The magazine exclusively for Members of the National Scleroderma Foundation.

CELEBRATING ONE YEAR OF THE

Establishing a circle of support for men

• CONNECTING OUR JOURNEYS
  Highlights from our 2022 National Scleroderma Conference

• CREATING SPACE FOR OUR CAREGIVERS
  “When one person gets sick, the entire family gets sick.”

• SCLERODERMA AWARENESS MONTH
  Raising awareness and advocacy during the month of June
**ANNOUNCING ...**

**More Knowledge and Inspiration for People**

**Living With PAH**

From the PAH Initiative, sponsored by United Therapeutics

Navigating life with PAH is about more than understanding the disease—that’s just the first step! The PAH Initiative is here to help with even more useful and encouraging content about living with PAH, including:

- Real patient stories and insights
- Self-care with PAH
- Nutrition and the impact of sodium on PAH
- Emotional well-being

PAHInitiative.com is always being updated with helpful and encouraging information featuring perspectives and insights from PAH experts and patients like you.

Did you know the PAH Initiative recently published an exciting new issue of a magazine for people with PAH and their caregivers? Get your free copy of the PAH Today magazine—available now at PAHInitiative.com/living-with-PAH.

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**TABLE OF CONTENTS**

<table>
<thead>
<tr>
<th>Page</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>05</td>
<td>CHAIR’S MESSAGE</td>
</tr>
<tr>
<td>06</td>
<td>SCLERODERMA AND THE LUNG</td>
</tr>
<tr>
<td>08</td>
<td>CELEBRATING ONE YEAR OF THE 20% Establishing a circle of support for men</td>
</tr>
<tr>
<td>10</td>
<td>COVID-19 VACCINATION, PREVENTION, AND TREATMENT FOR PATIENTS WITH SCLERODERMA</td>
</tr>
<tr>
<td>14</td>
<td>SUPPORT GROUP LEADER HOSTS BILINGUAL INTERNATIONAL SCLERODERMA CONFERENCE</td>
</tr>
<tr>
<td>15</td>
<td>PALLIATIVE CARE IN SCLERODERMA: IMPROVING THE QUALITY OF LIFE OF PATIENTS</td>
</tr>
<tr>
<td>16</td>
<td>CONNECTING OUR JOURNEY! Highlights from our 2022 National Scleroderma Conference</td>
</tr>
<tr>
<td>18</td>
<td>CREATING SPACE FOR OUR CAREGIVERS: “When one person gets sick, the entire family gets sick.”</td>
</tr>
<tr>
<td>19</td>
<td>EDUCATE AND EMPOWER</td>
</tr>
<tr>
<td>20</td>
<td>SCLERODERMA AWARENESS MONTH</td>
</tr>
<tr>
<td>22</td>
<td>NEDD9: NEW PAH TREATMENT TARGET? Foundation-supported research reveals one protein’s key role in pulmonary arterial hypertension.</td>
</tr>
<tr>
<td>24</td>
<td>OUR VIBRANT COMMUNITY Chapter news and activities</td>
</tr>
<tr>
<td>26</td>
<td>HELPFUL HACKS Assistive devices for everyday tasks</td>
</tr>
</tbody>
</table>

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scleroderma.org
SOME THINGS NEVER CHANGE

I’VE BEEN INVOLVED WITH THE Foundation for more than 20 years, and while we’ve been leading the way with some exciting, transformational changes over the last couple of years, I’m happy to see that some things haven’t changed.

When my wife Mariann and I joined the Foundation in 2001 after she was diagnosed with scleroderma, we were welcomed by the community with open arms. We were struck by the sense of belonging we felt and comforted to know we weren’t alone in our journey with this disease that we knew nothing about. We joined a local chapter - shout out to the Ohio Chapter! - and a support group. We poured over the website to learn more about this mysterious diagnosis. But most of all, we learned from our peers and newfound friends and colleagues that there was hope for a future with this disease. And 20 years later, we’re able to provide that same hope to those who are newly diagnosed and share a similar story to ours. It’s incredible to see that with all the growth the Foundation has experienced over the years, we’ve maintained a sense of community and belonging, and our commitment to being a relentless force in finding a cure.

As I reflect on the honor and privilege I now have serving as the Chair of your Board of Directors, I am truly honored and humbled. Thank you for the opportunity to serve this great organization. Thank you for continuing to inspire me, my family, and our leadership.

In writing this, I can share that in July I experienced yet another fantastic annual National Scleroderma Conference. To see so many incredible patients, caregivers, friends, speakers, and partners at the Conference, I feel both extra-motivated and very assured that the scleroderma family that embraced us 20+ years ago, will continue to grow its reach and help to change the lives of people affected by scleroderma, just as it has for Mariann and myself.

We have so many exciting activities planned as we continue (and accelerate) our work to advance medical research, promote disease awareness, and provide support and education to people with scleroderma, their families, and support networks. At the top of this list is keeping our commitment to you - our dedicated supporters - to ensure you have all the resources you need to find your best path.

Thank you for joining us on this journey, and for continuing to provide hope to those who need it most.

Kevin Boyanowski
Chair, Board of Directors
All patients with scleroderma should be screened with your healthcare provider. The pathobiology of scleroderma lung disease, both interstitial lung disease and pulmonary hypertension, involves the interplay of disordered fibrotic immunologic and vascular pathways coupled with autoimmunity.

