



# EXPANDING OUR REACH

2023 Annual Report



# Message from THE BOARD AND CEO

## IN 2023, THE FOUNDATION CELEBRATED 25 YEARS OF IMPACT

in advancing medical research, promoting disease awareness, and providing support and education to people with scleroderma, their families and support networks. Our progress stands as a testament to the collective efforts of our community, and a beacon of hope for the future.

Thank you for being partners in the journey, and for celebrating this milestone year with us.

Despite the advancements made in the last quarter century, challenges remain. Scleroderma is a complex disease, presenting a wide range of symptoms and progression rates among those living with the illness. Treatment options, while improved, are not universally effective, emphasizing the need for targeted therapies.

As the leading patient advocacy organization serving people living with scleroderma, the National Scleroderma Foundation plays an important role in addressing the challenges of the future. As we look ahead to the next 25 years, we are focusing our efforts on the impact we can make on complex issues facing those fighting scleroderma.

We also recognize the need for flexibility in an ever-changing world, while remaining steadfast in our vision of being a relentless force in finding a cure for scleroderma.

The trends in scleroderma research are encouraging. Departing from traditional treatments that broadly suppress the immune response, scientists are pioneering novel approaches. As we navigate this exciting era, it seems a paradigm shift is imminent. As Dr. Carol Feghali-Bostwick said in her closing statements at the 2023 National Scleroderma Conference, "There is a cure on the horizon, and research will get us there."

On behalf of the entire scleroderma community, we are grateful for your continued partnership and friendship. Together, we will continue to advance our shared mission.



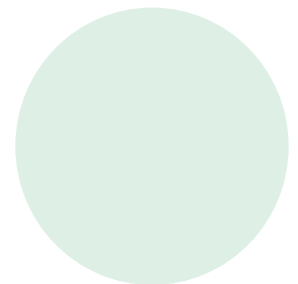
**Mary J. Wheatley, IOM, CAE**  
Chief Executive Officer

A handwritten signature in black ink, appearing to read "Mary J. Wheatley".



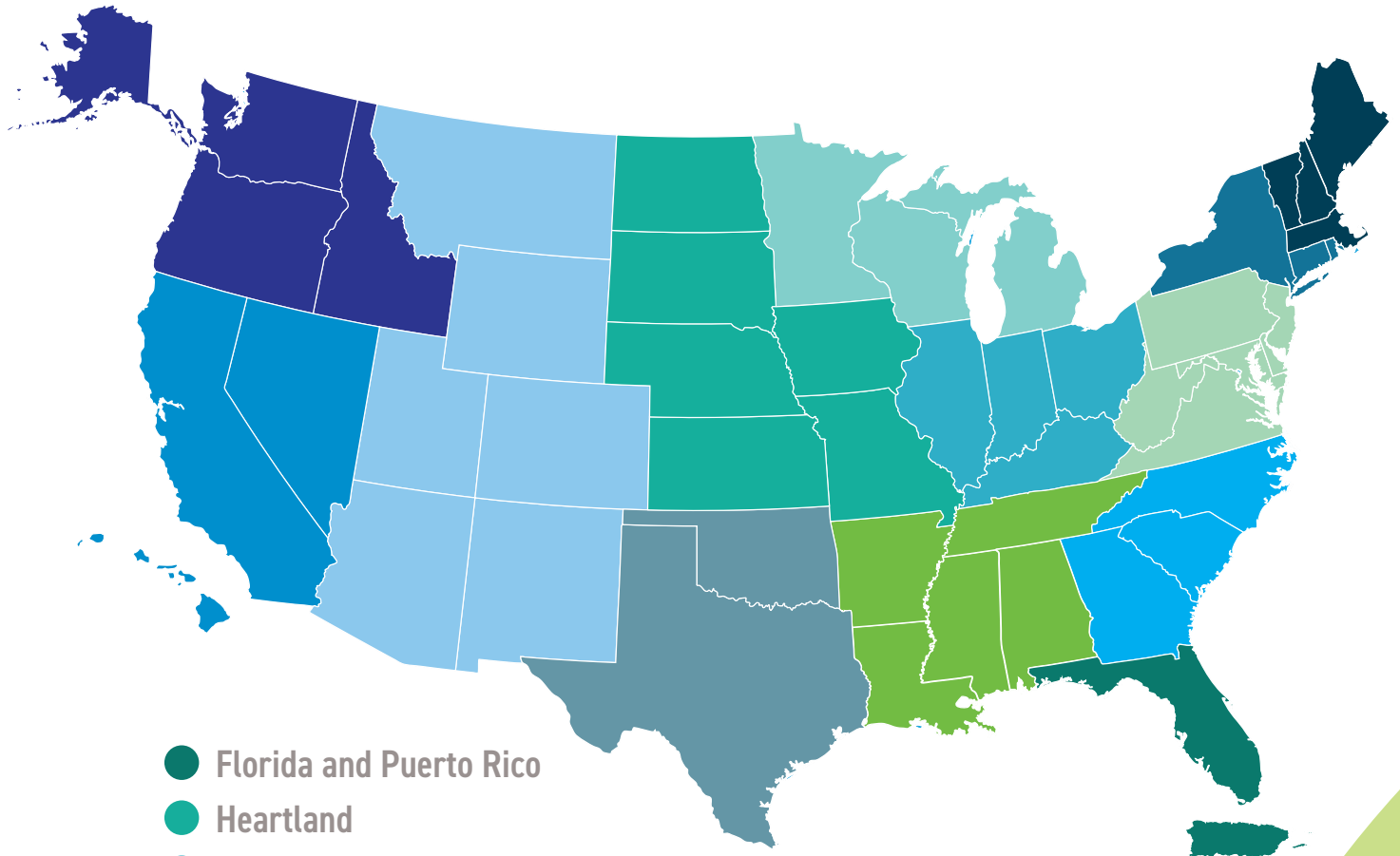
**Kevin Boyanowski**  
Chair, Board of Directors

