



All In

2023
ANNUAL
REPORT

SCLERODERMA
 RESEARCH
FOUNDATION

WHAT WE DO

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. Additionally, we are dedicated to educating people living with scleroderma and their loved ones as they learn about how to best manage the challenges of the disease.

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We're
ALL IN
to Find
a Cure

Message from the Chair

For the past 24 years, I have been proud to be a part of the Scleroderma Research Foundation (SRF). The mission has always been clear: to find, fund, and facilitate the most promising, highest-quality research aimed at improved therapies, and ultimately, a cure for scleroderma. This year we took massive strides in pursuit of that mission.

As you have heard us say before, we can ONLY make progress with your support. Our commitment to our mission remains unwavering but it is your investment that makes it possible. Over the years, your support has enabled us to contribute more than \$44 million to research, making the SRF the leading investor in scleroderma research in the United States. We strive to be the trusted source of disease awareness and educational resources and to provide the most relevant news and information for the scleroderma patient community, the science community, and the public at large. And for 2023, we are excited to report on our progress in this dimension as well.

Among the key advances for 2023 was the launch of the CONQUEST platform clinical trial which will revolutionize how scleroderma clinical trials are done. Our commitment to delivering impact from basic research through to the clinic is further evidenced by CONQUER, which continues to be the gold standard for longitudinal patient repositories in scleroderma, consistently generating new and valuable findings.

The Science Workshop remains a highlight for researchers by fostering conversations and idea-sharing, unlike any other scientific gathering. These innovative approaches and collaborative efforts, supported by you, make significant strides in understanding and combating this disease.

At the heart of all these achievements is you—a dedicated community of supporters. Our signature fundraising event Cool Comedy · Hot Cuisine, the ever-innovative Cure Crew, and the committed support of people like you have been instrumental in raising much-needed funds and awareness.

Your generosity, dedication, and belief in the mission fuel progress and bring us closer to a cure. Read on to learn more about what your support has made possible as we work together toward a world without scleroderma.

With gratitude,



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



David Knoller



Violetta Merin



Jeff Seaman



Deann Wright, JD



Caryn Zucker



Dana Delany, Emeritus

In Memoriam



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



Sharon L. Monsky
SRF Founder
1953-2002

SRF Staff

- Joanne Gold, Executive Director
- Gregory Gordon, MD, JD, Chief Medical Officer
- Gloria Blecha, VP of Programs and Operations
- Kate Ceredona, Director of Philanthropy
- Hannah Young, Director of Communications
- Neha Pamboo, Senior Accounting Manager
- Ruben Cordoba, Development Database Manager
- Jill Litman, Communications Specialist

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 the SRF's research program, evaluate research proposals, make funding recommendations, and foster collaboration among funded investigators.



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



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



Dan Kastner, MD, PhD
Distinguished and Senior
Investigator NHGRI, National
Academy of Sciences



Lloyd Klickstein, MD, PhD
CEO, Koslapp
Therapeutics



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



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



Bruce Wintroub, MD
University of California,
San Francisco

Emeritus



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



Jeff Bluestone, PhD
University of California,
San Francisco; Sonoma
Biotherapeutics; National
Academy of Sciences



