SCLERODERMA

VOICE

The magazine exclusively for Members
of the National Scleroderma Foundation.

FALL 2023

MANY JOURNEYS, ONE MISSION

Your recap of the 2023 National Scleroderma Conference

SING ME A STORY

An Excellent, Very, Very, Extraordinary Trip to Bass Lake

LET'S TALK ABOUT SCLERODERMA

A look at the 2023 Scleroderma Awareness Month campaign

25th ANNIVERSARY

National Scleroderma Foundation

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How it works

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It's time to push systemic sclerosis research forward, together. To learn more about our study, eligibility requirements and how you can help, you can visit our website.

https://www.23andme.com/systemic-sclerosis-study/

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SCLERODERMA VOICE

25th ANNIVERSARY
National Scleroderma Foundation

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The magazine exclusively for members of the National Scleroderma Foundation.
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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.

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PASSION, PRESENCE & ENTHUSIASM MAKE OUR COMMUNITY 'BEST-IN-CLASS'

My wife, Mariann, and I attended our first National Scleroderma Conference in 2002. We couldn't have known the advancements the field would see in the past 20 years, or that we would have a front-row seat this year and experience the success of our first in-person conference after four years due to a global pandemic!

After three days spent with members of the community, some that we only see once a year, and others we see almost weekly, Mariann and I were both in awe of the dedication and enthusiasm of everyone with whom we spent time. We soaked up the networking time, got to as many educational sessions as we could, and thoroughly enjoyed seeing friends and colleagues honored at the awards luncheon. The closing session given by Dr. Carol Feghali-Bostwick was truly the perfect way to cap off the weekend.

Exhausted, inspired and more motivated than ever, we returned home with a renewed sense of urgency to serve the Foundation, convinced that we are in great hands with folks like you in the mix. Our goal of being the "best-in-class" organization will be realized – and realized soon!

Whether you joined us virtually, in person, or just in spirit, I would like to thank you on behalf of the National Scleroderma Foundation Board of Directors (and the entire scleroderma community) for your efforts at our 2023 National Scleroderma Conference! What an amazing experience made possible by people like you, who tirelessly and enthusiastically supported the attendees, speakers and their families!

Please enjoy this edition of the Scleroderma Voice and see much of what we are doing to continue our critical mission pillar of education – and get a bit of the flavor of the amazing content that was available at our National Conference.

Thanks again,

Kevin Boyanowski

Kevin Boyanowski
Chair, Board of Directors

OUR COMMITMENT to education

Mary J. Wheatley, IOM, CAE

Our mission at the National Scleroderma Foundation is to advance medical research, promote disease awareness, and provide support and education to people living with scleroderma, their families and support network. In this issue of the Scleroderma Voice, we are proud to focus on the education pillar of our mission. We have a rich history of providing direct to community educational programming, whether at a local, regional or national level.

Over the last year, we have increased our smaller, regional educational opportunities in response to feedback from you, our community. Our Rocky Mountain, Southeast, and Upper Great Lakes Chapters all hosted great regional educational programming earlier this year. The Upper Great Lakes Chapter's monthly lunch and learn series is available to anyone who may be interested, and you can learn more on our website at **scleroderma.org.**

In addition, we've increased our outreach to potential research and treatment centers across all chapter areas to ensure we are providing the best possible referral network to people living with scleroderma, no matter where they are geographically or in their diagnostic journey.

Our website is full of helpful resources that have been researched, written and vetted by scleroderma experts and leaders from all over the world. And more than that, it's a gateway to connect with members of our community who have been living with scleroderma themselves — some for decades.

I hope you enjoy this very special issue of the Scleroderma Voice, and that you take this opportunity to engage with fellow members of the community around our educational programming. **Knowledge is power, and together, we will overcome this disease.**

25 years of leading SCLERODERMA EDUCATION

Mary J. Wheatley, IOM, CAE
Chief Executive Officer

YOUR SOURCE FOR SCLERODERMA EDUCATION FOR 25 YEARS

Since its founding in 1998, The National Scleroderma Foundation has been a leader in providing a wealth of information about the disease and the resources you need to find your best path. From sessions about the research being conducted to the latest disease management tools, the Foundation brings together experts across multiple disciplines to share their knowledge with you.

Educational programming provided by the Foundation has evolved over the past 25 years, from the annual national conference, regional educational days to virtual and even hybrid opportunities for everyone impacted by scleroderma, coast to coast.

I hope you will take advantage of all the Foundation has to offer through its educational programs and resources. This issue highlights just a few. You can reach out any time for more information at info@scleroderma.org.

The National Scleroderma Foundation has been gathering annually for the past 25 years for education, community, and friendship.

1998 Houston, TX
1998 San Diego, CA
2000 Orlando, Fl
2001 Arlington, VA
2002 Las Vegas, NV
2003 Washington, DC
2004 Los Angeles, CA
2005 Cambridge, MA
2006 Minneapolis, MN
2007 Philadelphia, PA
2008 Manhattan Beach, CA
2009 St. Louis, MO
2010 Boston, MA
2011 San Francisco, CA
2012 Dallas, TX
2013 Atlanta, GA
2014 Anaheim, CA
2015 Nashville, TN
2016 New Orleans, LA
2017 Chandler, AZ
2018 Philadelphia, PA
2019 Chicago, IL
2020 Virtual Summer Series
2021 Connect & Thrive Together, Virtual
2022 Connecting our Journeys, Virtual
2023 Orlando, FL

Continuing Education Programs for HEALTH CARE PROVIDERS

THE NATIONAL SCLERODERMA FOUNDATION offers Continuing Medical Education (CME) and Continuing Nursing Education (CNE) as vital tools in advancing awareness and understanding of scleroderma and its comorbid conditions among health care providers.

Because scleroderma is a systemic disorder, individuals living with scleroderma are typically under the care of multiple specialists in the course of disease management, depending on the particular organ system(s) affected by the disease (e.g., skin, heart, lungs, kidneys, digestive track, etc.).

To decrease the time to accurate diagnosis, the Foundation works to educate medical professionals on the various manifestations of scleroderma. Early diagnosis leads to better outcomes for people living with scleroderma.

Health care providers rely on CME to stay up to date on the ever-changing health care landscape, including new treatments and therapies. In addition, CME and CNE hours are required for maintenance of licensure, maintenance of certification, credentialing, membership in professional societies, and other professional privileges.

The Foundation's CME and CNE programs provide continuing education credits for health care providers to learn more about this complex disease. This year alone, the Foundation has hosted four programs, in person and online, with focus ranging from lung health to hand involvement.

This summer, the Foundation hosted a CME session on June 29, which is recognized globally as World Scleroderma Day. Presenting faculty included Drs. Flavia Castelino and Michael York, who presented didactic talks about how to diagnose, manage and treat hand involvement in scleroderma.

In support of improving patient care, these activities are planned and implemented by the Postgraduate Institute for Medicine and the National Scleroderma Foundation. The Postgraduate Institute for Medicine is jointly accredited by the Accreditation Council for Continuing Medical Education (ACCME), the Accreditation Council for Pharmacy Education (ACPE), and the American Nurses Credentialing Center (ANCC), to provide continuing education for the health care team.

You can visit **scleroderma.org/CME** to learn more about current programs.

> “CONTINUING EDUCATION IS VITAL FOR HEALTH CARE AND MEDICAL PROFESSIONAL DEVELOPMENT, NOT ONLY TO MAINTAIN AND UPDATE OUR CLINICAL AND SCIENTIFIC KNOWLEDGE, BUT TO TRANSFORM AND IMPROVE THE QUALITY OF CARE WE PROVIDE FOR OUR PATIENTS.”

Dr. Flavia Castelino —
Director of the Scleroderma Program at
Massachusetts General Hospital
and Associate Professor of Medicine
at Harvard Medical School.

Save the Date!

NATIONAL SCLERODERMA CONFERENCE

JULY 19-21, 2024

BELLEVUE, WASHINGTON

(JUST 9 MILES EAST OF SEATTLE)

2023 NATIONAL SCLERODERMA

MANY JOURNEYS One Mission

The 2023 National Scleroderma Conference was the Foundation's first ever HYBRID conference with live streaming and app navigation of nearly all 50 sessions presented by 54 faculty, including four native Spanish speaking sessions. More than 400 people attended in-person with another 160 logging into the virtual conference.

Scleroderma Research – Past, Present and FUTURE

Dr. Maureen Mayes

In 1944, only one medical journal included the key word scleroderma. This has changed dramatically as there were 1,266 journal articles including scleroderma. This session provided an overview of the types of research – from basic science to translational to clinical research and some of the lessons learned and successes. Basic science, conducted in labs and mice, has taught us a great deal about the role of immunology, vascular changes, fibrosis, and genetics, but what we do not know is what causes or triggers the disease or a cure.

