2022 National Scleroderma Foundation

AWARDS

ANNUAL AWARDS
Announcing the 2022 National & Chapter Leadership Awards

NEW SCLERODERMA CLINIC ESTABLISHED AT VANDERBILT UNIVERSITY

SCLERODERMA & ILD:
Practical Tips on the Diagnosis & Management of Systemic Sclerosis-Associated Interstitial Lung Disease

The magazine exclusively for Members of the National Scleroderma Foundation.
Are You Searching for Brighter Days Living With Systemic Sclerosis?

The BEACON Study is evaluating the effectiveness, safety and tolerability of an investigational medicine that may slow disease progression in participants with diffuse cutaneous systemic sclerosis (dcSSc). The total length of participation is approximately 60 weeks.

There is no cost to you or your insurance for any study treatment, visit or procedure related to the study and not part of your normal routine care. You may be reimbursed for some study-related expenses, including travel to and from the study site.

Eligible participants must:
- Be between 18 and 75 years of age
- Have a current diagnosis of dcSSc
- Not be diagnosed with sine scleroderma, limited cutaneous systemic sclerosis, scleroderma renal crisis or other autoimmune connective tissue diseases except for fibromyalgia, scleroderma-associated myopathy and secondary Sjögren’s syndrome
- Have skin involvement near the elbow or knee
- Have had less than three years pass since first experiencing systemic sclerosis symptoms, other than Raynaud’s phenomenon

There are additional eligibility criteria, which the study team will discuss with participants.

Learn more about the study at BEACONStudyforSSc.com
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ABOUT US

HISTORY: The 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 network.

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THE UNBELIEVABLE IMPACT OF VOLUNTEERISM

SIXTY-FIVE YEARS AGO,
Martin Luther King, Jr. said, “Life’s most persistent and urgent question is, what are you doing for others?” At the Foundation, we know that our greatest strengths come from the people who make up our organization. From our support group leaders to walk volunteers to chapter advisory committee members and board members, we heavily rely on the time and talents of our volunteers to realize our mission and vision. When volunteering with the Foundation, you are contributing directly to our work to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families, and their support network.

Through volunteerism, we see the best of our culture in action. Our volunteers share a common commitment to our mission and the fight against this disease. They take care as a team to build connections and foster trust with each other. Their grass-roots efforts are led with integrity while stewarding a community in which everyone can share openly and engage authentically. I have found that through working together we best provide a full spectrum of programs and services to choose from for everyone at all stages of their scleroderma journey. If you would like to help us, there are many opportunities to contribute your time, energy, and talents. Please let us know by reaching out at info@scleroderma.org.

In this issue of Voice, we are highlighting the recipients of our annual volunteer awards. On behalf of the National Board of Directors and the staff at the Foundation, we recognize the importance of acknowledging the outstanding achievements and commitments of our scleroderma community. This year, we received 80 nominations, and reviewers cast 250 votes for 13 awards. We recognized our awardees at this year’s Annual Leadership Day held in Boston, Massachusetts. It is our Foundation’s honor to be able to personally celebrate this community of helpers.

At the Annual Leadership Day awards ceremony, the Foundation’s highest honor, The Lifetime Achievement Award was bestowed to Cos and Ronni Mallozzi. It is awarded to individuals who have given extraordinary service to the organization over an extended period of time. Over their 30 years with the Foundation, the Mallozzi’s have made such an incredibly positive impact on the scleroderma community and National Scleroderma Foundation through their dedication and commitment. In all facets, Cos & Ronni Mallozzi certainly embody the true meaning of volunteerism through their selfless service for the greater good of our community.

You can find more information on Cos & Ronni and all our awardees beginning on page 6. Congratulations to all award recipients and nominees! Their stories and contributions are inspiring. These volunteers and the many others within our community represent all the incredible and passionate people supporting our critical mission work.

As each of you supports the Foundation’s advances in our important work, thank you for everything you have done, and will continue to do, truly making a difference in our fight against scleroderma.

Kevin Boyanowski
Chair, Board of Directors

P.S. A personal message of congratulations to my wife, Mariann, who is being honored by her peers as National Volunteer of the Year.
On October 1, 2022, The National Scleroderma Foundation announced its 2022 National and Chapter Volunteer Awards at its annual Leadership Day. 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 and education to people with scleroderma. This year, the Foundation received 80 nominations, and reviewers cast 250 votes for 13 awards. The Volunteer Awards Recognition Event was hosted by David Leader DMD, MPH, Director of Tufts University School of Dental DMD/MPH Dual Degree Program, and former recipient of the Doctor of the Year Award. “It is my honor to celebrate these exceptional volunteers, their inspirational stories, and contributions,” shared Dr. Dave Leader.

Congratulations to this year’s award recipients.
**The Outstanding Educational Program**
is awarded to an individual, group, or chapter that has maximized available resources within the community to provide individuals living with scleroderma with an excellent educational experience.

This year, the Black, Indigenous, and People of Color (BIPOC) Support Group was awarded for its national efforts to support all races that may face equality issues with scleroderma.

**The Outstanding Patient Support Award**
is awarded to an individual who has continuously supported, educated, and uplifted their community. This was awarded to Monica Ramirez, for her steadfast commitment to supporting our Spanish-speaking community through a bilingual support group and international conference.

**The Outstanding Chapter Awareness Award**
is awarded to a Chapter that consistently keeps awareness and advocacy as integral parts of chapter operations. This was awarded to the Ohio Chapter, as the Ohio Chapter advisory committee, volunteers and executive director have ensured it utilizes all media outlets to spread awareness to those it serves.

**The Support Group Volunteer of the Year**
is awarded to a support group leader who leads by example and encourages others to engage in their community. This year, Michael Bessert was awarded for co-founding the Men’s 20% Support Group and for being committed and dedicated to ensuring that men have their own place to gather and discuss scleroderma.

**The Individual Fundraiser of the Year Award**
is 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. This year, April Lehmann was awarded for raising more than $25,000 over the past three years, despite a national pandemic.
**THE ADVOCATE OF THE YEAR AWARD**
is 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. This was awarded to **Evamarie Cole**, for her commitment to advocacy and leadership this past year, both at the local chapter and national level.

**THE DOCTOR OF THE YEAR AWARD**
is awarded to the physician whose dedication has improved the lives of thousands of people living with scleroderma, as well as demonstrated exceptional skills in clinical practice and patient education while maintaining the mission, vision, and values of the Foundation. This year, **Dr. Elizabeth Volkmann** was awarded Doctor of the Year. Dr. Elizabeth Volkmann is a star in the field of scleroderma. She is the Director of the UCLA Scleroderma Program and the Founder and Co-Director of the UCLA Connective Tissue Disease-Related Interstitial Lung Disease Program. She is internationally recognized as an expert and leader in pulmonary and gastrointestinal complications of systemic sclerosis, as demonstrated by her national and international speaking invitations and participation and leadership in national and international research projects. She has received NIH support through a K23 award and has published more than 80 publications. Dr. Volkmann has established herself as an international expert in scleroderma, focusing primarily on its pulmonary and gastrointestinal complications.

