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Dear Friends:

The Scleroderma Foundation Board of Directors and staff are proud to present this report on efforts to advance our three-fold mission of support, education, and research. The report covers the 2017 fiscal year, which started July 1, 2016 and ended June 30, 2017. Included are a summary of our volunteer-led support groups around the country; an overview of patient education, including a recap of the National Patient Education Conference; and a review of research and grants awarded during the fiscal year.

Also in this report is a summary of the financial audit completed by the certified public accounting firm of Moody, Famiglietti & Andronico, LLP. Our total revenue was $5,619,735, which is an increase of nearly $1.5 million over fiscal year 2016. Our operating efficiency was very good, with only 12.5 percent of funds used for general and administrative, and 3.9 percent for fundraising... an impressively small number. We are deeply grateful to our generous donors and to our hard working volunteers and staff at chapters and in our national office for helping to achieve these results.

The challenges of living with scleroderma can be dramatic. For many, those challenges are life-threatening. While support and education are necessary and important, the only way we’re going to end scleroderma is by discovering the cause, understanding the mechanisms of the disease, and overcoming its symptoms. As we are already engaged in fiscal year 2018, we have planned and rolled out our first capital campaign, named Reach for the Cure.

The history of the Scleroderma Foundation is built on investing in new investigators with seed money to help them prove their ideas and then qualify for larger grants through the National Institutes of Health. It’s important to note that several of the most notable experts in scleroderma started their careers with funding from the Scleroderma Foundation’s predecessors. Additionally, we provide monies to established investigators to pursue innovative ideas that might not otherwise be funded by mainstream sources. We believe we stand at the threshold of a great new era in scleroderma research. To cross that threshold requires significantly more financial resources, hence the “Reach for the Cure” campaign.

The need is great. The time is now. The choice is yours. Join us as we reach for the cure.

Sincerely,

Cos M. Mallozzi
Chair, Board of Directors
Scleroderma is a chronic disease that affects the body’s connective tissue. Generally classified as an autoimmune rheumatic disease, it is characterized by an overproduction of collagen (fibrosis), which causes hardening of the 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 fatal. 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 is not uncommon for this form of the disease. En coupe de sabre is another classic form of scleroderma that 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.
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 20 chapters operate locally to provide support and education to individuals and families affected by scleroderma and to 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.

"We are at a point where we could start losing researchers."
– Virginia Steen, M.D.

"Scleroderma is a rare disease, and funding for scleroderma research through traditional public channels, such as the NIH, is more limited than for other diseases with larger populations," said Dr. Virginia Steen, chair of the foundation’s Medical and Scientific Advisory Board.

"The gap in available funding creates a far less promising environment for up and coming scientists."

"Receiving grants is the only way to establish and maintain a successful laboratory.

"It’s only natural that researchers tend to follow the path of study that offers readily available dollars," said Steen.
**Support**

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

**Inspire**

To facilitate connections among people who have scleroderma, the Scleroderma Foundation partners with Inspire.com, where a community of 33,642 (as of 6/30/17) freely exchange stories, seek advice, and encourage each other in their scleroderma journey.

- Discussions: 2,707
- Discussion replies: 24,838
- Journal entries: 374

Join the conversation at: www.inspire.com/groups/scleroderma-foundation.

**Public Policy Advocacy**

During fiscal year 2017, on September 13, 2016, 50 scleroderma advocates from 21 states, including people with scleroderma, caregivers, and Foundation staff and board members met in Washington, D.C., for Capitol Hill Day to engage Senators and Representatives on four critical issues.

1. Adequate funding for the National Institutes of Health, at least $34.5 billion, to expand and advance research.
2. Continue listing scleroderma as an eligible condition in the Department of Defense Peer-Reviewed Medical Research Program (PRMRP).
3. Co-sponsor the Scleroderma and Fibrosis Research Enhancement Act (H.R. 3666) to coordinate and advance fibrosis research at various NIH Institutes and Centers.
4. Co-sponsor the bipartisan Access to Marketplace Insurance Act (H.R. 3742) to ensure qualified charities can continue to provide payment assistance for individuals with rare, chronic conditions.

