FSR

FOUNDATION FOR
SARCOIDOSIS RESEARCH

# Q2 Board Update
July, 2021

# The FSR Team

**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

**Nicholas Zeppos**
Development and
Finance Project Coordinator

**Chase Hamilton**
Research Project Coordinator

**Lesley Baxter**
Outreach Coordinator

**Khaleelah Cohen**
Special Project Consultant

# Awareness Month

# Steroid and Sarcoidosis Townhall

- FSR Advocate, John Carlin, moderated session with panelists
  - Jessica Reid, FSR Advocate
  - Dr. Elliott Crouser, Chair of FSR's SAB
  - Dr. Sanjay Shukla, President and CEO of aTyr Pharma

- Event had **184** registered and event recording has had **397** views

- **100%** reported they found event valuable in post-event survey

# Sarcoidosis Awareness Month

- FSR held **8 educational, wellness, and social engagement events**
- **520+ people registered** for community events
- Over **1,000+ new members** joined the FSR Community in April
- Constituents reported in post-event survey that **information shared during Awareness month was helpful** –especially webinars

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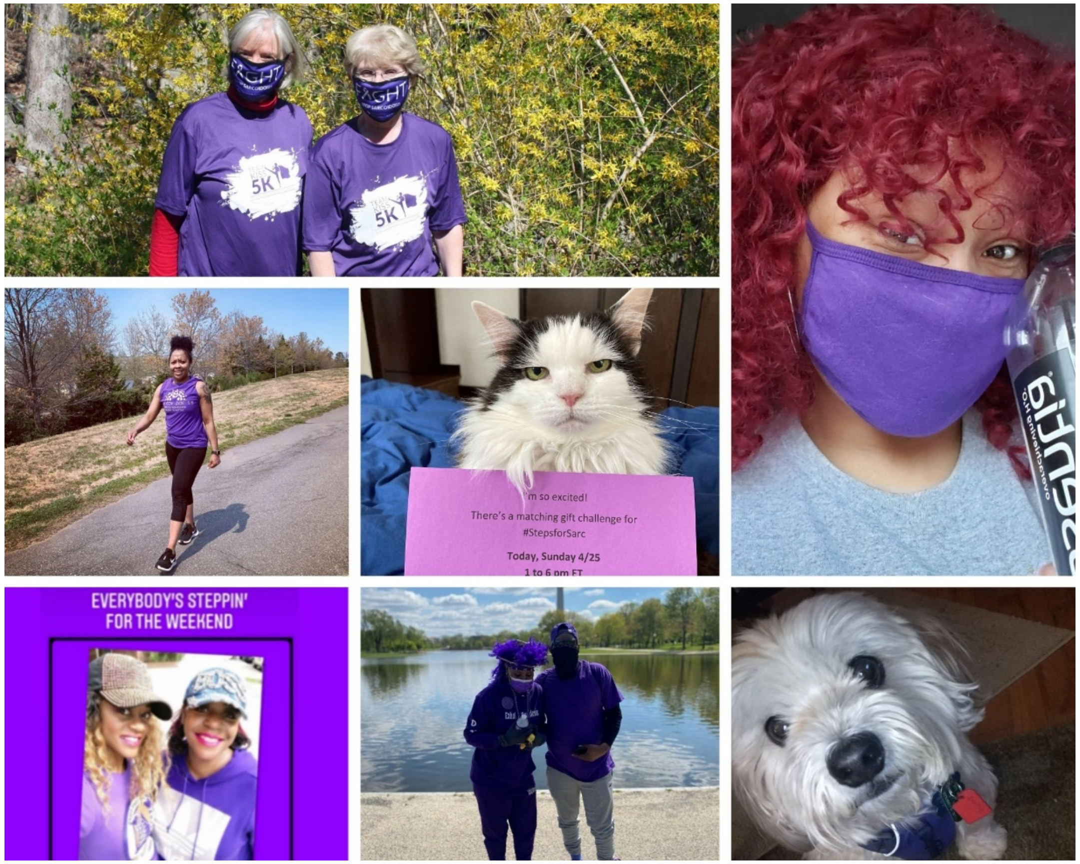
# Steps for Sarc

- **15+ MILLION steps** were completed
- DOUBLED our goal after over **$57,000+** was raised for the campaign
- **345 Participants joined**
- **54 Teams**
- FSR went international with participants joining from **Canada, United Kingdom, Australia, and Trinidad and Tobago**



# Sarcoidosis Awareness Month Outreach

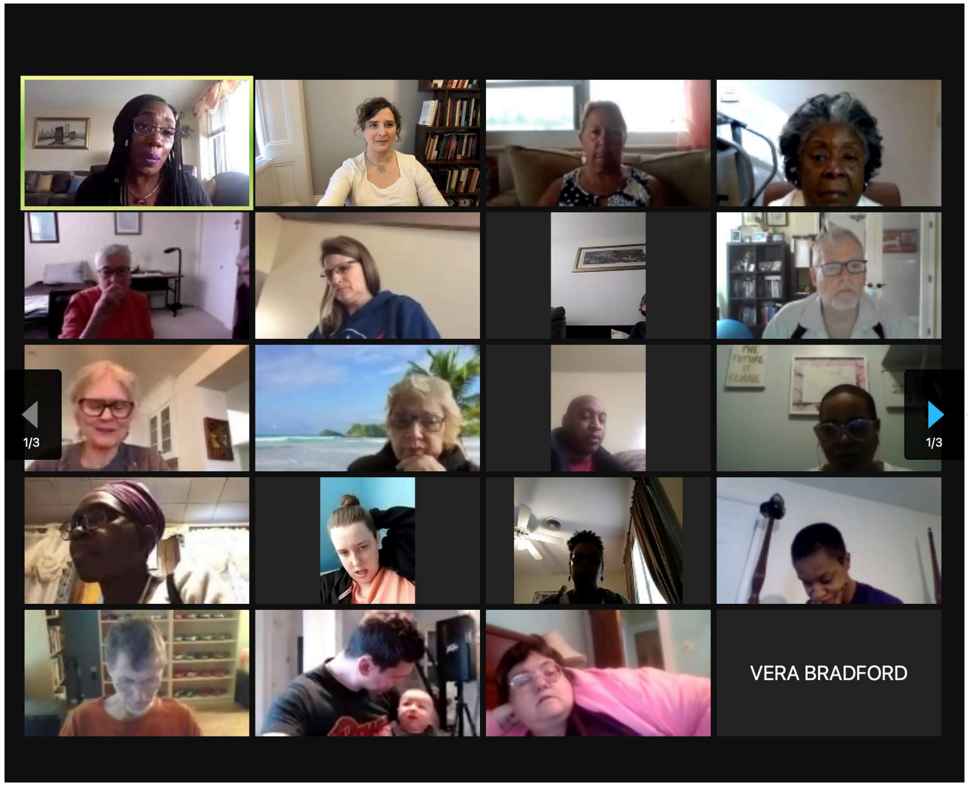
**Social Media Campaign**

- FSR messaging reached thousands during April
  - Reach – Over 56,000+
  - Impressions – 20,000+
  - Engagements – 5,200+

