SCLERODERMA VOICE

The magazine exclusively for members
of the National Scleroderma Foundation.

SPRING 2025

A LEGACY OF HOPE

Honoring a life through a new memorial research grant initiative

KNOWLEDGE IS POWER

Chapter education events provide opportunities to learn and share

ON THE ROAD TO ST. LOUIS

A preview of the National Conference in St. Louis

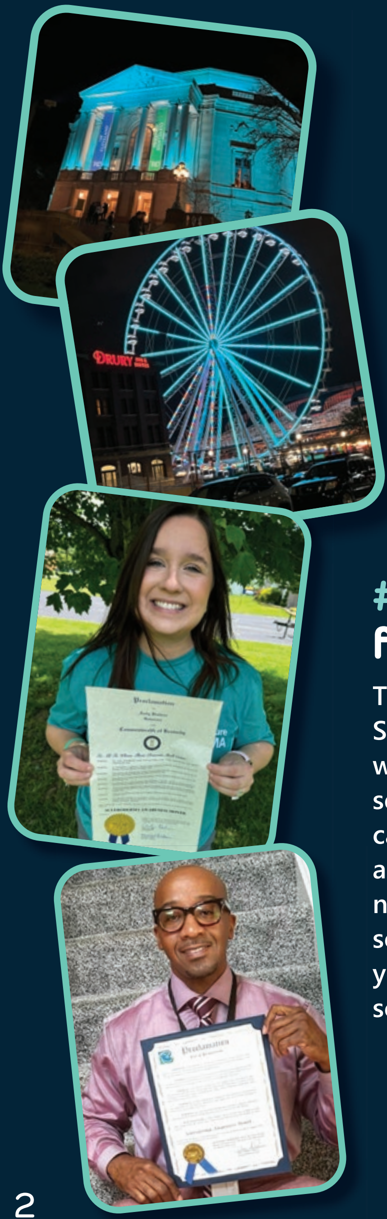
2025 RESEARCH GRANT AWARDEES

Recognizing the 2025 research leaders shaping the future

Share YOUR STORIES OF STRENGTH During SCLERODERMA AWARENESS MONTH

Join the National Scleroderma Foundation in sharing stories of hope and strength this June. Whether you're a newly diagnosed individual, long-time warrior, or supporting someone affected by this disease, your unique journey is important, and you're never on it alone.

This year's awareness month theme is #StoriesofStrength.



Request a Proclamation or Building Light Up in your area.

Each city and county will have its own guidelines and procedures for signing proclamations or securing buildings, bridges, homes, businesses, stadiums, other local points of interest, and landmarks requests for lighting it teal.

The easiest way to research your city or county guidelines is to look on its website and search for the term "proclamation" or "building light-ups." Some of the larger cities and counties will have guidelines listed. Smaller cities and counties may provide contact information on the website to call or email for information.

Together, we can light the nation with teal to spread scleroderma awareness.

#TealTalk Series Returns for Awareness Month

The Foundation continues its annual Scleroderma Awareness #TealTalk series with four engaging sessions. This year's series includes discussions about hand care and treating digital ulcers, staying active while living with scleroderma, navigating legalities of the workplace and social security, and life hacks for making your home fit the needs of your unique scleroderma journey.

Spread Awareness

The Foundation will be active on social media, sharing stories from our community, information about living your best life with scleroderma, and more. Follow our social media channels on Facebook, Instagram, and LinkedIn and join the conversation by using:

#SclerodermaAwareness

AND

#StoriesofStrength

SCLERODERMA VOICE

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ABOUT US

The National Scleroderma Foundation was founded in 1998 to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families and support networks.

CHANGE OF ADDRESS: To ensure timely delivery, please email info@scleroderma.org with the subject line "Change of Address." You may also call us toll-free at 800-722-4673 or write us at 55 Ferncroft Road, Suite 315, Danvers, MA 01923.

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Message from the Board and CEO

We're sharing stories of strength during Scleroderma Awareness Month, ***Stepping Out to Cure Scleroderma*** walk season is ramping up, and we are working on an exciting and informative lineup for the 2025 National Scleroderma Conference in St. Louis.

This spring, there is enhanced urgency to our advocacy efforts and our work supporting critically important medical research. With great uncertainty about funding streams for federally supported research, the Foundation's work is more important than ever. Through the advocacy efforts of our community, we have ensured scleroderma continues to be included in the Department of Defense's Peer-Reviewed Medical Research Program. This achievement opens doors for researchers to compete for grants that will advance our treatment options for those living with scleroderma.

The past few months have also demonstrated that Foundation-funded research is as important as ever. Thank you to everyone who has generously supported our spring research campaign. Since our founding, we have committed more than $34 million to investigator-initiated peer-reviewed research grants. Your generosity ensures we can continue this work.

In 2025, we are embracing the theme of ***strength*** in all that we do. We move with ***strength in every step*** as part of our ***Stepping Out to Cure Scleroderma*** walks; we will share our ***stories of strength*** and raise awareness throughout the month of June and beyond; and we will continue to demonstrate the ***strength of our voice*** through our advocacy work.

> IN 2025, WE ARE EMBRACING THE THEME OF **STRENGTH** IN ALL THAT WE DO.

We hope you will join us over the next several months. We are challenging everyone in our community to secure a proclamation or a teal light-up in your community recognizing Scleroderma Awareness Month. We hope you will join us at one of our ***Stepping Out to Cure Scleroderma*** walks taking place across the country. We will need your support and stories as we continue to advocate for federal research funding as part of the FY26 budget cycle. We also hope that you will join us and show the strength of our community at this year's National Scleroderma Conference.

There is much to be done, but we are strong. All of us at the Foundation are proud to be a part of this community, with you. We appreciate all your support and we are counting on your partnership in the months to come.

