At Boehringer Ingelheim, we understand how overwhelming a diagnosis of scleroderma (also known as systemic sclerosis) may be, no matter how the disease manifests itself.

It’s important to keep a careful eye on all of your symptoms, so tell your doctor if your current ones worsen or you experience any new ones.

Visit morethanscleroderma.com/us
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Welcome from the Host Chapter

Welcome to Chicago! We’re so glad you’re here!

It’s my pleasure to welcome you to the 2019 National Patient Education Conference and to the city of Chicago. Summer is the perfect time to enjoy the city’s lakefront, parks, beaches and the Chicago Riverwalk. There’s so much to see from Millennium Park, to the Lincoln Park Zoo, to the iconic Willis Tower—the second tallest building in the Western Hemisphere. Of course, don’t forget to try some of the amazing cuisine that Chicago is known for. I hope you are able to take some time to experience all that Chicago has to offer. Grab a bike, hop on the ‘L’ train or ride a boat—whichver way you choose, get out and explore!

The Greater Chicago Chapter is thrilled to be the host chapter for the National Patient Education Conference this year. Please stop by our booth to say hello! We would love to meet you and connect you with the education programs, support groups and fundraising events we host across Illinois, Wisconsin and Indiana. "Thank you" to all of our volunteers who support us year-round and those that helped make this weekend possible.

Maybe this is your first time at the conference. Maybe you’ve been attending for years. This will be my seventh time attending this event, and every year I still find that I learn so much and meet so many great people. I always leave feeling energized, more informed and better connected to our wonderful scleroderma community. I hope you do too.

Sincerely,

Stephanie Somers Gresh
Executive Director
Greater Chicago Chapter
Welcome to Chicago!

Dear Friends:

Our theme, *The Sky's the Limit*, reflects the boundless optimism and relentlessly positive spirit of our family and friends who have scleroderma. As its name indicates, the conference emphasizes the education part of the Foundation's three-fold mission. During your time here you'll also learn about the support available to you through the Foundation. And, you'll discover that the conference itself offers a remarkable networking opportunity with others who face similar scleroderma-related challenges.

You'll also learn about the Foundation’s highly regarded peer-review approach to research funding. In fact, this conference is a chance to meet and talk to scientists actively studying scleroderma in the Poster Hall session Friday evening. I strongly encourage you to visit and talk to these impressive individuals and learn about their work. Our program of workshops and presentations also provides attendees the opportunity to interact with leading experts on scleroderma from around the country.

The Foundation is deeply grateful to our colleagues here at the Greater Chicago Chapter. The conference is a team effort and it's a true pleasure to work with such dedicated professionals. Chicago is such a wonderful location for the National Patient Education Conference that it's hard to believe this is the first time the city has played host. The rich cultural heritage and incredible downtown atmosphere help make Chicago the stuff of legends. I hope you all find a little time in our busy conference schedule to venture outside the hotel and explore. Riverwalk, the Cloud Gate sculpture, and Navy Pier are just a few noteworthy sites.

Thank you for being part of this important conference experience.

Welcome and enjoy,

-Robert J. Riggs
Chief Executive Officer

---

Message from the Chair

Dear Friends:

Welcome and thank you so much for attending the 2019 National Patient Education Conference. If you are attending for the first time, it will quickly become apparent that the conference is a special experience. Scleroderma is so uncommon that it can leave you feeling isolated. One visit to the National Conference changes that feeling forever. You'll be welcomed into our community, and you'll feel a real sense of belonging.

Our national Board of Directors is an important part of the scleroderma family. Nearly every Board member has a personal connection to scleroderma. We’re living or have lived the same journey as you, which is why we attend the conference and why we are motivated to help researchers find the cure. We are also motivated to work with individuals who have scleroderma, their caregivers, and family members to provide hope and to give you the tools to help make your daily lives better. That’s the purpose of every workshop in this conference.

*Kids Get Scleroderma, Too!* (KSG2) is a key feature of the conference. Here you’ll find pediatric rheumatologists who are highly regarded scleroderma specialists and who understand that addressing the needs of the whole family is key.

Another value of the conference is the Friday night Poster Hall presentations, which will provide you with direct access to researchers in an informal setting where they discuss with you the implications of their work.

Take as much home with you as you can from your time here in Chicago, and remember that the Scleroderma Foundation is always here for you.

Sincerely,

-Cos M. Mallozzi
Chair, National Board of Directors
General Information

The Conference Registration/Information Booth is where you receive your name badge, pick up your conference bag and program book, and acquire general conference information. On Friday, registration is on the 7th floor in Salon II (map, pg. 7). Saturday and Sunday, registration is on the 5th floor by the escalators. Please note, your conference name badge must be worn at all conference events.

Conference Registration Hours
Friday, July 19: 4 p.m. - 8:30 p.m.
Saturday, July 20: 7:45 a.m. - 6:30 p.m.
Sunday, July 21: 7 a.m. - 12:30 p.m.

Medical Emergencies
PLEASE COMPLETE THE EMERGENCY CONTACT INFO ON THE BACK OF YOUR NAME BADGE WHEN YOU RECEIVE IT. If you experience a medical emergency while in the hotel, dial 5011 on any house phone to report the issue to hotel security. If no answer, dial 911. There is no physician or nurse on site who can legally see or care for a patient with a medical emergency.

Special Meal Requests
If you requested a vegetarian meal in advance, this is indicated on the front of your name badge. Please show your badge to your server at the start of each meal. The Foundation has made every effort to offer gluten-free and vegetarian options.

General Hotel or Sightseeing Questions
The hotel Concierge or Front Desk staff are pleased to assist you with room needs and hotel questions. Check-out time is 12 noon. The hotel bell staff can provide storage for your belongings.

Scleroderma Foundation Store
The T-shirt booth and the Scleroderma Foundation store are located on the 7th floor, near the escalators.

Conference Surveys
Please fill out the conference survey in your bag and return it to the registration booth on Sunday. Extra survey forms are available at registration and the survey is online: scleroderma.org/conferencesurvey. Your input is vital to making future conferences successful. We will randomly select one person from submitted surveys to win free hotel and registration to the 2020 National Conference, so be sure to complete and return your survey.

Beverage Breaks
Beverages are offered between sessions and can be found in Salon I on the 7th floor. Sunday’s final break includes substantial snacks, because lunch is not served.

Temperature
Conference centers tend to be over-cooled to accommodate large groups. Every effort is made to make the temperature comfortable for our conference attendees. Some people will find it warm and others too cold, so it is best to dress in layers. Also, blankets are available in most of the conference rooms.

Complimentary Internet Access
There is complimentary basic internet access in meeting rooms suitable for email and browsing only.

WiFi Network: Marriott_CONFERENCE
Password: scleroderma2019

Photography
The Scleroderma Foundation uses electronic and traditional media including, but not limited to photographs, video, audio footage, and testimonials during the national conference. All attendees, visitors, speakers, and guests are advised that during the conference, photographs will be taken as well as audio/video recordings made of various activities, events, and sessions. Each registrant grants the Foundation permission to be photographed in any session and to use such photographs and the names of attendees in any materials which either represent the proceedings of the conference or discuss future conferences. IF YOU DO NOT GRANT THIS PERMISSION, PLEASE VISIT THE REGISTRATION BOOTH FOR A SPECIAL NAME BADGE BEFORE ATTENDING ANY SESSIONS.

Industry Sponsored Presentation
Saturday evening after dinner, from 6:45 p.m. to 7:30 p.m., you are invited to attend "Overview of CATALYST, an Ongoing Study in Pulmonary Arterial Hypertension Associated with Scleroderma," Tracy Frech, M.D., presenter, presented by Reata Pharmaceuticals, in Chicago E.

The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials, or studies referenced during the 2019 National Patient Education Conference. Information presented is to keep attendees informed. Because the manifestations and severity of scleroderma vary among individuals, personalized medical management is essential. Therefore, it is strongly recommended that all drugs and treatments be discussed with the patient’s physician(s) for proper evaluation and treatment.
Enjoy the wide range of opportunities to learn at this conference from among the 64 workshop presentations by 55 speakers.

The Awards Luncheon is an opportunity for all attendees to learn about and celebrate the great work and impressive volunteer efforts contributed across the Scleroderma Foundation.

During the Saturday buffet dinner, enjoy music by **Standing Room Only Orchestra**, one of Chicago’s most versatile bands.

