



Director of Global Patient Programs

Reporting directly to FSR Chief of Staff and Strategy (COS) and working closely with other FSR Leaderships, the Director of Global Patient Programs is responsible for developing, communicating, executing, and sustaining strategic initiatives that advance all of FSR's patient education and support programs.

Patient education and support programs include but not limited to webinars, town halls, annual patient conferences, creation of educational infographics and special events. In addition, support programs include peer-led support groups, one-on-one patient navigator program, patient advocates program, patient advisory committees and other initiatives to educate, support and empower patients.

FSR works to ensure that every sarcoidosis patient in every community has access to free education, support services, and has a network of others living with sarcoidosis. One of the ways we accomplish this is through our Sarcoidosis Global Clinic Alliance (FSR-GSCA). The FSR-GSCA, is an innovative partnership and membership network of institutions nationwide focused on programs to support sarcoidosis patients and clinicians. The Director will oversee the patient trained FSR-GSCA leaders including Community Outreach Leaders and Community Group Leaders and will also create and run FSR combined patient and clinical engagement Alliance initiatives.

The Director is a dynamic, collaborative, and highly motivated leader with an interest in advancing patient education, support and empowerment with an interest in unique partnerships with hospitals/clinics for the purpose of advancing FSR's mission of educating, supporting and advocating for patients (and clinicians). The Director brings an entrepreneurial spirit to strategic patient programming, partnerships, conducting supporting the coordination of fundraising for related initiatives, outreach and marketing, and combined patient and clinical program development.

The Director is responsible for growth, development, and management of FSR's Director of Global Patient Programs Team including the Manager of Volunteer Fundraising and Senior Coordinator of Global Patient Programs, as well as relevant vendors, consultants and interns.

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 over \$6 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/> and <https://www.stopsarcoidosis.org/actnow/>

RESPONSIBILITIES

- **Oversees and directs all patient and caregiver education, support, advocacy, and initiatives for FSR at a global level.**
 - Works with the FSR Senior Coordinator of Global Patient Programs, the Director oversees the strategy and implementation of all patient volunteer and volunteer leadership programs including the FSR-GSCA Volunteers, advocates, navigators, patient advisory councils, and other patient leaders
 - Develops programming intended to continue to empower and engage leaders, patients, care partners, and community stakeholders to advance awareness, education, and support.
 - Creates, oversees, and orchestrates strategies and patient program development for Clinic Alliance, Patient Advisory Council, Navigators and other volunteer leadership, including overseeing the FSR Volunteer Fundraising Manager in their fundraising initiatives with volunteers.
 - Enhances and implements patient education programs utilizing newsletters, social media, webinars, patient education programs, combined patient and clinician programming and education and marketing materials.
 - Develops and oversees all training materials and volunteer-related policies to align with FSR's goals and mission.
 - Directs and oversees FSR patient education and engagement conferences including FSR's annual patient summit, regional in-person programs with FSR-GSCA members, webinars, town halls, and other events.
 - Leads the execution, analysis, planning, control and evaluation of events associated with the Alliance.
 - Works with volunteer leaders to build strategic relationships within the hospital community and to conduct a variety of outreach activities.
 - Oversees patient programs communications and marketing activities.
 - Manages and directs FSR Insurance and Disability support program coordinated through the Patient Advocate Foundation.
- **Represents FSR and acts, when needed, as FSR and FSR-GSCA spokesperson to hospitals, clinics, funders, coalitions, partners, major donors, and the general public.**
 - Engages in public speaking to highlight and develop/expand patient programming and membership in the FSR-GSCA including presentations to individual hospitals and at large medical conferences.
 - Assist with securing speaking engagements for Leadership or self at national conferences to highlight FSR's programs.
- **Develops, implements, and maintains a strategic patient volunteer and program growth plan.**
 - Leads initiatives to create new content, programs, strategies and models to meet FSR's mission.
 - Develops support, outreach and education programs in support the veteran population
 - Works with CSO and the Corporate and Donor Relations Specialist to obtain sponsorships, grants, and other financial and in-kind support patient programming for

- the FSR-GSCA and patient education programming.
 - Ensures appropriate metrics are in place to measure performance and progress towards strategic FSR-GSCA membership benefits and all patient support, education, volunteer and engagement goals.
 - Ensures all volunteer leaders are reporting on a monthly basis.
 - Acts as a key advisor to Executive Leadership on all volunteer, FSR-GSCA Alliance membership and support, and patient education and support programs.
 - Engages external business, industry, and sarcoidosis experts to learn about and leverage opportunities to grow FSR's footprint, reach, and optimize ROI of patient and joint patient/clinician engagement programs.
- **Management and Supervision**
 - Supervise and mentor Patient Programs staff to reach ambitious goals.
 - Management of vendors, consultants, and interns
 - Direct and manage all budgets and reporting for all education and outreach programming.
- Other duties as assigned.

REQUIREMENTS

- Minimum of 7 years experience in patient programming, marketing, sales, communications, preferably working in or with hospitals engaging with patients, clinicians, community partners.
- Strong executive presence, presentation, communication, and project management skills.
- Minimum of 7 years experience in non-profit, non-profit growth and strategic planning and implementation.
- Proven track record in patient programming design and implementation, tailoring messages for different stakeholders, and supporting and incentivizing volunteers.
- Experience in creating and implementing initiatives with measurable outcomes.
- Leadership skills in identifying gaps and opportunities for growth, problem-solving, strategy building and analysis.
- Ability to influence on a global and virtual stage, demonstrating courage, an approachable style and inspiring confidence.
- Minimum of 5 years direct supervisory/management experience.
- Knowledge of PCs including MS Word, Excel, and PowerPoint.
- Ability to write clearly and concisely.

Salary and Benefits:

The salary range for this position is \$95,000-105,000/year depending on experience.

FSR offers the following benefits:

- 18 PTO Days
- 13 Holidays
- Healthcare, Vision, Dental
- Life Insurance
- Short Term Disability Insurance
- Education and Professional Education Support
- 401K with a 6 % Match (upon eligibility)

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.