



**SCLERODERMA
RESEARCH
FOUNDATION**



2021 Annual Report

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.

Our Vision

A world without scleroderma

What We Do

The SRF is the United States' leading nonprofit investor in scleroderma research and is laser-focused on finding a cure for this rare and deadly disease. Led by the most distinguished scientific minds, our research program seeks to understand scleroderma by facilitating research and collaboration among the world's top scientists and medical institutions. We also strive to provide education for those living with scleroderma and increase knowledge about this disease in the medical community and the general public.

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.



*Rosemarie C. (dx 1998)
and her family.*

"I'm hopeful that now I can live to see my daughter grow up. If you found a cure, that would be the best...to see my family grow. Thank you to all of the SRF supporters for contributing to scleroderma research!" — Rosemarie C.

Message from SRF Chair, Luke Evin

Dear Friends,

At the close of 2021, despite the ongoing Covid-19 pandemic, the Scleroderma Research Foundation (SRF) was poised to look back and celebrate our many achievements after what had been a challenging, but ultimately very successful year. But now as I write this message in the new year, it's not possible to look back at 2021 without seeing it through the lens of the tragic loss we experienced on January 9th, 2022, when we—along with the rest of the world—mourned the unexpected passing of our beloved friend and SRF Board Member, Bob Saget.

For the past 30 years, the SRF has reported on our progress with Bob by our side to help lead the way, driven by his passion to find a cure for the disease that had claimed the life of his beloved sister, Gay, in 1994. Bob became a champion of the scleroderma community even before losing Gay, as a result of his friendship with SRF founder, Sharon Monsky. Beginning in 1991, he performed at—and later went on to be the host and producer of—SRF's signature Cool Comedy • Hot Cuisine event, to help raise awareness and funds for research. Bob later went on to join our Board of Directors in 2003, playing a pivotal role in the foundation's success by actively helping to shape our strategic vision and contributing to our day-to-day operations. He frequently met with patients, built lasting relationships, and shared his personal story in the media to shine a spotlight on this little-known disease. Bob passionately sought to find a cure and was deeply dedicated to the mission of the SRF in every way.

And so, with Bob in our hearts and minds, we are resolved to push forward, knowing he is cheering us on towards our shared goal: a world free from scleroderma.

To follow are a few highlights of the SRF's recent accomplishments that are driving efforts to achieve that goal:

- **Impactful Research Investments:** Turning donor's charitable dollars into the most promising, cutting-

edge scleroderma research continues to be at the center of what we do at the SRF. Top research priorities include advancing our understanding of the disease (who gets it and how it progresses), and enabling the development of improved, patient-specific treatments that may one day lead to a cure. In 2021, SRF-funded research progress continued as demonstrated by several significant scientific publications, including a manuscript from the Chang lab published in *Cell* (with insights on the gender bias in autoimmune diseases) and another in *PNAS* from a collaboration between the Longaker and Chang labs (on the key cell types in tissue repair).

Thanks to generous donor support, we were able to invest \$2.6 million in 2021 to support exceptional basic and translational research, continuing our impact as the nation's largest nonprofit investor in scleroderma research.

- **Advancing Precision Medicine:** While Covid-19 continued to disrupt lab and clinic operations in 2021, we take great pride in reporting that collaborating institutions were able to enroll over 100 new patients in CONQUER, the nation's only multi-institutional longitudinal patient registry which was launched by the SRF in 2018. More than 600 scleroderma patients are now participating in CONQUER, providing vital data needed to help researchers better understand the disease and how it progresses over time. In 2022, we will take this project to the next level of impact by welcoming additional participating medical centers and supporting novel translational research using the current CONQUER data.
- **Building a Collaborative Community:** In April 2021, we held our annual Science Workshop virtually for the second time, with excellent results. This impactful meeting assembled our distinguished Scientific Advisory Board along with funded scientists and new applicants who shared updates on their research endeavors and engaged in collaborative discussions. The intensive two days of meetings uniquely help to foster cross-institutional relationships among the world's top scleroderma scientists and clinicians and guides the SRF's funding decisions.

- **Leadership Distinction:** SRF Scientific Advisor, Dan Kastner, MD, PhD, was awarded the 2021 Crafoord Prize in Polyarthrititis by the Royal Swedish Academy of Sciences for his groundbreaking work at the NIH to discover and elucidate the characteristics of a class of diseases called autoinflammatory diseases. The Crafoord Prize is one of the most notable international science prizes. It is considered to be a complement to—and for some researchers a precursor to—a Nobel Prize. It's an honor to have such a distinguished scientist as Dr. Kastner as one of the esteemed members of our Scientific Advisory Board (page 7), and to be able to rely on his insights and guidance in optimizing the SRF's research program.
- **Raising Critical Funds and Awareness:** We held our signature Cool Comedy • Hot Cuisine (CCHC) virtually for the second time in 2021, and the online event not only raised more than \$700K to support SRF's research programs, it also reached an unprecedented global audience to spread awareness about scleroderma. Viewers from 13 countries watched the broadcast and interacted with the event via social media. And although it was gratifying to have so many people join us virtually for CCHC, we're looking forward to returning to in-person events in 2022.
- **Partnering with Supporters:** The ongoing pandemic prompted remarkable ingenuity from volunteers and advocates, as the scleroderma community sought ways to stay connected,

support one another, and raise funds to advance the SRF's mission. In the past year, our dedicated and ever-resilient Cure Crew members raised over \$100,000 to support research (both in-person and online) and devoted countless hours to raise critical awareness about this disease through social media advocacy, cause-marketing, and more.

As an organization, we continually assess our activities through the eyes of those we serve. Ultimately, we attribute our achievements this year to that viewpoint. All of our progress in 2021—and in the 34 years since our founding—was made possible through the support, dedication and unwavering determination of the scleroderma community. Your generosity and partnership has been, and continues to be, essential to our shared goal of one day ending this disease. Thank you.

Luke Evin, PhD
Chair, SRF Board of Directors

"The exceptional nature of the research we fund is not the only thing that distinguishes the SRF. We're also defined by the unwavering support of our scleroderma community."



 Board of Directors



Luke Evin, PhD, Chairman (2000)
Managing Director and Co-Founder, MPM Capital



Sharon Dobie, MD (2017)
Physician



Susan Feniger (1986)
Chef and Restaurateur



Regina Hall (2020)
Actor and Producer



Eric Kau, MD (2014)
Physician



David Knoller (2015)
Producer, Writer, and Director



Violetta Merin (2017)
Community Leader and Philanthropist



Bob Saget (in Memoriam)
Board Member, 2003–2022, SRF Ambassador since 1991, a scleroderma champion and beloved friend.



Bob Smith (2019)
Pharmaceutical Leader



Deann Wright, JD (2000)
Attorney



Caryn Zucker (2005)
Community Leader and Philanthropist



Dana Delany (2005, emeritus)
Actor



Sharon L. Monsky
1953–2002
SRF Founder

“When my mom was diagnosed with scleroderma, I knew I had to do everything in my power to help advance research and raise awareness about this disease so that others wouldn’t have to suffer. It’s an honor to serve on the SRF Board of Directors, and I’m dedicated to doing all I can to help achieve our mission of finding a cure.” — Regina Hall, SRF Board Member

 Scientific Advisory Board

The individuals on the SRF Scientific Advisory Board (SAB) are some of the world’s most honored and distinguished scientists. These renowned researchers volunteer their time and expertise to guide the Foundation’s research program, evaluate research proposals, make funding recommendations, and foster discussion and collaboration amongst funded investigators to help advance research progress. To learn more about the scientists of the SRF’s Scientific Advisory Board, please visit srfcure.org/about/scientific-advisory-board.



