TOGETHER WE THRIVE

2021 MID-YEAR UPDATE

FSR

FOUNDATION FOR
SARCOIDOSIS RESEARCH

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FSR's Team

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FSR Scientific Advisory Board: Elliott Crouser, MD (Chair), Robert Baughman, MD, John Belperio, MD, Edward Chen, MD, Ulrich Costabel, MD, Seamas Donnelly, MD, Wonder Drake, MD, Marjolein Drent, MD, PhD, Andrew Fontenot, MD, Skip Garcia, MD, Ennis James, MD Craig Lipset, Lisa Maier, MD, MSPH, FCCP, Adam Morgenthau, MD, Ogugua Obi, MD, MPH, MSc, Misha Rosenbach, MD, Milton Rossman, MD, Barney Stern, MD, Dominique Valeyre, MD.

FSR Staff: Mary McGowan (Chief Executive Officer), Tricha Shivas (Vice President of Research and Strategic Partnerships), Angela Frelander (Director of Development), Mindy Buchanan (Director of Patient Programs), Tamara Al-Hakim (Research Manager), Cathi Davis (Communications Manager), Lesley Baxter (Outreach Coordinator), Nicholas Zeppos (Development and Finance Project Coordinator), Chase Hamilton (Research Project Coordinator), and Khaleelah Cohen (Consultant, Special Projects).

A Letter from FSR's Board President and CEO

Mary McGowan, CEO (left) and Dr. Louise Perkins, Board President (right)

Dear Friends of FSR,

Over the last 21 years, the Foundation for Sarcoidosis Research (FSR) has been the leading, international organization accelerating sarcoidosis research and providing education and support resources to the patient community. This report will share with you the ways in which your contributions have helped to advance the critical work being done in the sarcoidosis research space and helped us build essential patient education and support programs. As a dedicated member of our community, we invite you to learn about how your generosity ensured that we could achieve our goals and improve the lives of patients worldwide.

Although 2020 and 2021 have been difficult years, FSR's community has risen to the occasion and, now, we are even more dedicated and steadfast in our mission to find a cure and provide support for all people living with sarcoidosis.

FSR's robust research program is beginning to yield powerful results. For example, FSR-funded fellows have received NIH funding and there has been an increased interest from industry in exploring clinical trials. Over the last year, FSR has expanded our support and engagement programs, through increased educational opportunities, advanced training of volunteers, expert-led wellness programs, and social events that aim to bring the community together. With your dedication and support, FSR is making great strides in raising awareness and understanding of this complex disease. We are proud of our passionate network of collaborations with researchers, medical experts, regulators, legislators, and partner organizations in support of goals.

While significant progress has been made, there are still considerable goals we want to achieve. Our fundamental belief is that the best pathway to success is by tapping into the passion and dedication of all impacted by sarcoidosis. With your support and commitment, we CAN and WILL ensure that no one living with sarcoidosis suffers alone. And with your support and dedication, we CAN and WILL advance towards a cure.

Yours in hope,

Louise and Mary

Louise M

Dr. Louise Perkins
President of the FSR Board of Directors

Mary E. McGowan

Mary McGowan
Chief Executive Officer

Thanks to the generous support of our donors and sponsors, FSR has invested over 5 million dollars in sarcoidosis research over the last 21 years and built a vigorous and diverse research program. FSR research funding is making an indelible mark on the field and has resulted in 29 publications in just this last year.

Fellowships

The FSR Fellowship Program is focused on building the pipeline of the next generation of sarcoidosis clinicians and researchers. FSR's fellowship program supports all aspects of the fellow's growth and understanding in the field. FSR fellows are trained in patient and disease management, diagnostic and therapeutic procedures, and in building, developing, and completing innovative research in sarcoidosis.

FSR's first class of fellows completed their projects in December of 2020, and already are showing great promise in the field. One of our fellows received NIH K Grant funding in 2021 in pulmonary fibrosis, which impacts many living with sarcoidosis. Another fellow is currently applying for NIH Grant funding in the sarcoidosis space. The two remaining 2020 graduating fellows are continuing their research in sarcoidosis, and actively participating in clinical trials.

In 2020, FSR funded a new fellow, Dr. Shu-Yi Liao, at National Jewish Health for his project titled, "An omics precision medicine approach to explore the susceptibility and phenotypes of sarcoidosis." Despite the additional challenges of COVID-19, Dr. Liao has already published multiple abstracts during the first year of his award and contributed to the ATS Clinical Practice Guidelines for the Diagnosis and Detection of Sarcoidosis.

In 2021, with the support of Mallinckrodt Pharmaceuticals, FSR awarded funding to Dr. Paula Barreras at Johns Hopkins University for her project titled "Discovering Pathogens in Neurosarcoidosis: Using Next Generation Immunological and Metagenomic Methods for Unbiased Pathogen Detection and Antimicrobial Antibody Profiling." This project will use data science and bioinformatics to gain deeper insight into causes of disease progression.

