

VOICE

SCLERODERMA

The magazine exclusively for Members
of the National Scleroderma Foundation.

SPRING 2023

NATIONAL SCLERODERMA FOUNDATION CELEBRATES 25TH ANNIVERSARY

A look back at
scleroderma support

● BACK TOGETHER AGAIN

2023 National Scleroderma Conference
happening hybrid from Orlando

● STEPPING OUT TO CURE SCLERODERMA

Turning 20 - walk season underway

● SUPPORTING CHILDREN AND FAMILIES

A Lasting Mark makes a lasting impression



25th NATIONAL SCLERODERMA CONFERENCE

ANNIVERSARY

2023




ORLANDO, FLORIDA
JULY 14-16



Learn more about the conference and register at [SCLERODERMA.ORG/CONFERENCE](https://scleroderma.org/conference)

VOICE

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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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chair's message

NEW YEAR NEW GOALS



Spring is a time for renewal. Here in Charlotte, North Carolina, the daffodils are blooming, the dogwoods are budding. The azaleas will be gone before we know it. As I reflect on renewing our focus on the future of our mission priorities, I wanted to share how we're approaching strategy work this spring at the Foundation.

This past winter, we wrapped up the actions detailed in our 2020 strategic plan. With our resources, processes and structure aligned to our overall strategic vision, our approach now is to be more focused on strategic thinking than strategic planning.

We are setting our course for the future by bringing our leaders and stakeholders together to refine our shared vision for what lies ahead. We'll consider our strengths and opportunities against our available resources – while being pragmatic and nimble in this ever-changing world in which we live.

With this in mind, we convened our national and chapter leaders at our annual Leadership Day in October, to synthesize our goals for the coming year and help define activities to achieve them. These include:

- Ensuring access to programs and services for everyone in our scleroderma community, regardless of where they are geographically or where they are at in their diagnostic journey
- Designing and delivering an intentional organizational culture in which everyone can share openly and engage authentically
- Increasing funding to support greater investment across all mission pillars (education, support and research)

Members of our Board of Directors, Patient Advisory Board, Medical & Scientific Advisory Board, and Chapter Leadership Council participated in a day-long workshop to think strategically about ways to maximize our effectiveness as an organization. These leaders were then asked to rank the strategies that we should commit to moving forward in the coming year.

In November, the Board of Directors reviewed the strategies that came out of our work together on Leadership Day. The following information lists the strategies that rated highest, and that the Board has endorsed for continued focus in 2023:

RESEARCH	Enhanced communication regarding research outcomes and return on investment Patient participation in research
EDUCATION	Smaller, regional opportunities Enhanced focus on regional resources
SUPPORT	Hybrid (in-person and virtual) offerings to meet a range of needs Balancing return to in-person while continuing virtual programs/services
CHAPTERS	Conduct a needs assessment to ensure programs and services are responsive to the needs of the community Improve efficiencies across chapters
PHILANTHROPY	Increased media presence to build awareness

A key role of the Board of Directors and the chapter leaders is to regularly review these goals and strategies (and our progress in meeting them), so we can continue to refine our approach at the chapter and national level. We are fortunate to have leadership through the Foundation who represent a variety of stakeholders within our community, including people living with scleroderma, their caregivers, health care providers, researchers and our supporters.

We have an increased focus on awareness building, access to programs and services, and building an intentional culture. We are committed to continually building a better Foundation to serve those living with scleroderma.

I welcome your thoughts and ideas on how we can best meet your needs as we move this work forward. Please reach out at Chair@scleroderma.org and let me know what you think of our approach.

I am grateful for the opportunity to serve this community and thankful for your support this year and always. As we celebrate our 25th anniversary, I am humbled by the progress we've made as a Foundation and a community, and I look forward to continuing our work on behalf of people with scleroderma, their families and support networks.

Kevin Boyanowski
Chair, Board of Directors

CELEBRATING 25 YEARS OF SCLERODERMA SUPPORT

Honoring our warriors



Written by Chief Executive Officer — Mary J. Wheatley

ABOUT 300,000 AMERICANS LIVE with some form of scleroderma, including people of all ages, genders and ethnicities. It can cause pain, disability and, in severe cases, can cause death.

Thanks to the passion and dedication of decades of scientists, volunteers and donors, great strides have been made. Today, people diagnosed with scleroderma can expect to live longer, fuller lives than ever before. Scientists are developing better, more novel treatments bringing even more hope for the future.

Yet despite these advancements, the challenges surrounding scleroderma remain great and require abundant, committed resources if we are to slow, stop or reverse this complex disease.

Twenty-five years ago, thanks to the visionary leadership of our predecessor organizations, the United Scleroderma Foundation and the Scleroderma Federation, we became one national organization united around a shared vision. This vision supports our mission today: advancing medical research, promoting disease awareness and providing support and education to people with scleroderma, their families and support networks.

Upon joining the National Scleroderma Foundation, I began to spend a lot of time in our headquarters, and I often wondered why our offices were located on the north shore of Boston, Massachusetts. After meeting with many of our longtime scleroderma champions, I learned the unanimous two-word answer: Marie Coyle.

At the age of 11, Marie was diagnosed with linear scleroderma and told she would not live to be twenty. As I've learned, Marie never backed down from a challenge and, not only did she disprove her doctors, but she also dedicated her life to helping others with scleroderma. As a young woman, she placed an ad in a Boston-area newspaper seeking others like herself interested in forming a support group. She connected

with two women and, together, the three founded the Scleroderma Federation, one of the precursor organizations of the National Scleroderma Foundation.

One of the most confounding aspects of scleroderma is it varies so greatly from one person to the next. No two journeys are alike. Marie's journey is just one of thousands that illustrates the complexity, the unpredictability and the unknowns of this disease.

Marie died in 2019, at the age of 87. She remained active with the National Scleroderma Foundation New England Chapter into 2018. Through the years, Marie was a relentless advocate for the needs of our community and an unsurpassed champion for funding scleroderma research.

Twenty-five years later, we are delighted to celebrate the impact Marie and so many others have had on our community. We are honored to carry forth their legacy of visionary leadership in service to those impacted by scleroderma. During our 25th anniversary, follow along on our social media pages as we continue to share these impactful stories of our scleroderma warriors.



25

YEARS OF SERVICE

THE NATIONAL SCLERODERMA FOUNDATION CELEBRATES A MAJOR MILESTONE

The National Scleroderma Foundation that you've come to know today celebrates 25 years of serving the scleroderma community. During this milestone year, we look back on the formation of the Foundation and the ongoing dedication to the cause.

Accomplishments THROUGH THE YEARS



FEBRUARY 1998 — *it's official*
The merger was signed in 1998, to create the Scleroderma Foundation, an organization dedicated to patient support, education and the advancement of medical research. That year kicked off exciting advances in research and expanded awareness efforts. Although scleroderma, as it remains today, is a rare disease with no cure, the Foundation began to broaden the nation's understanding of the disease and the importance of the lives of those battling scleroderma.

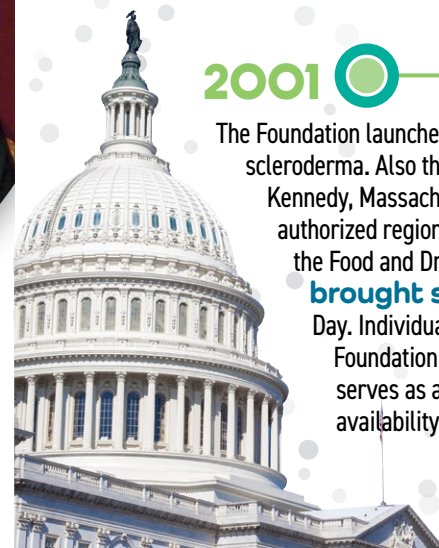
1998 The National Institute of Arthritis, Musculoskeletal and Skin Diseases coordinated a study looking at the prevalence of scleroderma in the Oklahoma Choctaw Native American population. The study implicated a **possible susceptible gene for scleroderma** called protein fibrillin-1.



1999 The Foundation introduced its first issue of the Scleroderma Newsline, a publication to keep the scleroderma community informed of news important to them, including profiles of individuals with the disease and details of organization happenings. Also that year, awareness got a boost as Luciano Pavarotti recorded **a series of nationally televised public service announcements**. He joined actor Jason Alexander as Foundation spokesperson.



2001 The Foundation launched an awareness campaign, **"Many Faces, Once Voice,"** featuring individuals living with scleroderma. Also that year, The Rare Disease Act was introduced by Senator Orrin Hatch, Utah, and Senator Edward Kennedy, Massachusetts. The legislation called for an Office of Rare Diseases at the National Institute of Health. NIH authorized regional centers of excellence to focus on rare disease research and training and to increase funding for the Food and Drug Administration's Orphan Product Research Grant Program. That year, **the Foundation brought scleroderma to the center stage on Capitol Hill**, holding its first Capitol Hill Day. Individuals living with the disease met in Washington, D.C., with legislators to share their stories. In 2001, the Foundation joined the Patient Consumer Coalition, of the National Organization for Rare Disorders. The coalition serves as a voice for individuals with rare diseases to advocate for federal policies that can lead to increased availability of affordable drugs.