Bruce Alberts, PhD, Chairman
UCSF, National Academy of Sciences



David Botstein, PhD
CSO, Calico Life Sciences; Princeton University; National Academy of Sciences



Hal Dietz, MD
Johns Hopkins University; HHMI; National Academy of Sciences



Dan Kastner, MD, PhD
Distinguished and Senior Investigator, National Human Genome Research Institute (NHGRI), National Academy of Sciences



Lloyd Klickstein, MD, PhD
CSO, Versanis Bio



Dan Littman, MD, PhD
NYU, HHMI, National Academy of Sciences



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



Bruce Wintroub, MD
University of California, San Francisco

 SRF Staff

- Joanne Gold**
Executive Director
- Cori Traub**
Director of Philanthropy
- Gloria Blecha**
Director of Community Engagement
- Adelyn Auza**
Database Manager
- Hannah Young**
Communications Manager



SRF Board Member, Bob Saget

May 17, 1956–Jan 9, 2022

It's not possible to look back at 2021 without seeing it through the lens of the tragic loss we experienced on January 9th, 2022, when we—along with the rest of the world—mourned the unexpected passing of our beloved friend and SRF Board Member, Bob Saget.

Bob was a passionate champion for scleroderma patients everywhere since 1991 when he first encountered the Scleroderma Research Foundation as an attendee at the SRF's signature fundraising event, Cool Comedy • Hot Cuisine (CCHC). Here he met Sharon Monsky, SRF Founder who, together with SRF Board Member Susan Feniger were the initial force behind CCHC. These three would become close friends through a shared desire to end this devastating disease. Though this was one year before his own sister Gay would be diagnosed with the disease, from that moment on Bob dedicated his life to raising awareness about scleroderma, advocating for research to find a cure, and giving a voice to all people impacted by this disease.



June 6, 1991

Bob attends Cool Comedy • Hot Cuisine for the first time and learns about scleroderma. Legendary comedian, Robin Williams, headlined the event.



1992

Bob first performs at Cool Comedy • Hot Cuisine. Later that year, his sister Gay Saget is diagnosed with scleroderma.



1993

Bob becomes the Cool Comedy • Hot Cuisine host, a role he would play for the rest of his life where he helped to raise more than \$25M for scleroderma research.

"I will spend my life dedicated to helping our amazing Board of Directors at the incredible Scleroderma Research Foundation to work with the best medical minds in science as we raise the funds for research to one day find a cure."

— Bob Saget

Bob Saget—A Lifetime of Dedication to Our Mission

Bob's commitment to the SRF may have started with his friendship with Sharon Monsky and later with his sister Gay's scleroderma diagnosis, but his passion and dedication for our mission grew as he personally came to know so many patients and people whose lives have been touched by scleroderma.





Bob pictured with SRF founder Sharon Monsky, a funded researcher, and scientific advisors at a 1999 Media Day event at UCSF.

In 1992, Bob first performed at CCHC; the next year, he became the event's co-host and producer. Nobody understood better than Bob the power of laughter to shed light on a serious subject. After Sharon passed in 2002, Bob was committed to continuing the SRF's fundraising efforts and, together with SRF Board Member Susan Feniger, he took on the mantle of CCHC Event Chair. Through his leadership, the event brought together some of the world's greatest comedians and performing artists and raised over \$25 million to support the SRF's research programs.

In 2003, Bob officially joined the SRF Board of Directors, where he served tirelessly throughout the rest of his life. He actively contributed to the day-to-day operations of our organization and played a pivotal role in the SRF's success. Bob helped to develop lasting, impactful relationships to benefit our programs and connected deeply and personally with

patients. He drew media attention to this little-known disease through his gift of storytelling and laughter, and he openly shared his own experience of losing his sister to scleroderma.

Bob's incisive wit coupled with his huge heart helped everyone—patients, SRF staff and Board Members, researchers, clinicians, supporters, and fans around the world—remain laser-focused on finding a cure. We could not have asked for a more passionate, creative, and dedicated partner in our efforts.

Despite the grief of losing our dear friend, all of us at the SRF are committed to ensuring the goal Bob so passionately sought to achieve is reached: a world free from scleroderma.

With that goal in mind, we created the **Bob Saget Memorial Scleroderma Research Fund** as a lasting legacy to his life's work so that Bob will be remembered not only for all the ways he inspired us and made us laugh, but—most importantly—for helping to one day bring an end to this complicated disease. Anchored by a \$1.5 million donation from fellow board members Luke Evnin and Deann Wright, our goal is to raise a significant research-dedicated fund to help carry on Bob's legacy. To donate in Bob's memory, please go to srfcure.org.



At the 2015 CCHC event in LA, John Mayer, John Stamos, Bob Saget, Jim Gaffigan, Jimmy Kimmel, Jeff Garlin, Jack Black, Queen Latifah, Don Rickles, and Brad Grey.

"I wish he knew how much his dedication and advocacy meant to so many of us. He helped so many of us feel seen and heard. Above all, he helped us feel less alone. Whether it was with his comedy, helping us connect with lifelong friends, or reminding those of us seeking answers that someone did believe us, he truly made a difference."

— Charlotte R., SRF Supporter



1994

Bob's sister, Gay, passes away from scleroderma complications.



1996

Bob releases *For Hope*, an ABC TV film he executive produced and directed, to honor Gay's battle with scleroderma. He also appears alongside SRF Founder Sharon Monsky & SRF Board Member Emeritus Dana Delany in front of Congress to advocate for scleroderma research funding.



2003

Bob joins the SRF Board of Directors and becomes co-chair of Cool Comedy • Hot Cuisine.



2014

Bob co-produced and narrated the documentary film *"Beneath the Surface,"* with Project Scleroderma's Christy McCaffrey to raise awareness about the everyday struggles of scleroderma patients.



2017

The 30th anniversary of the SRF is celebrated at Cool Comedy • Hot Cuisine-LA which honored Bob and his 25 years of service. This single event raises over \$1M.



2020–2021

Bob produces and co-hosts the first-ever virtual Cool Comedy • Hot Cuisine event, which is broadcast to a global audience.



January 9, 2022

The world mourns the loss of Bob, our beloved friend, Board Member, and scleroderma champion.

What Drives Our Research Program

Research advances are the result of innovative thinking and a collaborative approach:

Impactful funding that is both broad and deep, to support exceptional basic and translational scleroderma research. The SRF's research program actively seeks out and recruits a hybrid group of investigators, including clinicians with profound scleroderma knowledge and scientists with expertise in many areas related to scleroderma research. We invest \$2M–\$3M annually in direct grants to support projects that are likely to move scleroderma research forward, and commit to support those studies for as long as it takes to yield definitive results. The SRF is America's largest nonprofit investor in scleroderma research and devotes a greater percentage of its annual budget to scleroderma research than any other nonprofit organization in the country.

A world-class Scientific Advisory Board to guide research priorities and evaluation. The esteemed members of our Scientific Advisory Board (SAB) are some of the world's most honored and distinguished scientists who give their time and insights freely to guide the Foundation's research program (see page 14). They evaluate research proposals, challenge assumptions, probe each project's relevance and

limitations, and help make funding recommendations, ensuring that we invest in the most promising research that can lead to disease-modifying therapies, or one day a cure.

Building a COMMUNITY to tackle ambitious research projects. By uniting top-tier investigators from across the nation in a research community, the SRF fosters collaboration that drives scleroderma research forward. At our annual Science Workshop which brings together all funded investigators, new applicants, and the SRF SAB, we ask tough questions, help break down arbitrary barriers, and provide opportunities for collaboration. We challenge assumptions by asking probing questions;

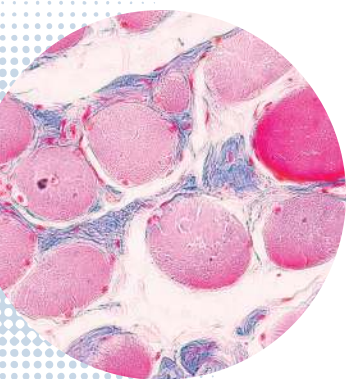
"Will this project create unique insights?"

"Will this answer a fundamental question about the scleroderma disease process?"

The constructive critiques and collaborative discussions at our Science Workshop often lead to new alliances, novel joint-research ventures, and a roadmap to future discoveries.

"Our research is trying to understand not just the symptoms, but to understand the root cause of the pathology that results in the symptoms. Ultimately, if successful, this type of approach is generally much more efficient because we can completely suppress the disease mechanism and not just suppress symptoms."

— Ruslan Medzhitov, SRF Funded Researcher



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



Francesco Boin, MD, Cedars Sinai, co-principal investigator of the SRF-funded GRASP project.

