

2022 Annual Report

SCLERODERMA
 RESEARCH
FOUNDATION



Our Vision

A world without scleroderma.

Our Manifesto

We find, fund, and facilitate the most promising research to cure scleroderma. We recruit the best and the brightest researchers to understand the causes, discover treatments, and ultimately eradicate this disease. No one should have to suffer with scleroderma. No one suffering should also have to explain what this disease is or does. Lack of awareness causes delays in treatment or misdiagnosis. This must end. We are a world-class team. We are the best hope of finding a cure. We can't stop. We won't stop.

❖❖❖ At the SRF, research is at the center of all we do to find a cure.



In Memoriam
Bob Saget, SRF Board Member
May 17, 1956 - Jan 9, 2022

Our Mission

The mission of the Scleroderma Research Foundation (SRF) is to fund and facilitate the most promising, highest quality research aimed at improved therapies and, ultimately, a cure for scleroderma.

Board of Directors



Luke Evnin, PhD, Chairman



Omar Baker, MD



Sharon Dobie, MD



Susan Feniger



Regina Hall



Eric Kau, MD



David Knoller



Violetta Merin



Jeff Seaman



Deann Wright, JD



Caryn Zucker



Dana Delany, Emeritus

In Memoriam:



Bob Saget
Board Member, 2003 – 2022,
SRF Ambassador since 1991



Sharon L. Monsky
SRF Founder
1953–2002

SRF Staff

Joanne Gold Executive Director

Gloria Blecha Senior Director,
Community Outreach & Education

Kate Ceredona Director of Philanthropy

Hannah Young Director of Communications

Ruben Cordoba Development Database Manager

Scientific Advisory Board

The individuals on the SRF Scientific Advisory Board are some of the world's most honored and distinguished scientists. These renowned researchers freely volunteer their time and expertise to help advance the search for a cure. They guide the SRF's research program, evaluate research proposals, make funding recommendations, and foster discussion and collaboration amongst funded investigators.



Lloyd Klickstein, MD, PhD
CSO, Versanis



Dan Littman, MD, PhD
New York University, Howard
Hughes Medical Institute,
National Academy of Sciences,
Pfizer Board of Directors



Bruce Alberts, PhD, Chairman
Ex-chair, National Academy of
Sciences University of California,
San Francisco




Antony Rosen, MD
Vice Dean - Research, Johns
Hopkins University




Bruce Wintroub, MD
University of California,
San Francisco



Hal Dietz, MD
Johns Hopkins University,
Howard Hughes Medical
Institute, GSK Board of
Directors

 **Scleroderma is a really serious disease, and we need to do everything we can to help. I can help by working with scleroderma investigators to the fullest extent that I can.**

— Lloyd Klickstein

 **The approach the SRF has brought to biomedical investigation will serve as a model for future medical and scientific discovery because of its unprecedented, unified plan of attack.**

— Bruce Alberts, PhD



Dan Kastner, MD, PhD
Distinguished Investigator
and former Scientific
Director, National Human
Genome Research Institute,
2021 Crafoord Prize Recipient

[CLICK HERE](#) to learn more about the
Scientific Advisory Board.

A Unique Approach to Research

Together—with scientists, clinicians, patients, industry partners, and donors—we are advancing research for a cure.

The SRF Research Program \$2.56M in Funded Research

SRF Funded Grants 2022

Regulation of Inflammation and IFN-I response in the Fibrotic Skin Environment
Franck Barrat, PhD
Hospital for Special Surgery

Gene Regulatory Mechanisms in Scleroderma
Howard Y. Chang, MD, PhD
Stanford University School of Medicine
Howard Hughes Medical Institute

Epigenetics of Sex Differences in Scleroderma
Howard Y. Chang, MD, PhD
Stanford University School of Medicine
Howard Hughes Medical Institute

Genomics of Calcinosis
Lorinda Chung, MD, MS

In collaboration with
Pravitt Gourh, MD
Stanford University School of Medicine
National Institute of Arthritis and Musculoskeletal and Skin Diseases

Lung Ultrasound for the Detection and Management of SSc-ILD
Lorinda Chung, MD, MS
Stanford University School of Medicine

Cell Surface GlycoRNAs in Autoimmunity
Ryan Flynn, MD, PhD
Boston Children's Hospital

In collaboration with:
Antony Rosen
Harvard University

Livia Casciola-Rosen
Johns Hopkins University School of Medicine

Elucidating the Role of Dynamic X Inactivation Maintenance in the Pathogenesis of SSc
Nikhil Jiwrajka, MD
University of Pennsylvania

