

# Spotlighting Sarcoidosis to #MakeItVisible



FOUNDATION FOR  
SARCOIDOSIS RESEARCH

2022 Update

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## Foundation for Sarcoidosis Research Team

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**FSR Board of Directors:** Louise Perkins, PhD (Board President), Craig Lipset (Board Vice President), Mary Cobb (Board Secretary), Jim Davis, Jr. (Treasurer), Yvette Cozier, D.Sc., MPH, Emerson ‘Randy’ Hall, Jr., PhD, Heidi Junk, Michael Kaplan, Michael Klingher, JD, MBA, Jeffrey Raich, Leslie Serchuck, MD, Rev. Michael Walrond, Jr., Elliott Crouser, MD (Ex-Officio).

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**FSR Staff:** Mary McGowan (Chief Executive Officer), Tricha Shivas (Chief Strategy Officer), Diane Driscoll (Global Head of Clinical Engagement), Mindy Buchanan (Director of Patient Programs), Angela Frelander (Director of Development), Cathi Davis (Communications Manager), Lesley Baxter (Outreach Coordinator), Chase Hamilton (Senior Research Coordinator), Nicholas Polk (Development and Administrative Coordinator), Khaleelah Cohen (Diversity & Inclusion Programs Consultant).

### Corporate Advisory Committee:



**Boehringer  
Ingelheim**

**kinevant**



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# Letter from FSR's Board President and CEO



**Dr. Louise Perkins**  
FSR Board President

A handwritten signature in black ink that reads "Louise M. Perkins". The signature is fluid and cursive.



**Mary McGowan**  
Chief Executive Officer

A handwritten signature in black ink that reads "Mary E. McGowan". The signature is cursive and elegant.

Dear Friends of FSR,

This year, FSR took great strides in making sarcoidosis visible, funding research, and putting patient needs front-and-center. We did this by increasing global awareness of sarcoidosis through our [#IgnoreNoMore](#) and [#MakeItVisible](#) campaigns, our expanded corporate partnerships, and our increased engagement with federal agencies like the NIH and FDA.

Since FSR's founding twenty years ago, we have invested over \$6 million in sarcoidosis research. In 2021, with the guidance of [FSR's Scientific Advisory Board](#), FSR awarded \$210,000 in funding for research on genetics and sarcoidosis, improved diagnosis, neurosarcoidosis, and increasing understanding of [COVID-19](#) and sarcoidosis. In 2022, FSR is poised to provide over \$300,000 in research funding, including a ground-breaking call for research focusing on cardiac sarcoidosis. Additionally, FSR's leadership in patient-centered research has created a fertile space for advancements in sarcoidosis drug development and [clinical trials](#). FSR is now partnering on seven industry-sponsored clinical trials with proposed start dates before 2023, a significant increase from the three trials underway in 2021.

Furthermore, FSR has taken bold steps to deepen federal agency understanding of the needs of those living with sarcoidosis by presenting at [NIH Rare Disease Day](#) on the power of the patient voice in clinical trial development and through a ground-breaking [FDA Patient Listening Session on Pulmonary Sarcoidosis](#). This latter session was attended by 50 members of the FDA from 16 offices in the agency that are charged with the advancement of diagnostic technologies, drug development and approval, and therapy innovation.

Through influential partnerships with celebrity spokespeople, like [Jeryl Prescott Gallien](#) and [Jeremy Levy](#), FSR was able to expand our global reach, garnering over one million media impressions through our awareness campaigns. These strategic campaigns and messaging resonated with the sarcoidosis community and beyond, resulting in increased corporate partnerships and support, more membership and engagement, and influence in global health policy.

Finally, at the conclusion of 2021, through our year-long strategic planning efforts, FSR's Board of Directors and staff created a new direction aimed at increasing patient programming and reducing isolation, diversifying funding in order to advance our mission, and clarifying our research priorities in order to maximize the impact of FSR's research funding and support. In this report, you will read about our bold new strategy to further our mission and increase our global reach through an exciting new initiative that will grow our partnership with clinicians and patients in local communities to improve diagnosis, patient care, and patient outcomes.

