Progress Made Bold

2025
ANNUAL
REPORT

SCLERODERMA
RESEARCH
FOUNDATION®

No one should have to suffer with scleroderma.

No one suffering should also have to explain what this disease is or does.

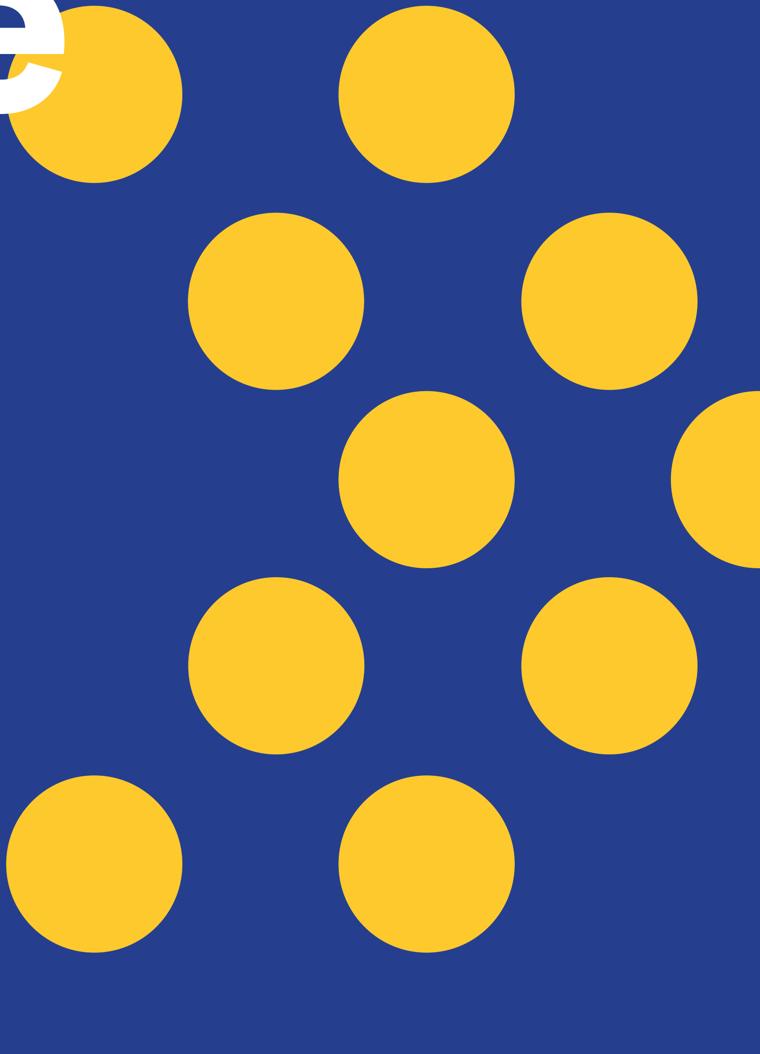
Lack of awareness causes delays in treatment or misdiagnosis.

We are on a mission to end scleroderma.

Research is the best hope.

Bold research turns hope into reality.

Progress Made Bold.



Dear Friends,

When the year began, a series of actions and spending cuts aimed at the National Institutes of Health and research-based universities threatened the foundation of scientific progress. Even in that environment, one thing never wavered: our commitment to boldly advancing scleroderma research.

Progress in science is not accidental—it is cultivated. At the core of our research program are funded grants that do more than support individual projects; they build a community of exceptional scientists, whose collective insight moves scleroderma research forward in ways no single investigator could alone. Since 2020, the Scleroderma Research Foundation (SRF) has grown its annual investment in core research by over 50%, while we invested over $7M in CONQUER across that same timeframe. This expansion has enabled a transformation in the breadth of the projects we are able to support.

This commitment to collaboration runs through the entirety of our research program. CONQUER, our landmark longitudinal patient registry, unites leading scleroderma centers around shared data only possible through the collaboration of multiple institutions. That dataset is now reshaping what the biopharmaceutical industry believes is possible in scleroderma. CONQUEST, a global clinical trial created by the SRF, takes that same collaborative conviction into the clinic, uniting researchers and patients across the world in a trial designed to move faster than conventional approaches allow.

I am proud to share that the SRF has joined as a Strategic Collaborator of Vie Ventures, an impact fund I helped co-found with Steven St. Peter, MD to fast-track promising therapies for people living with autoimmune diseases. For the SRF, partnering with a venture capital firm means elevating scleroderma's visibility in the biotech sector, forging connections across related disease communities, and creating new opportunities to strengthen the research program you make possible.

While we work steadfastly toward a cure, we are also committed to supporting our patient community with the critical information they need today. That is why our education and awareness efforts—such as our annual Scleroderma Awareness Month campaign, or new guides to disease complications on our website—are priorities we continue to advance and expand. We are committed to ensuring that the science we fund translates into information and resources that improve lives here and now.

All of these programs share an invaluable collaborator: you. From the SRF Cure Crew, to the hundreds joining us at Cool Comedy • Hot Cuisine, the support is extraordinary. **Every person who commits their resources, whether time or funds, fuels our forward motion.** That dedication, year after year, is what makes this mission possible.

We are living in a remarkable moment for scleroderma science. The tools we long anticipated—cell-by-cell molecular profiling, powerful computational platforms, artificial intelligence—are finally here. And they are meeting a community of researchers, clinicians, and data that the SRF has painstakingly built over decades. This convergence is not coincidence; it is the result of sustained, strategic investment in both the science and the infrastructure that makes it possible. **This is what transformation looks like.** A cure is a goal within our grasp, and we will boldly seize it together.