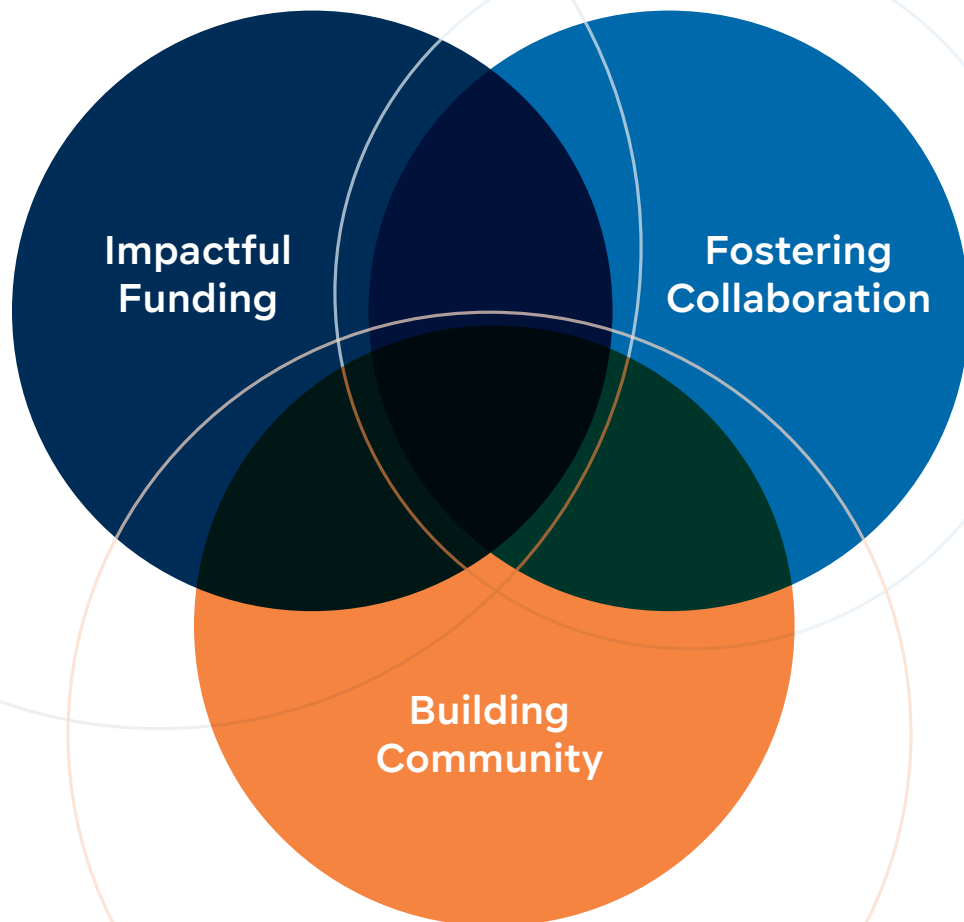
We're
ALL IN
on
Research

ch

THE SRF RESEARCH PROGRAM

Accelerating research discoveries requires cooperative relationships between medicine, academia, and industry. That's why the SRF research program focuses on building a community to tackle ambitious research projects together—an approach that is highly unique in a competitive field.

Research Priorities



SRF Research Program Pillars

1

CONQUEST

A global platform clinical trial enabling rapid and efficient development of new drugs for systemic sclerosis (SSc)

2

CONQUER

The first U.S.-based, longitudinal patient registry aimed at improving care by analyzing patient data over time to better understand how SSc progresses

3

Funded Research

Direct basic and translational research grants awarded to top institutions and researchers

4

Research Collaboration

Bringing together scleroderma researchers and expert scientists from outside the field; catalyzing large-scale research projects; hosting and participating in scleroderma consortiums, workshops, and conferences nationally and worldwide

1

CONQUEST

Launched in 2023, CONQUEST is a global, perpetual platform clinical trial developed and led by the SRF in coordination with partner biopharmaceutical companies.

UNRESTRICTED DONOR INVESTMENTS allow us to think big and direct the necessary resources to turn bold concepts like CONQUEST into reality.

Its goal is to accelerate the clinical development of potential therapies for scleroderma, making it the first platform clinical trial of its kind for autoimmune diseases.

A platform trial has many advantages compared to traditional clinical trials. A platform trial can test multiple therapies under a shared trial protocol and can pool the data from the control groups, while a traditional clinical trial can only test one therapy at a time. This makes a platform trial more efficient than a traditional clinical trial. This becomes particularly crucial in rare diseases like scleroderma. Also, the infrastructure built endures across multiple cycles of testing which leads to a faster path to results and lower costs on a per trial basis.

This revolutionary addition to the SRF research program represents a significant step in moving research from the lab directly to individuals living with scleroderma. This is how we are all in—we are bringing innovation to our community to accelerate drug development.

2023 Achievements



Sanofi joined as one of the two inaugural pharmaceutical partners of CONQUEST.



The CONQUEST Steering Committee was established.



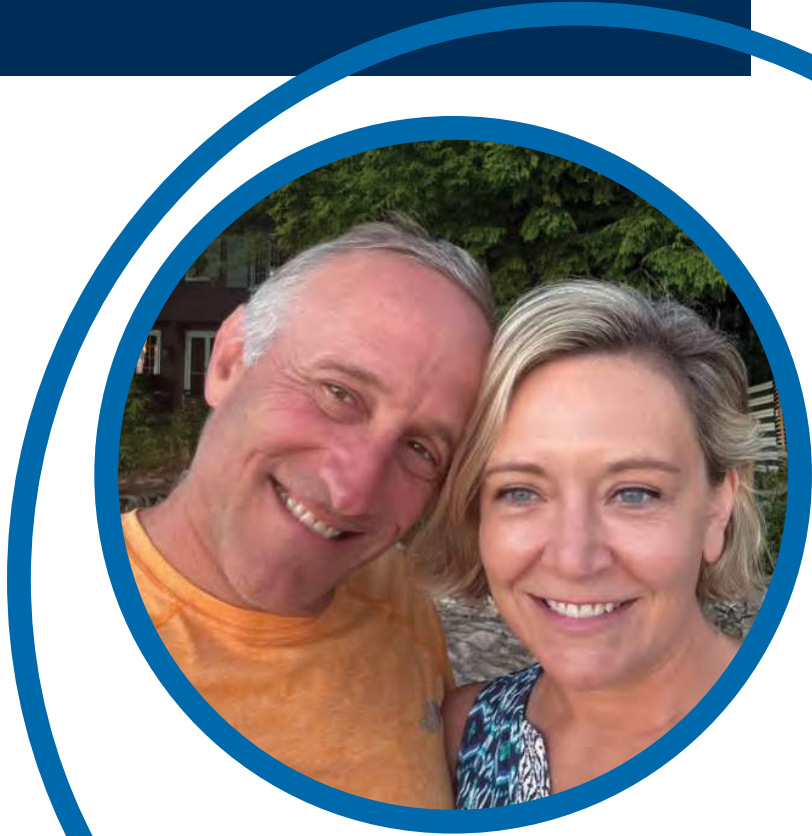
Boehringer Ingelheim joined as the second inaugural pharmaceutical partner of CONQUEST.



