PROGRESS REPORT
JULY 1, 2019 - JUNE 30, 2020
Leslie Cogan delivering acceptance speech for Lifetime Achievement Award presented to her and her husband, Jules Cogan, at the July 2019 National Conference in Chicago.
Dear Friends:

This progress report is a summary of Scleroderma Foundation activities to advance our mission of support, education, and research during the fiscal year ending June 30, 2020.

Transparency and accountability are important values for the Foundation. A statement of financial activities and pie charts showing revenue and expenses are on pages 16 and 17. Many thanks to the certified public accounting firm of Moody, Famiglietti & Andronico, LLP. The complete audited financial statements and IRS form 990 are available on our website, at www.scleroderma.org/annualreport.

The COVID-19 pandemic had a dramatic impact on fundraising and program delivery, as was the case with most non-profit organizations. We are grateful for the guidance of the National Board of Directors and the efforts of our dedicated staff and volunteers who have worked diligently to ensure the mission of the Foundation advances during this difficult time.

The vision of our National Board of Directors ensured that 2020 was not merely about surviving a pandemic. The Foundation began a comprehensive five-year strategic plan to address organizational efficiency, disease awareness, and fundraising capabilities. Undertaking this work requires significant resources, but it is positioning the Foundation for success now and for future growth.

Thank you so much to our many generous donors, our Medical and Scientific Advisory Board, the research community, our hard-working volunteers, and staff at chapters and in our national office, and to all those in the scleroderma community for your unwavering commitment to the Foundation’s mission.

Sincerely,

Cos M. Mallozzi
Chair, Board of Directors
Scleroderma is a chronic disease that affects the body’s connective tissue and vascular system. Generally classified as an autoimmune rheumatic disease, it is characterized by an overproduction of collagen (fibrosis), which hardens tissue and damages organs. Commonly known to affect the skin, which is how the disease was named (sclero means hard; derma means skin), scleroderma also affects the internal organs and can be life-threatening. There are several types of scleroderma.

Localized scleroderma, also known as morphea, primarily affects the skin, causing tightening and disfiguring of the joints, extremities, and facial features. While most people with localized scleroderma continue to work and to lead active lives, disability (such as losing range of motion in the joints) is not uncommon for this form of the disease. Another classic form of scleroderma is called en coupe de sabre, which produces a dramatic scar across the face. All forms of the disease can cause severe pain and can produce complications that rob a person of function.

Systemic sclerosis (SSc) is much more damaging, typically affecting the lungs, the heart, and the kidneys and is an underlying cause for related diseases such as pulmonary arterial hypertension and renal failure. The cause of scleroderma is not known, although there are many clues including genetic predisposition. Fibrosis, the overproduction of collagen, is at the heart of the disease, which makes it prototypic for all other fibrotic diseases.

Completed Project Summary:
Occupational Therapy Versus Home Exercise to Increase Upper Extremity Function in Individuals with Systemic Sclerosis: A Pilot Randomized Controlled Trial.
Susan Murphy, M.D., Dinesh Khanna, M.D., M.S.
University of Michigan

We were able to build evidence that supports upper extremity rehabilitation for people with scleroderma with different ways to deliver treatment. Participants with diffuse cutaneous scleroderma, within five years of disease onset, were randomized to receive one of two occupational therapy treatments. One treatment involved eight in-person sessions and the use of an App that had a tailored home exercise program. In the other treatment, participants were only provided with the App to participate in a tailored home exercise program. We hypothesized that people who received the more intensive intervention would have better upper extremity function over time compared to those who only received the App. Participants in the intensive group had improved upper extremity function immediately following the eight sessions, but these effects waned over time. Additionally, they were not as likely to continue using the App after in-person sessions ended. Participants in the App group performed their exercises more consistently over the entire study period. Interestingly, both groups had similar improvements in upper extremity function over 18 weeks. Use of the App alone with remote therapist interaction is a promising treatment for people with early scleroderma. Next steps are to conduct a larger study across different sites.
MISSION

The Scleroderma Foundation is thousands of individuals across the United States engaged in a great undertaking to help people affected by scleroderma while funding research to discover the cause, to understand the mechanisms, and to overcome the symptoms of scleroderma.

The Scleroderma Foundation is the realization of our founders’ vision. The United Scleroderma Foundation and the Scleroderma Federation chose to unite to gain strength from their common goal to help people affected by scleroderma. The history of our predecessors ranges into the 1970s and today provides the Foundation with a wealth of institutional knowledge.

Our national network of 19 chapters provide support and education to individuals and families affected by scleroderma and drive fundraising to fuel research. Chapters are managed by volunteer boards with staff. The national office establishes policy and provides support to chapters, while managing the National Patient Education Conference and the Peer-Review Grant Program.

SCLERODERMA FOUNDATION MISSION:

Support:
To help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals, and educational information.

Education:
To promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns.

Research:
To stimulate and support research to improve treatments and, ultimately, find the cause and cure of scleroderma and related diseases.

Completed Project Summary:
Long-Term Morbidity and Mortality Outcomes in Systemic Sclerosis-Related Interstitial Lung Disease

Elizabeth R. Volkman, M.D., M.S.
University of California, Los Angeles

The Scleroderma Foundation provided funding for me to conduct the first long-term follow up study of patients who participated in the Scleroderma Lung Studies (SLS) I and II. These are the two largest randomized controlled trials performed to date on patients with systemic sclerosis and interstitial lung disease. SLS I and II evaluated whether oral cyclophosphamide and mycophenolate were safe and effective treatment options for systemic sclerosis-related interstitial lung disease.

The long-term follow up study demonstrated that treatment with one-year of cyclophosphamide compared with placebo does not improve long-term survival outcomes in SLS I patients. The findings also showed that there is no difference in long-term survival between patients randomized to cyclophosphamide versus mycophenolate in SLS II. The study also found that the most important factors associated with improved survival in both studies were: 1) decreased age; 2) decreased extent of skin disease; and 3) improved course of lung function based on pulmonary function tests.

The next step of this research will be to investigate whether laboratory tests for biomarkers can be used to predict responses to treatments in patients with systemic sclerosis-related interstitial lung disease. The discovery of novel biomarkers may help us to develop more personalized treatment approaches for patients and understand why some medications are effective for some patients and not for others.

Elizabeth Volkman, M.D.
**SUPPORT**

To help patients and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals, and educational information.

**PUBLIC POLICY ADVOCACY**

On **Capitol Hill Day**, September 17, 2019, 50 volunteers from 22 states met key lawmakers and legislative aides in Washington, D.C., to seek support for The National Commission on Scleroderma and Fibrotic Diseases Act, introduced in the House (H.R. 3446) by **Representative Peter T. King** (R-NY-2) and in the Senate (S. 2477) by **Senator Kirsten Gillibrand** (D-NY). Scleroderma advocates whose legislators sat on key Congressional committees hand-delivered letters from constituents affected by scleroderma. Scholarships were provided to a number of participants. Policy objectives were:

1. Adequate funding of at least **$34.5 billion** for the National Institutes of Health to expand and advance scleroderma research.
2. Continue listing scleroderma as an eligible condition in the Department of Defense **Peer-Reviewed Medical Research Program** (PRMRP).
3. Co-sponsor The National Commission on Scleroderma and Fibrotic Diseases Act in the House (H.R. 3446) and in the Senate (S. 2477)

*I decided to apply to be a part of Capitol Hill Day because I was searching for my purpose,* explained **Tamanya Jones**, a 22-year-old tax accountant from Fredericksburg, Virginia.

*I went to Capitol Hill Day this year in honor of my mother, Terry Lewis,* said **Dallas Lewis** of Savannah, Georgia.

