Scleroderma
RESEARCH FOUNDATION

2019 ANNUAL REPORT

CHAIRMAN'S MESSAGE

Dear Friends,

It's been over 30 years since our friend, founder and inspiration, Sharon Monsky, challenged us to achieve one overarching goal: find a cure for scleroderma and then close the doors. We remain as dedicated today as ever despite a variety of challenges — including the pandemic that shut down the country and most of the research labs that we fund. However, for the period of this report (through the end of 2019), we have continued to make exciting progress for our patients.

As we have changed our fiscal year, this report will cover two periods: FY 2019 ending April 30, 2019 and a stub year for the remainder of 2019. Henceforth, we will report on a calendar year basis.

This 2018-19 period has been an especially significant one for us. As you know, the Scleroderma Research Foundation is the leader in nonprofit funding of scleroderma-oriented research. Over the 19 months ending December 2019, the SRF has been able to leverage its reputation for research leadership and its established role in bringing world-class talent to the problem of scleroderma. Those efforts have made a significant impact on translational and clinical issues that directly affect the patient community. Among the key accomplishments:

- **Novel drugs for our patients:** We were granted a major speaking slot as a patient advocate at the July 2019 FDA AdCom meeting in Bethesda, MD, which was convened to consider whether to recommend approval of the first drug for scleroderma fibrotic lung disease. And we are delighted to report that in September 2019, this drug (Boehringer Ingelheim's Ofev) was approved and is now a part of the arsenal that physicians have for this challenging complication of scleroderma.
- **GRASP:** The SRF hosted a meeting of the GRASP (Genome Research in African American Scleroderma Patients) consortium at the NIH in May 2019 punctuating a productive period for the consortium which included additional publications.
- **New disease measures:** We partnered with the Scleroderma Clinical Trials Consortium to deploy the Betty Benedict legacy gift towards the development of an essential resource that is still missing in the community: an accurate measure of disease activity that is sensitive to small changes.
- **Research community leadership:** We hosted our annual SRF Science Workshop in April 2019, bringing together all SRF funded researchers, advisors and selected guests. We continued our sponsorship of the International Scleroderma Workshop — a biannual meeting of scleroderma researchers from around the world, which took place in August 2019 in Cambridge, UK.
- **ACR leadership:** In November 2019, at the American College of Rheumatology meeting, attended by 30,000 rheumatologists from around the world, the SRF held major meetings to update the GRASP consortium, a Friends and Family networking dinner with Dr. Antony Rosen as speaker, and hosted a CONQUER industry session and annual meeting.
- At year end, we were delighted to report two fantastic **additions to the Scientific Advisory Board** — Dr. Dan Littman and Dr. Lloyd Klickstein. Their bios are presented in the body of this report and they are already diligently engaged in supporting our efforts.

Our mission and focus have not changed, but our presence and reputation as a leader in the field has allowed us to broaden our scope of influence and to expand the types of research we support.

A noteworthy achievement this year has been the advancement within CONQUER — a first-of-its-kind nationwide longitudinal registry that was founded and is run by the SRF. By the end of 2019, we enrolled over 300 unique patients and collected over 450 blood samples. As previously noted, this effort will yield the gold-standard database to track and understand the trajectory of scleroderma in the modern context. Clinicians, scientists and our pharmaceutical partners will use the underlying data in a variety of ways: To determine which disease features are associated with or predict outcomes; identify patients requiring early/aggressive intervention (as well as those to watch); and drive more personalized and effective therapy for patients. As a critical, pre-competitive resource, we are delighted to report that we have been able to partner with two companies on CONQUER, and we are in advanced conversations about additional support. Thank you, **Boehringer Ingelheim** and **Actelion** for your leadership.

> *"It's because of your contributions that we have arrived where we are today, and are able to continue to move forward, onward, and upward."*

We also recognize that serious business sometimes requires serious fun. And since our beginning, ***Cool Comedy • Hot Cuisine*** has brought together friends along with world-class performers for a night of great food and laughter in support of scleroderma research. On behalf of all of us at the SRF, I offer my thanks to fellow Board Members Bob Saget and Susan Feniger for being our shining stars once again. This effort just keeps on giving. In the past period, we have held three events, two in NY and one in LA. Overall, these events raised over $2.5 million for scleroderma research!