**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 PPFD 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. During 2017, the Foundation engaged with nine pharmaceutical/biotech companies to successfully develop unique PPFD programs. Several more are in planning stages for 2018. Looking ahead, we see PPFD and Patients as Partners continuing their rapid growth.
Volunteer-led **support groups** enable individuals with scleroderma to meet and exchange information with others who face similar problems. Groups host expert speakers from time to time on a range of topics. There are 160 Scleroderma Foundation-affiliated support groups around the country, although some geographic areas are less well represented.

**ALABAMA**
Calera
Florence *(Telephone)*
Huntsville

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

**ARKANSAS**
Benton

**CALIFORNIA**
Arcadia
Bakersfield
Camarillo
Culver City
Encinitas
Fountain Valley
Fresno
Glendale
Palm Desert
Palo Alto
Riverside
San Diego
Santa Barbara
Santa Maria
Santa Rosa
Sherman Oaks
Torrance
Turlock
Whittier

**COLORADO**
Colorado Springs
Denver
Grand Junction
Loveland
Virtual *(Telephone)*

**CONNECTICUT**
Enfield
Orange
Putnam

**DELAWARE**
Delaware *(Telephone/Email)*
Wilmington

**FLORIDA**
Boynton Beach
Ft. Myers *(Susan Marie Foundation)*
Jacksonville
Lady Lake
Margate
Miami
New Smyrna Beach
Orlando
Sarasota
Tampa

**GEORGIA**
Duluth
Peachtree City
West Poofer

**HAWAII**
Waipahu

**IDAHO**
Meridian

**ILLINOIS**
Decatur
Highland Park
Kankakee
Naperville
Peru/Illinois Valley *(Telephone)*

**INDIANA**
Hammond
Indianapolis *(Two)*

**IOWA**
Des Moines

**KANSAS**
Topeka
Wichita

**LOUISIANA**
Baton Rouge
Many
New Orleans

**MAINE**
Maine *(To Be Determined)*
South Berwick

**MARYLAND**
Chevy Chase
Columbia

**MASSACHUSETTS**
Boston
Topsfield
Worcester
Fall River

**MICHIGAN**
Ann Arbor
Auburn Hills
Clinton Township
East Detroit
Grand Rapids
Livonia
Taylor
Virtual *(Online)*

**MINNESOTA**
Duluth
Edina
Fridley

**MISSOURI**
Kansas City
Northeast Area
Poplar Bluff
Springfield
St. Louis

**NEBRASKA**
Lincoln
Omaha

**NEVADA**
Las Vegas

**NEW HAMPSHIRE**
Hamptstead
Bow

**NEW JERSEY**
Brick
Cherry Hill
Dover
Paramus

**NEW YORK**
Bay Shore
Binghamton
Clarence
Lake Success
Milford
New York City
Rochester
Schenectady
Scleroderma Super Starz *(Facebook)*

**NEW HAMPSHIRE**
ScleroMen *(Facebook)*
Walden

**NORTH CAROLINA**
Durham
Fayetteville
Winston-Salem

**OHIO**
Brecksville
Canfield
Cincinnati
Dayton
Dublin
Maumee
Mentor
Uniontown
Virtual *(Telephone)*

**OKLAHOMA**
Norman

**OREGON**
Portland
Beaverton

**PENNSYLVANIA**
Doylestown
Philadelphia
Pittsburgh
Williamsport
Wyomissing *(Reading)*

**PUERTO RICO**
San Juan

**SOUTH CAROLINA**
Charleston
Greenville
Rock Hill

**SOUTH DAKOTA**
Rapid City
Sioux Falls

**TENNESSEE**
Chattanooga
Gallatin
Memphis
Nashville

**TEXAS**
Austin
Bedford
Bryan

**UTAH**
Northern Utah *(Layton)*
Park City Utah

**VERMONT**
Williston
Brattleboro

**VIRGINIA**
Fairfax
Fredericksburg
Norfolk *(Telephone)*

**WASHINGTON**
Mount Vernon
Puyallup
Kennwick
Peninsula
Seattle
Spokane
Yakima

**WEST VIRGINIA**
Huntington
Weirton *(Telephone)*

**WISCONSIN**
Green Bay
Milwaukee
Madison

**SPANISH-SPEAKING**
Los Angeles
New York
Puerto Rico
Scleroderma Research & Treatment Centers

The Foundation has formal affiliations with Scleroderma Research & Treatment Centers around the United States. To be designated as a “center,” 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
Mayo Clinic Arizona (Scottsdale)

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

COLORADO
University of Colorado Scleroderma Program (Aurora)

