Scleroderma
RESEARCH FOUNDATION

YEAR-END UPDATE 2016

Founded in 1987 with a passionate commitment that lives on:
to use the power of collaborative medical research to advance a cure.

WHY RESEARCH MATTERS IN SCLERODERMA

A Year-End Message From Dr. Luke Evnin, Chairman of the Board of Directors

Dear Friends,

First, I want to thank you. You are reading this report today because you are one of our growing network of friends making a commitment to scleroderma research. As chairman of the Scleroderma Research Foundation (SRF), I am deeply grateful to our donors, volunteers, and corporations who support our mission. As a patient living with scleroderma, this gratitude extends to the greater scleroderma community of physicians and caregivers who treat patients, the drug companies pursuing new treatment options, and the scientists who work tirelessly toward our mutual goal of a cure.

Why Research Matters

As we approach our 30th anniversary, we wanted to take the time to reflect upon the importance of our mission, namely creating and fostering a place for exceptional research dedicated to finding a cure for scleroderma. In 1987, when Sharon Monsky founded the SRF, there were scant attention and resources aimed at the disease. I am proud to say that today the scleroderma field has evolved considerably into a robust, dynamic space. After years of advancing our research program, we are beginning to enjoy the fruits of our labor. There are now several novel treatments and more on the horizon. In addition, there have been significant discoveries recently that have the potential to provide new insights into the origins of scleroderma, which have eluded researchers thus far.

As an organization founded on the premise that Research is the Key, we have always understood why research matters, but what resonates most for us is what it means to our community. With this in mind, we launched a social media and communications campaign earlier this year directed at our constituency: patients, donors, clinicians, researchers, and caregivers. We asked "why research matters" to them. The community came back with many thoughtful statements that echoed our own feelings – that there is much to be said about the transformative power of research. Patients see research as life-saving, giving them hope for freedom and independence from their disease. For caregivers, it provides a foundation for making better-informed decisions as they navigate this challenging disease.

I would like for you to remember "why research matters" as you read this year's report and recognize that the incredible progress being made would not be possible without your support.

SRF Research Program

I am pleased to report that the SRF was able to direct over 85 percent of its budget into life-saving research and education. On an absolute basis, the SRF directed nearly $1.5 million in grants to high-impact work on three fronts: funding for investigators pursuing breakthrough basic science, a dedicated effort to facilitate leading translational research, and ongoing support of clinical Centers of Excellence. Following are some highlights from our work, and I encourage you to read about our entire research portfolio on pages 10-22.

Research Highlights

- Demonstrating the value of the SRF's approach to finding and supporting promising researchers, it has been gratifying to see the continued developments with the groundbreaking work of Dr. Hal Dietz. Dr. Dietz, a geneticist and pediatric cardiologist, came to the attention of the SRF for his work in Marfan Syndrome. His subsequent work in his lab at Johns Hopkins uncovered a mechanism that may be targeted to reverse fibrosis in scleroderma and other fibrotic disorders. This finding was so profound that it has led to the formation of a biotechnology company, Blade Therapeutics. Since its formation in 2015, Blade has secured more than $50 million in venture capital investment. We are excited to see the rapid progress from a researcher with a compelling idea to a company teeming with potential, focused on the mechanisms of fibrosis (please see our feature on Dr. Dietz and Blade, pages 8-9).

- Exciting results from the laboratory of Dr. Howard Chang of Stanford University have recently been published. A pioneering invention from the lab enables rapid, highly accurate epigenetic analysis of the DNA in single cells (called ATAC-seq). With ATAC-seq, Dr. Chang is analyzing scleroderma T-cells and other major cell populations at the single cell level, unlocking secrets that have evaded detection using older methods. In one article published in the world-renowned journal, *Nature*, Dr. Chang and collaborators reported insights into the "inactive X"-chromosomal material in females (who have two X-chromosomes, one active and another inactive) which is theorized to play a role in many autoimmune diseases. Given the striking 4-to-1 female to male prevalence ratio of scleroderma, there is reason to believe that these studies will have mechanistic import (page 12).

- The evolution of the work of Dr. Antony Rosen continues at Johns Hopkins. In this past year, his lab has continued to pursue the connection between cancer and the onset of scleroderma. In recent work, the team has defined an autoantibody which is strongly

associated with scleroderma and cancer. Dr. Rosen's lab is currently defining the risk of cancer in patients with this antibody in newly diagnosed scleroderma (page 17).

- Encouraging advances are coming from the lab of Dr. Michael Rosenblum at UCSF. Dr. Rosenblum's team has processed a particular subset of the CD4 T-cells called regulatory T-cells, or "Tregs." In 2015, we noted that Dr. Rosenblum had developed a humanized transplant mouse model of fibrosis, and discovered that Tregs are absent or not functioning properly in the skin of patients with scleroderma. Since those developments, Dr. Rosenblum has made the novel observation that Tregs may suppress myofibroblasts, which are known to play a role in fibrosis in the kidney, lung, gastrointestinal tract, and in the body's healing of wounds (page 18).

- The Genome Research in African-American Scleroderma Patients (GRASP) study has made exciting headway. The research team exceeded the initial goal of 1,000 patient samples and 1,000 healthy controls, and is continuing to enroll and collect samples from 19 study centers. Last year, we reported that the team completed the whole exome sequencing of 400 patient and 400 control samples. Gratifyingly, the team has identified genetic variants associated with scleroderma which point us to novel insights about the underlying biology of the disease. Work continues; in particular, the team has processed the remaining 600 patient and 600 control samples to replicate and confirm these initial results and is currently analyzing the data (page 21).

Beyond the Research

Cool Comedy — Hot Cuisine (CCHC) once again led our fundraising efforts. Due to the generosity of our donors, the events held in Los Angeles and New York raised over $1.4 million for fiscal year-end 2016. Our New York event honored the memory of SRF Board Member, Jeff Mace. It was a moving night that served as an emotional reminder of the deeper meaning behind CCHC. I invite you to read more about these events (page 25) as well as about our return to San Francisco and Las Vegas this past summer and fall. Without the ongoing support of Actelion Pharmaceuticals and all of the comedians, musicians, and chefs who generously donate their time and talent for the cause, we would not be able to make these events happen. We are deeply grateful.

I would also like to give special thanks to all of our Cure Crew members who year after year support life-saving research by hosting and participating in events across the country. Please read more about these devoted individuals on page 26.

Our commitment to education is leading to the launch of a new, user-friendly website, allowing our abundant and relevant content to be more easily accessible than ever before. The SRF also held several new webinars, adding to the growing archive of free discussions on topics that are most pressing to scleroderma patients.

On a final note, founding member and chairman of the SRF Scientific Advisory Board, Bruce Alberts, PhD, received one of the highest honors in biomedicine, the 2016 Lasker-Koshland Special Achievement Award in Medical Science. This prestigious recognition, bestowed every two years by the Albert and Mary Lasker Foundation, recognized Alberts for his "fundamental discoveries in DNA replication and protein biochemistry; for visionary leadership in directing national and international scientific organizations to better people's lives; and for passionate dedication to improving education in science and mathematics." We applaud our friend, Dr. Alberts, and the remarkable contributions he has made to science, and we are deeply honored by his devotion to a cure for scleroderma.

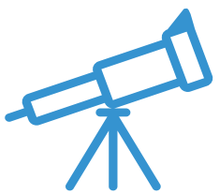
As you read through the 2016 Year-End Update, I hope, like me, you are inspired by the advancements your kindness has made possible and the difference you are making in the lives of patients. Research **really does matter**, and it is your continued investment that paves the way for a future without scleroderma.

Luke Evnin, PhD
Chairman, Board of Directors

RESEARCH IS THE KEY

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

Today, the SRF is America's leading nonprofit investor in scleroderma research. The SRF research program goals are to deepen our knowledge and understanding of this life-threatening condition. Funded projects are allocated across three broad categories: clinical, translational, and basic research. Approximately 20 percent of the budget is devoted to clinical endeavors including development and sustaining support for Clinical Centers of Excellence. The remaining 80 percent supports basic and translational research projects such as developing more predictive animal models, biomarker development, defining relevant biological pathways, and the advancement of new technologies to better understand the underlying causes of scleroderma.



Vision

Sharon envisioned a future where those living with scleroderma would have access to new treatments, and ultimately, a cure. Today, nearly 30 years later, new treatments are extending the lives of patients, and we are closer to the vision of a world without scleroderma. Our focus on medical research enables gifted researchers and clinicians to explore promising pathways, share encouraging findings, and take us closer to our goal every day.

Collaboration

Fostering collaboration is a principal tenet of the SRF. We unite exceptional scientists and clinicians across many disciplines in order to advance therapies and find a cure. We also partner with industry and academia, investigating scleroderma under a rigorous peer-reviewed research program. Creating an environment that encourages open lines of communication among a multidisciplinary community maximizes efficiency, improves the quality of results, and leads to new avenues of exploration.

Discovery

The SRF research program devotes 80 percent of its research budget to long-term fundamental discoveries in biology, basic and genomic science, and new technologies. Today, SRF investigators are creating a "GPS system" for navigating the regulomic landscape of scleroderma with the goal of reverse-engineering scleroderma down to the molecular and genetic level.

Comprehensive Care

Beyond the laboratory, SRF resources develop and sustain Scleroderma Centers of Excellence, where patients receive the most comprehensive care from clinicians specialized to treat scleroderma and its complications. Within these Centers, clinicians partner with frontline scientists to provide patient samples, the next generation of experts are trained, and new treatment strategies are developed to advance standards of care.

SEEKING THE KEY TO SCLERODERMA

Systemic sclerosis or scleroderma is a rare, difficult-to-diagnose condition that affects less than 100,000 people in the United States. One of the most deadly of all rheumatic disorders, scleroderma begins as an autoimmune attack and eventually causes devastating damage to body systems.

What is scleroderma?

Scleroderma is a chronic, complex, and debilitating disease. One of the most deadly of all rheumatic disorders, it begins as an autoimmune attack and eventually causes devastating fibrosis or vascular damage. Depending on the subtype of illness (localized, linear, systemic limited, systemic diffuse), scleroderma can damage multiple organ systems.

Who develops scleroderma?

Anyone can develop scleroderma. Although it is generally more common in women, the disease affects people of any race, age, or gender, anywhere in the world. The symptoms and severity of scleroderma vary greatly, and the course of the disease is often unpredictable. Because of its rarity, many healthcare professionals have little experience in recognizing its symptoms and confirming a diagnosis. One of the goals of the SRF is to bring greater awareness to the general public and educate healthcare professionals to increase understanding.

Who is at risk?

The cause of scleroderma is still unknown, and there is likely no single risk factor for it. Scientists are working to understand what biological factors contribute to scleroderma pathogenesis. A number of scientific studies suggest that a combination of genetic and environmental factors may trigger the disease. The most striking statistics show that women in their childbearing years outnumber men with scleroderma by about 4-to-1.

Can scleroderma be treated?

There are a number of treatments available to address the various complications associated with scleroderma. None of these are a cure — they are designed to treat symptoms of the disease. Several different classes of drugs are currently approved, either in the U.S. or Europe, to treat these complications. The primary mission of the SRF is to find, fund, and facilitate the most promising research that will result in improved therapies, and ultimately a cure for patients.

Scleroderma Research Foundation Projects Aim to:

Better understand the stem cells known as neural crest that are specifically targeted by the autoimmune response in scleroderma.

See Casciola-Rosen, McMahan, P 11

Describe and quantify differences between women and men and their immune systems, given that 4 out of 5 scleroderma patients are women.

See Chang, P 12

Identify and stratify scleroderma patients for more effective treatments and more meaningful clinical results.

See Hinchcliff, P 16

Further investigate cancer as an initiator of scleroderma, to understand the disease process in order to develop more effective, targeted therapeutics.

See Rosen, P 17

Understand mechanisms and potential interventions in the development of fibrosis, and the role of myofibroblasts in disease.

See Tager, P 19

Identify novel genetic variants associated with scleroderma susceptibility, providing insight into pathogenic pathways and isolating novel clinical phenotype-specific therapeutic targets.

See Wigley, Boin, Kastner, P 21

MEDICAL RESEARCH LUMINARIES

The SRF Scientific Advisory Board (SAB) is comprised of some of the world's most distinguished scientists who volunteer their time and insights to guide the SRF research program. Their leadership in their respective fields of genetics, autoimmunity, molecular biology, vascular biology, dermatology, and inflammatory disease drives innovation in science. The SAB is essential in directing the SRF research program in order to connect the dots from basic science to treatments. These individuals play an integral role in fulfilling our mission. They are responsible for evaluating research proposals and making funding recommendations that will increase our understanding of scleroderma.

Additionally, in their role, this esteemed group leads the annual SRF Scientific Workshop, a forum that brings together thought leaders with expertise from multiple backgrounds to broker the exchange of information and ideas. The results of this intensive workshop are new alliances and ideas that further develop the roadmap for vital research leading to better treatments and a cure.