With deep gratitude,

Luke

Luke Evnin, PhD

Chairman of the Board
Scleroderma Research Foundation

Board Members


Luke Evnin, PhD
Chairman


Omar Baker, MD


Sharon Dobie, MD


Susan Feniger


Regina Hall


Eric Kau, MD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Violetta Merin


Mark Scher


Dan Schimberg


Jeff Seaman


Deann Wright, JD


Dana Delany
Emeritus

In Memoriam


Sharon L. Monsky
SRF Founder
1953-2002


Bob Saget
Board Member
2003-2022

SRF Staff

Joanne Gold, Executive Director
Gregory Gordon, MD, JD, Chief Medical Officer
Gloria Blecha, VP of Programs and Operations
Anoushka Donnelley, Director of Philanthropy
Hannah Young, Director of Communications
Neha Pamboo, Senior Accounting Manager
Jill Litman, Communications Specialist
Marielle Phares, Operations Specialist

Scientific Advisory Board

The SRF Scientific Advisory Board is integral to our mission. These are among the world's most illustrious scientists, and they choose to spend their time with us in the fight against scleroderma. They guide our research program, evaluate proposals, make funding recommendations, and foster the collaboration that moves science forward. Their expertise and commitment are at the heart of our research progress.

Bruce Alberts, PhD
Chairman
University of California,
San Francisco;
National Academy
of Sciences

Howard Chang, MD, PhD
National Academy
of Sciences,
CSO of Amgen

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

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Distinguished and
Senior Investigator
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HHMI, National
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Harvard Medical
School, National
Academy of Sciences

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Weill Cornell
Medical School

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MB, ChB, BSc(Hons)
Vice Dean for
Research, Johns
Hopkins University

Bruce Wintroub, MD
University of California,
San Francisco

Emeritus

Jeff Bluestone, PhD
A.W. & Mary Margaret Clausen
Distinguished Professor of Endocrinology at
University of California, San Francisco

Former President and CEO of the
Parker Institute for Cancer Immunotherapy

Founding Director of the Immune Tolerance Network

David Botstein, PhD
National Academy of Sciences, formerly of Calico
Life Sciences, Princeton University
In memoriam

Research
Made

Bol


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Strategic investments targeting a complex disease

When building a well-rounded portfolio of projects, the SRF works closely with our Scientific Advisory Board to evaluate how each project can address one or more of the following objectives:

- Understanding Who Gets Scleroderma (Genetics and Epigenetics of Susceptibility)
- Unraveling How Scleroderma Progresses (Pathobiology of Initiation, Propagation, and Regulation)
- Helping Find a Cure (Enabling the Development of Patient-Specific Medicine)

Funded Grants

AWARDED IN 2025

1. Somatic Mutations in Scleroderma

   Shervin Assassi, MD
   McGovern School of Medicine at
   UT Houston

   David Beck, MD, PhD
   New York University

2. Alteration of Epigenetic Programs of HSPC Underlies the Chronic Activation of Innate Cells in SSc

   Franck Barrat, PhD
   Hospital for Special Surgery

3. Identifying Novel Antibody Reactivities to Explain, Define, and Predict Sub-phenotypes of Scleroderma

   Joe DeRisi, PhD; Aaron Bodansky, MD;
   Mark Anderson, MD, PhD
   University of California, San Francisco

4. Dynamics of XIST RNP Profiles in Scleroderma

   Diana Dou, PhD
   Duke University

5. Establishing a Connection Between RNA Glycosylation and Autoantigens

   Ryan Flynn, MD, PhD
   Boston Children's Hospital,
   Harvard University

6. Building a Cellular and Genetic Atlas of SSc for a Roadmap Towards a Cure

   Johann Gudjonssen, MD, PhD;
   Dinesh Khanna, MD, MS
   University of Michigan

7. Epigenetics of Sex Differences in SSc

   Jinwoo Lee, MD, PhD
   Stanford University

8. Establishing a Spatially-integrated Transcriptomic, Epigenomic, and Histologic Signature of Fibrosis in SSc

   Michael Longaker MD, MBA
   Stanford University

9. Identifying Autoantigens in SSc

   Ruslan Medzhitov, PhD
   Yale University, Howard Hughes Medical Institute

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

    Ami Shah, MD, MPH; Scott Zeger, PhD;
    Laura Hummers, MD; Ji Soo Kim, PhD
    Johns Hopkins University

11. DNAse1L3 and the Pathogenesis of SSc

    Kim Simpfendorfer, PhD
    The Feinstein Institutes for Medical Research

12. Identification and Validation of Novel Pathogenic Genes in Juvenile Scleroderma

    Kathryn Torok, MD
    University of Pittsburgh

(*Continued*)

Funded Grants

AWARDED IN 2025

(Continued)

13. Spatial Transcriptomics of Scleroderma Skin to Augment Understanding of Cellular Interaction and Disease Propagation (Juvenile Pre- and Post- Transplant, and Juvenile Localized)