> *Speaking on behalf of myself and my fellowship class, we all benefitted immensely from the diverse array of mentorship and collaborative resources made available by the FSR in developing early career physician-scientists.*
>
> Dr. Changwan Ryu, Yale University – 2018-2020 FSR Fellow
> Mentored by Dr. Erica Herzog

Small Grants

Since their launch in 2018, FSR has invested $250,000 in Small Grant Awards. This year FSR is dedicating $50,000 to these projects, which are critical for researchers and the pursuit of innovative research.

In 2020, FSR awarded Dr. Umesh S. Deshmukh from Oklahoma Medical Research Foundation, $25,000 for his proposal, "Humanized Mouse Model", to be completed in 2021. Dr. Umesh worked with 2018 FSR Fellowship Awardee, Dr. Lori Garman, from Oklahoma Medical Research Foundation, and 2019 FSR small grant awardee, Dr. Wonder Drake, from Vanderbilt University, on a publication titled "Single Cell Transcriptomics Implicate Novel Monocyte and T Cell Immune Dysregulation in Sarcoidosis." His work has already resulted in two abstracts and offers the promise of even more important insights to advance the field.

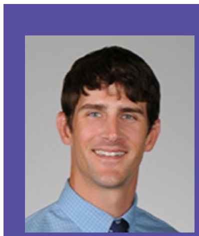
This year, FSR broadened our outreach to increase the quality and number of applications. In 2021, FSR received 11 applications for small grant funding, the highest number of small grant applications to date. These applications were reviewed by an External Review Committee and the Scientific Advisory Board, and approved by FSR's Board of Directors. FSR provided funding to two projects in 2021.

Clinical Studies Network

FSR's Clinical Studies Network (CSN) brings together an international consortium of world-renowned medical institutes and researchers for unprecedented collaboration in multi-site studies and drug trials in sarcoidosis research. The goals of the network are to decrease the time needed to advance drug development. With your generous support and funding from sponsors, FSR dedicated over $3 million for the Clinical Studies Network to ensure streamlined sarcoidosis clinical trials and collaboration among researchers to accelerate the advancement of the field.

FSR continues to enroll patients in the PAPLAND study to improve cardiac sarcoidosis screening and diagnosis. FSR, along with our 12 CSN sites, is working on upcoming manuscripts for submission based on current analysis for the upcoming 2022 American Thoracic Society Conference.

In 2021, FSR partnered with Mallinckrodt Pharmaceuticals to provide support for a cardiac sarcoidosis registry and biorepository through a project called PROMyS. Development of a biorepository and registry will enable a new generation of diagnostics and targeted therapies to improve clinical outcomes for cardiac sarcoidosis patients.



FSR's Clinical Studies Network is the first international effort focused on advancing sarcoidosis research. It provides a more efficient, collaborative platform to accelerate new studies evaluating novel diagnostic modalities and therapies that have already impacted our understanding and management of sarcoidosis.

Dr. W. Ennis James, Program Director, Susan Pearlstine Sarcoidosis Center of Excellence, Medical University of South Carolina (MUSC).

SARConnect Program

FSR's SARConnect program serves to bridge the gap between industry, clinicians, investigators, and patients. SARConnect helps to advance research in treatments, diagnostics, medical technology, and investigative studies by assisting with patient recruitment and ensuring the patient voice remains central to all aspects of sarcoidosis research.

By ensuring timely patient recruitment, FSR reduces the time it takes to conduct a trial, allowing for the possibility for faster trial completion and acceleration of treatment development. SARConnect also helps to decrease costs associated with clinical trials and patient recruitment.

In 2021, despite the barriers to research presented by COVID-19, through FSR's SARConnect program, in partnership with FSR's Clinical Studies Network, FSR helped aTyr Pharma with recruitment of their clinical trial for ATYR1923.

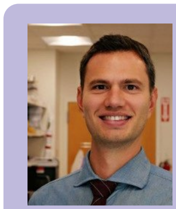
We are currently supporting two industry-supported trials and three academic studies.

Disease Model

The Chair of FSR's Scientific Advisory Board and FSR Grant Recipient, Dr. Elliott Crouser from Ohio State University notes, "The biggest hurdle towards developing new and more effective treatments for sarcoidosis is the lack of understanding of basic disease mechanisms to explain abnormal immune responses to environmental exposures leading to lung and other vital organ damage and related implications for reduced quality-of-life."

In 2017, with the support of a generous sponsor, FSR awarded $750,000 to five innovative projects designed to investigate possible disease models for sarcoidosis. In 2020, three of the five disease model awardees were selected for additional bridge funding totaling $300,000 in support. This bridge funding continues until the end of 2021 and aims to further develop, characterize, or improve the models and our understanding of the mechanism of sarcoidosis.

