SCLERODERMA VOICE

The magazine exclusively for Members
of the National Scleroderma Foundation.

SUMMER 2024

CELEBRATING COMMITMENT

Honoring exceptional support for the scleroderma community

- **WELCOMING NEW MEMBERS**
  Welcoming new members to the Board of Directors and saying thank you to two long-time leaders
- **MAKING THE DREAM WORK**
  A trio of strangers team up to create a support group in Central North Carolina
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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.

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© 2024 National Scleroderma Foundation
300 Rosewood Drive, Suite 105
Danvers, MA 01923

Info Line: 800-722-HOPE [4673}
Tel: 978-463-5843
Fax: 978-777-1313
info@scleroderma.org
scleroderma.org

STAFF CONTRIBUTORS

Mary J. Wheatley, IOM, CAE
Chief Executive Officer

Ashley M. Pruett, MEd
Vice President, Community Engagement

Kate Anastasia, MPA
Senior Director, Mission Delivery

Elizabeth Mulroy
Senior Director, Chapter Operations

Brian Perkins
Director, Communications

Jesse Saunders
Coordinator, Communications

Jayna McKiel
Manager, Fundraising Events

Lauren Galván
Senior Manager, Development

Lorraine Biaggi
Executive Director, Florida & Puerto Rico Chapter

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OUR SCLERODERMA JOURNEY

Twenty-three years ago, my family's lives changed forever when, after years of misdiagnosis, doctors diagnosed my wife, Mariann, with scleroderma. One of the first things we did was get involved with the National Scleroderma Foundation. We knew we had to get connected with people who could provide information about how to navigate the complexities of this disease and put us in touch with the experts. We needed to rely heavily on those who had walked this path before us. Little did we realize then that while there are so many similarities to this disease, it seems that every patient's journey is a bit different. Through the Foundation, we've been able to tap into a broad network that enables us to share and receive insights and experiences that have made our journey just a little less scary.

One of the earliest takeaways from our involvement with the Foundation was the passion that everyone had in fighting this disease. Having seen that passion, and feeling inspired by the legendary Yogi Berra's advice, "When you come to a fork in the road, take it," we did. And just two years after Mariann's diagnosis, we put together our first fundraising walk in Boardman, Ohio. This year marked our 21st *Stepping Out to Cure Scleroderma* walk in Boardman with the Lower Great Lakes Chapter! As always, we are blessed by such generous friends and family and extend our heartfelt thanks for helping us support those who have this disease and who are supporting our fight!

In 2022, I was honored to be elected as Chair of the Board of Directors. The privilege of holding this position has given me an even greater perspective on all the positive ways the Foundation supports people living with scleroderma, their care partners and support networks; provides education to the scleroderma community; and funds research to find the cause and the cure.

That's why this year's Scleroderma Awareness Month theme, Every Journey Matters, really resonates with me and my family. To say it's been a journey for us is putting more than 20 years of trials, tribulations, and small and big wins into one small word, but it's powerful to recognize we're just one of so many journeys in our scleroderma community. And we are deeply grateful to everyone who has helped us in ours.

Kevin Boyanowski

Kevin Boyanowski
Chair, Board of Directors

EVERY JOURNEY MATTERS

Mary J. Wheatley, IOM, CAE

ONE OF THE MOST CHALLENGING THINGS ABOUT SCLERODERMA is that it shows up differently in each person. It's more complicated to manage since there is not one clear path. At the National Scleroderma Foundation, we know that no two journeys are the same. Every journey matters, and that is why this June, we asked you all to share your journeys with the world. Our community answered the call by sharing their own informative and inspirational stories.

Barbara shared her journey with *en coupre de sabre,* and how her life changed when she was able to meet others living with scleroderma just eleven years ago. She also shouted out her localized scleroderma support group, and what it has meant to her journey.

Lino from Texas shared what brings him joy and motivates him, and just a few of his passions in life, including inventing. His advice to others: "Never give up."

Meghan from Virginia shared that "finding your tribe" can make all the difference in your journey, and recognized how much her emotional support pet, Daisy, has helped in her scleroderma journey!

These are just a few of the stories we received. Thank you to everyone who submitted. We will continue sharing these to help spread awareness all year long. We know the importance of increasing awareness, and that's why it's central to our mission. The more healthcare providers know about scleroderma, the more we can move the needle toward earlier diagnoses, which in turn leads to earlier treatment and better outcomes for people living with scleroderma. The more your friends, family and support networks know about scleroderma, the more (and better!) they can support you on your unique scleroderma journey. As we help more lawmakers understand scleroderma, we can more easily and efficiently continue our work to ensure access to care and treatments for everyone living with scleroderma, as well as increased federal funding for critical research.

We envision a future where collaboration, communication, and innovation intersect to make a transformative impact in the fight against scleroderma. Our continued excellence depends deeply on support from our community and friends like you. We are grateful for your investment in future support, education and research that will benefit people impacted by scleroderma for years to come.

Mary J. Wheatley, IOM, CAE
Chief Executive Officer

NATIONAL SCLERODERMA FOUNDATION WELCOMES
NEW LEADERS TO BOARD OF DIRECTORS

On July 1, the National Scleroderma Foundation welcomed Tera Carter, Scott Ceresnak, MD, and Falguni Desai to the Board of Directors.

The Board of Directors is a volunteer leadership group that serves as the Foundation's governing board. The Board oversees all Foundation programs and services and exercises its fiduciary responsibilities to ensure the success of the Foundation.

Tera Carter

Scott Ceresnak, MD

Falguni Desai

Tera Carter is a scleroderma warrior who has faithfully served her country for over 23 years in the Air Force Medical Service Corps. She feels a personal connection to the Foundation’s mission. ***“I understand the importance of researching this disease until we find a cure,”*** Carter said.

Scott Ceresnak, MD, and his family have been involved with the Foundation for many years. His oldest daughter was diagnosed with scleroderma at the age of five. ***“I believe in the National Scleroderma Foundation's mission,” Dr. Ceresnak said. “I want to do whatever I can to advance the mission of helping others with Scleroderma and finding a cure!"***

Falguni Desai is a scleroderma patient and advocate who spends her time volunteering to educate others about scleroderma and the Foundation’s mission. ***“My lived experience has given me the voice to promote disease awareness, provide support and educate patients on what I have learned through attending support groups and reaching out one on one with patients,”*** Falguni said.

“I am incredibly excited to welcome our new members of the Board,” the Foundation’s CEO, Mary Wheatley, IOM, CAE, said. “Tera, Falguni and Scott will bring their unique experiences and passion to the Foundation’s leadership.”