    Kathryn Torok, MD;
    Wei Chen, PhD
    University of Pittsburgh

14. Multi-omic Profiling of Interstitial Lung Disease in Scleroderma

    Gerlinde Wernig, MD
    Stanford University

15. A Gene Expression Map of Scleroderma

    Michael L. Whitfield, PhD
    Dartmouth College

16. Cellular Profiling of Scleroderma and Connective Tissue Disease Associated Interstitial Lung Diseases

    Paul Wolters, MD
    University of California, San Francisco

17. Deciphering the Female Bias of B Cell Tolerance Breach in SSc

    Bingfei Yu, PhD
    University of Southern California

SRF AND SCLERODERMA CLINICAL TRIAL CONSORTIUM JOINTLY FUNDED PROJECTS

1. Optimising the Assessment and Novel Mechanistic Insights into Digital Ulcers in SSc: The International '100 DU' Study

   Michael Hughes, PhD, MRCP
   The University of Manchester

   John Pauling, PhD, FRCP
   University of Bristol

2. CRISTAL: Developing the Combined Response Index for Scleroderma Trials Assessing Limited Cutaneous SSc (Continuing)

   Dinesh Khanna, MD, MS
   University of Michigan

   Alain Lescoat, MD
   University Hospital of Rennes

High Impact Research Investments

$2.7M

The SRF Annual Science Workshop

Convening experts across science and medicine

As the cornerstone of our collaboration strategy, this event brings together our Scientific Advisors, funded investigators, applicants, outside experts, and industry partners for an intensive two days of evaluation, discussion, brainstorming, and collaboration.

Every current investigator and invited new applicant presents their research project and progress to the Scientific Advisory Board and other attendees. The ensuing discussion of projects and new ideas is animated, yet collaborative. From this, our advisors recommend funding that results in a diverse portfolio of projects spanning multiple disciplines and facets of scleroderma research.

SRF Research Committee Co-Chair Deann Wright, JD, in conversation with a funded investigator.

Building the connections that move science forward

Our reach extends well beyond U.S. borders. We partner with the Scleroderma Clinical Trial Consortium to fund promising projects internationally, and we sponsor the International Workshop in Scleroderma Research, a gathering where the world's leading scleroderma researchers convene to exchange findings and advance the field. We also participate in conferences such as the American College of Rheumatology annual meeting, ensuring scleroderma remains visible across disciplines.

CONQUER

Transforming data into better care, better treatments

Launched by the SRF in 2018, CONQUER (COllaborative National QUality and Efficacy Registry) is a multi-center, longitudinal patient registry and bio-sample repository enabling sophisticated studies ranging from genetics to biomarkers—working toward more personalized, effective therapies for every patient. It has become the gold-standard scleroderma registry in the U.S., now being used to support emerging clinical trials, and is the cornerstone of our growing understanding of the disease pathology and clinical experience.

Scleroderma can look very different from one person to the next, so understanding those differences is essential to finding better treatments. Powered by more than 1,300 participants who have contributed nearly 3,000 samples through 6,000 visits, CONQUER captures how the disease affects diverse populations over time. Thanks to this collaborative participation, the registry is generating the depth and breadth of data needed to advance personalized medicine and help determine which treatments may work best for which people, and why. The registry has already contributed to multiple published manuscripts and is helping shape industry innovation in real time.

$8.5M invested in CONQUER to date

> “CONQUER has gone from just being an idea to a large database that will lead to better care.”
>
> — SHERVIN ASSASSI, MD, MCGOVERN SCHOOL OF MEDICINE AT UT HOUSTON, CONQUER STEERING COMMITTEE CO-CHAIR

2025 CONQUER Sponsors

abbvie

Boehringer Ingelheim

Scleroderma Foundation of California

Scleroderma Foundation Greater Chicago

REGENERON

Hauske Family Foundation

The Nancy P. and Richard K. Robbins Family Foundation

9 published papers

Seeing CONQUER data used to support research published in the broader scientific community is one of the most direct measures of impact we have.

CONQUEST

Mobilizing a global network to accelerate therapeutic discoveries

When working on a rare disease like scleroderma, building a strong pipeline of new treatments is a challenge for scientists and pharmaceutical companies alike. The SRF recognized this as a critical issue for our community and created CONQUEST—a global clinical trial—to address it.

In a conventional clinical trial, researchers test one drug at a time, which can be a slow and resource-intensive process. CONQUEST's design—the first of its kind in autoimmune diseases—allows multiple investigational study drugs to be evaluated at the same time, using a shared infrastructure and a single placebo group.

This model was pioneered in oncology before we adapted it for scleroderma, and no one else has tried it in rheumatology. By bringing it to our community, the SRF is helping to set a new standard for how research moves forward.

With CONQUEST, we've done something no scleroderma nonprofit has before: united researchers across five continents in a coordinated effort to find better treatments.

By the end of 2025, CONQUEST had enrolled patients in over 20 countries, to evaluate two investigational study drugs for scleroderma-associated interstitial lung disease.

> "We have been able to incorporate high-quality sites around the globe and to galvanize the international community."
>
> — DINESH KHANNA, MD, MS, UNIVERSITY OF MICHIGAN, CONQUEST STEERING COMMITTEE CO-CHAIR

20 countries with active CONQUEST sites

A Collaboration with Vie Ventures

What happens when venture capital and nonprofits join forces?

In 2025, the SRF stepped boldly into the venture capital arena, becoming a Strategic Collaborator in Vie Ventures, an impact fund co-launched by SRF Chairman Luke Evnin, PhD and Steven St. Peter, MD to advance innovative therapeutics for autoimmune diseases.

Alongside other leading autoimmune organizations, the SRF is helping Vie Ventures fast-track venture funding to advance therapies, which are already in or approaching the clinic, to patients living with autoimmune disease.