**THE CHAPTER OF THE YEAR**
is awarded to overall excellence in advancing the mission of the Foundation in the areas of support, education, and research by a chapter. This year, the **Rocky Mountain Chapter** was awarded for being a beacon of strength and hope for those living in Colorado during the pandemic.
The **Philanthropist of the Year Award** is awarded to an individual who has made an outstanding contribution to fundraising and shows consistent excellence through their actions and leadership. This year, **Greg Lurvey** was awarded for establishing the Debra Lurvey Memorial Research Grant - a transformational endowment gift to honor his late wife, Debra.

The **Chapter Volunteer of the Year Award** is awarded to an individual who leads by example and encourages others to engage in their local and regional community. This year, **Jane Ladas** was awarded for serving as the New England Chapter Board President for years, while also filling in many staffing gaps in her role, particularly during the COVID-19 pandemic when there were changes and there was only Jane left to do the work.

The **National Volunteer of the Year Award** is awarded to an individual who leads by example and encourages others to engage in their community. This year, **Mariann Boyanowski** was awarded for her support of the Ohio Chapter since 2001. She is a beacon of light through her volunteerism whether managing the 24-hour-a-day Scleroderma Hot Line, leading the Stepping Out to Cure Scleroderma Boardman walk, being a support group leader in Brecksville, Ohio, securing proclamations, holding leadership positions for the chapter, or any other area in which the chapter may need help.

The **Lifetime Achievement Award** is the Foundation’s highest honor and is awarded to individuals who have given extraordinary service to the organization. This year, **Cos and Ronni Mallozzi** were awarded the Lifetime Achievement Award for their 30+ years of service and dedication to the Foundation. Both Cos and Ronni have served in various leadership roles on behalf of the Foundation over the years, with Cos most recently serving as Chair of the National Board of Directors. Ronni started the Foundation’s first “scleroderma chat” on AOL in the 1990s and has been a beacon of hope for those living with scleroderma in New York and Florida, and across the country.
How can Yoga assist a person living with scleroderma?

Yoga is a mind-body practice that employs several strategies including physical postures, regulated breathing, and meditation to treat overall physical and mental distress and support health. Yoga has been found to alleviate symptoms of physical and psychosocial disorders by regulating the immune system, inflammation, metabolism, electrophysiology, and relaxation response. As many of the symptoms in scleroderma affect these systems Yoga could help patients manage their symptoms. However, Yoga is under-studied in scleroderma.

While Yoga postures are generally perceived to be for specific body types Gentle Yoga (GY) postures can be done while seated on a chair (sometimes called “Chair Yoga”) and have been shown to benefit people with chronic conditions. While most traditional Yoga postures can be practiced by anyone, people with scleroderma often have limited physical movement and can be prone to injury. Gentle Yoga postures are physically much easier to do than traditional Yoga and, thus, may be more accessible for scleroderma patients with musculoskeletal and other impairments.

Regulated breathing or Yogic breathing (YB) is typically done in conjunction with Yoga postures and activates the parasympathetic nervous system to produce a relaxation response among participants. Studies using YB in various patient groups have shown QoL improvements. YB increases abdominal/diaphragmatic breathing, vagal tone, and parasympathetic dominance. Conversely, YB decreases sympathetic discharges and improves cognitive function and relaxation response. YB is shown to help individuals manage stress, effectively reduce anxiety and depression, and improve perceived QoL.

We have published data from a proof-of-concept trial showing that YB stimulates alterations that reflect associated reductions in inflammatory biomarkers. As the Yogic breathing exercises stimulate salivary secretion, and biochemicals are stimulated within the saliva, it is a possibility that inflammation and dysregulation in the immune responses could be reduced by Yogic breathing. We have been providing these easy-to-learn exercises for the past six years in several scleroderma patient education conferences at the national and regional levels. Participants from those meetings have expressed overwhelming interest to continue the practice.

Is more research being conducted on scleroderma and Yoga-related benefits?

Yes, we have an active clinical trial to study gentle Yoga and Yoga breathing in scleroderma at the Medical University of South Carolina.

This research study is to:
- Test the feasibility of a scleroderma self-management intervention that combines Gentle Yoga postures and Yoga Breathing (GYYB) as adjunctive treatment with standard care.
- Explore the effectiveness of GYYB for improving health-related quality-of-life (QoL) outcomes.
- Provide information about acceptance and adoption of a GYYB intervention by scleroderma patients of African ancestry and non-Hispanic white scleroderma patients.
- Investigate, for the first time in scleroderma patients, the relationship between GYYB and inflammatory biomarker changes which may provide insight into biological changes associated with improved health-related QoL outcomes.
The following are frequently asked questions about gastrointestinal (GI) related symptoms found in people with scleroderma. Thank you to Dr. Zsuzsanna H. McMahan, M.D., M.H.S., Assistant Professor of Medicine, Johns Hopkins Scleroderma Center, and Dinesh Khanna, M.D., M.Sc., Professor of Medicine, University of Michigan for taking the time to answer them for the National Scleroderma Foundation.

Q: I began having a lot of acid reflux a few months ago. I went to my doctor and was diagnosed with scleroderma. Why am I having reflux? What can I do to ease it?

A: Reflux in scleroderma can be a consequence of different complications of the disease. First, the motility of the gastrointestinal tract is often not normal in scleroderma. As a result, delays in the emptying of the stomach can cause food to reflux from the stomach into the esophagus. The second complication of scleroderma is related to hypotension (low pressures) in the lower esophageal sphincter (the one-way valve between the esophagus and stomach). When this valve is incompetent, it allows gastric acid and food to enter the esophagus and irritate the tissue.

There are a variety of interventions that can be initiated to ease acid reflux. Modification of dietary intake or avoidance of aggravating foods can help. Some of these foods and beverages include chocolate, citrus fruits/fruit juices, tomatoes, spicy food, fatty meals, and caffeine. It may also help to consume small meals more frequently, quit smoking, and avoid alcohol. Elevating the head of the bed, sleeping in the left decubitus, and avoiding food within three to four hours of bed can also help. Weight loss in patients who are overweight can also help with the management of symptoms.

Medications play a role in the management of acid reflux as well. Medications that block the histamine-2 receptor (e.g. ranitidine), proton pump inhibitors (e.g. omeprazole), and barriers (e.g. sulfacrate) or combinations of these medications may all be utilized to supplement lifestyle modification in the management of acid reflux. More information is available on the Scleroderma Foundation website on gastrointestinal tract involvement, written by Dinesh Khanna (scleroderma.org/resources-center/Eatingwell).