The first meeting of the new Board of Directors was held on July 19, 2024, in Bellevue, Washington, just before the National Scleroderma Conference.

SERVICE and Dedication

The Foundation Board of Directors bids farewell to Cos Mallozzi and Mike Levengood.

THE JOY OF BRINGING NEW MEMBERS to the National Scleroderma Foundation Board of Directors is a bittersweet experience. New voices and fresh perspectives are crucial ingredients to continued growth and improvement. At the same time, it is easy to be sentimental as long-serving members take this opportunity to move on to other commitments in their lives.

This year, the Foundation Board of Directors bids farewell to Cos Mallozzi and Mike Levengood. Cos and Mike have come to epitomize service and dedication during their time with the Foundation.

Cos Mallozzi has served the Foundation for more than 20 years. He served as Chair for many years, and his final year as Chair culminated in June of 2023. He and his late wife, Ronni Schulman Mallozzi, were honored with the Lifetime Achievement Award in 2023.

"It has been an honor to serve on the Board of Directors," said Cos, who estimated he has close to 100 Board meetings under his belt. "All of this has given me a sense of purpose because of my love for the person in my life who lived with the disease. It helped me understand the marathon people living with scleroderma endure and how they deal with life's daily challenges. The bottom line is it has made me feel happier and I have been much more fulfilled. It has always been at the top of my priority list and will always be," he added.

"Cos' commitment to the mission of the National Scleroderma Foundation has been unwavering for decades," Board Vice Chair Carol Feghali-Bostwick, PhD, said. "He and his late wife, Ronni, have given of their time unconditionally. His strong and exemplary leadership as recent Chair of the Foundation's Board of Directors was instrumental in having the Foundation emerge stronger and with a clear vision and strategic plan throughout the reorganization. It has been a pleasure to serve under his leadership."

"There is no one in the scleroderma community who has been more instrumental in establishing the National Scleroderma Foundation as the cornerstone organization supporting patients, caregivers, supporters, researchers and medical providers/partners than Cos over the past 20+ years," Board Chair Kevin Boyanowski said. "His unwavering passion for the well-being and engagement of our community is a standard that most of us should aspire to achieve."

Mike Levengood, JD, has been a member of the National Board of Directors since 2017, and most recently served as the Secretary. Mike joined the Foundation Board after supporting local efforts in Georgia in memory of his late sister-in-law, Kathleen Basile, who passed away from scleroderma in 2009.

“The National Scleroderma Foundation invited me to serve the National Board of Directors in 2017,” Mike recalled. “My wife, Peggy, and her family founded the Georgia Chapter in 2011, and in doing so, we met many wonderful patients, caregivers and donors. When the National Board of Directors Nominating Committee reached out for candidates, they encouraged me to serve, and I was nominated. I found my service on the National Board to be inspiring. Robert Riggs and Mary Wheatley have both led highly professional teams dedicated to supporting patients and their caregivers, and to supporting research to find a cure for a disease that has no known origin or cure. Cos Mallozzi, Kevin Boyanowski, and Carol Feghali-Bostwick have provided excellent volunteer leadership as Chairs and Vice Chair of the Board during my tenure. I am in awe of the positive impact that my fellow Board members have made while collaborating to develop a strategic plan to assist the Foundation in achieving its mission. I am confident that the National Scleroderma Foundation is in good hands with the incoming Board of Directors, which will build upon the achievements of its predecessors.”

“I always admired Mike’s calm, strong, professional, and thoughtful, leadership style, Dr. Bostwick said. “He has been a role model and a source of wisdom for our Board and community. His commitment to the scleroderma mission and dedication to the National Scleroderma Foundation has contributed to the organization’s success and helped steer us in the right direction.”

“Over the many years that I have known Mike, and that he has been engaged with the Foundation, his insightful leadership has been a true blessing that all of us are grateful to have received,” Kevin Boyanowski said. “His dedication to the entire community is unsurpassed. All of us will very much miss him as National Board member, but we can rest easier knowing that he will be very engaged in assisting us to build out our very important Southeast Chapter.”

“I had the pleasure of working with Cos for over 20 years and with Mike for four years,” former Foundation CEO, Robert Riggs, said. “Cos’ vision for the future of the National Scleroderma Foundation has helped secure its continued growth and success. Mike’s expertise in the law and nonprofit healthcare space has provided the National Board and staff with wise counsel and unwavering support. Both gentlemen have been stalwart leaders, and the scleroderma community owes them an enormous debt of gratitude.”

“We are so grateful for the service of Cos Mallozzi and Mike Levengood, and we wish them all the best in their next chapters,” shared Mary J. Wheatley, IOM, CAE, CEO of the Foundation. “On behalf of the entire Foundation staff and volunteer leadership teams, we hope you know the Foundation is better because of your service and dedication.”

> NO ONE IS MORE CHERISHED IN THIS WORLD THAN SOMEONE WHO LIGHTENS THE BURDEN OF ANOTHER.”
> - Joseph Addison

CENTRAL NC SCLERODERMA SUPPORT GROUP

ABOUT ONE YEAR AGO, a trio of scleroderma warriors who had never met before, began an ambitious project to fill an unmet need by forming a support group to serve central North Carolina.

Donna Dinkin, Marty Jones and Kheesa Jones co-lead the Central NC Support Group. The group meets monthly, and its virtual meetings are open to anyone and everyone to attend. The group also hosts four in-person meetings per year in Greensboro, NC. Donna and Marty got involved thanks to some encouragement from a shared doctor.

"While seeing (my pulmonologist) for care, we chatted about his interest in getting more people involved in either the local pulmonary fibrosis group or in a new scleroderma support group," Donna said. "He asked me if I would be interested in starting a new group."

Soon, Marty contacted Donna after hearing about the plans for a support group from a doctor they each see. Donna reached out to Kheesa after seeing her story in the local newspaper during Scleroderma Awareness Month. The three had never met.

"I was interested in starting a group because I believed our local community had missed an opportunity to support people with ILD and scleroderma during the height of the COVID-19 pandemic," Donna said. "I am thankful they both agreed," she added. "We have had different journeys, which helps us think more broadly about our group's needs."

"I actually called her with the intention of only being a member," Marty said. "She appealed to me for help running (the group) and told me about the Support Group Facilitator training provided by the Foundation. I learned a lot during the training, and I want to help others like me."