The creativity and commitment of our volunteers, including the indomitable grassroots Cure Crew, are pillars of the SRF. Thank you! And our efforts to connect and communicate with our community via social media continue to evolve. We look forward to reaching out to you more frequently through multiple platforms and keeping you apprised, amused and inspired on a real-time basis.

The SRF maintains a lean team. In addition to our board of directors, scientific advisory board, and funded investigators, our San Francisco office is comprised of five tireless employees who are committed to our efforts. On behalf of Scleroderma Research Foundation, thank you for all your support. It's because of your contributions that we have arrived where we are today, and are able to continue to move forward, onward, and upward.

Sincerely,

Luke Evnin, PhD
Chairman

SRF Leadership

SRF Board of Directors

Luke Evnin, PhD
Chairman

Deann Wright, JD
Secretary

Bob Smith
Treasurer

Dana Delany*
Sharon Dobie, MD
Susan Feniger
Eric Kau, MD
David Knoller
Violetta Merin
Bob Saget
Caryn Zucker

*Emeritus

Founder

Sharon L. Monsky
1953-2002

MISSION & VISION

Our Mission

The mission of the Scleroderma Research Foundation is to fund and facilitate the most promising, highest quality research aimed at improved treatment options and, ultimately, a cure for scleroderma.

What We Do

Founded in 1987, The Scleroderma Research Foundation (SRF) is America's leading nonprofit investor in scleroderma research. Research is at the center of all we do, and we are singularly focused on bringing the best minds to work toward a cure for scleroderma. The SRF research program devotes most of its research budget to long-term fundamental discoveries in basic, translational and clinical projects. We seek to deepen knowledge and understanding of this life-threatening condition by facilitating collaboration among the world's top scientists and clinicians to open new doors to therapeutic development and ultimately, a cure.

About Scleroderma

One of the most serious and complex of all rheumatic disorders, scleroderma is not a single disease, but a set of related disorders involving a similar set of symptoms, making a concise definition – and diagnosis – very difficult. The disease often causes the hardening and tightening of the skin and connective tissues, but depending on the subtype of illness, scleroderma also can severely damage the body's digestive, respiratory and circulatory systems. It can be disfiguring, debilitating and even deadly. Systemic sclerosis affects approximately 100,000 people in the U.S. and strikes men, women and children of all ages and ethnicities. However, 80% of those afflicted with the disease are women in the prime of their lives, 30-50 years old.

The cause of scleroderma is unknown, yet significant progress has been made in managing the symptoms and some of the most serious complications of scleroderma. People with the disease are living longer, fuller lives. Still, no therapies yet exist to halt or reverse the disease process.

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 $2.0M+ annually to fund pioneering research studies led by the most gifted scientists, because **research is the key.**

We advocate for comprehensive care

The SRF helps to sustain Scleroderma Centers of Excellence so patients can receive the most comprehensive care.

Our Vision: A World Without Scleroderma

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.

Scientific Advisory Board

The individuals on the SRF's Scientific Advisory Board (SAB) are some of the world's most honored and distinguished scientists who give their time and insights freely to the SRF's research endeavors. These renowned researchers guide the Foundation's research program, evaluate research proposals, and make 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.

Bruce Alberts, Ph.D

Chairman of the SRF Scientific Advisory Board

UCSF

A renowned biochemist and distinguished professor at UCSF, Dr. Alberts has also been recognized for his leadership in science policy and education. He served two terms as the President of the National Academy of Sciences, three years as a U.S. Science Envoy, and he has received countless awards, including the National Medal of Science from President Barack Obama. Dr. Alberts is a member of the National Academy of Sciences.

David Botstein, Ph.D

Chief Scientific Officer

Calico Life Sciences

An eminent geneticist whose research laid the foundation for the Human Genome Project, Dr. Botstein has been at the forefront of genomic research for decades. Having been a distinguished professor at MIT, Princeton and Stanford, he now leads the effort to understand the aging process at Calico, a Google company. A recipient of the Breakthrough Prize and numerous other prestigious awards, Dr. Botstein is a member of the National Academy of Sciences and the Institute of Medicine.