Check out the **Yoga Room** stationed in Chicago H. Back by popular demand, wake-up sessions get Saturday and Sunday started right. Other yoga classes are offered as workshops throughout the day. Classes are led by a yoga instructor and all sessions can be modified for your abilities.
Awards Luncheon

Join us for the Saturday Awards Luncheon and help us celebrate the achievements of our volunteers around the country for their passion and commitment to the mission of the Scleroderma Foundation to those who live with the disabling effects of the disease. The following awards will be presented.

CHAPTER AWARDS
Outstanding Education Program
Outstanding Chapter Awareness
Outstanding Patient Support
Support Group Volunteer of the Year
Chapter Volunteer of the Year

NATIONAL AWARDS
National Volunteer of the Year
Individual Fundraiser of the Year
Philanthropist of the Year
Messenger of Hope
Outstanding National Advocate
Chapter of the Year
Doctor of the Year
Lifetime Achievement

Social Media, Rest Stop, Taxi

#HASHTAGS
#TheSkystheLimit
#KidsGetSclerodermaToo
#KGS2

We know you’re tweeting and posting selfies—and that’s great! Why not let your social network know what you’re up to at the National Patient Education Conference. Post, tweet, snap, whatever... Use #TheSkystheLimit in all your messages, and tag the Scleroderma Foundation. You can find us at:

Facebook.com/sclerodermaUS
Twitter.com/scleroderma
Instagram.com/sclerodermaUS
YouTube.com/sclerodermaUS

WiFi Network: Marriott_CONFFERENCE
Password: scleroderma2019

SCLERODERMA REST STOP

Houston Room
The Scleroderma Rest Stop is a quiet sitting area for conference attendees to take a break. Visit the Houston Room on the 5th floor. HOURS:

• Saturday - 7:45 a.m. - 5 p.m.
• Sunday - 8 a.m. - 12:30 p.m.

WHEELCHAIR TAXI SERVICE
Complimentary short-term wheelchair "taxi" service is available to conference attendees who are fatigued and need a ride within the conference area only (not including guest rooms). There are a limited number of wheelchairs and volunteers who will gladly give you a push between conference rooms. If you are in need of a lift, look for the “TAXI” sign to flag down a ride.
OPENING KEYNOTE: Friday, 7:30 p.m. - 8:30 p.m.

Endure: The Life & Art of Paul Klee
Richard M. Silver, MD
Medical University of South Carolina

Paul Klee, one of the 20th century’s most important artists, lived with systemic sclerosis (scleroderma). Klee’s life was fascinating and, at times, tragic. His art is an expression of his time and the disease he so bravely endured.

CLOSING KEYNOTE: Sunday, 11:15 a.m. - 12:15 p.m.

UNSTOPPABLE: When Strong Is All There Is
Betsy Craig, Public Speaker, Author, and Founder of MenuTrinfo, LLC

After falling ill from scleroderma in the early to mid-2000s, Betsy Craig had to find a strength she did not know was there. Being UNSTOPPABLE was her only option, and in the end, she credits her success with business, disease, and life with that exact trait, being UNSTOPPABLE. Staying in recovery with scleroderma, starting a cutting-edge, award-winning, million-dollar business, MenuTrinfo, LLC, and living her best life has made her a much sought-after national speaker who carries a message of hope, triumph, and pure joy. In 2018, she released her first book, UNSTOPPABLE: A Recipe for Success in Life and Business, and today she shares parts of her journey with you.

(NOTE: Both keynote presentations will be filmed.)
SHARE YOUR AWARENESS SELFIE!

Visit the Advocacy booth in the Exhibit Hall and snap a scleroderma awareness selfie, then tweet your selfie and tag the Foundation’s Twitter handle, @scleroderma.

If you’re on Facebook, post it there, too, and tag the Foundation @ sclerodermaUS.

Don’t stop there! Tag your chapter, your support group, and others in your social network.

Use hashtags to spread the word.

• #TheSkystheLimit
• #KidsGetSclerodermaToo
• #SclerodermaAware
• #SpeakUpForScleroderma

After posting, please email your selfie to selfie@scleroderma.org with your name in the subject line.

Don’t forget to sign a photo release to give the Foundation permission to share your selfie to raise awareness.

Exhibit Hall

Enhance your conference learning experience with a visit to the interactive Exhibit Hall! Engage in informative discussions with our many exhibitors.

An exhibitor game card is located in your name badge lanyard. Have each exhibitor stamp in the appropriate spot on the card. Once all have been stamped, sign and turn it in to the registration booth, starting on Saturday, and you will be entered to win a $50 American Express gift card! The drawing will be held at the end of the conference and the winner will be notified after the conference.

This activity was developed to encourage all attendees to visit the Exhibit Hall during the 2019 Conference. Support from our sponsors and exhibitors helps make this conference possible. Please show your gratitude by visiting their booths.
# Schedule at a Glance - Main Conference

## FRIDAY, JULY 19

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>4:00 p.m. - 8:30 p.m.</td>
<td>Registration</td>
<td>Salon II, 7th Floor</td>
</tr>
<tr>
<td>4:00 p.m. - 7:15 p.m.</td>
<td>Exhibit Hall</td>
<td>Salon I, 7th Floor</td>
</tr>
<tr>
<td>5:00 p.m. - 7:15 p.m.</td>
<td>Poster Hall</td>
<td>Pre-Function Area, 7th Floor</td>
</tr>
<tr>
<td>6:30 p.m. - 7:15 p.m.</td>
<td>Welcome Reception</td>
<td>Salon III, 7th Floor</td>
</tr>
<tr>
<td>7:15 p.m. - 7:30 p.m.</td>
<td>Please find a seat for the Opening Keynote</td>
<td>Salon III, 7th Floor</td>
</tr>
<tr>
<td>7:30 p.m. - 8:30 p.m.</td>
<td>Welcome &amp; Opening Keynote*</td>
<td>Salon III, 7th Floor</td>
</tr>
</tbody>
</table>

## SATURDAY, JULY 20

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:45 a.m. - 6:30 p.m.</td>
<td>Registration</td>
<td>5th Floor</td>
</tr>
<tr>
<td>7:45 a.m. - 9:00 a.m.</td>
<td>BREAKFAST BUFFET</td>
<td>Salon II &amp; III, 7th Floor</td>
</tr>
<tr>
<td>8:30 a.m. - 5:00 p.m.</td>
<td>Exhibit Hall</td>
<td>Salon I, 7th Floor (closed during Awards Luncheon)</td>
</tr>
<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Systemic Sclerosis Lecture: <em>Lung Involvement in Scleroderma</em></td>
<td>Salon II &amp; III, 7th Floor</td>
</tr>
<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Localized Scleroderma Lecture: <em>Diagnosis &amp; Treatment</em></td>
<td>Chicago D, 5th Floor</td>
</tr>
<tr>
<td>10:15 a.m. - 10:45 a.m.</td>
<td>BEVERAGE BREAK</td>
<td>Exhibit Hall, Salon I, 7th Floor</td>
</tr>
<tr>
<td>10:45 a.m. - 11:45 a.m.</td>
<td>Workshops</td>
<td>See page 14 for workshop location</td>
</tr>
<tr>
<td>12:15 p.m. - 1:45 p.m.</td>
<td>AWARDS LUNCHEON</td>
<td>Salon II &amp; III, 7th Floor</td>
</tr>
<tr>
<td>2:15 p.m. - 3:15 p.m.</td>
<td>Workshops</td>
<td>See page 14 for workshop location</td>
</tr>
<tr>
<td>3:15 p.m. - 3:45 p.m.</td>
<td>BEVERAGE BREAK</td>
<td>Exhibit Hall, Salon I, 7th Floor</td>
</tr>
<tr>
<td>3:45 p.m. - 4:45 p.m.</td>
<td>Last Workshops of the Day</td>
<td>See page 14 for workshop location</td>
</tr>
<tr>
<td>5:00 p.m. - 6:15 p.m.</td>
<td>DINNER BUFFET (Entertainment by <em>Standing Room Only Orchestra</em>)</td>
<td>Salon II &amp; III, 7th Floor</td>
</tr>
<tr>
<td>6:45 p.m. - 7:30 p.m.</td>
<td>Industry Sponsored Presentation: Overview of CATALYST</td>
<td>Chicago E, 5th Floor</td>
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## SUNDAY, JULY 21

