Annual Progress Report

July 1, 2021- June 30, 2022

Support
Education
Research

scleroderma.org
A milestone year - 25th anniversary

Join Us!

In 2023, the National Scleroderma Foundation will celebrate 25 years of serving the scleroderma community.

This milestone year will be honored in all things we do — including major events — such as the National Scleroderma Conference and June Awareness Month.

Watch for regular communication in 2023 about the big impact the organization has had on support, education and research. We'll tell the history of the Foundation through social media posts, videos, magazine articles and more.

Thanks to those who have played a major role in the success of the Foundation over the last quarter century!
A message from the Chair and CEO

Building a Foundation for the Future

2022 was a banner year for the Foundation and represented a season of tremendous change. After more than 20 years advancing medical research, promoting disease awareness and providing support and education to people with scleroderma, their families and support networks, the Foundation ushered in a new era with a new name, a new brand and unified presence as a single 501c3 organization.

Since our founding in 1998, we have grown to 16 chapters that support people affected by scleroderma across 28 states. With every chapter and support group, we reach more people with the resources they need to find their best path.

Our growth and the connections we’ve made with and for the community would not be possible without the tireless dedication from our chapter leaders and staff, local volunteers and the many friends and partners who continue to support us. Because of your work, we have helped tens of thousands of people affected by scleroderma this year.

This growth has expanded awareness of scleroderma among the general public, but also within the medical and research community. It has led to a record number of research grants funded this year and allowed us to more than double our research funding to $2.4 million. We are “putting our money where our mouth is” as we aggressively work toward a cure.

Our chapters have been steadfast in their commitment to increasing awareness and fundraising for the organization. Among their many activities, the chapters hosted 40 walks, organized more than 40 education events and conducted 104 support groups, even when they had to get creative during the pandemic.

Our community came together to continue our rich history of support and education to host our second virtual conference, bringing together more than 500 members of our community to share and learn together. We look forward to being together again next year in Orlando. We lit up landmarks and bridges and buildings in #tealforscleroderma from coast to coast to bring much-needed awareness to our rare disease state.

As we looked at all the Foundation and its chapters were doing for the scleroderma community, we wanted to make sure the name and brand more accurately reflected the organization we are today. Our reach spans across the country, and we work every day to expand that reach in every community. We needed a name that reflected those national connections. We truly are

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the National Scleroderma Foundation. We brought more than 150 members of our community together for a nationwide brand launch event, which we hosted virtually to ensure access for participants across the country, to celebrate our new name and vision for the future. We also welcomed our first official celebrity ambassador, recording artist Ashley Barron. Barron was diagnosed with scleroderma at age five. At that time, her family had never heard of scleroderma, a common experience with the rare disease, which affects more than 300,000 Americans. Now as celebrity ambassador, Barron is working to represent the organization and increase awareness and understanding of scleroderma as she travels the country for performances.

This year, we also received our sixth consecutive four-star rating from Charity Navigator. The National Scleroderma Foundation’s exceptional 4-star rating sets it apart from its peers and demonstrates its trustworthiness to the public. Only a quarter of charities rated by Charity Navigator receive the distinction of our 4-star rating. This adds the Foundation to a preeminent group of charities working to overcome our world’s most pressing challenges. Based on its 4-star rating, you can trust that your support is going to a financially responsible and ethical charity when you support us.

The National Scleroderma Foundation helps unite us by bringing all chapters, stakeholders, outreach and research under one roof so we can grow our community and maximize our impact. We continue to strengthen and leverage our resources for the national scleroderma community.

This year has been one of tremendous change, but one thing remains unchanged: our dedication to our mission and our relentless commitment to find a cure. Each of us plays a critical role in our work toward a cure, whether through advocacy, education, research or support. We intend to keep the momentum going and challenge you to find new or additional ways to support the Foundation’s work. Thank you for joining us on this journey. Together, we are making a difference every day in the lives of those affected by scleroderma.
What is scleroderma?

Scleroderma

is a rare rheumatic disease that affects connective tissue and the vascular system producing excessive collagen that causes fibrosis in the skin (localized), also known as morphea, or in internal organs (systemic sclerosis). The result can be disfigurement and disability, and for some, it’s life-threatening. The cause is unknown, and there is no cure.

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 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. While the cause of scleroderma is not known, there are many clues, including genetic predisposition. More than 300,000 Americans are estimated to live with some form of the disease. Scleroderma can affect people of all ages, genders and backgrounds.