25 YEARS OF ACCOMPLISHMENTS

2002 Technology advances allowed awareness to turn to the internet. The chapters and **support groups launched their web presence** that year.

2003 Big strides and big steps were launched with the **beginning of Stepping Out to Cure Scleroderma**. The premier awareness walks offer communities across the country the opportunity to bring awareness about scleroderma while raising critical funds.

2004 The growth of **internet access expanded opportunities to connect** to others living with the disease. The Foundation launched "Get Connect," which served as the organization's first discussion board. The platform offered support and inspiration.

2007 The Foundation got a boost that year as **scleroderma became eligible for Department of Defense research funding** due to a Congressional act that deemed the disease of impact to military personnel and their beneficiaries.

2008 Awareness took a front seat in 2008, as the Scleroderma Foundation **co-sponsored a NASCAR Bush Series vehicle**. The Foundation logo appeared on the team's car, uniforms, crew race day T-shirts and trailer.

2009 An "Echo Campaign" launched that year to inform medical professionals of **the importance of echocardiogram screening for people living with scleroderma**. It's the first-line screening test to determine if a person with systemic sclerosis has developed pulmonary arterial disease hypertension. The campaign featured its own microsite on the internet and introduced a medical journal about PAH-related research, called Scleroderma Spectrum.

2010 The U.S. House of Representatives of the 111th Congress **passed the Scleroderma Research and Awareness Act**, thanks to national advocacy committee work.

2011 The first African American **Scleroderma Patient Education Program was held** in Washington, D.C., with more than 70 people in attendance.

2012 Awareness work continued in 2012, as **Canadian and U.S. officials helped turn Niagara Falls teal**. Since then, annual events have been held nationwide during National Scleroderma Awareness Month to light up in teal landmarks from coast to coast.

2013 Research remained a priority in 2013, as the **first New Investigator Conference was held**. The event nurtured the next generation of scleroderma investigators (researchers) and provided career mentoring in a supportive environment. Annual awards continue today to ensure a pipeline of researchers dedicated to furthering treatment and finding a cure for the disease. In 2013, Jason Alexander was joined by Barry Sanders to be part of public service announcements. They both shared information about how their sisters lived with scleroderma. That year, education efforts included launching a new interactive body tool to show people how scleroderma affects the skin, gastrointestinal system, eyes, kidneys, lungs and other parts of the body. **The Foundation also held continuing medical education programs** to inform the medical community about the disease. Also that year, the Foundation partnered with the Scleroderma-Centered Intervention Network. This was a collaboration of patient organizations, individuals with the disease, caregivers, clinicians and researchers to create a first-of-its-kind online intervention program to help minimize the symptoms and effects of scleroderma.

HOW THE NATIONAL SCLERODERMA FOUNDATION GOT STARTED

In 1996, leadership of the West Coast-based United Scleroderma Foundation and the East Coast-based Scleroderma Federation began negotiations to merge the two organizations into one that would be national in scope and eliminate duplication of effort and overlapping services. A merger, it was believed, would diminish competition for much-needed financial support. Within 18 months of starting those conversations, the two organizations came together, with a combined board of directors, shared staff and a united vision to serve the scleroderma community.

2014 Collaboration continued that year with the formation of the Scleroderma Collaborative Research Grant that allowed for collaborative research between two or more established scleroderma centers. Also that year, the **National Patient Education Conference introduced a juvenile program**.

2015 Funding drives research, and for the first time in the Foundation's history, it **earmarked more than \$2 million to fund research** projects. Between ongoing grants and new awards, the Foundation remains committed to awarding approximately \$2 million, as funds allow.

2016 An international awareness campaign launched as the National Scleroderma Foundation partnered with the Scleroderma Society of Canada and the Scleroderma Research Foundation to **focus on the challenges individuals with scleroderma face**. The campaign was called "Scleroderma: Hard Word, Harder Disease." Also that year, the Foundation's National Medical and Advisory Board designated a new Scleroderma Center, Massachusetts General Hospital, in Boston, Massachusetts.

2017 The NIH established a national commission on scleroderma and fibrosis research to develop **a long-term, comprehensive plan for research**. Also that year, the Foundation engaged nine pharmaceutical/biotech companies to successfully develop unique Patient as Partners-Focused Drugs programs. The programs continues to grow.

2018 The Foundation **celebrated its 20th anniversary**, much like we're celebrating 25 years now - highlighting major achievements and the many individuals who have impacted the Foundation's work.

2020 Due to the COVID-19 pandemic, for the first time ever, the Foundation had to cancel the in-person National Patient Education Conference due to concerns for attendees' health. The **events and meetings transitioned to virtual**. A "Virtual University" was offered and included weekly webinars, live meetings, workshops and scleroderma-related patient education videos. Also that year, the Congressionally Directed Medical Research Program, through the Department of Defense, designated \$5 million for scleroderma research. Thanks to the pandemic, all Stepping Out to Cure Scleroderma walks turned into virtual campaigns.

2021 Promoting safety and well-being of individuals living with scleroderma continued to be a top priority as the global pandemic grew. The National Scleroderma Conference was held virtually but continued to deliver much-needed information on a wide range of topics. That year, despite economic uncertainty, felt around the globe, the Foundation **increased its funding commitment to research to \$2.723 million** - \$500,000 of that focused on the pediatric population, for the first time ever. That year, the Foundation welcomed new CEO Mary J. Wheatley, IOM, CAE., who implemented a board-approved strategic plan focused on growth and operations.

2022 in January, the organization got a new name, logo and launched a new website that included a directory for chapters, support groups and research/treatment centers. The Foundation received its sixth consecutive four-star rating from Charity Navigator, demonstrating to the public its ongoing trustworthiness. Only a quarter of charities rated by Charity Navigator receive the distinction. In 2022, the Foundation continued to further its mission pillar work with June 29, Scleroderma Day of Action., taking part in 17 Senate meetings and sending hundreds of letters to Senate offices. Support groups, both regionally and topic focused offered information and support in a virtual setting. In fiscal year 2022, the Foundation held **more than 40 educational events, with an estimated 1,500 participants**. New initiatives were launched, including a Celebrity Ambassador program, with Ashley Barron sharing her personal scleroderma story with a national audience. The Foundation created a new brand, and renewed its commitment to those living with the disease - to further treatment and help find a cure.

IN 2023,

we celebrate 25 years of serving the scleroderma community, which includes individuals with the disease, along with their caregivers and families. It's also been a quarter century full of raising awareness and funds to further scleroderma research so we have a path to advance treatment and hopefully one day, find a cure. **This year, we reflect on the developments from the last 25 years**, but also pause to remember the many lives lost to the disease. Each scleroderma warrior has fought or continues to fight, and we honor your journey.



S U P P O R T

GROUP LEADERS

Supporting each other



CENTRAL TO THE MISSION OF THE NATIONAL

SCLERODERMA FOUNDATION IS

offering support and is the primary focus of this edition of Scleroderma Voice. Since its formation in 1998, support groups have provided individuals living with scleroderma an outlet and source of connection and information. Support groups are a safe space for those affected to share their fears, triumphs, hopes and dreams and frustrations, while meeting others who have scleroderma.

In the 1990s, support groups could be found in limited parts of the United States. In person-meetings were common but not accessible to everyone. As time has continued, technological advances made virtual options the norm. Still, many prefer those face-to-face opportunities to get together.

Participation is essential for the success of support groups. Just as important, if not more important, is leadership of those groups. We are grateful to the many leaders across the United States who selflessly lead our support groups with care, compassion, empathy and wisdom. The National Scleroderma Foundation ensures support group leaders are well equipped and prepared with Scleroderma Support Group Leader Education training, which helps them take on the challenges of coordinating meetings, including offering valuable educational content to inform attendees about issues most relevant to them when it comes to living better with scleroderma and how to navigate the many emotions one's journey with scleroderma can travel.

The training program was developed in collaboration with Scleroderma Patient-centered Intervention Network, and is commonly referred to as SPIN-SSLED. It's 13 weekly sessions of 60-90 minutes of content led by a trained instructor. Each week addresses different aspects of leading a support group, including structure

of meetings, recruiting members, fostering positive group culture, supporting yourself and more. Those who complete the required training, become certified.

As we reflect on more than two decades of support, and the invaluable role of our support group leaders, we are sharing two journeys – a seasoned support group leader and a new support group leader.