Q: I was diagnosed with scleroderma six years ago and one of my symptoms is that I often have diarrhea. I was speaking with a member of the support group that I am in and she said that she is often constipated. Why are we having such different symptoms with the same disease?

A: Patients with scleroderma may have different regions of the GI tract affected by dysmotility (i.e. trouble with food transit). For example, some have involvement of the large bowel or colon, others have involvement of the small bowel, and others have involvement in both. Depending on the GI region(s) affected by scleroderma, different symptoms can occur. In patients with slow transit of food in the small bowel, small bowel bacterial overgrowth may occur and lead to malabsorption of food and diarrhea. On the other hand, constipation may predominate in patients with significant involvement of the colon. Some people can develop overflow diarrhea—a symptom that develops when there is significantly impacted stool in the large bowel. Simple X-rays of your large bowel can identify this problem.

Q: I have been losing weight since I began having gastrointestinal symptoms with my scleroderma. I try very hard to eat things that agree with me and nothing seems to help me gain weight. Why is this happening? What can I do?

A: There are multiple reasons for weight loss in scleroderma. We will try to address these. This may be due to reduced size of the mouth opening and dry mouth (Sicca syndrome). Or, the ability of the gastrointestinal tract to transport food is dependent on compression and forward propulsion of a food bolus by smooth muscle. The smooth muscle lining the gut in scleroderma can become very weak, and this may interfere with the normal transport and digestion of food. Weak smooth muscle can cause trouble with food transport in the esophagus, where it can feel stuck. It can interfere with the ability of the stomach to accommodate the usual volume of food your stomach can hold, and cause delays in (Continued on Page 22)
When Falguni Desai noticed tingling and swelling in her fingers and toes, she knew something was awry.

Falguni went to a doctor who diagnosed her with carpal tunnel syndrome, but after six weeks of occupational therapy, she didn’t improve. Falguni could not hold her laptop in her hands, pull a door open, or shut it closed. She went back to the doctor who then diagnosed her with rheumatoid arthritis.

“I noticed I was getting slower and slower. I needed to work from home more, and I had pain everywhere. I thought I had a high pain threshold, but it was a throbbing, burning pain. I couldn’t take a shower, couldn’t wash my hair, couldn’t dry myself, couldn’t even put my socks or underwear on. I was vomiting too, and experienced a whole host of other things like fatigue...I would cry because the pain was so severe.”

Eventually, doctors did an ANA (Antinuclear Antibody) test and Falguni was correctly diagnosed with diffuse scleroderma and myositis. Unfortunately, the doctors told her her illness would just go away. But it didn’t. In December 2019, Falguni went into renal crisis.

“It didn’t make sense why they would say that to me. I had to go on medical leave, the medication caused my whole mouth to swell and my lips to blister. I even tried Chinese herbs and acupuncture, but nothing helped. I went into complete renal crisis because of constricting blood vessels and was put on dialysis on Christmas day. Going to the hospital made me realize that this wasn’t just something that was going to go away.”

Falguni had been a strong, independent, high-powered professional and didn’t understand why this was happening to her. Amid the turmoil, Falguni wondered where her scleroderma could have come from. Although there is not yet a definitive cause for scleroderma, many scientists have suggested stress and thyroid dysfunction may play a role in the onset of the disease.

“I had a lot of stress at work. I also had endometriosis and hypothyroidism, and I was on a hormone drug for 20 years. You know, we women think we’re invincible. But we have hormones and stress...We have this ‘go, go, go’ mentality, but we need to listen to our bodies.”

Today, Falguni receives monthly IVIG (Intravenous Immunoglobulin) infusions, which have allowed her skin to heal and her voice to improve. While she still visits her medical team regularly, Falguni says that she has emerged from the trauma and is steadily managing her disease. She is even an active member of a local scleroderma support group because she wants to help others by sharing what she has learned throughout her journey.

“I’ve learned that scleroderma is not me. It is something that I have. I still have bad days, but I’m here and I’m standing. This is what I would say to others: Live your life. Mask up and do what you want to do. Don’t be afraid. Don’t be pulled down. I couldn’t have said this to anyone a year ago, but I’m in a good place now. Scleroderma is your companion for life but embrace it and move forward.”
Debra Droux’s son, Alex, was diagnosed with scleroderma last year when he was 16 years old.

“Alex noticed he couldn’t open water bottles and his hands didn’t look right. The doctors did bloodwork at first, but the pediatrician didn’t know what was going on.”

After receiving a diagnosis of scleroderma and Raynaud’s from a rheumatologist, Debra’s family was quickly catapulted into a staggering series of doctor’s appointments, procedures, hospital stays, and infusions. The Droux family also faced the harsh reality that many children with scleroderma in our community experience—there was no pediatric rheumatologist nearby, so the family relied on—and still relies on—a traveling one.

“As a mom, Alex’s diagnosis was shocking,” Debra said. “It scared me, and it was so unexpected. We don’t have a history of autoimmune disorders in our family, so I’m always thinking and speculating about how this happened. Our experience taught me that scleroderma can happen to anyone at any time to any family. It doesn’t matter what your socioeconomic status is, who you are, or anything like that.”

Coincidentally, when Alex was diagnosed, Debra was in the process of applying to medical school.

“Because of Alex’s stressful journey, I didn’t know if I was going to get accepted. But I was, and I actually just started! I’m thinking of going into rheumatology because I wish I knew more about scleroderma. In the future, I hope scleroderma is something everyone knows about by word of mouth and that scleroderma research can be accelerated as much as possible because, right now, it’s still not something anyone really hears about.”

Following in his mother’s footsteps, Alex also wants to attend medical school. Although he has missed a lot of school because of his disease, Debra says that Alex has persevered with his work and doing well in school.

“Alex had to quit soccer but he still plays guitar and trumpet. I know scleroderma has affected him but, thankfully, his treatments helped his hands and he’s been managing well for the most part. Right now, as a senior in high school, he’s researching where he wants to go to college. He says he wants to go to college somewhere in Florida, where it’s warm!”

In the short time Alex and Debra have been part of the scleroderma community, they’ve both helped to raise awareness about the disease. At a local university’s health career fair, the mother-son duo handed out flyers and information about scleroderma and the Foundation. In addition, Debra is currently one of three mothers of teens with scleroderma who leads the Rocky Mountain Chapter’s Albuquerque Support Group for Teens and Parents in New Mexico.