# Programs and Support Update

# Sarc Socials and Wellness Programs

- Vision Health
- ILD
- Nutrition and Cooking
- Fostering Growth and Resilience



# Virtual Patient Education Summit – Together We Thrive

**Attendees:**

- **273** registered patients and caregivers
- **318** total attendees
- **7** Countries represented
- **46** States
- **52** expert speakers

**Sessions:**

- **33** Sessions
- Average Registration per session: **143**
  - Average registrations per user: **16**

**Networking:**

- **283** active users
- **738** contacts made
  - Average of 2.3 contacts per active user
- **454** discussions created
- **45** minutes: average duration of video calls
- **2,572** messages exchanged

- **8** Sponsors
- **3** FSR-WASOG Centers of Excellence
- **7** Partner booths

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

# Summit Participant Feedback

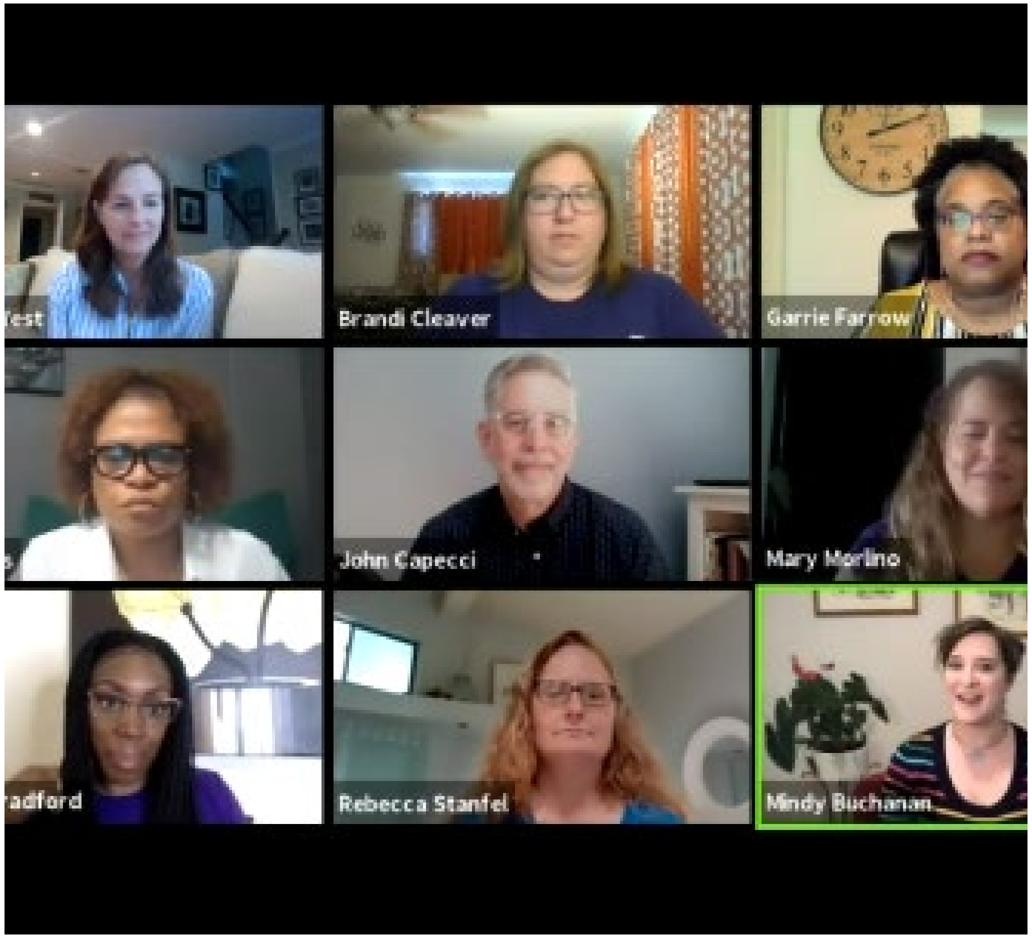
"Excellent summit. I wish I could have experienced this many years ago."

"What a very informative Patient Summit."

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

"In 18 years, this is the first time I have received such comprehensive information."

# FSR Speakers Bureau



- **14** Trained Advocates
- **Professionally trained** by John Capecci, author of *Living Proof, Telling Your Story to Make a Difference*
- **Opportunities**
  - Awareness Events
  - Op-Eds
  - Live presentations
  - Medical Education/ Grand Rounds
  - Legislative Engagement

# Women of Color Campaign

**Update**

- Received 71 applications for those interested in committee
  - Robust application review and interview process
  - 14 committee members selected as committee members
  - Support and Education for network of applicants not selected
- Clinical Advisory Committee Selected
  - Dr. Yvette Cozier
  - Dr. Divya Patel
  - Dr. Ogugua Obi
  - Dr. Ennis James
- Educational Training for Committee Members – July 9

**Upcoming**

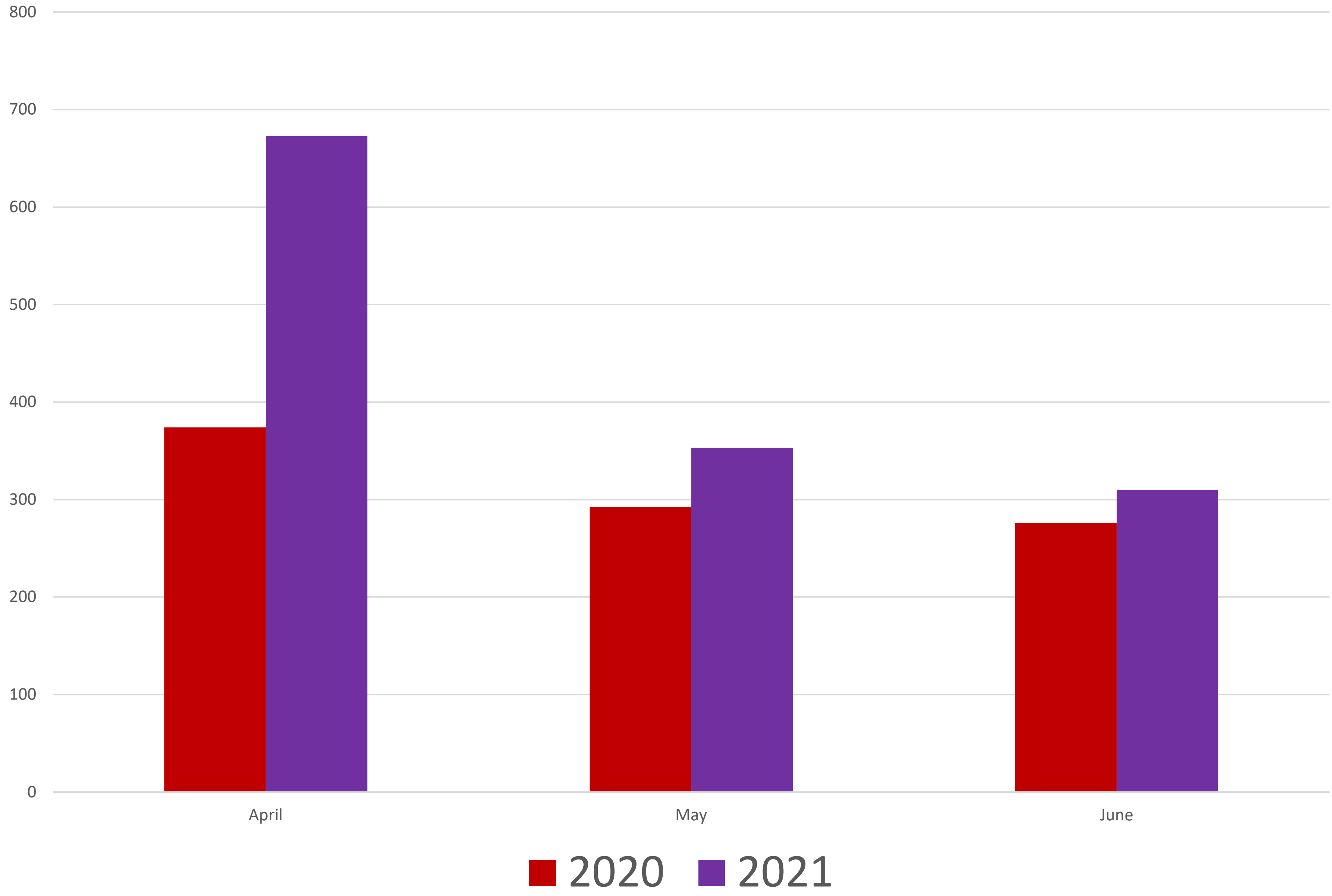
- Fall
  - Press Release
  - Educational Webpage
  - Infographic
  - Twitter Chat
- Black History Month 2022
  - Webinar
  - Social Media Campaign

