SCLERODERMA VOICE

The magazine exclusively for members
of the National Scleroderma Foundation.

FALL 2024

RISING STAR

Celebrating newer members who are making a difference

• WELCOMING THE FUTURE OF SCLERODERMA RESEARCH

The Foundation celebrates its Pre-Doctoral Summer Fellowship Award winners

• TAKE ME OUT TO THE BALLGAME

Upper Great Lakes Chapter and America's pastime team up for the mission

• GIVINGTUESDAY

Ring in the holiday season and double your impact

SCLERODERMA VOICE

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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 PO Box 411533 Boston, MA 02241-1533.

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CHAMPIONS FOR THE MISSION

This fall, we convened our annual Leadership Retreat, bringing together key volunteers to review our strategic framework, and discuss how we can best serve our community.

This year's retreat was virtual, allowing us to broaden our network of leaders participating nationwide. I am incredibly grateful for the leaders who champion our mission to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families and support network each and every day.

As the leading patient advocacy organization serving people living with scleroderma in the United States, the National Scleroderma Foundation is positioned to play an important 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. You can learn more about our organizational priorities on our website at https://scleroderma.org/mission-vision-values/.

As I reflect on our time together, I am energized by our work to expand programming that serves our scleroderma community. Expanding our reach means that we must increase our funding to support the expansion of programming and services that make lives better. I hope you'll join me in making scleroderma a priority in your charitable giving this fall.

Here are just a few opportunities to maximize your impact through philanthropy:

- **GivingTuesday** is a global day of giving where you can support the National Scleroderma Foundation. I hope you can share some kindness with this special community on this special day. Thanks to support from our partners at Amgen Rare Disease, your gift will be doubled, so don't forget to mark your calendars for GivingTuesday this year on December 3!
- During the **holiday season of giving**, you have an opportunity to do even more to provide hope, help and vital resources for those facing this devastating disease. Thanks to an amazing $75,000 gift from an incredibly generous family in our community, all gifts will be matched dollar for dollar. I hope you'll take advantage of this opportunity to double your impact by making a gift by December 31.

In the fight against scleroderma, our shared purpose is strengthened by you. Together, we'll accelerate research for a cure, while increasing awareness, support and education nationwide. Visit scleroderma.org/fall to donate now. We're counting on you to join us with your gift today!

Kevin Boyanowski

Kevin Boyanowski
Chair, Board of Directors

Mary J. Wheatley, IOM, CAE

CHAMPIONING THE CAUSE:

ACTIONS YOU CAN TAKE TODAY TO ADVANCE THE MISSION

WHILE LIVING WITH SCLERODERMA CAN BE CHALLENGING, there are so many ways to advance the mission and build awareness in your community. Here are some actionable steps that can help you and others champion the cause.

1 Share Your Story Understanding scleroderma is the first step in building awareness. Sharing your personal experience with scleroderma can create connections and community and inspire others. Whether you're living with scleroderma yourself, caring for someone who is, or serving the community as a healthcare professional, your story is powerful. Participating in support groups are another way to empower others in the community, and share your support.

2 Get Social Make sure you're following National Scleroderma Foundation on social platforms like Facebook, Linkedin, Instagram, and X. Sharing articles, infographics, as well as your personal thoughts and stories from the community on social media is a great way to build awareness and champion the cause.

3 Raise Support Fundraising events are a great way to bring people together, raise awareness about scleroderma, and have fun! You can create a team for one of our Stepping Out to Cure Scleroderma walks across the country or host your own fundraising event to help raise funds for the mission. Hosting your own event is a creative and high-impact way to raise funds and meet the growing demands of our critical mission work. Learn more at https://scleroderma.org/start-a-fundraiser/.

Take Out
Scleroderma

HOW TO GET STARTED

Local and chain restaurants are a great and easy way to raise money for the National Scleroderma Foundation! Many restaurants offer "give-back" nights that will provide a portion of the proceeds to the non-profit of choice. To get started, find a restaurant that participates and call or email them to sign up. For chains, click here for more informaton.

Then email specialevents@scleroderma.org to notify the Foundation of your event.

THE MAIN COURSE

FIND A RESTAURANT
This can be a local or chain restaurant! Check your favorite restaurant.

CONTACT RESTAURANT & PROVIDE NON-PROFIT PAPERWORK
Most places will require information on the Foundation like the 501(c)3 letter, EIN number, address, and email contact.

PICK A DATE
Typically, give-back nights are held on the weekdays. We suggest picking a Thursday or Friday if possible.

SET A FUNDRAISING GOAL
Think BIG when setting your goal and share this with your invites! Take into consideration the type of restaurant, typical food prices, and location.

PROMOTE THE EVENT
Promoting the event is key! Use social media to create an event and share with your connections. Send an email blast to your constituents. Use **#takeoutscleroderma** when posting to social!

EVENT NIGHT!
Time to eat! Introduce yourself to restaurant staff upon arrival, bring brochures and flyers, and say thank you!

FUNDS DISTRIBUTED TO FOUNDATION
After the event, all funds will be sent directly to the Foundation via check or ACH. Confirm with the Foundation and the restaurant the best option for payment.

THE SWEET STUFF

Putting on a give-back night is a *sweet* way to fundraise locally for the Foundation - and eat some good food! It is also fairly easy to run, making it a good fundraiser for volunteers to lead. Make sure to invite friends, family, other volunteers, and chapter staff to come. Share on social media!

HELPFUL SIDE TIPS

Remember, have fun!
Any questions related to Take-Out-Scleroderma should be sent to specialevents@scleroderma.org.

National Scleroderma Foundation

300 Rosewood Dr. #105
Danvers, MA 01923
EIN #: 52-1375827

specialevents@scleroderma.org

4 Volunteer! Our national network of chapters provides support and education for people affected by scleroderma in the communities where they live. By volunteering with your local chapter, you can help deliver programs and services where they are needed most. Find your chapter on our website at https://scleroderma.org/find-your-local-chapter/.

