

2019

YEAR-END INVESTOR REPORT

Foundation for
Sarcoidosis Research



A NOTE FROM OUR FOUNDERS

The Wilsons

Since we started the Foundation for Sarcoidosis Research in 2000, we have been astounded by the tremendous growth of this organization. We have been overwhelmingly supported by the sarcoidosis patient and research communities alike, and remain so grateful for everyone who has contributed to our success.

Yet, we know we can and will do more. This year marks our 20th anniversary and while we are excited to celebrate all of FSR's accomplishments to date, we are also excited to measure our growth and ensure that the next 20 years are even more impactful than the last two decades.

Thank you for being a part of FSR's progress and joining us in our mission to stop sarcoidosis.

Andrea Wilson
Co-founder

Reading Wilson
Co-founder



OUR HISTORY

The Foundation for Sarcoidosis Research (FSR) is the nation's leading nonprofit dedicated to finding a cure and better treatments for sarcoidosis while remaining a resource for patients, family members, and the greater healthcare community. The research agenda and patient advocacy programs built by the foundation have been fueled by the patient voice which is central to FSR's success.

Throughout FSR's twenty-year history, the organization has maintained the belief that patients must come first. The progress of sarcoidosis research and advocacy efforts are dependent on patient participation. As FSR grows, the initial promise made to patients in 2000 continues to fuel the success in FSR's future.

HIGHLIGHTS of 2019

ACHIEVEMENTS

Funds raised through Team KISS 5K

\$229,966

Funds raised on GivingTuesday

\$30,375

Funds raised through major gifts

\$323,051

Amount awarded to sarcoidosis research

\$1,550,548

Number of research grants awarded

65 grants

It is impossible to ignore the progress and accomplishments that our devoted patients, friends, family members, healthcare community, and sarcoidosis warriors have directly contributed to through various programs and initiatives which FSR led this year. We could not have achieved these incredible milestones without the support of the entire sarcoidosis community.

Below are a few of the triumphs the FSR team celebrated this year:

- Over 1,000 patients and caregivers attended FSR's 9 patient conferences held across North America in 2019
- Over 1,900 individuals joined Team KISS in April 2019 including virtual walkers, fundraisers, and satellite walk participants
- Over \$30,000 was raised for #GivingTuesday on December 3rd, 2019 making it our most successful #GivingTuesday yet
- Over 87 landmarks in 2 countries were #litforsarc on World Sarcoidosis Day, including One World Trade Center
- 38 state and 46 local governments awarded proclamations recognizing April as Sarcoidosis Awareness Month

FSR is truly grateful for all that our supporters and community leaders have done to advance our mission this year. FSR has a big dream - to one day cure sarcoidosis - and will achieve this dream with the support and collaboration of the sarcoidosis community.

RESEARCH SUMMARY

FSR Small Grant Program

- FSR's Small Grant Program focuses on awarding funds to new or early stage research on sarcoidosis. In 2019, \$50,000 was provided to Small Grant awardees with projects focused on immunological and clinical gender-specific differences in cardiac sarcoidosis and the role of IL-6 blockade on sarcoidosis-related pulmonary fibrosis.

Clinical Studies Network

- FSR's Clinical Studies Network (CSN) and SARConnect programs continued to engage and partner with pharmaceutical companies through patient outreach and recruitment for large multi-center trials. Both programs help carry out multiple studies with focus in cardiac and pulmonary sarcoidosis.

"2019 was a year of immense progress for FSR's strategic research agenda."

-Noopur Singh,
Director of Research Programs

Sarcoidosis Disease Model

- The FSR Sarcoidosis Disease Model initiative began in 2017 when we awarded five promising projects a total of \$750,000 to investigate possible disease models for sarcoidosis. The grant cycle culminated with a dynamic symposium at the European Respiratory Society Congress in Madrid in 2019. The awardees presented their finding to an audience of sarcoidosis experts, industry partners and international advocacy group members.
- Three of the five Disease Model awardees were selected for additional bridge funding through 2020. A cumulative \$300,000 grant aims to further the development, characterization, or improvement of these models for sarcoidosis research purposes.