Kevin Boyanowski

Kevin Boyanowski
Chair, Board of Directors

Mary J. Wheatley, IOM, CAE
Chief Executive Officer

National
Scleroderma
Foundation

STRENGTH IN RESEARCH

STRENGTHENING THE FUTURE OF RESEARCH

The National Scleroderma Foundation's 2024 Class of Investigators

Yen Tzu Chen, PhD,
University of Michigan

New Investigator Award

Brain boost program to improve cognitive function in people with systemic sclerosis: A pilot randomized controlled trial

Mathew Lammi, MD, MSCR
Johns Hopkins University

Established Investigator Award

Quantitative CT scanning to examine the pulmonary vascular effects of mycophenolate and nintedanib in patients with scleroderma

Erica L. Herzog, MD, PhD,
Yale University

Established Investigator Award*

Nerve-Fibroblast Interactions in Scleroderma ILD

**This grant is supported in part by the Marta Marx Fund for the Eradication of Scleroderma*

Ian Douglas Odell, MD, PhD
Yale University

New Investigator Award

Regulation of fibroblast metabolism by EGFR during skin fibrosis

James Jarvis, MD
University of Washington

Mark Flapan Award
Established Investigator Award

Mechanistic Studies of Genetic Risk Scleroderma

Patricia A. Pioli, PhD
Dartmouth College

Walter and Marie Coyle Award
Established Investigator

The Role of Paracrine WNT5A in Immuno-metabolic Regulation of SSc Macrophage Activation

A LEGACY OF HOPE:

The National Scleroderma Foundation is thrilled to announce the **Indu Sapra, MD Memorial Research Grant.** Thanks to a generous $5 Million commitment from Bob Nickerson in memory of his late wife, Indu Sapra, MD, this endowment will fund a grant honoring investigators conducting research related to scleroderma.

Indu was a remarkable person who lived her life to the fullest, despite her scleroderma diagnosis. Born in India, she moved to the United States as a young woman and built the American dream for herself. She was incredibly bright and energetic, serving as a physician for more than 20 years, she delivered more than 5,000 babies over the span of her career, while providing life-saving medical treatment for countless others. She developed meaningful relationships with many individuals around the country and world and made a tremendous impact on the lives of so many.

> “INDU WAS A FORCE OF NATURE. EVERYONE WHO KNEW HER KNEW SHE MEANT BUSINESS, WITH A RADIANT SMILE. SHE NEVER STOPPED FIGHTING. MY HOPE IS THAT THIS GRANT WILL SUPPORT THE RESEARCH NEEDED TO FIND A CURE. INDU WAS SO MOTIVATED BY RESEARCH AND SCIENCE, AND THE PROMISE THEY HELD.”
>
> **- BOB NICKERSON**

INDU SAPRA, MD MEMORIAL RESEARCH GRANT

The Foundation is grateful that Bob and Indu chose us for the honor of such an important legacy.

"Dr. Sapra's work literally brought life into this world," Mary J. Wheatley, Chief Executive Officer of the National Scleroderma Foundation, said. "Now her legacy is creating hope for hundreds of thousands more who will benefit from the research that is powered by this generous gift."

A Force of Nature and a Legacy Making an Impact

Indu Sapra was born in 1944 in a rural hillside village in what is now Pakistan (then India). She grew up in a strict household, with a backdrop of war and conflict. Despite her circumstances, she achieved scholarship and athletic recognition. As a teenager, Indu entered and won the national 10-meter diving championship in India. The president of India presented her with her medal, and suggested she train for the Olympics. But Indu couldn't be convinced. She knew at an early age that she wanted to be a doctor, and this early idea was cemented after she lost her younger brother to illness. She competed and won an invitation to a highly regarded and prized Medical School, where she met many of the brightest and most able young women in all of India, many of which she had kept in touch with all her life.

Indu's life and career took her from Germany to the UK to Canada and eventually to Baltimore for her American medical training. Her steely determination, willingness to work hard, along with her intelligence led her to much success in life.

In Baltimore, Indu met the love of her life, Bob, who fell in love with her soft, beautiful smile, and her heroic and resilient spirit. They met later in life and when the time came to retire, they sought warmer weather. After finding a home in Ponte Vedra, they took up near-daily golf games and made many new friends that became like family.

In retirement, she relished playing competitive golf or bridge, trekking the highest mountains, including Everest, Kilimanjaro and Machu Picchu, and spending time with her beloved husband of more than 25 years, Bob Nickerson. She built many deep and wonderful relationships with friends in the Sawgrass community and enjoyed spending time with friends and extended family in Ponte Vedra and around the world.

GETTING TO KNOW Mo

We're proud to welcome Mohamed Eldosoky as the new Research Manager at the National Scleroderma Foundation. Mo, as he is known around the team, has a background in medicine and public health. He brings both clinical expertise and a deep understanding of the broader health landscape to his role.

As Research Manager, Mohamed works closely with both researchers and people living with scleroderma to make research more understandable, accessible, and impactful.

Outside of work, he finds balance on the trails - whether he's training for a long-distance run or heading out for a hike.

In the Q&A that follows, get to know Mohamed and hear more about his vision, passions, and plans for the future of scleroderma research.

Q: What brought you to the National Scleroderma Foundation?

Scleroderma is a very interesting disease. A similar disease runs in my family, so when I saw the opportunity with the Foundation, I thought it would be a great fit since I also have experience in grant management with many organizations.

Q: You are the research manager; can you tell us a little about that role and how you'll be working with our community?

As Research Manager, I oversee research funding and make sure it aligns with the needs of the scleroderma community. I work with researchers and patients to ensure the science is understandable, relevant, and leads to real improvements in care and quality of life.

Q: What would you say is one special talent or skill you bring to this role?

The ability to understand science on a deeper level and make it more easily understood by the general public. I went to medical school and studied medicine, and then I decided to shift my studies and career to public health. I completed my Masters of Public Health where I gained skills to tailor different types of health messaging to the public.

Q: At the National Scleroderma Foundation when a new person joins the team, we ask for one thing that we won't learn about them from their LinkedIn profile. You mentioned you're a long-distance runner and a hiker.

Could you tell us a little about one or both of those activities and why you enjoy them?

