DRIVING DISCOVERY FORWARD

2017 ANNUAL REPORT

Scleroderma RESEARCH FOUNDATION

Scleroderma RESEARCH FOUNDATION

30 YEARS

DRIVING DISCOVERY FORWARD »

MAKE A GIFT TO MAKE A DIFFERENCE

CONSIDER A GIFT TO THE SCLERODERMA RESEARCH FOUNDATION

The Scleroderma Research Foundation (SRF) is the nation's leading nonprofit investor in medical research to find improved therapies and a cure for scleroderma. Our progress is entirely dependent upon charitable gifts from generous people like you.

www.srfcure.org/donate

Dear Friends,

It's been 30 years since our friend, founder and inspiration, Sharon Monsky, challenged us to achieve one overarching goal: find a cure for scleroderma.

As she said then,"We are in business to go out of business." We continue to dream of that day. As her successor and as Board chair of the SRF for the past 15 years, I know she would be proud of all we've accomplished, including raising more than $45 million for research.

Her spirit of giving, doing more, pushing limits, and never accepting "no" as an answer provided the original impetus for the SRF to move faster, be smarter, and invest the vast majority of its resources (more than 85%) in research, outcomes and education. "Lean and Mean" has real meaning at the SRF. Today we are able to invest over $1.5 million in research annually and we aspire to double that in the near future as we connect more broadly with our pharmaceutical company partners and our network.

The SRF continues to be the largest nonprofit investor in scleroderma-oriented research in the nation. And over the recent past, with its expanded investment reach, we have been able to not only drive an ambitious research agenda but we have meaningfully expanded the roster of collaborating institutions in our translationally oriented programs. For example, in the GRASP project the SRF has helped bring together 23 centers across the country. I am amazed by the engagement of some of the most esteemed scientists at the greatest medical research institutions in the world who have taken up the SRF cause, and humbled by the investment of time, dollars and talent of our donors and corporate partners.

Our emphasis on basic research, in particular defining relevant cell types and biological pathways with the primary goal of identifying points of therapeutic intervention, is paying off. One notable success is with Blade Therapeutics which has attacked one of the targets identified in the lab of Dr. Hal Dietz. Moving swiftly, their drug is headed into clinical trials in 2018. And holding true to one of the principle tenets of the SRF established 30 years ago, collaboration is paving the way for the SRF to significantly impact the patient community. With participation from 12 leading U.S. scleroderma centers, the first national longitudinal patient registry, CONQUER will launch in early 2018. This registry is the perfect example of the SRF's steadfast, never accept no approach that will change the lives of patients living with this disease.

We also recognize that serious business sometimes requires serious fun. And since our beginning *Cool Comedy—Hot Cuisine* has brought together friends, both old and new, along with world-class performers for a night of great food and laughter, in support of scleroderma research. The event just keeps getting bigger and better. On behalf of all of us at the SRF, I want to applaud Susan Feniger and Bob Saget, our Board members who have continued to lead this series of events to new highs, a record which now stretches back across 40 events and 30 years.

While I spend the majority of my time in the business world, I am never far from the purpose and promise of the SRF. So, on the occasion of this milestone anniversary, we thought it would be appropriate to share some personal stories—including mine. We hope that by reading about our respective journeys with the SRF, you will not only find validation of your commitment, but perhaps a desire to inspire others to join us on this path to a cure.

Our tiny organization has achieved so much due to the creativity and commitment of our donors and our volunteers, including the indomitable grass-roots Cure Crew. So, this 30th anniversary Annual Report is dedicated to all of you—patients, families, researchers, universities, corporate partners, volunteers, *Cool Comedy—Hot Cuisine* performers and donors—on behalf of the Board and staff of the Scleroderma Research Foundation, we offer you our profound thanks.

Sincerely,

Luke Evnin, PhD
Chairman

Minnie Ruth (Patient) and Travis Carr

FIND, FUND & FACILITATE

FIND, FUND & FACILITATE

The Scleroderma Research Foundation (SRF) is America's leading nonprofit investor in scleroderma research, laser-focused on finding a cure for this rare, and often deadly, disease.

Because scleroderma affects fewer than 100,000 people in the U.S. annually, it does not have the profile of other, better-known and more prevalent illnesses. But a cure for scleroderma may hold the key to cures and better outcomes for a host of other diseases.

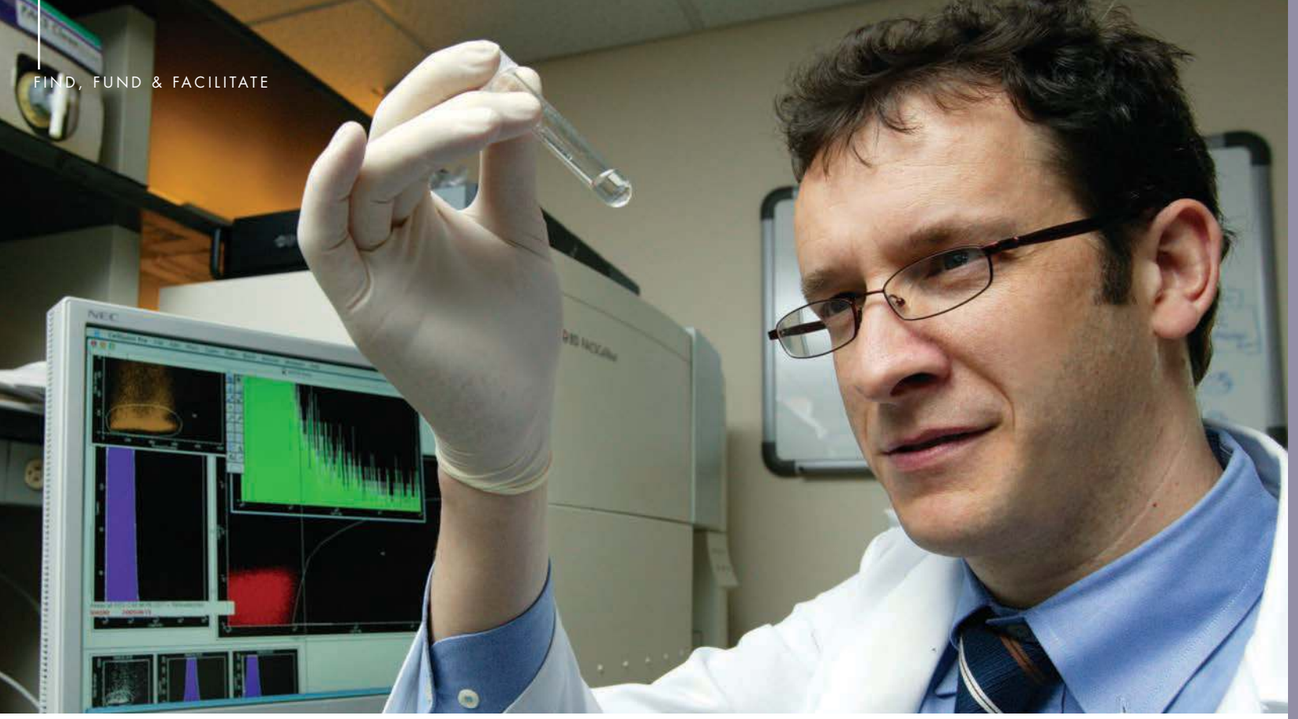
In 1987, patient Sharon Monsky founded the SRF with the belief that funding medical research was the best way to give hope to those living with the disease. For those who knew Sharon, it's no surprise that her passion, commitment, and ability to galvanize people toward a noble cause has gained continued momentum and success under the thoughtful leadership she inspired to carry her vision forward.

The SRF research program seeks to deepen knowledge and understanding of this life-threatening condition, by facilitating research and collaboration among the world's top scientists and medical institutions. Funded projects are allocated in three broad categories: clinical, translational and basic research. While 20% of the SRF's budget is devoted to clinical endeavors, including development and sustaining support for Clinical Centers of Excellence, 80% 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

A WORLD WITHOUT SCLERODERMA

Sharon envisioned a future where those living with scleroderma would have access to new treatments, and ultimately, a cure. Today, 30 years later, new treatments are extending the lives of patients, and we are closer to her vision. 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.



« The SRF research program seeks to deepen knowledge and understanding of this life-threatening condition, by facilitating research and collaboration among the world's top scientists and medical institutions. »

COLLABORATION

UNITING EXCEPTIONAL SCIENTISTS & SCIENCE

Fostering collaboration is a core principle of the SRF; it's the way we approach our business. 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

RESEARCH IS THE KEY

The SRF research program devotes the majority (80%) 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

CONNECTING PATIENTS AND PHYSICIANS WITH CLINICAL EXCELLENCE

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.

Above: Dr. Francesco Boin (Researcher)

Right: Cythia Yagi (Patient)

ABOUT SCLERODERMA

One of the deadliest of all rheumatic disorders, scleroderma is chronic, complex and debilitating. Scleroderma 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. 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 four-to-one.

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.

When it comes to leading the campaign to find new therapies and treatments for a mysterious and often fatal disease, few people are more qualified and dedicated than Luke Evnin.

An accomplished scientist who has used his research background to fund and build biotech and pharmaceutical companies, the venture capitalist has spent the last 15 years chairing the Board of the Scleroderma Research Foundation. He has witnessed not only the growth of the organization in terms of funding, but great strides in the treatment of the disease.

Today Evnin says he has more hope and optimism than at any point since he found and joined the organization. And no one understands the research process and progress quite like Evnin, who tracks the studies with vital interest—he has been living with scleroderma for more than 20 years.

“Today we’re running the most powerful scleroderma research program in the country, and we’re very proud of that," he said. “But we’re not on some ivory tower, academic mission to figure out what’s going on with scleroderma. We are trying to get to the cure today and, in the meantime, we are trying to help patients who are struggling with the disease.”

MORE HOPE THAN EVER BEFORE

MORE HOPE THAN EVER BEFORE: LUKE EVNIN

« The broader pharmaceutical community has come to understand that scleroderma is a significant and unmet serious healthcare challenge. »

NO LONGER JUST A WORD IN A MEDICAL DICTIONARY

Evnin's predecessor and SRF founder Sharon Monsky lost that struggle in 2002, 15 years after she came up with the prescient idea that the best way to cure scleroderma was to create a collaborative research model and motivate some of the best scientific and medical minds in the country to focus attention and research on the disease. And if that vision began when most physicians hadn't even heard of the disease—or could even diagnose it—it's no longer just a word in a medical dictionary, thanks largely to the work of the SRF and its scientific partners.

According to Evnin, giant strides are being made in the search to solve the mysteries behind the disease, which affects approximately 85,000 Americans. (In the U.S. a rare disease is defined as a disorder or illness with a prevalence of fewer than 200,000 affected people.) "But unlike a decade ago, there's a tremendous amount of interest in rare diseases," Evnin said. "In particular, smaller biotech companies are targeting rare diseases because the current legal and corporate research landscape gives small companies a viable path to profitability. This creates a fertile environment for developing potential drug therapies. The broader pharmaceutical community has come to understand that scleroderma is a significant unmet and serious healthcare challenge. And it is really refreshing

and rewarding to be able to partner with companies that bring new energy and focus to the effort."

RESEARCH IS BEGINNING TO PAY OFF: FIRST DRUG ON THE HORIZON

Even more encouraging is that the research efforts funded by the Scleroderma Research Foundation are paying off. Blade Therapeutics, a start-up company founded on research funded by the SRF, has raised more than $50 million to support discovery against a novel target. This depth of funding means patients will now have the opportunity to see this drug—designed to treat fibrosis—in a clinical trial in 2018.

That's a giant leap from the early days of the Foundation, when Monsky was just trying to get the scientific and medical community's attention focused on this little-known autoimmune disease.

As a scleroderma patient, Evnin also understands the need to balance the research part of the Foundation's work with the needs held by those personally grappling with the disease. He said that even with the mission of funding essential research, the Foundation believes its responsibility is also to be a resource center for scleroderma patients.

"I'm on the phone with a patient every second week or so," Evnin said. "It's very personal because I'm living with the disease every day and taking medication every day, so I'm never very far from the disease. I just try to lay out the best options for them and help them find the right doctor who understands scleroderma."

CONQUER REGISTRY WILL BE TRANSFORMATIVE

In order to improve the standard of care for patients and provide clinicians and researchers with the data they need to accelerate the development of novel therapies, the SRF will soon launch the "CONQUER Registry." In this effort, a consortium of leading scleroderma centers will collect longitudinal data on thousands of patients and assemble a vast database that can be queried to advance patient care and scleroderma research. The concept is to use big data to identify ideal points of intervention, and accelerate and improve outcomes. It will be the first and only national patient registry to track the disease.

The progress of the SRF's work may also invite other changes, including more partnerships and an expanded board. But what will be key, as the work and network grows, is to never lose sight of the "family feel" of the SRF and its leadership—which has remained intact for decades and has kept the board focused on what Evnin calls its "incredibly committed core." As the SRF enters its fourth decade, the opportunity is ripe for an expanded community of individuals and organizations who understand and share the passion, compassion and scientific focus that are part of the SRF's DNA.

