In Focus

2024
ANNUAL
REPORT

SCLERODERMA
RESEARCH
FOUNDATION®

We are on a
mission to cure
scleroderma.

No one should
have to suffer from
scleroderma.

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

This Must End.

This Must End

At the Scleroderma Research Foundation, we have a clear vision for a world without scleroderma.

Finding a cure remains in focus—because of you.

In Focus

A clear vision for a world without scleroderma

> “The road ahead is clear. It will demand hard work, but there are breakthroughs just around the corner.”
>
> **—LUKE EVNIN, PHD**
>
> Chairman of the Board
> Scleroderma Research Foundation (SRF)

Message from the Chair

As most of you are well aware, our mission is to find, fund, and facilitate the most promising, high-quality research that leads to better treatments and, ultimately, a cure. Today, that mission brings us to a remarkable moment: the intersection of incredibly powerful analytical tools and the power of a dedicated community of researchers and physician-scientists.

On the one hand, tools we have long anticipated—cell-by-cell molecular profiling, powerful computational platforms, and artificial intelligence—are finally here. On the other hand, is the community of clinicians and the patient-level data and samples that the SRF has painstakingly assembled and nurtured over the years.

This is what transformation looks like. And it is happening now, in the fight against scleroderma. The SRF research program continues to be at the forefront in both basic research on the disease and in work to support clinically oriented efforts.

In 2024, we took bold steps toward our vision of a world free of scleroderma. The most exciting milestone was the launch of CONQUEST—a groundbreaking clinical trial platform. Now enrolling patients across the world at more than 100 sites in over 20 countries, CONQUEST is already setting a powerful precedent for the future. By allowing multiple therapies to be tested simultaneously, the platform increases the chance that patients will receive active treatment, offering not just hope but also tangible progress. The platform trial is not only a huge win for patients but also by lowering the cost and complexity of launching clinical trials in scleroderma, a wider range of investigational drugs can be tested, with an expectation that more options for our patients will emerge.

We also advanced CONQUER, our landmark longitudinal patient registry, which continues to be a vital resource for understanding this complex disease. Thanks to donor support, over 1,000 patients across 19 leading U.S. research sites have been enrolled since 2018, with some now entering their sixth year of follow-up. Together, these efforts reflect a banner year for the SRF and, more importantly, for scleroderma research advancements.

Although we remain firmly focused on our mission, and as we highlight the achievements of 2024, it is critical to note the current research climate here and now in 2025. We would be remiss if we did not comment on what we are witnessing in Washington. The medical breakthroughs that we rely on today—and those we hope for tomorrow—are the direct result of foundational investments made by the American government and, of course, the American taxpayer. For over three decades, support for this investment has been a bipartisan hallmark, helping to make American science the envy of the world.

However, we see a series of actions directed at the National Institutes of Health and research-based universities that threaten to undermine this legacy. We believe these actions risk significantly diminishing the capacity and capabilities of American biomedical science for many years into the future. We sincerely hope that a renewed bipartisan commitment will soon emerge, ensuring that our shared vision for a future with better therapies for all patients is preserved.

Whatever may come, we will not stop until we end scleroderma, and that’s only within reach because of you. At the heart of every achievement this year is you—our passionate and unwavering community. From the unforgettable energy of Cool Comedy • Hot Cuisine to the creativity and drive of the Cure Crew, your support allows us to stay focused on what truly matters: real progress toward a cure.

Your generosity, commitment, and belief in what is possible make this goal a reality. The road ahead is clear. It will demand hard work, but there are breakthroughs just around the corner.

With gratitude,

Luke Evnin, PhD
Chairman of the Board
Scleroderma Research Foundation

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In Memoriam


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SRF Ambassador
since 1991


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SRF Founder
1953-2002

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The SRF Scientific Advisory Board