Running or hiking for a long distance allows my brain to enter a phase where I feel like I am meditating. When the sore muscle pain starts to kick in - for me it is around 5 miles into the run - it helps my mind to not focus on many daily life stressors. I finished many half marathons and one marathons with the Marine Corps, and my goal is to finish an ultra marathon.

I encourage everyone to walk, run, hike for a long distance. Your long distance can be less than 1 mile. Always listen to your body, because it is a form of therapy as research has proven in many studies.

Q: What is your favorite travel destination? Where is one place you haven't traveled that is still on your bucket list?

Iceland and Switzerland, because they have beautiful landscapes. I have many countries on my bucket list, but Japan and South Korea are on the top for 2026.

Q: Last, but not least, what is your biggest goal for the year?

To be a better version of myself on a daily basis is something I strive for since I had children. From a career perspective, it is to become a subject matter expert and key decision maker to give back to our patient community and to improve their long-term health.

Shining a Light on Rare Disease Day: How Our Chapters Made an Impact

Rare Disease Day, observed annually on the last day of February, is a global movement that raises awareness and generates support for the millions of people living with rare diseases - including scleroderma. This year, our National Scleroderma Foundation chapters across the country came together in creative and inspiring ways to make a difference, advocate for change, and foster community among those affected by scleroderma.

Lower Great Lakes Chapter: Nationwide Children's Hospital Rare Disease Day Event

The Lower Great Lakes Chapter participated in the Nationwide Children's Hospital Rare Disease Day event on March 1 in Columbus, Ohio. Attendees had the opportunity to engage with medical professionals, patients, and advocates to share information and discuss the impact of rare diseases on individuals and their families.

> "Rare Disease Day means coming together as a diverse, empathetic, and supportive community to share facts, stories, and experiences with patients and medical professionals about the impact these conditions have on the life of the individual and everyone around them," Doris Caceres Schumick, a member of the Lower Great Lakes chapter who participated in the event said. "It's an opportunity for spreading awareness at the local, national, and global level to improve patient health outcomes."

The event fostered meaningful conversations and strengthened connections within the rare disease community, highlighting the importance of awareness and advocacy.

Shining a Light on Rare Disease Day: How Our Chapters Made an Impact

Florida and Puerto Rico Chapter: Jazz at MOCA Awareness Event

The Florida and Puerto Rico Chapter took part in Jazz at MOCA Rare Disease Day event at the Museum of Contemporary Art North Miami. With more than three hundred attendees in attendance, the event provided a valuable opportunity to raise awareness about scleroderma, introduce the Foundation's mission to new audiences, and strengthen community connections.

The evening began with recognition of Rare Disease Day and the National Scleroderma Foundation, setting the stage for impactful conversations and outreach. Lorraine Biaggi, executive director of the Florida and Puerto Rico Chapter; Desiree James, chapter chair; and Monica Ramirez, a support group leader in the chapter, engaged with attendees, shared resources, and helped bring greater visibility to scleroderma.

"Rare Disease Day provides an opportunity to shine a bright light on diseases such as scleroderma that many in our society - and around the world - know nothing about," Desiree James said. "Participating in these types of events provides a platform to raise awareness by sharing my personal story with others as well as being a strong voice for our community of patients, family members, and caregivers."

Shining a Light on Rare Disease Day: How Our Chapters Made an Impact

New England Chapter Logs in to Rare Disease Day Hackathon

The New England Chapter took action to amplify awareness and advocate for those affected by scleroderma.

Mirian Moultrie, executive director of the New England Chapter, serving as a guest speaker at Harvard University's Rare Disease Hackathon. Addressing future researchers, engineers, and advocates, she shed light on the challenges scleroderma patients face—delayed diagnosis, symptom management, and the need for more inclusive research. She emphasized the power of technology combined with patient experiences to drive real solutions, encouraging participants to develop innovative approaches to early detection and personalized treatment.

Mirian and Jane Ladas, chair of the New England Chapter, also attended the Boston Globe's Rare Disease Summit. The conference brought together experts in medicine, biotechnology, and patient advocacy to discuss the future of rare disease research, treatment access, and policy advancements. The event reinforced the importance of collaboration in addressing the gaps in diagnosis and disparities in clinical trials for rare diseases like scleroderma.

By participating in these important conversations, the New England Chapter continues to raise awareness, advocate for better treatments, and push for a future where rare diseases receive the attention they deserve.

THANK YOU
FOR MAKING A DIFFERENCE

Rare Disease Day was a powerful reminder of what we can achieve when we come together. The dedication, creativity, and passion displayed by our Foundation chapters made a lasting impact - not just on Rare Disease Day, but for the future of scleroderma awareness and advocacy. Thank you to everyone who participated, shared their stories, and stood in solidarity with the rare disease community.

A MOTHER'S LOVE, A SISTER'S STRENGTH, A FAMILY'S LEGACY

WHEN MIKE HART TALKS ABOUT HIS FAMILY, there is a mix of pride and pain in his voice. Mary Lynn, his younger sister and the strongest person he knows, has been living with scleroderma for the past 15 years. And their mother, Kathy, recently passed away in October 2023.

For their mother, supporting Mary Lynn throughout her journey meant more than just checking in with her or helping her manage symptoms. It was about being her rock, her fiercest advocate, and her most steadfast source of encouragement. A bond that was already strong between mother and daughter grew even deeper through their shared determination to fight this disease together.

Even as Kathy faced her own health challenges, she never wavered in her commitment. Before her passing, she made a decision to leave a generous bequest to the National Scleroderma Foundation. Her gift ensures that her fight to find a cure for this disease will continue.

> “MY MOM DIDN'T PICK ANY OTHER ORGANIZATION TO LEAVE MONEY TO. TO ME, THAT SAYS ALL YOU NEED TO KNOW ABOUT THE BOND BETWEEN A MOM AND HER DAUGHTER.”
>
> **- MIKE HART**

Growing up, Kathy Hart was one of three children, but conversations about health always made her nervous because her older sister died from pneumonia at an early age.