“Scleroderma took my ability to walk, so I learned to fly. If I can fly, I can do anything.”

-Michael Ferrin, diagnosed in 2007, preparing to launch his paraglider in Draper, Utah, in 2021.
Our mission

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 provide 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. Additionally, the Foundation helps individuals and their families cope with scleroderma through mutual support programs, peer counseling, physician referrals and educational information. We also promote public awareness and education through patient and health professional seminars, literature and publicity campaigns.

Our vision

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.

As we find ourselves in an ever-changing world, we are re-thinking the way we plan for our future. We are more interested in strategic thinking than strategic planning. Strategic thinking is how we set our course for the future by bringing our leaders and stakeholders together to examine our current realities and use this information to define a shared vision for the future. This allows us to consider our strengths, weaknesses and opportunities against our available resources. With this in mind, we convened our leaders at our annual Leadership Day in 2022, to synthesize our goals for the coming year and help define strategy around them. These include:

- Ensuring access to programs and services for everyone in our scleroderma community, regardless of where they are geographically, or in their diagnostic journey.
- Designing and delivering an intentional organizational culture in which everyone can share openly and engage authentically.
- Increasing funding to support increased investment across all three mission pillars (noted below).

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
The National Scleroderma Foundation’s network of advocates were met by another year of pandemic restrictions, but that didn’t hold us back.

During Awareness Month, in June, and beyond, our dedicated advocates and supporters lit up the skies across the U.S., bringing attention to scleroderma with an estimated 150+ building and landmark light-ups in teal. Our advocates showed that the simple splash of teal lights in the sky could trigger conversations about scleroderma and the urgent need to find its cause, treatments and cure.

Bringing the conversations to statehouses and city halls, our advocates helped educate their elected officials about scleroderma, securing approximately 75 official proclamations recognizing Scleroderma Month, Scleroderma Week, or Scleroderma Day. Congratulations and thanks to our advocacy corps across the country and to every official who supported our cause with a signature on a scleroderma proclamation.

June 29, 2022 was our dedicated Scleroderma Day of Action, and we encouraged everyone in the scleroderma community to reach out to their representatives in Washington, D.C., to advocate for increased funding for scleroderma research. Our Action Alert alone helped members of our community, both experienced and new to scleroderma advocacy, to generate almost 500 compelling letters of support to three quarters of the U.S. Senate.

Above and beyond these efforts, we targeted influential House and Senate offices on both sides of the aisle — including officials sitting on key appropriations committees — to encourage their support of crucial research funding in the field. Led by volunteers who shared heartfelt stories of their own journeys with scleroderma, we made a strong case for support in dozens of federal meetings over the course of the year.

To help encourage, thank and arm our advocates with the tools they needed, we hosted a Facebook Live, held live advocate trainings and hosted a mock meeting with an elected official. Finally, with the help of our most experienced scleroderma advocates, we highlighted advocacy in a special breakout room at our National Scleroderma Conference.

Scleroderma advocacy thrived in 2022 because our staunchest supporters spread the word and told their stories to people in their own communities and to audiences on a national level. We are grateful for our advocates’ unflagging efforts during the year.

482
Action Alert letters sent to 74 of 100 Senate offices

17
Took part in 17 Senate meetings
# Regional Support Groups

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<td>Alabama</td>
<td>Calera, Florence</td>
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<td>Rapid City, Sioux Falls</td>
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<td>Vermont</td>
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<td>Washington</td>
<td>Mount Vernon County, Seattle, Tri-Cities area</td>
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<td>West Virginia</td>
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Supporting the scleroderma community

THE 20%: A VIRTUAL SUPPORT GROUP FOR MALES LIVING WITH SCLERODERMA
Scleroderma diagnoses are less common among males. In fact, only 20% of individuals living with scleroderma are male. We have designed a support group especially for males with scleroderma. Participants learn scleroderma tips and resources and find support from others in their same position. Each meeting focuses on a different topic, from mental health to intimacy and much more.

BILINGUAL-SPANISH
Spanish speakers gather across the country virtually to learn more about living better with scleroderma.

BLACK, INDIGENOUS, AND PEOPLE OF COLOR
The National Scleroderma Foundation's BIPOC Support Group was founded to address the needs of Black, Indigenous and People of Color affected by scleroderma. This new virtual support group provides innovative educational opportunities, emotional support and scleroderma-related resources.

CAREGIVER CONNECTION
Those caring for individuals living with scleroderma have an opportunity to gather virtually to connect and get resources and support in their journey walking alongside those diagnosed with the disease.