Establishing a Spatially-integrated Transcriptomic, Epigenomic, and Histologic Signature of Fibrosis in Systemic Sclerosis
Michael Longaker, MD
Howard Chang, MD, PhD
Stanford University School of Medicine

Macrophage-stromal Cell Interactions in Tissue Homeostasis and Fibrosis
Ruslan Medzhitov, PhD
Yale University School of Medicine
Howard Hughes Medical Institute

Identification of Novel Pathogenic Genes in Juvenile Systemic Sclerosis
Jay Pasricha, MD
Subhash Kulkarni, PhD, MS
Johns Hopkins University School of Medicine

Macrophage-Stromal Cell Interactions in Tissue Homeostasis and Fibrosis
Ruslan Medzhitov, PhD
Yale University
Howard Hughes Medical Institute

Identification of Novel Pathogenic Genes in Juvenile Systemic Sclerosis
Dr. Kathryn Torok, MD
Pittsburgh Children's Hospital

In collaboration with
Dan Kastner, MD, PhD
Elaine Remmers, PhD
National Human Genome Research Institute

Spatial Transcriptomics of Skin to Augment Understanding of Cellular Interactions and Disease Propagation in Juvenile Scleroderma
Kathryn Torok, MD
UPMC Children's Hospital of Pittsburgh

Wei Chen, PhD
University of Pittsburgh

Next Generation Proteomics to Identify Novel Immune Targets for Scleroderma
Gerlinde Wernig, MD
Stanford University School of Medicine

A Gene Expression Map of Scleroderma
Michael L. Whitfield, PhD
Geisel School of Medicine at Dartmouth

Multi-omic Profiling of Interstitial Lung Disease in Systemic Sclerosis
Paul Wolters, MD
University of California San Francisco

Gerlinde Wernig, MD
Howard Chang, MD, PhD
Stanford University School of Medicine

Identifying unique molecular profiles of subtypes of scleroderma-associated ILD
Paul Wolters, MD
University of California
San Francisco

Identifying and Optimizing Care for Mechanistically-Driven, Clinically-Relevant Scleroderma Subgroups
Scott Zeger, PhD
Ami Shah, MD, MHS
Johns Hopkins University School of Medicine

On-Going Projects

Genome Research in African American Scleroderma Patients (GRASP) Study
Francesco Boin, MD
Cedars-Sinai Medical Center

Fredrick M. Wigley, MD
Johns Hopkins University School of Medicine

Pravitt Gourh, MD
National Institute of Arthritis and Musculoskeletal and Skin Diseases

Dan Kastner, MD, PhD
National Human Genome Research Institute

Scleroderma Twin Study
Howard Y. Chang, MD, PhD
Stanford University School of Medicine
Howard Hughes Medical Institute

Naturally Presented Topoisomerase Epitopes in Scleroderma Patients with HLA-DPB1*13:01
Erika Darrah, PD
Elena Tiniakou, MD
Hopkins University School of Medicine

SRF and Scleroderma Clinical Trials Consortium (SCTC) Jointly Funded Projects

Systemic Sclerosis Interstitial Lung Disease Progression (SILPRO) Score: Development of a Disease-Specific Model to Define Progression of SSc-ILD
Cosimo Bruni, MD
Oliver Distler, PhD
University Hospital of Zurich, Switzerland

CRISTAL: Developing the Combined Response Index for Scleroderma Trials Assessing Limited Cutaneous Systemic Sclerosis)
Dinesh Khanna, MD, MSc
University of Michigan

Alain Lescoat, MD
University Hospital of Rennes

CONQUER

Collaborative, National Quality and Efficacy Registry

Holding true to our belief that research is the best hope of finding a cure, the SRF launched CONQUER in 2018 - the first nationwide patient registry and biorepository to track clinical data and health outcomes of scleroderma patients over many years with the goal of improving care and paving the way for more patient-specific therapies.

CONQUER became operational in 2019 through a collaborative effort among some of the largest scleroderma centers in the U.S., and has grown from 12 founding consortium members to 17 participating centers in 2022.

Since its launch, more than 750 scleroderma patients have enrolled in the registry, contributing vital data for analysis to increase our understanding of the scleroderma. As a result, CONQUER is becoming an international gold standard registry and patient data contributed is now being used to drive innovative scleroderma research.

How CONQUER data advanced scleroderma research in 2022:

- Four manuscripts were published by CONQUER consortium members, with more in the pipeline for release in 2023, helping to increase the science community's understanding of this disease.
- CONQUER data was used in securing a \$1M Department of Defense grant to support innovative, high-impact scleroderma research.
- Pharmaceutical company, Boehringer Ingelheim, (founding sponsor of CONQUER) funded a \$450K CONQUER substudy to assess protein markers found in patient biosamples to see how they may correlate with disease progression over time.
- This year the SRF announced the newly created "Wright/Evvin CONQUER Research Grant" to offer funding exclusively for innovative projects that leverage CONQUER data.
- CONQUER aims to enroll more than 875 patients by the end of 2023, and with each patient's enrollment and new collaborating center that joins the consortium, we take one step forward on the path to a cure.