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


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In Focus

In Focus

Research for a Cure

The SRF Research Program

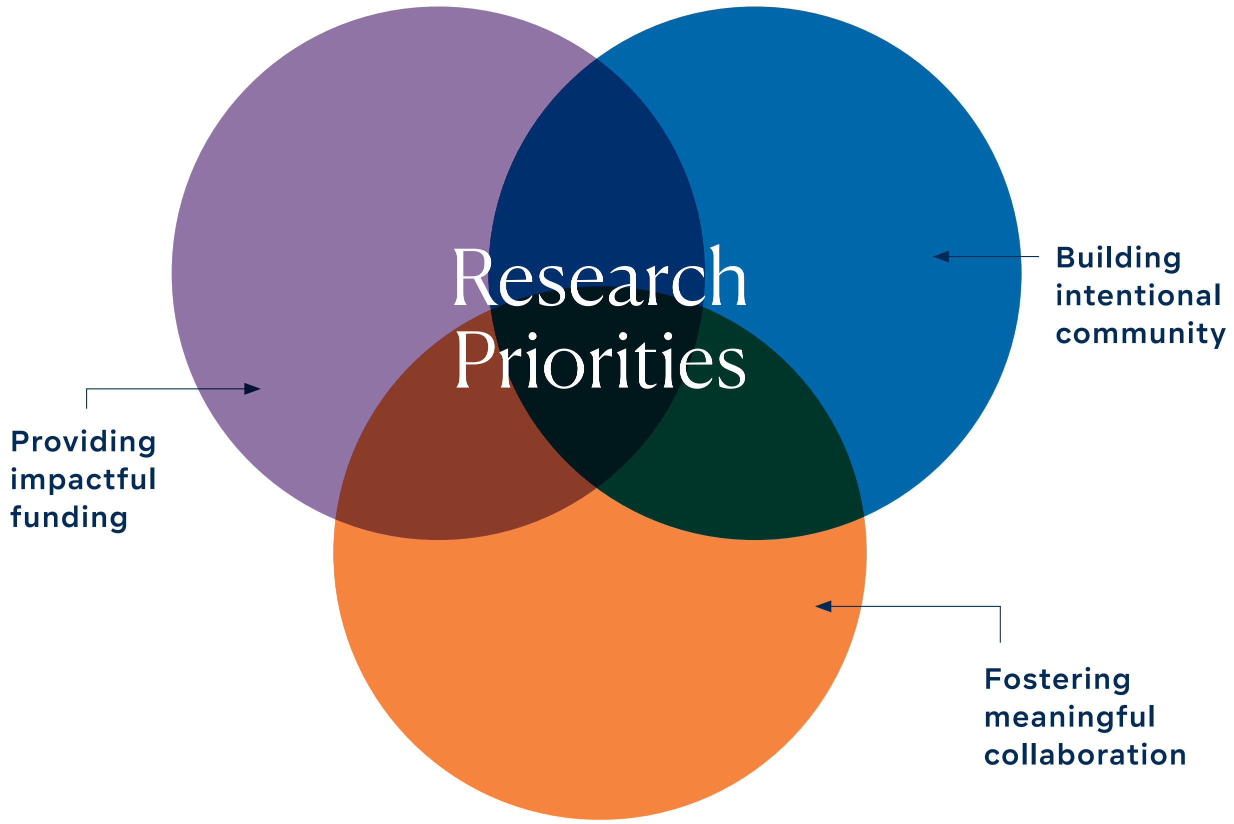
Program Pillars

Research Grants

Research Collaboration

CONQUER

CONQUEST



Research Grants

The SRF funds direct research grants for basic and translational projects to top institutions and researchers. When evaluating how to build a well-rounded portfolio of projects, the SRF looks to see 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 to Find a Cure

(Enabling the Development of Patient-Specific Medicine)

SRF Funded Grants

$2.56m

High Impact Research
Grants Awarded
in Fiscal Year 2024

FUNDED PROJECTS

Regulation of Inflammation and IFN-1 Response in the Fibrotic Skin Environment

Franck Barrat, PhD
Hospital for Special Surgery

Gene Regulatory Mechanisms in Scleroderma

Howard Y. Chang, MD, PhD*
Stanford University, Howard Hughes Medical Institute

Epigenetics of Sex Differences in Scleroderma

Howard Y. Chang, MD, PhD*
Stanford University, Howard Hughes Medical Institute

Scleroderma Twin Study

Howard Y. Chang, MD, PhD*
Stanford University, Howard Hughes Medical Institute

Establishing a Connection Between RNA Glycosylation and Autoantigens

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

with

Elana J. Bernstein, MD, MSc
Columbia University

Building a Cellular and Genetic Atlas of Systemic Sclerosis for a Roadmap Toward a Cure

Dinesh Khanna, MD, MSc;
Johann Gudjonsson, MD
University of Michigan

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

Michael Longaker, MD, MBA
Stanford University

Howard Y. Chang, MD, PhD*
Stanford University, Howard Hughes Medical Insitute

Macrophage-stromal Cell Interactions in Tissue Homeostasis and Fibrosis

Ruslan Medzhitov, PhD
Yale University, Howard Hughes Medical Institute

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

Spatial Transcriptomics of Scleroderma Skin to Augment Understanding of Cellular Interaction and Disease Propagation

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

Identification and Validation of Novel Pathogenic Genes in Juvenile Scleroderma

Kathryn Torok, MD
University of Pittsburgh

A Gene Expression Map of Scleroderma

Michael L. Whitfield, PhD
Dartmouth College

*Joined Amgen in Dec. 2024

FUNDED PROJECTS (CONTINUED)