Their deep personal commitment, independent judgement, and ability to foster high-level scientific investigation are vital to the success of the SRF research program.

Bruce Alberts, PhD (Chair)

University of California, San Francisco
President Emeritus, National Academy of Sciences

Dr. Alberts is recognized around the world as a scientist and educator. He served two terms as President of the National Academy of Sciences (NAS) (1993-2005), and was also Chairman of the National Research Council at the NAS. Dr. Alberts is one of the original authors of *The Molecular Biology of the Cell*, now in its sixth edition and the standard cell biology textbook in most universities. He served as Editor in Chief of one of the research community's leading journals, *Science*, from 2009-2013. In his third decade of educating future scientists, he is the Chancellor's Leadership Chair in Biochemistry and Biophysics for Science and Education at the University of California, San Francisco (UCSF). Beginning in 2000 and through 2009, he served as the Co-Chair of the InterAcademy Council, an international organization established to provide scientific counsel to the world and governed by the Presidents of 15 national academies of sciences. In 2009, Dr. Alberts was one of three leaders appointed to serve as the nation's first scientific envoy by then Secretary of State Hillary Clinton. In 2014, he was awarded the National Medal of Science by President Barack Obama. This year, he was named recipient of the Lasker-Koshland Special Achievement Award in Medical Sciences for discoveries in DNA replication and leadership in science and education.

This Advisor is a member of the National Academy of Sciences, the United States' most highly regarded scientific nonprofit organization. Since its founding in 1863 by President Abraham Lincoln, members serve pro bono as "advisors to the nation on science, engineering and medicine." As a national academy, new members are elected annually based on their distinguished and continuing achievements in original research.

Jeffrey A. Bluestone, PhD

University of California, San Francisco

Dr. Bluestone joined the University of California, San Francisco (UCSF) faculty in 2000. He holds the A.W. and Mary Margaret Clausen Distinguished Professorship in Metabolism and Endocrinology and is the Director of the Hormone Research Institute. In March 2010, he was appointed Executive Vice Chancellor and Provost (EVCP), to serve as Chief Academic Officer guiding the research and academic enterprise at UCSF, advancing the campus priorities in collaboration with the Chancellor and campus leadership. Dr. Bluestone has also served as the Director of the UCSF Diabetes Center where he emphasized translating basic research in both type 1 and type 2 diabetes into improved therapies for patients. Dr. Bluestone founded and directed the Immune Tolerance Network, a consortium of more than 1,000 of the world's leading scientific researchers and clinical specialists. As an international scientist and leader in the field of immunotherapy, his expertise has helped to clarify the body's immune response on a molecular level, and has catalyzed recent progress in stem cell research, islet cell transplantation, and immune tolerance therapies – studies that have been translated into drugs to treat human disease. This year, he was named President and CEO of the Parker Institute for Cancer Immunotherapy.

David Botstein, PhD

Calico (California Life Company)

Dr. Botstein is a renowned geneticist, educator, and pioneer of the Human Genome Project. He currently serves as the Chief Scientific Officer of Calico, a research and development biotech company established in 2013 by Google Inc., with the goal of tackling the aging process. Dr. Botstein served as the Director of the Lewis–Sigler Institute for Integrative Genomics at Princeton University from 2003-2013, where he remains the Anthony B. Evnin Professor of Genomics. He was an esteemed professor and research scientist at

the Massachusetts Institute of Technology for two decades. He then served as Vice President for Science at Genentech, Inc. for two years before joining the faculty at the Stanford School of Medicine, where he chaired the Department of Genetics. Dr. Botstein is known for his use of genetic methods to understand biological functions and systems. His insights into human gene mapping over 25 years ago helped lay the foundation for the Human Genome Project. Among the many accolades for his work on the Human Genome Project, in March 2013, Dr. Botstein received the Breakthrough Prize from the Life Sciences Foundation. In April 2010, he was awarded the Albany Medical Center Prize in Medicine and Biomedical Research. Often lauded as "America's Nobel," this is one of science's most prestigious awards.

Shaun R. Coughlin, MD, PhD

University of California, San Francisco

Dr. Coughlin directs the Cardiovascular Research Institute (CVRI) at the University of California, San Francisco, where he also holds professorships in Medicine and Cellular and Molecular Pharmacology. He is an expert in the field of vascular biology and has led the burgeoning field of thrombogenesis. Among his contributions, Dr. Coughlin has identified a new family of protease-activated receptors that are involved in a number of biological processes and have important implications for the development of novel treatments for atherosclerosis and pathologic events, including heart attacks and many strokes. His discoveries have led to a greater understanding of how platelets and clot formation are regulated, and how signals that control inflammation of blood vessels are transmitted.

Dan Kastner, MD, PhD

National Human Genome Research Institute (NHGRI)

Dr. Kastner is Scientific Director of the National Human Genome Research Institute (NHGRI), where he oversees clinical studies. He continues the quest for genes underlying human disease by the development and application of advanced gene mapping and sequencing technologies. Prior to his NHGRI appointment, Dr. Kastner was Chief of the Laboratory of Clinical Investigation, Clinical Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and Deputy Director for Intramural Clinical Research at the National Institutes of Health (NIH). His lab focused on human genetic disorders of inflammation. He led an international consortium that identified the gene causing familial Mediterranean fever (FMF) in 1997. And in 1999, Dr. Kastner's lab discovered mutations in a TNF-receptor responsible for causing a dominantly inherited periodic fever syndrome similar to FMF, a discovery that has led to the successful use of anti-TNF agents in the disorder. His team also established the association of STAT4 polymorphisms with several autoimmune diseases and is currently studying the genetics of Behçet's disease. Dr. Kastner is the recipient of the NIH Director's Award, the Paul Klemperer Award of the New York Academy of Medicine, the Lee C. Howley Prize for Research in Arthritis from the National Arthritis Foundation, and the NIAMS Mentoring Award.

Antony Rosen, MD

Johns Hopkins University

Dr. Rosen is the Vice Dean for Research and also directs the Division of Rheumatology at the Johns Hopkins University School of Medicine, where he is also Deputy Director of Medicine, the Mary Betty Stevens Professor of Medicine, and a Professor of Cell Biology and Pathology. His expertise and research focuses on the mechanisms of autoimmune diseases, with particular emphasis on defining the role of autoantigens in rheumatic diseases such as scleroderma, lupus, and arthritis. He has overseen a significant expansion to the Division of Rheumatology at Johns Hopkins University, nearly doubling the faculty size. Dr. Rosen continues to be highly successful in recruiting and mentoring the next generation of clinical and translational investigators who are dedicating their careers to research that will provide new treatment options for patients living with rheumatic diseases. His recent landmark paper published in the leading journal *Science* provides evidence that a certain cancer mutation may trigger scleroderma. In addition to his substantial research efforts, Dr. Rosen is a skilled clinician deeply committed to caring for his patients.

Bruce U. Wintroub, MD

University of California, San Francisco

Dr. Wintroub is a distinguished dermatologist and Vice Dean of Medicine at the University of California, San Francisco, where he also serves as Chair of Dermatology and has a professorship in dermatology. Dr. Wintroub was formerly Assistant Professor of Dermatology at Harvard Medical School. His research projects have included pathogenesis of bullous (blistering) diseases, characterization of human mast cell enzymes, and use of photopheresis in cutaneous T-cell lymphoma, atopic dermatitis, and scleroderma. Dr. Wintroub is Chairman, Board of Trustees of the Dermatology Foundation and is very active in the area of health care delivery and management.

George Yancopoulos, MD, PhD

Regeneron Pharmaceuticals Inc.

Dr. Yancopoulos is Founding Scientist, President of Regeneron Laboratories, and Chief Scientific Officer for Regeneron Pharmaceuticals Inc. His scientific efforts have focused on growth factors, their mechanisms of action, and their role in a wide variety of diseases. His research group discovered the angiopoietins and the ephrins, new families of growth factors that help mediate growth of blood vessels and other cell types. Many of the discoveries of Dr. Yancopoulos and his research group have resulted in therapeutic candidates now in clinical trials such as the VEGF-Trap for cancer and blinding eye diseases, including AMD, and the IL-1 Trap for inflammatory diseases. His research group has also developed an innovative set of technology platforms that will greatly speed drug development. He has been listed among 11 of the most highly cited scientists in a survey by the Institute for Scientific Information.

FIGHTING FIBROSIS

Dr. Hal Dietz reverses fibrosis and starts a company

In 1987, when Sharon Monsky founded the Scleroderma Research Foundation (SRF), and the SRF Scientific Advisory Board Members were beginning to build a research program focused on scleroderma, Dr. Hal Dietz was nowhere near the disease. Yet, in less than a decade of work with the SRF, Dr. Dietz and his team at Johns Hopkins have demonstrated in animal models that fibrosis, the prominent scarring of tissue in scleroderma, can be halted and, more importantly, reversed. Not only is Dietz's team at Hopkins aggressively pursuing the mechanisms for taming fibrosis, their work is the founding science for the formation of a new biotechnology company, Blade Therapeutics. In the past year, Blade has raised critical capital, hired researchers, and begun moving forward with its efforts to bring new therapies to patients.

A Brilliant Researcher and Caring Clinician

Dietz's path to the SRF was a long and winding one and it wouldn't have happened without his relentless curiosity. Initially trained as a pediatric cardiologist, the clinician already enjoyed a distinguished career at Johns Hopkins, when he turned his focus to helping children with a rare disease called Marfan Syndrome. At that time, for those who suffered from the disease, it often meant multiple cardiac surgeries, and too often, early death.

The puzzling condition is a rare and often fatal disorder that causes patients to grow much taller than their peers and have problems with multiple organ systems. The most dangerous and lethal complication causes the aorta, the large artery that carries oxygenated blood from the heart, to grow until it ruptures.

Dietz's ambition was to find an effective intervention that would slow aortic dilation and prevent aortic rupture in Marfan patients.

Researchers knew the disease was hereditary, but the tools for DNA sequencing were just beginning to be employed to find the genetic causes of diseases. In the early 90s, Dietz left cardiology to train in the then-emerging field of molecular genetics.

"My hope was to find the cause of some of these conditions, better understand the mechanism and potentially come up with better treatments."

"My hope was to find the cause of some of these conditions, better understand the mechanism, and potentially come up with better treatments," said Dietz.

Working alongside Drs. Clair Francomano and Victor McKusick (who launched the nation's first medical genetics division), Dietz was among the first to describe Marfan as a connective tissue disorder. With time and a renewed set of genetic tools, Dietz and his colleagues discovered that genetic mutations in the gene for fibrillin-1 cause Marfan. The team also discovered that the fibrillin-1 protein plays a regulatory role in many tissues, including the aorta. Remarkably, several years later, Dietz and his team discovered that a well-known drug that had been used in thousands of patients to treat hypertension acted on this pathway.

While not a cure for Marfan, the use of an existing, approved medication to modify disease activity has helped transform treatment for Marfan patients. This remarkable outcome — disease target identification and repurposing of an existing drug — is one that researchers studying many different diseases, including scleroderma, hope to emulate.

Tracking Down a Rarer Culprit

While Dietz had not previously worked in scleroderma, the SRF recognized Dietz's ability to understand and unravel the mysteries of connective tissue disease. Further, Dietz was interested in exploring the idea that "simple" genetic diseases (those inherited due to a mutation in a single gene, like Marfan Syndrome) could illuminate more complex diseases, like scleroderma. Continuing the approach of applying out-of-the-box strategies to advance its research program, the SRF approached Dietz about working in scleroderma. With support from the SRF in 2008, Dietz and his team began to explore the disease mechanisms underlying fibrosis by investigating a scleroderma-like genetic condition called stiff skin syndrome (SSS). Patients with SSS have thickened, hard skin, much like scleroderma patients, and the Dietz lab hoped their findings in SSS might illuminate the fibrosis of systemic sclerosis. Although like scleroderma in its characteristic skin fibrosis, SSS differs from scleroderma in a few important ways: it is less severe, patients have minimal internal organ involvement and SSS is

hereditary, making it amenable to genetic analysis. Dietz was especially intrigued because he suspected SSS might arise from mutations in fibrillin-1 (the same protein that is affected in Marfan Syndrome).

While most forms of systemic sclerosis are associated with minimal hereditary risk, the Choctaw Native Americans have a higher incidence of scleroderma than the general U.S. population, indicating that they may be susceptible to a form of systemic sclerosis that has a stronger genetic component. Interestingly, the form of scleroderma found in the Choctaw population has been associated with a mutation in the regulatory regions of the fibrillin-1 gene. This evidence provided additional support for the idea that studying SSS might illuminate molecular pathways involved in systemic sclerosis.

Dietz and his team worked aggressively to confirm the genetic cause of SSS.

"There are perhaps fifteen families, total, that have SSS," said Dietz. "But we were able to use some of the most powerful scientific tools available in order to understand that disease and its causes."