With every research study, we are on the verge of the next breakthrough.

— Raele Robison, dx 2017

Introducing

CONQUEST

Scleroderma Research Foundation
Platform Clinical Trial

The SRF's Groundbreaking Platform Clinical Trial

After years of development, in 2022 the Scleroderma Research Foundation received FDA approval for CONQUEST—a highly innovative clinical trial platform aimed at advancing treatments for interstitial lung disease associated with systemic sclerosis (SSc-ILD), one of the most life-threatening complications of the scleroderma. **Conceived and led by the SRF, the CONQUEST platform clinical trial is the first of its kind to be used for rare autoimmune diseases.**

Using a model created over a decade ago to accelerate oncology drug development, CONQUEST is designed to rapidly advance promising treatments for scleroderma and to identify those agents that should progress from Phase 2b to Phase 3 clinical trials. Its revolutionary "Pick-the-winner" design will substantially speed the process of bringing new, effective therapies to market, and maximizes patient welfare.

With an anticipated launch sometime in 2023, this groundbreaking effort will ultimately enroll approximately 400 patients across more than 130 participating centers in over 22 countries.

Data Sharing is Extremely Important To Us.

As investigational drugs move through CONQUEST, the SRF will work closely with its pharmaceutical partners to share news about the outcome(s). The SRF will also own non-proprietary outcomes data collected from placebo patients. We believe this data will be an important component of a growing asset base that has the potential to identify and accelerate new therapies for scleroderma.

CONQUEST is Made Possible by Donor Support.

As with all of our research efforts, the incubation and administration of CONQUEST has been underwritten by the generosity of the scleroderma community. Thanks to initial seed funding from Tony & Judy Evvin and Dan & Jayna Schimberg, plus generous support from annual donors, and essential contributions from industry, science, and medical partners, today we are poised to rapidly advance promising new treatments for all people living with scleroderma.



CONQUEST is a huge step forward and I am honored to lead a truly global effort that will speed the introduction of highly effective therapies to patients.

— Dinesh Khanna, MD
CONQUEST Principal Investigator and Frederick G.L. Huetwell Professor of Medicine and Director, University of Michigan Scleroderma Center

Bob Saget's legacy:

The Bob Saget Memorial Scleroderma Research Fund

❖❖❖ The SRF will cure scleroderma — that I am positive of.

— Bob Saget

Even before losing his sister, Gay Saget, to the disease in 1994, Bob Saget was a devoted champion for the scleroderma community. He passionately sought to find a cure and was deeply dedicated to the mission of the SRF. When Bob passed suddenly on January 9, 2022, we—along with the entire world—were overcome with grief. We channeled our loss into action so that we could keep Bob's dream ending scleroderma alive, and so we formed the Bob Saget Memorial Scleroderma Research Fund.

More than 4,180 individuals responded generously, demonstrating the impact Bob had on raising awareness and his passion for finding a cure.

These gifts seeded The Bob Saget Memorial Scleroderma Research Fund, which directly supports the SRF's core research initiatives. The fund is already being used to support the most promising, innovative scleroderma research through grants awarded in 2022.

This fund is and will continue to be instrumental to driving research forward until the day we can celebrate because we have found a cure.



❖❖❖ We, along with Bob's family, want to honor him and the legacy he wanted to leave behind, to recognize his singular and lifelong commitment to the Scleroderma Research Foundation, and to help us find a way to turn this horrible moment into something for the good. Deann and I have pledged to match the first \$1.5 million that is received in this tribute.

— Luke Evnin, PhD, Chairman of the SRF Board

Lovingly remembered by his family, friends, and the scleroderma community.



In the weeks following the loss of Bob, his friends and family gathered to celebrate his life with laughter at The Comedy Store. Jim Carrey, Chris Rock, Jeffrey Ross, John Mayer, and John Stamos joined Bob's wife, Kelly Rizzo, for a special evening that raised \$7,500. This show is streaming on Netflix as *Dirty Daddy: The Bob Saget Tribute*.



David A. first met Bob in the 90's when he attended CCHC with his mother who had scleroderma. Although she passed away in 2015, he continues to volunteer to this day, inspired by Bob's commitment to find a cure.



In the days following Bob's passing, his dear friend John Mayer had a hoodie designed to keep Bob's memory and his enduring fight for a cure alive. All proceeds—a total of \$80,000—have directly benefited our work to fund research for a cure.