5 Advocate for Change Advocacy is a powerful tool for driving change on a greater scale. Reach out to your local representatives to advocate for policies that support scleroderma research and access to care. Visit https://scleroderma.org/take-action/ to learn more about how you can become a scleroderma advocate.

By taking action today, you can significantly contribute to raising awareness, providing support, and advocating for change. Remember, you are not alone in this journey—together, we can find a cure and improve the lives of people affected by scleroderma.

Mary J. Wheatley, IOM, CAE
Chief Executive Officer

Play Ball!

UPPER GREAT LAKES COMBINES AWARENESS WITH AMERICA'S PASTIME!

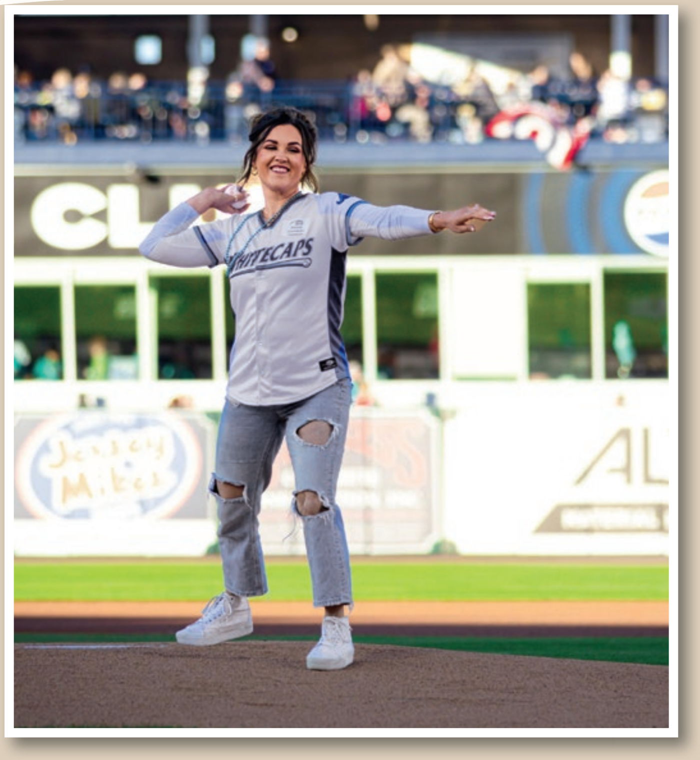
UPPER GREAT LAKES CHAPTER RAISES AWARENESS AMONG MORE THAN 14,000 SPECTATORS.

Take me out to the ball game! The National Scleroderma Foundation Upper Great Lakes Chapter did just that this summer, embarking on a series of Stepping Out to Cure Scleroderma ballpark walks. These walks brought a new level of awareness about the disease, the Upper Great Lakes Chapter, and the Foundation. Over the course of three games, the chapter raised awareness among more than 14,000 spectators.

The summer series began on June 29, World Scleroderma Day, in Appleton, WI. The walk is the Upper Great Lakes Chapters first in Wisconsin and was held in memory of Linda Peterson, who passed away earlier this year.

A group of more than 120 walkers and physicians, including Dr. Mary Ellen Csuzka, who won the National Scleroderma Foundation Doctor of the Year award earlier this summer, walked the track around the field. As the walkers rounded the third base side, they received a standing ovation and high fives from the crowd. After completing the walk, Linda's physician, Dr. James Runo, threw the first pitch. In addition to making a major impact on everyone in attendance at the game, the walk raised close to $25,000.

The series moved on to Turtle Creek Stadium in Northern Michigan in July. Traverse City held its first-ever ballpark walk on July 27. They also walked on the ball field and



raised awareness among nearly 2,500 in attendance for the game. The intimate setting allowed Peggy Collins, the Upper Great Lakes Chapter chair, and Randy Slikkers, the chapter's executive director, to get quality one-on-one time with each participant. A number of new volunteers committed to the Foundation following these walks.

For the homerun in West Michigan, Ashley Baron threw out the first pitch and performed "Take Me Out to the Ballgame" to the entire crowd. Among the 150 Stepping Out to Cure Scleroderma Walkers, Ashley Pruett, vice president of community engagement for the Foundation, also walked along the baseline. Larry Malace, who lost his mother, Connie Malace, was pictured "In Memory Of" on the scoreboard.

As a bonus this summer, the Upper Great Lakes Chapter also made it to the big leagues with an awareness event at the Detroit Tigers' Comerica Park. The chapter set up a table on the main concourse and was recognized on the scoreboard before a sell-out crowd. The event was such a large success, planning has already begun to host another Scleroderma Awareness event at a Tigers game next season.

FOSTERING A COMMUNITY OF SCLERODERMA RESEARCHERS

Yan Wang, MD, PhD

IN 2021, I received a New Investigator Award from the National Scleroderma Foundation to investigate the role of Hyaluronan and O-GlcNAcylation in fibroblast turnover and function in scleroderma. Essentially, I was interested in how the sugar molecules, either in the cells or in extracellular matrix, interact with proteins and may contribute to increased fibrosis in scleroderma when they are at abnormal levels. Our findings were encouraging, most notably that targeting on these sugar molecules may alter skin fibrosis in scleroderma. These findings will help us understand the underlying mechanisms of fibrosis in scleroderma and identify new treatment targets.

While this grant allowed me to conduct important experiments, collect valuable data, and make significant discoveries, it also helped me advance my career and build my network. As a result of this work, I have at least two manuscripts in preparation and have secured new funding from the National Institutes of Health (NIH), enabling me to continue my research. My research team and I also had the opportunity to present our findings at numerous national and international academic conferences.

