



Living with — Sarcoidosis

Insights from the FSR-SARC Patient Registry

A Global, Patient-Reported
Outcomes Program

2015 - 2025



The information in this report is for general informational purposes only and does not constitute official medical advice or recommendations. Contact your clinician with any medical or treatment related questions.

The data contained in this report should be considered raw and should not be used for research purposes. Researchers who would like to request registry data for a research study should complete the formal application and confidentiality-usage agreement found on our website at www.stopsarcoidosis.org/research/fsr-sarc/



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What is in this Report

This report presents data from nearly 7,000 individuals with sarcoidosis as of March of 2025 collected through the FSR Registry, an online patient registry dedicated to understanding sarcoidosis. Within these pages, you will find detailed information about participant demographics, clinical characteristics, treatment histories, health outcomes, and quality-of-life measures.

Please note that the number of participants represented in each analysis may vary. Some surveys or survey questions were answered by only a subset of individuals enrolled in the FSR Registry, either because some questions didn't apply to certain participants, or they chose not to answer or update certain questions. Each figure will tell you how many responses are included. Additionally, the data in this report are from the Baseline Questionnaire collected at the time each individual joined the FSR Registry. As we move into the future, one of the greatest strengths of the FSR-SARC Patient Registry will be that it is longitudinal (over time) as we encourage participants to return to the website at least annually to fill out new surveys with additional data regarding aspects of their disease, organs affected, and other responses that may have changed.

If you are a participant, please be sure to fill out your Annual Update Survey to help researchers understand how your disease changes over time.

To learn more about the FSR Registry or how to get involved, please visit www.stopsarcoidosis.org/registry.



FSR

Foundation for
Sarcoidosis Research

Letter *from the* President and CEO of FSR

Dear FSR Sarcoidosis Community,

As we mark a significant milestone—the 10 year anniversary of the FSR-SARC Patient Registry (FSR Registry)—I want to extend my deepest gratitude to the FSR Board members and researchers who worked diligently alongside us to design the scientifically rigorous and community-driven questionnaires, the researchers and partners who have turned the FSR Registry into a resource for shaping patient-centered research, and most importantly to each and every one of you who generously shared your experiences in order to accelerate and advance sarcoidosis research. This report is just a snapshot of the extraordinary insights that can be mined from this invaluable resource.

FSR launched the FSR Registry with a bold vision: to unite patient experiences with clinical research in order to deepen our understanding of sarcoidosis and accelerate better care, treatments, and ultimately a cure. Today, thanks to your courage, your voice, and your commitment, that vision is stronger than ever.

Over the past decade, the FSR Registry has grown from a visionary idea to a robust, international resource at the heart of sarcoidosis research. Together, we have:

- Fostered a global community where patients, clinicians, and scientists collaborate to drive progress.
- Served as a resource for informing the FDA, industry, and funders about your needs, priorities, and preferences.
- Supported the development of studies and clinical trials for new potential therapies by providing researchers with real-world, patient-driven data, and spreading awareness of how to participate in them.

Your participation has helped identify new disease patterns, highlighted the need for improved treatments, and given voice to the

challenges faced by those living with sarcoidosis. Each survey completed and every update provided has brought us closer to better answers and continues to bring us closer to a cure.

Each step of the way, we sought your feedback on the types of information that are most relevant, your needs with regard to data use and privacy, ways to ensure all voices are included, and the types of information you would like to receive about how your experience compares to the experiences of others. And, with your guidance, in the spring of 2025, we launched a new version of the FSR Registry. Our goals for the next decade include expanding the FSR Registry's reach, deepening our partnerships with researchers and clinicians, and accelerating the translation of data into new treatments and improved patient care.

For those who have been with us along this journey, we thank you and ask you to recommit by renewing your participation and adding your voice to our annual update and new surveys. For those who have not yet participated, now is the time to join these efforts. We need your insights now more than ever. For our clinicians, researchers, and partners seeking to improve the lives of those with sarcoidosis, we invite you to look to the FSR Registry as a central resource for patient experiences, challenges, and needs.

On behalf of the FSR Governing Board of Directors, the FSR Scientific Advisory Board, and the FSR Staff, thank you for your trust, your time, and your unwavering commitment to advancing sarcoidosis research. The progress we celebrate today would not be possible without you. Together, we are making a difference—one story, one patient, and one discovery at a time.

With gratitude and hope for the future,



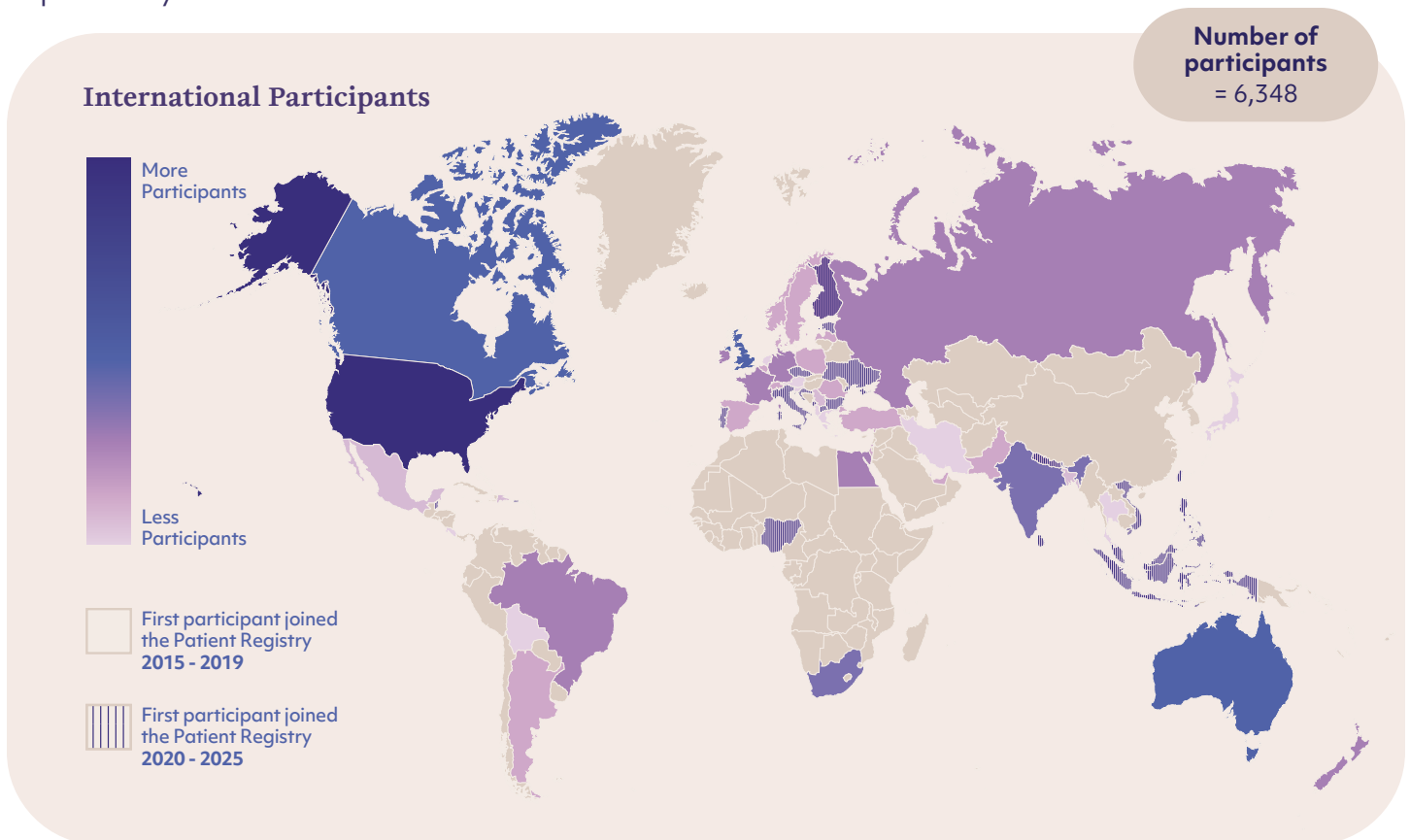
A handwritten signature in black ink that reads "Mary E. McGowan".

Mary McGowan | President and CEO
Foundation for Sarcoidosis Research (FSR)

Registry Participants

Geography

The FSR Registry welcomes patients from around the world! Since everyone experiences sarcoidosis differently and it is believed that sarcoidosis is influenced by both genetics and environmental exposures, it is important that the data captured in the FSR Registry reflect a wide array of experiences of patients impacted by sarcoidosis.



As we seek better representation, we encourage more global participants to share their experiences.



Visit the report webpage for a list of all countries represented in the FSR Registry.

www.stopsarcoidosis.org/registry_report

Since the previous [2019 FSR Registry Report](#), the FSR Registry has seen a 56% increase in countries represented around the world. This includes new participants from Belize, Bulgaria, Croatia, Czech Republic, Estonia, Finland, Hong Kong, Indonesia, Italy, Macedonia, Malaysia, Micronesia, Montenegro, Nepal, Nigeria, Philippines, Portugal, Sri Lanka, Taiwan, Ukraine, and Vietnam.

Through the FSR Scientific Advisory Board, the FSR Global Sarcoidosis Clinic Alliance (GSCA), and the FSR Clinical Studies Network (CSN), we continue to expand our network of global researchers to work together on innovative, impactful studies in sarcoidosis. You can learn more about the FSR-CSN by visiting the webpage www.stopsarcoidosis.org/clinical-studies-network/.

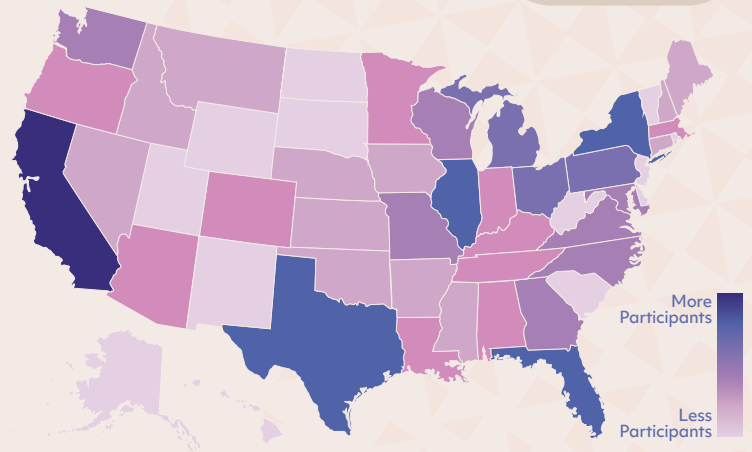
82% of Registry participants are from the United States. One of the goals for the FSR Registry is to have representation across all 50 states and from every country around the globe. As FSR continues to grow its FSR-GSCA, a 45 member program consisting of clinics, hospitals, and individual providers committed to finding a cure and offering evidence-based, patient-centric care for those living with sarcoidosis, FSR is expanding its geographic reach.

In the United States, participants live in most every state, with the largest representation found in Florida, Texas, California, New York, and Illinois. These states also have the most FSR-GSCA member clinics in the U.S.

This highlights the power of the FSR-GSCA in reaching directly to patients and in encouraging them to participate in sharing their voices. The FSR-GSCA offers many resources for patients with the help of the FSR-GSCA Volunteer Leaders including peer-led support groups and community outreach and awareness events and programs. Through the commitment and dedication of our clinician leadership committees, the FSR-GSCA also provides clinician education opportunities, early career mentoring, and clinical best practice sharing. You can learn more about the FSR-GSCA by visiting www.stopsarcoidosis.org/global-clinic-alliance/.

Participants in the United States

Number of participants
= 5,194



75 participants were from Puerto Rico or other US territories.

The FSR Registry will soon offer translated surveys in languages other than English. We further encourage patients from across the US and especially residing in Connecticut, Mississippi, Oklahoma, and Utah to share your insights as we seek to have a better geographically represented group of participants.