CONNECTICUT
UConn Health Outpatient Pavilion (Farmington)
Yale University (New Haven), The Interventional Immunology Center
Yale University (New Haven), Winchester Chest Clinic (ILD)

DISTRICT OF COLUMBIA
Georgetown University, PHC Building, Dept. of Rheumatology

FLORIDA
Cleveland Clinic Florida (Weston)

ILLINOIS
Northwestern Scleroderma Program, Northwestern Medicine (Chicago)
University of Chicago, Scleroderma Clinic (Chicago)
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 (New Orleans)

MARYLAND
Johns Hopkins University School of Medicine, Johns Hopkins Scleroderma Center (Baltimore)

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

MICHIGAN
University of Michigan, Scleroderma Program (Ann Arbor)

MINNESOTA
Rheumatology Clinic, Clinics and Surgery Center (Minneapolis)
Mayo Clinic (Rochester)

NEW JERSEY
Division of Pediatric Rheumatology, Joseph M. Sanzari Children's Hospital (Hackensack)
Rutgers-RWJ Medical School (New Brunswick)

NEW YORK
Steffens Scleroderma Center (Albany)
Northwell Health Division of Rheumatology (Great Neck)
HSS, Scleroderma, Vasculitis, & Myositis Center (New York City)
Columbia University Medical Center/New York-Presbyterian Hospital Scleroderma Program (New York City)

NEW JERSEY
Division of Pediatric Rheumatology, Joseph M. Sanzari Children's Hospital (Hackensack)
Rutgers-RWJ Medical School (New Brunswick)

NEW YORK
Steffens Scleroderma Center (Albany)
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Northwell Health Division of Rheumatology (Great Neck)
HSS, Scleroderma, Vasculitis, & Myositis Center (New York City)
Columbia University Medical Center/New York-Presbyterian Hospital Scleroderma Program (New York City)

NORTH CAROLINA
Duke Scleroderma Research Center Clinic (Durham)

OHIO
University of Cincinnati Medical Center – CTD-ILD and Scleroderma Clinic (Cincinnati)
University of Toledo Scleroderma Program (Toledo)

PENNSYLVANIA
The Scleroderma Center of Thomas Jefferson University (Philadelphia)
Penn Scleroderma Center, Hospital of the University of Pennsylvania (Philadelphia)
Penn Scleroderma Center, Penn Medicine Radnor (Philadelphia)
Penn Scleroderma Center, Penn Medicine Valley Forge (Philadelphia)
UPMC & University of Pittsburgh, Arthritis and Autoimmunity Center (Pittsburgh)
UPMC & University of Pittsburgh, Children's Hospital of Pittsburgh, Pediatric Rheumatology Department (Pittsburgh)

SOUTH CAROLINA
Medical University of South Carolina (Charleston)

TENNESSEE
University of Tennessee Health Science Center (Memphis)

TEXAS
University of Texas Scleroderma Clinic (Houston)

UTAH
University of Utah Scleroderma Center (Salt Lake City)

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

WISCONSIN
Medical College of Wisconsin/ Froedtert Hospital (Milwaukee)
Education

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

Information is possibly the most valuable service we offer. Our National Patient Education Conference is the preeminent 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

- 18th Annual Conference
- July 29-31, 2016
- New Orleans, Louisiana
- Record-breaking 638 registered guests
- Record-breaking 77 attendees for fifth Youth Program.
- 75 chapter leaders and 7 national board members attended Leadership Day.
- Scientific poster session Friday night
- Mary Woolley, president and CEO of Research!America, keynote session, “Turning a Moment into a Movement: Your Role in Advocacy for Research.”
- Grand Lecture by Dr. Richard Silver, “Shortness of Breath?”
- Keynote address by Andrew Botieri
- 74 presentations (58 first time offerings)

Many thanks to sponsors and exhibitors:

- Actelion Pharmaceuticals US, Inc.
- Bayer Healthcare
- Andrew Botieri
- Caring Voice Coalition
- Cytori Therapeutics, Inc.
- Gilead Sciences, Inc.
- Hawaiian Moon
- TOSS: An internet self-management program for scleroderma
- Laclede Inc.
- NeilMed Pharmaceuticals Inc.
- Pulmonary Fibrosis Foundation
- Pulmonary Hypertension Association
- Reata Pharmaceuticals, Inc.
- Scleroderma Foundation Advocacy Program
- Scleroderma Patient-centered Intervention Network (SPIN)
- Tulane Lung Center
- United Therapeutics
- Waterblocker Skin Cream
- Welmedix Consumer Healthcare
- Wristies, Inc.