“Our New Mexico support group is still getting off the ground. We’re planning a walk next year and other educational events...but I want people to know that the Foundation is a supportive place. I always feel supported here. It doesn’t matter who I talk to. Everyone has the same purpose—they want to raise awareness. I always feel welcomed. No family affected by scleroderma should feel alone because there is always hope and support.”

To learn more about joining a support group, please visit scleroderma.org
In September 2019, nintedanib became the first treatment approved by the U.S. Food & Drug Administration (FDA) to slow the rate of decline in pulmonary function of patients with systemic sclerosis-associated interstitial lung disease (SSc-ILD). FDA approval of tocilizumab for the same indication followed in March 2021.

As rheumatology providers, we can all agree that additional treatment options for systemic sclerosis (SSc)—especially those with FDA approval—are a welcome change to the SSc treatment landscape. However, no one-size-fits-all approach exists for the care of patients with SSc and pulmonary involvement. SSc and SSc-ILD are clinically heterogeneous, and optimal pulmonary monitoring and therapeutic strategies are not yet clearly defined.

In January 2022, Khanna et al. published a clinically relevant review on the diagnosis and treatment of SSc-ILD and proposed a clinical approach for risk stratification and therapeutic management in a clinical context. In this article, we discuss their recommendations and offer additional input from another SSc expert, Laura K. Hummers, MD, co-director, Johns Hopkins Scleroderma Center, associate professor of medicine, Division of Rheumatology, Johns Hopkins University, Baltimore.

Background
SSc is a heterogeneous autoimmune disease with the highest individual mortality of all rheumatic conditions. Over the past decade, research has focused on defining clinical subtypes of SSc to predict disease course and better tailor therapies. Clinical subtypes are stratified by degree of skin involvement (i.e., limited vs. diffuse) and autoantibody seropositivity.

Given the efficacy of angiotensin-converting enzyme inhibitors in scleroderma renal crisis, SSc-ILD is now among the leading causes of SSc-related death. The prevalence of SSc-ILD depends on multiple factors, such as screening strategy (i.e., high-resolution computed tomography [HRCT] vs. pulmonary function tests [PFTs]); however, national observational registries and international cohorts show that approximately 65% of SSc patients have or will develop SSc-ILD at some point during their disease course.

In 2006 and 2016, the results of two scleroderma lung studies changed practice patterns in SSc-ILD after demonstrating the benefits of cyclophosphamide (CYC) and mycophenolate mofetil (MMF). However, neither treatment has been FDA approved for this indication to date.

Regarding FDA-approved therapies, the Safety and Efficacy of Nintedanib in SSc (SENSCIS) trial showed the agent, an anti-fibrotic tyrosine kinase
inhibitor, slowed the rate of decline in pulmonary function in patients with SSc-ILD. Tocilizumab, an anti-interleukin 6 receptor antagonist, was studied in patients with SSc and early, diffuse cutaneous disease and elevated acute phase reactants. Although the primary end point for improvement in skin fibrosis was not met, forced vital capacity (FVC) data indicated that tocilizumab may preserve lung function in this population. A follow-up trial demonstrated that preservation of percent predicted FVC was greater with tocilizumab treatment than placebo, leading to the FDA approval.

Diagnosis & Screening of SSc-ILD
Khanna et al. reviewed the evidence supporting the use of both HRCT and complete PFT for the initial screening and diagnosis of SSc-ILD. They recommend baseline HRCT and PFT in all patients with SSc. They reasoned that PFTs alone aren’t adequate because values may be normal early in the course of disease.

Dr. Hummers offers a slightly different take. “At our center, all SSc patients get baseline and follow-up PFTs to evaluate for evolving SSc-ILD and pulmonary hypertension,” she says. “We don’t perform HRCT on all patients because there are lower risk subsets for whom this likely isn’t necessary. However, this is a nuanced decision, and it may be safer to just say everyone needs one.

“My real concern is that routine HRCT may lead to low-risk patients with mild SSc-ILD receiving unnecessary, expensive and potentially toxic treatment. Let’s say you refer a patient with limited cutaneous disease, anti-centromere antibody positivity and mild SSc-ILD to a pulmonologist. This patient is probably at very low risk of ILD progression, but pulmonologists may think about these patients as similar to the patients with idiopathic pulmonary fibrosis they treat most often. Nintedanib could be prescribed ... for a patient who should never be exposed to it.”

Differentiation & Risk Stratification of SSc-ILD
Khanna et al. recommend the differentiation of subclinical from clinical SSc-ILD and risk stratification of patients at low vs. high risk of SSc-ILD progression (see Figure 1, below). These terms are defined as:

- Subclinical SSc-ILD: an absence of clinical symptoms, minimal SSc-ILD findings on HRCT and a normal or stable FVC;
- Clinical SSc-ILD: clinical symptoms with either SSc-ILD on HRCT and/or abnormal or clinically meaningful decline in FVC or diffusing capacity of the lungs for carbon monoxide (DLCO); and
- High risk of progressive SSc-ILD: patients with progressive skin disease, anti-topoisomerase I (anti-Scl-70) antibody positivity or elevated acute phase reactants.

Khanna et al. recommend treatment for patients with clinical SSc-ILD or subclinical SSc-ILD with a high risk of disease progression. Those with subclinical SSc-ILD with low risk of progression require close monitoring (at least every six months) to confirm stability. Monitoring should involve assessment for new or worsening symptoms, PFTs (FVC and DLCO), a six-minute walk test and HRCT as indicated.

Initial Treatment of SSc-ILD
If treatment is indicated for a patient, which therapy should we choose? It’s truly the dawn of a new era in rheumatology when the question is not “What drug?” but which to use. Khanna et al. recommend basing treatment decisions on the presence of extrapulmonary manifestations of disease. Dr. Hummers agrees with this approach, noting “the treatment approach for clinical SSc-ILD is similar at our institution.” (Continued on Page 16)
For clinical SSc-ILD without extrapulmonary manifestations, the authors recommend MMF as a first-line treatment given its favorable toxicity profile compared with CYC. They also list nintedanib as an option.

Dr. Hummers practices similarly, using MMF as a first-line treatment. If patients are unable to tolerate MMF, she’ll switch them to nintedanib if there are no extrapulmonary manifestations of disease that warrant use of a different immunomodulatory drug.

“Of note, if patients don’t tolerate MMF due to GI [gastrointestinal] side effects, the chances of them tolerating nintedanib are low, in my experience. Patients often run into the same GI side effects with nintedanib,” she says.

For clinical SSc-ILD with active extrapulmonary manifestations, the authors recommend MMF or tocilizumab as a first-line treatment. CYC and rituximab are also options. They note that up-front combination therapy with MMF and nintedanib may be considered in patients with rapidly progressive pulmonary disease. Nintedanib monotherapy is not recommended given a lack of proven benefit for skin or musculoskeletal manifestations of disease.