Multi-omic Profiling of Interstitial Lung Disease in Scleroderma

Paul Wolters, MD
University of California, San Francisco

Gerlinde Wernig, MD
Stanford University

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

Paul Wolters, MD
University of California, San Francisco

Deciphering the Female Bias of B Cell Tolerance Breach in SSc

Bingfei Yu, PhD
University of Southern California

with

Elizabeth Volkmann, MD
University of California, Los Angeles

ONGOING PROJECT

Characterization of Somatic Mutations in Scleroderma

Shervin Assassi, MD
University of Texas Health Science Center at Houston

David Beck, MD, PhD
New York University

SRF AND SCLERODERMA CLINICAL TRIAL CONSORTIUM JOINTLY FUNDED PROJECT

CRISTAL: Developing the Combined Response Index for Scleroderma Trials Assessing Limited Cutaneous Systemic Sclerosis

Dinesh Khanna, MD, MSc
University of Michigan

Alain Lescoat, MD
University Hospital of Rennes

> “We act BOLDLY, seeking out scientists with fresh perspectives and a broad range of expertise.”
>
> —**DEANN WRIGHT, JD**
>
> SRF Research Committee Chair

Research Collaboration

Accelerating research discoveries requires cooperative relationships between medicine, academia, and industry. That's why our program focuses on building a community that can tackle ambitious research projects together and creating spaces for connection—a highly unique approach in a competitive field.

Scientific Advisor Dan Kastner, MD, PhD, in conversation at the Science Workshop

Science Workshop

Each year, we host our annual Science Workshop. Led by the SRF's Scientific Advisors, this gathering brings together all funded investigators, new applicants, outside experts, and industry partners for an intensive two days of evaluation, discussion, and brainstorming.

Co-Sponsorship of NIH Workshop on Systemic Sclerosis

In 2024 the SRF co-sponsored a workshop with the National Institutes of Health (NIH) and other nonprofits to explore advances in immunotherapies and cellular therapies for systemic sclerosis and chronic graft-versus-host disease. The event brought together over 100 experts for sessions on shared disease mechanisms, fibrosis biology, and emerging treatment strategies.

CONQUER

What is CONQUER?

Launched in 2018, CONQUER (COllaborative National QUality and Efficacy Registry) is a groundbreaking, multi-center, longitudinal patient registry and bio-sample repository that can enable sophisticated studies ranging from genetics to biomarkers. It is helping to transform our understanding of scleroderma and will enable more personalized, effective therapies for patients.

Collecting Data That Can Drive New Treatments

By collecting and sharing high-quality, anonymized patient data, CONQUER provides insights into how scleroderma affects diverse populations over time, driving scientific progress toward better treatments and therapies.

A Collaborative Effort

CONQUER creates a unique opportunity for clinicians and researchers at participating centers to connect through SRF-led events, facilitating research collaborations that might not happen otherwise.

In 2024, CONQUER reached a key milestone, enrolling over 1,000 patients.

> "CONQUER is the only nationwide registry. It has the potential to be bigger and more powerful than any U.S. scleroderma center's registry—and the spirit of collaboration it fosters is especially important."
>
> **—TRACY FRECH, MD, MSCI**
>
> Vanderbilt University Medical Center
> CONQUER Co-Chair

Sponsors

Thank you to our partners for helping to underwrite the costs of CONQUER.

Scleroderma Foundation
Greater Chicago

Scleroderma Foundation
Greater Washington DC

Hauske Family Foundation

The Nancy P. and Richard K. Robbins Family Foundation

CONQUEST

Created and operated by the SRF, CONQUEST is a platform clinical trial, which means it can evaluate multiple investigational study drugs at the same time. Currently, it is evaluating two investigational study drugs for scleroderma across the world. Over time, CONQUEST plans to look at more investigational study drugs, which can be added to the platform.

We sat down with Gregory Gordon, MD, JD, the SRF's first-ever Chief Medical Officer and leader of CONQUEST strategy and operations, to learn more about CONQUEST, its design, and why it's truly a huge step forward for the entire scleroderma community.

Gregory Gordon, MD, JD,
Chief Medical Officer

> "Think of a traditional clinical trial like building an entire soccer stadium just to play one game—and then tearing it down afterward.
>
> With a platform trial, we still build that stadium, but instead of using it for just one game, we use it to host many."

How CONQUEST breaks the mold

A Q&A with Dr. Gregory Gordon

Q: Can you give us a quick refresher—how do traditional clinical trials usually work?

A: In a traditional trial, researchers test one experimental treatment at a time. Patients are randomly assigned to either receive the treatment or a placebo.

Q: What's different about a platform trial?