Addressing a Complex Disease

The SRF takes a multi-faceted approach, investing in the best ideas that will expand our knowledge of scleroderma, its underlying causes, and novel treatments that will allow patients to live longer, fuller lives. SRF-funded projects fall within one or more of these categories of discovery:

1 Understanding Who Gets Scleroderma: Genetics and Epigenetics of Susceptibility

This line of research is foundational to understanding who is more susceptible to getting the disease in the first place. Our research is examining the underlying genes and gene expression in people to learn, for example, why women are more susceptible than men, or why African-American scleroderma patients often have more severe disease than European-ancestry patients. This foundational research helps pinpoint the genes and complicated biological processes underlying the disease. One example of this type of research follows:

Scleroderma Twin Studies

Howard Chang, MD, PHD, Stanford University School of Medicine, Howard Hughes Medical Institute

In this study, Dr. Chang and his team are recruiting genetically identical twins where one twin has scleroderma and the other twin does not. Such identical, but “discordant twins” are uniquely informative because researchers have a perfect control for each patient—another person having the same genes, same age, and same household. Thus, the small differences researchers find between the twins will hopefully pinpoint disease-relevant differences. The study involves three key components: (i) careful evaluation of the clinical findings of each twin pair; (ii) a new ultra-sensitive technology called ATAC-seq to map the functional difference in gene control from the blood cells of the twin pairs; (iii) advanced bioinformatics methods to identify disease-relevant biomarkers and pathways.

Dr. Chang’s experience with a similar study looking at a more common disease in identical, but discordant twins (asthma) shows that this is a uniquely powerful approach to identifying disease-relevant mechanisms.

2 Unraveling How Scleroderma Progresses: Pathobiology of Initiation, Propagation, and Regulation

Several SRF-funded research projects are examining how and why immune responses differ between scleroderma and non-scleroderma patients by exploring what exactly is going wrong in the biological processes between the two groups. This can lead to a better understanding of how the disease will develop over time in patients as well as leading to improved diagnosis, monitoring and treatment. One example of this type of research follows:

Role of CXCL4-induced TLR9 Defects Promote the Production of Autoreactive B-cells in Scleroderma

Franck Barrat, PhD, Hospital for Special Surgery
Eric Meffre, PhD, Yale University School of Medicine

One of the hallmarks of scleroderma is the presence of autoantibodies and abnormalities of B cell function, which has been demonstrated in both animal models of scleroderma and in patients. SRF-funded research has shown that an important biomarker of scleroderma, called CXCL4, can inhibit a pathway that is critical for the elimination of B cells that produce these autoantibodies. In this collaborative project, Dr. Barrat and Dr. Meffre are investigating how CXCL4 impacts B cell selection and activation. Furthermore, they are exploring whether it is possible to block CXCL4’s undesirable effect on the elimination of autoreactive B cells. The ability to characterize the pathways controlled by CXCL4 in B cells in scleroderma patients may identify potential targets for drug development. Other potential benefits would be finding novel biomarkers to help predict disease evolution and select appropriate treatments.

3 Helping to Find a Cure: Enabling the Development of Patient-Specific Medicine

This line of research will enable the design of better clinical trials by helping to develop and test new treatments and generate information about which types of patients respond best to which therapies. When patients are categorized into specific groups (related to how the disease is progressing or whether they have ILD or GI symptoms, for example), testing of therapies can be more targeted to the specific types of patients, and thus clinical trials may have a greater likelihood of success. One example of this type of research follows:

Multi-omic Profiling of Interstitial Lung Disease in Systemic Sclerosis

Dr. Paul Wolters, MD, UC San Francisco
Gerlinde Wernig, MD, Stanford University
Howard Chang, MD, PhD, Stanford University, Howard Hughes Medical Institute

In this collaborative multi-institutional project, three SRF-funded researchers will study interstitial lung disease (ILD), a life-threatening complication of scleroderma, using multiple single-cell technologies. The study will generate rich data that will not only enable a detailed understanding of the cellular and molecular makeup of SSc-ILD lungs, but also will enhance our understanding of the two main classifications of SSc-ILD: Usual Interstitial Pneumonia and Nonspecific Interstitial Pneumonia. This innovative project will provide much-needed information about SSc-ILD that is impossible to acquire by other methods, and cannot be obtained from animal models. In addition, direct comparison of the SSc-ILD data with similar data obtained from Idiopathic Pulmonary Fibrosis (IPF) patients, will enable a detailed dissection of the similarities and differences between these two fibrotic lung diseases. It is a first-of-its-kind in SSc study that will substantially advance our understanding of SSc-ILD and help to inform the development of new therapies.

\$2.6M in Funded Research

Autoantibodies Targeting the Telomerase Complex in Scleroderma

Brittany Adler, MD
Johns Hopkins University School of Medicine

Role of CXCL4-induced TLR9 Defects Promote the Production of Autoreactive B-cells in Scleroderma

Franck Barrat, PhD
Hospital for Special Surgery

Eric Meffre, PhD
Yale University

Genome Research in African American Scleroderma Patients (The GRASP Project)

Francesco Boin, MD
Cedars-Sinai

Fredrick Wigley, MD
Johns Hopkins University School of Medicine

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

Pravitt Gourh, MD
National Institute of Arthritis & Musculoskeletal Disease

Gene Regulatory Mechanisms in Scleroderma

Epigenetics of Sex Differences in Scleroderma

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

Stanford Scleroderma Center of Excellence

Lorinda Chung, MD, MS
Stanford University School of Medicine

POL3-specific CD8+ T Cells as the Link Between Scleroderma and Anti-tumor Immune Responses

Naturally Presented Topoisomerase Epitopes in Scleroderma Patients with HLA-DPB1*13:01

Erika Darrach, PhD
Eleni Tiniakou, MD
Johns Hopkins University School of Medicine

Assessment of the Complement Cascade as a Novel Biomarker, Genetic Risk Factor, and Treatment Target for Systemic Sclerosis-associated Pulmonary Arterial Hypertension

Benjamin Korman, MD
University of Rochester

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

Measuring and Objectively Characterizing Patterns of Gastrointestinal Dysmotility in Scleroderma

Zsuzsanna McMahan, MD
Johns Hopkins University School of Medicine

Understanding the Biological Basis of Enteric Nervous System Dysfunction in 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

Immune Checkpoint Inhibitors as Antifibrotic Therapy 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

Johns Hopkins Scleroderma Center of Excellence

Fredrick Wigley, MD
Laura Hummers, MD, MPH
Ami Shah, MD, MHS
Johns Hopkins University School of Medicine

Identifying unique molecular profiles of subtypes of scleroderma-associated ILD

Paul Wolters, MD
University of California San Francisco

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 and Optimizing Care for Mechanistically-Driven, Clinically-Relevant Scleroderma Subgroups

Livia Casciola-Rosen, PhD
Scott Zeger, PhD
Ami Shah, MD, MHS
Antony Rosen, MD
Laura Hummers, MD, MPH
Johns Hopkins University School of Medicine

Betty Z. Benedict Award

(Co-funded with the Scleroderma Clinical Trials Consortium)

Sensitivity Analysis of Thermal Imaging in System Sclerosis-related Digital Vasculopathy (SATISS)

Andrea Murray, MD
University of Manchester, UK

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

The CONQUER Registry (Collaborative, National, Quality and Efficacy Registry)

see page 17 for Participating Institutions & Investigators

For more information about our Current Projects, visit srfcure.org/research/current-projects

Collaborating for a Cure: Patient Registries

The CONQUER Registry

- Why is it so difficult for physicians to predict an individual patient's disease course?
- What is the range of outcomes that a scleroderma patient might expect?
- What is the right therapy for any one patient?

The path to answering important questions like these requires tracking and collecting large amounts of data on patients' health status, disease complications, treatments, and outcomes over many years. The critical need for this type of comprehensive data is what inspired the Scleroderma Research Foundation to launch the CONQUER Registry in 2018, with the goal of helping researchers and clinicians to learn as much as possible about all forms of scleroderma in patients of all backgrounds. And, importantly, how scleroderma progresses.