> I KNEW SO LITTLE TWO DAYS AGO. SO MUCH INFORMATION THAT I NEEDED TO HEAR. THANK YOU SO MUCH!

African American Patients with Scleroderma

Dr. DeAnna Baker Frost

African Americans tend to have higher incidences of diffuse scleroderma, develop the disease at an earlier age and experience more serious disease. This can also lead to lower body image satisfaction impacting self-esteem. Dr. Baker Frost discussed disease characteristics that are prominent in African Americans and the current research topics which explore causes of these differences including the NIH funded Genome Research in African American Scleroderma Patients (GRASP) study. The session looked at social determinants of health and the need for more research to understand what leads to the differences in African American patient outcomes.

Lung Involvement in Scleroderma

Dr. Richard Silver

While not every scleroderma patient will experience lung involvement, patients experiencing dyspnea, or shortness of breath, should be evaluated for complications. This "mini medical school" taught about the anatomy of the lung — from what can go wrong to what is involved in the physical exam and testing. This session was an introduction to the diagnosis and management of the two major pulmonary complications — interstitial lung disease (ILD) and pulmonary arterial hypertension (PAH).

> THANK YOU FOR THIS CONFERENCE! THE PRESENTATIONS WERE VASTLY BENEFICIAL. WOW!

CONFERENCE RECAP

> GOOD CONFERENCE, ESPECIALLY FOR A FIRST-TIMER!
> THANK YOU FOR THE TECHNICAL EDUCATION
> AND THE SELF-HEALING REMINDERS AND TECHNIQUES.

How Research is Conducted

Early Investigator Panel Discussion

Panelists: Eleanor Valenzi, MD, University of Pittsburgh; Adri Chakraborty, PhD, Boston University; Yan Wang, MD, PhD, Cleveland Clinic Lerner Research Institute; Roxane Darbousset, PhD, Boston Children's Hospital

Moderated by: DeAnna Baker Frost, MD, PhD, Medical University of South Carolina

This session discussed why research is important, and the various aspects that go into the development of research with the goal of producing new scleroderma therapies and treatments. Through the different stages of research, investigators learn more about the exact mechanism of how the disease progresses, apply new ideas, and build collaborations to advance the progress of research. Each investigator presented their research work, and shared with attendees their passion and dedication that drives them to continue working and advancing scleroderma research. They also shared how the support of donors, their institutions, and grant funding plays a vital role in their success.

> EXCELLENT CONFERENCE!
> KEEP UP THE GOOD WORK AND HOPE FOR A CURE!

Scleroderma and Dentistry

Dr. Luis Del Castillo

Dental care in scleroderma can be difficult to navigate, and finding an expert can feel impossible sometimes. Dr. Luis Del Castillo focused his session on discussing what to expect when visiting your dentist, how to maintain proper oral health, and how to navigate scleroderma specific struggles. Dr. Del Castillo also revealed some great tips and tricks on how to locate oral health care providers who have the training and experience to treat people affected by scleroderma. This session was also presented in Spanish for all our native Spanish speaking attendees.

> WONDERFUL CONFERENCE WITH
> A MULTITUDE OF USEFUL INFORMATION FOR THOSE
> LIVING WITH SCLERODERMA!

Support Groups and Federal Advocacy Initiatives

Panelists: Evamarie Cole, Lucille Miller, Phillip Goglas II, and Caryn Anatriello

This interactive session shared support group best practices, answered audience questions on how to start a support group in their community, provided updates on support currently being offered by the National office, gave updates on Federal Legislative initiatives and shared how a support group can help leverage advocacy initiatives on a small to large scale.

VIRTUAL CONFERENCE Highlights

As we continued to navigate life and work after the COVID-19 pandemic, and under the theme of "Many Journeys, One Mission," organizers felt it was critical to ensure that no matter who or where someone was, they would be able to participate in the 2023 National Scleroderma Conference. As a hybrid event, everyone affected by scleroderma, including doctors, speakers, and caregivers, had the chance to attend the conference virtually from anywhere in the world.

In fact, 143 people registered for the virtual program, and thanks to a dedicated live-streaming team, virtual attendees were able to listen to sessions in real time and ask questions of speakers whether they presented remotely or in person in Orlando.

Two days before the conference, virtual attendees received early access to the AirMeet platform and were able to update their profile, view the conference schedule, and add their favorite sessions to their own personal schedule.

Whatever mobile device participants accessed the Conference from — a cell phone, tablet, laptop, or other device — the online AirMeet platform was replete with a myriad of resources including a virtual selfie photo booth, welcome video, networking tables, and a research poster and exhibit hall. Participants were even invited to compete in a virtual game and earn points by completing various tasks for the chance to win cash prizes!

DON'T FORGET!

Virtual participants have 60 days to access sessions and slides after the conference. After 60 days, all attendees will have access to the sessions on our YouTube channel at YouTube/sclerodermaUS.

Aside from the excellent medical knowledge participants gained from the speakers, two of the most moving parts of the virtual conference were the welcome session and concert by Celebrity Ambassador Ashley Barron on Thursday as well as the Awards Luncheon Friday afternoon.

To demonstrate their reactions to sessions, attendees selected different emojis that were then displayed on screen. The welcome concert and awards luncheon received a symphony of hands applauding, "wows," hearts and even personal shout-outs from the friends and family of those who won awards this year. Without a doubt, virtual attendees were engaged and so happy to be included in these special events.

From The Virtual Crowd

Thanks to EVERYONE who made this conference happen. I wish I had attended in person now. May God bless you all with safe travels, too.

—Jo Ann Bokenkamp

I have been impressed with the virtual conference. Tech issues are hard to handle. The **professionalism of the team** is appreciated and recognized. Thank you!

—Julie Spriggs

Many thanks for an **excellent conference.**

—Judy Snyder

Thank you to all who made this conference possible! Safe travels to all going home.

—Katherine Fox

Thank you for this conference! The presentations were vastly beneficial! **WOW!**

—Marilyn Hyatt

Good conference, especially for a first-timer! Thank you for the technical education and the **self-healing reminders** and techniques.

—Sue Au

THANK YOU ALL who put this together. Very **informative, very helpful.** Hope you all get a break before starting next year's.

—Laurie Kemper

Thanks to all presenters and providers for their passion for and care of scleroderma patients. You **provide more hope** than I thought possible!

—Sue Duff

FROM A FIRST-TIMER'S *perspective*

FINGERS TINGLING AND TURNING different colors, GERD and pain were some of the first symptoms Cynthia began experiencing back in 2019. She immediately made an appointment with her primary care physician but left with no diagnosis and feeling as if she was not being heard or receiving proper care.

Her daughter who had been diagnosed with lupus a few years earlier had suggested that she go to see a rheumatologist. She received a diagnosis of Sjogren's disease, but no additional testing was done. She remembers being in terrible pain and ending up spending Christmas 2020 in the hospital. She saw two additional rheumatologists before one of them suggested she go to a scleroderma research and treatment center in early 2021. "When you have a chronic illness, you want to find answers," she said. She was unable to find information or really anything scleroderma related in the libraries or local bookstores, so went to Google and that is where she found the National Scleroderma Foundation.

She immediately joined and received information and educational materials about scleroderma. *Finally!* "I have five grandchildren, and I want them to know I did my best to help to find a cure for this disease… When I was young, we did not talk about illnesses or being sick. I want to talk about scleroderma!"

When she heard about the conference in Orlando, she immediately registered, booked her room and travel, but then she admitted to getting cold feet. She explained, "I had not traveled in such a long time and was so nervous about the airports and getting around." Her daughter was not going to let her fear stop her from attending and agreed to attend the conference with her.

When she arrived at the conference registration area and saw people who looked like her and knew they were experiencing the same symptoms, she was, "in seventh heaven." After picking up her badge at registration she went to the Exhibit Area and found the National Scleroderma Foundation booth. As she placed her pin on the map to identify where attendees were from, she mentioned that there was another pin close to where she placed hers in High Point, North Carolina. Kheesa Jones had just placed her pin and was nearby, allowing a new friendship to be born!

When asked about the most valuable aspect of attending the conference, Cynthia's response was:

> "I FOUND MY FAMILY – BROTHERS AND SISTERS IN PEOPLE WHO LOOK LIKE ME AND DON'T LOOK LIKE ME. THIS CONFERENCE WAS EVERYTHING TO ME."

When Cynthia went to breakfast Saturday morning, she sat with a man who had just been diagnosed with scleroderma only six months earlier. They spoke and shared similar experiences. They even exchanged phone numbers! Cynthia left the conference with connections and friends.