**PATIENTS AS PARTNERS**

The Scleroderma Foundation is a leader in programs for patient focused drug development (PFDD).

Our successful **Patients as Partners** program is an opportunity for people with scleroderma to engage with pharmaceutical and biotech companies—specifically clinical trial development teams actively involved in scleroderma-related research and development.

The more pharmaceutical partners learn and understand about the complex issues of our patient community, the better tailored clinical trials can be, which helps ensure more successful outcomes for people affected by scleroderma.

Patients as Partners has been ahead of the curve, serving as a model for other patient advocacy organizations as drug developers make PFDD a major focus in their clinical trial development and implementation.

The Foundation’s program is tailored to the needs of each pharmaceutical company we work with.

Programs range from focus groups for marketing materials and website content, patient-perspective clinical trial protocol reviews, medication packaging/delivery devices, and “patient journey” sessions that teach clinical teams about the unique challenges faced by people with scleroderma.

While most Patients as Partners meetings are held in person, COVID-19 brought many unique challenges to the program. Fortunately, we were able to transition to an online platform quickly, thanks to our eager and adaptable scleroderma community.

Looking ahead, we see PFDD and Patients as Partners continuing their rapid growth.

In fiscal year 2020, **$5 million** was designated for scleroderma research through the **D.O.D. Congressionally Directed Medical Research Program** (CDMRP), which was a direct result of years of consistent advocacy efforts with Defense Appropriators and members of Congress about the importance of scleroderma research and the connection to military service.
Volunteer-led support groups enable individuals with scleroderma to meet and exchange information with others who face similar problems. There are 155 Scleroderma Foundation-affiliated support groups around the country. The Foundation has rolled out the Scleroderma Support Group Leader Education (SPIN-SSLED) program developed in collaboration with SPIN (Scleroderma Patient-centered Intervention Network).

**Support Groups**

ALABAMA
Calera
Florence (Telephone/ Email)
Huntsville

ARIZONA
Mohave Valley (Bullhead City)
Phoenix
Southern Arizona (Tucson)

ARKANSAS
Benton (Telephone/ Email Support)

CALIFORNIA
Bakersfield
Camarillo/Ventura
Central Coast
Crescenta Valley/ Pasadena
Fountain Valley
Fresno
Imperial County/ El Centro
Inland Empire/ San Bernardino
Los Angeles
Palo Alto
San Diego/Encinitas
San Diego/Mission Valley
San Fernando Valley/ Sherman Oaks
Santa Barbara
Santa Rosa
San Gabriel
Turlock
Whittier

COLORADO
Colorado Springs
Denver
Grand Junction
Loveland
Virtual (Teleconference/ Videoconference)

CONNECTICUT
Eastern Conn.
North Haven

DELAWARE
Delaware (Telephone/ Email)
Dover
Wilmington

FLORIDA
Boca Raton
Fort Myers (Susan Marie Foundation)
Jacksonville
Miami
New Smyrna Beach
North Palm Beach
Orlando
Tampa

GEORGIA
Peachtree City
West Pooler

IDAHO
Meridian

ILLINOIS
Chicago
Decatur/Springfield
Highland Park
Kankakee
Winfield

INDIANA
Inactive

IOWA
Des Moines

KANSAS
Topeka

LOUISIANA
Baton Rouge
Many
New Orleans

MAINE
Scarborough
South Berwick

MASSACHUSETTS
Boston
Fall River
Topsfield
Worcester

MICHIGAN
Auburn Hills
Clinton Township
Dexter
Dryden
East Detroit
Grand Rapids
Livonia
Parents of Children with Scleroderma (Virtual)
St. Joseph

MINNESOTA
Brainerd
North Metro (Fridley)
West Metro (Edina)

MISSOURI
Kansas City
Northeast Area
Poplar Bluff
Springfield
St. Louis

NEBRASKA
Lincoln
Omaha

NEW HAMPSHIRE
Bow
Hampstead

NEW JERSEY
Brick
Burlington/Camden (Cherry Hill)
Wayne

NEW YORK
Albany (Schenectady)
Buffalo (Clarence)
Cooperstown (Milford)
Greater Rochester
Long Island (Bay Shore)
Nassau/Queens (Success)
New York City
Walden

NORTH CAROLINA
Durham
Fayetteville

OHIO
Akron/Canton
Central Ohio/Greater Columbus (Dublin)
Dayton (Huber Heights)
Greater Cincinnati
Northeast Ohio/ Greater Cleveland (North Royalton)
Toledo
Virtual (Telephone)
Youngstown

OKLAHOMA
Broken Arrow (Inactive)
Norman (Inactive)

OREGON
Beaverton
Medford
Portland
Powell
Salem

PENNSYLVANIA
Doylestown
Enola
Pittsburgh
Reading
Williamsport

SOUTH CAROLINA
Charleston
Greenville
Rock Hill

SOUTH DAKOTA
Rapid City
Sioux Falls

TENNESSEE
Chattanooga
Gallatin (Telephone)
Memphis

TEXAS
Austin
Brazos Valley (Bryan)
Corpus Christi
Dallas/Fort Worth (Bedford)
Deer Park
El Paso
Houston
Lubbock
San Antonio

UTAH
Northern Utah
Greater Salt Lake City

VERMONT
Brattleboro
Williston

VIRGINIA
Fredericksburg
Norfolk (Telephone)
Richmond

WASHINGTON
Kennewick
Mount Vernon
Olympia/Tacoma
Seattle
Spokane
Yakima

WEST VIRGINIA
Huntington
Weirton (Telephone)

WISCONSIN
Green Bay
Madison
Milwaukee

SPANISH-SPEAKING
Los Angeles
New York
Miami

Support Groups as of March 2021
**EDUCATION**

To promote public awareness and education through patient and health professional seminars, literature, and publicity campaigns.

**Information** can be considered the most valuable service offered by the Scleroderma Foundation. The **National Patient Education Conference** is the premiere learning and networking experience for individuals affected by scleroderma. Each chapter also offers at least one patient education program in their respective territories every year. And, **scleroderma.org** is a vast resource of reliable information.

## National Patient Education Conference

### The Sky is the Limit

- **21st National Conference**
  - July 19 - 21, 2019, Chicago, Illinois
- Record-breaking **700** registered guests
- More than **50** percent first-time attendees
- **46** presentations by **55** scleroderma experts and healthcare professionals
- Scientific poster session Friday night
- Opening keynote address: “**Endure: The Life & Art of Paul Klee**” by Richard M. Silver, M.D.
- Featured lecture: “**Lung Involvement in Scleroderma**” by Virginia Steen, M.D.
- Closing keynote address: “**When Strong is All There Is**” by Betsy Craig.

### Kids Get Scleroderma, Too!

- Youth education program operated concurrently.
- **72** attendees, including youth, parents, and siblings.
- **17** presentations by **12** pediatric scleroderma experts and healthcare professionals.
- Youth Carnival
- Aquarium road trip
- Family ice cream social

### Many Thanks to Our Sponsors

**Diamond National Sponsor:**
- Janssen Pharmaceutical Companies of Johnson & Johnson

**Platinum National Sponsor:**
- Boehringer Ingelheim Pharmaceuticals, Inc.

**Corporate Sponsors:**
- Bayer HealthCare
- Reata Pharmaceuticals, Inc.
- United Therapeutics Corporation
- CSL Behring
- Corbus Pharmaceuticals

**And Exhibitors:**
- Bodi Metrics
- Feel Good, Inc.
- Health Advocacy Summit
- Laclede, Inc.
- Pulmonary Fibrosis Foundation
- Pulmonary Hypertension Association
- Scleroderma Foundation Advocacy Program
- Scleroderma Lung Study III
- Scleroderma Patient-centered Intervention Network (SPIN)
- Scleroderma Self-Manage Program
- Yoga for Scleroderma

---

**Central Fund Sponsors**

- **Diamond National Sponsors**
- **Platinum National Sponsor**

---

**Janssen Pharmaceutical Companies of Johnson & Johnson**

**Boehringer Ingelheim**
The COVID-19 pandemic demanded action on many fronts. Most importantly, the Foundation and its Medical & Scientific Advisory Board had to help our scleroderma community understand the very real risks from this new and dangerous virus and what they could do to protect themselves. A series of four webinars occurred during March and April of 2020 covering a range of essential information.