Major Sponsors
Physician education programs, with continuing education credits (CME), keep the medical community abreast of scleroderma issues.

The continuing medical education (CME) and continuing nurse education (CNE) initiatives are vital tools in advancing awareness and understanding of scleroderma and its comorbid conditions among medical professionals.

Because scleroderma is a systemic disorder, patients are typically under the care of multiple specialists in the course of disease management, depending on the particular organ system(s) affected by the disease (e.g., skin, heart, lungs, kidneys, digestive track, etc.).

There is a great need to educate medical professionals on the various manifestations of scleroderma to foster quick and accurate diagnosis to enhance patient outcomes and quality of life.

The CME and CNE program allows the Scleroderma Foundation to provide continuing education credits to professionals as they learn more about this complex disease.

Patient Education

On May 20, 2017, in collaboration with the American Thoracic Society Public Advisory Roundtable, the Foundation hosted a “Meet the Expert” event in Washington, D.C.

On June 10, 2017, in collaboration with the American Thoracic Society Public Advisory Roundtable and the University of Pittsburgh Scleroderma Center, the Foundation hosted a patient education day. The free, day-long event was well-attended by 78, and was live streamed.

Research gives hope to people living with scleroderma for a better and fuller quality of life.”
- Janet Pope, M.D.

Scleroderma is a rare disease, but research has already improved the survival time of those living with pulmonary arterial hypertension, a complication in 15% of people living with scleroderma. This is one example of why research matters. Following people living with scleroderma in registries allows for characterization of treatments that can help patients when there is no proven therapy.

Utilizing many expert researchers in scleroderma, we have gained consensus for second and third line treatment for many symptoms and complications such as Raynaud’s, interstitial lung disease, inflammatory arthritis, kidney involvement and others. This helps patients who need treatment after other medications have been tried. Research allows for some of the experts’ suggestions to be tested in patients to see which treatment is superior.
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** the symptoms of scleroderma.

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 19 years, the Foundation has funded **$23 million** in grants through the generosity of donors who share our commitment to stimulate innovative research.

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 the following:

- **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?

In fiscal year 2017, we funded three different 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.

- **Multi-Center Collaborative Research Grants** to foster a more synergistic research community. Made possible by a grant from the Kao Family Foundation, this award supports two or more institutions to significantly enhance scleroderma research.

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 Marie Coyle Award** is named in honor of a founder of the Scleroderma Foundation who also has scleroderma.

- **The Multi-Center Collaborative Grant** is funded by the generosity of the Kao Family Foundation.

We wish to acknowledge and thank the Scleroderma Foundation **Tri-State Chapter** for generously funding an additional research grant of $150,000 through the Foundation’s Collaborative Research Grant Program.

The 2017 research grant awards on the following page honor the efforts of those who are making significant commitments to searching for a cure. The Scleroderma Foundation continues to foster and support education among scleroderma research programs internationally, and we are grateful to the donors who make this critical research program possible.
2017 Scleroderma Foundation Research Grant Awardees

Robert A. Lafyatis, M.D.
University of Pittsburgh
Marta Marx Fund for the Eradication of Scleroderma
**PROJECT:** Single Cell Transcription of Dermal Mesenchymal Cells in Systemic Sclerosis

Ai P. Lam, M.D.
Northwestern University
The Mark Flapan Award
**PROJECT:** Monocyte Differentiation by Wnt/Beta-Catenin in Signaling Systemic Sclerosis Interstitial Disease

Bradley A. Maron, M.D.
Brigham and Women’s Hospital
Marie A. Coyle Research Grant
**PROJECT:** Endothelial Exosomes Regulate Pulmonary Vascular Fibrosis in Scleroderma

Maria Trojanowska, Ph.D.
Boston University Medical Center
The Kao Family Foundation Score Grant
**PROJECT:** Preclinical Assessment of Dimethylfumarate (Tecfidera®) as a Novel Therapeutic for SSC-PAH

Theresa Lu, M.D., Ph.D.
Hospital for Special Surgery
Tri-State Chapter Research Grant
**PROJECT:** Leptin Receptor-Expressing Adipose-Derived Stromal Cells as a Putative Skin-Protective Subpopulation