A: The big difference is that a platform trial lets us test multiple treatments at the same time using shared infrastructure—including one common placebo group. **This makes it faster, more cost-effective, and more efficient than running several separate trials.** Think of a traditional clinical trial like building an entire soccer stadium just to play one game—and then tearing it down afterward. It takes a ton of time and resources. With a platform trial, we still build that stadium, but instead of using it for just one game, we use it to host many. It's a smarter, more sustainable way to test new treatments.

Q: Why is using a shared placebo group important for patients?

A: In your typical traditional trial, about half the participants are assigned to the placebo. But in a platform trial, we only need one shared placebo group for all the treatments being tested. **That means more patients are likely to receive an active treatment, which is an important advantage.**

Q. What happens to all the data you gather from the placebo group?

A. When a pharmaceutical company runs a study, they own the data, and it can be difficult for others to access it. In CONQUEST, the SRF will own the data from the placebo patients, and we're committed to making the data and our findings accessible.

Q. Who else is running a platform trial like this?

A: This platform trial design is still relatively new. It was first used in oncology trials, which is where we drew our inspiration from. But what's exciting is that no one else is trying this in rheumatology yet. As an innovator for scleroderma, the SRF is hoping to pave the way for others working on rheumatic diseases.

In Focus

Education and Awareness

Education and Awareness Program

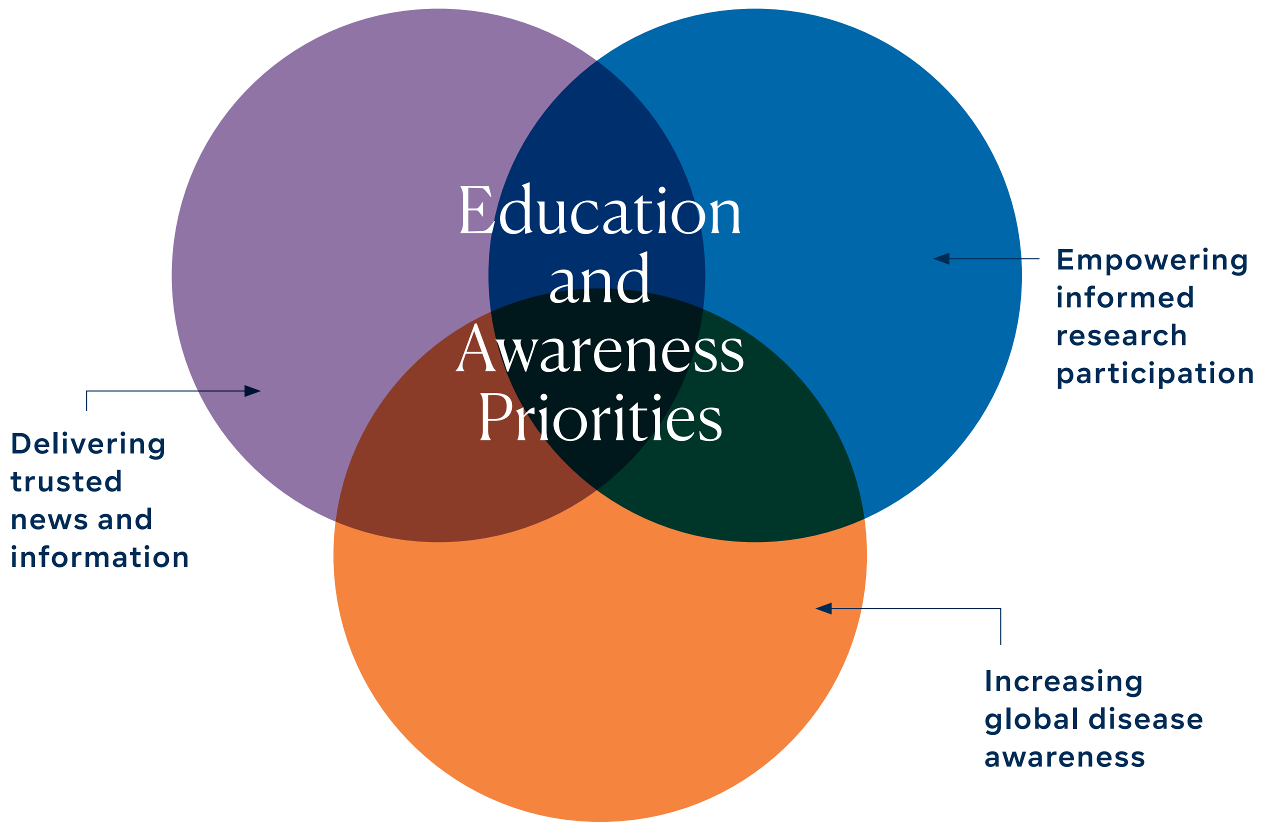
Program Pillars

Resources and Outreach

Patient Forum

Cure Crew

Partnerships



Resources and Outreach

In 2024, we delivered content featuring the most relevant news and information about scleroderma, its complications, treatments, and how to participate in research.