> “Biopharmaceutical companies need investors who can provide more than just capital: they can benefit from partners with expertise within distinct disease-focused ecosystems.”
>
> — LUKE EVNIN, PHD,
> SRF CHAIRMAN AND
> VIE VENTURES CO-FOUNDER

An Alliance That Puts Scleroderma on a Bigger Stage

+ Elevating scleroderma's visibility within the biotech sector
+ Building cross-community connections with foundations across related diseases
+ Creating new opportunities to strengthen the SRF research program

Vie Ventures Strategic Collaborators Include:

Arthritis Foundation

American Diabetes Association

Beyond Celiac

Crohn's & Colitis Foundation

Immune Boost Capital

National Multiple Sclerosis Society

National Psoriasis Foundation

Scleroderma Research Foundation

Sjögren's Foundation

Luke Evnin, PhD and
Steven St. Peter, MD

Learn More:
vieventures.com/strategic-collaborators

Education and Awareness Made Bol


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SCLERODERMA
RESEARCH
FOUNDATION

Helping the world see, say, and know scleroderma

The research you've helped make possible isn't limited to the lab. We deliver it back to you, translated into live webinars, in-depth complication guides, advocacy toolkits, and more—resources designed to meet the full spectrum of needs across this community.

While we make these strides, ultimately, a movement is what can truly change what the world knows about scleroderma—and that's what this community has become. This year, the partnerships and communities built around this cause boldly expanded what was possible, from fundraising to making sure the world knows what scleroderma is.

With gratitude to Johnson&Johnson
Patient Education & Disease Awareness Diamond Sponsor

Social Media

Expanding the Scleroderma Conversation

In 2025, we brought you stories that captured every dimension of scleroderma—from a bride's dream wedding, to news about research and emerging therapies, to straightforward answers to the question so many have: what exactly is this disease? You showed up for this content all year long—and then you shared it. Every interaction helped bring scleroderma in front of someone who may never have heard of it before.

Kristina H. (dx 2022), pictured here with her husband, was one of many who shared her experiences with scleroderma

220K+

social media impressions

Proof our voice is being heard.

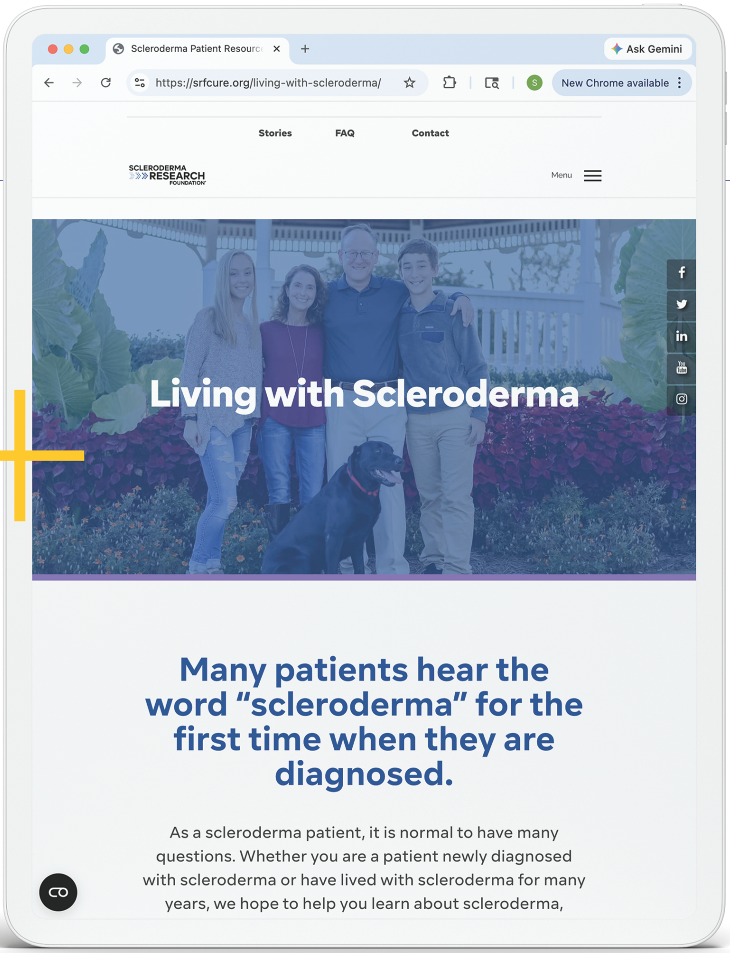
The SRF Website

Your Questions, Answered in Depth

As the scleroderma landscape evolves, so do your questions—and so do our website resources. People are spending more time than ever before learning about scleroderma and its complications. Among this year's updates: we expanded our ILD content and launched a brand-new section on nutrition. We built these to give you the practical guidance and the deeper understanding you need to navigate these complications with confidence.

64K+

visitors on our website



Living with Scleroderma

Many patients hear the word "scleroderma" for the first time when they are diagnosed.

As a scleroderma patient, it is normal to have many questions. Whether you are a patient newly diagnosed with scleroderma or have lived with scleroderma for many years, we hope to help you learn about scleroderma,

The SRF Patient Forum

World-Class Expertise, Wherever You Are

Your questions sparked conversations that reached across the globe. At events like the SRF Patient Forum—a half-day online program uniting the community—leading scleroderma researchers and clinicians brought their deepest expertise directly to you, wherever you were. Attendees didn't just watch; they asked hard questions, engaged in live Q&As, and left with knowledge they could act on.