# Upcoming

- FSR and Stronger than Sarcoidosis – Diversity Summit
- Educational Webinar Series
- Sarc Socials and Wellness Programs
- Fall Advocate Training

# Development and Strategic Partnerships Update

# New Member Comparison April - June 2020-2021



# Partnerships

- **CHEST – FSR** MOU
- **Boehringer Ingelheim**
  - FSR patient participation in future treatment focus group (Confidential)
  - International Patient Advocacy Group
- **Xentria**
  - Behind the Mystery (Lifetime Television Show)
    - Filming August 10 with FSR Patient Advocate Cheryl Bradford
- **Mallinckrodt**
  - Patient Advisory Group Meeting
- **Black Health Matters**
  - Presentation at summit
- **Global Genes**
  - Booth at upcoming summit
  - Appointed to Global Genes' Health Equity Committee
  - Presentation on Diversity and Inclusion at Global Genes Summit
- **ATS**
  - Patient Advisory Roundtable (PAR)
  - Joint Funding
- **Needy Meds**
  - Content and Resource Sharing
- **MJH Life Science**
  - Interviews and News on Sarcoidosis Research
- **ILD Day**
  - September, date TBD

# Corporate Advisory Committee Meeting

- Second Quarterly Meeting
- Patient Speaker, Susan D’Agostino
- Strategic Plan Discussion

Boehringer
Ingelheim

Mallinckrodt
Pharmaceuticals

# Major Donors

- Major Donors from April to June
  - CEO, VP of Research and Strategic
  - Partnerships and Director of Development Calls
  - Q2 2021
    - Total amount of major gifts – 13
    - Total revenue of major gifts received - $51,375
  - Q2 2020
    - Total amount of major gifts – 9
    - Total revenue of major gifts received - $7,500

- Shimmering Snowflake Event
  - 9 attendees
  - Board and SAB Participation
  - Major Donor Strategic Planning Exchange

# Memorials and Tributes

**Memorial and Tribute Outreach**

Condolence and acknowledgements sent to families of all tribute donors to invite family and friends to join FSR community.

**Year-End Tribute**

FSR will honor those and remember those who lost their lives to sarcoidosis through a **year-end tribute** opportunity.

**Memorial and Tribute Revenue**

- **Q2 2021**
  - **Total amount of tribute gifts – 159**
  - **Total revenue of tribute gifts received - $22,178**
- **Q2 2020**
  - **Total amount of tribute gifts – 94**
  - **Total revenue of tribute gifts received - $8,302**

**Memorial Monday Candlelight Vigil - April 26**

**129 Registered** for the event and **53 attended live**

# Upcoming

- Together We Thrive – **Mid-year report**
- **Fundraising Campaigns**
  - Annual Appeal
  - Fall Fundraising Campaign – Gratitude and Giving
    - Giving Tuesday
  - End of Year
- **Fall Memorial and Tribute Event**
- **Upcoming Conferences**
  - Global Genes (free booth)
  - World Orphan Drug
  - Bio
  - PCORI Annual Meeting
  - CHEST (free booth)
  - WASOG (free booth)

# Advocacy and Coalitions

- **Coalitions Joined**
  - Global Heart Hub
  - Global Skin
  - Friends of NIH Office of Women's Health Research
  - Rare Disease Diversity Coalition- Member of Clinical Trials Subcommittee
  - Long Covid Coalition
  - Immunocompromised Coalition

- **FY2022 budget proposal**
  - The President's proposal recommends increasing the budget for the National Institutes of Health (NIH) by $2.5 billion
  - $3.6 million increase for the Food and Drug Administration (FDA)
    - $500 million exclusively for funding the FDA under the 21st Century Cures Act.

# Advocacy and Coalitions

- Recognition of **April as Sarcoidosis Awareness month**
  - Passed the House and the Senate in Illinois
  - Have until the end of June for governor’s signature
- **NHLBI – Sex and Gender Working Group**
- **Virtual Capitol Hill Visits**
  - **Rare Disease Day on Capitol Hill** (Virtual)
    - July 12-14
  - **The 2021 Rally for Medical Research Hill Day**
    - September 22-23

# Research Update

# FSR/MNK Fellowship Grant Awardee

- Received **7** applications

- Grant Writing Webinar Series
  - How to write a winning FSR Fellowship Grant – Dr. Herzog and Dr. Ryu
    - **19** registrants
    - **12** live attendees
    - **66** views on YouTube
  - Series to expand on tips for writing other types of grants including NIH grants

**Grant for 2021-2023**

- Grant awardee Dr. Paula Berreras from Johns Hopkins University Hospital
- “Discovering pathogens in neurosarcoidosis: using next generation immunological and metagenomic methods for unbiased pathogen detection and antimicrobial antibody profiling.”