Growing Community Through Social Media

Through sharing trustworthy information and consistent engagement, we used social media to spread awareness and rally support for research.

7 Platforms

40k+ Followers

1.6m Impressions

Providing Website Tools and Information That Empower

A new clinical trial search tool and robust educational content made our website a go-to resource.

141k+ Website Views

164 Countries

Delivering High-Impact News

Timely updates, research breakthroughs, and powerful personal stories kept our community connected and informed.

9k Email Subscribers

43% Average Email Open Rate

Driving Global Awareness

From global disease days to the SRF #SayScleroderma campaign, our outreach elevated awareness of pulmonary hypertension, Raynaud's phenomenon, and more. This year's initiatives also included a 3-part collaborative PSA series and national TV features.

> "Thank you for the ongoing updates about the research into this crazy disease we suffer from."
>
> —**LYNN S.**
> dx 2001

Patient Forum

The SRF Patient Forum, "Collaborating for a Cure," is a yearly online, half-day forum with new information about scleroderma and research that anyone can attend for FREE.

This forum connects the scleroderma community with leading experts and research opportunities, empowering participants with the latest information and ways to get involved in advancing science.

A Global Gathering for the Scleroderma Community

The Patient Forum is designed for anyone affected by scleroderma. Open to all, the event draws a global audience, with hundreds of participants from 21 countries—76% of whom are patients.

459	21	76%
Registrants	Countries	of attendees live with scleroderma

Direct Access to Experts

Each session concludes with a live Q&A, giving attendees rare access to leading specialists. Participants receive clear information on disease management, emerging treatments, and current research opportunities, enabling informed conversations with their healthcare providers.

A Lasting Resource for the Community

Beyond event day, the forum continues to provide value through recordings available on YouTube, our website, and social media. More than 3,697 people viewed the recorded session in 2024 alone.

Education that Matters to People Living with Scleroderma

2024 Patient Forum Sessions

Non-Pharmacologic Management of Scleroderma
Dr. Ankoor Shah, MD
Duke University

Heart Disease in Scleroderma
Dr. Monica Mukherjee, MD
Johns Hopkins University

Platform Trials: Accelerating Clinical Research in Scleroderma
Gregory Gordon, MD, JD
Scleroderma Research Foundation

Dinesh Khanna, MD, MS
University of Michigan

Toby Maher, MD
University of Southern California

CAR T-Cell Therapy & Scleroderma – Today and Future
Peter Merkel, MD
University of Pennsylvania

Max Konig, MD
Johns Hopkins University

Peter Maag, PhD
Kyverna

David Shook, MD
Nkarta

Luke Evnin, PhD
Scleroderma Research Foundation

Scleroderma and Cancer: Implications for Cancer Screening & Therapy
Ami Shah, MD, MPH
Johns Hopkins University

Stem Cell Transplant in Juvenile Scleroderma
Kathryn Torok, MD
Pittsburgh Children's Hospital

Cure Crew

This grassroots volunteer program is focused on the SRF mission, spreading awareness and raising vital funds to support research that helps people with scleroderma live longer, fuller lives.

The unstoppable Cure Crew raised over $120,000 in 2024 and connected the community in powerful ways that we can't even begin to measure.

1,917

Cure Crew Members


1


2

Scan to learn more.

srfcure.org/curecrew

3


4


5

6

1

Alvin C., dx 2017, wrote a book and shared his story on social media to spread awareness of scleroderma.

2

Sofia Q., dx 2006, was one of more than 115 people who hosted a Facebook birthday fundraiser, turning a personal milestone into meaningful impact.

3

Carl Mayer focused on scleroderma in his Instagram Live "15 Dollar Game Show," using his platform to raise both funds and awareness for the SRF.

4

Ally's Allies returned for their second annual "Golfing for a Cure," a heartfelt fundraiser launched by Linda W. (center) in honor of her daughter Ally, dx 2022 (far right).

5

Cynthia W., dx 2021, teamed up with her brother to create a powerful PSA, sharing why research participation and scleroderma awareness are so important to her.

6

Beth L. (far right) and Lisa D. (far left) served up a second round of Picklepalooza, rallying their community on the courts to help fund the search for a cure.

In Focus

Working Together for Meaningful Progress

We share a bold goal with our partners: to end scleroderma. Progress depends on collaboration, and our work with advocacy groups and industry leaders is driving meaningful progress every step of the way.