FSR Fellowship Grant

- The FSR Fellowship Grant continued to fund 4 fellows into their second and final year of research. Areas of study for this 2-year grant cycle include patient-centered research in imaging and biomarkers of cardiac and thoracic sarcoidosis as well as focus in the gender differences in sarcoidosis, the genetic and environmental factors affecting immune cells that may predispose individuals to sarcoidosis, the association between extracellular mitochondrial DNA and poor clinical outcomes in African Americans with sarcoidosis.





MEET OUR PARTNERS

These research partners are working with FSR to improve progress in the sarcoidosis space.



AMBASSADOR PROGRAM SUMMARY

2019 was another successful year of advocacy and patient engagement from our ambassadors. 72 ambassadors attended a training retreat in Washington DC, preparing them to spread awareness, education, and support throughout the country. The list of ambassador achievements is as impressive as it is lengthy.



- 11 local and state health fairs or events attended
- 38 state Sarcoidosis Awareness Month proclamations
- 46 local Sarcoidosis Awareness Month proclamations
- 87 landmarks illuminated purple on World Sarcoidosis Day
- 9 5K events raising over \$64,000
- Additional fundraising events raising over \$10,000
- 60 support groups facilitated by ambassadors throughout the year
- 32 local and national speaking engagements by ambassadors
- First national online support group developed, hosting over 30 attendees each month
- 400 surveys collected to advance understanding of attitudes toward research from populations traditionally underrepresented in research



Attendees at FSR's 2019 Ambassador Training in Washington, DC.



MEET THE FSR TEAM

These are some of the hardworking individuals who made our 2019 accomplishments possible.

FSR staff, top left to bottom right: Reading Wilson, Interim Executive Director and Co-Founder; Andrea Wilson, Co-Founder; Noopur Singh, Director of Research Programs; Angela Frelander, Director of Development; Mindy Buchanan, Patient Engagement Manager; Maggie Hudson, Patient Resource and Communications Manager; Tamara Al-Hakim, Research Coordinator; Hana Nabulsi, Administrative and Research Project Coordinator; Nick Zeppos, Development and Finance Project Coordinator; Lesley Baxter, Physician Coordinator.

OUR FUNDERS

The people whose generous support made it all possible.



FSR is grateful for the generous contributions from individuals, corporations and foundations across the country and around the world. The following is a list of those who made gifts of \$1,000 or more in fiscal year 2019.

\$100,000 or more

Anonymous
aTyr Pharma
Jarve Family Legacy
Mallinckrodt Pharmaceuticals

\$50,000 - \$100,000

Mr. and Mrs. Jerome Serchuck

\$25,000 - \$49,999

John and Janet Mockovciak
The Raich Family Fund

\$10,000 - \$24,999

Alex and Alice Fruth
Anonymous
Anonymous
Global Genes
Harlene and Marvin Wool Foundation
Jacobs, Malcolm and Burt
Meitheal Pharmaceuticals, Inc.
Michael and Heidi Junk
Miles and Marcie Stuchin
The Cedar Street Foundation
The Gies Foundation

\$5,000 - \$9,999

Alabama Power Foundation, Inc.
Denise Wool
Dorothy A. Williams
Dr. Emerson R. Hall and Dr. Freda C. Lewis Hall
June JAMR
Louise Perkins, PhD
Novartis Pharmaceuticals

\$1,000 - \$4,999

Andrew Sveikauskas
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BlueCross BlueShield of Arizona
Carla Hahn
Christine Hostetter
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Richard Clapp
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Sandra Asmussen
Sarah and Bo O'Connell
The Langille Family Fund
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FINANCIALS