March 21 **Scleroderma & COVID-19: A Conversation with the Experts**  
Tracy Frech, M.D., M.S., University of Utah

March 27 **Staying Well During COVID-19**  
Tracy Frech, M.D., M.S., University of Utah

April 16 **Taking Care of Yourself at Home: Maintaining Hand and Face Mobility**  
Janet Poole, Ph.D., University of New Mexico

April 24 **Balancing Your Immune System: A Special Webinar on Nutrition for Scleroderma Patients**  
Elizabeth R. Volkmann, M.D., M.S., University of California, Los Angeles

**CHAPTER EDUCATION PROGRAMS**

Each chapter also offers at least one local educational program every year. The impact of the COVID-19 pandemic during the last half of Fiscal Year 2020 was significant, causing the cancellation of all in-person programs starting in late March. However, chapters showed resilience and flexibility by converting many of those activities into virtual events.

**Delaware Valley Chapter**  
Philadelphia, Penn. 11/16/19

**Heartland Chapter**  
Des Moines, Iowa 10/5/19

**Minnesota Chapter**  
Minnetonka, Minn. 10/19/19

**Missouri Chapter**  
Chesterfield, Mo. 9/28/19

**New England Chapter**  
Virtual 5/6/20

**Northwest Chapter**  
Tacoma, Wash. 10/19/19  
Boise, Idaho 11/16/19

**Ohio Chapter**  
Beachwood, Ohio 10/12/19

**Oregon Chapter**  
Virtual 4/26 - 5/2/20

**Tri-State Chapter**  
Albany, N.Y. 9/14/19  
Rochester, N.Y. 10/5/19  
New York City, N.Y. 10/19/19

**Texas Bluebonnet Chapter**  
Houston, Texas 9/28/19  
Dallas/Ft. Worth, Texas 2/9/20

Systemic sclerosis (SSc, scleroderma) is a disease in which the immune system attacks the body causing hardening of the skin, and organs. Sclerodema is heterogeneous and an ability to classify patients within subsets could help for prognosis and aid in appropriate screening for complications.

SSc subset definitions are outdated and patients may erroneously be excluded from trials and denied access to treatment. Multiple qualitative interviews with scleroderma experts in USA and Europe allowed for themes that were incorporated into the development of new subset criteria (published).

There has been a systematic review to study what has been proposed for sub-setting patients with scleroderma (in progress).

We have combined data from thousands of patients with scleroderma using registries. Analyses are underway for cross sectional subsets and also to determine in early (initial visits) if the subsets are predictive over time using state of the art statistics for longitudinal data.

The sub-setting criteria in scleroderma has been an important project that will allow for prognostication for people living with scleroderma, and possible earlier interventions, and enrollment in trials based on factors that may allow for the best chance of finding benefits for the individuals studied.
The Scleroderma Foundation’s investment in research seeks to **discover** the cause, **understand** the mechanism, and **overcome** scleroderma forever. Our leadership, through a rigorous peer-review grant process, has been a contributing factor in the impressive growth in scleroderma research activity since our founding in 1998.

Over 22 years, the Foundation has funded **$28 million** in grants through the generosity of donors who share our commitment to stimulate innovative research. These achievements are only the groundwork for far more promising studies that need greater funding to pursue. Some notable achievements include:

- Since 2000, there have been 12,550 papers published in scleroderma research.
- The classification of systemic sclerosis in 1980 and in 2013 dramatically aided diagnosis and changed the way physicians treated patients.
- Development of better therapies and treatments that have reduced mortalities
- Understanding the balance between genetic and environmental factors

The **Peer-Review Research Committee** is composed of highly respected scleroderma medical experts who review, critique, and rank all applications based on the National Institutes of Health’s ranking system. Only projects of significant scientific merit are funded. Review criteria are highly disciplined and include:

- **Significance**: Does this study address an important issue related to systemic sclerosis?
- **Approach**: Are the design, methods, and analyses appropriate and adequate?
- **Innovation**: Does the research represent new ideas and technologies?
- **Investigator**: Are reviewers properly trained and sufficiently experienced?
- **Environment**: Does the scientific environment contribute to its success?

Three research grants are named in honor of individuals who made major contributions to those affected by scleroderma:

- The **Marta Marx Fund for the Eradication of Scleroderma** was established by bequests from Ms. Marx and her brother, Rudolph Juhl. It is awarded annually to the researcher whose proposal achieves the highest score.
- The **Mark Flapan Award** is named in memory of the late psychologist and scleroderma patient.
- The **Walter & Marie Coyle Research Grant** is named in honor of a founder of the Scleroderma Foundation, Marie Coyle, who also had scleroderma, and her husband.

The Foundation funds two types of grants:

- **Early Career Investigator Grants** designed for new investigators who hold faculty positions and wish to pursue careers in research related to scleroderma. This award is designed to mentor and encourage the next generation of researchers.
- **Established Investigator Grants** are for promising, established investigators who wish to propose pilot studies with highly innovative themes related to the disease.

The Scleroderma Foundation is proud of class of 2020 awardees. These eight researchers represent an impressive array of scientific skill and knowledge, in addition to exciting avenues of study with great potential. Half of this group are investigators new to the field of scleroderma, and in many ways they represent the future of scleroderma research. The four established investigators are using their experience to chart new avenues of study in scleroderma.

During this funding cycle, the **Michigan Chapter** contributed additional dollars toward the work of David A. Fox, M.D., at University of Michigan. This is not unusual for a chapter to raise additional dollars to fund a project occurring within their operational territory.
2020 Scleroderma Foundation Research Grant Awardees

**Benjamin Korman, M.D.**
University of Rochester
The Marta Marx Fund for the Eradication of Scleroderma
New Investigator Award
Pathogenic Role of TNF-α and TNF Receptors in Experimental Scleroderma Associated Pulmonary Arterial Hypertension

**David A. Fox, M.D.**
University of Michigan
Established Investigator Award (funded by the Michigan Chapter)
Targeting CD13 as a novel therapeutic approach for scleroderma

**Franck J. Barrat, Ph.D.**
Hospital for Special Surgery
The Mark Flapan Award
Established Investigator Award
Functional Impact of TLR7/8 Biallelism in SSc Patients

**Cory Perugino, D.O.**
Massachusetts General Hospital
New Investigator Award
Unbiased and Comprehensive Adaptive Immunophenotyping to Determine the Relevance of CD4+ Cytotoxic T Lymphocytes in the Pathogenesis of Systemic Sclerosis

**Maria Trojanowska, Ph.D.**
Boston University
Walter & Marie Coyle Research Grant
Established Investigator Award
Regulation of Lymphatic System in Scleroderma

**Catherine Elizabeth Simpson, M.D., M.H.S.**
Johns Hopkins University
New Investigator Award
The Role of Xanthine Oxidoreductase Activity and Altered Metabolism in Scleroderma-Associated Pulmonary Arterial Hypertension

**Tomoko Hayashida, M.D., Ph.D.**
Ann & Robert H. Lurie Children’s Hospital of Chicago
Established Investigator Award
Role of Smad Anchor for Receptor Activation (SARA) in Skin Fibrosis

**Eleanor Valenzi, M.D.**
University of Pittsburgh
New Investigator Award
Transcriptional and Epigenetic Investigation of the Master Regulator of Myofibroblast Transformation in Systemic Sclerosis-Associated Interstitial Lung Disease
Scleroderma Research & Treatment Centers

The Foundation has formal affiliations with Scleroderma Research & Treatment Centers around the United States. To be designated as a “center” by the Foundation, a clinic must:
- Demonstrate expertise in the care of patients with scleroderma.
- Conduct scleroderma research (clinical and/or observational and/or laboratory-based).
- Conduct educational activities about scleroderma, and provide information about the advances in the care and treatment of patients with scleroderma to health care professionals and the public.

