




PROGRESS REPORT
JULY 1, 2019 - JUNE 30, 2020

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A photograph of Leslie Cogan, a woman with short brown hair, wearing a bright yellow blazer over a dark top. She is speaking into a microphone at a podium, with her right hand raised near her chin. In the background, another person is partially visible but out of focus.

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.

CHAIR'S MESSAGE

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,

A handwritten signature in cursive script that reads "Cos M. Mallozzi".

Cos M. Mallozzi
Chair, Board of Directors

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



Susan Murphy, M.D.



Dinesh Khanna, M.D., M.S.

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.

SCLERODERMA

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.

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



Elizabeth Volkman, M.D.

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.

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.*

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.

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.

SUPPORT GROUPS

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).

ALABAMA

Calera
Florence (*Telephone*)
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

Fredricksburg
Norfolk (*Telephone*)
Richmond

WASHINGTON

Kennwick
Mount Vernon
Olympia/Tacoma
Seattle
Spokane
Yakima

WEST VIRGINIA

Huntington
Weirton (*Telephone*)

WISCONSIN

Green Bay
Madison
Milwaukee

SPANISH- SPEAKING

Los Angeles
New York
Miami

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



VIRTUAL EDUCATION PROGRAMS

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**

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

Completed Project Summary:

Development of Systemic Sclerosis Subset Classification Criteria

Marta Marx Fund for the Eradication of Scleroderma

*Janet Pope, M.D., M.P.H.
University of Western Ontario*



Janet Pope, M.D., M.P.H.

Systemic sclerosis (SSc, scleroderma) is a disease in which the immune system attacks the body causing hardening of the skin, and organs. Scleroderma 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.

RESEARCH

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

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**

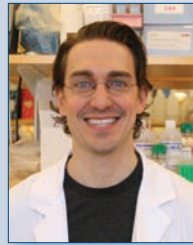


Franck J. Barrat, Ph.D.
Hospital for Special Surgery

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

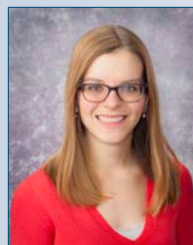
**The Role of Xanthine
Oxidoreductase Activity
and Altered Metabolism in
Scleroderma-Associated
Pulmonary Arterial
Hypertension**



**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

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

Snohomsh, Wash.
Northwest Chapter

Westfield, Mass.
New England Chapter

Dixon, Ill.
Greater Chicago Chapter

Boston, Mass.
New England Chapter

Spokane, Wash.
Northwest Chapter

Omaha, Nebr.
Heartland Chapter

Stampede, Detroit, Mich.
Michigan Chapter

Allaire, N.J.
Delaware Valley Chapter

AUGUST 2019

Springfield, Ill.
Greater Chicago Chapter

Dayton, Ohio
Ohio Chapter

Aurora, Ill.
Greater Chicago Chapter

Cleveland, Ohio
Ohio Chapter

OCTOBER 2019

Kansas City, Mo.
Missouri Chapter

Des Moines, Iowa
Heartland Chapter

Kansas City, Mo.
Missouri Chapter

York, Penn.
Delaware Valley Chapter

San Diego, Calif.
Southern California Chapter

Germantown, Wisc.
Greater Chicago Chapter

FEBRUARY 2020

Coconut Creek, Fla.
Southeast Florida Chapter

Lilburn, Ga.
Georgia Chapter

Twin Cities (St. Paul), Minn.
Minnesota Chapter

SEPTEMBER 2019

St. Louis, Mo.
Missouri Chapter

Philadelphia, Penn.
Delaware Valley Chapter

North Shore, Mass.
New England Chapter

MARCH 2020

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Southern California Chapter

Sweet Briar, Va.
Greater Washington DC Chapter

Worcester, Mass.
New England Chapter

LA/OC (La Mirada), Calif.
Southern California Chapter

MAY 2020

Sherman Oaks, Calif.
Southern California Chapter

Dallas, Tex.
Texas Bluebonnet Chapter

Denver (Centennial), Colo.
Rocky Mountain Chapter

JUNE 2020

Boardman, Ohio
Ohio Chapter

Fort Collins, Colo.
Rocky Mountain Chapter

Houston, Tex.
Texas Bluebonnet Chapter

Oregon
Oregon Chapter

* figures reflect calendar year 2020 activity

Completed Project Summary:

Molecular Characterization of Multi-Organ Involvement in Patients with Systemic Sclerosis

SCORE Grant

Lorinda Chung, M.D., M.S.
Stanford University



Lorinda Chung, M.D., M.S.

Our collaborative group at Stanford, UCSF, and the Geisel School of Medicine continues to make progress. Previous studies identified several molecules that are important in causing scarring

and fibrosis (hardening) in single organ systems in systemic sclerosis (SSc). But no studies have looked at multiple organ systems to identify molecules that are important in causing scarring throughout the body. We made significant progress by establishing the necessary infrastructure, protocols, and personnel to collect multiple biopsies from different organ systems in the same individual SSc patients.