CONQUER (an acronym for **CO**llaborative **N**ational **QU**ality and **E**fficacy Registry) is a first-of-its-kind nationwide patient registry and biosample repository. It is a highly collaborative effort involving some of the largest scleroderma centers throughout the U.S. Since its launch, more than 600 scleroderma patients have enrolled in the registry, contributing clinical data and blood samples collected during routine doctor visits twice a year. Although the Covid-19 pandemic

The GRASP Project

The GRASP Project, which stands for **G**enome **R**esearch in **A**frican-**A**merican **S**cleroderma **P**atients, was created to better understand from a genetic standpoint why African Americans seem to be affected by scleroderma more frequently and with greater severity than patients of European-ancestry.

The Scleroderma Research Foundation has been involved in the development and funding of the GRASP project since the very beginning, when the idea to develop a multi-center study was envisioned by Drs. Fred Wigley and Dan Kastner at an SRF Science Workshop. Today, more than 1,350 African American scleroderma patients, enrolled from 26

The SRF is grateful to the following participating institutions and principal investigators who lend their expertise and leadership to power the CONQUER Registry.

Participating Institution	Principal Investigator
Columbia University	Elana Bernstein, MD, MSc
Duke University	Ankoor Shah, MD
Georgetown University	Virginia Steen, MD
Hospital for Special Surgery	Jessica Gordon, MD
Johns Hopkins University	Ami Shah, MD, Laura Hummers, MD
Mass General Hospital	Flavia Castelino, MD
Mayo Clinic	Ashima Makol, MD
Medical University of South Carolina	Faye Hant, DO, MSCR
Northwestern University	Carrie L. Richardson, MD
Stanford University	Lori Chung, MD, MS
The University of Texas Health Science Center at Houston	Shervin Assassi, MD
University of California Los Angeles	Elizabeth Volkmann, MD, MS
University of Michigan	Dinesh Khanna, MD
University of Minnesota	Jerry Molitor, MD
University of Pennsylvania	Nora Sandorfi, MD
University of Utah	Tracy Frech, MD
Vanderbilt University Medical Center	Tracy Frech, MD

presented many challenges for participating centers to collect specimen samples and enroll new patients in the past year, the CONQUER registry has continued to grow, and aims to double the number of enrolled patients by the end of 2022.

participating U.S. academic centers are participating in the GRASP Project. And thanks to the collaboration of patients, clinicians and researchers, GRASP's comprehensive database is already enabling important analyses which may lead to earlier detection and treatment of the disease.

Research is the key to finding new treatments for scleroderma. And while the differences in disease onset and severity in African American scleroderma patients can only be understood by studying African American patients, the discoveries made from understanding the genetics of scleroderma in African Americans will benefit patients of all ethnic backgrounds.



Raising Awareness and Providing Resources

As an innovator in scleroderma research, the SRF is uniquely qualified to provide the most relevant news and information about scleroderma complications, treatments, and research. Our resources reach not only those living with scleroderma, but also the medical community and the general public.

Here are a few highlights of our efforts to raise awareness and provide educational resources in 2021.

A New Look for SRFCURE.ORG:

In July, we rolled out a new look for our website, srfcure.org, to make information more discoverable. By providing improved navigation features and enhanced graphic design, site visitors can now more easily find content that is relevant and informative. And, to underscore the SRF's laser focus on research, we rolled out a refreshed look for our logo and have added a tagline: "Research is at the center of all we do."



New Features/New Tools:

Along with a refreshed look and feel, we substantially increased the educational content on our website. Here are some of the new and enhanced features:

- An expanded resource library detailing disease complications and treatments
- An easy-to-read introduction to scleroderma for newly diagnosed patients
- A comprehensive directory of U.S. treatment centers specializing in scleroderma
- Information on research participation and clinical trials
- A brand-new blog that centralizes patient stories, research updates, and more
- A glossary of key terms to know related to scleroderma and medical research
- An on-demand listing of 30 educational webinars



The #SayScleroderma Campaign:

As part of June's Scleroderma Awareness Month, we launched the first-ever #SayScleroderma campaign via social media to help make "scleroderma" a household word. Why? Because lack of awareness about this disease causes delays in treatments and diagnoses. And because not enough people know what scleroderma is or does. As a result, thousands of followers took part by posting videos, sharing content, and tagging us, as they posted stories about how the disease impacts them or someone they love.

Expanding our Reach Through Social Media:

With a goal of bringing our awareness messaging and educational content to an ever-expanding worldwide community, in 2021 we re-dedicated ourselves to delivering high-quality editorial content through our social media platforms. As a result, over the past year, the number of followers of @srfcure on Facebook and Instagram has increased by more than twenty five percent. We've shared hundreds of posts featuring stories of inspiration, educational tools, and resources, scientific & medical news, and more, all to help the global community understand more about scleroderma.

The Cure Crew: Volunteers Making a Difference

The Scleroderma Research Foundation's Cure Crew is a grassroots volunteer program that raises awareness about scleroderma and funds to support SRF's research. Cure Crew members around the world are united by a shared belief in the power of research to help people with scleroderma live longer, fuller lives, and lead us closer to a cure. Despite the challenges caused by the pandemic, our dedicated and ever-resilient Cure Crew members raised over \$100,000 to support research (both in-person and online) and devoted countless hours to raise critical awareness about this disease through social media advocacy, cause marketing, and more.



Online Fundraiser—Devin L.

Devin recently lost her mother, Brenda, to scleroderma. "She was my best friend," she says, "and getting through these first birthdays without her has been difficult." Last year, Devin joined the SRF's Cure Crew by creating a Facebook birthday fundraiser and asking her friends and family to contribute to the SRF in lieu of gifts as a meaningful way to make a difference in honor of her mother.



Event Host—Beth L.





In honor of her mother Betty who passed from scleroderma in 2009, Beth held a fundraiser at all four locations of The Grove Wine Bar restaurants that she co-owns in the Austin, TX area on June 28th, World Scleroderma Day. Not only did Beth donate 10% of all net sales to the SRF, she also encouraged those unable to dine in her restaurants to make tribute donations online to the SRF, helping to raise both funds and awareness for scleroderma research.



Cause-Related Fundraiser—Jamie M.

When fitness teacher Jamie discovered that her friend had been recently diagnosed with scleroderma, she leveraged her professional skills and marketing savvy to offer a special fundraising workout session designed to raise funds and bring awareness about this little known disease. The response to her workout class exceeded expectations, raising almost four times her targeted goal.

Join us!

-  facebook.com/srfcure
-  instagram.com/srfcure
-  [@srfcure](https://twitter.com/srfcure)
-  [srfcure](https://youtube.com/srfcure)



Peer-to-Peer Fundraiser—David H.

In November 1987, David began sending letters to friends and family to request donations to support the SRF in honor of his mother. More than 30 years later, he continues to make scleroderma research a priority by sending out his annual mailing and has raised over \$15,000 to date.



Inspirational Advocate—Lovette R.

In addition to participating in research to advance a cure, Lovette has shared her scleroderma journey in several formats, including a video that broadcast to a global audience during the 2021 Cool Comedy • Hot Cuisine virtual event. She says, “When people are inquisitive, it helps to advance the understanding of what scleroderma is and finding a cure.”

“The Cure Crew members are among the foundation’s most important allies in our search for a cure. We simply could not do what we do to raise funds and awareness without their dedication and support!” — Eric Kau, SRF Board Member



Awareness Advocate—Will W.

“I believe so strongly in the power of scleroderma research, that I have worn a Scleroderma Research Foundation wristband since I was in middle school to help prompt conversations about the disease, my dad’s diagnosis, and our family’s experience,” says Will.

For a full list of the more than 600 Cure Crew members who have so generously given their time and energy, in many creative ways to help us fund research that will lead to a cure, visit srfcure.org/cure-crew-2021

Cool Comedy • Hot Cuisine Goes Virtual—Again!

After re-imagining **Cool Comedy • Hot Cuisine** (CCHC) as an online broadcast with much success in 2020, the SRF held our signature fundraising event in a virtual format for a second time in 2021, in response to the continuing Covid-19 pandemic.

Once again, SRF Board Members Bob Saget and Susan Feniger co-hosted the evening and welcomed a global audience of thousands who tuned in to the live-stream broadcast on October 17th for an amazing night of laughter and inspiration. To enhance the at-home viewing experience, participants were able to bid in an online auction, order “Hot Cuisine” take-home meals from participating restaurants, and download a Watch Party Toolkit with CCHC-themed Bingo, cocktail recipes, music playlists, and more.