This funding has already yielded exciting advancements as our awardees are currently working with industry partners in testing potential therapeutics in preparation for potential clinical trials in the space. Dr. Elliott Crouser's model, which expands on his NIH-funded pilot project, has received particular attention and is now being further tested in clinical trials. As Crouser notes, "The new treatments arising from the FSR Model Grant project include existing drugs that are very safe, have few side effects, and can be rapidly repurposed for the treatment of sarcoidosis."



FSR has proven to be invaluable for identifying patients for our clinical trial. Their network of patients and experienced team conducting outreach has boosted our recruitment significantly. We are very grateful for the support of the FSR, which has enabled us to connect with patients and conduct our study efficiently, which we hope will ultimately positively serve the sarcoidosis community.

Dr. Matthew Baker, Clinical Chief in the Division of Immunology and Rheumatology at Stanford University.

Patient Registry

The FSR-SARC, FSR's patient registry, was created in 2015. Since this initial launch, the registry has grown to over 5,000 participants. Thanks to the support of our generous donors this registry is now fully funded through FSR.

The goal of the registry is to collect the patient experience of living with sarcoidosis in order to provide academic researchers and industry with a better understanding of how sarcoidosis impacts the patient's everyday life. The initial survey is comprised of 72 questions intended to capture information on patient demographics, medical history, familial history, organ-specific disease details, treatment history, and elements that indicate the burden of the disease on the patient's quality of life. In December 2020, FSR launched a "second visit questionnaire" to allow patients to update their information on their experiences on an annual basis.

One study that used the registry data explored how organ involvement was reported in the registry. The most common manifestation identified by participants across all races and genders was pulmonary sarcoidosis. Male participants report significantly higher incident of cardiac sarcoidosis than women. Women reported a significantly higher incidence of skin and eye involvement than men and African Americans had significantly higher incidents of skin and eye involvement than their white counterparts.[1]

Since the launch of the FSR Patient Registry, there have been 16 publications and abstracts, and over 5,000 patients have enrolled.

This registry helps to take us beyond understanding the manifestations and treatment options and allows us to dig deeper into how the disease is impacting patients' everyday lives. Despite the fact that 90% of registry participants were insured, nearly 45% reported that sarcoidosis has significantly impacted their family financially and over 30% of participants indicated that they had to quit their job as a result of their sarcoidosis diagnosis. In fact, as a result of this registry, it has been noted that socioeconomic factors play a significant role in more severe disease and increased mortality among those living with sarcoidosis.[2]

Although the FSR-SARC registry has already helped to drive and deepen our understanding of the day-to-day impact of living with sarcoidosis, we know there is still much more to learn and more voices and experiences important to capture. FSR believes that the voice of the patient is critical to progress towards better treatments and a cure for sarcoidosis. We are so grateful to all the registry participants, donors, and financial partners for making it possible for us to gather detailed information to help researchers better understand aspects of the disease from the patient perspective.

Sources: 1. A.K. Gerke, et. al. (2019) "Income and Other Contributors to Poor Outcomes in US Sarcoidosis Patients." and Critical Care Medicine.
2. FSR Patient Registry Report (2019)
www.stopsarcoidosis.org/wp-content/uploads/FSR_PatientREgistryReport_r7.3.pdf

Endpoints

Over the last two years, FSR convened world-leading experts in sarcoidosis to identify and standardize outcome measures for pulmonary sarcoidosis trials. Having clear, measureable endoints is essential to drug development because in order for clinical trials to receive FDA approval, researchers must be able to demonstrate clinical improvement. In order for these endpoints to be meaningful, there needs to be consensus among clinicians that they are useful to measure changes in sarcoidosis patients.

FSR completed a manuscript as a first attempt to elucidating these pulmonary endpoints. The manuscript has been accepted for publication in the next volume of Sarcoidosis Vasculitis and Diffuse Lung Disease. Next steps in this research will require further validation of these endpoints and identification of endpoints in other areas that impact those living with sarcoidosis.