> "HE ASKED ME IF I WOULD BE **INTERESTED IN STARTING A NEW GROUP.**"

"When I was diagnosed with scleroderma in 2006, I was terrified and would have loved to have had someone to talk to that truly understood what living with scleroderma was like," Kheesa said. "I became a support group facilitator because I want to be the person," she added.

Kheesa, Donna and Marty share the load of planning and organizing group events.

"I have two school-age children who are constantly pulling me in different directions," Kheesa said. "My role is more to support the other facilitators; I participate in planning sessions and while I don't typically lead the meetings, I can jump in and take over if something should come up."

"Donna tends to have the responsibilities of setting up the meetings and sending out the emails and I try to help facilitate meetings and line up speakers," Marty said. "We all share input and ideas as we meet as leaders each month."

Donna mentioned that even she has been surprised by how important this work has become to her own life.

"When I started, I didn't really actually feel that I needed support, but I thought I might be able to help others," Donna said. "Since starting the group, I learned that I was wrong about not needing the support. I hope I

am right in thinking that by hosting this group we are helping others."

"I would encourage people to do it," Kheesa said. "I have gotten so much out of this group as a patient myself by knowing that I am helping others."

"Support groups are made up of people with many of the same questions, concerns, frustrations and fears that you are facing with scleroderma," Marty said. "It's nice to be able to share with people who understand—even our family members may not fully get it. You are likely to feel less alone in the world with this crazy disease if you are in a support group."

For Marty, Kheesa and Donna, they have found support in their group and in each other.

If you are interested in learning more about support groups affiliated with the National Scleroderma Foundation and its chapters, **visit: https://scleroderma.org/support.**

SHINING BRIGHT
DURING AWARENESS MONTH

TEALTALK RECORDINGS:

1,214 views in June

FACEBOOK REACH:

40,292 users in June

INSTAGRAM REACH:

33,249 accounts in June

YOUTUBE VIDEOS:

12,500 video views,

1,500 hours watched in June

PROCLAMATIONS:

30+ proclamations and light-ups

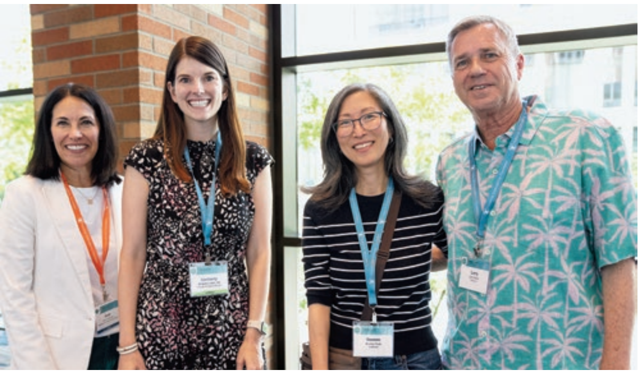
***STEPPING OUT TO CURE SCLERODERMA* WALKS:**

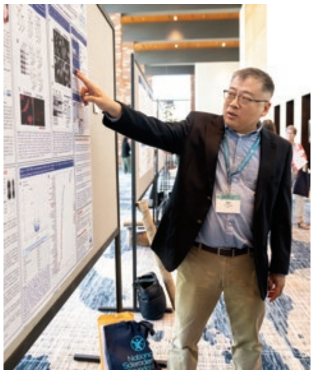
17 walks in June

A first-time walk at a ballpark for the Upper Great Lakes Chapter. The walk was held before a minor league baseball game with more than ***4,000*** *people in attendance.*

> “IT IS SO NICE TO KNOW THERE ARE SO MANY TOOLS OUT THERE TO HELP US WITH OUR DAILY ACTIVITIES. SOMETIMES DAY TO DAY LIFE IS SO HARD THAT HAVING SOME OF THESE TOOLS MAKES IT JUST A LITTLE EASIER.”

2024 NATIONAL SCLERODERMA CONFERENCE RECAP





WHAT AN EXCITING WEEKEND WE HAD IN BELLEVUE, WASHINGTON, for our National Scleroderma Conference! This conference was truly five years in the making, as this was scheduled to be our destination for the 2020 conference, but COVID had other plans. This year, we had yet another curve ball thanks to the infamous software glitch that affected services across the globe. Our fantastic Foundation staff made a few adjustments, and the conference did not miss a beat.

On Friday, we hosted a Continuing Medical & Nurse Education (CME) program, "The Lung and Scleroderma." The event allowed healthcare providers in the Pacific Northwest to learn from some of the nation's leading scleroderma experts. The program was recorded and will be available to providers around the country to complete and earn CME credit. We also hosted a joint meeting with members of the Board of Directors, Patient Advisory Board and Medical and Scientific Advisory Board as conference is the perfect opportunity for all to gather to review the past year and discuss goals for the next few years.

The exhibit hall and poster hall were also abuzz with conference attendees, sponsors and speakers. These displays and exhibits allow attendees to learn more about the latest clinical research and the programs and services offered by our Foundation's supporters.

A special thanks to Dr. Tracy Frech, who provided our opening keynote presentation. Dr. Frech talked about the resiliency of the scleroderma community and the importance of self-care and listening to your body. A key theme of the event was that being healthy is more than just focusing on our physical health.

On Saturday, the Foundation's annual Volunteer Awards Luncheon celebrated the exceptional contributions of volunteers and chapters across the country. This event always presents an opportunity to share ideas about what is working well in different chapters and to give a special thank you to those who truly put our mission in motion.

Saturday evening kicked off with the *Tune In To Lung Health* program in partnership with Boehringer Ingelheim designed to raise awareness of Interstitial Lung Disease (ILD) and how music and breathing may help people cope with the mental, emotional, and physical disease burden. The sessions included a conversation with Aly, a scleroderma patient; Dr. Elizabeth Volkmann, a rheumatologist; Yankees legent Bernie Williams, a former caregiver for his father; and Mary J. Wheatley, CEO of the National Scleroderma Foundation.

Sunday arrived with final sessions and the closing keynote panel with Falguni Desai, Erion Moore, Monica Ramirez, and Evan Rood sharing stories from key moments and experiences in their individual journeys with scleroderma. We officially closed the 2024 conference with participants from our Kids Get Scleroderma, Too! Conference and members of our Heartland Chapter announcing next year's destination, St. Louis, Missouri!

2024 NATIONAL SCLERODERMA FOUNDATION VOLUNTEER AWARDS

Each year the Foundation recognizes volunteers for their outstanding work in support of its mission to advance medical research, promote disease awareness, and provide support to people with scleroderma, their caregivers and support networks. On July 20, 2024, the National Scleroderma Foundation announced its 2024 Volunteer Awards at the annual conference in Bellevue, Washington. Anne Sweeney, Manager of Volunteer Experience, hosted the event.