Pictured above: We produced a three-part PSA video series on scleroderma and PAH in partnership with Johnson & Johnson, Project Scleroderma, and Scleroderma Outreach Northwest.

Collaboration

We are deeply grateful for the generous support of our partners. They support critical education and awareness initiatives that empower patients, inform physicians, and inspire broader understanding of this complex disease.

Community Partners

- Global Genes
- ILD Day Consortium
- Mogil's Mobcast
- National Institute of Arthritis and Musculoskeletal and Skin Diseases
- PF Warriors
- PHAware
- Project Scleroderma
- Pulmonary Fibrosis Foundation
- Rare Disease Diversity Coalition
- Raynaud's Association
- Scleroderma and Raynaud's UK
- Scleroderma Canada
- Scleroderma Foundation of California
- Scleroderma Foundation of Greater Chicago
- Scleroderma Foundation of Greater Washington, DC
- Scleroderma Outreach Northwest
- Scleroderma Patient-centered Intervention Network (SPIN)
- The Waiting Room Entertainment

Industry Partners

- Johnson&Johnson
- Bristol Myers Squibb®
- MERCK INVENTING FOR LIFE
- sanofi

COOL COMEDY
HOT CUISINE

BENEFITING THE SCLERODERMA RESEARCH FOUNDATION

On October 29, **Cool Comedy • Hot Cuisine (CCHC)** returned to Los Angeles for an unforgettable evening honoring John Mayer and Jeff Ross with the Bob Saget Legacy Award.

Kelly Rizzo with
Bob Saget Legacy
Award Recipients,
John Mayer and Jeff Ross

Named for our beloved longtime Board Member, the Bob Saget Legacy Award honors those who, like Bob, use their voice and platform to shine a spotlight on scleroderma and help move us closer to a cure. For more than 25 years, Bob led Cool Comedy • Hot Cuisine with heart, humor, and unwavering dedication—a legacy carried forward by John and Jeff.

Since the early 2000s, both performers have been instrumental to the event's success, whether through performing on stage or lending their presence and support. Their continued commitment and advocacy have helped raise vital awareness and funds for the SRF, and for this, we are profoundly grateful.

That same spirit of generosity and dedication was reflected throughout the evening, as a remarkable community of supporters and performers came together to support the cause. Their contributions helped raise more than $1.1 million to advance critical research and bring hope to all affected by this disease.

+ Talent Lineup: **Whitney Cummings**, **Alex Edelman**, **Chris Hardwick**, **Jim Jefferies**, **John Mayer**, and **Jeff Ross** (event host)
+ Event Co-Chairs: **Susan Feniger***, **Regina Hall***, **Caroline Hirsch**, and **Kelly Rizzo**

CCHC talent
lineup

Candace Cameron Bure and
Lori Loughlin

A celebratory
moment during the
live auction

Erion M., dx 2008, with
Kierra F., dx 2020

*Board Member

Scenes from Cool Comedy • Hot Cuisine 2024

SRF Board Members

Macaulay Culkin with guests

Adam Saget, Candace Cameron Bure, Jodie Sweetin, and John Stamos

Board Member Regina Hall takes the stage

Beyond the Evening:

Bob Saget's Legacy Lives On

The Bob Saget Memorial Scleroderma Research Fund, established in 2022 by the SRF Board of Directors, is a heartfelt tribute to Bob's unwavering dedication to finding a cure after the loss of his beloved sister. He gave generously of his time, energy, and heart, championing the SRF mission with deep personal commitment.

Gifts to this fund, including those made during Cool Comedy • Hot Cuisine, directly support bold, promising research with the ultimate goal of ending scleroderma. As of the end of 2024, more than $3.9 million has been raised in Bob's honor—a powerful reflection of the impact he made and the legacy he continues to inspire.

Scan to learn more.

support.srfcure.org/bobsaget

In Focus

Your Impact

Fiscal Year 2024 Financial Highlights

The Impact of Your Investment

Since 1987, the SRF has led the way in scleroderma research—driving major advancements in understanding the disease, how it progresses, and how it's treated. But it's your support that makes this all possible. Your generosity powers every breakthrough, fuels progress year after year, and positions the SRF as the most trusted and impactful nonprofit funder of scleroderma research in the U.S.