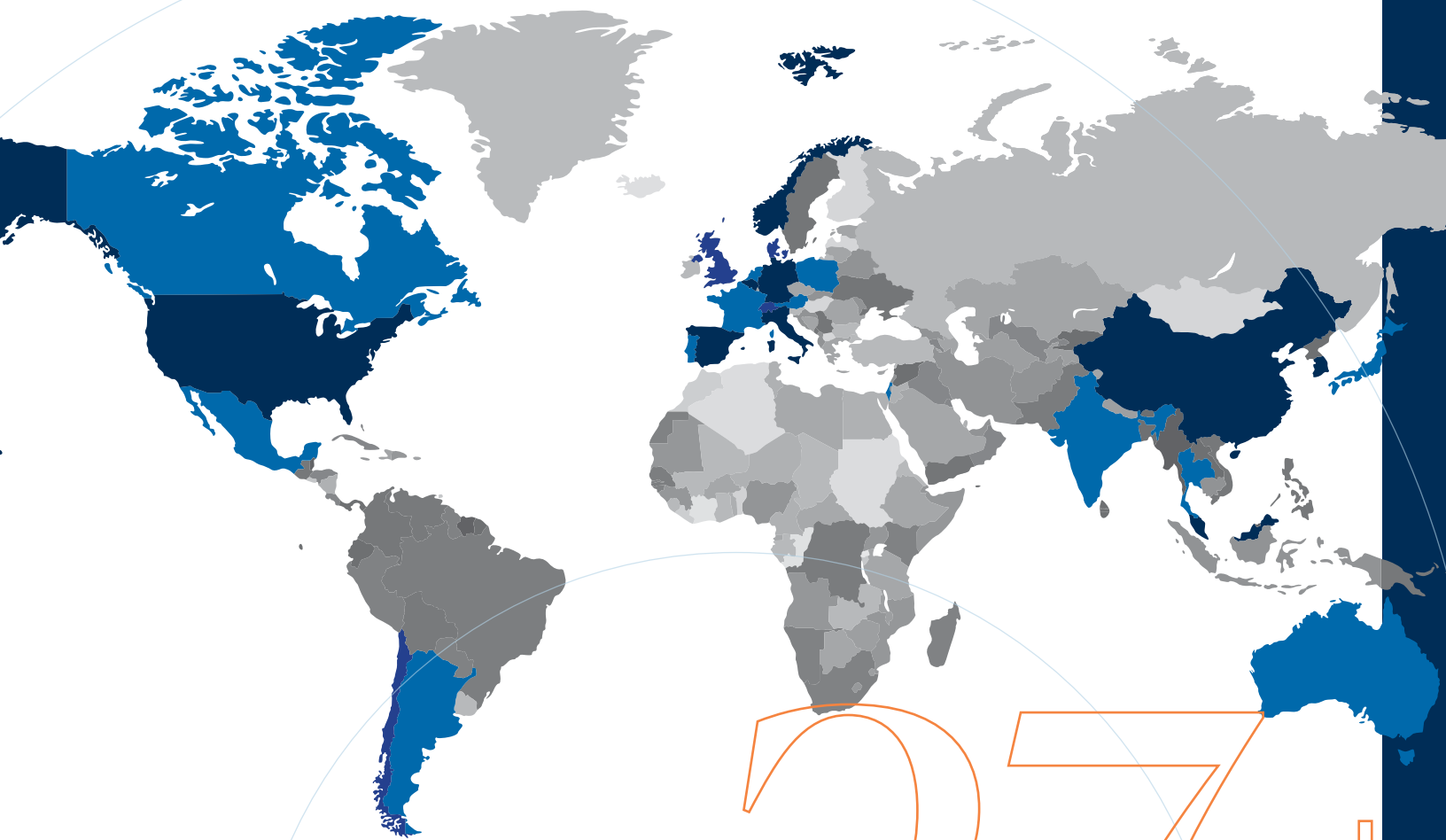
CONQUEST received Investigational New Drug approval to open the trial, opening the door for for the SRF to start enrolling patients in this landmark study.

“Our family knows the SRF is the path to a cure, which is why we were proud to contribute early seed funding to help develop CONQUEST. This was a way to show the world we are serious about finding a way to end this disease.”

— DAN AND JAYNA SCHIMBERG



Where CONQUEST sites will be in 2024–2025



165

participating centers

27+

countries

Next Steps for CONQUEST

The CONQUEST study will include 165 participating centers in more than 27 countries. The majority will be open for enrolling patients by the end of 2024, and the goal is to eventually enroll the first cohort of over 400 patients. As we move forward with this first iteration of CONQUEST focused on SSc-ILD (interstitial lung disease secondary to scleroderma), we are already looking to the future of how this platform trial can be used to evaluate more possible therapies.

CONQUEST in the News

Wall Street Journal

AUGUST 1, 2023

“Venture capitalist Luke Evinin has financed several successful biotechnology startups that develop treatments for cancer. Now he is encouraging drugmakers to tackle another disease: a rare autoimmune condition that he has himself.”

San Francisco Business Times

AUGUST 15, 2023

“Even as drugs advanced against arthritis, psoriasis and other diseases connected to the body’s immune system turning against healthy tissue, Luke Evinin saw potential treatments for scleroderma get passed by. He decided to do something about it.”

Endpoints News

DECEMBER 18, 2023

“Over three decades of investing, Luke Evinin has backed and advised dozens of biotechs developing medicines. Now, the longtime VC is turning his know-how and industry contacts loose on his own rare disease.”