My partnership with the Foundation has been essential in advancing my career as a research scientist. It has helped me transition from being completely dependent on other researchers' grants to becoming, at least partially, an independent investigator with my own research focus and funding. I am truly grateful for the Foundation team's dedication to supporting emerging researchers like me, particularly through the efforts of Shenna Giannetta and the network she has built of Foundation-funded investigators. This network provides invaluable guidance and resources, creating an encouraging environment for new scientists in the field of scleroderma.

For instance, I wouldn't have received funding from the NIH without the Foundation's support. This funding allowed me to gather crucial data to support my research hypothesis. Early in the development of my hypothesis, I had the opportunity to attend the Foundation's Early Career Investigator Workshop and presented my idea there. This workshop was designed to bring together investigators who have received 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. Participating in the workshop helped me gain insights from successful established researchers like Drs. Carol Feghali-Bostwick, Maria Trojanowska, and John Varga. Their advice helped me refine my research focus and improve the design of my experimental approaches. Later, Dr. Trojanowska kindly reviewed my NIH grant proposal draft and offered valuable suggestions. All these efforts contributed to the success of my application, which is vital for the next stage of my career.

I look forward to maintaining my partnership with the Foundation, and the scleroderma community. Being part of this community has been a rewarding experience, and I am committed to contributing to better healthcare and improved quality of life for scleroderma patients.

LEARN MORE
about the Foundation's research programs at

scleroderma.org/research

National
Scleroderma
Foundation

SAVE THE DATE

GIVINGTUESDAY

is December 3, 2024

Give early, give now—and know that every dollar you donate will be worth double, thanks to a $25,000 matching gift from Amgen Rare Disease!

One day
One purpose
ONE MISSION

SCAN TO GIVE

Together, we can help overcome scleroderma forever!

Don't miss this chance to DOUBLE your life-changing impact.

Make Your Gift Early at scleroderma.org/givingtuesday

VOLUNTEER SPOTLIGHT:

REEMA ADUSUMILLI

REEMA ADUSUMILLI is a senior at South Forsyth High School in Cumming, Georgia. When she isn't studying or publishing articles in the Academic Medicine & Surgery Journal, you can find her playing basketball, watching movies with her family, hanging out with her friends, and most recently, co-chairing the Atlanta *Stepping Out to Cure Scleroderma* Walk.

Her connection with scleroderma began three years ago when her mother, Chandra, was diagnosed. She saw first-hand how scleroderma affected her mom and became dedicated to finding a cure. Reema and Chandra, after the diagnosis, began searching for resources, and that is how they found the National Scleroderma Foundation.

"Right then and there, my mother and I knew we had to take part," Reema said. They became members of the Foundation but wanted to do more. That's when they found the opportunity to revitalize a walk in the Atlanta area.

Reema and her mom became integral members of the Atlanta walk committee. Reema, and her co-chair, Peggy Levengood, spent many months planning, recruiting team members, reaching out to sponsors and asking for donations from their community. There is no better mentor for a new walk chair than Peggy Levengood! And when the day arrived, more than 100 people attended.

"The walk showed me how much love people living with scleroderma have around them," she said. "The amount of people that showed up to support their friend or family member living with scleroderma was wonderful! I got the opportunity to hear about their journeys and I gained lots of valuable knowledge."

Reema is one of the Foundation's youngest volunteers. Her passion to find a cure will always be her mother.

"I hope one day my mom will be able to go back to her old self, where we would go out on mother-daughter dates, go to the movies, and get ice cream," Reema said. "Most importantly, I want to see my mother without the pain and stress she goes through daily. I want to see that smile back on her face every single day."

> “ THE WALK SHOWED ME **HOW MUCH LOVE** PEOPLE LIVING WITH SCLERODERMA HAVE AROUND THEM ”

Because of Reema's passion and support, the Atlanta *Stepping Out to Cure Scleroderma* Walk raised $20,000 for the Foundation's mission. When asked about her advice to someone who wants to get involved or start a walk, Reema said, "Just do it. It doesn't matter how old you are. All you need is passion towards bettering the lives of those living with scleroderma. If you want to make a difference in your community, nothing should be stopping you."

As Reema looks towards the future, she plans on continuing her impact through medical school. "I want to become a doctor, specifically either a rheumatologist or an orthopedic surgeon. I plan on playing a crucial role in continuing to spread awareness about scleroderma and find a cure."

Scleroderma ★ Hope Society

Hope

JOINING THE SCLERODERMA HOPE SOCIETY is a moment where an individual, couple or family leave their mark and legacy by strengthening their name and philanthropic gift to the future of the National Scleroderma Foundation.

On behalf of our future, thank you.

To learn more, visit:
www.scleroderma.org/leave-a-legacy

Jean Martinho, JD
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The National Scleroderma Foundation partners with Carebox to create an optimized experience for individuals looking for scleroderma clinical trials.

The Carebox Connect trial database is synchronized daily with the ClinicalTrials.gov clinical trial data maintained by the National Library of Medicine (NLM) at the National Institutes of Health (NIH). Users have the option to browse trials or to complete a brief questionnaire to identify specific trials based upon eligibility. It is then up to the user to take the next step to contact the trial site. No user information is shared with the trial site.

carebox

CELEBRATING THE NEXT GENERATION OF RESEARCHERS

FOUNDATION RECOGNIZES 2024 PRE-DOCTORAL FELLOWSHIP AWARDEES

The National Scleroderma Foundation's Pre-Doctoral Summer Fellowship Award Program is a demonstration of the Foundation's commitment to fostering the next generation of scleroderma researchers. An annual award program designed to recognize PhD students conducting research related to scleroderma, the program cultivates and supports students' early interests in working to discover the cause and cure of scleroderma.

"The National Scleroderma Foundation is committed to supporting the training of the next generation of scleroderma researchers, ensuring a pipeline of future investigators," says Carol Feghali-Bostwick, Ph.D., vice chair of the Foundation's Board of Directors.