Interstitial lung disease is more commonly seen in patients with diffuse skin disease, and pulmonary hypertension is more often seen in patients with limited skin disease, but both can occur in any variant of scleroderma. Interstitial lung disease occurs very early in the disease course when there is more inflammation, while pulmonary hypertension happens a little bit later in the disease course, when there are more severe vascular changes. Frequently interstitial lung disease and pulmonary hypertension overlap.

Symptoms of lung involvement can include shortness of breath and decreased exercise tolerance. Patients may notice that it is harder to go up the stairs or to do daily tasks like carrying a laundry basket or groceries. They may notice a dry cough or lightheadedness or a faster heart rate.

“If I could give you a piece of advice, though, I would say to exercise daily. This can serve as a stress test and marker of inflammation. Exercise training has been shown to increase the size of the lungs and decrease the amount of inflammation and fibrosis.”

Interstitial Lung Disease

All patients with scleroderma should be screened for interstitial lung disease. The first important test is the pulmonary function test (PFT). A respiratory therapist will put a clip on your nose and ask you to blow as hard as you can through a tube. Healthcare providers are looking for restriction, where the lungs are smaller than they’re supposed to be, and the measures are the forced final capacity or the total lung capacity. Providers also look at a measure called the diffusion capacity or the diffusion capacity for carbon monoxide and we call that DLCO. That represents how well oxygen gets into your bloodstream, and how well carbon dioxide gets out. About 25 percent of patients with scleroderma may have some abnormality on their pulmonary function tests.

The second important test is the CT scan. You’ll be asked to take a deep breath and hold it while cross-sectional images of your lungs are produced. Most scleroderma patients have some scarring of the lungs, but fortunately, interstitial lung disease causing chronic respiratory failure occurs in only approximately 10 percent of patients.

Patients with interstitial lung disease can be staged by looking at the CT scan and considering the results in light of the pulmonary function test. Risk factors for progression may include African American race and male sex.

Generally, patients who have extensive interstitial lung disease are treated, or if the disease is progressing, or if there are risk factors for progression. Treatment has evolved based on a number of successful studies.

The Food and Drug Administration (FDA) approved the first specific therapy for SScILD, following a randomized, double-blind placebo-controlled trial among patients with ILD associated with SSc that showed the annual rate of decline in FVC was lower with nintedanib than with placebo. TCZ recently became the second drug ever FDA-approved for scleroderma associated interstitial lung disease. A study was launched that looked at skin thickening. Patients were randomized to tocilizumab or placebo. Unfortunately, it did not seem to have a benefit in skin disease, but it had a significant benefit in the lung.

Pulmonary Hypertension

Pulmonary Hypertension is high blood pressure in your lungs, which causes a strain on the right side of your heart. It can be caused by a number of factors: scarring in the lungs, clots in the blood vessels, thick or narrowed blood vessels, congested veins, and tumors. It is not a stretch of imagination to understand the reason that patients with scleroderma get pulmonary hypertension, because scleroderma is a vascular disease.

Pulmonary hypertension can be due to multiple causes. Group One pulmonary hypertension is when patients have thickening and narrowing of their pulmonary arteries. It’s called pulmonary arterial hypertension, and it can be caused by scleroderma. But, sometimes patients get pulmonary hypertension for other reasons. Group Two pulmonary hypertension is when the left side of the heart is not functioning properly, and it cannot pump blood around the body. This is very different from group one and does not respond to the same therapies. Group three is caused by low oxygen levels, sometimes due to interstitial lung disease. Group four is chronic thromboembolic pulmonary hypertension, when blood clots in your lungs clog up pulmonary arteries.

To evaluate the pulmonary hypertension, healthcare providers will get a detailed history, get a chest x-ray, get an EKG, do a test called V/Q scan which looks for blood clots, do a breathing test for evidence of ILD, do blood work, a six-minute walk test, and right side of the heart catheterization.

The echocardiogram, which is the ultrasound of your heart, is our best screen for pulmonary Hypertension. You’re looking for a right ventricular systolic pressure to be less than 35. It is very important to also look for other signs of abnormalities in the morphology or functions. The gold standard for making the diagnosis of pulmonary hypertension is a right-sided heart catheterization. In this procedure, the cardiologist will put an IV in your jugular vein in your neck, or maybe a vein in the arm or leg, and through that IV, they will thread a wire that can measure pressure in the heart and into the lungs. It can measure the right atrial pressure and the pulmonary pressure and something called the wedge pressure, which measures the left side of pressure. Pulmonary vasculature and the cardiac output are also measured. We can also look for things like holes in your heart, and whether medicines may improve your hemodynamics.

Your healthcare provider will also try to determine your functionality. We call this the functional classification or WHO Function Class. Class one would be no symptoms, class two would be normal activities but with discomfort, class three is progressively slower with activities being more difficult, class four is being unable to perform any physical activity without signs or symptoms of right ventricular failure or shortness of breath.

We want to keep you in the low-risk status with stable symptoms. That requires regular tests, labs, and visits with your doctor.