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# Updates From 2020-2022 Fellowship Grant Awardee Shu-Yi Liao (National Jewish Health)

**Grant project**

- *An Omics Precision Medicine Approach to Explore the Susceptibility and Phenotypes of Sarcoidosis*

**Publications**

- **Abstract**
  - "Gene-Based Analysis of Sarcoidosis Susceptibility in European-Descent Americans" submitted to American Thoracic Society 2021
- **Manuscripts**
  - "Single-cell RNA sequencing identifies macrophage transcriptional heterogeneities in granulomatous diseases" has been resubmitted in response to reviewers
  - "Genome-Wide imputation study identifies multiple HLA locus for sarcoidosis susceptibility" is in preparation

# FSR Small Grant

- **FSR Small Grant**
  - $25,000 to support pilot research

- **Grant Writing Webinar Series**
  - Dr. Wonder Drake and Dr. Ozioma Chioma
    - **22** Registrants
    - **13** Live Attendees
    - **62** Views Since Posted to YouTube

- **11** applications received – under review

- **ATS/FSR Partnership Grant**
  - $50,000 over two years
  - Application cycle launches July 20

# Endpoints

**Update**

- Completed Phase 1
- Two papers submitted for publication

**Next Steps**

- Phase 2- to use real-world models to validate
- Applying to measure the best ones

# Registry Update

- 3 new manuscripts under review
    - Hispanics and Sarcoidosis
    - Lymphoma and Sarcoidosis
    - Hyper/Hypothyroidism and Sarcoidosis

# Clinical Studies Network (CSN)

**Active Projects:**

- **Papland**
  - 181 patients in the randomized portion out of 600
  - 158 patients in the chart screen portion out of 600
  - First abstract in process for ATS 2022
- **PROMyS**
  - Contracting is underway with lead site
  - Contract with Mallinckrodt has been amended
  - Anticipated enrollment to begin at all 8 sites by Q3 2021
  - 225 patients waiting to be enrolled
- **Xentria**
  - Patient focus group in Q1 2021
  - Actively working with Xentria to recruit
  - Anticipated start in 2022

**Completed Projects:**

- **Roivant (confidential)**
  - Patient Focus group in Q2 2021
  - Working on contract for support of clinical trial with CRO Syneos
- **aTyr**
  - Completed enrollment through COVID-19 pandemic
  - Finalizing payment support on patient visits

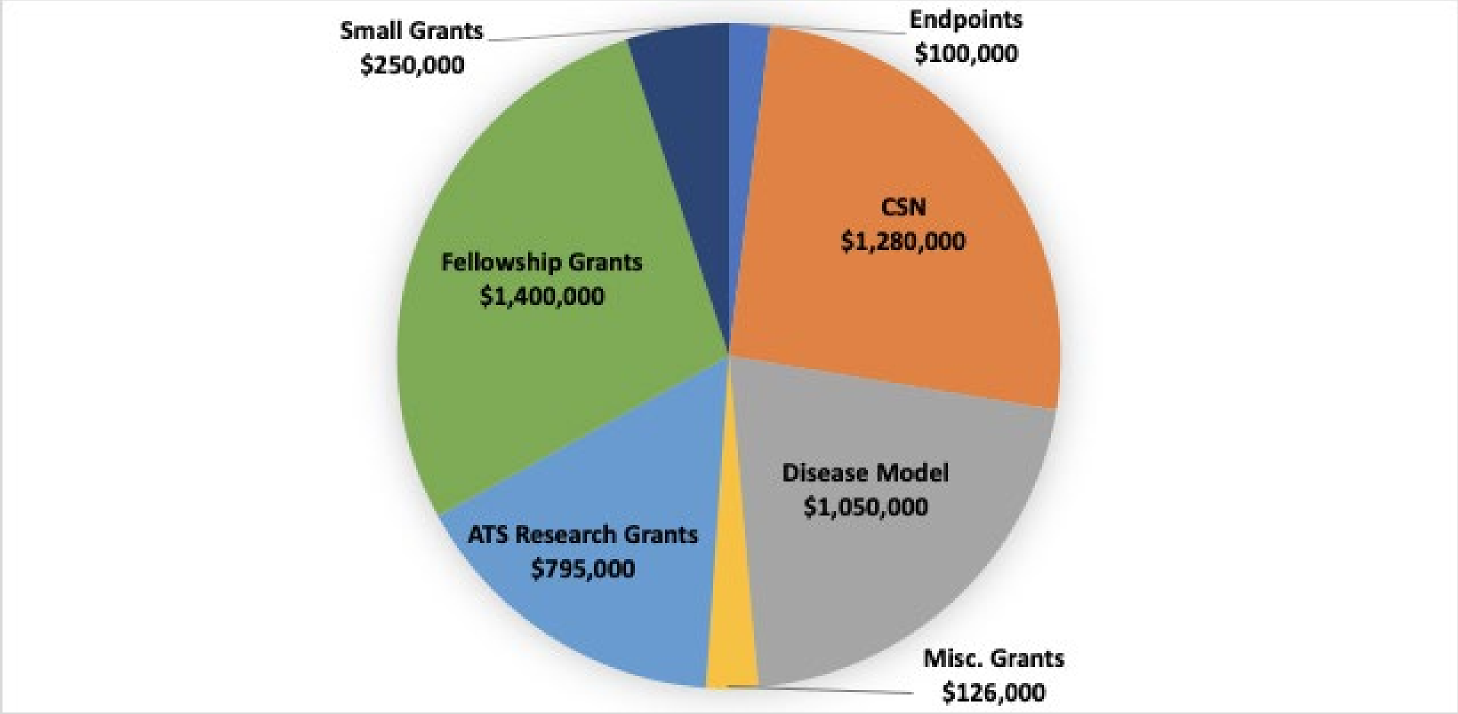
# SARConnect

By using FSR’s patient network, we are able to quickly facilitate patient recruitment for trials, which creates more interest in sarcoidosis research.

**Active Project Update**

- Novartis
  - Expanded funding and engagement in process
- Xentria
  - Recruitment in process
- BRITE
  - Recruitment in process
- Stanford
  - 1 patient away from full enrollment