IT'S GOOD TO BE BACK

"THESE PEOPLE **GET** ME"

IN 2005, KHEESA JONES WAS IN HER mid-twenties, under a great deal of stress, and about to move into a new place. She and her girlfriends moved everything – all the boxes and furniture – on their own. She noticed that her legs, arms, and body hurt, but chalked it up to the move.

A few months later, in July 2005, her hands were continuing to bother her and turned a weird color. She thought it could be the air-conditioning used to cool the summer heat. But that all changed on her birthday at the end of August. You see, Kheesa did not fit into her birthday shoes, or many of the other pairs of nearly 200 shoes she had in her closet. She had been saving her new favorite shoes, a birthday present to herself, and now was unable to get her foot into the shoe. She called her doctor that day and was able to get an appointment for later that day. She rarely ever got sick, but now she had pain in her hands, her body ached, and her feet were swollen.

She was referred to a rheumatologist who diagnosed her with Raynaud's and thought she could have arthritis or lupus. She started losing weight, even after getting pregnant. It wasn't until a nurse who was present during the delivery of her daughter told her that she had thick skin and she needed to share this with her doctor. *She made her promise to share it with her doctor.* When she told her doctor, he referred her to the Scleroderma Center at Duke University. She remembers that her father went with her to her first appointment – the appointment where she finally received a diagnosis of scleroderma.

A few years later, she had expressed her desire to meet others with scleroderma to her doctor, so he suggested she contact the National Scleroderma Foundation. She, along with her mother, best friend and boyfriend attended a mini conference in Philadelphia. She said it felt amazing to finally know people with the same disease, symptoms, and feelings!

In 2015, she then applied for a First-Time Attendee scholarship to attend the educational conference in Nashville, TN and it was life-changing – just as she was starting to get cold in one of the session rooms, she was handed a blanket. She said it felt like home, and she thought to herself, "These people *get* me." Since then, she has attended more conferences, both in-person and virtual, and has learned so much about managing and living with scleroderma – from the importance of dental care and using a special toothbrush and floss to focusing on facial exercise.

In 2023, when the Foundation announced Orlando would be in-person, she knew she would attend because it would be great to see friends she had made at other conferences and she might even make some new friends – like Cynthia Walker, a first-time conference attendee who lives 20 minutes away from her home in Greensboro, North Carolina. In fact, by the time they left the conference, they already had a planned lunch together.

THE LAST 25 YEARS OF PROGRESS IN Scleroderma

> “I’M OPTIMISTIC BECAUSE WE ARE LEARNING A LOT AND WE NOW HAVE TECHNOLOGIES AVAILABLE THAT ARE ALLOWING US TO ACCELERATE THE PACE OF RESEARCH.”

OVER THE PAST 25 YEARS, scleroderma research has made significant progress in various aspects of the disease, including fibrosis, lung complications, endothelial cells, the vascular system, the immune system, autoantibodies, and skin manifestations, all as part of “the quest to identify the cause and identify the cure for scleroderma,” shared Dr. Carol Feghali-Bostwick. Fibrosis, a major hallmark of the disease, has become a crucial focus, given its role in numerous other diseases, contributing to nearly 45% of worldwide deaths and affecting conditions such as asthma, cystic fibrosis, diabetic retinopathy, and lupus nephritis. “So, why is research in scleroderma so important?” questioned Dr. Feghali-Bostwick. “Because scleroderma is the prototypic disease. If we solve the fibrosis puzzle in scleroderma we will positively impact all these diseases that experience fibrosis in one organ or more.”

Recently, scleroderma research has accelerated due to increased collaboration among researchers worldwide. This sharing of knowledge and resources has led to remarkable advancements. Single-cell RNA sequencing has shed light on the thousands of genes involved in the disease, pinpointing responsible cells and even identifying new cell types.

Additionally, research has revealed the varying effects of scleroderma among different demographic groups, including African Americans and pediatric patients. Gender differences in disease progression have also been recognized. Understanding these nuances is crucial for developing treatments.

One fascinating discovery has been the difference in the gut microbiome of individuals with scleroderma compared to healthy individuals. This shift in the microbiome has implications for disease duration and inflammation levels, providing much needed insights into disease management.

The past 25 years have seen a surge in publications and key findings, such as methods to avoid renal crisis and repurposing medications from other diseases. “What does the future hold?” asked Feghali-Bostwick. “I honestly think that the reality of tomorrow is that we will have a cure — it could be tomorrow or next month that someone has made the key observation that gets us the treatment — it could be next year. There *is* a cure on the horizon and research *will* get us there,” Dr. Feghali-Bostwick explained.

The National Scleroderma Foundation’s grant program, which has provided $33 million in funding over the last 25 years, has been instrumental in providing support to researchers and attracting young talents to the field. This effort includes workshops for early career investigators, and student fellowship awards to nurture the next generation of researchers. Additionally, patients, donors, and advocates actively engage in promoting awareness and providing support for research endeavors.

Dr. Feghali-Bostwick closed by sharing, “I want you to leave here feeling empowered — be inspired to support each other, to advocate, to contribute to research and be the force behind our foundation.”

National Scleroderma Foundation Announces 2023 VOLUNTEER AWARDS

Each year, the National Scleroderma Foundation recognizes volunteers for their outstanding work in support of its mission to advance medical research, promote disease awareness, and provide support and education to people with scleroderma. This year, after receiving 170 nominations, the Foundation announced 14 Volunteer Awards at the 2023 Annual Conference in Orlando, Florida. Desiree James of the Florida and Puerto Rico Chapter, host of the event, said, "Hosting the awards ceremony was an honor, and I was truly humbled to play a role in recognizing an outstanding group of volunteers who give their all every day on behalf of our scleroderma community."

CONGRATULATIONS TO THIS YEAR'S RECIPIENTS!

Lifetime Achievement Award

Awarded to an individual who has given extraordinary service to the organization.

Marilyn Sibley was recognized for consistently going above and beyond to help patients, caregivers, and friends with scleroderma, and serving as a relentless force of commitment and hope. In addition to leading the Rochester support group, the Rochester Stepping Out walk, and countless awareness efforts, Marilyn is one of the creators and leaders of the BIPOC (Black, Indigenous, People of Color) Support Group. She has also held Tri-State Chapter board and committee positions and continues to represent the scleroderma community with an unwavering passion.

Outstanding Educational Program

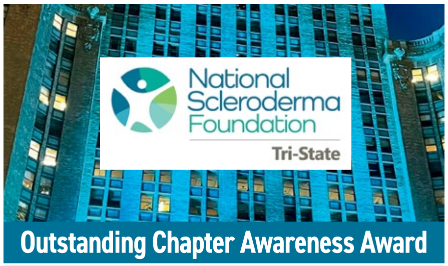
Awarded to an individual, group, or Chapter that has maximized available resources within the community to provide patients with an excellent educational experience.

The South Carolina Chapter & The 13th Annual Amy K. Parrish Scleroderma Education Conference was recognized for their continued service in their annual patient education offerings. Year after year, they have produced a fact-based conference with leading scleroderma experts who share clear, timely disease updates. Between the leadership in the Chapter and the medical experts at the Medical University of South Carolina, this conference continues to bring relevant information to the South Carolina community.

Support Group Volunteer of the Year

Awarded to a support group leader who leads by example and encourages others to engage in their community.

Meryl Parr was recognized for her steadfast commitment to being a trained support group leader for the Florida and Puerto Rico Chapter. Meryl is an occupational therapist who joined her late husband, Shepp, as a support group leader years ago. She merged her professional world and her role as a caregiver to provide dedicated support to our community and continues her work to this day.



Outstanding Chapter Awareness Award

Awarded to a Chapter that consistently keeps awareness and advocacy as integral parts of its operations.

The Tri-State Chapter was recognized for their ongoing work, keeping awareness and advocacy at the heart of all they do. Through light-ups, strategic communications, hosting walks and more, this Chapter is a leader in the space of awareness for scleroderma.

Chapter Volunteer of the Year

Awarded to an individual who leads by example and encourages others to engage in their local and regional community.

Rhonda Costa of the Missouri Chapter was recognized for many years of leadership service, as well as effective mission delivery while achieving positive financial success on a limited budget. She leads by example, positivity, and persistence.

National Volunteer of the Year Award

Awarded to an individual who leads by example and encourages others to engage in their community.

Evamarie Cole was recognized for her consistent dedication to the National Scleroderma Foundation through her work as a support group leader who sits on many Foundation committees, and as a committed patient advocate who promotes the Foundation, raises awareness, and fights for research money.

Outstanding Patient Support Award

Awarded to an individual who has continuously supported, educated, and uplifted their community.