Dan Kastner, MD, Ph.D

Scientific Director

Intramural Program of the National Human Genome Research Institute (NHGRI)

Dr. Kastner's distinguished career at the NIH has been focused on using genetic and genomic strategies to understand inherited disorders of inflammation. Prior to joining the NHGRI, Dr. Kastner, a rheumatologist, also served for many years as the Clinical Director of the Intramural Program of the National Institute of Arthritis and Musculoskeletal Diseases (NIAMS). He has received numerous awards, including the NIH Director's Award, and the Service to America Award ("Sammie") as the Federal Employee of the Year. Dr. Kastner is a member of the National Academy of Sciences and the Institute of Medicine.

Lloyd Klickstein, MD, Ph.D

Chief Innovation Officer

Adicet Bio, Inc.

Dr. Klickstein, a rheumatologist and immunologist, has had a long and successful career in the biopharmaceutical industry and biomedical research. Prior to joining Adicet Bio, Inc., he served for thirteen years at Novartis as the Head of NIDU — the unit that researches new drug targets and evaluates them for potential drug development. Prior to his industrial career, he was a physician-scientist over more than a decade with his own successful lab at Harvard's BWH where he also had a clinical practice. Dr. Klickstein also serves as an independent board member at Blade Therapeutics.

Dan Littman, MD, Ph.D

New York University

Howard Hughes Medical Institute

Dr. Littman, a world-renowned immunologist, heads a large research group at NYU that focuses on T cells, a critical cell of the adaptive immune system and its role in inflammatory diseases. Dr. Littman also has extensive biopharmaceutical experience, currently serving on the Board of Directors of Pfizer and having founded two biotech companies: Vedanta Biosciences, Inc. and Orca Pharmaceuticals, Ltd.. Dr. Littman has been an Investigator of the Howard Hughes Medical Institute since 1987 and is a member of the National Academy of Sciences and the Institute of Medicine.

Antony Rosen, MD

Vice Dean for Research

Johns Hopkins University

A Distinguished Professor at Johns Hopkins University and a rheumatologist, Dr. Rosen's research focuses on autoimmunity in the rheumatic diseases. By studying subgroups of patients with distinct phenotypes, disease trajectories and specific autoimmune responses, his research group is at the forefront of identifying the molecular mechanisms that are disrupted in scleroderma. Dr. Rosen is also the Chair of the Department of Rheumatology and Co-Director of the Johns Hopkins Precision Medicine Initiative.

Bruce Wintroub, MD

Chair of Dermatology

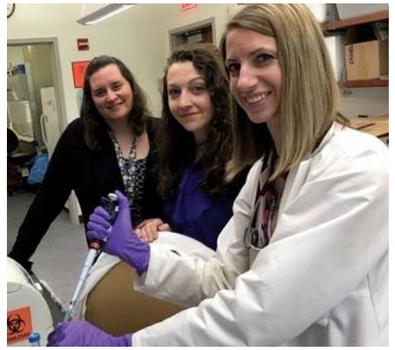
UCSF

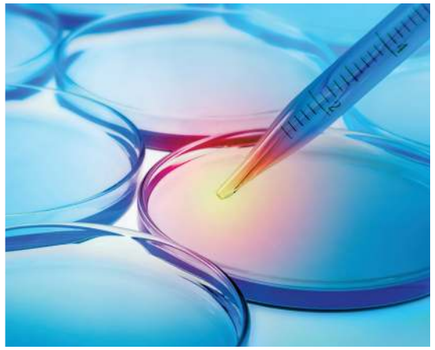
Dr. Wintroub is a Professor and Chair of the Department of Dermatology and Vice Dean of Medicine at UCSF. His research has focused on the interface of dermatology and immunology in several diseases that affect the skin, including scleroderma. Dr. Wintroub has also served as the Chairman of the Dermatology Foundation.