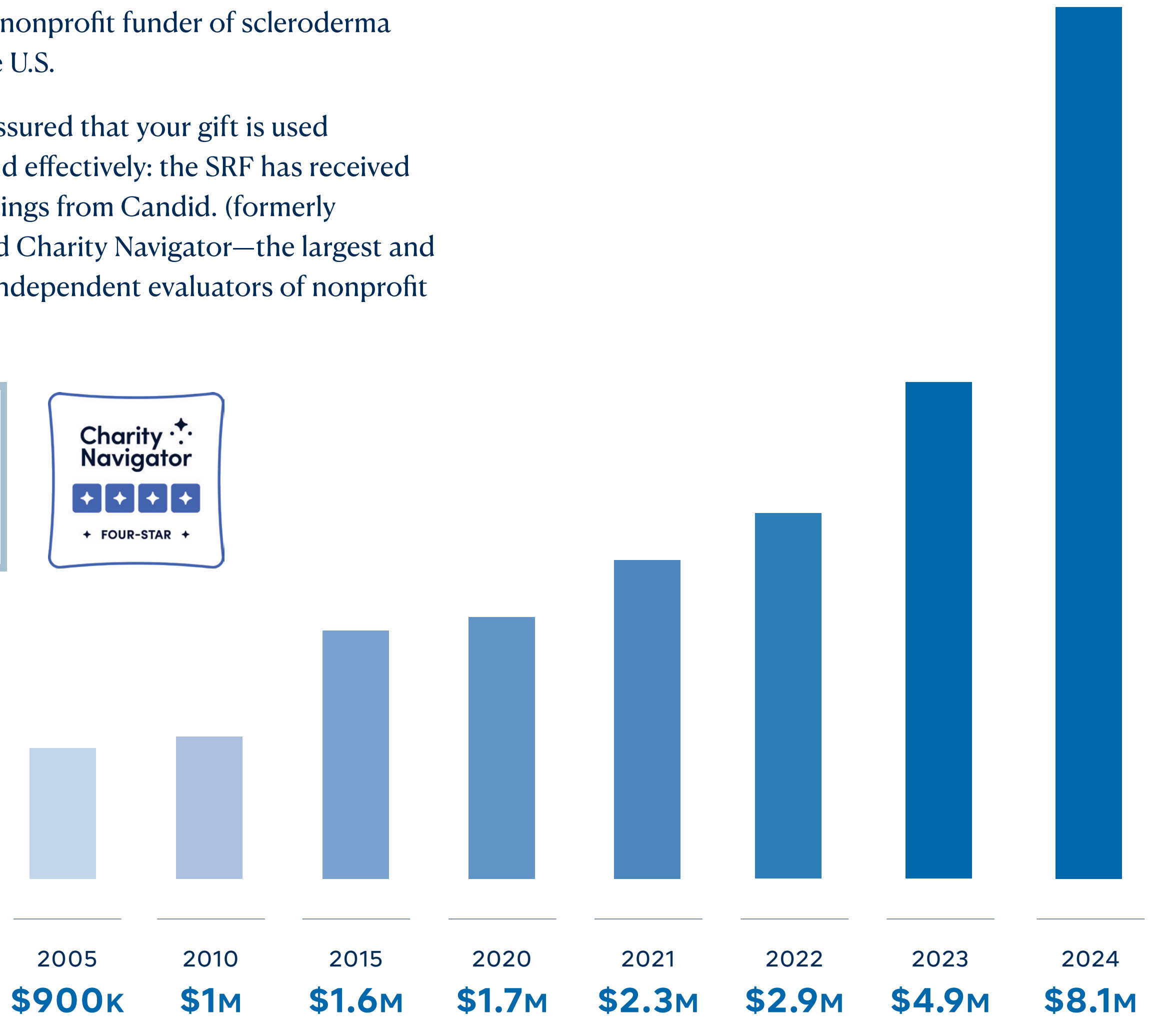
You can rest assured that your gift is used responsibly and effectively: the SRF has received the highest ratings from Candid. (formerly GuideStar) and Charity Navigator—the largest and most trusted independent evaluators of nonprofit organizations.

Platinum Transparency 2024
Candid.

Charity Navigator
✦✦✦✦
✦ FOUR-STAR ✦

Research Investment Growth

This year, we made our largest-ever investment in research—a significant increase that reflects both the growing momentum in the field and the deep commitment of donors like you, who are helping to accelerate bold science and the breakthroughs it makes possible.