The therapies available for pulmonary hypertension target the three big pathways: the endothelial pathway, the nitric oxide pathway, and the prostacyclin pathway. There are three drugs that are endothelium receptor antagonists: bosentan, ambrisentan, and macitentan. There are three drugs that target the nitric oxide pathway: sildenafil, tadalafil, and ruxitumab. There are a variety of ways of targeting the prostacyclin pathway. There are prostacyclin receptor agonists, like selexipag, as well as prostacyclin analogs including iloprost, epoprostenol, and treprostinil.

The National Scleroderma Foundation is grateful for the assistance of Dr. Kristin B. Highland, MD with the development and review of this article.

Dr. Kristin Highland, MD
Establishing a circle of support for men

RELENTLESS. UNABATING. TRAUMATIC.

These are the three words that best describe Michael Bessert’s journey with scleroderma. Michael, now 64, was diagnosed with scleroderma nine years ago when he was 55 years old.

“I was symptomatic for a long time, but didn’t know what I had. I started out with GERD, Raynaud’s, and fatigue. Later, I developed skin tightening. One year later, I was diagnosed with scleroderma and my doctor gave me five years to live.”

An estimated 20% of people living with scleroderma are male. Michael, who has diffuse scleroderma, is even more rare, “part of the 20% of the 20%,” he says.

During the years following his diagnosis, Michael began volunteering with the National Scleroderma Foundation Michigan Chapter and attended support groups hosted by the Foundation. But, as a man, it was difficult for Michael to find a home with the groups he attended, since they were primarily comprised of female members.

“I tried attending support groups with women, but it wasn’t right for me. Guys have distinct issues from women. Sometimes, we’d be in groups and the women would apologize to us men as a preface to having a women-only discussion.”

Having experienced a lack of support for men with scleroderma firsthand, Michael made it a point to “advocate within advocating” for other men like him.

Michael contacted national office staff, encouraging the staff to represent men in communication materials and at sessions during the National Scleroderma Conference. Michael also posted resources for men on social media. These were just a few of the ways Michael pushed for greater awareness that scleroderma is a men’s disease, too.

Because of his advocacy work, Michael received an email from Laura Dyas, former Executive Director of the National Scleroderma Foundation Michigan Chapter, requesting his help to launch a men’s-only support group with the late Jacob Davila of the National Scleroderma Foundation Texas Bluebonnet Chapter.

“When Laura asked me to lead the men’s group with Jacob Davila, a bunch of emotions hit me. Jacob was my hero. He was the most profound leader with scleroderma in the world, and he devoted his life and put his own health on the backburner because of scleroderma. When I got that email from Laura asking me to join him and help other men with scleroderma, it was a big deal. I was being recognized for my own work, and was among the ranks of Jacob Davila. Wow. It was validation that my voice had been heard—that I matter.”

After much preparation, Michael and Jacob launched The 20%: A Virtual Support Group for Males Living with Scleroderma during our June 2021 Scleroderma Awareness Month. Four months later, Jacob Davila passed away from scleroderma. The entire scleroderma community was riddled with grief. But Michael, who was with Jacob when he passed away, knew that he had to persevere to serve the other men in his and Jacob’s shoes.

“After Jacob passed away, I broke down,” Michael said. “At our next meeting, after he died, I told everyone ‘This is tough, guys, but we’re going to carry on because this is what Jacob would have wanted.’”

In Scleroderma Awareness Month of June 2022, The 20%: A Virtual Support Group for Males Living with Scleroderma celebrated its one-year anniversary.

“Our anniversary meeting was awesome,” said Michael. “Some of the guys who showed up were also at our very first meeting one year prior!”

Now, Michael leads the men’s group with Erion Moore of the National Scleroderma Foundation Oregon Chapter.

“Before he passed, Jacob asked me to replace him,” Erion said. “I said ‘Sure, Jacob—I’ll jump in with Mike.’ And right from the beginning, Mike and I clicked. It is pretty cool to lead the group with him.”

The 20%: A Virtual Support Group for Males Living with Scleroderma has truly become the world’s strongest circle of support specifically for men living with the disease. Both Michael and Erion are proud that men from across the world make it a point to attend their support group meetings every month.

“We are an international group. There are men who join us from all over the US, but the need is so great that we also have men from other countries like New Zealand who have started to join us as well. Eventually, we’d love to be able to accommodate these different time zones with two meetings per month instead of one,” Michael, Jacob, and Erion are among the men in the Foundation’s community who are truly men for others. Selfless, empathetic, purpose-driven, and servant-leaders, these three men are invested in supporting other men suffering from scleroderma. The Foundation is grateful for everything they’ve done.

“Now, men have a space to be free, open, and honest about how we really feel,” Erion said. “Our support group offers men a chance to talk about our experience having scleroderma and how to navigate our daily lives living with this disease.”