ARIZONA
Banner University Medicine
Mayo Clinic Arizona

CALIFORNIA
Stanford University Scleroderma Center, Stanford University Medical Center (Redwood City)
UCSF Scleroderma Center, University of California, San Francisco
University of California, Los Angeles Division of Rheumatology
Loma Linda University, Division of Rheumatology
Cedars-Sinai Medical Center

COLORADO
National Jewish Health
University of Colorado Scleroderma Program

CONNECTICUT
UConn Health Outpatient Pavilion
Yale Scleroderma Program
District of Columbia
Georgetown University Hospital

ILLINOIS
Bernie Mac Sarcoidosis Translational Advanced Research (STAR) Center
Northwestern Scleroderma Program, Northwestern Medicine
University of Chicago, Scleroderma Clinic
University of Illinois at Chicago Outpatient Care Center (OCC)
University of Illinois at Chicago, Section of Rheumatology

LOUISIANA
Tulane University School of Medicine - Tulane Lung Center
Southeast Louisiana Veterans Health Care System
University Medical Center
Comprehensive Pulmonary Hypertension Center

MARYLAND
Johns Hopkins University School of Medicine, Johns Hopkins Scleroderma Center

MASSACHUSETTS
Boston University Scleroderma Program
Scleroderma Program - Massachusetts General Hospital (Boston & Waltham)

MICHIGAN
University of Michigan, Scleroderma Program

MINNESOTA
Mayo Clinic (Rochester)
MHealth Rheumatology Clinic, Clinics & Surgery Center
University of Minnesota Health, Maple Grove Clinics

NEW HAMPSHIRE
Dartmouth Hitchcock Medical Center

NEW JERSEY
Joseph M. Sanzari Children’s Hospital, Pediatric Rheumatology Clinic (Hackensack Meridian Health)
Rutgers-RWJ Scleroderma Program

NEW YORK
Columbia University Medical Center/New York-Presbyterian Hospital Scleroderma Program
The Hospital for Special Surgery, Scleroderma, Vasculitis & Myositis Center
Northwell Health Division of Rheumatology (three locations)
Steffens Scleroderma Center, Ballston Spa, N.Y.
North Carolina
Duke Health

OHIO
Cleveland Clinic
Ohio State University Wexner Medical Center, Martha Moorehouse Clinic
University of Cincinnati Medical Center, Scleroderma Clinic
University of Toledo Scleroderma Program, The Ruppert Center at University of Toledo Health Center Campus

PENNSYLVANIA
Penn Scleroderma Center:
University of Pennsylvania, Perelman Center for Advanced Medicine
Penn Medicine Radnor
Penn Medicine Valley Forge
The Scleroderma Center of Thomas Jefferson University
UPMC & University of Pittsburgh, Arthritis & Autoimmunity Center
Children’s Hospital of Pittsburgh of UPMC

SOUTH CAROLINA
Medical University of South Carolina

TENNESSEE
University of Tennessee Health Science Center:
University Methodist Medical Practice Regional One Health (Medplex)
UT Regional One Health
University Clinical Health
LeBonheur Children’s Hospital

TEXAS
University of Texas Scleroderma Clinic, Frank C. Arnett Center for Autoimmunity

UTAH
University of Utah Scleroderma Center, Chronic Disease Clinic

WASHINGTON
Seattle Children’s Hospital
The Scleroderma Clinic at the University of Washington
Virginia Mason Medical Center

WISCONSIN
Medical College of Wisconsin, Froedtert Hospital

as of March 2021
FUNDRAISING

STEPPING OUT TO CURE SCLERODERMA: JULY 1, 2019 - JUNE 30, 2020

Stepping Out to Cure Scleroderma walks and 5K runs are the signature fundraising events of the Scleroderma Foundation. Organized by chapters and volunteers in select locations, they provide a rallying point for individuals and families affected by scleroderma. Thank you to all participants and donors for your flexibility in adapting to the virtual environment and continuing to support the Foundation’s mission.

Total Stepping Out Events: 38  Total Dollars: $904,600*
Total Participants: 2,428

Stepping Out Locations

JULY 2019
Plymouth, Mass.
    New England Chapter
Columbus, Ohio
    Ohio Chapter
St. Paul, Minn.
    Minnesota Chapter

AUGUST 2019
Springfield, Ill.
    Greater Chicago Chapter
Dayton, Ohio
    Ohio Chapter
Aurora, Ill.
    Greater Chicago Chapter
Cleveland, Ohio
    Ohio Chapter
York, Penn.
    Delaware Valley Chapter
San Diego, Calif.
    Southern California Chapter
Germantown, Wisc.
    Greater Chicago Chapter

SEPTEMBER 2019
St. Louis, Mo.
    Missouri Chapter
Philadelphia, Penn.
    Delaware Valley Chapter
North Shore, Mass.
    New England Chapter

Snohomsh, Wash.
    Northwest Chapter
Westfield, Mass.
    New England Chapter
Dixon, Ill.
    Greater Chicago Chapter
Boston, Mass.
    New England Chapter

OCTOBER 2019
Kansas City, Mo.
    Missouri Chapter

FEBRUARY 2020
Coconut Creek, Fla.
    Southeast Florida Chapter

MARCH 2020
Santa Barbara, Calif.
    Southern California Chapter
Sweet Briar, Va.
    Greater Washington DC Chapter

MAY 2020
Sherman Oaks, Calif.
    Southern California Chapter

JUNE 2020
Boardman, Ohio
    Ohio Chapter

Spokane, Wash.
    Northwest Chapter
Omaha, Nebr.
    Heartland Chapter
Stampede, Detroit, Mich.
    Michigan Chapter
Allaire, N.J.
    Delaware Valley Chapter
Des Moines, Iowa
    Heartland Chapter
Kansas City, Mo.
    Missouri Chapter
Lilburn, Ga.
    Georgia Chapter
Twin Cities (St. Paul), Minn.
    Minnesota Chapter
    New England Chapter
LA/OC (La Mirada), Calif.
    Southern California Chapter
Dallas, Tex.
    Texas Bluebonnet Chapter
Denver (Centennial), Colo.
    Rocky Mountain Chapter
Fort Collins, Colo.
    Rocky Mountain Chapter
Houston, Tex.
    Texas Bluebonnet Chapter
Oregon
    Oregon Chapter

* figures reflect calendar year 2020 activity
Karen and Bruce Bittmann have two reasons to contribute to the Scleroderma Foundation. The first is family. “Scleroderma affected my life, my sister’s life, and my father’s, who raised us as a single parent after my mother passed away,” said Bruce Bittmann, who was five years old at the time his mother died from scleroderma. His sister was nine. “In 1952 no one knew too much about this disease, and still today not many people understand much about scleroderma. As time has gone on, it’s been something I’ve wanted to learn more about.”