NEWLY DIAGNOSED SUPPORT GROUP
Patients newly diagnosed as having scleroderma face an overwhelming number of questions about how it will affect their lives. Participation in a support group is one way to obtain information and receive support from others.

PARENTS OF CHILDREN WITH SCLERODERMA
Each meeting focuses on a different juvenile scleroderma topic — from managing the needs of everyone in the house to self-care for caregivers. The goal is to address questions, help parents find comfort and leave participants with a sense of hope and support for their child.

SCLERODERMA YOUNG ADULTS SEEKING CONNECTIONS
SYNC is a virtual community for young adults between ages 18-42 who are looking to connect with others in their age group who are affected by scleroderma.
Reliable and up-to-date information can be considered the most valuable service offered by the National Scleroderma Foundation. The Foundation’s education programs give community members the knowledge they need to seek proper care and feel empowered throughout their scleroderma journey. Over the last year, the Foundation has increased its reach by expanding virtual education programming.

Our signature National Scleroderma Conference and Kids Get Scleroderma, Too! conferences were held virtually for the very first time. These conferences provide access to world-renowned scleroderma experts and are the central meeting for the scleroderma community. Transitioning these events to a virtual platform allowed the Foundation to keep the community safe from the risk of COVID-19, while continuing to deliver high-quality education to attendees.

The national conference has long-served as the premiere learning and networking experience for individuals affected by scleroderma. The Foundation continued to deliver on these standards by incorporating several virtual networking sessions into the 2022 event. Each chapter also offered at least one patient education program in their respective territories throughout the year.

Registered attendees, with more than 30% first-time attendees

Sessions presented by 41 scleroderma experts and health care professionals

Registered - a new record!

Sessions presented by 16 scleroderma experts and health care professionals
Chapter learning opportunities
Education

In FY 2022, the Foundation held more than 40 educational events, with an estimated 1,500 participants.

Monthly
Music Therapy for Wellness, New England

August
Scleroderma Tri-State Chapter-wide Support Group Educational Meeting, Tri-State, Aug. 30

September
Albany patient education 2021 virtual videos (a virtual option to original Sept. 25 Albany Patient Education forum)

2021 Scleroderma Education Summit, Rocky Mountain Chapter, Sept. 25

Tri-State Chapter Support Group Educational Event, Tri-State, Sept. 27

October
Caregiver Support & Relationships Roundtable, Tri-State, Oct. 10

Sclero-What? Ninth Annual Scleroderma Regional Education Day, Heartland, Oct. 9

Florida Education Day, Southeast Florida, Oct. 16

Tri-State Chapter Support Group Educational Event, Tri-State, Oct. 25

November
Patient Education Event, Missouri, Nov. 6

2021 Education Webinar on Cardiac Issues in Scleroderma, Delaware Valley, Nov. 17

El Corazón en la Esclerodermia, National, Nov. 19

Hospital for Special Surgery - Patient Education Forum, Tri-State, Nov. 20

December
Nourishing the Scleroderma Patient, New England, December 2021

January
Hospital for Special Surgery - Scleroderma, Vasculitis and Myositis Center, Tri-State, Jan. 5

February
12th Annual Amy K Parrish Scleroderma Education Conference, South Carolina, Feb. 12

March
2022 Scleroderma Education Summit, Rocky Mountain Chapter, March 12

Tri-State Chapter-wide Support Group Education Event, Tri-State, March 28

April
New England Virtual Patient Education Series:
April 2 - Lung Involvement with Scleroderma
April 4 - Music Therapy for Wellness
April 6 - Navigating the Social Security Disability Process
April 7 - Managing Stress and Chronic Disease
April 20 - Raynaud's Phenomenon
April 22 - Learning to Love Our Friends

An Update on Sjogren’s, Delaware Valley, April 6

May
Pulmonary Arterial Hypertension in Scleroderma Webinar with Soumya Chatterjee, M.D., M.S., National, May 4

21st Annual Cheri Woo Scleroderma Education Seminar, Oregon, May 14

June
The Scleroderma Body: Head to Toe - Inside & Out with Dr. Maureen Mayes, Texas Bluebonnet, June 4
The National Scleroderma Foundation is the leading nonprofit supporter of peer-reviewed research to discover the cause, understand the mechanism and overcome scleroderma forever. Our leadership has been a contributing factor in the impressive growth in scleroderma research activity and a catalyst to fund and stimulate innovation and scientific advancement.

Since its inception, the Foundation has funded more than $30 million in grants, thanks to the generosity of donors who share our commitment to advancing scleroderma research.

