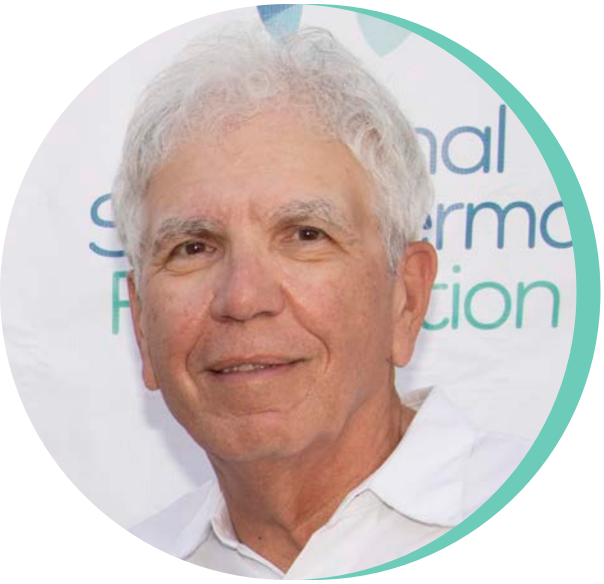
National Scleroderma Foundation

Progress Report

Fiscal Year July 1, 2020 - June 30, 2021

Emilie Grace Julian (left), diagnosed 2016, and her mother, Fernella Julian.

Chair's Message



Dear Friends:

Since 1998, the National Scleroderma Foundation has been a relentless force in finding a cure and improving the lives of people affected by scleroderma. Since its early days, my family has had the honor of being involved with the Foundation, but this past year stands out for many reasons.

In the fiscal year 2021 (July 1, 2020 – June 30, 2021), the Foundation committed more than $3.4 Million to its mission pillars of support, education, and research.

Our chapter and support group leaders provided meaningful peer-to-peer connections at the local level for everyone; from those newly diagnosed to long-time champions. With our 19 chapters and 147 support groups across the country, our community has led the way in meeting the needs of people impacted by scleroderma. Whether it is a virtual support group bringing together people from a specific city or town or a topical support group connecting individuals' shared experiences, the value of this work is immeasurable.

Our signature National Scleroderma Conference and Kids Get Scleroderma, Too! Conference provide access to world-renowned scleroderma experts and are the central meeting ground of the scleroderma community. We hosted our first-ever virtual conferences last year and drew the same audience we have come to expect at our in-person events. This is a testament to the quality of education our experts provide and the engagement of our people.

The Foundation is the leading nonprofit funder of peer-reviewed research. In fact, last year, the Foundation more than doubled its commitment to research and pledged to continue investment in tomorrow's treatments and care. By advancing research to discover the cause of scleroderma and understand its mechanisms, we are working to overcome this disease forever. As we pursue this goal, the Foundation also works to provide people with better treatment and increased access to care at our designated research and treatment centers across the country.

While the last year found us amid a pandemic, our community has proved that our resolve is stronger than ever, and our fight against scleroderma cannot be stopped. Thanks to the generous support of our donors, we have made great strides to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families and support networks. With this year's Annual Report, we invite you to learn more about our mission's impact on the scleroderma community and join us on this journey.

Sincerely,

Cos M Mallozzi

Cos M. Mallozzi
Chair, Board of Directors

Scleroderma

Scleroderma is a rare 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 (systemic sclerosis) 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. Skin involvement can also occur in systemic sclerosis.

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.

More than 300,000 Americans are estimated to live with some form of scleroderma. The face of scleroderma includes people of all ages, genders, and backgrounds. Scleroderma can affect young adults, children, grandparents, and teenagers. Symptoms of scleroderma can impact a person's life by ending a career or causing isolation from peer groups and society.

Katie Kinson, diagnosed 2003

Mission

Ian Crego, diagnosed 2016

A relentless force in finding a cure and improving the lives of people affected by scleroderma, the mission of the National Scleroderma Foundation is to **advance medical research, promotes disease awareness, and provides support and education to people with scleroderma, their families and support networks**.

Supported by a network of thousands of individuals across the United States, the Foundation is the leading nonprofit funder of peer-reviewed research to **discover** the cause, **understand** the mechanisms, and **overcome** scleroderma forever.

Our signature **National Scleroderma Conference** and **Kids Get Scleroderma, Too!** conference provide access to world-renowned scleroderma experts and are the central meeting ground of the scleroderma community.

In 2022, the Foundation reaffirmed the nationwide breadth and scope of the organization and changed its name to the National Scleroderma Foundation. Our network of chapters operate locally to provide support and education to individuals and families affected by scleroderma and to drive fundraising to fuel research.

No two scleroderma journeys are the same. No matter what form of scleroderma or where you or your child or loved one are in your journey, the National Scleroderma Foundation can help you find your best path.

Mission Pillars

Support

To help individuals 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.

Support

Public Policy Advocacy

On June 29, 2020, the Foundation conducted a **National Day of Action** to channel the energy of the nationwide scleroderma community into a clear request to Congress to hear the needs of people affected by scleroderma.

