/engagement status for management.
- Assists in facilitating meetings, workshops, webinars, or conferences; coordinates logistics, scheduling and participant communications.
- Leads in the planning and revising of recruitment procedures.
- Travel required – US-based as appropriate to fulfill responsibilities.

**Experience:**

- Two to five years' experience in public health projects and/or patient registry and engagement work.
- Project management skills
- Science (trial recruitment, epidemiological studies etc.) and/or marketing/communications background
- Excellent organizational ability and reporting detail
- Excellence in communicating in all forums with multiple demographics
- Commitment to patient confidentiality and best practices.
- Goal oriented, fast-paced, with a focus on service excellence office environment.

**Education:**

- MPH ideal.
- Required Bachelor's degree in preferably relevant scientific or communications relevant field.

**We are an Equal Opportunity Employer and do not discriminate against any employee or applicant for employment because of race, creed, color, national origin, age, religion, disability, sex, gender identity, sexual orientation, status as a veteran, and basis of disability or any other federal, state or local protected class. This position is full-time FLSA exempt.**