Their research pinpointed the genetic mutation responsible for SSS, in the gene for fibrillin-1. Their findings, published in *Science and Translational Medicine* in 2010, seemed a watershed moment.

The fibrillin-1 protein plays a role in other connective tissue disorders, such as Beals Syndrome and Marfan Syndrome. In some types of tissues, including skin, fibrillin-1 constitutes part of the scaffolding for cells that holds tissue together and communicates with cells. The particular genetic changes in fibrillin-1 in SSS impair the protein's ability to make contact with the cells through bridging molecules called integrins.

In SSS, and perhaps in scleroderma, the researchers postulated, the cells in the skin lose their ability to attach to the extracellular matrix (through fibrillin-1) and to sense their surroundings. Those cells then activate and stimulate an immune response causing surrounding cells to produce excessive amounts of collagen in the skin. The findings were a crucial first step toward halting the merciless progression of fibrosis in scleroderma.

Building a Better Model

"Scleroderma has, for years, been a frustrating and mysterious disease to study," said Dietz. "People can show no obvious signs of the disease, and then within a year, have catastrophic consequences."

Among some of the more frustrating elements of studying scleroderma is the heterogeneity of the disease. Scleroderma, like other complex, adult-onset autoimmune diseases, had proven resistant to the development of animal models, due to weak hereditary links and the uncertain etiology, which makes it difficult to recreate a disease process in a model system. Also, the fact that the disease can present in many different ways and with different levels of severity further confounds development of a single model.

Dietz, however, was convinced that having identified the genetic cause of fibrosis in SSS, he could create a mouse model that would be informative for scleroderma. Subsequently, his team was successful in developing transgenic mice with SSS and this model has allowed them to tease out how the molecular defect caused by the mutation in fibrillin-1 leads to fibrosis. They found that SSS created a condition that impaired fibrillin's interaction with integrins. And, as separate proof of this insight, animal models that were manipulated to express artificially low levels of integrins never developed fibrosis (i.e. they were protected).

They then found that blocking certain integrins, or activating others suppressed the inflammatory response that preceded fibrosis and even turned off the production of collagen, the key protein that is over-expressed in scleroderma. The team tested their fibrillin-1 pathway blocking and activating compounds on cultured skin cells from scleroderma patients and saw the same results. Their subsequent research has identified many components in the pathway that interact to initiate and sustain fibrosis. Thus, the first and one of the most complicated parts of finding a potential treatment for scleroderma's signature fibrosis — identifying the mechanism for how fibrosis develops — may be beginning to crack open.

"Indeed, it would seem that the study of a very rare disorder has informed the study of scleroderma," said Dietz.

Building a Company, Building a Drug

The work done by Dietz and his team has paved the way for the next phase in the evolution of the discovery, the development of potential therapies. In 2015, Dietz took a giant leap toward translating his research into treatments with the formation of a biotech company, Blade Therapeutics. To do this, Dietz turned to SRF Chairman Dr. Luke Evnin to help get it done. Evnin, a scleroderma patient and co-founder of the life sciences venture capital firm MPM Capital, knew Dietz and his fibrosis work very well.

With MPM leading the way, a number of highly respected life science investors, including Deerfield, Osage, Novartis, Pfizer, Inc., and Bristol-Myers Squibb, saw value in moving the research forward. Blade Therapeutics has raised more than $50 million in two venture financings, an exceptional amount for an early-stage biotechnology company.

"The SRF has been a critical, essential partner. Scientists need a community to form and check ideas, and we need funding."

Armed with the cutting edge research provided by Dietz, Blade's focus is to discover potential drugs against therapeutic targets that are critical to the fibrotic process and advance them into clinical development. With several potential leads already identified, Blade will now be tasked with narrowing the field to a promising drug compound. This is no small task. "Going in, we thought that fibrosis couldn't be reversed," said Dietz. "While I can't overestimate my excitement, getting this eventually to patients is the goal."

The SRF as an Essential Partner

The SRF's strategy of finding, funding, and facilitating the most promising, highest quality research, and fostering the community of scientists to tackle the problems presented by scleroderma has, with Dietz, Blade Therapeutics, and his fibrosis research, provided reasons for optimism.

"The SRF has been a critical, essential partner," said Dietz. "Scientists need a community to form and check ideas, and we need funding. The SRF Scientific Advisory Board nudged and sometimes shoved us into some very important new directions in the research."

The direction is promising and we look forward to what the future holds. "I'm proud of the funding of Hal's work," said Evnin. "It was catalyzing, and it is the foundation of a promising company that we are all proud to be playing a role in."

2016–2017 Funded Research Grants

Total Awarded: $1,456,500

Investigator	Institution	Research Project
Livia Casciola-Rosen, PHD Professor of Medicine Zsuzsanna McMahan, MD, MHS Assistant Professor of Medicine	Johns Hopkins University School of Medicine	Autoantigen Discovery in Scleroderma Subsets: Possible Targeting of the Neural Crest in Patients with Severe Gastrointestinal Disease
Howard Chang, MD, PHD Professor of Dermatology, Director, NIH Center of Excellence in Genomic Science: Center for Personal Dynamic Regulome	Stanford University School of Medicine	Gene Regulatory Mechanisms in Scleroderma Epigenetics of Sex Differences in Scleroderma
Lorinda Chung, MD, MS Associate Professor of Medicine, Division of Immunology and Rheumatology Paul Wolters, MD Associate Professor of Medicine, Pulmonary and Critical Care Medicine	Stanford University School of Medicine University of California, San Francisco	Northern California Scleroderma Research Consortium
Lorinda Chung, MD, MS Associate Professor of Medicine, Division of Immunology and Rheumatology David Fiorentino, MD, PHD Associate Professor of Dermatology, Divsion of Immunology and Rheumatology	Stanford University School of Medicine	Stanford University Scleroderma Center of Excellence
Hal Dietz, MD Victor A. McKusick Professor of Genetics and Medicine, Investigator, HHMI	Johns Hopkins University School of Medicine, Howard Hughes Medical Institute	Interrogation of the Pathogenesis of Stiff Skin Syndrome: A Congenital Form of Scleroderma
Monique Hinchcliff, MD Assistant Professor of Medicine	Northwestern University Feinberg School of Medicine	DNA Microarray and Traditional Scleroderma Biomarkers: Does Microarray Provide Additional Prognostic Information?
Antony Rosen, MD Vice Dean for Research, Mary Betty Stevens Professor of Medicine	Johns Hopkins University School of Medicine	Defining Novel Autoantibodies and Associated Cancer Mutations in Scleroderma
Michael Rosenblum, MD, PHD Assistant Professor of Medicine	University of California, San Francisco	Dissecting the Role of Regulatory T-Cells in Regulating Tissue Fibrosis
Andrew Tager, MD Associate Professor of Medicine	Massachusetts General Hospital and Harvard Medical School	Biomechanical and Biochemical Drivers of Scleroderma Fibrogenesis: Targeting Myofibroblast Resistance to Apoptosis to Reverse Established Fibrosis
Michael Whitfield, PHD Associate Professor of Genetics	Dartmouth Medical School	A Gene Expression Map of Scleroderma
Fredrick Wigley, MD Professor of Medicine, Associate Director of the Division of Rheumatology, Director of the Johns Hopkins Scleroderma Center Francesco Boin, MD Associate Professor of Medicine In collaboration with: Dan Kastner, MD, PHD Scientific Director	Johns Hopkins University School of Medicine University of California, San Francisco National Human Genome Research Institute	Genome Research in African-American Scleroderma Patients (GRASP)
Fredrick Wigley, MD Professor of Medicine, Associate Director of the Division of Rheumatology, Director of the Johns Hopkins Scleroderma Center	Johns Hopkins University School of Medicine	The Johns Hopkins Scleroderma Center of Excellence

LIVIA CASCIOLA-ROSEN, PHD
ZSUZSANNA MCMAHAN, MD, MHS

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

Autoantigen Discovery in Scleroderma Subsets: Possible Targeting of the Neural Crest in Patients with Severe Gastrointestinal Disease

Project Summary

Scleroderma is a systemic autoimmune disease that is characterized by inflammation, scarring of the skin, damage to internal organs, and an immune response to specific cellular proteins. Patients with scleroderma have several characteristic features, including gastrointestinal failure, loss of pigment in the skin, and disfigurement of the face that are common among scleroderma patients, but not patients with other autoimmune connective tissue diseases. These unique characteristics may provide insight into the biology of the disease.

Interestingly, each of these tissues — the cells in the gastrointestinal tract responsible for motility, pigmentary cells of the skin, and craniofacial cartilage — are derived from a distinct lineage of stem cells known as the neural crest. Casciola-Rosen and McMahan hypothesize that cells derived from this lineage are specifically targeted by the autoimmune response in scleroderma, and that autoantibodies generated against such targets may be biomarkers of gastrointestinal complications in scleroderma.

Research Update

Dr. McMahan identified a cohort of 20 carefully phenotyped scleroderma patients with severe gastrointestinal disease. Dr. Casciola-Rosen's team then employed a newly developed technique, phage-immunoprecipitation sequencing, to look for new autoantibodies in sera from these patients. This technique allowed the researchers to identify several novel autoantibodies that were previously unrecognized in these patients. After validation, the team prioritized several of the antibodies that have not previously been linked to scleroderma patients with severe GI disease. The team plans to pursue further studies to define the specificity of these autoantibodies for the severe GI patient subset. Ultimately, the team will work to evaluate the role of these antibodies in the diagnostic and clinical risk stratification of patients.

DR. CASCIOLA-ROSEN ON WHY RESEARCH MATTERS

"Research is critical in diseases like scleroderma because the currently utilized therapies are inadequate in the prevention of disability and life-threatening complications, and existing therapies currently aimed at broadly suppressing the immune response have a high risk profile and contribute further to the development of clinical complications. Biomarkers that predict disease course, or that can be used to stratify response to therapy or readout treatment effectiveness, are critical. In addition, research aimed at understanding disease subsets and pathogenesis will provide data which will inform future studies related to the biology of the disease."

DR. CHANG ON WHY SRF RESEARCH MATTERS

"The SRF is absolutely special because the organization identifies top scientists and brings them together to work on scleroderma. The SRF creates a community that works together to tackle very difficult, but fundamental questions and problems that stymie progress in developing treatments for the disease. The Foundation provides not only money but also organization and leadership to the search for a cure."

HOWARD CHANG, MD, PHD

STANFORD UNIVERSITY SCHOOL OF MEDICINE

Gene Regulatory Mechanisms in Scleroderma

Project Summary

Systemic scleroderma (SSc) is a disease characterized by excess fibrosis (hardening) in skin and other organs, and the immune system is clearly involved in the initiation and maintenance of fibrosis. Dr. Chang's research is focused on how the genes involved in scleroderma are turned on or off in immune cells and in the cells that produce excessive collagen, causing fibrosis. The Chang team is investigating, at the most basic level, gene control switches that are like command lines that run each cell's software. His lab is characterizing exactly how and why the gene control switches that regulate the immune system cells and the cells in the skin are altered in scleroderma in order to treat the disease at the most fundamental level.

Research Update

Previous methods used to obtain this critical information were not sensitive enough to be performed on small amounts of patient tissue and instead required growing millions of cells in the lab in order to have sufficient numbers to analyze. To solve this problem, Dr. Chang and his collaborators invented a new technology, ATAC-seq, which is one million-fold more sensitive and a hundred times faster than previous methods and allows for visualization of the gene switches that are altered in SSc, even in single cells. Using ATAC-seq, the Chang team has discovered a fundamental difference in how cells go awry in SSc. Although SSc can affect skin from any part of the body and many internal organs, some anatomic sites are more affected than others. To begin to address these differences, the team asked whether the clinically normal skin in SSc might be already harboring seeds of disease. They found that there are two types of cells that are abnormal in every part of the body in a patient with SSc, even in clinically normal appearing skin. There are other cell types that are only different in clinically active lesions, so they are actively examining gene control in these distinct cell types. Ultimately, Dr. Chang's work may point to new therapeutic targets for SSc and it may also improve the ability to match scleroderma patients to the right treatments or clinical trials to treat their disease. The new generation of drugs can target very precise events in cells, but may only work if those cellular events are taking place. Dr. Chang's goal is to make it possible to see those events in patients, instead of guessing based on symptoms, and to accurately predict which drugs will be effective in an individual patient.

Epigenetics of Sex Differences in Scleroderma

Project Summary

The majority of patients with scleroderma are female, with women having an incidence four times that of men. Scleroderma in men, although rarer, is often a more aggressive form of the disease. Despite compelling epidemiological evidence of sex-related differences in the pathogenesis of the disease, there is very little consensus as to what is happening at the molecular level. Dr. Chang and his team are investigating "X chromosome inactivation," a female-specific epigenetic mechanism. The body's inefficient or incomplete silencing of the activity of one of the two X chromosomes in the female cells (known as X chromosome inactivation escape), has been theorized to be involved in scleroderma and other autoimmune diseases. This project aims to build upon Dr. Chang's finding of strong sex-related differences in gene regulation in T cells from scleroderma skin.