Michael Bessert was recognized for his dedication to the Foundation and the patient community. He is the "de-facto" leader of the 20% Men's support group – providing support to all men with scleroderma. Michael helps people all over the country, and even in other parts of the world, and we are proud of his work and accomplishments.

Philanthropist(s) of the Year

Awarded to individuals who have made an outstanding contribution to fundraising and show consistent excellence through their actions and leadership.

David Rosenberg & Bruce Gordon were recognized for their combined efforts in fundraising through the New England Annual Golf Classic held in Salem, Mass. Each of these men personally contributed $190,000 over the last 20 years in support of David's mother, Judy, and Bruce's dear friend, the late Marie Coyle. Their long-standing, unwavering, and generous commitment to our community is commendable.

Individual Fundraiser of the Year

Awarded to an individual who has made an outstanding contribution to fundraising in their Chapter and who shows consistent excellence through their actions and leadership.

Maria Bartoszewicki was recognized for her continued leadership and fundraising excellence in the Deer Island Stepping Out to Cure Scleroderma event. She has worked tirelessly over the last seven years to uplift her community and raise over $100,000 to find a cure for scleroderma.

Advocate of the Year

Awarded to an individual who personifies what it means to "speak up for scleroderma," and is active in awareness and advocacy to better the scleroderma community on a national level.

Lucille Miller was recognized for her outstanding advocacy efforts in Ohio. She helped raise awareness with proclamations, building light-ups, and contacting state representatives. Few people speak up for Scleroderma more than Lucille.

Chapter of the Year

Awarded for overall excellence in advancing the mission of the Foundation in the areas of support, education, and research.

The Ohio Chapter was recognized for exceeding its fundraising goals and reaching many new patients while still in a hybrid environment. To grow their local community and extend their overall reach, they used creative, innovative programming and positive messaging.

Jacob Davila Memorial Leadership Award

Inaugural award – presented to a volunteer who is committed to service and consistently demonstrates servant leadership, while always enriching and ennobling the lives of others in the scleroderma community.

Evamarie Cole was recognized for constantly serving the scleroderma community through her leadership, awareness efforts, and steadfast determination to serve others and find a cure.

Messenger of Hope Award

Awarded to an individual whose words and/or actions offer continued hope and inspiration to our community.

Elizabeth Auman was recognized for her patient support in the Florida and Puerto Rico Chapter. Elizabeth provides answers to all inquiries, no matter how complex, whether it's physician information, research data, or just general guidance for living with scleroderma.

Doctor of the Year Award

Awarded to a health care provider who demonstrated the most exceptional skills in clinical practice and patient education while maintaining the mission, vision, and values of the Foundation, and whose dedication has improved the lives of thousands of people living with scleroderma.

Dr. Janet Poole was recognized as an incredible contributor to the quality of life for people living with scleroderma. She is respected throughout the world as the occupational therapy "guru" in systemic sclerosis. Thanks to her, we are recognizing that the sooner a person with systemic sclerosis focuses on hand exercise, the less likely they are to develop contractors and hand disability, and the more likely they are to see decreased arthritis symptoms and improved circulation. Her teaching and research have also focused on increasing circulation to the face and the mouth, hand function, fatigue, and so much more. Her quiet research efforts have a huge importance in terms of preventing disability and increasing quality of life.

AN EXCELLENT, VERY, VERY, EXTRAORDINARY TRIP TO BASS LAKE

THERE ARE COINCIDENCES, AND THEN THERE IS MEANT TO BE.

One recent collaboration had everyone involved feeling those "meant to be" vibes. The Foundation had the opportunity to partner with Horizon Therapeutics' #RAREis program and Sing Me A Story to bring a once-in-a-lifetime experience to a very special child living with juvenile systemic scleroderma. The result is an extraordinary musical performance that has a very special and rare backstory.

Sing Me a Story is an organization that helps children in need write a story that captures their lives and their imaginations. Through their partnership with #RAREis, they then send the finished storybooks to professional musicians who turn these stories written by children living with rare diseases into songs. You can listen to dozens of these rare songs by going to **RAREisPlaylist.com.**

In Orlando, for Conference, we heard the latest song from the #RAREis playlist inspired by Julia's Ceresnak's story, who was connected to one of our biggest advocates our celebrity ambassador, Ashley Barron, who is also living with scleroderma and received her diagnosis at age 5.

"When I was diagnosed with scleroderma, I knew nobody," recalls Ashley Barron. "My parents didn't know this disease existed; we didn't know there was a foundation. We had nobody. When I found the Foundation, all the joy came flooding in. And then when I learned that I got to team up with a little girl who was just around the same age I was when I was diagnosed, and help tell her story, I could not *NOT* say yes!"

When Ashley received Julia's story, she was shocked by the parallels:

> "NOT ONLY WERE WE DIAGNOSED AROUND THE SAME AGE, BUT WE'RE BOTH FROM CALIFORNIA, AND WE'VE BOTH BEEN TO THIS AMAZING PLACE THAT HER AND HER FAMILY WENT ON VACATION, WHERE JULIA SET HER STORY."

Ashley unveiled the song in a very special acoustic performance with Julia and her family just hours before the Opening Session of the 2023 National Scleroderma Conference in Orlando.

But she didn't stop there. Ashley and her band put on an amazing show for everyone in attendance later that evening, and absolutely brought the house down. Their last song of the evening was Julia's song. Everyone in the room was moved to (happy) tears, hearing it for the first time, and seeing the pure joy on Julia's face as she got to see everyone else react to her special song. We are so thankful to Ashley Barron and her band, and to the Ceresnak family for allowing us to be part of not only Julia's life but their family's.

Scleroderma is an ugly disease that impacts beautiful people, and thanks to Horizon, #RAREis, Sing Me A Story, Ashley Barron and the Ceresnak family, for one night we got to showcase how beautiful our community is. To download and listen to Julia's song, entitled "Trip to Bass Lake," please visit **RAREisPlaylist.com.**

Yoga for SCLERODERMA

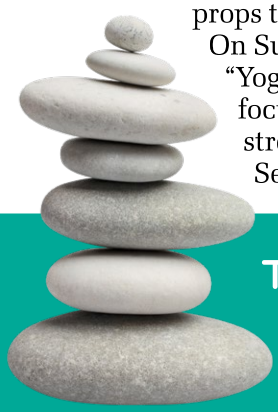
Keep those scleroderma bodies moving, because yoga is for EVERY scleroderma body!

MEET THE TEAM:

The Yoga for Scleroderma Team has been a huge part of the National Scleroderma Conference since 2002. Alexis Harrison, RYT-200 and living with scleroderma, Cheryl Albright, OTR/L, C-IAYT, Pat McMillan, living with scleroderma, and Kathy Randolph C-IAYT, have dedicated so much of their time and expertise toward empowering the scleroderma community to take back their lives through yoga, exercise, and breathing. The team was one of the first scleroderma groups to pivot to virtual education several years ago and they were one of the first groups we invited to welcome the community back to in-person.

This year the Yoga for Scleroderma team joined the National Scleroderma conference to host three fantastic sessions for both adults and Kids Get Scleroderma, Too! attendees. Alexis Harrison, Registered Children's Yoga Teacher, taught the benefits of classic yoga to all children and their families. This was a fun and engaging session that got all the kids moving. They didn't stop at hosting sessions in-person though – Kathy and Pat also met many attendees from their virtual booth! The booth was a fantastic way to facilitate one-on-one conversations and answer questions all weekend long.

Cheryl and Alexis also led two sessions for adults over the weekend. On Saturday, they opened the day with "Yoga for Your Scleroderma Body." This session covered topics such as options for yoga poses, important safety measures, and tips on using props to get the most out of the experience. On Sunday, the team led a session on "Yoga for Your Hands." This session focused on increasing circulation, strength, and mobility in the hands. Several props were used to increase the effectiveness of the practice and the team also touched on the importance of breathwork for symptom management. Did you know that you can experience some symptom relief from things like Raynaud's and GI issues through meditation and breathwork? Check out the Yoga for Scleroderma YouTube channel at **www.youtube.com/c/YogaforScleroderma** for up-to-date information.



The mission of the Yoga for Scleroderma Team is to provide yoga to as many individuals in the scleroderma community as possible and to assist them in living with the best quality of life possible. To accomplish this, the Team teaches at support group meetings, offers video and podcast programming, and trains Yoga for Scleroderma teachers to meet the needs of the community. Their dedication to this mission was evident when seeing the excitement that Alexis and Cheryl showed while leading their sessions.

The team at Yoga for Scleroderma also offers weekly guided relaxation/meditation/breathwork sessions live on Zoom every Wednesday! For more information on upcoming classes and to see a schedule of upcoming events, check out their website at **www.yogaforscleroderma.com**

Alexis Harrison

Cheryl Albright

The National Scleroderma Foundation is very grateful for this partnership and for the dedication of the entire Yoga for Scleroderma Team. Lori Pierce, you are missed and honored.