“Until the day she died, Mom just wanted to be there for Mary,” Mike said. “She didn't want to pester her, but as a mother, you're never not a mom. It doesn't matter how old your kids are. She worried about Mary every moment of her waking life because—if you have kids, you'll understand this—that's your child.”

The loss of her sister early in life helped Kathy understand the incredible value of family. In sixth grade, she attended a small school in the Toledo area, where she would meet her future husband to whom she was married for 40 years.

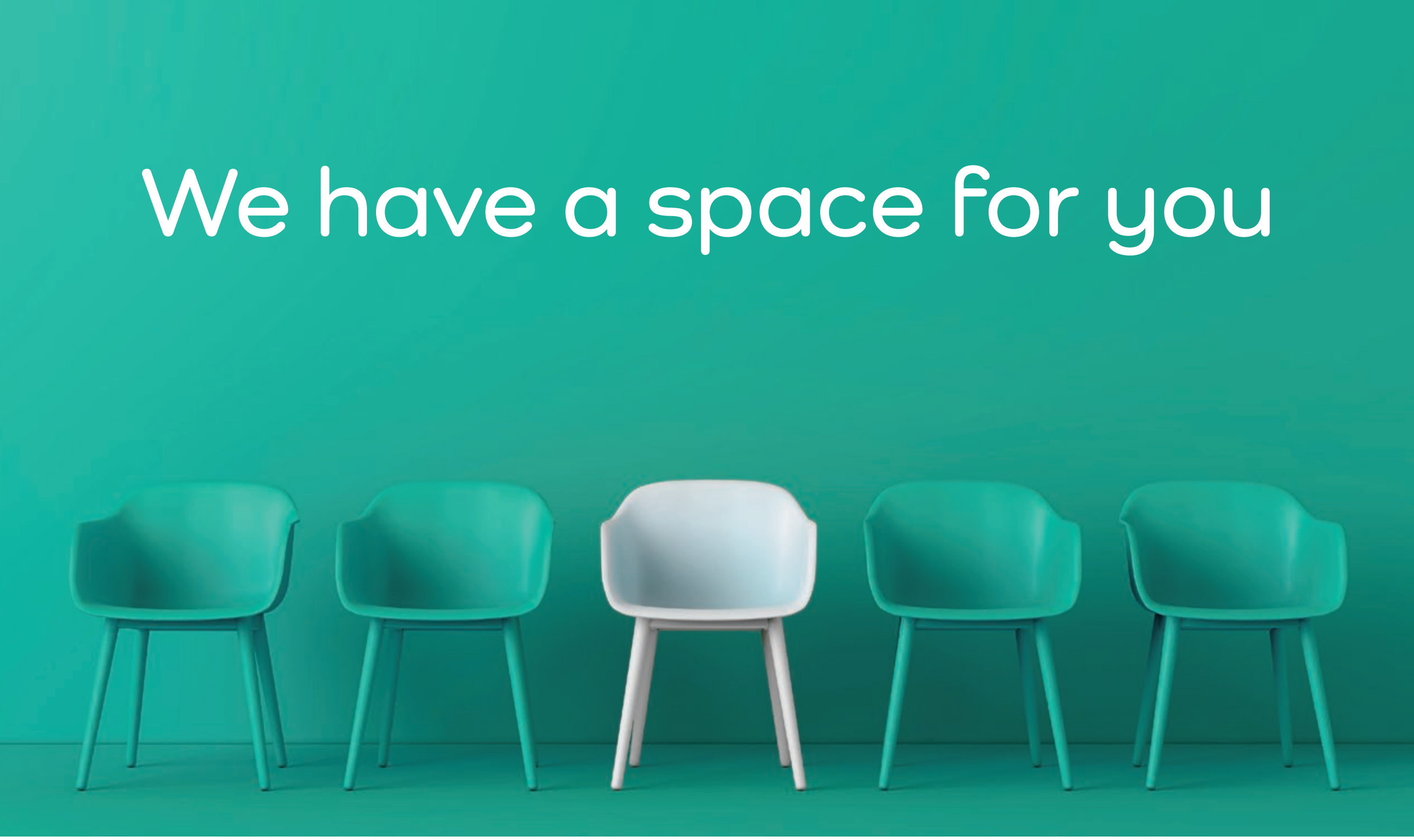
“We lost my dad when he was 62. And we hated to lose mom, but we're glad they're back together.”

Kathy's plans to name the Foundation as a beneficiary of her retirement plan were completely her own decision. According to Mike, “It was her way of taking care of her baby girl. When your kids are sick, you just want to solve the problem, and since Mary's disease is advanced, if there's anything mom could have done to find a cure, she would have done it. That's why she gave.”

Though teary-eyed, Mike reflects on his family's journey with the same resolve and determination that his mother had for Mary Lynn.

“I see what my sister goes through. She can't get gloves on her hands, she has sores on her fingers, and she experiences all sorts of aches and joint pain. But she's still holding on—God love her. If I could take that disease and put it in my body, I would do that in a minute.”

We have a space for you



National Scleroderma Foundation

Support Groups

We offer more than 40 Foundation-affiliated scleroderma support groups around the country. We have virtual and in-person group meetings, along with groups dedicated to specific patient experiences and journeys.

Our support group leaders are trained volunteers who are committed to creating safe, welcoming and inclusive environments where all can share about their journey with scleroderma.

Learn More

Contact Us:
support@scleroderma.org

Upcoming Meetings

Advocacy in Action

Legislative Outlook for FY26 Budget Cycle

IT IS NOT A STRETCH to say that this Spring has been a tumultuous one in Washington, D.C., especially for advocates of medical research. As changes to funding have affected many agencies that support research this year, the upcoming FY26 budget cycle will be an important opportunity for the scleroderma community to share their stories and make sure legislators understand the importance of medical research to our community.

The Foundation's leadership is closely monitoring the legislative landscape. As a nonpartisan organization, the National Scleroderma Foundation is fortunate to have strong relationships with both sides of the aisle that has resulted in continued advocacy success for our community.