A handwritten signature in black ink, appearing to read "Kevin Boyanowski".



# EXPANDING OUR REACH

## Spreading Support Coast-to-Coast



- Florida and Puerto Rico
- Heartland
- Great Lakes
- Mid-Atlantic
- New England
- Pacific Northwest
- Rocky Mountain
- South
- Southeast
- Texoma
- Tri-State
- Lower Great lakes
- West Coast

Supporting the journeys of all individuals affected by scleroderma will continue to be our top priority. Broadening our reach allows us to serve more people through support and resources and help each individual find their best path forward.

We are proud of the strides we've made and inspired by how each chapter has risen to the occasion.

# RESEARCH UPDATES

## ADVANCES IN SCLERODERMA RESEARCH

Last year, we hosted three Advances in Scleroderma Research Global Webinars as part of our efforts to bring together the global community of scleroderma research scientists to share and discuss the latest breakthroughs from the field. The webinar series drew 896 participants from all over the world.

## BIOMARKERS CONSORTIUM

The Foundation is also a member of the Biomarkers Consortium, which convenes government, industry, patients and patient advocacy groups, and not-for-profit organizations to address one of the most pressing needs in the diagnosis and treatment of disease: the development and the seeking of regulatory approval for disease biomarkers and surrogates.

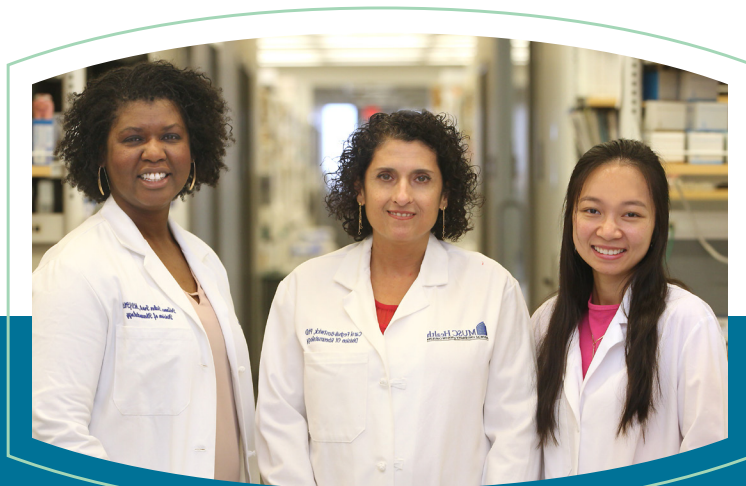
The Foundation is proud to support the Consortium's latest project, "Novel Prognostic Biomarkers Of Systemic Sclerosis To Aid Future Drug Development (PrognOSScis)." This project aims to discover novel prognostic molecular biomarkers to provide information on the likely natural course of Systemic Sclerosis (SSc) in a patient on standard-of-care treatments and better inform on the rate of progression of organ-specific diseases such as interstitial lung disease and skin fibrosis. Further discerning the heterogeneity among this patient population will enable better patient stratification for clinical trials and the likelihood of response to targeted therapeutics, ultimately improving patient outcomes and opportunities for more tailored and effective treatment options.