**Thank you for your [generous support](#) of these efforts. FSR is honored to illuminate this path to progress and to shine the spotlight on sarcoidosis.**



# Spotlighting the Path to Progress

Over the last year, incredible strides have been made in our efforts to foster and grow a collaborative community. People around the world have joined our movement and partnered with FSR to support innovative sarcoidosis research and patient programming initiatives. Through these efforts, our community has helped drive the strategic investments in research and patient care to move the needle forward.

Through expansive communication and responsive programs, the FSR community has come together to amplify messaging and invite friends, family members, and others in the sarcoidosis space to join us. Our efforts to deliver resources, education, and information have created a deeper understanding and increased support for those impacted by sarcoidosis. Awareness initiatives such as [#IgnoreNoMore: African American Women and Sarcoidosis](#), [Steps for Sarc](#), [Gratitude and Giving](#), [heart month](#), [mental health month](#), [Sarcoidosis Awareness Month](#), our [COVID-19 programs](#), and [#MakeItVisible](#) have resulted in more worldwide engagement than ever before and have begun to get sarcoidosis the recognition it deserves. New donors and partners have supported these efforts and raised more funds to help us provide the tools that make an even greater impact towards our mission.

FSR's increased collaboration efforts with clinicians and hospitals, the pharmaceutical industry, the FDA, NIH, other non-profit organizations, and corporate entities from all over the world have expanded our reach and influence. FSR has listened to our community and our partners to develop strategies to improve the quality-of-life for those impacted by sarcoidosis. We have also created new and unique ways for businesses to raise awareness and support our mission through customized training and competitive campaigns. Through these strategic partnerships, FSR has gained the support of organizations whose voices and power can truly make a difference.

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I can't make (sarcoidosis) disappear for my wife, so I will do what I can to make it visible to the community at large in search of a cure.

- Paul  
sarcoidosis caregiver

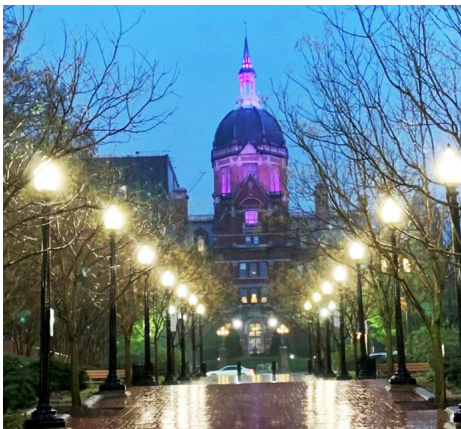






**By reaching new and larger audiences, we are able to:**

- **Invite and encourage more people to engage in clinical trials.** The more patients who participate in clinical trials, the more we are able to learn about sarcoidosis, and get closer to finding better treatments and a cure.
- **Increase understanding of how sarcoidosis can impact an individual.** FSR has taken innovative approaches to increase education and awareness in support of earlier diagnosis, better treatments, and improvements for those living with this disease.
- **Improve clinician practices and increase awareness throughout the healthcare system.** Through the facilitation of clinician networking and best-practice sharing, patient storytelling, and early career support, FSR has provided a platform for researchers and clinicians to develop a deeper understanding of how sarcoidosis affects peoples' lives and foster innovative research and treatment approaches to improve patient care and patient outcomes.
- **Influence change.** By establishing and building relationships with corporate organizations, industry partners, policymakers, and other powerful groups, we are igniting efforts to help fuel change.