"I look at our portfolio, the brain power focused on this disease, and the sophistication of the research, and it would be hard to imagine 10 years from now that all these ideas didn't turn out to have a positive impact on patients' lives," he said. "It's just hard to say which ideas will be 'the ones' that provide the ultimate breakthrough. But as we pass this 30-year marker, the guideposts are very promising."

Thirty years after SRF's founding, hope has evolved into optimism, and big ideas will soon become candidate drugs for clinical trials. Evnin said the progress confirms that the vision for a scientific, research-based foundation was the right one—past, present and future.

MORE HOPE THAN EVER BEFORE

« Today we're running the most powerful scleroderma research program in the country. »

Left: Luke Evnin
Above: Dr. Zsuzsanna McMahan

EXPERTS ON A MISSION
SCIENTIFIC ADVISORY BOARD

Comprised of some of the world's most honored and distinguished scientists, these individuals give freely of their time and insights, guiding the Foundation's research program, evaluating research proposals and making funding recommendations.

Drawn from the fields of genetics, autoimmunity, molecular biology, vascular biology, dermatology and inflammatory disease, board members' expertise and philosophy of collaboration drives the SRF research program forward, by uncovering connections between basic science in the lab, to treatments at the bedside. The magnitude of this depth of knowledge, coupled with an unwavering commitment to the mission, nurtures an environment where new questions are raised, probed and examined, catalyzing research that, in turn, fosters progress towards a cure.

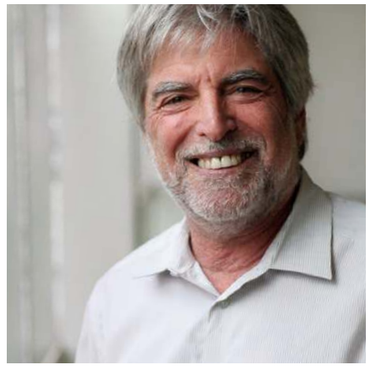
Each year, the SAB convenes and leads the SRF Scientific Workshop, which brings together thought leaders from diverse backgrounds, to exchange information and ideas. The results of this intensive work are new alliances and ideas that further develop the roadmap for vital research leading to better treatments and a cure for scleroderma.

Their deep personal commitment, independent judgment and ability to foster high-level scientific investigation is crucial to our vision set some 30 years ago: a future where those living with scleroderma have access to new treatments—and ultimately, a cure.

The power of collaboration to drive scientific discovery and breakthroughs is the hallmark and mission of the SRF Scientific Advisory Board (SAB).

BRUCE ALBERTS, PHD (CHAIR)*
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO, PRESIDENT EMERITUS, NATIONAL ACADEMY OF SCIENCES

Dr. Alberts is recognized around the world for his work in the fields of biochemistry and molecular biology. 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. He 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 the leading scientific journal, *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. In 2016, he received the Lasker-Koshland Special Achievement Award in Medical Sciences for discoveries in DNA replication and leadership in science and education.



JEFFREY A. BLUESTONE, PHD*
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

As an international scientist and leader in the field of immunotherapy, Dr. Bluestone 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. He joined the University of California, San Francisco (UCSF) faculty in 2000, and holds the A.W. and Mary Margaret Clausen Distinguished Professorship in Metabolism and Endocrinology and is 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 also has 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. He founded and directed the Immune Tolerance Network, a consortium of more than 1,000 of the world's leading scientific researchers and clinical specialists. In 2016, he was named President and CEO of the Parker Institute for Cancer Immunotherapy.

DAVID BOTSTEIN, PHD*
CALIFORNIA LIFE COMPANY (CALICO)

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, 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 a professor and research scientist at the Massachusetts Institute of Technology for two decades, before joining Genentech as Vice President for Science, followed by the Stanford School of Medicine faculty, where he chaired the Department of Genetics. Dr. Botstein is known for his use of genetic methods to understand biological functions and systems. His pioneering insights into human gene mapping helped lay the foundation for the Human Genome Project more than 25 years ago. He has received numerous awards for his work on the Human Genome Project, including the Breakthrough Prize from the Life Sciences Foundation (2013), and the Albany Medical Center Prize in Medicine and Biomedical Research, often lauded as "America's Nobel," in 2010.

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. His career has focused on using genetic and genomic strategies to understand inherited disorders of inflammation. 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. 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 Vice Dean for Research and Director of the Division of Rheumatology at the Johns Hopkins University School of Medicine. He also serves as Deputy Director of Medicine, the Mary Betty Stevens Professor of Medicine, and a Professor of Cell Biology and Pathology at Johns Hopkins. 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. At UCSF, he also serves as Chair of Dermatology, having joined UCSF from Harvard Medical School, where he was Assistant Professor of Dermatology. 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 the Chairman of the Dermatology Foundation and is very active in promoting best practices and advances in of health care delivery and management.

GEORGE YANCOPOULOS, MD, PHD*

REGENERON PHARMACEUTICALS INC.

Dr. Yancopoulos is Founding Scientist, President, 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 recognized among the most highly cited scientists in the world, in a survey by the Institute for Scientific Information.

*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.

2017–2018 FUNDED RESEARCH GRANTS

TOTAL AWARDED: $1,723,880*

*Includes projects approved for inclusion in 2017 portfolio, but funded in FYE 2018
**Indicates new addition to project portfolio

Investigator	Institution	Research Project
LIVIA CASCIOLA-ROSEN, PHD *Professor of Medicine* AMI SHAH, MD *Assistant Professor of Medicine*	Johns Hopkins University School of Medicine	Defining Novel Autoantibodies and Associated Cancer Mutations in Scleroderma
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 Epigenetic Investigation of Twins Discordant for Scleroderma** Epigenetics of Sex Differences in Scleroderma
LORINDA CHUNG, MD, MS *Associate Professor of Medicine* DAVID FIORENTINO, MD, PHD *Associate Professor of Dermatology*	Stanford University School of Medicine	Stanford Scleroderma Center of Excellence
LORINDA CHUNG, MD, MS *Associate Professor of Medicine* PAUL WOLTERS, MD *Associate Professor of Medicine*	Stanford University School of Medicine University of California, San Francisco	Northern California Scleroderma Research Consortium
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 E. HINCHCLIFF, MD *Assistant Professor of Medicine*	Northwestern University Feinberg School of Medicine	DNA Microarray and Traditional Scleroderma Biomarkers: Does Microarray Provide Additional Prognostic Information?
DAVID LAGARES, PHD *Director of the Matrix and Mechanobiology Program* 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
RUSLAN MEDZHITOV, PHD *Sterling Professor of Immunobiology Investigator, HHMI*	Yale University	Macrophage-stromal Cell Interactions in Tissue Homeostasis and Fibrosis**
ANTONY ROSEN, MD *Vice Dean for Research* *Mary Betty Stevens Professor of Medicine* LIVIA CASCIOLA-ROSEN, PHD *Professor of Medicine* SCOTT ZEGER, PHD *Professor and Vice Provost for Research*	Johns Hopkins University School of Medicine	Trajectory Modeling**
KATHRYN TOROK, MD *Assistant Professor* ANNE STEVENS, MD, PHD *Associate Professor, Department of Pediatrics*	University of Pittsburgh School of Medicine University of Washington School of Medicine	Juvenile Scleroderma / Trios**
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	Genomic Research in African American Scleroderma Patients (GRASP)
FREDRICK WIGLEY *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

PUTTING THE PIECES IN PLACE

In the complicated world of scientific research Deann Wright encounters each day, only one thing is simple. The description of her role: **puzzle solver**.

Above and Right: Deann Wright

Twenty years ago when her husband was diagnosed with scleroderma, Deann Wright said she had never even heard of the disease. Today, as one of the key people at the SRF working to identify great clinicians, researchers and research projects to present to the SRF's Scientific Advisory Board, she is putting many of those pieces into place.

"The science is so far beyond where it was when Luke and I joined the SRF in the late 1990's, that it's like comparing night and day," Wright said. "We have benefitted from advances in many disciplines and we've gained sophistication about the types of questions we need to ask. That has led us to better research projects."

Wright, a biochemistry major as an undergraduate at the University of Wisconsin, never thought she would be one of the driving forces underlying the growth of the Scleroderma Research Foundation when she joined its board 17 years ago. But like so many people impacted by the autoimmune disease, Wright found that dedication and commitment are necessary traits in leading the effort to discover and fund research that may one day lead to a cure.

ATTRACTING THE BEST AND BRIGHTEST

Wright and her husband, SRF Chairman Luke Evnin, have become part of the "family" of board members who have guided the organization into one of the country's most respected non-profits for cutting-edge research. And it has attracted some of the best and brightest scientists, clinicians and physicians in the process. And it's that process that Wright focuses on in her quest to identify the research most likely to advance our understanding of scleroderma.

This approach led the Foundation to Dr. Hal Dietz, a geneticist and pediatric cardiologist from Johns Hopkins whose work has led to a breakthrough that may ultimately help reverse fibrosis in scleroderma and other fibrotic diseases. Dietz's research has resulted in the recent formation of a biotech company, Blade Therapeutics—just the sort of outcome the SRF sought when bringing him into the fold.

« Our ability to attract great people with extraordinary ideas has over time transformed the Foundation and allowed our program to evolve. »

TRULY COLLABORATIVE RESEARCH

"We are always looking for clinicians with unique insights or highly skilled basic or translational researchers with incredible track records," Wright said. "We can sit down with our Scientific Advisory Board to determine how great an idea is or whether the researcher we're considering has the skills to carry out a proposed project. And that's important to us because we fund for the long-term and try and build on our research.

"We take a holistic approach to putting together a research portfolio and that has led us to bring together a group of investigators with a broad range of expertise. This makes our research environment richer and our collaborative projects more sophisticated. In recent years, we've seen a dramatic increase in the number of projects we're able to undertake, but we are always cautious not to overextend ourselves because research teams are hard to put together and if you let a team go, you can't put it back together easily," she noted.

Wright said one of the Foundation's initial moves—adding a Scientific Advisory Board of renowned researchers including UCSF's Bruce Alberts—has proved to be one of its greatest strengths. Indeed, one of her favorite events during the year as a board member is the Annual SRF Workshop when she, along with fellow Board members Luke Evnin and Eric Kau, and the SRF Scientific Advisors discuss new and ongoing projects, evaluate research proposals, and make funding recommendations. Often, great new directions for scleroderma research arise from the brainstorming that is an essential element of the Workshop. Wright points to the launch of the Genome Research in African American Scleroderma Patients (GRASP) project as one such success.

RICH, REWARDING ENVIRONMENT

"Having these brilliant advisors, with their long-term commitment to the Scleroderma Research Foundation, guiding our investments toward the highest quality projects has helped us become more successful. And this success, coupled with our rigorous process has made people believe in us," Wright said. "Working with the advisors and the investigators makes for an amazingly energizing environment and it's incredibly rewarding."

If Wright's penchant for evaluating research seems natural, it's because she's no stranger to a lab. After she left Wisconsin, she worked as a research assistant for several years and during this time she met a doctoral student named Luke Evnin. Years later, after Evnin was diagnosed with scleroderma, they found their way to the SRF, which, with its impressive group of Scientific Advisors, seemed like a natural fit.

Wright ultimately earned a law degree, but determined that she much preferred the challenges of medical research to those facing a corporate attorney. As a result, she now spends a great deal of her time reading about new studies, vetting new investigators, and looking for that "out of the box" research project that fills out the SRF's funding portfolio.

PROMISING, LONG-TERM IDEAS

"We have to balance our portfolio with long-term ideas that hold promise for disease-modifying therapy, or even a cure, with ideas we've determined will help patients in the nearer term," Wright said. "Our near-term focus has led us to support select Centers of Excellence. The clinicians there see a high volume of patients and develop an incredibly nuanced view of the disease that, in turn, informs our basic and translational research. The Centers also have the capacity to build assets, such as a clinical databases and extensive collections of patient samples that make some of our other research projects possible," she said.

For Wright, the breakthroughs in research just show how far the Foundation has come on its 30th anniversary. And she believes that now it is just a matter of time before the puzzle pieces fit together and all that information leads to effective therapies, and ultimately, a cure.

"We have put all the resources in place to focus on the best science," she said. "Our ability to attract great people with extraordinary ideas has over time transformed the Foundation and allowed our program to evolve. I'm buoyed by the enthusiasm of our Scientific Advisors, and convinced more than ever that we will be able to make a major difference in the lives of patients and their families. There are so many reasons to be optimistic, and I'm thrilled that our work is helping to grow a vibrant community of clinicians and researchers and advance significant discovery."

The following pages describe the projects funded by the SRF in 2017-2018.

Each year, the SRF receives and evaluates applications for more projects than it has the resources to fund. The process for determining which projects get funded is holistic. We ask numerous questions in considering projects for funding, such as: does this project answer a fundamental question about the scleroderma disease process? Would this project yield unique insights into targeting therapies to patients?

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

The SRF's focus on building a solid and integrated research platform, leads us to consider other factors, such as: would the project complement or balance the SRF's existing portfolio? Will this project build upon the SRF's previous research successes? Does this project allow us to leverage other expertise, assets, or outside funding to which we have access, or in some way create an opportunity to amplify the SRF's efforts?