> "When I was diagnosed 29 years ago, there was nothing like the Patient Forum. Now I can sit in the comfort of my home, and I can have access to world-renowned scleroderma researchers."
>
> — MARY LOU H.
> (DX 1996)

Cure Crew

Your Community Driving the Mission Forward

These volunteers didn't wait for change—they went out and made it happen. United by a shared belief that research is the path to a cure, Cure Crew members carried the SRF mission into their own communities through fundraisers and campaigns that raised both dollars and awareness.

1,012

volunteers collaborating for greater impact

1

1. Grace P. (dx 2015 at age 8) and her family partnered with Jeep Jamboree USA to raise awareness and funds for scleroderma research, with her family matching every donation up to $5,000.
2. Tracy M. (dx 2006) is pictured here selling handmade paper goods; she donates 100% of proceeds each June to raise funds for research.
3. Joseph W. (dx 2019), a pharmacist living with scleroderma and ILD, shared his story to advocate for earlier screening and greater empathy in healthcare approaches.

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4. Sydney N. (dx 2020) launched a limited-edition apparel collection called “The iLLEST,” donating all proceeds to the SRF and rallying her online community around the need for research.
5. Jordan C. organized a John Mayer tribute benefit concert to raise funds in honor of his sister, Jessie, who lives with juvenile diffuse systemic scleroderma.

The Kosmach Family

30 Years of Fundraising for a Cure

When Joan Kosmach passed away from complications of diffuse systemic scleroderma, her family had only recently come to understand this devastating disease—and they wondered what they could do to help find a cure for others. The answer came naturally: their mother had been an avid bowler and league secretary for years—so two months later, the family hosted their first "Strike Out Scleroderma" candlelight bowling event at Lombard Lanes, where Joan had bowled.

That was 1995, and they haven't stopped since. In 2025, the Kosmach Cure Crew marked 30 years of fundraising for scleroderma research with two celebratory events: *Bet on a Cure* and *Scare Out Scleroderma*.

$600K+

raised over three decades

> **"The Kosmach Cure Crew events in 2025 mark a heartfelt milestone, honoring our mother's legacy and the incredible impact we've made towards scleroderma research over the years. While we also remember our beloved sister, Sandra, who passed away from cancer last June, we celebrate the strength and unity of our family. We will continue our fundraising and awareness efforts with steadfast hope and determination in honor of our mother, dad and sister until a cure for scleroderma is found."**
>
> —JOAN'S FAMILY

The SRF is deeply grateful for the Kosmach family's unwavering dedication to finding a cure in Joan's memory through meaningful action.

Raising Awareness

Saying Scleroderma Louder, Together

In partnership with the Scleroderma Foundation of Greater Chicago, the Scleroderma Foundation of California, Scleroderma Canada, Scleroderma Outreach Northwest, and you.

Through #SayScleroderma, our annual campaign for Scleroderma Awareness Month, organizations and individuals across the community made this disease impossible to ignore. Dedicated campaigns for pulmonary arterial hypertension and Raynaud's phenomenon reached people who may be encountering scleroderma and its complications for the very first time. And we stood with the entire rare disease community on Rare Disease Day, because being rare doesn't mean being alone.

Tiffany P. (dx 2007) joins the #SayScleroderma movement

65K+

likes, clicks, and shares of our awareness campaigns

COOL COMEDY HOT CUISINE

November 12, 2025

Some of the biggest names in comedy came out to support the SRF's mission

In an unforgettable evening of laughter and fine dining, hundreds of generous donors at Cool Comedy • Hot Cuisine 2025 in NYC raised more than $1.2 million to advance our mission of funding cutting-edge scleroderma research—bringing us closer than ever to a cure.

The night delivered side-splitting comedic sets and genuine you-had-to-be-there moments—like when Matt Friend made a surprise appearance and brought down the house with his signature impressions. But the evening had heart alongside the laughter through the Bob Saget Legacy Award, presented to Adam Duritz, as a testament to the passion and purpose that Bob continues to inspire in this community.

All gifts made that night were directed to the Bob Saget Memorial Scleroderma Research Fund, a heartfelt tribute to Bob's unwavering dedication to finding a cure and the pride he took in serving on our Board.

1

Talent Lineup

Jeff Ross (host)

Hannibal Buress

Kelsey Cook

Jim Gaffigan

Nikki Glaser

Special appearances by
Katie Couric and Matt Friend

Event Co-Chairs

Susan Feniger, Regina Hall,
Caroline Hirsch, Kelly Rizzo

2

3

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5

1. Co-Auctioneer Katie Couric
2. SRF Board Members
3. Host Jeff Ross
4. Nikki Glaser with Kimberly G., dx 2008
5. Jim Gaffigan
6. Kelsey Cook