The leadership works closely with the Health and Medicine Counsel to ensure we're advocating in the most effective way possible on behalf of our community. Josh Fein, a legislative consultant, answered a few of our questions about how our community can continue its strong advocacy work heading into this critical budget season.

Q. What should be the key points to focus on during the upcoming budget cycle?

A. First and foremost the most important point is that the annual appropriations process is a bipartisan effort. That means lawmakers need to arrive at a consensus to pass any final measures.

Congress is currently working on the spending bills for Fiscal Year (FY) 2026 and they will be deciding between many different priorities. Lawmakers will be listening to their constituents about what agencies and programs are most important for them as they make their decisions. That is why it is important for lawmakers to hear from members of the scleroderma community as to why the research programs at the National Institutes of Health (NIH) and the Department of Defense (DOD) deserve robust funding.

Q. Given all the changes and uncertainty we saw this Spring, do you expect this budget cycle to be different than those in years past?

A. The House and Senate will be using the next few months working to write the drafts of the FY 2026 spending bills and marking them up through the various subcommittees. Once this process is completed, the House and Senate will have to work together on any final appropriations bill.

The administration released a "skinny" budget request recently that proposed severe cuts for many federal healthcare agencies and programs. While Congressional Republicans may try to consider some of the administration's proposals, drastic changes to agencies that have historically received bipartisan support such as the NIH are not expected to be able to pass. With Republicans holding slim majorities in the House and Senate, consensus and compromise (as always) is the only path forward to passing a final appropriations bill.

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Q. Before speaking with legislators, how should members of our community prepare? What should they remember during the meeting?

A. The most important aspect of speaking with your member of Congress is your scleroderma story. While becoming familiar with our policy priorities would be helpful, members of the National Scleroderma Foundation and the Health and Medicine Counsel will be attending Congressional visits with you and can assist in filling in key legislative details.

It's critical to remember that members of Congress care about their constituents and want to hear about their journeys and what's going on in the local communities. It's also important to consider that Congressional offices may not be aware of scleroderma, so preparing to explain to the basics of scleroderma would be of use.

Advocates are also encouraged to attend any training sessions or #TealTalk events that will provide more information about advocacy in general and how to properly conduct Congressional visits.

Q. During Scleroderma Awareness Month the Foundation is working with you on Virtual Hill Day events. What is Virtual Hill Day and how can our community get involved?

A. Virtual Hill Days is an event aimed at connecting our advocates with their Members of Congress. The Foundation will be holding Virtual Hill Days June 10-12. During Virtual Hill Days, advocates will have the opportunity to participate in meetings with Congressional offices via Zoom to share their scleroderma stories and educate offices on the issues facing our community along with our legislative and funding priorities.

We can encourage all advocates to register for Virtual Hill Days so we can schedule visits on their behalf with their Members of Congress. To get involved this June, please sign-up by completing the form at: scleroderma.org/HillDay.

To get involved with advocacy activities, visit: scleroderma.org/advocacy

VOLUNTEER APPRECIATION MONTH: CELEBRATING THE CHAMPIONS BEHIND OUR MISSION

Throughout the month of April, the National Scleroderma Foundation proudly celebrated Volunteer AppreciationMonth — a time to shine a well-deserved spotlight on the individuals who power our mission with heart, hope, and determination.

Volunteers are the backbone of our organization, serving in countless capacities — from national leadership and chapter support to event planning, peer mentoring, and advocacy. This month was dedicated to recognizing their contributions and saying two simple but powerful words: thank you.

Daily and Weekly Spotlights: Telling the Stories Behind the Service

Our social media channels served as a vibrant space of gratitude all month long. Each week, we featured one of our national volunteer leadership bodies — the Board of Directors (BOD), Medical & Scientific Advisory Board (MSAB), Chapter Advisory Council (CAC), and Patient Advisory Board (PAB), and our Support Group Facilitators. These spotlights offered insight into the vital roles these individuals play in shaping our strategy, research priorities, and community programs.

We highlighted chapter volunteers every day during Volunteer Appreciation Week, showcasing personal stories, photos, and testimonials that brought their passion and impact to life. These daily posts reminded us of the incredible diversity, resilience, and generosity that define our volunteer family.

Annual Volunteer Awards: Nominations and Scoring

In a fitting close to Volunteer Appreciation Month, we initiated scoring for our **Annual Volunteer Awards**, which will be presented at the 2025 National Scleroderma Conference this July. These awards recognize outstanding contributions in leadership, innovation, advocacy, mentorship, and community impact. Earlier this winter, volunteers and staff were encouraged to nominate individuals who exemplify our values and uplift the scleroderma community through their service.

This is a moment to elevate and celebrate those whose dedication inspires us all — and we can’t wait to honor them on our biggest stage of the year.

"The Foundation is very fortunate to be supported by such a talented volunteer base. Because of our national Board of Director members and advisory councils, support group facilitators, and chapter leadership, we are more impactful and successful in delivery the promise of our mission every single day," said Ashley Pruett, Vice President of Community Engagement. "The time, energy, and love they put into their work meets important needs of members in our community. It is an honor and pleasure to serve, support, and celebrate our Foundation volunteers."

Looking Ahead with Gratitude and Purpose

Volunteer Appreciation Month gave us space to celebrate — and to reflect. In recent months, we've streamlined our volunteer onboarding process, created clearer role descriptions, and strengthened support systems across chapters and national programs. These improvements are a direct response to what our volunteers need and deserve: structure, support, and recognition.

As we look to the future, we do so with renewed energy and deep appreciation. Our volunteers are not just supporters of our mission — they are the *drivers* of it.

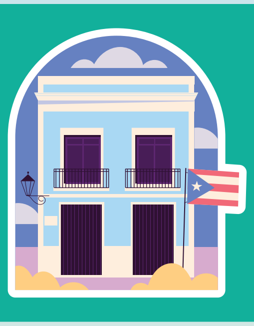
To every volunteer: Thank you. Your time, your voice, and your heart make a difference. You are the champions behind our cause, and we are endlessly grateful.