**FSR's sarcoidosis awareness initiatives are effective ways to improve treatment, access, and support for all.**

Under the guidance of the [FSR Scientific Advisory Board](#), we continue to provide the community up-to-date information on sarcoidosis research, advance our clinician education and engagement, and ensure our educational material is reflective of the most up-to-date science and best practices from the field. We invite you to build upon these efforts by [supporting our programs](#), [sharing your story](#) and FSR messaging with your own network, and helping us grow the [FSR community](#) to shed more light on sarcoidosis to spotlight the path to progress.



# Underscoring Research Successes

This past year, incredible progress has been made in advancing efforts towards a cure by increasing knowledge improving diagnosis, and accelerating treatment development for sarcoidosis.

FSR ensures that the voice of the patient is represented in all stages of research through direct patient engagement, patient storytelling, and gathering of patient feedback. An unprecedented number of new [clinical trials](#) focusing on sarcoidosis are currently underway. There are six different pharmaceutical and biotech companies exploring avenues to address treatment challenges for those living with sarcoidosis – with seven potential new clinical trials starting as early as this summer. FSR is playing a critical role in driving interest and enticing engagement in the sarcoidosis space to advance these clinical trials.

Through the [generous support](#) of our donors, FSR is funding and coordinating a [groundbreaking multi-site international study](#) exploring the importance of enhanced screening methods for early identification of cardiac sarcoidosis. In this trial, we have reached a key milestone of 50% enrollment, which moves us one step closer to earlier and more accurate diagnosis of cardiac sarcoidosis.

Furthermore, FSR is redoubling our efforts in accelerating research through an innovative and multidisciplinary approach to our grant programs. Thanks to our generous donors, FSR has invested over \$6 million to facilitate sarcoidosis-specific research. The FSR Grant Awardees have gone on to receive over \$15 million in NIH funding, demonstrating the promise of progress through FSR-funded research initiatives. FSR has ensured that our [FSR Fellowship Grant](#) is an important mechanism for establishing strong mentorships and growth in the future leaders of sarcoidosis research.

Through our pilot grants, FSR has provided an opportunity for groundbreaking research to take place that otherwise would not be possible - funding two grants in 2021 and two grants in 2022. The [FSR Pilot Grant](#) provides researchers the support to obtain vital data they can use as a foundation for more advanced research initiatives in the future.

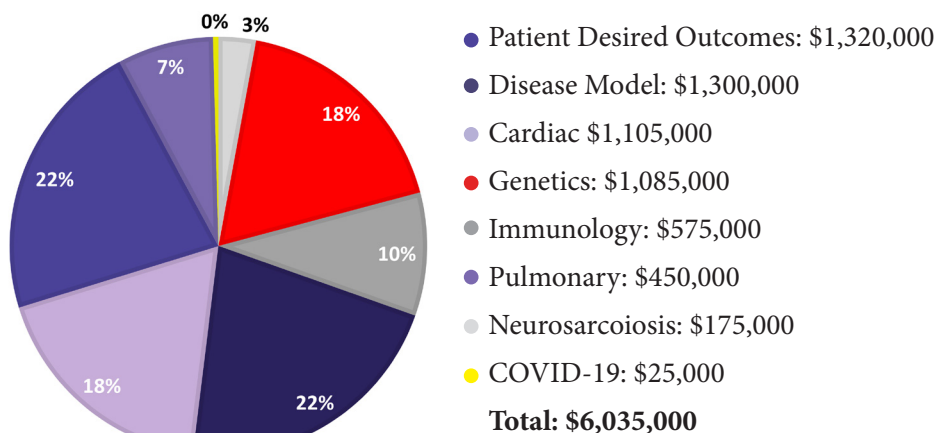
These research programs and partnerships, made possible by our sponsors and the generous [support](#) of our donors, aim to catalyze innovation and creativity in research. This research is important in the development of improved treatments, understanding of the disease, and diagnosis for patients with sarcoidosis. With continued support, FSR can keep driving groundbreaking research to assist in better understanding of this complex disease.