Best of all, the virtual event featured appearances by an unparalleled gathering of comedy greats and music legends, all of whom generously donated their time and talents to help raise funds and awareness for scleroderma, generating more than \$700,000 to support the SRF’s research and patient education programs.



The SRF is grateful to the brilliant comedians, musicians, and actors who generously lent their time and talents to help us find a cure



Our Donors

Our ability to facilitate the development of new treatments for scleroderma is only possible with generous donor support. Thank you to the following SRF supporters who made gifts of \$1,000 or more in 2021.

23andMe	Boehringer Ingelheim Pharmaceuticals Inc.	Jon and Robin Dracos	James Gergurich
Robert and Annmarie Adamo	Kevin Bomer	Chuck and Linda Duvall	Dr. Jeffrey Gevirtz
Lorene Adams	Nizana Brautmman	Mieke Duxbury	Wendy Glenn and Marianne Lowenthal
Dr. Bruce Alberts and Betty Alberts	Kevin and Claudia Bright	Jim Dwyer and Sally Nagel	Joanne and Ed Gold
Meredith and Mark Allister	David and Suzanne Brown	Edward and Lida Robinson Charitable Trust	Alan and Barbara Goldenberg
Almafi Estates	Sari Brown	Emerald Health Pharmaceuticals	Ronald and Pamela Goldman
Altavant Sciences	Harold and Ofelia Careway	Robert and Dana Emery	Google Matching Gifts Program
Amazon Smile Foundation	Dr. Janet Carminati and Dr. Sid Shaw	Peter and Alison Engel	Gossamer Bio Inc.
Shari Annes	John Caroli	Christian and Jacqueline Erdman	Michael Gould and Sara Moss
Appraisal Service, Inc.	Geneva Carr	Elena Evnin	Gaile and Ronald Green
John and Debra Apruzzese	Travis Carr	Luke Evnin, PhD	Donald Greenberg and Beverly Daniels-Greenberg
The Art Laboe Foundation	Jeffrey T. Chambers and Andrea Okamura	Mary and Timothy Evnin	Dr. Bruce Grossman and Cheryl Grossman
Linda Bailey	Albert and Rosanne Clifford	Brenda Fauth	The Grove Wine Bar & Kitchen
John and Audrey Bamberger	Cohen Family Charitable Giving Fund	Susan Fawcett	Jeanmarie Guenot
Susan Baran	Gayle Cohen and Dr. Maurice Cohen	Susan Feniger and Liz Lachman	Jayne Hall
Estate of Irene Adele Barg	Scott Collingwood	Tony and Julie FitzPatrick	Regina Hall
Joyce Baskin	Francie Connelly	Robert Force	Holly Hauser
Richard Baskin	Scott Constantine	Kristin Fossum	Hauske Family Foundation, Inc.
Mara and Joshua Baumgarten Force	Craig Cummings	The Fox Foundation	Sandra Heppenheimer
Reginald and Margaret Bayley	Marie Cummings	Jeff Franklin	The Hill Family Charitable Foundation
Betty Z. Benedict Estate	Bill DeRonde	Cheryl Frederic	Gene and Joan Hill
Joel and Bonnie Bergstein	Vin and Erica Di Bona	William and Audrey Frederic	Eric and Tara Hirshberg
David and Gayle Bernhaut	Dr. Sharon Dobie	Barry Frey	Gerry Hodes
Evan Bernstein	Robert Donnelly	Joseph and Nora Funaro	Donald Holmes
Mary Bertolli		Samantha Gabriel	
Bethpage Federal Credit Union			
Helena and Peter Bienstock			

Leadership Donors

We recognize with gratitude the following generous supporters whose leadership level gifts fueled our research progress in 2021.

Abbey, Weitzenberg, Warren & Emery	Luke Evnin, PhD	Estate of Eva Jenkins	Mark Scher
AE Family Foundation	Judy Evnin and Dr. Tony Evnin	Kao Family Foundation	Dan and Jayna Schimberg
Sara and Arthur Lloyd Campbell	Heather and Michael Green	Andy and Violetta Merin	Victoria West and Marc Trachtenberg
ConocoPhillips	Regina Hall	The Nancy P. and Richard K. Robbins Family Foundation	Deann Wright
	Joseph Hulston		

Industry Partners

We wish to thank the following industry partners for their generous research funding, sponsorship support, and strategic input to help us better serve the scleroderma community and speed our mission to find a cure.

23andMe	Emerald Health Pharmaceuticals	Janssen Pharmaceuticals, Inc.
Altavant Sciences	Gossamer Bio Inc.	Kadmon Corporation
Boehringer Ingelheim Pharmaceuticals Inc.	Horizon Therapeutics	

Sharon and John Hopper
Horizon Therapeutics
Hunter Insurance
Roberta Hunter
Frank and Barbara Hurst
Ed Hurwitz and Sharon Lichtenfeld
Janssen Pharmaceuticals, Inc.
John R. and Beverly J. Larson Foundation
John S. and Florence G. Lawrence Foundation
Della Johnson
Jacob Johnson
JP Morgan Chase Foundation
Kadmon Corporation
Alan and Donna Kaminsky
Jay and Cindy Kasin
Dr. Eric Kau and Eliz Lee
Elaine and Scott Keller
Samuel Kenberg and Marcella Magiera
Timothy Kenrick
Debra and Paul Kleban
Lloyd Klickstein
Jeremy and Melissa Kline
Steven Klucik
David and Wendy Knoller
Steven and Ellen Koch
Joan Kosmach Memorial Fund
Kraft-Engel Management
David and Nancy Lacey
Lamb Family Foundation
Beth and Anthony Lasita
Lear Family Foundation
Norman and Lyn Lear
Kerri and Mark Lehmann
Mark and Linda Levine
Tom Lockard and Alix Marduel
Looped
Isabel Luengo
James and Debbie Lustig
Rhonda Mace
Margie Mahler
Barbara Malina
Shekinah Mandelbrot
Dr. Deborah Manjoney and Dr. Scott Stanwyck
Mary and Danny Mar
Jamie Martinez
Rita and Joseph Meistrell
Rj Melman
Dr. Charles Melone
Fredric and Deanna Metzger
Microsoft Matching Gifts Program
Arleen Yvonne Miles
Jacob Miles
Lauree Moffett

Jolynn Mohr
Anita Monaghan
MTS Health Partners, LP
Patricia Musanti
Arden Nagler
National Christian Foundation
Jon and Hanneke Nesvig
Chris Norton
Carol Oldham
Maggie Ostrow
OTSOG Fund
Melanie and Harold Oyster
William and Heather Packer
Sula and Robert Pearlman
Harrison Peltz
PHE, Inc.
Adam Platt
John and Cynthia Pohlen

Brad Smith
James Smith
Linda Sorge
Carren Soules
Southpoint Capital Advisors LP

TPG, Inc.
Estate of Deborah Ann Trapani
Turan Family Foundation
Deborah Vickers Grisamore and Greg Grisamore



Martha S. and her daughter, Sophie Anne (dx 2019).

“Supporting the SRF is personal to me. You are helping to save our daughter. The more people give, the more quickly we can find a cure. I am so thankful for all the SRF does.”

— Martha S.