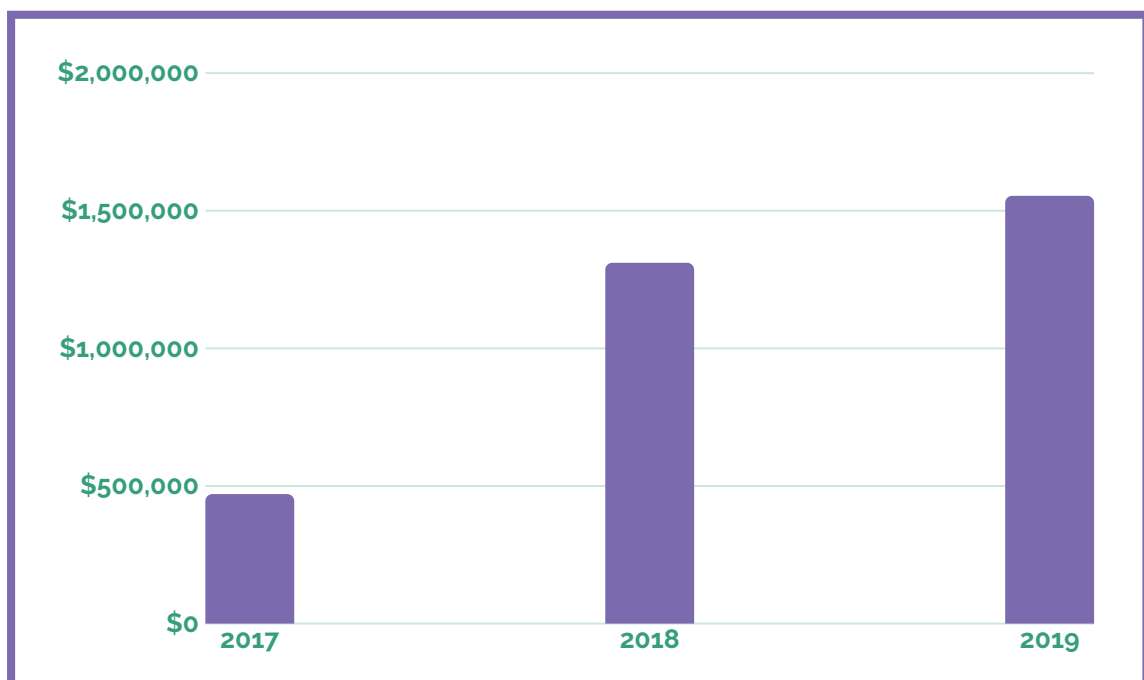
A Growing Investment in Sarcoidosis Research

Since our founding in 2000, FSR has invested over \$5 million in sarcoidosis-specific research efforts.

In 2019, our investment topped \$1.5 million.

At the Foundation for Sarcoidosis Research, we are committed to our patients and stakeholders by working each and every day to maximize every dollar to drive science to ultimately develop better treatments and a cure. In 2019 alone, over \$1.5 million was directly funded to sarcoidosis research.

A primary focus of FSR's strategic plan in the past several years has been the diversification of revenue sources. One focus of 2019 was the expansion of the services rendered by FSR through the SARConnect program to assist in outreach and recruitment for clinical trials. This not only aims to ensure these important trials do not fail, but also resulted in \$25,000+ revenue for FSR to invest back in sarcoidosis research and resources for patients.



