We find, fund, and facilitate the most promising research to cure scleroderma. We recruit the best and the brightest researchers to understand the causes, discover treatments, and ultimately eradicate this disease. No one should have to suffer with scleroderma. No one suffering should also have to explain what this disease is or does. Lack of awareness causes delays in treatment or misdiagnosis. This must end. We are a world-class team. We are the best hope of finding a cure. We can’t stop. We won’t stop.

At the SRF, research is at the center of all we do to find a cure.
Our Vision: A World Without Scleroderma

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

Our Guiding Principles

We believe in collaboration
We unite exceptional scientists and clinicians across many disciplines in order to advance our understanding of scleroderma.

We promote discovery
We invest nearly $2.0M annually to fund pioneering research studies led by the most gifted scientists because research is the key.

SRF Founder Sharon Monsky envisioned a future where those living with scleroderma would have access to new treatments and, ultimately, a cure. She proudly stated that the SRF was “in business to go out of business.” Today, over 30 years later, we are accelerating our understanding of scleroderma through our innovative research program. Our focus on medical research enables gifted researchers and clinicians to explore promising ideas, share encouraging findings, and take us closer to our goal every day.
Dear Friends,

Never in our wildest dreams could we have imagined a year like 2020. When Covid-19 hit, our world and lives were changed seemingly overnight. But recognizing that people living with scleroderma—and all who care about them—were counting on the SRF to ensure vital research continued, we put our heads down, our masks on, and got to work.

I’m proud to say that thanks to the unwavering support of our scleroderma community, not only did we maximize our impact during this challenging year, the SRF was able to pivot and succeed in innovative ways. For example:

- **CONQUER** (the SRF-founded/administered longitudinal registry for scleroderma patients) adapted to the challenge of clinic visits during the pandemic by embracing telemedicine, enabling patients to complete Patient Reported Outcomes (PRO) surveys that are essential to the registry. Participating centers also coordinated with local labs to collect patient biosamples and ship them overnight to the CONQUER Biorepository, so the Biorepository continued to grow.

- The annual SRF Scientific Workshop, which convenes all funded investigators, Scientific Advisory Board members and select guests from academia and industry, was held as a 2-day virtual meeting with excellent results. Online video conferencing tools supported a robust agenda of presentations and collaborative discussions that helped to evaluate research progress, promote discovery, and informed future funding decisions.

- Innovation was on full display at the reimagined Cool Comedy • Hot Cuisine which also went virtual with unparalleled success. Hosted by SRF Board members Bob Saget and Susan Feniger, the live broadcast aired from a covid-safe studio and featured video appearances by more world-class performers than ever before. The new format offered unlimited capacity so thousands of viewers around the globe were able to participate, including many patients who could attend for the first time. As a result, the event helped to raise unprecedented awareness and generated $1.1 million to advance scleroderma research.

- Despite having to shelter in place and remain socially distant, our Cure Crew advocates and fundraisers never waned in their enthusiastic support of the SRF. In record numbers, these volunteers stepped up to share their stories and host virtual or online fundraisers. Every person who learns about this disease is a potential new champion for our mission to find a cure, so we’re truly grateful for Cure Crew members’ grassroots efforts.

- Most significantly, despite the economic challenges experienced by our entire nation, the SRF awarded $1.8M in grants for research and CONQUER, all made possible by support from our deeply generous donors. Research funding supported a range of basic, translational, and clinically-oriented projects ultimately aimed at better therapies. Looking ahead to 2021 when both labs and clinics are able to return to a more normal post-Covid environment, we anticipate the funded investigators and the CONQUER consortium will be able to aggressively pursue their aims. And, with this projected effort, we expect to return to pre-pandemic research funding targets of ~$3 million per year.

It goes without saying that this has been a remarkable year in ways we never anticipated, yet today the Scleroderma Research Foundation remains a world-class team, and the best hope of finding a cure. With the dedication and support of the scleroderma community by our side, in the coming year we will continue to aggressively drive scientific discovery forward. Thank you for standing with us so that ultimately, we will end scleroderma together.