## EARLY CAREER INVESTIGATOR WORKSHOP

This intensive workshop brings together investigators who have received or are interested in receiving funding from the Foundation to discuss their research in depth. The goal is to facilitate interactions, provide constructive feedback and offer career mentoring in a highly interactive supportive environment. In 2023, the Foundation hosted three Early Career Investigator Workshops.

## PRE-DOCTORAL SUMMER FELLOWSHIP AWARD PROGRAM

The Pre-Doctoral Summer Fellowship Award Program fosters the next generation of researchers by cultivating interest in scleroderma under the mentorship of an established scleroderma researcher. In 2023, the Foundation funded six Pre-Doctoral Fellowships. Helen Jarnagin, Dartmouth College; Qinmengge Li, University of Michigan; Qiannan Ma, Case Western Reserve University; Elfa Beaven, University of Texas at El Paso; Enze Xing, University of Michigan; and Chanhyuk Park., Dartmouth College. You can learn about their work at [www.scleroderma.org/mentor-program-recipients/](http://www.scleroderma.org/mentor-program-recipients/).



## MAKING CLINICAL TRIALS MORE ACCESSIBLE

In 2023, the Foundation partnered with Carebox to launch an experience optimized for scleroderma clinical trials. The new web application gives individuals living with scleroderma, caregivers and healthcare professionals, an easy and effective way to search and match with scleroderma clinical trials. The Carebox Connect trial database is synchronized daily with ClinicalTrials.gov data. Access to the new web application is available from the Foundation website under "Find a Clinical Trial."

# ADVOCACY AND AWARENESS

## PROCLAMATIONS AND LIGHT-UPS

Proclamations are an official designation of an event. Local chapter volunteers led the charge for securing proclamations helping educate the public about scleroderma. Light-ups are when local municipal and/or private buildings and monuments are lit up in a specific color. In June 2023, the National Scleroderma Foundation launched a tracking system for proclamations and light-ups supporting Scleroderma Awareness Month. We are happy to share that a total of 31 proclamations and light-ups were reported in our new tracking system. And as a grassroots organization, we know there may be others that occurred throughout the United States that were not reported to us directly.



## DEPARTMENT OF DEFENSE FUNDING FOR SCLERODERMA RESEARCH

The Foundation, along with members of the Advocacy & Awareness Committee members, people living with scleroderma, and their families met with all 16 members of the Senate Appropriations Committee to ensure that scleroderma will be included as an eligible disease in the DOD's Peer Reviewed Medical Research Program (PRMRP). Meetings were held both in person and virtual and allowed congressional leaders to learn more about the impact of scleroderma and the need for more research.

## NIAMS COALITION

The National Scleroderma Foundation, along with 50 representatives from more than 40 organizations attended The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition Outreach and Education Meeting on September 19, 2023, at the National Institutes of Health (NIH) campus in Bethesda, MD. The NIAMS Coalition is an independent group of more than 95 professional and voluntary organizations interested in the research and mission areas of NIAMS. The day featured presentations from NIH leadership and breakout sessions with topics focused on The NIAMS Strategic Plan, including the patient voice in research, accelerating better health outcomes and other important topics.



# FUNDING INNOVATIVE, PEER-REVIEWED RESEARCH



Since its founding in 1998, the Foundation has committed nearly \$35 million to advancing medical research in scleroderma. In the spring of 2023, eight researchers began work on their Foundation funded projects.

For this round of funding, the Foundation received 27 proposals from investigators representing 23 institutions. All funded projects were rated as “high impact” by reviewers, and the success rate for FY 2023 applicants was 30% (compared to 33% last year). The FY 2023 portfolio includes three New Investigator Awards and five Established Investigator Awards, and a good mix between basic and more clinically focused science. The portfolio also includes research focused on the pediatric population.

The Foundation’s peer-reviewed research grants program prioritizes scientific merit and provides funding for both early career and established investigators. The program is administered by the Foundation’s Research Committee. The committee makes funding recommendations to the Board of Directors annually after a rigorous peer review process. Each application is carefully reviewed, critiqued and ranked by a panel of scleroderma experts. Only projects of significant scientific merit are recommended for funding.