Presented in Partnership with

NEW YORK
COMEDY
FESTIVAL

6

Scenes from

COOL COMEDY HOT CUISINE 2025

8

7

9

10

7. Adam Duritz
8. Kelly Rizzo and Breckin Meyer
9. Hannibal Buress
10. Matt Friend

11

12

14

13

15

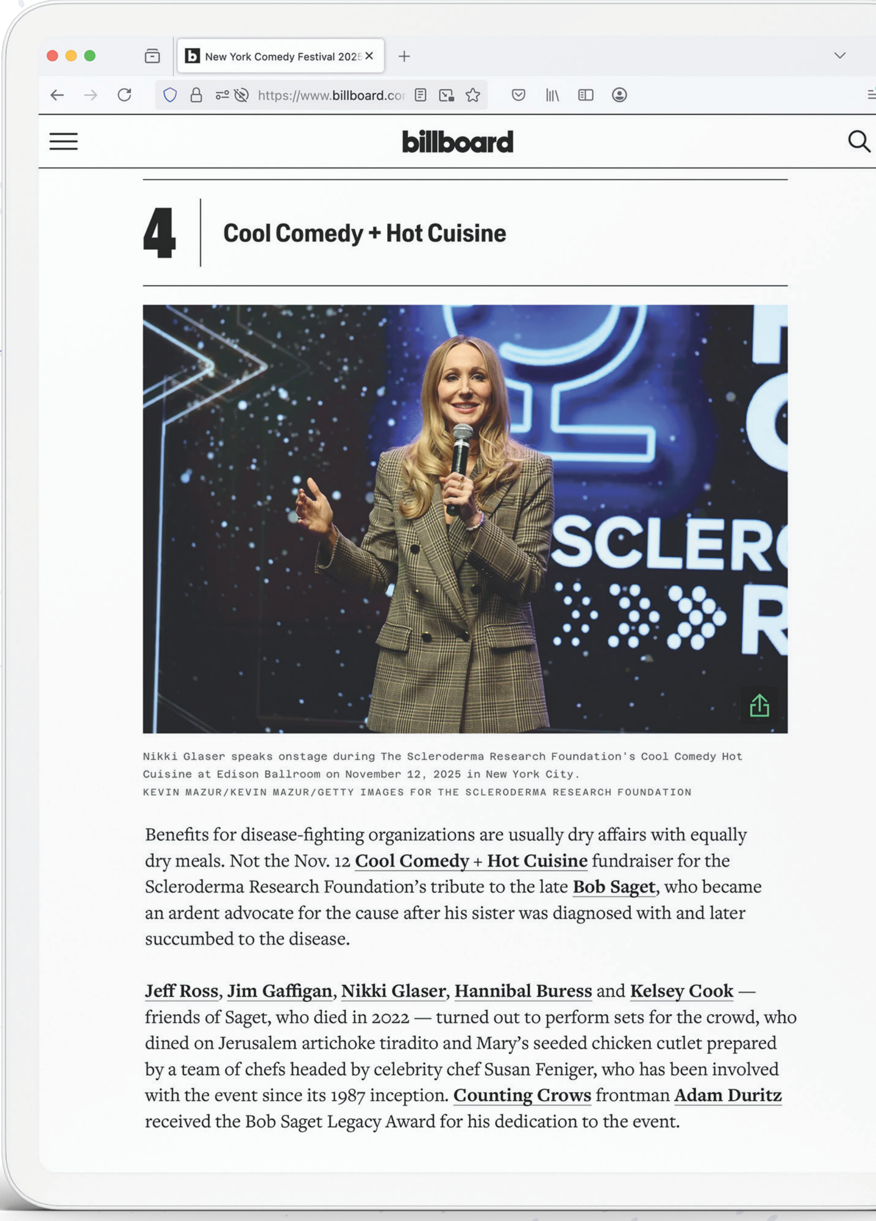
11. Jeff Ross
12. Dale Badway and Carl Mayer
13. CCHC talent line up with Adam Saget
14. Susan Feniger
15. Lara Saget

COOL COMEDY HOT CUISINE

Makes Headlines for Scleroderma Research

From the pages of *Billboard* to *People* magazine, Cool Comedy • Hot Cuisine, benefiting the Scleroderma Research Foundation, made waves far beyond the Edison Ballroom in New York City.

Presented in partnership with the New York Comedy Festival, the country's largest and longest-running annual comedy festival, the star-studded evening drew media attention that amplified our message well beyond the room—putting scleroderma in front of new audiences across the country.



4 | Cool Comedy + Hot Cuisine

Nikki Glaser speaks onstage during The Scleroderma Research Foundation's Cool Comedy Hot Cuisine at Edison Ballroom on November 12, 2025 in New York City.
KEVIN MAZUR/KEVIN MAZUR/GETTY IMAGES FOR THE SCLERODERMA RESEARCH FOUNDATION

Benefits for disease-fighting organizations are usually dry affairs with equally dry meals. Not the Nov. 12 **Cool Comedy + Hot Cuisine** fundraiser for the Scleroderma Research Foundation's tribute to the late **Bob Saget**, who became an ardent advocate for the cause after his sister was diagnosed with and later succumbed to the disease.

Jeff Ross, **Jim Gaffigan**, **Nikki Glaser**, **Hannibal Buress** and **Kelsey Cook** — friends of Saget, who died in 2022 — turned out to perform sets for the crowd, who dined on Jerusalem artichoke tiradito and Mary's seeded chicken cutlet prepared by a team of chefs headed by celebrity chef Susan Feniger, who has been involved with the event since its 1987 inception. **Counting Crows** frontman **Adam Duritz** received the Bob Saget Legacy Award for his dedication to the event.

Bob Saget's Legacy Lives On

For more than 30 years, SRF Board Member Bob Saget was a passionate advocate for the scleroderma community. After losing his sister Gay to scleroderma, Bob made it his mission to ensure the disease would never be forgotten. Although we and the world mourned his loss in 2022, the SRF remains committed to Bob's vision of a world free from scleroderma.

To honor his commitment, we established the Bob Saget Legacy Award to recognize individuals who, like Bob, use their voice and platform to shine a light on scleroderma.