John Mayer with Bob at Cool Comedy Hot Cuisine, Los Angeles in 2019

"Bob Saget may have been America's dad, Danny Tanner on *Full House*, the host of *America's Funniest Home Videos*, and a stand up comic, but to the scleroderma community he is known as one of the biggest advocates and heroes for finding a cure for scleroderma."

— Evamarie Cole



"There are no words for the loss. RIP Bob and fly with the angels. We all miss you and are filled with eternal gratitude."

— Cheryl Grossman



In Netflix's *The Hall*, Jeff Ross asked viewers to remember Bob and honor his lifelong work to help find a cure for scleroderma by supporting the SRF. And, he participated in *Celebrity Game Face*, hosted by Kevin Hart, where he won \$10,000 to help us advance research for a cure.

Jeff with Bob at Cool Comedy • Hot Cuisine, in 2018



After posthumously airing an interview with Bob, *Luminary* and its show *Til This Day with Radio Rahim* generously matched gifts made to the Bob Saget Memorial Scleroderma Research Fund and helped to raise awareness in Bob's memory.



This year, Jodie Sweetin played for the Scleroderma Research Foundation on *Name that Tune* in Bob's honor. The SRF received a gift of \$10,000 in prize money after she won the popular TV show.

Jodie with Bob at Cool Comedy • Hot Cuisine in 2015



Candace Cameron Bure partnered with The Shop Forward to create a special series of Bob Saget themed apparel. The Shop Forward then donated 100% of proceeds from sales in honor of Bob, raising \$215,000.

Candace with Bob at Cool Comedy Hot Cuisine, New York in 2015

[CLICK HERE](#) to make a gift to the Bob Saget Memorial Scleroderma Research Fund.



Cool Comedy • Hot Cuisine

A Tribute To Bob Saget

On Sept. 21, 2022, SRF's annual Cool Comedy • Hot Cuisine was held as a special tribute to our beloved Bob Saget. Many of Bob's dearest friends & family – including some of the world's most talented performers and comedy industry legends - gathered in LA at the Beverly Wilshire Hotel to remember Bob not only for how he made us laugh, but also for being a relentless champion for all those affected by scleroderma.

Hosted by: **Jimmy Kimmel, John Mayer, Jeff Ross**

Co-Chairs: **John Mayer, Kelly Rizzo, and Jeff Ross, with Chef Susan Feniger**

Featuring: **Regina Hall, Howie Mandel, Joel McHale, Kevin Nealon, & John Stamos with surprise performances by Mike Binder, Bill Burr, and Dave Chappelle**

All who supported the event honored Bob's legacy and celebrated his life by sharing love, laughter, incredible food, and **raising an astounding \$1.3 Million** to fund research that will achieve his goal of ending this disease.



❖❖❖ The heart and soul of every event is to raise as much money as possible for research focusing on how to eradicate this horrific disease—while laughing. It's just part of what Bob had always taught me, and taught everybody. To get through the hard times, you have to laugh.

— Kelly Rizzo



A Community United

Collaborating together with volunteers, advocates, and supporters to educate, inform, and share stories of impact.



❖❖❖ The scleroderma community gives me the motivation to keep fighting day by day.

— Kimberly G., dx 2008

Providing Education and Awareness

The Scleroderma Research Foundation strives to provide the most relevant news and information about scleroderma complications, treatments, and research. We do this by creating informative website content, educational webinars, disease awareness campaigns, and more to provide trusted resources and amplify awareness.

Awareness Month Campaigns

Raynaud's Phenomenon Awareness

Pulmonary Arterial Hypertension Awareness

Rare Disease Awareness

Scleroderma Awareness

Interstitial Lung Disease Awareness

3.2M+ impressions on 465 social media posts

265,800+ direct emails sent to the SRF community

Expanding our reach to a global community

Facebook
Instagram
LinkedIn
Twitter
TikTok (new)
YouTube
SRF Website
eNewsletter

242,403 visitors to the SRF website

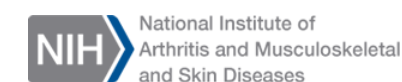
43,400+ views of videos on our YouTube library

Grew social media audience by **30k+**

Hosted webinars with **843 registrants**

New: SRF online Patient Forum with **7 topical sessions**

Community Partnerships



ProjectScleroderma

Providing Education and Awareness

The SRF Patient Forum

On June 1, the SRF hosted the inaugural Patient Forum, "Collaborating for a Cure", a half-day online educational forum for people living with scleroderma and those who care about them.