Sign up for the FSR Registry today by visiting www.stopsarcoidosis.org/fsr-sarc/



FUTURE RESEARCH QUESTIONS

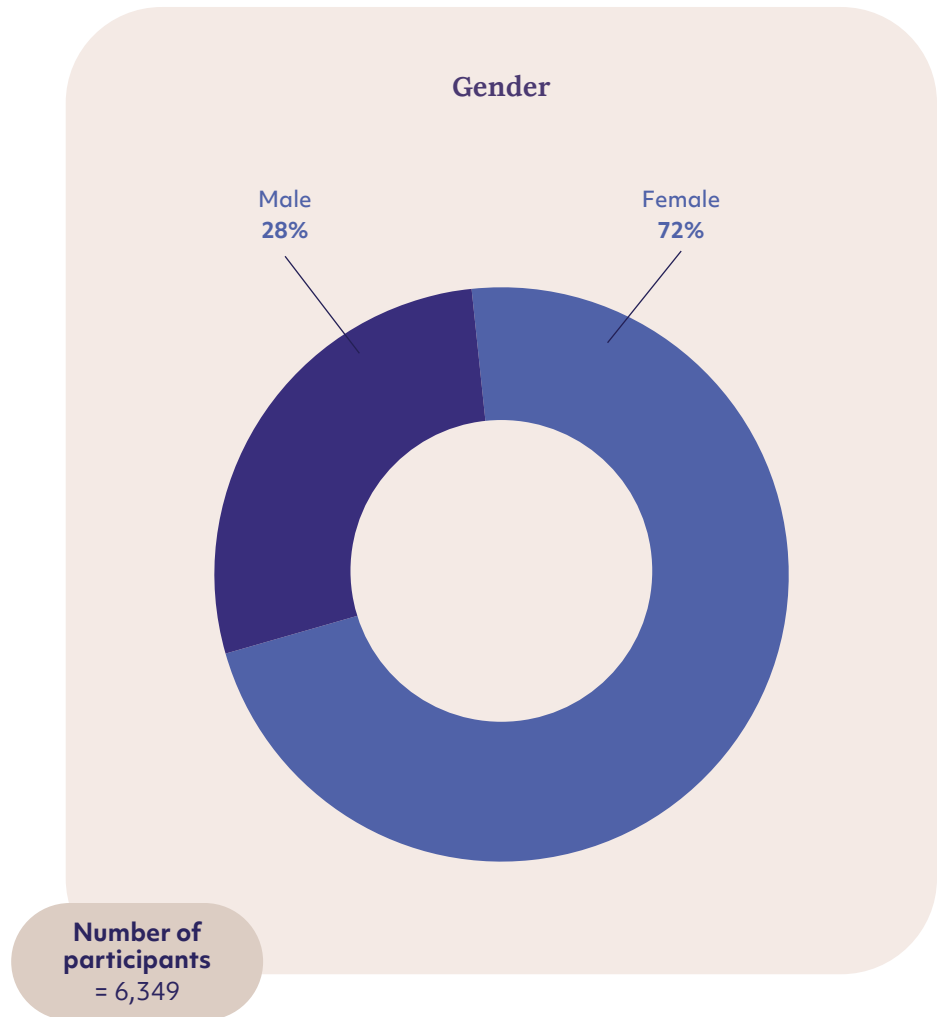
- ▶ How do patients' disease experiences differ between states?
- ▶ What are the differences in the ways doctors around the globe diagnose or manage sarcoidosis?

Registry Participants *(cont.)*

Participant Characteristics

Since the launch of the FSR Registry in 2015, nearly 7,000 individuals impacted by sarcoidosis have signed up to participate.

The FSR Registry includes a wide range of voices from people around the world. Most participants (72%) identified as female.



In 2021, FSR launched the *Ignore No More: ACTe Now!* (Advance Clinical Trials for Equity in Sarcoidosis) Campaign to convene patients, clinicians, researchers, and other stakeholders to engage in an initiative to address racial health disparities by increasing representation of Black sarcoidosis patients in clinical trials.¹

During this time, the FSR Registry saw an increase in participation by Black and African American participants from 17% to nearly 20%. We are continuing to expand our outreach efforts to reach historically underrepresented patient populations in research.



References and citations
[www.stopsarcoidosis.org/
registry_report](http://www.stopsarcoidosis.org/registry_report)

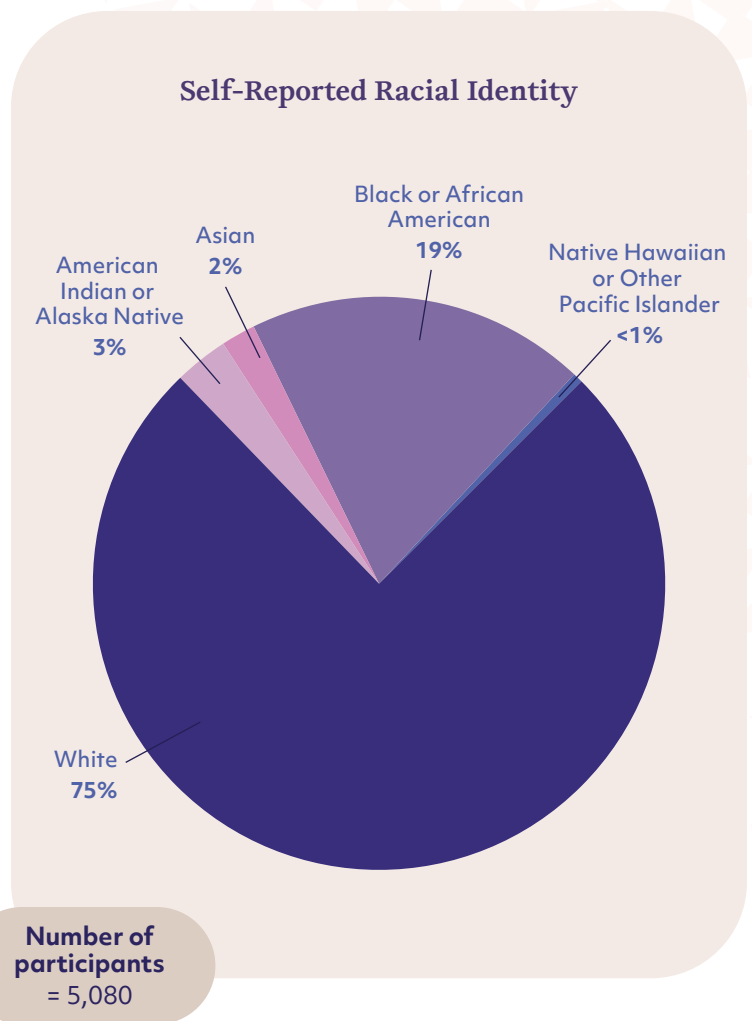
25% of participants said they belong to more than one racial group.

**The data was simplified in the chart below*

A total of 75% identified as white, 19% as Black or African American, and 6% as Hispanic or Latino. However, the data also show that how people identify their race is often more complex.

In the US, Black and African American women bear the greatest burden when compared to all other groups impacted by sarcoidosis. They experience higher hospitalization and mortality rates, and more severe symptoms than white and African American men on average.ⁱⁱ

The FSR Registry is largely capturing data from white, Non-Hispanic patients. However, FSR recognizes the importance of also engaging with Black, African American, Hispanic, East Asian, West Asian, and global indigenous patients to more accurately reflect the unique needs and experiences of the global community impacted by sarcoidosis. We encourage participants from all countries, genders, and racial/ethnic backgrounds to share your stories so we can ensure that future research and clinical trial designs, diagnosis strategies, and clinical care is reflective of everyone's experiences.

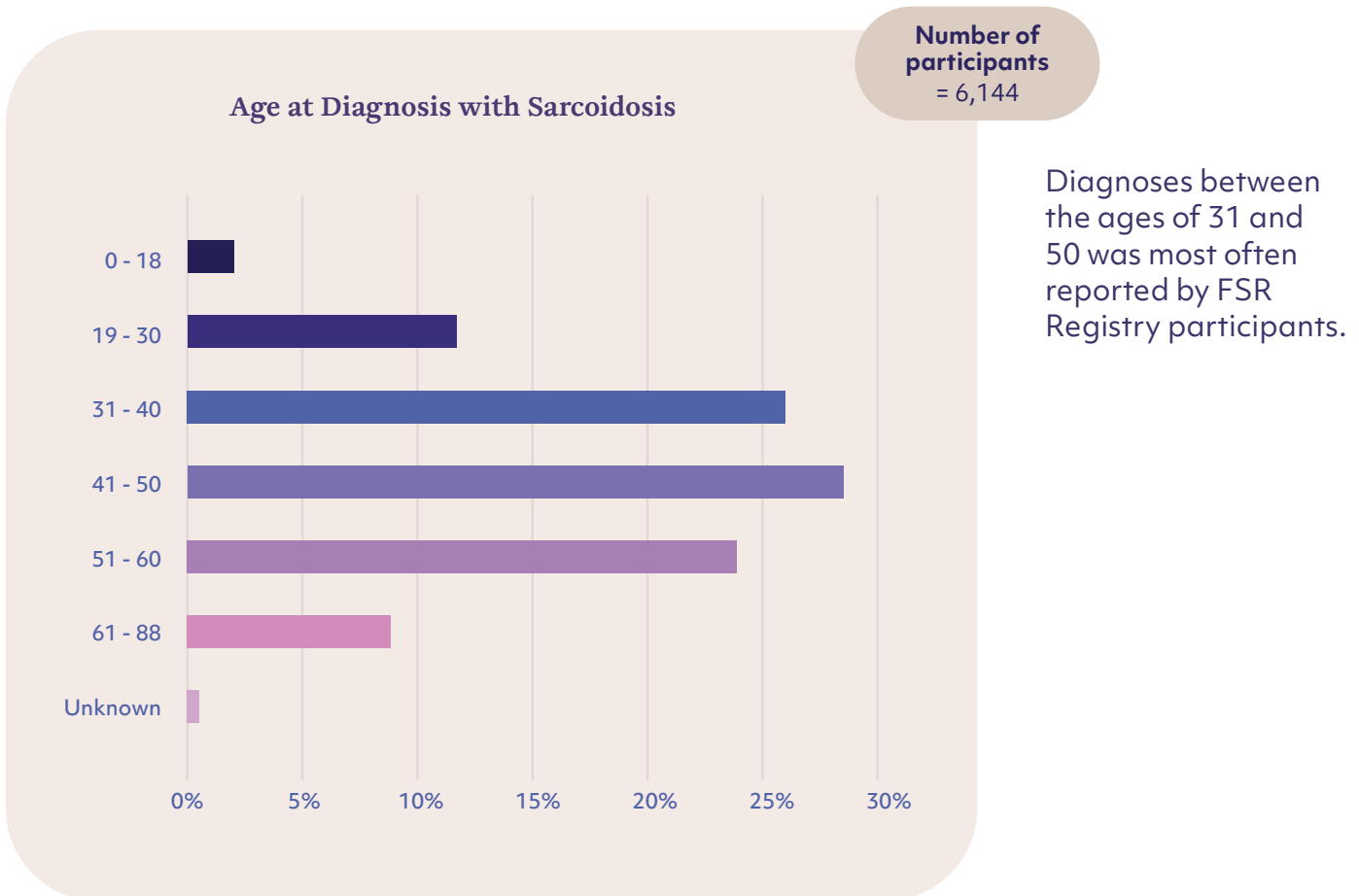


Registry Participants *(cont.)*

Diagnosis

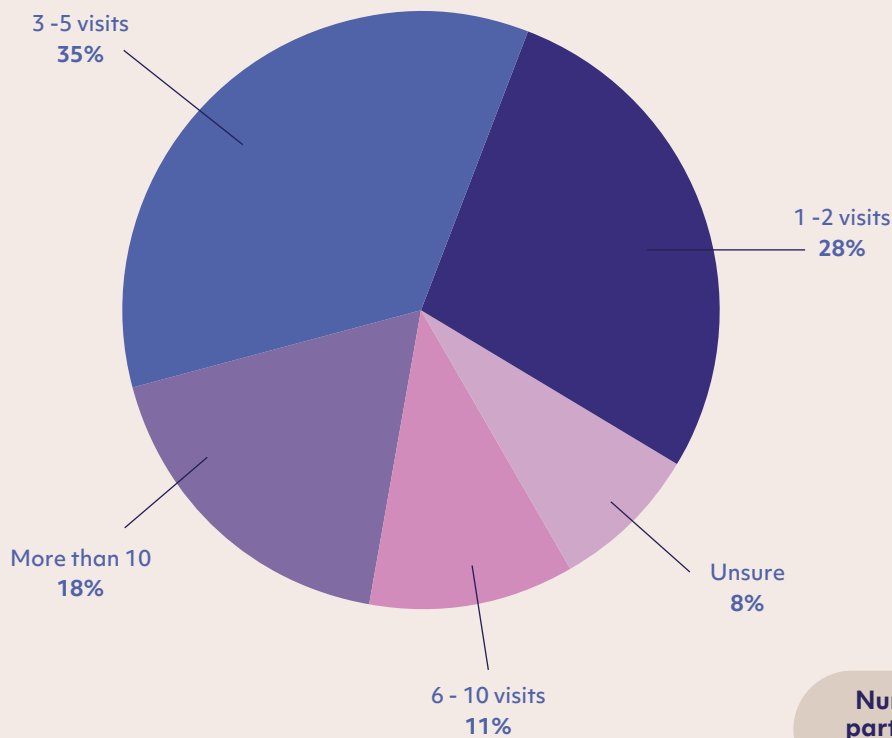
Sarcoidosis is a diagnosis of exclusion, meaning that doctors will oftentimes have to rule out other possible diseases before confirming that your symptoms are caused by sarcoidosis. There is no single objective test which can easily diagnose the disease. Numerous exams and tests are required to confirm your diagnosis and help the doctor decide on the best treatment options.ⁱⁱⁱ

The average age of diagnosis in the US is 55, though people of all ages can be affected, and many are diagnosed anywhere between ages 20 and 70. **In the FSR Registry, the average age of diagnosis reported was 44.5, nearly 10 years younger than the national average.** Black and African American participants reported an even younger average age at diagnosis of 39. This may demonstrate that the participants in our registry are representative of those with more aggressive and complex disease.