Kids GET SCLERODERMA, TOO!

THE KIDS ATTENDING THIS YEAR'S Kids Get Scleroderma, Too! Conference in Orlando were absolutely thrilled to be in-person and among friends — not only other kids living with scleroderma, but their siblings as well. They found their community or "tribe."

The fun started Friday evening with a party featuring a caricaturist and magician, followed by a private meeting with Celebrity Ambassador, Ashley Barron, after her concert to celebrate the National Scleroderma Foundation's 25th Anniversary. Needless to say, the meeting left them all completely starstruck.

The kids and their parents were able to attend the following sessions:

- The Importance of Play
- Pediatric Localized Scleroderma: What You Need to Know facilitated by Dr. Suzanne Li
- Young Adult Panel: An Open Conversation with Peers
- Pediatric Systemic Sclerosis: What You Need to Know facilitated by Dr. Kathryn Torok
- Scleroderma Q&A Session: A Space for All Your Questions

Saturday morning brought a Paint Party that was a fun and interactive opportunity to connect with peers and get the kids' creative juices flowing. Then, they were off to SeaWorld on a bus ride where they sang their hearts out to everything from Encanto's "We don't talk about Bruno" to Journey's "Don't Stop Believing."

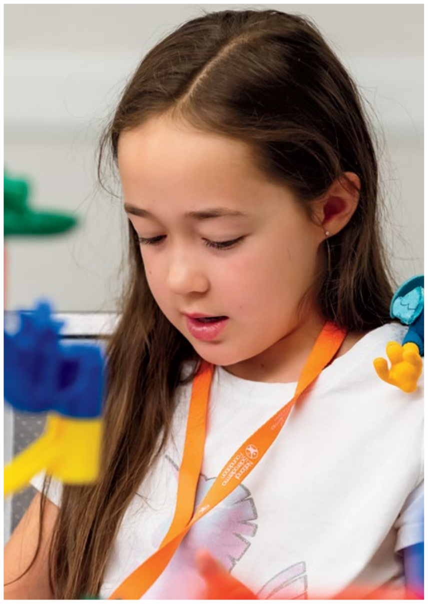
When they first saw the park, an excited scream echoed across the bus, as if they had just seen the best thing on earth.

While the trip could have been dampened by the rain, it was just the contrary as the kids were more than happy to be among their new friends. They were extremely excited to visit the aquariums and gift shops and just talk among themselves. When a wheelchair was needed for one little girl, everyone was concerned and wanted to ensure that at she would feel comfortable and be able to keep going with the group… not missing a beat.

Later Saturday evening, another outing, sponsored by A Lasting Mark — a foundation started by Marybeth Medolla and her son Luke — brought the children, along with parents and doctors to ICON Park where the group climbed aboard three capsules on the 400-foot observation Ferris wheel. The 20-minute ride allowed for amazing views of Orlando and all of its parks, and an incredible fireworks show. The evening ended with ice cream for all.

On a more serious note, during Sunday morning's session, "Journaling: Taking Care of the Body and Mind," facilitated by Mary Lou LaPergola, a special education teacher versed in trauma, the kids began opening up and sharing their concerns about living with scleroderma. They journaled, drew, and verbally shared their feelings and concerns in a safe space.

WHILE THE KIDS WERE NERVOUS AT THE BEGINNING OF MUSIC THERAPY, BY THE END EVERYONE WAS HUMMING AND SINGING ALONG WHILE ALSO GETTING IN TOUCH WITH THEIR EMOTIONS.



The conference ended with The Big Reveal. The children had been secretly creating artwork to reveal the location of the 2024 conference during the final session. Looking forward to seeing you all near SEATTLE!

Save the date for

GIVING TUESDAY

NOVEMBER 28, 2023

ONE DAY

ONE PURPOSE

ONE MISSION

25th ANNIVERSARY

National Scleroderma Foundation

Thank you

TO OUR NATIONAL CONFERENCE SPONSORS!

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PALLIATIVE CARE Q&A

Is Palliative Care the Next Best Step in Your Systemic Sclerosis Management Plan?

Vanderbilt rheumatologists answer your questions about palliative care

Palliative care is specialized, team-based care for anyone living with a serious illness such as systemic sclerosis. Palliative care can be provided alongside rheumatology care. The focus of palliative care is to relieve symptoms of your illness, in addition to addressing related psychological, social, and spiritual concerns. Thus, palliative care aims to address the needs of the whole person living with a serious illness, and to help you achieve the best possible quality of life. The palliative care team may include physicians, nurses, chaplains, social workers, and psychologists. Palliative care can also support you in future health care planning (called advance care planning) to ensure that the medical care you receive is aligned with your goals and needs.

How Should I Prepare for a Palliative Care Consultation?

There are no specific steps that must be taken to prepare for a palliative care consultation. Generally, you can expect to have a meaningful conversation with the palliative care team about:

1. Your illness, including any burdensome symptoms
2. Your goals and needs
3. Possible medical decisions that may lie ahead

What is Advance Care Planning?

Independent of a diagnosis of systemic sclerosis, an unexpected medical crisis could leave you unable to communicate your health care preferences. Therefore, many people put their preferences in writing via legal documents called advance directives. A lawyer can help with advance directives but is not required to create them. The two most common advance directives for health care are the living will and the durable power of attorney (DPOA).

Completing a living will document involves considering your preferences under hypothetical future medical scenarios. It often includes your perspectives on measures like cardiopulmonary resuscitation (CPR) and respiratory support on a mechanical ventilator.

A DPOA for health care is a legal document that names your health care proxy, also known as a surrogate. This should be the person you want to make health care decisions for you in case you are unable to make them yourself. Your proxy should be familiar with your goals and preferences, so please share your advance directive forms with your proxy as well as your medical team.

Will Insurance Companies Cover Palliative Care Services?

Most private insurance plans, Medicare, and Medicaid at least partially cover palliative care services. Veterans may also be eligible for palliative care through the Department of Veterans Affairs. If you have concerns about paying for palliative care, a social worker at your clinic may be able to help.

How Does Hospice Care Differ from Palliative Care?

Hospice care is a specialized form of palliative care that is delivered in the final months of life. Like palliative care, hospice provides comprehensive comfort care as well as family support, but, in hospice, attempts to cure the person's illness are stopped. Typically, you would no longer see your rheumatologist once enrolled in hospice care.

Where Can I Find Palliative Care and Hospice Resources?

getpalliativecare.org and **www.nia.nih.gov** offer credible information on palliative care and hospice in the United States.

Tracy Frech
Vanderbilt University Medical Center,
Division of Rheumatology and Immunology

Sarah Homann
Vanderbilt University Medical Center, Division
of General Internal Medicine and Public Health,
Section of Palliative Care

Getting to know ANGEL SOTO

Angel Soto has been involved with the scleroderma community since 2016 and has served as the National Scleroderma Foundation's Associate Director of Education since 2021. A Boston native, he is a graduate of Salem State University where he completed his degree in social work. Before joining the Foundation, Angel worked with adults living with developmental disabilities, which sparked his passion for nonprofit work. "Working with a community that is vulnerable and under-resourced, you can see the difference you're making in a real way," Soto said.

While he was going to school and interning, the Foundation was one of the places he most frequently visited because he found the community so inspiring. "I found them to be so resilient," he said. "Within the scleroderma community, there was such complexity and so many ways people were being impacted by the disease. When the Foundation reached out about a full-time position, I jumped at the chance."

HIGH HOPES FOR A STRONG FUTURE

When Angel started with the Foundation as a temp in 2016, he noticed that there were only a few companies doing early scleroderma studies. Now, compared to then, the sheer number of medical trials taking place is unbelievable. Angel said, "It's been inspiring to see physicians and companies starting earlier to include patients and their perspective in trials. That's one reason to get excited and have hope for the future!"

Angel is also excited for the Foundation's growth, especially when it comes to building out new areas of programming, reinforcing others, and revamping and/or creating some of the Foundation's patient information materials. "There's a lot of new energy with our Patient Advisory Board and Medical and Scientific Advisory Board that we can harness moving forward," Angel said. "And with the new chapter model, I think there's a big opportunity for more regional educational events for our community."

2023 CONFERENCE REFLECTIONS

Reminiscing on the National Scleroderma Conference in Orlando, Angel shared how enthused he was to see everyone again after finally returning in person, adding that the new virtual offering added an exciting element to the event. "We didn't know what to expect going hybrid this year, so breaking 600 for overall attendance (450 in person) was incredible," he said.