Congratulations to our recipients!

Individual Fundraiser of the Year

Kelley Hill

Chapter Support Group Volunteer of the Year

Debbie Charlton

Outstanding Educational Program

Upper Great Lakes Chapter

Outstanding Patient Support Award

Ann Mogilevsky

Outstanding Chapter Awareness Award

Upper Great Lakes Chapter

Advocate of the Year Award

Amy Gietzen

The Foundation is so proud to work alongside each of this year's awardees. Each person recognized this year contributes day in and day out to improving the lives of people affected by scleroderma.

Chapter Volunteer of the Year

Camille “Cami” Novacheck

Philanthropist of the Year

Martin “Marty” Lehmann

Messenger of Hope Award

Lucille Miller

Distinguished Service Award

Dr. Virginia Steen

National Volunteer of the Year

Peggy Collins

Chapter of the Year

Upper Great Lakes Chapter

Doctor of the Year

Dr. Mary Ellen Csuka

Jacob Davila Memorial Leadership Award

Debbie Charlton

Lifetime Achievement Award

Dr. Carol Feghali-Bostwick

Read more about the awardees and their accomplishments at scleroderma.org/2024awards.

COMING OF AGE AS A PATIENT AND A PHYSICIAN LIVING WITH SCLERODERMA

Elizabeth Vukin, MD

MY STORY SPANS 20 YEARS. As a pediatrician and a parent, much of my adult life is spent watching young people grow—watching them come of age. Each young child grows and learns, and as they experience new things their mindsets change along the way. Adults know this all too well, like how our own mindsets change about our parents as we ourselves grow. My change helped me move through the fear, frustration and anger that comes with being undiagnosed, and then being diagnosed, with scary diseases. Eventually, it all brought me to a place of understanding.

There are more than 100 autoimmune diseases. These diseases affect multiple organ systems but are largely invisible. They are lifelong, incurable, and we don't yet fully understand them.

> “YOU ARE THE EXPERT OF WHAT YOU FEEL IN YOUR BODY”

Now, I have been diagnosed with three autoimmune diseases, two of them quite rare, so in the world of, “if you hear hoof beats, think horses, not zebras”, I think that makes me a unicorn.

My story begins when I was 20 and a pre-med in college. At first, it was a vague symptom. For months, I was exhausted. I fell asleep in all my classes. I fell asleep while driving and crashed my car. That did not prompt me to see the doctor. The weird symptom did. I developed a purple web-like rash covering my lower arms and legs (livedo reticularis). I go to the doctor. I have some tests. I get diagnosed with lupus.

Fast forward and now I am 24 years old and a third-year medical student. I am exhausted. Then, the weird rash is back. A few months later, another weird symptom! One day, I couldn't lift the back of my right hand upwards. A few weeks later, I couldn't flex my right toes up towards my shin. Mononeuritis multiplex.

This time, as a med student, I was like, “No problem. I am surrounded by like 100 doctors! They are going to figure it out. These people know what they are doing, and I am training to be one of them!”

It took many months, many tests and many doctors. So, like a teenager and a patient, I hear what the doctors are saying, but I am also like, “Really, doc? Do you have any idea what you are doing?” But, as healthcare professionals, we know that diagnosis can be a multistage process. Finally, I got a diagnosis: polyarteritis nodosa.

Twenty years go by and, as a doctor, I learn from people's unique experiences. Even as doctors, we know what the textbooks say and then we share in the patient's frustration when that is not what actually happens. During that time, my relationship with medicine evolved. I saw over and over that medicine is complicated and we don't always know the answers.

I am a pediatric hospitalist. You know what can get you admitted to the hospital? Prolonged vague symptoms that no one can explain. Also, the weird ones. I have spent my career trying to explain the unexplainable. I have heard over and over, “We are not leaving until we know what is going on.” And when people hear there is no explanation, they think a few things: “these doctors don't know what they are doing,” or, “they don't believe me, they can't help me, maybe my symptoms are not real.” At the same time, doctors question their abilities and feel powerless to help.

With my own health, for the past three years, I felt like there was still something wrong. I saw doctors. I talked with friends who are doctors. Still, all my tests are normal. Also, my symptoms of fatigue, brain fog, muscle aches and joint pain are diagnosed as being a middle-aged working mom by society. Let me pause here to say that it is hard to go to the doctor—especially as a doctor. When I go to see a doctor myself, I want to be right that I needed to go to the doctor. I don't want to be wrong, because then it feels like I don't know enough, and I've wasted someone's time.

Then ah-ha: a weird symptom! Two years ago, my hands

got puffy! And my forearms got really tight and swollen. Yes! A physical sign! And a weird one! We can figure this one out!

I read and came to believe I have scleroderma. Good thing I have a Rheumatologist! I have seen this doctor for years. I message him and he sees me right away.

Well, we ran a lot of tests, and everything was "normal" or "non-specific." So, I fell into the "let's see what happens" and "if nothing else turns up, let's repeat labs in a year."

Medicine could not give me an answer. So, I did what we tell patients with unexplained symptoms to do. Let's focus on treatment. Nutrition, movement and stress management. Let's do what we can.

At this stage, I am an adult in the house of medicine. Let's think about that adult-child relationship with your parents. Some things you agree on and others you don't. You sort of tread lightly when you don't agree because you want to be respectful and because they probably know more than you, but maybe on some things they don't.

My rheumatologist had moved when it was time for my follow-up, so I saw someone new.

"I think I have scleroderma. All my testing is negative, but now my hands are stiff and contracted and my forearms are so tight. I really do think I have scleroderma and I was just wondering what you think," I tell the doctor.

She takes a look at my hands. I know that, even when I feel like I am dying, I present as doing well. I don't complain. I hold it together. I go to work, and I take care of other people because that is what we do. So, I preemptively say, "Now the swelling has decreased. I have worked really hard on taking care of myself, so I look and feel really good right now. I know what my triggers are so if you want, I can put myself into a flare and I can come back in, and you can see how bad I look."

That is when she said, "I believe you." That simple phrase gave me permission to believe myself.

Ten months ago, I was diagnosed with a systemic form of scleroderma.

My own journey of uncertainty pushed me into the mature-adult phase of the 'child - parent relationship'. I am now middle-aged in the relationship with my parents in the house of medicine, and a lot has changed from when I was a kid. As a mature adult child, we don't get mad at our parents for not knowing the right way to help us (well, let's say that is a goal anyway). We see them as human. As people, trying the best they can with what they know.