We created this forum to provide a deeper knowledge and understanding of scleroderma, updates on the current research including new initiatives, and information on how to participate in research. Topics included the basics of scleroderma, managing GI symptoms, the impact of Interstitial Lung Disease on those with scleroderma, how genomics can help us find a cure, and more.



It was wonderful to get first-hand data in a format that was understandable to me.

— Donna J.

[CLICK HERE](#) if you missed the Patient Forum, you can watch the sessions on our YouTube channel.

Providing Education and Awareness

Corporate Partnerships

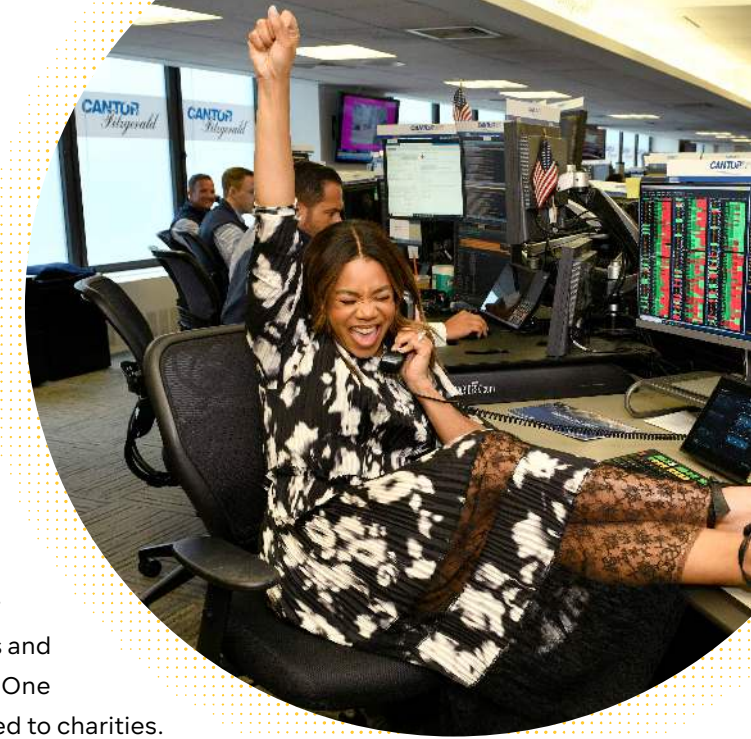
The SRF is honored to collaborate with corporations who believe in and support our mission through their cause-related partnerships.

Advancing research is only possible through collaboration.

— Regina Hall, SRF Board Member

This year, SRF Board Member Regina Hall represented the Scleroderma Research Foundation as our Celebrity Ambassador for the annual Cantor Fitzgerald Charity Day, an event where celebrities and licensed brokers team up on trading floors to conduct transactions. One hundred percent of the firm's global revenues that day are distributed to charities.

Together, Regina and Cantor Fitzgerald helped to make a meaningful difference by funding research and spreading awareness to end scleroderma.



Education and Awareness Corporate Partners

We wish to thank the following industry partners for their generous support of our education and outreach initiatives. Their partnership enables us to provide resources, education, and information to the scleroderma community and beyond.



Golf for a Cause

Over 100 golfers participated in the inaugural Elfus Sports Management (ESM) Foundation Charity Golf Tournament and helped raise over \$10,000 for the SRF.

The tournament was created by Brian Elfus to bring awareness and financial support to the rare diseases that changed the lives of his mother and wife. Committed to making a difference for those living with fibromuscular dysplasia and scleroderma, Brian and a close group of friends and family came together for a day of fundraising and fun at the Aviara Golf Club in San Diego.



NFTs for Scleroderma Awareness

Skincare company FOREO Sweden wanted to help shine a spotlight on skin conditions and support people struggling with diseases like scleroderma by donating a percent of sales of their first-ever NFT to the SRF. They also helped raise awareness about scleroderma and the work of the SRF on social media.

Advancing Research Together: The Cure Crew

The Scleroderma Research Foundation's Cure Crew is a grassroots volunteer program that raises awareness about scleroderma and funds to support the SRF's research to help people with scleroderma live longer, fuller lives, and lead us closer to a cure.

This collaborative community of dedicated Cure Crew members raised more than \$157,000 this year alone to support scleroderma research and devoted countless hours to raising critical awareness about this disease through social media advocacy, cause-related marketing, and more.



Staying Sharp for Research

Jess M., who lives with scleroderma, contributed 10% of sales from her knife sharpening service—more than \$3,000—to fund scleroderma research and spread awareness of scleroderma.

❖❖❖ Scleroderma affects my hands in various ways and having a sharp knife is truly safer... I'm proud of our business and proud to have the opportunity to raise money for the Scleroderma Research Foundation.