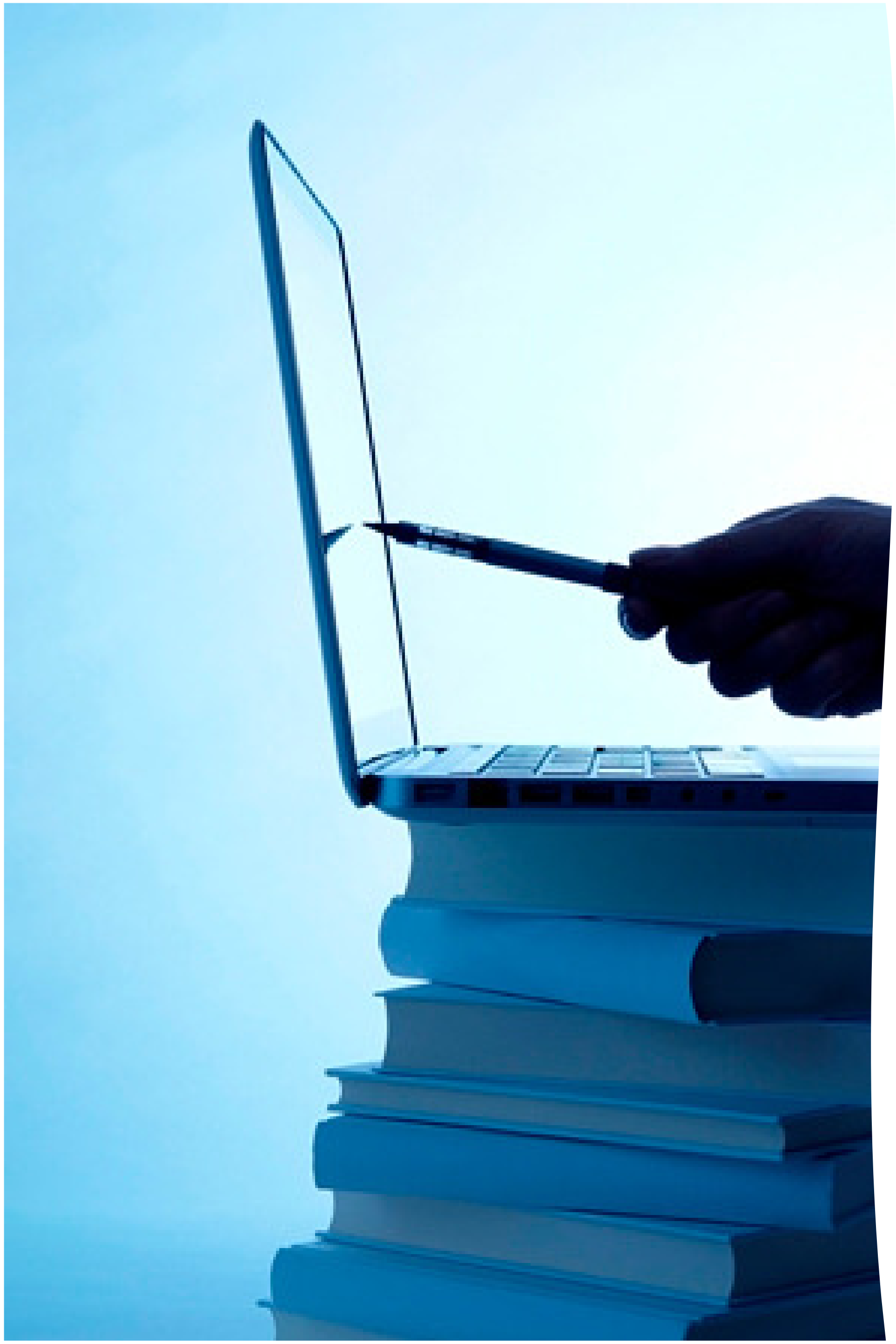
# Research Publications and Funding



# Scientific Advisory Board Meeting

# SAB Bylaws Development Underway

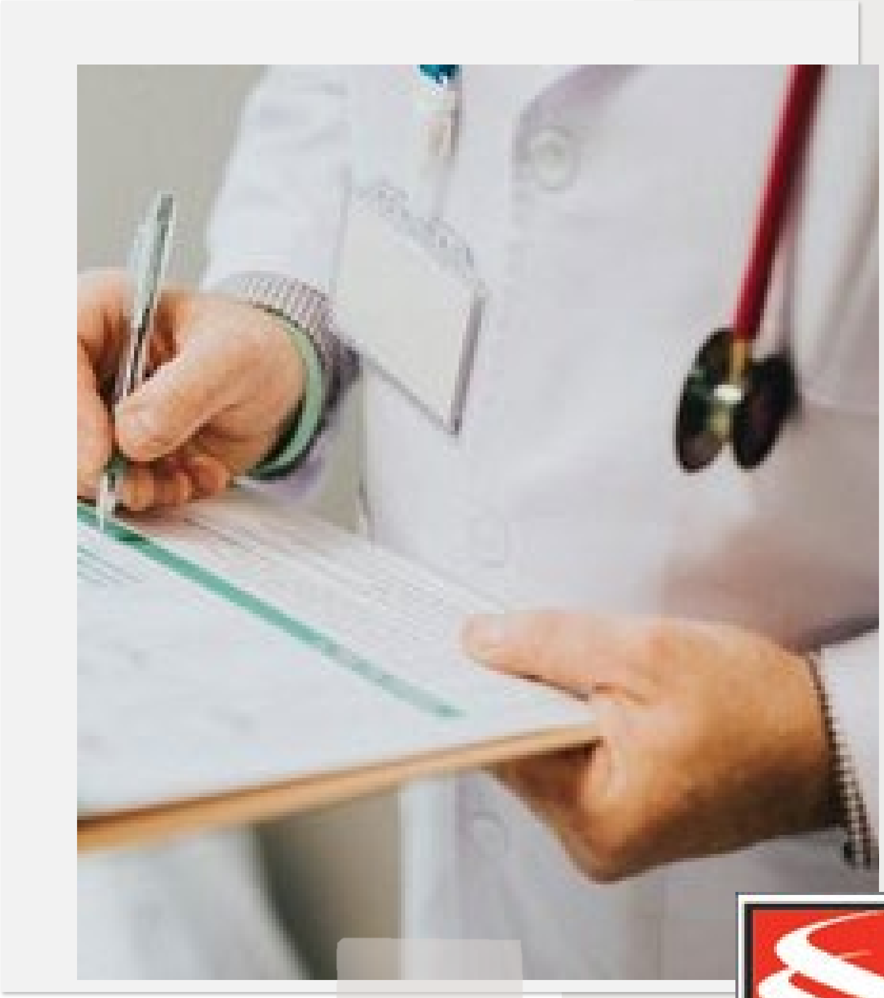
- Develop Ascension Plan
- Create Nomination and Roll-Off Structure
- Identify Leadership Roles



# Research Committee

**Primary Goals**

- Review applications
  - Small Grants
  - Fellowships
  - Other grant applications as required
- Review FSR funded publications
- Help drive research strategic goals
- NHLBI/NIH/NIAMS
- Industry- teach more about the mechanisms of Sarcoidosis



# Communications Committee

**Primary Goals:**

- Grand Rounds and Speaking Engagement
- Media outreach/engagement
- Expand social media outreach
- Help in development of educational materials
- Help identify pivotal publications
- Publish books (electronically)
    - One for patients
    - One for physicians
    - Help develop content

# Nominations Committee

**Primary Goals**

- Nominate new potential members
- Identify experts from diverse disciplines- Dermatology, Cardiology, Neurology, etc..
- Identify experts from diverse specialties – APN, APP, Lab research, Research Coordinators, Post-docs, Radiologists
- Identify potential early career members

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# Strategic Planning

- CEO working with consultant on time frame and goals
- Research presentations schedule for Board

