



## Capacity Building Grants for FSR Global Sarcoidosis Clinic Alliance (FSR-GSCA)

### **Overview:**

Foundation for Sarcoidosis Research (FSR) is dedicated to advancing the needs of all patients impacted with sarcoidosis and with closing the gap around health care disparities that are affecting our community. As an expansion of our Ignore No More efforts, FSR is offering three capacity building grants to hospitals and clinics that serve a high percentage of underserved patients and who have expertise in advancing clinical trials and clinical trial success.

Building from the FSR recently published white paper on Sarcoidosis and Clinical Trial Diversity, applicants for this grant will be charged with creating actionable recommendations to ensure successful and diverse recruitment of clinical trials.

This capacity building grant will award 3 hospitals/clinics with a 1-year membership (valued at \$5,000) in the FSR-GSCA. The FSR-GSCA is a member program consisting of clinics, hospitals, individual providers, patients, and clinicians committed to finding a cure and offering evidence-based, patient-centric care for those living with sarcoidosis.

Below please see the full list of membership benefits.

**Application Deadline:** Applications are due September 15, 2023. Applicants will be notified of their award October 1, 2023. Membership will be effective from October 1, 2023, through December 31, 2024.

### **Eligibility:**

- 1) Hospitals or clinics with a high percentage of underserved and under-resourced patients to address health disparity as defined by Health People 2030. Health disparity is defined as “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”
- 2) Hospitals or clinics serving a high percentage of Medicaid patients.
- 3) Hospitals or clinics with experience or expertise in clinical trials (especially in sarcoidosis)

**Note:** Current members of the FSR- GSCA are not eligible to apply for this grant.

Commented [TS1]: @Diane please include below the application

**How to apply:**

Please send answers to the questions below in a word document [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org). Please use the subject line: "FSR-GSCA Capacity Building Grant Application."

Please include the questions along with your answers.

**Name of Primary Contact:**

**Title:**

**Email:**

**Institution:**

1. Approximately how many patients with sarcoidosis does your institution see in a year?
2. What percentage of the sarcoidosis patients seen have a chronic or multi-organ, multi-system form of the disease?
3. What is the percentage breakdown of sarcoidosis patients in rural/urban/suburban populations?
4. What percentage of your sarcoidosis patients are from underserved or under-resourced populations?
5. To be successful in helping the capacity building grant recipients build a long-term strategy for sustainable membership in the FSR-GSCA, participants need to recruit 4 volunteers to serve as Community Group and Community Outreach Leaders. In 200 words or less please provide your plan for recruiting volunteers.
6. Are you actively engaged in clinical trials for sarcoidosis? For other rare diseases?
7. In 200 words or less, can you describe your strategies for diversity in clinical trials?
8. In 300 words or less, why would you like to be a member of the FSR-GSCA?

**Questions:**

If you have any questions, please send them to [info@stopsarcoidosis.org](mailto:info@stopsarcoidosis.org)

## FSR Global Sarcoidosis Clinic Alliance

### Mission:

The Foundation for Sarcoidosis Research (FSR) is the leading international organization dedicated to finding a cure for sarcoidosis and improving care for sarcoidosis patients through research, education, and support. FSR believes in the global power of many to join forces for true game-changing results in sarcoidosis research. To improve patient outcomes of thousands of patients depends on a true collaborative process. The *FSR Global Sarcoidosis Clinic Alliance* is a member program consisting of clinics, hospitals, individual providers, patients, and caregivers committed to offering evidence-based, patient-centric care for those living with sarcoidosis.

### Purpose:

- To ensure that sarcoidosis patients in every community have access to information, education, clinical trials, and patient support services.
- To identify, acknowledge and support clinicians through networking opportunities/forums that enable learning, sharing and advancements in continuity of care.
- To accelerate research through FSR's global assets and provided funding. To structure research initiatives with a strategic approach driven by measurable data and insights.
- To contribute to business outcomes through patient benchmarks and community health improvement services.