Sincerely,

Luke Evnin, PhD
Chairman, Board of Directors and scleroderma patient

*CONQUER: Collaborative National Quality and Efficacy Registry*
SRF Leadership

Board of Directors

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

Sharon Dobie, MD (2017)
Physician

Susan Feniger (1986)
Chef and Restaurateur

Regina Hall (2020)
Actor and Producer

Eric Kau, MD (2014)
Physician

David Knoller (2015)
Producer, Writer, and Director

Violetta Merin (2017)
Community Leader and Philanthropist

Bob Saget (2003)
Actor, Comedian, Director, Writer, and Producer

Bob Smith (2019)
Pharmaceutical Leader

Deann Wright, JD (2000)
Attorney

Caryn Zucker (2005)
Community Leader and Philanthropist

Dana Delany (2005, emeritus)
Actor

Staff

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

Sharon L. Monsky
1953-2002
SRF Founder
The members of the SRF’s Scientific Advisory Board (SAB) are some of the world’s most honored and distinguished scientists who give their time and expertise freely to guide the SRF’s research endeavors by evaluating research proposals, and making funding recommendations. Each year, the SAB convenes and leads the annual SRF Science Workshop, which brings together thought leaders from diverse backgrounds to exchange information and ideas. The results of this intensive work are new alliances and ideas that further develop the road map for vital research, which will lead to better treatments and ultimately to a cure for scleroderma.

*Emeritus
Autoantibodies Targeting the Telomerase Complex in Scleroderma
Brittany Adler, MD
Johns Hopkins University School of Medicine

Role of CXCL4-induced TLR9 Defects Promote the Production of Autoreactive B-cells in Scleroderma
Franck Barrat, PhD
Eric Meffre, PhD
Hospital for Special Surgery
Yale University

Genome Research in African American Scleroderma Patients (The GRASP Project)
Francesco Boin, MD
Cedars-Sinai

Cancer Detection Strategies in Patients with Scleroderma
Livia Casciola-Rosen, PhD
Ami Shah, MD, MHS
Johns Hopkins University School of Medicine

Gene Regulatory Mechanisms in Scleroderma
Epigenetics of Sex Differences in Scleroderma
Scleroderma Twin Study
Howard Chang, MD, PhD
Stanford University School of Medicine
Howard Hughes Medical Institute

Stanford Scleroderma Center of Excellence
Lorinda Chung, MD, MS
David Fiorentino, MD, PhD
Stanford University School of Medicine

Molecular Subsets, Integrative Geonomics and Tissue Models of Scleroderma
Michael L. Whitfield, PhD
Geisel School of Medicine at Dartmouth

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

Telomere Length and Interstitial Lung Disease in Systemic Sclerosis
Paul Wolters, MD
University of California San Francisco

Systemic Sclerosis Lung Disease Trajectory Modeling Study
Scott Zeger, PhD
Ami Shah, MD, MHS
Antony Rosen, MD
Livia Casciola-Rosen, PhD
Laura Hummers, MD, MPH
Fredrick Wigley, MD
Johns Hopkins University School of Medicine

Betty Z. Benedict Award, co-funded with the Scleroderma Clinical Trials Consortium
Sensitivity Analysis of Thermal Imaging in System Sclerosis-Related Digital Vasculopathy (SATISS)
Andrea Murray, MD
University of Manchester, UK

Development and Validation of a Disease Activity Index in Systemic Sclerosis
Mandana Nikpour, MBBS, FRACP, FRCPA, PhD
McGill University/Jewish General Hospital
Laura Ross, MBBS, FRACP
University of Melbourne

The CONQUER Registry (Collaborative, National Quality and Efficacy Registry)
see page 8

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

$1.8M in Funded Grants
Each year, the SRF receives and evaluates applications for research projects aimed at understanding the biological processes that go awry in scleroderma and how these might be addressed therapeutically.

The process for determining which projects get funded is holistic. We ask numerous questions in considering projects for funding, such as: does this project answer a fundamental question about the scleroderma disease process? Would this project yield unique insights into targeting therapies to patients?

We also consider the investigator’s potential contributions to the SRF research program with questions such as: would this project and investigator contribute unique and relevant cross-disciplinary insights to our understanding of scleroderma? Does the investigator have the appropriate skills, background and access to excellent mentorship, if needed, to accomplish the project goals? Will this investigator make a real effort to add to our community through collaboration and generous sharing of ideas or resources?