Jeffrey and Belinda Pop
Laura Pope and Craig Smith
Ellyn and Ed Potokar
Paul and Melinda Pressler
Lois Pribanic
William Prinzmetal
William and Natalie Raaths
Richard Rabin
Elizabeth Race
Phyllis and Arthur Rendell
Angela and Richard Renneke
Ronald Renzi
Richard and Nancy Robbins
Bob Saget
Saint Francis Hospital-Bartlett
Lolly Salmen
Stephen Salmen
San Ysidro Investors, LLC
Ron Scholtisek
Diane and Michael Schumacher
Jeff and Martha Seaman
Vivian and John Seaman
Patricia Seffens
Kyle Shanklin
George Shapiro
Shawangunk Valley Conservancy
Bob and Laurie Smith

Betty and Jon St. George
Peter and Martha Stabler
Bruce Stein and Susan Stremple
Craig Stein
Lisa Steiner
Gary Stollerman
Dr. Liz Stoner and Dr. David Cowburn
Stuczynski Trucking & Excavating, Inc.
Dr. William Swenfurth
The Swig Foundation
Marjorie A. Swig
Mark and Kathy Taylor
Carl and Susan Thomsen
Melinda Thompson
Dr. Kathryn Torok

Lucy Waletzky
Rachel Weiss and Joseph Traub
David and Lisa Welsh
Sandy and Barbara Wernick
Westmount Asset Management, Inc.
Dr. Barbara White
Steven Williams
Susie and Jamie Williamson
Carin Gerard Wilson and Tony Wilson
Bruce and Marya Wintroub
Deann Wright
Meredith and Mike Zappert
David Ziegler

We are grateful for each and every donation to the SRF. For a list of additional 2021 supporters, visit srfcure.org/about/our-donors

The Sharon Monsky Legacy Society

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. When first diagnosed, she was given less than two years to live. Despite this prognosis, Sharon forged ahead to lead the SRF for 16 years, cultivating a network of some of the nation’s most respected scientists—all working together to find a cure.

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. We deeply appreciate the thoughtful planning involved in making a meaningful gift through a bequest, retirement plan asset, life insurance, or charitable trust. 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.

Please contact Cori Traub at cori@sclerodermaresearch.org for questions about making an estate gift to the SRF.



The Sharon Monsky Legacy Society honors people who have chosen to support the future of scleroderma research beyond their lifetimes. Thank you to the following members whose thoughtful planning will impact the SRF research program in years to come.

James C. Adams	Timothy A. Davis	Rudolf Gutierrez	Joyce Prime
Douglas M. Beltzner	Herbert E. Freedman	Melanie Hill	Bruce E. Starkey
Heather J. Byrnes	Meryl B. Friedland	Cindy Kronman	Linda Tarantino
Harold Careway	Jeffrey Gevirtz	Jennifer D. Langer	Nathan W. Turner
Stephanie Colotti	Ileana Gonzales	Jeffrey Mannion	Cheh Yung Kim

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

Estate of Maria D. Anargyros	Estate of Mary Keith	McHenry	Estate of Robert Shutan
Estate of Harold E. Aust	Estate of Edward Klinger	Ramelle Ferer Monsky Trust	James Simon Family Trust
Estate of Irene Adele Barg	Margaret E. Lee Irrevocable Trust	Neptune Charitable Remainder Trust	Estate of Helen I. Steffanus
Estate of Sylvia M. Becherer	Estate of Janice Lowry	Neptune Family Trust	Estate of Clinton Ternstrom
Estate of Betty Z. Benedict	Estate of Thomas Malanowski	Estate of Jerome Osborne	Marion Ternstrom Endowment Fund
Ralph Benner	Estate of La Verne B. McCrory	Estate of Frans Peltzer	Estate of Deborah Ann Trapani
Estate of Teresa Duggan	Estate of Neal McGuire	Anne D. Ramsier Family Trust	Estate of Mary Ann Wolff
Estate of Carol Lynn Hulsing	Estate of Martha Laberdee	Estate of Julian C. Roberts	
Estate of Eva Jenkins			

In Honor Donations

Gifts made to the Scleroderma Research Foundation in honor of special people and milestones have a significant impact on our research. The following individuals were recognized in 2021 by family and friends who made a gift in their honor.

Suzanne Alder	Judy and Tony Evnin	Meghan Kufiak	Sophie Anne Seaman
Meredith Allister	Susan Feniger	LaRae Kuhar	Barbara Stanton
Medy Baltazar-Lamorena	Vivian Fix	Michelle Langmead	Beth Ann Stewart
Deborah Bartlett	Loretta Gallo	Beth Selbe Lasita	Sharon Stricker
Preston Barton	Analisa Garces	Nancy Leskanich	Sylvia Strouch
Barrie Bazarsky	Teri Gerson	Lenora Lewis	Marjorie Swig
Maria Becker	Edward Gevirtz	Mary Anne Locatell	Angella Switzer
Melita Belgrave	Tammy Gilbert	Laura Lopez	Jannie Tanner
Denise Beltzner	Joanne Gold	Harold Mahler	Melissa Tarantino
Deborah Bischoff	Joi Goodbread	Anne Terrell Masters	Angela Taylor
Jason Blank	Catherine Gorgoni	Katie McGrath	Angela Thomas
Cindi Brannum	Anna Green	Jamie Mintzer	Merideth Thompson
Bonny Lee Bruner	Randy and Rob Greenspan	Janice Moffett	Susan Thredkeld
Lori Butler	Evelyn Harris	Matt Murphy	Mollie Traub
Bette Callaway	Nancy Hazelton	Maggie Ostrow	Debbie Upthegrove
Connie Chalfant	Barb Heenan	Josephine Parker	Terri Vokel
Cameron Clark	Virginia Hensington	Bharat Patel	Betsy Warrick
Peggy Collins	Amy Hewitt	Kiley Pesce	Eve Weinberg
Julie Connolly	Heather Hopkins	Shelley Raaths	Julie Weinstein
Kerri Constantine	Dan Hopper	Shelly Raaths	Marlene Weintraub
Maria Crespo	Mary Lou Hughes	April Randolph	Maryclaire Wilkinson
Mary Daby	Roberta and Brian Hunter	Ben Reiff	Sal Williams
Lori DeFranco	Ann Jackson	Maxine Reiff	Haley Wilson
Dana Delany	Kathy Jasper	Malia Lovelace Ritchie	Deann Wright
Chandler Diedrich	Stephanie Jensen	Bonnie Robbins	Kris Yates
Nicholas Dobie	Rachel Johnson	Leigh Rockey	Michael and Joan Zaccaro
Susan Draper	Kathy Karson	Naomi Rothfield	
Glenda Dunham	Saville Kellner	Diane Rubins	
Addie Duxbury	Jessica Kersey	Bob Saget	
Vicki Ehrenman	Linda Keschl	Tami Sauer	
Monica Espinoza	David Knoller	William Schau	
Luke Evnin, PhD	Katy Koval	Cindy Schlett	

“My daughter was diagnosed with scleroderma in 2014 and I want her, and all others living with scleroderma, to be cured. I support the SRF because they share in the same ‘mission’ as me and that is to find a cure for scleroderma. Until a cure is found, I will not stop supporting research through the SRF.” — Linda T.



Linda T. with daughter Melissa (dx 2013).

In Memory Donations

We express our deepest sympathy to the families and friends of the following people in whose memory gifts were made during 2021.

Nancy Gayle Abrams
Linda Adkisson
Dennis Allen
Hilda Allen
Norma and Phillip Altus
Walter Amstutz
Bruce Anderson
Marsha Andrews
Elaine Aresco
Lety Armstrong
O'Dell Ayres
Donna Baggett
Kathy Baird
Shirley J. Ballard
Bill Banks
Agnes Barksdale
Susan Bash
Joyce Baskin
Joyce Bauer
Thomas Bautz
Susan Belisle-Hall
Shirley Belo Mocho
Clara Benedetti
Gwen Benford
Richard Benton Elder
Maureen Bernardi
Lois Bieniek
Marie Blair
Barbara Blake

Michelle Blecha-Baie
Kathleen Bosworth
Ron Botchan
Doris Bourgeois
Kevin Breaux
Suzanne Brenner
Karen Brooks
Jerry Bruinooge
Renee Brull Miller
Barbara An Budd
Darlene Bullard
Regina Callahan
Amy Capell
Michael Capello
Minnie Carr
Claudia Carrillo
Debra Caven
Marilyn Cervantes
Mitchell Chamlin
Greg Christensen
Betty Bluma Chutkow
Goldie Cohen
Jody Cohen
Soledad Conforti
William Conger
Kaelin Connolly
Patricia Connors-Zini
Dick Cook
Linda Counterman