Funded Grants and Ongoing Research Projects *2019-2020*

INVESTIGATOR	INSTITUTION	RESEARCH PROJECTS
Franck Barrat, PhD Eric Meffre, PhD	Hospital for Special Surgery Yale University	Role of CXCR3 Agonists in the Generation of Autoreactive B cells in Scleroderma Patients
Francesco Boin, MD Fredrick Wigley, MD *In collaboration with* Dan Kastner, MD, PhD Pravitt Gourh, MD	Cedars-Sinai Johns Hopkins University School of Medicine National Human Genome Research Institute National Institute of Arthritis & Musculoskeletal Disease	Genome Research in African American Scleroderma Patients (The GRASP Project)
Livia Casciola-Rosen, PhD Ami Shah, MD	Johns Hopkins University School of Medicine	Cancer Detection Strategies in Patients with Scleroderma
Howard Chang, MD, PhD	Stanford University School of Medicine Howard Hughes Medical Institute	Gene Regulatory Mechanisms in Scleroderma Epigenetics of Sex Differences in Scleroderma Scleroderma Twin Study
Lorinda Chung, MD, MS	Stanford University School of Medicine	Stanford Scleroderma Center of Excellence
Lorinda Chung, MD, MS Paul Wolters, MD	Stanford University School of Medicine University of California, San Francisco	Northern California Scleroderma Research Consortium
Erika Darrah, PhD Eleni Tiniakou, MD	Johns Hopkins University School of Medicine	POL3-specific CD8+ T Cells as the Link Between Scleroderma and Anti-tumor Immune Responses Naturally Presented Topoisomerase Epitopes in Scleroderma Patients with HLA-DPB1*13:01
Hal Dietz, MD	Johns Hopkins University School of Medicine Howard Hughes Medical Institute	Novel Therapeutic Vulnerabilities in Systemic Sclerosis and Fibrosis
Benjamin Korman, MD	University of Rochester	Assessment of the Complement Cascade as a Novel Biomarker, Genetic Risk Factor, and Treatment Target for Scleroderma-Associated Pulmonary Arterial Hypertension (SSc-PAH)
Zsuzsanna McMahan, MD	Johns Hopkins University School of Medicine	Measuring and Objectively Characterizing Patterns of Gastrointestinal Dysmotility in Scleroderma
Zsuzsanna McMahan, MD Jay Pasricha, MD	Johns Hopkins University School of Medicine	Discovery of Novel Autoantigens in Scleroderma Patients with Gastrointestinal Dysmotility
Ruslan Medzhitov, PhD	Yale University Howard Hughes Medical Institute	Macrophage-Stromal Cell Interactions in Tissue Homeostasis and Fibrosis
Dr. Kathryn Torok, MD	Pittsburgh Children's Hospital	Identification of Novel Pathogenic Genes in Juvenile Systemic Sclerosis
Gerlinde Wernig, MD	Stanford University	Immune Checkpoint Inhibitors as Antifibrotic Therapy for Scleroderma
Michael L. Whitfield, PhD	Geisel School of Medicine at Dartmouth	Molecular Subsets, Integrative Genomics and Tissue Models of Scleroderma
Fredrick Wigley, MD	Johns Hopkins University School of Medicine	Johns Hopkins Scleroderma Center of Excellence
Scott Zeger, PhD Antony Rosen, MD Livia Casciola-Rosen, PhD Laura Hummers, MD, MPH Fredrick Wigley, MD Ami Shah, MD	Johns Hopkins University School of Medicine	Scleroderma Lung Disease Trajectory Study

Research Is the Key





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.

In the following pages, please read about a few selected research projects.

Featured Projects from the 2019-2020 SRF Research Program

Epigenetics of Sex Differences in Scleroderma

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

PROJECT OVERVIEW

One of Dr. Chang's SRF-funded projects aims to discover why four out of every five scleroderma patients are female, which he believes is connected to special features of the X chromosome. While there are two X chromosomes in every cell in a female body, every cell in a male body contains only one X chromosome plus a Y chromosome. In order to balance the gene products from the female X chromosomes to what is produced in male cells, one X chromosome is silenced in every female cell through a process called X-inactivation. Dr. Chang believes that this process of X-inactivation and the cellular machinery that carries it out might be involved in females' increased susceptibility to scleroderma (as well as many other autoimmune diseases). In their quest to understand how X-inactivation might be involved, Dr. Chang's group has discovered that many proteins that are autoantigens for autoimmune diseases work together with a special RNA molecule in silencing the extra X chromosome and they are investigating whether this association is involved in initiating autoimmunity. Dr. Chang's group is also working to develop an animal model to further examine why autoimmunity might be skewed toward females.