All applicants, whether new or seeking continued funding, present their projects to the SRF’s Scientific Advisory Board and other attendees at the SRF Annual Workshop. There, assumptions are challenged, the project’s relevance and limitations are probed, and constructive critique and collaborative discussion ensues.

It is worth noting that, at the end of the process, there are always worthy projects that the SRF cannot fund, due to budgetary considerations. Our goal, and deepest hope, is to continue to expand the SRF’s ability to fund great research in our search for a cure.
Featured Projects
Highlights of a Few Promising Research Projects Funded in 2020

Gene Regulatory Mechanisms in Scleroderma
Howard Chang, MD, PhD
Stanford University School of Medicine
Howard Hughes Medical Institute

Project Overview
This study is focused on how the genes involved in scleroderma are turned on or off. The control of these genes determines a cell’s behavior, such as how active an immune cell may be or whether a fibroblast becomes activated to produce excess extracellular matrix, leading to fibrosis. The gene control switches are like the command lines that run the cell’s software. Dr. Chang’s team is working out how gene control is altered in scleroderma in order to detect and treat the disease at the most fundamental level.

Through this project, Dr. Chang has identified the gene switches that are different in scleroderma skin compared to normal skin. He believes these results may yield insights into the cell types that initiate scleroderma. The next step is to understand how the gene switches that are changed in scleroderma affect their target genes, for example, by making the genes turn on too long or in response to the wrong stimuli.

Dr. Chang’s group developed a new technique for determining the exact gene(s) that are controlled by a particular switch, which will improve researchers’ ability to interpret data from large-scale genomic projects (such as GRASP: Genome Research in African American Scleroderma Patients Project). Insights about the cells and the specific gene switches that cause disease manifestations also open new avenues for scleroderma diagnosis and treatment, including potentially matching patients to the therapies that target those genes.

Systemic Sclerosis Lung Disease Trajectory Modeling Study
Scott Zeger, PhD; Ami Shah, MD, MHS; Antony Rosen, MD; Livia Casciola-Rosen, PhD; Laura Hummers, MD, MPH; Fredrick Wigley, MD
Johns Hopkins University School of Medicine

Project Overview
While scleroderma presents in many different ways, recent studies underscore that patients can be divided into much more homogeneous subgroups. One of the most powerful indicators of disease biology is its trajectory over time, with different subgroups developing distinct complications at different rates.

This project combines the biostatistical expertise of Drs. Zeger, Kim and colleagues around defining disease trajectories, with the clinical expertise in scleroderma (Drs. Hummers, Shah and Wigley) in defining disease subgroups as well as the immunological expertise of Drs. Rosen, Casciola-Rosen and colleagues to identify clinically relevant, biologically-driven subgroups in scleroderma.

The Johns Hopkins team is studying subgroups of patients with different rates of disease progression to identify novel biomarkers that may predict disease course.

A predictive biomarker “signature” for disease progression would give clinicians an early indicator that could help them make more informed decisions about drug therapies for their patients. Such biomarkers may also point toward a mechanism that can be targeted to produce novel therapies.
Identification of Novel Pathogenic Genes in Juvenile Systemic Sclerosis

Kathryn Torok, MD
Pittsburgh Children's Hospital

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

Project Overview
Understanding the genetic factors underlying a disease is an important step toward improved therapies and, potentially, a cure. Genetic background can also determine prognosis, as well as medication response and toxicity, guiding treatment choices. Dr. Torok has discovered that some genes associated with juvenile-onset SSc (jSSc) are different from those associated with adult-onset SSc.

This study leverages the extensive genetics experience and pipeline of SRF investigators Drs. Dan Kastner and Elaine Remmers at the National Human Genome Research Institute (NHGRI). Patients and their healthy family members are recruited at Children’s Hospital of Pittsburgh (one of the largest pediatric rheumatology centers in the world) and at other centers. DNA from these individuals is sent to the NHGRI, where whole genome sequencing is performed with the aim of identifying novel candidate genes.