All applicants, whether new or seeking continued funding, present their projects to the SRF's Scientific Advisory Board and other attendees at the annual SRF Workshop. There, assumptions are challenged, the project's relevance and limitations are probed, and constructive critique and collaborative discussion ensues. It is worth noting that, at the end of the process, there are always worthy projects that SRF cannot fund, due to budgetary considerations. Our goal, and deepest hope, is to continue to expand the SRF's ability to fund great research in our search for a cure.

In the following pages, the 2017/18 SRF-funded investigators describe their research in their own words:

Left: Dr. Hal Dietz
Above: Dr. Livia Casciola-Rosen

DEFINING NOVEL AUTOANTIBODIES THAT ARE PROBES OF CANCER-INDUCED AUTOIMMUNITY AND RISK IN SCLERODERMA

LIVIA CASCIOLA-ROSEN, PHD
AMI SHAH, MD
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

PROJECT OVERVIEW

Dr. Casciola-Rosen and Dr. Shah: Emerging findings indicate that distinct subgroups of scleroderma patients have a high risk of cancer at the time scleroderma develops. These subgroups are marked by the presence of specific autoantibodies. We are only beginning to understand what the important autoantibodies are in this regard, and how they are associated with cancer risk. Our project aims to discover new scleroderma autoantibodies and disease patterns that predict either an increased or decreased risk of cancer developing in scleroderma.

PROJECT UPDATE

Last year, we established novel methods for detecting new autoantibodies. This important step was accomplished in collaboration with Drs. Zeger and Wu, both at Johns Hopkins (JH), using biostatistical methods to analyze data from the JH Scleroderma Center's clinical database. With this new statistical tool, we can now identify distinctive autoantibody patterns from blood samples and use this to cluster scleroderma patients into subgroups based on their autoantibody pattern. Our initial studies strongly suggest that this new method will provide important insights into possible anti-cancer immune responses present in some of these subsets. This new method will be used to further define subsets of scleroderma patients who are either susceptible or resistant to the emergence of cancers. This is relevant both clinically and to our investigation of disease mechanisms, and will be the focus of our work in the coming year.

HOW THIS WORK WILL IMPACT PATIENTS

Our proposed studies are designed to discover novel autoantibodies in two very specific subsets of scleroderma patients: those in which cancer is detected close in time (within five years) to the diagnosis of scleroderma, and those in which cancer is never detected. Defining antibodies that are specifically associated with cancer detection close to the time of scleroderma onset will eventually enable clinicians to predict cancer risk when patients are first seen in a rheumatology clinic, and to guide cancer screening tests. New antibodies associated with cancer protection will give important information about the mechanism of disease and will help to design more effective treatments.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

In addition to providing direct funding for this project, it is the SRF's longstanding support of the Scleroderma Center at Johns Hopkins that laid the groundwork for this project. Over many years, the SRF has provided funding that established and maintains the JH Scleroderma Center, enabling the establishment of a large biorepository of banked blood samples from well-characterized scleroderma patients. Our studies looking for new antibodies are intimately linked with access to this serum bank, and could not be performed without it.

As researchers, we also look forward to the annual SRF Workshop, which provides a wonderful opportunity for interaction between funded and prospective researchers, and the Scientific Advisory Board. We always return from this meeting with renewed enthusiasm and commitment for continuing our studies that will further understanding of scleroderma, and improve treatment for patients.

« Insights about the cells and the specific gene switches that cause disease manifestations open new avenues for scleroderma diagnosis and treatment. »

Above: Dr. Howard Chang

GENE REGULATORY MECHANISMS IN SCLERODERMA

HOWARD CHANG, MD, PHD

STANFORD UNIVERSITY SCHOOL OF MEDICINE

PROJECT OVERVIEW

Dr. Chang: Scleroderma is a disease characterized by excess fibrosis of skin and other organs, and the immune system is involved in triggering and sustaining this fibrosis. My research is focused on how the genes involved in scleroderma are turned on or off. The control of these genes determines a cell's behavior, such as how active an immune cell may be or whether a fibroblast becomes activated to produce excess extracellular matrix, leading to fibrosis. The gene control switches are like the command lines that run the cell's software, and we are working out how gene control is altered in scleroderma in order to detect and treat the disease at the most fundamental level.

PROJECT UPDATE

We have identified the gene switches that are different in scleroderma skin compared to normal skin. Because skin is a complex tissue composed of several types of cells, we have invested a lot of effort to understand which gene switches are changed in which cell types. We found that two cell types in skin have different gene switch activities in scleroderma patients in both fibrotic skin and even in skin that still appears normal. Other cell types only show changes in gene switch activities in the fibrotic skin. Because we can detect these different gene switch activities in "pre-fibrotic" skin, we believe these results may yield insights into the cell types that initiate scleroderma. Our next steps are to understand how the gene switches that are changed in scleroderma affect their target genes, for example, by making the genes turn on too long or in response to the wrong stimuli.

We recently published our new technique for determining the exact gene(s) that are controlled by a particular switch (Mumbach et al. *Nature Genetics* 2017). Since many of the variations in DNA that have been associated with autoimmune diseases occur in these gene switches, we believe this new technique will greatly add to our knowledge about these diseases. Additionally, this technique will enhance the value of large-scale genomic projects (such as the GRASP project) by improving our ability to interpret the data those projects generate.

HOW THIS WORK WILL IMPACT PATIENTS

Insights about the cells and the specific gene switches that cause disease manifestations open new avenues for scleroderma diagnosis and treatment. For example, we are testing whether we can learn about tissue fibrosis in different organs by analyzing gene switches in cells from the blood. If successful, such an approach would help patients monitor disease progression without invasive tissue biopsies. We are also asking whether insights about changes in gene switches in scleroderma can match patients to the therapies that target those genes. We hope this will make treatment strategies more rational and precise.

EPIGENETICS OF SEX DIFFERENCES IN SCLERODERMA

PROJECT OVERVIEW

The majority of patients with scleroderma are female, with women having an incidence four times that of men. Scleroderma in men, although rarer, can be 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. We are investigating "X chromosome inactivation," a female-specific cellular mechanism that silences one of the cell's two X chromosomes. The body's inefficient or incomplete silencing of the activity of one X chromosome in 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 our finding of strong sex-related differences in gene regulation in T cells from scleroderma skin.

RESEARCH UPDATE

Using a technique we developed called ATAC-seq, we have demonstrated marked differences in gene regulation in immune cells from males and females. We have discovered that the inactive X chromosome has many proteins associated with it that are autoantigens in systemic autoimmune diseases and we are investigating this connection to scleroderma and other autoimmune disorders.

SCLERODERMA TWIN STUDY*

PROJECT OVERVIEW

Systemic sclerosis is challenging to study because it is rare and multi-factorial. The conventional approach to medical study is to find a large number of subjects afflicted with a disease and to compare them to a large number of healthy controls. The hope is that, somehow, the average profile of patients and controls would balance each other out and reveal a disease-relevant signal. This approach has been applied to scleroderma with limited success, because the small number of scleroderma patients and controls is often not sufficient to tease apart relevant disease-causing factors from inadvertent associations.

In this study, we are employing a new precision approach to understanding scleroderma pathogenesis. We are recruiting genetically identical twins where one twin has scleroderma and the other twin does not. Such "divergent twins" are uniquely informative because we have a perfect control for each patient—the same genes, same age, same household—the small differences we find between the twins will hopefully pinpoint disease relevant differences. Our experience with a more common disease, asthma, in divergent twins shows that this is a uniquely powerful approach to identify disease-relevant mechanisms. We estimate that the number of subjects needed for this twin approach is far less (perhaps by 100-fold) than conventional designs. Our study involves three key components: (i) careful evaluation of the clinical findings of each twin pair; (ii) a new ultra-sensitive technology called ATAC-seq to map the functional difference in gene control from the blood cells of the twin pairs; (iii) advanced bioinformatics methods to identify disease-relevant biomarkers and pathways.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

The SRF has played crucial roles in my research. They approached me a number of years ago about working on scleroderma and it is the reason my lab is working in this field. I have been continually impressed and moved by the dedication and vision of the people at the SRF. For example, when we developed a technology to look at gene switches in human blood samples, we had the idea that we could apply this technique to look at the genetic basis of scleroderma. The SRF arranged for me to speak at a special dinner for clinical investigators who treat scleroderma patients and collect patient samples. This opportunity allowed me to connect with these investigators, and accelerate the application of our new technology to impact scleroderma patients.

The SRF is absolutely special because they seek out the best scientists and bring them in to work on scleroderma. The SRF creates a community that works together to tackle scleroderma. The Foundation brings not only money, but also organization and leadership to the search for a cure. The SRF constantly connects scientists and ideas to each other to accelerate progress.

STANFORD UNIVERSITY SCLERODERMA CENTER OF EXCELLENCE

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

Dr. Chung: The primary goal of the Stanford Scleroderma Center is to provide outstanding multi-specialty care for patients with scleroderma, with experts from Rheumatology, Dermatology, Pulmonology, Gastroenterology, Cardiology, Immunology, and Hand/Vascular Medicine working together to take care of each patient as a whole. At our Scleroderma Clinic held at the Stanford Redwood City Outpatient Center, each patient is seen by a team of physicians from Rheumatology, Dermatology, and Internal Medicine all at the same time. Our Center has grown substantially over the past several years, with over 650 scleroderma patients evaluated and treated. We are also actively carrying out state-of-the-art research using tissue samples from patients with scleroderma and working with basic scientists to better understand what causes scleroderma, and to find markers in the skin or blood that can tell us which patients will go on to develop serious complications, like pulmonary arterial hypertension (PAH). In particular, we hope to develop a simple blood test to identify scleroderma patients who will ultimately develop PAH.

RESEARCH UPDATE

We have collected a large number of blood samples from scleroderma patients who have developed PAH over time from Scleroderma Centers throughout the US. In collaboration with the Stanford Human Immune Monitoring Core, we are evaluating these blood samples for 62 different markers of immune dysfunction. Over the course of the year, we hope to identify the most promising blood markers of PAH in scleroderma patients. We will then confirm our results in a completely separate group of scleroderma patients.

HOW THIS WORK WILL IMPACT PATIENTS

PAH affects about 10% of patients with scleroderma. Luckily, over the past two decades, multiple treatments have been developed that are effective for the treatment of PAH. However, scleroderma patients tend to do worse than other patients with PAH, in large part, because once the patients are found to have PAH, their disease is already very advanced. We hope to develop a simple blood test to identify, at the time of their initial clinic visit, scleroderma patients who will ultimately develop PAH. This will enable doctors to start effective treatments as early as possible to prevent the onset and progression of this potentially deadly complication.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

The SRF has supported the Stanford Scleroderma Center of Excellence for eight years. Without its support, we would not have been able to develop our large group of scleroderma patients who serve as the core of our translational and clinical research studies. In addition, the SRF has been instrumental in connecting us with other top scleroderma researchers both within our own institution as well as throughout the country. The annual SRF Workshop provides a perfect environment to share scientific ideas and brainstorm with new and old collaborators.

The SRF is a unique funding agency in that they support the development and growth of Centers of Excellence, as well as collaborative research groups such as our Northern California Scleroderma Research Consortium between Stanford and UCSF. They work hard to develop and sustain a close-knit community of researchers with a common goal to cure scleroderma.

NORTHERN CALIFORNIA SCLERODERMA RESEARCH CONSORTIUM

LORINDA CHUNG, MD, MS
STANFORD UNIVERSITY SCHOOL OF MEDICINE
PAUL WOLTERS, MD
UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

The Northern California Scleroderma Research Consortium (NCSRC) comprises a group of investigators at UCSF and Stanford who collaborate on efforts to understand the clinical characteristics and molecular mediators of patients with scleroderma. A core feature of this collaboration has been the creation of a longitudinal registry of patients and a database of detailed clinical information linked to biological samples obtained from scleroderma patients. This registry is being used to advance the understanding of scleroderma by investigating pathobiological and clinical endpoints in scleroderma patients. Members of the consortium use the registry, database and associated biospecimens for joint or independent research projects.

This year's summary will focus on the work in Dr. Paul Wolters' group.

Dr. Wolters: Our research has focused on understanding the pathobiology of scleroderma-associated interstitial lung disease (SSc-ILD) and whether SSc-ILD shares clinical characteristics or underlying biological mechanisms with idiopathic pulmonary fibrosis (IPF), a genetically mediated, age-associated, interstitial lung disease. By comparing these diseases, we developed a model (SADL model) that can be used to predict survival in patients with SSc-ILD. The SADL model predicts 1, 2 and 3-year risk for mortality from SSc-ILD and was recently published (Morisset et al. *Chest* 2017).

In collaboration with Dr. Richard Locksley at UCSF, we recently reported (Van Dyken et al. *Cell* 2017) that the accumulation of environmental chitin (a polysaccharide found in the cell walls of fungi or arthropods) in the lungs of mice or humans can lead to lung fibrosis. Interestingly, we found that chitin accumulates in the lungs of patients with either SSc-ILD or IPF. We are now in the process of trying to understand whether this accumulation contributes to, or is the consequence of lung fibrosis in patients.

In addition, we have been comparing serum levels of circulating molecular markers that predict survival in patients with IPF in patients with SSc-ILD, in order to determine whether there is a subset of patients with SSc-ILD whose disease results from biological mechanisms similar to those seen in IPF. We have found several IPF biomarkers to be elevated in SSc-ILD patients. We are now in process of determining whether they predict outcomes in SSc-ILD patients.