One highlight for Soto was the awards luncheon where community members celebrated an afternoon of camaraderie. "Seeing the reactions from our members was the real highlight," he said. "It's easy to forget the impact of the work you do, so seeing it in real time is pretty amazing."

Soto also highlighted the four Spanish sessions offered at Conference this year, noting that he is particularly proud of the increase in the Foundation's programming for native Spanish speakers. He also said a bonus to growing these programs is the opportunity to work with community champion **Monica Ramirez.**

KEEPING COOL UNDER PRESSURE

Angel said his greatest source of inspiration is his mother. She set an example of hard work and dedication as a single mother that has stayed with him and helps him keep his cool under pressure.

"My Mom raised all of her kids to be independent, and said I was always pretty easygoing," Angel shared. He even recalled the time, at four years old, when he took a walk to the corner store to buy a snack, unbeknownst to his sister, who was supposed to be watching him, and sparked panic. While his family was in the middle of a frantic search party, Angel coolly strolled in, chips in hand, unaware of the worry he caused.

"I've always been independent and kind of unphased by most things," he said. "I think most problems can be fixed, and stress rarely helps the situation, so I like to focus on what I can do to help."

When he's not planning the National Scleroderma Conference, Angel enjoys trying new foods, being outdoors, soaking up the sunshine, running and hitting the New England beaches – especially when he can bring along his dog Delilah.

> "I'M GRATEFUL FOR THE COMMUNITY'S COMMITMENT, DRIVE, & UNWILLINGNESS TO GIVE UP. ANY TIME I MAY BE FEELING DOWN OR DISCOURAGED, ALL I HAVE TO IS THINK ABOUT OUR SCLERODERMA WARRIORS & ALL THEY GO THROUGH ON A DAILY BASIS & IT GIVES ME PERSPECTIVE & INSPIRES ME TO KEEP MOVING FORWARD."

Support groups

25th ANNIVERSARY
National Scleroderma Foundation

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 below.

Support Groups and Leaders, by State

Alabama
- Birmingham
  - Jo Ann Bokenkamp

North Alabama
- Sarah Logan

Arizona
- Mohave Valley
  - Carol Hayward
- Phoenix/Glendale
  - Holly Roberts

Colorado
- Southern Colorado/Caregiver Connection
  - Gary Keschl
- Denver
  - Barb Frodin
- Western Slope
  - Rocky Mountain Chapter

Northern Colorado
- Connie Osborn

Connecticut
- Eastern Connecticut
  - Tri-State Chapter
- Yale/New Haven
  - Tri-State Chapter

Delaware
- Dover
  - Jennifer Cropper

Florida
- Central Florida
  - Jan Gura
  - Jenn Scheinberg
- Tampa Bay Area
  - Arlene Sweeney-Cornwall
- Palm Beach/Broward/Dade Counties
  - Desiree James
  - Jessica Massengale
  - Meryl Parr
  - Beth Taber
- Jacksonville
  - Hannah Bose
  - Lorraine Meide

Georgia
- Peachtree City
  - Demetra Newton
  - Vernita White
- Savannah
  - Robin Edwards

Iowa
- Statewide
  - Karen Fragale
  - Renee Hyde

Kansas
- Topeka Area
  - Emily Morris

Louisiana
- Baton Rouge
  - Del Anselmo
- Many
  - Tina Dowden
- New Orleans
  - Joy Mitchell

Maine
- Statewide
  - Sandy Lunner
- South Berwick
  - New England Chapter
- York
  - New England Chapter

Massachusetts
- Boston
  - Mary McClay
- Fall River/Bristol County
  - Donna Bernier
- North Shore
  - Roberta Mauriello
  - Donna Ahern
- Worcester
  - Nancy Velleco

Michigan
- The Autoimmune and Scleroderma Support Group
  - Nancy Stephens
  - Peggy Collins
- Dryden
  - Michigan Chapter

Minnesota
- North Metro
  - Deanna Hokanson
- West Metro
  - Elaine Robashkin

Missouri
- Poplar Bluff Area
  - Fran Atwell
- Springfield Area
  - Gerry Robertson
- St. Louis Area
  - Debbie Morris

Montana
- Statewide
  - Montana Chapter

Nebraska
- Statewide
  - Karen Fragale
  - Renee Hyde

New Hampshire
- Central New Hampshire
  - Cathy Legere
  - Don Legere
- Southern New Hampshire
  - Carla King
  - Jean Chapman

New Jersey
- Bergen County
  - Tri-State Chapter
- Northern New Jersey
  - Tri-State Chapter
- Young Adults/Ages 18 to 30's
  - Amanda Lippincott

New Mexico
- Albuquerque/Teens and Parents
  - Debra Droux
  - Jackie Martinez
  - Maria Tafoya

New York
- Albany
  - Tri-State Chapter
- Buffalo
  - Paulette Reed
- Long Island/Telephone Support
  - Evamarie Gilbes-Cole
- Nassau/Queens
  - Evamarie Gilbes-Cole
- New York City
  - Zeba Hyder
  - Tiese Mahabir
- Orange County
  - Barbara Celnick
  - Jodi Lynn
- Rochester
  - Marilyn Sibley
  - Diane Reynolds

North Carolina
- Fayetteville
  - Donna Thomas

Ohio
- Youngstown Area
  - Leni Schulz
- Cleveland
  - Lucille Miller
- Columbus
  - Allison Fish

Oklahoma
- Norman
  - Karla Shelby

Oregon
- Statewide
  - Christina Fidalgo

Pennsylvania
- Doylestown
  - Kelly A. Kelly
- Enola/Central PA
  - Dan Caruso
- Pittsburgh
  - Caroline Graettinger
  - Tim Graettinger
- Reading
  - Dawn Batzel
- Williamsport
  - Jayne Young

South Carolina
- Charleston
  - Sarah Budd
  - Patti Newman

Columbia
  - Paula Billingsley'
  - Christine Jensen
- Piedmont
  - LaKesha Williams

South Dakota
- Sioux Falls
  - Annie Schock

Texas
- Dallas/Fort Worth
  - Serita Gibson
  - Carla Sutton
- San Antonio
  - Deborah Charlton
  - Florence Diaz
  - Christy Lopez

Utah
- Greater Salt Lake City
  - April Torres

Vermont
- Brattleboro
  - Ilene Wax
- Burlington
  - Blythe Leonard

Virginia
- Fredericksburg/Richmond
  - Christine Hamblin
- Norfolk/Phone Support
  - Blythe Leonard

West Virginia
- Huntington
  - Karen Baker
- Weirton/Telephone Support
  - Sandra Fennych

Virtual Support Groups

- Black, Indigenous, People of Color (BIPOC)
  - Marilyn Sibley
  - Zynovia Hetherington
- Caregivers
  - Debbie Haussler
- LGBTQ+
  - Mary Forte
- Localized for Adults and Parents
  - Barbara Burke
  - Angela Bledsoe
  - Kira Kistner
- Newly Diagnosed
  - Ron Sasso
- Parents of Children with Scleroderma
  - Pamela Pour
- Scleroderma Young Adults Seeking Connection (SYNC)
  - Amanda Lippincott
  - Tiare Tolzmann
- Spanish Speaking/Bilingual
  - Monica Ramirez
- The 20%: Males Living with Scleroderma
  - Michael Bessert
  - Erion Moore

Please note every effort was made to include the most accurate information at the time of publication. If we have made an error, please let us know at info@scleroderma.org.

BRINGING EDUCATION TO OUR LOCAL COMMUNITIES

IMPORTANT ISSUES SURROUNDING scleroderma require solid, vetted education where individuals feel safe and supported. For this reason, our educational activities come in various forms and venues, from virtual to in-person. As of March 1, 2023, the Foundation returned to in-person educational events, offering hybrid options that allow for live streaming nationwide.

Providing new and innovative formats for Chapter educational events is a Foundation priority. For instance, the Music Therapy program's virtual class, offered by the New England Chapter, helps strengthen the lungs and improve breathing control. (See related article). The Upper Great Lakes Chapter also offers its monthly RestorACTIVE (RA) program by Rachel Lando as a movement option created by individuals living with scleroderma to help others discover tools to manage chronic pain or discomfort, move and feel better, and build the resilience to return to a well-lived life. Classes are accessible for all levels on the fourth Monday of every month at 4 p.m. ET.

Another innovative program is the monthly Lunch & Learn program, offered on the third Wednesday of the Month from Noon to 1 p.m. ET. Each month focuses on a different topic and consists of a 45-minute presentation followed by a 15-minute question and answer period.

Several other innovative projects are underway, such as developing age-appropriate information brochures for children with scleroderma and their parents. These brochures break down critical information on the disease into language geared for children and target schools and other institutions where these children interact.