Knowing it would not be possible to conduct a traditional, in-person Capitol Hill Day due to the COVID-19 pandemic, the Foundation turned to a dynamic option: a virtual advocacy activity that respected social distancing and helped allow the Foundation to keep its promise to advocate for people whose lives are affected by scleroderma.

In total, 225 people registered for the event, and we generated more than 200 emails and phone calls to legislators. Of the registrants, 65 percent were new to advocacy -- a strong showing of members of the scleroderma community who were ready to step up and say that they need their government to work for them. Significantly, the advocacy effort also brought on two new cosponsors for H.R. 3446, the National Commission on Scleroderma and Fibrotic Diseases Act.

As in other years, our public policy advocacy this year was a vital activity of the National Scleroderma Foundation. With input from our advocates, legislators learned how their laws could improve the lives of people with scleroderma, their families, and their communities. First-hand accounts from constituents (our advocates) provided uniquely compelling information for their elected officials.

The Foundation's Advocacy Program and 2020 National Day of Action were sponsored in part by grants from Diamond National Sponsors Actelion and Boehringer Ingelheim.

Patients as Partners

Bringing the VOICE of the patient to the development of NEW therapies

The Foundation is a leader in programs for patient focused drug development (PFDD). Our successful **Patients as Partners** program (PaP) is designed to work in concert with industry on a variety of needs across all areas of drug development from clinical trial protocol development through FDA approval and post-approval activities. PaP is a unique an opportunity for people with scleroderma to engage with pharmaceutical and biotech companies ensuring their voice is heard in all stages of drug development, thus better tailoring their experience while advancing drug and therapy development.

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 and 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 allowed the program to expand virtually. We are excited to continue working with companies on this critical work ensuring those living with scleroderma have the best possible medications and therapies available to them.

Support Groups

Volunteer-led **support groups** enable individuals with scleroderma to meet and exchange information with others who face similar problems. There are 147 volunteer-led support groups around the country that affiliated with the Foundation. To ensure a quality experience for all participants, the Foundation utilizes 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

CALIFORNIA
Bakersfield/Kern
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 Connecticut
North Haven

DELAWARE
Delaware (*Telephone/Email*)
Dover
Wilmington

FLORIDA
Boca Raton
Fort Myers
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

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
The 20% Men's Support Group (*Virtual*)
Parents of Children with Scleroderma (*Virtual*)
St. Joseph

MINNESOTA
North Metro (Fridley)
West Metro (Edina)

MISSOURI
Kansas City
Poplar Bluff
Springfield
St. Louis

NEBRASKA
Omaha

NEW HAMPSHIRE
Bow
Hampstead

NEW JERSEY
Brick
Burlington/Camden (Cherry Hill)
Monmouth/Ocean County
Northern New Jersey

NEW MEXICO
Albuquerque (*Parents and Teens*)

NEW YORK
Albany (Schenectady)
Buffalo (Clarence)
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)
Northeast Ohio/Greater Cleveland (North Royalton)
Toledo
Virtual (*Telephone*)
Youngstown

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*)

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

WEST VIRGINIA
Huntington
Weirton (*Telephone*)

WISCONSIN
Green Bay
Madison
Milwaukee

WYOMING
Rawlins (*Virtual*)

SPANISH-SPEAKING
Los Angeles
New York
Miami

Support Groups as of March 2022

Education

In response to the outbreak of the COVID-19 pandemic in 2020, the Foundation pivoted to a series of webinars called *Virtual University* to maintain quality programming while protecting the health and safety of individuals who have scleroderma. The free, weekly webinars ran from July to November. Recordings are available on the Foundation's YouTube channel.

Virtual University Education Series

Summer Series:

July 8 - ***Telemedicine: Strategies for a Successful Visit***; JoAnna Harper, PharmD, RPh, CEO of Pain Partners, LLC

July 15 - ***Scleroderma Medications: What Works? How Can I Get It?*** Jessica Farrell, PharmD, Albany College of Pharmacy and Health Sciences

July 22 - ***Cannabis Conundrum: Weighing the Pros and Cons of THC, CBD, and Related Compounds in Scleroderma***; JoAnna Harper, PharmD, RPh, CEO of Pain Partners, LLC

July 29 - ***How to Navigate Going Back to College in the Age of COVID-19***; Sneha Dave, Founder & Executive Director, Health Advocacy Summit

August 5 - ***Scleroderma Lung Disease***; Jerry Molitor, MD, PhD, University of Minnesota Medical School

August 12 - ***Fun Science: How to Extract DNA from Fruits*** (Kids Get Scleroderma, Too! Webinar); Carol Feghali-Bostwick, PhD, MUSC College of Medicine.

August 19 - ***What Do Your Dentists and Your Physicians Want You to Know About Scleroderma, Oral Health, and You?*** David Leader, DMD, MPH, Tufts University School of Dental Medicine

August 26 - ***Skin Care and the Art of Camouflage Makeup***; Vivian Stephens, professional makeup artist.