When looking at the average age at diagnosis by affected organ, those with sarcoidosis in their sinuses reported the youngest at 39 years, while those with sarcoidosis in their heart reported oldest age at diagnosis at 46. Additional information on organ specific data can be found in the following sections.

Number of Visits Before Diagnosis



Number of participants
= 5,860

Participants reported an average of 3.5 doctor visits before diagnosis, with nearly 20% reporting it took more than 10 visits focused on symptoms of sarcoidosis before confirmation.



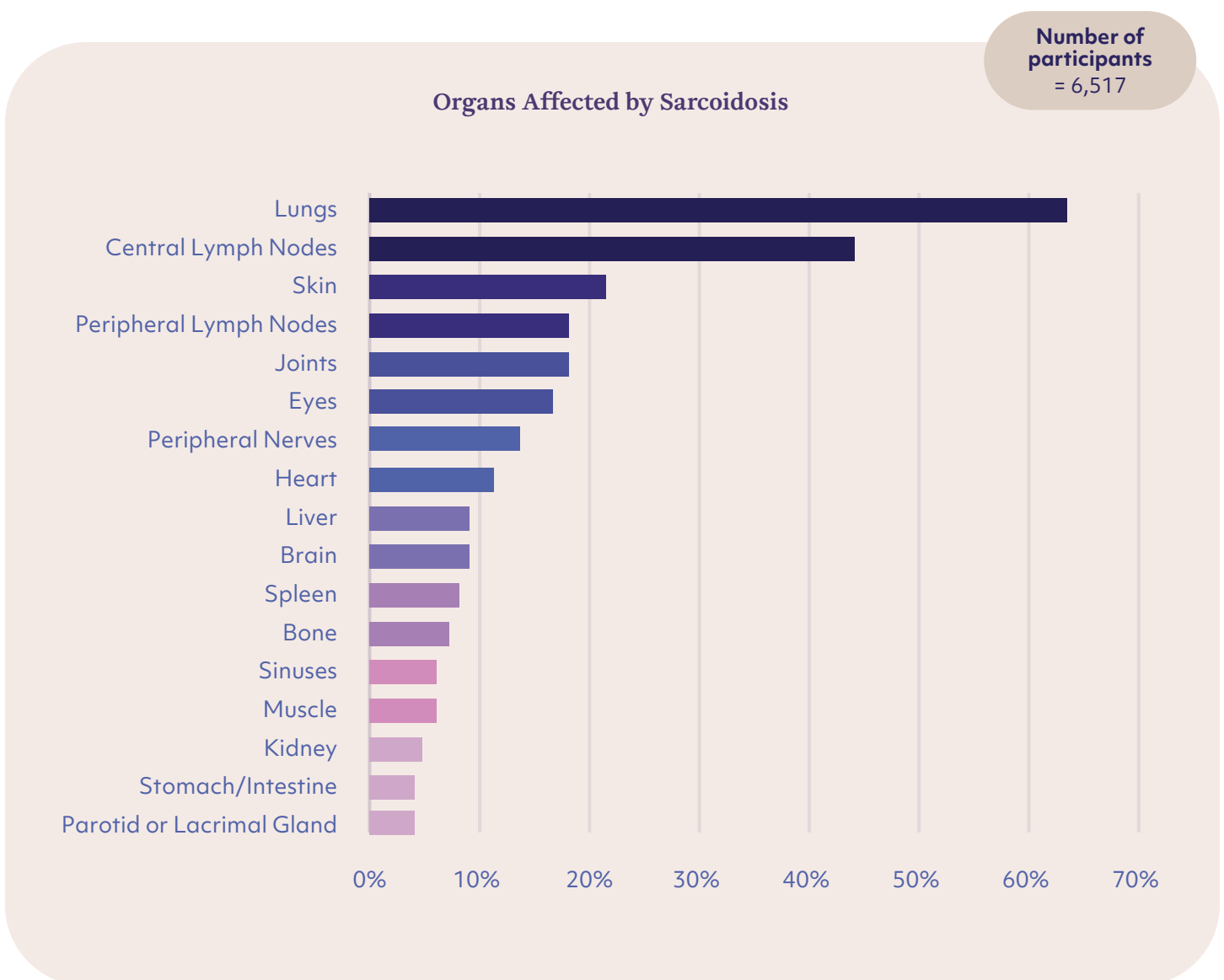
FUTURE RESEARCH QUESTIONS

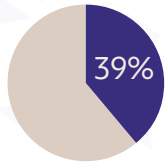
- ▶ Why might patients with sarcoidosis in their sinuses be diagnosed earlier than patients with other organs impacted?
- ▶ Do patients believe they have symptoms of sarcoidosis that can be traced back even further in their health history, and how might this help us identify potential triggers or susceptibility?
- ▶ Does the age that a patient is diagnosed predict how long they will need to be on treatment?
Registry participant follow-up surveys will be essential to answer this type of question.

Registry Participants *(cont.)*

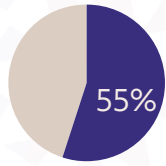
Organ Involvement

By definition, sarcoidosis is a systemic disease - for many it will affect multiple organs in the body. 90% of people experience lung involvement; however, for some this may not be the organ that presents the most significant health risk or challenges. Some patients experience higher risks for advanced diseases, such as fibrosis of various organs, heart block or heart failure, and other complications.^{iv} Having participants in the FSR Registry report multiple organ involvement is important because sarcoidosis can affect many parts of the body in different ways. When patients share which organs are affected, researchers can better understand how the disease behaves, which symptoms often occur together, and what treatments might work best. This also tells us that participants who join the FSR Registry are more likely to have severe disease or multiple organs impacted.





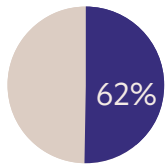
Black women



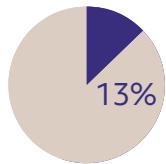
white women

39% of Black women and 55% of white women with pulmonary sarcoidosis reported they have **central lymph node involvement**.

Black women



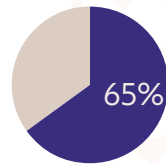
pulmonary sarcoidosis



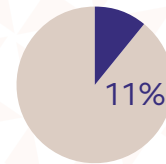
cardiac sarcoidosis

62% of **Black women** in our registry reported that they have pulmonary sarcoidosis, whereas only 13% reported cardiac sarcoidosis.

white women



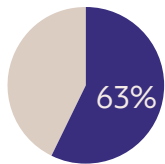
pulmonary sarcoidosis



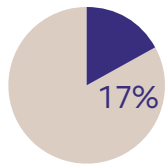
cardiac sarcoidosis

65% of **white women** in our registry reported pulmonary sarcoidosis while only 11% reported cardiac sarcoidosis.

Black men



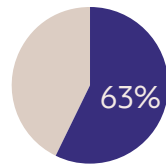
pulmonary sarcoidosis



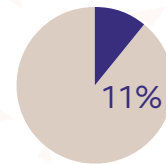
cardiac sarcoidosis

63% of **Black men** reported lung sarcoidosis while reporting a higher percentage of cardiac sarcoidosis than other participants at 17%.

white men



pulmonary sarcoidosis



cardiac sarcoidosis

Similarly, 63% of **white men** reported pulmonary sarcoidosis while 11% reported cardiac sarcoidosis.

** Many people have multi-organ involvement, so the totals may add up to more than 100%*



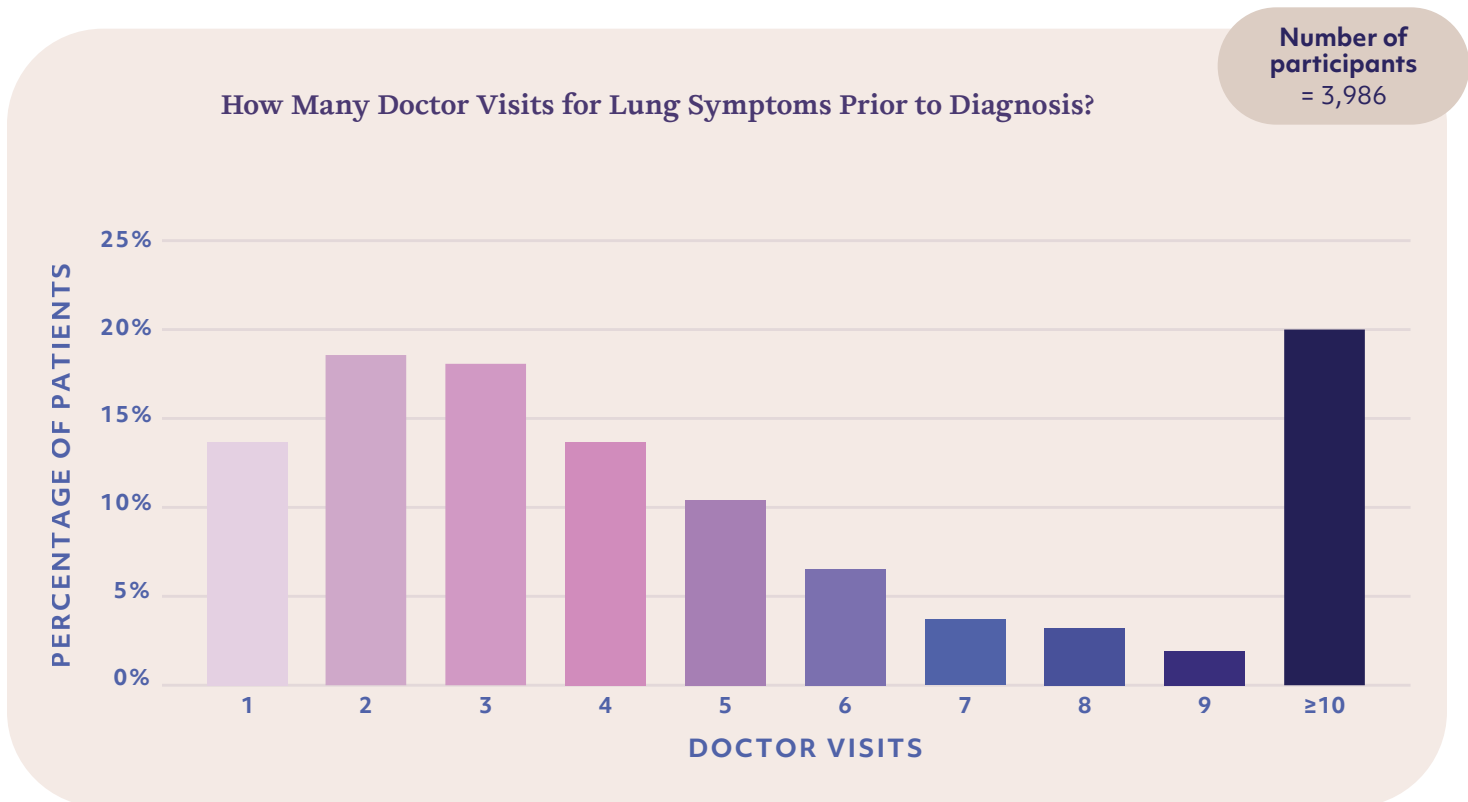
Use of FSR Registry Data:

**AMERICAN THORACIC SOCIETY
INTERNATIONAL CONFERENCE ABSTRACTS**

An abstract featured at the American Thoracic Society Annual Meeting in 2018 using FSR Registry data showed that there were different rates of skin, eye, and heart involvement between white and Black patients, and men and women. Work like this can provide clues to the cause of sarcoidosis and help inform trials to test new drugs that will benefit all sarcoidosis patients.^y

Sarcoidosis of the *Lungs*

Pulmonary sarcoidosis can present with a variety of symptoms and imaging findings that differ from person to person. Making the diagnosis involves reviewing medical history, performing appropriate tests, and ruling out other conditions that may appear similar to pulmonary sarcoidosis.