ACCEPTING A NEW CHALLENGE – SCLERODERMA AND SUPPORT

Amanda Lippincott's journey with scleroderma started in 2018.

"I had recently gotten engaged, and I wanted to look and feel my best for my wedding day in 2019," Lippincott said. "At this point, my engagement ring, even in the intense summer heat, always fit my finger."

But she said in May 2019, she woke up unable to move her hands because they were so swollen. She said she felt like they would pop open if she tried to close them. She thought perhaps she slept on them wrong. She tried to put her engagement ring on, and it wouldn't fit over her second knuckle.

"Immediately, I knew something was wrong, and I made an appointment with my primary doctor," Lippincott said.

She said she received a referral to a rheumatologist. One month later, she had her first appointment. Aside from the swelling, she started to experience joint pain and skin tightening. Within three months, her doctor diagnosed her with scleroderma.

Almost one year after being diagnosed with scleroderma, in September 2020, Lippincott found out about the National Scleroderma Foundation. She was looking for support and found just what she needed on the Foundation's website.

"I started attending a virtual support group, and it was amazing to connect with people who knew how I was feeling," she said.

"I STARTED ATTENDING A VIRTUAL SUPPORT GROUP, AND IT WAS AMAZING TO CONNECT TO PEOPLE WHO KNEW WHAT I WAS FEELING."

Amanda Lippincott

She said she was met with compassion at the local Doylestown Chapter, and the support group leader took the time to answer her questions on being newly diagnosed. From there, she said she started attending the support group for young adults.

"When I sought support, I was in a really bad mental space," Lippincott said. "I was just getting my life together, when suddenly I received this diagnosis that shattered my world. Since scleroderma is rare, I felt so alone and vulnerable."

She said attending support group meetings created a sense of relief. It was a source of inspiration for her.

"I never want someone to feel the way I felt after my diagnosis, that's why I decided to lead a support group," she said. "I wanted to be there for anyone who needs a friend or someone to just listen to what they're going through. I want to make a difference in our community."

Today she leads a virtual young adult support group. She's spoken on panels at the National Scleroderma Conference about mental health and being a young adult with scleroderma. Her involvement with the Foundation has expanded even more. She's a co-leader for the Scleroderma Young Adults Needing Connecting support group and on the Patient Advisory Board.

SYNC is for young adults between ages 20-40. They meet monthly. She says they use the meetings to discuss what's going on in their lives, bring up questions and talk about new symptoms they're experiencing.

"We use the meetings to express how we're feeling," she said. "Some topics we've talked about are dating, pregnancy and generally living with scleroderma."

Lippincott encourages others to join support groups to know they're not alone and to relate to others living a shared experience.

PASSION FOR OFFERING SUPPORT

Carla King has a similar story to Lippincott. She was diagnosed in 2005 with scleroderma. She connected with Marie Coyle (whose story was detailed earlier in the magazine) who gave her some information about a local support group in New Hampshire – the closest one at the time. When the leader of the group had to step down, she stepped in.

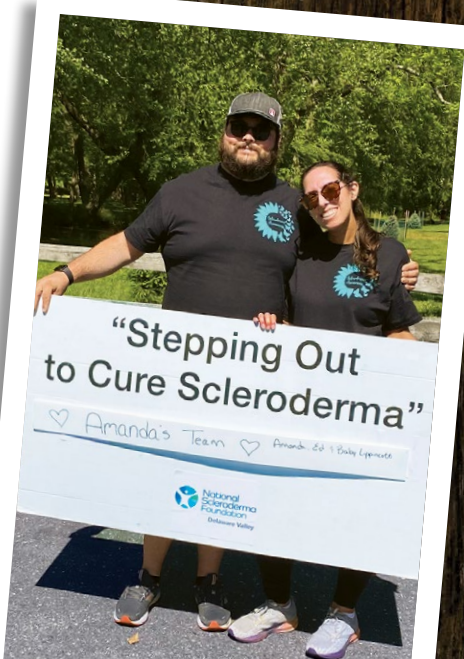
"SOMEHOW I JUST SLID INTO THE ROLE WHEN IT WAS NEEDED"

She now co-leads the Southern New Hampshire Support Group. She says support has been an important part of her life.

"For me, it's so important to be able to talk to someone like me – someone with the same challenges," King said. "This is not a disease like any other, and it's important to have someone to talk to and share with. I get inspiration from my meetings. Seeing another member still work as a house cleaner, with tight, bent fingers, or another who was still teaching elementary school, made me feel like, 'it's OK, I can still do this.'"

Although the concept of support is nothing new, she says over the last couple of decades, the way members connect has changed drastically – now including social media groups, in-person conferences, and most recently, virtual meetings.

(continued on page 22)



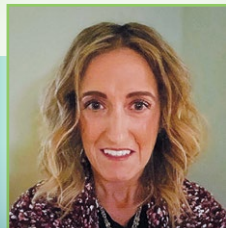
Supporting THE SCLERODERMA BIPOC COMMUNITY

Three years ago, longstanding passionate volunteers began discussions to create a scleroderma support group for Black, Indigenous, and People of Color. The team wanted to provide a platform to support people of all races, ethnicities and backgrounds who may face equality issues and are living with scleroderma – a place where they felt they could be seen, heard and supported. Together the group and facilitators focus on issues that impact their daily lives, such as health disparities, navigating community care

services, socioeconomic gaps and how to create self-care strategies. These areas have a direct impact on the health of those in the BIPOC community. The benefits of being a part of the group include having the opportunity to network with individuals with scleroderma, participating in innovative educational programs and topics unique to the needs of the group, and having access to an understanding environment to share similar experiences.

THANKS TO THE ORIGINAL FOUNDERS OF THE BIPOC TEAM

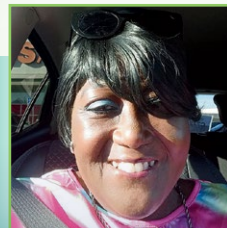
Jacob Davila, Demeshia Montgomery, and Marilyn Sibley and the original Scleroderma Patient-Centered Intervention Network-trained facilitators from different regions of the country, including:



Evamarie Gilbes-Cole
Tri-State Chapter



Zynovia Hetherington
Pacific Northwest Chapter-
Leader Facilitator



Latrina Hill
Michigan Chapter



Christy Loeza
Texas Bluebonnet Chapter



Erion Moore II
Pacific Northwest
Chapter



Demetra Newton
Georgia Chapter



Tomisa Starr
California Chapter



Kabrina Bass
Advisor

“THE GOAL IS TO FULFILL THE NEEDS OF THIS UNDERSERVED POPULATION BY SOLICITING INPUT FROM THE MEMBERS IN ORDER TO PROVIDE APPROPRIATE RESOURCES TO PROMOTE A HEALTHY LIFESTYLE”

*Marilyn Sibley—
a co-founder and
facilitator of the
BIPOC support group.*



We honor the memory of two special individuals who were a part of the BIPOC team. Jacob Davila, who was a member of the Texas Bluebonnet Chapter and Sy Fuller, who was a member of the then Southern California Chapter. Although they're no longer with us, their spirit continues to inspire the BIPOC group to serve the scleroderma community.

BIPOC invites the scleroderma community to consider attending its meetings. It's an opportunity to make new connections, deepen mutual understanding and respect for each other's cultures and better understand the needs of this diverse community. Facilitators and members offer support, encouragement and comfort to their peers as they learn how to adjust to their new lives. Participants are provided up-to-date information on scleroderma and resources to support them.

This tight-knit group truly reinforces the mission of the National Scleroderma Foundation. It includes individuals with the disease, caregivers and the public by offering well-executed programs and topics. Learn more, scleroderma.org/virtual-groups/.

FINDING A SUPPORT GROUP THAT'S RIGHT FOR YOU

Support is central to the mission of the National Scleroderma Foundation. It offers topic-based support groups and support groups connected to local chapters. There are more than 100 Foundation-affiliated support groups around the country. And support group leaders are trained volunteers ready to help.

Pre-pandemic, support groups met in person, but as gatherings moved to a virtual setting for safety reasons in the midst of COVID-19 spread, opportunities were realized to create national group meetings that allowed for a broader audience. Although some in-person meetings are starting to take place, others remain remote to maintain nationwide participation.

You can search for a scleroderma support group on the Foundation's website at scleroderma.org/support. There you can filter by location, virtual, in-person or by topic. Here's a look at the topic-based groups. Information is detailed on the webpage for how to join the group, the frequency of meetings, about the group and the setting.

Chapter-hosted meetings are spread across the country. Here's a look at some of the topic-based groups that are available virtually no matter where you reside.