Research Update

Using ATAC-seq, Dr. Chang's group demonstrated marked differences in gene regulation in immune cells from males and females. This July, Dr. Chang and other researchers published in *Nature* details about the structural organization of the inactive X chromosome in mice, which they believe will inform our understanding of X inactivation in humans. Further, Dr. Chang's team has discovered that the inactive X chromosome has many proteins associated with it that are autoantigens in autoimmune diseases and his team will continue to investigate this connection to scleroderma and autoimmune disorders.

LORINDA CHUNG, MD, MS
STANFORD UNIVERSITY SCHOOL OF MEDICINE

PAUL WOLTERS, MD
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Northern California Scleroderma Research Consortium

Project Summary

The Northern California Research Consortium is a collaboration between investigators at the University of California, San Francisco (UCSF) and Stanford University aimed at accelerating basic, clinical, and translational research. The Consortium is working on clinical characteristics and molecular mediators of patients with scleroderma. A core feature of this collaboration has been the development of a multicenter longitudinal registry of detailed scleroderma patient clinical information linked to biological samples. By combining the clinical and research assets of the two scleroderma centers, the data is strengthened by increasing its size and diversity, making it large enough to capture various subsets of scleroderma patients. The database of information and sample repository will be used to test and answer critical clinical and molecular questions relevant to scleroderma patients.

Research Update

In the past year, the Northern California Scleroderma Research Consortium database has been used to develop a model (SADL model) of predicting progression of patients with scleroderma-associated interstitial lung disease (SSC-ILD). The SADL model predicts 1-, 2-, and 3-year risk for mortality from SSc-ILD. Using a simple point scoring system that measures readily accessible clinical variables, the model can predict outcome in SSc-ILD. The model is currently being validated in a separate clinical cohort.

In addition, the Consortium has been pursuing molecular analysis of patient samples to define the overlap of molecular mediators of fibrosis in SSc-ILD patients with idiopathic pulmonary fibrosis (IPF). In a preliminary evaluation, the data suggests that roughly 20 percent of patients with SSc-ILD represent a distinct subtype of ILD that is molecularly similar to IPF. If confirmed, this finding may influence how medications developed to treat IPF are used in SSc-ILD patients.

DR. WOLTERS ON WHY RESEARCH MATTERS

"The only way to advance knowledge and improve patient care is through research. The SRF is the most important philanthropic organization dedicated to developing novel treatments for patients with scleroderma."

DR. CHUNG ON WHY RESEARCH MATTERS

"Research, through collaborative efforts among patients, clinicians, and scientists, is the only road to new discoveries. Research discoveries result in better understanding of diseases, and allow us to know who is at risk, what to expect, how best to treat, and ultimately to allow us to develop cures for diseases like scleroderma."

LORINDA CHUNG, MD, MS
DAVID FIORENTINO, MD, PHD
STANFORD UNIVERSITY SCHOOL OF MEDICINE

Stanford University Scleroderma Center of Excellence

Project Summary

The primary goal of the Stanford University Scleroderma Center of Excellence is to provide outstanding multi-specialty care for patients with scleroderma, with experts from rheumatology, dermatology, pulmonary, gastroenterology, cardiology, immunology, and hand/vascular specialists working together to take care of each patient as a whole. At the Stanford Scleroderma Clinic held at the Stanford Redwood City Outpatient Center, every scleroderma patient is seen by a team comprised of physicians from each of these specialty areas. The Center provides access to novel therapies through clinical trials and conducts groundbreaking clinical and translational research in order to unravel the pathogenesis of this disease, discover new biomarkers, and test new therapies for scleroderma and related diseases.

The Center's research is supported by their clinical database with physician assessments, patient questionnaires and outcomes, as well as an established database of biologic samples from patients. This collaboration of patients working with scientists will enable us to better understand what causes scleroderma—and to find markers in the skin or blood that can tell doctors which patients will respond best to which therapies. The ultimate objective is to provide state-of-the art individualized treatment for patients with scleroderma to improve their quality of life and survival.

Research Update

Systemic sclerosis (SSc) is an autoimmune disease that leads to scarring in many organ systems including the skin, blood vessels, gastrointestinal tract, and the lungs. Each patient is different with respect to clinical findings and disease severity. Several molecules have been identified in single organ systems as important in causing fibrosis to develop in that specific organ; but no studies have looked at multiple organ systems to identify molecules that are important in causing fibrosis throughout the entire body. The Stanford group has developed cutting-edge technologies that will be used to identify common molecules in several organ systems that are key players in causing SSc. In order to control for the effects of patient-to-patient differences, these technologies will be used on tissue samples taken from several organ systems from the same SSc patient.

This year, the team collected tissue from at least three different organ systems from 18 individual SSc patients. Preliminary analysis shows that if inflammatory pathways are overactive in the skin, they are also overactive in other tissues in the same patient. Confirmation of these findings could mean that markers in the skin or blood could also be used to monitor internal organ involvement, such as in the lung and gastrointestinal tract in patients with SSc.

HAL DIETZ, MD

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

Interrogation of the Pathogenesis of Stiff Skin Syndrome: A Congenital Form of Scleroderma

Project Summary

Dr. Hal Dietz's laboratory focuses on understanding the process of excessive collagen production (fibrosis) through the comprehensive study of a rare genetic form of scleroderma called stiff skin syndrome (SSS). It is the lab's hope and expectation that this work will inform both the cause and treatment of more common forms of scleroderma such as systemic sclerosis (SSc).

Through their research, Dietz's team learned that patients with SSS have a change (mutation) in the gene that encodes the connective tissue protein fibrillin-1 and showed that the mutation prevents proper interaction between cells of the body and their neighboring connective tissue.

Using genetically engineered mouse models of stiff skin syndrome, the Dietz lab showed that SSS is associated with all the abnormalities seen in SSc, including a predisposition for skin and organ fibrosis, autoimmunity, and autoinflammation. Most importantly, manipulation of the proteins that normally make connections between cells and connective tissue (called integrins) was able to prevent all abnormalities seen in SSS mice, including fibrosis, and selected manipulations could actually reverse established fibrosis. These data suggest new and entirely novel treatment strategies that hold promise for people with various forms of scleroderma. The Dietz lab is also studying events that are required for the body to generate cells that are capable of producing excessive collagen called myofibroblasts.

Research Update

All of the current work in the Dietz lab implicated a specific cell type in the various problems seen in scleroderma. This cell type (the plasmacytoid dendritic cell or pDC) is normally involved in the body's ability to mount a response to viruses and other environmental insults, but is inappropriately activated in their mouse models of scleroderma. They have already shown that simple depletion of pDCs can prevent or reverse existing fibrosis in scleroderma mice. The Dietz team's current work is looking at specific chemicals that are made by pDCs. The team is using both drugs and genetic techniques to block these chemicals to try to find the "Achilles' heel" of fibrotic diseases. Dietz and his team have also found that drugs that block a specific class of enzymes called calpains can prevent myofibroblast formation and fibrosis in mice.

The work will benefit patients by providing a framework to identify and test new treatment strategies for scleroderma. It has identified the first purely genetic form of scleroderma that can be studied in a very detailed and robust manner in the laboratory. This has allowed the creation of the first animal model of scleroderma that fully mirrors the mechanism of a human condition. This gives unprecedented confidence that discoveries will be relevant to people.

The lab is also investigating a new treatment for fibrosis that should be relevant to a wide variety of fibrotic conditions and to many different parts of the body including the lungs, liver, skin, and the heart. This strategy has also shown promise in protecting mice from experimental provocations that result in overt fibrosis in each of these tissues.

DR. DIETZ ON WHY RESEARCH MATTERS

"Research provides knowledge and knowledge provides power to identify vulnerabilities in disease progression that can be leveraged to develop treatments. New technologies should allow us to move beyond understanding what will help the average patient with a given condition to understanding what will be best for a specific individual. This includes knowing what treatment at what dose will work best with the least side effects. These are now the achievable goals of so-called 'precision medicine'."

DR. HINCHCLIFF ON WHY SRF RESEARCH MATTERS

"Research matters because it is the ONLY way to identify better treatments and a cure. The SRF brings together a multitude of scientists and physicians with complementary areas of expertise and encourages "cross talk." I look forward to gaining wisdom from experts who may not be directly involved with scleroderma research, but whose approaches or analyses might be useful to my work."

MONIQUE E. HINCHCLIFF, MD

NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF MEDICINE

DNA Microarray and Traditional Scleroderma Biomarkers: Does Microarray Provide Additional Prognostic Information?

Project Summary

Dr. Hinchcliff believes developing our understanding of different scleroderma disease subsets and the factors that drive them is critical to our ability to effectively treat patients. Her group uses gene expression analysis of skin and esophagus, two tissues commonly affected by scleroderma, to understand different subtypes of disease as well as gain insights into the cause(s) of scleroderma and how best to treat it.

Research Update

The team at Northwestern actively recruited subjects for the Scleroderma Lung Study II, a clinical trial evaluating whether mycophenolate mofetil (MMF) is as effective as cyclophosphamide for the treatment of scleroderma lung and skin disease. The SRF-funded group discovered that differences in the activation of macrophages (white blood cells that are key players in the immune response to foreign invaders of the body) in skin might explain why some patients demonstrate dramatic improvement in skin and lung disease during MMF treatment, while other patients demonstrate negligible improvement. Patients with more inflammation and more macrophage activation in skin are likely to benefit most. Further, Hinchcliff's group discovered that treatment beyond two years may be beneficial, as they witnessed the return of skin inflammation when patients stopped MMF at 24 months.

Hinchcliff is investigating the hypothesis that MMF and other immune modulatory therapies may also benefit scleroderma patients with esophageal symptoms. Currently, there are no medications to modify scleroderma esophogeal disease progression: doctors just treat the symptoms. Hinchcliff and colleagues have developed protocols to obtain esophageal biopsies for gene expression analysis from scleroderma patients undergoing esophagrams. With these samples, they will be able to discern whether immune supression might be a useful strategy to prevent and treat scleroderma-related esophageal disease, at least in some patients. Through this work, Hinchcliff's team hopes to identify clinically meaningful groups of patients that will likely benefit from similar treatment and gain important insights into the causes of scleroderma esophogeal disease.

ANTONY ROSEN, MD

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

Defining Novel Antibodies and Associated Cancer Mutations in Scleroderma

Project Summary

One of the key characteristics of scleroderma is activation of the immune system by a small but highly specific group of self-molecules (autoantigens) and understanding the mechanisms underlying this activation of autoimmunity is a critical foundation for more specific and rational intervention. The Rosen lab recently found that in some scleroderma patients who have cancer diagnosed around the same time as their scleroderma presents, mutations in genes that encode for scleroderma autoantigens in the patient's cancer may underlie activation of the scleroderma immune response. The lab's studies are focusing on defining additional immune responses associated with cancer in scleroderma.

Research Update

The team has recently identified an additional autoantibody, RNPC3, which is strongly associated with scleroderma and cancer and is present in a group of patients who do not have any of the other known scleroderma autoantibody specificities. Dr. Rosen and his team are currently working to understand the risk of cancer in patients with this antibody in newly diagnosed scleroderma patients and to define the clinical presentation of scleroderma in these patients. In the coming months, the team hopes to better understand how these specific immune responses may induce the damage and dysfunction of tissues in scleroderma. This work will benefit patients by defining new tests that may predict specific types of scleroderma or particular complications, such as cancer. It will also benefit patients by advancing our understanding of the mechanisms whereby specific immune responses cause tissue damage and dysfunction in scleroderma.

DR. ROSEN ON WHY RESEARCH MATTERS

"Defining rational and specific therapies in scleroderma requires an in-depth understanding of the molecular mechanisms underlying the disease. The current era is exceptionally promising in terms of the new tools that allow highly precise determination of thousands of analytes from tiny amounts of human material. This is the era in which the chances of defining disease mechanisms using new tools is extremely promising. Highly innovative approaches will be critical to solving complex diseases like scleroderma.

The SRF, with its scientific advisors including some of the most prominent scientists in the U.S., has always pushed to bring novel approaches and tools to the understanding of scleroderma."

DR. ROSENBLUM ON WHY SRF RESEARCH MATTERS

"The SRF has played an instrumental role in supporting scleroderma research. Not only from a funding perspective, but also from the perspective of bringing world class researchers from different scientific disciplines together to try to solve this problem. Brainstorming and networking with this elite group of scientists has challenged us to re-think how we are approaching this disease. In addition, we have made invaluable tangible collaborations that greatly helped move our work forward faster and at a higher level. These collaborations would never have happened without the SRF."