Fall Series:

September 2 - ***Pain: Its Causes and Its Treatments***; Daniel E. Furst, MD, MACR, University of California, Los Angeles

September 9 - ***Manifestaciones Gastrointestinales de la Esclerodermia*** (Presentado en Español); Fabian Mendoza-Ballesteros, MD, Thomas Jefferson University

September 16 - ***The Importance of Sleep When Living with Chronic Lung Disease***; Mihaela Teodorescu, MD, MS, University of Wisconsin, School of Medicine and Public Health

September 23 - ***Gentle Yoga & Yogic Breathing for Scleroderma Symptom Management***; Sundar Balasubramanian, PhD, C-IAYT, Medical University of South Carolina

September 30 - ***Part I: Taking the Mystery Out of Hospice and Palliative Care***; Mary Crowe, LICSW, ACHP-SW, CDS, Care Dimensions

October 7 - ***Learning to Love Our Friend - The Gut***; Lesley Ann Saketkoo, MD, MPH, Tulane University School of Medicine

October 14 - ***Connecting as a Young Adult with Scleroderma***. Panel Moderator: Amy Gietzen, Patient Advocate (Dx 2001). Panelists: Cat Davis (Spokane), Alejandra Serrano (Los Angeles), Fatema Shahab (Los Angeles), Shervin Ghanoongooi (Los Angeles)

October 21 - ***Coping with Both a Pandemic and Scleroderma***, Lee Shapiro, MD, Albany Medical College, and Steffens Scleroderma Foundation

October 28 - ***Making Decisions When It Matters Most: Conversations About Health Care Proxy, Five Wishes and More!*** Mary Crowe, LICSW, ACHP-SW, CDS, Care Dimensions

November 18 - ***Manejo de la Esclerosis Sistemica: Perspectivas Actuales y Futuras*** (Presentado en Español); Fabian Mendoza-Ballesteros, MD, Thomas Jefferson University

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Many Thanks to Our Virtual University Sponsors

Diamond National Sponsors

ACTELION
A JANSSEN PHARMACEUTICAL COMPANY OF Johnson&Johnson

Boehringer Ingelheim

Corporate Sponsors

CORBUS PHARMACEUTICALS

HORIZON

Virtual Education Programs

The Foundation is committed to providing the highest quality educational opportunities for people affected by scleroderma, In Fiscal Year 2021, two webinars were offered on the topics below.

> The March 9, 2021, the **Coping with Mental Health** young adult panel discussion focused on the mental health attributes of chronic illness. Panel members, led by facilitator Amy Gietzen, walked through the hardships of coping with the disease and discussed how it also affects loved ones.
>
> On March 24, 2021, the Foundation, along with American Thoracic Society (ATS), and the PH Aware Global Association hosted Pulmonary Vascular Diseases, presented **Pulmonary Hypertension & Scleroderma MYTHBUSTERS**, as a virtual roundtable discussion. The webinar was part of the "Lung Disease Week at the ATS" initiative, a program designed to facilitate information exchange between patients and experts on matters relating to lung and airway disorders.

Chapter Education Programs

Foundation chapters play an important role in educating the community. The impact of the COVID-19 pandemic during Fiscal Year 2021 was significant. However, chapters showed resilience and flexibility by converting many of those activities into virtual events.

Delaware Valley Chapter
March 9, 2021

Greater Chicago Chapter
Webinar Series
July 14, 2020
July 29, 2020
August 4, 2020
October 15, 2020
February 13, 2021
March 4, 2021
Scleroderma 101
April 22, 2021

Heartland Chapter
8th annual Sclero-What?
October 10, 2020

Michigan Chapter
Webinar Series
July 202
August 2020
September 2020
October 2020,
November 2020
December 2020
January 2021
February 2021
March 2021
April 2021
May 2021

Minnesota Chapter
Oct. 17, 2020

Missouri Chapter
October 17, 2020

Oregon Chapter
Annual Cheri Woo Scleroderma Education Seminar
March 13, 2021

Rocky Mountain Chapter
Virtual Education Day
October 3, 2020

South Carolina Chapter
11th Annual Amy K. Parrish Education Conference
February 2021
Scleroderma Awareness Live Q&A
June 17, 2021

Southeast Florida
October 2020

Southern California Chapter
Webinar
April 10, 2021

Texas Bluebonnet Chapter
Virtual Education Day
February 27, 2021

Tri-State Chapter
HSS Virtual Education Conference
October 25, 2020
Support Group Education Event
April 26, 2021
Support Group Education Event
May 24, 2021

Monica Ramirez, diagnosed 2016

Research

The National 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 the course of our history, the Foundation has funded more than **$30 million** in grants thanks to 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:

- **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?

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.

For many years, three research grants, named in honor of individuals who made major contributions to those affected by scleroderma, were awarded to the highest scoring projects:

- 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 National Scleroderma Foundation, Marie Coyle, who also had scleroderma, and her husband.

In June of 2021, the Foundation announced the new **Debra Lurvey Memorial Research Grant,** an endowed grant established thanks to the generosity of Greg Lurvey, in memory of his wife, Debra Lurvey, who lost her battle to scleroderma. The award will be presented annually, starting in the 2022 grant year, to an established researcher focusing on scleroderma-related lung research. The $200,000 award is for a two-year commitment.

The Foundation also announced an increase in research funding, more than doubling the annual commitment to $2.73 million. These funds will be available also starting in the 2022 grant year.

The National Scleroderma Foundation is delighted to support the class of 2021 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.