The 20%: A Virtual Support Group for Males Living with Scleroderma meets virtually on the fourth Wednesday of every month at 7 to 8 PM ET. If you or someone you know would like to join or obtain more information about the men’s group, we invite you to email Michael Bessert at mbessert@scleroderma.org or Erion Moore at emoore@scleroderma.org.
Patients with systemic sclerosis (scleroderma) are potentially at higher risk of poor outcomes related to COVID-19 because of an altered immune system, the presence of cardio-pulmonary involvement such as lung fibrosis and pulmonary arterial hypertension, and the use of immunosuppressive drugs. Therefore, vaccination is critical to reduce transmission and severity of COVID-19 infection in the vulnerable scleroderma population. As of July 2022, four vaccines are available in the US, none of which contain the live virus. Two mRNA vaccines made by Pfizer (Comirnaty®) and Moderna (Spikevax) are FDA approved. A viral-vector vaccine made by Janssen ([&]) has Emergency Use Authorization (EUA) and in July 2022 a protein-based vaccine made by Novavax newly obtained EUA. Approval of a drug by the FDA means that the agency has determined, based on substantial evidence, that the drug is effective for its intended use, and that the benefits of the drug outweigh its risks when used according to the product’s approved labeling. In contrast, the FDA can issue EUA during a public health emergency, such as the COVID-19 pandemic, to allow the use of unapproved medical products to diagnose, treat or prevent serious or life-threatening diseases. Prior to issuing EUA, safety and efficacy must be demonstrated, certain FDA criteria must be met; and there also must be evidence that strongly suggests that patients have benefited from a treatment or test, and there are no adequate, approved or available alternatives. Scleroderma patients on long-term steroids and/or immunosuppressive medication such as Cellcept (mycophenolate mofetil), methotrexate, or Actemra (tocilizumab) or any other biologic therapy are considered immunocompromised. Plaquenil (hydroxychloroquine) monotherapy or intravenous immunoglobulin is not considered an immunosuppressive therapy.
COVID-19 vaccination in immunocompromised patients pose unique challenges as they may not mount adequate immune response after initial vaccination and vaccine effectiveness wanes over time. Studies have shown additional primary dose and booster doses improve protective immune response against COVID-19, and the highly transmissible Omicron variant, leading to fewer emergency room visits, hospitalizations, and death. Holding certain immunosuppressive medication(s) such as methotrexate prior to and/or after vaccination can also improve vaccine response and should be discussed with your rheumatologist. In addition to efficacy, safety is an important consideration, and some scleroderma patients may be hesitant to receive COVID-19 vaccination. In a recent study focusing on scleroderma patients, localized arm pain, muscle ache, and fatigue were most commonly reported after vaccination, and the proportion experiencing these adverse reactions were similar to the general population.

In June 2022, the CDC updated vaccination guidelines for immunocompromised patients as shown in the Figure and up to date information can be found on the CDC website. Immunocompromised patients who initiated vaccination with either Pfizer or Moderna should receive 3 doses of either mRNA vaccine to complete their primary series. Those who received the J&J vaccine as their primary dose should get a second dose of vaccine with either Pfizer or Moderna at least 28 days after the initial J&J dose, to complete the primary vaccination series. For better vaccine efficacy, the American College of Rheumatology (ACR) recommends immunocompromised patients complete primary vaccination series with either Pfizer or Moderna, over the J&J vaccine.

All immunocompromised patients should receive two booster doses with either Pfizer or Moderna. The first booster should be given at least 3 months after the last dose of the three-part mRNA primary series or at least 2 months after the additional mRNA dose if J&J was the initial primary dose. The second booster for all immunocompromised patients should then be given at least 4 months after the first booster dose. In summary, immunocompromised scleroderma patients should receive a total of five doses if their initial primary dose was the J&J vaccine to be considered “up to date” with COVID-19 vaccination according to current CDC guidelines.

As of July 2022, more than 70% of the population received at least one dose of COVID-19 vaccination, however, less than half received booster doses according to the most current CDC guidelines. The newly available Novavax vaccine is a protein-based vaccine like the human papillomavirus (HPV) or hepatitis B virus vaccine. This may help holistically improve rate among those with vaccine hesitancy with the mRNA-based Pfizer and Moderna vaccines. However, as the Novavax vaccine was only recently approved, there are currently no available CDC guidelines regarding its use in the immunocompromised population. We suggest that the Novavax vaccine may be effective against the Omicron BA.5 variant and Pfizer and Moderna are planning to release Omicron-adapted vaccines in Fall 2022.

Additional CDC and ACR updates recommend patients on B-cell depleting therapy such as Rituximab who received doses of COVID-19 vaccine prior to or during treatment to be revaccinated. Furthermore, on a case-by-case basis, mRNA COVID-19 vaccines may be administered outside of the FDA and CDC dosing intervals when the benefits of vaccination are deemed to outweigh the potential and unknown risks. Immunocompromised scleroderma patients should discuss with their rheumatologists need for further vaccination and timing of certain immunosuppressive medications, as recommended by the ACR, to improve vaccine effectiveness.

Vaccination is critical to prevent progression to severe COVID-19 infection in the immunocompromised population, however, patients with a history of severe allergy to vaccination or ongoing severe infection should not receive vaccination. For unvaccinated scleroderma patients or those who have not had an appropriate antibody response after vaccination Evusheld® may be of benefit. Evusheld (tixagevimab-cilgavimab) is a long-acting monoclonal antibody therapy, administered as two intramuscular injections, available under EUA for the prevention of COVID-19 infection in immunocompromised patients. The use of Evusheld does not replace need for vaccination. For COVID-19, however, Evusheld should be deferred for at least two weeks after vaccination. The comparative effectiveness of additional booster doses versus Evusheld is yet unknown and Dr. Dinesh Khanna at the University of Michigan is co-leading a multi-center NIH clinical trial to address this scientific question. The adaptive trial is assessing effect of booster doses in autoimmune diseases, including scleroderma. More details are available at https://www.autimmuneCOVIDvaccinebooster.org.