Several Chapters are also partnering with the University of Michigan to bring its scleroderma Peer Mentor program to the scleroderma community. We are developing unique tools to use with the peer mentor program, such as updating the 2019 Health Management Binder – Patient Edition. An app and website are also being explored.

Our in-person education events are ramping up as well. Things kicked off on April 1 with the 13th Annual Amy K. Parrish Scleroderma Education Conference. The Mid-Atlantic Chapter has several upcoming educational events, including its October 28th health conference in Pittsburgh and November 4th conference at the Penn Scleroderma Center in Philadelphia. In addition, the chapter is working on a Kids Get Scleroderma Too (KGS2) event in the Philadelphia area for late fall or early 2024.

The Upper Great Lakes Chapter has in-person health conferences planned for September 30 in Minneapolis, partnering with Dr. Jerry Molitor and the University of Minnesota Scleroderma Center, and October 28 in Ann Arbor, partnering with the University of Michigan Scleroderma Center staff. Also, the New England Chapter is planning its Biennial Patient Education Seminar, tentatively scheduled to happen in April 2024.

Additionally, The Lower Great Lakes' will host an August event featuring Dr. Elizabeth Volkmann in Boardman, Ohio, and a November event featuring Dr. Nina Ramasser, as a part of a new quarterly series. The Florida + Puerto Rico Chapter will host a virtual Scleroderma Education Day on November 4. Many support groups also provide guest speakers.

Chapter educational events are an intricate part of the mission to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families, and support networks. We will continue to innovate to bring trusted information to the local scleroderma communities.

MUSIC THERAPY:

An Enjoyable and Effective Way to Strengthen the Lungs, Help Improve Breathing Control and Your Well-Being

Offered monthly by the New England Chapter and hosted by Erin Raber, MA, MT-BC, a board-certified music therapist, mental health counselor, and certified sound healing practitioner, these 75-minute, virtual (Zoom) sessions explore ways to use your voice as an instrument of healing through music therapy and sound healing techniques.

Participants experience how music and sound can help those navigating scleroderma with pain management, reduce stress and anxiety, improve breathing capacity, increase energy and mental clarity, improve mood, decrease feelings of isolation, and promote emotional transformation and release. In fact, music therapy has been shown to improve the health of those suffering from respiratory conditions such as pulmonary fibrosis.[1]

Group activities include breath work, toning, vocal meditation, mantra, and singing chants and songs. No prior musical or vocal training is necessary to engage in music therapy.

Erin shared, "It's been amazing to witness how vocal music therapy practices have benefited scleroderma patients. The group members that participate regularly and use the tools I've given them have reported seeing significant changes in their lung health, GI issues, and in their emotional and spiritual life." She adds that "singing creates more saliva in the mouth which can help with dry mouth, and when we sing, we are breathing differently and more deeply, so we are strengthening the diaphragm and improving breathing and lung capacity over time. Singing, especially humming, also helps to stimulate the vagus nerve, which, when stimulated in this way, directly stimulates our parasympathetic nervous system activity which tells our body it's ok to rest and digest. This is why it can relieve GI tract issues and aid digestion.

She added that while some of the members of the group initially had some challenges with the humming, toning, and singing, such as coughing, the constant need to clear their throat, or having trouble holding out tones, they found that with suggested adjustments and somewhat regular practice, they eventually could do the vocal exercises with fewer obstacles.

New England's North Shore Support Group Member, Tris Windle shared,"Music therapy has helped improve and inspire my goal to maintain my emotional and physical well-being. The professional, yet compassionate techniques have greatly helped with my breathing challenges due to my autoimmune-related lung and vascular disease."

> "MOST IMPORTANT, IS THE CONNECTION, UNDERSTANDING, AND JOY THAT WE FIND TOGETHER THROUGH THE SHARING OF MUSIC IN A SAFE AND WELCOMING SPACE."

In addition to presenting monthly for New England constituents, and at the chapter's 2022 Virtual Living Well with Scleroderma Series, Erin is a two-time presenter at the National Scleroderma Conference, first in 2022 and then as a part of the Kids Get Scleroderma Too module in 2023.

Curious?

You are welcome to join one of our sessions, held monthly on the 4th Monday at 6:30 PM via Zoom. Contact the New England Chapter at NEChapter@scleroderma.org, for more information or Zoom access.

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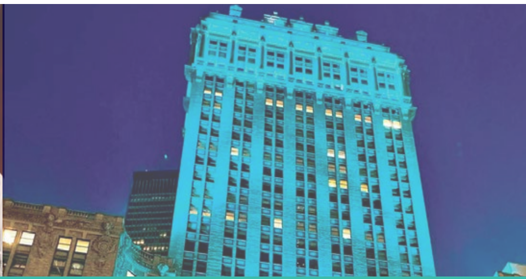
[1] Canga, B.,et al. (2015). AIR: Advances in Respiration - Music therapy in the treatment of chronic pulmonary disease. Respiratory medicine, 109(12), 1532–1539.

ADVOCACY AND AWARENESS IS A YEAR-ROUND EFFORT

25th ANNIVERSARY
National Scleroderma Foundation



Thanks to all who participated in June Advocacy and Awareness activities.

Whether you emailed, called, or met with your senators to ask that they continue to support the inclusion of scleroderma in the Peer-Reviewed Medical Research Program during the 2024 Fiscal Year appropriations process or secured a proclamation or light-up, your efforts are appreciated and impactful!

For more information on how to get involved in advocacy and awareness, email info@scleroderma.org.

LET'S TALK ABOUT SCLERODERMA

#TealTalk

This year's theme for Scleroderma Awareness Month was "Let's Talk About Scleroderma #TealTalk." We chose this year's theme because it gets to the essence about what Scleroderma Awareness Month is all about – talking about scleroderma, what it is, highlighting the thousands of people it has affected, and, most importantly, spreading awareness in our communities, both virtually, and with our own friends and families.

Our month-long awareness campaign featured multiple opportunities to engage with the Foundation and other members in the scleroderma community including proclamations and light-ups, our Stepping Out to Cure Scleroderma Walks, and hearing the stories of those affected by this disease.

Our #TealTalk series was an initiative to bring our community together for a series of virtual roundtable discussions and live conversations with special guests and had two components: #TealTalk Tables and #TealTalk Lives.

- Our #TealTalk Tables were special events to meet each other and share our journeys. The Foundation hosted five #TealTalk table events in June, and are grateful to the hundreds who participated, sharing memories, stories, personal experiences, and most importantly, hopes for the future.
- During our four #TealTalk Live events on Facebook, special guests shared about how they became part of our community and are working to raise scleroderma awareness across the country. Thousands tuned in to hear from members of our community like Desiree James, Dr. Elizabeth Volkmann, Demetra Newton, and our celebrity ambassador, Ashley Barron!

This year, we were also pleased to support the 3rd Annual International Scleroderma Conference, which welcomed more than 300 participants from 31 countries. For the first time ever, the conference offered full audio Portuguese interpretation live for attendees. You can view all sessions in English, Spanish or Portuguese, on the Foundation's YouTube channel now! We are dedicated to breaking down language barriers around scleroderma education and empowering individuals affected by scleroderma living around the world.

Many of you also participated in awareness month by securing light-ups and proclamations, like those featured here. In total, more than 30 proclamations and light-ups were secured this year – that we know of! Well done, advocates!

You can view our #TealTalk playlist on YouTube at scleroderma.org/tealtalklives.

OUR vibrant COMMUNITY

The goal of the National Scleroderma Foundation's Chapters is to support you, no matter where you are in the country. As we continue our Chapter realignment, here are updates from just a few of our Chapters.

Florida & Puerto Rico Chapter

The Florida & Puerto Rico Chapter will kick off the 2024 Stepping Out to Cure Scleroderma walk season with its Coconut Creek Walk on February 24, 2024. Stay tuned for more information. If you are interested in joining the walk, email **frobin@scleroderma.org.**

Heartland Chapter, Missouri

St. Louis Missouri will hold its annual Stepping Out to Cure Scleroderma walk on Saturday, October 7, 2023, at Creve Coeur Lake, Tremayne Shelter. Registration is from 9:00 - 11:00 AM, and the walk begins at 11:00 AM. For some October fun, wear your Halloween best! Sign up at: **www.scleroderma.org/steppingoutstlouis** For questions, contact **rcosta@scleroderma.org.**

New England Chapter

Join the New England Chapter on Saturday, September 30, 2023, for the Stepping Out to Cure Scleroderma Boston Walk at Artesani Park. Over the last seven years, the Chapter has hosted its Boston walk along the beautiful Charles River to raise funds to support scleroderma programs and research. It will be a day of fun, fresh air, raffles, and a (just under) 5K walk. Walk as an individual or grab some friends and start a team! Wear something silly and stand out from the crowd! Learn more: **https://scleroderma.org/boston23.**

Mid-Atlantic Chapter

The Mid-Atlantic Chapter is busy planning several educational events with our excellent Scleroderma centers. First, the Chapter is planning an event on October 28 at our UPMC in Pittsburgh. Then, the Chapter is working with the Penn Scleroderma Center in Philadelphia for an event for November 4. Lastly, the Chapter is beginning work on a KGS2 event in the Philadelphia area to be held in the late fall or early 2024. For more information, email **jlapergola@scleroderma.org.**

Rocky Mountain Chapter

The Rocky Mountain Chapter's annual Denver Food Fight occurs on Wednesday, October 11, 2023, at the BAC Appliance Center. The event is an elite culinary competition featuring some of Denver's talented chefs and bartenders. Patrons indulged in delectable tastes from the extraordinary culinary talent the city has to offer. This year's Food Fight will feature our celebrity ambassador, Ashley Barron!