When causative gene defects exist, they usually lead to onset of disease early in life. Thus, Dr. Torok hypothesizes that a whole genome study of early-onset SSc will lead to identification of causative genes that cannot be identified in adult-onset populations. The results may lead to a better understanding of the molecular mechanisms of all kinds of scleroderma—localized, systemic, juvenile, and adult.

Immune Checkpoint Inhibitors as Antifibrotic Therapy for Scleroderma

Gerlinde Wernig, MD
Stanford University

Project Overview
Dr. Wernig and her research group recently discovered that c-JUN is activated in fibroblasts in scleroderma patients. Activation of the gene also causes fibrosis reminiscent of scleroderma when induced in adult mice. This is a significant observation, because it represents a non-chemical, purely genetic, inducible model of scleroderma and highlights one critical transcription factor at the core of a general fibrotic response.

Using this model, Dr. Wernig has identified two immune-regulatory proteins (checkpoint molecules) that have increased expression when c-JUN is activated. Her group also showed that chemically blocking these two checkpoint molecules reversed fibrosis in their model. This is of particular interest because excellent reagents have already been developed by multiple pharmaceutical companies to target immune checkpoint molecules for cancer.

The group is working to expand their understanding of the role of immune checkpoint molecules in fibrosis and to determine whether checkpoint inhibitors can used to treat the fibrosis that is common in scleroderma.
Founded and run by the SRF, the groundbreaking CONQUER Registry is a national longitudinal patient registry and biosample repository that promises to transform our understanding of scleroderma by enabling the study of thousands of patients over the entire course of their disease. Although the rate of enrollment of new patients into the Registry was negatively impacted by COVID, substantial progress continued to be made. Over 70 new patients were enrolled and follow-up continued on the patients that are already enrolled.

By embracing telemedicine, clinical data from enrolled patients was able to be collected and entered into the database, along with bio-samples that were processed and shipped overnight to the centralized repository. This critical data is shared with a collaborative network of leading clinicians, institutions, and pharmaceutical partners, allowing them to learn as much as possible about all forms of scleroderma. And, importantly, how scleroderma progresses.

Thanks to the dedication of patients, consortium partners and the generosity of CONQUER's Corporate Sponsors, Boehringer Ingelheim and Janssen Pharmaceuticals, the registry remains on track to achieve its ambitious enrollment goal of 1,000 patients by the end of 2022, and we look forward to welcoming several new participating institutions in 2021.

The GRASP (Genome Research in African American Scleroderma Patients) Project was established by the SRF to enhance our understanding of how scleroderma affects African American populations. Previous studies have found they are more likely to get scleroderma, tend to have an earlier age of onset, and more severe disease than Americans of European ancestry. Using GRASP clinical data, researchers have now confirmed these findings, and are conducting large-scale genomic research through DNA sequencing of scleroderma patient samples in order to better understand scleroderma in African Americans at the molecular level, so that new therapies and improved standards of care can be developed.

Thanks to the strong partnership of GRASP leadership and continued financial support of the SRF, the GRASP Project continues to make progress. So far, more than 1,250 African American scleroderma patients, enrolled from 23 participating U.S. academic centers, are participating in this largest group of African American scleroderma patients ever studied.
At the SRF, we take seriously our responsibility to the scleroderma community and work hard to maximize every dollar invested in our work. Your generous contributions—coupled with strategic operational measures across the organization—created a strong foundation for our financial success in 2020, despite the advent of the COVID-19 pandemic and the economic challenges that followed in its wake.

Research is at the center of everything we do, and as we forge ahead with this laser focus, we remain committed stewards of the financial resources you entrust to us.

82% of your support goes directly towards research and education programs.
Once again, SRF Board Member Bob Saget hosted the evening alongside fellow board member and Top Chef Master, Susan Feniger. The star-studded show featured an unparalleled line-up of comedy greats and music legends, including appearances by Jason Alexander, Jack Black, Reggie Brown, Bill Burr, Kelly Clarkson, Jim Gaffigan, Jeff Garlin, Nikki Glaser, Regina Hall, Ken Jeong, Queen Latifah, George Lopez, Howie Mandel, John Mayer, Joel McHale, Pat Monahan, Ray Romano, Jeff Ross, Sarah Silverman, and John Stamos.