HOW THIS WORK WILL IMPACT PATIENTS

The SADL model can be used to advise patients with SSc-ILD on their individual risk for progression, and possibly identify those at highest risk for progression and who may benefit from lung transplantation.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

The SRF's funding is essential for the NCSRC because it supports clinical coordinators and the database, which are the foundation of our joint research projects.

Left: Dr. David Fiorentino
Above: Dr. Lorinda Chung

INTERROGATION OF THE PATHOGENESIS OF STIFF SKIN SYNDROME: A CONGENITAL FORM OF SCLERODERMA

HAL DIETZ, MD

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

PROJECT OVERVIEW

Dr. Dietz: In broad terms, our lab has focused on the development of experimental models of scleroderma for use in exploring the events that trigger the onset and progression of tissue scarring (fibrosis). Initially we identified the gene underlying a rare inherited form of scleroderma called Stiff Skin Syndrome (SSS) and learned that manipulation of this gene in mice caused skin fibrosis through activation of a specific type of immune system cell called a plasmacytoid dendritic cell or pDC. We went on to show that manipulations that deplete pDCs or impair their function can prevent or even reverse fibrosis in SSS mouse models.

In a second series of experiments, we have been studying the basic molecular changes that are required to stimulate certain types of cells to transition to an aggressive cell type that drives tissue fibrosis (myofibroblasts). Importantly, we were able to implicate a specific family of enzymes (calpains), and even a specific enzyme within this family, in myofibroblast formation. Our work has shown that mice lacking this enzyme are remarkably resistant to various forms of fibrosis—pointing toward a potentially powerful treatment strategy.

Recently, we have initiated studies of skin cells from patients with systemic sclerosis (SSc) to try to understand why they remain "activated" even after removal from the body. One plausible explanation for a permanently altered cellular program in patient cells relates to the body's ability to add stable marks to the DNA that essentially tell a given cell or cell type to ignore certain genes, but to drive other genes to produce proteins. Such marks are not inherited from our parents, but rather occur in response to various stimuli including cellular stress and environmental cues. We are using a variety of methods to learn about the location and nature of these "epigenetic marks" that distinguish skin cells from patients with SSc from those derived from healthy controls. We are also exploring whether cells from patients with SSc can stimulate abnormal epigenetic marks when grafted onto mice. If so, this would allow the generation of a bona fide mouse model of SSc for use in treatment trials.

RESEARCH UPDATE

Over the past year, we have been able to show that calpain inhibition can protect mice from fibrosis of many different tissues and organs, now including the lungs, skin, liver and heart. We have identified certain human fibrotic diseases associated with increased calpain production, and have learned about the underlying cellular mechanisms. This work has formed the basis of a new biopharmaceutical company, called Blade Therapeutics.

We have also identified specific genes that show altered epigenetic regulation in cells from patients with SSc. We have developed both genetic and pharmacologic strategies to either inhibit problematic genes that show excessive protein production or to prevent or even reverse the underlying abnormal epigenetic marks. In the process, we are learning about the environmental cues that can stimulate the onset of fibrosis in scleroderma.

HOW THIS WORK WILL IMPACT PATIENTS

All the work in our lab is very translationally focused, meaning that we are generating and testing hypotheses that have the potential to directly improve the length and/or quality of life for people with scleroderma. This relates to the development of drug strategies (e.g. inhibitors of pDCs or myofibroblasts), identification of biomarkers (that point toward specific tissues or diseases that might be amendable to a given treatment or indicate how well a specific patient is responding to an intervention) or the creation of new and powerful experimental systems (e.g. cell culture or animal models of SSc) that can be used to develop, test or refine treatment strategies.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

In the SRF, I have found a new family of collaborators, mentors, critics (in a friendly and productive way) and partners. The annual SRF Workshop is a highlight of my professional year. My lab spends the next few months digesting and implementing new ideas and scientific approaches. The SRF has facilitated every aspect of our work, including an exciting transition from a purely academic focus to a corporate endeavor—an essential event if we hope to bring powerful new treatments to patients.

DNA MICROARRAY OF SKIN BIOPSIES AND TRADITIONAL SSC BIOMARKERS: DOES MICROARRAY ANALYSES PROVIDE ADDITIONAL PROGNOSTIC INFORMATION?

MONIQUE E. HINCHCLIFF, MD

NORTHWESTERN UNIVERSITY FEINBERG SCHOOL OF MEDICINE

PROJECT OVERVIEW

Dr. Hinchcliff: My lab uses gene expression measurement in skin and the esophagus, the two tissues most commonly affected by systemic sclerosis (SSc), to understand the different subtypes of disease, and to discover the cause(s) of the disease and how best to treat the disease. The 'one size fits all' treatment approach will likely not benefit patients. Understanding the different molecular subsets of scleroderma and the distinct underlying molecular pathways offers the best hope for successful treatment.

PROJECT UPDATE

This year we published our skin biopsy gene expression results that identified a 415-gene signature that is specific for SSc and identified a scleroderma skin severity score (4S) that is predictive of skin disease progression. This is the first predictive skin disease biomarker to be discovered, and validation studies are underway to confirm our exciting results. We discovered that the epidermal growth factor pathway may be an important treatment target in SSc. In the coming year, we will conduct studies in animal models of scleroderma to test the efficacy of treatments that specifically target the epidermal growth factor pathway.

HOW THIS WORK WILL IMPACT PATIENTS

There are several FDA-approved drugs that target the epidermal growth factor pathway that are currently being used to treat cancer patients and potentially could be repurposed for the treatment of patients with SSc. We hypothesize that these drugs will be safe for use in patients with SSc and that they will be effective in treating the skin and internal organ complications of scleroderma.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

The SRF took a gamble on me, providing me with critical research funding when I was an early-stage investigator. Now, the SRF funds the cutting-edge research that I conduct with other SRF-funded investigators. My best research collaborations, that provide the greatest benefit to patients, stem from my interactions with other SRF-funded investigators.

The annual SRF Workshop features research presentations and a chance to share ideas over dinner, and it provides investigators with unparalleled opportunities to formulate new ideas and design novel experiments. The SRF is a scientific family that fosters my scientific development by exposing me to top-notch researchers from a broad range of research backgrounds.

BIOMECHANICAL AND BIOCHEMICAL DRIVERS OF SCLERODERMA FIBROGENESIS: TARGETING MYOFIBROBLAST RESISTANCE TO APOPTOSIS TO REVERSE ESTABLISHED FIBROSIS

DAVID LAGARES, MD
ANDREW TAGER, MD
MASSACHUSETTS GENERAL HOSPITAL
HARVARD MEDICAL SCHOOL

ANDREW "ANDY" M. TAGER

FEBRUARY 25, 1959 – AUGUST 11, 2017

Vibrant, kind and generous, Andy sought to improve the quality of life for countless patients not only with his indomitable spirit, but through his passionate commitment to his scientific work as a physician and researcher. He truly embodied the SRF belief that collaboration is essential, never missing an opportunity to seek and share knowledge. Andy's legacy will live on through all those he inspired.

PROJECT OVERVIEW

Dr. Lagares: Fibrosis, or scarring of tissues, contributes heavily to the suffering and deaths caused by scleroderma. Whereas drugs capable of halting, or even just slowing, the progression of scleroderma fibrosis would be highly valuable additions to treatment options for 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. Developing such therapies requires understanding how and why fibrosis is characteristically so persistent. We believe that one of the central reasons for this persistence is that fibroblasts, the cells that are responsible for producing scar tissue in scleroderma, become resistant to the normal process of dying when they are not needed, much in the way that cancer cells do.

PROJECT UPDATE

Our group has tested this hypothesis in mouse models of scleroderma and we have found that specific cancer drugs may be able to overcome fibroblast resistance to death and reverse established fibrosis. These results suggest that specific cancer drugs may be able to reverse established fibrosis in the skin, lungs and other organs of scleroderma patients. Additionally, our group has developed the ability to determine which scleroderma patients might benefit from these drugs by testing fibroblasts obtained from biopsies of their fibrotic skin.

HOW THIS WORK WILL IMPACT PATIENTS

Our project aims to better understand how fibroblasts become resistant to normal cell death processes in scleroderma fibrosis; and then to develop treatment strategies to reverse established fibrosis in scleroderma by overcoming this resistance of scleroderma fibroblasts to normal cell death processes. It is our hope that this will lead to improved treatment options for patients living with scleroderma.

Previous Left: Dr. Hal Dietz

Previous Right: Dr. Monique E. Hinchcliff

Left: Dr. Andrew M. Tager

Above: Dr. Ruslan Medzhitov

MACROPHAGE-STROMAL CELL INTERACTIONS IN TISSUE HOMEOSTASIS AND FIBROSIS

RUSLAN MEDZHITOV, PHD
YALE UNIVERSITY

PROJECT OVERVIEW

Dr. Medzhitov: One of the hallmarks of scleroderma is fibrosis: the buildup of scar tissue that leads to thickening of the skin and, in extreme cases, causes the lungs and other organs to stiffen. That stiffening is responsible for much of the mortality caused by scleroderma. This scar tissue is made up of dense extracellular matrix (the proteins that form the normal scaffolding of any organ) that in scleroderma, is produced excessively. Fibroblasts are the main producers of extracellular matrix, but it is not known how that production is controlled. How is the extracellular matrix monitored to make sure that it does not go awry? We hypothesized that macrophages, immune cells that regulate other conditions within tissues, monitor the extracellular matrix to keep it in check.

We have shown that macrophages can sense changes in the state of the extracellular matrix, and we have early evidence that they use that information to control the production of extracellular matrix by fibroblasts. We are working to determine whether these control mechanisms are broken in scleroderma, leading to excessive production of extracellular matrix and the formation of scar tissue that causes suffering for scleroderma patients. Our goal is to determine, in detail, how macrophages monitor the extracellular matrix and control fibroblast behavior, and what part of this circuit goes awry in scleroderma, so that we can help develop effective treatments that target that pathway.

GENOME RESEARCH IN AFRICAN AMERICAN SCLERODERMA PATIENTS (GRASP)

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

PROJECT OVERVIEW

Dr. Wigley and Dr. Boin: There is evidence that racial differences exist in the susceptibility to and severity of systemic sclerosis. African Americans have a higher age-specific incidence and prevalence of scleroderma compared to European Americans. The incidence of severe scleroderma-associated interstitial lung disease (SSc-ILD) and pulmonary hypertension (high blood pressure between the heart and lung; a life-threatening complication in scleroderma) is reported to be higher in African Americans than in other ethnic groups. Disease severity is greater and, as a consequence, the disease burden as measured by morbidity and mortality is greater in African Americans. Socioeconomic factors and impaired access to health care do not fully account for the predilection of African American scleroderma patients to poor health outcomes. To date, attempts to elucidate the factors influencing increased disease severity have been hindered by the relatively small size of available African American scleroderma studies.

The Genome Research in African American Scleroderma Patients (GRASP) project was established to enhance our understanding of the clinical phenotype of scleroderma in African Americans and to perform genomic analyses with the aim of identifying factors contributing to the cause(s) and severity of their disease. In order to achieve these goals, a large cohort of African American scleroderma patients has been identified and clinical data as well as biological samples have been collected from enrolled patients.

The GRASP cohort currently consists of more than 1,200 extensively evaluated African American scleroderma patients enrolled from 23 participating U.S. academic centers. It is the largest multicenter cohort of African American scleroderma patients; consequently, GRASP's comprehensive clinical database and the significant size of the cohort enable informative analyses; including, in our initial phase, careful description of clinical features and the analysis of samples from these patients to understand the biology of the disease. Our initial study (in press) emphasizes the unique and severe disease burden of scleroderma in African Americans and highlights factors associated with clinically significant manifestations of scleroderma in African Americans.

The GRASP consortium is now working to define how variation in the DNA across the genome of African American patients may affect the expression of scleroderma. Subtle and rare differences between the DNA makeup of African Americans who have scleroderma and African Americans not affected by the disease or other ethnic populations may explain their increased risk of developing scleroderma as well as its severe clinical manifestations.

HOW THIS WORK WILL IMPACT PATIENTS

One of the challenges of caring and managing a complex multisystem disease like scleroderma is to be able to define not only its stage of disease activity, but to be able to predict the future course of the disease in an individual. We know that scleroderma does not follow one well-defined path; rather, every patient is unique and disease manifestations are highly variable. The heterogeneous disease expression (mild in some and severe in others) needs to be understood in order to guide physicians to the best treatment for an individual patient. We hope that the GRASP project will provide novel insights into the basis for disease expression in African Americans by discovering specific genes or genetic areas that associate with a specific clinical picture. This would allow clinicians to identify individuals at risk for certain outcomes, to follow those patients closely, and to intervene with therapies at the appropriate moment.

The GRASP project will have a major impact not only in helping us understand and manage African Americans with scleroderma, but also it will have an impact on scleroderma patients of other racial backgrounds. Because GRASP will likely identify genes associated with scleroderma and with specific manifestations of the disease, it also provides an incredible opportunity for novel studies of the disease process and the underlying biological processes that cause the disease to occur and progress.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

At the annual SRF Workshop, Drs. Wigley and Kastner envisioned an interactive, multicenter project to study why African Americans are at greater risk for scleroderma and also have worse disease, with the idea that there may be unique disease-modifying genes in the population. The SRF not only brought the leadership of GRASP together in an environment that encourages brainstorming, ambitious research goals and collaboration, but it has provided critical financial support for the project at every step.