After the awards are made, all recipients are required to submit annual reports on their progress. All reports are reviewed by the Foundation’s Research Committee to ensure compliance with programmatic, scientific, fiscal and administrative policies and requirements.

# OUR NEW INVESTIGATORS



**Andreea Bujor, MD, PhD,  
Boston University**

Spatial Frequency Domain Imaging as a New Method to Quantify Skin Changes in Scleroderma

Established Investigator Award



**Justin Lui, MD,  
Boston University**

Cardiac Strain Phenotyping of Systemic Sclerosis-related Pulmonary Hypertension

Walter and Marie Coyle Award – New Investigator Award



**Rafael Contreras, PhD,  
University of Minnesota**

Centromeres, Chromosome Instability, and cGAS-STING Activation in Scleroderma Fibrosis

Supported in part by the Marta Marx Fund for the Eradication of Scleroderma

Established Investigator Award



**Peter Morawski, PhD,  
Benaroya Research Institute  
at Virginia Mason**

Cutaneous T Cell Dependent Regulation of Scleroderma-associated Fibroblasts

New Investigator Award



**Roxane Darbousset, PhD,  
Boston Children's Hospital**

Platelets as Driver of NET Formation in Systemic Sclerosis

The Mark Flapan Award – New Investigator Award



**Elena Netchiporouk, MD,  
McGill University Health  
Centre**

Investigating the Impact of the Environment on Systemic Sclerosis in Canada

Established Investigator Award



**Suzanne Li, MD, PhD,  
Hackensack University  
Medical Center**

Developing Classification Criteria for Juvenile Systemic Sclerosis: An International Effort to Enable Pediatric-focused Clinical Trials

Established Investigator Award



**Natalie Saini, MSc, PhD,  
Medical University of  
South Carolina**

Determining the Somatic Mutation Burden and its Consequences in Scleroderma-lung Disease

Established Investigator Award

# PROMOTING DISEASE AWARENESS

## AWARENESS MONTH

Throughout June, the Foundation featured videos, social posts, live chats, roundtables, light-ups, proclamations, and Stepping Out to Cure Scleroderma walks. The month-long campaign was completed on World Scleroderma Day, June 29. All videos created for Scleroderma Awareness Month can be found on our YouTube channel.

In 2023, the National Scleroderma Foundation launched its inaugural #TealTalk Series. The series offers virtual roundtable discussions called #TealTalk Roundtables and live conversations, with special guests on/for #TealTalk Live. This pilot program was a great success, and the Foundation will continue it into 2024 and beyond.

#TealTalk Roundtables were on Zoom and provided the scleroderma community an opportunity to join together and rotate rooms to share their journeys and find support and care for the lives of those battling scleroderma and their support networks. Over 300 people registered for #TealTalk Table.







# #TealTalk



#TealTalk Lives allowed the community to hear from special guests interviewed by CEO, Mary Wheatley on Facebook and reposted on YouTube. Lives were held on June 6 with Ashley Barron, National Scleroderma Foundation Celebrity Ambassador; June 13 with Desiree James, Local Chapter Volunteer; June 20 with Dr. Elizabeth Volkmann; and June 27 with Demetra Newton, Local Chapter Volunteer. Lives were well attended, with an average of 40 live viewers, 584 views, 111 engagements, and 236 views on YouTube.

“Teal Talk Table is a wonderful and much-needed platform for patients outside of their local support groups. Battling scleroderma for 23 years I love sharing and learning firsthand from patients about their journey.”

“I learned so much. I enjoyed hearing from others. It was really nice to meet and make connections. Very useful.”

“A perfect platform to invite newly diagnosed people to get to know us! It was easy for new as well as existing patients to tell their story, positive conversations were had, and I feel that gave patients hope!”

# STEPPING OUT TO CURE SCLERODERMA

The Foundation celebrated 20 years of its premier national awareness walks in 2023, hosting over 20 walks in June alone. Over the year, the series hosted 38 walks with nearly 3,000 participants actively engaged across the country, raising awareness and funding for critical scleroderma research.

Due to the tremendous outpouring of support from our community, those living with scleroderma, volunteers, staff, and supporters like you, the National Scleroderma Foundation elevated the awareness around scleroderma and supporting those who are battling the disease.