2021 National Scleroderma Foundation Research Grant Awardees

Ido Amit, PhD

Weizmann Institute of Science

The Marta Marx Fund for the Eradication of Scleroderma

Established Investigator Award

Comprehensive Single Cell Analysis of Skin and Blood of Scleroderma Patients: Towards Identification of Disease Molecular Mechanisms, Prognostic Biomarkers and Potential Therapeutic Targets.

Jonathan A. Garlick, DDS, PhD

Tufts University School of Dental Medicine

The Mark Flapan Award

Established Investigator Award

Functional Analysis of Cellular Diversity and Cell-Cell Interactions in Scleroderma 3D Skin-Like Tissues

Hans Dooms, PhD

Boston University

Walter & Marie Coyle Research Grant

Established Investigator Award

Functional Characterization of Aberrant PD-1+TIGIT+T Cell Subsets Expanded in Systemic Sclerosis Patients

Harry Karmouty-Quintana, PhD

University of Texas Health Science Center at Houston

Established Investigator Award

The Role of SIX1 in SSc-ILD

Mengqi Huang, PhD

University of Pittsburgh

New Investigator Award

Investigation of Disease Associated Skin Endothelial Cells in Systemic Sclerosis Using Single-Cell Transcriptomics and Epigenomes

Kimberly Showalter, MD, MS

Hospital for Special Surgery

New Investigator Award

Dermal Fibroblast Immunophenotype to Predict Clinical Trajectory in Early and Late Diffuse Systemic Sclerosis

Stephanie Stanford, PhD

University of California, San Diego

New Investigator Award

LCM-RNAseq for Topological Mapping of Scleroderma Skin Pathology

Yan Wang, MD, PhD

Cleveland Clinic Foundation

New Investigator Award

The Role of Hyaluronan and O-GlcNAcylation in Fibroblast Turnover and Function in Scleroderma

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
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
Children's Hospital Colorado, Section of Pediatric Rheumatology
National Jewish Health
University of Colorado Scleroderma Program

CONNECTICUT
UConn Health Outpatient Pavilion
Yale Scleroderma Program
Yale Interstitial Lung Disease Center of Excellence

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
Rutgers, Adult Clinical Research Center

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, Rheumatology Clinic 1J

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

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 2022

NEDD9: New PAH Treatment Target?

Foundation-supported research reveals one protein's key role in pulmonary arterial hypertension.

New research supported by the Foundation reveals that a protein called NEDD9 plays a role in fibrosis in pulmonary arterial hypertension (PAH). PAH is a possibly serious scleroderma complication where lung blood vessels become narrow, blocked or damaged. High blood pressure in their lungs can impair quality of life and even lead to heart failure.

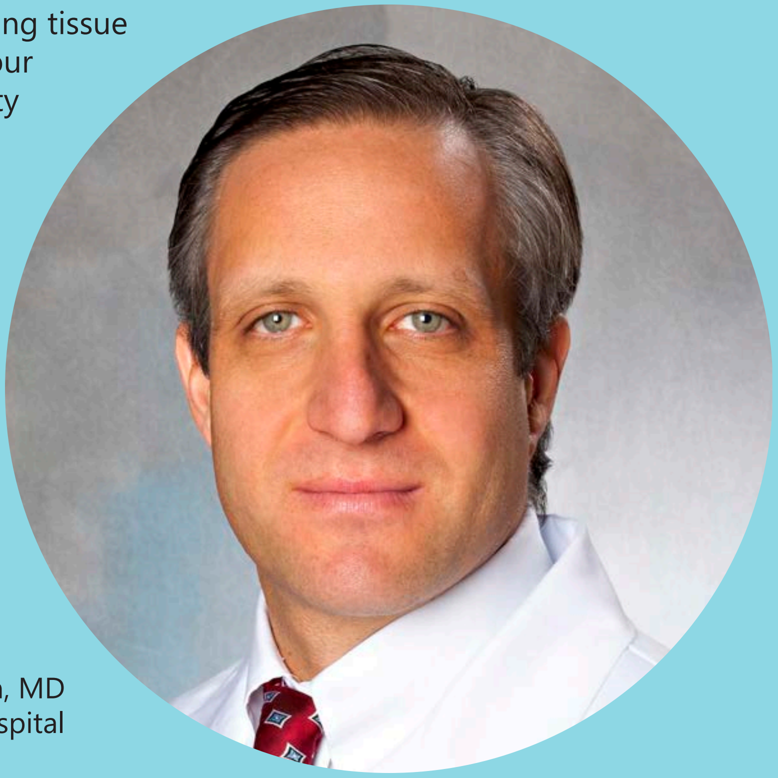
"Pulmonary hypertension is a major driver of hospitalization and shortened life span in patients with connective tissue diseases, especially scleroderma," says cardiologist and vascular biologist Bradley A. Maron, MD, of Brigham and Women's Hospital in Boston. In PAH, platelets flock and adhere to tissue lining the blood vessels in the lungs, and release inflammatory proteins. "This intracellular communication helps drive and propagate an injury pattern that we see in systemic sclerosis."