Molecular Subsets, Integrative Genomics and Tissue Models of Scleroderma

Michael Whitfield, PhD
Dartmouth University
School of Medicine

PROJECT OVERVIEW

Dr. Whitfield has been working for many years to develop a classifier via an artificial intelligence algorithm for scleroderma patients based on gene expression data. The goal is to predict how individual patients might respond to a given treatment. Because certain scleroderma treatments can be risky, or have serious side effects, it would be hugely advantageous for patients to understand upfront whether they are likely to respond to a potential treatment. For example, in the SCOT (Scleroderma: Cyclophosphamide or Transplantation) trial, blood samples taken from patients prior to treatment were examined by Dr. Whitfield using his classifier. The classifier assigned each patient to one of three possible categories based on gene expression data obtained from their pretreatment sample. After determining which patients responded to transplantation and which didn't, each of the three categories was analyzed to see if it was able to predict a response or not. The classifier was able to identify one category of patients likely to respond to transplantation while also identifying a category of patients that would likely NOT respond to transplantation. Dr. Whitfield hopes to be able to obtain additional samples from patients undergoing transplantation therapy to confirm these results. He is also working with other clinical trials to further explore the use of his classifier for predicting responsiveness to other treatments.

Measuring and Objectively Characterizing Patterns of Gastrointestinal Dysmotility in Scleroderma

Discovery of Novel Autoantigens in Scleroderma Patients with Gastrointestinal Dysmotility (in collaboration with Dr. Jay Pasricha, MD, Johns Hopkins University School of Medicine)

Dr. Zsuzsanna McMahan, MD
Johns Hopkins University
School of Medicine

PROJECT OVERVIEW

Gastrointestinal (GI) disease is a common and often early complication for scleroderma patients. Its presentation varies from patient to patient, meaning that in individual patients, different parts of the digestive tract can be affected. The severity of GI dysfunction also varies. However, research on scleroderma GI disease has historically been lacking; thus, while subgroups of GI disease are thought to exist, too little data exists to definitively characterize different patterns of disease. Dr. McMahan is a Principal Investigator for two different SRF-funded GI projects aiming to generate additional data to help define subgroups of patients with different patterns of GI dysmotility. Subgrouping would help physicians better understand and treat the disease and even potentially to develop more tailored treatments. In one project, Dr. McMahan obtains direct measurements of transit time through the gut of scleroderma patients and will be able to determine overall variation in transit times as well as different patterns of transit. In a joint project with Dr. Jay Pasricha, Dr. McMahan is working to discover novel autoantigens in scleroderma patients with GI dysmotility and to determine if the autoantibodies associate with or can identify different subgroups of GI disease. By assessing patterns of gut transit, and correlating these patterns with known and novel autoantibodies, Dr. McMahan and her collaborators will enable researchers to better study GI disease in scleroderma and potentially to develop targeted treatments.

Assessment of Complement Cascade as a Novel Biomarker, Genetic Risk Factor, and Treatment Target for Scleroderma-Associated Pulmonary Arterial Hypertension (SSc-PAH)

Dr. Ben Korman, MD
University of Rochester

PROJECT OVERVIEW

Scleroderma patients are frequently affected by vascular complications, which include Raynaud's phenomenon, digital ulcers, cardiovascular disease, and pulmonary hypertension. Pulmonary arterial hypertension (PAH) is a type of high blood pressure that affects the arteries of the lungs and the right side of the heart. Scleroderma-associated PAH (SSc-PAH) is a severe vascular manifestation of scleroderma that currently has poor outcomes, is under-diagnosed, has no established biomarkers, and responds poorly to standard pulmonary hypertension medication.

The complement cascade is an important part of the immune system that helps to clear microbes and damaged cells. Dr. Korman and his research group are studying the potential role of the complement cascade as a risk factor for SSc-PAH, a marker of disease onset and severity, and a potential treatment target for SSc-PAH. They have shown that circulating levels of complement factor D are altered in patients with scleroderma and particularly in patients with pulmonary hypertension. Further characterization of patients with SSc-PAH and mouse models of PAH have shown additional abnormalities in certain parts of the complement cascade. In evaluating the role of complement in SSc-PAH, Dr. Korman is using several different approaches. They are analyzing data from large-scale genetic studies (including the GRASP Project—see page 11) to evaluate variation in complement genes as a risk factor for SSc-PAH. They are also analyzing blood from SSc-PAH patients to evaluate the levels of various complement factors as possible SSc-PAH biomarkers. To assess whether blocking complement may be an effective therapeutic strategy for treating SSc-PAH, they will use genetic and pharmacologic approaches to treat mice with PAH and abnormalities in lung complement.