Scleroderma patients who develop mild to moderate COVID-19 that does not require hospitalization or oxygen therapy should contact his/her rheumatologist or primary care provider within 5 days of symptom onset to discuss treatment options. A number of drugs for treatment of COVID-19 infection are available under EUA in the outpatient setting. Paxlovid is the preferred therapeutic agent and effective against Omicron which is the current dominant variant in the US. However, Paxlovid is contraindicated in patients with severe kidney or liver disease and is a protease inhibitor with a lot of drug-interaction challenges. Scleroderma patients who take certain medications, including over the counter and herbal supplements, should discuss with their physicians whether Paxlovid can be safely administered with holding of medications. Drugs that treat COVID-19 vaccination are not subunit vaccines and vaccination shots and there are no recommendations to defer COVID-19 vaccination after monoclonal antibody treatment.

7. CDC Covid Data Tracker: https://covid.cdc.gov/covid-data-tracker/#/vaccinations
8. Vaccines and Related Biological Products Advisory Committee (VRBPAC). June 28, 2022, available online https://www.fda.gov/media/159498/download
9. FDA. Evusheld Factsheet: https://www.fda.gov/media/154702/download
10. Adapted from the National Institute of Health (NIH) COVID-19 Treatment Guidelines. https://www.covid19treatmentguidelines.nih.gov/
**THE FOLLOWING CONTRIBUTION**
is from Monica Ramírez, National Scleroderma Foundation support group leader & national bilingual support group and Angel Soto, Associate Director, Education & Mission Delivery

**Angel:** Tell me about the 2nd Annual International Scleroderma Conference that you helped build?

**Monica:** On June 29, for the second consecutive year, the National Scleroderma Foundation was part of organizing the committee of the 2nd International Scleroderma Conference together with the scleroderma associations of Mexico, Argentina, Colombia and Spain. Our goal was to share valuable information in Spanish and English to patients living with scleroderma worldwide. We had over 280 attendees for the event from 19 different countries. I was very happy that we were able to cover several topics such as juvenile scleroderma, scleroderma fatigue, Research updates in scleroderma and much more. All of the sessions were well attended, and this shows that there is a big need for Spanish language resources in the community.

**A:** How did this event first begin?

**M:** This event began because we saw there was a need for more educational sessions for Spanish speaking patients. What language to be a barrier for a person that needs good scleroderma care. I believe that information and education is the most important thing that we can give to patients, so I got to work building the event. With help from the National Scleroderma Foundation and the scleroderma associations of Mexico, Argentina, Colombia and Spain, we were able to build and host the first international scleroderma conference. We each recruited scleroderma experts and we came together to share high quality information with the community. Of course, we only wanted to get better from there. We want this event to get bigger and better each year. That is one of the reasons that we made the event fully bilingual this year, so attendees could view the sessions in Spanish or English. I will not continue to get better each year. Stay tuned for news about the 3rd annual Scleroderma International Conference on June 29, 2023.

**M:** Is there anything else that you would like to highlight?

**A:** One of the missions of the National Scleroderma Foundation is to help support groups because it is the place where patients go to find people who speak the same language and the emotional support that we provide to each other as patients. I want the scleroderma community to know that the bilingual support group is available for anyone to attend. We host many education events throughout the year and will be featuring Spanish language events. We record all of our education events and will host more throughout the year. I just want everyone to know that each of us here plays an important role in the scleroderma community. Some of us run support groups, others participate in research, some advocate for us politically to have our voices heard in both Congress and the Senate for more research funding. We all play a role in advancing the mission to find the cure.

If you know of anyone that speaks Spanish and would like to join our support group, please email miamiragro@gmail.com or the National Scleroderma Foundation at info@scleroderma.org.

**THE FOLLOWING ARTICLE IS** developed from a webinar presented in partnership with the American Thoracic Society in March 2022. The panel included several experts in scleroderma and sarcoidosis. For this article, we collaborated Elizabeth Volkmann, MD, and Angel Soto, Associate Director of Education & Mission Delivery at the National Scleroderma Foundation.

**Soto:** How and when do you approach the topic of palliative care with your patients?

**Volkmann:** This is a topic that usually does not get discussed until a later stage, but it is something that can and should be spoken about exceedingly early in the course of the disease. The goal of palliative care is to improve the quality of life of patients with any condition. When we speak about scleroderma, this is a condition that can affect organ systems, leading to various different symptoms. As a result, it is sometimes difficult to address all symptoms at one time during each patient visit. Introducing palliative care at an earlier point, at least for those battling scleroderma, can help to improve the lives of our patients.

**Soto:** Does accepting palliative care mean that a patient’s team of physicians will change?

**Volkmann:** This is a wonderful question! Accepting palliative care does not mean that a patient’s team of physicians will change. If your physician is providing therapies that are considered curative, then a patient would be eligible for palliative care. You can even do palliative care if curative treatments are not being pursued. In terms of the interdisciplinary approach, patients can continue to see their primary pulmonologist or rheumatologist while receiving palliative care services. I often refer to these primary doctors as the quarterback for the team. Other important team members may include nutritionists, psychologists, social workers, and respiratory therapists. The primary doctor who knows the patient best can help coordinate the patient’s care. It truly is a team effort - I think that the more different specialists a patient has involved can tremendously improve their overall care experience.