I want to be sure this does not come across as a missed diagnosis story. No one was negligent or mal intended in anyway. This is just the way it happens sometimes —things are not missed, so much as they are hard to diagnose. Sometimes, exams and tests are normal. Sometimes we need more time for diseases to evolve to help us figure out what is going on.

We want to do something to make the patient feel better right? So, we try to be positive. When we say, "Everything looks normal," we intend to be reassuring, but as a patient, that sounds dismissive.

So, as a patient and a doctor, what would I suggest instead?

Be vulnerable. Be ok to be uncomfortable in the uncertainty. The story does not end here. Do what you can do--offer treatments and symptom relief and a plan for follow up. Keep re-evaluating. If it gets better, great! If not, we will keep thinking together.

If you are a patient (and we are all patients), I ask you to promise to believe and trust yourself. You are the expert of what you feel in your body. Advocate for yourself just as parents advocate for their children.

If you are a caregiver (and we are all caregivers), when you are with someone who is going through a hard time, and you don't know what to do, don't let them be alone. Promise to believe them. Promise to be with them. Because, even if you cannot shed light on the journey ahead, you can be with each other in the darkness.

CLINICAL TRIALS:
WHAT YOU NEED TO KNOW

Shervin Assassi, MD

PARTICIPATION IN RESEARCH IS NOT ONLY CRITICAL, it can also be rewarding—and even exciting—to play an active role in something that has the potential to pay dividends for future generations. As medicine becomes more personalized, it's increasingly important that we continue to build a pool of interested participants.

If you've been interested in participating in clinical trials, but weren't sure where to start, read on!

TALK TO YOUR HEALTHCARE PROVIDER

Patients and doctors are partners in care and must work together to make decisions that meet each patient's needs. For doctors, that means providing information to patients about their diagnoses and possible treatments in a way that patients and family members can understand. For patients and family, that means telling doctors what's important to them and asking questions to ensure they fully understand. When they work together, patients and doctors can make the best possible, personalized plan.

Clinical trials should be considered when discussing treatment choices. Whether it's initial treatment or later treatments in the disease journey, a conversation about clinical trials is appropriate to have at any time.

KNOW THE LINGO

- **Recruitment -** Recruitment is the process of identifying potential subjects to participate in the trial. It also involves screening potential subjects to determine whether a subject meets the inclusion/ exclusion criteria for the study, including any procedures necessary to get the information needed to make that determination.
- **Informed consent -** Before you agree to participate in a clinical trial, you will be taken through the informed consent process. This process gives you the opportunity to obtain information about the study, including the risks and benefits of participation and ask questions. By signing the informed consent, you decide to join the study. Participation in a clinical trial is always voluntary and patients can leave the study at any time.
- **Study "arms" -** An arm of a clinical trial is a group of patients receiving a specific treatment (or no treatment). Randomized trials assign randomly-selected groups of patients to different therapies to compare their medical outcomes.
- **Placebo-controlled trials:** This type of trials compare the clinical outcomes in the arm receiving the study drug or procedure to the study arm in which participants receive placebo. Placebo is a substance or procedure with no therapeutic effect. This is done because there might be a psychological benefit affecting clinical outcomes, when participants think they are receiving an effective treatment.
- **Background treatment:** Many trials allow the participants to continue their current medications that are routinely taken as standard of care for a condition. These medications are called background treatment.

ASK QUESTIONS

By asking questions, participants gain a better understanding of the trial's purpose, procedures, potential risks, and benefits.

- What is the purpose of the study?
- Who is sponsoring the study?
- Who is participating in the study?
- What are the eligibility requirements?
- How long will the trial last?
- What do researchers already know about the drug and what other studies have been done?
- Where is the study being conducted? Multiple sites?
- Will I be permitted to continue my current treatment for the condition (i.e., what is the permitted background treatment)?
- Does the study involve a placebo and if so, what are my chances of getting a placebo?
- What are potential side effects of the study drug?
- What kinds of tests and procedures are involved?
- Will I be reimbursed for any out-of-pocket expenses?
- How will I know if the treatment is working?
- What happens if I quit the study?
- What if I get the placebo but need the actual drug?
- How much of my time will this take?
- How will this affect my daily life?

CHECK THE FOUNDATION WEBSITE

Last year, the Foundation partnered with Carebox to launch a new experience optimized for scleroderma clinical trials. The new web application gives individuals living with scleroderma, caregivers and healthcare professionals an easy and effective way to search and match to scleroderma clinical trials.

Individuals can complete a short six-question questionnaire about their condition and then instantly see which clinical trials are potentially relevant for them. They can then get connected to a trial site for next steps.

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). Applying its human-supervised AI, Carebox converts the unstructured text in ClinicalTrials.gov that describes eligibility criteria for enrollment into a searchable index of clinical criteria for matching with patient characteristics.

Access to the new web application is available from the Foundation website at: **scleroderma.org/find-a-clinical-trial.**

carebox

STREAMING AWARENESS ON TWITCH

THROUGHOUT THE MONTH OF JUNE, we shared stories and highlighted the unique nature of every individual's journey with scleroderma. One member of our community was truly a pioneer and found a unique way to spread awareness and encourage giving to support the Foundation's patient services and research programs.

Lyss was diagnosed with linear morphea at a young age. Growing up, she didn't understand scleroderma and struggled to find a safe space for herself at school.

"I was bullied in school for the way I look," Lyss said. "I felt so isolated and alone it caused me to fall into depression at a very young age."

She persevered with the help of her family.

"It was the strength from my Grandma and my mother that taught me to be resilient," Lyss said. "Now that I am older, I am glad that it happened to me because it made me strong. It is part of me and will always be. Living with linear scleroderma has taught me to express myself and I learned to truly love myself."

Now, at 27 years old, Lyss has formed a community of her own on Twitch, one of the world's most popular video streaming platforms, especially among gamers.

"I have a growing community of 4,153 followers on Twitch. My community is so important to me," Lyss said. "I strive to cultivate a community where no one feels isolated or overlooked."

This year, Lyss used her platform to spread awareness about scleroderma and the National Scleroderma Foundation and became the first person in the Foundation's history to fundraise on Twitch.

"This was the first fundraiser I have hosted on my platform," Lyss said. "It means the world to me to be able to raise money for the National Scleroderma Foundation. It makes me happy knowing that I could be helping a little girl just like me growing up."

> “IT MAKES ME HAPPY KNOWING THAT I COULD BE HELPING A LITTLE GIRL JUST LIKE ME GROWING UP.”