# Spotlight on Support

## ANDREA RAMIREZ

Andrea Ramirez was diagnosed with scleroderma as a young teenager and is thankful for the support of her mother, Maria Ramirez, throughout her journey. Maria started the National Scleroderma Foundation's Rocky Mountain Chapter support group with several other moms.

The group offers a safe space for parents and their teenagers living with scleroderma to share experiences and process difficult emotions.

"I am processing it. Everyone else is processing too. Mom is super involved and that's how she handles it with me," says Andrea.

Andrea is now opening up about her scleroderma journey for the first time. She says it began in 2018 when, after undergoing appendix surgery, she began experiencing inflammation in her body and various symptoms that included difficulty swallowing, skin lesions and bruises. After initially being misdiagnosed with a nickel allergy, she was diagnosed with scleroderma at age 11.

It's estimated that about 300,000 Americans are living with scleroderma. Localized scleroderma is more common in children. Andrea describes both good days and bad days throughout her journey. She recalls missing a lot of school due to treatments and was initially hesitant to talk to anyone about her diagnosis. Andrea, who lives in Albuquerque, New Mexico, enjoys reading, journaling and spending time with family. Her advice for others who have been recently diagnosed with scleroderma is to understand and accept that your body is going to feel different, and the process will be a roller coaster.



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“IT WAS A VERY OVERWHELMING TIME. I DIDN'T WANT TO TALK ABOUT IT. I DIDN'T WANT PEOPLE TO KNOW.”

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Right now, Andrea is focused on how she can best help herself outside of treatments. She's hopeful that one day there will be a cure and that research will lead to improved treatment options.

Maria is inspired by her daughter's strength and resilience.

"I want to share her story," she says. "I know sometimes she wants to give up, but she doesn't."

The National Scleroderma Foundation's mission is to support patients like Andrea and their families by advancing medical research, promoting disease awareness and providing educational resources.

Now that Andrea and her scleroderma friends are all adults, the support group has transitioned to allow anyone living with scleroderma to be part of it. Maria and the moms who started the group are continuing to support those with scleroderma.



# CONTINUING MEDICAL EDUCATION

The National Scleroderma Foundation offers Continuing Medical Education (CME) and Continuing Nursing Education (CNE) as a vital tool in advancing awareness and understanding of scleroderma and its comorbid conditions among healthcare providers.

Because scleroderma is a systemic disorder, individuals living with scleroderma 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 tract, etc.). There is a great need to educate medical professionals on the various manifestations of scleroderma to foster more accurate diagnosis to enhance outcomes. The Foundation's CME and CNE programs provide continuing education credits for healthcare providers to learn more about this complex disease.

The Foundation hosted two CME programs last year, which are available to healthcare professionals free of charge at <https://scleroderma.org/cme/> for one year.

## EDUCATIONAL WEBINARS

The Foundation hosted more than 40 educational events, including national and chapter webinars and in-person events. All recorded activities are made available on the Foundation's YouTube channel, which has more than 10,000 subscribers, and a catalog of more than 500 videos with 150,000 views and 2.1 million impressions annually.

## SUPPORT GROUPS

To ensure equitable programming within our support group offering, we participate in the Scleroderma Support Group Leader Education (SSLED) program hosted by the Scleroderma Patient-Centered Intervention Network (SPIN). SSLED provides support group leaders with a cost-effective training program via webinar. Training groups are limited to 12 people, creating a safe space for learning and exploration.

In 2023, the Foundation supported training for twenty-nine new Support Group Facilitators, in three cohorts (January, May and September). Fifty-eight (58) Support Group Facilitators attended the National Scleroderma Conference in July 2023 in Orlando, Florida.

In 2023, the Foundation hosted about 500 support group meetings, both in-person and virtually, across the country, all supported by SPIN/SSLED-trained Facilitators.