**Soto:** With progressive lung disease there is so much loss – loss of activities, community engagement, etc. – what role does palliative care have in restoring that independence?

**Volkmann:** Palliative care can help patients regain autonomy and live their life to its fullest. A notable example to help answer this question is when a patient may not want to go out in public using oxygen due to fears of being stigmatized. However, palliative care specialists have helped many of my patients learn about the benefits of oxygen therapy and how this tool can help patients with scleroderma and lung disease feel and function better. Through this, the patient becomes more active in their life, more functional, and more independent. If they are doing palliative care, they can have more positive reinforcement about that process. Finally, palliative care works closely not only with the patient but with their family and caregivers. Specifically, palliative care specialists can work with loved ones and caregivers to educate them on how to support the patient. This can often improve the relationship between caregivers and patients, as the caregivers gain greater insight into the experience of the patient and how they can help.

**PALLIATIVE CARE IN SCLERODERMA: IMPROVING THE QUALITY OF LIFE OF PATIENTS**
ON JULY 15, 16 AND 17, the National Scleroderma Foundation hosted the “Connecting Our Journeys” Conference. The three-days consisted of poster and exhibitor hall, education sessions and break out rooms. This year, we had over 500 registrants, 43 speakers and 17 hours of educational programming.

EDUCATIONAL AND NETWORKING SESSIONS:
MUSIC THERAPY AND WELLNESS
Eran Margor Fishbein, MA, MFT/BC
This presentation explored ways to use your voice as an instrument of healing through music therapy and sound healing techniques. Music and sound can help those navigating scleroderma with pain management, improve breathing/lung capacity and throat irritation, reduce stress and anxiety, increase energy and mental clarity, improve mood, decrease feelings of isolation, and promote emotional transformation and release. Experientials included breath work, vocal meditation, toning, and singing. Modifications available for musical activities which may have presented challenges for individuals with Sc-leroderma experiencing lung and throat issues.

THE POWER OF SELF-COMPASSION
Kristin Neff, Ph.D.
Associate Professor, University of Texas at Austin
Self-compassion involves treating ourselves kindly, like we would a close friend we cared about. Rather than making global evaluations of ourselves as “good” or “bad,” self-compassion involves generating kindness toward ourselves as imperfect humans, and learning to be present with the inevitable struggles of life with greater ease. It motivates us to make needed changes in our lives not because we’re worthless or inadequate, but because we care about ourselves and want to lessen our suffering. During the “Power of Self-Compassion” session, Kristin Neff, Ph.D., discussed present theory and research on self-compassion, which a burgeoning empirical literature has shown to be powerfully associated with psychological and physical wellbeing. Dr. Neff taught a short practice during the session which allowed participants to give themselves compassion when needed in daily life.

STAYING ACTIVE WITH SCLERODERMA
Rachel Lando, E-RYT 200, YACEP
Founder of Patient Care Movement
It is not easy staying active with scleroderma. During the “Staying Active with Scleroderma” session with movement professional and fellow scleroderma warrior Rachel Lando, participants examined the research-supported benefits of exercise, considered the obstacles specific to scleroderma patients, and received tips on how to bounce back softly – even with a hard shell.

Example of the 2022 session offerings:
- Exercise is Medicine: Dr. Lesley Saketkoo, MD, MPH
- Yoga is for Every Scleroderma Body Caregivers
- Men Living with Scleroderma Support Groups
- Young Adults National Scleroderma Foundation BIPOC Support Group Various Networking Sessions

The National Scleroderma Foundation hosts an educational conference annually. The conference is a three-day event which enables individuals with scleroderma and their support network to learn and interact with experts and others affected by scleroderma. If you have any ideas or suggestions on programming for our future conferences, please email info@scleroderma.org. Save the date for next year’s National Scleroderma Conference on July 14, 15 and 16 in Orlando, Florida.
THIRTY-THREE-YEAR OLD KIERRA
Flowers registered for the 2022 National Scleroderma Conference at the last minute. Little did she know that what she would learn at Conference would help her the very next day at an appointment with her rheumatologist.

“I didn’t know what to expect but the conference was very good. I learned a lot of information. I went to the talks presented by Dr. Volkmann about the lungs, and she taught me how to read a PFT (Pulmonary Function Test). I never understood what all those numbers meant or how to read the report. But I was so grateful because I had just had a PFT done the Monday before conference, and after Conference, I could actually read and understand the results for my next rheumatology appointment. I felt more empowered!”

The 2023 National Scleroderma Conference will be held on July 14, 15, and 16, 2023 in Orlando, Florida. It will be the Foundation’s first in-person Conference since the COVID-19 pandemic began. We look forward to reuniting with members of our community.
LIGHT-UPS: As part of its efforts to educate the public about scleroderma, the all-volunteer Advocacy Committee launched a campaign to “Light It Up in Teal.” The campaign involved reaching out to government officials, local business owners, and individual community members to ask them to put teal lights up on their buildings and light them up for one day, one week, or even a full month to bring awareness to scleroderma. There were approximately 150+ light ups nationwide throughout the month of June.