“Grants funded by the National Scleroderma Foundation have formed the basis of novel discoveries in the field, created better understanding of the disease process, and led to the development of potential new therapies. Funding from the National Scleroderma Foundation over the years has launched the careers of leading experts in the field and is supporting the careers of junior investigators to ensure that there is a pipeline of future investigators who will continue to conduct research on scleroderma,” said Carol Feghali-Bostwick, Ph.D., Vice Chair, National Scleroderma Foundation Board of Directors.

The National Scleroderma Foundation’s peer-reviewed research grant program prioritizes scientific merit and provides funding for both early career and established investigators. The Peer-Review Committee is composed of highly respected scientific experts who review, critique and score all proposals based on the National Institutes of Health’s guidelines and ranking system. Upon completion of the scoring, funding recommendations are made to the Board of Directors for those proposals of the highest scientific and technical merit.

Each grant application contains very specific eligibility and review criteria. Details regarding these requirements are available at scleroderma.org. All proposals undergo rigorous peer review and are scored and ranked according to the review criteria and overall merit of the proposal. Review criteria are meticulous and include:

- **Significance**: Does this study address an important issue related to scleroderma?
- **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?

After awards are presented, all recipients are required to complete funding contracts with institutional sign-off and must also submit annual reports on their progress. All reports are reviewed by the Foundation’s Research Committee to ensure compliance with programmatic, scientific and fiscal and administrative polices and requirements.

The Foundation funds two types of grants:

- **New Investigator Awards** are three-year grants designed for early career investigators who wish to pursue careers in research related to scleroderma. This award is designed to mentor and foster the next generation of researchers.
- **Established Investigator Awards** are two-year grants given to promising, established investigators proposing pilot studies with highly innovative themes related to the disease.
Several grants are named in honor of individuals who made major contributions to those affected by scleroderma. These named awards are presented to the highest scoring projects:

- **Debra Lurvey Memorial Grant**
  - Established through the generosity of Greg Lurvey, in memory of his wife, Debra, who lost her battle to scleroderma. The award is presented every other year to an established researcher focusing on scleroderma-related lung research.

- **Marta Marx Fund for the Eradication of Scleroderma**
  - Established by bequests from Ms. Marx and her brother, Rudolph Juhl. It’s awarded annually to the researcher whose proposal achieves the highest score.

- **Mark Flapan Award**
  - Named in memory of the late psychologist and scleroderma patient.

- **Walter & Marie Coyle Research Grant**
  - Named in honor of the founder of the Foundation, Marie Coyle, who also had scleroderma, and her husband.

- **Cogan Family Research Grant Award**
  - Ongoing grant given each year in honor of the Cogan Family of Chicago.

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### 2022 National Scleroderma Foundation Research Grant Awardees

**Congratulations!**

- **Debra Lurvey Memorial Grant**
  - Robert Lafyatis, MD
  - The role of lymphatic Erg deficiency on pulmonary fibrosis
  - University of Pittsburgh

- **Marta Marx Fund for the Eradication of Scleroderma**
  - Monica Mukherjee, MD, MPH
  - Cooperative transcription factor regulation of myofibroblast differentiation in scleroderma-associated interstitial lung disease
  - Johns Hopkins University

- **Mark Flapan Award**
  - Janet Poole, PhD, OTR/L
  - Feasibility and acceptability of the Making it Work Program for Systemic Sclerosis
  - University of New Mexico Health Sciences Center

- **Walter & Marie Coyle Research Grant**
  - Peter James Niedbalski, PhD
  - MRI for Screening and Monitoring Systemic Sclerosis Interstitial Lung Disease
  - University of Kansas Medical Center Research Institute

- **Cogan Family Research Grant Award**
  - Sean Fortier, MD
  - Lung and Skin Myofibroblast De-Differentiation and Fibrosis Resolution in Systemic Sclerosis Depend on cAMP-Mediated Inhibition of p38
  - University of Michigan

- **Debra Lurvey Memorial Research Grant Award**
  - Deepa Soundara Rajan, MD
  - "Are Somatic Mutations Underlying Craniofacial Scleroderma Phenotypes?"
  - University of Pittsburgh

- **Marta Marx Fund for the Eradication of Scleroderma award**
  - Yue Ding, MD
  - The development of TRPM8-targeted therapy against Raynaud’s phenomenon
  - University of Toledo