Sergei P. Atamas, M.D., Ph.D.
Baltimore Research and Education Foundation
**PROJECT:** Exploring the Antifibrotic Potential of SIRT7

Rebecca Lee, M.D., M.S., Ph.D.
Medical University of South Carolina
**PROJECT:** MSC Fate and Treatment of SSC: Modulation by Chemokine Receptor Antagonists

Monica Mukherjee, M.D., M.P.H.
Johns Hopkins University School of Medicine
**PROJECT:** Noninvasive Detection of Occult Right Ventricular Dysfunction in Systemic Sclerosis

Peter Joseph Wermuth, Ph.D.
Thomas Jefferson University
**PROJECT:** Characterization of The Molecular Content and Paracrine Effects of Profibrotic and Antifibrotic MicroRNA in Exosomes Isolated from Serum of Systemic Sclerosis

**VOLUNTARY RESEARCH FUND CHAPTER PLEDGES**

- Delaware Valley: $30,000
- Georgia: $40,000
- Greater Chicago: $50,000
- Greater Washington, DC: $5,000
- Heartland: $20,000
- Michigan: $10,000
- Minnesota: $10,000
- Missouri: $23,000
- New England: $78,000
- Ohio: $40,000
- Oklahoma: $10,000
- Oregon: $35,000
- Rocky Mountain: $10,000
- South Carolina: $7,500
- Southeast Florida: $5,000
- Southern California: $48,000
- Tennessee: $10,000
- Texas Bluebonnet: $8,250
- Tri-State: $150,000
- Washington Evergreen: $15,000

**Total pledges:** $604,750
Fundraising

Stepping Out to Cure Scleroderma: July 1, 2016 - June 30, 2017

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.

Total Stepping Out events: 60
Total active registrations: 6,931
Total number of donors: 10,366
Total number of teams: 748
Total dollars from gifts: $783,085
(Offline gifts: $343,270)
(Online gifts: $439,815)
Total registration fees: $151,051

Stepping Out Locations by Chapter

DELWARE VALLEY
Farmingdale, N.J.
Ventnor, N.J.
Downington, Penn.
Philadelphia, Penn.
York, Penn.

GEORGIA
Lilburn, Ga.

GREATER CHICAGO
Dixon, Ill.
Geneva, Ill.
Highland Park, Ill.
Springfield, Ill.
Highland, Ind.
Germantown, Wis.
Madison, Wis.

GREATER WASHINGTON D.C.
Baltimore, Md.

HEARTLAND
Des Moines, Iowa
Omaha, Nebr.

MICHIGAN
Detroit, Mich.

MINNESOTA
St. Paul/Twin Cities, Minn.

MISSOURI
Kansas City, Kans.
St. Louis, Mo.

NEW ENGLAND
Boston, Mass.
Plymouth, Mass.
Topsfield, Mass.
Westfield, Mass.
Westbrook, Me.

OHIO
Boardman, Ohio
Cincinnati, Ohio
Dayton, Ohio
Peninsula, Ohio
Toledo, Ohio

OKLAHOMA
Broken Arrow, Okla.

OREGON
Portland, Ore.

ROCKY MOUNTAIN
Aurora/Denver, Colo.
Fort Collins, Colo.

SOUTH CAROLINA
Columbia, S.C.

SOUTHEAST FLORIDA
Coconut Creek, Fla.

SOUTHERN CALIFORNIA
San Diego, Calif.

TENNESSEE
Nashville, Tenn.

TEXAS BLUEBONNET
Dallas, Texas
Houston, Texas
San Antonio, Texas

TRI-STATE
Hartford, Conn.
Stamford, Conn.
Ridgefield Park, N.J.
Albany, N.Y.
Binghamton, N.Y.
Buffalo, N.Y.
Long Island, N.Y.
Manhattan, N.Y.
Poughkeepsie, N.Y.
Rochester, N.Y.
Staten Island, N.Y.
Syracuse, N.Y.
Westchester County, N.Y.

WASHINGTON EVERGREEN
Seattle, Wash.
Spokane, Wash.

INDEPENDENT
Jacksonville, Fla.
Barbourville, W.V.
Chesapeake, Va.