Students submit a proposal on research relevant to adult or pediatric scleroderma. Applications are accepted annually and due each spring, with awards given out at the beginning of June. Join us in congratulating the 2024 Pre-Doctoral Summer Fellowship Award Program honorees:

Neerja Marwaha Bhagat Research Scholar

Madeline Morrisson

Each year, one recipient will be honored as the Neerja Marwaha Bhagat Research Scholar in recognition of their drive to discover the cause and cure of scleroderma. The Neerja Marwaha Bhagat Research Scholar Fellowship was established to honor the legacy of a longtime leader of the National Scleroderma Foundation Mid-Atlantic Chapter. Neerja Marwaha Bhagat served as Chair of the Chapter for more than a decade and was a tireless advocate for people living with scleroderma. She led the planning of the chapter's Stepping Out to Cure Scleroderma walks and helped build much-needed awareness about scleroderma in her community.

The Arnold Postlethwaite Summer Fellowship

Aarohi Mehendale

Annually one recipient will be awarded the Dr. Arnold Postlethwaite Summer Fellowship. The endowed memorial fellowship was established by the family of Dr. Arnold Postlethwaite, an esteemed academician and physician who dedicated his life to advancing the treatment of rheumatic diseases, including scleroderma, and honors his career as a scleroderma specialist and his 22-year relationship with the National Scleroderma Foundation's Medical & Scientific Advisory Board and support group leader.

ANNOUNCING THE 2024 PRE-DOCTORAL SUMMER FELLOWSHIP AWARDEES

For more information on this award program, and other Foundation research initiatives, please visit **https://scleroderma.org/research-program/**

Madeline Morrisson, Dartmouth College

Named the 2024 Neerja Marwaha Bhagat Research Scholar

Graduate Program: Molecular and Cellular Biology

Mentor: Michael Whitfield, PhD

Project Title: Characterization of the Causative Mutation of a Mouse Model of Scleroderma

Aarohi Mehendale, Boston University

Awarded the 2024 Dr. Arnold Postlethwaite Fellowship Award

Graduate Program: Biomedical Engineering **Mentor:** Darren Roblyer, PhD

Project Title: Spatial Frequency Domain Imaging (SFDI) as a method to track skin involvement in Scleroderma

Emily Ann Morris, Dartmouth College

Graduate Program: Molecular and Cellular Biology

Mentor: Patricia A. Pioli, PhD

Project Title: The Role of Fibroblast-derived Exosomal Wnt5a in Pro-Fibrotic Macrophage Metabolic Activation in SSc

Gayathri Guru Murthy, University of Rochester

Graduate Program: Translational Biomedical Science

Mentor: Benjamin Korman, MD

Project Title: Role of Insulin Growth Factor Binding Protein 7 (IGFBP7) in Scleroderma pathogenesisIGFB7 in Scleroderma Pathogenesis

Michelle Wu, Yale University

Graduate Program: Biomedical Engineering

Mentor: Anjelica Gonzalez, PhD

Project Title: Unraveling TNFα-TGFβ1 Crosstalk in Microvascular Driven Fibrosis of Localized Scleroderma

Sandra Sandria, Yale University

Graduate Program: Cell Biology

Mentor: Megan King, PhD

Project Title: Defining a mechanism for SUN2’s mechanical regulation of SSc-associated skin fibrosis

RISING STAR: HANNAH BOSE

Join the National Scleroderma Foundation in celebrating the accomplishments and dedication of some of its newest members and volunteers.

Hannah Bose is a cherished facilitator for the Jacksonville Support Group, known for her vibrant energy and dedication. Her co-facilitator, Lorraine Meide, lovingly refers to her as a "mover and a shaker," and a "blessing to our group," a testament to her dynamic role in the group.

As the tech expert, Hannah makes certain that every meeting is accessible, ensuring that members who may have difficulty attending in person can join remotely.

Diagnosed with scleroderma at an early age, Hannah has faced the disease with remarkable courage and resilience. She does not let scleroderma define her. She has flourished as a pre-licensed mental health counselor, yoga and embodiment facilitator and yoga mentor. Her strength and determination are evident in every aspect of her life.

Hannah's commitment to the Foundation extends beyond her role as a support group facilitator. In 2023, she took the initiative to organize a local walk in Jacksonville. Hannah successfully formed and led the Jacksonville Support Group Team/Walk, and raised an impressive $3,950. Her passion shone brightly again in 2024 when the team raised $4,450, with generous donations from local businesses.

In January 2024, Hannah joined the National Scleroderma Foundation Florida & Puerto Rico Chapter Advisory Committee, where she quickly became an active and engaged member. She brings ideas for fundraising and is now part of the 2025 Stepping Out to Cure Scleroderma Walk Committee.

Hannah has also attended the National Scleroderma Conference for the past two years, driven by her desire to deepen her understanding of scleroderma and to connect with others in the community. Her warmth, strength, and dedication make a significant impact wherever she goes.

> DIAGNOSED WITH SCLERODERMA AT AN EARLY AGE, HANNAH HAS FACED THE DISEASE WITH REMARKABLE COURAGE AND RESILIENCE. **SHE DOES NOT LET SCLERODERMA DEFINE HER.**

CRITERIA FOR "RISING STAR"

Do you know a "rising star" in the scleroderma community who deserves some recognition? Here's how to identify one:

- They've recently become involved (within the last 1-5 years) in scleroderma awareness, education, or support—whether they're newly diagnosed or have been living with the condition for a while.
- They take the initiative by organizing impactful support groups, events, or awareness campaigns.
- They share their personal story to inspire and educate others in the community.
- They bring fresh and creative ideas to scleroderma advocacy and patient support.
- They offer emotional and educational support, especially to those who are newly diagnosed or facing challenges.
- They show a true passion for improving the lives of those with scleroderma through their dedicated volunteer efforts.

If you know a "rising star" in your chapter or beyond, we'd love to hear about them! Please submit their name and your reasons for the nomination to **volunteers@scleroderma.org.**

JOIN THOUSANDS LIVING WITH SCLERODERMA ON INSPIRE

The National Scleroderma Foundation is proud to support a free online community on Inspire for individuals and their loved ones navigating scleroderma.