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 a.m. - 12:30 p.m.</td>
<td>Registration</td>
<td>5th Floor</td>
</tr>
<tr>
<td>7:00 a.m. - 8:15 a.m.</td>
<td>BREAKFAST BUFFET</td>
<td>Salon II &amp; III, 7th Floor</td>
</tr>
<tr>
<td>8:00 a.m. - 11:30 a.m.</td>
<td>Exhibit Hall</td>
<td>Salon I, 7th Floor</td>
</tr>
<tr>
<td>8:30 a.m. - 9:30 a.m.</td>
<td>Workshops</td>
<td>See page 15 for workshop location</td>
</tr>
<tr>
<td>9:30 a.m. - 9:45 a.m.</td>
<td>BEVERAGE BREAK</td>
<td>Exhibit Hall, Salon I, 7th Floor</td>
</tr>
<tr>
<td>9:45 a.m. - 10:45 a.m.</td>
<td>Workshops</td>
<td>See page 15 for workshop location</td>
</tr>
<tr>
<td>10:45 a.m. - 11:15 a.m.</td>
<td>SNACK BREAK</td>
<td>Salon I, 7th Floor</td>
</tr>
<tr>
<td>11:15 a.m. - 12:15 p.m.</td>
<td>Closing Keynote*</td>
<td>Salon II &amp; III, 7th Floor (&quot;filmed&quot;)</td>
</tr>
<tr>
<td>12:15 P.M. - 12:30 P.M.</td>
<td>Please return completed conference evaluations on Sunday to the Registration Booth, 5th floor</td>
<td></td>
</tr>
</tbody>
</table>
Speakers and Facilitators

Cheryl Albright, OTR/L, C-IAYT
Soul to Soul Yoga, Yoga for Scleroderma

Mary Alore, MBA, Patient Partner, University of Michigan Scleroderma Center

Sundar Balasubramanian, PhD, C-IAYT
Medical University of South Carolina

Swati Bhattacharyya, PhD
Northwestern University

Maggie Blaisdell, Youth Patient Advocate

Jill Blitz, PT, DPT, ATP
Children's Hospital of Los Angeles

Richard Burt, MD, Feinberg School of Medicine, Northwestern University

Adam Cerilli, Support Group Leader, Patient Advocate

Yvonne Chiu, MD
Medical College of Wisconsin

Philip Clements, MD, MPH
University of California, Los Angeles

Betsy Craig, Public Speaker, Author, Founder of MenuTrinfo, LLC

Sneha Dave, Executive Director, Health Advocacy Summit

Seema Dave, Youth Patient Advocate

Jason Delaney, Patient Advocate

Laura Dyas, LSW, LPC, CCTP, AMTP, MA
Executive Director, Michigan Chapter

Jessica Farrell, PharmD, Albany College of Pharmacy and Health Services

Claire Fedoruk, SPIN (Scleroderma Patient-Centered Intervention Network)

Carol Feghali-Bostwick, PhD
Medical University of South Carolina, Scleroderma Foundation Board of Directors

Tracy Frech, MD, MS, University of Utah, Salt Lake Veterans Affair Medical Center

Benjamin H. Freed, MD, FACC, FASE
Division of Cardiology Northwestern Medicine

Daniel Furst, MD
University of California, Los Angeles

Elaine A. Furst, RN, MA
Independent Patient Advocate

Ashraf Girgis, MSN, SC&T, ND
Cure Naturally, LLC

Philip Goglas, II
Health and Medicine Counsel of Washington

Roberta Goncalves-Marangoni, MD, PhD
Northwestern University

JoAnna Harper, PharmD, RPh
Pain Partners, LLC/Idaho Support Group

Alexis Harrison, RCYT, RYT200, Yoga for the Special Child®, Yoga for Scleroderma

Karen Ho, MD, Northwestern University

Martin Hogan, DDS
Loyola University Chicago

Laura Hummers, MD, ScM
Johns Hopkins University Scleroderma Center

Dinesh Khanna, MD, MS
University of Michigan Scleroderma Center

Jennifer La Civita, PsyD, LCPC, ATR-BC
La Civita Healthcare Private Practice

Anna Lam, MD, Northwestern University

David Leader, DMD, MPH
Tufts University School of Dental Medicine

Suzanne Li, MD, PhD
Hackensack Meridian Health

Maureen Mayes, MD, MPH, University of Texas, McGovern Medical School, Houston

Kendra McAnally, DO, Pulmonary/Critical Care, Lafayette General Hospital

Luke Medolla, A Lasting Mark, Youth Patient Advocate

Marybeth Medolla, RN, A Lasting Mark, Youth Patient Advocate

Lori Pierce, RYT200, Kodawari Studios

Janet Poole, PhD, OTR/L
University of New Mexico

Janet Pope, MD, MPH
University of Western Ontario

Natalie Puccio, Patient Advocate

Kathy Randolph, C-IAYT
The Yoga Center Reno

Lesley Ann Saketkoo, MD, MPH
Tulane University School of Medicine

Ron Sasso, MS, LPC
Scleroderma Foundation Black Hills South Dakota Support Group, Author

Maggie Sepkowitz, LCSW
Children's Hospital Los Angeles

Richard Silver, MD
Medical University of South Carolina

Virginia Steen, MD
Georgetown University Hospital

Melissa Tarantino, Patient Advocate

Kathryn Torok, MD
Children's Hospital of Pittsburgh

John Varga, MD, Northwestern University-Director of Scleroderma Program

Elizabeth R. Volkman, MD, MS
University of California, Los Angeles

Deborah Winter, PhD
Northwestern University

Michael York, MD, Boston University School of Medicine Scleroderma Program
Friday Schedule - Main Conference

4:00 P.M. - 8:30 P.M.
Registration
Salon II, 7th floor

4:00 P.M. - 7:15 P.M.
Exhibit Hall
Salon I, 7th Floor

5:00 P.M. - 7:15 P.M.
Poster Hall
Pre-Function Area, 7th Floor

Interact with researchers who are advancing the understanding of scleroderma and developing treatment possibilities. A poster session is a relaxed format that allows an up close view of the scientists' work and a chance to ask one-on-one questions. It is an invaluable learning experience for attendees and presenters alike.

6:00 P.M. - 7:15 P.M.
Welcome Reception
Salon III, 7th Floor

Reconnect with the friends you made at conference last year and make new ones while you enjoy light refreshments. Young adults, look for yellow balloons at the welcome reception and in meal rooms to sit together.

7:30 P.M. - 8:30 P.M.
Opening Keynote:
"Endure: The Life & Art of Paul Klee" by Richard M. Silver, MD
Salon III, 7th Floor
(This presentation will be filmed.)

We strive to help PH patients thrive.

We work every day to help patients with pulmonary hypertension. It’s more than a mission; it’s our promise.
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
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</thead>
<tbody>
<tr>
<td>7:45 a.m.</td>
<td>BREAKFAST - Salon II &amp; III (Young adults, look for tables with yellow balloons to sit together)</td>
</tr>
<tr>
<td>7:45 a.m. - 8:15 a.m.</td>
<td>Wake Up With Yoga - Chicago H</td>
</tr>
<tr>
<td>9:15 a.m.</td>
<td>Localized Scleroderma: Diagnosis &amp; Treatment*</td>
</tr>
<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Systemic Scleroderma: Lung Involvement in Scleroderma*</td>
</tr>
<tr>
<td>10:15 a.m.</td>
<td>BEVERAGE BREAK - Exhibit Hall (Salon I)</td>
</tr>
<tr>
<td>10:45 a.m.</td>
<td>Heart Disease in Scleroderma*</td>
</tr>
<tr>
<td>10:45 a.m. - 11:45 a.m.</td>
<td>Scleroderma 101</td>
</tr>
<tr>
<td>12:15 p.m.</td>
<td>AWARDS LUNCHEON - Salon II &amp; III (Young adults, look for tables with yellow balloons to sit together)</td>
</tr>
<tr>
<td>2:15 p.m.</td>
<td>For Our Loved-Ones (Caregivers)</td>
</tr>
<tr>
<td>2:15 p.m. - 3:15 p.m.</td>
<td>Nutrition and the GI Microbiome in Systemic Sclerosis*</td>
</tr>
<tr>
<td>3:15 p.m.</td>
<td>BEVERAGE BREAK - Exhibit Hall (Salon I)</td>
</tr>
<tr>
<td>3:15 p.m. - 4:45 p.m.</td>
<td>Emergencies in Scleroderma</td>
</tr>
<tr>
<td>5:00 p.m.</td>
<td>DINNERS BUFFET - Salon II &amp; III, Entertainment by Standing Room Only Orchestra (Young adults, look for tables with yellow balloons to sit together)</td>
</tr>
<tr>
<td>6:45 p.m.</td>
<td>Industry Sponsored Presentation: Overview of CATALYST, an Ongoing Study in Pulmonary Arterial Hypertension Associated with Scleroderma</td>
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</table>