MICHAEL ROSENBLUM, MD, PHD
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

Dissecting the Role of Regulatory T-Cells in Regulating Tissue Fibrosis

Project Summary

Scleroderma is thought to result from an overactive immune system attacking normal tissues and organs. All of us have specific cells in our bodies that control our immune systems and ensure that normal, healthy tissues are not mistakenly attacked. Dr. Rosenblum's lab has found that a specific subset of these cells, called regulatory T-cells (Tregs) are absent and/or not functioning properly in the skin of scleroderma patients. Using specific mouse models they have developed, the Rosenblum team is exploring the role that Tregs play in regulating skin fibrosis. They have found that Tregs are able to directly inhibit cells that cause fibrosis. In addition, the team has developed a transplant mouse model of scleroderma that utilizes human skin from scleroderma patients in an attempt to better model the human disease in mice. By using these models to understand how Tregs prevent or modulate skin fibrosis, Dr. Rosenblum's group hopes to pioneer new therapies that enhance the function of Tregs to prevent or treat tissue fibrosis in patients with scleroderma.

Research Update

This past year, Dr. Rosenblum's lab discovered that Tregs directly inhibit the activation of fibroblasts, the cells in connective tissue that produce excessive collagen. In ongoing research, the team is attempting to manipulate Tregs in their mouse models to ascertain the role that these cells play in regulating fibrosis. Dr. Rosenblum's long-term goal is to elucidate whether enhancing Treg function will be of therapeutic benefit for patients with scleroderma.

ANDREW TAGER, MD

MASSACHUSETTS GENERAL HOSPITAL
HARVARD MEDICAL SCHOOL

Biomechanical and Biochemical Drivers of Scleroderma Fibrogenesis: Targeting Myofibroblast Resistance to Apoptosis to Reverse Established Fibrosis

Project Summary

Dr. Tager's SRF-funded research is focused on developing new strategies to treat the fibrosis, or scarring, that occurs in the skin, lungs, and other internal organs of patients with scleroderma. This scarring is responsible for a great deal of the suffering and many of the deaths caused by scleroderma, and currently available drugs have not been successful in treating this aspect of the disease. To find new drugs to treat fibrosis in scleroderma, Dr. Tager and his team are investigating "fibroblasts," the cells in the body that are responsible for producing abnormally high levels of collagen, thereby causing fibrosis of tissues. Collagen fibers support the skin and other body tissues and give them strength. Loss of collagen in the skin causes it to become weak and to wrinkle, but too much collagen in the skin, as scleroderma patients have, causes the skin to thicken and harden. Too much collagen in the lungs makes it difficult to breathe and to get enough oxygen into the bloodstream.

Whereas drugs capable of halting, or even just slowing, the progression of scleroderma fibrosis would be highly valuable additions to treatment of this disease, the ultimate goal of scleroderma fibrosis drug development is to provide therapies that are capable of reversing established fibrosis, and consequently, that are capable of making patients suffering from this disease better. Understanding how and why fibrosis is so persistent in scleroderma is crucial for developing these new therapies. Dr. Tager hypothesizes that one of the central reasons for this persistence is that fibroblasts in scleroderma become resistant to the normal cellular process of dying when they are no longer needed, much in the way that cancer cells do. The team further believes that as long as these fibroblasts remain alive and active, the cells continue to produce the excessive collagen that causes fibrosis of the skin and other tissues of scleroderma patients. The goals of Tager's SRF-funded research are to better understand how fibroblasts become resistant to normal cell death processes in scleroderma fibrosis and to develop treatment strategies to reverse established fibrosis by overcoming this resistance.

Research Update

Fibrosis makes tissues stiffer. Dr. Tager and his team have recently found that tissue stiffness, in addition to causing a lot of the clinical problems associated with scleroderma, stimulates the scarring process to progress further. This biological "feed-forward loop," whereby fibrosis reinforces itself, causes tissues to become even stiffer. In their efforts to understand this phenomenon, Dr. Tager's group has demonstrated that increased tissue stiffness causes fibroblasts to become resistant to a normal cell death process that eliminates cells that are no longer needed. They believe this occurs because increased tissue stiffness causes fibroblasts to make the same set of proteins that many cancer cells make when they become abnormally resistant to dying. Tager's group has found that fibroblasts in scleroderma use the same "molecular tricks" that cancer cells do to resist dying; therefore, they are testing the hypothesis that drugs already developed for cancer to overcome these tricks and encourage cell death could be used to cause fibroblasts to die in the tissues of scleroderma patients. Dr. Tager's group has tested this hypothesis in mouse models of scleroderma and they have found that these specific cancer drugs are able to overcome fibroblast resistance to death and reverse established fibrosis. These results suggest that these specific cancer drugs may be able to reverse established fibrosis in scleroderma patients with fibrosis of the skin, lungs or other organs. Additionally, in the past year, the lab has developed the ability to determine which patients with scleroderma might benefit from these drugs, by testing fibroblasts obtained from small biopsies of their fibrotic skin.

DR. TAGER ON WHY RESEARCH MATTERS

"Fibrosis of tissues such as the skin and lungs, is responsible for a great deal of the suffering and many of the deaths caused by scleroderma. Currently available drugs have not been very successful in treating this aspect of scleroderma. Developing effective new drugs to treat fibrosis will require much better understanding of how and why fibrosis develops and progresses in scleroderma. This understanding can only come from more research into this devastating disease, and the research funded by the Scleroderma Research Foundation is at the heart of these efforts. This research consequently matters enormously for improving the lives of patients with scleroderma, and the lives of all those who love them."

DR. WHITFIELD ON WHY SRF RESEARCH MATTERS

"The SRF has funded innovative research into scleroderma that would be considered too risky for the National Institutes of Health. This innovative research has resulted in significant advances that change how we think about the disease. They have brought new researchers into the community that may never have worked on the disease otherwise. This type of new knowledge, novel paradigms and fresh ideas help get us closer to a cure with each passing day."

MICHAEL WHITFIELD, PHD
DARTMOUTH MEDICAL SCHOOL

A Gene Expression Map of Scleroderma

Project Summary

There is a wide range of clinical manifestations and disease severity among scleroderma patients. The Whitfield lab is working to investigate this variability in scleroderma by examining gene expression in skin and other tissue samples from patients. Dr. Whitfield's lab has identified "molecular finger prints" of disease that determine where a patient is in their disease progression. Dr. Whitfield and his team have been able to identify the genes that change most often across multiple affected tissues in patients, and determine how the genes may interact and connect with one another. Additionally, based on their work, genetic changes that predispose individuals to develop scleroderma can now be linked to the molecular fingerprint of the patient. Dr. Whitfield's group has shown that all of these molecular changes can be tied back to common molecular pathways.

Data generated in Dr. Whitfield's lab and others, is being combined and analyzed using new computational methods. This is enabling identification of common mechanisms and specific cell types that researchers believe they can now target therapeutically. This "big data" approach may help develop diagnostic assays and therapeutic interventions to bring precision medicine to systemic sclerosis.

Research Update

The Whitfield lab and its collaborators have developed multi-tissue networks that implicate specific cells of the innate immune system (alternatively-activated macrophages and dendritic cells) that are believed to drive scleroderma in skin and internal organs affected by the disease. They have shown these cells produce many of the molecules that have been implicated in the disease. The team is performing experiments in mouse models to confirm that eliminating these cells prevents fibrosis, something that has already been shown in other diseases, such as kidney fibrosis. The diagnostic assays that the lab has developed, in part with SRF funding, help Dr. Whitfield's team identify patients with activated macrophages and dendritic cells. The lab is developing methods to target these cells in collaboration with academic and industry partners. In particular, they are leveraging the methods being pioneered in cancer immunotherapy at Dartmouth to develop immunotherapy for patients with scleroderma. They hope to combine their diagnostic assays with therapeutic targeting to develop a precision medicine strategy in scleroderma.

FREDRICK WIGLEY, MD
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

FRANCESCO BOIN, MD
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

In collaboration with

DAN KASTNER, MD, PHD
NATIONAL HUMAN GENOME RESEARCH INSTITUTE

Genome Research in African-American Scleroderma Patients (GRASP) Study

Project Summary

Research conducted in several centers around the United States has confirmed that scleroderma has a higher incidence and prevalence among African-Americans, manifesting with earlier onset, more aggressive disease course, and ultimately higher mortality. Previous studies, including genome-wide association studies (GWAS), have identified several genetic factors conferring general susceptibility for scleroderma. However, these investigations have been mostly focused on Caucasian patients of European descent and have not been replicated in other populations.

The GRASP (Genome Research in African-American Scleroderma Patients) consortium was established with the main goal of defining how changes in the DNA across the genome of African-American patients affected by scleroderma may explain why in this ethnic population the disease manifests with greater severity. The enrollment of a very large cohort of more than 1,000 African-American scleroderma patients from 16 participating centers across the U.S. and the study of their DNA with cutting-edge techniques will allow the investigators to determine whether specific variations in the sequence of the bases of the DNA may explain their increased risk to developed scleroderma as well as its severe clinical manifestations.

Research Update

The GRASP study has made significant progress over the past year. The main goal was to collect samples from at least 1,000 African-American patients and 1,000 healthy controls. The team has surpassed this initial goal and now are continuing further subject enrollment and sample collection. The 1,000 healthy controls have been screened for ANA positivity and the investigators included in the study only those who were ANA negative. The team's second goal was to perform whole exome sequencing (WES) on 400 scleroderma patients and 400 controls to identify rare coding variants associated with scleroderma. The sequencing has been completed and the genetic data have been assembled after multiple quality control measures. Preliminary analyses are underway. GRASP researchers are currently in the process of replicating the findings from the whole exome sequencing in the remaining 600 patients and 600 controls. The third goal for study was to perform single nucleotide polymorphism (SNP) genotyping using two Illumina arrays to identify low frequency and common variants associated with scleroderma. The custom Illumina HumanOmniExpressExome array has been synthesized including 20,000 variants from the WES. One-third of this array genotyping is completed, and the remaining is ongoing. The Illumina Multi-Ethnic Genotyping (MEGA) array genotyping is also ongoing and approximately 500 samples (including cases and controls) have been already processed.

The team expects to fully analyze the exome sequencing data and replicate the findings within the next year. GRASP leaders also plan to start functional studies based on the confirmed genetic associations. The genotyping of 1,000 scleroderma cases and 1,000 healthy controls will continue using the two different Illumina arrays until completion and will include approximately 2.5 million single nucleotide polymorphisms.

The GRASP study and its results will ultimately benefit patients by helping researchers and clinicians to understand with more precision the genes responsible for increased risk of developing scleroderma. Additionally these findings will likely shed light on the disease process in patients of all racial backgrounds.

DR. BOIN ON WHY SRF RESEARCH MATTERS

"The Scleroderma Research Foundation has streamlined and accelerated the pipeline from public awareness to scientific discovery. Their ability to attract substantial funding dedicated to scleroderma research matched by the partnership with the most brilliant scientists in the field of immunology, genetics, fibrosis and vascular biology have been rewarded by some of the most outstanding discoveries in the field of scleroderma of the past 10 years. The SRF continues to be at the forefront of the ultimate fight to find a cure for this dreadful disease."

DR. WIGLEY ON WHY RESEARCH MATTERS

"Without research and efforts to work toward new discoveries, we would be forever stuck in traditional modes of patient care. We know now that past research efforts have taught us lessons that have improved not only our understanding of scleroderma and the disease process, but have also led us to new and better ways to treat patients. We are making a difference right now due to our improved methods for treating the disease. Research not only defines the process, it forces the caregiver to move from failed methods to exciting and novel therapies."

FREDRICK WIGLEY, MD

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

The Johns Hopkins Scleroderma Center of Excellence

Project Summary

The mission of the Johns Hopkins Scleroderma Center is to cure scleroderma with a strategy combining three different approaches: 1) provide comprehensive and compassionate care to scleroderma patients; 2) perform research to discover new treatments that will end the human suffering caused by scleroderma; and 3) provide education to patients, trainees, physicians, and the public about all facets of scleroderma.

The Center has a talented group of individuals dedicated to its including five faculty members who are physician scientists with years of research experience and the superb clinical skills to care for patients with scleroderma. The Center's physician-scientists work with other physicians and researchers at Johns Hopkins, other academic institutions, the National Institutes of Health (NIH), and industry. Their research includes both clinical and basic science projects.