PROCLAMATIONS: In an effort to educate the public about scleroderma, members of the Advocacy Committee reached out to their local and state officials to secure official proclamations that declare Scleroderma Days, Weeks, or Months. Our persistent volunteers reached out to their governors and mayors, knowing each proclamations issued landed scleroderma squarely in the public record. There were approximately 50-75 proclamations designated to scleroderma during June.

DURING THE MONTH OF JUNE, the National Scleroderma Foundation’s chapters hosted 19 Stepping Out to Cure Scleroderma Walks. These walks took place across the country and served as key fundraising opportunities for each chapter. Due to Covid-19, the Stepping Out Walks were either virtual, in-person or hybrid, to protect the safety of our autoimmune population. In addition to chapter’s hosting Stepping Out events, the Foundation held a National Virtual Walk for anyone without a chapter organized Stepping Out event nearby. If you did not have an opportunity to participate in a Stepping Out Walk in June, visit our Stepping Out to Cure Scleroderma website to find a walk near you.

AWARENESS MONTH: The National Scleroderma Foundation recognizes June as Scleroderma Awareness Month. During the month of June, the Foundation raises awareness and advocacy by hosting an awareness campaign, securing state proclamations, and illuminating the sky in teal with “light-ups” nationwide.

THIS YEAR, the Foundation’s "Know Scleroderma" Awareness Month campaign consisted of 13 awareness month videos, 20 social media posts, and two press releases. Since no two scleroderma Journeys are the same, the “Know Scleroderma” campaign highlighted what scleroderma awareness and understanding look like to various individuals affected by scleroderma. A special video was released on World Scleroderma Day to amplify the need for scleroderma research and funding, highlight the Foundation’s resources for individuals affected by scleroderma, and give voice to individuals affected by the disease.
Creating Space for Our Caregivers

(Continued from Page 18) Members in our community have expressed interest in starting a national support group all caregivers who care for people impacted by scleroderma.

“We’ve never had a formal support group for scleroderma caregivers based out of the national office,” Caryn Anatrillo, Manager of Advocacy and Support, and Angel Soto, Associate Director, Education and Mission Delivery, said. “For many years at the National Scleroderma Conference, we would hear from community members that they wished one would exist. But leading a support group is a significant commitment. Finally, after several years, a strong leader emerged, one who is passionate about caregiving, can lead the group for at least one year, and who could go through our 13-week SPIN-SLEED training program to ensure they provide the best support to our caregiver community.”

The National Scleroderma Foundation is proud to announce that, by January 2023—the start of the Foundation’s 25th anniversary year—we will launch our first national support groups for caregivers led by Debbie S. Haussler of the National Scleroderma Foundation Ohio Chapter, whose husband has been living with scleroderma for many years.

“Debbie is amazing,” Caryn and Angel said. “She currently leads a support group for caregivers at her place of work, but she is ecstatic to launch a support group for the Foundation for all those who care for and support people specifically affected by scleroderma.”

What Rachel said about scleroderma resonates so strongly: when one person in a family gets sick, the whole family is impacted. But the Foundation is proud to say that when someone with scleroderma gets our support, the whole family gets it. And not only the whole family, but friends and other caregivers as well.

For more information about the National Scleroderma Foundation’s support group for caregivers, please email Caryn Anatrillo, Manager of Advocacy and Support, at canatrillo@scleroderma.org, or call (800) 722-HOPE (4673).

NEDD9: New PAH Treatment Target?

Foundation-supported research reveals one protein’s key role in pulmonary arterial hypertension.

New research supported by the Foundation reveals that a protein called NEDD9 plays a role in fibrosis in pulmonary arterial hypertension (PAH). PAH is a possibly serious scleroderma complication where lung blood vessels become narrow, blocked or damaged. High blood pressure in their lungs can impair quality of life and even lead to heart failure.

“Pulmonary hypertension is a major driver of hospitalization and shortened life span in patients with connective tissue diseases, especially scleroderma,” says cardiologist and vascular biologist Bradley A. Maron, MD, of Brigham and Women’s Hospital in Boston. In PAH, platelets flock and adhere to tissue lining the blood vessels in the lungs, and release inflammatory proteins. “This intracellular communication helps drive and propagate an injury pattern that we see in systemic sclerosis.”

Scleroderma has “unique underpinnings” that may make the usual pulmonary hypertension treatments less effective, he says. NEDD9 appears to be involved in this crosstalk between platelets and blood vessel walls and plays a role in a damaging process of hypoxia (low oxygen), fibrosis (tissue scarring), and thrombosis (vessel blockage) in PAH. This made NEDD9 an intriguing target to explore.

Maron and his group conducted experiments on both mice and human cells to explore mechanisms of PAH, including the role of NEDD9. They customized an anti-NEDD9 antibody and showed that it could block platelets from adhering to blood vessel cells in the lab, lessening the damage seen in PAH. Their findings suggest that NEDD9 is a “modifiable mediator” of interactions between platelets and blood vessels in PAH, making it an exciting target for new treatment development.