*filmed session
<table>
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<th>Session</th>
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<tbody>
<tr>
<td>7:00 a.m. - 8:15 a.m.</td>
<td><strong>BREAKFAST</strong> - Salon II &amp; III (Young adults, look for tables with yellow balloons to sit together)</td>
</tr>
<tr>
<td>7:00 a.m. - 7:30 a.m.</td>
<td><strong>Wake Up with Yoga</strong> - Chicago H</td>
</tr>
<tr>
<td>8:30 a.m. - 9:30 a.m.</td>
<td>Living with Scleroderma After 10 Years Janet Pope, MD, MPH Chicago A</td>
</tr>
<tr>
<td>9:30 a.m. - 9:45 a.m.</td>
<td><strong>BEVERAGE BREAK</strong> - Exhibit Hall (Salon I)</td>
</tr>
<tr>
<td>9:45 a.m. - 10:45 a.m.</td>
<td>Pregnancy in Scleroderma Laura Hummers, MD, ScM Chicago A</td>
</tr>
<tr>
<td>10:45 a.m. - 11:15 a.m.</td>
<td><strong>SNACK BREAK</strong> - Salon I</td>
</tr>
<tr>
<td>11:15 a.m. - 12:15 p.m.</td>
<td>CLOSING KEYNOTE - UNSTOPPABLE: When Strong Is All There Is Betsy Craig - Salon II &amp; III *FILMED SESSION</td>
</tr>
</tbody>
</table>
The lungs are potentially affected in all patients with systemic scleroderma. Patients need to know how they can be proactive in helping the doctors identify any lung involvement as early as possible. We now have more than 14 treatments for the once deadly complication of pulmonary hypertension and over the last 5 years, there have been lots of exciting advances in the treatment of pulmonary fibrosis. We will review these important complications of scleroderma and the newer treatments.

The workshop will provide a brief overview of the different forms of localized scleroderma and how localized scleroderma differs from systemic sclerosis. The speaker will discuss the natural history of the disease, treatment options, and experimental approaches.

A discussion of the different kinds of scleroderma (localized versus diffuse systemic versus limited systemic forms). Also discussed are the meanings of typical scleroderma autoantibodies such as the Scl 70 (Scleroderma-70 antibody) and the centromere antibody; and what they mean for predicting organ involvement in scleroderma. Additional discussion on what tests are usually done in scleroderma to monitor organ involvement and what current and future medications are routinely used.

Scleroderma 101
Maureen Mayes, MD, MPH
Chicago A

Raynaud and Digital Ischemia (Ulcerations)*
Philip Clements, MD, MPH
Chicago D

Ninety percent of persons with scleroderma have the distinctive color changes in the hands that defines Raynaud. About half of persons with scleroderma may also develops painful ulcers of the skin, particularly in the fingers. A much small percentage of persons will develop severe painful ischemic involvements of the fingers. In this module, there will a discussion of the changes in the blood vessels and in the flow of blood that can lead to Raynaud, ulcers and severe ischemia. In addition, the treatments that can be used to manage Raynaud, ulcers and severe ischemia will be discussed.

*FILMED SESSION
Medications in Scleroderma*
Jessica Farrell, PharmD
Chicago E

Current medications used to treat patients with scleroderma focus on the four main features of the disease: inflammation, autoimmunity, vascular disease, and tissue fibrosis. Because there are multiple subtypes and different clinical presentations of scleroderma, medication regimens vary greatly from patient to patient. This presentation will review common medications prescribed in scleroderma and will include a description of how the medication works, common side effects, and monitoring. Additionally, medications to avoid that can worsen symptoms of scleroderma will be discussed.

Hematopoietic Stem Cell Transplantation for Systemic Sclerosis
Richard Burt, MD
Chicago F

The speaker will touch on various topics pertaining to stem cell transplantation procedures for scleroderma patients. Learn about the most current information on this treatment option.

Know the Face of Scleroderma
Advocacy Committee: Demi Montgomery, Tina Fellows
Chicago G

In this awareness workshop, you’ll hear inspiring stories from people whose lives and families have been affected by scleroderma. You’ll learn creative ways to raise awareness, to educate others about scleroderma, and how to use social media to reach a wider audience. No previous social media experience necessary. Visit the advocacy booth in the Exhibit Hall before (and after) the workshop to learn how to tweet and post your own awareness selfie.

*filmed session
Breathe Well and Feel Better--

Easy Breathing Exercises for Scleroderma

Sundar Balasubramanian, PhD, C-IAYT
Chicago H (Yoga Room)

Join this 60-minute hands on experience workshop to learn how to improve your breathing and use the easy breathing exercises to reduce your stress. Research by Dr. Balasubramanian shows that regulated breathing exercises can help stimulate saliva and can promote healing within the body and mind. You can sit on a chair comfortably and practice these easy exercises. No prior experience necessary. Caregivers, friends and families are most welcome to join! Do not miss this on both days!

2:15 P.M. - 3:15 P.M. (SATURDAY, JULY 20)

Heart Disease in Scleroderma*

Benjamin H. Freed, MD, FACC, FASE
Chicago A

This talk will review how scleroderma affects the heart and the various manifestations of the disease. In addition, we will discuss the standard workup in patients with scleroderma who have cardiac symptoms and outline some of the therapies that are commonly used.

A Gentle Approach to Healthy Living: The Arts, Art Therapy, and Adlerian Art Therapy Methods

Jennifer La Civita, PsyD, LCPC, ATR-BC
Chicago B

Dr. Jennifer La Civita explores the use of art combined with Adlerian art therapy methods to help navigate life in a healthy, holistic way.

Understanding and Living with Scleroderma as a Man

Richard Silver, MD
Chicago C

Scleroderma affects men less often than women. When it does, men with scleroderma face certain challenges that often impact their daily lives. Various aspects of men with scleroderma will be discussed in an informal setting with ample time for Q&A. (Men Only)

Nutrition and the GI Microbiome in Systemic Sclerosis*

Elizabeth Volkmann, MD, MS
Chicago D

This session explores how nutrition can affect microbial composition and symptoms in patients with systemic sclerosis.

For Our Loved Ones (Caregivers)

Lesley Ann Saketkoo, MD, MPH
Chicago E

Whether someone with SSc or a loved one of someone with SSc, together we live with changing dynamics that influence our physical and emotional health. Despite these challenges, we aspire to be our best selves for our loved ones. This session, for patients and loved ones, presents current research on chronic illness burden for patients and family members (caregivers), highlighting interventions that can help families develop strategies to protect each other’s physical and emotional health.

Learn About the Self-Management Website

Mary Alore, MBA
Chicago F

The Self-Manage Scleroderma website is a resource designed to help you learn about scleroderma, manage your symptoms, and learn strategies to help you advocate for yourself. Learn about how it started, who contributed, and how it can help you gain knowledge and skills on managing a chronic disease.

Awareness and Advocacy:

Essential to the Legislative Process

Philip Goglas II, Health & Medicine Counsel of Washington (HMCW)
Chicago G

“Advocacy isn’t political, it’s personal.” “The only different between awareness and advocacy is the audience.” These quotes are from support group leaders whose scleroderma stories motivated them to become advocacy powerhouses! Facilitated by a public policy expert who works directly with the Scleroderma Foundation, you’ll learn about research funding to find a cure. Hear about advocacy success

*FILMED SESSION
stories at local and national levels, and take home practical resources that will help you develop a strong voice that elected officials need to hear.

How to Go to a Yoga Class
Kathy Randolph, C-IAYT, Cheryl Albright, OTR/L, C-IAYT, Lori Pierce, RYT200, Alexis Harrison, RCYT, RYT200
Chicago H (Yoga Room)
Learn what you need to know to go to a yoga class near you! Included are modifications for yoga poses that will work for you, using a chair or the wall instead of the floor, using props—both common yoga props found at studios and small portable items you can bring in your own “yoga kit”—and a 30-second answer to “What does your yoga teacher need to know about your scleroderma?”

3:45 P.M. - 4:45 P.M. (SATURDAY, JULY 20)
Emergencies in Scleroderma*
Tracy Frech, MD, MS
Chicago A
In this session Dr. Frech will discuss scleroderma renal crisis, digital ischemia, severe unremitting abdominal pain, concern for infection on immunosuppression medications, and change in respiratory symptoms. Attendees will learn strategies for management and prevention. Time is set aside for questions and group discussion.

African Americans and Scleroderma
Virginia Steen, MD
Chicago B
Studies have suggested that African Americans suffer more severely with scleroderma and its complications. Listen to a scleroderma expert with a particular interest in treating the African American population.