The SRF has a unique philosophy and method of supporting scleroderma research and programs. They have broken away from the traditional format of providing research funding by first being proactive and searching for talented researchers (even those that are not directly working on scleroderma); and seeking out gifted clinical programs. While there is an open door for application, this process of seeking the very best talent drives the creation of a very robust program. The SRF is also unique among funding organizations in how they decide whom to support and how to use their funds. The SRF has talented professional leadership that is knowledgeable about the disease, biology and research; and it has an incredibly talented, dedicated, and independent Scientific Advisory Board that is able to decide which programs are the best to support. Through this process, the SRF has built a highly successful research network and community that is making a difference and will continue to bring about important new discoveries.

« The SRF has built a highly successful research network and community that is making a difference and will continue to bring about important new discoveries. »

Above: Dr. Francesco Boin

JOHNS HOPKINS SCLERODERMA CENTER OF EXCELLENCE

FREDRICK WIGLEY, MD

JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE

PROJECT OVERVIEW

Dr. Wigley: The Johns Hopkins Scleroderma Center of Excellence now has four full-time faculty members and one part-time faculty member who evaluate and manage scleroderma patients referred to us from all over the world. Additionally, two of the Center's outstanding fellows, Dr. Nadia Morgan and Dr. Chris Mecoli, will join the Center's faculty as clinical-investigators. Members of the faculty continue to interact daily, discussing complex cases. We also take full advantage of the expertise at Johns Hopkins (JH) by utilizing superb specialists in other areas of medicine (skin, lung, heart, gastrointestinal tract, psychological, endocrine) and surgery (plastics, vascular, orthopedic) to help manage the complex care our patients require. We received about 450 new patient requests in 2016. The Center now has over 3,500 scleroderma patients in our research database; we evaluate and manage 10-11 new patients and 60-70 return scleroderma patients each operational week. This clinical practice remains fully integrated with our research and educational programs.

The Scleroderma Center has built a world-renowned framework for characterizing the breadth of scleroderma phenotypes, investigating underlying disease mechanisms and testing novel therapies for scleroderma. The cornerstone of this approach involves providing comprehensive, longitudinal patient care to scleroderma patients and, at the same time, prospectively collecting and storing clinical data and biological samples from patients. Coupling this exceptional data and sample resource to the discovery engine at Johns Hopkins has resulted in outstanding productivity.

Investigators in and affiliated with our Center recently discovered that cancer (many types) can be associated with and likely trigger the onset of scleroderma and together we are working to determine exactly how this happens. The work on the cancer-scleroderma connection brings together outstanding investigators across oncology, cancer genetics, and immunology. This year Dr. Ami Shah has worked with Dr. Tak Igusa, a civil engineer and leader in the Johns Hopkins Systems Institute, to study the prevalence of cancer among our patients with scleroderma compared to the general population without scleroderma. They confirmed an increased risk for cancer among patients with the anti-RNA polymerase III antibody and a decreased risk of cancer among patients who are anti-centromere positive. This work now guides physicians in understanding which patients with scleroderma have a unique risk of cancer and need to be carefully screened. Additionally, we believe that treating the cancer will have a beneficial impact on the scleroderma disease process and, in addition, managing the immune system may help control cancer.

We continue several studies with Drs. Antony Rosen and Livia Casiola-Rosen and others to better understand how the immune system initiates and propagates the disease process as well as studies with Dr. Hal Dietz's lab investigating mechanisms of regulating tissue fibrosis (see page 24 for a summary of this project).

We continue to provide leadership to a multi-center program called GRASP (see page 34 for a profile of this project). We also continue our collaborative work with Drs. Suchi Saria and Scott Zeger working on the Trajectory Modeling project (see page 32 for a summary of this project).

Dr. Zsuzsanna McMahan has discovered novel autoantibodies that associate with vascular disease and she is working on the gastrointestinal manifestations of scleroderma. Dr. Laura Hummers continues to act as the

JH site Principle Investigator for multiple clinical trials with pharmaceutical companies and investigator-initiated studies.

Our Center's research program continues to have exceptional momentum and is making major progress in understanding the disease process and novel treatments for this disease.

The Educational Program effort continues to be another major priority of our Center, driven by a faculty known for their expertise both as clinical scientists and educators.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

The best way to understand how the SRF has played a key role in our program is to see the incredible growth of the Johns Hopkins Scleroderma Center. Several of our critical assets, such as our clinical database and biorepository, as well as the physicians, fellows, clinical coordinators and database managers who are so critical to our research efforts, have received long-standing support from the SRF. Our ability to conceive of and execute cutting-edge research depends on these assets and critical personnel. Further, the SRF has invested in projects that stem from the nuanced clinical observation and longitudinal care that is prized at our Center. Our program would not have the resources to fully operate without the support of the SRF.

A GENE EXPRESSION SIGNATURE OF SCLERODERMA

MICHAEL WHITFIELD, PHD

DARTMOUTH MEDICAL SCHOOL

PROJECT OVERVIEW

Dr. Whitfield: SRF-funded work from my lab has allowed us to understand the patient-to-patient and disease-stage variability seen in systemic sclerosis (SSc), link this variability to disease progression and identify molecular mechanisms that results in fibrosis of the skin, internal organ dysfunction (e.g.: GI symptoms), and pulmonary problems. My lab, with SRF support, has identified "molecular fingerprints" of SSc that determine where a patient is in their disease progression and allow us to identify drugs that may be useful in treating these patients. We have also linked these SSc disease states to model systems that we can use to better understand the disease. These include mouse models of disease in which we can test hypotheses, but more recently, we have developed 3-dimensional tissue models that resemble human skin. These culture models are made using SSc or healthy control skin cells and reproduce many disease features (skin thickness and fibrosis) that we observe in patients. Robust model systems allow us to test our hypotheses about how SSc progresses and what drives it—all critical parts of developing effective treatments.

A second major component of my lab is integrating the genomic data generated from my laboratory as well the vast amounts of genomic data available in the public domain, to better understand SSc pathogenesis. These analyses use bioinformatics, gene-gene networks and systems biology to understand how groups of genes act together (or against each other) in SSc patients. We have been able to use these methods to generate a molecular model of SSc pathogenesis. We have been able to further show that the molecular processes that drive skin fibrosis are likely the same processes that are driving disease in other organ systems (GI tract and lungs) of the body. We are now testing these hypotheses by analyzing data from multiple organs from single patients and asking if they show the same deregulated molecular processes. We are also performing molecular experiments in model systems to test our hypotheses. These data tell us that a common mechanism is likely driving disease across organs in SSc patients. Our goal is to target this fundamental mechanism therapeutically.

Finally, my lab is constantly working to actively translate our findings from bench to the bedside. These studies have included development of molecular measures of disease severity that can be used in clinical trials, diagnostic markers that identify a patients molecular state (i.e., which gene expression fingerprint is found in a patient), and finally, using our data to identify novel therapeutic targets and then establishing collaborative efforts to develop therapies against those targets. Our goal is to bring precision medicine efforts that are now becoming commonplace in cancer to SSc.

PROJECT UPDATE

We have developed multi-tissue networks that implicate cells of the innate immune system (such as alternatively-activated macrophages and dendritic cells) that we believe are driving SSc in skin and internal organs affected by the disease. We have shown that these cells produce many of the molecules that have been implicated in driving SSc. Our network methods have also been used to perform a meta-analysis of multiple SSc clinical trials and we have been able to use these methods to predict possible combination therapies. We are performing experiments in mouse models and in our model skin-equivalents to confirm that eliminating these cells prevents fibrosis, something that has already been shown in other diseases such as kidney fibrosis. Our diagnostic assays that we have developed in-part with SRF funding help us identify the

Left: Dr. Fredrick Wigley

Above: Dr. Michael Whitfield

patients with these cells in the clinic. We have implemented new efforts to develop novel therapeutics that can be used to treat SSc. These include efforts to target the cells driving SSc in collaboration with academic and industry partners. In particular, we are leveraging the methods pioneered in cancer immunotherapy at Dartmouth to develop immunotherapy for patients with SSc. We will combine our diagnostic assays and therapeutic targeting to develop a precision medicine strategy in SSc.

HOW THIS WORK WILL IMPACT PATIENTS

Our work is providing a comprehensive molecular mechanism for SSc that will help us develop better therapies. The active translation of our work from bench to bedside means that our measures of disease severity and our diagnostic subsetting of patients are already being actively used in SSc clinical trials around the country. Our methods are helping physicians interpret the outcomes of these clinical trials and identify the patients most likely to improve on a particular treatment. Our network-based methods are now being used to analyze the molecular data derived from clinical trials; we have started to use these methods to predict combinations of drugs that may be most beneficial to SSc patients. We hope that our efforts to find new and improved therapies will ultimately benefit patients by developing drugs (or combinations of drugs) with greater efficacy.

ROLE OF THE SCLERODERMA RESEARCH FOUNDATION

I would not be working on SSc if it were not for the Scleroderma Research Foundation. And they are part of the reason that my entire lab now works on this disease. In recent years, this has now gone beyond me as an investigator and my laboratory at the Geisel School of Medicine at Dartmouth, as students and post-doctoral fellows that trained in my lab are now studying SSc in their own labs, have become the computational biology experts in rheumatology and fibrotic disease, or are advocates for SSc in their own spheres of influence. Most of these individuals attended SRF workshops, collaborated with SRF investigators and had their work supported by grants we receive from the SRF. With these investments, the SRF is helping to build a community of young, talented investigators to advance scleroderma research.

The interactions that the SRF has fostered bring together some of the best scientific minds to think about this disease. In my opinion, there is no better "think tank" for scleroderma. The annual SRF Workshop provides a place and time for individuals to discuss the disease, trade their best ideas and get expert advice from a Scientific Advisory Board that includes some of the best scientific minds in the world.

SCLERODERMA LUNG DISEASE TRAJECTORY STUDY**

SCOTT ZEGER, PHD
ANTONY ROSEN, MD
LIVIA CASCIOLA-ROSEN, MD, PHD
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICNE

PROJECT OVERVIEW

Dr. Zeger, Dr. Rosen and Dr. Casciola-Rosen: Although scleroderma and other rheumatic diseases are quite heterogeneous in their presentation and disease course, recent studies underscore that these diseases can be effectively divided into much more homogeneous subgroups when relevant filters are applied. For example, the association of cancer and scleroderma appears highly variable in different studies. When the population is filtered by the types of autoantibodies each patient has, and by whether cancer and scleroderma appear clustered together in time, there is a striking clarification of the cancer-scleroderma association. This analysis reveals two clear subgroups within scleroderma —patients with anti-RNA polymerase III antibodies or patients lacking the three most frequent scleroderma autoantibodies (called CTP-negative). In these two groups, cancer and scleroderma are clustered in time, and carry a higher overall risk of cancer. Within the CTP-negative group, we were able to apply new measurement approaches to define novel antibodies associated with cancer. Such approaches are very valuable for their definition of diagnostic and prognostic tools, but particularly for their identification of novel pathways relevant to disease pathogenesis.

Many filters can potentially be applied to segregate disease into more homogeneous subgroups. The more closely related to biology, the more useful such filters will be. One of the most powerful indicators of disease biology is its trajectory over time, with different subgroups developing distinct complications at different rates. This integrated representation of forward and reverse pathways has great power to define subgroups, measurements of their distinct states, and their underlying biological pathways. This project will combine the biostatistical expertise of Dr. Zeger and colleagues around defining disease trajectories with the clinical expertise in scleroderma in defining disease subgroups as well as the immunological expertise of Drs. Rosen, Casciola-Rosen and colleagues to identify clinically relevant, biologically-driven subgroups in scleroderma.

From the Johns Hopkins (JH) clinical database, we will identify a group of scleroderma patients with well-defined skin disease and antibody status, and characterize each patient by their trajectory of lung function (FVC and DLCO). Among these patients, we will identify an appropriate group of cases (patients with a steep lung-disease trajectories), plus a group of relevant control cases (patients lacking steep lung-disease trajectories). We will use a novel antibody discovery approach to define whether novel autoantibody specificities are associated with either the cases or controls. In subsequent studies, we will also address whether genetic polymorphisms known to be associated with scleroderma susceptibility are enriched in the different trajectory subgroups.

« *The interactions that the SRF has fostered bring together some of the best scientific minds to think about this disease. In my opinion, there is no better "think tank" for scleroderma.* »

IDENTIFICATION OF NOVEL PATHOGENIC GENES IN JUVENILE SYSTEMIC SCLEROSIS**

DR. KATHRYN TOROK, MD
PITTSBURGH CHILDREN'S HOSPITAL
DR. ANNE STEVENS, MD, PHD
SEATTLE CHILDREN'S RESEARCH INSTITUTE

PROJECT OVERVIEW

Dr. Torok and Dr. Stevens: Causative gene defects usually lead to onset of disease earlier in life; therefore, we hypothesize that a whole exome study of very early-onset systemic sclerosis (SSc) may lead to identification of causative genes that cannot be identified in adult-onset populations, as well as a better understanding of the molecular mechanisms of all kinds of scleroderma—localized, systemic, juvenile and adult.