CONQUER

2019-2020 brought noteworthy achievements in the advancement of **CONQUER** (**CO**llaborative, **N**ational **QU**ality and **E**fficacy **R**egistry), a first-of-its-kind, nationwide, longitudinal patient registry for scleroderma patients that was founded and is run by the SRF. As of mid-2020, CONQUER has enrolled over 300 unique patients. For each patient, clinical data and blood samples are periodically collected. This effort will yield a rich database and biorepository that can be used to track and understand the trajectory of scleroderma in different subsets of patients.

Additionally, clinicians, scientists and our pharmaceutical partners will use the underlying data to:

- **determine which disease features are associated with or predict outcomes**
- **identify patients requiring early/aggressive intervention–as well as those to watch**
- **drive more personalized and effective therapy for patients**

As a critical, pre-competitive resource, we are proud to partner with our generous CONQUER corporate sponsors: Boehringer Ingelheim and Actelion. The SRF is grateful for their leadership and we look forward to including additional corporate partners in the coming year.

PARTICIPATING INSTITUTION	INVESTIGATOR
Columbia University	Elana Bernstein, MD, MSc
George Washington University	Victoria Shanmugam, MD
Georgetown University	Virginia Steen, MD
Hospital for Special Surgery	Jessica Gordon, MD
Johns Hopkins University	Ami Shah, MD Laura Hummers, MD, MPH
Mass General Hospital	Flavia Castelino, MD
Medical University of South Carolina	Faye Hant, DO, MSCR
Northwestern University	Chase Correia, MD
Stanford University	Lori Chung, MD, MS
University of Michigan	Dinesh Khanna, MD
University of Pennsylvania	Nora Sandorfi, MD
The University of Texas Health Science Center at Houston	Shervin Assassi, MD
University of Utah	Tracy Frech, MD

grasp

GENOME RESEARCH IN AFRICAN AMERICAN SCLERODERMA PATIENTS

Previous epidemiological studies have indicated that African Americans are more likely to get scleroderma than Americans of European ancestry; they also tend to have an earlier age of onset of scleroderma and more severe disease. The Genome Research in African American Scleroderma Patients (GRASP) Project was established to enhance our understanding of the clinical manifestations of scleroderma in African Americans and to perform genomic analyses with the aim of identifying key factors contributing to the onset and severity of their disease.

The GRASP Project has obtained clinical data from a sufficiently large population of African American patients for researchers to better understand scleroderma in African American patients. Using the GRASP clinical data, researchers have confirmed the increased incidence, earlier age of onset and more severe disease in African American patients. They are also developing a better understanding of how scleroderma typically presents in African American patients, which will aid physicians in treating them.

Another goal of the GRASP Project is to generate a large set of genomic data, through DNA sequencing of scleroderma patient samples and control patient samples from other studies, that can be compared and used to determine whether specific scleroderma clinical manifestations correlate with specific DNA variants. Through these associations, researchers hope to learn about DNA variants that might affect scleroderma susceptibility, age of onset and disease severity. To achieve these goals, a large cohort of African American scleroderma patients has been gathered and clinical data as well as DNA samples have been collected from all enrolled patients.

The GRASP cohort currently consists of more than 1,300 extensively evaluated African American scleroderma patients enrolled from 23 participating US academic centers. This is the largest multi-center cohort of African American scleroderma patients ever studied. The SRF has been instrumental to the development of the GRASP Project since the very beginning.

The strong partnership with the GRASP leadership and the continued financial support provided by the SRF has enabled the participation of a large number of academic centers in the GRASP consortium. Moreover, the SRF has provided the perfect framework for GRASP: an environment that encourages brainstorming, formulation of ambitious research goals, and streamlined collaboration among leaders in the field of scleroderma research and clinical care.