Karen said, “Sixty years ago I don’t think people really had resources like support groups for families. That’s an important component of local chapters, getting people together to understand the disease and resources available. That didn’t exist back then.”

The second reason for their giving is their belief in the importance of well-funded research. Bruce said, “Funding attracts the researchers; it’s only natural.” Karen added, “As we get older and feel more vulnerable, we want to know more about our medical backgrounds. We’re motivated to leave a better, healthier world for our kids and grandkids. A cure to scleroderma would do that. Research is the key.”

Bruce and Karen make a significant annual contribution of appreciated securities to the Foundation. “We’re proud to contribute what we can and hope we can motivate other people to do the same thing. A gift of stock is easy.”

As Bruce concluded, “I wish I could have known my mom. I lost her as a five-year-old; it is hard to remember much about her. Through this gift and others, we can honor and remember her, as well as help prevent other little five-year-olds from losing a mom.”

The Scleroderma Foundation is deeply grateful to the Bittmanns and to all of our generous donors.
Hope Raisers

Thank you to the many friends of the Scleroderma Foundation who fundraise independently to help support our mission of support, education, and research. The Foundation provides an online fundraising platform, called Hope Raisers, that uses the same peer-to-peer fundraising tools that participants in Stepping Out have at their disposal. The beauty of Hope Raisers is that you can use it for just about anything you think of to raise money. If you run in a local marathon to raise money, you can create a Hope Raiser. If you’re hosting a golf tournament, you can create a Hope Raiser. If you want to honor a loved one with scleroderma, you can create a Hope Raiser. The only limit is your imagination. To create a Hope Raiser fundraising event, visit www.scleroderma.org/hoperaisers. Thank you!

Jet Ski for Julia is a great example of the creative use of Hope Raiser fundraising tools. Julia Ceresnak of Palo Alto, California, was five years old in May of 2016 when she and her parents, Karen and Scott, were told that Julia had systemic sclerosis.

When her great uncle, Thomas Cronin, a retired police officer from Shelter Island, NY, found out that Julia had a life-threatening disease, he knew he had to do something. Thomas had experience raising money for other causes, including memorials in Washington, D.C. for Vietnam, WWII, and Korea. His friend, Tobey, had been after him for some time to do a jet ski trip to the Florida Keys. For Thomas, if it was going to happen it had to be about fundraising and it had to help Julia. He set the goal at $50,000 and contacted the Scleroderma Foundation, who helped him set up a Hope Raiser web page to accept online donations. Thomas discovered that when he talked to others about his effort, stories of scleroderma emerged. “Everyone’s talking about it.”

Thomas and Tobey planned a 3,500-mile trip from Shelter Island, NY (on Long Island) to Key West, then to the Bahamas and back to Shelter Island. The trip is also an attempt to set a Guinness World Record. The pair embarked June 30, 2019 and returned 17 days later on July 17 to a cheering crowd. The journey was difficult but fruitful, as Thomas met his fundraising goal. Thank you, Thomas, Tobey, and Julia!

Preclinical Assessment of Dimethylfumarate (Tecfidera) as a Novel Therapeutic for SSC-PAH

The Kao Family Foundation SCORE Grant
Maria Trojanowska, Ph.D.
Boston University School of Medicine

Scleroderma Foundation funding made it possible to pursue a collaborative research project between the laboratories of Dr. Maria Trojanowska at Boston University and Dr. Elena Goncharova at the University of Pittsburgh. The team effort led to novel key discoveries on the function of transcription factor GATA6 in pulmonary vasculature and provided the evidence demonstrating attractiveness of GATA6 axis as a molecular target pathway for therapeutic intervention in Pulmonary Arterial Hypertension (PAH).

The main findings of the study demonstrated that: i) GATA-6 has a critical role in maintaining healthy lung vasculature and its loss in PAH leads to oxidative stress and mitochondrial dysfunction; ii) GATA6 is engaged in a bi-directional cross-talk with BMP10/BMP receptors axis and its loss in PAH contribute to BMP receptor loss; and iii) targeting GATA6 axis with dimethyl fumarate (DMF) resolves oxidative stress and BMP receptor deficiency and ameliorates experimental PAH in preclinical models.

Our work laid the basic and translational science foundation for a clinical study of therapeutic effects of dimethyl fumarate (DMF) in SSC-PAH.

The findings of this study have been submitted for publication (now in revision).

The Scleroderma Foundation funding led to a funded NIH RO1 grant “GATA-6 in pulmonary arterial hypertension.”
FINANCIALS

REVENUE

Contributions Received from Affiliates 10.1%
Contributions 71.4%
Bequests 4.7%
Returned Grant Awards 0.8%
Registration Fees 3.5%
Voluntary Research Contributions 5.2%
Investment Income, Net 3.2%
Special Events, Net 1.2%

EXPENSES

Research 25.8%
Education and Support 56.5%
Fundraising 4.2%
General and Administrative 13.5%
STATEMENT OF ACTIVITIES FOR THE YEAR ENDED JUNE 30, 2020

<table>
<thead>
<tr>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>REVENUE AND OTHER SUPPORT:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributions</td>
<td>$2,312,438</td>
<td>$2,627,315</td>
</tr>
<tr>
<td>Contributions Received from Affiliates</td>
<td>373,144</td>
<td>$373,144</td>
</tr>
<tr>
<td>Special Events, Net of Direct Benefit to Donor Costs of $235,114 and $255,417. Respectively</td>
<td>42,981</td>
<td>$42,981</td>
</tr>
<tr>
<td>Investment Income, Net</td>
<td>-</td>
<td>$118,497</td>
</tr>
<tr>
<td>Voluntary Research Contributions*</td>
<td>-</td>
<td>$190,000</td>
</tr>
<tr>
<td>Registration Fees</td>
<td>128,846</td>
<td>$128,846</td>
</tr>
<tr>
<td>Returned Grant Awards</td>
<td>29,435</td>
<td>$29,435</td>
</tr>
<tr>
<td>Bequests</td>
<td>172,010</td>
<td>$172,010</td>
</tr>
<tr>
<td>Net Assets Released from Restrictions</td>
<td>620,623</td>
<td>$0</td>
</tr>
<tr>
<td><strong>Total Revenue and Other Support</strong></td>
<td>3,679,477</td>
<td>2,751</td>
</tr>
<tr>
<td></td>
<td><strong>3,682,228</strong></td>
<td></td>
</tr>
</tbody>
</table>

**EXPENSES:**

<table>
<thead>
<tr>
<th>Program Services:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and Support</td>
<td>2,803,960</td>
<td>2,803,960</td>
</tr>
<tr>
<td>Research</td>
<td>1,280,376</td>
<td>1,280,376</td>
</tr>
<tr>
<td><strong>Total Program Services</strong></td>
<td><strong>4,084,336</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support Services:</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>General and Administrative</td>
<td>672,226</td>
<td>672,226</td>
</tr>
<tr>
<td>Fundraising</td>
<td>207,761</td>
<td>207,761</td>
</tr>
<tr>
<td><strong>Total Operating Expenses</strong></td>
<td><strong>4,964,323</strong></td>
<td></td>
</tr>
</tbody>
</table>

(Decrease) Increase in Net Assets from Operations | (1,284,846) | 2,751 | (1,282,095) |

Non-Operating Activities: Investment Income, Net | 377,852 | - | 377,852 |

Increase in Net Assets | (906,994) | 2,751 | (904,243) |

Net Assets, Beginning of Year | 8,618,498 | 1,800,124 | 10,418,622 |

Net Assets, End of Year | $7,711,504 | $1,802,875 | $9,514,379 |

* Voluntary research contributions from Chapters, greater than required.
Audit performed by MFA: Moody, Famiglietti & Andronico, LLP, Tewksbury, Mass.
Complete copies of the Foundation’s fiscal year 2019 audited financial statements and IRS form 990 are available from the National Office and on scleroderma.org.
DONORS

THANK YOU to our community for choosing to support the critical work of the Scleroderma Foundation. Your friendship and generosity supports our three-fold mission and provides continued hope for everyone affected by scleroderma.