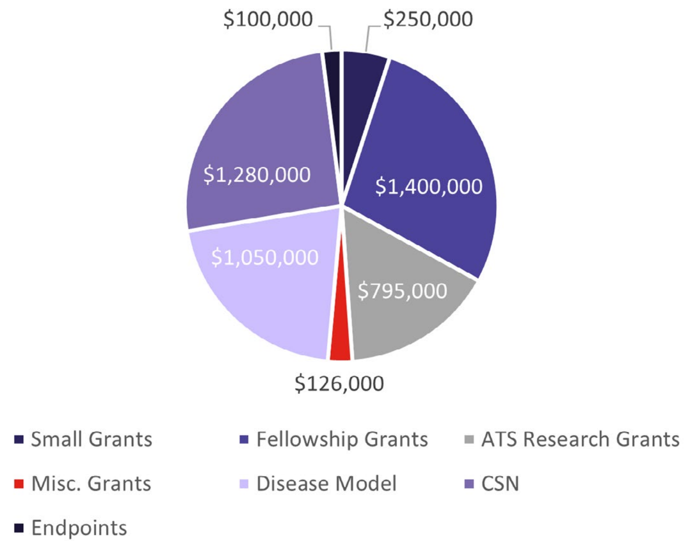
Clinical Engagement

As we move into the Fall, FSR will be expanding networking and learning opportunities for clinicians, nurses, clinical coordinators, and researchers. In early October, FSR will host our inaugural Clinical Engagement Conference to provide clinicians, researchers, and support staff with opportunities to workshop challenges that arise when treating sarcoidosis patients. We are grateful to our sponsors Boehringer Ingelheim and Xentria, Inc. for making this event possible.

Additionally, we will be launching a journal club which will help sarcoidosis clinicians and researchers to stay up-to-date and encourage open discussions about recently published articles.

These events, made possible by our sponsors and the generous support of our donors, aim to catalyze innovation and creativity in research. FSR is proud to support our dedicated clinical professionals and researchers as they network and learn.

FSR Funded Research Initiatives



WASOG Clinics and Centers of Excellence

The Foundation for Sarcoidosis Research is proud to support the WASOG Centers of Excellence, international, multidisciplinary clinics dedicated to providing state-of-the-art clinical support for those living with sarcoidosis. WASOG Centers of Excellence are recognized as comprehensive care centers with expertise in sarcoidosis.

As Dr. Divya Patel, Director of the University of Florida Sarcoidosis Center, notes, "WASOG Centers of Excellence allow us to feel confident that we are meeting benchmarks to ensure we provide the best care to our patients. They also help us to encourage specialists in many other fields at the institution to dedicate time to caring for sarcoidosis patients. WASOG Centers of Excellence allow patients to have access to multidisciplinary care that meets their needs, across multiple states and regions." These sarcoidosis centers are central to providing good care and support to patients.

As Jim Kuhn, Sarcoidosis Patient and FSR Patient Advocate and Navigator noted, from his first touch [at a WASOG Center of Excellence] he felt the profound benefit and relief to have all the high-level specialists all in one place. "Upon arrival at the Center, the check-in process was simple and friendly. I have to say that being seen by all the specialists, testing personnel, blood techs, etc., over a couple day period can be quite draining, but it was so well worth it. In those initial two days, I learned so much about my disease."

WASOG Centers of Excellence allow patients to have access to multidisciplinary care that meets their needs, across multiple states and regions.

Dr. Divya Patel, Director of the University of Florida Sarcoidosis Center

Corporate Advisory Committee

FSR has long relied on partnerships with industry to advance the field. In 2021, to build on this momentum, FSR formed the Corporate Advisory Committee (CAC). The CAC includes members who are dedicated to advancing initiatives and research for sarcoidosis and serves as a sounding board for FSR leadership.

The CAC provides the opportunity for open dialogue among industry partners in the sarcoidosis space to explore topics including research and drug development, access challenges for patients, and healthcare legislation. This committee represents a prestigious group of corporations committed to advancing initiatives and research for sarcoidosis and works collaboratively among the group and with FSR.

Thank you to the following partners who are the founding members of FSR's Corporate Advisory Committee!

Boehringer Ingelheim

Mallinckrodt Pharmaceuticals

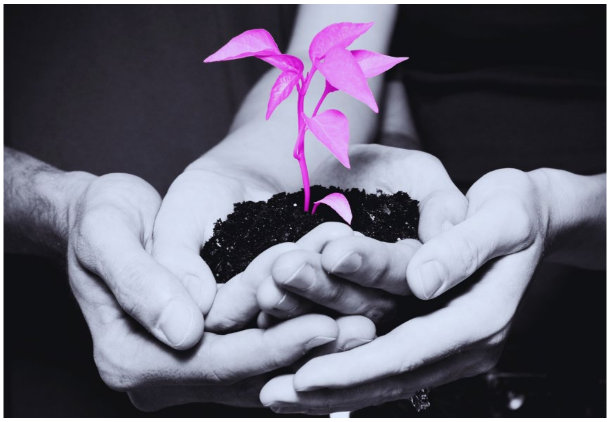
WE CAN’T DO IT WITHOUT YOU!

As you can see, FSR has accomplished a great deal to accelerate research in 2020 and 2021, but there is much more work to be done. We need support so we can fund research to encourage creative and innovative researchers into the field. We need more support to provide avenues of funding for pilot studies. We need more support to help us better understand the mechanisms and origin of sarcoidosis. We need more support to assist in development and validation of clinical endpoints. And, we need more support to grow our collaborative network of clinicians and researchers to ensure successful clinical trials and to help accelerate the development of new therapies. Finally, we need to expand our patient registry and patient engagement efforts to ensure that all research is centered around patients needs and desires. All that we have accomplished is because of our generous donors and volunteers. **Please consider a donation** to help us build on this momentum to continue our efforts towards better treatment and a cure.