1 out of 5 participants with sarcoidosis in their lungs reported 10 or more doctor visits for symptoms before being diagnosed.

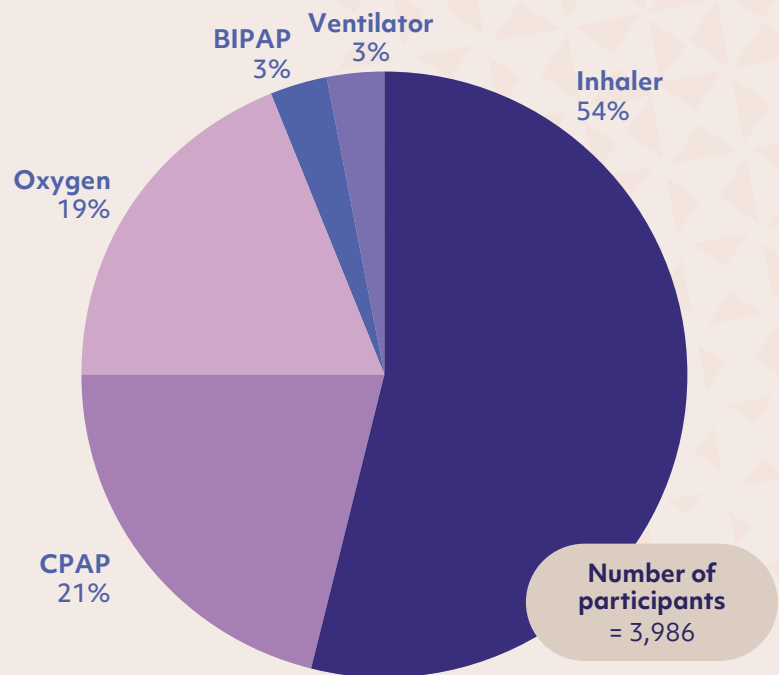


Over 4,100 FSR Registry participants (76%) reported a diagnosis of sarcoidosis in their lungs.

A small number of patients with pulmonary sarcoidosis are also impacted by a more advanced pulmonary condition called pulmonary arterial hypertension, a condition in which scar tissue narrows or blocks arteries in the lungs, causing high blood pressure. The high blood pressure, also known as hypertension, forces the heart to work harder to pump blood through the vessels. Over time, heart muscle builds up and weakens, hindering its ability to deliver oxygen to lungs and other parts of the body.^{vi}

Nearly 300 participants (6% of those with pulmonary sarcoidosis) reported experiencing pulmonary arterial hypertension.

Use of Oxygen or Breathing Devices for Participants with Lung Involvement



Symptoms of pulmonary sarcoidosis can include shortness of breath or labored breathing. Over 50% of FSR Registry participants reported using an inhaler, while nearly 20% reported needing oxygen to support their breathing.



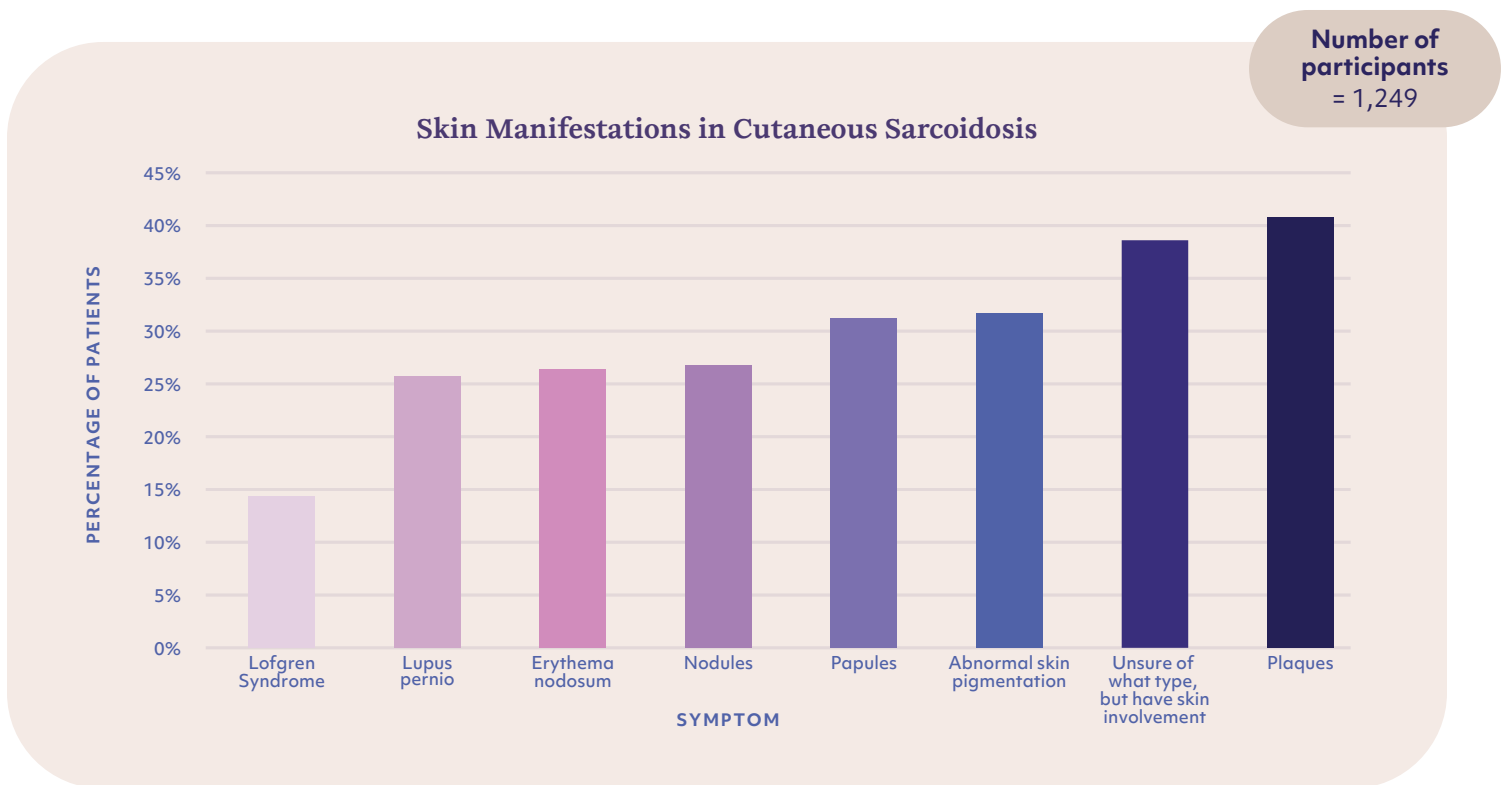
FUTURE RESEARCH QUESTIONS

- ▶ Can we identify characteristics of sarcoidosis or treatments that are associated with improvement of symptoms?
- ▶ What symptoms or patient characteristics can serve as clues for advanced pulmonary disease like fibrosis or pulmonary arterial hypertension?

Sarcoidosis of the *Skin*

22% of FSR Registry participants reported a diagnosis of cutaneous sarcoidosis.

Cutaneous sarcoidosis may appear differently in different individuals as raised bumps, patches of red or darkened skin, or open sores. It is often called 'the great mimicker' because it can look like many other conditions that impact the skin. The face is a common site, as are tattoos and scars.^{vii}



The most common reported skin symptoms in the FSR Registry were plaques (41%), abnormal skin pigmentation (32%), and papules (small, raised bumps) (31%).



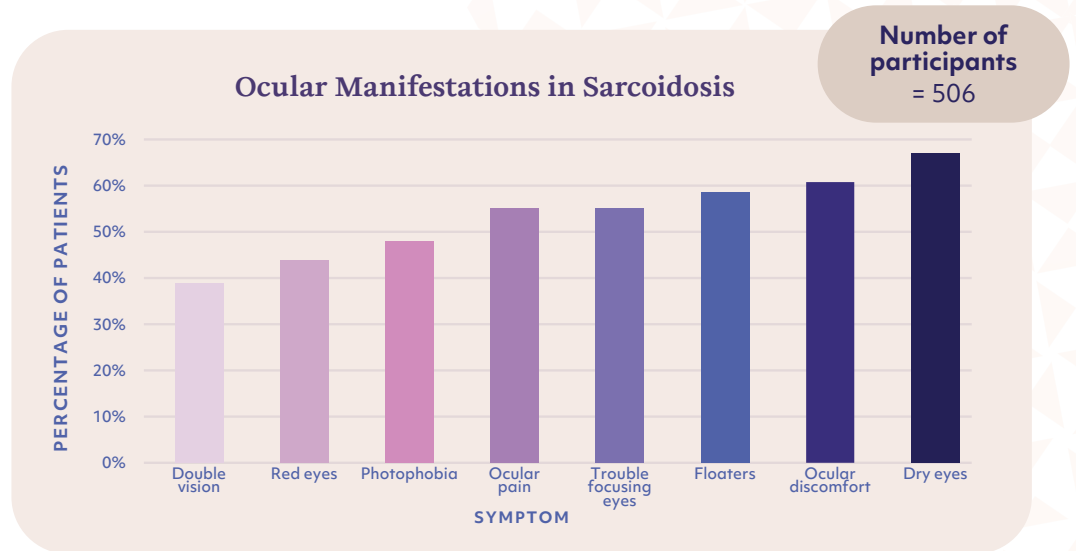
FUTURE RESEARCH QUESTIONS

- ▶ How long does it take for cutaneous sarcoidosis to improve? Are there certain treatments that seem to work better than others?
- ▶ Does skin color impact timeliness of diagnosing skin rashes?

Sarcoidosis of the *Eyes*

18% of FSR Registry participants reported a diagnosis of ocular sarcoidosis.

More than half of participants with ocular sarcoidosis reported dry eyes, discomfort, floaters, trouble focusing their vision, and pain post-diagnosis.



Use of FSR Registry Data:

AMERICAN THORACIC SOCIETY INTERNATIONAL CONFERENCE ABSTRACTS

“The FSR Registry provided information from a wide geographic area and was not driven by individual sarcoidosis centers. There were significant differences in rate of involvement for skin, eye, and heart based on gender, race, and US versus non-US centers.”^{viii}

The conference abstract quoted here, using FSR Registry data, revealed that ocular sarcoidosis is more likely to be reported in Black and African American women than anyone else. The FSR Registry data have revealed that 24% of Black men reported ocular sarcoidosis involvement, while it was reported by only 17% of white patients (no gender differences found) and 15% of Black women.



FUTURE RESEARCH QUESTIONS

- ▶ What could make an individual more likely to develop new or worsening impairment of vision due to sarcoidosis?
- ▶ Are there certain groups of patients who are not being appropriately screened for sarcoidosis of the eye?