Research Update

Founded in 1990 with support from the SRF, the Scleroderma Center has over the last 26 years built a world-renowned framework for characterizing the breadth of scleroderma phenotype, discovering the underlying mechanisms of the disease, and testing novel therapies for scleroderma. The Center is the site for several studies with Drs. Antony Rosen and Livia Casciola-Rosen and others aimed at better understanding how the immune system initiates and propagates the disease process. Together with the Rosen group, the Center's team has discovered that cancer is a potential trigger of scleroderma in a subgroup of patients. Work on the cancer connection has brought together outstanding investigators of human disease at Hopkins across oncology, cancer genetics, and immunology. The team provides leadership to a multi-center program called GRASP (Genome Research in African-American Scleroderma Patients, see page 21) established to investigate the genetic factors accounting for the unique disease expression among African-Americans. The Johns Hopkins research team is also developing further focus on cellular mediators involved with defective repair mechanisms and tissue injury in scleroderma. Additionally, the Center continues to interact with the laboratory of Dr. Hal Dietz in the discovery of the mechanism of regulating tissue fibrosis (see page 8). Dr. Wigley and his team have established a collaborative effort with the Department of Computer Science and Institute for Computational Medicine. This program is now utilizing unique and sophisticated modeling techniques and the rich clinical data in the Center's database to refine thinking on classification and prediction of major adverse outcomes in scleroderma. In addition to performing as a clinical trial site for nearly all of the major scleroderma trials, the Center and the team are now engaged in over 12 projects focused on major organ disease that occurs in scleroderma.

Dr. Wigley is one of the editors of the recently published textbook *Scleroderma: from Pathogenesis to Comprehensive Management*.

LIKE WINNING THE LOTTERY: SAVILLE KELLNER

Saville Kellner first heard about scleroderma through a request from Susan Feniger and Mary Sue Milliken. Over a decade ago, Feniger (an SRF Board Member) and Milliken reached out to the jovial South African, a business associate with an outsize personality, to support *Cool Comedy—Hot Cuisine* (CCHC). Kellner, a father of three, successful entrepreneur, and CEO of Lake Industries, happily donated and enthusiastically attended *Cool Comedy—Hot Cuisine* events in Los Angeles, not knowing the deeper meaning it would ultimately have in his life.

After that first event, the tall, always-joking Kellner continued to support the Foundation's CCHC events, and what he learned there was the extent of his understanding of scleroderma.

He did not make the connection to the symptoms of scleroderma when, playing a local soccer game, his fingers turned an eerie "Smurf-like" blue, then deep red, then white.

At first, Kellner thought it was a heart attack, and was relieved that it was not.

Within a short period of time, he began to feel more out of breath than usual as he played. Perhaps, he thought, as an aging man, he just needed to get into better shape and stop neglecting his health. Losing a step as you get older is normal, he reasoned.

In the months that followed, his hands began to change, losing flexibility, with the skin becoming increasingly tight. He thought surely this must be carpal tunnel syndrome. Or arthritis. When he had difficulty swallowing, it had to be heartburn.

"Men are not in touch with their bodies," said Kellner. "At this point, I'd been to several *Cool Comedy* events, and heard patients talk about scleroderma, and never did I think for a second that I had it."

Like so many other patients searching for a diagnosis, he spent the next couple of years visiting doctor after doctor, enduring test after test. Becoming winded during short walks, he tried to increase his activity, only to find that the more effort he put in, the worse it became. The difficulty with swallowing he thought was heartburn was becoming more bothersome. Just before his fiftieth birthday, having relocated to Las Vegas, as family and friends were flying in to celebrate, Kellner got the dreadful news. He had scleroderma.

"The first thing I did was call Susan," said a stunned Kellner. "And, after some tears, she urged me to immediately see a specialist at Johns Hopkins."

The fateful visit to the SRF-funded Scleroderma Center of Excellence at Johns Hopkins in Baltimore was a pivotal moment for Kellner. Dr. Zsuzsanna McMahan, then a fellow at Johns Hopkins University

School of Medicine, held his hands, looked at his fingertips, and confirmed with his nailfold capillaries the diagnosis. Dr. Fred Wigley came in and quickly diagnosed systemic scleroderma. Dr. Wigley's intuition and examination also led to a neurology referral for myositis.

Within two years of the first Raynaud's attacks, Kellner had lost 30-40 percent of his lung capacity to irreversible fibrosis. His hands had become so stiff that they seemed to be perpetually contracted. He had no stamina for any physical exertion and was afraid that soccer would be a thing of the past.

After the initial shock subsided, Saville and his wife Katie made the resolution. "We're going to kick this thing in the butt," said Katie Kellner.

Grateful to his team at Hopkins to have the right diagnosis and the right medications, Saville began to feel like himself again. The fear of what might be that had consumed him and his family was beginning to fade, and within four months, determined to not let the disease defeat him, Kellner finished a half-marathon.

"Thank God for Susan, the SRF, Dr. McMahan, and Dr. Wigley," said Kellner. "If it were up to me, I would have stayed in Las Vegas with my local doctor and would be in much worse shape than I am today."

Advocating for Patients and the SRF

Not one to take a passive approach to anything, Kellner's intensity and focus, always the drivers for his professional success, are now being channeled into supporting the SRF and scleroderma research. While he continues to lead several companies, the scleroderma diagnosis has redefined his commitment to finding a cure, and not just for himself, but for the patients he feels so devoted to.

In 2013, he joined the SRF Board of Directors and advocated to bring *Cool Comedy—Hot Cuisine* to his hometown of Las Vegas. This past October, CCHC Las Vegas celebrated its second successful event. With Saville's infectious passion and enthusiasm for the cause, friends, family, and colleagues rallied in support. And rally they did. They gave their time, talent, and financial resources to help find a cure. Among many others, his wife Katie and Dr. McMahan moved the audience with their keynote speech. His close friend Chef Rick Moonen, not only lent his culinary skills, but also made an emotional plea in honor of his friend.

Saville wryly remarks, "The night was what I imagine seeing my own funeral might be like." However, underlying the humor is a deep gratitude for his ability to make a difference in the lives of others who have been affected. "There was an unbelievable amount of love and friendship on display. I hate talking about my disease—I am lucky as I have Katie to help me with this disease. But to be there and see other scleroderma patients look to me with hope and appreciation—I cry when they say thank you for caring and trying to do something about this."

Life with Scleroderma

In the five years since his initial diagnosis, the pace of life is a little slower, but only marginally. Sixteen-hour work days have become ten, sometimes it's only one round of golf a week, and periodically he will take a break from his morning Pilates sessions. Half the battle for Saville is mental, and he has decided he will not let the disease get the best of him.

"Because of his strong outer persona, we can forget that he's sick," said Katie Kellner. "What has changed is that now things have a timeline, and he can't do the things he used to. It's been humbling."

"He never complains, but I've watched his expression and everything about him change slightly, and it reminds me how aggressive and nasty this disease is," said Moonen. "What hasn't changed is his knowledge, energy, and sense of humor. He is the driving force behind why I've pushed hard to find a cure."

In his own way, Saville Kellner chooses to deal with his scleroderma by ignoring it as much as he can. "He's very secretive about his health," said Chef Moonen. "He never complains, but I've watched his hands turn blue, [I've seen him] get exhausted, and everything about him change slightly, and it reminds me how aggressive and nasty this disease is. He is the driving force behind why I've pushed hard to find a cure."

Humbling as the circumstances can be, Saville inspires in spite of it all. "He sets a shining example in a troubled world," said friend Robin Leach. "I can only imagine what he faces, but the thing that struck me was this—despite knowing about the disease, his humor and personality are better and stronger than all of us."

As put by his friend and fellow Board Member, Susan Feniger, "Saville in many ways reminds me of Sharon [SRF Founder, Sharon Monsky]—he's passionate, focused, a catalyst for improving the lives of patients. Believe me, I was shaken when I got the call about his diagnosis, but I knew in my heart that he would be impactful for this community and do everything in his power to make a difference…he is not proving me wrong. I'm grateful that we are in this fight together."

Reflecting back on the irony of how these different parts of his life converged, Saville says, with his signature touch of humor, "The odds of people flying to the moon on their own wings are far greater than the chances that as a supporter of the SRF I would develop scleroderma… but everybody loves a lottery winner, and that's how I see myself. I won the lottery to become a face of scleroderma."

COOL COMEDY – HOT CUISINE

Cool Comedy — Hot Cuisine (CCHC) is the SRF's signature gala to raise funds and awareness in support of a cure. Through events held in Las Vegas, Los Angeles, New York, and San Francisco, each night celebrates the remarkable advancements in research, serves to bring greater visibility to the disease, and most importantly raises the funds essential to fulfilling our mission of a world without scleroderma. The SRF thanks event sponsor Actelion Pharmaceuticals and each of the generous donors who helped us raise nearly $2 million over the last year to advance the Foundation's groundbreaking research program. CCHC is not complete without the support of the incredible entertainers, and the SRF is deeply grateful to all who donated their time and talents in support of a cure. Additionally, we thank *Top Chef Masters* Susan Feniger (SRF Board Member) and Mary Sue Milliken for the *Hot Cuisine* they have provided since the very first event in 1987.

New York City, December 2015

With support from Title Sponsors The Arthur Zimtbaum Foundation and Sutherland Asbill & Brennan, friends both old and new joined together at Carolines on Broadway for *Cool Comedy — Hot Cuisine* New York. Hosted by SRF Board Member Bob Saget, it was an especially poignant evening held in memory of SRF Board Member Jeffrey Mace. Serving as a reminder that sometimes laughter can be the best medicine, the unforgettable night featured *Cool Comedy* appearances by Michael Che, Louis C.K., and Andy Cohen.

San Francisco, June 2016

Cool Comedy — Hot Cuisine San Francisco returned to the Grand Ballroom at the historic Fairmont Hotel where the first San Francisco event was held in 1989. Once again, Bob Saget hosted, and the line-up featured comedy by George Lopez and Bill Bellamy. During the evening, scleroderma patient and author Lisa Goodman Helfand delivered a moving speech that inspired all guests. A special musical set from the Goo Goo Dolls closed out the night.

Las Vegas, October 2016

With the support from Title Sponsor Breakthru Beverage, *Cool Comedy — Hot Cuisine* made its second appearance in Las Vegas at the Brooklyn Bowl. The event was hosted by Bill Bellamy, and featured comedy from Bob Saget and unique performances from Absinthe's Duo Vector and the Gazillionaire. Also included was a moving segment with Katie and Saville Kellner and Dr. Zsuzsanna McMahan which shed light on scleroderma's impact from a patient's, a loved one's, and a doctor's perspective. The festivities ended with an energetic set from the Neon Trees. Guests were up and out of their seats to dance and sing along.

Attendees were treated to a very special culinary experience with the *Hot Cuisine* provided by four Bravo *Top Chef Masters*. Susan Feniger and Mary Sue Milliken were accompanied in the kitchen by legendary chefs Rick Moonen and Hubert Keller, with dessert by pastry chef, Keris Kuwana.

Looking to the Future, *Cool Comedy – Hot Cuisine* 2017

The SRF is excited to share that *Cool Comedy — Hot Cuisine* will be returning to Los Angeles in Spring 2017 to celebrate the 30th Anniversary of the SRF and CCHC. The event will honor Board Member Bob Saget for his lifetime achievements toward a cure. Stay tuned for more details.

CURE CREW

Since the SRF's founding, our network of friends has been turning passion and creativity into significant dollars for scleroderma research. The Foundation's Cure Crew program consists of a growing group of grassroots supporters across the country who demonstrate what one person, one family, one group of people can accomplish when they set out to inform and inspire others.

From bake sales to golf tournaments to walk-a-thons and comedy shows, Cure Crew events reach into communities, build support, and provide opportunities for motivated individuals and groups to show their support for a great cause.

We are deeply grateful for the enthusiasm and hard work of our Crew Members who are making a difference in the lives of patients everywhere.

CURE CREW FOR SCLERODERMA RESEARCH Volunteer Spotlight

For Jodi McIver, supporting the SRF is truly a family affair. When her sister and best friend, Becky Denlinger, was diagnosed with scleroderma in 2003, Jodi was determined to make an impact.

"I wanted to do something in honor of her. . . and not in memory," said McIver.

Four years ago, McIver and her family began a walk — Moving Forward for a Cure — in their hometown of Troy, Ohio, to raise funds for the SRF. With the help of Foundation staff and the entire McIver/Denlinger clan and friends, the walk brings together the community in a fun way to educate and rally support for a cure.

Inspiring the next generation of scleroderma advocates, even Becky's four-year-old granddaughter plays a role in the effort, setting up a lemonade stand at the walk. It truly is a family affair.

"I am committed to [doing the walk] every year and to raising awareness," said Jodi. When considering an advocacy organization to partner with, Jodi reflected on her priorities and where she could have the most long-term impact. For her and her family, it was the Scleroderma Research Foundation. "For me and my sister," said Jodi, "what we like most of all is that the SRF is all about the research."

Jodi, Becky, and Moving Forward for a Cure represent what Cure Crew and its members are all about: joining together and educating the community about the disease, the need for a cure, and inspiring others to make a difference.

Cure Crew members are part of a growing team of volunteers. They have fun, share stories, and raise awareness and funds for research. Join Cure Crew today: www.srfcure.org

CONNECTING WITH THE COMMUNITY

Education

As an innovator and leader in scleroderma research, the SRF is uniquely qualified to provide patients, caregivers, and medical professionals with the most up-to-date and relevant news and information about the disease and related research. The SRF seeks to increase knowledge about scleroderma and its complications, improve quality of care, and provide a greater understanding about the research taking place and advancements that are leading toward new treatments and, ultimately, a cure.