TOPIC-BASED GROUPS WITH REGULAR MEETINGS:

- **Newly Diagnosed Support Group**
7 p.m., Eastern Time, second Wednesday of the month
- **Caregiver Support Group**
7 p.m., Eastern Time, fourth Thursday of the month
- **LGBTQ+ Support Group**
Begins this spring
- **Localized Scleroderma Support Group**
Begins this spring
- **Thriving with Scleroderma Support Group**
Begins this spring

TOPIC-BASED MEETINGS, SCHEDULE DETERMINED BY FACILITATOR (go to scleroderma.org/support for more information):

- **Young Adults (ages 18-39)**
- **Scleroderma Young Adults Seeking Connection Support Group (SYNC) (ages 18-42)**
- **Teens and Parents**
- **Parents of Children with Scleroderma Support Group**
- **The 20%: A Virtual Support Group for Males Living with Scleroderma**
- **Spanish Speakers Support Group**
- **Caregiver Connection**
- **Black, Indigenous People of Color (BIPOC) Support Group (additional details on page 12)**

ENSURING CHILDREN WITH SCLERODERMA RECEIVE THE SUPPORT THEY NEED

a valued partnership with A Lasting Mark celebrates 10 years

Marybeth Medolla went into action when her son, Luke, was diagnosed with linear scleroderma in May 2013, at the age of 13. Not knowing where to turn for support, finding a pediatric specialist and information on the disease, she turned to the National Scleroderma Foundation. Marybeth reflects on her initial contact with the Foundation.

“I was filled with reassurance from the Foundation that they will be there to help guide us on our journey with this rare and often misdiagnosed disease,” she said.

Being diagnosed with a chronic disease was life-changing for Luke and the entire Medolla family. Again, the family went into action, knowing that more research, education and support for other families with a child with pediatric scleroderma was needed. In response, they founded A Lasting Mark, a 501c3 charity. Luke and Marybeth Medolla serve on their foundation’s executive board as co-presidents.

Since A Lasting Mark’s inception, they have fundraised and donated \$100,000 to Dr. Thomas Lehman, the chief of Pediatric Rheumatology at the world-renowned Hospital for Special Surgery. Dr. Lehman, with the help of colleagues, launched his research study of genetics and linear scleroderma. His goal is to advance the development of targeted therapies and improve the quality of life of children affected by this rare and underfunded disease. In addition to the two research studies at the Hospital for Special Surgery, A Lasting Mark helped support and fund two national pediatric and research forums with the National Scleroderma Foundation Tri-State Chapter and Kids Get Scleroderma Too!. They also provided

support for children to help pay expenses related to their scleroderma medical needs and treatment.

Luke, 21, currently works as a community habilitation provider for an adult with special needs. Luke accompanies this adult to work every day and provides supervision and protective oversight. He also gives one-on-one training to develop and enhance the adult’s skills needed to live more independently at home and within his community.

Luke and A Lasting Mark this past winter, donated holiday swag bags to the National Scleroderma Foundation members in the pediatric community living with scleroderma. Each bag was unique to the child/teen with a heartfelt note from Luke.

“I was happy to share a note that let them know that they are not alone in this disease,” Luke said.

Caryn Anatriello, Manager of Advocacy and Support at the National Scleroderma Foundation said the Foundation greatly appreciates the Medolla family’s support.

 **Learn more about A Lasting Mark at alastingmark.com.**

“THE FOUNDATION VALUES OUR 10-YEAR PARTNERSHIP WITH A LASTING MARK AND APPRECIATES ALL THEY DO FOR THE PEDIATRIC SCLERODERMA COMMUNITY.”



Luke Medolla.

Marybeth Medolla and Luke Medolla.

SAVE THE DATE FOR THE 2023 KIDS GET SCLERODERMA TOO! KGS2! CONFERENCE



Taking place virtually and in person July 14, 15, 16, in Orlando, Florida. Get full details at scleroderma.org/conference.

NAVIGATING A NEW LIFE WITH SCLERODERMA



Mindy and Laurin Quiat

IN 2018, MINDY QUIAT FROM DENVER, Colorado was preparing for a much-anticipated family vacation to Italy, when instead, she suddenly found herself hospitalized. The vacation was going to have to wait. She was diagnosed with scleroderma just five days prior and was now experiencing a life-threatening emergency. She spent nearly 100 days in the hospital, much of it in an induced coma so her lungs could heal.

Mindy miraculously survived, and after re-learning to walk, now lives with advanced interstitial lung disease, systemic scleroderma, Raynaud’s Syndrome and Sjogren’s Syndrome. Although scleroderma felt like it came out of nowhere, she looks back and realizes that there were signs.

“For about 18 months, I should have been paying attention to my body,” Mindy said. “I had been feeling increasingly breathless with exertion, and I had horrible tingling and numbness in my discolored (purple and red) fingers. Even my toes would become cold and turn purple.”

For more than six months she sought help from many different medical specialists, including her rheumatologist, but the symptoms didn’t point to anything specific. When visiting with a second rheumatologist months later, she asked whether she might have scleroderma.

“He told me, ‘You don’t want scleroderma, it’s awful,’” she said. “He ordered the simple blood work necessary, and two weeks later, I was told that I had scleroderma.”

Mindy’s husband, Laurin, had spent the evening packing as she napped with signs of labored breathing. The next morning when he woke her up, she was disoriented and her breathing had become more labored. He realized that there was something serious going on and called 911. The devastating turn of events impacted not just the couple,

but their children as well, who spent 12 days in Denver at the hospital instead of being in Italy.

After that, the couple resolved not to look back but to maintain a positive attitude and move forward.

“Scleroderma really attacks in places that we all take for granted, little things,” Laurin said. “Waking up in the morning and watching Mindy try to stretch her fingers so that she can grab a water bottle so she can take water with the morning medications. We take things one day at a time.”

Mindy requires around-the-clock oxygen support. It means traveling with a personal oxygen concentrator.

She’s most grateful for the support of friends and family, her medical team and the National Scleroderma Foundation that she initially hesitated to reach out to.

“I didn’t do so at first because I was reluctant to get involved with people, so many of whom would have terrible stories such as my own,” Mindy said. “I’m happy to say that that wasn’t the case at all, and I wish I had reached out sooner. The Foundation and the local Rocky Mountain Chapter provide those affected by scleroderma, both the patients and their families, with wonderful resources, educational opportunities and support groups.”

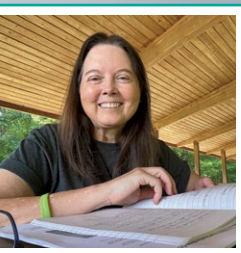
Although life has taken a dramatic turn, Mindy looks forward to a future filled with family, friends, travel, music, books and more. She has hope that continued research into the disease will bring even more tomorrows for her and others living with scleroderma.

“I ASK THAT YOU GIVE GENEROUSLY TO FUND THE NATIONAL SCLERODERMA FOUNDATION AND IT’S AMAZING WORK ON BEHALF OF ALL OF US WHO ARE AFFECTED BY THIS HORRIBLE DISEASE.”

LEARN MORE ABOUT HOW YOU CAN HELP SUPPORT MISSION-CRITICAL WORK AT SCLERODERMA.ORG/DONATE. YOU CAN WATCH A VIDEO ABOUT MINDY’S STORY ON THE NATIONAL SCLERODERMA FOUNDATION YOUTUBE CHANNEL.

Beyond the ORGANIZATION

The National Scleroderma Foundation offers a wide range of opportunities to receive support – whether it’s through a topic-based group or during a Stepping Out to Cure Scleroderma awareness walk to connect with others. Support comes in many forms. No matter the form, it’s important for every person to know they’re not alone in their journey.



STORYTELLING SUPPORTS THERAPEUTIC JOURNEY

Coming to terms with a scleroderma diagnosis can be difficult and overwhelming. For Donna Dinkin, she turned to therapy and decided to share the benefits of that experience with others by telling her story in a book. In February,

her scleroderma story was published in *Thursdays with Eugene A Memoir of Living While You Think You're Dying*.

In 2015, at age 55, Dinkin was diagnosed with interstitial lung disease caused by scleroderma. Her autobiography outlines a six-year journey of how she learned to deal with the emotional side of her diagnoses.

In the book, Dinkin describes her interactions with Eugene, but she also examines the shortcomings of the medical system related to the treatment of behavioral health issues that often occur with chronic diseases.

“I’ve become more resilient and alive,” Dinkin said of her interactions with Eugene.

But she’s quick to add that Eugene would say that she was “already alive and just needed to become more aware.”

Dinkin began her story in 2011, when she was diagnosed with Graves Disease, a hyperactive thyroid. From there, she began to suffer from breathlessness and symptoms of Raynaud’s Syndrome. She was told she had asthma and was provided an inhaler, but her symptoms didn’t improve.

“I was passing for healthy, but I knew that I was not,” Dinkin said.