> Our volunteers are not just supporters of our mission — **THEY ARE THE DRIVERS OF IT.**

If you are interested in volunteering, email volunteer@scleroderma.org.

VOCES BORICUAS UNIDAS

Voces Boricuas Unidas: Un grupo de apoyo se convierte en un faro de solidaridad



EN LA COMUNIDAD DE ESCLERODERMIA, los grupos de apoyo son más que un simple encuentro: son un salvavidas. Ofrecen conexión, comprensión y fortaleza compartida. Para Voces Boricuas Unidas, el grupo de apoyo con sede en Puerto Rico es todo eso y mucho más. Es un espacio vibrante y de relevancia cultural, donde los miembros hispanohablantes pueden expresarse libremente, conectar a través de experiencias compartidas y sentirse vistos no solo como pacientes, sino como personas con una identidad rica y raíces compartidas.

Antes de la creación de Voces Boricuas Unidas, la Fundación Nacional de Esclerodermia no tenía presencia oficial en Puerto Rico a través de grupos de apoyo. Para muchos miembros, unirse a este grupo marcó la primera vez que conocieron a alguien con el mismo diagnóstico. Marisol González, una miembro activa, captó este sentimiento a la perfección:

“Cuando te diagnostican esta enfermedad, crees que el mundo se derrumba. No conoces a nadie que esté pasando por lo mismo. [Ahora] me siento acompañada en este camino. ¡No me siento sola!”

El grupo es facilitado por Mónica Ramírez, defensora de la esclerodermia desde hace mucho tiempo y quien también facilita el grupo nacional de apoyo en español Conexión en Español. Desde el lanzamiento del grupo en Puerto Rico en octubre de 2024, el cálido liderazgo de Mónica y su profundo conocimiento de las necesidades de la comunidad han ayudado a crear un espacio seguro y de confianza para la conexión, el crecimiento y el aprendizaje.

Las reuniones, que se realizan completamente en español, se adaptan a la cultura local y destacan los recursos, profesionales de la salud y servicios accesibles en Puerto Rico. El grupo se reúne mensualmente y ofrece no solo apoyo emocional, sino también sesiones educativas durante todo el año. Con más de 20 miembros activos, incluyendo cuidadores y personas recién diagnosticadas, el grupo se está convirtiendo en una sólida red de apoyo.

“Reunirse con personas que realmente comprenden lo que estás pasando es esencial”, dijo Marisol. “El apoyo del grupo ha sido fundamental para mí. Las charlas educativas han sido increíblemente valiosas”.

Esto ha sido posible gracias a la dedicación de Mónica Ramírez y al apoyo continuo de Lorraine Biaggi, Directora Ejecutiva del Capítulo de Florida y Puerto Rico de la Fundación Nacional de Esclerodermia. La experiencia de Mónica con la esclerodermia impulsa su empatía y propósito, mientras que la defensa de Lorraine garantiza que las voces de la comunidad puertorriqueña sean escuchadas, incluidas y empoderadas.

Juntos, sus esfuerzos han transformado a Voces Boricuas Unidas en más que un simple grupo: es un faro de solidaridad, educación y esperanza. Está amplificando las voces de las personas con esclerodermia en Puerto Rico, destacando la importancia de la atención con relevancia cultural y construyendo puentes entre la isla y la comunidad de esclerodermia en general.

A través de la compasión, la comunidad y una dedicación inquebrantable, Voces Boricuas Unidas está trazando un camino más conectado y equitativo no solo para Puerto Rico, sino para todas las personas que viven con esclerodermia.

Para obtener más información sobre Voces Boricuas Unidas o para unirse a una futura reunión, comuníquese con floridaprchapter@scleroderma.org.

PUERTO RICAN UNITED VOICES

A Support Group Becomes a Beacon of Solidarity

IN THE SCLERODERMA COMMUNITY, support groups are more than just a gathering - they are lifelines. They offer connection, understanding, and shared strength. For Voces Boricuas Unidas, the Puerto Rico-based support group, it's all that and more. It's a vibrant, culturally relevant space where Spanish-speaking members can express themselves freely, connect through shared experience, and feel seen not only as patients, but as people with rich identities and shared roots.

Before Voces Boricuas Unidas was founded, the National Scleroderma Foundation had no official presence in Puerto Rico through support groups. For many members, joining this group marked the very first time they met someone else with the same diagnosis. Marisol González, an active member, captured this feeling perfectly:

"When you are diagnosed with this disease, you believe that the world falls apart. You don't know anyone who is going through it. [Now] I feel accompanied on this road. I do not feel alone!"

The group is facilitated by Monica Ramirez, a longtime scleroderma advocate who also facilitates the national Spanish-language support group Conexión en Español. Since launching the Puerto Rico group in October 2024, Monica's warm leadership and deep understanding of the community's needs have helped create a safe, trusted space for connection, growth, and learning.

Held entirely in Spanish, meetings are tailored to reflect the local culture and highlight accessible resources, healthcare professionals, and services in Puerto Rico. The group meets monthly, offering not only emotional support but also educational sessions throughout the year. With over 20 active members including caregivers and those newly diagnosed, the group is blossoming into a powerful support network.

"Meeting with people who truly understand what you're going through is essential," Marisol said. "The support of the group has been fundamental for me. The educational talks have been incredibly valuable."

This has been made possible through the dedication of Monica Ramirez and the ongoing support of Lorraine Biaggi, Executive Director of the Florida & Puerto Rico Chapter of the National Scleroderma Foundation. Monica's lived experience with scleroderma fuels her empathy and purpose, while Lorraine's advocacy ensures that the voices of the Puerto Rican community are heard, included, and empowered.

Together, their efforts have transformed Voces Boricuas Unidas into more than just a group it is a beacon of solidarity, education, and hope. It's amplifying the voices of people with scleroderma in Puerto Rico, shining a spotlight on the importance of culturally relevant care, and building bridges between the island and the broader scleroderma community.