# NATIONAL SCLERODERMA CONFERENCE

The National Scleroderma Conference was held July 14-16, 2023, in Orlando, Florida. Over 600 people registered for the event (423 in person and 185 virtual). Of those in attendance (either in person or virtual), 266 declared it was their first time in attendance, with 276 returning participants. Fifty-two sessions were provided through our multi-modal conference offering. The top nine sessions, as ranked by participants included:

- Opening session with guest speaker NIAMS Director Dr. Lindsey Criswell
- Lung Involvement in Scleroderma
- Navigating GI Issues in Scleroderma
- Raynaud's, Ulcerations and Calcinosis in Scleroderma
- Closing Session with Dr. Carol Feghali-Bostwick
- Common Scleroderma Complications
- Pain Management in Scleroderma
- Scleroderma & Dentistry
- Scleroderma-Related Interstitial Lung Disease

## HIGHLIGHTS OF THE CONFERENCE INCLUDE THE FOLLOWING:

- Our new chapter realignment
- Kids Get Scleroderma, Too! was filled with essential opportunities for those with juvenile scleroderma and their parents/guardians.
- Friday night's Anniversary Celebration with a special concert from Celebrity Ambassador Ashley Barron was an uplifting experience. Ashley debuted a new original song in partnership with Sing Me A Story. Ashley's new song showcased Julia, a child living with juvenile scleroderma. Ashley's song can be found on RAREisPlaylist.com.
- Annual Awards Luncheon celebrating the many contributions of our volunteers who are the backbone of our grassroots mission delivery efforts.
- Four sessions were offered in Spanish supporting our native Spanish-speaking community.
- The announcement to provide unwavering coverage to all people in the scleroderma community from coast to coast.



## PATIENT ASSISTANCE

Last year, we launched a partnership with The HealthWell Foundation to provide financial assistance to individuals living with systemic sclerosis with interstitial lung disease (SSc-ILD). Through the new fund, HealthWell will provide up to \$9,000 in medication copayment or insurance premium assistance to eligible patients with annual household incomes up to 500% of the federal poverty level to manage their condition.

# FINANCIALS

## Statement of Activities For the Year Ended June 30, 2023

	Without Donor Restrictions	With Donor Restrictions	Total	%
<b>REVENUE AND OTHER SUPPORT:</b>				
Contributions	1,383,512	1,110,472	2,493,984	38.2%
Contributions Received from Affiliates	1,659,500	395,455	2,054,955	31.5%
Special Events (Net of Direct Benefit to Donor Cost)	850,362	—	850,362	13.0%
Bequests	517,110	—	517,110	7.9%
Returned Grant Awards	381,686	—	381,686	5.8%
Voluntary Research Contributions	—	141,197	141,197	2.2%
Investment Income Designated for Operations	—	87,583	87,583	1.3%
Net Assets Released from Restriction	1,349,514	(1,349,514)	—	0.0%
<b>Total Revenue and Other Support</b>	<b>6,141,684</b>	<b>385,193</b>	<b>6,526,877</b>	<b>100.0%</b>
<b>OPERATING EXPENSES:</b>				
Education and Support	2,573,410	—	2,573,410	40.1%
Research	2,177,271	—	2,177,271	33.9%
<b>Total Program Services</b>	<b>4,750,681</b>	<b>—</b>	<b>4,750,681</b>	<b>74.0%</b>
General and Administrative	1,021,183	—	1,021,183	15.9%
Fundraising	645,725	—	645,725	10.1%
<b>Total Operating Expenses</b>	<b>6,417,589</b>	<b>—</b>	<b>6,417,589</b>	<b>100.0%</b>
(Decrease) Increase in Net Assets from Operations	(275,905)	385,193	109,288	
<b>NON-OPERATING ACTIVITIES:</b>				
Investment Income (Loss), Net	1,070,124	169,786	1,239,910	
Appropriation of Investment Income Designated for Operations	—	(87,583)	(87,583)	
Gain on Extinguishment of Long-Term Debt – Paycheck Protection Program	—	—	—	
<b>Total Non-operating Activities</b>	<b>1,070,124</b>	<b>82,203</b>	<b>1,152,327</b>	
(Decrease) Increase in Net Assets	794,219	467,396	1,261,615	
Net Assets, Beginning of Year	6,893,709	1,655,912	8,549,621	
Net Assets, End of Year	7,687,928	2,123,308	9,811,236	

Audit conducted by Baker Tilly US, LLP.

Complete copies of the Foundation's fiscal year 2023 audited financial, and IRS form 990 are available at [www.scleroderma.org](http://www.scleroderma.org)

## Revenues

- Contributions **38.2%**
- Contributions Received from Affiliates **31.5%**
- Special Events (Net of Direct Benefit to Donor Cost) **13.0%**
- Bequests **7.9%**
- Returned Grant Awards **5.8%**
- Voluntary Research Contributions **2.2%**
- Investment Income Designated for Operations **1.3%**



## Expenses

- Investment Income Designated for Operations **1.3%**
- Research **33.9%**
- General and Administrative **15.9%**
- Fundraising **10.1%**



# OUR FRAMEWORK FOR THE FUTURE

As the leading patient advocacy organization serving people living with scleroderma in the United States, the National Scleroderma Foundation is positioned to play a key role in addressing the challenges of the future. To that end, the Board of Directors has approved a strategic framework that enables us to focus the Foundation's efforts toward maximizing the impact we can have on complex issues facing those living with scleroderma, their families and support networks as well as the medical and scientific communities.