In collaboration with Dr. Dan Kastner's lab at the NHGRI, we are initiating a project to identify novel candidate genes in juvenile SSc. Whole exome sequencing will be performed with genomic DNA from 30 children with systemic sclerosis and their parents (30 triads).

Patients will be recruited at our respective centers--two of the largest pediatric rheumatology centers in the world (Children's Hospital of Pittsburgh, University of Pittsburgh and Seattle Children's Hospital), both of which have long histories of scleroderma research and clinical care.

The study will be the first whole exome sequencing study to focus on juvenile SSc, and may lead to a new understanding of the disease and, hopefully, pediatric-specific treatment targets.

Left: Dr. Antony Rosen

**Indicates New Addition to the Project Portfolio*
***These projects were funded in fiscal year 2018*

Dr. Dan Kastner and Dr. Fred Wigley chuckled as they sat down for dinner together at the SRF Workshop.

Both were interested in meeting the many new scientists present that evening, but as the last people to join the table, the two old friends were seated together. They had known each other for years, but they did not often have a chance to sit and just talk. And, after listening to scientific presentations all day, they had plenty to discuss. As it happened, it was a fortuitous moment: they conceived the Genome Research in African American Scleroderma Patients (GRASP) project over dinner that night.

Dr. Fred Wigley, Director of the Johns Hopkins (JH) Scleroderma Center has been treating patients for more than 35 years. Wigley is the kind of physician who listens and observes closely, and has developed patient care into an art. With support from the SRF, he has built his practice into a premier multi-specialty Scleroderma Center, with four full-time rheumatologists serving one of the largest groups of patients in the country. The SRF also has helped Dr. Wigley build a large clinical database to track patients and their data, as well as a biorepository filled with patient samples, which together give him unique abilities to study scleroderma. Located in Baltimore, his patients include members of the strong African American community there. Dr. Wigley, knowing that African Americans have an increased incidence and prevalence of scleroderma and often a more severe presentation of the disease has, for many years, been interested to try to figure out why, and what can be done for his patients.

SRF-Scientific Advisor, Dan Kastner, MD, PhD, is widely known for his research into the causes of autoinflammatory diseases, such as Behçet's. As Scientific Chief of the intramural program at the National Human Genome Research Institute (NHGRI), he oversees the work of more than 50 genomics researchers within the NIH. Having traveled the world to identify extended families afflicted by unusual fever syndromes, Kastner, together with his own research group, has identified the genes mutated in several of these rare autoinflammatory disorders. These discoveries have not only identified therapeutic targets for these disorders, but they have advanced our understanding of many key molecules and processes of the immune system.

ASKING THE RIGHT QUESTIONS

Could it be, the two researchers asked, that African Americans' increased risk for scleroderma and severe form of disease are at least partially genetically driven? Would it be possible to sequence DNA from a sufficiently large number of African American scleroderma patients to reveal any such underlying genetic factors? And, most importantly, could this help researchers and clinicians discover biological pathways to target in treating these and other patients?

Scleroderma does not have a clear-cut genetic basis, unlike some diseases, like cystic fibrosis, which results from a mutation in a single gene. These single-gene diseases clearly run in families, whereas others, known as complex diseases, are different. However, scientists are discovering that many complex diseases also have a genetic component. Complex diseases, which include many autoimmune disorders like scleroderma and lupus, but also diseases like Alzheimer's and heart disease, arise from a combination of several genetic and environmental factors. Many of these factors are not well understood. Further, complex diseases often do not have readily discernible inheritance patterns, making it harder to pinpoint genetic contributors to disease. This means that studying the genetics of complex diseases requires analyzing greater numbers of patients in order to tease apart truly relevant disease associations from inadvertent associations.

Often, in studying complex diseases, genomic researchers try to improve the likelihood of finding disease-relevant associations by studying so-called "enriched populations", in which genetics may play a more significant role, for one reason or another. Compared to patients of European ancestry, African American patients have increased incidence and severity of scleroderma, leading Dr. Wigley and Dr. Kastner to speculate that genetics might play an enhanced role in these patients.

Enriched populations can be defined in other ways too. For example, the SRF is supporting genetic analyses in another enriched population of systemic sclerosis patients—those diagnosed before the age of eight (see page 33 for a summary of this project). The very early onset of scleroderma, which most commonly presents in mid-life, may indicate a stronger genetic component in pediatric patients. This, too, may provide an opportunity to find a gene or genes that play a role in the disease.

Knowing the genes that play a role in disease can be important in assessing risk for a patient as well as identifying therapeutic targets. "The GRASP study has the potential to provide novel insight into the genetic basis for the disease expression in African Americans by discovering specific genes or genetic areas that associate with a specific clinical picture," explains Dr. Wigley. "For example, if we discover that a group of African Americans who all have gene X develop severe scleroderma lung disease, while members of another ethnic group without gene X never get lung disease; then we know that gene X associates with the risk of getting severe lung disease. Knowing this will allow us to identify individuals at risk for lung disease. Then we can not only detect the lung disease early, but we can intervene before irreversible damage is done. Likewise, if we know patients lacking gene X are unlikely to progress to severe lung disease, then we can personalize their therapy without subjecting them to toxic or unnecessary medications." Dr. Wigley adds, "it will also open the opportunity to study how having gene X causes lung disease by studying the specific gene and its biological function. We might even be able to develop a drug for the biological pathway driven by gene X that would prevent or reduce lung disease."

ENGAGING A BROAD COMMUNITY TO FIND ANSWERS

Shortly after that SRF Workshop dinner, Drs. Kastner and Wigley enlisted Dr. Francesco Boin, then a scleroderma physician in the JH Scleroderma Center, to work with them on a plan for the GRASP project. The Hopkins group would enroll the

GRASP

patients, do the clinical work-ups and analyze the clinical data, while Dr. Kastner's group at the NHGRI would sequence their DNA and perform the genomic analyses.

Since that evening, more than four years ago, the GRASP project has progressed in important ways. Under the leadership of Drs. Kastner, Wigley and Boin (now Director of the Scleroderma Center at UCSF) and in partnership with the Scleroderma Research Foundation, the GRASP project has evolved from a partnership between the JH Scleroderma Center and the NHGRI into a multi-center, national effort. Dr. Boin, a talented physician and native of Italy with considerable charm and an inclusive leadership style, has been critical in this expansion.

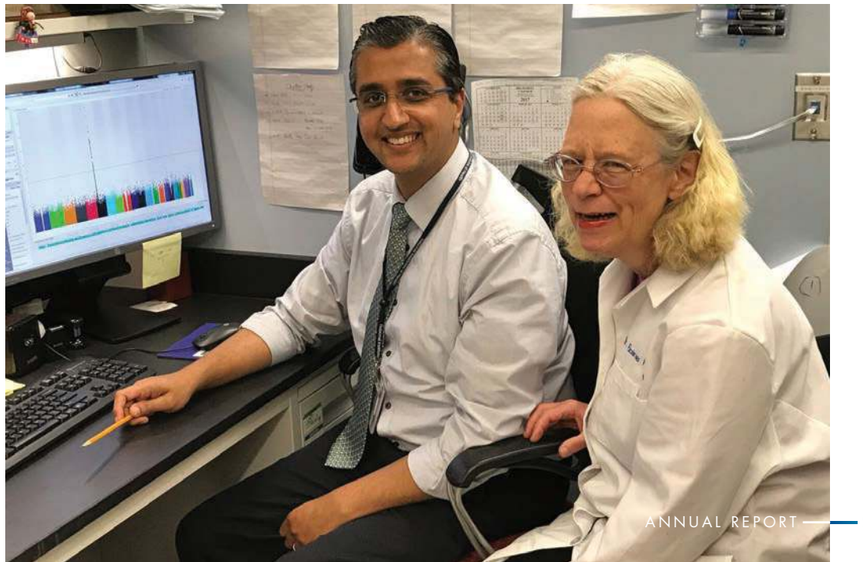
The GRASP project now includes a consortium of physicians from 23 U.S. scleroderma clinics and centers that enrolls African American patients into a national registry, located at Johns Hopkins. The SRF supports the consortium, clinical data and sample collection, the database and the expert staff that runs it at the JH Center, as well as investigator time devoted to the project. Biological samples are shipped directly to the NHGRI, where post-doctoral fellow Dr. Pravitt Gourh supervises the DNA sequencing and performs much of the genomic analysis.

Today, the GRASP registry includes more than 1,200 African American Scleroderma patients. Clinical data has been collected on all patients and is stored in the GRASP database at Johns Hopkins. Extensive genomic analyses are being conducted at the NHGRI. The initial step was sequencing a large fraction of the DNA from the first 400 patients, plus a comparable number of age- and ancestry-matched control subjects. This initial phase looked for variants that would have a very strong effect, such as those likely to result in changes to a protein's structure. This helped identify genes and other DNA regions of interest. These results were then used to customize tools for a much broader, genome-wide analysis of samples from all 1,200 patients, plus the control group. Specific commercial tools that have been designed for studying the genetics in African American subjects have also been used. The DNA areas of highest interest are being further analyzed through targeted "re-sequencing" of samples from 600 patients plus controls. This will confirm the initial "hit" and collect additional data on those areas. Importantly, the NHGRI group employs sophisticated biostatistical methods at every step for analyzing the massive amount of data generated.

RESULTS ARE EVIDENT; ENGAGEMENT IS HIGH

The GRASP project is beginning to produce results. At the most recent meeting of the American College of Rheumatology (ACR), the GRASP investigator group was granted three oral presentations—an extremely high rate of acceptance. Dr. Nadia Morgan of the JH Center presented her findings regarding clinical manifestations of the disease in African American scleroderma patients. Notably, while scleroderma is overall a heterogeneous disease, meaning that it does not present in one way, with a predictable path of progression, the GRASP clinical data suggests that African American patients, as a group, have some clearly definable characteristics. For example, compared to patients of European ancestry, African Americans are more likely to have diffuse scleroderma with anti-topoisomerase antibodies and less likely to have limited scleroderma with anti-centromere antibodies—two quite different forms of scleroderma. Further, African American patients are more likely to develop a severe form of interstitial lung disease and pulmonary hypertension, both serious, life-threatening complications of scleroderma. These findings support the importance of research into inherited or genetic factors that may play a role in the incidence and severity of disease in this at-risk group. They also provide much-needed insight for physicians and other healthcare providers involved in the care of African American scleroderma patients.

With respect to the genomic analyses, the emerging results are very encouraging.



Previous: Dr. Dan Kastner

Right: Dr. Pravitt Gourh and Dr. Elaine Remmers

« What has become clear is that not only will patients benefit from this large-scale effort, but the broader community of scleroderma researchers will benefit as well. »

With just the initial analysis done, several candidate genes have popped out as having statistically significant associations with disease, giving researchers confidence that the project will yield important insights into some of the subtle genetic elements of the disease. Dr. Elaine Remmers, PhD, of the NHGRI, noted that certain HLA genes particularly stood out. HLA genes play critical roles in shaping immune responses in both health and disease, and specific HLA alleles, or "flavors" of those genes, are known to be associated with different autoimmune diseases. Often an HLA allele will have a stronger association with an autoimmune disease than any other gene. This is also the case in scleroderma. Dr. Remmers discovered unique scleroderma-associated HLA alleles in the African American patients that differ from those previously identified in patients of European ancestry. And, in pediatric patients still other scleroderma-associated HLA alleles have been found. Intriguingly, the biological mechanisms that cause particular HLA alleles to be strongly associated with autoimmune diseases are beginning to be unraveled. Thus, Dr. Remmers' discovery will certainly lead to intense interest and further inquiry.

Another exciting early result is that Dr. Gourh has found DNA differences in the gene control regions of TGFβ-3, a gene that is known to play a role in fibrosis. Dr. Gourh's ability to connect these particular DNA variants to the TGFβ-3 gene stemmed from his collaboration with Dr. Howard Chang's group at Stanford. For DNA variants that occur outside of protein-coding sequences, Chang's newly developed technique pinpoints the specific gene(s) they affect (see page 20). In this case, although the DNA variants are distant from the TGFβ-3 gene, the technique shows that they lie within a region that controls the gene. This technique is broadly applicable and will vastly improve researchers' abilities to interpret their genetic data.

Since the goal of any genomic study is to identify DNA variants that cause or contribute to disease, the next step is a "functional study"—actually showing that a DNA variant functions in the disease. In Dr. Gourh's work, because DNA variants affecting TGFβ-3 popped out as having a statistically strong association with scleroderma in African Americans, he identified TGFβ-3 as a "candidate" gene. Since TGFβ-3 is known to be involved in fibrosis in many contexts, he hypothesizes that these DNA variants may change its function, thereby contributing to fibrosis. And he has already begun his first experiments aimed at proving it. Using powerful new gene-editing tools, he can introduce these same variants into normal human fibroblasts to see if they change the function of the TGFβ-3 gene in a manner that would lead to fibrosis.