Scleroderma has "unique underpinnings" that may make the usual pulmonary hypertension treatments less effective, he says. NEDD9 appears to be involved in this crosstalk between platelets and blood vessel walls and plays a role in a damaging process of hypoxia (low oxygen), fibrosis (tissue scarring), and thrombosis (vessel blockage) in PAH. This made NEDD9 an intriguing target to explore.

Maron and his group conducted experiments on both mice and human cells to explore mechanisms of PAH, including the role of NEDD9. They customized an anti-NEDD9 antibody and showed that it could block platelets from adhering to blood vessel cells in the lab, lessening the damage seen in PAH. Their findings suggest that NEDD9 is a "modifiable mediator" of interactions between platelets and blood vessels in PAH, making it an exciting target for new treatment development.

"We have identified a protein that seems to be regulating the fibrosis pattern in lung tissue in people with systemic sclerosis. What our work does is set in motion an opportunity to develop anti-fibrotic drugs. It's the beginning of a new story to be told with specific impact on patients."

Citation: Alba GA, Samokhin AO, Wang RS, et al. "NEDD9 Is a Novel and Modifiable Mediator of Platelet-Endothelial Adhesion in the Pulmonary Circulation." Am J Respir Crit Care Med. 2021 Jun; 203(12):1533-1545.



Bradley A. Maron, MD
Brigham and Women's Hospital

Lung Capacity Decline Key Test Score in ILD

Drop in lung function over two years helps predict severe outcomes more than baseline test score.

People with systemic sclerosis (SSc) may develop interstitial lung disease (ILD), a complication that causes progressive lung fibrosis, or scarring. ILD can lower their ability to breathe over time and is a leading cause of death in people with SSc.

“We currently don’t have great ways to predict their progression to mortality over time,” says Elizabeth R. Volkmann, MD, MS, Director of the UCLA Scleroderma Program. Doctors typically test two measure of lung function, forced vital capacity (FVC) and diffusing capacity for carbon monoxide (DLCO), to guide ILD treatment. FVC decreases call for quick treatment, while we typically wait to treat those with normal FVC, she says. “The problem is that patients with normal lung function can progress quickly,” even in just two years.

More effective tools to predict disease progression are needed, says Volkmann. She led a study supported by the Foundation that shows that two-year declines in both FVC and DLCO more accurately predict mortality than baseline lung function in people with SSc-ILD.

In Phase I, 158 people took either oral cyclophosphamide or placebo. In Phase II, 142 people took one year of cyclophosphamide, followed by either two years of mycophenolate mofetil or one year of placebo. After a median of eight years, 42% of people in Phase I died, with SSc-ILD the most common identifiable cause. Higher baseline skin score, older age, and two-year declines in FVC and DLCO were associated with increased risk of death for people in Phase I, and this finding was confirmed by the Phase II results.

“It’s important to do this testing early in the course of scleroderma, because that’s when most increases in lung damage are likely to occur, even in people who present with normal lung function,” says Volkmann. Doctors should consider moving away from the delayed treatment approach in people with SSc-ILD who have normal lung function, she adds.

Volkmann and her lab team are now looking for blood biomarkers in people with SSc-ILD who have lung function declines. They hope to develop even more tools to predict disease progression in scleroderma to help guide effective treatment.

Citation: Volkmann ER, Tashkin DP, Sim M, et al. “Short-term progression of interstitial lung disease in systemic sclerosis predicts long-term survival in two independent clinical trial cohorts.” Ann Rheum Dis. 2019 Jan;78(1):122-130.

Elizabeth R. Volkmann, MD, MS
University of California, Los Angeles

BE PART OF THE CURE
STEPPING OUT TO CURE SCLERODERMA
NATIONAL SCLERODERMA FOUNDATION

July 1, 2020 *to* June 30, 2021

2,407
Participants

$960,399
Total Raised

63
Virtual Walks

Stepping Out to Cure Scleroderma walks and 5k runs are the signature fundraising events of the National Scleroderma Foundation.

Walks are organized and led by our 19 chapters throughout the United States.

Due to COVID-19, all Stepping Out to Cure Scleroderma awareness events were held virtually during the Fiscal Year 2021.

Thank you to all participants and donors!


Scleroderma Ohio @OhioScleroderma · Sep 9, 2021
Sign up today for the 2021 Stepping Out to Cure Scleroderma TOLEDO Virtual Walk on September 18th! Go to scleroderma.org/toledowalk to get info and sign up or donate! Walk anytime and anywhere you want!
#sclerodermastepout


National Scleroderma Foundation Roc... @Scleroder... · Jul 6, 2021
Fun moments from our Stepping Out to Cure Scleroderma Adventures! Thank you for stepping out to help support the Rocky Mountain scleroderma community.
#scleroderma #rockymtadventure #sclerostepout

To learn more about 2022's Stepping Out to Cure Scleroderma events, go to:

www.scleroderma.org/steppingout

Creating a Legacy and Ensuring Our Future

In 2021, the National Scleroderma Foundation was honored to receive two endowed gifts establishing new and exciting opportunities to advance scleroderma research. Gregory Lurvey of Wisconsin and the family of the late Dr. Arnold Postlethwaite of Tennessee respectively established the Debra Lurvey Memorial Research Grant and the Dr. Arnold Postlethwaite Summer Fellowship.