“I select a therapy based on what will treat the most symptoms,” says Dr. Hummers. “If they have lung plus skin or lung plus muscle [involvement], I opt for MMF. If they have lung plus joints, I’d consider tocilizumab. However, the problem with tocilizumab is that the population studied was so narrow. These were patients very early in their disease course with diffuse cutaneous disease. They didn’t all have ILD, and you had to have elevated acute phase reactants to be included in the trial. So it’s tough to know what the true impact of tocilizumab is on lung disease outside of this narrow target population.”

For subclinical SSc-ILD at high risk of progressive disease, the authors recommend tocilizumab as a first-line therapy given the evidence from tocilizumab trials.14 MMF and CYC are also listed as options; however, randomized controlled data do not currently exist to support the use of one treatment over the other in this regard.

This last bit is where Dr. Hummers’ approach differs the most from that suggested by Khanna et al. “I would argue that there are still some people in this group [subclinical SSc-ILD at high risk of progressive
disease] who I would still just watch,” she says. “For example, patients with limited cutaneous disease, anti-centromere antibody positive, elevated acute phase reactants and mild ILD; or patients with limited cutaneous disease, anti-Scl-70 positivity and mild ILD. I wouldn’t automatically reach for tocilizumab [for] these patients, especially given the narrow population studied in the trials, their expense and the potential for toxicity.”

**Treatment of Progressive SSC-ILD**

Should a patient’s pulmonary disease progress while they are on the initial regimen, the authors recommend:

- Switching therapies;
- Considering combination immunomodulatory therapy (e.g., MMF plus tocilizumab) or adding nintedanib; and
- Considering hematopoietic stem cell transplant or lung transplant.

Dr. Hummers agrees. When it comes to adding nintedanib, she says, “I am almost always using it in someone who has or is at risk for progressive ILD. In the nintedanib trial, a subset analysis showed the lowest amount of lung function decline was in those taking combination MMF and nintedanib. The study wasn’t powered to look at the effect of combination therapy, but we can infer that combo therapy may be beneficial.”

**Future Directions**

Regarding the future direction of research in SSC-ILD, Dr. Hummers says, “For me, there are two burning questions: 1) Outside the narrow population studied in the tocilizumab trials, is there any role for tocilizumab in ILD?; and 2) Is there a population of patients who should get combination MMF and nintedanib up front?”

In summary, Khanna et al. provide a practical approach to the care of patients with SSC-ILD that serves as a valuable resource to practicing rheumatology providers.

Dr. Hummers offers additional expert insight on the impact and incorporation of new trial data on clinical practice.

Treatment choices should consider disease severity, risk of progression and extrapulmonary disease activity. Baseline PFTs should be acquired in all patients with SSC, with consideration of HRCT in most patients. In those with subclinical SSC-ILD at high risk of progression, treatment may also be considered.

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**References**


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**Samantha C. Shapiro, MD, is an academic rheumatologist and an affiliate faculty member of the Dell Medical School at the University of Texas at Austin. She received her training in internal medicine and rheumatology at Johns Hopkins University, Baltimore. She is also a member of the ACR Insurance Subcommittee.**

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For many in the Scleroderma community, Cos and Ronni Shulman Mallozzi are household names.

Together they have served for over 30 years with the Foundation. Cos served as the Foundation’s most recent National Board of Directors Chair and his wife, Ronni, who has scleroderma, played an instrumental role in promoting a merger between the United Scleroderma Foundation and the Scleroderma Federation, which resulted in the National Scleroderma Foundation we have today.

Throughout the years, the dynamic duo has been a powerful force in raising awareness about scleroderma, but their early years weren’t as bright.

Ronni shared, “I was diagnosed with systemic scleroderma in 1990...I was frightened. The internet was in its infancy, not much of a resource. What I found in the library were medical sources that showed the worst-case scenarios: very ‘visual’ cases of severe skin tightening. Cos was also upset, even angry at our fate at first. When I eventually got up the courage to go to a meeting with other patients and their caregivers, he didn’t want to go. I went alone.”

Meeting different people with scleroderma gave Ronni new insight into life with scleroderma. Eventually, Cos attended a conference with her, and was pleased to see a diverse group of patients—many living full, long and productive lives, which gave them both hope.

A skilled public relations professional, Ronni had her own firm, but she closed her office due to the exhaustion brought on by scleroderma.

Her talent coupled with her passion to help newly diagnosed people and their families gave Ronni the impetus to get involved with the Foundation.

“Persuasive writing was my forte and I had a useful message to convey. I wanted others to know that a scleroderma diagnosis wasn’t necessarily a death sentence, that scleroderma was a very variable disease affecting everyone in a different way. I wanted other people to know there was hope and help.”

Thus began Ronni and Cos’s involvement in the National Scleroderma Foundation. Over the years, Ronni attended conferences and support group meetings, wrote articles and speeches, and Cos led numerous fundraisers over the decades raising nearly $800,000 for scleroderma research.

“The Foundation has played such a critical role in our lives for the past 30+ years,” Cos said. “Getting to know the top doctors and researchers, see the progress that is being made in research, see the commitments of our pharmaceutical partners, witness the incredible work of our chapter and support group volunteers...it’s all second to none. Being so involved has given us a new purpose in our lives.”

Cos and Ronni also loyally support the Foundation’s mission through their charitable giving.

“We contribute financially to the Foundation every year via our Donor Advised Fund and eventually via our will/estate plans,” Cos noted. “We are fortunate to be able to pay it forward to help others who have been impacted by this awful disease, and we encourage others to do the same.”

From day one, Cos and Ronni Mallozzi have been pivotal players in the Foundation’s history. Because of them, the Foundation has grown to what it is today. The Foundation would like to extend its deepest gratitude to Cos and Ronni for their leadership and for leaving a legacy that will help the scleroderma community for generations to come and we humbly welcome them into the Scleroderma Hope Society, the premier planned giving society of the National Scleroderma Foundation. If you or a loved one are interested in learning more about the Scleroderma Hope Society, please email development@scleroderma.org or call 978-463-5843 ext. 241.
“My mom was hospitalized two weeks before Christmas, so I flew out from New Mexico to New Jersey to see her a week before. I always thought dreams of deceased loved ones were far-fetched and difficult to understand. But early Christmas morning, I had a dream I was sitting in my mother’s hospital room having a conversation, but I couldn’t hear her voice. She turned her back, walked to the window, and raised her hands to indicate ‘this is goodbye’.”