This framework is meant to serve our organization in an ever-changing world and provide flexibility in scope and scale, while providing a clear vision of where we want to go, and where we need to be, to best serve the scleroderma community.

Rooted in our 2024 strategic framework, our vision is delineated by six pillars that encapsulate our aspirations, guiding us toward a future marked by progress and unity.



## INCREASED COLLABORATION

Collaboration serves as the cornerstone of our framework. We are committed to fostering an environment that encourages partnerships among researchers, healthcare professionals, patient communities and advocacy groups. By forging alliances and synergies, we aim to accelerate the pace of discovery, pooling expertise and resources to drive groundbreaking advancements in scleroderma research and care.



## CLEAR AND OPEN COMMUNICATION

Transparent and effective communication is pivotal in fostering trust and unity. We will facilitate clear, accessible and open channels of communication. This commitment spans interactions within our organization, with the community we serve and among our diverse stakeholders. By fostering dialogue and transparency, we aim to build strong, enduring relationships built on trust and understanding.



## BUILD ON OUR REPUTATION AS A TRUSTED SOURCE

In an era inundated with information, we will emerge as the beacon of trust and credibility. Our dedication to accuracy, reliability and integrity in disseminating information underscores our commitment to becoming a trusted source for scleroderma-related resources, guidance and support. We aspire to be the go-to authority, empowering individuals with credible information to make informed decisions about their health and well-being.





MARY J. WHEATLEY, IOM, CAE  
CHIEF EXECUTIVE OFFICER



## CREATE A DIVERSE AND UNIFIED COMMUNITY

Our vision encompasses a community that celebrates diversity and embraces unity. We will create an inclusive environment that values and respects the unique experiences, backgrounds and perspectives of all individuals affected by scleroderma. By fostering a sense of belonging and solidarity, we aim to unite our community in a collective journey towards empowerment, support and resilience.



## EMBODY INNOVATION

Innovation propels progress. We are committed to embracing innovation across all facets of our endeavors, from research methodologies and treatment approaches to outreach strategies and advocacy efforts. By fostering a culture that encourages creativity, experimentation and the adoption of innovative technologies, we strive to drive transformative change in the fight against scleroderma.



## BUILD A CULTURE OF PHILANTHROPY

Philanthropy forms the bedrock of our mission. The Foundation aims to cultivate a culture of giving and generosity, inspiring individuals, corporations and philanthropic entities to support our cause. Through philanthropy, we aim to expand our reach, amplify our impact, and ensure sustainable initiatives that continue to advance research, provide support and advocate for the needs of those affected by scleroderma.

As we chart the course forward guided by these pillars, our commitment is steadfast. Together, with our community, partners and supporters, we look forward to a future where the burden of scleroderma is alleviated, where innovation leads to breakthroughs, and where unity and collaboration pave the way toward a world free from the constraints of this disease.

# CORPORATE PHILANTHROPY

We are grateful for the generous support of our corporate donors. Our vision is to be a relentless force in finding a cure for scleroderma, and corporate partners are key to our success. The partners listed below help advance our shared mission and provide critical support for signature programs, like the National Scleroderma Conference and Stepping Out to Cure Scleroderma.

## PLATINUM

**Johnson & Johnson**

## GOLD



## SILVER



## ADDITIONAL CORPORATE SUPPORT PROVIDED BY

23andMe  
Columbia Construction  
Environmental Products Group, Inc.  
Genentech Inc.

Talaris Therapeutics  
United Therapeutics Corporation, Inc.  
WebMD Inc



The Scleroderma Hope Society recognizes those who have included the Foundation as part of their estate plans.

Angela Alleman  
Cyndy R. Besselievre  
Loretta and Michael Bessert

Dorothy Jarczynski  
Gregory Lurvey  
Cos M. Mallozzi

While every effort is made to ensure the accuracy of these lists, please let us know if we have made an error. We welcome the opportunity to make it right.



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