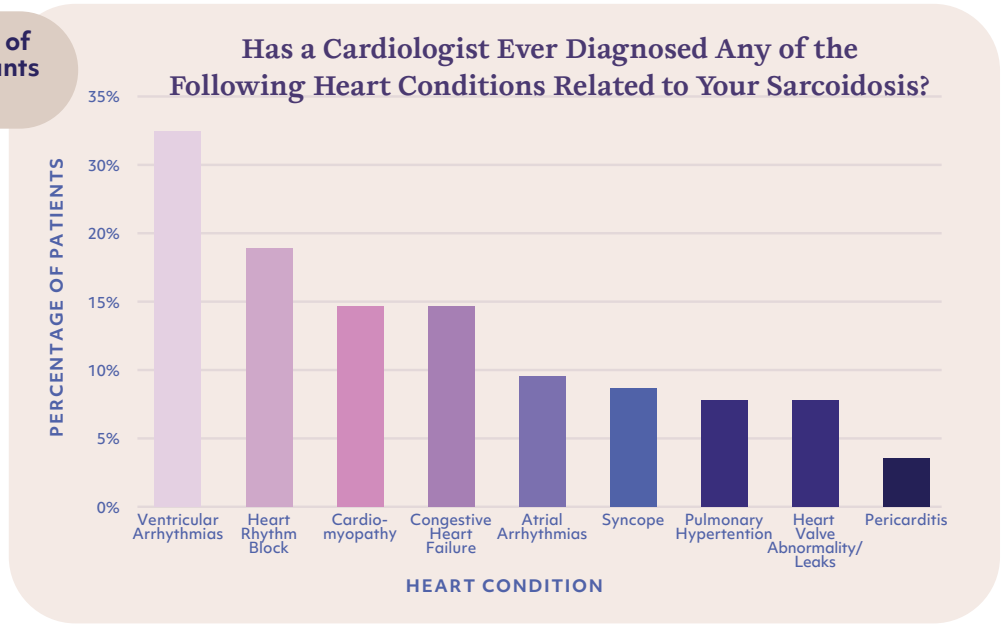
Sarcoidosis of the *Heart*

12% of FSR Registry participants indicated cardiac sarcoidosis involvement.

The most commonly reported heart condition for FSR Registry participants with diagnosed cardiac sarcoidosis was ventricular arrhythmias (32%).

Complications from cardiac sarcoidosis can be particularly serious and sometimes deadly. It is so important for patients to work with their clinicians to monitor symptoms like palpitations, lightheadedness, and worsening shortness of breath, especially if they have normal lung function.

Number of participants = 741



Use of FSR Registry Data:
AMERICAN THORACIC SOCIETY INTERNATIONAL CONFERENCE ABSTRACTS

Investigators from the FSR Clinical Studies Network (CSN) are working how to best detect cardiac sarcoidosis through the FSR-founded PAPLAND Routine Cardiac Screening in Sarcoidosis Patients Study. Data presented at the 2025 American Thoracic Society Conference showed that components of medical history, blood tests, and specific cardiac testing could be used to predict cardiac involvement. The FSR Registry allows further understanding of how to best use these tests to find cardiac sarcoidosis before dangerous events occur.^{ix}

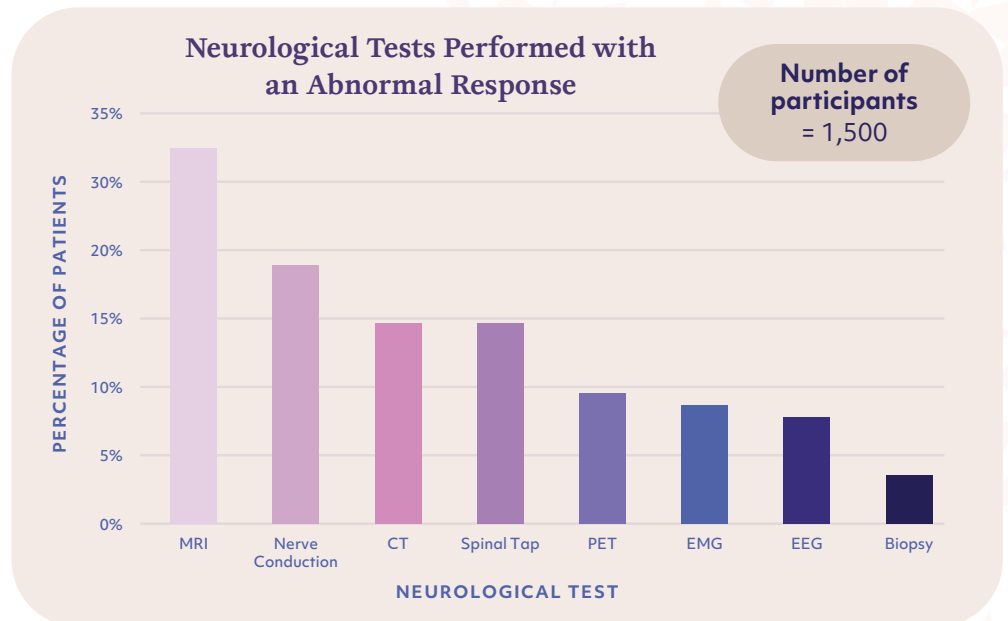


FUTURE RESEARCH QUESTIONS

- ▶ Does the number of organs involved predict duration of sarcoidosis symptoms?
- ▶ Do patients receive different care if they have multiple organs involved?

Sarcoidosis of the *Brain & Nervous System*

Although it can affect almost any part of the nervous system, the cranial nerves, which are important nerves at the base of the brain, are commonly involved.^x Of the 1,500 participants reporting a diagnosis of neurosarcoidosis, peripheral nerve involvement was most common at 60%, followed by brain and/or lining of the brain at 43%. Spinal cord involvement was less commonly reported by 18% of neurosarcoidosis participants.



The FSR Registry is the largest neurosarcoidosis collection to date with nearly 1,500 patients reporting neurological involvement.

Cranial nerve involvement can primarily lead to facial palsy (drooping on one side of the face) and vision loss. There may be difficulties with hearing, balance problems, or nerves controlling eye movement.

Peripheral nerve involvement includes small fiber neuropathy including burning pain, tingling, numbness, dry eyes/mouth, and problems with urination or digestion.



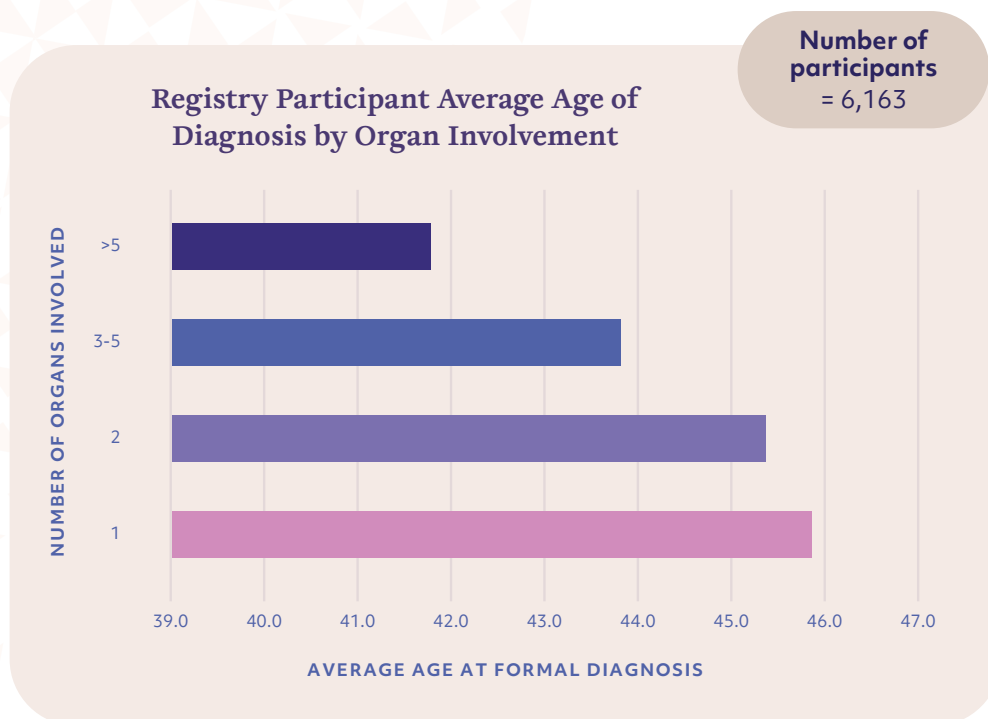
Use of FSR Registry Data:

SARCOIDOSIS, VASCULITIS AND DIFFUSE LUNG DISEASES

In 2024, a study using FSR Registry data looked at sarcoidosis in the brain and nervous system (called CNS or neurosarcoidosis). The research team from the University of Florida – Gainesville, a founding member of the FSR-GSCA, found that people with neurosarcoidosis often had more organs affected than those without it. They were also more likely to have chronic pain, trouble getting around, and need devices to help them move. This important study encouraged ongoing efforts to improve quality of life for people with neurosarcoidosis.^{xi}

Sarcoidosis with *Multi-Organ Involvement*

According to FSR Registry data, some participants experience sarcoidosis symptoms in just one organ, while others report as many as 18 different organ systems affected. When more body systems are involved, it can lead to a wider experience of symptoms and disease activity to monitor and manage throughout the sarcoidosis journey.



Participants with 5 or more organ systems involved were diagnosed with sarcoidosis almost 3 years fewer than those with less than 5 organ systems involved.

Additionally, participants with significant organ involvement (5 or more organ systems involved) also experienced their first sarcoidosis symptoms nearly 4 years earlier than those with fewer organs involved.

Overall, FSR Registry data show that patients with more organs involved were formally diagnosed younger than when fewer organs were involved.



FUTURE RESEARCH QUESTIONS

- ▶ How frequently do patients develop cardiac sarcoidosis after being diagnosed with pulmonary sarcoidosis? How long after diagnosis does this happen?
- ▶ What clinical signs, symptoms, and tests are most effective in detecting cardiac sarcoidosis?



More figures and insights on treatments and therapies available on the website.

www.stopsarcoidosis.org/registry_report

Sarcoidosis of *Bone & Mineral Metabolism*

As an inflammatory disease sarcoidosis can lead to or be associated with other significant metabolic issues including hypercalcemia (too much calcium in the blood), hypercalciuria (too much calcium in urine), suppressed parathyroid hormone (usually released by four small glands in the neck when vitamin D metabolites and low levels of calcium are detected in the blood), and vitamin D dysregulation.^{xii}

Of these, the most commonly reported complication in the FSR Registry was vitamin D deficiency - reported by 29% of FSR Registry participants.

FSR has been working with the FSR-GSCA on bone and mineral health issues and is working on a consensus paper on appropriate testing, monitoring, and treatment. If you are a clinician specializing in sarcoidosis and are interested in being a part of these efforts, please reach out to us.



FUTURE RESEARCH QUESTIONS

- ▶ What are common co-morbidities associated with sarcoidosis?
- ▶ What steps and precautions should clinicians and patients take when monitoring for non-sarcoidosis related symptoms and diseases?



Use of FSR Registry Data:
SPRINGER NATURE

A 2021 paper, led by researchers at the University of Florida – Gainesville, an FSR-GSCA Founding Member, explored the link between sarcoidosis and lymphoma. This study found that sarcoidosis patients develop lymphoma more often than the general population, especially in those with sarcoidosis affecting the skin or salivary glands, although only 1% of sarcoidosis in the FSR Registry reported lymphoma.

“Those who developed lymphoma also reported more severe symptoms overall, including fatigue, pain, and symptoms affecting multiple body systems. These findings stress the importance of keeping clinical vigilance on changing symptoms when dealing with sarcoidosis patients and exploring other causes of non-organ related manifestations in this patient population.”^{xiii}



Use of FSR Registry Data:
**AMERICAN ASSOCIATION
OF CLINICAL
ENDOCRINOLOGY**

Another paper in 2022 from the same research group looked at hyperthyroidism in FSR Registry participants. Hyperthyroidism, also known as an overactive thyroid, occurs when the thyroid gland produces and releases too much thyroid hormone, and can cause a range of symptoms.