“ The organization and support provided by the Foundation for Sarcoidosis Research to conduct this multi-site cardiac sarcoidosis trial is irreplaceable. Regardless of the results of this current trial, it demonstrates the key role of FSR in advancing the clinical care of sarcoidosis patients by addressing very practical questions.

- Daniel Culver, DO  
Chair of the Department of Pulmonary Medicine, Cleveland Clinic



FSR Multidisciplinary Funding Allocation







## Patient Programming: Unveiling Possibilities

Advancing understanding, providing support, and reducing isolation is at the heart of FSR's patient programs. Thanks to your generosity, FSR delivers holistic and evidence-based programming to ensure all patients have access to quality resources and support.

With world-renowned sarcoidosis experts, mental health specialists, and dedicated patients, our [education and wellness webinars](#) have become a lifeline for the global sarcoidosis community to inform and promote self-advocacy.

In addition to our acclaimed webinar series, 2022 brought the launch of our first-ever [Virtual Patient Support Group](#). Facilitated by two patients who also have professional backgrounds in clinical mental health and nursing, this group provides much-needed emotional support for those struggling with sarcoidosis.

For patients who need additional support, our [Patient Navigator Program](#) provides one-on-one peer assistance for up to 45 days. Thanks to our donors, FSR facilitates a unique, annual, three-day training for the Patient Navigators to aid them in their service to other patients.

Last year, FSR hosted our most successful virtual Patient Education Summit ever! Reinforced by the theme of *Together We Thrive*, 318 attendees joined and received more tailored disease information with the newly developed tracks, engaged in more networking opportunities, and were provided support resources to help navigate their journeys.

FSR takes special care to ensure the patient voice is threaded throughout all of our education and outreach. Our [patients and caregiver advocates](#) take leadership roles in illuminating the experiences of those impacted by sarcoidosis to establish a deeper connection, inspire action, and raise awareness. Whether sharing patient experiences at this year's [FDA Listening Session](#), on the [FSR SarcFighter Podcast](#), in a local newspaper, or on national television, FSR's trained advocates empower others and catalyze progress.

**FSR is grateful to our donors and our corporate sponsors for making these programs possible!**

“

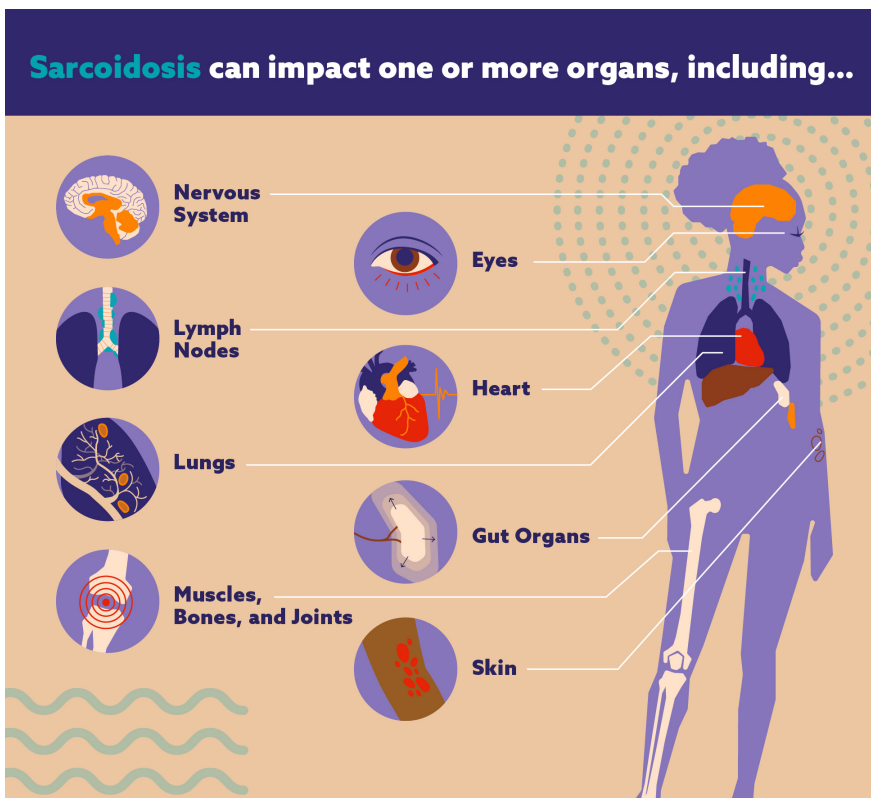
In over 20 years of having sarcoidosis, this is the most information I have ever received on my diagnosis.