“We have identified a protein that seems to be regulating the fibrosis pattern in lung tissue in people with systemic sclerosis. What our work does is set in motion an opportunity to develop anti-fibrotic drugs. It’s the beginning of a new story to be told with specific impact on patients.”

On June 4, the Texas Bluebonnet Chapter hosted “The Scleroderma Body: Head to Toe - Inside & Out with Dr. Maureen Mayes” an educational webinar. During the event, Maureen D. Mayes, MD, MPH, discussed the symptoms of scleroderma that may be visible with the skin and the invisible symptoms when internal organ systems are affected. Over 240 people attended the virtual event. The webinar was made available to make the content accessible to everyone interested in learning.

The webinar made available on the Chapter’s YouTube channel to make the content accessible to everyone interested in learning. The Chapter will continue The Scleroderma Body series on the 3rd Saturday of September, November, January, March, and May.

The Albany Walk: Attended by Congressman Tonko

The Tri-State Chapter held its annual Albany Stepping Out for Scleroderma walk on June 4. Chapter members met at Mohawk Harbor and were joined by Congressman Paul Tonko. Congressman Tonko represents New York’s 20th Congressional District, including the communities of Albany, Schenectady, Troy, Saratoga Springs, and Amsterdam. Since he arrived in Congress, Paul Tonko has co-sponsored every piece of legislation the Tri-State Chapter had in Congress. He has been a fiercely strong advocate. At this year’s walk, the chapter asked the Congressman to reach out to their Senators in an effort to contact the Senators on the Senate Defense Appropriation Committee.

The 18th Annual Scleroderma Foundation New England Chapter Golf Classic 2022

The New England Chapter hosted their 18th Annual Scleroderma Foundation New England Golf Classic 2022 on Monday, July 11, at the Salem Country Club in Peabody, Massachusetts. The golf tournament is a beloved event and a highlight of the New England Chapters’ annual fundraising initiatives. The event was both fun and competitive as The Salem Country Club is renowned for having hosted six national championships, including the 2017 USGA Men’s Senior Open Championship. The tournament held additional fundraising opportunities and competitions such as a betting hole and the longest drive hole to amplify donations. Overall, the Golf Classic had 100 players and raised $85,000 for the National Scleroderma Foundation. 

https://birdieae.com/SFNEGolfClassic

The National Day of Action Facebook Live

On the last Sunday of each month the Ohio Chapter held a Facebook live session with Lucille Miller. These Facebook Live sessions cover various topics but, most importantly, serve as a time to connect with others who live with the challenges of scleroderma. On June 29, World Scleroderma Day, the Ohio chapter held a Facebook live session with Lucille Miller and National Scleroderma Foundation Support and Advocacy Manager Caryn Anastreilto to highlight the National Day of Action and instruct individuals on how to advocate. The live session had 232 views.

The Sunday Sit-down!

Join us LIVE on the last Sunday of every month at 1 p.m. Eastern on the Ohio Chapter Facebook page! www.facebook.com/ SCLERODERMATWOGO

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HELPFUL HACKS

EASI-GRIP ARTHRITIS CARVING KNIFE

The Easi-Grip Arthritis Carving Knife is a helpful tool for anyone with limited hand mobility. Unlike a traditional knife, this adaptive kitchen aid has a handle with a substantially large grip to lessen the effort needed to hold the knife.

As described by the seller, “The contoured handle of this lightweight carving knife is molded in soft plastic and set at a 90-degree angle from the blade. The handle was designed especially for people with weak hands or wrists but is comfortable for all users. The ergonomic handle provides a firm grip in both the left and right hands and can be used safely with wet or greasy hands.” Overall, the device works well for less strenuous, controlled chopping, cutting, and dicing.

Easi-Grip Arthritis Carving Knife

RECEIVE-ALL

The Receive-All is a device that makes strenuous hand activities more accessible and more comfortable. The device allows users to easily switch between activities by having an arm brace with velcro straps to lock in the necessary tool or equipment. As described by the seller, “The Receive-All is a versatile gripping solution for sports equipment, DIY tools, gardening and around the home. The Receive-All consists of an arm brace that fits around your forearm with two velcro straps, each with a D-ring so you can simply slide your finger through and pull to secure it. The items you wish to grip are secured to an adapter using cable ties. To hold the item, simply put on the arm brace and connect the adapter by hooking it onto the rear of the arm brace and secure using a lever mechanism at the front.” This might be a helpful solution if you are looking for an outdoor gardening or sporting aid.

Receive-All

NUMUV MULTI USE GRIP AID

The NuMuv Multi Use Grip Aid is a versatile device that can make holding a relatively small object easier for all users. The device works by wrapping around a smaller object, such as pens or toothbrushes, to allow for a lessened grip when holding the object. Once the device is secure on the object, the user can independently grip the pen or utensil without extensive effort. The device’s round shape fits the curved structure of almost any hand, making the process of holding items both comfortable and convenient. The device’s silicone structure allows for individuals with limited hand mobility to have hand control without gripping tightly. For more information, please visit the seller’s site.

Numuv Multi Use Grip Aid

for various small objects

Save the Date

National Scleroderma Conference

2023

Save the Date

ORLANDO, FLORIDA

JULY 14, 15 & 16 2023
We look forward to celebrating our 25th anniversary with you in 2023!
Stay tuned for exciting updates!