Complementing the virtual experience was an online silent auction featuring one-of-a-kind packages such as the chance to join Bob Saget and Joel McHale for tequila shots in a Zoom room, a virtual cocktails & conversation with Susan Feniger and Superstore star Ben Feldman, and many more unique opportunities.

Thanks to the incredible support of our generous scleroderma community, the re-imagined virtual event raised a remarkable $1.1M to support the SRF’s innovative research program.
Our thanks to the comedy greats and music legends who generously appeared on the broadcast, helping to generate an incredible $1.1 M to fund vital scleroderma research!

The 2020 Cool Comedy • Hot Cuisine was presented by Actelion, a Janssen Pharmaceuticals Company of Johnson & Johnson and all funds raised benefited the Scleroderma Research Foundation.
The SRF’s Cure Crew members have always been an important voice for scleroderma awareness and have helped to raise vital funds for the SRF’s research program. Even during a global pandemic, this dedicated advocacy community did not stop—they adapted.

In 2020, Cure Crew members went above and beyond by launching campaigns to build awareness, creating Facebook fundraising pages, and organizing meaningful charity events. We’re grateful for their efforts to raise funds and awareness. The following are just a few examples of the creative ways the SRF Cure Crew supported research for a cure:

**The Bake Sale**
10 year-old Addie, who lives with scleroderma, was joined by her fourth-grade classmates Zoe, Liv, and Bia, and raised $300 from their tasty homemade treats. But that’s not all: their efforts inspired Addie’s grandparents, Jon and Hanneke Nesvig, to generously double their fundraising revenue, making it $600. That money was strategically donated to SRF during the matching gift challenge of Cool Comedy • Hot Cuisine, so $600 became $1,200—all in all quadrupling the girls’ efforts!

**Bet on a Cure**
Before Covid-19 took hold of our country, the Kosmach-Schumacher Family “raised the stakes” in 2020, bringing in $20k through their 11th Annual Bet on a Cure event, held in memory of their mother Joan Kosmach. The family has been hosting events for the SRF for more than 20 years, and have raised nearly a half-million dollars in total! We are very grateful to the entire Kosmach-Schumacher family’s commitment to the mission of SRF.

**Best Medicine**
The Connors-McBride and Zini family transformed their annual Best Medicine event (A Night of Comedy in Memory of Patricia Connors-Zini) into a virtual experience, raising critical funds for the SRF. “We’re hopeful that someday there will be a cure, but for now we’ll keep using laughter to spread awareness since it is, of course, the best medicine,” says Maureen.
The Scleroderma Research Foundation’s Cure Crew is a grassroots volunteer program that raises awareness about scleroderma and funds to support SRF’s research programs. These dedicated Cure Crew members are joined together with a shared belief in the power of research to help scleroderma patients live longer, fuller lives and lead us closer to a cure.
I have seen firsthand the devastating effects of scleroderma with my father and want to help the research community in any way to hopefully prevent future generations having to endure this.” – Chef George Rallis
Teshah Murrell
James Muscataell
Robert Naranjo
Amanda Dorean Neal
Charlie Nesbitt
Karen Nesmith
Ninoska Newman
Joanna Nicole
Craig Nielsen
Cindy Kowit North
Mangeni Norton
Lindsey Norwood
Tracy Lynn Nowak
Britney Palowitch Nuckolls
Shane Stone Obrien
Ashley Ochoa
Maria Olsen
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Troy Wydra
Chris Wyman
Joseph Yates
Joidyn Young
Carlos Zaragoza
Jeri-Lynne Zimmerman
Catherine Zini
Frank Zini
Zoe, Liv & Bia

“We hope to educate and inspire others with scleroderma to live their BEST lives!!” – Barb Heenan

Cure Crew members
Barb Heenan and Randine Crouch

Scleroderma Research Foundation 2020 Annual Report 17
Our ability to advance important science and facilitate the development of new treatments for all types of scleroderma is only possible with generous donor support. Acknowledgments listed here reflect contributions of $250 or more made to the SRF between January 2020–December 2020.