Lyss hopes others will use their platform to spread awareness about causes that matter to them.

"To anyone out there who wants to fundraise. I implore you to do it. Make a difference for your community. Educate others about your condition. During this fundraiser I have fostered a deeper connection with my Twitch community. Sharing my story made others feel comfortable to share their own. I realized that I have WARRIORS in my community. I am so thankful for them. I see them and I think they are brilliant. I want them to know I could not have crafted this space without them."

Lyss welcomes you to join her community on Twitch.

"I do offer a safe space in my community if you are looking for a community who thrives on uplifting each other or gaming you can find us here https://www.twitch.tv/saelysss."

https://www.twitch.tv/saelysss

Scleroderma ★ Hope Society

Hope

JOINING THE SCLERODERMA HOPE SOCIETY is an opportunity for 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, we thank you.

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

Jean Martinho, JD
Senior Director, Development
jmartinho@scleroderma.org
(978) 624-4085

THIRD PARTY FUNDRAISERS

A third-party fundraiser is a unique way to contribute to the Foundation's mission of research, education, and support while spreading awareness in your community. When hosting a third-party fundraising event, individuals invite their family, friends and peers to events with proceeds going to the National Scleroderma Foundation.

Have some fun! Host a bowling tournament, partner with a local restaurant for a give-back night or have your supporters sponsor a mile of run. The ideas are limitless.

Create awareness! Hosting a third-party fundraiser provides others with information about the National Scleroderma Foundation, how they can get involved, and how to get resources.

Give back! The National Scleroderma Foundation appreciates your support!

Ready to start your own fundraiser or need help getting started?
Email specialevents@scleroderma.org for more information.

8TH SYSTEMIC SCLEROSIS PATIENT WORLD CONGRESS

Monica Ramirez

SINCE ITS INCEPTION IN 2010, the Systemic Sclerosis Patient World Congress has become a beacon of hope and empowerment for scleroderma patients worldwide.

IN MARCH, I had the profound privilege of attending the 8th Systemic Sclerosis Patient World Congress, an event masterfully organized by FESCA (Federation of European Scleroderma Associations) in partnership with the World Scleroderma Foundation. Held in the enchanting city of Prague, a UNESCO World Heritage site, this congress offered an inspiring and culturally rich backdrop to our gathering, adding to the history and impact of this event on the global scleroderma community.

Since its inception in 2010, the Systemic Sclerosis Patient World Congress has become a beacon of hope and empowerment for scleroderma patients worldwide. This revered platform is dedicated to patient education, networking, capacity building, and the exchange of ideas and experiences. It underscores the crucial role that every individual—patient, physician, or researcher—plays in fighting systemic sclerosis.

This year's program, meticulously designed by and for scleroderma patients, featured presentations from renowned professionals and passionate patient advocates. The congress fostered an open and friendly environment, encouraging active participation and rich discussions.

In a time of significant advancements in systemic sclerosis research and treatment, the congress stood out as a global hub of knowledge and collaboration. With translations available in Spanish, Czech, Hungarian, and German, the event transcended linguistic barriers and embraced a diverse international audience. More than just an educational forum, the congress cultivated a sense of global community, where patients, physicians, and researchers shared insights and experiences, highlighting the global impact of our collective efforts.

Plenary sessions were graced by the expertise of prominent healthcare professionals from the United States. Monique Hinchcliff, MD, MS, shared updates on interstitial lung disease; James Seibold, MD, explored whether systemic sclerosis is one disease or several; Dinesh Khanna, MD, and Elizabeth Volkmann, MD, MS, examined the intestinal tract and microbiome in systemic sclerosis; Janet Poole, PhD, OTR/L, emphasized the importance of staying active; Elana Berstein, MD, discussed advances in transplants; and Maureen Mayes, MD, MPH, presented clinical cases. These sessions enriched our understanding and gave us hope and direction in our journey toward finding a cure.

Beyond the formal sessions, the congress provided invaluable opportunities to connect with leaders of patient associations, such as Alfonso Sánchez from the Spanish Association of Scleroderma, Catarina Leite from the Portuguese Association of Scleroderma Patients, Ilaria Galetti from the Italian Group Fighting Scleroderma, and Sue Farrington from Scleroderma and Raynaud's UK. These organizations play a crucial role in supporting those of us living with scleroderma, helping us understand our daily needs and challenges, and promoting awareness of this rare, degenerative, and debilitating disease. Informal conversations during breaks and social gatherings fostered new friendships and collaborations, amplifying the spirit of unity and shared purpose.

A highlight of the congress was an impressive art exhibition by photographer Lenka Laňková, organized by the Revma League of the Czech Republic under the leadership of its founder, Michaela Linková. This exhibition showcased powerful images of women with scleroderma, capturing the challenges they face and the strength they embody. The artwork provided an accessible and moving way to initiate conversations about scleroderma, highlighting the resilience of those living with this disease.

The 8th Systemic Sclerosis Patient World Congress was a testament to the power of knowledge, community, and hope. It revitalized our sense of belonging within a supportive network and reinforced our commitment to mutual assistance and the pursuit of a better quality of life for all those affected by scleroderma.

As we look ahead to the future, we eagerly anticipate the next congress in Athens, Greece, in 2026. It will be another opportunity to reconnect with old friends, make new ones, and continue our journey of learning and advocacy. I invite all those interested to join us for this unparalleled experience, where we can continue to share, learn, and advance together in our fight against this challenging disease.

EULAR Task Force Develops Recommendations for Non-Pharmacological Management of Scleroderma

Janet Poole, PhD, OTR/L

The European Alliance of Associations for Rheumatology (EULAR) is an organization dedicated to improving treatment, prevention and management of persons with musculoskeletal diseases (https://www.eular.org). EULAR is similar to the American College of Rheumatology and Association of Rheumatology Professionals in the United States; both organizations develop guidelines and recommendations for health professionals and patients about management of different rheumatic diseases.

I was invited to be part of a EULAR task force, that included health professionals and patients, to develop recommendations for non-pharmacological (non-drug) management of systemic lupus erythematosus (SLE, lupus) and systemic sclerosis (SSc). The task force systematically reviewed the research studies on self-management, patient education, physical exercise, behavior and lifestyle interventions, cognitive behavioral therapy, psychological interventions, relaxation or yoga, hand and foot exercises, mouth exercises, oral hygiene, assistive devices, modalities (paraffin, massage, etc), wound care and ulcer management.