This free online community offers a safe environment for peer-to-peer support. Connect with others navigating scleroderma journeys similar to yours.

You can start or respond to discussions in the community, upload photos and search for specific topics to find other members who share the same interests or questions. Join more than 85,000 individuals in the scleroderma community and get inspired today.

Visit scleroderma.inspire.com to learn more.

inspire

National
Scleroderma
Foundation

Last Call FOR 2025 NATIONAL SCLERODERMA CONFERENCE PRESENTATIONS

The National Scleroderma Foundation is searching for engaging and inspiring presentations that will provide current and practical information to our 2025 conference attendees.

Workshop Proposal Submission Deadline is November 15, 2024

The National Scleroderma Conference is the premier setting for patients, family members and caregivers affected by scleroderma to learn more living with this disease. This is an opportunity to hear from medical experts, attend educational workshops, learn about local resources, visit with exhibitors and network with others in the scleroderma community.

Workshops are intended to educate and support learning. Presenters may not sell, promote or pitch any specific product, company, or service. Each workshop is 60 minutes in length, including time for questions and answers. **Use the QR code below to submit your presentation ideas for the 2025 National Conference in St. Louis, Missouri.** Clinicians and researchers wishing to present at the 2025 National Scleroderma Conference should reach out to Angel Soto at education@scleroderma.org.

A limited number of workshop slots are available, so don't forget to submit your proposal by November 15, 2024. We look forward to seeing you at our 2025 National Scleroderma Conference!

National Scleroderma Foundation
SCLERODERMA.ORG

Let your teal show all year long. Get the latest gear from the National Scleroderma Foundation Store.

scleroderma.org/store

Save the Date

National Scleroderma Conference

STL 2025

JOIN US IN ST. LOUIS FOR THE 2025 NATIONAL SCLERODERMA CONFERENCE, JULY 18-20, 2025

Whether you are newly diagnosed or have had scleroderma for many years, the National Scleroderma Conference is a great way to learn about the disease and become connected with others who are dealing with the same experiences.

Join us in St. Louis, Missouri, July 18-20, for a fully in-person conference that offers an information-rich opportunity for people living with scleroderma, their caregivers, family members, and friends. The 2025 conference will be held at the Hilton St. Louis at the Ballpark just two blocks away from Busch Stadium.

We are so excited to host this year's conference in St. Louis! This vibrant city is full of many fun and interactive attractions. Whether it's a ride to the top of the iconic Gateway Arch, a stroll through the immersive Forest Park or free admission to the St. Louis Zoo, there is something for everyone!

Workshops, panel discussions and other educational sessions are led by leading scleroderma researchers and health care professionals from around the country. There is no better place to connect with local and national scleroderma experts.

Early Bird Registration opens in March! Updates on venue, pricing and educational programing will be available over the next few months on our website. **Sign up for *Connections*, the Foundation's e-newsletter, and visit our website scleroderma.org for updates.**

JULY 18-20, 2025

Join us!

2024 NATIONAL SCLERODERMA CONFERENCE
REFLECTIONS AND NEXT STEPS

Kryston Skinner

As the executive director of the National Scleroderma Pacific Northwest Chapter, I am thrilled to share the resounding success of our recent national conference held in Bellevue, Washington. This landmark event marked a significant milestone for our chapter, as it was the first time our entire region, encompassing Alaska, Idaho, Oregon and Washington, came together as one chapter for an event. The conference provided a unique and special opportunity for individuals living with scleroderma, their families, and healthcare providers to connect, learn and find inspiration.

Building upon the momentum of this incredible gathering, we held our *Stepping Out to Cure Scleroderma* walk in Portland this September, marking our first in-person event since 2019. It was a truly remarkable experience to see our community come together again, re-igniting connections and hope. The walk was a tremendous success, drawing participants from across the region and fostering a renewed sense of camaraderie and purpose. I want to shout out a specific team, Stepping Out in Memory of Jeff Hudson, who raised nearly $3,000 in memorial of Jeff Hudson. Jeff Hudson was diagnosed with an extremely aggressive form of scleroderma in May 2015. Prior to his diagnosis, his family had never heard of scleroderma. After courageously battling scleroderma and undergoing various medical treatments and trials, Jeff passed away on July 27, 2016. He wanted to tell people his story so he could raise awareness about this debilitating autoimmune disease. It was a powerful reminder of the strength and love within our community. This year, we had the joy of reconnecting in-person not just once, but twice, underscoring the resilience of our chapter and the importance of community in our shared journey.

> “THE 2024 NATIONAL SCLERODERMA CONFERENCE WAS A **TREMENDOUS SUCCESS**”

I am deeply grateful to all who made the conference possible. From the dedicated volunteers and staff to the generous sponsors, everyone played a crucial role in creating a memorable and impactful experience. The energy and enthusiasm of the attendees were inspiring, and I was heartened by the strength and resilience of the scleroderma community.

Overall, the 2024 National Scleroderma Conference was a tremendous success, and I am confident that it will have a lasting impact on the lives of those affected by scleroderma in the Pacific Northwest. As we continue our mission to provide support, education, and advocacy for individuals with scleroderma, we are committed to organizing more events that bring our community together. Thank you again to everyone who participated in this historic gathering; you inspire me every day.

2024 National Scleroderma Conference Session Recordings Are Available

Check out the conference video playlist by visiting **OUR YOUTUBE CHANNEL** at YouTube.com/SclerodermaUS. If you have any questions, please email info@scleroderma.org.

Cosmetic Procedures in Systemic Sclerosis—Heidi Jacobe, MD, MSCS

Are you curious about cosmetic procedures related to scleroderma? Check out this session to better understand the risks and benefits associated with these procedures.