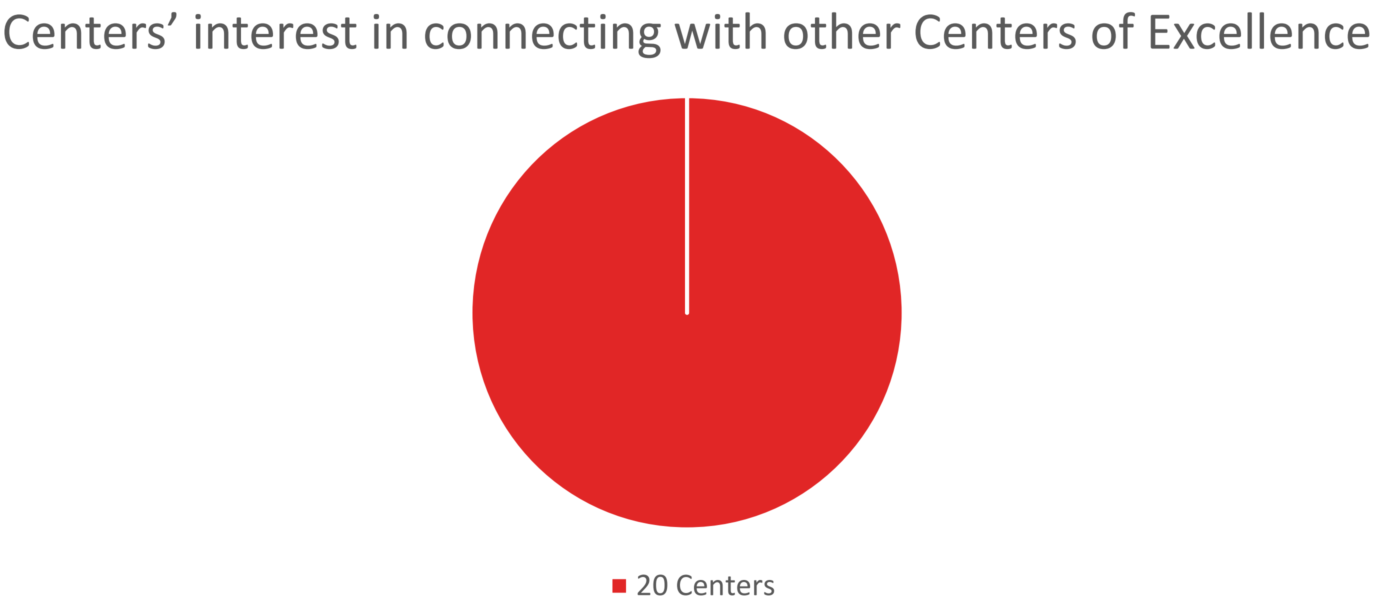
# Centers of Excellence

# Centers of Excellence Survey

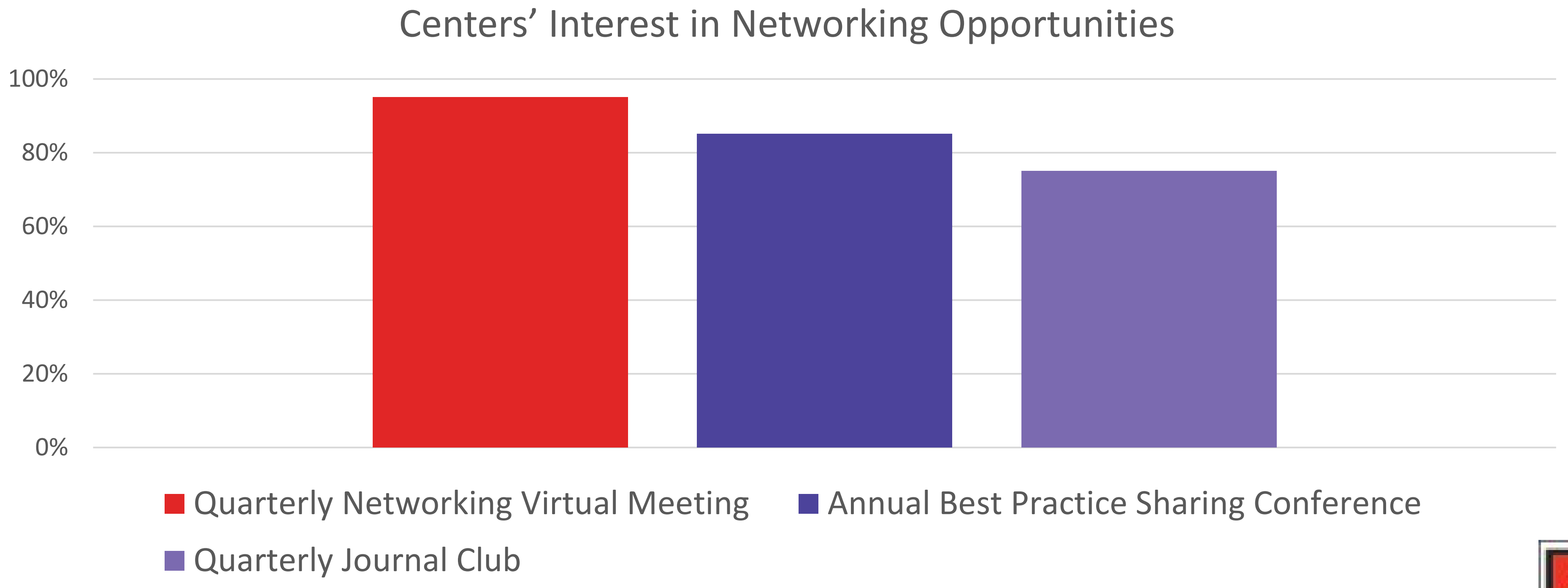
44 Centers sent survey to
determine interest in future collaboration
with FSR

21 Centers responded/ 8 international

# 100% of Centers are interested in more opportunities to connect with other COE's.

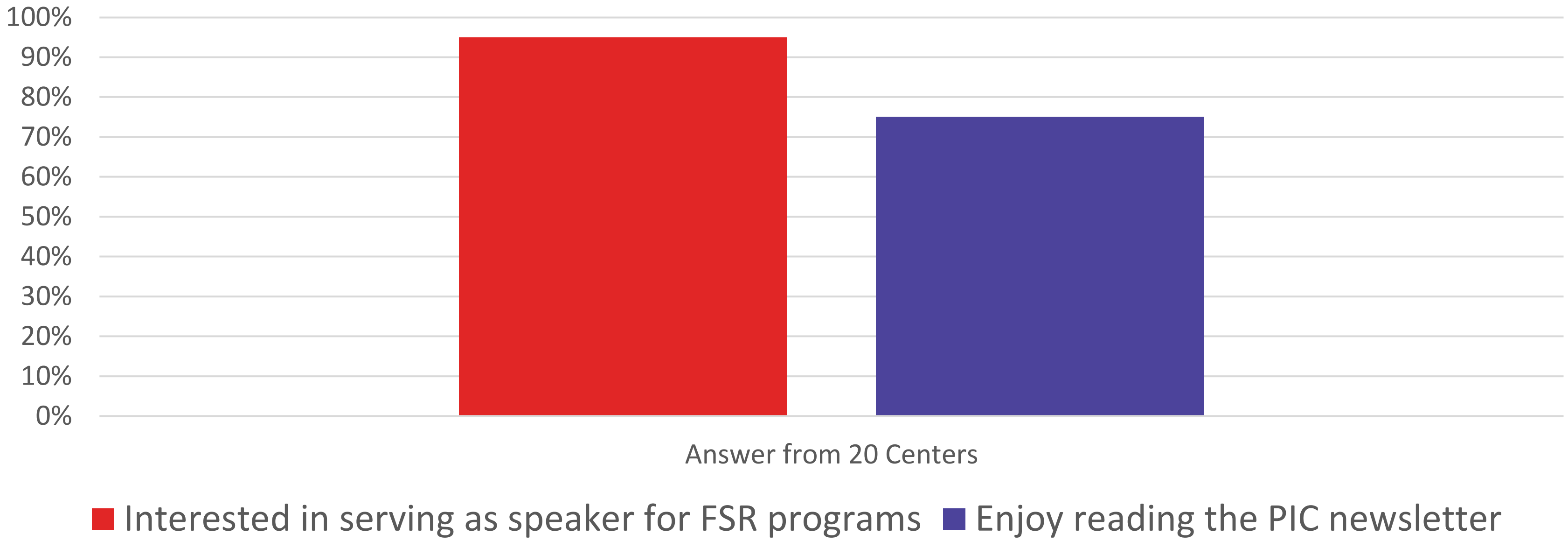


# Centers interested in engagement with FSR through Quarterly Networking Virtual Meetings, Annual Best Practice Sharing Conference, and Quarterly Journal Club.