Summary of Audited Financials

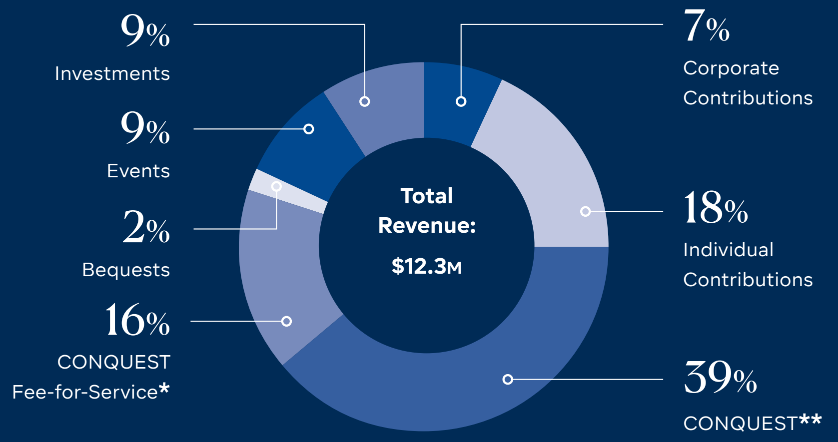
$8.16M

invested in research—the largest annual investment in our history

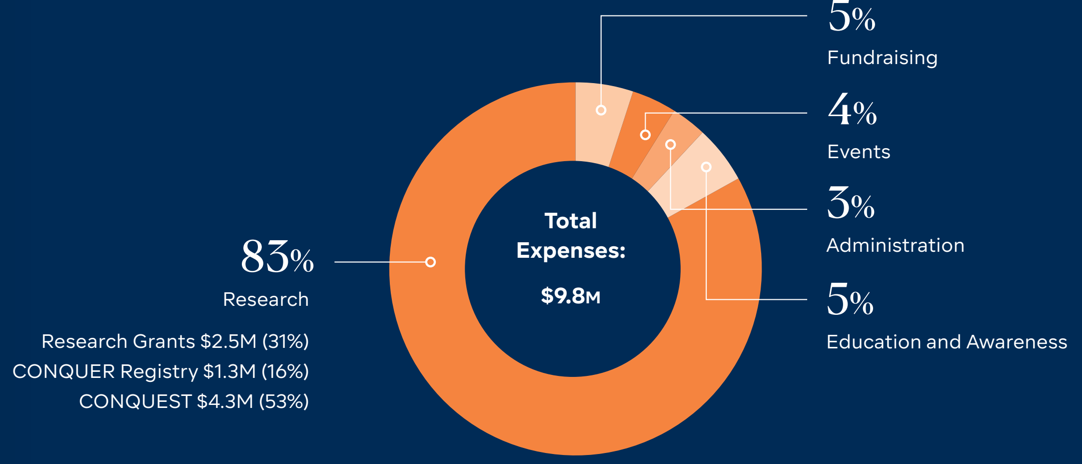
83%

of every dollar goes directly to advance research efforts

Revenue (How We Raise Funds)



Expenses (Where Your Money Goes)



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.

Our Donors

The SRF is grateful to the donors who make our mission possible. Your trust in our work fuels our mission and helps to drive research progress forward.*

Leadership Circle

The SRF extends our heartfelt gratitude to the donors who made leadership-level contributions of $25,000 or more in 2024.

Anonymous (2)
Abbey, Weitzenberg, Warren & Emery
AE Family Foundation
Amgen, Inc.
Dolores C. Anderson Trust
Dr. Omar Baker and Behnaz Baker
Estate of Karl Franz Bergmann
Bristol Myers Squibb
Sara and Arthur Lloyd Campbell
Judy Evnin and Dr. Tony Evnin
Luke Evnin, PhD
Heather and Michael Green
Bill and Marjorie Holodnak
Johnson & Johnson
Kao Family Foundation
Masters Family Charitable Fund
Merck & Company
Violetta and Andy Merin
A.J. and Erica Nahmad
Patricia Nicklowitz
The Nancy P. and Richard K. Robbins Family Foundation
Max, Samantha, Montana, and Mark Scher
Dan and Jayna Schimberg
Schimberg Family Foundation
Scleroderma Foundation of Greater Washington DC
Victoria West and Marc Trachtenberg
Estate of Mary Ann Wolff
Deann Wright
Wright and Evnin Family Foundation
Meredith and Mike Zappert

Annual Donors

Below, we proudly recognize the donors who have contributed $1,000 or more in 2024.

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Ally's Allies
Richard and Christina Ambrosini
Arielle Anderson
Shari Annes
The Apatow-Mann Family Foundation
Appraisal Service, Inc.
The Art Laboe Foundation
The Artists & Athletes Alliance
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> “Thank you to all the people who work to find a cure. I am so looking forward to the day when people can say they HAD scleroderma.”
>
> **—KENNETH H., SRF SUPPORTER (DX 2011)**

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> “We give to the Scleroderma Research Foundation because their sole focus and dedication is towards research to find a cure.”
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> **—HEATHER GREEN**
>
> mother of Anna (dx 2019)

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In 1987, scleroderma patient-turned-activist Sharon Monsky founded the SRF, understanding that funding medical research was the best way to make 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 the future of scleroderma research beyond their lifetimes. Belonging to the Sharon Monsky Legacy Society allows us to celebrate these individuals now for a 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.

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A vision for a world free of scleroderma.

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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