While the research progress is encouraging, the GRASP project's goals have continued to grow. Last February, the SRF sponsored a meeting of the entire GRASP consortium at the NHGRI, where new research ideas were considered. The group decided to collect serum from enrolled patients in order to conduct a number of different experiments, including more extensive autoantibody screening. This will add to the group's ability to correlate measurable data with clinical outcomes and to confirm involvement of genes identified in the genomic analyses.

"We are very proud of the GRASP project and the SRF's role in moving this project forward," says SRF Board member Deann Wright. "Additionally, the impact of the SRF's funding has really been amplified by working with the NHGRI. Funds from our donors have been leveraged more than four-to-one, with combined support for this project totaling over $2 million at this point."

"I believe this project will yield insights about disease in African American patients, leading to improved patient care in this at-risk population," she adds. "Also, it is likely to produce significant insights into the biological processes involved in scleroderma, enhancing our understanding of the disease and potentially leading us to new therapeutic targets that could benefit all patients."

"In terms of its effect on the research community," Wright notes, "everyone involved–the GRASP leadership, investigators and consortium members–has come together, with incredible spirit and enthusiasm, to take part in this collaborative effort. I really think the progress achieved in GRASP is changing the way members of the scleroderma research community work together. What has become clear is that not only will patients benefit from this large-scale effort, but the broader community of scleroderma researchers will benefit as well." The GRASP consortium is allowing its members and selected outside investigators to submit proposals to query the data with questions relevant to their own research. In this way, the GRASP data is becoming a rich resource for the broader scleroderma research community, aiding a broad range of projects. Ultimately, the data will be made even more widely available, further amplifying the impact of the project.

From Wright's perspective, "the GRASP project embodies the two principal tenets of the SRF—supporting strong research and encouraging collaboration. Working together on this large and complex effort, we will significantly advance scleroderma research."

Recipe for Success

Susan Feniger

Susan Feniger's recipe for success has always been straightforward – equal parts hard work, steely determination and unyielding compassion…

« I feel like I have this commitment to Sharon to stay there and get this figured out before I stop. And it's getting closer. I believe we'll find a cure within my lifetime. And that's what it's all about. »

…It explains why 30 years after her best friend and former college roommate Sharon Monsky convinced her to join the board of a small research foundation, Feniger pushes on, unwavering in her desire to find a cure.

Today, 15 years after Monsky died from complications from scleroderma, Feniger remains more committed than ever, helping to lead the Scleroderma Research Foundation in its pursuit of new treatments and therapies that scientists believe are within their grasp.

"I remember being at a fundraising dinner many years ago with these scientists that included SRF Scientific Advisory Board Member, Dr. Antony Rosen, and they were saying that they felt that this was a disease they could cure," Feniger said. "It was sort of magical. They were very emotional. I feel I have this commitment to Sharon to stay and get this figured out before I stop."

GIVING BACK IS IN HER DNA

And stopping is something that Feniger rarely, if ever, does. Despite the celebrity chef's vast array of projects—new restaurants, licensing deals and ongoing expansion of some of her signature outlets—she continues to add to the community and philanthropic efforts that she says are simply "part of my DNA."

In addition to her three decades as a board member of the Scleroderma Research Foundation, Feniger sits on the boards of the Los Angeles LGBT Center, the Los Angeles Convention and Tourism Bureau and continues to work with organizations such as the Human Rights Watch and the Los Angeles Food Bank.

"My parents taught us about the importance of giving back," she said. "It's how they lived their lives. I feel it's my responsibility to give back because it is such a powerful way to be able to support things that I believe in. It's hugely rewarding and it makes me feel good about how I live my life."

SENSE OF DUTY, PASSION & MISSION

Her sense of duty is something she shares with Monsky, whom she said helped instill in her an inspirational attitude. Feniger recalls that no matter how many things Monsky was dealing with in her life that "she would always make room for me."

That is at the very core of Feniger's unrelenting drive to contribute to the Foundation's success. Now entering her 31st year on the SRF Board, she still pours her heart into making the *Cool Comedy—Hot Cuisine* events a sell-out in every market.

"Sharon stood for so much," Feniger said. "She was unbelievably positive. Anytime I get down or negative about something I remember Sharon. She had this inspirational attitude that was just contagious.

"No matter what she had going on, or if the scleroderma was wearing on her, she'd be there with her brilliance to help me strategize our business growth or meet with investors. It felt crazy selfish for me to even ask. But that's why this Foundation has always felt very connected for me. I believe we'll find a cure within my lifetime. And that's what it's all about."

DRAWING FROM INSPIRATION

The *Cool Comedy—Hot Cuisine* fundraiser of today draws from the original inspiration 30 years ago when Feniger and Monsky were persistent in their desire to put comedy front and center.

Feniger said she and business partner, Chef Mary Sue Milliken, came up with the formula based upon royal feasts back in the days of the court jester. History has shown that "laughter is good for digestion." She, Milliken and Monsky went on a tireless mission to get Robin Williams to appear at their first event, by plying him with food when he came into their restaurants and badgering his manager with pleas to help them out.

"Three days before the first event, we heard that he would come and support us but not perform" she said. "And then some of his friends showed up and performed. About 45 minutes into the dinner, Williams got up and performed for 30 minutes."

And with that, the recipe for *Cool Comedy—Hot Cuisine* was perfected, with Williams and a pack of comedians stirring the pot since that very first event. Feniger said the memory of Monsky bringing all these disparate people together for a great cause remains the driving force behind her own public service, and the core essence of the Foundation and the scleroderma community.

HER PIONEERING PATH

That very same passion that fueled Feniger aided her in her own mission over the years, as she navigated a culinary world dominated almost exclusively by men.

Feniger said that when she first started training at the Culinary Institute of America, there were three women in a class of 75. The trail blazing continued as she and Mary Sue broke through the gender barrier by landing jobs, in the all-male kitchen at Chicago's Le Perroquet, and then again when she was the first woman working in Wolgang Puck's Ma Maison restaurant.

"I was fine competing with the boys, especially in the French kitchens," she said. "I had a vision of where I was going. I didn't get deterred if I got yelled at by a chef, it just didn't bother me. I was always very determined, very focused. I'd work for free in kitchens in the morning to learn, then go to school and then clock-in to do my night shift. And when you do that you end up getting a ton or respect." It is just this kind of tenacious drive and "can do" attitude that keeps her pursuing Sharon's vision.

NEVER EVER GIVE UP

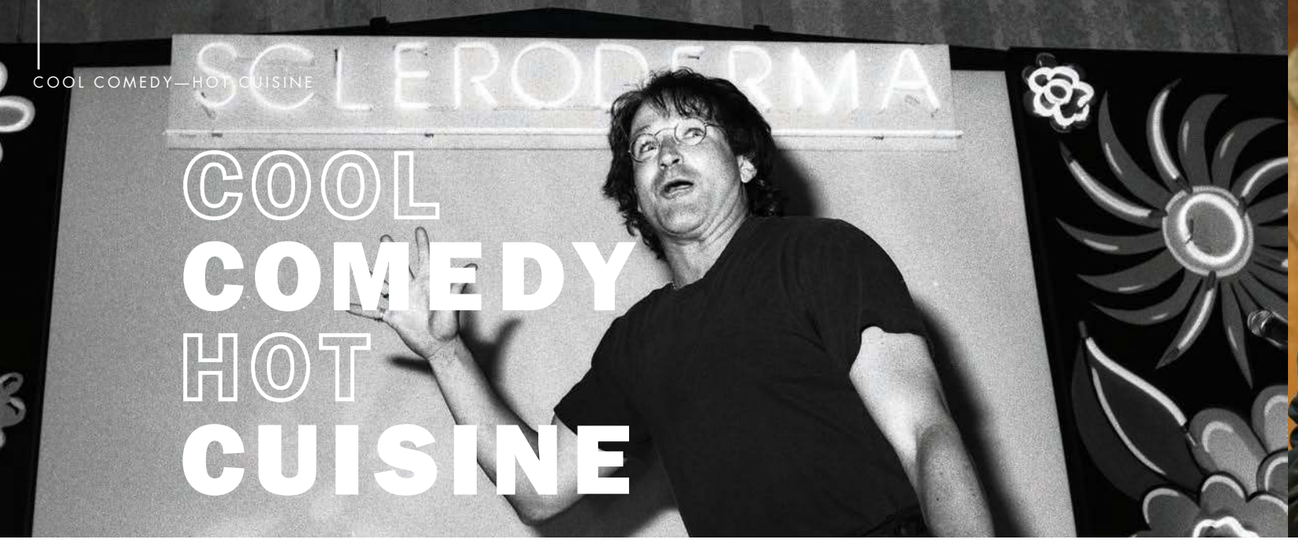
Even with all of her commitments to business and social justice projects, one thing has never changed—her commitment to orchestrating the dinners served at the Foundation's comedy fundraiser—an endeavor that has grown tremendously in size and popularity. It's nothing short of miraculous. What began as a one-off idea in her restaurant serving 100, has evolved into multiple events around the country with 700 guests, serving up unparalleled cuisine and Hollywood star power. Although Feniger is masterful at bringing all of the right elements together and overseeing armies of volunteers in cramped kitchens, her support is so much more than that.

"It's all part of an incredible experience that allows people to give back," Feniger said. "I'm amazed that so many people are willing to do it. There are so many causes that need funding, but I feel great about supporting things that are dear to my heart, and this is one of them."

Feniger says it's still hard for her to grasp the impact the Foundation and its work has had on so many people, particularly patients. "When Sharon and I were pioneering this idea 30 years ago, I never imagined how far we could take it; nor how key Cool Comedy would be to our quest for a cure. Tens of thousands of dinners and millions of dollars later, we're still laughing, still fighting, and still determined. We're getting closer and closer to a cure. That's why I tell everyone in our SRF family to never, ever give up hope. Just as Sharon ordered!"

Above: Susan Feniger speaks at *Cool Comedy–Hot Cuisine* San Francisco 2016

Right: Susan Feniger, Robin Williams and Sharon Monsky *Cool Comedy–Hot Cuisine* Los Angeles 1998



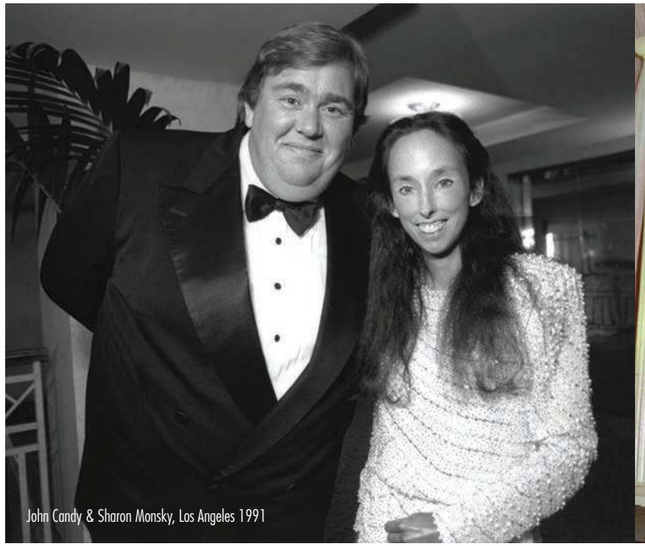
COOL COMEDY HOT CUISINE

Jerry Seinfeld, New York 2010

COOL COMEDY—HOT CUISINE

30 YEARS
4 CITIES
40 EVENTS

$20+ MILLION RAISED


John Candy & Sharon Monsky, Los Angeles 1991

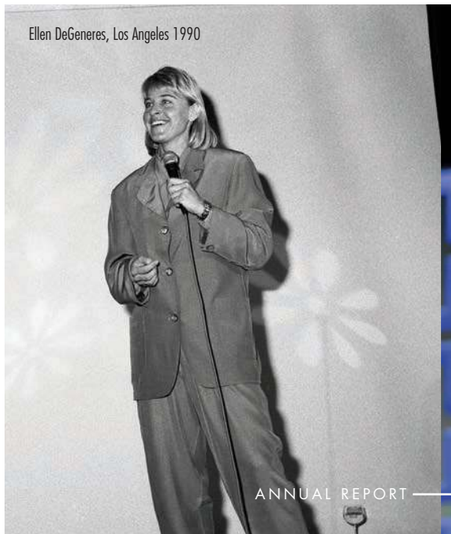

Rosie O'Donnell, Los Angeles 1992

Jeff Garlin, New York 2010


Lily Tomlin, Los Angeles 1994


Rodney Dangerfield, Los Angeles 2001


Tim Allen, Los Angeles 2004


Ellen DeGeneres, Los Angeles 1990


Bill Burr, Los Angeles 2017

Bob Saget & John Stamos, New York 2009


Neon Trees, Las Vegas 2016


Jimmy Fallon, New York 2007


Dana Carvey, Marina Duque & Bob Saget, San Francisco 2007


COOL COMEDY—HOT CUISINE
Jay Leno, Las Vegas 2014


Adam Duritz, San Francisco 2011

400
VOLUNTEER CHEFS

14,000+
GUESTS SERVED


Caryn Zucker, Colin Quinn, John Stamos, Mary Kate & Ashley Olsen, Bob Saget and Jeff Ross, New York 2009