- 2021 Summit Attendee

# Elevating More Equitable Care

To fully understand sarcoidosis, we must understand the differences in each patient's experience. Sarcoidosis is underrepresented in clinical trials and creates complex relationships with healthcare providers. FSR has been focused on addressing the health disparities impacted by those in our community.

The first initiative FSR embarked on to shed light on disparities within the sarcoidosis community was the [Disparities and Diversity in Sarcoidosis Summit](#) in partnership with Stronger Than Sarcoidosis. Bringing key stakeholders together, identifying barriers, and suggesting strategies helps take us one step closer to more equitable care.



You can read more about the specific findings of this summit in the [white paper](#) FSR created to share critical learnings and to advance future treatment.

Following the summit, FSR began the development of programming aimed at addressing health disparities among sarcoidosis patients, starting with the group (African American women) most severely impacted by the disease according to the data. FSR launched the [#IgnoreNoMore: African American Women & Sarcoidosis \(AAWS\) National Awareness Campaign](#) to provide information and education to patients, physicians, and the general public to better understand how sarcoidosis disproportionately impacts African American women.

With the support of dedicated corporate partners and [individual donors](#), FSR created an [educational infographic](#), presented at 11 national and international conferences, conducted educational programming through podcasts and webinars, and hosted a Twitter Chat

garnering over 21,000+ impressions. This innovative campaign immediately made waves in the rare disease community and beyond, peaking the interest of AMC's *Walking Dead* actress, [Jeryl Prescott Gallien](#), who was motivated to share her own personal sarcoidosis journey and to help elevate this movement. This campaign reached over [515,300+ viewers](#) and was picked up by media outlets around the world, including FOX, ABC, Good Day Chicago, The Tavis Smiley Show, Roland Martin "Unfiltered" Show, and USA Today affiliates.

The momentum of this program has led to increased interest and financial support, allowing for our continued efforts to address health disparities. In the fall, FSR was awarded the prestigious [Rare as One grant through The Chan Zuckerberg Initiative](#), allowing us to build on this outreach by creating working groups to explore ways to improve diagnosis and treatment for African Americans with sarcoidosis. Additionally, FSR will be continuing this important work in the coming year with a program focused on increasing representation of African Americans in clinical trials.

**Thank you to all our partners and donors that have made this critical work possible.**



# Furthering Advancements Through Collaboration

Engaging clinicians on innovative platforms with programming designed to celebrate contributions and enrich outcomes is critical to our primary goal of finding a cure.

Building on the success of our 2021 Clinical Engagement Conference, FSR has launched a quarterly series of interactive and educational forums “Fostering Collaboration to Inspire Progress.” This series aims to promote sarcoidosis experts in the field of groundbreaking research and, at the same time, foster learning and sharing of best practices for the medical sarcoidosis community at every stage of their career.

FSR will continue to expand our clinician support programming through our Grand Rounds efforts and the launch of a much-needed journal club, and by providing community-level education to connect local clinicians with sarcoidosis experts around the country.

We are proud to provide vehicles for our clinicians to connect regionally and globally to elevate the level of sarcoidosis care. Events throughout the year are made possible because of the [generous support](#) we receive from sponsors and donors.

“ Building this network of provider and support resources for patients puts us several years ahead of where would be if we tried to do it on our own.