The Debra Lurvey Memorial Research Grant was established to honor the memory of Debra Lurvey, a loving mother, grandmother, devoted wife, and entrepreneur who lived with scleroderma for many years and who was a strong supporter of the National Scleroderma Foundation. This is the Foundation's first fully endowed research grant. A $200,000 award, the Debra Lurvey Memorial Research Grant is set aside for an investigator focused on lung-related research and launched in January 2022 with its first award to Robert Lafyatis, MD, of the University of Pittsburgh.

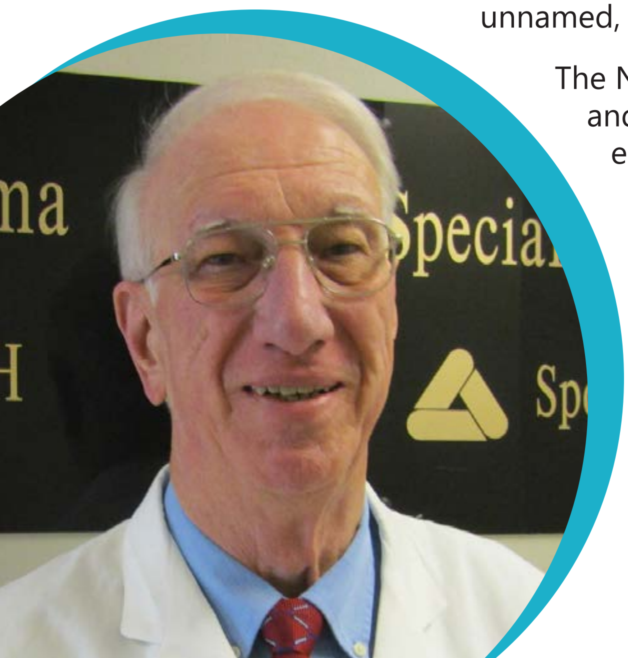
Debra Lurvey

The Dr. Arnold Postlethwaite Summer Fellowship was established to honor the legacy of Dr. Arnold Postlethwaite, who was a leading scleroderma researcher and physician throughout his lifetime. The Dr. Arnold Postlethwaite Summer Fellowship will be the first endowed fellowship recognizing PhD students conducting research related to scleroderma and will award $2,000 annually to one recipient beginning in the summer of 2022.

Endowed gifts to the National Scleroderma Foundation sustain and secure our mission to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families and support networks in perpetuity. When you endow a gift, you make an impact that starts today but lasts forever. Endowed gifts are a unique opportunity to establish a legacy for the donor, while ensuring a future for the Foundation. Endowments can be made to support any or all mission pillars of the National Scleroderma Foundation—support, education, and research—and they can be named in honor or in memory of a loved one, or go unnamed, depending on the donor's preference.

The National Scleroderma Foundation humbly thanks Gregory Lurvey and his family as well as Sue Postlethwaite and her family for establishing endowed gifts in memory of their loved ones.

If you or someone you know is interested in discussing their legacy and the impact it could have, please call the National Scleroderma Foundation at (800) 722-HOPE [4673] or email us at development@scleroderma.org.



Dr. Arnold Postlethwaite

HopeRaisers: How Love Powers Action

Ciszon Family

Fundraisers raise more than funds. They raise HOPE for a cure. They raise HOPE for those living with scleroderma that they will have a better quality of life.

At the National Scleroderma Foundation, we are honored to have a strong community of HopeRaisers who have taken the initiative to host creative fundraisers of their own to support our mission to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families and support networks.

Some of our most committed HopeRaisers are members of the Ciszon family from Crystal Lake, Illinois. Each year for over a decade, the Ciszon family has hosted the "Tournament of Non-Champions" to honor their beloved mother, wife, grandmother, and friend. A few months before their 7th annual golf tournament, the Ciszons lost her in 2016 due to complications from scleroderma.

"[Our mom] is no longer in pain and is watching over all of us, but we miss her every single day...She defined so many things we should all strive to be: Strong willed, strong minded, determined, witty, funny, loving, caring, passionate, intelligent, beautiful inside and out, the list goes on."

The Ciszon family's tragic loss didn't stop them from continuing to host their "Tournament of Non-Champions." What began as a small golf tournament with just 15 golfers has now grown to over 150 participants, and support has also increased. In sum, the tournament has raised more than $80,000 over the years!

On the family's online HopeRaiser page, they share their gratitude for those who support the event: "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!'"