Nutrition and the Microbiome in Systemic Sclerosis—Elizabeth Volkmann, MD, MS

Nearly all patients with systemic sclerosis will experience gastrointestinal tract symptoms on their journey with this condition. This session addresses ways to modify your diet to improve how you feel and rebalance your gut microbiome.

Medication Side Effects and Vaccinations—Carrie Richardson, MD, MHS

Scleroderma is a serious autoimmune condition, and many people with scleroderma will need to take at least one medication. While medications can help people with scleroderma feel better and become healthier, the side effects of these medications can sometimes be intimidating. This lecture will focus on how to have a conversation with your doctor about medication side effects.

Calcinosis in Scleroderma—Carrie Richardson, MD, MHS

This session covers the causes, symptoms, and potential complications of calcinosis. It explores diagnosis and treatment options, including medications, lifestyle changes, and surgical interventions to manage and alleviate symptoms.

The Pregnancy Journey in Scleroderma—Kimberly Lakin, MD

This session covers topics related to pregnancy and scleroderma, including why pre-conception planning is so important, considerations for pregnancy timing, possible pregnancy outcomes, fertility, and more.

Scleroderma and Cancer: What are the Connections—Laura K. Hummers MD, ScM

While studies have suggested that the risk of cancer might be increased in scleroderma patients, the reason for this association has not been well understood. Possible reasons for the connection will be explored in this session. Specifically, however, we will focus on more recent data suggesting that cancer is the source of the autoimmune response in scleroderma, suggesting that it may be part of what may cause scleroderma in a subset of patients. Implications this may have for treatment and screening for cancer amongst patients with scleroderma will also be discussed.

Understanding Interstitial Lung Disease in Systemic Sclerosis

Eleanor Valenzi, MD

MY RESEARCH focuses on interstitial lung disease (ILD), a condition that causes progressive scarring in the lungs, making it difficult for the body to get enough oxygen. This condition is a major cause of death in people with systemic sclerosis, and furthering our understanding of ILD is critical.

I'm particularly interested in a type of cell called fibroblasts. Normally, these cells help produce the proteins that support tissues like the lungs and skin. However, in systemic sclerosis, fibroblasts change into myofibroblasts, which produce too many of these proteins, leading to scarring and stiffness in the lungs and skin.

The Foundation is the **LARGEST FUNDER OF PEER-REVIEWED SCLERODERMA RESEARCH** outside of the NIH. You can support our efforts by donating now at scleroderma.org/donate

To understand how this transformation happens, we study proteins called transcription factors. These proteins attach to specific parts of DNA and can turn genes on or off, affecting important processes like inflammation and cell death. By examining how DNA structure changes in fibroblasts, we can learn what drives the change into myofibroblasts and work on new treatments for ILD.

Our lab uses lung tissue from patients with ILD who are undergoing lung transplants, as well as from healthy donors whose lungs were not suitable for transplant. We break down these lung samples to study individual cells and their DNA. We use a method to identify which parts of the DNA are open in each cell, and another method to measure the RNA present in the cells. RNA is important because it helps turn DNA instructions into proteins.

So far, our research has revealed new insights about the changes in DNA regions in the fibroblasts of patients with systemic sclerosis compared to normal fibroblasts. Notably, we've found that certain transcription factors are more active in diseased myofibroblasts. This knowledge helps us develop potential new treatments and enhances our understanding of how genetics affect scleroderma.

I'm grateful to the National Scleroderma Foundation for supporting this work with a three-year New Investigator Award. Receiving an award from the Foundation has been crucial for my career as a physician-scientist. It provided me with a faculty position that allows me to focus 75% of my time on research. This funding helped me gather important data for an application to the National Institutes of Health (NIH) and develop skills that will benefit others in the field for years to come. The support early in my career has also helped establish my identity as a scleroderma researcher, and I hope to mentor future researchers in this area.

I'm excited about my ongoing projects, including a pilot grant associated with the University of Pittsburgh's Systemic Sclerosis Center, focusing on lung culture models, and a Boehringer Ingelheim award for studying myofibroblast dynamics in systemic sclerosis.

HAPPENING IN OUR

20TH ANNUAL GOLF CLASSIC FOR THE CURE OF SCLERODERMA

The National Scleroderma Foundation New England Chapter hit the links for the 20th edition of the Annual New England Golf Classic for the Cure of Scleroderma earlier this summer. A fantastic lineup of generous sponsors from all over New England and beyond came out in full force to rally behind the dynamic hosts and Platinum Partners, Bruce Gordon and David Rosenberg.

Bruce and David have been driving forces behind this invitational tournament for two decades now. David does so in honor of his mother, Judy Rosenberg, a scleroderma warrior. Bruce champions the cause in honor, and now in memory, of his long-time friend and neighbor, Marie Coyle—a co-founder of the National Scleroderma Foundation.

This year's event featured more than 100 golfers, 30 sponsors, and the awesome crew from Professional Electrical Contractors of CT, and Subaru of New England.

For Mirian Moultrie, executive director of the New England Chapter, this was her first year at the event since taking over the role. "It was incredibly thrilling! Seeing so many people come together to play and compete for such a fantastic cause was heartwarming," Mirian said. "The energy was absolutely contagious!"

After an exhilarating round filled with thrilling prizes, players gathered in the clubhouse for a fabulous banquet, buzzing raffles, and a lively auction. It was a day where everyone walked away a winner, especially the New England Chapter, which netted more than $82,000!

What a day of fun, camaraderie, and impact! Here's to swinging clubs and making a difference in the lives of people affected by scleroderma.

LUNCH & LEARN MONTHLY WEBINAR SERIES CONNECTS SCLERODERMA COMMUNITY

The National Scleroderma Foundation is excited to expand its series of vibrant Lunch & Learn webinars nationwide. Harnessing the combined power and reach of all 13 chapters, this newly expanded series dives into essential topics for our community members.

The webinar series, offered the first Tuesday and the third Wednesday of each month at 1 p.m. ET, features engaging speakers exploring the complexities of living with scleroderma, offering practical strategies to help you manage your journey more effectively.