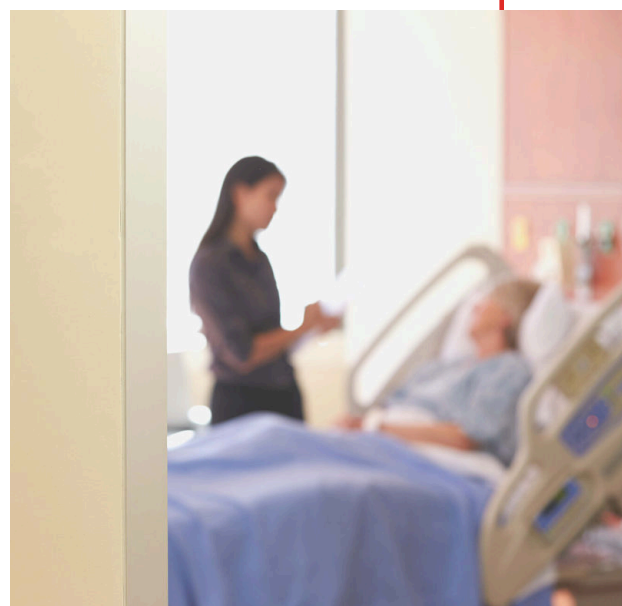
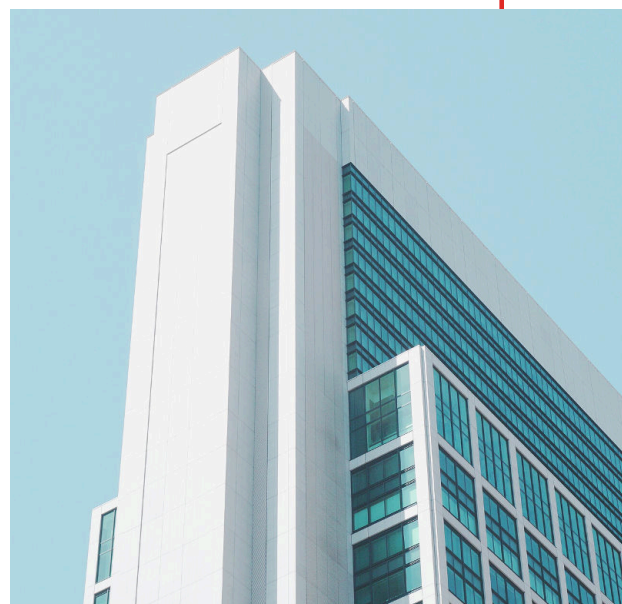
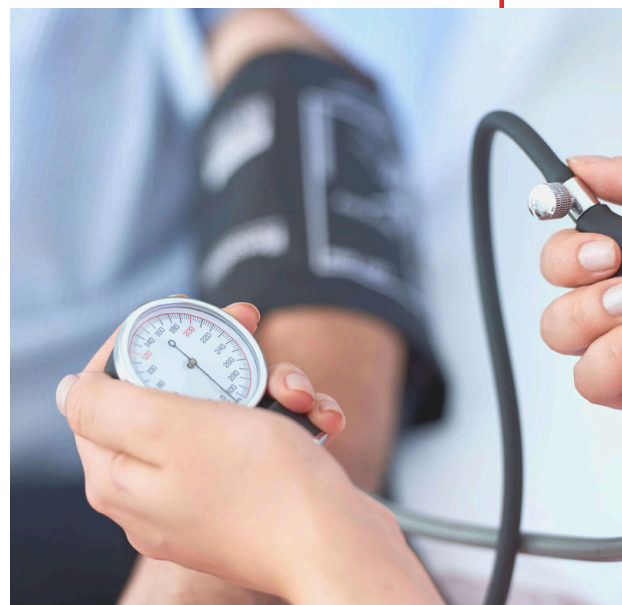
LOOKING FORWARD

2020 is a year for celebration with FSR's 20th anniversary

This year marks FSR's 20th anniversary and we couldn't be more excited to celebrate! Over the past two decades, FSR has become the leading nonprofit dedicated to sarcoidosis patients and research. Our educational and advocacy programs have provided services and resources for thousands of individuals navigating this disease worldwide. Additionally, FSR has invested over \$5 million into sarcoidosis-specific research and the overall advancement of the sarcoidosis research space.

FSR will spend 2020-2021 celebrating our progress and unveiling new programs and resources for our patients and researchers. We couldn't be more grateful to the sarcoidosis community that has supported us and helped make our work possible.

2020 marks the 20th anniversary of the founding of FSR. We're celebrating two decades of unprecedented progress and growth.