Nellie Cree
Jon Robert Cummings
Anna Damiani
Nancy Daniel
Zavion Davenport (Chi Chi DeVayne)
Eileen Davey
Deborah DeFrancis
Lillian DeBiase
Georgianna Dengler
Rosanna Dimarco
Rodney Dirth
Brent Dobbie
Ruth Dobbins
Matthew Dobie
Cindy Dolly-Panka
Melissa Dowd
Emma Duvall
Patricia Dziak
Betty Eckhard
Darin Eible
Rori Wilensky Eisenberg
Sally English
Dominick Esposito
Karen Everett
Mary Lou Faile
Judi Fair
James Fecko
Alyce Ferrari
Mary Fitzgerald
Mary Alice Fitzpatrick
Rosina Flaccavento
Lori Dana Forman
Mildred Fortin
Deborah Frantz
Charlie Freeny
Margaret Frenthway
Colleen Frey
Catalda Gasparetti
Robert Gertner
Nancy Gervitz
Jennie Gibson
Phyllis A. Gibson
Judith Golub
Donald Gooding
Lisa Barkin Goodman
Cyrile Goren
Barbara Gottfried
Sidney Gould
Sharonda Graham
Harriet Grauer
Gloria Grey
Marilyn Grieshop
Janice Grochmal

Sylvia Grossman
Christopher Guadagnini
Margaret Guelker
Sandra Hagen
Ruby Hall
Jean Handelong
Jean Anne Harn
Rebecca Harrison
Ray Harvey
Barbara Hawkes
Pamela Hayes
Sandy Hazelhofer
Gillian Rose Heath
John Heilala
Dorothy Heinlein
Jennifer Hemley
Johnny Katt
Martha Robles Hernandez
Rosaline Hernandez
Florence Herring
Annette Hess
Sherley Higuera
Marilyn Hines
Kathryn Doub Hinman
Colleen Hochreiter
Sally Holmes
Bobbie Hsi
Ruby Hullum
Mary Nell Hutchens
Patricia Hynes
Joseph P. Ingrassia
Natlee Ann Tovar Jackson
Marcia Janicki
Debbie and Selena Johnson
Helene Jung
Susan Kalian
Doris Kandros
Nina Karouna
Belinda "Bede" Karr
Rona Kaufman
Priscilla Kenyon
Yasmin Khan
Margaret Kinaitis
Grace Kirby
Margaret Kollitides
Joan Kosmach
Helmut Kramer
Joan Kroutil
Leon T. Lambeth
Kim Lanou
Kerry Adair Larkin
Beverly Larson
Vera LaRusso
Joan Lauer

Daniel R. Lave
Joan Laver
Barbara Pittman Lawler
John and Ann LeBlanc
Beverly Leigh
Frederick W. Leone, Jr.
Sue Lewis
Harvey Leiberman
Rosalinda Ramon Lillis
Mary Lofstrom
Lorraine Ludwig
Heidi Lulich
Kevin Lynch
Colleen Lyons
Jeff Mace
Shigenobu Machida
Robert Mahler
Elizabeth Malanowski
Jeanette Malanowski
Thomas Malanowski
Brenda Malone
Sally Mancino
Dawn Manjoney
Joanne Marcus
Frank Marisi
Tony Markley
Gloria Marotta
Miriam Marshall
Jane Martin
Amparo Martinez
Sharon Martinez
Marion Massey
Andie Matis
Gale Hope Matis
Perry Mayes

Doris Moore
Erin Moore
Linda Moore
Helen Mosley
Samuel Muhlfelder
Serena Mulston
Dolores (Lorie) Murphy
Loretta Murphy
Genevieve Musanti
Barbara Musco
Bernie Naiman
Elaine Nalbandian
Ellen Nathanson
Geraldine Neugent
Steve Nickerson
Valerie Niles
Lillian Nishimoto
Laurie Noonan
James Noz
Denise Nusom
Andrea Oakland
Valerie Oles
Margaret Olson
Eugenia O'Neill
Vicki Opal
Tiffany Orrick
Stephanie Ostrander
Kay Ostrom
Connie Palladino
Marlene Paluta
Jonathan Parker
Dee Dee Parman
Ana Patterson
Gregory R. Pellicano
Cheryl Peloquin

Phyllis Renzi
Gwen Renzullo
Ann Reynolds
Carol Reynolds
Debi Rizzo Rivelli
Carol Rizzo
Raymond Rizzo
Carol Rosenberg
Lance Rosenblatt
Roy Rufh
Barbara Ryan
Ben Saget
Dolly Saget
Gay Saget
Kathy Santolo
Leonard Savino
Lotte Scharman
Matthew Schenone
Steven Schliem
Mary Gail Seffens
Betty Selbe
Jean L. Shanklin
Barbara K. Shepard
Nancy Shore
Theresa Skatz
Anita Smith
Caroline Rice Smith
Enid Smith
Harvey Smith
Rhoda Solow
Jo Ann Sonis
Marco Sorge
Mary Sorge
Daryl Srail
Anthony A. Staiano



Patty D. who passed from scleroderma complications, pictured here with her son.

Carol Tavares
Bernice Tesmer
Liz Thompson
Jeanie Tkach
Norma Torres
Kimberly Touron
Carmela Trupia
Gwendolyn S. Turner
Marjorie B. Turner
Jeannette Twining
Cornelia Van Der Lee
Margarita Velasquez
Carolyn Venuti
Teresa "Terri" Vokel
Anne F. Votze
Marie Walker
Marlene Waller
Peggy Wanner
Kathleen Ward
Martha Ward
Ronnie Warner
Mary Weiner
Sompit and David E. White
Susan White
William Whitehurst
Allyson Whiting
Mary Wick
Carolyn Wiles
Curley Williamson
Shirley Willman
Paul Wilson
Bonnie Berry Wiseman
Barbara Wollenburg
Cynthia Woodgate
Lucille Wozniak
Eugenia Ann Benke Wright
Leslie Wright
Georgia Xenakis
Cynthia Yagi
Keith Yagi
Fay Young
Millie Zerobnick
Joseph P. Ziegler
Mary Ellen Ziff
Barbara Zimmerman



Board Member Sharon Dobie with her son, Matt, who passed away from scleroderma complications.

"In loving memory and in support of critical research for future treatments and a cure."

— Renae R.

Billy McCain
Ruby C. McCall
Bernadette McCarroll
Carol McChesney
Laura McGuire-Weinfeld
Jo Ann Meaney
Cece Medina
Elizabeth Megliola
Hamilton Mencher
Renee Miller
Eleanor Mitterling
Lena Moccia
Richard J. Mohr
Sharon Monsky

Jennifer Pepitone
Allison Peterson
Grace Pezrow
Robert Piraro
Beverly Pizzuto
Rebecca Plude
Carlin Popke
Diana Pralgo
Margaret Pulice
Dagmar Pulkkinen
Barbara Ann Ray
Alissa Reich
Peter Reich
Virginia Reid

Sue Starr
Lenore Steinhart
Sophie Stepien
Shirley Stern
Sharon Stevens
Kyrán J. Stevenson
Marjorie M. Stalker
Eleanor Stone
Harold Sullivan
Barbara Sunseri
Mary Alice Swenfurth
Emilia Szajdecki
Rob Takai
Deborah Tascone-Kennedy

Advancing Research for a Cure Together

Researchers, clinicians, patients, families, supporters, SRF leadership, and staff—we are united as a community, stronger together, behind one strategic goal: advancing scleroderma research, our best hope for a cure. Thank you for standing with us and please know that you are part of something bigger. Our global community is uniting. Our research portfolio is deepening. Our hope is advancing.

Together, we are advancing research for a cure.

“It was really nice to see people talk about scleroderma OUT LOUD. Seeing such familiar faces say the word SCLERODERMA brought such wholeness to me. Thank you for allowing me to feel seen.” — Ali D., CCHC Attendee

“After I’m gone, I want to help others with scleroderma by supporting research. It made me feel good to put the SRF in my estate plan, because although there won’t be a cure in my lifetime, there might be in the next.” — Ile G.

“The thing that we need to understand is that I alone cannot do the research. It takes an incredible team of people working together in order to solve the problems that lead to new treatments.”

— Fredrick Wigley, MD, Johns Hopkins University School of Medicine

“It’s very heartwarming to know the great possibilities in the near future of treatments and ending scleroderma. We can never lose hope as it can lift us all and give us strength!” — Jennifer T.