CONQUER

In 2018, the SRF launched the CONQUER Registry (an acronym for COLlaborative National QQuality and Efficacy Registry)—a first-of-its-kind nationwide patient registry and biosample repository aimed at improving care and developing more effective, personalized therapies for systemic sclerosis (scleroderma) patients.

CONQUER was created through a collaborative effort among the largest scleroderma centers in the U.S. The goal is to enroll thousands of scleroderma patients from around the country. With the data amassed from an intensively curated and sustained study of patients, researchers and clinicians will be able to gain new insights into scleroderma in patients of all backgrounds and ethnicities. This knowledge will in turn inform research advancements and ultimately, drug and therapy discovery.

participating institutions

By the end of 2023, there were 17 participating institutions with more than 890 patients enrolled. Two papers based on CONQUER data were published this year, for a total of 6 papers based on CONQUER data. Upcoming planned longitudinal analyses include investigating the modified Rodnan skin score and conditions that affect the circulatory system, as well as using high-resolution computed tomography.

patients enrolled by the end of 2023



ALL IN ON RESEARCH: DR. SHERVIN ASSASSI

CONQUER STEERING COMMITTEE CO-CHAIR
UTHEALTH HOUSTON MCGOVERN SCHOOL OF MEDICINE

“What is so special about CONQUER is that it is based on 17 specialized academic centers in the U.S. and is a nationally representative cohort of systemic sclerosis patients,” says Dr. Assassi. “This is unique. There’s no other cohort in the U.S. that has that feature.”

Funded Research

Approaches to Understanding Scleroderma

The SRF funds direct research grants for basic and translational projects to top institutions and researchers. Tackling a disease as complex as scleroderma requires a strategic and multifaceted approach. 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:

1

Understanding Who Gets Scleroderma
(Genetics and Epigenetics of Susceptibility)

2

Unraveling How Scleroderma Progresses
(Pathobiology of Initiation, Propagation, and Regulation)

3

Helping to Find a Cure
(Enabling the Development of Patient-Specific Medicine)

SRF Funded Grants and Ongoing Research Projects 2023–2024

FUNDED PROJECTS

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

Franck Barrat, PhD
Hospital for Special Surgery

Characterization of Somatic Mutations in Scleroderma

David Beck, MD, PhD;
Shervin Assassi, MD, MS
New York University,
UTHealth Houston McGovern
School of Medicine

Gene Regulatory Mechanisms in Scleroderma

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

Epigenetics of Sex Differences in Scleroderma

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

Scleroderma Twin Study

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

Establishing a Connection between RNA Glycosylation and Autoantigens

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

Elucidating the Role of Dynamic X Inactivation Maintenance in the Pathogenesis of SSC

Nikhil Jiwrajka, MD
University of
Pennsylvania

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

Michael Longaker, MD, MBA;
Howard Y. Chang, MD, PhD
Stanford University School
of Medicine, Howard Hughes
Medical Institute

Macrophage-stromal Cell Interactions in Tissue Homeostasis and Fibrosis

Ruslan Medzhitov, PhD
Yale School of Medicine,
Howard Hughes Medical
Institute

Identifying and Optimizing Care for Mechanistically-driven, Clinically-relevant Scleroderma Subgroups

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

Identification and Validation of Novel Pathogenic Genes in Juvenile Scleroderma

Kathryn Torok, MD
Pittsburgh Children's
Hospital

A Gene Expression Map of Scleroderma

Michael L. Whitfield, PhD
Geisel School of Medicine
at Dartmouth

(CONTINUED)

\$1.85M

total funded research

FUNDED PROJECTS (CONTINUED)

Multi-omic Profiling of Interstitial Lung Disease in Scleroderma

Paul Wolters, MD;
Gerlinde Wernig, MD;
Howard Chang, MD, PhD

University of California, San Francisco;
Stanford University School of Medicine

Identifying Unique Molecular Profiles of Subtypes of Scleroderma-associated ILD

Paul Wolters, MD

University of California, San Francisco

Examining Mechanisms of Autonomic Nervous System Dysfunction and GI Disease in Scleroderma

Zsuzsanna McMahan, MD;
Gabsang Lee, MD

Johns Hopkins University School of Medicine

ONGOING PROJECT

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

Pittsburgh Children's Hospital

ONGOING SRF AND SCTC JOINTLY FUNDED PROJECTS

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

Dinesh Khanna, MD, MSc;
Alain Lescoat, MD

University of Michigan, University of Hospital of Rennes

Representative Papers Published in 2023 Resulting from SRF Investment



Lori Broderick, MD, PhD

Variant STAT4 and Response to Ruxolitinib in an Autoinflammatory Syndrome

PUBLISHED BY
THE NEW ENGLAND JOURNAL
OF MEDICINE



Erika Darrah, PhD

The XIST lncRNA Is a Sex-Specific Reservoir of TLR7 Ligands in SLE

PUBLISHED BY
JCI INSIGHT



Zsuzsanna McMahan, MD

Anti-Gephyrin Antibodies: A Novel Specificity in Patients with Systemic Sclerosis and Gastrointestinal Dysfunction

PUBLISHED BY
ARTHRITIS & RHEUMATOLOGY

4

Research Collaboration

Thanks to you, we can create spaces for meaningful interaction and innovation. Your unrestricted donations facilitate research collaboration—not only by funding projects but also by actively fostering conversations.