After the research studies were reviewed in terms of how the studies were done and the findings, the task force developed specific recommendations for both SSc and SLE. Here, I will discuss the recommendations for systemic sclerosis. A more comprehensive version of the recommendations is available by using the QR code below.

FOR MORE INFORMATION ABOUT THE EULAR RECOMMENDATIONS FOR NON-DRUG MANAGEMENT OF SCLERODERMA VISIT:

https://scleroderma.org/EULARrecommendations

What were the recommendations for people living with systemic sclerosis?

- People with systemic sclerosis should be offered patient education and self-management support which can help people learn how to manage their disease and symptoms.
- Patient education and self-management should be considered to improve hand function, mouth outcomes, such as mouth opening, and performances of activities of daily living.
- Face and mouth, hand, and aerobic and resistive exercises should be considered to improve mouth opening, hand function and physical capacity. Stretching exercises to increase mouth opening and joint motion and function in the hands were the main interventions that were reviewed along with exercise interventions to improve aerobic capacity and muscle endurance. The research showed that mouth stretching exercise and physical activity increased strength and reduces fatigue. People who have cardiopulmonary involvement may want to check with their health care providers before starting physical activity programs and that physical activity programs should be designed specifically for each person.
- For people with SSc who have puffy hands, manual lymph drainage could be considered to improved hand function.
- In addition, although the scientific evidence was not strong, the task force recommended that people with SSc stop smoking and avoid cold temperatures and sudden changes in temperature especially when one has Raynaud's phenomenon.

The guidelines outline additional areas of research, including skin and wound management and diet. They also discuss the need for education for healthcare professionals on patient education, self-management and other exercise programs for patients with systemic sclerosis.

Non-pharmacological interventions are underutilized in the management of SSc; thus, the education section of the guidelines recommend training health care providers and patients to facilitate referrals to disciplines that provide non-pharmacological interventions such as physical and occupational therapists, nutritionists, psychologists, social workers and provide resources that offer self-management and education programs tailored for people with SSc.

Janet Poole, PhD, OTR/L is a professor, division chief and director of the Occupational Therapy Graduate Program at the University of New Mexico. She also serves on the National Scleroderma Foundation Medical & Scientific Advisory Board.

FLORIDA & PUERTO RICO CHAPTER:

UNITING FOR SCLERODERMA AWARENESS

Lorraine Biaggi

Scleroderma Awareness Month was remarkable for the Florida and Puerto Rico Chapter of the National Scleroderma Foundation.

Our chapter proudly launched the inaugural TOSS (Take Out Scleroderma Soon) event, a heartfelt initiative spearheaded by Advisory Committee member Noel Weinstock. Inspired by a historic 1978 fundraiser in New York, this innovative take-out dinner brought together friends and neighbors to champion Scleroderma Awareness Month—uniting our community while raising substantial funds for vital research and support services.

We also celebrated alongside the Miami Marlins, blending baseball excitement with fundraising initiatives. Visits to Tampa and Puerto Rico were particularly impactful, fostering deeper connections with community members and healthcare providers. These efforts culminated in a government proclamation declaring June as Scleroderma Awareness Month and June 29 as World Scleroderma Day in Puerto Rico.

Other proclamations included the cities of Orlando, Key West, Boynton Beach, Lauderhill, and Miami-Dade County. Our local communities illuminated landmarks like the Bank of America Las Olas, Miami-Dade Courthouse, Kaseya Center, and Lake Eola Fountain in teal on World Scleroderma Day, symbolizing hope and solidarity.

This Scleroderma Awareness Month showcased the profound impact of community-driven initiatives, thanks to the unwavering dedication of leaders like Janett Acevedo, Desiree Jame, Marty Lehman, Monica Ramirez, and Noel Weinstock, among others, and partners such as Raccoon Coffee and Café Crème that joined our inaugural Coffee for a Cure campaign.

We are excited for all that lies ahead and welcome everyone in our chapter to connect with us at https://scleroderma.org/FloridaPRChapter/ and join our efforts our efforts to fundraise and create awareness.

El Mes de Concientización sobre la Esclerodermia fue extraordinario para el Capítulo de Florida y Puerto Rico de la Fundación Nacional de Esclerodermia.

Nuestro capítulo se enorgulleció de lanzar el evento inaugural de TOSS (Take Out Scleroderma Soon), una admirable iniciativa encabezada por Noel Weinstock, miembro del Comité de Asesores del Capítulo. El evento, inspirado en una histórica recaudación de fondos realizada en 1978 en Nueva York, reunió a amigos y vecinos en un innovador formato alrededor de comida para llevar, en favor del Mes de Concientización sobre la Esclerodermia, uniendo a nuestra comunidad y al mismo tiempo recaudando fondos sustanciales, destinados a la investigación y servicios de apoyo vitales para nuestra comunidad.

También celebramos junto a los Miami Marlins, combinando la emoción del béisbol con iniciativas de recaudación de fondos. Visitas a Tampa y Puerto Rico fueron particularmente trascendentes, fomentando conexiones más profundas con miembros de la comunidad y proveedores de atención médica. Estos esfuerzos culminaron con una proclama emitida por el gobierno del Estado Libre Asociado de Puerto Rico, declarando junio como el Mes de Concientización sobre la Esclerodermia y el 29 de junio como el Día Mundial de la Esclerodermia en la isla.

Otras proclamaciones incluyeron las ciudades de Orlando, Key West, Boynton Beach, Lauderhill y el condado de Miami-Dade. Nuestras comunidades locales iluminaron lugares emblemáticos como el Bank of America Las Olas, el Palacio de Justicia de Miami-Dade, el Kaseya Center y la Fuente del Lago Eola en color verde azulado celebrando el Día Mundial de la Esclerodermia.

Este Mes de Concientización sobre la Esclerodermia mostró el profundo impacto de las iniciativas impulsadas por la comunidad, y agradecemos la dedicación inquebrantable de líderes como Desiree James, Janett Acevedo, Marty Lehman, Mónica Ramírez y Noel Weinstock, entre otros, y socios como Raccoon Coffee y Café Crème, quienes se unieron a nuestra campaña inaugural Coffee for a Cure (Café para una Cura).

Estamos emocionados por todo lo que nos depara el futuro e invitamos a todos los miembros de nuestro capítulo para que se conecten con nosotros en https://scleroderma.org/FloridaPRChapter/ uniéndose a nuestros esfuerzos para recaudar fondos y crear conciencia.

DAY-LONG CELEBRATION MARKS INAUGURAL EVENT FOR WEST COAST CHAPTER

ON MAY 18, the National Scleroderma Foundation celebrated the inaugural *Stepping Out to Cure Scleroderma* walk in Napa, California. The walk hosted 140 people and raised more than $36,000 for the Foundation.