Ultimately, her allergist referred her to a pulmonologist. After several tests, including blood tests, a CT scan and a pulmonary function test, he diagnosed her with interstitial lung disease, which he believed was caused by scleroderma.

“I COLLAPSED EMOTIONALLY, I WAS NOT FAMILIAR WITH ILD BUT HAD DETERMINED THAT ANYTHING CALLED ‘LUNG DISEASE’ HAD TO BE BAD.”

She had some familiarity with scleroderma and was devastated by her diagnosis. She said she felt like she had weeks to live.

“I was a working wife and mom. I kept on working, and I kept on being a parent and a wife,” Dinkin said. “I was going through the motions of life, but in reality, a non-stop horror story was on a continuous loop inside of my head. I deserved an Academy Award for my acting abilities during the first year after my diagnosis.”

One week after her diagnosis, in October 2015, she reached out to a therapist whom friends had recommended. She knew she was in crisis and needed help. In the beginning, she said she met weekly with Eugene, and as time went on, visits were less frequent.

“I started therapy with one goal in mind – to reduce the feelings of panic and anxiety that I was experiencing,”

she said. “As I worked with Eugene, however, my goals of therapy became more about becoming more resilient. In general, I wanted to emotionally bounce back faster from life’s curve balls and not create additional suffering to my already full plate.”

Dinkin is clear that anxious thoughts will still pop up from time to time. She admits that she is a “worrier.” But now she has a toolbox of activities to cope. An example is what she and Eugene call a “Meeting to Worry.” She collects agenda items for a one-hour meeting later in the week to worry about. The goal is to not continue to ruminate but decide if action needs to be taken or if the thoughts are false and need to be let go.

Dinkin said that instead of focusing on false futures she continuously works to enjoy the moments in front of her. She does this by practicing the three takeaway messages from her therapy journey – acceptance, curiosity and connection.

In addition to therapy, Dinkin says sources of support include her husband and her village of girlfriends.

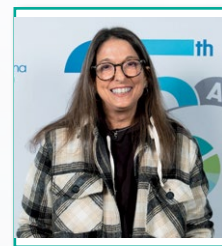
“I continue to work on my ability to accept support from others and to find ways to support others,” she said.

She is hopeful, that her memoir will provide support to people dealing with health issues or other life-altering experiences.

Dinkin says that after she was diagnosed she found comfort in reading others’ health stories.

“I read a whole stack of illness memoirs. I could relate to the authors’ experiences. I was scared with them, I laughed with them and I was frustrated with them. I’ve always wanted to write a book, but didn’t think I had the talent,” she said.

“I suppose I could have written a work-related book



MOGIL’S MOBCAST REACHES SCLERODERMA PODCAST LISTENERS TO OFFER SUPPORT

Sometimes the best way to feel supported is just by hearing about someone else’s experience. For individuals living with scleroderma, Mogil’s Mobcast has become a resource to turn to. In July 2021, Ann

Mogilevsky of the National Scleroderma Foundation’s Minnesota Chapter hosted her first podcast for individuals living with scleroderma. Since then, she has produced 40 episodes of Mogil’s Mobcast with an assortment of guests. Her goal is to cover a broad spectrum of topics and introduce listeners to individuals who can shed light on all aspects of scleroderma. While this podcast has become a staple for those affected by the disease, the road to a successful podcast was challenging

either on public health leadership or on organizational crisis preparedness – areas I studied for years.”

But Dinkin said that as she started to realize how important her emotional health was to her sense of well-being, regardless of the status of her physical health. She determined that this was the story she wanted to share.

To gain control of her feelings of chaos after her diagnoses, she kept notes and recorded symptoms and complaints. She made lists of questions, recorded test results and jotted down notes from doctor visits. She also kept a journal of her conversations with Eugene. Dinkin used these notes to enhance her memory while writing her story.

Beyond helping other individuals with scleroderma, Dinkin also hopes her book will inspire members of the medical system to do more to care for the emotional side of a person, while treating their physical side.

“After all, humans are not split into sides and pieces,” she said. “Our physical health affects our emotional health, and our emotions affect our physical health.”

Dinkin recommends therapy to anyone facing life challenges. She suggests that individuals ask friends, family members and their health care providers for the names of potential therapists. She says it’s important to recognize that counseling is a collaborative process that takes time.

“Eugene once told me that ‘people who say that they want a good cry often want a good ramble,’” she said. “I hope that my rambling helps someone having a good cry.”

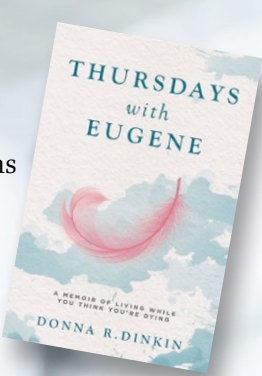
Thursdays with Eugene – a Memoir of Living While You Think You're Dying is available on Amazon.

and required hard work and patience.

Her ambition to create this podcast stems from her experience with scleroderma and her desire to help others answer the multitude of scleroderma questions.

When she was 40 years old, a healthy mother of two kids, she began seeing doctors for health issues. Upon switching to her second doctor and seeing a rheumatologist, internal bleeding in her stomach, also known as watermelon stomach, was detected. Upon her first of 27 endoscopies, she was diagnosed with scleroderma.

“Much of the current information and tests were not available 23 years ago when I first experienced symptoms,” Mogilevsky said. “My goal for this podcast is to help the world better understand scleroderma and provide the information I wish I had when I first learned about my diagnosis.”



After teaching for 39 years, she retired amidst the COVID-19 pandemic. Mogilevsky searched for a new outlet to pursue her love of exercise. She decided to take up walking and listening to podcasts, which became a beloved hobby. While searching for podcasts on her walks, she realized there were podcasts about autoimmunity, but almost none focused on scleroderma specifically. As an individual living with scleroderma and a lifelong teacher, she rose to the occasion and began her work designing a podcast specifically about scleroderma. With the help of friends and family, she was ready to face the challenge and began reaching out to individuals who she believed would provide helpful content to the show. Over time, the following has grown.

Mogilevsky's methodology for each episode is a blend of

structure and natural conversation. Her process starts by connecting on social media with an individual interested in a specific topic, or she writes to doctors and explores themes she is interested in covering. Although there's structure to the format, she also encourages natural and unscripted conversation. Podcast topics include yoga for scleroderma, how to get involved with the Foundation, scleroderma stories, test and treatment options and much more.

Although she has had a great time connecting with amazing individuals for the podcast, her work has been invaluable to those living with scleroderma – helping ease fears and create a resource of support.

Check out the latest editions of Mogil's Mobcast where you regularly listen to podcasts and at mogilmobcast.com.

content to what will be beneficial and positive for others living with the disease.

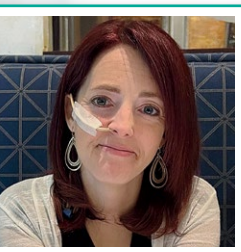
Often, Miller is accompanied by guest speakers who provide essential insight for the scleroderma community. While the Sunday Sit-downs do not include discussion about medicine or treatments, they do include discussion about scleroderma-related topics from new and positive perspectives. Sunday Sit-down topics have included Foundation activities, upcoming conferences, scleroderma stories, art and more. The Sit-downs have garnered international attention as Facebook allows individuals from everywhere to tune in. Her candidness and humor help her audience feel less alone in their experience with scleroderma.

Overall, the driving force of Sunday Sit-downs comes from Miller and the Ohio Chapter's desire to help establish community and support for anyone who is feeling lost or unheard. The Sit-downs encourage audience members to find happiness in their day and stay hopeful. Miller attributes this sense of connection to the Ohio Chapter's supportive community of extraordinary individuals.

Watch the Sunday Sit-down by visiting the Ohio Chapter's Facebook page on the last Sunday of the month at 1 p.m., Eastern Time.

SOCIAL CONNECTIONS

A substantial portion of the world's population is actively engaged on social media. Whether it's to catch up on the latest happenings for loved ones or to receive much-needed support. There's something for everyone. Inspire's online discussion board can be a great way to connect with others and find answers to scleroderma questions in a safe and secure location for individuals looking for a virtual community outside of support groups. To access the Inspire community, visit inspire.com/groups/scleroderma-foundation/. From there, you can create a profile and become a member of our National Scleroderma Foundation community.



SUNDAY SIT-DOWN WITH LUCILLE MILLER

When you first meet Lucille Miller, she radiates positivity and spirit. As an individual living with scleroderma for much of her life, she has never let her disease stop her from advocating for and supporting others in the scleroderma community. As a member of the National

Scleroderma Foundation Ohio Chapter, Miller has utilized her upbeat personality to bring the community together through her monthly Sunday Sit-down.

On the last Sunday of each month, she livestreams from the chapter's Facebook page and talks to the community. The topics vary weekly, but the format allows followers to ask questions and communicate in real-time. Miller tries to keep the topics enjoyable and the Sunday Sit-downs fun for the audience.