COOL COMEDY HOT CUISINE

Since its inception in 1986, ***Cool Comedy • Hot Cuisine*** (CCHC) has become our signature fundraising event, featuring some of the world's greatest comedians and performing artists – all of whom donate their time and talents to support the SRF's innovative research programs and help raise awareness about this rare autoimmune disease.

For more than 30 years, CCHC has been led by the indefatigable efforts of Board members **Bob Saget** and **Susan Feniger**. Attendees have included generous partners and supporters from the entertainment world and corporate industries, as well as patients, physicians and many others who have been directly or indirectly affected by scleroderma.

In this past period, three CCHC events, two in New York and one in Los Angeles, collectively raised an amazing $2.5 million to support the work of the SRF and our commitment to finding improved treatments and – one day – a cure for scleroderma!

2018 New York Highlights


Bob Saget and Susan Feniger

Live auction with Bob Saget, Susan Feniger, Andy Cohen and Elizabeth Falkner

Jeff Ross, Bob Saget, Jackson Browne and Dave Attell

2019 Los Angeles Highlights


Ray Romano

Ken Jeong, Norman Lear and Bob Saget


John Mayer

Macaulay Culkin, Bob Saget, and Seth Green


John Mayer, John Stamos, Bob Saget and Dave Chappelle

COOL COMEDY HOT CUISINE

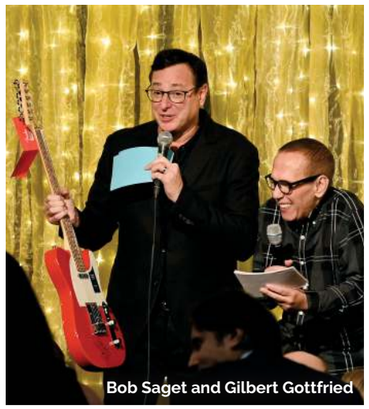
2019 New York Highlights

Bob Saget, Gilbert Gottfried, Susan Feniger and John Oliver


Deann Wright, Bob Saget and Luke Evnin


Melissa Tarantino, Erin Murtha, and Lucille Miller


Michael Che


Bob Saget and Gilbert Gottfried


John Oliver

Bob Saget and Susan Feniger


Susan Feniger and the Hot Cuisine team

Cure Crew

*A volunteer network where **YOU** can make a difference!*

Cure Crew members make a real impact in the lives of people living with scleroderma and their loved ones – as well as honoring those who have died from complications caused by the disease. They know that lack of awareness causes delays in treatment or misdiagnosis, and funding research is the best hope of finding a cure. At the very heart of the program are people joined for a shared cause doing what they enjoy while helping to raise funds and awareness.

In 2019 our Cure Crew members raised the bar by launching awareness-building campaigns, creating 2,607 Facebook fundraising pages and organizing innovative charity events. Their efforts inspire us and the scleroderma community to work together to find a cure!


Mitzvah Luncheon


Bash for Barbara


Best Medicine in Memory of Patricia Connors-Zini

Chicago Marathon, Emily Hinderer


Kosmach Family's Bet on a Cure

Fright Night

Bike Ride Across Iowa, Barbara Heenan

Landry's Bake Sale

Powering Our Research Until There's a Cure

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 SRF between May 2018–December 2019.

$50,000+

Actelion Pharmaceuticals US, Inc.
AE Family Foundation
Arthur Zimtbaum Foundation, Inc.
Estate of Betty Z. Benedict
Boehringer Ingelheim Pharmaceuticals Inc.
Eversheds Sutherland
Judy Evnin and Dr. Tony Evnin
Dr. Luke Evnin
Estate of Shane M. Flann
The Kao Family Foundation
Andy and Vi Merin
Brooke Musselman
The Nancy P. and Richard K. Robbins Family Foundation
Mark Scher
Deann Wright

$25,000 - $49,999

Estate of Maria D. Anargyros
The Anita May Rosenstein Foundation
Corbus Pharmaceuticals, Inc.
Coretz Family Foundation
Tim and Mary Evnin
Dr. Jeff Gevirtz
Joseph Hulston
Lamb Family Foundation
Thomas Osborne and Joan Lowry
John Mayer
Redbox
Adam and Tracey Stern