Webinar Series

The SRF Webinar Series is a free, interactive program, rich and relevant for the scleroderma community. In an information-packed hour, the live sessions give patients and caregivers access to top medical experts who provide the very latest on research progress, disease management tools, and current and emerging treatments. Sessions are archived and accessible at no cost on the SRF website (www.SRFcure.org/for-patients/webinars). Recent topics include "Treating Scleroderma Interstitial Lung Disease: An Update on Recent Research and Treatment Options;" "Improving Function of Hands and Face: Tips and Exercises for Scleroderma Patients;" "How to Manage Scleroderma with Lifestyle," and "Update on Scleroderma Pulmonary Hypertension."

E-Newsletter

"*Insights*" is the SRF's monthly e-newsletter. Each month, recipients get a highly relevant and curated collection of the very latest news and information from the scleroderma research and treatment world. Covering a wide variety of topics, patients can explore aspects of the disease and therapeutic advancement and learn more about on-going clinical trials, as well as how SRF-funded research is progressing.

Conference Leadership

The SRF was honored to support and participate in the annual American College of Rheumatology Conference, held in Washington, D.C. In addition to using the opportunity to interact and provide clinical, research, and program information to rheumatologists from all over the globe, the SRF hosted scleroderma thought leaders to facilitate discussion among investigators to further accelerate research efforts, and cultivate relationships with industry and academia.

Social Media

Social media is an integral part of the SRF's efforts to connect with patients, caregivers, and medical professionals and bring our community together. Through various channels, the SRF is able to share information, connect directly with our followers, and most importantly allow our friends from all over the world to connect with one another.

facebook.com/SRFcure

twitter.com/SRFcure

youtube.com/SRFcure

instagram.com/SRFcure

SRFcure.org

Disease Awareness

The SRF was also pleased to be part of the Bow Tie for a Cause Campaign this past summer. As a result of the campaign's social media component, Fox Sportscaster Ken Rosenthal wore the SRF bowtie, designed by a scleroderma patient, during one of Major League Baseball's most highly viewed games of the 2015-2016 season.

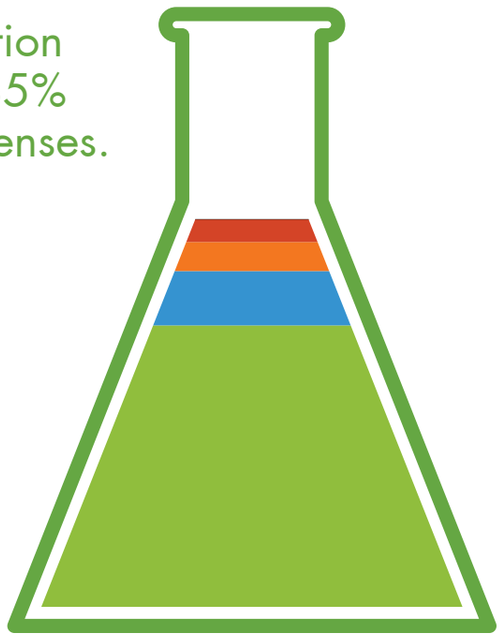
This year through social media the SRF launched its Why Research Matters campaign. The campaign asked our community to share why research mattered to them, and the response was overwhelming. The stories shared were inspiring, and served as a reminder of the importance of the SRF's mission.

PATIENT AND BLOGGER CHANEL WHITE ON WHY RESEARCH MATTERS

"Research signifies the possibility of a shot at a real life someday; one where I can live without the aid of tubes and tanks. A life where I can regain independence, no longer relying on physicians, medications, and caretakers to survive."

FINANCIAL INFORMATION

Scleroderma research and education constitute 85% of SRF expenses.



Research 69.4%
Education 16%
Fundraising 8%
Management & General 6%

Total 100%

Expenses: FYE 2016

The SRF receives no government funding and is entirely dependent upon charitable gifts.

Individuals 53%
Corporate 26%
Foundations 17%
Other Income 1%
Payroll Campaigns 3%

Total 100%

Support and Revenue: FYE 2016

Statement of Financial Position

**For the years ended April 30, 2016, and 2015*

	2016	2015
ASSETS		
Cash & Cash Equivalents	92,514	1,020
Investments	2,205,561	2,130,326
Other Current Assets	30,076	77,259
Contribution Receivable	784,285	936,550
Property and Equipments, Net	27,474	16,976
TOTAL ASSETS	**$3,139,910**	**$3,162,131**
LIABILITIES AND NET ASSETS		
Liabilities		
Accounts Payable	56,692	8,973
Other Current Liabilities	32,689	26,991
Research Grants Payable	0	0
Total Liabilities	89,381	35,964
Net Assets	3,050,529	3,126,167
TOTAL LIABILITIES AND NET ASSETS	**$3,139,910**	**$3,162,131**

Statement of Activities and Changes in Net Assets

**For the years ended April 30, 2016, and 2015*

	2016	2015
SUPPORT AND REVENUE		
Support	2,434,140	2,408,106
Other Income	2,749	67,348
TOTAL SUPPORT AND REVENUE	**$2,436,889**	**$2,475,454**
EXPENSES		
Research	1,742,807	1,782,995
Education	396,515	346,595
Fundraising	212,488	184,611
Management and General	160,717	142,820
TOTAL EXPENSES	**$2,512,527**	**$2,457,021**
NET CHANGE IN ASSETS	**($75,638)**	**$ 18,433**
NET ASSETS, BEGINNING OF YEAR	**$3,126,167**	**$3,107,734**
NET ASSETS, END OF YEAR	**$3,050,529**	**$3,126,167**

Corporate Partners

As the leading nonprofit investor in scleroderma research, the SRF values its partnerships with industry.

The Corporate Partners Program was established to deepen the SRF's relationships with companies that are on the forefront of translating science into potential new treatments while providing necessary support to the Foundation's top research and educational initiatives.

The Program offers our partners numerous opportunities for collaboration. Additionally, the Corporate Partners gain greater insight into the SRF's research program. The SRF believes that fostering relationships between industry and academia will result in the optimum outcome and ultimately better lives for patients.

The SRF recognizes its Corporate Partners and thanks them for their vital support to the Foundation's programmatic priorities and most importantly, for their ongoing commitment to the health and well-being of scleroderma patients:

ACTELION

APRICUS BIOSCIENCES

FIBROCELL SCIENCE

BLADE THERAPEUTICS

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EMPLOYER MATCHED GIFTS

The power of partnership extends beyond the SRF's Corporate Partners Program. We salute not only each individual who talks with his or her employer about the possibility of matching a personal gift made to the SRF, but also the leaders of the organizations who have made a commitment to stand by their employees—doubling their efforts to find a cure for scleroderma. The following organizations have generously matched contributions made by their employees:

Actelion Pharmaceuticals US, Inc.
ADP
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United Health
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The Scleroderma Research Foundation's success and continued progress depends upon charitable gifts.

We are deeply grateful to the many individuals, companies, and foundations whose support—at every level—helps to fund lifesaving medical research.

The following pages acknowledge those who contributed $250 or more during the Foundation's fiscal year ending April 30, 2016.

$50,000+

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Dr. Luke Evnin
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$10,000 - $24,999

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Marion Ternstrom Endowment Fund
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$5,000 - $9,999

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LINDA TARANTINO ON WHY RESEARCH MATTERS

"For those suffering with scleroderma, and those of us who love them, research can be described in one word: HOPE. Scleroderma entered my life two and a half years ago when my daughter, Melissa, was diagnosed days before her 20th birthday. All I can remember from that diagnosis meeting with her doctor are the words "no cause" and "no cure." Without knowing the cause, how can there be a cure? That is where research comes in, and why it is so important. Research will be what allows medical professionals to find the cause of scleroderma, which will help lead them to a cure. Until that happens, research allows for the evaluation of current treatments being used and the discovery of possible new treatment options."

CHRISTY MCCAFFREY ON WHY RESEARCH MATTERS

"Research matters because it offers hope to every scleroderma patient throughout the world, hope that in their lifetime they will see a cure. Research matters because their lives depend on it."

JACK JOHNSON ON WHY RESEARCH MATTERS

"When I was eight, my mom was diagnosed with an aggressive form of scleroderma, and when I was nine, we nearly lost her. Research saved her, and research is the only way to cure her."

Gifts $1,000 - $4,999

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Shari Adler and Edward I. Adler
Geraldine Ah Moo and Baron Ah Moo
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Gloria S. Woods
Deann Wright and Luke Evnin
Cynthia Yagi
Mike and Joan Zaccaro

IN MEMORY

All of us at the Scleroderma Research Foundation express our deepest sympathy to the families and friends of the following people in whose memory gifts were made during our fiscal year.

Nancy Gayle Abrams
Arlin M. Adams
Rose A. Adams
Juanette Adger
Hilda Allen
Miriam Almeida
Carlos Alonso
Norma and Phillip Altus
Walter G. Amstutz
Sidney Applebaum
Elaine Aresco
Lety Armstrong
Ugo Arnoldi
Shirley Arons
Elmie Austin
Catherine Welch Baez
Ginger Bailey
Shirley J. Ballard
Bill Banks
Cynthia Barlup
Esther Barnett
Dorothy Bartlett
Susan Bash
Lorraine Batton
Thomas Bautz
Denise E. Beaule
Steven Becker
Martin Bednarski
Margaret Beene
Margaret Belanger
Shirley Belo Mocho
Gwen Benford
Nancy Ann Bennett
Carole Berg
Antonietta Bernardi
Suzzane Mary Bickert
Helen Bielski
Lois Bieniek
Mary Gloria Bionaz
Kathryn Bishop
Barbara Blake
Marcia Borg-Jankowsky
Ida Borgatello
Laura Borgatello
Judy Boss
Mae Boulger
Lloyd Bowman
Joan Britton
Kathleen Brkljacich
Baby Brown
Marjorie Brown
Megan A. Brown
Taitum Makaila Brown
Jerry A. Bruinooge
Ritz Brunello
Linda Bryant
Barbara An Budd
Karen Kummer Bybee
Barbara Byrnes
Carol Young Calder
Regina Callahan
Jean Simone Campion
Mario Canelon
Anna Marie Capalupo
Michael Capello
Norma Caporale
Vivienne Cardullo
Sylvia Cardwell
Marilyn Carminati
Ron Carminati
Beatrice Carter
Travis Carter
Shirlie Casier
Kathryn Catanzaro
Rona Greenberg Chapman
Bernard Charapp
Sonja Chow
Virginia Chowdhry
Philip Christ
Debra Ciemeux
Brian Cincotta
Greg Clark
Eileen Clary
Barbara Clifford
Natalie Cohen
Virginia Cohen
Iris Cohn
Betty Coit
Kaelin Connolly
Patricia Connors-Zini
Kelley Cordeira
Judy Cottle
Harriet Crystal
Anna Damiani
Wanda Davis
Mary Jane De Sipio
Debbie's Beloved Mother
Russell A. DeGraw, Jr.
Mary DeMartini
Honor Dempsey-Carter
Albert DiEva
Celeste Doria
Sally Dougherty
Dierdre Driscoll
Ginny Driscoll
Frank B. Duggan
Vernon Dunn
Marina Duque
Cathy Caprino Dutschke
Emma Gold Duvall
Patricia Dziak
Priscilla Dzurus
Betty Eckhard
Veronica Rush Eckhardt
Lori Edidin
Herb Eisenberg
Rori Eisenberg
Curtis Eugene Elder
Carmen Elera
Iris Blatt Ellison
Cheryl Elmore
Sally English
Dominick Esposito
Kay Etow
Thelma Ewell
Jenny Faenza

JOE PELESKA ON WHY RESEARCH MATTERS

"When my dad found out he had scleroderma in 2000, he learned that there not only wasn't a cure, there weren't treatments. By then, he had not been feeling well for a long time. He passed away in 2001. Near the end, he was not concerned about himself, but was hoping that something that doctors were doing would help the next person diagnosed with the disease. I see the difference that 16 years of research has made with the treatment of this disease and know that the money we help raise goes to that research. It is our hope that the research leads to the development of a disease altering treatment or a cure for all that may be diagnosed with any type of scleroderma. I believe my dad made a difference and our love for him has allowed us to continue to help make a difference."

