

## **Building community-informed research funding priorities for a patient advocacy organization focused on sarcoidosis**

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### Rationale

The Foundation for Sarcoidosis Research (FSR) has served the community of those impacted by sarcoidosis and has supported dedicated sarcoidosis researchers and clinicians for 25 years. Progress in the management of sarcoidosis is limited due to knowledge gaps relating to the biological processes leading to highly variable disease manifestations, the inability to predict disease course, and limited knowledge relating to risk factors for contracting the disease or for promoting disease severity. To strategically prioritize research topics of most value to the diverse sarcoidosis community, FSR undertook a structured process to develop a new research agenda that will guide its funding priorities and strategic direction.

### Methods

FSR employed a multi-stage mixed-method consensus-building approach, comprised of 1) conducting a literature review, 2) convening a brainstorming workshop with key stakeholders (including physicians, patients, and caregivers), 3) conducting individual stakeholder interviews and 4) facilitating a quantitative prioritization survey of the resulting list of priority research topics and values. The last stage employed the Best-Worst Scaling (Case 1) method requiring survey participants to make tradeoff decisions between research priorities. This method minimizes common biases experienced in traditional surveys and provided FSR with rankings and relative weights to facilitate group decision-making.

### Results

Through this process, FSR established five primary research priorities and six research values to guide future FSR-funded research (Figure 1). The employed process was viewed as highly transparent and collaborative by participating sarcoidosis representatives and by community stakeholders. By working collaboratively with the FSR community to generate 24 “criteria” and honing them down to eleven force-ranked priorities and values, FSR achieved its key objectives. These include not only increased understanding of the existing gaps in sarcoidosis research, but the incorporation of FSR leadership, patient, and key opinion leader input to develop prioritization criteria, values and relative weights for each of the identified gaps. The resulting weighting framework will be implemented into the research grant review process for FSR’s 2025 funding mechanisms, providing additional insight alongside scientific merit criteria.

### Conclusions

This process revealed the sarcoidosis community’s strong preference for identifying and standardizing outcome measures that matter to patients, followed by biomarker development and improved diagnostics. When implemented, this research agenda will represent a significant evolution in FSR’s approach, establishing clear priorities while maintaining the flexibility to adapt to emerging opportunities. Through careful implementation and monitoring of key metrics and goals set for each of these priorities, FSR aims to accelerate progress toward improved treatments a cure for sarcoidosis.

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**Figure 1: Research Agenda primary priorities and values utilized by the Foundation for Sarcoidosis Research's funding decisions in 2025 and beyond**

<u>FSR will fund research that:</u>	<u>When possible, FSR-funded research should:</u>
<ol style="list-style-type: none"><li>1. Identifies and standardizes outcome measures and endpoints that matter to patients</li><li>2. Identifies or defines biomarkers for disease prognosis or progression</li><li>3. Discovers or improves upon techniques for diagnosing the disease</li><li>4. Improves consistency and quality of patient care</li><li>5. Identifies or defines biomarkers for monitoring treatment effects</li></ol>	<ul style="list-style-type: none"><li>• Be supported by high quality data</li><li>• Address the needs of underserved, marginalized, historically disadvantaged or vulnerable populations</li><li>• Leverage real world evidence</li><li>• Reflect or capture the patient voice, perspective and priorities</li><li>• Be conducted in an environment that fosters independent sarcoidosis investigators</li><li>• Leverage existing research</li></ul>