To make the weekend even more special, Ashley Barron, the Foundation's celebrity ambassador, attended the walk with her entire family. She hosted a meet and greet featuring special teal macarons from Bouchon Bakery and then played a benefit concert at JaM Cellars Ballroom.

This was an exciting debut event for the Foundation's newly named West Coast Chapter. Members of the chapter are already hard at work spreading awareness, creating amazing connections and raising funds for scleroderma research.

"This was such a special day for our community in northern California to come together, and spend the day together, from the walk in the morning, to our mid-day meet-and-greet, culminating with an amazing benefit concert with Ashley Barron. We had the opportunity to make real connections, and I know I came away inspired for the future," said Mary J. Wheatley, CEO of the National Scleroderma Foundation.

Rhonda Costa, Heartland Chapter Chair and long-time Foundation volunteer, is originally from the Bay Area. She was especially excited to be part of this event in California.

"It was great to share the experience with my family and friends and to meet new scleroderma warriors and to reconnect with other warriors and their families. It was a day I will never forget!"

For the Foundation's celebrity ambassador, Ashley Barron, the special event was a homecoming. As another California native, Ashley made the day very special for everyone.

"I want to first thank the Foundation for having me be a part of such a special event," Ashley said. "Thank you to all the volunteers and everyone who came out and supported a cause that means so much to me. I know my mom was looking down and smiling during the whole event. My band and I had a great time getting to perform for everyone and watching them dance the night away."

The Foundation is so excited to see our West Coast Chapter and its efforts come to life and grow to support the scleroderma community in California. We cannot wait to see what they do next!

AN EVENING OF Hope

National Scleroderma Foundation

MEREDITH A. Cowden FOUNDATION

ON APRIL 30, the National Scleroderma Foundation and Meredith A. Cowden Foundation hosted medical and scientific leaders in GVHD and scleroderma cellular therapies for *An Evening of Hope.* The event was held in conjunction with the NIH Workshop on Immunotherapies and Cellular Therapies for Systemic Sclerosis and Chronic GVHD.

Dr. John Varga, one of the Workshop Co-Chairs, opened the evening by sharing the scientific community's enthusiasm for potentially transformative cellular therapies. He shared his gratitude for the speakers and attendees who shared their important work and ideas during the workshop earlier that day, and stressed the importance of partnering with patients and patient organizations to ensure patients are included in the research and development process from the very beginning.

Meredith Cowden and Dr. Steven Pavletic hosted a discussion on the power of collaboration. Meredith shared her journey living with Chronic GVHD, and how she found her voice to become her own best advocate, and a passionate patient advocate for others living with cGVHD. Dr. Steven Pavletic, shared the importance of collaborating with patients in the clinic, and within the broader community. He also shared his journey as a clinician and researcher, and the evolution of the GVHD Alliance. Both Meredith and Steven noted the importance of increasing awareness and early diagnosis. Meredith also stressed the importance of relationship-building with your care team, which leads to more open discussion around treatment options and your overall health outcomes and quality of life.

We were so fortunate to have Dr. John O'Shea as our Keynote Speaker for the evening. Dr. O'Shea made a compelling case for hope for the future when it comes to cross-science discoveries, and cellular therapies. He gave a brief history of targeted therapies over the last forty years, with a specific focus on autoimmune disease, immune response and autoimmunity, highlighting throughout the role of collaboration with patients and the inspiration they provided to find better solutions.

A key theme of the evening was the importance of collaboration, both with the patient and nonprofit communities, as well as within the medical and scientific communities. What an amazing opportunity to bring together thought leaders around such a compelling topic: HOPE.

ABOUT THE WORKSHOP:

Chronic graft-versus-host disease (cGVHD) and systemic sclerosis (SSc) are life-threatening immune-mediated chronic diseases characterized by systemic inflammation, immune dysregulation, damage to target organs, and tissue fibrosis. Despite substantial advances in understanding disease biology over the last two decades, there has been little progress in discovering effective therapies, while prevention and cure remain elusive.

To identify new ways to address these challenges, NCI and NIAMS organized a one and half-day workshop focusing on Immunotherapies and cellular therapies toward restoring immune homeostasis and mitigating the often debilitating fibrosis that accompanies cGVHD and SSc. The meeting was held April 30-May 1, 2024, at the NIH Bethesda campus.

Workshop presenters discussed current concepts in the basic science of fibrosis, identified commonalities and distinctions between cGVHD and SSc, and provided updates and future directions in the latest therapeutic advances including their rationale and interface with precision medicine.

This setting provided a unique opportunity to understand better mechanisms that contribute to both cGVHD and SSc, the biology of and therapeutic approaches to preventing and treating fibrosis, and to develop and foster collaborations across the fields, including exploring in vivo models of human disease. Presentations focused on basic and translational science with reference to and in the context of the latest clinical trials research.

This was intentional as the organizers felt there are lessons to be learned by engaging investigators from these two fields that may lead to studies of pathogenesis and outcomes that have some similarities but also disease-specific differences.

The presentations and panels led to lively discussions, Q&A sessions and new ideas and collaborations that will help energize the field, foster dialogue, and guide future efforts.

The Workshop was sponsored by the National Cancer Institute, the National Institute for Arthritis and Musculoskeletal and Skin Diseases, National Scleroderma Foundation, Meredith A. Cowden Foundation and Scleroderma Research Foundation.

NATIONAL SCLERODERMA FOUNDATION

VIRTUAL CONNECTIONS FOR SUPPORT

Bereavement

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

Bilingual (Spanish)

Second Saturday of the Month
11:00 a.m. ET
Email support@scleroderma.org
for more information.

Black, Indigenous, and People of Color (BIPOC)

Email supportgroups@scleroderma.org
for more information.

Caregivers

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

General Patient Support

Starting Fall 2024
Email support@scleroderma.org
for more information

LGTBQ+

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

Localized Adults & Parents

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

Newly Diagnosed

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

Young Adults Seeking Connection (SYNC)

Ages 18-42
Email alippincott@scleroderma.org or
ttolzmann@scleroderma.org
for more information.

20% for Males: Living with Scleroderma

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

National
Scleroderma
Foundation

In addition to the national support groups above, we have a variety of in-person and virtual chapter support groups. See the full schedule of support group meetings at scleroderma.org/calendar.

National
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Save the Date

2025 National Scleroderma Conference

St. Louis, Missouri
July 18-20, 2025