On Christmas day in 2004, Kelley Hill’s mother, Thelma Marie Hill, passed away from scleroderma. “My mom was visiting me and my family in North Carolina when she started discovering she had symptoms of scleroderma, yet she didn’t know of the disease scleroderma at the time. One evening we were preparing dinner, and she dropped a plate on the floor. ‘I’m sorry Kelley,’ my mom said. ‘I’m losing dexterity and grip strength in my hands, and I need to go to the doctor to identify the problem.’ I told my mother, ‘It’s only a plate, and I’ve broken many dishes among other things as a kid.’”

A plate shattering into a hundred pieces is analogous to what was happening inside Thelma’s body. But unlike that clamorous sign, Thelma’s scleroderma was silent in its destruction.

“My mom was a thyroid cancer survivor but surviving cancer didn’t aid in trying to combat scleroderma. Scleroderma started aggressively attacking her skin causing it to darken, but it didn’t affect her skin alone. It also attacked her organs, especially her lungs, liver, and kidneys. Scleroderma even caused thyroid problems to resurface even though she had survived the worst that could happen to it.”

For the first six years after his mother’s death, his mom’s scleroderma rendered Kelley silent. There was very little emotion with short periods of grieving.

“In year eight (2012), I slowly began to go through an emotional catharsis. Over the years, my wife noticed how I would suppress emotion, and sit quietly in my recliner, when I’m normally very talkative, and the life the of the party. I found myself crying in the shower, on the way to work, and while cutting the lawn; I was healing.”

Kelley was tired of the silence. He wanted to make some noise about scleroderma and its devastating consequences.

One day, a dear friend (Jaclyn Monahan) told Kelley that she had experience with golf fundraisers, and that’s what inspired Kelley to start his fundraiser for the National Scleroderma Foundation. Golf was too silent a sport, so Kelley chose a sport with a little more noise —bowling!

“My mom was a sports fanatic, and neither golf nor bowling was her sport of choice. However, bowling was a great way to bring people together for a good cause, and there was a bowling alley five minutes up the road. Jaclyn and I drafted an initial blueprint of how we wanted the event to go, but it was tough getting started. We finally just said ‘OK, let’s just get 40 participants.”

Kelley got in touch with many leaders at the National Scleroderma Foundation Ohio Chapter who wanted to help make his first “Bowling for Scleroderma” event a success. One day after work, Kelley and Jaclyn went from business to business seeking in-kind donations he could auction off at the event. He received wine baskets and chocolate baskets—after seeing the generosity of all the (Continued on Page 23)
The National Scleroderma Foundation congratulates Tracy Frech, MD, MS, Associate Professor of Medicine in the Division of Rheumatology, and Immunology, on the launch of the new Scleroderma Clinic at Vanderbilt University Medical Center. Dr. Frech specializes in the treatment of scleroderma, also known as Systemic Sclerosis, and any issues that are directly related to scleroderma. The goal of this new scleroderma clinic is to deliver excellent care to individuals living with scleroderma. The team at Vanderbilt University understands that symptoms may vary between individuals, and they have built a multidisciplinary team of specialists to help you navigate your unique challenges. Depending on your symptoms, you can see several of the providers at Vanderbilt. Their team includes pulmonologists, cardiologists, wound care specialists, dermatologists, and gastroenterologists. The Vanderbilt Scleroderma Clinic will work together with you to optimize your health outcomes.

Another great reason to engage with the Vanderbilt Scleroderma Clinic is to take part in valuable scleroderma research. Frequently, research studies are being conducted that you may qualify for and have the opportunity to participate in. These studies are designed to allow you to participate on a national and international level in discovery work with scleroderma. The Vanderbilt Scleroderma Clinic has research coordinators involved in the clinic to identify whether you qualify for any of the research studies that are currently being conducted. If you do qualify for a particular study, a research coordinator will meet with you during your clinic visit to review the study and invite you to participate. Your participation in any research study is always voluntary; you are never obligated to talk with a coordinator or participate in any research study. However, if you have questions or would like more information about the research study opportunities that the clinic is currently involved with, please do not hesitate to reach out to providers or staff at the Vanderbilt Scleroderma clinic. If you aren’t local to Vanderbilt University and want to participate in scleroderma research, call the Foundation to connect to your local scleroderma center.

To ensure individuals with scleroderma are provided with knowledgeable resources about diagnosis, care, and research, the National Scleroderma Foundation’s Medical and Scientific Advisory Board reviews each center to ensure that it meets the following criteria: 1) Demonstrate expertise in scleroderma including expertise in clinical and laboratory-based research. 2) Conduct current clinical trials in the field of scleroderma. 3) Scleroderma centers must conduct educational activities on scleroderma and provide information on advances in the care and treatment of patients living with scleroderma to health care professionals and the public.
Support Groups

Whether you are battling scleroderma or are a caregiver we have a support group for you! The National Scleroderma Foundation support groups provide individuals opportunities for education, emotional support, and connecting with others who share the disease. Due the global pandemic many support groups have transitioned to a virtual outlet. Visit scleroderma.org/support to find your group today!

Alabama
City: Calera
GROUP LEADER: Jo Ann Bokenkamp
City: Florence
GROUP LEADER: Sarah Logan

Arizona
City: Mohave Valley
GROUP LEADER: Carol Hayward

Arkansas
City: Little Rock
GROUP LEADER: J. Donnal它的

California
City: Central Valley
GROUP LEADER: Kathy Wheelock
City: Orange County
GROUP LEADER: Blythe Leonard
City: Northern California
GROUP LEADER: Penny Davis

Colorado
City: Denver
GROUP LEADER: Barb Frodin
City: Fort Collins
GROUP LEADER: Anna Germain

Connecticut
City: New Haven
GROUP LEADER: Adam Cerilli

Delaware
City: Dover
GROUP LEADER: Jennifer Cropper

Florida
City: Central Florida
GROUP LEADER: Beth Taber
City: South Florida
GROUP LEADER: Lorraine Meide

Georgia
City: Atlanta
GROUP LEADER: Yvonne White

Hawaii
City: Honolulu
GROUP LEADER: Lorraine Meide

Idaho
City: Boise
GROUP LEADER: Joanne Francis

Illinois
City: Chicago
GROUP LEADER: Cheryl Kohn

Indiana
City: South Bend
GROUP LEADER: Kris Garthe
City: Indianapolis
GROUP LEADER: Donna Thomas

Iowa
City: Des Moines
GROUP LEADER: Jill Condell

Kansas
City: Topeka
GROUP LEADER: Emily Morris

Louisiana
City: Baton Rouge
GROUP LEADER: Del Anselmo

Maine
City: Portland
GROUP LEADER: Sarah Logan

Maryland
City: Baltimore
GROUP LEADER: Marilyn Miller

Massachusetts
City: Boston
GROUP LEADER: Nancy Velizzo

Michigan
City: Detroit
GROUP LEADER: Barb Talicska

Minnesota
City: Minneapolis
GROUP LEADER: Bev Pogue

Mississippi
City: Jackson
GROUP LEADER: Mary Frank

Missouri
City: Kansas City
GROUP LEADER: Blythe Leonard

New Mexico
City: Santa Fe
GROUP LEADER: Jo Ann Bokenkamp

New York
City: New York City
GROUP LEADER: Audrey Gutterman
City: Buffalo
GROUP LEADER: Daniela Rehak