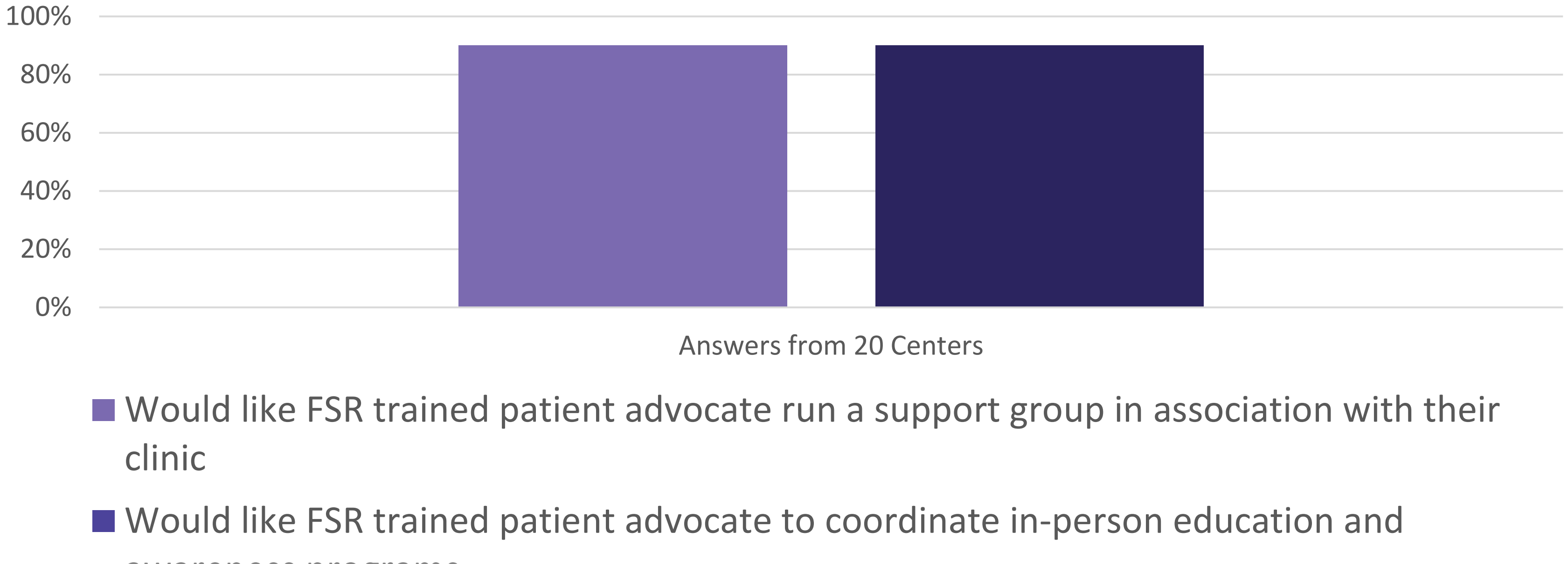
**95%** interested in serving as speaker for FSR’s patient education programs.

**75%** find monthly physician and investigator newsletter from FSR helpful and informative.

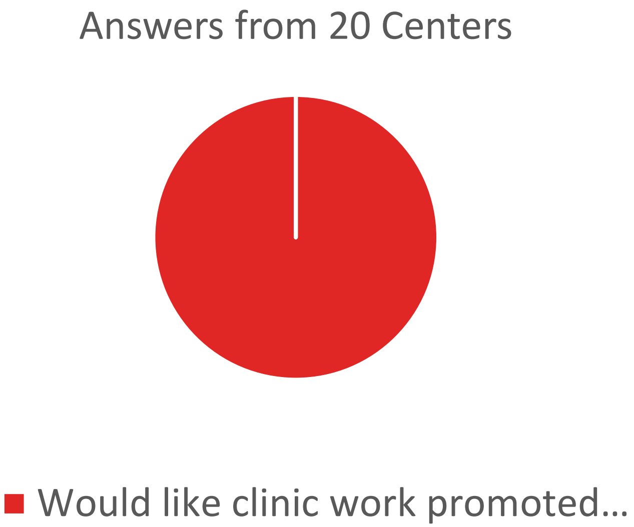


**90%** **interested in FSR-trained patient advocate to run support group in association with their clinic.**

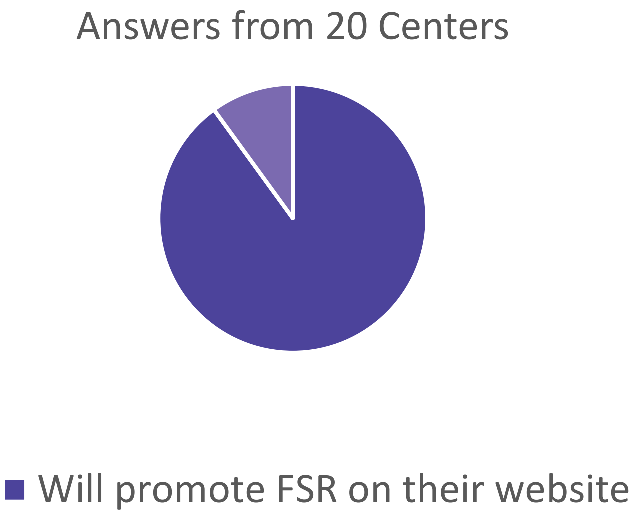
**90%** **interested in an FSR-trained patient advocate to coordinate in-person education and awareness programs in their clinic's community.**



**100% interested in their team and clinic's work highlighted on FSR's website, social media and patient outreach.**

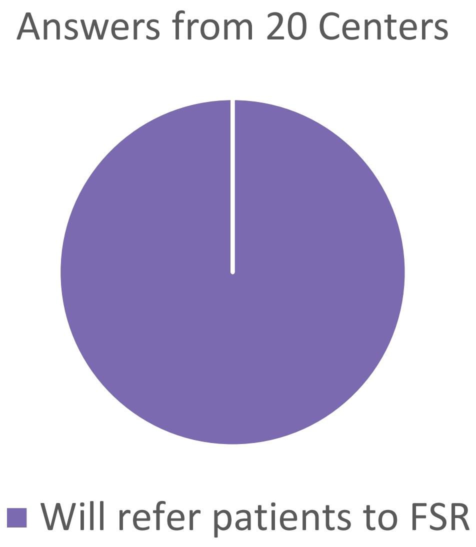


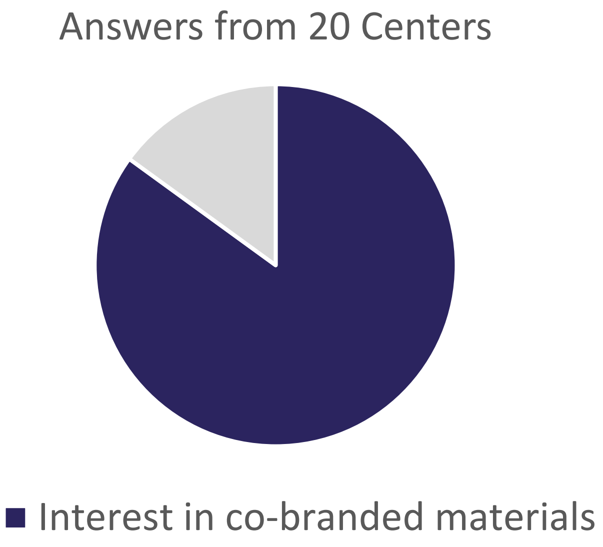
**90% willing to promote FSR's website on their Center site.**