Through compassion, community, and unwavering dedication, Voces Boricuas Unidas is charting a more connected and equitable path forward not only for Puerto Rico, but for all people living with scleroderma.

To learn more about Voces Boricuas Unidas or to join a future meeting, contact floridaprchapter@scleroderma.org.

MEET Elle

As 2024 came to an end, Elle Hurley joined the National Scleroderma Foundation team as the new Support Programs Manager. Elle's primary responsibility is to provide support and resources to the Foundation's support groups and facilitators.

Originally from San Francisco, Elle as recently moved to Maine from Oregon. If you have a few minutes on your hand, she'd be happy to talk Hamlet thanks to her background in English with a focus on Shakespeare. She has also studied social work and is eager to pursue a master's degree in Global Public Health.

Elle was kind enough to answer a few questions to help the rest of our community get to know her a little better.

Q: What brought you to the National Scleroderma Foundation?

I've worked in patient advocacy for 6 years. I've supported communities including psoriatic disease, hemophilia, and endometriosis, but I've been looking for an organization and a community where I could stay for the long haul. After researching the National Scleroderma Foundation and the scleroderma community, I really felt I'd found that place.

Q: You are the manager for support programs, can you tell us a little about that role and how you'll be working with our community?

The Support Programs Manager oversees support group programs, the HOPE Line, and the peer mentor program. I get to work with nearly everyone on the Foundation's staff to support volunteers and community members, and I've already had the opportunity to meet many members of the scleroderma community. I talk with patients every day, and it's my favorite part of this work.

Q: What would you say is one special talent or skill you bring to this role?

I would say that my special skill is my ability to listen. I am genuinely interested in what our community has to say and the diverse experiences they bring. Our Support Group Facilitators are the experts and I'm the person who gets to support them in the incredible work they do. Being a good listener allows me to better understand their needs and the needs of the community, so I can provide the right support and resources.

Q: What is your favorite travel destination? Where is one place you haven't traveled that is still on your bucket list?

My answer is two-in-one! I loved visiting Tokyo last year, and I want to go back to Japan to visit Hokkaido.

Q: At the National Scleroderma Foundation when a new person joins the team, we ask for one thing that we won't learn about them from their LinkedIn profile. What is your one thing we wouldn't learn about you from LinkedIn?

I got into weight training a few years ago, and it has changed my life. Not only do I love feeling stronger, but it also helps lessen some of my own chronic pain. I love being active and being able to deadlift or do a pull-up has revolutionized the way I see my own health and my body. Despite limitations from my chronic illness, I see that my body is capable of so much.

Q: Last, but not least, what is your biggest goal for the year?

My Foundation-related goal is to raise the visibility of our HOPE Line. It's a fantastic resource. I envision a world where anyone who's newly diagnosed and feeling unsure or overwhelmed about next steps can reach out and get connected with support groups, scleroderma education, and information about treatments and research.

My personal goal is to explore as much of New England as possible. I love it so far!

THROUGH HER EYES:

A Daughter's Story of Love, Strength, and Scleroderma

AT JUST 13 YEARS OLD, Camryn Norder faced a reality most teenagers couldn't imagine - her mother was diagnosed with a life-threatening illness. What began as a misdiagnosis of lupus eventually led to a diagnosis of systemic scleroderma.

Along with the diagnosis came devastating news - her mother was given a life expectancy of ten years.

"In that moment, it felt like I was losing everything," Camryn said. "And I still feel like that some days."

Now at 19 years old, Camryn describes her mom not only as her parent but as her world and best friend. The journey since that diagnosis has been anything but easy.

For Camryn, the most painful part hasn't just been seeing the physical toll but facing the emotional reality.

"The hardest realization is knowing that I'm more than likely going to lose my mom because of this disease," she says. "But what's stuck with me through everything is how strong she is."

Camryn has grown into an advocate - not only for her mom, but for every family touched by scleroderma. She speaks honestly about the emotional weight that comes with being loved of someone living with a rare disease.

When asked how she would describe scleroderma in one word, Camryn paused before saying, "Painful. And heartbreaking."

Still, she finds strength in the bond she shares with her mom and in the hope that more people will learn about scleroderma, support research, and join the fight for a cure.

Despite the crushing challenges scleroderma brings, the strength of Camryn's relationship with her mother remains a shining testament to resilience, love, and an unbreakable bond.

WHILE THE DISEASE MAY CONTINUE TO TAKE MUCH, IT CANNOT TAKE THE LOVE AND HOPE THAT DRIVE THEM FORWARD EACH DAY.

KNOWLEDGE IS POWER:

Chapters Gather to Share the Latest in Scleroderma Care & Research

This Spring has been a season of sharing and learning across the country for our scleroderma community. Chapters from coast to coast hosted educational events as we build to our keystone educational event, the National Scleroderma Conference.

24th Annual Cheri Woo Educational Seminar

The Pacific Northwest Chapter hosted its annual educational event in memory of the Cheri Woo, a dedicated advocate for the scleroderma community. Dr. Whitney Elg-Salsman led a discussion about Raynaud's Phenomenon, and Dr. Kamini Kuchinad discussed gastrointestinal complications often associated with scleroderma. Finally, Dr. Jeffrey Robinson gave a comprehensive presentation on pulmonary hypertension in scleroderma.

15th Annual Amy K. Parrish Education Forum

The Southeast Chapter hosted the 15th Annual Amy K. Parrish Education Forum at the Medical University of South Carolina. More than one hundred people participated in the hybrid event. Dr. Richard Silver, Dr. Kimberly Hashemi, Dr. DeAnna Baker Frost, Dr. Aravind Menon and Dr. Kathleen Oare Lindell all gave presentations during the event.

Spring Health Resource Conference

On Saturday, March 29, the Upper Great Lakes Chapter held its Spring Health Resource Conference in West Allis, Wisconsin.