I KNOW LIFE WITH SCLERODERMA CAN BE HEAVY AND EMOTIONALLY CHALLENGING TO DEAL WITH AT TIMES.

"I hope these monthly streams provide comfort and connection to others in the community," Miller said.

Her journey with scleroderma has been an inspiration. Upon her diagnosis at 12 years old, Miller and her family found there was little information about the disease and almost nothing about pediatric scleroderma. Later in her experience with the disease, she recalls watching Bob Saget's 1996 film *For Hope*, one of the only films about scleroderma.

Years later as an adult, Miller serves as a source of support and information for the Foundation's Ohio Chapter and beyond. Having had scleroderma for almost 30 years, she understands her audience and tailors the

support

COORDINATING SUPPORT ACROSS THE COUNTRY



Meet Caryn Anatriello
ADVOCACY AND SUPPORT MANAGER

The National Scleroderma Foundation is comprised of many individuals who have a passion to serve the scleroderma community. Caryn Anatriello is no exception. Her role is a special one to the Foundation's support groups. She serves as the advocacy and support manager.

Since March 2022, when she began her tenure with the Foundation, Anatriello has been a source of innovative solutions and a friendly compassionate support to those living with scleroderma and their families. Anatriello is the voice of the HOPE line phone calls and responder of emails. Whether you are newly diagnosed or have been living with scleroderma for decades, Anatriello is one of the many friendly faces at the Foundation to help.

In addition, she oversees the nationwide network of support groups, including topic-based groups. Making sure leaders are trained and ready to lead meetings is essential. Anatriello does that too, with the Scleroderma Patient-Centered Intervention Network.

Support is a central piece of her work, but advocacy is another hat she wears well. She coordinates virtual and in-person visits with Congressional members and helps with grassroots advocacy work at the chapter level. If you've been involved in National Day of Action, she along with the Advocacy and Awareness Committee, are the joint task force leading the charge.

"As I approach my first year at the Foundation, I reflect on the valued relationships I have made within the community," Anatriello said. "Our community motivates me to work strategically and swiftly to strengthen and expand our support offerings – no matter where the member/caregiver is located in the country."

As she looks ahead to the future of the Foundation, she's excited to launch a few new national support groups aimed at general support, bereavement, and a quarterly support group leader check-in, to ensure needs are being made.

She wants members of the Foundation to know we're here to walk alongside you.

NO MATTER WHERE YOU ARE AT IN YOUR SCLERODERMA JOURNEY, THE FOUNDATION STAFF, VOLUNTEERS AND COMMUNITY ARE HERE TO SUPPORT YOU AND YOUR FAMILY.

"Whether it's to connect you to a support group, share educational resources, research updates or send you information on a designated scleroderma research and treatment center, we are here for you." Anatriello said.

CALL THE HOPELINE AT 800-722-HOPE [4673] OR EMAIL US AT INFO@SCLERODERMA.ORG

Eye of the STORM

SURVIVING A DOUBLE LUNG TRANSPORT DURING A HURRICANE - 10 YEARS LATER

OCT. 29, 2012 IS A HISTORIC DAY

– when Hurricane Sandy struck the Atlantic coast. It claimed lives, homes and caused extreme damage. President Obama and Governor Christie visited Brigantine, New Jersey, the eye of the storm. As the natural disaster rolled into the area, Linda J.B. Baum, O.D, was facing a crisis of her own – one that had been brewing since 1994, when she first was diagnosed with scleroderma.

Just as Hurricane Sandy was wreaking havoc at her house in Brigantine, a team of doctors were working to save her life. She underwent a double lung transplant on that day and survived, celebrating her scleroderma story in 2023, 10 years later.

“Interstitial lung disease is a fight to breathe,” Dr. Baum said. “I felt as if I was suffocating, gasping for air. I coughed from everything.”

Her journey started with Raynaud’s, and multiple bouts of pneumonia, that were difficult to recover from. As an optometrist in a multidisciplinary office, one of her patients was a rheumatologist. After yet another bout of pneumonia, at evaluation, he suspected scleroderma and interstitial lung disease.

Being me, I recovered and blew off the diagnosis, Dr. Baum said.

She continued working long hours seeing patients, all while continuing to feel sick. As she attempted to start a family, she began to focus more on her health. She gave birth to two daughters just 11 months apart. The

pregnancies were difficult because of the progression of her illness. Multiple experts provided no viable treatments for lung fibrosis at the time, and treatment protocols were inconsistent.

“Lung damage was already there and definitive,” Dr. Baum said. “My skin was taut, my kidneys not working optimally, nor was my heart. Not just external disfigurement, but the fibrosis hardened my internal organs, so every moment felt like being on another planet with insufficient air. I had young children. I just carried on.”

But as time went on, the struggle to breath intensified. She could barely finish a sentence without coughing. In 2008, she was again diagnosed with pneumonia. But this time, she was admitted to the hospital and placed on oxygen around the clock.

“My career was over,’ I thought. But life continued,” Dr. Baum said.

She took oxygen tanks with her everywhere. Coughing continued. She coughed so hard, she produced blood and broke ribs. She traveled with oxygen tanks, placing them in nice bags to try and conceal the severity of her condition.

“IT WAS NOT INFREQUENTLY THAT I’D HEAR ‘BUT YOU LOOK SO GOOD!’”



“INTERSTITIAL LUNG DISEASE IS A FIGHT TO BREATHE, I FELT AS IF I WAS SUFFOCATING, GASPING FOR AIR. I COUGHED FROM EVERYTHING.”

Linda J.B. Baum, O.D

NOWHERE TO RUN

In 2010, Dr. Baum was told she had no options but a double lung transplant. She researched who might do such a risky operation. Few centers at the time accepted a patient for solid organ transplant with scleroderma as an underlying diagnosis. She was rejected by two centers. Just when her hopes were nearly gone, she was accepted at the University of Pittsburgh Medical Center – a seven-hour commute from her home.

“My wonderful international team of dedicated physicians and nurses listed me according to the United Network for Organ Sharing scoring in June 2012,” Dr. Baum said. “In July 2012, I had right heart failure and was cardioverted twice. My lung allocation score went from 46 to 70, which meant I was critical.”

Her family was on the east coast, her daughters in school and her spouse working as she lived alone – visitors paying their last respects.

“I was dying. At age 54, cachectic, all bones and skeleton, unable to breath or eat,” she said. “I just waited.”

As Hurricane Sandy raged through the east coast, on Oct. 29, 2012, Dr. Baum finally got the call. A friend who had just left from visiting quickly returned to be by her side. But as they set out on the journey to undergo the procedure, the only thing that now stood in her way was a destructive Category 3 hurricane that left all roads and major highways blocked. The transplant team was ready. The donor was matched.

She made it to the hospital. Her transplant was one of 30 or so of its type that year – experimental – but lifesaving. Mortality and survival statistics were daunting. “But I beat the odds,” she said.

Recovery remains challenging, but every day that goes by is a blessing. “One step at a time, one day at a time,



the team and I worked together tirelessly so I would recover and live with new lungs,” Dr. Baum said. “It was a process to learn how to breathe without machines.”

Walking, eating and reconnecting with family were all part of the aftermath. “There is so much to live for, and I swore to myself that if I survived, I would bring awareness about scleroderma and its devastating effects on the body and be a beacon of hope and inspiration,” she said.

Although struggles continue, including the daily need for special medication to keep her body from rejecting the transplant, she is grateful to be alive.

“I thrive in ways I did not think possible,” Dr. Baum said. “My quality of life is better than it has been for decades.”

Dr. Baum’s lungs were donated to research. The challenge to find a cure for fibrosis continues. The National Scleroderma Foundation is grateful for Dr. Baum’s friendship, leadership and for hosting a third-party fundraiser this fall to celebrate her 10-year lung transplant anniversary. If you are interested in hosting a third-party fundraising event, please contact development@scleroderma.org to learn more.

(Support group leaders continued from page 12)

FROM ONE LEADER TO ANOTHER

Lippincott and King had the opportunity to visit about their experiences as support group leaders. King offered Lippincott some advice on growing a successful support group.

Q Lippincott What's your advice for keeping participants coming back each meeting?

A King We need to keep people connected, so they want to come back.

Q Lippincott Do you have speakers come to your group? If so, how do you find them?

A King We have not had a speaker in several years. But I think that speakers add interest for those looking for information.

Q Lippincott Any tips for someone looking to start their own group?

A King I would say to find a co-leader – someone who can cover if you can't make it. A team is much easier, and each leader brings their own strengths to the group

Q Lippincott What have you learned from being a support group leader?

A King I have learned to work with different personalities.