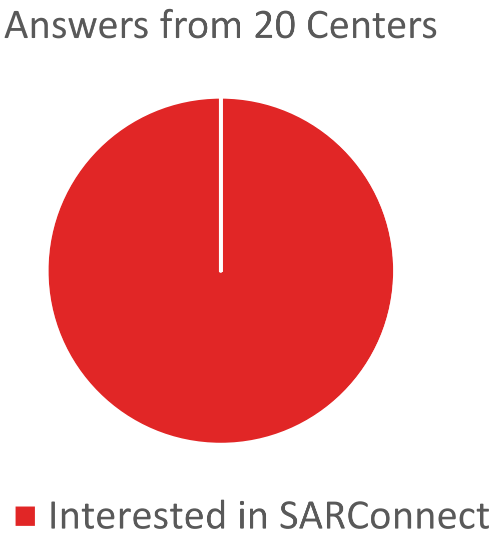
**100% willing to refer patients to FSR for patient support/education.**

**85% interested in co-branding educational materials for their patients.**

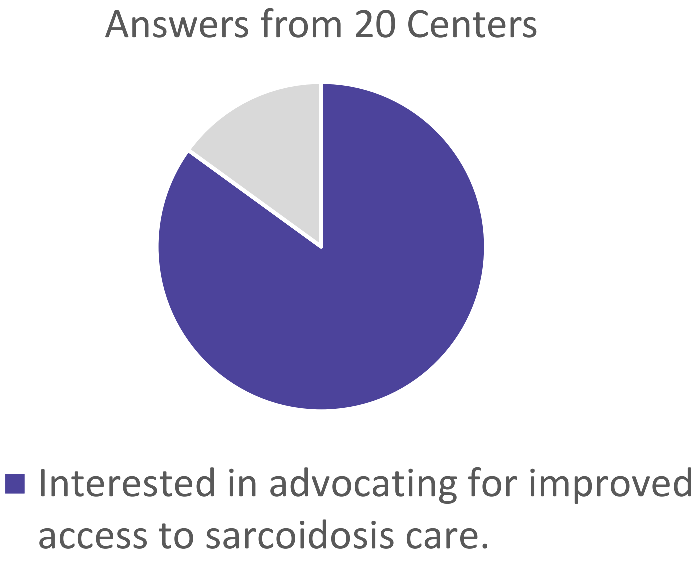




**100% interested in SARConnect, an FSR program that assists with clinical trial recruitment**

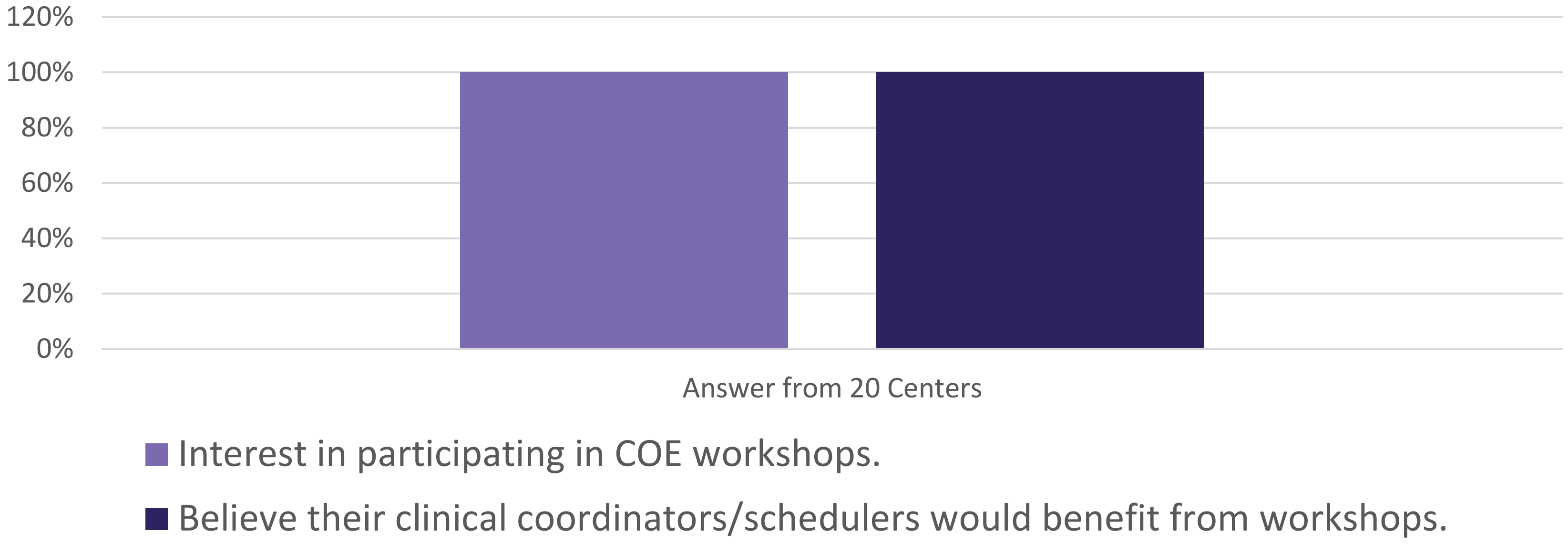


**85% interested in opportunities to advocate to legislators for improved access to care for more patients.**



**100%** interested in participating in COE workshops to enhance our relationships with patients and increase patient satisfaction.

**100%** believe their clinical coordinators and schedulers would benefit from workshops that enhance their relationships with patients and increase patient satisfaction.



# Center of Excellence Application's Main Requirements Finalized

- Have established registry of sarcoidosis patients
- Have at least 500 sarcoidosis patients seen at the Center, at least 100 in the last year
- Must enroll clinical trials
- Must have a sarcoidosis generalist
- Must diverse specialists
- Must have team of ancillary specialists
- Must have clinical coordinator and fixed research coordinator
- Must provide patient education and presented research in sarcoidosis
- Must have published at least 5 publications in sarcoidosis in the past 5 years

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# Timeline Centers of Excellence Application Process

- Webinar on application process with WASOG leadership
- Application opens – soon
- Application Due – Mid-September
- Application Decision – Mid-November

# Upcoming: Clinical Engagement Conference

- Single Day Conference in Fall 2021
- Focus on Clinical Best Practices
- FSR- WASOG Centers of Excellence/Clinical Centers
- Case Studies Workshop
- Debate topics
  - Steroids or no steroids
  - Autoimmune vs. Immunological
  - Length of time of treatments
  - Other?

**Thank you for reviewing update!**