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.



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

National & Global Convenings

The SRF unites top-tier investigators for innovative collaboration through several meetings. We gathered over 50 representatives from participating CONQUEST sites worldwide at a meeting in San Diego in November. We also hosted two meetings with all CONQUER Registry investigators and research coordinators.

Webinars

The Spotlight Series: Breakthroughs in Scleroderma Research is a new webinar series that began in 2023 for the purpose of connecting the broader scientific and medical research community. These webinars are available to stream on the SRF website:

Scleroderma and Cancer: An Example of Immunoediting?

presented by Antony Rosen, MB ChB, BSc(Hons),
Johns Hopkins University School of Medicine

New Mechanisms Underlying Disabling Pansclerotic Morphea

presented by Lori Broderick, MD, PhD,
University of California, San Diego

We're
ALL IN
on Education
and Awareness



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The Kosmach Cure Crew at the 2023 Bet on a Cure

All In on Education and Awareness— THANKS TO YOU

Your support makes our education and awareness initiatives possible—work that empowers patients to advocate for themselves and participate in research. The more people know about scleroderma, the sooner diagnoses can be made. Our goal is to improve the quality of life for people living with this disease NOW while continuing the search for a cure.

Community Partners

Collaboration is essential to finding a cure. We continue to build relationships with scleroderma and rare disease organizations, both locally and globally:

EsclaroSalud

Global Genes

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Scleroderma Foundation

Project Scleroderma

Rare Disease Diversity Coalition

Raynaud's Association

Scleroderma Canada

Scleroderma Foundation of Greater Chicago

Scleroderma & Raynaud's United Kingdom

The Waiting Room Entertainment

Patient Education and Outreach Priorities

Delivering high-quality, trusted information directly to patients is a top priority. We provide content on the most relevant news and information about scleroderma, its complications, treatments, how to participate in research, and more.

Social Media

We provide robust and diverse editorial content for a highly-engaged social media audience of more than 37,000 followers worldwide across all platforms. In addition, we lead the annual #SayScleroderma social media campaign for Scleroderma Awareness Month in June. In its third run in 2023, the campaign was viewed nearly 110,000 times.

37K+

followers

110K

views of 2023 #SayScleroderma campaign

Patient Forum

On June 6, the SRF hosted the 2nd Annual Patient Forum, “Collaborating for a Cure,” a half-day online educational event attended by people from around the world. This information-packed forum provided the latest updates and clinical advice for people living with scleroderma and those who care about them. 366 participants registered (70% of whom were patients) and learned about scleroderma and its management from 11 expert presenters and panelists. This event also expanded the SRF’s self-serve educational offerings; in 2023 alone, there were 3,950+ post-event views of the sessions on YouTube.

366

registered participants (70% patient)

3,950+

post-event views on YouTube

Behind the Mystery

For Rare Disease Awareness Month in February, the SRF was featured on *Behind the Mystery*. This recurring series, dedicated to rare and genetic diseases, airs on Lifetime Network’s *The Balancing Act* program.

Susan Feniger (Board Member), Dr. Lori Chung (SRF-funded researcher, Stanford University), and Melissa B. (Cure Crew member, dx 2014) shared their respective experiences with scleroderma and why they’re excited about the research progress today. In addition to spreading awareness to live viewers, the episode has achieved nearly 75,000 views online.