North Carolina
City: Charlotte
GROUP LEADER: Peggy Collins

Ohio
City: Columbus
GROUP LEADER: Debby Ross

Oklahoma
City: Oklahoma City
GROUP LEADER: Pam Bedford

Oregon
City: Portland
GROUP LEADER: Blythe Leonard

Pennsylvania
City: Pittsburgh
GROUP LEADER: Kathy Griffin

Rhode Island
City: Providence
GROUP LEADER: Mary Frank

South Dakota
City: Sioux Falls
GROUP LEADER: Jo Ann Bokenkamp

South Carolina
City: Charleston
GROUP LEADER: Jo Ann Bokenkamp

South Dakota
City: Rapid City
GROUP LEADER: Blythe Leonard

Tennessee
City: Nashville
GROUP LEADER: Tiese Mahabir

Texas
City: Dallas
GROUP LEADER: Lee Taylor

Utah
City: Salt Lake City
GROUP LEADER: Blythe Leonard

Virginia
City: Richmond
GROUP LEADER: Blythe Leonard

Washington
City: Seattle
GROUP LEADER: Judy Harlan

West Virginia
City: Charleston
GROUP LEADER: Blythe Leonard

Wisconsin
City: Milwaukee
GROUP LEADER: Mary Frank

Wyoming
City: Cheyenne
GROUP LEADER: Blythe Leonard
COMMONLY ASKED GI QUESTIONS IN SCLERODERMA

(Continued from Page 11) stuck. It can interfere with the ability of the stomach to accommodate the usual volume of food your stomach can hold, and cause delays in gastric emptying following a meal. These motility problems can result in the sensation of early satiety (feeling full after a small meal), nausea, and vomiting which can contribute to weight loss. Finally, some patients with scleroderma develop difficulty with swallowing, and dry mouth, with or without dental problems. Lower bowel involvement can also contribute to weight loss. Patients with decreased motility of the small bowel and/or colon can develop bacterial overgrowth, malabsorption, distention, and bloating with foul-smelling stools, which can further contribute to weight loss. Appropriately addressing the clinical complications of weight loss in scleroderma depends on the cause of the weight loss. In patients with dry mouth and dental problems, we recommend oral lubrication through the supplemental product (e.g. Xylimelts, Biotene products, etc.), and regular dental visits. For patients with trouble swallowing the cause of the dysphagia should be evaluated. If it is a consequence of uncontrolled acid reflux, more aggressive management of GERD should be pursued. If a patient is losing weight in the setting of persistent nausea, vomiting, and/or early satiety, then studies evaluating gastroparesis should be pursued, and if positive, pro-motility agents (e.g. metoclopramide) should be considered. If a patient has persistent diarrhea, then the causes of diarrhea should be evaluated, including small bowel bacterial overgrowth, superimposed infections (e.g. C. difficile), and food intolerance (e.g. fructose intolerance). Addressing the problem with cyclic antibiotics, targeted antibiotics, or dietary modification, respectively, may be beneficial. Probiotics may also play a role in controlling reflux, distention, and bloating. If you are unable to maintain your body mass index within normal limits with oral intake alone, supplemental tube feeding may be required to support your nutritional needs (e.g. enteral or total parenteral nutrition).
Scleroderma can be a silent disease, especially at first. It creeps its way around the body and destroys it bit by bit. External manifestations of scleroderma, like the skin changing colors, being unable to hold a plate, or developing digital ulcers, are just the tip of the iceberg of how scleroderma can wreak havoc on someone’s life. What was Kelley’s mom trying to say to him in his dream all those years ago? We may never know what Thelma’s silent words were. But now, Kelley is taking action by speaking out himself, and hosting a third-party fundraising event each year that benefits the mission of the National Scleroderma Foundation. We couldn’t be more grateful to Kelley for doing his part to help our community’s dream of a cure become a reality for all.

If you or someone you know would like to host a third-party fundraising event to support the mission of the National Scleroderma Foundation, please email development@scleroderma.org. The most important thing to us is knowing that you’re making the mission of the Foundation your mission, too, in a way that brings you joy and fulfillment.

“Seeing all the support we’ve received over the years is amazing, and I can’t thank our extended family and friends enough,” Kelley said. “That’s what keeps you motivated.”

Kelley named his event “Bowl for Scleroderma,” but he also added a tagline: Thelma’s Silent Words. Kelley wanted to make sure that the dream he had all those years ago on Christmas morning would be remembered forever.

BrEaking The SilEnce THROUGH BOWLING

(Continued from Page 19) store owners, Kelley was further inspired to reach out to colleges and professional sports teams, too. Because so many resonated with his mom’s story, Kelley received baskets from the in-state professional sports teams, colleges and universities.

“Our ‘Bowl for Scleroderma’ event accommodates on average 40+ bowlers each year. The most we’ve had is probably 60 people – our best turnout to date. Each year, we have a silent auction, which provides a lot of excitement over the two-hour event. Don’t get me wrong, bowling is fun too, but our silent action is super exciting because of the cool and unique items.”

Kelley named his event “Bowl for Scleroderma,” but he also added a tagline: Thelma’s Silent Words. Kelley wanted to make sure that the dream he had all those years ago on Christmas morning would be remembered forever.

To find out if your company will match your donation, contact your employer’s Human Resources department.
FUNDING THE BEST PEER-REVIEWED SCLERODERMA RESEARCH

THE NATIONAL SCLERODERMA Foundation is the leading nonprofit supporter of peer-reviewed research to discover the cause, understand the mechanism, and overcome scleroderma forever. Since its inception, the Foundation has committed over $30 million to scleroderma research.

“The need to accelerate the pace of discovery in scleroderma research is urgent, and we are proud of our leadership role in advancing scientific discovery and doing so with the integrity of the peer-review process,” says Foundation CEO Mary Wheatley.

The Foundation’s peer-reviewed research grants program prioritizes scientific merit and provides funding for both early career and established investigators. The Peer-Review Committee is composed of highly respected scientific experts who review, critique, and score all applications based on the National Institutes of Health’s guidelines and ranking system. Upon completion of the scoring, funding recommendations are made to the Board of Directors for those proposals of the highest scientific and technical merit.

Each grant application contains very specific eligibility and review criteria. Details regarding these requirements are available at scleroderma.org. All applications undergo rigorous peer-review and are scored and ranked according to the review criteria and overall merit of the proposal.