- **Walter & Marie Coyle Award**
  - Karin Wuertz-Kozak, MS, PhD, MBA
  - The Role of Estradiol Production in Systemic Sclerosis
  - Rochester Institute of Technology

- **Cogan Family Research Grant Award**
  - DeAnna Baker Frost, MD PhD
  - A novel 3D scleroderma skin model to test therapeutic TRPC6 modulation
  - Medical University of South Carolina

- **New Investigator 3-year award**
  - Kerri Ilene Aronson, MD, MS
  - Development of a Stakeholder Engaged Intervention to Improve Knowledge and Health-Related Quality of Life in SSc-ILD
  - Weill Medical College of Cornell University

- **New Investigator 3-year award**
  - Patrizia Fuschiotti, PhD
  - Molecular mechanisms of CXCL13+ T cell-B cell interactions in inflammatory systemic sclerosis skin lesions
  - University of Pittsburgh

- **New Investigator 3-year award**
  - Robert Lafyatis, MD
  - Feasibility and acceptability of the Making it Work Program for Systemic Sclerosis
  - University of New Mexico Health Sciences Center

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  - A novel 3D scleroderma skin model to test therapeutic TRPC6 modulation
  - Medical University of South Carolina
2021 marked the first year for the National Scleroderma Foundation Pre-Doctoral Summer Fellowship Award Program. All 2021 recipients were named in the memory of Dr. Arnold Postlethwaite and received the award. Dr. Postlethwaite was an esteemed academician and physician who dedicated his life to advancing the treatment of rheumatic diseases, including rheumatoid arthritis and scleroderma. In 2022, and moving forward, one recipient each year will receive the named Dr. Arnold Postlethwaite Summer Fellowship Award.

In 2022, the award was given to Vivek Jani from Johns Hopkins University School of Medicine, in the department of Cardiology. He is currently in graduate school, working on his doctorate in Biomedical Engineering and is enrolled in the Medical Scientist Training Program.

His mentor is Monica Mukherjee, M.D., M.P.H. Under the guidance of Dr. Mukherjee, his project submitted is titled: **Machine and Deep Learning for the Early Detection of Scleroderma-Associated PAH.**

Dr. Mukherjee started as an Early Career Investigator and participated in the Foundation’s research grant program. She is now an Established Investigator — mentoring the next generation of researchers.

2022 Summer Fellowship Awardees

**Adegboyega Adewale**
Medical University of South Carolina

The role of the IL-6-IGF-II axis in Systemic Sclerosis-Associated Lung Fibrosis

**Rithika Behera**
University of Pittsburgh

Understanding FOSL2 mediated regulation of dermal myofibroblasts in systemic scleroderma

**Vrinda Dambal**
Boston University

Characterization of secretome of GATA-6 deficient Pulmonary Arterial Endothelial cells and to check its effect on activation of fibroblasts in SSc-PAH model

**Vivek Jani**
Johns Hopkins School of Medicine

Machine and Deep Learning for the Early Detection of Scleroderma-Associated PAH

**Suneeti Madhavan**
Case Western Reserve University

Adipocyte lipolysis is activated by Wnt-induced ER stress

**Dillon Popovich**
Dartmouth College

Pathway-Driven Drug Repositioning in Systemic Sclerosis from Omics Data
The Foundation has formal affiliations with scleroderma research and treatment centers around the United States. To be designated 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**
Cedars Sinai Scleroderma Center
Loma Linda University Scleroderma Center
University of California, San Francisco Health Scleroderma Clinic
University of California, Los Angeles Scleroderma Clinic

**COLORADO**
Children’s Hospital Colorado
National Jewish Health Scleroderma Program
University of Colorado Scleroderma Program

**CONNECTICUT**
University of Connecticut Health Outpatient Pavilion
Yale Scleroderma Program

**DISTRICT OF COLUMBIA**
Georgetown University Hospital

**FLORIDA**
Mayo Clinic Florida

**ILLINOIS**
Northwestern Scleroderma Program
University of Chicago Scleroderma Program
University of Illinois Health Rheumatology

**LOUISIANA**
University Medical Center New Orleans
Tulane University

**MASSACHUSETTS**
Boston University Scleroderma Program
Massachusetts General Scleroderma Program

**MARYLAND**
Johns Hopkins Scleroderma Center

**MICHIGAN**
University of Michigan Scleroderma Program

**MINNESOTA**
University of Minnesota Health Mayo Clinic

**NORTH CAROLINA**
Duke Health Scleroderma Center

**NEW HAMPSHIRE**
Dartmouth Health Scleroderma Clinic

**NEW JERSEY**
Hackensack Meridian Health
Rutgers Health Scleroderma Program

**NEW YORK**
Northwell Health Scleroderma Program
Albany Medical College Scleroderma Center
Hospital for Special Surgery, Scleroderma, Vasculitis & Myositis Center
Columbia University Scleroderma Treatment Center