Lori Chung, MD, MS



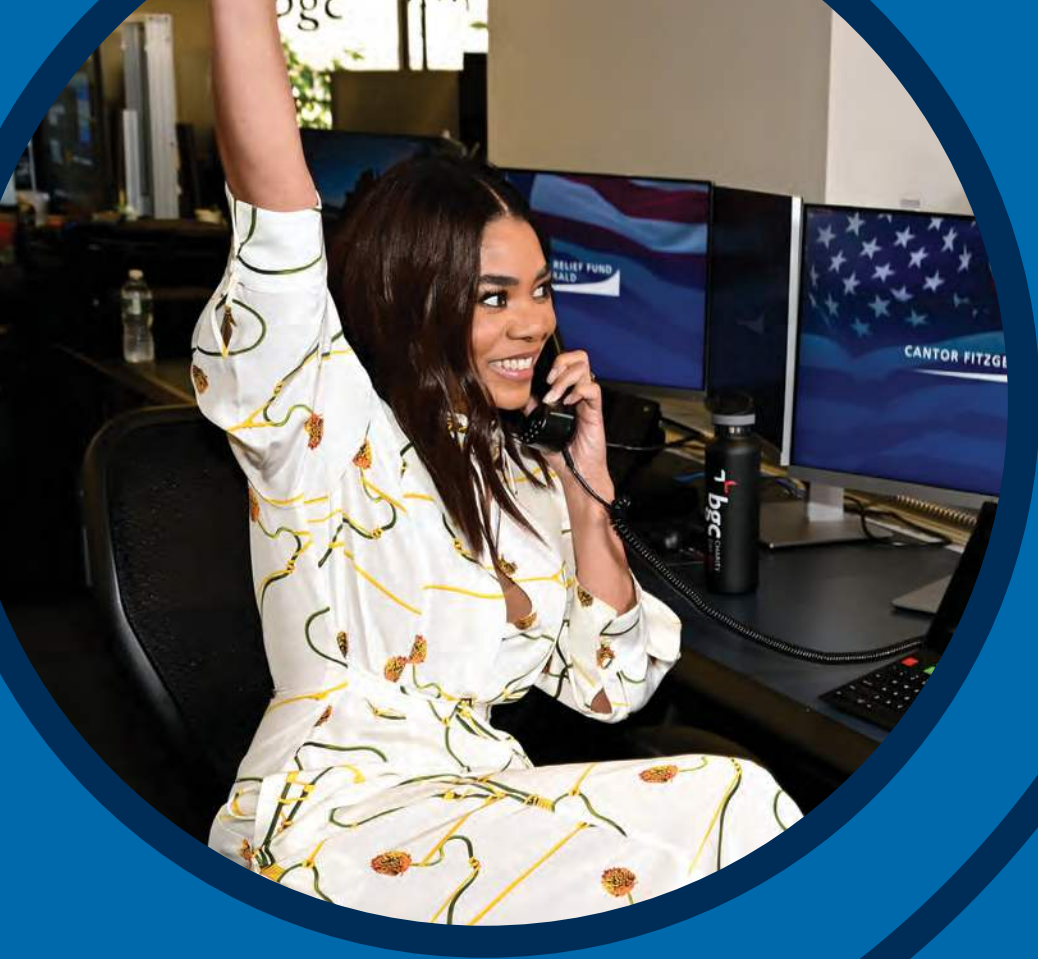
Susan Feniger



Melissa B.

“Working with *Behind the Mystery* was a wonderful experience. Not only did it bring awareness to the Scleroderma Research Foundation but it also brought awareness of scleroderma to a different audience.”

—MELISSA B., DX 2014



ALL IN ON AWARENESS: REGINA HALL

Board Member Regina Hall represented the SRF at the Cantor Fitzgerald Charity Day. "I'm honored to represent the SRF as part of this event to inspire hope globally," she says.

Regina's commitment to scleroderma research is deeply personal. In 2006, she became involved with the cause after her mother was diagnosed with the condition. "I learned about scleroderma when my mom was diagnosed," she shares. "There isn't a cure yet, but there are treatments when it's discovered early that can make a big difference."

Cause-Related Partnerships

The SRF is honored to collaborate with corporations who believe in and support our mission.

Golf for a Cure

Longtime sports agent and founder/CEO of Elfus Sports Management Brian Elfus fundraised to positively impact people living with scleroderma by supporting research at the 2nd Annual ESM Charity Golf Tournament.



“My mother, Roberta, suffered from scleroderma for over 25 years. I am determined to help find a cure for scleroderma.”

— BRIAN ELFUS

Infillion's TrueGiving

Infillion's TrueGiving generously donated an online ad campaign to increase awareness of scleroderma and the need for research.

Education and Awareness Corporate Partners

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



Gloria Blecha (SRF Vice President of Programs and Operations), Maureen Suave (Scleroderma Canada), and Anna Salas (EsclaroSalud) attend the Boehringer Ingelheim Global Patient Partnership Summit



Cure Crew

The Cure Crew is a grassroots volunteer program that raises awareness about scleroderma and fundraises to support the SRF's research program, helping people with scleroderma live longer, fuller lives.

In 2023, the SRF's Cure Crew welcomed 193 new members. A collaborative community of now 1,901 members devoted countless hours to raising funds and critical awareness about this disease. In 2023, they raised \$163k alone.

1,901

total members of Cure Crew as of the end of 2023

\$163K+

raised in 2023



In honor of Bob Saget, Caitlin McHugh Stamos and John Stamos created three unique blue bracelets in partnership with My Saint My Hero, donating 100% of the Stamos family's share of the proceeds to the SRF (modeled here by Kierra F., dx 2020, center).



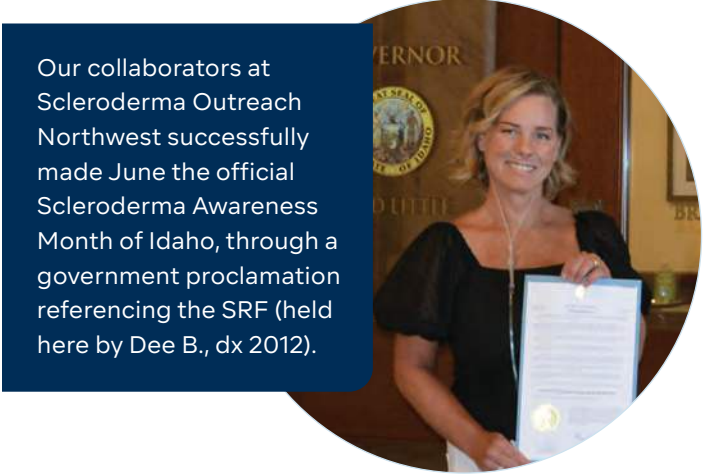
Beth L. (left) and Lisa D. (right) premiered the first-ever Pickleball Tournament to raise funds for the SRF, honoring their respective family members with scleroderma.

“When my daughter was diagnosed with scleroderma, it gave us the will and determination to fight this disease by any means necessary. The SRF has given us hope that we will one day find a cure.”

— LISA D.