Thriving Together through Education and Wellness

FSR's COVID-19 Education

COVID-19 is an ever-evolving challenge and FSR has made it a top priority to ensure the community stays up to date on research, vaccines, and treatments. FSR has created and posted critical educational materials to help our community better understand and navigate these new challenges resulting from COVID-19. FSR created a web page dedicated to COVID-19-related resources, including tips from the CDC, information from a survey of our community on vaccines and vaccine hesitancy, a vaccine guideline, and educational webinars and Q&A sessions with leading sarcoidosis experts, Dr. Divya Patel, Dr. Peter Sporn, Dr. Matt Baker, Dr. Wonder Drake and Dr. Marc Judson. These COVID-19 educational webinars have been viewed over 33,000 times. These webinars, along with other valuable resources, can be located on our COVID-19 web page.



In addition to helping to address the technical questions raised by our community to better understand COVID-19, FSR has put a focus on providing resources to support the mental health needs of our community as we have dealt with isolation and uncertainty. In response to this need, FSR developed a mental health series including meditation, QiGong, and a lecture series by mental health experts on how to cope with uncertainty and change.

FSR Education & Awareness

Webinars 2021

24 webinars, networking events, and town halls hosted by FSR in 2021

760 people attended live in 2021

4,600 views of recorded webinars in 2021

In response to patient feedback and surveys, FSR has designed a comprehensive education and support program to better meet the needs of the sarcoidosis community. In February, National Heart Month, FSR hosted two webinars with expert leaders from Yale and Stanford to provide the most up-to-date information on clinical best practices and research in cardiac sarcoidosis. In April, FSR hosted, *Steroids and Sarcoidosis Town Hall*, in partnership with aTyr Pharma. This panel discussion delved into the impact and risks associated with steroid therapy and the needs for more emphasis on steroid sparing agents. FSR has also hosted education programs to address common sarcoidosis symptoms like fatigue and chronic pain.

> *I want to say how grateful I am for this program! ...I am astounded how my type A+ personality drifts into meditation without hesitation. My lungs even work better as a result! It is a wonderful, peaceful time for me and influences the rest of my day in a positive manner! Quite simply, WOW!*
>
> Wendy, Mindfulness & Meditation Participant

2021 Virtual Patient Summit

This year, FSR took our Virtual Patient Education Summit to a whole new level with an innovative program and online platform. The summit had 273 patient attendees and their loved ones representing seven different countries. Our summit provided outstanding content with leading experts in sarcoidosis research and treatment. Whether newly diagnosed, or a patient expert, the program met patients wherever they are on their sarcoidosis journey.

273

Total people who attended the summit

52

Expert speakers

Through our three different educational tracks, we provided content for patients at all levels. Plenary sessions covered important and broad topics, including a 50-minute Q&A with a panel of leading experts from diverse specialties.

In response to our community's desire for more networking, we sought a more comprehensive and user-friendly platform that allowed for video chats, chat board discussions and made connections with participants by matching up their interests. Through these advanced networking tools, attendees made over 700 individual connections generating over 2,500 direct messages, and over 450 discussions!

> *In 18 years, this is the first time I have received such comprehensive information. Thank you. Excellent summit!*
>
> Summit Attendee

FSR's Patient Advocates also played a pivotal role in bringing the community together during the summit by serving as greeters and connectors, virtually welcoming and initiating conversations. Advocates also hosted FSR's virtual "coffee break," which allowed for social gathering throughout our entire summit. Patient Advocates managed 12 chat boards covering both manifestation-specific topics to living with the disease, research, and supporting someone with sarcoidosis.

Following the summit, FSR surveyed attendees and 90% reported that they felt they learned valuable information and 93% felt they learned something new. Additionally, 100% of attendees noted the agenda covered topics of interest to them.

The 2021 Virtual Patient Education Summit – *Together We Thrive* was made possible by our generous corporate and Center of Excellence sponsors: aTyr Pharma, Boehringer Ingelheim, Mallinckrodt Pharmaceuticals, Xentria, Inc., Medical University of South Carolina, Susan Pearlstine, Sarcoidosis Center of Excellence University of Alabama–Birmingham and Virginia Commonwealth University.

15

Exhibitor booths

90%

Said they learned new and valuable information

Patient Advocates and Navigators

Our Patient Advocates, our volunteers, are the heart of FSR. At 95 strong, our volunteer Patient Advocates hail from all over the United States, as well as Europe and Canada. Thanks in part to sponsorship by Mallinckrodt Pharmaceuticals and the EveryLife Foundation for Rare Diseases, FSR's Patient Advocates are specially trained to share their stories, support others, and raise awareness in their communities. FSR staff provide year-round support through education programs, one-on-one training, and materials to empower our Patient Advocates to raise awareness and funds for research and support programs in their local communities and to assist others as they navigate through their sarcoidosis journey.