$10,000 - $24,999

John and Debra Apruzzese
BCS Private Wealth Management
Joel and Bonnie Bergstein
Blade Therapeutics, Inc.
Kevin and Claudia Bright
Sara and Buddy Campbell
Andrea Okamura and Jeff Chambers
Macaulay Culkin
Dana Delany
Vin and Erica Di Bona
Dr. Sharon Dobie
Jon and Robin Dracos
Robert and Dana Emery
Debbie and Greg Grisamore
Bill and Marjorie Holodnak
Mary Lou Houle
Henry Jones
Alan and Donna Kaminsky
Eliz Lee and Dr. Eric Kau
Estate of Mary Keith
Kraft - Engel Management LLC
Lear Family Foundation
Norman and Sarah Livingston
Kimbrough Towles and George Loening
Rhonda Mace
Scott Matis
George and Suzanne Montgomery
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> *"My mother died of systemic scleroderma after a progressively painful battle with the disease. She inspired and encouraged me to advocate for others less fortunate in life and health."*
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Robert M. Reznick
Sandra Roeder
Landry Rufo
Bob Saget
Suzanne Salerio
Bobbi Salmon
Tami Sauer
Cindy Schlett
Vicky Schneider
Sophie Anne Seaman
Janet Settle
Merle Shapiro
Christine A. Silver
Steven Smith
Beth A. Stewart
Barbara Sunseri
Angela Switzer
Anne Terrell Masters
Wilma Jane Timmins
Pat Van Gorp
Elizabeth Vogel
Luke Wachter
June Waldman
Eve Weinberg
Beverly Weingartz
Marlene Weintraub
Nancy Whitaker
Heidi Wilensky
Maryclaire Wilkinson
Deann Wright
Jack Zerobnick
Barbara Zimmerman

"Someone I care about has just been diagnosed. Please find a cure!" *– Roberto*

Your Gifts At Work

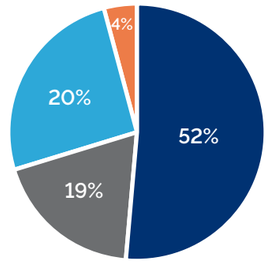
Financial highlights

At the SRF, we take seriously our responsibility to the scleroderma community and we value donor trust above all else. To earn and maintain this trust, we work hard to maximize every dollar invested to advance research with the greatest potential to benefit patients and families. Research is at the center of all we do and it will continue to drive us until we ultimately eradicate this disease.

**Note: As we have changed our fiscal year, this report covers two periods - FY 2019 covering the 12 month period of May 1, 2018 through April 30, 2019 and a stub year period for the 6 remaining calendar months through December 2019. We will report henceforth on a calendar year basis.*

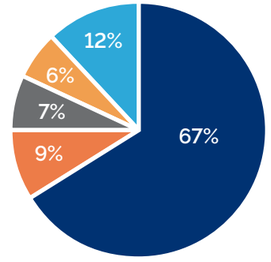
FY May 2018 – April 2019

Total Annual Revenue: $5.7M



- Contributions – $2.9M
- Bequests – $1.06M
- Events – $1.5M
- Investments – $200K

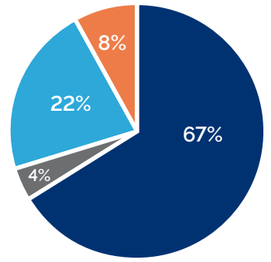
Total Annual Expenses: $3.8M



- Research – $2.5M
- Education – $326K
- Administration – $265K
- Fundraising – $211K
- Events – $457K

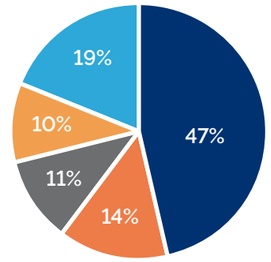
Stub Year May 2019 – December 2019*

Total Revenue (6 Mos.): $3.2M



- Contributions – $2.1M
- Bequests – $115K
- Events – $712K
- Investments – $246K

Total Expenses (6 Mos.): $1.3M



- Research – $609K
- Education – $180K
- Administration – $145K
- Fundraising – $124K
- Events – $245K

**Majority of research expenditures occurred in Q2 and are not reflected in stub year totals.*

FINANCIALS

Scleroderma
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