VIRTUAL
Cytori Therapeutics, Inc.
Hope Raisers

Many who fundraise to overcome scleroderma do so independently by organizing events and inviting their family, friends, and coworkers to participate. The Scleroderma Foundation provides a platform for online fundraising through its website, called Hope Raisers. This robust software 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 online fundraising for just about anything you do to raise money. If you are running in a local marathon and want to use it as a vehicle to raise money, you can create a Hope Raiser event. If you’re hosting a theme party or a golf tournament, you can create a Hope Raiser. If you want to honor a loved one who has scleroderma, you can create a Hope Raiser.

During fiscal year 2017, there were 25 independent fundraising events planned, organized, and executed by local folks all over the country. Their combined efforts raised $27,292 to advance our three-fold mission of support, education, and research. Thank you!

Among the Hope Raisers were the Ciszon family, which hosts the Tournament of Non-Champions golf event to honor a beloved member of their family who passed away from complications caused by scleroderma. This annual golf tournament is a fun event that started seven years ago with just 15 golfers and now hosts more than 100. It has grown not only in the number of participants but in dollars raised. Participants enjoy on-course competitions, raffle prizes, and more. Many golfers show up decked-out in teal. The day even includes a unique “Tournament of Non-Champions” teal trophy for the winner.

The Ciszon’s family lost a beloved mother, wife, grandmother, and friend in 2016. They continue to honor her each year with this unique event. Marty Ciszon wrote, “We cannot thank you enough for your generosity and contributions. It’s truly an amazing experience to see so many people come together for a single cause and have such a tremendous impact and not to mention to do so while having an absolute blast together at the Tournament of Non-Champions!”

“We still have many unanswered questions in systemic sclerosis, and research is our key to getting these questions answered.”
- Jessica Gordon, M.D., M.Sc.

In order to define optimal treatments for the diverse manifestations of scleroderma, we need to better understand the molecular mechanisms of this disease.

Many advances have been made in the tools that are available today to determine and analyze levels of thousands of genes and proteins at any moment in a given individual.

I am hopeful that the information we are able to generate coupled with deep clinical understanding will lead to improvements in treatment options and outcomes for our patients.
“One just needs to look at the current state of these avenues of research to be deeply heartened about the almost tangible future.”

- Lesley Ann Saketkoo M.D., M.P.H.

Systemic sclerosis (SSc), a not so rare ‘rare’ disease, provides a quintessential model for examining multi-tiered mechanisms of all potentially inflammatory or fibrosising diseases. But because of the life-threatening nature and the multi-organ, extreme and diffuse landscape symptom burden that SSc carries, the research community is charged with two overarching tasks:

1. Find a cure, or at least a treatment that has significant and lasting impacting on disease progression, and
2. Understand how to help people live as fully as possible in all major life areas (that means loving, working, and playing).

Both of these seemingly overwhelming areas, with the research support, are within our reach. There is a strong contribution we can make to other life-impairing diseases by dedicated research to systemic sclerosis.
## Statement of Activities for the Year Ended June 30, 2017

### Revenue & Other Support:

<table>
<thead>
<tr>
<th>Description</th>
<th>Unrestricted</th>
<th>Restricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
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<tr>
<td>Contributions</td>
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<td>$378,443</td>
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<td>$2,353,052</td>
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<tr>
<td>Bequests</td>
<td>699,891</td>
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<td>Special Events, Net</td>
<td>620,947</td>
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<td>620,947</td>
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<tr>
<td>Voluntary Research Contributions</td>
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<td>474,989</td>
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<td>474,989</td>
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<td>Net Unrealized Gains (Losses) on Investments and Endowment</td>
<td>415,890</td>
<td>47,365</td>
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<td>463,255</td>
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<td>Contributions Received from Affiliates</td>
<td>430,581</td>
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<tr>
<td>Net Realized Gains on Investments and Endowment</td>
<td>260,794</td>
<td>40,748</td>
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<td>301,542</td>
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<td>Interest and Dividends</td>
<td>127,355</td>
<td>39,317</td>
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<td>166,672</td>
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<td>Registration Fees</td>
<td>106,806</td>
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<tr>
<td>Other Income</td>
<td>2,000</td>
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<tr>
<td>Net Assets Released from Restrictions</td>
<td>982,650</td>
<td>(982,650)</td>
<td></td>
<td></td>
<td>-</td>
</tr>
<tr>
<td><strong>Total Revenue &amp; Other Support</strong></td>
<td><strong>5,621,523</strong></td>
<td><strong>(1,788)</strong></td>
<td></td>
<td></td>
<td><strong>5,619,735</strong></td>
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</table>