Upper Great Lakes Chapter

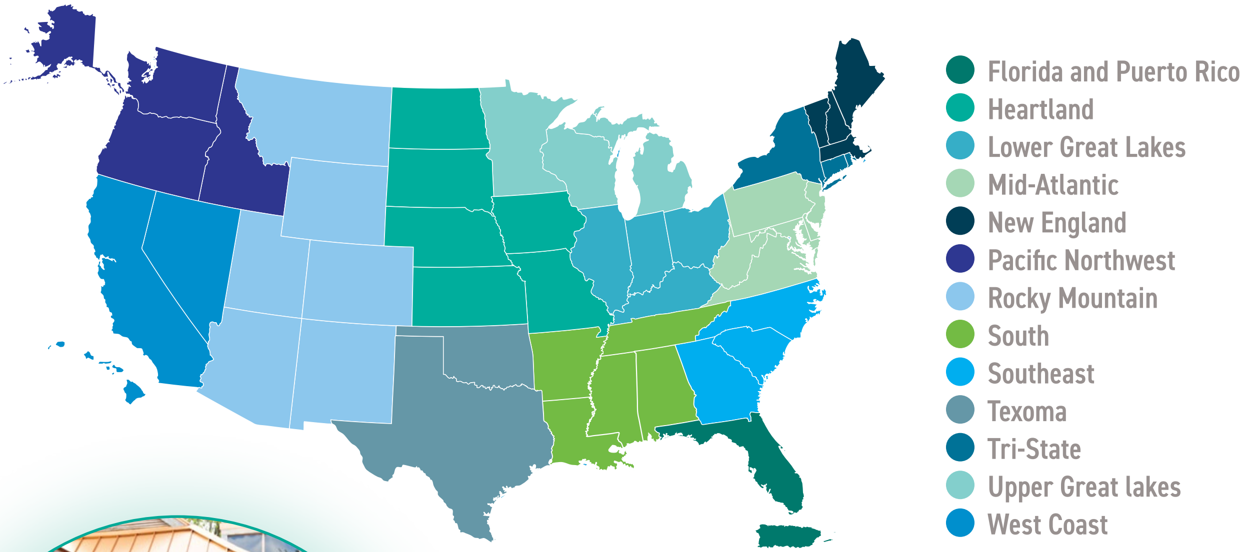
The Upper Great Lakes Chapter is excited to announce two upcoming in-person health conferences! On September 30, 2023. The Chapter will have its first conference in Minneapolis/St. Paul, Minnesota, featuring Dr. Jerry Molitor, from the University of Minnesota Scleroderma Center, as the presenter. Additionally, the conference will have a patient panel and a roundtable discussion on several topics related to managing scleroderma.

On October 28, 2023, the Chapter will hold its second in-person health conference in Ann Arbor, Michigan, where the team from the University of Michigan Scleroderma Center will present on several topics. In addition, Dr. Susan Murphy, will present the exciting results of the RENEW study that has now been completed.

Location and registration information is available through the UGL Chapter. Email **uglChapter@scleroderma.org** for more information.

JOIN A LOCAL CHAPTER!

The National Scleroderma Foundation has 13 chapters to serve you. To find your local chapter visit **scleroderma.org/find-your-local-chapter/** or use the QR code below.



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Heartland
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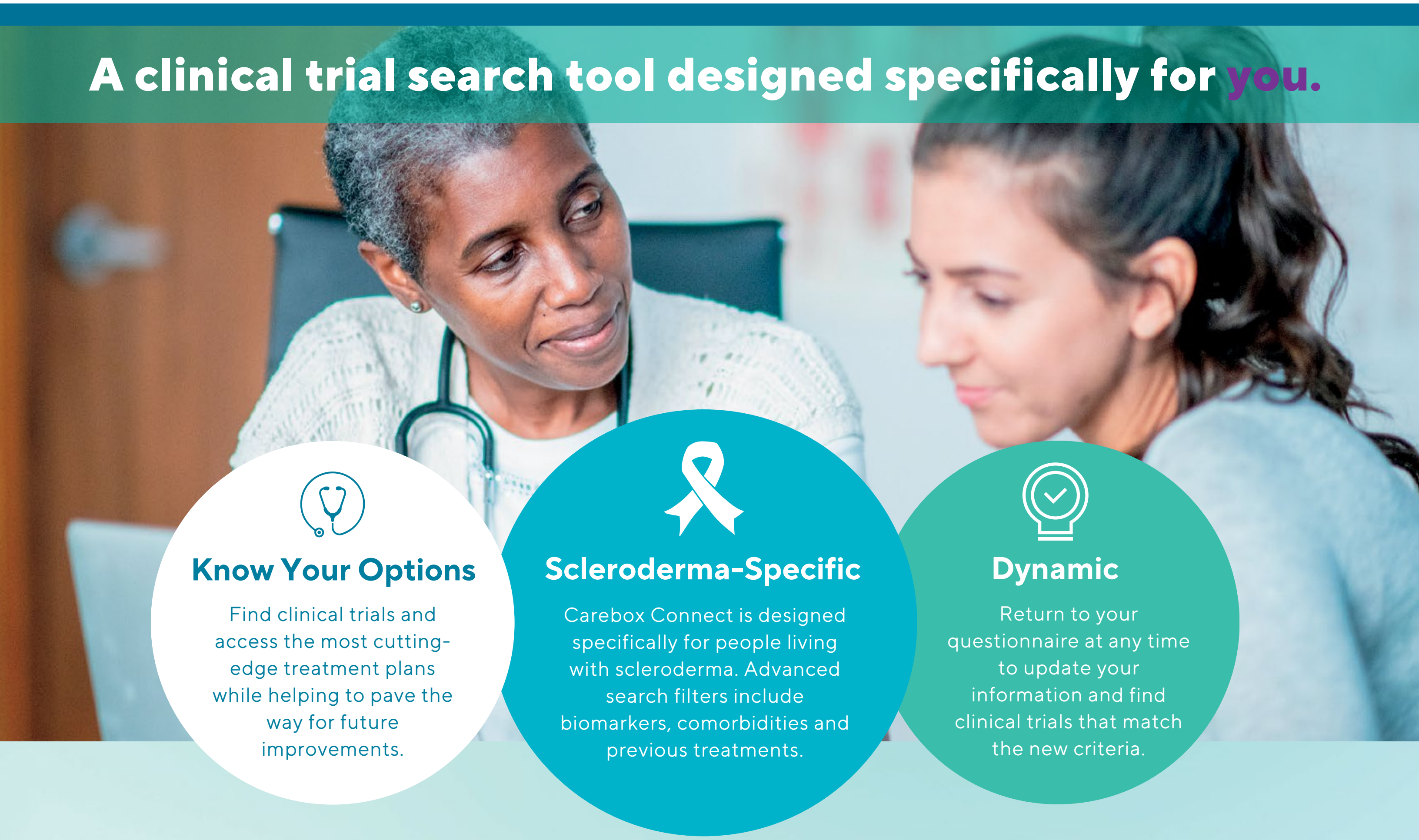
A clinical trial search tool designed specifically for you.



Know Your Options

Find clinical trials and access the most cutting-edge treatment plans while helping to pave the way for future improvements.

Scleroderma-Specific

Carebox Connect is designed specifically for people living with scleroderma. Advanced search filters include biomarkers, comorbidities and previous treatments.

Dynamic

Return to your questionnaire at any time to update your information and find clinical trials that match the new criteria.

carebox

Carebox Connect is a service that is free and confidential. Individuals are under no obligation to participate in clinical trials they are matched with. Matching does not guarantee enrollment. Individuals can discontinue Carebox services at any time.

National Scleroderma Foundation