INDIVIDUALS

$25,000 +

John Boehm
Monte & Janice Klein
Paula and Roy May
Donald Ward
Sol & Tina Waxman

$10,000 - $24,999

Diane Adamec
Dennis Benner
Philip Bookman
Jerry & Carol Denham
Estate of Madeline Reilly
Estate of Paul Randolph
Perkins
Estate of Julia Hazel
Hayfield
Estate of Margaret Starmer
George & Lisa Etheridge
Thomas Familetti
Denise & Mark Lammert
Harry Mansfield
Donna Martz
Reiko Matsushima
Ted Paetzol
Susan Pierce
Michael Purcell
Stephen & Linda Skinner

$1,000 - $4,999

Order Ahepa
Knut & Norma Akseth
Meredith Allister
Jonathan Balkind
Nelson Ball
Jeffrey Barath
Robert Bartlett
Maria Bartoszewicki
Linda J.B. Baum, O.D.
Margaret & Reginald Bayley
Cyndy Besselievre
Mary Blades
William Blair
James Bogaski
Tina Brake
Dana Brewer
Michael Broida
Thomas & Janis Brunell
Walter Bruner
Connie Buchholz
Marco Burnette
Debbie Callahan
Jason Calverley
Thomas Camerino
Terese Cantrell
Mary Caruso
Murtaza Cassoobhoy
Ron Chapman
Howie Cherman
Inga Cherman-Lurie
Paul Childs
Vernon Childs
Agnes Cimini
Gene Ciufno
Philip Clements, M.D.
Leslie & Jules Cogan
Tony Cogan
Dennis Coit
Terry Cole
Richard Coleman
Sally Connolly
Bob Conrey
Theresa Coughlin
Kortnie Cox
John Crayton
Carmen’s Crew
Jeff Cummings
Mauricio Dangot
Elizabeth Daniels
Ken & Sharron Davidson
Frank DeLuca
Cynthia Dillon
Laura Dyas
Orbie Edwards
Mary Elizabeth
Edward Elliott
Andrew Emmett
Victoria Ennis
Annette Epps
Laurie Epstein
David Ernst
Estate of Isabelle Patten
Stan & Denise Eskridge
Robert Eustice
Monte Ewing
Robert Fairfield
Christina Fields
Tom Filippini
Darlene Fisher
Carole Flam
Abbie Fougeron
Willard Fraumann
Tracy Frech, M.D., M.S.
Monte Friedkin
Steve Garnett
Jay & Faina Gellee
Frank & Irma Gioia
Ashraf Girgis
Jeff Glanzer
Alan Gold
Cynthia Goldberg
Joe Gonzalez
Lorraine Goodwillie

$5,000 - $9,999

Kathleen & Bruce Adamec
Thomas Adamec
Bruce & Karen Bittmann
Jonna Blaser
Mary Anne Boehm
Greg Brake
Darina & Andrew Chesterton
Nancy Christman
Douglas Colbeth
Stephanie Dickman
Daniel Dowling
Troy Duell
Dr. Mark Eaker
Valentine Fenti
Daniel Forst, M.D.
Jean Hartman
John & Patricia Heilala
Serena Hines
Susan Huber

Allen Gorrellick
Neil Graff
Ronald & Helen Greenburg
Ben Grohmann
Elizabeth Guenther
Harriet Gutnecnht
Tracy Hagel
Regina Hall
Frances Hasson
Ryan Hayman
Reggie Henry
Dolores Hertel
Linda & Robert Herzfeld
Cynthia & Michael Hiltwein
Jeff Hoen
Jill & Patrick Holland
Mr. & Mrs. Douglas Horn
Jody Horner
William Hossom
Eileen Hovey
Julia Hurd
Fred Jackson
Jennifer Jozefowski
Mary Jones
Suzanne Kafaja
William Kahn
Stanley & Charlotte Kandel
James Kane
Marc Kawakami
Rebecca Kenyon
Robert Kerr
Linda Keschel
Werner Kettelhack
Patrick Kinlan
Elizabeth Kinney
Juergen Kirschke
Debra Kleban
Maryanne Klima
Mark Kompa
James Krantz
Kristy Kubota
Sheri Lanoff
Bonnie Leboff
Martin & Sharon Lehmann
Patsy Leopold
Mark & Linda Levine
Fran Lewbel
Katherine Light
Mark Lindstrom
Michael Loricchio
Mary Louise
Alice Loveless
Sandee Maas
Mark Macumber
March Madness
John Magliocco
Betty Mallon
Richard & Michelle Manson
Mary Mar
Kenneth Mardick
Harold Masor
Carl May
Joe Mazur
Phil McMahon
John McNamara
Sharif Metwalli
Steve Miller
Kristen Moe
Mark & Marsha Moon
Kenneth Morain
Karen Morano
Sheila Morris
Donna Mueller
Dennis Musher
Tameka Nelson
Dan Neyer
Anne Nguyen
Dean Nims
David Noon
John Nooncaster
Geraldine Nunes
Mayra Oberto
Annette O’Connor
Margaret O’Connor
Alice Okuno
Carol Oldham
Mark Orozco
Sara Othon
Sherry Paetzold
Amanda Papaeftathiou
Virtual Parrot
John Paizdra
Carol Pearson
Jackie & Paul Pepperman
Terry Perkins
Misha Pesicek
Melinda Pettit
James Phillips
Joan Pinezich
Regina Pinotti
John Port
George Poschner
Pamela Pour
Joseph Purcell
Teresa Puskedra
Deanna Quinn
William & Natalie Raaths
Frank Rahn
Estelle Randolph
Lisa Rehberger
Charles Renninger
Karin Rhoads
Robert Rich
Sharon Riestis
Arnold Riggs
Patti Riina
Peter Robinson
Robert & Jean Rogers
Paul Rom
Raphael Rossi
Sandra & Marvin Rubin
Brian Russell
Fred Saab
Gwen Sabo
Adel Saleh
Norton Sarnoff
Heidi Schaeffer
Kathy Schell
David & Stacey Schimberg
Lee & Martha Schimberg
Robert Schneider
Nick Schulte
Kathie Schwartz
Ileen Scriven
Jack Seagraves
Jeff & Martha Seaman
Steven Seidemann
Mark Seiler
Christine Shephard
Paul Shiaras
Marnie Shreeman
Jeffrey Sienkiewicz
Floyd Simpson
James Skovron
Robert Slappey
Ann & Larry Smith
Linda Sorge
Jo Stanfield
Michael Stave
Penelope Steiner
Nancy Steinhaus
Janet Stucky
Colleen Surnow
Mary Sutherland
Robert Sutherland
Richard & Barbara Swiftney
Gary Sylvan
Ross Taff
Kenneth & Christine Talley
Judy Tamkin
Heidi & Kris Tanacea
Garry & Joanne Tank
Bob Terrien
Henry Thierry
Matt Thomas
Melinda Thompson
William Thompson
Karen Thorpe
Joseph Topel
Sheri Uno
David Veatch
James Vogel
Jenna Vreugdenhil
Pamela Walders
Michael & Christie Walsh
Frederick Walter
Robert Waltermire
Diana Warner
Alvin Warsaw
Michael Waxman
Thomas Weirath
Nancy Wempe
Martha White
Martha Wiebers
D. Wesley Davis & Winona D. Davis
Steve & Cindy Wolfe
Lee Zajac