— Jess M., dx 2011

Restaurant Revenue Supports the SRF

On June 28, longtime Cure Crew member Beth L. (center), co-owner of the Grove Wine Bars, hosted a fundraiser for the SRF. By contributing 10% of her restaurants' profits, she raised \$11,190 to advance research in memory of her mother, Betty, who passed from scleroderma complications in 2009.

Best Medicine for a Cure

Over the past 7 years, this Connors-McBride and Zini family event has raised over \$30,000 through their annual Best Medicine for a Cure event benefiting the SRF. This event is in memory of Patty, pictured here, who passed from scleroderma complications.

Advocating for Awareness & Research

Jamie spreads scleroderma awareness to thousands of people. She shares her disease journey and scleroderma education on social media and wherever she goes.

❖❖❖ Scleroderma has given me a new purpose in life to share my love with those who are also affected, while also sharing my knowledge of the disease.

— Jamie M., dx 2015



27th Annual Casino Night Fundraiser

The Kosmach-Schumacher family have hosted their annual Bet on a Cure event for 27 years after losing their mother Joan Kosmach to scleroderma in 1995. They have raised almost half a million dollars for the SRF.



Running for Research

After a friend passed from scleroderma complications, Sam L. raised more than \$10,000 by running the 2022 Chicago Marathon in his friend's memory.

The Impact of Your Support

Your support enables research that will translate into better, longer lives for those living with scleroderma.



FY22 Financial Highlights

The Impact of Your Investment

Since its founding in 1987, the SRF has remained at the forefront of scleroderma research contributing to a significantly greater understanding of the disease, its progression, and treatment options. Year after year, important and generous donor support has been the driving force behind our relentless pursuit of a cure, and it ensures we remain the leading, trusted, and most impactful nonprofit investor in scleroderma-related research in the United States.

Where Your Money Goes:

76.8%

Research & Education:
\$3,740,099

5.8%

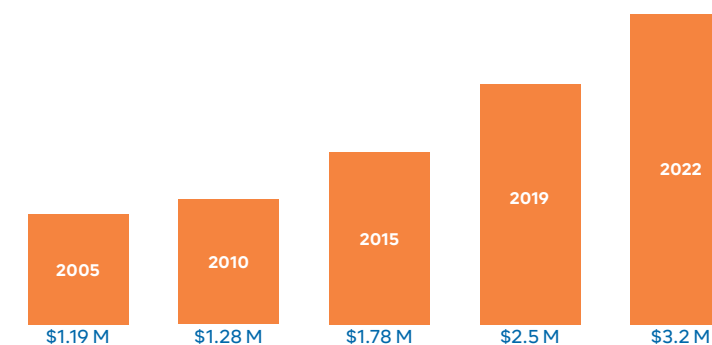
Administration:
\$284,544

17.4%

Fundraising:
\$845,671

Total Expenses: \$4,870,314

Research Investment Growth



Your Donations Fuel Our Mission

Contributions: \$4,410,598 (84%)

Bequests: \$313,228 (5%)

Events: \$1,291,842 (22%)

Investment Income: - \$715,680 (-12%)

Total Revenue: \$5,299,988

You can rest assured that your gift will be used responsibly and effectively because the SRF has received the highest ratings from Candid. (formerly GuideStar) and Charity Navigator, the largest and most trusted independent evaluators of nonprofit organizations.



❖❖❖ If research continues to expand, my lifespan will be lengthened.

— Jessica M., dx 2010

[CLICK HERE](#) to view our complete audited financials.

Our Donors



❖❖❖ The work that SRF is doing honestly gives us some hope for our daughter Kate, and we are honored to partner with you and your team to bring hope to others.

— Matthew Prior

Matt P., pictured with Kate (dx 2012) and wife, Becky.

Leadership Donors

Over 7,100 generous donors supported our research mission in 2022. We offer our deepest gratitude to the following supporters whose generous leadership-level gifts fueled our progress and helped us achieve our ambitious research agenda.

A Little Help Foundation Fund	Cantor Fitzgerald Relief Fund Administration	Janssen Pharmaceuticals, Inc.	The Nancy P. and Richard K. Robbins Family Foundation
AE Family Foundation	Macaulay Culkin and Brenda Song	Estate of Eva Jenkins	The Shop Forward
Omar and Behnaz Baker	Luke Evnin	Kao Family Foundation	Christine Lico Weigelt
Boehringer Ingelheim Pharmaceuticals Inc.	Bill Fairey	Janine Luke	Victoria West and Marc Trachtenberg
Kevin and Claudia Bright	Leslie Gaynor	Merck & Company	Deann Wright
Gretchen and Stephen Burke	Jill Grey	Andy and Violetta Merin	
Cameo	Bill and Marjorie Holodnak	Max, Samantha, Montana, and Mark Scher	
Sara and Arthur Lloyd Campbell	Horizon Therapeutics	Dan and Jayna Schimberg	

We are grateful for every single gift that helps bring us closer to a cure. The following is a list of SRF supporters who made gifts of \$1,000, or more in 2022.