**OHIO**
Cleveland Clinic
University of Toledo Scleroderma Center
Wesner Medical Scleroderma
University of Cincinnati

**PENNSYLVANIA**
Thomas Jefferson Health Scleroderma Center
Pennsylvania Scleroderma Center
University of Pittsburgh Scleroderma Center
University of Pittsburgh, Children's Hospital of Pittsburgh

**SOUTH CAROLINA**
Medical University of South Carolina Scleroderma

**TENNESSEE**
University of Tennessee Health Center
University Clinical Health
Vanderbilt University Medical Center

**TEXAS**
University of Texas Southwestern Medical Scleroderma Center

**WASHINGTON**
Seattle Children’s Hospital
Virginia Mason
University of Washington

**WISCONSIN**
University of Wisconsin
The Jacob Davila Memorial Leadership Award embodies the values that Jacob lived out every day. As a teenager, Jacob was diagnosed with scleroderma. Like many with the disease, his path was not an easy one. However, he chose to utilize his education and his convictions as a servant leader to embrace his diagnosis and humbly lead and support those within the scleroderma community.

Because of his empathy and sympathy for others, Jacob not only directly supported those with scleroderma, but he was also a fierce advocate for scleroderma awareness. Jacob was a long-standing leader of the National Scleroderma Foundation Texas Bluebonnet Chapter, and he worked at both the state and federal level to fight for increased research funding for a cure.

Although Jacob knew he may never see a cure for scleroderma during his lifetime, his love and passion for his community drove him to ensure that others had a fighting chance. Every day, he chose to lift others up, ensuring that everyone — regardless of age or stage of disease — felt valued, supported, cared for and well informed about scleroderma and its effects.

The Jacob Davila Memorial Leadership Award will be awarded annually to one recipient attending the National Scleroderma Conference and will cover all conference-related expenses. The inaugural award will be granted in 2023 during the National Scleroderma Foundation’s 25th anniversary.

The National Scleroderma Foundation continues to raise funds to support this award, furthering Jacob’s enduring effort to find a cure to this devastating disease. Learn more at scleroderma.org/DavilaLeadershipAward.
In April 2021, the National Scleroderma Foundation proudly announced that recording artist Ashley Barron was named our official celebrity ambassador. A new initiative for the Foundation found a perfect partner in Ashley Barron.

A star on the country music scene, Ashley was diagnosed with scleroderma at age five. At that time, her family had never heard of the disease, a common experience with scleroderma, a rare disease that only affects 300,000 Americans. Now, as celebrity ambassador, she is working to represent the organization and increase awareness and understanding of scleroderma as she travels the country for performances. Tragically, Ashley lost her mother, Carol Lee Barron, to scleroderma in October 2020. Her mother was diagnosed with systemic sclerosis only four months before her death.

“I am so honored to have the opportunity to work alongside the National Scleroderma Foundation to bring awareness to this disease,” said Ashley. “I never thought when I was diagnosed at 5 years old, that I’d one day get the opportunity to bring support and community to others that I did not have. I’m very excited for the future and what is to come.”

Ashley has shared her gratitude for the overwhelmingly positive response that she received from the scleroderma community on the announcement of her role as celebrity ambassador.

“Music has been my passion my entire life. I knew from a young age I wanted to create music. I knew I’d always write from the heart and share my stories in hopes they would resonate with someone out there. Never did I dream I’d have the opportunity to connect with something bigger —especially with a community, I share this horrible disease with,” said Ashley.

Her self-titled, debut album is available on Spotify. To connect with Barron, visit ashleybarronofficial.com, where you can sign up for her email newsletter, stay up to date on her performances and find links to her social media accounts.