Our group has developed and applied cutting-edge technologies to identify key drivers of SSc across organ systems. We applied these technologies to tissue samples from the different affected organ systems from the same SSc patient. Our most recent results show that the same molecular deregulation occurring in one organ of an individual is also similar to the deregulation in the other organs. The study also identified key markers of lung disease using only data derived from the blood of patients with SSc. These two findings are integral to being able to treat the disease across multiple organs in patients, using information derived from blood. Ultimately, we hope to identify and develop therapies to target critical molecules involved in causing scarring throughout the body in patients with SSc. This indeed could lead to individualized therapies to control and potentially reverse scarring affecting different organ systems in patients with SSc.

PROFILE IN GIVING

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.



Karen and Bruce Bittmann with 2020 Philanthropists of the Year Award.

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!

Completed Project Summary:

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



Maria Trojanowska, Ph.D.

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).

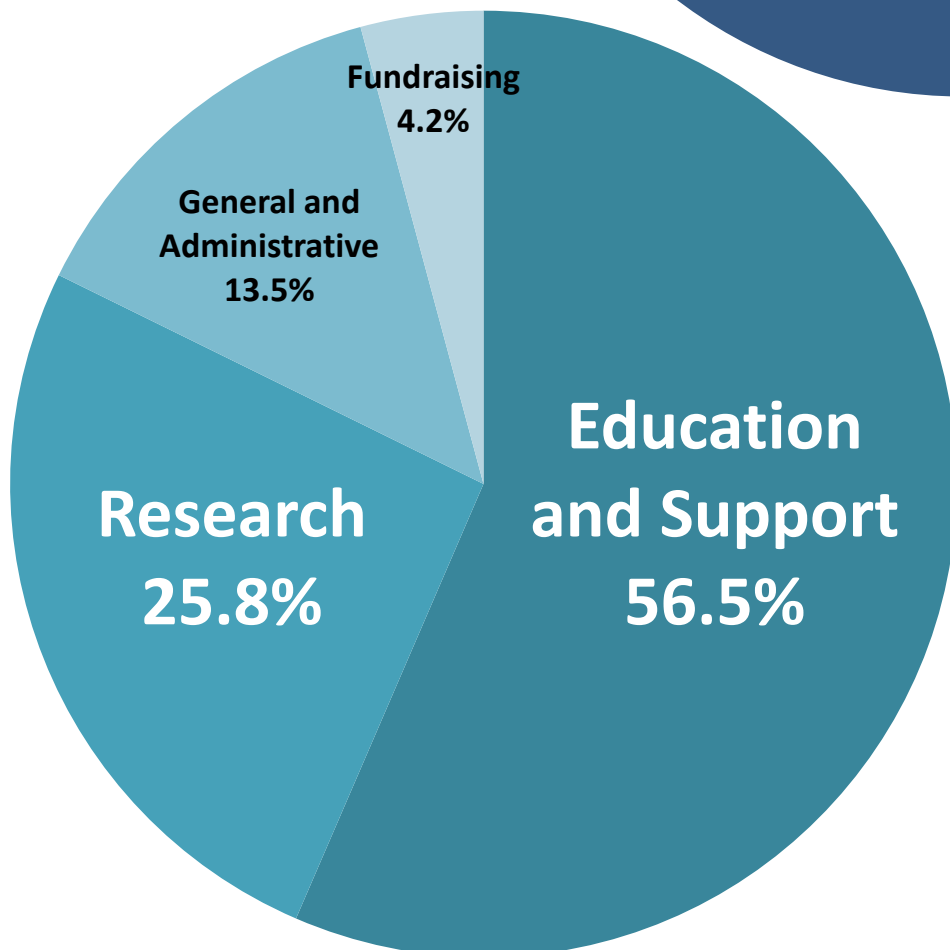
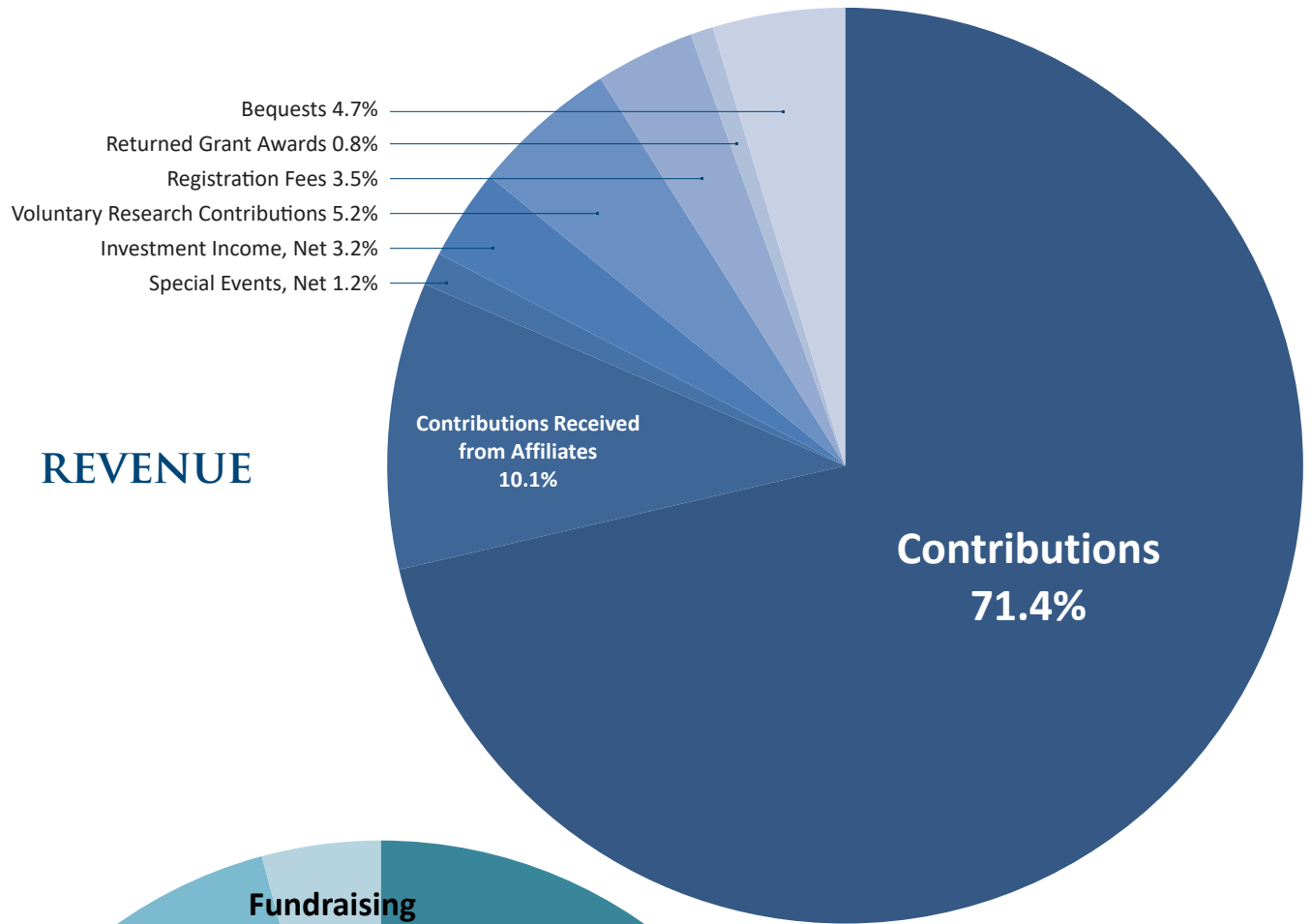
The main findings of the study demonstrated that: i) GATA-6 has a critical role in maintaining healthy lung vasculature and its loss in PAH leads to oxidative stress and mitochondrial dysfunction; ii) GATA6 is engaged in a bi-directional cross-talk with BMP10/BMP receptors axis and its loss in PAH contribute 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