In 2025, we were proud to present the award to Adam Duritz, frontman of Counting Crows and a dear friend of Bob's. Moved by Bob's deep commitment to this cause, Adam Duritz has shared his time and talents at Cool Comedy • Hot Cuisine since 2004—channeling both his friendship with Bob and his artistry into work that continues to bring us closer to a cure.

Legacy Award Recipients

2025 Adam Duritz

2024 John Mayer, Jeff Ross

2023 Caroline Hirsch

> "Bob was very devoted to making a change for people with scleroderma. He instilled in me a deep respect for this organization."
>
> — ADAM DURITZ, COUNTING CROWS

Impact made

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Fiscal Year 2025 Financial Highlights

Your Investment at Work

For nearly four decades, this dedicated community has been the force behind the Scleroderma Research Foundation's progress—driving major advancements in understanding this disease, how it progresses, and how it can be treated. Your generosity powers every breakthrough, and it positions the SRF as the most trusted and largest nonprofit funder of scleroderma research in the U.S.

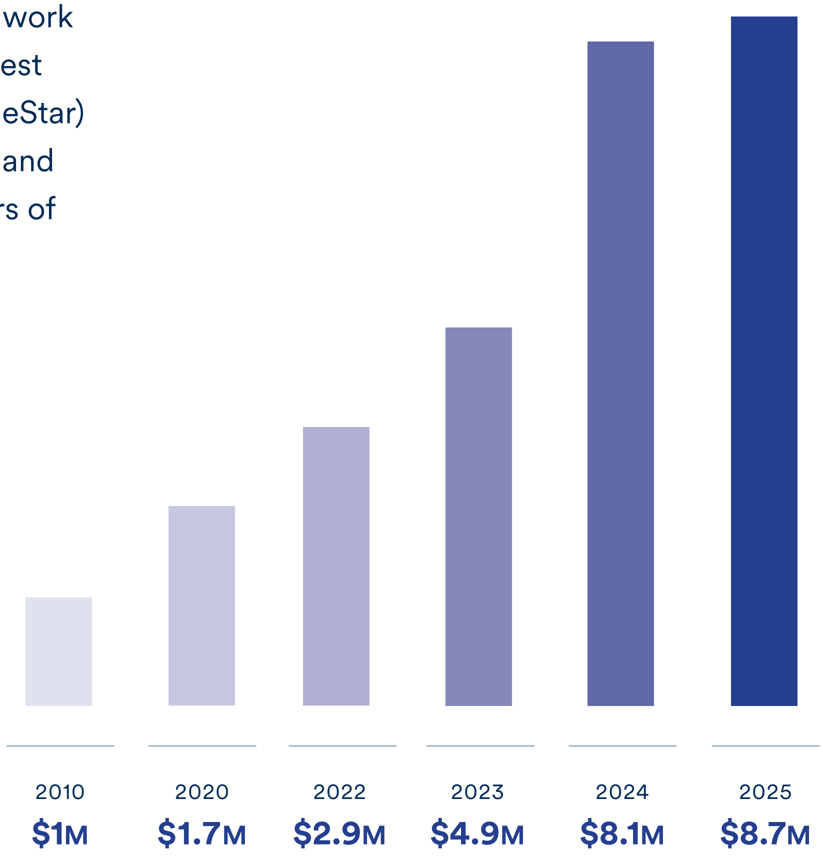
You can trust that your gift is put to work responsibly. The SRF holds the highest ratings from Candid. (formerly GuideStar) and Charity Navigator—the largest and most trusted independent evaluators of nonprofit organizations.

Platinum Transparency 2025
Candid.

Charity Navigator
✦ ✦ ✦ ✦
✦ FOUR-STAR ✦

Driving Ever-Growing Research Funding

Your support helped fund our largest single-year investments in research—a milestone that reflects both the extraordinary momentum building in the field and the incredible generosity of donors like you. Every dollar you give accelerates bold science and brings us closer to the breakthroughs that people living with scleroderma need.



Summary of Audited Financials[†]

$8.7M

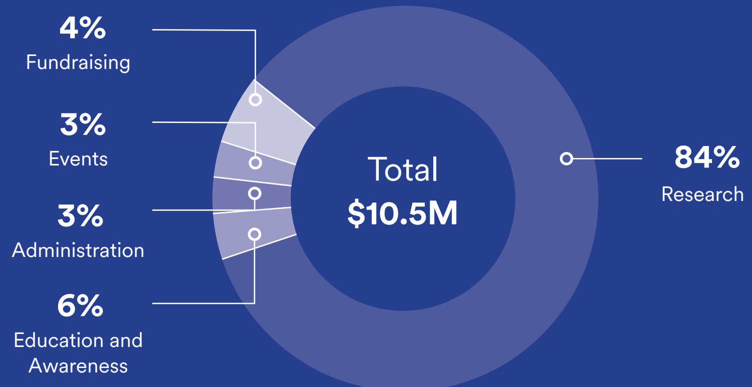
invested in research—
more than any other year
in our history

84%

of every dollar goes
directly to advance
research efforts

Where Your Money Goes

(Expenses)