*FILMED SESSION
(continued)
How to Train Your Doctor
Elaine A. Furst, RN, MA
Chicago C

Doctors are human. We rely on them to help us. What do you do when your doctor means well but isn’t an expert on scleroderma diagnosis and treatment? What about when your doctor doesn’t seem to want to learn about your disease? Elaine has some thoughts about these and other scenarios. Come listen and share experiences with the group.

Treatment of Scleroderma: More Options Are Coming (EULAR/ACR 2018)*
Dan Furst, MD
Chicago D

With greater understanding of how scleroderma occurs and better outcome measures, trials of new drugs and new mechanisms of action are beginning to appear—both successes and failures. In alphabetical order, the following will be discussed: Hematological stem cell transplantation, Lenabasum, Nintedanib, Riocicquat, Tocilizumab. If there is time, lung transplantation will be discussed. Finally, research is beginning to learn how to choose the best drug for each person.

How to be Master of Your Universe Within
Ashraf Girgis, MSN, SC&T, ND
Chicago E

The objectives of this workshop are 1) learn about naturopathic medicine approach toward inflammatory diseases. 2) Learn about stress management techniques. 3) Understand the role of food and inflammatory diseases. 4) Understand the role of environmental toxins and inflammation. 5) Learn about herbs and inflammation; and much more.

Lung Transplants in Scleroderma
Kendra McAnally, DO
Chicago F

What to expect in the pre-transplant evaluation, while being listed, and post-transplant period. The focus of this discussion is to help you and your family navigate the complicated transplant process.

Living Life to the Fullest: Young Adults Panel
JoAnna Harper, PharmD, RPh, Natalie Puccio, Adam Cerilli, Melissa Tarantino, and Jason Delancy
Chicago G

The young adult panel is created for all those burning questions that may not be appropriate to ask random people, answered by scleroderma warriors who have experienced the hardships and the joys. Dating, marriage, education, having children, raising a family, having a career, and much more will be discussed. Please join us, "cool kids," for a lively conversation and bring all your questions, big or small.

Keep Your Scleroderma Body Moving with Yoga
Lori Pierce, RYT200
Chicago H (Yoga Room)

Lori Pierce guides you through one of the yoga routines that she uses to keep her body moving! Lori will share her own journey with scleroderma and yoga from a dismal prognosis and unable to dress herself to a travelling yoga teacher, living on her own and encouraging others with scleroderma to keep their bodies moving, too. Lori will take away all your excuses with her tips and tricks, adaptations and modifications, inspiration and hope!

SUNDAY, JULY 21, 2019

8:30 A.M. - 9:30 A.M.

Living with Scleroderma After 10 Years
Janet Pope, MD, MPH
Chicago A

In this session, find out answers to what happens in long standing scleroderma. Topics discussed will include blood vessels in the finger, the gut, hand contractors, dry mouth, and more. The speaker will also answer other hot topic questions such as Is this as bad as I will get? and What should I still be screened for?

*FILMED SESSION
Interstitial Lung Disease (ILD)/Pulmonary Fibrosis
Lesley Ann Saketkoo, MD, MPH
Chicago B

The session is dedicated to raising awareness of key risk factors and symptoms of SSc-related ILD/PF such as breathlessness, cough, and fatigue. The session will look at health outcomes and address both medication and healthy living strategies for preserving health and quality of life.

How Scleroderma Affects Your Family
Elaine A. Furst, RN, MA
Chicago C

Any chronic disease affects everyone who cares about the person suffering from that disease. How does it particularly affect members of the family? Using science and experience with patients and their loved ones, Elaine will discuss the answer to that question.

GI Issues in Scleroderma*
Dinesh Khanna, MD, MS
Chicago D

In this session, you will learn about the gastrointestinal tract in systemic sclerosis. We will cover common conditions, treatments, and the importance of tracking symptoms. Frequently ordered tests will also be discussed.

Cannabis Conundrum: Weighing the Pros and Cons of THC, CBD and Related Compounds in Scleroderma*
JoAnna Harper, PharmD, RPh
Chicago E

By popular demand, we will take an in-depth look into cannabis for medicinal purposes, including possible ways it works, differences between products (CBD from hemp, medical cannabis, cannabis from dispensaries, THC vs. CBD, etc.), as well as important concerns that need to be addressed. Since this is a hot topic, we anticipate many questions and opinions, with the primary goal to educate you from an open-minded, yet cautious medical provider perspective.

*FILMED SESSION
Sicca Syndrome and Sjögren Syndrome
Philip Clements, MD, MPH
Chicago F

Sixty percent of persons with scleroderma complain of dry eyes and dry mouth. A smaller percentage (about 15 percent) have Sjögren Syndrome (an auto-immune disease that slowly destroys the glands that produce saliva and tears) as the underlying cause of dryness. In this module, there will be a discussion of causes of dryness and how to manage the problems associated with dryness as well as the particular problems that may be seen in Sjögren Syndrome.

Toward Finding a Cure: Exciting Recent Research
Advances from Scleroderma Foundation Supported New Investigators, Part 1
John Varga, MD, Carol Feghali-Bostwick, PhD
Chicago G

This workshop presents an overview of the Scleroderma Foundation Research Grant Program, including what “Peer Review” means. Also included are presentations by researchers Swati Bhattacharyya and Anna Lam; plus, a question and answer period.

Yoga for Your Hands
Cheryl Albright, OTR/L, C-IAYT
Chicago H (Yoga Room)

An entire program just for increased circulation, strength, and mobility for your hands. This practice will include hand work from “Yoga for Scleroderma” and “Assisted Yoga for Scleroderma” all in one class, plus new material for hands and wrists, how to use props so you can go further on your own, and tips on symptom relief for Raynaud. Yoga is performed while seated in chairs, so come as you are!

9:45 A.M. - 10:45 A.M. (SUNDAY, JULY 21)

Pregnancy in Scleroderma
Laura Hummers, MD, ScM
Chicago A

In this session we will review what needs to be considered if a patient with scleroderma is contemplating pregnancy. This will include information on fertility, pregnancy risks, patient risks, and medication management.

Taking Care of Your Hands & Face
Janet Poole, PhD, OTR/L
Chicago B

In this session, participants will learn about modalities and exercises to improve movement and function in the hands, face, and mouth. Suggestions will be also be provided on the use of assistive devices and alternate techniques to accomplish tasks of daily living to increase independence, protect the hands, or when patients have limited finger movement.

Adjusting to Change and Loss, Moving Forward
Ron Sasso, MS, LPC
Chicago C

Scleroderma causes changes in many areas of a person’s life. It also brings different types of loss, from the tangible to the ambiguous. This session will explore those areas and help you find a way through toward acceptance (not complacency) and moving forward.

What Do I Need to Know About Immunizations*
Tracy Frech, MD, MS
Chicago D

In this session Dr. Frech will review recommendations from the Center for Disease Control on immunizations. Participants will learn why health care maintenance and immunosuppression planning includes immunizations. There will be time for questions and group discussion.

*FILMED SESSION
Pulmonary Hypertension in Systemic Sclerosis*
Dinesh Khanna, MD, MS
Chicago E

In this talk we are going to discuss several questions you might ask. What exactly is pulmonary hypertension? What are the chances that I will develop it? What are the signs and symptoms that I might experience if I develop pulmonary hypertension? How do we diagnose pulmonary hypertension? Will pulmonary hypertension shorten my life? How do we treat pulmonary hypertension?

The Who, Why, and How of Getting Involved in Scleroderma Research
Claire Fedoruk
Chicago F

People with scleroderma and their caregivers can help advance scleroderma research in many ways, from answering online surveys to partnering with researchers to design a study. This session will address some basic questions you might have about getting involved in research, including: who can get involved in research, why get involved with research, and how can I get involved?

Toward Finding a Cure: Exciting Recent Research Advances from Scleroderma Foundation Supported New Investigators, Part 2
John Varga, MD and Carol Feghali-Bostwick, PhD
Chicago G

This workshop presents an overview of the Scleroderma Foundation Research Grant Program, including what “Peer Review” means. Also included are presentations by researchers Roberta Goncalves, Deborah Winter, and Karen Ho; plus, a question and answer period.