“Hyperthyroidism is infrequent in patients with sarcoidosis but is potentially associated with different cardiac manifestations [including atrial arrhythmias, ventricular arrhythmias, congestive heart failure and heart block].”^{xiv}

Medications *for* Sarcoidosis

Health care providers will carefully monitor patients with sarcoidosis to see if the disease is getting better or worse, and will then adapt the treatment based on how the patient's body is doing. Many physicians will choose to treat when their patient's quality of life is severely affected or when they believe there is danger of organ damage or death.^{xv} Patients with sarcoidosis often have very different experiences with the disease, which means that patients with sarcoidosis often have to try multiple drugs while balancing the benefits and side effects, and make constant adjustments as the individual's disease evolves. This complexity underscores the need for more research and progress toward personalized, targeted therapies.

79% of participants reported being prescribed medications to treat their sarcoidosis at some point at time of enrollment in the FSR Registry.

There are currently just a few FDA-approved therapies for sarcoidosis. The majority of the therapies are being utilized off-label, based on small investigator-led studies and standard clinical practice for controlling or reducing inflammation in other illnesses.



FUTURE RESEARCH QUESTIONS

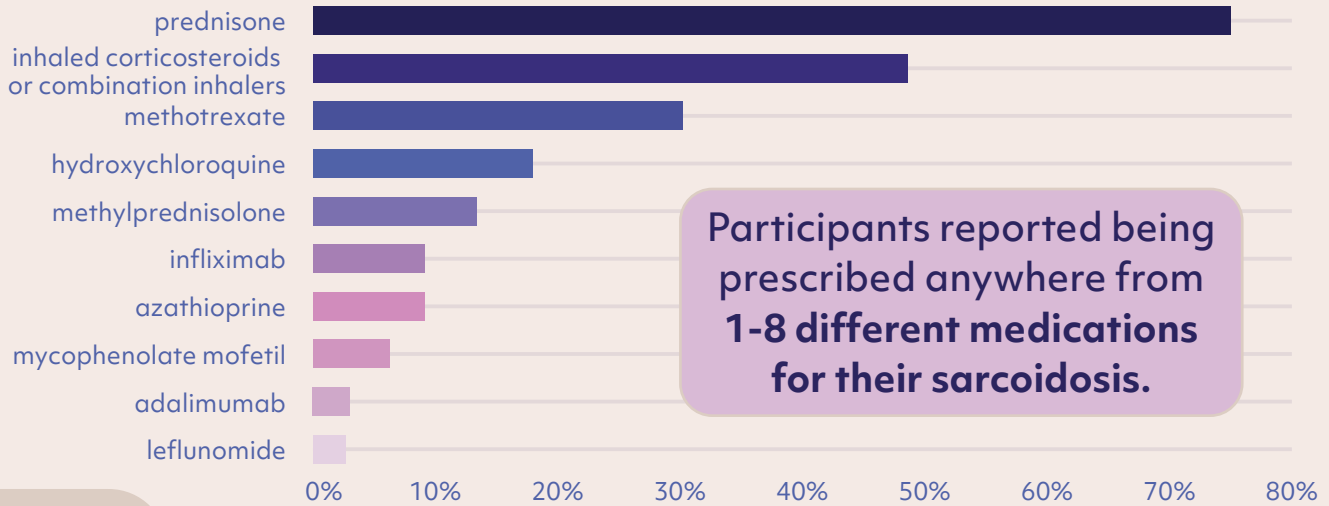
- ▶ What do treatment patterns in sarcoidosis look like, especially as we learn more about how well they work in specific patients?
- ▶ Have there been changes in prescription patterns and treatment strategies over time?



EMERGING THERAPIES ON THE HORIZON

The landscape of sarcoidosis therapy is expanding rapidly, with new investigational drugs, repurposed drugs and biologics showing promise for treating sarcoidosis. These advances aim to reduce reliance on steroids and improve long-term outcomes, though further research is needed. The FSR Registry's new [Annual Update Survey](#) will collect data on patients using these new therapies to help understand how they work in sarcoidosis.

Medication Ever Taken for Sarcoidosis



Number of participants
= 4,856

Participants reported being prescribed anywhere from **1-8 different medications** for their sarcoidosis.

75% of participants taking medication for their sarcoidosis reported being prescribed prednisone at some point, with nearly **50%** reporting inhaled corticosteroids or combination inhalers.

[Not Shown in Graph] IVIG: intravenous immunoglobulin, etanercept, golimumab, certolizumab, pentoxifylline, chloroquine, cyclophosphamide, rituximab, corticotropin, and thalidomide reported <5%.

Prednisone, corticotropin (repository corticotropin/corticotrophin), and nintedanib are the only drugs that currently hold Food and Drug Administration (FDA) approval for the treatment of sarcoidosis in the United States. Other medications are often prescribed for sarcoidosis but do not have FDA approval specifically for this condition – this is called “off-label” use and is based on clinical experience and supporting evidence.



Use of FSR Registry Data:

AMERICAN THORACIC SOCIETY INTERNATIONAL CONFERENCE ABSTRACTS

FSR Registry data was presented at the American Thoracic Society International Conference in 2018. This analysis synthesized results of self-reported description of the disease burden, including duration of disease, reported organ involvement, new comorbidities occurring after the diagnosis, medications used as well as financial impact of the disease. “Those using steroids are at risk of developing diabetes and/or osteopenia,” said the authors, who collaborated from the University of Iowa, Cleveland Clinic- an FSR-GSCA Founding Member, University of Cincinnati, Albany Medical College, National Jewish Health – an FSR Global Sarcoidosis Clinic Alliance Founding Member, and Maastricht University Medical Centre. “Many patients lost employment or experienced financial strain despite greater than 90% of patients having medical insurance.”^{xvi}

Quality of Life Impact

Pain

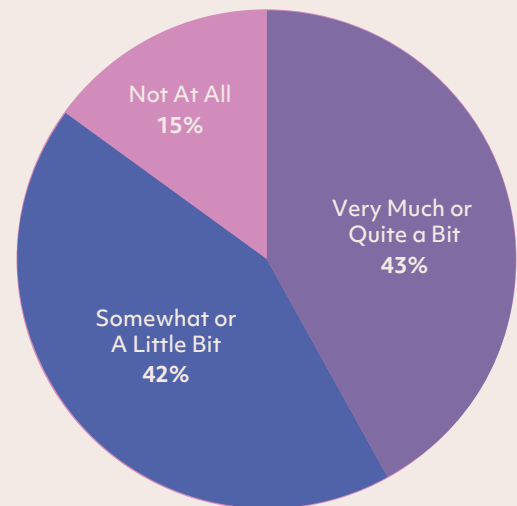
Pain is a substantial and sometimes overlooked aspect of sarcoidosis, affecting patients in several physical and psychological ways. Its significance lies in how it impacts symptoms, quality of life, and clinical management. The FSR Registry is helping to quantify the impact of pain on quality of life in sarcoidosis.^{xvii}

Only 15% of patients reported that pain does not at all interfere with their enjoyment of daily life, while 85% of patients reported varying degrees of interference.

71% of patients who reported experiencing the highest level of pain reported that completing tasks around the house was one of their biggest challenges.

Number of participants
= 4,462

How Much Did Pain Interfere with Life Enjoyment Over the Past Two Weeks?



FUTURE RESEARCH QUESTIONS

- ▶ Why do age at diagnosis, age at start of symptoms, sex, use of immunosuppressant medications, or financial factors make an individual more likely to report a high burden of pain?
- ▶ What are the various aspects of daily life most impacted by pain?



Use of FSR Registry Data:

WASOG ANNUAL CONFERENCE ABSTRACT

A 2025 abstract using FSR Registry data was presented at the WASOG Annual Conference. This analysis found that **respondents with high compared to low pain burden** were younger at the time of diagnosis (average age of 43 years compared to 46) and at the start of symptoms (average age of 39 years compared to 43). Participants with high pain burden were also 1.6 times more likely to be female, 1.55 times more likely to be prescribed immunosuppressant medications, 3.74 times more likely to report job loss due to sarcoidosis health effects and 2.93 times more likely to report an annual household income under \$35,000 compared to those with low pain burden.^{xviii}

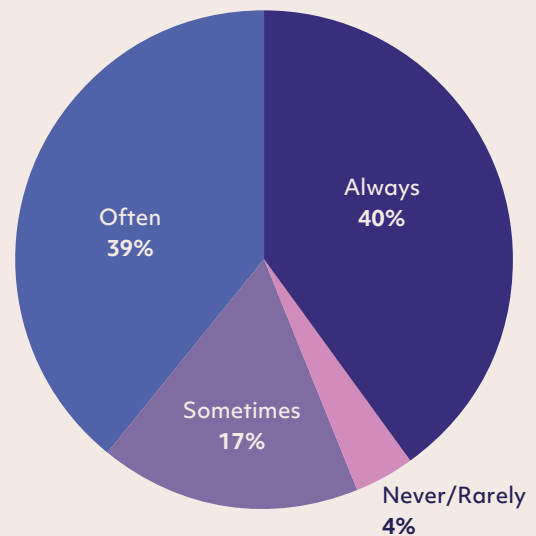
The FSR Registry utilizes validated tools to measure quality of life including the Sarcoidosis Health Questionnaire and the Patient-Reported Outcomes Measurement Information System (PROMIS).

Fatigue

Fatigue affects most sarcoidosis patients, even when other symptoms are well controlled. On October 28, 2024, the Foundation for Sarcoidosis Research hosted the Externally-Led Patient Focused Drug Development Meeting (EL-PFDD) with the FDA, an interactive, virtual, public meeting that provided patients and caregivers with a unique opportunity to share about their unmet needs, the quality of life impacts of sarcoidosis, and preferences in respect to symptom management and the development of new therapies. When asked what symptoms have had the most impact on sarcoidosis patients' lives, fatigue was the highest reported.^{xix}

Number of participants
= 4,354

How Often Did Participants Feel Tired Over the Past Two Weeks?



Measured with the Patient-Reported Outcomes Measurement Information System (PROMIS) tool.

Most FSR Registry participants reported fatigue with 40% reporting that they always feel tired.



FUTURE RESEARCH QUESTIONS

- ▶ How does fatigue impact patients' economic, social, and emotional well-being?
- ▶ How does the impact of fatigue change over time?

To learn more about the EL-PFDD, visit www.stopsarcoidosis.org/pfdd/

Quality of Life Impact *(cont.)*

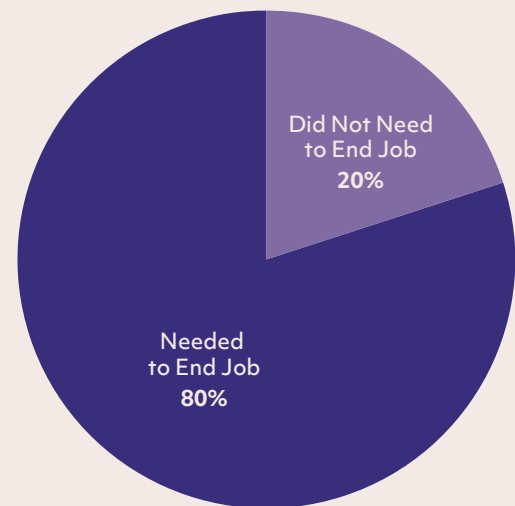
Employment

Since many individuals diagnosed are of working age, the disease can significantly affect their employment and family life. Living with a chronic illness like sarcoidosis often leads to secondary issues such as depression and fatigue, which may interfere with a person's ability to work, pursue education, or care for themselves and their loved ones.

23% of FSR Registry participants reported that they are no longer working due to disability, and 80% of those who are no longer employed needed to end their jobs due to the health effects from sarcoidosis.