We are grateful to Ashley and her partnership in support of our community.
**Financials**

**Revenues**

- Contributions received from affiliates: 1.3%
- Investment income designated for operations: 1.6%
- Voluntary research contributions: 4%
- Special events, net of direct benefit to donor costs: 10.4%
- Bequests: 26.6%
- Contributions: 56.1%

**Expenses**

- Fundraising: 8.9%
- General and administrative: 13.1%
- Education and support: 33.5%
- Research: 44.4%
## Statement of Activities
For the year ended June 30, 2022

### REVENUES AND OTHER SUPPORT

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$1,112,619</td>
<td>$1,285,747</td>
<td>$2,398,366</td>
</tr>
<tr>
<td>Contributions received from affiliates</td>
<td>56,507</td>
<td>-</td>
<td>56,507</td>
</tr>
<tr>
<td>Special events, net of direct benefit to donor</td>
<td>443,271</td>
<td>-</td>
<td>443,271</td>
</tr>
<tr>
<td>Investment income designated for operations</td>
<td>-</td>
<td>69,985</td>
<td>69,985</td>
</tr>
<tr>
<td>Voluntary research contributions</td>
<td>-</td>
<td>173,415</td>
<td>173,415</td>
</tr>
<tr>
<td>Registration fees</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Returned grant awards</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Bequests</td>
<td>1,140,911</td>
<td>-</td>
<td>1,140,911</td>
</tr>
<tr>
<td>Net assets released from restrictions</td>
<td>1,784,797</td>
<td>(1,784,797)</td>
<td>-</td>
</tr>
</tbody>
</table>

**Total revenues and other support**

4,538,105 (255,650) 4,282,455

### EXPENSES

#### Program services

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education and support</td>
<td>2,074,271</td>
<td>-</td>
<td>2,074,271</td>
</tr>
<tr>
<td>Research</td>
<td>2,747,437</td>
<td>-</td>
<td>2,747,437</td>
</tr>
</tbody>
</table>

**Total program services**

4,821,708

#### Support services

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>General and administrative</td>
<td>810,881</td>
<td>-</td>
<td>810,881</td>
</tr>
<tr>
<td>Fundraising</td>
<td>552,920</td>
<td></td>
<td>552,920</td>
</tr>
</tbody>
</table>

**Total operating expenses**

6,185,509 (255,650) 6,185,509

(Decrease) Increase in net assets from operations

(1,647,404) (255,650) 1,903,054

#### Non-operating activities

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investment income, net</td>
<td>(970,640)</td>
<td>(155,350)</td>
<td>(1,125,990)</td>
</tr>
<tr>
<td>Approp. of investment income designated for operations</td>
<td>-</td>
<td>(69,985)</td>
<td>(69,985)</td>
</tr>
<tr>
<td>Gain on extinguishment of long-term debit</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paycheck protection program</td>
<td>249,962</td>
<td>-</td>
<td>249,962</td>
</tr>
</tbody>
</table>

**Total non-operating expenses**

(720,678) (225,335) (946,013)

<table>
<thead>
<tr>
<th>Description</th>
<th>Without Donor Restrictions</th>
<th>With Donor Restrictions</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase (decrease) in net assets</td>
<td>(2,368,082)</td>
<td>(480,985)</td>
<td>(2,849,067)</td>
</tr>
<tr>
<td>Net assets at beginning of year</td>
<td>9,261,793</td>
<td>2,136,897</td>
<td>11,398,690</td>
</tr>
</tbody>
</table>

**Net assets at end of year**

$6,893,711 $1,655,912 $8,549,623

Audit performed by Baker Tilly US, LLP, Tewksbury, Massachusetts.
Complete copies of the Foundation’s fiscal year 2022 audited financial states and IRS form 990 are available at scleroderma.org.
Strategic planning allows us to align our business and operations to plan for transformational change and growth. There are two key types of strategic planning that organizations undertake — internal strategic planning for the future and building a competitive strategy for the external environment. Different plans serve organizations at different places in their lifecycle. The Foundation’s three-year plan was internally focused, allowing us to build capacity and infrastructure for the future, better positioning us to deliver our mission in a more cohesive way.

The planning process included an analysis of environmental factors impacting the Foundation, as well as an assessment of current activities and stakeholder input from chapter and national leadership and staff, as well as members of the community and donors. Each of these informed the final plan, which was approved by the Board in February 2020, refined over the summer and shared with leadership and staff at Leadership Day 2020.
As we formulated our Strategic Plan, top of mind in our design were our Mission and Vision. These remain steadfast.

**MISSION**

Advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families and support network.

**VISION**

To be a relentless force in finding a cure and improving care for people with scleroderma.

The details of the Strategic Plan addressed many facets of the organization. Each strategy was designed to:

- Establish or enhance effectiveness
- Simplify and increase efficiency of activities
- Leverage our scale and extend our reach

With these activities in mind, our goals were to create a national organization with strong chapters serving people with scleroderma wherever they are, operating from one resource pool.