*FILMED SESSION
Breathe Well and Feel Better--

*Easy Breathing Exercises for Scleroderma*

Sundar Balasubramanian, PhD, C-IAYT

*Chicago H (Yoga Room)*

Join this 60-minute hands on experience workshop to learn how to improve your breathing and use the easy breathing exercises to reduce your stress. Research by Dr. Balasubramanian shows that regulated breathing exercises can help stimulate saliva and can promote healing within the body and mind. You can sit on a chair comfortably and practice these easy exercises. No prior experience necessary. Caregivers, friends and families are most welcome to join! Do not miss this on both days!
Kids Get Scleroderma, Too! (KGS2) offers a robust agenda throughout the weekend. Working closely with pediatric providers from across the United States, the program is designed for our younger attendees and their caregivers to learn about scleroderma in a fun environment that promotes making new connections.

The entire weekend is filled with engaging, fun workshops and activities. Parents and caregivers can go to any conference session offered throughout the weekend. If you are looking to focus on the youth aspect of scleroderma, there are plenty of options.

All attendees associated with KGS2, whether child or adult, should attend the orientation/check-in session Friday evening, Northwestern & Ohio, 6th floor, 4 to 6 p.m.

The Scleroderma Foundation has contracted with a professional childcare agency, KiddieCorp (kiddiecorp.com), that specializes in supervised activities for large events. You are welcome to check in with your child via text or cell phone. You may also check in with the KiddieCorp manager.

KGS2 is divided into two rooms that provide programming for the whole family. The Kids’ Activity Room, located in Northwestern & Ohio (6th floor), is for youth aged 5 to 17. The activity room, managed by KiddieCorp, provides programming that runs concurrently with the other workshops.

The Kids’ Activity Room is a great place for young children who have scleroderma and their siblings, plus children whose parent has scleroderma, to meet and do projects together while the parents and older youth with scleroderma attend workshops.

Lincolnshire I & II (6th floor) is home to programming aimed at the older youth population, aged 11 to 17.

Parents, guardians, and caregivers meet in Indiana & Iowa (6th floor), where experts run educational workshops for adults who have a young person with scleroderma in their life. Join other parents, guardians, and caregivers to learn about and how to cope with the disease.

To participate in KGS2, parents, guardians, or caregivers must sign a liability release and sign their child or children in and out whenever arriving or leaving the KGS2 area.
## Schedule at a Glance - Kids Get Scleroderma, Too!

### FRIDAY, JULY 19

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>4:00 p.m. - 6:00 p.m.</td>
<td>Orientation/Check-In w/KiddieCorp</td>
<td>Northwestern &amp; Ohio, 6th Floor (After registering on 7th floor)</td>
</tr>
<tr>
<td>4:00 p.m. - 7:15 p.m.</td>
<td>Exhibit Hall</td>
<td>Salon I, 7th Floor</td>
</tr>
<tr>
<td>5:00 p.m. - 7:15 p.m.</td>
<td>Poster Hall</td>
<td>Pre-Function Area, 7th Floor</td>
</tr>
<tr>
<td>6:00 p.m. - 8:30 p.m.</td>
<td>Carnival</td>
<td>Northwestern &amp; Ohio, 6th Floor (Please pick up children by 8:30 p.m.)</td>
</tr>
<tr>
<td>7:15 p.m. - 7:30 p.m.</td>
<td>Please find a seat for the Opening Keynote</td>
<td>Salon III, 7th Floor</td>
</tr>
<tr>
<td><strong>7:30 p.m. - 8:30 p.m.</strong></td>
<td><strong>Welcome &amp; Opening Keynote</strong>*</td>
<td><strong>Salon III, 7th Floor</strong> (<em>filmed</em>)</td>
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### SATURDAY, JULY 20

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:45 a.m. - 6:30 p.m.</td>
<td>Information &amp; Registration</td>
<td>5th Floor Registration Booth</td>
</tr>
<tr>
<td>7:45 a.m. - 8:15 a.m.</td>
<td>Wake Up with Yoga</td>
<td>Chicago H, 5th Floor</td>
</tr>
<tr>
<td>7:45 a.m. - 9:00 a.m.</td>
<td>BREAKFAST BUFFET</td>
<td>Salon II &amp; III, 7th Floor</td>
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<tr>
<td>8:30 a.m. - 5:00 p.m.</td>
<td>Exhibit Hall</td>
<td>Salon I, 7th Floor (Closed during Awards Luncheon)</td>
</tr>
<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Workshops</td>
<td>See page 28 for workshop location</td>
</tr>
<tr>
<td>10:15 a.m. - 10:45 a.m.</td>
<td>BEVERAGE BREAK (parents/caregivers)</td>
<td>Outside Indiana &amp; Iowa, 6th Floor</td>
</tr>
<tr>
<td>10:45 a.m. - 11:45 a.m.</td>
<td>Youth Workshop</td>
<td>Northwestern &amp; Lincolnshire II &amp; III, 6th Floor</td>
</tr>
<tr>
<td><strong>12:15 p.m. - 1:45 p.m.</strong></td>
<td><strong>AWARDS LUNCHEON (parents/caregivers)</strong></td>
<td><strong>Salon II &amp; III, 7th Floor</strong></td>
</tr>
<tr>
<td>12:15 p.m. - 4:45 p.m.</td>
<td>Youth Lunch &amp; Field Trip</td>
<td>Northwestern, 6th Floor &amp; Shedd Aquarium</td>
</tr>
<tr>
<td>2:15 p.m. - 3:15 p.m.</td>
<td>Parent/Caregiver Workshop</td>
<td>Indiana &amp; Iowa, 6th Floor</td>
</tr>
<tr>
<td>3:15 p.m. - 3:45 p.m.</td>
<td>BEVERAGE BREAK (parents/caregivers)</td>
<td>Outside Indiana &amp; Iowa, 6th Floor</td>
</tr>
<tr>
<td>3:45 p.m. - 4:45 p.m.</td>
<td>Parent/Caregiver Workshop</td>
<td>Indiana &amp; Iowa, 6th Floor (Please pick up children at 4:45 p.m. for dinner)</td>
</tr>
<tr>
<td><strong>5:00 p.m. - 6:15 p.m.</strong></td>
<td><strong>DINNER BUFFET (youth/parents/caregivers)</strong></td>
<td><strong>Salon II &amp; III, 7th Floor</strong> (Entertainment by Standing Room Only Orchestra)</td>
</tr>
<tr>
<td>6:15 p.m. - 7:45 p.m.</td>
<td>Family Ice Cream Social, Pillow Art &amp; Awareness Discussion</td>
<td>Northwestern &amp; Ohio, 6th Floor</td>
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### SUNDAY, JULY 21

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<td>Salon I, 7th Floor</td>
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<td>8:30 a.m. - 9:30 a.m.</td>
<td>Workshops (teens/parents/caregivers)</td>
<td>See page 29 for workshop location</td>
</tr>
<tr>
<td>8:30 a.m. - 9:45 a.m.</td>
<td>Youth Workshop</td>
<td>Northwestern &amp; Ohio, 6th Floor</td>
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<tr>
<td>9:30 a.m. - 9:45 a.m.</td>
<td>BEVERAGE BREAK (parents/caregivers)</td>
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<td><strong>10:45 a.m. - 11:15 a.m.</strong></td>
<td><strong>SNACK BREAK (teens/parents/caregivers)</strong></td>
<td><strong>Outside Indiana &amp; Iowa, 6th Floor</strong></td>
</tr>
<tr>
<td>11:15 a.m. - 12:15 p.m.</td>
<td>Youth Workshop</td>
<td>Northwestern &amp; Ohio, 6th Floor</td>
</tr>
<tr>
<td>11:15 a.m. - 12:15 p.m.</td>
<td>Teen/Parent/Caregiver Workshop</td>
<td>Lincolnshire I &amp; II/Indiana/Iowa, 6th Floor</td>
</tr>
<tr>
<td><strong>12:15 P.M. - 12:30 P.M.</strong></td>
<td>Please return completed conference evaluations to the Registration Booth, 5th Floor</td>
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</tbody>
</table>
Friday Schedule - KGS2

4:00 P.M. - 6:00 P.M.

Orientation & Check-In
Northwestern & Ohio, 6th Floor

6:00 P.M. - 8:30 P.M.

Carnival
Northwestern & Ohio, 6th Floor

Kids Get Scleroderma, Too! (KGS2) is divided into two rooms that provide programming for the whole family.

The Kids’ Activity Room, located in Northwestern & Ohio (6th floor), is for youth aged 5 to 17. Managed by KiddieCorp, the Kids’ Activity Room provides programming that runs concurrently with the other workshops.

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Parents, guardians, and caregivers meet in Indiana & Iowa (6th floor), where experts run educational workshops for adults who have a young person with scleroderma in their life.

