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.

“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 Evnin

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 Polyarthritis 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 Evnin, 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 Evnin, 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

Deann Wright, JD (2000)
Attorney

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

Caryn Zucker (2005)
Community Leader and Philanthropist

Dana Delany (2005, emeritus)
Actor

Sharon L. Monsky
1953–2002 SRF Founder

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.

“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

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

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

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

Bruce Wintroub, MD
University of California, San Francisco

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, Versama Bio

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

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

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
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.

“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.

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.
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.

“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
The SRF Research Program

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.

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

“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
The SRF Research Program

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 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.
The SRF Research Program

$2.6M in Funded Research

Collaborating for a Cure: Patient Registries

The CONQUER Registry

- Why is it so difficult for physicians to predict on 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 CoLaborative Na-tional QUality and Ef-ficacy 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 amounts of data on patients’ health status, disease complications, treatments, and outcomes.

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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.

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.

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.

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.
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.

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.

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

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.

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.
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.

Bethpage Federal Credit Union
Mary Bertolli
David and Gayle Bernhaut
Joel and Bonnie Bergstein
Betty Z. Benedict Estate
Reginald and Margaret Bayley
Richard Baskin
Joyce Baskin
The Art Laboe Foundation
We recognize with gratitude the following generous supporters whose leadership level gifts fueled our research progress in 2021.

Shari Annes Campbell
Amazon Smile Foundation
Sara and Arthur Lloyd
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.

Altavant Sciences
Kadmon Corporation
EmeraldHealth Pharmaceuticals Inc.
Janssen Pharmaceuticals, Inc.
Boehringer Ingelheim Pharmaceuticals Inc.
Gossamer Bio Inc.
Horizon Therapeutics

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

Abby, Weitzenberg, Warren & Emery
AE Family Foundation
Sara and Arthur Lloyd Campbell
ConocoPhillips

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
Robert and Ammania Adamo
Lorene Adams
Dr. Bruce Alberts and Betty Alberts
Meridith and Mark Allister
Almaf Estates
Alavit Sciences
Amazon Smile Foundation
Sharari
Appraisal Service, Inc.
John and Debra Apruzese
The Art Laboe Foundation
Linda Balestra
John and Audrey Bamberger
Susan Baran
Estate of Irene Adelaide Barg Joyce Baskin
Richard Baskin
Mara and Joshua Baumgarten Force Regneild and Margaret Bayley Betty J. Benedict Estate
Joel and Bonnie Bergstein
David and Gayle Bernhardt
Evren Bernstein
Mary Bertolli
Bethpage Federal Credit Union
Helena and Peter Biestock
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 beyond their lifetimes. Thank you to the following members whose thoughtful planning will impact 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 ctrait@ scleroderma.org or for questions about making an estate gift to the SRF.

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.

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 program in years to come.

James C. Adams
Douglas M. Beltman
Heather J. Byrnes
Harold Caneave
Stephanie Colotti
Timothy A. Davis
Herbert E. Freedman
Mary B. Friedland
Jeffrey Gevirtz
Ileana Gonzales
Rudolf Gutierrez
Melanie Hill
Cindy Kranman
Jennifer D. Langer
Jeffrey Mannion
Joyce Primé
Bruce E. Storkey
Cindy Kranman
Nathan W. Turner
Chen Yang Rbm

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.

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
Meredith Alston
Mady Baltzer-Lamarna
Deborah Bartlett
Preston Barton
Berne Bazansky
Maria Basler
Melita Belgrade
Denise Beltner
Deborah Bischoff
Jason Black
Cindi Brannum
Bonny Lee Bruner
Lon Butler
Betty Callaway
Connie Chaffant
Camron Clark
Peggy Collins
Julie Connolly
Keri Constantine
Maria Crespo
Mary Daby
Lori DeFranco
Dana Delany
Chandell Diedrich
Nicholas Dobie
Susan Draper
Glenda Durham
Addie Dubury
Vicki Ehrenman
Monica Espinosa
Luke Evrin, PhD
Judy and Tony Evnin
Susan Fegan
Vivan Feo
Loretta Galli
Analia Garcia
eri Garson
Edward Gevirtz
Tammy Gilbert
Joanne Gold
Joi Goodbread
Catherine Gorgoni
Anna Green
Randy and Rob Greenspan
Evelyn Harris
Nancy Hazleton
Barb Heenan
Virginia Hensington
Amy Hewitt
Heather Hopkins
Dann Hopper
Mary Lou Hughes
Robert and Brian Hunter
Ann Jackson
Kathy Jasper
Stephanie Jensen
Rachel Johnson
Kathy Karsen
Savile Kallner
Jessica Kersay
Linda Kazihi
David Knoller
Katy Koval
Meghan Kuflik
LaRae Kuhar
Michelle Langmead
Beth Selkie-Laasta
Nancy Leskanich
Lenora Lewis
Mary Anne Locatelli
Lauren Lopez
Harold Makler
Anne Terrell Masters
Katie McGrath
Jame Mintas
Jessica Moffett
Matt Murphy
Maggie Ostrow
Josephine Parker
Bharat Patel
Kiley Pesce
Shayla Reaths
Shayla Raaths
April Randolph
Ben Reiff
Maxine Reiff
Maka Lovelace Ritchie
Bonne Robins
Leigh Rockey
Nasre Rofield
Diane Rubins
Bob Saget
Tami Sauer
William Schau
Cindy Schlett
Sophie Anne Seaman
Barbara Stanton
Beth Ann Stewart
Sharon Strocker
Sylvia Strouch
Marjorie S. Steeg
Angela Switzer
Jannie Tanner
Melissa Tarantini
Angela Taylor
Angela Thomas
Marjorie Thompson
Susan Thredfield
Mollie Traub
Debora Uphedgegrove
Timi Volk
Betsy Warnick
Eve Weinberg
Julie Weinstein
Mariann Weintraub
Maryclare Wilkinson
Sal Williams
Hailey Wilson
Deean Wright
Kris Yates
Michael and Joan Zaccaro