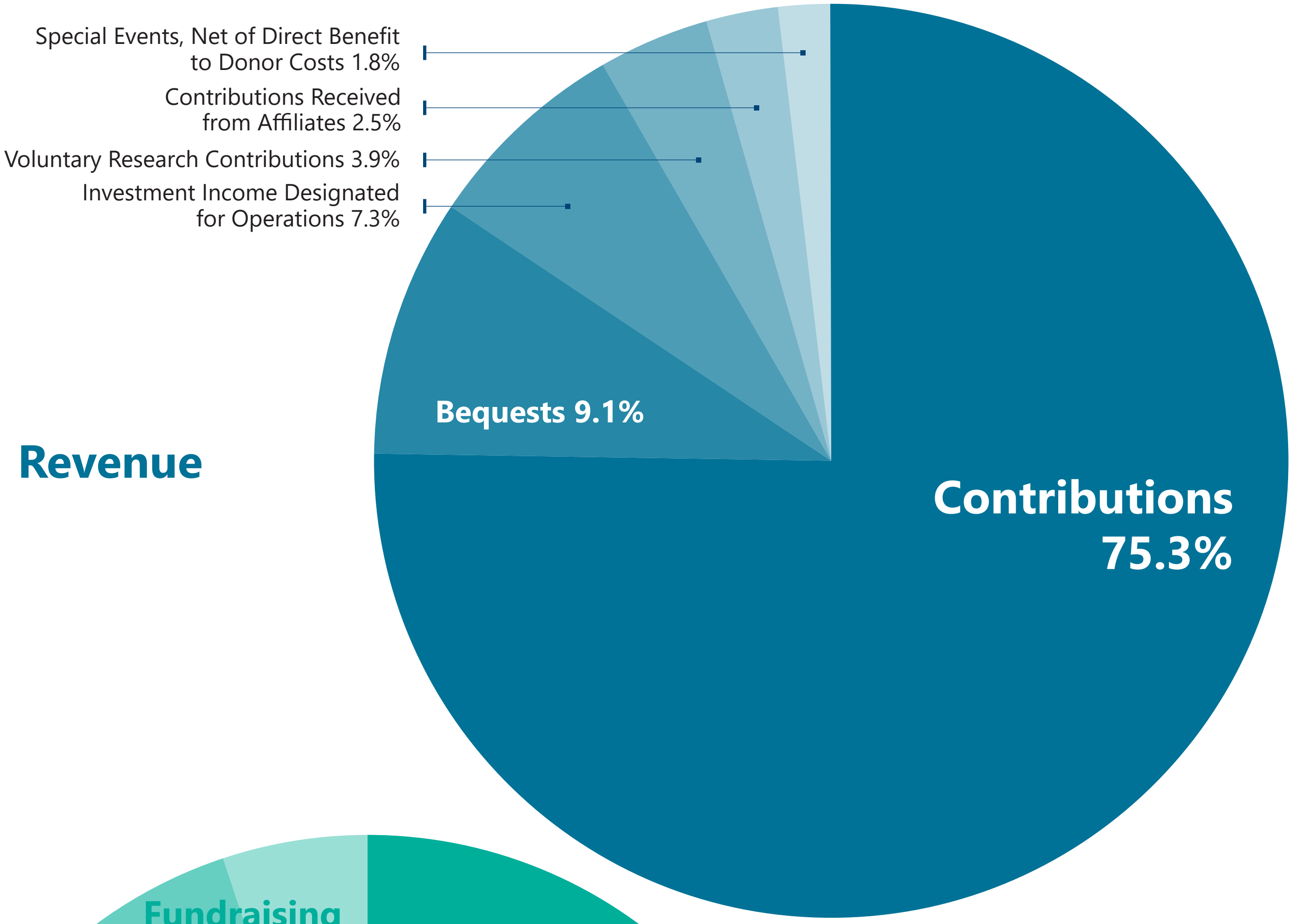
The Ciszon family's story is a true testament to how love powers action and can have such a tremendous impact on so many people. They may have lost their mom, but her legacy certainly lives on through the hope her family has raised and will continue to raise throughout the years.

The family is looking at reengaging an event in 2022 and appreciates all of the support through the years from the Foundation and all that have participated and supported the cause.

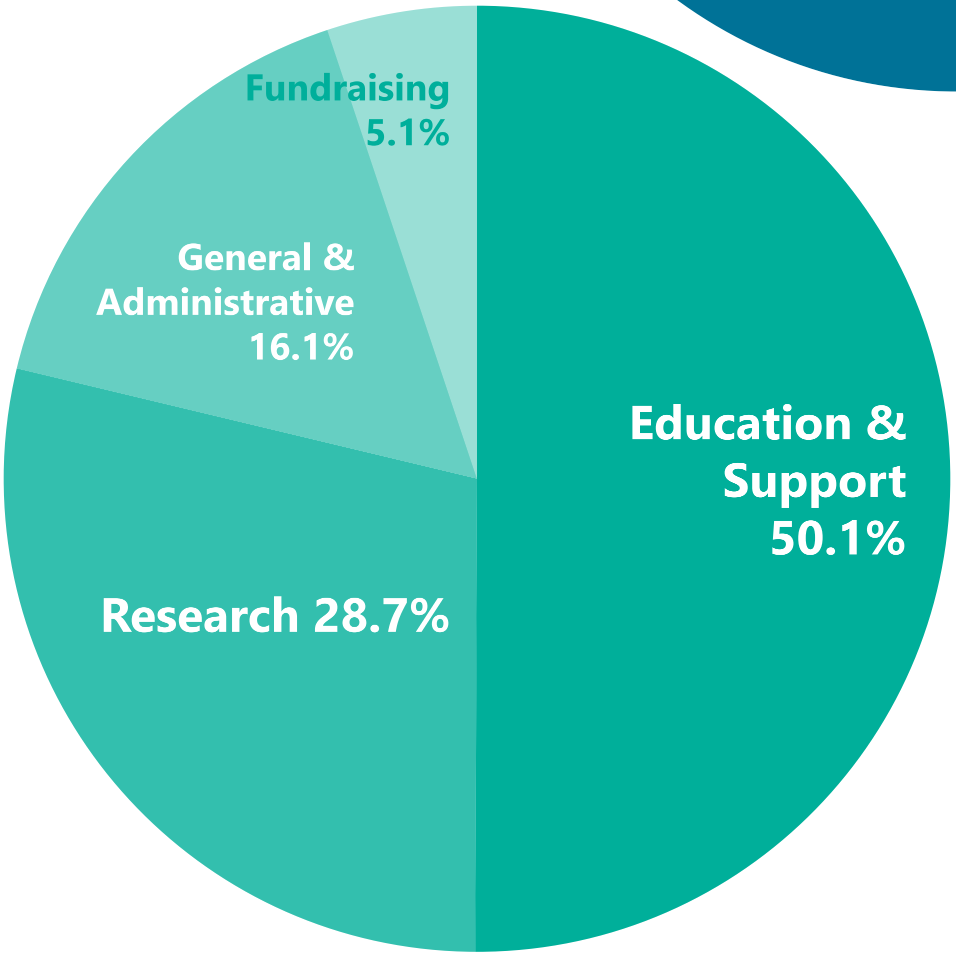
If you would like to become a HopeRaiser and support the mission of the Foundation, please visit Scleroderma.org/HopeRaiser or email development@scleroderma.org.