"Each chapter will have opportunities to host a webinar, featuring speakers from their regions," Foundation CEO Mary Wheatley, IOM, CAE said. "This collaboration harnesses the power of all of our chapters and enables members of our community from anywhere in the country to hear from speakers in other regions."

The Foundation hopes these webinars provide valuable insights and empower our participants to deepen their understanding of the disease and improve their lives with useful tools and resources. Keep an eye out for updates about upcoming Lunch & Learn webinars on the Foundation's social media channels, in the *Connections* e-newsletter and on the Foundation website.

LUNCH & LEARN
NATIONAL SCLERODERMA FOUNDATION

OUR COMMUNITY

FULFILLING THE MISSION WITH A LITTLE HELP FROM OUR FRIENDS

Kelley Hill hosted the 11th Annual *Bowl for Scleroderma-Thelma's Silent Words* event on September 28. Hill, a long-time supporter of the National Scleroderma Foundation and the Lower Great Lakes Chapter, leads this amazing event in honor of his mother, Thelma, who passed away from scleroderma. This year, 56 bowlers competed for the Best Bowler Trophy. The tournament raised $5,045 for the Foundation's mission, the best year yet!

Thanks to Kelley and his efforts, the National Scleroderma Foundation is closer to finding a cure for scleroderma.

You can help too! Third-Party Fundraisers raise funding for our mission of research, education, and support through multiple different avenues. These fundraisers invite their family, friends, and peers to events that they host with proceeds going to the Foundation.

If you're interested in creating your own Third-Party Fundraiser, like Bowl for Scleroderma, email specialevents@scleroderma.org for more information.

TRI-STATE CHAPTER WALK IN BINGHAMTON

Bringing Friends and Families Together for More than Two Decades

The Tri-State Chapter gathered for the *Stepping Out to Cure Scleroderma* walk at Otsiningo Park in Binghamton, NY, on Sunday, June 9. Despite the rain, participants wore their scleroderma t-shirts and walked along the tree-lined path by the river. This event has been held for more than 20 years, raising funds for the National Scleroderma Foundation. The event aimed to raise awareness about the disease and support efforts to find a cure.

Paul Filiak, a participant, mentioned that multiple families and teams come from near and far every year to raise awareness about scleroderma. People travel hundreds of miles to attend with their families, and their participation and support are greatly appreciated.

The National Scleroderma Foundation expresses gratitude to the families and friends of Binghamton for their continued support and is looking forward to next year's walk in June!

NEWS, CONTINUED

MID-ATLANTIC PARTNERING WITH LOCAL HOSPITALS TO HOST EDUCATION EVENTS

The Mid-Atlantic Chapter and Medstar Georgetown University Hospital hosted an educational event on Saturday, September 21 in the Goldberg Auditorium at Medstar Georgetown University Hospital.

More than 75 people registered for the complimentary education event featuring Dr. Virginia Steen and Dr. Lauren Smith from Medstar Georgetown University Hospital and Dr. Laura Hummers and Dr. Matthew Lammi from The Johns Hopkins Hospital. The lectures focused on Raynaud's; skin, joint, and muscle management; GI and Nutrition; Lung PH and ILD diagnosis and treatment; and Scleroderma in the African American community.

The Mid-Atlantic Chapter will host an event with Penn Medicine in Philadelphia on November 9 focusing on lung transplantation and scleroderma. This event will be offered both in-person and virtually. A spring event is being planned with The Johns Hopkins Hospital.

For more details, please call JoAnne LaPergola, Mid-Atlantic Chapter executive director, with any questions at 978-624-4042.

NATIONAL SCLERODERMA FOUNDATION

VIRTUAL CONNECTIONS FOR SUPPORT

Bereavement

Third Tuesday of the Month at 7:00 p.m. ET (Virtual)
Email **bereavement@scleroderma.org** for more information.

Grupo De Apoyo Conexión En Español

Segundo sábado del mes a las 11:00 a.m. ET (Virtual)
Envíe un correo electrónico a **support@scleroderma.org** para obtener más información.

Black, Indigenous, And People Of Color (Bipoc)

(Virtual)
Email **msibley@scleroderma.org** for more information.

Caregivers

Fourth Thursday of the Month at 7:00 p.m. ET (Virtual)
Email **caregivers@scleroderma.org** for more information.

LGTBQ+

Fourth Wednesday of the Month at 7:00 p.m. ET (Virtual)
Email **LGBTQ@scleroderma.org** for more information.

Localized Adults & Parents

Third Tuesday of the Month at 7:00 p.m. ET (Virtual)
Email **localizedSG@scleroderma.org** for more information.

Newly Diagnosed

Second Wednesday of the Month at 7:00 p.m. ET (Virtual)
Email **newlydiagnosedsg@scleroderma.org** for more information.

Parent Support Group Of Children/Teens With Scleroderma

Second Tuesday of the Month at 6:30 p.m. MT (Virtual)
Email **nmsclero@gmail.com** for more information.

Young Adults Seeking Connection (Sync)

Ages 18-42 (Virtual)
Email **alippincott@scleroderma.org** or ttolzmann@scleroderma.org for more information.

20% For Males: Living With Scleroderma

Fourth Wednesday of the Month at 7:00 p.m. ET (Virtual)
Email **mensg@scleroderma.org** for more information.