189 Anonymous Donors	Alan Baral and Sharre Jacoby	Brillstein Entertainment Partners	Cedar Park Grove
3Red Partners	Glen Barros	Sari and Alan Brown	Jeffrey T. Chambers and Andrea Okamura
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John and Audrey Bamberger	Katy Bradley	Harold and Ofelia Careway	
Bank of America Foundation (Matching Gift Program)	Kristy Braga	John Caroli	
	Brigitte and Bobby Sherman		
	Children's Foundation		

❖❖❖ I donated to the SRF in honor of my mother, Beatrice Gaynor, who was afflicted with this terrible disease. I hope my gift will enable researchers to better understand why scleroderma so disproportionately impacts women and will help to lead to a cure.

— Leslie G.

Beatrice Gaynor, 1919 - 1978, with Leslie Gaynor



Our Donors

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Peter and Sandra Irvin

❖❖❖ My wife Sandra was diagnosed with scleroderma in 2021 so the disease is front and center in our lives. We truly believe SRF can find a cure with the proper funding.

— Peter Irvin

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❖❖❖ Thanks for giving us hope! We so appreciate your hard work and determination to find a cure. Bless you all!

— Marnie, Josh, and Maddy S.



Josh, Maddy, and Marnie Shreeman

[CLICK HERE](#) to view even more of our 2022 donors.

In Memory Donations

The following individuals were remembered by friends and family members who made gifts to honor their memory in 2022. We extend our deepest sympathies to all those who have lost these loved ones.

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Ron (dx 2008) and Sharon LaMar

❖❖❖ Thank you for doing what you do — it gives hope to people affected by this disease and to those left behind. I donate in loving memory of my husband who lived with scleroderma for 9 years. — Sharon L.

In Honor Donations

Gifts made to the SRF in honor of special people or celebrating important milestones make a significant impact on our research progress. The following people were recognized with a tribute gift in 2022.

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After I'm gone, I want to help others with scleroderma by supporting research.

I am so proud of my dear friend in her fight with scleroderma. Her bravery, courage, dignity, and the way she lives out each day are incredibly inspiring to others.

— Lauren C.

Katherine Wall (dx 2018) and Lauren Crow

The Sharon Monsky Legacy Society



SRF Founder Sharon Monsky, 1953-2002

In 1987, scleroderma patient Sharon Monsky founded the SRF with the belief that funding medical research was the best way to give hope to those living with scleroderma. Sharon understood that research is a journey; one that would not be completed in her lifetime—but that the journey had to begin somewhere and ultimately a cure would one day be found. Although Sharon passed away from complications of scleroderma in 2002, her passion, commitment and fearless determination to end this disease continues to inspire people today.

The Sharon Monsky Legacy Society honors compassionate, philanthropic individuals who have chosen to support the future of scleroderma research beyond their lifetimes. Participation in the Sharon Monsky Legacy Society gives the SRF an opportunity to celebrate donors now for a gift they will make in the future and helps ensure that we are able to continue our mission for years to come.



After I'm gone, I want to help others with scleroderma by supporting research.

— Ile G., Legacy Society Member, dx 2019

Thank you to the following Legacy Society members whose thoughtful planning will impact the SRF research program in years to come.