Join other parents, guardians, and caregivers to learn about and cope with the disease.

To participate in the KGS2 program, parents or guardians must sign a liability release, and sign their child or children in and out when arriving and leaving.

All attendees associated with the KGS2 program, whether child or adult, should attend the orientation/check-in session Friday evening, located in Northwestern & Ohio (6th floor) from 4 to 6 p.m.

Carnival

Also Friday evening in Northwestern & Ohio, the carnival starts at 6 p.m.

Additionally, there are Nintendo Wii games, carnival games, a caricature artist, and carnival food.

Teal Balloons

To sit with other kids at breakfast and dinner, look for teal colored balloons at particular tables.

SATURDAY NOTE:

Aquarium Trip & Lunch

Saturday’s lunch for youth is followed by a visit to Shedd Aquarium, departing the hotel at 1 p.m. and returning by 4:30 p.m.

While the youth are having a great time and are well looked after, lunch for parents, guardians, and caregivers is served at the Awards Luncheon in Salon II & III on the 7th floor. At 4:45 p.m., when the last afternoon workshop concludes, parents sign out their child from Northwestern & Ohio.
<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location/Room</th>
</tr>
</thead>
</table>
| 7:30 a.m. - 9:00 a.m. | **BUFFET BREAKFAST** - Salon II & III, 7th Floor  
(Kids & teens, look for tables with teal balloons to sit together) | Kids Room 5-17 Year Olds  
Northwestern & Ohio, 6th Floor |
| 9:15 a.m. - 10:15 a.m. | Yoga for the Special Child®  
Alexis Harrison, RCYT, RYT200  
Advocacy for Youth with Scleroderma  
Sneha Dave, Health Advocacy Summit | Older Kids Room 13-17 Year Olds  
Lincolnshire I & II, 6th Floor |
| 10:15 a.m. - 10:45 a.m. | Hands-On Cupcake Art  
Cupcake Decorating Leaders: Maggie Sepkowitz, LCSW, and Jill Blitz, PT, DPT, ATP | Parent/Caregiver Room  
Indiana & Iowa, 6th Floor |
| 10:45 a.m. - 11:45 a.m. | Dermatology & Skin Care in Scleroderma  
Yvonne Chiu, MD |  |
| 12:15 p.m. - 1:45 p.m. | KIDS’ LUNCH  
Northwestern & Ohio, 6th Floor |  |
| 2:15 p.m. - 3:15 p.m. | FIELD TRIP:  
Shedd Aquarium  
KiddieCorp, Maggie Sepkowitz, LCSW, and Jill Blitz, PT, DPT, ATP  
*Board bus at 1:00 p.m.  
Return to the hotel by 4:30 p.m.*  
*Parents/caregivers must pick up children at 4:45 p.m. for dinner* |  |
| 3:45 p.m. - 4:45 p.m. |  
BEVERAGE BREAK  
Outside Indiana & Iowa, 6th Floor |  |
| 5:00 p.m. - 6:15 p.m. | DINNER BUFFET - Salon II & III, 7th Floor  
*Entertainment by Standing Room Only Orchestra  
Kids & teens, look for tables with teal balloons to sit with each other* |  |
<p>| 6:15 p.m. - 7:45 p.m. | Family Ice Cream Social, Pillow Art &amp; Awareness Discussion - Northwestern &amp; Ohio, 6th Floor |  |</p>
<table>
<thead>
<tr>
<th>Time</th>
<th>Kids Room 5 - 17 Years Old</th>
<th>Older Kids Room 13-17 Years Old</th>
<th>Parent/Caregiver Room</th>
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<td>7:00 a.m. - 8:15 a.m.</td>
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<tr>
<td>8:30 a.m. - 9:30 a.m.</td>
<td><strong>Scleroderma 101: L-E-A-R-N</strong></td>
<td>Talking to Your Peers About Scleroderma</td>
<td>How to be an Effective School Advocate for a Child with Scleroderma</td>
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<td>Maggie Sepkowitz, LCSW</td>
<td>Luke Medolla</td>
<td>Marybeth Medolla, RN</td>
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<td>9:45 a.m. - 10:45 a.m.</td>
<td><strong>Play, Fun, Move in Just a Minute</strong></td>
<td>Transition Mindshift</td>
<td>Teach Your Children to Be Masters of Their Universe Within by Setting an Example</td>
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<td>Jill Blitz, PT, DPT, ATP</td>
<td>Maggie Sepkowitz, LCSW</td>
<td>Ashraf Girgis, MSN, SC&amp;T, ND</td>
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<td>10:45 a.m. - 11:15 a.m.</td>
<td><strong>SNACK BREAK</strong> - Outside Indiana &amp; Iowa, 6th Floor</td>
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<td>11:15 a.m. - 12:15 p.m.</td>
<td><strong>The Big Reveal</strong></td>
<td><strong>Penny For Your Thoughts: Questions from the Jar Are Answered</strong></td>
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<td>KiddieCorp</td>
<td>Facilitator: Maggie Sepkowitz, LCSW</td>
<td>Kathryn Torok, MD, Jessica Farrell, PharmD, Suzanne Li, MD, PhD, Maggie Blaisdell</td>
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<td><em>Lincolnshire I &amp; II, 6th Floor</em></td>
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Education Workshops - KGS2

SATURDAY, JULY 20

9:15 A.M. - 10:15 A.M.

Yoga for the Special Child®
Alexis Harrison, RCYT, RYT200
Northwestern & Ohio

Yoga for the Special Child® is an innovative and effective approach to early intervention. Founded in science, enriched with compassion, Yoga provides infants, children, and their parents with a pleasurable way to improve their quality of life. A yoga session includes: singing with hand motions to improve attention, imitation and calming skills; eye exercises to improve ability to control movements and scan smoothly; breathing exercises; yoga poses to improve strength, flexibility, balance and attention; and guided deep relaxation to relieve stress and calm body and mind.

Advocacy for Youth with Scleroderma
Sneha Dave, Health Advocacy Summit
Lincolnshire I & II

This is a discussion heavy workshop on advocating for yourself as a youth. You can connect your peers and learn ways to become a stronger advocate for yourself and others in different situations.

Pediatric Scleroderma: What Is it? Where Do We Go From Here?
Suzanne Li, MD, PhD
Indiana & Iowa

This session is aimed at helping parents and caregivers better understand what pediatric scleroderma is, and how it can be managed. We will discuss the two types of scleroderma (localized scleroderma and systemic sclerosis), as well as their similarities and differences. We will review the ways localized scleroderma and systemic sclerosis can each present, along with common problems and current treatment strategies. We will talk about ways parents can help participate in their child’s care, support research, increase awareness, and hopefully improve outcomes for these diseases. The intention of this session is to educate parents and caregivers about their child’s disease so that they can better manage and advocate for their children.

10:15 A.M. - 11:45 A.M.

Hands-on Cupcake Art
Cupcake Decorating Leaders:
Maggie Sepkowitz, LCSW and Jill Blitz, PT, DPT, ATP
Northwestern/Ohio/Lincolnshire I & II

There are many ways to strengthening your hands and they don’t all involve going to the gym or doing exercises. You can also strengthen your hands by doing something you already love! For example, who likes cake?! We all love to eat cake, but half the fun is decorating. In this session you will strengthen your hands by learning some simple cake decorating techniques, get creative, and make your cake a piece of art. We will also learn how to adapt cake decorating for all abilities. The benefits of resistive hand activities include strengthening, range of motion, blood flow, sensory input, and the satisfaction of making something you love!

10:45 A.M. - 11:45 A.M.

Dermatology & Skin Care in Scleroderma
Yvonne Chiu, MD
Indiana & Iowa

In this workshop, parents will learn about the topical therapy options and healthy skin care tips for children with localized and systemic scleroderma. In addition, cosmetic options to camouflage skin lesions will be discussed.

2:15 P.M. - 3:15 P.M.

Navigating Chronic Illness: A Parent’s Perspective
Seema Dave
Indiana & Iowa

As you see your child slapped with chronic illness, life takes a new turn. New challenges set in. Lessons learned. A parent’s perspective.

3:45 P.M. - 4:45 P.M.

What’s Happening in Scleroderma Research
Kathryn Torok, MD
Indiana & Iowa

Though few clinical trials exist for pediatric scleroderma, localized scleroderma (LS) or systemic sclerosis (SSc), there has been advancement in international collaboration to gather and summarize clinical data and collect blood and tissue for current and future research. Also, a few smaller studies are emerging. This talk will review research updates, including: Juvenile Systemic sclerosis (jSSc) updates: clinical monitoring; genetic studies; other smaller clinical observational studies; and SCORE CARRA
Talking to Your Peers About Scleroderma
Luke Medolla
Lincolnshire I & II

Talking about your disease with your friends probably isn’t comfortable or something you want to do, but it can’t always be avoided and it probably shouldn’t be. Gain the confidence you need to talk with your friends about scleroderma so they understand and so you can move forward as friends.