In order to ensure our advocates were adequately prepared for the changes in social interactions brought on by COVID-19, FSR provided advanced training in navigating meet-up technology and discussions on how to interact effectively with others in an online environment.

Our Advocates also support the sarcoidosis community by:

- Supporting patients on FSR's Inspire Network, StopSarcoidosis
- Managing and provide guidance on social media groups
- Sharing their story via publishing an op-ed, being a podcast guest, or speaking at an event or conference
- Hosting virtual support groups
- Lead ing fundraisers
- Attending virtual health fairs/events
- Participating in civic engagement, such as Rare Disease Week on Capitol Hill

Our Navigators have helped patients in the United States, Canada, New Zealand, and South Africa!

Having someone to bounce thoughts and symptoms off of has made it bearable. Sometimes I have felt very alone and now I feel I have support that understands.

Patient Navigatee

Our Patient Advocates have hosted 12 SarcSocials this year. SarcSocials are live virtual community-building, support, and networking events focusing on topics like resilience, legislative outreach, and disease management. Each SarcSocial concentrates on a relevant topic or theme meant to ignite lively and supportive conversations. Advocates also share insights on the lived experience of sarcoidosis.

FSR's Patient Navigator program provides emotional and educational support to those in need. Navigators and Navigatees are paired up for 45 days of direct one-on-one assistance. Patient Navigators complete a special three-day training to aid them in their support of other patients. Our Patient Navigators are there for patients when they feel most alone, confused about resources available, feel like they are not being heard or understood by their physician or family, and are desiring the connection to someone who has the shared experience of living with the burden of a rare and chronic illness. As Jim, one of FSR's Patient Navigators notes, "The first thing I tell new patients is, 'the pain and symptoms you're experiencing are for real' and the second thing I tell them is, 'you're not alone.'"

FSR Speakers Bureau

Stories help us make sense of our lives, our place in the world, and in many cases the journey with chronic illness. To help address these needs, FSR launched our inaugural Patient Speakers Bureau this year. Fourteen Patient Advocates and members of our Patient Advisory Committee took pen to paper in crafting their stories to increase awareness, educate providers, empower their peers, and increase research in sarcoidosis. Patients sharing their lived experience is a valuable way to explain the burden of this disease, identify barriers to research, education, or even alert someone to their potential risk for sarcoidosis. Telling a story is not the same as crafting a story, and over our four training sessions, sponsored by Mallinckrodt Pharmaceuticals and provided by Living Proof Advocacy, our Patient Speakers Bureau members identified moments important to them and created impactful stories for their audiences. The Speakers Bureau Members shared their storytelling skills as part of FSR's Virtual Summit.

Our Speakers Bureau members have been featured on national television programs, published in newspapers including the Washington Post and Huffington Post, spoken at national conferences, and have helped drive policy changes.

The FSR Speakers Bureau members are Cheryl Bradford, Brandi Cleaver, Garrie Farrow, Yvonne Holt James, Jim Kuhn, Mary Morlino, Michael Patterson, Jessica Reid, Tara Sims, Rebecca Stanfel, Sammy Suriani, Rhonda Underhill, Della Washington and Leanne West.

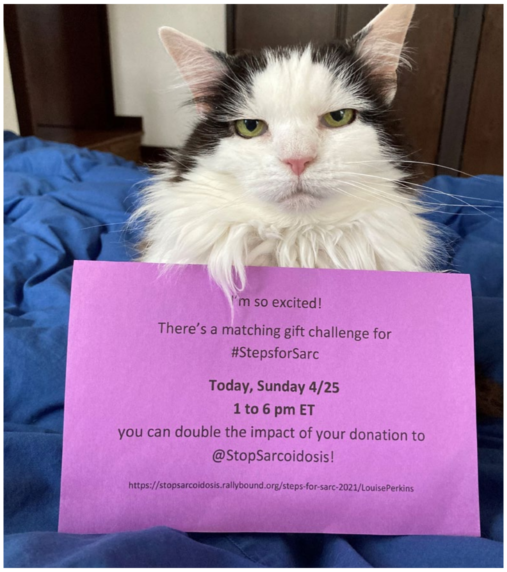
> *FANTASTIC! I want to learn how to tell stories like that! Every single speaker is a new hero for me!*
>
> Summit Attendee

Sarcoidosis Awareness Month

Increasing awareness for sarcoidosis is a critical part of FSR's advocacy. Engaging patients, physicians and legislators leads to improved care and research funding.

This April's Sarcoidosis Awareness Month was a tremendous opportunity to mobilize the sarcoidosis community through online educational programming, fundraising events, and social media activities. With your support and the support from our generous sponsors, April 2021 Sarcoidosis Awareness Month was a great success!