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

Estate of Jefferson A. Angrisano
Estate of Harold E. Aust
Estate of Irene Adele Barg
Estate of Sylvia H. Becker
Estate of Betty F. Benedict
Ralph Benner
Estate of Teresa Bigan
Estate of Carol Lynn Bluhm
Estate of Eva Jenkins
Estate of Mary Keith
Estate of Edward Klingler
Margaret E. Lee Inurable
Trust Estate of Janice Lowry
Estate of Thomas Malakowski
Estate of La Verne B. McCrory
Estate of Neal McGuire
Estate of Martha Labedee
McJenny
Ramelle Farer Monsky Trust
Neptune Charitable
Remanacer Trust
Neptune Family Trust
Estate of Jerome Osborne
Estate of Frank Palmer
Anne D. Ramsay Family Trust
Estate of Julian C. Roberts
Estate of Robert Shutan
James Simon Family Trust
Estate of Helen J. Steffans
Estate of Clinton Terestrom
Marion Ternstrom
Endowment Fund
Estate of Deborah Ann Trapani
Estate of Mary Ann Wolff

“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.
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
Denise Allen
Hilda Allen
Norma and Philip Altus
Walter Amstutz
Bruce Anderson
Marsha Andrews
Elaine Anseo
Latya Armstrong
Donna Baggett
Kathy Band
Shirley J. Ball
Bill Banks
Agnes Baradale
Dusan Bash
Joyce Baskin
Thomas Baust
Susan Beford
Linda Belk
Shirley J. Ball
Chip Ballard
Kathy Baird
O’Dell Ayres
Lety Armstrong
Bruce Anderson
Walter Amstutz
Linda Adkisson
Nancy Gayle Abrams
We express our deepest sympathy to the families and friends of the following people in whose memory gifts were made during 2021.

In Memory Donations

— Renae R.

Daniel R. Lave
Joan Laver
Barbara Pittman Lawler
John and Ann LeBlanc
Beverly Leigh
Frederick W. Levine, Jr.
Sue Lewis
Harvey Leiberman
Rosalinda Ramon Lillo
Mary Lisofski
Lorraine Ludvig
Heidi Lulich
Ken Loven
Colleen Lyons
Jeff Mace
Shengduo Machida
Robert Mahler
Elizabeth Malanowski
Thomas Malanowski
Brenda Malone
Sally Mancono
Dawn Marjone
Joanne Marcus
Frank Marla
Tony Markley
Gloria Marotta
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Jane Martin
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Sharon Martinez
Marion Mason
Andie Mata
Gale Hope Mata
Perry Hayes
Doris Moore
Eve Moore
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Genevieve Musanti
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Geradine Naughten
Steve Nickerson
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Debra Noom
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Roy Ruth
Barbara Ryan
Ben Safeg
Dolly Saget
Gay Saget
Kathy Santols
Leonard Savino
Lotta Schman
Matthew Schonauer
Steven Schlein
Mary Gay Sailens
Betty Selbe
Jean L. Shankin
Barbara K. Shepard
Nancy Shore
Theresa Skatz
Anita Smith
Caroline Rice Smith
End Smith
Harvey Smith
Rhoda Slow
Jo Ann Sosin
Marco Sorge
Mary Sorge
Daryl Sra
Anthony J. Staiasano

In Memoriam and In Loving Memory of people who passed away from scleroderma complications, pictured here with their children.

Carol Tavares
Bennett Teiser
Lo Thompson
Jeanne Tuch
Norma Torres
Kimberly Touron
Carmela Tropea
Gwendolyn S. Turner
Marjorie B. Turner
Jeanette Twining
Cornelia Van Der Lee
Marganta Velasquez
Carolyn Venuti
Teresa “Toni” Voiles
Anne P. Voit
Marie Walker
Marlene Waller
Peggy Warner
Kathleen Ward
Martha Ward
Bonnie Warner
Mary Weiner
Simpson and David E. White
Susan White
William Whiteman
Alison Whitman
Mary Wic
Carolyn Wiles
Curley Williamson
Shirley Willman
Paul Wilson
Bonnie Berry Wiseman
Barbara Wollfen
Cynthia Woodgate
Lucie Wosnak
Eugena Ann Banke Wright
Leslie Wright
Georgia Xanakis
Cynthia Yagi
Katie Yagi
Fay Young
Millie Zerockin
Joseph P. Ziegler
Mary Ellen Ziff
Barbara Zimmerman
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.
80% of your support goes directly towards research and education programs.

$2.6M invested in funded research.

"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.