STATEMENT OF ACTIVITIES FOR THE YEAR ENDED JUNE 30, 2020

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE AND OTHER SUPPORT:			
Contributions	\$2,312,438	\$314,877	\$2,627,315
Contributions Received from Affiliates	373,144	-	\$373,144
Special Events, Net of Direct Benefit to Donor Costs of \$235,114 and \$255,417. Respectively	42,981	-	\$42,981
Investment Income, Net	-	118,497	\$118,497
Voluntary Research Contributions*	-	190,000	\$190,000
Registration Fees	128,846	-	\$128,846
Returned Grant Awards	29,435	-	\$29,435
Bequests	172,010	-	\$172,010
Net Assets Released from Restrictions	620,623	(620,623)	\$0
Total Revenue and Other Support	3,679,477	2,751	3,682,228
EXPENSES:			
Program Services:			
Education and Support	2,803,960	-	2,803,960
Research	1,280,376	-	1,280,376
Total Program Services	4,084,336	-	4,084,336
Support Services:			
General and Administrative	672,226	-	672,226
Fundraising	207,761	-	207,761
Total Operating Expenses	4,964,323	-	4,964,323
(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.

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\$25,000 +

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Paula and Roy May
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\$10,000 - \$24,999

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\$25,000 - \$99,999

Boehringer Ingelheim

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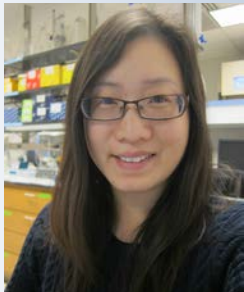
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Completed Project Summary:

Histone Deacetylases in Scleroderma: Investigation of Their Roles in Dysregulated Angiogenesis

Eliza PS Tsou, Ph.D., University of Michigan



Eliza PS Tsou, Ph.D.

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.

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