In Memory (continued)

Betty Falk
Patrice Fauver
James Fecko
Lee Fein
Laurie Feinstein
Milton Feldman
Cynthia R. Fell
Elaine Ferkauf
Camille R. Ferrara
Alyce Ferrari
Larry Fiegleman
Elizabeth (Betty) Firing
Angela Fisher
Stuart Fishkin
Mrs. Marty Folger
Michael Forman
Gail Fournier
Joyce Faye Freeman
Rebecca Garcia
Betty Gardner
Bonita Garfield
Catalda Gasparetti
Betty Gayle
Nancy Mao Gevirtz
Judy Giangrande
Helen Gibbons
Jennie Gibson
Dr. Leslie S. Gillespie
Peggy Ann Gilmore
Carole Goldman
Dorothy and George Goldman
P.J. Gomez
Perla Gonzalez
Hyman Goren
Sidney Gould
Amy Grabina
Sharonda Graham
Harriet Grauer
Norman Gray
Kim Gregg
Gloria Grey
Marilyn Grieshop
Wanda Griffith
Beverly Gromer
Sylvia Grossman
Margaret Guelker
Sandra Hagen
William B. Hallyburton
Sally Seader Halperin
Mariam Hassan and Abdul Aziz Al-Saif
George Harold
Becky Harrison
Ehud Havazelet
Sandy Hazelhofer
Helen A. Heffernan
Lawrence Heimes
Jennifer Hemley
Bill Henderson
Rosaline Hernandez
Martha Robles Hernandez
Annette Hess
Kathryn Doub Hinman
Elsie K. Hoch
Azucena Holguin
Sally Holmes
Barbara A. Horensky
Gilbert Horrach
Mike Hovendon
Marcy Howard
Patricia Berti Hulsewede
Ruby Hullum
Mary Nell Hutchens
Edward Hyman
Jack Irmscher
Terry Irmscher
Joan Mitchell Jenkins
Richard (Rickie) A. Jenkins, Jr.
Dorothy Johnson
Gerry Jones
Jane Joyce
Jeanne Joyce
Cindy Kamenitsa
Nina Karouna
Bruce Katchen
Joanne Kavanagh
Joyce Deveau Kennedy
Priscilla Kenyon
Yasmin Khan
Ann Kleban
Susan J. Klein
Robert Knapp
Henry Knoller
Janice Joy Knopf
Katherine and Robert Koegel
Joan Kosmach
Anne Kovach
Helmut Kramer
Irene Kroll
Sandra Kuebler
Donna Kuwada
Gae Celeste Lach
Edward Lackner
Kerry Adair Larkin
Beverly Larson
Joan Lauer
Daniel R. Lave
Yuet Wa Law
Norma Layne
Steven Clark LeClaire
Evenly Leavitt
John and Ann LeBlanc
Beverly Leigh
Rita Leiter
Elizabeth Lemere
Frederick Leone, Jr.
Cathy Mae Lesher
Mary Lofstrom
Eloise Logan
Mary Lou Long
Augusta Lord
Sandra Best Lumbert
Jeffrey Mace
Sam Machida
Shigenobu Machida
Robert Mahler
Jeanette Malanowski
Catherine Manion
Elsie Manning
Melissa Marcial
Joanne Marcus
Frank Marisi
Nancy Marsalli
Jane Martin
Sharon Martinez
Marion Massey
Luisiana Mateo
Gale Hope Matis
Perry Mayes
Tina McCaffrey
Ruby C. McCall
Carol McChesney and Brightric Brown
Cheryl McCrum
Francis McDonald
Mrs. Mitzi C. McGinnis
Laura McGuire-Weinfeld
Antoinette Medina
Elizabeth Megliola
Joann Mento
Mary Mertz
Dolores Messori
Alta Meunier
Carol King Michie
Eve Milani
Morton Miller
Rita Miller
Lena Moccia
Dr. Richard J. Mohr
Phyliss Monistere
Sharon Monsky
Erin Moore
Nancy Moore
Lisa Morton
Helen Mosley
Marlene C. Moulis
Samuel Muhlfelder
Dolores (Lorie) Murphy
Sheila Hill Murray
Donna Musto
Sina Nahavandian
Josh Narins
Ellen Nathanson
Marijo Neuburger
Valerie Niles
Laurie Noonan
James K. Noz
Rose O'Brien

THE SRF LEGACY SOCIETY

When Sharon Monsky founded the Scleroderma Research Foundation, she wanted her contributions to advance the care and health of scleroderma patients long after she was gone.

The SRF Legacy Society honors this noble goal by providing an opportunity for individuals who would like to support the Foundation through a will, trust, designation, or other planned gift. Given the thoughtful planning of a bequest, planned gifts are often among the most generous and impactful. The SRF Legacy Society provides a way to appropriately thank donors who have included the SRF in their estate during their lifetimes.

Involvement in the Legacy Society gives contributors the opportunity to enjoy the company of others who want to make a lasting gift to the scleroderma community. Participation in the Legacy Society inspires others to look toward the future and consider leaving a lasting gift that will impact the SRF research program for years to come.

Andrea Lindstrom Oakland
Mary Olsen
Tammy Wrinkle Orrick
Kay Ostrom
Steven Pace
James Pahler
Marlene Paluta
Isabelle Patten
Robert Pavelock
Karin Pedersen
Joseph Peleska
Cheryl Peloquin
Richard Perman
Allison Peterson
Grace Pezrow
Kim T. Phan
Benji Piel
James Pietras
Shirlee Friedman Pilch
Robert Piraro
Melissa Pitter
Jerry Pivato
Beverly Pizzuto
David Pollock
Carlin Popke
Mary Porter
Cheri Potter
H. James Province
M.K. Purtich
Carmella Quattrone

Esther Radtke
Richard Raichle
Eileen Ramirez
Kevin Ramplin
John Rashti
Nancy Records
Luisa Reginato
Robert Reichert
Virginia Reid
Ben Reiff
Gwen Renzullo
Ann Trevillian Reynolds
Carol Reynolds
Vicky Wooten Rhodes
Sydney Richards
William "Bud" Rifkin
Mary E. Riggs
Debi Rizzo Rivelli
Raymond Rizzo, Sr.
Victoria Zbreznu Robbins
Dorothy B. Roberts
Elizabeth Rochford
Irene Rodriguez
William (Bud) Roeder
Linda Kay Royer
James Rubel
Donna Ruchfi
Sarah Rudolph
Roy Rufh
Sharon Runner

Virginia Russ
Iantha M. Rutledge
Elizabeth Sabo
Ivan Sachs
Ben Saget
Dolly Saget
Gay Saget
Iyoume Salazar
Michael "Caveman" Salyer
Adele Sanford
Alex Saucedo
Suzanne Saupp
Leonard Savino
Leonard Schaub, Jr.
Irene Schliem
Carla Scopeletis
Larry Scott
Mrs. Betty Selbe
Sandy Selfridge
Rosa Shaw
Cheryl E. Shea
Barbara Shepard
Susan Shirley
Thomas Shores
Temi Shorr
Randi Shutan
Marcello Silva
Dani Silverstein
Vanessa Simon
Caroline Rice Smith

Patricia Taylor Smith
Zenobia Smith
Rhoda Solow
Jo Ann Sonis
Gloria Sotelo
Barbara Spillman
Susan Spivack
Marian Spozio
Virginia Stachmus
Anthony A. Staiano
Carolyn Starbird
Robert Stearns, Sr.
Eileen Steinhart
Sophie Stepien
Goldie Stern
Kyran Jerrilyn Stevenson
James Sullivan
Ester Sweeney
Emilia Szajdecki
Virginia Talevi
Rose Marie Tartaglia
Marion Taube
Zara Taylor
Clinton Ternstrom
Marion Ternstrom
Cecily J. Terra
Edith Terry
Bernice Tesmer
Elizabeth Lacy Thompson
Marjorie Thompson

Norma Torres
Nancy Trosin
Carmela Trupia
Henrietta Truscello
Gwendolyn S. Turner
Marjorie Turner
Marie Valdez
Cornelia van der Lee
Eileen Van Der Wende
Martha Veloz
Karen Viets
Ellen Vukovich
Georgia Waddell
Patty Walters
Peggy Wanner
Bonnita Wehrenberg
Mary Weiner
Sompit and David E. White
Lynda Williams
Shirley Willman
Bonnie Wiseman
Barbara Wollenburg
Janet Wong
Keith Yagi
Celina Romero Ynzunza
Amedeo Zandona
Harry Zaslow
Maria Zavala
Joseph P. Ziegler

Barbara F. Zimmerman
Helen Zirn

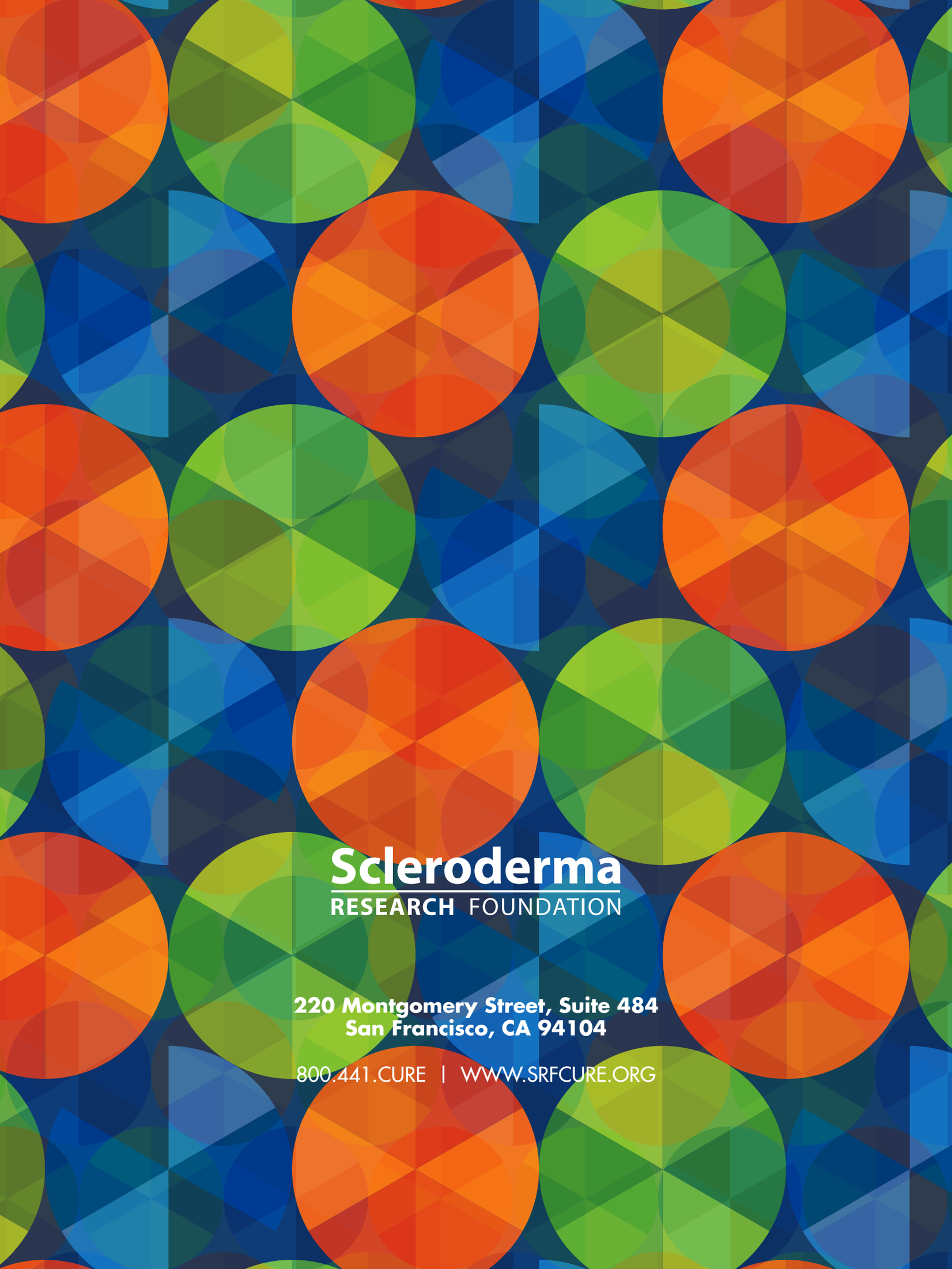
We are deeply honored to include the following individuals in the SRF Legacy Society:

Estate of Maria Anargyros
Estate of Harold E. Aust
Sylvia Marie Becherer Revocable Trust
Karen Fraley 2005 Family Trust
Marie C. Kronman Charitable Lead Annuity Trust
Margaret R. Lee Irrevocable Trust
La Verne B. McCrory
Martha L. McHenry
Estate of Neal McGuire
Neptune Family Trust

Estate of Jerome T. Osborne Sr.
Frank W. Peltzer
Anne D. Ramsier Family Trust
Dolly Saget
Mary Scott Trust
Cheryl E. Shea
Robert H. Shutan Trust
James Simon Family Trust
Estate of Helen I. Steffanus
Clinton Ternstrom

If you have included the Scleroderma Research Foundation in your will or another planned gift, please let us know so that we may honor you as a member of the SRF Legacy Society.

For more information, please call the SRF at 800.441.2873 or email Alex Gonzalez, Director of Development at alexg@sclerodermaresearch.org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