- Clinician Member of the FSR Global Sarcoidosis Clinic Alliance

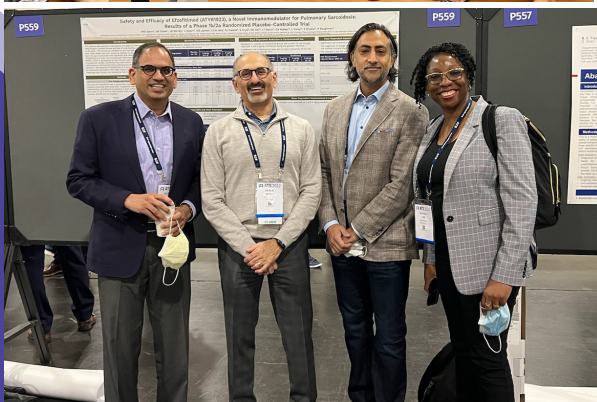
## Driving Best Practices and Better Patient Outcomes



The *FSR Global Sarcoidosis Clinic Alliance* brings together sarcoidosis clinics and hospitals committed to finding a cure and offering evidence-based, patient-centric care for those living with sarcoidosis. Alliance members will benefit from innovative resources, sustainable programming, and tools to accelerate treatment, research, and the continuum of patient care. FSR believes in the power of many to join forces for true game-changing results in sarcoidosis care and research.

Through this program FSR will host educational and networking programs for clinicians, initiate programs like the FSR Sarcoidosis Journal Club to support early career researchers and clinicians in the field, and educate local level care providers through education programs and Grand Rounds. In addition, through this groundbreaking initiative, FSR will expand the local support and outreach programs for patients by creating local peer-to-peer support groups led by trained patient advocates, which will be hosted in partnership with member hospitals. We will also expand local-level education and outreach for those living with the disease and for those improving patient resources access in their communities.

As of June 2022, FSR has already begun collaborating with 22 esteemed founding members and will continue to grow this network to ensure every patient in every community across the world has access to expert-level education, care, and support.



# Making Strides for Better Understanding

This year, FSR is working to make significant strides in improving the drug development process and one example is hosting a [virtual Patient Listening Session on Pulmonary Sarcoidosis](#) with the [US Food and Drug Administration \(FDA\)](#). Patient listening sessions are small, informal, non-regulatory, non-public discussions from the patient perspective that seek to deepen the FDA's understanding of a rare disease, the burden of the disease on those it impacts, and the challenges and barriers to effective diagnosis, treatment, and new drug development. During this closed-door session, FSR's CEO, six patients, one caregiver, and one medical expert framed the issues and shared stories about their journeys, trials, and needs for better therapies.

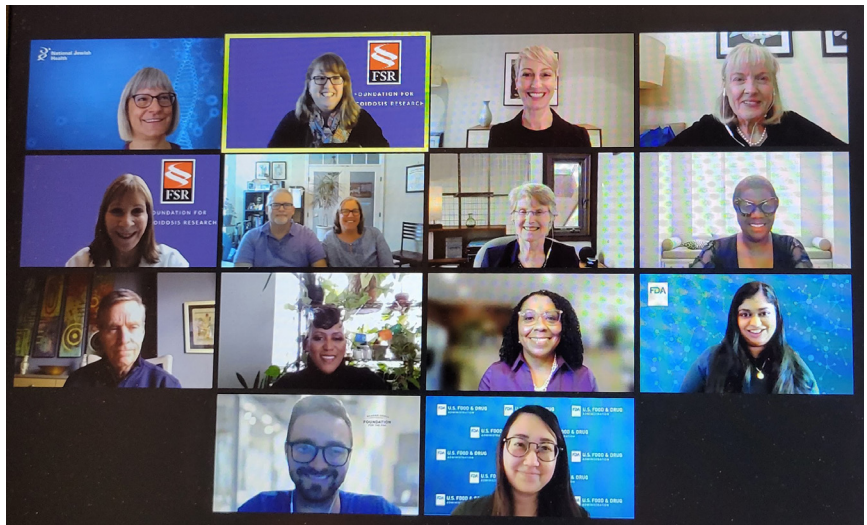
FSR spoke directly to over 50 representatives from 16 offices and divisions including: the Office of the Commissioner (OC), Office of Regulatory Affairs (ORA), Center for Biologics Evaluation and Research (CBER), Center for Devices and Radiological Health (CDRH), and Center for Drug Evaluation and Research (CDER).