CHAPTER BASED CONNECTIONS FOR SUPPORT

COLORADO (Rocky Mountain Chapter)

Southern Colorado (Virtual)
1st Sunday of the month at 3:00 p.m. MT
More information:
rmchapter@scleroderma.org

Denver (Hybrid)
2nd Saturday of the month at 10:00 a.m. MT
For more information:
rmchapter@scleroderma.org

Northern Colorado
4th Saturday of even months at 10:00 a.m. MT
For more information:
rmchapter@scleroderma.org

GEORGIA (Southeast Chapter)

Atlanta (Virtual)
3rd Sunday of the month at 3:00 p.m. ET
For more information:
support@scleroderma.org

FLORIDA (Florida & Puerto Rico Chapter)

Florida & Puerto Rico (Virtual)
1st Wednesday of the month at 7:00 p.m. ET & 3rd Saturday of the month at 11:00 a.m. ET
For more information: djames@scleroderma.org

Jacksonville (Virtual)
2nd Saturday of the month at 10:00 a.m. ET
For more information:
floridaprchapter@scleroderma.org

Tampa
1st Saturday of the month at 11 a.m. ET
For more information:
floridaprchapter@scleroderma.org

Central Florida (Virtual)
2nd Saturday of odd months at 10:30 a.m. ET
For more information:
floridaprchapter@scleroderma.org

Fort Meyers
4th Saturday of the month at 10 a.m. ET
For more information:
floridaprchapter@scleroderma.org

LOUISIANA (South Chapter)

South Chapter-Geaux Teal (Virtual)
3rd Saturday of the month at 9:30 a.m. CT
Virtual/Chapter Specific (open to Alabama,Arkansas, Louisiana, Mississippi, andTennessee)
For more information:
support@scleroderma.org

MASSACHUSETTS (New England Chapter)

Fall River/Bristol County
(In-person & Virtual)
3rd Saturday of the month
In-person 1:00 p.m. - 3:00 p.m. ET /
Virtual 1:30 p.m. - 3:00 p.m. ET
For more information:
NEchapter@scleroderma.org

North Shore (Virtual)
2nd Wednesday of the month at 11:00 a.m. ET
For more information:
NEchapter@scleroderma.org

MICHIGAN (Upper Great Lakes Chapter)

Autoimmune and Scleroderma (Virtual)
2nd Saturday of the month at 9:30 a.m. ET
For more information:
pcollins@scleroderma.org

MINNESOTA (Upper Great Lakes Chapter)

North Metro Support Group (MPLS)
(Virtual)
2nd Thursday of the month at 6:00 p.m. CT

For more information:
uglchapter@scleroderma.org

West Metro Support Group (MPLS (Virtual))
3rd Wednesday of the month
at 6:30 p.m. CT
For more information:
westmetrosupport_ugl@scleroderma.org

MAINE & NEW HAMPSHIRE (New England Chapter)

Granite State (Virtual)
Last Saturday of the month
at 10:00 a.m. ET
For more information:
NEchapter@scleroderma.org

MISSOURI (Heartland Chapter)

St. Louis (Virtual)
3rd Saturday of odd months
For more information:
support@scleroderma.org

NEW JERSEY (Tri-State Chapter)

Young Adults, Ages 18-30s (Virtual)
1st Thursday of the month at 7:30 p.m ET
For more information:
alippincott@scleroderma.org

NEW MEXICO (Rocky Mountain Chapter)

New Mexico (Virtual)
Last Wednesday of the month
at 6:30 p.m. MT
For more information:
rmchapter@scleroderma.org

NORTH CAROLINA (Southeast Chapter)

Raleigh/Durham (In-person)
For more information: support@
scleroderma.org

Central North Carolina SSc (Hybrid)
For more information:
support@scleroderma.org

NEW YORK (Tri-State Chapter)

Metro 5 (In-person & Virtual)
1st Wednesday of the month
at 7:00 p.m. ET
3rd Sunday of the month, time varies
For more information:
nynysupport@scleroderma.org

Long Island/Queens
(Telephone Support)
For more information:
ecole@scleroderma.org

Buffalo (Virtual)
For more information:
tristatechapter@scleroderma.org

PENNSYLVANIA (Mid-Atlantic Chapter)

Central Pennsylvania (Hybrid)
1st Wednesday of the month
at 7:00 p.m. ET
For more information:
midatlanticchapter@scleroderma.org

Pittsburgh (Virtual)
For more information:
midatlanticchapter@scleroderma.org
(In-person & Virtual)

Orange County (Virtual)
For more information:
tristatechapter@scleroderma.org

Greater Rochester (Virtual)
For more information:
msibley@scleroderma.org
(Not meeting at this time)

OHIO (Lower Great Lakes Chapter)

Sunday Sit-Down Facebook Live
(Not meeting at this time)
Last Sunday of the month at 1:00 p.m. ET
For more information: lmiller@
scleroderma.org

Cleveland (Virtual)
(Not meeting at this time)
1st Tuesday of odd months at 5:30 p.m. ET
For more information:
lmiller@scleroderma.org

Boardman/Youngstown
(In-person & Virtual)
1st Monday of the month at 5:30 p.m. ET
For more information:
lglchapter@scleroderma.org

OREGON (Pacific Northwest Chapter)

Pacific Northwest Virtual)
1st Saturday of the month at 10:00 a.m. PT
For more information:
cfidalgo@scleroderma.org.

SOUTH CAROLINA (Southeast Chapter)

South Carolina (Virtual)
2nd Saturday of the month at 11:00 a.m.
ET For more information:
sechapter@scleroderma.org

TEXAS (Texoma Chapter)

San Antonio (Virtual)
3rd Thursday of the month at 7:00 p.m.
CT For more information:
dcharlton@scleroderma.org

UTAH (Rocky Mountain Chapter)

Utah (Virtual)
1st Saturday of the month at 10:00 a.m.
MT For more information:
rmchapter@scleroderma.org

WISCONSIN (Upper Great Lakes Chapter)

Wisconsin (Virtual - Wisconsin Residents)
4th Thursday of the month
at 6:00 p.m. CT
For more information:
uglchapter@scleroderma.org

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To find and connect with a support group near you, or in your area of interest, please visit scleroderma.org/support or scan the QR code. ▶

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For other types of mail, work with a member of the Foundation team or reach out to us at info@ scleroderma.org for options.

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Boston, MA 02241-1533

☎ 800-722-HOPE
✉ info@ scleroderma.org
🌐 scleroderma.org