For Sarcoidosis Awareness Month, FSR created a unique webpage where people could learn more about sarcoidosis, find support, and access educational resources and awareness toolkits with social media graphics to download and post on their accounts. With your help, we were able to reach well over 155,000 people online to help raise awareness for sarcoidosis!



Beyond the generosity of our community through their personal donations, sarcoidosis warriors worldwide have come together to raise awareness and expand fundraising opportunities for sarcoidosis through the FSR Team KISS program. KISS stands for Kick In to Stop Sarcoidosis and since it began, that is what patients, caregivers, and supporters have been doing.

Sarcoidosis Awareness Month

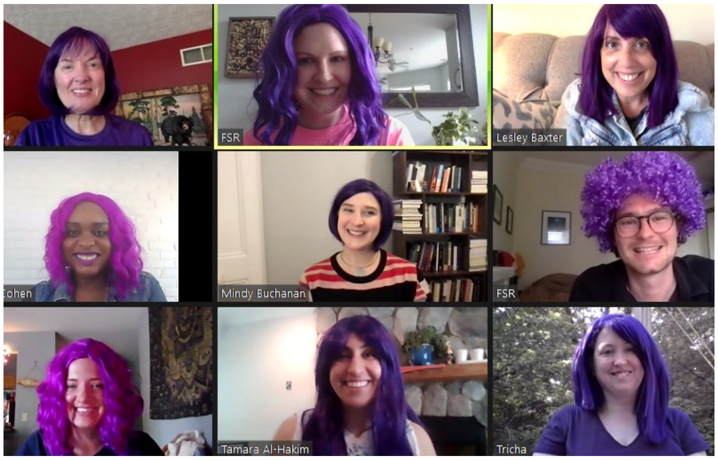
Continued

To continue building FSR's fundraising and to celebrate April's Sarcoidosis Awareness Month, FSR hosted the first-ever community-wide virtual Team KISS campaign, Steps for Sarc.

Thanks to your generosity, we more than doubled our goal - over $57,000 was raised for the campaign, over 15 MILLION steps were completed and together we helped unite sarcoidosis warriors from around the world. Steps for Sarc participants together walked the distance from Chicago, IL to China. This remarkable success is because of you and for that we are incredibly grateful. All the donations made to FSR raised through Steps for Sarc will help continue to support FSR's research agenda, groundbreaking sarcoidosis research projects, as well as FSR's comprehensive patient education and resource programs.

A big thank you to all who participated in 2021. If you weren't able to join this year, we hope you will be able to join in the future. This project really shows that together we can make a huge difference.

We are so grateful to our donors and sponsors, Boehringer Ingelheim and Mallinckrodt Pharmaceuticals, for helping make these awareness efforts possible! Even now, you can help keep the conversation going all year long and get involved in educating people about sarcoidosis and raising funds for the mission. Visit our website to learn how!



> *Awareness is one of our biggest battles! Even many members of the medical community don't know or don't think about sarcoidosis. In order to have an eventual cure, it's important that we keep sarcoidosis on everyone's radar. Hopefully then, us patients will be able to have a fighting chance at beating the disease!*
>
> John C., FSR Patient Advocate

African American Women & Sarcoidosis Campaign

FSR is excited to be launching a one-of-a-kind campaign focused on African American women and sarcoidosis this year. African American women experience the highest incidence of sarcoidosis in the US compared to any other group. They are more likely to experience chronic and severe symptoms and higher hospitalization rates than Caucasians and more than double that of African-American men. Additionally, their sarcoidosis-related mortality rate is 12 times higher than that of Caucasians and 1.5 times higher than that of African-American men. Thanks to the generous support of our sponsors, Global Genes and Mallinckrodt Pharmaceuticals, FSR has an opportunity to address these disparities.

FSR developed a Women of Color Patient Advisory Committee, composed of 15 African American women from across the US, both sarcoidosis patients and care partners. These women will be at the forefront of this critical initiative, empowered to tell their own stories on the public stage.

2021 Women of Color Patient Committee Members are: Cheryl Bradford, Erica Courtenay-Mann, Garrie Farrow, Jonette Harper, Brenda Harris, Marsha Henderson, Gloria McDaniel, Mary Oldham, Chasta Posey, Jessica Propps, Jessica Reid, Ora Riley, C. Ann Scott, Rhonda Underhill, and Kathryn Washington.

Using their lived experiences and armed with the tools and education provided by FSR, this committee will be essential in creating and disseminating educational materials and messaging that resonate with African Americans.

FSR felt the creation of a Women of Color Clinical Advisory Committee (WOC CAC) was essential to ensure a clinical perspective is included in the planning and execution of this campaign. The WOC CAC is comprised of four practicing clinicians and an epidemiologist to bring a wealth of clinical experience and rich data specific to African American Women and sarcoidosis. On this esteemed committee are: Divya Patel, DO of University of Florida Department of Medicine; Ogugua Obi, MD, MPH, MSc of East Carolina University; Yvette Cozier, DSc of Boston University; and W. Ennis James, MD of Medical University of South Carolina.