Number of participants
= 1,183

Participants who needed to end their jobs due to health effects from sarcoidosis



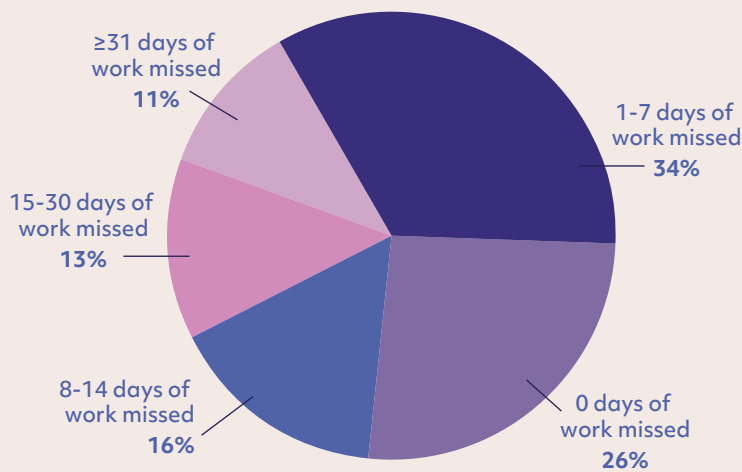
Use of FSR Registry Data:

AMERICAN JOURNAL OF RESPIRATORY AND CRITICAL CARE MEDICINE

In a 2020 study using FSR Registry data by researchers at Cleveland Clinic – an FSR-GSCA Founding Member – researchers looked at individuals who had to stop working because of sarcoidosis. “We have demonstrated consistent associations of income on a range of health and social outcomes. Patients of lower income were more likely to develop new sarcoidosis-related and steroid-related comorbidities, had worse health-related [quality of life], and experienced a greater negative effect on their family finances. This effect persisted even after correction for other markers of socioeconomic status and disease severity, including insurance status...these results demonstrate a higher burden of disease impacting patients with sarcoidosis who are economically disadvantaged, even years after diagnosis.”^{xx} People who had nerve, eye, or skin problems caused by sarcoidosis, who had symptoms for a longer time, who were taking medication for sarcoidosis, or who developed other health conditions were also more likely to have to stop working.

Number of participants
= 4,487

Days of work missed in the past 12 months by sarcoidosis patients with full time jobs



How sarcoidosis affects full-time employment

46% of FSR Registry participants reported that they are full-time employees. When completing the survey, participants reflected on the 12 months prior, and 40% of those FSR Registry participants with full-time jobs reported that they have missed more than one week of work due to health effects of sarcoidosis.



Use of FSR Registry Data: **RESPIRATORY MEDICINE**

A 2021 paper using FSR Registry data, led by researchers at the University of Florida – Gainesville, an FSR-GSCA Founding member, explored how sarcoidosis affects Hispanic patients specifically. They found that **employment was a particular challenge**, with Hispanic patients reporting 1.7 times higher odds of job loss due to sarcoidosis and greater financial strain on families.^{xxi} **Research like this helps shine a light on the unique challenges faced by Hispanic patients and encourages more studies focused on understudied groups or people with rare symptoms.**



FUTURE RESEARCH QUESTIONS

- ▶ What kind of symptoms were most likely to lead to job loss?
- ▶ Are there differences observed by gender, race, or type of organ involvement?

Quality of Life Impact *(cont.)*

Through Legislative and Educational Efforts, FSR Secured Job Protections for Any American Living with Chronic Illness

Through the *IgnoreNoMore* initiative, FSR revealed a significant barrier to patients participating in clinical trials. This survey revealed that fear of job loss and the risk of losing pay, job assignments, promotions, training, and access to fringe benefits (such as leave and health insurance) were primary concerns. In an effort to address this barrier, FSR wrote a letter to the Department of Labor seeking clarification about the FMLA.

On November 8, 2024 FSR received a letter of clarification from the Department of Labor that ensures employees who wish to participate in clinical trials and family caregivers who support them have access to Family Medical Leave benefits when participating in clinical trials under the Family Medical Leave Act ensuring that all patients impacted by chronic disease do not need to fear for their jobs when pursuing clinical trials.^{xxii}

To learn more, visit: www.stopsarcoidosis.org/fmla/

Fear of flare

How fear affects life experiences

In 2019, a sarcoidosis patient and advocate wrote about her experience with fear of flare-up in a blog for FSR. The patient shared that this fear is ever-present because a flare can mean emergency room visits or long hospital stays, disrupting both daily life and travel plans. The patient worried about what might happen if a flare occurred while away from home. To cope, she and her husband made contingency plans for potential medical emergencies during trips.^{xxiii}



FUTURE RESEARCH QUESTIONS

- ▶ How can clinical trials be designed to protect patients from fear of flare-ups?
- ▶ What sarcoidosis manifestation (organ involvement) is more likely to experience a flare-up?



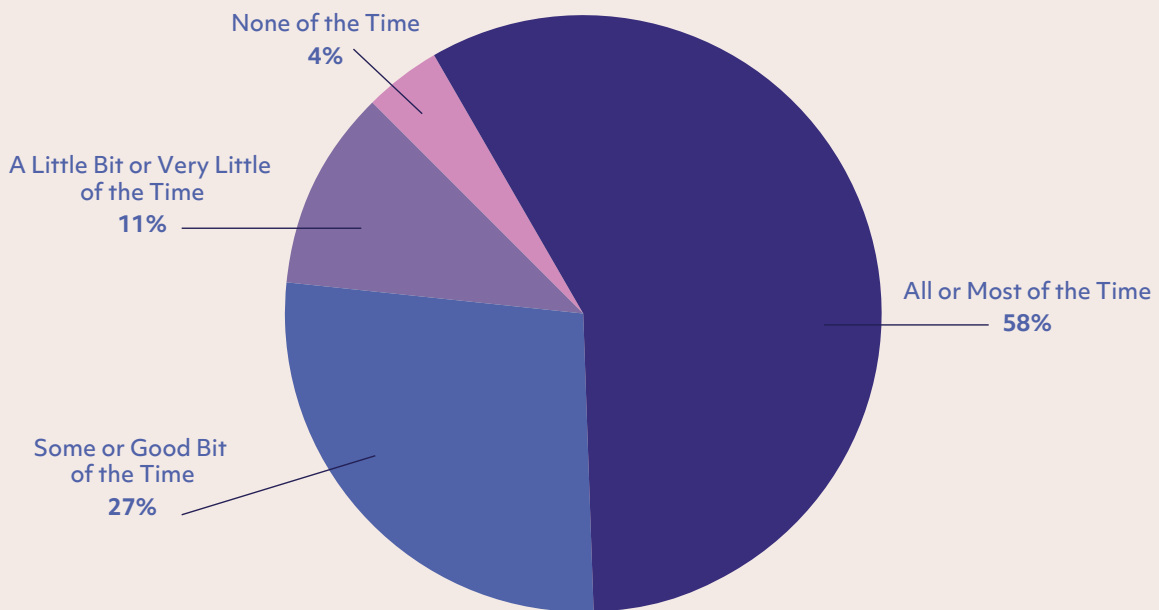
More figures and insights on quality of life available on the website

www.stopsarcoidosis.org/registry_report

97% of participants spend their time worrying about their next flare-up with over half of them worrying most or all the time.

Number of participants = 4,398

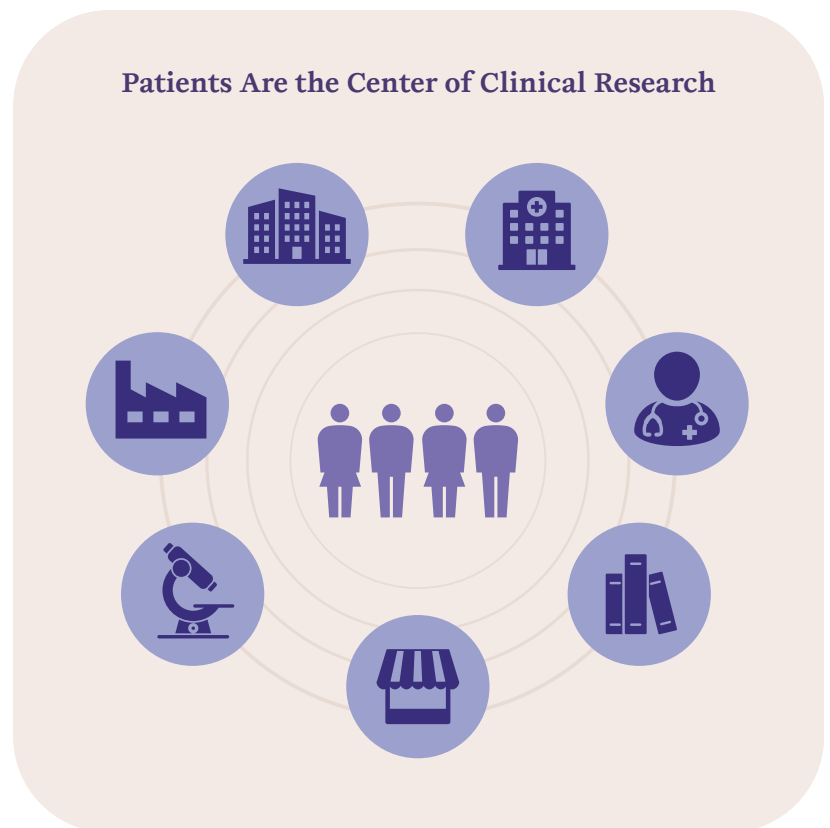
How often do you worry about your next flare-up?



FSR Registry Participant Impact on Clinical Research Success

Patients are at the center of clinical research and especially clinical trials. The lived experiences and perspectives of those with sarcoidosis not only lead to new research studies but also inform the design and implementation of future clinical trials. By participating in the FSR Registry, patients and caregivers are truly lifting their voice to accelerate sarcoidosis research and reach major milestones in real-time, bringing us ever closer to a cure for sarcoidosis.

As a rare disease, and due to many known barriers, it is challenging to reach full enrollment for sarcoidosis clinical trials. It is important as a community to collaborate in overcoming these barriers and ensuring that all patients have access to and are aware of sarcoidosis clinical trial opportunities.



FSR Registry Outreach Strategies

Step 1



Step 2



Step 3

New Partnered Study Available

Participants Matched with Research Opportunities

Matched By Location and/or Study Criteria

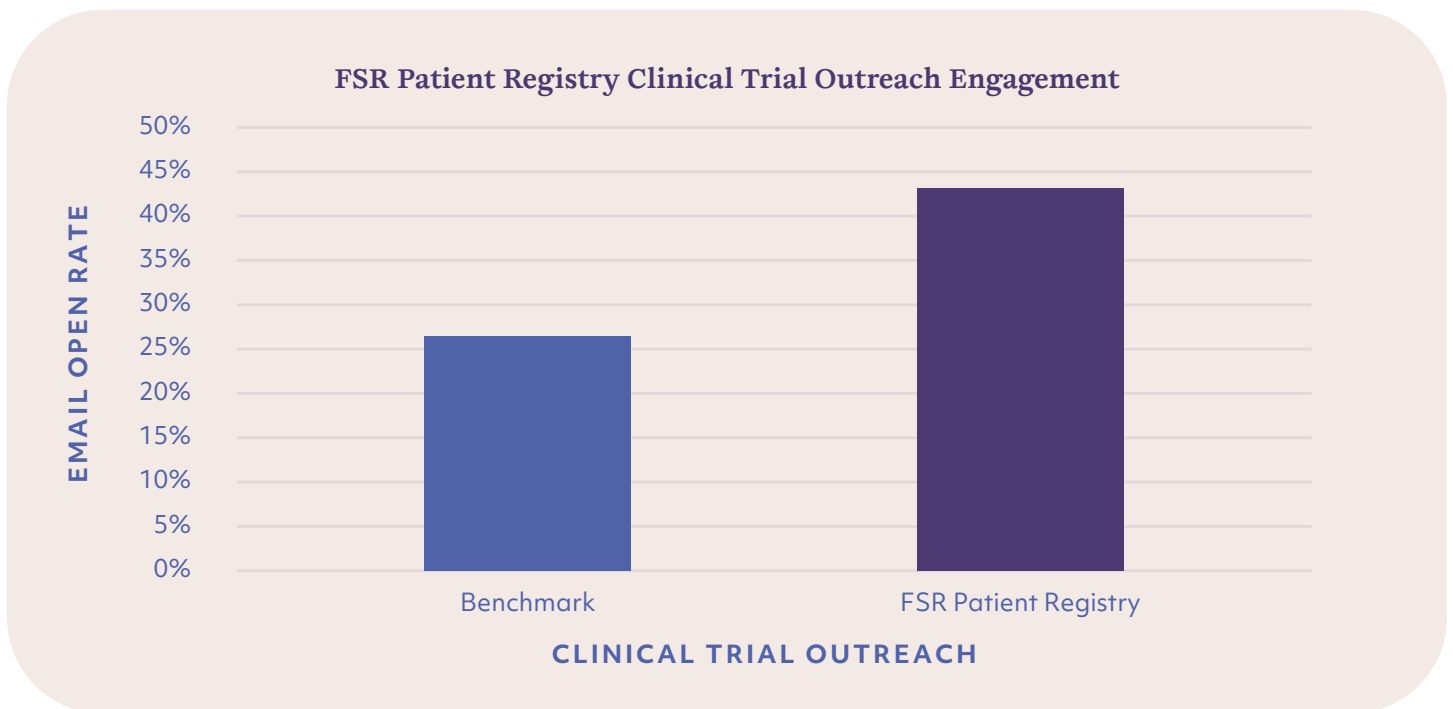
Participants Receive Email About Study Opportunity

FSR Registry participants show remarkable engagement with clinical trial email alerts at 44% exceeding the known comparative benchmarks for clinical trial outreach of 27%.^{xxii}



FSR has found that the FSR Registry allows for focused, targeted study recruitment, which in turn helps partnered clinical trials successfully enroll in their studies more quickly.