$500 - $999

Ella 1
Alexis Abate
Jacqueline Albin
Heidi Alcock
Marc Alteim
Lisa Altman
Jayson Amandus
Arnold Aprahamian
Rosemary Arnold
Jon Arnott
Rochelle & Clinton Arsenault
Patricia Auman
Carol Avery
Janet Baeder
Kaitie Baker
Heritage Baptist
Colleen Barclay
Daniel Basile
Aryeh Batalion
Dawn Batzel
Charles Beckman
Lorena Bendig
Wade Benton
Paul Berger
Roy Bishop
Benjamin Blades
The Block
Bradley Bloom
Ellie Bolde
Kathleen Bonaguro
Janice Boudreau
Martin & Penelope Bowin
Kevin Boyanowski
Patricia Brennan
David Brooks
Lucy Buffett
Terry Burgess
Hot Burritos
Tricia Buscio
Denise Butkus
Marilyn Bybee
John Caccamo
William Cahill
Janelle Calkins
Sara Campbell

Patti Riina
Peter Robinson
Robert & Jean Rogers
Paul Rom
Raphael Rossi
Sandra & Marvin Rubin
Brian Russell
Fred Saab
Gwen Sabo
Adel Saleh
Norton Sarnoff
Heidi Schaeffer
Kathy Schell
David & Stacey Schimberg
Lee & Martha Schimberg
Robert Schneider
Nick Schulte
Kathie Schwartz
Ileen Scriven
Jack Seagraves
Jeff & Martha Seaman
Steven Seidemann
Mark Seiler
Christine Shephard
Paul Shiaras
Marnie Shreeman
Jeffrey Sienkiewicz
Floyd Simpson
James Skovron
Robert Slappey
Ann & Larry Smith
Linda Sorge
Jo Stanfield
Michael Stave
Penelope Steiner
Nancy Steinhaus
Janet Stucky
Colleen Surnow
Mary Sutherland
Robert Sutherland
Richard & Barbara Swiftney
Gary Sylvan
Ross Taff
Kenneth & Christine Talley
Judy Tamkin
Heidi & Kris Tanacea
Garry & Joanne Tank
Bob Terrien
Henry Thierry
Matt Thomas
Melinda Thompson
William Thompson
Karen Thorpe
Joseph Topel
Sheri Uno
David Veatch
James Vogel
Jenna Vreugdenhil
Pamela Walders
Michael & Christie Walsh
Frederick Walter
Robert Waltermire
Diana Warner
Alvin Warsaw
Michael Waxman
Thomas Weirath
Nancy Wempe
Martha White
Martha Wiebers
D. Wesley Davis & Winona D. Davis
Steve & Cindy Wolfe
Lee Zajac

Ella 1
Alexis Abate
Jacqueline Albin
Heidi Alcock
Marc Alteim
Lisa Altman
Jayson Amandus
Arnold Aprahamian
Rosemary Arnold
Jon Arnott
Rochelle & Clinton Arsenault
Patricia Auman
Carol Avery
Janet Baeder
Kaitie Baker
Heritage Baptist
Colleen Barclay
Daniel Basile
Aryeh Batalion
Dawn Batzel
Charles Beckman
Lorena Bendig
Wade Benton
Paul Berger
Roy Bishop
Benjamin Blades
The Block
Bradley Bloom
Ellie Bolde
Kathleen Bonaguro
Janice Boudreau
Martin & Penelope Bowin
Kevin Boyanowski
Patricia Brennan
David Brooks
Lucy Buffett
Terry Burgess
Hot Burritos
Tricia Buscio
Denise Butkus
Marilyn Bybee
John Caccamo
William Cahill
Janelle Calkins
Sara Campbell

Geri Campopiano
Jo-Anne Carmel
Chris Carroll
Scott Ceresnak
Rose Cervo
Joel Cherman
Susan Chorpenning
Kevin Christal
Nicholas Christensen
Julie & Alan Christopher
Len Cimini
Martin Ciszon
Charles Clarke
Nancy Cohen
Oliver Cole
Peter Cole
Nell Comer
Pamela Constantine
Adam Cooper
Kelly Coors
Betsy Craig
Julie Crego
Harold Crews
Diana Crispi
Wayne Crouch
Terry & Kate Crouthamel
June Cummings
Jessica Currie
Zak Daboll
Peter Daniels
Elizabeth Dardes
Margaret Dastur
Bruce Dembo
George Depasquale
Jeanne DeSa
Saurabh Desai
John Dettmers
Clifford DeVine
Felice DiCrasto
Sharon Dobie
Kathleen Dooley
Charles Dunhour
James Dunran
Robert Dwyer
Sarah & Tony Earley
Mike Eaton
Stephen Elrod
Jean Elwing
Carol Feghali-Bostwick, Ph.D.
Christina Ferrari
Elizabeth Finlay
Bruce Fischer
Joy Fishman
Lisa Fleisher
Peter Fogliano
Susan Fried
Deborah Gallup
Barbara Gamer
Ronald & Elizabeth Garver
Fran Geidel
Denise Gesuale
Alan Glicklich
Jan Gnall
Jamie Gobel
Michael Godnick
Cecilia Gonzales
Christy Goralnik
Melanie Gornick
Jack & Catherine Gorski
Richard Gray
Brett Green
Francis Greguras
Maria Guarnieri
Ron Hadfield
George & Elizabeth Hainsworth
Peter Hall
Kiran Hamid
Lynn Harms
David Harris
Cheryl Harrison
Dana Hart
Jeffrey & Kathryn Hart
Robert Hartline
Dwane Hartwill
Jigna Heble
Sandra Heibel
Jill Helf
James Himonidis
Rick Hood
Christine Hooper
Denise & Tim Horan
Frontstream
Ronald Hudson
Wesley Hughes
Yvonne & Kevin Hull
Jeff Hurley
Michael Hyde
Joan Issac
Vanessa Jaunes-Diaz
Della Johnson
Diane Johnson
Lloyd A. Jones
Christie Joyce
Linda Kaminski
Aziz Karsan
Zak Karsan
Monica Kelley-Salvador
Karen Kemper
Jeanette Kennedy
Antoine Khouri
Nancy Kidd
Nancy Kieffer
Terry Kilmer
Bobby & Chris King
Verna King
Elyse Klein
Danielle Koepke
Barbara Kolesar
Kim Kondo
Nancy Koth
Judith Kotick Hans
Edward Kotula
Jill Kuebler
Herbert Lampert
Glenn Lane
Chris LaPorte
Dee Ann Lee
Janet Lee
Tommy Lee
April Lehmann
Daniel Leib
Cynthia Lemere
Pamela Lenhard
Daniel Leonard
Jason LeVett
Sheila Lewellen
Susan Little
Howard Littler
Donna & Richard Loraine
Ally Lowney
William Ludel
Karyn Lutz
Terri Lyons
Tony Magiocco
Serge Mallat
Lawrence & Nancy Marcus
Rick Martinez
Andrew Marwaha
Vijay Marwaha
Kevin McCaffrey
Henrietta McCarville
Roslyn McClendon
Neil McCormick
Nancy McDonald
Joan Meissner
Steven Meissner
Linda Merican
Peter Merkel
Nora Middleton
Patrick Middleton & Friends
Diane Miller
Lucille Miller
Tom Miller
Brad Millian
Stephanie Monaco
Ann Montera
Cynthia Mooneyham
Alyssa Moore
John Moore
Plante Moran
Susan Morano
Corinne Neukirch
Zoraida Nielsen
John Niemi
Darleen Norman
Thomas O'Donnell
Annie Olszewski
Janie O'Neal
Sarah Paccione
Thomas Paccione
Danielle Palomino
Paradise Park
Paul Pascutti
Gwyn Pellegrini
Tina & Joe Perri
Karen Pomeroy
Daniel Poneman
Debra Pospiech
Richard Prosser
Richard Rabin
Ted Rappaport
Tom Renninger
Minna Riber
Alan & Sharon Richards
Robert Richardson
Robert Riggs
Elaine Robison
Mary Ann Rocco
Dawn Rock
Christopher Rothko
Barbara Rudzin
Carol Ruskin
David Rustum
Ellen Sachs
Farrukh Saeed
Charles Saporito
Brad Sarnoff
Bill Savage
Thomas Scally
Stephen Schantz
Richard Schnaterbeck
Leni Schulz
Karen Schumacher
Steve Shepard
Jerry Shriner
Edward Simmons
Inder Singh
Ellen J. Skinner Feingold
Henry Skoros
Barbara Smith
Duane Smith
Joseph Smith
Darla Snyder
Susan Sovel
Jeanine Spicer
Gretchen Spring
Allan Staats
Mark Staley
Kathleen Stauffer
Virginia Steen, M.D.
Barb Steves
Rachel Stempel
Sharon Sternheim
Anne Stinson
Richard Stone
Norm Strauss
Jason Sttock
DanielleSucich
Laura Swan
Carol Sweeney
Mary Taughner
Kym Taylor
Vickie Templeton
Falah Thamir
Jack Thompson
Walter & Cindy Tieck
Richard Tillison
Alan Tolmas
Tiare Tolzmann
Gina Trovato
Marion & John Tucker
James Uvena
John Uvena
Nancy Van Coverden
Dennis Vann
Rob Vella
Kevin & Rachel Visscher
Alice Walker
Barry Walker
Daniel Wallace
Jim Walsh
Jaclyn Welder
Nancy Welly
Ria Whalen
Stephen & Nova Wheeler
Francine White
Wes & Shelly Whitlock
John & Lynn Williams
Dr. Michelle & Steven Windmueller
Ronald Wolf
Allen Wright
Schaeelder Yesco
Robert Zaslow
Susan Zeigler
William Zucker