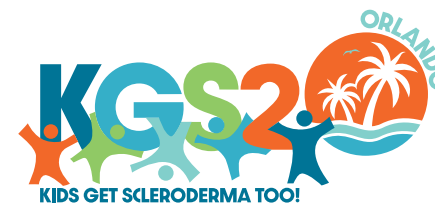
Learn how to become a support group leader at spinsclero.com/projects/ssled. Get additional information about joining a support group at scleroderma.org/support.

HAVE WHAT IT TAKES TO LEAD?

- Work with the national office
- Meet requirements to become a support group leader
- Arrange meeting times and send invites/reminders about meetings
- Act as a role model through your own honesty and self-disclosure
- Enforce guidelines and encourage appropriate participant conduct and confidentiality
- Create an environment that encourages sharing and acceptance
- Act as a representative of the National Scleroderma Foundation

education

REGISTRATION OPENS FOR NATIONAL SCLERODERMA CONFERENCE



This summer, individuals living with scleroderma, their families and caregivers, will come together both in-person and virtually for the 2023 National Scleroderma Conference and Kids Get Scleroderma, Too! conference. This year's gathering is being held July 14-16 in Orlando, Florida.

"We're excited to work with Signia by Hilton Orlando Bonnet Creek, to offer this premiere destination for our community," said Angel Soto, National Scleroderma Foundation education director. "We have an amazing line up of presenters and events for people of all ages."

As the Foundation celebrates its 25th anniversary, the milestone year theme (Many Journeys, One Mission) will be weaved throughout the conference that serves as the largest convening for the scleroderma community.

The agenda includes panel discussions and educational sessions led by leading scleroderma experts such as Virginia Steen, M.D.; Tracy Frech, M.D.; Dinesh Khanna, M.D., and many more health care professionals. As always, we will be covering a variety of sessions such as lung involvement in scleroderma, navigating intimacy, skin care, Raynaud's and hand care, meditation and much more. The Kid's Get Scleroderma, Too! program will also feature great speakers and sessions such as Kathryn Torok, M.D., and Suzanne Li, M.D. The conference will cover important topics such as transitioning from pediatric to adult care, medications and research updates in the world of scleroderma. Whether this is your first time at conference, or it's an event you look forward to year after year, no two conferences are the same.

The National Scleroderma Conference is primarily geared towards adults, while the Kids Get Scleroderma, Too! conference is held simultaneously and is focused on children and their families and caregivers.

There are many exciting events planned for this year's conference, including outings for young people, a kid's field trip and a musical performance.



Some of the important takeaways from the conference

will include achieving a better understanding of how to cope with the emotional challenges of living with scleroderma, developing strategies to stay motivated, meeting others who face similar challenges and building a network, learning about current therapies and medical advances and finding out how to raise awareness for scleroderma.

The early bird rate to attend the conference is \$275 for general attendees and \$115 for youth attendees. Needs-based scholarships are available to help individuals living with scleroderma attend. All scholarship applications are due by March 31. A reduced room rate of \$199 has been secured for attendees and is available for three days prior and three days after the conference.

Check out our conference webpage, scleroderma.org/conference, for information on medical device rentals. Safety precautions are also being taken to promote health and well-being. The Foundation encourages those considering in-person attendance to consult with their medical team in advance to reduce health risks or complications from illness.

For those interested in joining the conference remotely, every effort is being made to ensure a great virtual experience. Participants will receive a reduced conference rate and still have complete access to presentations and certain conference materials.

Learn more about the conference and register at scleroderma.org/conference.

education

BECOME A SCLERODERMA advocate



ADVOCACY IS THRIVING AT THE NATIONAL SCLERODERMA FOUNDATION!

Our Advocacy & Awareness Committee is launching and re-energizing our hands-on subcommittees/workgroups – and they need you!

Whether you're a dedicated scleroderma advocacy and communications leader or someone who is ready to add your voice to ours, please help us spread the word about scleroderma, advocate for action that supports those living with scleroderma and promote scleroderma research. Step up to be a part of our new advocacy and awareness working subcommittees, including groups for Awareness Month, Proclamations, Light-Ups, federal advocacy and our 25th Anniversary.

Learn more by reaching out to us by email at info@scleroderma.org.

\$1.6 MILLION AWARDED FOR TREATMENT & RESEARCH

Each year, the National Scleroderma Foundation proudly announces grant awards to identify and develop new treatments and a cure for scleroderma. This year, the Foundation awarded grants to eight new and established researchers (also known as investigators) totalling \$1.6 million.

“We are incredibly grateful to our volunteer leadership who put such time and care into the peer review and grants administration process,” says Foundation CEO Mary J. Wheatley. “This oversight includes broad representation from our community, including scleroderma experts, scientists and people living with the disease to help ensure we are investing in the most meritorious projects.”

Because there is no known cause or cure, continued research is critical to provide hope to individuals living with the disease.

For this round of funding, the Foundation received 27 proposals from investigators representing 23 institutions. All funded projects were rated as “high impact” by reviewers, and the success rate for Fiscal Year 2023 applicants was 30% (compared to 33% last year). The Fiscal Year 2023 portfolio includes three New Investigator Awards and five Established Investigator Awards, and a good mix between basic and more

clinically focused science. The portfolio also includes research focused on the pediatric population. Since its founding, in 1998, the Foundation has committed more than \$30 million to advancing medical research in scleroderma.

ABOUT THE SELECTION PROCESS

The Foundation’s peer-reviewed research grants program prioritizes scientific merit and provides funding for both early career and established investigators. The program is administered by the Foundation’s Research Committee. The committee makes funding recommendations to the Board of Directors annually after a rigorous peer review process. Each application is carefully reviewed, critiqued and ranked by a panel of scleroderma experts. Only projects of significant scientific merit are recommended for funding.

After the awards are made, all recipients are required to 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 policies and requirements.

Learn more about the Foundation’s scleroderma research program on scleroderma.org.

AWARD RECIPIENTS:

Rafael Contreras, Ph.D., University of Minnesota
Marta Marx Fund for the Eradication of Scleroderma Award - Established Investigator Award
Centromeres, Chromosome Instability, and cGAS-STING Activation in Scleroderma Fibrosis

Roxane Darbousset, Ph.D., Boston Children’s Hospital
The Mark Flapan Award - New Investigator Award
Platelets as Driver of NET Formation in Systemic Sclerosis

Justin Lui, M.D., Boston University
Walter and Marie Coyle Award - New Investigator Award
Cardiac Strain Phenotyping of Systemic Sclerosis-related Pulmonary Hypertension

Natalie Saini, MSc, Ph.D., Medical University of South Carolina
Established Investigator Award
Determining the Somatic Mutation Burden and its Consequences in Scleroderma-lung Disease

Elena Netchiporouk, M.D. M.Sc. FRCPC, The Research Institute of the McGill University Health Centre
Established Investigator Award
Investigating the Impact of the Environment on Systemic Sclerosis in Canada

Peter Morawski, Ph.D., Benaroya Research Institute at Virginia Mason
New Investigator Award
Cutaneous T Cell Dependent Regulation of Scleroderma-associated Fibroblasts

Andreea Bujor, M.D., Ph.D., Boston University
Established Investigator Award
Spatial Frequency Domain Imaging as a New Method to Quantify Skin Changes in Scleroderma

Suzanne Li, M.D., Ph.D., Hackensack University Medical Center
Established Investigator Award
Developing Classification Criteria for Juvenile Systemic Sclerosis: An International Effort to Enable Pediatric-focused Clinical Trials

Celebrating 20 YEARS OF Stepping Out to Cure SCLERODERMA



2023 MARKS A MILESTONE YEAR

for Stepping Out to Cure Scleroderma - together we are celebrating 20 years of awareness walks! The National Scleroderma Foundation, like many other non-profits, launched walks and 5Ks in the peak of the 1990s. This new and exciting avenue was beneficial both in spreading awareness and raising critical funds to support the Foundation’s mission pillars of support, education and research. Small, local walks were held by chapters across the county, but it wasn’t until 2003 that the walks were officially branded and named Stepping Out to Cure Scleroderma.

As an early participant in the Stepping Out to Cure Scleroderma walks, Ferne Robin, executive director of the Southeast Florida Chapter who began her tenure with the Foundation in 2005, was ready to participate in her first of many walk events. Robin, has seen the evolution of the event from the beginning.

“Just the ability to register online and not via a paper registration that needed to be mailed in made a world of difference,” Robin noted, “In addition, the rise of technology and social media paved the way to spread awareness easily and raise more funding. The National Scleroderma Foundation provided an outlet through the walk, allowing patients to share their stories and opportunities for the scleroderma audience to meet up in person with their community.”