### Patient Advantage:

- Structured turn-key peer guided program that delivers patient support, engagement, and education, led by FSR trained Community Group Leaders
  - Activate virtual/on-site meetings to improve adherence to treatment and medications, provide education for wellness, and foster community
  - Provide a safe space to share experiences, connect with peers, be empowered through knowledge, and feel supported by the community
  - Increase understanding of disease management
  - Better outcomes and increased patient satisfaction
  - More effective communication with providers
  - Metrics and Data Points Reports
- Patient Navigator Program
  - Volunteer, peer support
  - One-on-one support for those newly diagnosed with sarcoidosis, in the diagnosis process, experiencing their first flare, and/or new organ manifestation. FSR's Patient Navigators are experienced sarcoidosis warriors and caregivers who have passed Navigator training program

### Clinician Advantage:

- Networking events (live/virtual) for sharing clinical best practices
  - FSR Clinical Education and Engagement Series

- Peer Case Review Discussions
- FSR SAB-led clinical educational webinars (annual)
- Clinicians and other clinic experts serve as faculty for FSR global programmatic activities
- Provide Grand Rounds speaking opportunities – toolkit
- FSR Sarcoidosis Journal Club
- Provider Directory: Annual complimentary listing (\$35 value per clinician listed)

**Research Advantage:**

- Early notification for FSR Research Grant RFPs
- FSR Community Database – 50,000+
  - 20% discount trial recruitment, research
- FSR Patient Registry – 5,000+
  - 20% discount trial recruitment, research
  - 15% discount for survey builds
- Legislative advocacy updates
- Invitations to Congressional Briefings and KOL meetings (key opinion leader)

**Clinic Advantage/Partner Outcomes:**

- Sustainable, cost-effective, turn-key patient program
  - Volunteer patient peer-led model to support patients for better outcomes
  - Tools to maintain improved compliance, reduced readmission, and no-show rates
  - Connecting group leaders with group leaders
  - Opportunity to impact infrastructure
  - Dedicated, trained Community Outreach Leaders
- **Exhibit Booth – FSR Global Patient Summit – Bronze Sponsorship (\$1,500)**
- Patient referrals
- Positions and differentiates clinics and providers as leaders in sarcoidosis care
  - Increases brand positioning and community visibility
  - FSR Global Clinic Alliance logo to recognize and distinguish commitment
- 360 marketing support through the FSR network; clinic branding, events, successes, milestones
  - YouTube Website avg visitors = 25k
  - Email database = 59,000
  - Sarcoidosis newsletter database = 55,000
  - Clinician Newsletter (PIC) database = 1,499
  - Website page views/month average = 195,000
  - Website unique visitors/month = 45,000
  - Facebook follows = 15,933
  - Instagram followers = 2,303
  - Twitter followers = 2,850
  - Dedicated Alliance web page
  - Exposure in all FSR public presentations and speaking engagements
  - Educational materials for patient support
  - Opportunity for joint partnerships on awareness and education campaigns

- Exclusive member-only grants for psychosocial patient support
- Data for community benefit reports for non-profit hospitals under ACA
  - Community health improvement services and metrics
- Co-branding of FSR educational materials approved by FSR Scientific Advisory Board (SAB) and Patient Advisory Committee (PAC)
- Launch meeting

#### **FSR Global Sarcoidosis Clinic Alliance – *Membership***

The FSR Global Sarcoidosis Clinic Alliance is an innovative program that connects clinics for the purpose of engaging in best practices and collaboration to develop innovative treatments for sarcoidosis patients across the globe. With FSR’s advocacy resources, the Alliance will ensure that all patients living with sarcoidosis have access to accurate education and support services to take charge of their health. By joining with the leading international sarcoidosis organization and leading clinics, Alliance members will be a force to move the needle toward finding a cure.

#### **FSR Marketing Advantage**

The 360-marketing program promises exposure and recognition on all FSR digital and print platforms; website – special Alliance page, social media channels, presentations, and public events. Materials created for support groups will be co-branded.

#### **Symposiums, Conferences and Educational Programs**

The Clinical Education and Engagement quarterly series will feature current topics based on member input, giving clinicians the opportunity to participate as speakers and presenters as well as the target audience. When the series moves from virtual to onsite, each member will have the opportunity to host a conference or Journal Club meetings at their location. FSR will collaborate and produce the event and all marketing will be co-branded with the on-site host.

#### **Awards Gala**

FSR is planning to launch an awards program dedicated to the leaders/heroes in sarcoidosis research. The Gala launched in 2023 and rotate every other year to a region near members. There will be opportunities for members to participate as committee chairs/members, finalist judging, and much more. The host clinic will receive one complimentary table at the Gala.

#### **Patient Support and Community Outreach**

FSR and *Member* will work together to identify 4 patients to serve as *Support Group Leaders* and *Community Outreach Leaders*. These individuals will be trained to run a turn-key support group for *Member* – on-site/virtual. They will also be trained in community and media outreach to support the clinic activity, build awareness for sarcoidosis care at *Member’s* clinic and encourage participation in public events. FSR will partner with Members to potentially develop onsite training opportunities.