Research

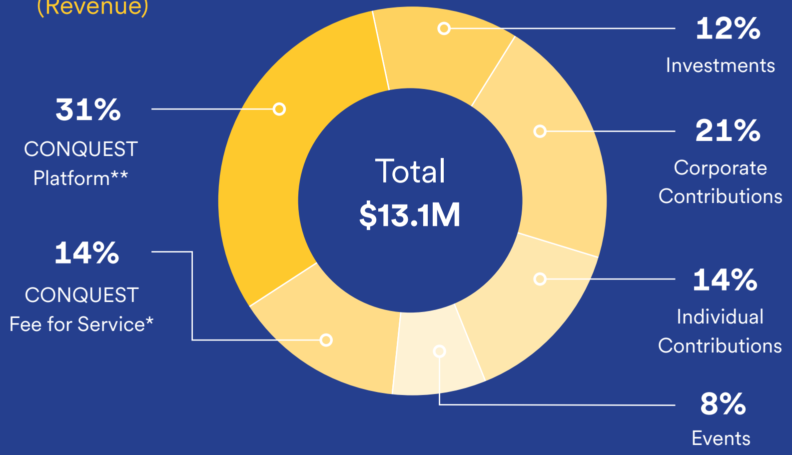
51%
($4.4M)
CONQUEST

31%
($2.7M)
Core Research

18%
($1.6M)
CONQUER

How We Raise Funds

(Revenue)



CONQUEST's Financial Impact Accelerates Research Progress:
*Participating pharmaceutical companies have agreed to pay an unrestricted fee to the SRF for putting their trial therapies into CONQUEST. This fee can be used to underwrite the broader SRF mission.

CONQUEST Operations Are Fully Funded by Participating Partners:
**The revenue and expense reflect pass-through agreements with participating pharmaceutical companies to cover the actual costs of adding their investigational products to CONQUEST. Expenses include the work of the SRF's CONQUEST clinical team.

Separately, the SRF—as the study sponsor—hires an independent clinical research organization to help plan, manage, and carry out the clinical trial, ensuring trial integrity, efficiency, and regulatory compliance.

[†] Amounts have been rounded for presentation purposes. As a result, percentages may not calculate exactly.

Leadership Donors

It takes thousands of donors to drive this bold progress, and while we can only list those who make a gift of $5,000+ here, every gift of any size makes a meaningful difference.*

Anonymous (5)
Abbey, Weitzenberg, Warren & Emery
AbbVie
AE Family Foundation
Jim and Judy Alison
Ally's Allies
Amgen, Inc.
John and Debra Apruzzese
aTyr Pharma, Inc.
Avalyn Pharma
Dr. Iyad Baker and Sara Baker
Dr. Omar Baker and Behnaz Baker
BCS Private Wealth Management
Joel and Bonnie Bergstein
Boehringer Ingelheim Pharmaceuticals Inc.
Kevin and Claudia Bright
Bristol Myers Squibb
Michael Byrne and Tracey Thomson
Sara and Buddy Campbell
Jeffrey T. Chambers and Andrea Okamura
David Cohen and Laureen Seeger
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We apologize in advance for any errors or omissions.

*For a full list of donors, visit **srfcure.org/our-donors**

In Memory

The following individuals were lovingly remembered by friends and family through gifts made in their memory in 2025. Our hearts go out to all who have lost these cherished loved ones, and we extend our deepest sympathies to you.

David Abate
Lisa Abbatomarco
Don Abert
George Abraham
Shirley Abraham
Nancy G. Abrams
Denise Albert
Hilda Allen
Elaine Aresco
Helen Argiropoulos
Alice R. Atkinson
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Ron LaMar
Trina Lampl
Michelle Langmead
Jodie Laubenberg
Ann LeBlanc
Kay Lindquist
Mary Lofstrom

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In Memory

(Continued)

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Jeffrey H. Mace
Helen Mai
Klaus L. Mai
Jeanette Malanowski
Brenda Malone
Catherine Manion
Dawn Manjoney
Johanna Elizabeth Y. Mann
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Daniel Mitchell
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Demeshia Montgomery
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Linda Moore
Nancy Moore
Richard Moore
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Carlin Popke
Diana Pralgo
Kathryn Preston
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Susan Word
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Susan Yoast
Barbara F. Zimmerman
Sylvia Zinz

We apologize in advance for any errors or omissions.

In Honor

In 2025, we had the privilege to take part in celebrating the following individuals through generous tribute gifts made in their honor.

Whitney Aronson
Laura Avrett McCormick
Preston Barton
Melita Belgrave
Debbie Bischoff
Amy Boyce
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Kori Woodlief
Deann Wright
Cordelia Wylde Larue
Alexis Zappert

> **“In honor of our wedding, we chose to celebrate the life and legacy of Agnesa’s mother by supporting a cause that reflects her compassion and strength. The generosity of friends and family will help carry her light forward with love and support.”**
>
> — AGNESA L. AND ROBERT G.

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The Sharon Monsky Legacy Society

In 1987, scleroderma patient-turned activist Sharon Monsky founded the SRF, understanding that funding medical research was the best way to build a better future for those with scleroderma.

Though Sharon passed away in 2002, her determination to end this disease continues to inspire people today.

The Sharon Monsky Legacy Society honors donors who have chosen to support scleroderma research beyond their lifetimes. Belonging to the Sharon Monsky Legacy Society allows us to celebrate these individuals now for a planned gift they will make in the future, ensuring that we can continue our mission.

Learn more about the Sharon Monsky Legacy Society and its generous members:
srfcure.org/planned-gift

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At the SRF, we believe research is the best hope for a cure—and we pursue it relentlessly.

We can’t stop.

We won’t stop.

And it’s because of you.

This is progress made bold.

THE MISSION of the Scleroderma Research Foundation is to fund and facilitate the most promising, highest-quality research aimed at improved therapies and, ultimately, a cure for scleroderma. Until that time comes, we are dedicated to providing education, raising awareness, and sharing the most up-to-date information that the scleroderma community needs.

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