2019 Fundraisers of the Year, The Ciszon Family with Stephanie Gresh (left), Executive Director, Greater Chicago Chapter

Financials



Revenue



Expenses

STATEMENT OF ACTIVITIES FOR THE YEAR ENDED JUNE 30, 2021

	Without Donor Restrictions	With Donor Restrictions	Total
REVENUE AND OTHER SUPPORT:			
Contributions	$2,597,117	$428,543	$3,025,660
Contributions Received from Affiliates	102,138	-	102,138
Special Events, Net of Direct Benefit to Donor Costs of $78,598 and $157,686, Respectively	73,619	-	$73,619
Investment Income Designated for Operations	-	293,349	$293,349
Voluntary Research Contributions	-	157,725	$157,725
Registration Fees	-	-	$0
Returned Grant Awards	1,340	-	$1,340
Bequests	366,941	-	$366,941
Net Assets Released from Restrictions	912,517	(912,517)	-
Total Revenue and Other Support	**4,053,672**	**(32,900)**	**4,020,772**
EXPENSES:			
Program Services:			
Education and Support	2,210,880	-	2,210,880
Research	1,267,100	-	1,267,100
Total Program Services	**3,477,980**	**-**	**3,477,980**
Support Services:			
General and Administrative	712,554	-	712,554
Fundraising	226,189	-	226,189
Total Operating Expenses	**4,416,723**	**-**	**4,416,723**
(Decrease) Increase in Net Assets from Operations	(363,051)	(32,900)	(395,951)
Non-Operating Activities:			
Investment Income, Net	2,002,250	321,399	2,323,649
Appropriations of Investment Income Designated for Operations	-	(293,349)	(293,349)
Gain on Extinguishment of Long-Term Debit - Paycheck Protection Program	249,962	-	249,962
Total Non-Operating Activities	**2,252,212**	**28,050**	**2,280,262**
Increase (Decrease) in Net Assets	1,889,161	(4,850)	1,884,311
Net Assets at Beginning of Year	7,711,504	1,802,875	9,514,379
Net Assets at End of Year	**$9,600,665**	**$1,798,025**	**$11,398,690**

Audit performed by MFA: Moody, Famiglietti & Andronico, LLP, Tewksbury, Mass.

Complete copies of the Foundation's fiscal year 2021 audited financial statements and IRS form 990 are available at scleroderma.org.

Donors

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

INDIVIDUALS

$25,000 +

Cyndy Besselievre
Murray Levy
Gregory Lurvey
Paula & Roy May
Ali Metwalli
Gladys N. Showalter Revocable Trust
Estate of Allan Staats

$10,000 - $24,999

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Nelson & Sylvia Ball
Bruce & Karen Bittmann
Ben Grohmann
Jean Hartman
Denise & Mark Lammert
Estate of Anne M. Mulqueen
Troy Martinez
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Dean & Gwenn Polik
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TRIBUTES AND MEMORIALS

Throughout fiscal year 2021, families, friends, coworkers, and organizations chose to donate to honor an individual who has scleroderma, or to memorialize someone who lost their battle with the disease. The following list are the individuals in whose name the donations were received.

A good buddy's wife
Anna
District 171
Helen
Izzy
Jeanne
Maria
Mary
Netty
Seenat
Betty L. Abert
Don Abert
Alan Abram
Mary Acevedo
Shirley Ackerman
Catherine Eileen Adams
Sandra Adams
Debbie Ann Aebig
Donna Ahern
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Sharon Marie Alger
Joan Allen
Joan Colangelo Allen
Martin Aloof
Mabel Alvarez
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Doug Baker
Etta Marie Baker
Helen Baker
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