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Co-Founder

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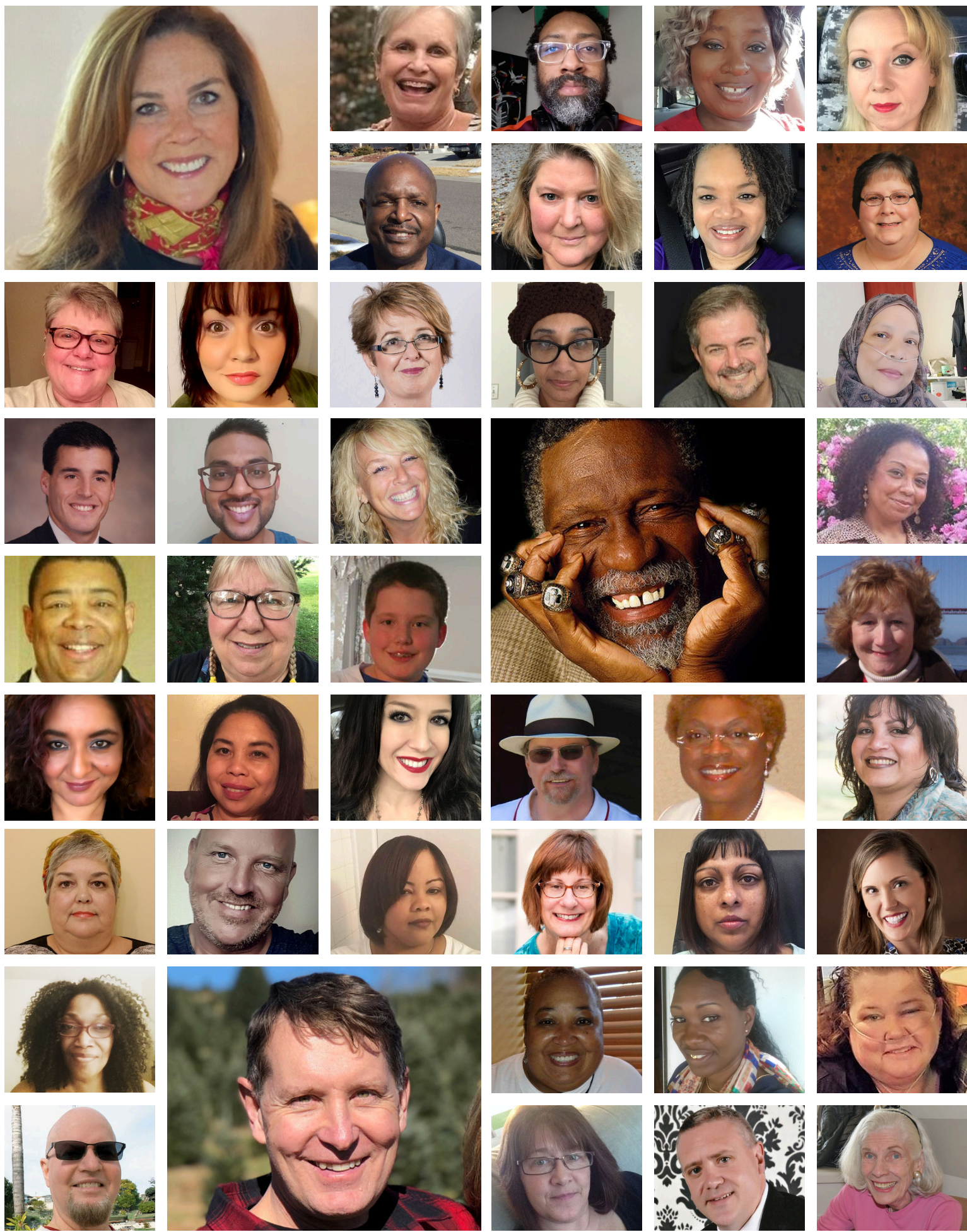
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Milton Rossman, MD
University of Pennsylvania

Barney Stern, MD
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Dominique Valeyre, MD
Hôpital Avicenne



The many faces of sarcoidosis - we're with you in this fight.



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