ORGANIZATIONS

$100,000 +
Janssen Pharmaceutical Companies of Johnson & Johnson
Rudi's Kids Foundation

$25,000 - $99,999
Boehringer Ingelheim

$10,000 - $24,999
Beta Sigma Phi Endowment Fund
Bethpage Federal Credit Union
Corbus Pharmaceuticals
Global Genes
Reata Pharmaceuticals, Inc.
Teri’s Run Foundation Inc.
United Therapeutics Corporation, Inc.
<table>
<thead>
<tr>
<th>$5,000 - $9,999</th>
<th>$1,000 - $4,999</th>
</tr>
</thead>
</table>
Completed Project Summary:
Histone Deacetylases in Scleroderma: Investigation of Their Roles in Dysregulated Angiogenesis
Eliza PS Tsou, Ph.D., University of Michigan

Thanks to the funding from the Scleroderma Foundation, we were able to determine the reason for misregulated blood vessel formation in dermal vascular cells from scleroderma patients.

We found that alterations in epigenetics, which refer to changes in gene activity that are not caused by changes in the DNA sequence, play a critical role in this issue. We showed that in vascular cells from patients, two key epigenetics mediators, HDAC5 and HDAC7, are dysfunctional and this leads to inhibition of blood vessel growth.

Using state-of-the-art techniques, we were able to identify the genes, including CYR61, that were affected by HDAC5 in scleroderma. In addition, we found that the machinery to activate HDAC7 in scleroderma blood vessel cells is impaired when they are treated with vascular endothelial growth factor, a protein that increases blood vessel growth under normal conditions but not in scleroderma.

Moving forward, we are interested in studying the genes that are controlled by these epigenetic mediators, so that development of therapies aimed at promoting vascular formation in the skin of these patients can be achieved.

Our work was the first to show alterations of these epigenetic mediators in scleroderma vascular cells, and this would not have been possible without the support from the Scleroderma Foundation.
LEADERSHIP & CHAPTERS

BOARD OF DIRECTORS

Cos M. Mallozzi, Chair
Carol Feghali-Bostwick, Ph.D., Vice Chair
Greg Marion, Treasurer
Mike Levengood, Esq., Secretary

Linda J. B. Baum, O.D.
Cyndy Besseliervre
Mary Blades
Kevin Boyanowski
Courtney Caliendo

Christina Loccke
Mark Orozco
Marcia Walker

MEDICAL & SCIENTIFIC ADVISORY BOARD

Steering Committee
Virginia D. Steen, M.D., Chair
John Varga, M.D.
Immediate Past Chair
Lorinda Chung, M.D.
Maureen D. Mayes, M.D., M.P.H.
Richard Silver, M.D.

Members
Philip Clements, M.D., M.P.H.

Kathryn Torok, M.D.
Maria Trojanowska, Ph.D.

Members Emeriti
Frank Arnett, M.D.
Dame Carol Black, M.D.
Michael Ellman, M.D.
Thomas Medsgner, Jr., M.D.
Frederick Wigley, M.D.

FOUNDATION STAFF

Robert J. Riggs
Chief Executive Officer
Michael B. Hyde
Chief Operations & Financial Officer
Marta Brill
Associate Director of Development, Corporate & Foundation Relations
Kerri A. Connolly
Director of Chapter Relations
Shenna Gianetta
Research & Programs Manager
Karen Gottesman
Director of Pharma & Biotech Engagement
Jess Haas Gréus
Director of Development & Major Gifts
Diane Maguire
Finance Associate
David Murad
Director of Chapter Relations
Linda Norris
Database Administrator

Molly Paradis
Office Associate
Irina Shuruyeva
Accounting Assistant
Steven R. Sookikian
Director of Communications
Angel Soto
Programs & Services Associate
Maureen Zuluaga
Associate Director of Database Operations

CHAPTERS

DELAWARE VALLEY
(Eastern Pennsylvania, Southern New Jersey, and Delaware)
Katie Higgins, President
Darek Raguza, Executive Director

GEORGIA
Peggy Levengood and Doreen Towhey, Co-Presidents

GREATER CHICAGO
(Illinois, Indiana, and Wisconsin)
Tony Cogan, President
Stephanie Gresh, Executive Director

GREATER WASHINGTON D.C.
(Washington, D.C., parts of Virginia, and Maryland)
Sharon Fine, President

HEARTLAND
(Iowa, Nebraska, and South Dakota)
Lacey Bodnar, President

MICHIGAN
Kathryn Rehrauer, President
Laura Dyas, Executive Director

MINNESOTA
Kris Maas, President

MISSOURI
Rhonda Costa, President

NEW ENGLAND
(Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont)
Don Legere, President
Lindsay DeSantis, Executive Director

O HIO
Lucille Miller, President
Tina Fellows, Executive Director

OKLAHOMA
Donna Roberts, Vice President

OREGON
Christina Fidalgo, President

ROCKY MOUNTAIN
(Colorado)
Mike Pursel, President
Maria Dastur, Executive Director

SOUTHERN CALIFORNIA
(洛杉矶 and San Diego areas)
Peggy Hickman, President
Andrew Emmett, Executive Director

SOUTHEAST FLORIDA
(Palm Beach, Broward, Miami Dade, and Monroe counties)
Arnold Brownstein, President
Ferne Robin, Executive Director

TEXAS BLUEBONNET
(Texas)
Kathryn Torok, M.D.

TRI-STATE
(Connecticut, Northern New Jersey, and New York State)
Marc Krieger, President
Bruce Cowan, Executive Director

as of March 2021