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“I hope that one day we can find a cure for scleroderma.” – Kevin Bergman

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William Greene
Sam Grey
"I was diagnosed with scleroderma three years ago, so I want to fund any research for the good of others like myself. May this small amount be multiplied for the good of many!" – BH
"I’ve lived with scleroderma for over 35 years, which makes me lucky in many ways. But we need a cure! If not for me, then for the next generation.” – Kathy Brokaw
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Zoe Lowery
Omar Lugones
Tom and Terry Luria
Daniel Lynes
Eishin Machida
Lynn Therese Mai
Martin and Laurie Mai
Sandra Mann
Marcella Fire Company
Bill Markson
Dalton Martin
Leslie Martin
Michael McCall
Jaclyn and Ben McClain
Greg and Michelle McConville
William and Patricia McGuire
Sheri McKenna
Les and Renee McNair
Kristine and Michael Meiners
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John Murphy
Lauren and Tam Murray
James Murtha
Rebecca Randall and Jeff Musser
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Tamara Nazal
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Jack and Laila Nilles
Roger Norris
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Nathalie Odernheimer
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Linda Tsui and Gordon Wong
Gary and Marilyn Wright
Steven and Julie Wright
Mark Zelenak
Hilary Zunin
Gifts made to the Scleroderma Research Foundation in honor of special people and milestones have a significant impact on our research. The following individuals were recognized in 2020 by family and friends who made a gift in their honor:

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<thead>
<tr>
<th>Name</th>
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“In Supporting you, Dominique, in any way we can. We hold hope for you!” – Karen Bellous
We express our deepest sympathy to the families and friends of the following people in whose memory gifts were made during 2020.

Nancy Gayle Abrams
Linda Olsen Adams
Hilda Allen
Norma and Phillip Altus
Lois Alviar
Elaine Aresco
Lety Armstrong
Donna Baggett
Deborah Layton Bailey
Holly Bailey
Shirley J. Ballard
Joyce Baskin
Joyce Bauer
Joan Beaman
Susan Belisle-Hall
Clara Benedetti
Betty Z. Benedict
Gwen Benford
Maureen Bernardi
Elnor Berryessa
Dorothy V. Betz
Helen Bielski
Lois Bieniek
Marie Blair
Barbara Blake
Mae Boulger
Doris Bourgeois
Lloyd Bowman
Kevin Breaux
Suzanne Brenner
Jerry Bruinooget
Barbara An Budd
Sarah Burgess
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Zavion Davenport
Deborah DeFrancis
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Jackie Dietrich
Brent Dobbie
Matthew Dobie
Vernon Dunn
Mary Dyer
Patricia Dziak
Betty Eckhard
Mary Einspanjer
Rori Wilensky Eisenberg
Sefani Eisenstat
Sally English
Dominick Esposito
Kay Etow
Thelma Ewell
James Fecko
Alyce Ferraro
Frances Ferraro
Melvin Fradkin
Aida Fregozo
Catalda Gasparetti
Nancy Gevirtz
Thomas Gilbert
Arleen Gilbertson
Jerry Ginsburg
Bobby Glick
P. J. Gomez
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Christopher Guadagnini
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Sandra Hagen
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Rosaline Hernandez
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Kathryn Doub Hinman
 Eloise Hocking
Sally Holmes
Merle Holstein
Stacie B. Hooper
Carol Lynn Hulsing
Mary Nell Hutchens
Deborah Shure Jacobson
Shefli Jenkins
Mimi Keane
Cathi Keilty
Joyce Deveau Kennedy
Priscilla Kenyon
Yasmin Khan
Paula King
Virginia Klasy
Ann Kleban
Arthur Koellmer
Margaret Kollitides
Joan Kosmach

“This year we wanted to give something meaningful to Sherri, so we chose to make a donation in memory of Sherri’s beloved Mom Janice.” – The Clark Girls

Barbara Gottfried
Grace Goudswaard
Sharonda Graham
Harriet Grauer
Marilyn Griesshup
Jerry Groce
Sylvia Grossman
Beverly Grossman
Helmut Kramer
Sandra Kuebler
Richard Kusterbeck
Beverly Larson
Yuet Wa Law
Barbara Pittman Lawler
John and Ann LeBlanc
Beverly Leigh

continued
“My gift is made in memory of my wonderful father. May a cure be found for this debilitating disease so no one will ever suffer from it again.” – Carolyn Waters
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 the disease. For those who knew Sharon, it’s no surprise that her passion, commitment, and ability to galvanize people toward a noble cause has gained continued momentum and success under the thoughtful leadership she inspired at the SRF.