Update your Annual Update Survey to let us know if you've joined a study or clinical trial since signing up at www.stopsarcoidosis.org/registry_report.



As of July 2025, FSR Registry participants' engagement in sarcoidosis clinical trials has contributed to the successful enrollment of five separate industry-sponsored clinical research studies within the last five years. In an abstract presented at the 2024 National Organization for Rare Disorders (NORD) Conference, FSR found that its partnered clinical trials in sarcoidosis completed enrollment sooner than the average rare disease trial duration. This not only saves time, but also contributes to notable cost savings, as clinical trials are often expensive to conduct. These factors underline the important role that FSR and the patient community play in contributing to the success of sarcoidosis research.

The impact of patient participation in clinical trials is central to advancing research and achieving new treatments for sarcoidosis. Actively enrolling partnered clinical trials are updated frequently on the FSR website at www.stopsarcoidosis.org/participate-in-a-clinical-trial/ and by signing up for the FSR Registry, you will receive email updates when an active clinical trial or research study might be of interest to you.

Make a difference and participate in sarcoidosis research today!

Conclusion & Next Steps

The FSR Registry contains a wealth of knowledge about the lived experience of patients that isn't available anywhere else. FSR is grateful to see the impact of the program so far and to continue to collect crucial insights.



Individuals with sarcoidosis

Join our mission to advance sarcoidosis research by signing up for the FSR Registry today. We invite you to share this report with anyone you think would be interested in learning more about FSR's mission and impact.



Clinicians treating patients with sarcoidosis

Invite your patients to help us better understand their lived experience with sarcoidosis by encouraging them to participate in the registry.



Sarcoidosis researchers

The FSR Registry is a powerful recruitment tool as well as a rich resource for patient-reported data on sarcoidosis. Contact the FSR team today to learn about opportunities to collaborate (Registry@stopssarcoidosis.org).



Thanks & Acknowledgements

The Foundation for Sarcoidosis Research extends its deepest gratitude to all the patients and families who generously contributed their time and experiences to the FSR Registry. Your participation is invaluable and forms the cornerstone of our efforts to advance understanding and improve care for those affected by sarcoidosis.

We also thank the Scientific Advisory Board, Patient Advisory Committee, the FSR Registry Co-Chairs (Dr. Leslie Serchuck and Dr. Logan Harper), and other advisors whose feedback was invaluable in the development of the FSR-SARC Patient Registry.

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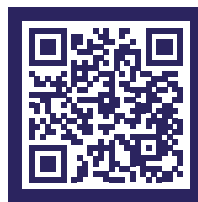
Figure Permissions

To request use of charts and data provided in this report, contact the FSR Registry team at Registry@stopsarcoidosis.org

To learn more about the Foundation for Sarcoidosis Research (FSR) and the FSR-SARC Patient Registry, please visit www.stopsarcoidosis.org/registry

Contact us

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References and citations
www.stopsarcoidosis.org/registry_report

Endnotes

- ⁱ African American Women & Sarcoidosis. (2022, October 18). Foundation for Sarcoidosis Research. Retrieved May 10, 2025. <https://www.stopsarcoidosis.org/aaws-campaign/>
- ⁱⁱ Ignore No More: ACTe Now! Campaign. (2024, March 19). Foundation for Sarcoidosis Research. Retrieved June 19, 2025. <https://www.stopsarcoidosis.org/actnow/>
- ⁱⁱⁱ How Sarcoidosis is Diagnosed. (n.d.). Foundation for Sarcoidosis Research. Retrieved May 10, 2025. <https://www.stopsarcoidosis.org/what-is-sarcoidosis/diagnosis/>
- ^{iv} Organs Affected by Sarcoidosis. (n.d.). Foundation for Sarcoidosis Research. Retrieved May 10, 2025. <https://www.stopsarcoidosis.org/what-is-sarcoidosis/organs-involved/>
- ^v D103. TRANSPLANT AND ILD POTPOURRI [Review of D103. TRANSPLANT AND ILD POTPOURRI]. Atsjournals.org. Retrieved May 16, 2025. https://www.atsjournals.org/doi/epdf/10.1164/ajrccm-conference.2018.197.1_MeetingAbstracts.A7482?role=tab
- ^{vi} Organs Affected by Sarcoidosis. (n.d.). Foundation for Sarcoidosis Research. Retrieved May 10, 2025. <https://www.stopsarcoidosis.org/what-is-sarcoidosis/organs-involved/>
- ^{vii} Sarcoidosis of the Skin (Cutaneous Sarcoidosis). (2024, August 13). Foundation for Sarcoidosis Research. Retrieved May 10, 2025. <https://www.stopsarcoidosis.org/skin-sarcoidosis/>
- ^{viii} D103. TRANSPLANT AND ILD POTPOURRI [Review of D103. TRANSPLANT AND ILD POTPOURRI]. Atsjournals.org. Retrieved May 16, 2025. https://www.atsjournals.org/doi/epdf/10.1164/ajrccm-conference.2018.197.1_MeetingAbstracts.A7482?role=tab
- ^{ix} Thillai, M., Courtier, D., Willard, J., Bhargava, M., Baughman, R. P., Gupta, N., Cattran, A. M., Hamzeh, N. Y., James, W. E., Judson, M. A., Maier, L., Raghu, G., Sporn, P. H. S., Sweiss, N., Veltkamp, M., William, L., Stoneman, V., Legenzoff, T., Hoover, E., & Shivas, T. (2025). Risk Factors Associated With Cardiac Sarcoidosis: Analysis of 499 Patients From the Multicentre Papland Study. *American Journal of Respiratory and Critical Care Medicine*, 211(Abstracts), A3520–A3520. <https://doi.org/10.1164/ajrccm.2025.211.abstracts.a3520>
- ^x Yazan Al-Zamer, Sami Al-Horani, Marah Akhdar, Ghaydah Majali, Hamza Alzghoul, Younis, M., Pouya Ameli, & Bashar Alzghoul. (2024). Central Nervous System Sarcoidosis: A National-Based Registry study. *PubMed*, 41(3), e2024040–e2024040. Retrieved April 15, 2025. <https://doi.org/10.36141/svldl.v41i3.15103>
- ^{xi} Complications. (2025, June 16). Foundation for Sarcoidosis Research. Retrieved June 1, 2025. <https://www.stopsarcoidosis.org/what-is-sarcoidosis/complications/>
- ^{xii} Alzghoul, B. N., Zayed, Y., Obeidat, A., Alzghoul, B., Naser, A., Shilbayeh, A.-R., Innabi, A., Al-Hakim, T., Buchanan, M., Mehrad, B., & Patel, D. C. (2021). Clinical Characteristics of Sarcoidosis Patients with Self-Reported Lymphoma: A US Nationwide Registry Study. *Lung*, 199(6), 611–618. Retrieved May 1, 2025. <https://doi.org/10.1007/s00408-021-00485-z>

- ^{xiii} Amer, F., Alzghoul, B. N., Jaber, J. F., Ali, A., Kalra, S. S., Innabi, A., Alzghoul, B., Ghaith, S., Al-Hakim, T., Gomez, D. M., Barb, D., Woodmansee, W. W., & Patel, D. C. (2022). Prevalence and Characteristics of Hyperthyroidism Among Patients With Sarcoidosis in the United States. *Endocrine Practice*, 28(7), 654–659. Retrieved May 1, 2025. <https://doi.org/10.1016/j.eprac.2022.03.017>
- ^{xiv} Sarcoidosis Treatment Options - Foundation for Sarcoidosis Research. (2016). Foundation for Sarcoidosis Research. Retrieved June 1, 2025. <https://www.stopsarcoidosis.org/what-is-sarcoidosis/treatment-options/>
- ^{xv} (n.d.). A103. ILD: OUTCOMES [Review of A103. ILD: OUTCOMES]. *Atsjournals.org*. Retrieved June 23, 2025. https://www.atsjournals.org/doi/abs/10.1164/ajrccm-conference.2018.197.1_MeetingAbstracts.A2540
- ^{xvi} Hudson, M. (2020, May 16). Self-Care for Sarcoidosis Warriors. Foundation for Sarcoidosis Research. Retrieved May 17, 2025. <https://www.stopsarcoidosis.org/mental-health-awareness/>
- ^{xvii} FSR Externally-Led Patient Focused Drug Development Meeting (EL-PFDD). (2024, December 3). Foundation for Sarcoidosis Research. Retrieved May 22, 2025. <https://www.stopsarcoidosis.org/pfdd/>
- ^{xviii} Legenzoff, T., Crouser, E., Harper, L., Serchuck, L., McGowan, M., Shivas, T., Hoover, E. Understanding the patient burden of pain and symptoms in sarcoidosis: learnings from the Foundation for Sarcoidosis Research (FSR) Patient Registry. Presented at: WASOG/AASOG 2025 Conference; August 24-27, 2025; Ottawa, Canada. Accessed September 1, 2025. <https://event.fourwaves.com/wasog2025/abstracts/e0497442-a127-498e-b9b4-3b1cbc3d1aa1>
- ^{xix} Harper, L. J., Gerke, A. K., Wang, X.-F., Ribeiro Neto, M. L., Baughman, R. P., Beyer, K., Drent, M., Judson, M. A., Maier, L. A., Serchuck, L., Singh, N., & Culver, D. A. (2020). Income and Other Contributors to Poor Outcomes in U.S. Patients with Sarcoidosis. *American Journal of Respiratory and Critical Care Medicine*, 201(8), 955–964. Retrieved June 12, 2025. <https://doi.org/10.1164/rccm.201906-1250oc>
- ^{xx} Innabi, A., Alzghoul, B. N., Kalra, S., Al-Hakim, T., Buchanan, M., Shivas, T., Xue, W., Gomez-Manjarres, D., & Patel, D. C. (2021). Sarcoidosis among US Hispanics in a Nationwide Registry. *Respiratory Medicine*, 190, 106682. Retrieved May 23, 2025. <https://doi.org/10.1016/j.rmed.2021.106682>
- ^{xxi} Davis, C. (2024, November 18). FSR receives confirmation from the Department of Labor ensuring patient access to FMLA for participation in clinical trials. Foundation for Sarcoidosis Research. Retrieved 6/20/2025. <https://www.stopsarcoidosis.org/fsr-receives-confirmation-from-the-department-of-labor-ensuring-patient-access-to-fmla-for-participation-in-clinical-trials/>
- ^{xxii} Hudson, M. (2019, December 5). Traveling the World with Sarcoidosis. Foundation for Sarcoidosis Research. Retrieved June 3, 2025. <https://www.stopsarcoidosis.org/traveling-the-world-with-sarcoidosis>
- ^{xxiii} Jayasundara, K., Hollis, A., Krahn, M., Mamdani, M., Hoch, J. S., & Grootendorst, P. (2019). Estimating the clinical cost of drug development for orphan versus non-orphan drugs. *Orphanet Journal of Rare Diseases*, 14(1). <https://doi.org/10.1186/s13023-018-0990-4>



FSR created the Patient Registry to provide researchers with data directly from patients about their experience with sarcoidosis.



LEARN MORE HERE

www.stopsarcoidosis.org/registry_report

THE FSR REGISTRY IS A RESOURCE FOR:

- Real-world, patient-reported data
- Information on individuals with different organ involvement, treatment experiences, and stages of disease
- Understanding changes in patients' experience with sarcoidosis over time

This depth and scale of data has never been available before to those working to find a cure for sarcoidosis.