



FOUNDATION FOR
SARCOIDOSIS RESEARCH

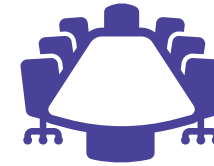
Year-end Gratitude Gathering
December 16, 2021



2021 Organization Updates and Highlights



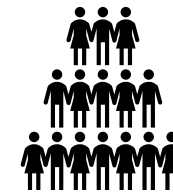
Board Diversification



**FSR Strategic
Planning**



**Research Program
Success**



**Patient Education and Support
Program Growth and
Expansion**

IGNORE NO MORE!

African American women have more severe and chronic forms of **sarcoidosis**, and higher rates of **hospitalization and mortality**.

AFRICAN AMERICAN WOMEN

3X are nearly **3x more likely** to develop sarcoidosis than white women and white men. They are also up to **2x more likely** to have the disease than African American men.

- Have more severe and chronic forms of sarcoidosis.
 - More chronic and severe forms of pulmonary sarcoidosis
 - More organ involvement outside of the lungs (lymph nodes, eyes, skin, liver)
 - More difficult to treat, advanced forms of sarcoidosis

Have a higher mortality rate than other groups.

- 13X** White Men & Women
- 1.5X** African American Men

Have the highest hospitalization rates compared to all groups.

- 2X** African American Men
- 10X** White Women
- 18X** White Men

ASK about the symptoms. **ENGAGE** in the treatment. **CONNECT** with your community.

SARCOIDOSIS is a rare disease characterized by the creation of tiny clumps of cells that cause inflammation in one or more organs of the body. When too many of these clumps form, they can interfere with an organ's function, leading to serious and sometimes fatal complications. Sarcoidosis affects roughly 200,000 Americans.



LEARN MORE
stopsarcoidosis.org/aaws-campaign/

Ignore No More: African American Women & Sarcoidosis Campaign

- Launched October 12, 2021
- Developed educational infographic for African American Women & Sarcoidosis
- 19 Partners (*and counting*)
 - 6 Centers of Excellence Clinics & Hospitals
 - 12 Community Organizations & Non-Profits
 - 1 Media Sponsor
- The campaign has had tremendous reach since its launch!



2,374 views



4,961 views



2,356 views



4,308 impressions



1,062 impressions



1,582 impressions



2,245 impressions



Ignore No More: African American Women & Sarcoidosis Campaign



- Women of Color Committee Members have been featured in:
 - Distinctive Discussion of Disparities and Diversity in Sarcoidosis
 - FSR Clinical Engagement Conference
 - #IgnoreNoMore Twitter Chat
 - SarcFighter Podcast
 - SarcNews
 - Balm in Gilead 's Annual Healthy Churches 2030 Conference
 - Black & Rare: Sarcoidosis in Black Women Webinar (Rare Disease Diversity Coalition/ Black Women's Health Imperative)
- Presentations & Expos:
 - Global Genes: *RARE Patient Advocacy Summit*
 - Black Health Matters: *Building the Bridge Summit*
 - NORD: *How to make Clinical Trials More Diverse and Equitable*
 - NIH/NIAMS: *Raising Awareness – Educating and Motivating the General Public*



Chan Zuckerberg Initiative Awardee- \$600,000

- Chan Zuckerberg Initiative – Rare As One Cycle 2
- Prominent award in rare disease space
- CZI empowers rare disease communities by providing resources, tools, network to be more effective advocates and partners in research
- **Grant awarded to 20 non-profit organizations, with over 200+ applicants**
- Award - **\$600,000 over 3 years, \$200,000 per year**
- Allows FSR to build program to support diversity and inclusion efforts
 - develop possible solutions to improve care and patient outcomes in African American patients, and share our findings with the healthcare community

Chan
Zuckerberg
Initiative 

aTyr Clinical Trial Success

- FSR partnered with aTyr on trial coordination and patient trial enrollment
- Clinical Studies Network sites participated
- Trial met primary endpoint, ATYR1923 was safe and well-tolerated
- Outcomes included steroid reduction (33% able to taper off completely), and observed improvements in forced vital capacity (FVC), cough and fatigue



Exciting Update in Sarcoidosis Research!!

FSR is thrilled to share that aTyr Pharma has announced positive results from their Phase1b/2a clinical trial for ATYR1923 in pulmonary sarcoidosis. FSR is proud to have supported this clinical trial

Clinical Engagement Conference: *Bridging the Gap to a Brighter Future*



Attendee Feedback:

"Thanks for organizing such a fantastic meeting. It was definitely one of the best virtual meetings I've been to since Covid started."

"Thanks for your great effort. It was a fantastic idea, and I hope that you will make this a recurring event."

"All of the breakout sessions I found really useful - much more intimate and applicable. Particularly with a topic as broad as sarcoid this is very valuable."

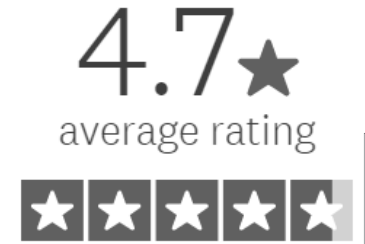


- **71 Attendees from 40 institutions**
- **28 Speakers**
- **95%** of physician track attendees and **100%** of ancillary track attendees state they'd be interested in attending a similar in the future.

Social Media Impressions:



Physician track



Ancillary track



#GivingTuesday

- Most impactful #GivingTuesday ever
- Over **\$100,000** raised for #GivingTuesday efforts
- This success will make more research and patient support programs possible