### Expenses:

<table>
<thead>
<tr>
<th>Description</th>
<th>Unrestricted</th>
<th>Restricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Services:</td>
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<tr>
<td>Education and Support</td>
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<td>Research</td>
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<tr>
<td><strong>Total Program Services</strong></td>
<td><strong>4,349,933</strong></td>
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<td></td>
<td></td>
<td><strong>4,349,933</strong></td>
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<td>Support Services:</td>
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<td></td>
</tr>
<tr>
<td>General and Administrative</td>
<td>649,463</td>
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<td></td>
<td>649,463</td>
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<tr>
<td>Fundraising</td>
<td>203,168</td>
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<td></td>
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<td>203,168</td>
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<tr>
<td><strong>Total Support Services</strong></td>
<td><strong>852,631</strong></td>
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<td></td>
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<td><strong>852,631</strong></td>
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<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>5,202,564</strong></td>
<td></td>
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<td></td>
<td><strong>5,202,564</strong></td>
</tr>
</tbody>
</table>

| Increase (Decrease) in Net Assets                | 418,959      | (1,788)    |                        |                        | 417,171     |

| Net Assets at Beginning of Year                  | 7,834,454    | 274,668    | 1,542,375              |                        | 9,651,497   |

| Net Assets at End of Year                        | **$8,253,413**| **$272,880**| **$1,542,375**         |                        | **$10,068,668**|

*Audit performed by MFA: Moody, Famiglietti & Andronico, LLP, Tewksbury, Mass. Complete copies of the Foundation’s fiscal year 2017 audited financial statements and IRS form 990 are available from the National Office and on scleroderma.org.*
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**THANK YOU** to all of our donors for choosing to take action and advancing the mission of the Scleroderma Foundation. Their generosity creates hope for everyone affected by scleroderma.

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“Without research there is no discovery; with discovery comes the potential for cure.”

- Tracy M. Frech, M.D., M.S.

Research is a commitment from the scientific community to bring discovery to the patients who have generously provided valuable information about their disease process.

Research can include questionnaire answers, laboratories, clinical imaging results, and/or tissue biopsies; all which have value in moving the field forward.

This research partnership matters because it is how our community can improve its understanding of diagnosis, treatment, and outcomes.
“There is every cause for optimism, but there is also much work to be done.”
- Maureen D. Mayes, M.D., M.P.H.

Our best hope for discovering safe and effective therapies for scleroderma lies in research efforts by physicians and scientists. Current treatments are helpful but by no means curative and they frequently include a risk of side effects which limit their use.

Over the past 3 decades, I have been privileged to take part in the development of clinical and basic science research centers focusing on scleroderma. As a result, there have been major advances in our knowledge of underlying mechanisms of this disease. But so much more needs to be done.

We now understand that there are multiple subsets of scleroderma and not everyone can be expected to respond to the same medication. We need to better define these subsets, identify biomarkers that predict response and target the right drug in the right patient.
<table>
<thead>
<tr>
<th>ORGANIZATIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>$100,000 +</strong></td>
</tr>
<tr>
<td>Actelion Pharmaceuticals US, Inc.</td>
</tr>
<tr>
<td>Estate of Angela Solicalcio Bertoli Family Trust</td>
</tr>
<tr>
<td>Bayer Healthcare</td>
</tr>
<tr>
<td>Reata Pharmaceuticals, Inc.</td>
</tr>
</tbody>
</table>

| **$25,000 +** |
| Gilead Sciences, Inc. |
| Genentech Inc. |
| Haberman Family Foundation |

| **$10,000 - $24,999** |
| Estate of Gusinda Brown Paper Tickets, LLC Beta Sigma Phi/Northern California Council The Benevity Community Impact Fund Estate of Eleanor Dibello Estate of Jarrett and Patricia Rose Bethpage Federal Credit Union |

| **$5,000 - $9,999** |
| Carmen’s Crew Key West Beta Sigma Phi/Southern California Council Canyon Vista Middle School Beta Sigma Phi/Endowment Fund Corbus Pharmaceuticals Cytori Therapeutics, Inc. Schwab Charitable Fund Select Rehabilitation, Inc. Walter J. & Natalie M. Rais Charitable Trust Crane Foundation, Inc. Jarden Foundation |

| **$1,000 - $4,999** |
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