Molly S. (right) raised funds via a sold-out, two-night cabaret in honor of her friend Jess M., dx 2011 (left), who lives with scleroderma.



Our collaborators at Scleroderma Outreach Northwest successfully made June the official Scleroderma Awareness Month of Idaho, through a government proclamation referencing the SRF (held here by Dee B., dx 2012).



Greg C., dx 2017, ran four marathons to globally spread awareness of scleroderma while raising funds for a cure.



For National Kidney Month, Falguni D., dx 2020, shared how experiencing scleroderma renal crisis motivated her to learn about scleroderma—and now she encourages others to do the same.



A TRIBUTE TO BOB SAGET

On November 8th,
we hosted our annual
Cool Comedy •
Hot Cuisine (CCHC),
a tribute to Bob Saget
in New York City.

This year marked the first-ever presentation of the Bob Saget Legacy Award to Caroline Hirsch, founder and owner of Carolines and the New York Comedy Festival.

Caroline was a dear friend of Bob and founding Board Member Susan Feniger. Her support over the past 30 years was one of the reasons so many legendary comedians continued to donate their time and talents to perform at CCHC. This award recognizes those who, like her, follow in Bob's footsteps to shine a spotlight on scleroderma and raise funds for a cure.

We cannot say thank you enough to all the incredibly generous donors and all the talented performers who generously donated their time, which resulted in raising more than \$1.2M for research.



Susan Feniger presents
the Bob Saget Legacy
Award to Caroline Hirsch

- + **Featuring:** Ronnie Chieng, Michael Che, Nikki Glaser, Jeff Ross (event host), and Adam Durlitz & David Immerglück of the Counting Crows
- + **Event Co-Chairs:** Susan Feniger*, Regina Hall*, and Kelly Rizzo
- + **Event Committee:** Luke Evnin*, David Knoller*, Rhonda Mace, Violetta Merin*, Jayna Schimberg, Deann Wright*, Caryn Zucker*

*Board Member



Kelly Rizzo, Jeff Ross,
and Adam Saget



Lara Saget, Ashley Oslen,
and Aubrey Saget



Board Member
Omar Baker, MD,
and guests



Nikki Glaser,
Michael Che, and
Ronnie Chieng



SRF Volunteers



A representative of
the Emerson College
"Bob Squad"



Board Member
Deann Wright, JD and
Jon LaPook, MD

Scenes from Cool Comedy • Hot Cuisine 2023



Janine Luke and Board
Chairman Luke Evin



Kelly Rizzo,
Tony Giannini, and
Allison Saget



David Immerglück and
Adam Duritz



Luke Evin, Lara Saget,
Deann Wright, Susan
Feniger, and Board
Member Caryn Zucker



Dale Badway
raises a glass to
toast Bob Saget



Nikki Glaser and Jeff Ross



Andrew Merin, Board Member
Violetta Merin,
James Dunning,
and Susan Magrino
Dunning



Event Committee member Rhonda Mace (third from left) with family and friends



Board Member Eric Kau, MD (center) and guests



Event Committee member Jayna Schimberg (fourth from right) with friends and guests from The Los Angeles LGBT Center

Continuing Bob Saget's Legacy

The Bob Saget Memorial Scleroderma Research Fund was established in 2022 by the SRF Board of Directors as a lasting testament to his life's work. Bob passionately sought to find a cure for scleroderma after losing his sister to the disease, and he was deeply dedicated to the mission of the SRF. All gifts made to this fund, including those during CCHC, will directly support the most innovative and promising research projects that will move scleroderma research forward to find a cure. As of the end of 2023, more than \$3.6M has been raised in Bob's honor.

Bob Saget's History with the SRF

Bob joined the SRF Board of Directors in 2003, but he began his involvement in 1991 through the SRF's annual signature event, Cool Comedy • Hot Cuisine (CCHC)—first as an attendee, then the next year as a performer.

In a strange twist of fate, his sister Gay was diagnosed with scleroderma after his introduction to the SRF. When she passed from scleroderma complications, Bob became even more committed to finding a cure. He ultimately became a key figure not only in organizing and producing CCHC, but also as part of the SRF's efforts to understand and end scleroderma. He contributed hugely to national awareness of this disease for 30 years, making thousands of scleroderma patients feel that they had an invincible champion fighting for them.

Under his years of leadership with Co-Chair Susan Feniger, the event raised \$25M for vital scleroderma research.



FY23 Financial Highlights

The Impact of Your Investment

Since 1987, the SRF has remained at the forefront of scleroderma research, contributing to a significantly greater understanding of the disease, its progression, and treatment options.

Year after year, important and generous donor support has been the driving force behind our relentless pursuit of a cure, and it ensures we continue to be the leading, trusted, and most impactful nonprofit investor in scleroderma-related research in the United States.

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



CONQUEST's Financial Impact

The launch of the CONQUEST platform clinical trial was among the key advances for 2023. Pharmaceutical corporations that enroll their therapies into the platform pay 100% of the cost for the trial operations, including support for a dedicated team built inside the SRF to expertly oversee and manage the global trial. In addition, the SRF collects a modest administrative fee from our pharmaceutical partners.

These unrestricted administrative fees are not only used to offset internal costs but also to underwrite the broader SRF mission. Among those efforts is the work that goes into evolving the platform clinical trial and leveraging the data collected to speed the introduction of new and more effective therapies for people living with scleroderma.