How to be an Effective School Advocate for a Child with Scleroderma
Marybeth Medolla, RN
Indiana & Iowa

Advocating for your child in school is our responsibility as well as theirs. The school community can be a tremendous support system for your child. Services and help are available! You are not alone on this journey.

Scleroderma 101: L-E-A-R-N
Maggie Sepkowitz, LCSW
Northwestern & Ohio

Come play and learn about the basics of scleroderma while playing fun table top games. This session is designed for siblings, relatives, or friends who have a loved one living with scleroderma. We hope to provide education and strategies that can help increase understanding of this chronic illness and various ways to help support one another. Yes, there will be small prizes.

Transition Mindshift
Maggie Sepkowitz, LCSW
Lincolnshire I & II

Transitions happen throughout our lifetime and preparing for some of them can be overwhelming. But don’t worry, “You Got This!” Please come for a discussion about transitions and preparing for transfer of care. Let’s help one another to navigate what comes next.

Teach Your Children to Be Masters of Their Universe Within By Setting an Example
Ashraf Girgis, MSN, SC&T, ND
Indiana & Iowa

The objectives of this workshop are to learn about naturopathic medicine approach toward inflammatory diseases. To learn about stress management techniques. To understand the role of food and inflammatory diseases. To understand the role of environmental toxins and inflammation. To learn about herbs and inflammation, and much more.

Play, Fun, Move in Just a Minute
Jill Blitz, PT, DPT, ATP
Northwestern & Ohio

Come join us for a fun filled hour of “Minute to Win It” games and activities to get you moving. Learn team work and wrap up the weekend with some silliness. By the end you will get to know each other a little better and feel energized.

The Big Reveal
KiddieCorp
Northwestern & Ohio

We’ve been keeping a secret and need your help letting it out! Join us as we use art and fun to share the location of the Foundation’s 2020 National Conference. This workshop uses art therapy techniques to debrief from the weekend and to generate excitement around the next conference.

Penny For Your Thoughts: Questions from the Jar Are Answered
Facilitator: Maggie Sepkowitz, LCSW, Kathryn Torok, MD; Jessica Farrell, PharmD; Suzanne Li, MD, PhD; Maggie Blaisdell
Lincolnshire I & II

We are so happy you are joining us for the unique session. Place your questions in a jar throughout the conference and we will come together for an open Q & A. This panel will consist of an MD, RN and a clinical social worker to help facilitate an open dialogue.
Win Free Registration & Hotel at the 2020 National Conference!

It is easy to enter!
Just fill out and return your conference evaluation!

The conference evaluation form is included in the conference bag you received at registration. The evaluation is an important planning tool, as we use your feedback to make improvements for future conferences.

Please remember to write your name and contact information on the contest entry form attached to the evaluation. Turn in your completed evaluation and entry form to the registration desk on Sunday. We will separate the entry form and the evaluation, so your feedback remains anonymous. After the conference, we randomly select one person to win free hotel and registration to the 2020 National Conference.

Be sure to attend Sunday’s Closing Keynote to find out where the 2020 National Patient Education Conference will be!

Show Your Scleroderma Colors!

Scleroderma awareness items are available at the Scleroderma Store and on CafePress.

Come to the Scleroderma Store on the 7th floor to browse many items that feature the Scleroderma Foundation brand.

Also, check out our collection of T-shirts, sweatshirts, mugs, baseball hats, and more online at our CafePress store. Proceeds benefit the Scleroderma Foundation.

cafepress.com/sclerodermafoundation

Don’t Forget Your Free T-Shirt!

Look for this flyer in your conference bag. T-shirt sizes cannot be guaranteed, so act quickly!

*RULES AND REGULATIONS APPLY. THE PRIZE IS NOT REDEEMABLE FOR CASH AND IS NON-TRANSFERABLE. IT MAY ONLY BE USED TO ATTEND THE 2020 NATIONAL PATIENT EDUCATION CONFERENCE.
Special Thanks

The success of the National Patient Education Conference depends on many individuals and groups in addition to the efforts of our professional staff. The list is far too long to name everyone. Below are those who deserve special attention for their contributions to the 2019 conference. Thank you!

Special thanks to Greater Chicago Chapter Executive Director Stephanie Somers Gresh and Marketing & Fundraising Manager Melissa Spear and the many gracious volunteers from the Chicago area for helping to make the conference run smoothly!

Additional Thanks:
- A Lasting Mark, Inc.
- Brogan & Partners
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- Childhood Arthritis and Rheumatology Research Alliance (CARRA)
- Betsy Craig
- Tracy Duvall
- Tonya Fyke and Dennis Fyke
- Dr. Ashraf Girgis, Cure Naturally, LLC
- Health Advocacy Summit (HAS)
- Health & Medicine Counsel of Washington
- LaPlume & Sons Printing
- Magnus Media Group
- Pediatric Dermatology Research Alliance (PeDRA)
- Robb Cohen Photography & Video
- Scleroderma Foundation Advocacy Committee
- Scleroderma Foundation Chapter Relations Committee
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- Anne Sweeney
- Diane Weber
- Candace Wright

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**SRO**

**STANDING ROOM ONLY ORCHESTRA**

During the Saturday buffet dinner, 5 p.m. to 6:15 p.m. in Salon II & III, enjoy the joyful sound of the *Standing Room Only Orchestra*, one of Chicago’s most versatile bands. These talented and inspired musicians love to perform a wide variety of music including Swing, 50s and 60s, Motown, Disco, 80s, and Top 40 hits.

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**LET’S WORK TOGETHER!**

Step by step Reata and the Scleroderma community are partnering in research to find a potential treatment for patients with Scleroderma associated Pulmonary Arterial Hypertension.

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Chapters

Delaware Valley
Delaware, Eastern Pennsylvania, Southern New Jersey
(866) 675-5545 sfdv.org
DChapters@scleroderma.org

Georgia
(770) 925-7037 scleroderma.org/georgia
GChapters@scleroderma.org

Greater Chicago
Illinois, Indiana, Wisconsin
(312) 660-1131 scleroderma.org/chicago
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Greater Washington, D.C.
District of Columbia, Maryland, Virginia
(240) 283-768 scleroderma.org/dc
DCChapters@scleroderma.org

Heartland
Iowa, Nebraska, South Dakota
(515) 661-8089 HeartlandChapter@scleroderma.org

Michigan
(248) 595-8526 scleroderma.org/michigan
MIChapters@scleroderma.org

Minnesota
(877) 794-0347 scleroderma.org/minnesota
MNChapters@scleroderma.org

Missouri
(636) 527-3599 scleroderma.org/missouri
MOChapters@scleroderma.org

New England
Maine, Massachusetts, New Hampshire, Rhode Island, Vermont, parts of Connecticut
(978) 887-0658 scleroderma.org/newengland
sclerodermainfo@sfnwengland.org

Ohio
(866) 849-9030 scleroderma.org/ohio
OHChapters@scleroderma.org

Oklahoma
(918) 693-9488 scleroderma.org/oklahoma
OKChapters@scleroderma.org

Oregon
(503) 245-4588 scleroderma.org/oregon
ORChapters@scleroderma.org

Rocky Mountain
Colorado
(303) 806-6686 scleroderma.org/colorado
COChapters@scleroderma.org

South Carolina
(864) 617-0237 scleroderma.org/southcarolina
SCChapters@scleroderma.org

Southeast Florida
Miami-Dade, Broward, Palm Beach Counties
(954) 798-1854 scleroderma.org/sefl
SEFLChapters@scleroderma.org

Southern California
Santa Barbara, south to borders of Mexico and Arizona
(424) 227-6475 scleroderma.org/socal
SOCALChapters@scleroderma.org

Tennessee
(800) 722-4673 scleroderma.org/tennessee
TNChapters@scleroderma.org

Texas Bluebonnet
(281) 880-4992 scleroderma.org/texas
TXChapters@scleroderma.org

Tri-State
New York, Connecticut, Northern New Jersey
(800) 867-0885 scleroderma.org/tristate
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How does PAH affect the heart?

How causes PAH?

How common is PAH?

What happens to the pulmonary arteries in PAH?

Find answers to your questions at PAHuman.com