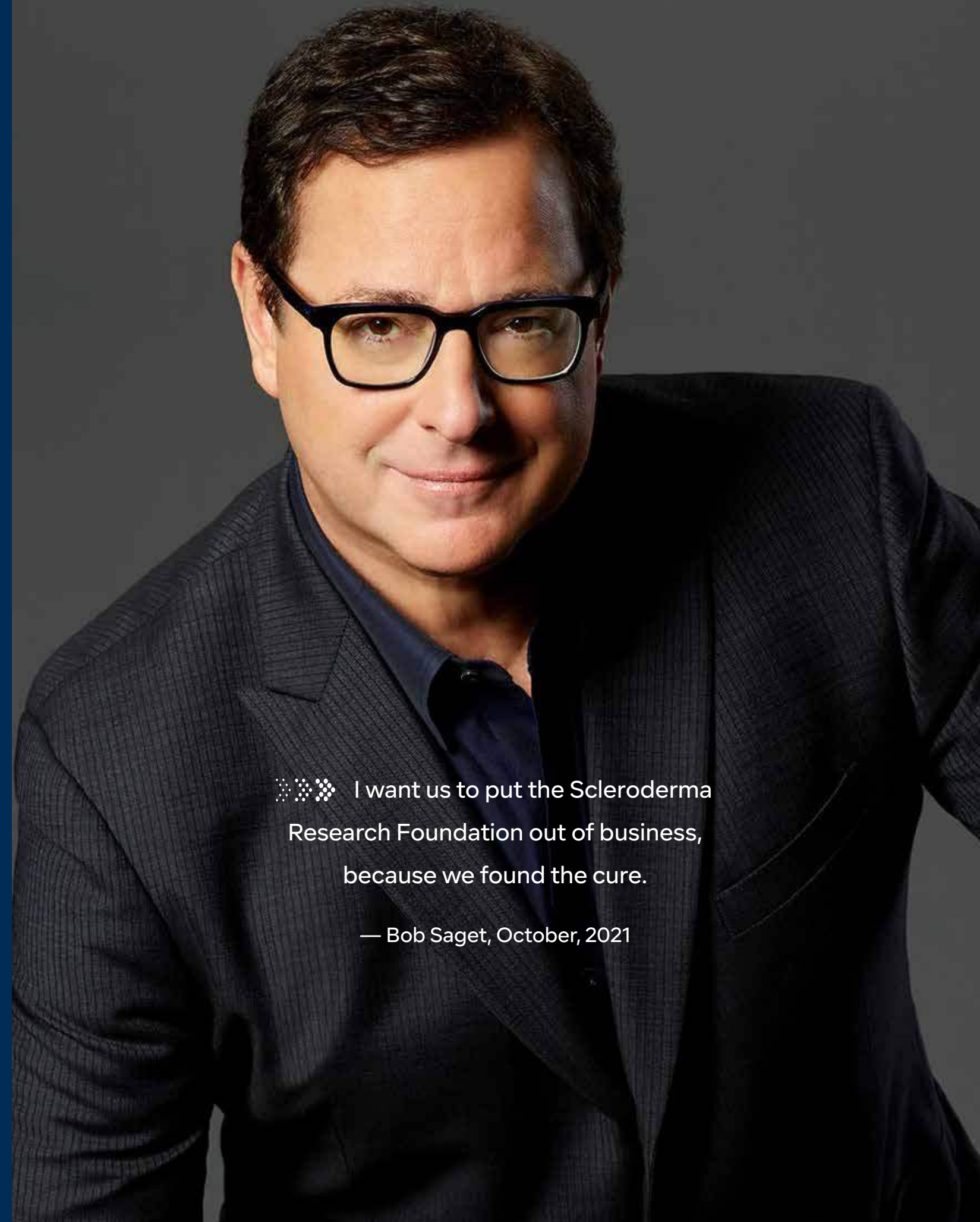
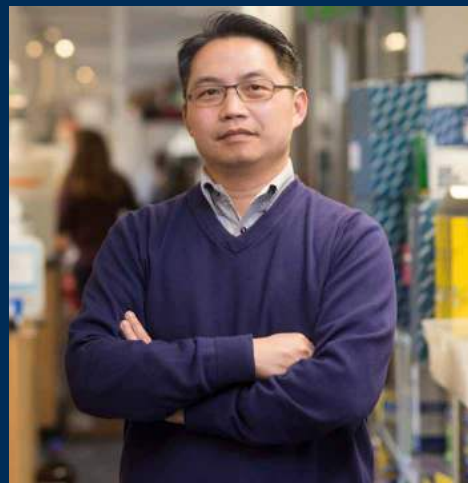
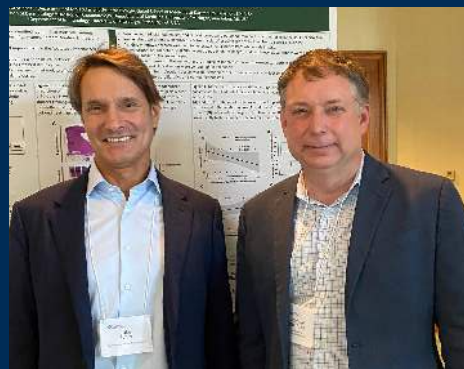
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We honor the following Legacy Society members whose estate gifts have made a lasting impact on the scleroderma community.

- | | | | |
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| Estate of Irene Adele Barg | Estate of Edward Klinger | Neptune Family Trust | Marion Ternstrom Endowment Fund |
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Research is the key to ending scleroderma, and the collaboration of our entire community is the key to moving research forward.

— Luke Evin, PhD, Chairman of the Board



I want us to put the Scleroderma Research Foundation out of business, because we found the cure.

— Bob Saget, October, 2021

SCLERODERMA
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