FSR will partner with numerous health and community-based organizations and clinical centers to produce various awareness activities beginning this Fall. In February 2022, Black History Month, we will celebrate by launching a month-long social media campaign. Join our community to stay informed.

Sources: Mirsaeidi, M., Machado, R. F., Schraufnagel, D., Sweiss, N. J., & Baughman, R. P. (2015). Racial difference in sarcoidosis mortality in the United States. Chest, 147(2), 438–449. Hena, K. M. (2020). Sarcoidosis Epidemiology: Race Matters. Frontiers in immunology, 11. Foreman, M. G., Mannino, D. M., Kamugisha, L., & Westney, G. E. (2006). Hospitalization for patients with sarcoidosis: 1979-2000. Sarcoidosis, vasculitis, and diffuse lung diseases: official journal of WASOG, 23(2), 124-129.

Honoring Those We Lost

This year, FSR has launched a comprehensive program to ensure those who have lost loved ones to sarcoidosis never feel alone on their journey. During April's Sarcoidosis Awareness Month, FSR hosted a tribute event to celebrate the lives of those who have been impacted by sarcoidosis. At the event, our community paid tribute to those who are no longer with us as we had a candle lit to illuminate their spirit and memories shared together. Later this year, we will be honoring the lives lost in a special year-end tribute and will be hosting a webinar on November 10, 2021 to provide support to family and friends coping with grief and loss around the holidays.

We are so grateful to be a part of the journey for all impacted by sarcoidosis. Sarcoidosis can be a lonely disease.

Your support of our Patient Advocacy and Navigator Programs, FSR's education and wellness programs, and awareness and our tribute programs ensure that everyone facing this challenging disease knows there is a community to support them.

Please help us as we continue in our efforts to ensure that no one walks this path alone.

Patient Advisory Committee (PAC)

The FSR Patient Advisory Committee (PAC) was created to identify and fill gaps in the FSR patient community in relation to research projects and advancement, patient education, and communication. The PAC consists of a small group of dedicated patients and caregivers who volunteer their time to advance patient-centered sarcoidosis research and ensure the creation of patient-friendly educational material and messaging.

FSR's PAC has taken a leadership role in ensuring the patient voice is at the center of sarcoidosis research. PAC members have participated in patient focus groups with industry, reviewed research protocols and consent documents, and served as speakers for research-related events.

In addition to its role in helping to shape sarcoidosis research, FSR's PAC helps to improve FSR's patient-facing educational materials and communication. The committee provides thoughtful and timely feedback to ensure that messaging is clear, understandable and meaningful to the patient population.

FSR looks forward to continued involvement in research and the enhancement of our patient education materials through the insightful feedback of this committee.

FSR's PAC Mission Statement:

The mission of the Patient Advisory Committee is to strengthen and amplify the patient perspective & participation with FSR and with external stakeholders.

FSR's current Patient Advisory Committee members are: Susan Bassi, Theresa Govan, Garrie Farrow, John Carlin, Kevin McKean, Jim Kuhn, Leanne West, Michael Hamrell, Janet Mockovciak, Michael Patterson. And thank you to the former Patient Advisory Committee members: Heidi Junk, Dena Aruta, Elizabeth Duruz, Aretha Lyles, and Ronald Willis.

Click here to learn more.

Join Us - Get Involved!

As a 501(c)(3) organization our foundation relies on the generosity of our community. There are several ways you can support those living with sarcoidosis and become a leader in the community by using your voice and passion to create change!

- **Donate** – By making a financial contribution to FSR, you will be helping to grow and expand the programs and initiatives. Donate online at www.stopsarcoidosis.org or mail a check to: 1820 W. Webster Ave., Ste 304, Chicago, IL 60614.

- **Patient Registry** – If you or someone you know is living with sarcoidosis, we need them to join the FSR Patient Registry to better understand this disease and how it impacts patients' lives.

- **Advocate** – Help us raise awareness for sarcoidosis by using your passion to ignite change in your hometown! The FSR Advocacy Program has tools and resources for our community specifically on rare disease legislative advocacy. Connect with the National Organization for Rare Disorders (NORD) Rare Action Network and the EveryLife Foundation for Rare Diseases to learn how you can become involved in your state!

- **Legacy Society** – Support the fight to stop sarcoidosis for the generations to come by becoming a Legacy Society member. The Legacy Society ensures you can support innovative sarcoidosis research in the future as well as patient programs and education for our community.

To learn more about these programs contact FSR today by emailing us at info@stopsarcoidosis.org or by calling us at 312-341-0500.

Your involvement is critical – only together can we stop sarcoidosis!

FOUNDATION FOR
SARCOIDOSIS RESEARCH

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