“Thank you for the work you do. I’m living with scleroderma and ILD and know how important the work is.” — Cheryl G.

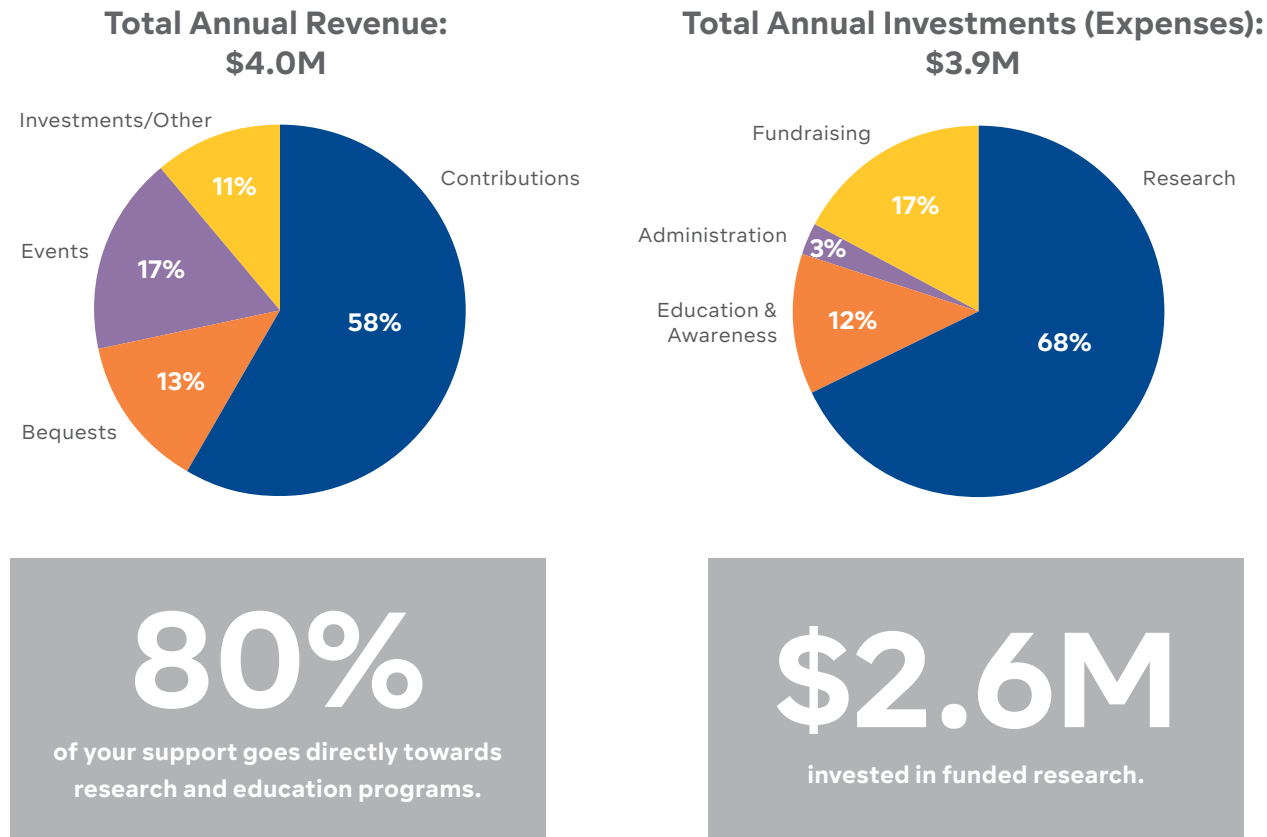
Pictured at right are SRF-funded researchers, clinicians, patients, and families, Cure Crew members, advocates, donors, and SRF Board Members.



Financials

Impact of Your Investment

For over 30 years, the SRF's targeted and collaborative research investments have contributed to a substantially greater understanding of disease genesis, progression, and treatment options, thanks to your generous support. At the SRF, we take seriously our responsibility to the scleroderma community, and we work hard to maximize every dollar invested in our work.



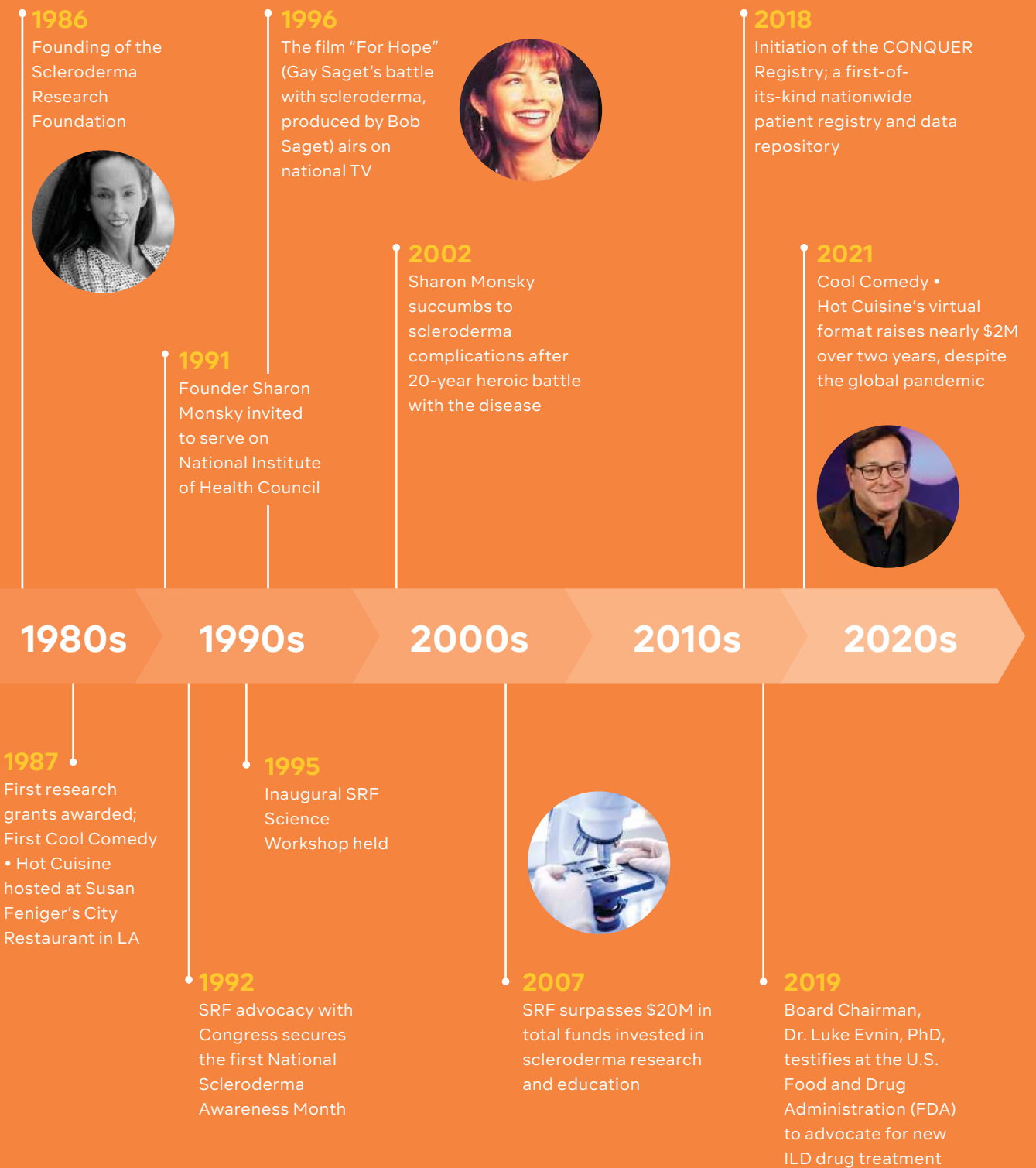
"It's the collective energy, inspiration, and generosity of the entire scleroderma community working together that make research advances happen."

— Deann Wright, SRF Board Member and Research Chair



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

Our History



**SCLERODERMA
RESEARCH
FOUNDATION**

220 Montgomery Street
Suite 484
San Francisco, CA 94104

800.441.CURE
info@srfcure.org
Tax ID #68-0087234

srfcure.org