As Sharon once said, “I could organize a support group to help people in my community living with scleroderma or I could establish an organization that would bring the best of science and technology together in an effort to discover better treatments and a cure for people everywhere living with scleroderma. It wasn’t easy, but I chose the latter.” Though Sharon passed away from the complications of scleroderma in 2002, her mission and vision live on today.

The SRF is now America’s largest nonprofit investor in scleroderma research and devotes a greater percentage of its annual budget to scleroderma research than any other nonprofit organization. Thanks in large part to the SRF and its many generous donors, research is progressing at a faster pace than ever before.

The Sharon Monsky Legacy Society

The Legacy Society honors donors who have chosen to support the future of scleroderma research beyond their lifetimes. We deeply appreciate the thoughtful planning involved in making a gift that will impact the SRF research program in years to come through a bequest, retirement plan asset, life insurance, or charitable trust. Membership in the Legacy Society gives donors the opportunity to share the company of others who want to make a lasting gift to the scleroderma community.

Estate of Maria Anargyros*
Estate of Harold E. Aust*
Sylvia Marie Becherer Revocable Trust*
Estate of Betty Z. Benedict*
Estate of Ralph Benner*
Heather Jean Byrnes
Stephanie Colotti
Estate of Teresa W. Duggan*
Karen Fraley 2005 Family Trust
Herbert E. Freedman
Melanie Hill
Estate of Carol Lynn Hulsing*
Estate of Eva Jenkins*
Estate of Mary Taylor Keith*
Cheh Yung Kim
Estate of Edward Klinger*

Marie C. Kronman Charitable Lead
Annuity Trust*

Jennifer Langer
Margaret E. Lee Irrevocable Trust*
Estate of Janice Lowry*
Estate of Thomas I. Malanowski*
La Verne B. McCrory*
Estate of Neal McGuire*
Martha McHenry*
Estate of Ramelle Ferer Monsky*
Neptune Charitable Remainder Trust*
Neptune Family Trust*
Estate of Jerome T. Osborne, Sr.*
Frank Peltzer Living Trust*
Joyce Prime
Anne D. Ramsier Family Trust*

Estate of Julian C. Roberts*
Dolly Saget*
Mary Scott Trust
Cheryl E. Shea*
Robert H. Shutan Trust*
James Simon Family Trust*
Estate of Helen I. Steffanus*
Estate of Clinton and Marion Ternstrom*
Nathan Turner
Estate of Lorraine Wempner*
Estate of Mary Ann Wolff*

*Indicates estate gift

*Indicates estate gift

Sharon Monsky
Our Founder
Our History

1986
Founding of the Scleroderma Research Foundation

1987
First research grants awarded; First Cool Comedy • Hot Cuisine hosted at City restaurant

1990
The SRF secures 1st NATIONAL SCLERODERMA AWARENESS WEEK

1991
Founder Sharon Monsky invited to serve on National Institute of Health Council

1995
Inaugural SRF Scientific Workshop held

1996
The film “For Hope” (Gay Saget’s battle with scleroderma, produced by Bob Saget) airs on national TV

1999
First Cool Comedy • Hot Cuisine hosted at City restaurant

2002
Sharon Monsky succumbs to scleroderma complications after 20-year heroic battle with the disease

2007
SRF surpasses $20M in total funds invested in scleroderma research and education

2011
Initiation of the CONQUER Registry; a first-of-its-kind nationwide patient registry and data repository.

2019
Board Chairman, Dr. Luke Evnin, PhD, testifies at the U.S. Food and Drug Administration (FDA) to advocate for new ILD drug treatment

2020
First virtual Cool Comedy • Hot Cuisine broadcast on YouTube during global pandemic, raising $1.1M
“Today the Scleroderma Research Foundation remains a world-class team, and the best hope of finding a cure.” – Luke Evnin, Board Chair