

Director of Global Patient Programs

Reporting directly to the Chief of Staff and Strategy, 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 (GSCA). The FSR-GSCA, is an innovative partnership and membership network of institutions nationwide focused on programs to support sarcoidosis patients and clinicians. The Senior Director will oversee the patient trained Alliance leaders including Community Outreach Leaders and Community Group Leaders and will also create and run FSR combined patient and clinical engagement Alliance initiatives.

Working with the Chief of Staff and Strategy and the CEO, the Director will prospect and identify opportunities for new Alliance memberships and identify synergies with new and potential partners to engage them in capacity building opportunities for future growth of the Alliance.

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, hospital partnerships, conducting fundraising for related initiatives, outreach and marketing, and combined patient and clinical program development. The Director must have extensive volunteer management and program development experience.

The Director is responsible for growth, development, and management of FSR's Patient Programs team members, as well as the management of all vendors, consultants and interns associated with Patient Programs activities.

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.

- Leads and directs all patient volunteer leadership programs including Alliance, advocates, navigators, patient advisory councils, and other patient leaders, while developing programming intended to continue to empower and engage leaders, patients, care partners, clinical stakeholders.
- Creates, oversees and orchestrates strategies and patient program development for Clinic Alliance, Patient Advisory Council, Navigators and other volunteer leadership, including leading 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.
- Directs and oversees FSR Patient education and engagement conferences including FSR's annual patient summit, webinars, town halls, and other events.
- Leads the execution, analysis, planning, control and evaluation of events associated with the Alliance.
- Works closely with the Development Department on alignment to achieve Alliance related fundraising goals. Leading and coordinating the planning, implementation, and support local fundraising events and volunteer expense tracking and fundraising tracking.
- Leads Alliance-related committee meetings.
- 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.
- Aims to build out new efforts through engagement with international partners, veterans, and other underserved populations to ensure that FSR programming and support reaches all impacted by sarcoidosis.
- Works across teams to provide strategic insights on how to improve outreach, support, and engagement with underserved and unrepresented communities.

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.
- Builds out strategies to increase opportunities and engagement for volunteers.
- Plans and executes all in-person and virtual programming to train, support, and expand reach of volunteers
- Creates membership support programs for hospitals that serve a high percentage of underserved sarc patients.

- Plans and executes all webinars, summits, in-person and virtual patient educational and support programming.
- Works with the Development Team to identify corporate partners for sponsorship and grant opportunities for capacity building for the Alliance program and patient support programming.
- Ensures appropriate metrics are in place to measure performance and progress towards strategic Alliance membership and patient engagement goals. Ensure all volunteer leaders are reporting on a monthly basis.
- 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

- Supervises and mentor Patient Programs staff to reach ambitious goals.
- Manages all vendors, consultants, and interns associated with Patient Programs.
- Directs and manages all budgets and reporting for all education and outreach programming.

Other duties as assigned.

REQUIREMENTS

- Minimum of 5 years of experience in patient programming, volunteer management, 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 5 years of 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 3 years of 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 \$90,000-\$100,000/year depending on experience.

FSR offers the following benefits:

- 18 Days of PTO
- 13 Holidays
- 401k with 6% Match (starts in 2025)
- 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.