Review criteria are meticulous and include:

• **Significance:** Does this study address an important issue related to scleroderma?
• **Approach:** Are the design, methods, and analyses appropriate and adequate?
• **Innovation:** Does the research represent new ideas and technologies?
• **Investigator:** Are reviewers properly trained and sufficiently experienced?
• **Environment:** Does the scientific environment contribute to its success?

Peer-review rankings are sent to the Foundation’s Research Committee for qualification before being presented to the Foundation Board of Directors for final approval of funding. After the awards are made, all recipients are required to complete funding contracts with institutional sign-off and must also submit annual reports on their progress. All reports are reviewed by the Foundation’s Research Committee to ensure compliance with programmatic, scientific, and fiscal and administrative polices and requirements.

By investing in the Foundation’s research program, you can ensure your resources are being carefully stewarded every step of the way.
HELPFUL HACKS

**PREVENTING SLIDING ITEMS**

- Prevents plates, bowls, etc. from sliding on tables, counters, trays
- Keeps cutting boards in position
- Holds small kitchen appliances and mixing bowls in place
- Holds objects firmly on surfaces that are subject to motion or tipping

**FREEDOM GAS CAP WRENCH**

If you are an individual who has limited hand mobility and drives a car, the Freedom Gas Cap Wrench can help you independently fuel your vehicle.

While traditional gas caps require a tight grip and pressure on the lid, the Freedom Gas Cap Wrench has a supporting bar to help alleviate the grip needed to loosen the gas cap. The device is small and can easily be stored in a car between fueling. For an individual living with limited hand mobility, this device is an excellent addition for assistance on the go.

[thewrightstuff.com/gas-cap-tools.html](thewrightstuff.com/gas-cap-tools.html)

**PALMER PEELER**

If you enjoy cooking independently but struggle with holding a peeler, the Palmer Peeler might be useful for you. The Palmer Peeler is a device that rests in the palm and can peel fruits and vegetables while limiting the amount of stress on the hand. According to the seller, ActiveHand.com, “This palm peeler is great for those with reduced hand function. It sits in the palm, and fruit and vegetables can be easily peeled by running your hand over them. The single finger loop helps the peeler to stay in place.” Additionally, the peeler’s blade cover shields the hands and fingers from the sharp stainless steel blade. Overall, this device allows for quality peeling and independence in the kitchen for individuals with limited hand mobility.

[activehands.com/product/palm-peeler/](activehands.com/product/palm-peeler/)

**UCCELLO EASY-POUR KETTLE**

The Uccello Easy-Pour Kettle is a helpful device for individuals who struggle to hold the weight of a traditional kettle with their hands. Whether you are an individual with limited hand mobility or strength, this kettle can allow you to boil water freely and without extreme effort. According to the Seller, ActiveHand.com, “When you have reduced hand function, kettles can be heavy to lift or pour from without burning yourself! This easy-pour kettle pours when you tip it by pushing the handle – no need for a grip!” Additionally, the seller notes the key features of the kettle: its ability to tip and pour rather than lift, its non-slip base, an easy opening lid, a narrow open for controlled flow of hot water, and a removable water reservoir for easy refill.

[activehands.com/product/easy-pour-kettle/](activehands.com/product/easy-pour-kettle/)
The Tri-State Chapter hosted its Striking Out for Scleroderma event at the Binghamton Rumble Ponies baseball game on September 14, 2022. The team played the Hartford Yard Goats at the Mirabito Stadium in Binghamton, New York. The Chapter received all proceeds from tickets sold.

The Missouri Chapter hosted its Stepping Out to Cure Scleroderma St. Louis Walk on August 27, 2022. The walk was hosted at Creve Coeur Park, Creve Coeur, Missouri. The Chapter also hosted a Stepping Out to Cure Scleroderma walk in Kansas City, Missouri.

The Minnesota Chapter hosted its Mind Body Connection Virtual Conference on October 15, 2022, in recognition of the role the mind body connection plays in autoimmune health. The conference covered topics such as “The Happiness Practice,” “Research and Reasons for Mindfulness,” and “Mind-Gut Connection.” The virtual conference also featured break activities like yoga for scleroderma and meditation.
**DELTA MOVES**
The Delaware Valley Chapter’s Stepping Out to Cure Scleroderma Philadelphia Metro Walk came back strong in 2022 as the first in-person walk at its new Cooper River Park location. The walk took place on Saturday, September 10, 2022, and has raised almost $38,000.

**NEW ENGLAND MOVES**
The New England Chapter hosted its Sixth Annual Boston Stepping Out to Cure Scleroderma event was dedicated in memory of Carol Taylor, former Boston Support Group Leader and founder of the Boston Stepping Out to Cure Scleroderma Walk.

**OREGON SUPPORT**
On September 10, the Oregon Chapter hosted its monthly virtual support group. During the meeting, the group watched and discussed “GI Involvement and Nutrition in Systemic Sclerosis: Myths and Facts,” which was a recording from the 2021 National Scleroderma Conference. The Chapter hosts its support group meetings on the second Saturday of each month and welcomes all to attend!

**OHIO’S HEART OF IT ALL**
The Ohio Chapter hosted the Heart of It All, a friendly virtual competition between the Cleveland, Cincinnati, and Dayton areas. It lasted the entire month of October with daily games, contests, and prizes. The competition also included three Stepping Out to Cure Scleroderma walks in Cleveland, Cincinnati, and Dayton.

**HEARTLAND EDUCATIONAL EVENT**
The Heartland Chapter virtually hosted its 10th Annual Sclero-What? Education Day on Saturday, October 15, 2022. The education day featured a keynote address by Dr. Monique Hinchcliff, Associate Professor and Director of the Yale Scleroderma Program. The event also featured speakers such as Sundar Balasubramanian, PhD and Erika Enos, ND. In addition to excellent guest speakers, the event also had over $800 in giveaways.

**SOUTHEAST FLORIDA**
The Southeast Florida Chapter is pleased to announce its new evening support group. The group will meet on the second Wednesday of the month at 7:00 p.m. Eastern. This support group will meet in addition to the Chapter’s other support group, which takes place on the third Saturday of the month. If you are interested in joining, please contact Ferne Robin at frobin@scleroderma.org.
Join thousands living with scleroderma.

Inspire is the world’s largest online health community, with millions finding peer support for thousands of health conditions.

We provide a safe, friendly, and personal space to connect. Our scleroderma support community, offered in partnership with National Scleroderma Foundation, includes more than 78,000 members who support one another by sharing practical tips, personal experiences, and emotional support.

Join our scleroderma support group and discussion community today and become part of a life-changing experience. Visit scleroderma.inspire.com to learn more.