Building off feedback we gathered from surveys of patients, clinicians, researchers, and industry partners, we shared stories and data to highlight our priorities for the FDA.

We asked the FDA to:

- Provide support for the identification and approval of better tools for early diagnosis of sarcoidosis.
- Recognize the urgency for the development of better therapies by moving past the antiquated position that long-term, high-dose steroids are an acceptable pathway to prolonged treatment of this disease.
- Take a broader approach in defining acceptable data, outcome measures, trial requirements, and endpoint selection.
- Work with FSR and other rare disease organizations to identify paths, like decentralized trials, to ensure clinical trial representation of the population that is underserved and disproportionately impacted.

Stay tuned for more about this milestone event, as FSR will create a [white paper](#) and host a webinar later this year to share the details of this session and the outcomes!



“

I am willing to endure the risk of different therapies if they can potentially better treat symptoms, more permanently address my sarcoidosis, and improve my quality of life. We can't wait!

- Jessica, FSR Patient Advocate

# Illuminating the Way Towards a Brighter Future

FSR is proud to announce the launch of our new strategic plan. Designed to unleash the power of community and partnership, this plan was created in response to feedback from patients, clinicians, researchers, donors, and corporate partners. The establishment of this plan by [FSR Board of Directors](#), in collaboration with the FSR staff, sets the course for FSR's future by laying out four overarching goals and specific objectives that we will work to accomplish in the next five years.

Guided by this plan, our efforts will focus on:

- **The Pursuit of Patient Education and Support:** Working with patients, caregivers, clinicians, institutions, and companies at the local level to reduce isolation, provide education and support, and grow the reach and impact of the FSR community.
- **The Pursuit of Advancements in Research and a Cure:** Creating a research agenda to identify the most fruitful path towards acceleration and advancement of sarcoidosis research, drug development, and understanding of sarcoidosis; Prioritizing the needs of those with the highest prevalence and greatest severity of the disease to increase our understanding and improve our strategies for all impacted by the disease; Developing and implementing strategies to de-risk clinical trials in pursuit of better therapies and cure.
- **The Pursuit of Sustainability and Growth:** Diversifying funds and growing funding sources to create the scaffolding to increase investment in research and patient support programming.
- **The Pursuit of Partnerships:** Increasing strategic partnerships with hospitals, clinicians, governmental entities, and international partners to foster collaboration, encourage resource sharing, exchange best practices, and raise international awareness to improve the education, support, and treatment of those with sarcoidosis.







We are so grateful for the generous donors and sponsors who have helped us make these incredible programs and initiatives possible! The dedication, commitment to collaboration, and support from the following partners has led to extraordinary progress in efforts towards better treatments and a cure.

Thank you to our 2021-2022 funding partners:

Assurant, aTyr Pharma Inc., Boehringer Ingelheim, Chan Zuckerberg Initiative, EveryLife Foundation, The Gies Foundation, Global Genes, GlobalSkin, HighSwartz, The June JAMR, Kinevant Sciences, Mallinckrodt Pharmaceuticals, Susan Pearlstine Sarcoidosis Center at the Medical University of South Carolina, Taos Community Foundation, University of Alabama at Birmingham, Virginia Commonwealth University, and Xentria, Inc.

Together we will continue to illuminate sarcoidosis, support those in need, and accelerate groundbreaking sarcoidosis research.

**Foundation for Sarcoidosis Research**

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