We see how Stepping Out to Cure Scleroderma has impacted the National Scleroderma Foundation as the premier awareness walk event across the country. As we celebrate this important milestone together, the Foundation has made exciting changes to the walk experience beginning this year. The walk brand has a new look and feel, with an updated logo and color palette. The Foundation, also launched a new, user-friendly walk website for easier registration and fundraising.

Throughout its 20-year history, Stepping Out to Cure Scleroderma has experienced tremendous growth, evolving from a handful of local walks in 2003, to its current reach of more than 35 planned events this year, with participants who endeavor to raise record-breaking numbers. However, the walks are most successful because of our community, which includes those who volunteer to plan the walks, to the attendees who participate annually, some in memory of loved ones, and to the sponsors who have become family. Whether you have never attended a Stepping Out to Cure Scleroderma walk or are a loyal annual participant, we look forward to seeing you in 2023! We have a walk for everyone - in-person or virtual. Visit our website at scleroderma.org/steppingout or use the QR code below to find the perfect opportunity for you.



Together we are making a difference in the fight against scleroderma – let’s step out to cure scleroderma!



FERNE HAS SEEN THE WALKS THROUGH MANY SEASONS, FROM TECHNOLOGY ADVANCEMENTS, A PANDEMIC AND MOST RECENTLY, THE BRANDING UPDATE.

OUR vibrant COMMUNITY



Delaware Valley Chapter welcomes subject matter expert

On Nov. 3, Fredrick Wigley, M.D., presented an education session for the Delaware Valley Chapter. More than 50 people attended the event organized by Dan Caruso and the Central Pennsylvania support group, which meets the first Wednesday of each month at 7 p.m., Eastern Time.

Dr. Wigley, a physician-scientist whose specialty is Raynaud's phenomenon and scleroderma, shared information on living your best life with scleroderma. He encouraged attendees to take the wheel and put scleroderma in the back seat.



Heartland Chapter prepares for Stepping Out to Cure Scleroderma

The Heartland Chapter has been busy planning an in-person walk for June 3, at Grandview University, in Des Moines, Iowa. On the day of the walk, the chapter will start in-person registration at noon, with the walk launching at 1 p.m. There will also be a raffle and silent auction.

Michigan launches educational series

The Michigan Chapter is excited to announce a new monthly Lunch & Learn Scleroderma Educational Series beginning March 15. The Lunch & Learn will be held from noon to 1 p.m., Eastern Time, on the third Wednesday of the month. The virtual meeting will address a pressing issue of the scleroderma community. The format will include a brief update of Foundation activities and an introduction to the monthly guest, followed by a question and answer and discussion about future presenters. Each session will be followed by an Adaptive Physical Fitness Session from 1 – 1:15 p.m. The Adaptive Physical Sessions may include yoga, tai-chi and other movement-related activities.

Topics for upcoming sessions:

- Common tests for those living with scleroderma
- Dental issues of scleroderma
- Occupational therapy tips for face, hands and mind
- Lessons Learned from the University of Michigan RENEW study

Minnesota gears up for state advocacy day

Advocacy is an essential part of raising scleroderma awareness. The Minnesota Chapter will hold its Minnesota State Advocacy Day on March 23. If you are interested in joining or learning more, please email Randy Slikkers at rslikkers@scleroderma.org.



Missouri holds education event

The Missouri Chapter held its Patient Education Event on Nov. 19 virtually. During the event, the chapter reviewed video recordings from the 2023 National Scleroderma Conference.



New England Chapter takes a cold dip for a worthy cause

On New Year's Day, the New England Chapter and friends jumped into the water at L Street Beach, in South Boston, Massachusetts. Paul Lombard and his family and friends gathered their courage and took the plunge as part of their "Southie Swims for Scleroderma" event. Southie Swims for Scleroderma was started by Paul's uncle, Kevin Conroy, in the mid-2000s. He swam every year and spearheaded the fundraiser for more than 10 years to honor his sister, Elizabeth Lombard, who was diagnosed with systemic sclerosis in 1996. The chapter is deeply grateful to the Lombard and McKenna families for their commitment and support, having raised more than \$100,000 over the years.

Northwest Chapter welcomes volunteers

Looking for a way to get involved? Volunteers can become a part of local chapter committees, help plan events, lead support groups and so much more. The Northwest Chapter invites you to join by taking on an important role to further the chapter's work. Learn more by emailing northwestchapter@scleroderma.org.



Ohio Chapter highlights volunteer opportunities

Volunteers make a real difference by sharing their time, skills, knowledge and resources to help find a cure for scleroderma. The Ohio Chapter relies on volunteers to assist in supporting fundraising efforts, increase awareness and promote advocacy needs. Volunteers are needed for ongoing and one-time commitments. All opportunities include training.

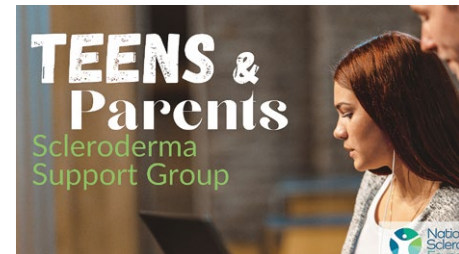
Available opportunities Include:

- Fundraising volunteer – third-party fundraisers, contacting Stepping Out to Cure Scleroderma team captains, sharing informational materials
- Advocacy volunteer - making telephone calls to elected officials from the State of Ohio, sending current materials to the offices and working on the Awareness Month campaign, securing proclamations and landmark light-ups
- Support group leader volunteer - provide educational information and emotional support to those living with scleroderma, caregivers, family members, friends and the community
- Stepping Out to Cure Scleroderma walk – various tasks for day-of-walk support such as registration, raffle, food service, set up, tear down, coordinate games

For information on becoming a volunteer, contact emulroy@scleroderma.org

Pacific Northwest Chapter hosts nationwide virtual support group

The National Scleroderma Foundation's Oregon Chapter hosts a virtual support group on the second Saturday of every month. The meetings are held from 10 a.m. to noon, Pacific Time, over Zoom. Everyone is welcome to attend – individuals living with scleroderma, newly diagnosed, family, friends, caregivers, medical professionals, Oregonians and non-Oregonians. Each meeting covers different topics related to scleroderma. If you are interested in joining, email ORchapter@scleroderma.org.



Rocky Mountain Chapter offers support to teens and parents

The Rocky Mountain Chapter's Albuquerque Support Group hosts a monthly Teens and Parents Support Group to help teens living with scleroderma. The group meets from 6 – 8 p.m., Mountain Time, on the fourth Wednesday of the month. The group allows teens to share and learn from people tackling the same challenges. If your teen is looking for support, call 505-503-3545 or email the support group leaders, Maria Tafoya and Jackie Martinez, nmsclero@gmail.com; or Debra Droux, debra@droux.org. The group asks that a parent or caregiver be present at least for the beginning of the meeting.



South Carolina Chapter looks forward to education conference

On April 1, the South Carolina Chapter will host the 13th Annual Amy K. Parrish Scleroderma Education Conference. This educational conference is offered in collaboration with the Medical University of South Carolina to honor the memory of Amy K. Parrish, former South Carolina Chapter president, who passed away from scleroderma in 2010. She always said that "knowledge is power." The conference honors that. This year, the conference will feature Keynote Speakers Lee Shapiro, M.D. To learn more, email scchapter@scleroderma.org.



Southeast Florida Chapter kicks off walk season

On Feb. 25, the Southeast Florida Chapter hosted its 19th Annual Stepping Out to Cure Scleroderma Coconut Creek walk at Tradewinds Park. Enthusiastic teams, individuals and families joined together to support the Southeast Florida Chapter and those living with scleroderma. In addition to the walk, the day was filled with special activities, such as an art auction and raffle, kids' games and arts and crafts. Thank you to our participants and all who donated to support the mission.

Texas Bluebonnet Chapter to host three walks

On Sept. 25, The Texas San Antonio Support Group Team participated in Sicloviva to spread awareness about scleroderma to the public. Sicloviva is a free, bi-annual event that turns city streets into a safe place for exercise and play. The Texas Bluebonnet Chapter is honored to be asked to participate in this event by the YMCA every year. This event has been a great networking opportunity every year for the Texas Bluebonnet Chapter and individuals living in the community affected by scleroderma.



Tri-State Chapter serves young adults through support group

On Feb. 10, the Tri-State Chapter's Scleroderma Young Adults Seeking Connection support group met. During the meeting, the group discussed dating, relationships and self-care tips. SYNC is a virtual community for young adults between the ages of 18 and 42 looking to connect with others affected by scleroderma. If you are a young adult looking for support, email support group leaders Amanda Lippincott, alippincott@scleroderma.org or Tiare Toltzmann, ttoltzmann@scleroderma.org.



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



"One of the best things that happened in my life is Inspire. When I read the words of support, they are a treasure for my soul and body, here in this part of the world."

INSPIRE SCLERODERMA COMMUNITY MEMBER