Building on a 20+ year organizational history and the strength and engagement of our community, the Foundation’s strategic planning process focused on building a foundation for the future. From improving our effectiveness and efficiency, to extending our scale and reach nationally, this strategy was grounded in deepening donor engagement and strengthening the overall value proposition for our community coast to coast.

Setting these clear priorities allowed our leadership team to focus its priorities, energy and resources to support our mission priorities. We have been able to streamline our operations, adjust our governance structure to reflect our organization’s makeup and expand access to our programs and services by offering virtual programming. We are committed to our development as a hybrid organization. As we slowly begin to return to in-person opportunities, we remain committed to virtual opportunities to ensure broad access to our programs and services. By ensuring that our volunteers, staff and stakeholders are working toward common goals, we are poised for continued success in the future.
The strategic initiatives outlined in the Strategic Plan have now been completed.

The activities include the following:

**Fundraising capacity**
- Conduct basic training for staff leadership on fundraising approaches and strategies
- Implement engagement opportunities for major donors

**Donor focus**
- Centralize all donor records
- Establish donor acknowledgement platforms
- Create a Legacy Society for planned giving donors
- Create comprehensive stewardship plans

**Events planning and management**
- Provide guidance and standards for events to chapters
- Establish “think tank” of chapter representatives and individual event organizers to identify and design new types of events
- Identify new and refreshed events with a unified and synchronized calendar of activities

**Operations**
- Streamline financial reporting
- Assess chapter capacity
- Position chapters to achieve actual or virtual coverage for any patient or caregiver
- Clarify roles and responsibilities across the organization
- Centralize gift entry
- Formalize comprehensive onboarding toolbox for leadership

**Organization structure**
- One national, unified organization - bring affiliate chapters under national organization
Thank you to our 2022 national corporate sponsors

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HORIZON
National Leadership

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Michael B. Hyde, Chief Operations & Financial Officer
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Ashley M. Pruett, M.Ed., Senior Director, Chapter Operations
Lisa Tobin, JD, Senior Director, Mission Delivery
Julio Garcia, Executive Director, Tri-State Chapter
JoAnne LaPergola, Executive Director, Delaware Valley Chapter
Rhaslyn McGee, Executive Director of Chapter Development and Support
Liz Mulroy, Executive Director, Ohio Chapter
Ferne Robin, Executive Director, Southeast Chapter
Randall Slikkers, Executive Director, Michigan Chapter
Anne Sweeney, Executive Director, New England Chapter
Theresa Freed, Communications Director
Marta Brill, Associate Director, Development, Corporate & Foundation Relations
Angel Soto, Associate Director, Education
Maureen Zuluaga, Associate Director, Database Operations
Caryn Anatriello, Manager, Support & Advocacy
Lauren Galvan, Manager, Annual Giving & Stewardship
Shenna Gianetta, Manager, Research
Olivia Ogden, Manager, Communications
Claire Nelson, Project Manager, Development
Molly Paradis, Office Associate
Diane Maquire, Finance Associate
Kristin Sullivan, Senior Generalist, Human Resources
Max Halbert, Central Processing Coordinator
Chapter Leadership

Delaware Valley
JoAnne LaPergola, Executive Director

Georgia
Peggy Levengood and Doreen Towhey, Co-Chairs, Chapter Advisory Committee

Heartland
Renee Hyde, Chair, Chapter Advisory Committee

Michigan
Randall Slikkers, Executive Director
Peggy Collins, Chair, Chapter Advisory Committee

Missouri
Rhonda Costa, Chair, Chapter Advisory Committee

New England
Anne Sweeney, Executive Director
Jane Ladas, Chair, Chapter Advisory Committee

Oklahoma
Donna Roberts, Chair, Chapter Advisory Committee

Ohio
Liz Mulroy, Executive Director
Lucille Miller, Chair, Chapter Advisory Committee

Oregon
Christina Fidalgo, Chair, Chapter Advisory Committee

Northwest
Vacant

Rocky Mountain
Mike Pursel, Chair, Chapter Advisory Committee

South Carolina
Susan Melvin, Chair, Chapter Advisory Committee

Southeast Florida
Ferne Robin, Executive Director
Desiree James, Chair, Chapter Advisory Committee

Texas Bluebonnet
Renee Berlandier, Chair, Chapter Advisory Committee

Tri-State
Julio Garcia, Executive Director
Marc Krieger, Chair, Chapter Advisory Committee

Chapter support
Rhaslyn McGhee, Executive Director of Chapter Development and Support