NEARLY 100,000
U.S. PATIENTS
WILL BENEFIT


Sharon Monsky, Los Angeles 1993


Goo Goo Dolls, San Francisco 2016


Seth Meyers, New York 2005


John Mayer, Jimmy Kimmel, Bob Saget, Jeff Garlin, Don Rickles, John Stamos, Jim Gaffigan, Brad Grey & Jack Black, Los Angeles 2015


Bill Belamy, Los Angeles 2013


Jim Gaffigan, Los Angeles 2015

Michael Che, New York 2015


Ben Folds, Las Vegas 2014

John Oliver, New York 2016

COOL COMEDY—HOT CUISINE

72
COMEDIANS


Ray Romano, Los Angeles 2017

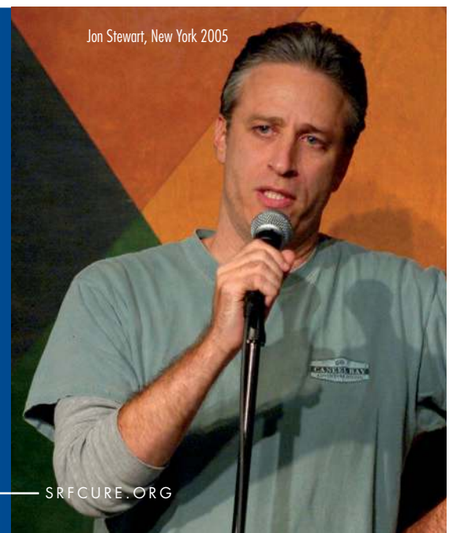

Conan O'Brien, Bob Saget & Lewis Black, New York 2004


Jimmy Kimmel, Los Angeles 2013

Train, San Francisco 2014


John Mayer, Los Angeles 2008

75
RESEARCH
PROJECTS
FUNDED


Jon Stewart, New York 2005


Dana Carvey, San Francisco 2009


Craig Ferguson, Los Angeles 2013

Katie Couric & Jimmy Fallon, New York 2007

21
MUSICAL
ACTS

Sheryl Crow, Los Angeles 2001

COOL COMEDY—HOT CUISINE

Sarah Silverman, Los Angeles 2008

John Mayer, Los Angeles 2015

Zach Galifianakis, Los Angeles 2017

1,500
POUNDS OF ONIONS
CHOPPED

58,000
GLASSES OF WINE
CONSUMED

Jeff Garlin, Los Angeles 2017

Tracy Morgan, Bill Bellamy, Bob Saget, Caryn Zucker, Bill Hader, Dana Delany, Lewis Black & Susie Essman, New York 2008

Jerry Seinfeld & Bob Saget, New York 2010

George Lopez, Bob Saget, John Oliver, Whoopi Goldberg & Jeff Ross, New York 2014

CURE CREW
FOR SCLERODERMA RESEARCH

Thank You, Cure Crew.

We Couldn't Do This Without You!

Cure Crew members are passionate about raising money and awareness to find a cure for scleroderma. Their creativity and commitment to the cause are always inspiring. Our Cure Crew members are "on the ground" advocates for our mission, and vital in our goal to build awareness and understanding of this disease as we drive toward a cure.

Sometimes Cure Crew members utilize traditional fundraising methods, such as walks, runs and cycling events. Pot luck dinners, bowling tournaments and garage sales are also part of the mix. They are as varied as the imaginations of these committed volunteers.

Emerging trends shows that supporters are looking for more flexibility in the way they fundraise to support a cause. Donors are more interested in unique and less traditional organization-led efforts. They want to fundraise by doing activities they find the most meaningful at a time convenient and enjoyable for them.

Cure Crew members have always excelled at raising funds in a way that appeals to their personal style, and 2017 was no exception. Our Cure Crew volunteers are adept at finding unique and creative ways to carry the legacy of their loved ones forward, while raising funds for scleroderma research. Here's a look at a few 2017 Cure Crew events that can inspire all of us.

Moving Forward for a Cure - Troy, OH

RAISING THE BARRE

Lexie Sachs organized a "Fundraise the Barre" to celebrate her 30th birthday, but most importantly to remember her beloved mother, Jo Ann Sonis, whom she lost to scleroderma in 2016. The event brought together Lexie's friends at a New York City Core Fusion Barre class, with a fee of $30 for 30 spots, to honor Lexie's 30th year. The Cure Crew creativity knows no bounds! "Thank you SRF for fighting for this cause," says Lexie, "I'm right there fighting along with you!"

LAUGHTER IS THE BEST MEDICINE

"We are the remainders, the ones left behind after scleroderma does its worst; specifically, we are the family of Patricia Connors-Zini, a woman who was our gravitational center, our moral compass and our strength." In her honor, and with those words, in 2015 her daughter Maureen and others began an off-shoot *Cool Comedy—Hot Cuisine* aptly named "Best Medicine" to remember Patricia, and to celebrate her life as she lived it—with laughter. The annual event draws on some dynamic and emerging comedians, drawing inspiration from the larger SRF-hosted *Cool Comedy—Hot Cuisine* events in New York, San Francisco, Los Angeles and Las Vegas.

AT THE FOREFRONT: TOP GOLF BENEFIT

The Austin event, now in its 18th year, was started by Beth Selbe Lasita who paired her passion for golf and bringing friends, family and colleagues together for a cause that has deep personal meaning for her. She is driven to find a cure for the disease that took her mother, Betty, in 2009 after a long 20-year battle. For Beth, this tournament, held at Top Golf in Austin, is the silver lining to a very dark cloud. It has allowed her to raise more than $350,000 to help people everywhere who are living with scleroderma. "Each year," Beth says, "we reach a few more people—educating them about this terrible disease and about the Scleroderma Research Foundation that exists to fund research that will find a cure."

The Scleroderma Research Foundation is grateful to Maureen, Lexie, Beth and all of our Cure Crew Members for their unwavering support and commitment to a cure.

Top Left: Raise the Barre - New York, NY

Top Right: Top Golf - Austin, TX

Middle: Best Medicine - Philadelphia, PA

EXPANDING THE SRF COMMUNITY

Community was once limited by where you lived. But now, the internet and social media are bringing the world to your doorstep. It's also helping the Scleroderma Research Foundation spread the word and connect our community in countless ways.

The SRF strives to be an online resource that offers the highest quality content for all types of users. The goal is to make sure that there is significant and valuable information available for patients, loved ones and the variety of caregivers who seek to improve the quality of life for those living with scleroderma.

The information delivered covers a wide variety of topics: facts, patient tips, educational resources, webinars, news articles, clinical trials, research findings and calls to action. A renewed emphasis on the Foundation's online presence is at work with plans for a new website and a particular focus on making information organized and easily accessible for the community.

WEBINARS

The SRF utilizes the power of the internet and social media to bring its educational webinar series to patients all over the globe. The webinars bring scleroderma experts and the latest information to participants, who might otherwise be limited by the resources available where they live or receive treatment.

LIVE FROM OUR WEBINARS

« I take great comfort in the hope of a cure being found in my lifetime by virtue of the Foundation working with colleagues around the world. »

« Today's presentation answered so many questions. I have found it difficult to find this level of information in the area I live in. »

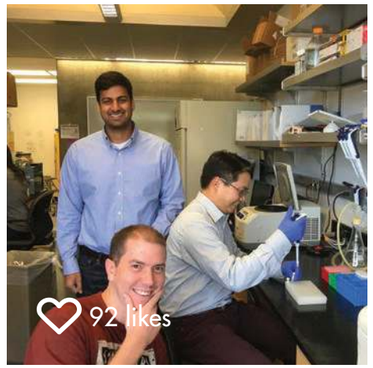
« It's nice to know that scleroderma is recognized in the scientific world. »

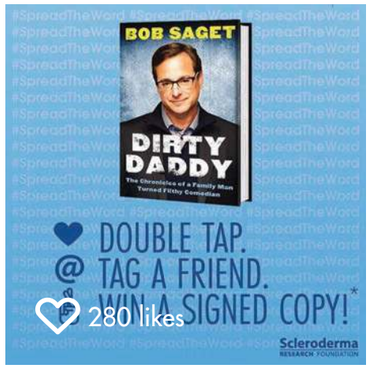
« An invaluable source of information. »

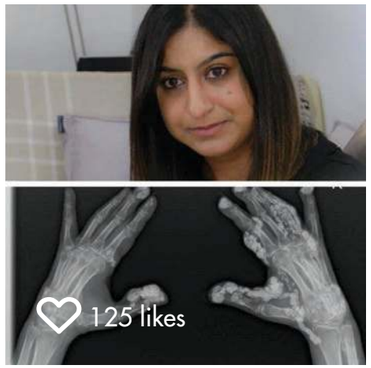
« I am glad that I am able to connect with information from the comfort of my home. »

SOCIAL MEDIA IS A COMPANION ON THE PATIENT JOURNEY

People use social media in different ways and with multiple purposes in mind. An individual might be newly diagnosed. Or a patient might be seeking to find comfort in community or to give hope to others. Here are some examples of posts that have informed and engaged our community, and united our efforts to find a cure.







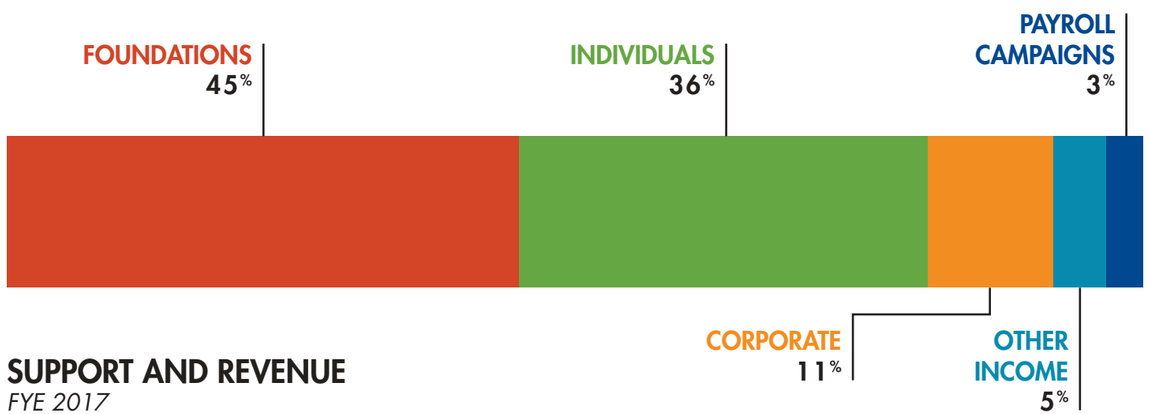
FOLLOW US

FINANCIAL FACTS

FINANCIAL INFORMATION

Scleroderma research and education comprise 86% of SRF expenses

EXPENSES
FYE 2017



SUPPORT AND REVENUE
FYE 2017

STATEMENT OF FINANCIAL POSITION
**FOR THE FISCAL YEARS ENDING APRIL 30, 2017 AND 2016*

		2017	2016
ASSETS			
	Cash & Cash Equivalents	991,765	92,514
	Investments	2,213,308	2,205,561
	Other Current Assets	57,850	30,076
	Contribution Receivable	396,351	784,285
	Property And Equipments, Net	19,366	27,474
TOTAL ASSETS		**$3,678,640**	**$3,139,910**
LIABILITIES AND NET ASSETS			
Liabilities			
	Accounts Payable	13,640	56,692
	Other Current Liabilities	42,735	32,689
	Research Grants Payable	110,000	0
Total Liabilities		166,375	89,381
Net Assets		3,512,265	3,050,529
TOTAL LIABILITIES AND NET ASSETS		**$3,678,640**	**$3,139,910**

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS
**FOR THE FISCAL YEARS ENDING APRIL 30, 2017 AND 2016*

		2017	2016
SUPPORT AND REVENUE			
	Support	2,825,476	2,434,140
	Other Income	163,896	2,749
TOTAL SUPPORT AND REVENUE		**$2,989,372**	**$2,436,889**
EXPENSES			
	Research	1,794,632	1,742,807
	Education	376,313	396,515
	Fundraising	189,598	212,488
	Management and General	167,093	160,717
TOTAL EXPENSES		**$2,527,636**	**$2,512,527**
INCREASE IN NET ASSETS		**$461,736**	**$(75,638)**
NET ASSETS, BEGINNING OF YEAR		**$3,050,529**	**$3,126,167**
NET ASSETS, END OF YEAR		**$3,512,265**	**$3,050,529**

The SRF has seen tremendous growth during the last 30 years, and we are closer to a cure than ever before.

Our success and continued progress in driving discovery forward depends upon charitable gifts. Your generous support propels our work into the future, and ultimately, we will end scleroderma together.

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, 2017.

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$50,000+

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Cool Comedy—Hot Cuisine, Las Vegas 2016

Cool Comedy—Hot Cuisine, Las Vegas 2016

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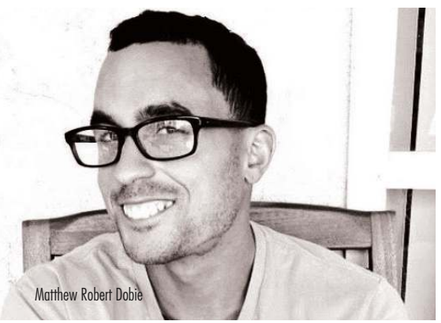
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