More than thirty participants were treated to an interactive event consisting of several modules and breakout sessions meant to educate, empower, and support our participants from a mind and body perspective. The day began with a creative ice breaker activity. Participants painted butterflies, the symbol of scleroderma awareness, and then attached them to the chapter's community tree. The plan is to have participants paint butterflies at future events. The chapter will continue adding butterflies to the tree as a symbol of our growing and strong community.

ST. LOUIS: GATEWAY TO fun

The National Scleroderma Conference will be full of learning and community-building. If you are also looking to enjoy the St. Louis region, here are a few of the great opportunities just miles away from the conference site.

Take a Ride to the Top of the Arch

There are few things more synonymous with St. Louis the Gateway Arch. Take a four-minute ride to the top of the arch and get a bird's eye view of the region. Learn about the mighty Mississippi River and the history of the region in the museum at the base of the arch.

Union Station

Once one of the largest and busiest passenger rail terminals in the world, Union Station is now home to a lot of family-friendly fun. Take a ride in the 200-foot St. Louis Wheel, pay a visit to more than 13,000 aquatic friends at the St. Louis Aquarium, or get a sweet treat at The Soda Fountain.

Forest Park

Forest Park has something for everyone! The Saint Louis Science Center and world-renown Saint Louis Zoo are great ways to spend a day—and admission to each is free! Forest Park also features the Missouri History Museum, the Saint Louis Art Museum, The Jewel Box and the World's Fair Pavilion. All of it is a short car ride or ride on the Metro away from the site of the conference.

City Museum

The city museum offers a unique way to reconnect with your inner child. Housed in a 60,000 square foot former warehouse, the architectural playground offers an immersive experience that includes a lot of activities for kids.

Missouri Botanical Garden

Take a stroll among more than 27,000 types of plants and flowers. A site of beauty, serenity and discovery, the Missouri Botanical Garden has it all.

We're just scratching the surface. Visit Grant's Farm, the National Blues Museum, one of St. Louis' many local breweries, or one of the many parks in the area.

To learn more, visit scleroderma.org/stlouis

2025 NATIONAL SCLERODERMA CONFERENCE

JULY 18-20, 2025

ST.LOUIS, MISSOURI

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Friday, July 18

4:00 p.m.	**Doors, Registration & Exhibit Hall Open**
4:30 p.m.	**Research Poster Hall Opens**
6:30 p.m.	**Dinner Buffet**
7:30 p.m.	**Opening Ceremonies**

Saturday, July 19

7:45 a.m.	**Breakfast Buffet**
9:15 a.m.	**Breakout Sessions & Exhibit Hall**
12:00 p.m.	**Awards Lunch**
2:15 p.m.	**Breakout Sessions #2 & Exhibit Hall**
5:00 p.m.	**Lungs & You**
6:15 p.m.	**Dinner Buffet**

Sunday, July 20

7:00 a.m.	**Breakfast Buffet**
8:30 a.m.	**Breakout Sessions & Exhibit Hall**
11:15 a.m.	**Closing Keynote - Dr. Afton Hassett**

*All times are Central Time

Conference Breakout Session Schedule

Saturday, July 19

9:15 a.m. - 10:15 a.m.

Scleroderma 101 - Dr. DeAnna Baker-Frost
Living with Scleroderma as a Man - Dr. Michael York
Yoga for Digestion/Vagus Nerve - Cheryl Albright & Pat McMillan
Taking Care of Others and Yourself - Maria Tafoya
ABC's of Scleroderma Lung Care - Dr. Virginia Steen

10:45 a.m. - 11:45 a.m.

Scleroderma & the African American Comm. - Dr. DeAnna Baker-Frost
Oral Surgery - Dr. Reza Movahed
Raynaud's and Ulcerations - Dr. Jessica Gordon
Localized Scleroderma - Dr. Michael York
ILD in Systemic Sclerosis- Dr. Shervin Assassi
GI and the Microbiome - Dr. Elizabeth Volkmann

2:15 p.m. - 3:15 p.m.

Dental Care in Scleroderma - Dr. Reza Movahed
Clinical Trials: What You Need to Know - Dr. Shervin Assassi
Patient Experience Panel Discussion
Managing Emergencies in Scleroderma- Dr. Tracy Frech
Meditation & Breathing - Dr. Sundar Balasubramanian
Predicting Progression in Scleroderma - Dr. Laura Hummers

3:45 p.m. - 4:45 p.m.

Medications in Scleroderma - Dr. Joseph Washington
CAR-T in Scleroderma - Dr. Elizabeth Volkmann
GI in Scleroderma - Dr. Joy Liu
Young Adult Panel Discussion
Pulmonary Hypertension in SSc - Dr. Virginia Steen

Sunday, July 20

8:30 a.m. - 9:30 a.m.

Taking Care of Your Hands and Face - Dr. Janet Poole
Art in Spite of Adversity - Amy Gietzen & Evamarie Cole
Wound Care - Dr. Kimberly Lakin
Blood Work & Understanding Test Results - Dr. Tracy Frech
The Importance of Scleroderma Research - Dr. Cristina Padilla
Cardiac Involvement in SSc: Open Q&A - Dr. Tania Ruiz

9:45 a.m. - 10:45 a.m.

Ask the Experts Anything Panel Discussion
ABLE Today - Yvonne Rydman
How to Get Involved: Stepping Out to Cure Scleroderma
Taking Care of Your Skin - Dr. Jessica Gordon
Advocacy & Scleroderma

11:15 a.m. - 12:15 p.m.

Closing Keynote: Chronic Pain Reset: Building Resistance - Dr. Afton Hassett
Please join Dr. Hassett for a book signing event following the address. Space is limited.

Activity Room: Saturday & Sunday

Networking
Support Group
Yoga

*All times are Central Time

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CLINICAL TRIALS CONNECTIONS

- Get information about the latest clinical trials related to scleroderma research
- Learn more about clinical trials and how they help pave the way for a better future for people affected by scleroderma.

Sign-Up Today

scleroderma.org/clinicaltrials