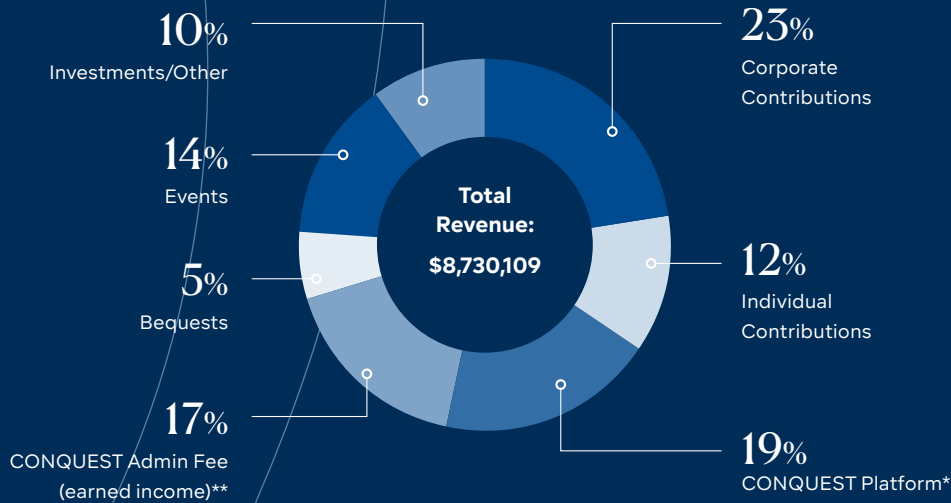
Summary of Audited Financials

\$5.6M **82%**

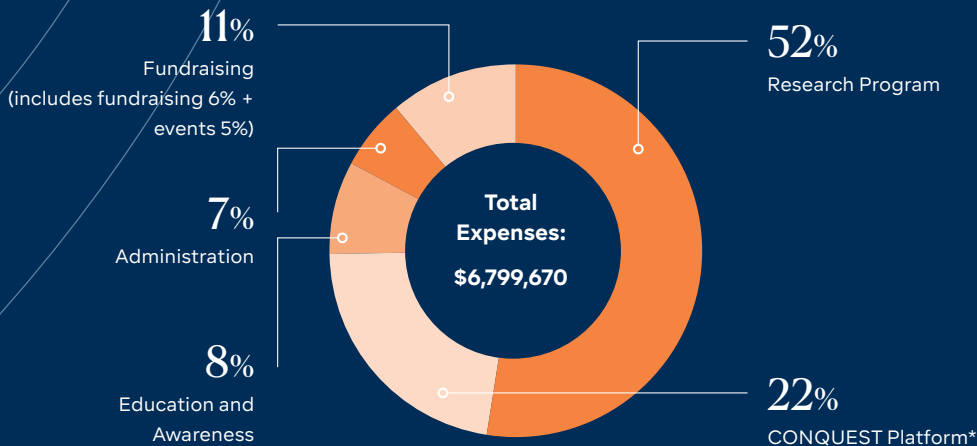
invested in research & education

of your donation goes directly to support the SRF's research & education programs

Revenue (How We Raise Funds)



Expenses (Where Your Money Goes)



*Participating pharmaceutical companies pay the direct costs for putting their novel therapies into the CONQUEST Platform Clinical Trial. These payments fully offset the payments to external companies including a third-party clinical research organization (CRO) that conducts trial operations and is responsible for payments to the individual trial sites for the clinical care of the trial participants.

**The SRF collects an unrestricted Administrative Fee as earned income for its oversight of the program which can be used to underwrite the broader SRF mission.



Linda W. (left) with her daughter Ally W., dx 2022 (second from right), and family at their August fundraiser.

ALL IN TO FIND A CURE: LINDA AND ALLY

Though Ally began experiencing scleroderma symptoms as a freshman in high school in 2015, it wasn't until January 2022 that she was officially diagnosed. "We knew nothing of this disease named scleroderma," Ally's mother, Linda, recalls.

After being told by a doctor that scleroderma is incurable, everything clicked for Linda. She says, "It was at that moment I decided I'm going to do what I can to raise funds to find a cure."

Linda then founded the nonprofit Ally's Allies. Its inaugural fundraising event "Golfing for a Cure" benefited the SRF and brought together 100 attendees for a day of golf, raffles, and scleroderma awareness and education.

Our Donors

The following remarkable donors have made leadership-level contributions of \$25,000 or more to support groundbreaking research and meaningful resources for those impacted by scleroderma.

Abbey, Weitzenberg,
Warren and Emery

AE Family Foundation

Dolores C. Anderson Trust

Omar and Behnaz Baker

Boehringer Ingelheim
Pharmaceuticals, Inc.

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In 1987, scleroderma patient Sharon Monsky founded the SRF with the belief that funding medical research was the best way to give hope to those living with scleroderma.

Sharon understood that research is a journey; one that would not be completed in her lifetime—but that the journey had to begin somewhere and ultimately, a cure would one day be found. Although Sharon passed away from complications of scleroderma in 2002, her passion, commitment, and fearless determination to end this disease continue to inspire people today.

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



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

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have to suffer from
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Lack of awareness
causes delays
in treatment or
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