

NATIONAL PATIENT EDUCATION
CONFERENCE

PHILADELPHIA PA TH

20 Years Reaching for the Cure

SCLERODERMA
FOUNDATION

SUPPORT · EDUCATION · RESEARCH

1998-2018



**Different people.
Different symptoms.
Same disease.**

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](https://www.morethanscleroderma.com/us)



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Welcome to Philadelphia!

Dear Conference Attendees:



Thank you for joining us here in Philadelphia for the 20th National Patient Education Conference. Our theme this year is *Reach for the Cure*, which embodies the energy, enthusiasm, and effort of tens of thousands of people around the country who give their time and treasure to advance the mission that we all share a stake in: support, education, research.

Over 20 years, the Scleroderma Foundation has invested more than \$22 million in research

to *discover, understand, and overcome* scleroderma. During this conference, you will hear several speakers provide updates on current scleroderma research. We are hopeful, as we look to the future, that new breakthroughs will generate new and more effective treatments. Additionally, you will learn a great deal about managing symptoms and ways you can live better despite the challenges scleroderma creates.

Conference is also a time to connect with others who are on the scleroderma path. The energy that comes from these connections is a powerful tool that can help you in your daily life. It is remarkable to witness, particularly for those of us who work behind the scenes, when attendees reunite after a year apart as if the last conference was just yesterday. Equally moving is the first conversation between someone whose scleroderma has only recently been diagnosed and a person who has learned to thrive despite the disease.

These two experiences, learning about the disease and connecting with others, are really what the conference is all about.

We owe a great deal of gratitude to all who committed time to organize and operate the 2018 conference, including our colleagues at the Delaware Valley Chapter. It's a team effort, and I am very thankful for our hard working staff and volunteers who make it happen.

Welcome and enjoy,



Robert J. Riggs
Chief Executive Officer

Message from the Chair

Dear Conference Attendees:



It is a great honor for me to welcome you to the 20th National Patient Education Conference, on behalf of the Board of Directors. It means a great deal to each one of us that you're here, because it is our intent to create an educational and inspirational experience that will give you the tools you need to cope effectively with the challenges of living with scleroderma. And, I believe that our organization has achieved that aim.

Twenty years is a great deal of time, and that history has helped our staff refine the program to meet your needs on many levels. The broad range of workshop topics, the depth of knowledge and expertise embodied in the presenters, and the Kids & Teens program are all outgrowths of your feedback over these many years. Our dedicated staff seeks to continually improve the conference which, as you might know, has become not only our signature event of the year, but has been recognized as the preeminent patient education program for individuals affected by scleroderma.

Anniversaries are a time to reflect on successes of the past. As proud as we all are of our organization's accomplishments since its founding in 1998, we understand, perhaps better than others, that there is still so much more to do. People with scleroderma don't have the luxury to wait for a cure. We must unite and move forward with a sense of urgency to increase the funding resources available for research so that we can dramatically increase the volume of work being done to *discover the cause, to understand the mechanism, and to overcome the symptoms* of scleroderma. Please join me and my dedicated colleagues on the Board of Directors as we *reach for the cure!*

Sincerely,



Cos M. Mallozzi
Chair, National Board of Directors

#ReachfortheCure

Social media is a great platform for sharing your experience at the National Patient Education Conference. Post, tweet, snap, whatever... Just use #ReachfortheCure in all your messages, and tag the Scleroderma Foundation. You can find us at:

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

Scleroderma Rest Stop

Adams Room (third floor)

The Scleroderma Rest Stop is a sitting area for conference attendees to take a break. Visit the Adams Room on the third floor.

HOURS:

- Saturday - 8:30 a.m. - 4:45 p.m.
- Sunday - 8 a.m. - 1:30 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. There are a limited number of wheelchairs available along with volunteers, who will push you between conference rooms. If you are in need of a lift, just look for the "TAXI" sign to flag down a ride!



If you're affected by scleroderma, join the Scleroderma Foundation Support Community on Inspire today!

[Scleroderma.Inspire.com](https://www.scleroderma.inspire.com)

43,000 members strong!



General Information

The Conference Registration/Information Booth is where you receive your name badge, pick up your conference gift bag and program book, and acquire general conference information. Registration is located in the **Millennium Hall pre-function area** on the second floor (*see map, page 4*). Please note, your conference name badge must be worn at all official events.

Conference Registration Hours

Friday, July 27: 4 p.m. - 8:30 p.m.

Saturday, July 28: 7:45 a.m. - 6:30 p.m.

Sunday, July 29: 7 a.m. – 1:30 p.m.

Medical Emergencies

PLEASE COMPLETE THE EMERGENCY CONTACT INFO ON THE BACK OF YOUR NAME BADGE AS SOON AS YOU RECEIVE IT. If you experience a medical emergency, dial **5500** on any house phone and report the issue to hotel security. If not available, dial **911**. There is no physician or nurse on site who can legally see or care for a patient with a medical emergency. If you need help with medical supply issues, please contact your specialty pharmacy or oxygen carrier company for assistance. If you are in need of wheelchairs and/or oxygen tanks, the hotel can refer you to a service that has rentals available. Please contact the hotel Front Desk for more information.

Special Meal Requests

If you requested special dietary meals 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 are pleased to assist you with room needs or hotel questions. Check-out time is **11 a.m. Sunday**. The hotel bell staff can provide storage for your belongings at no charge.

Scleroderma Foundation Store & Literature Table

The Scleroderma Foundation literature table is located outside the Exhibit Hall in the **Millennium Hall pre-function area** (*see map, page 4*).

Conference Surveys

Please fill out the conference survey in your gift bag and return it to registration on Sunday. Extra survey forms are available at registration and you can find the survey on our website at **scleroderma.org/conferencesurvey**. Your input is vital to making future conferences successful. We will randomly select one person to win free hotel and registration to the 2019 National Conference, so be sure to complete your survey and return it.

Refreshments

Beverages are offered between sessions, and can be found in the Exhibit Hall (*Millennium Hall*). Sunday's final break includes substantial snacks as 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.

Complementary Internet Access

There is complementary basic internet access in meeting rooms suitable for email and browsing only.

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.**

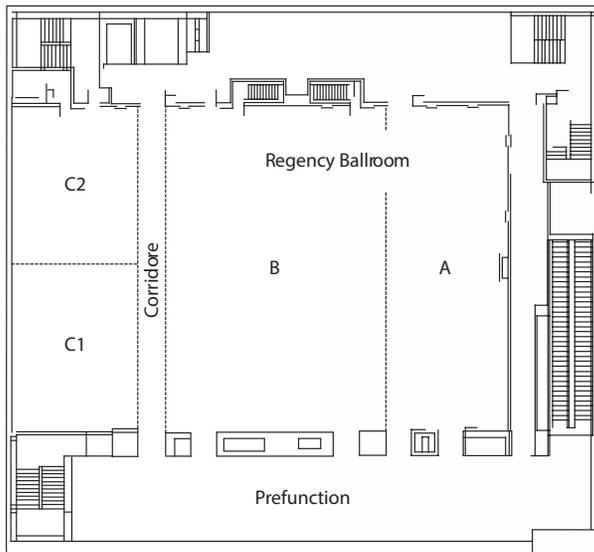
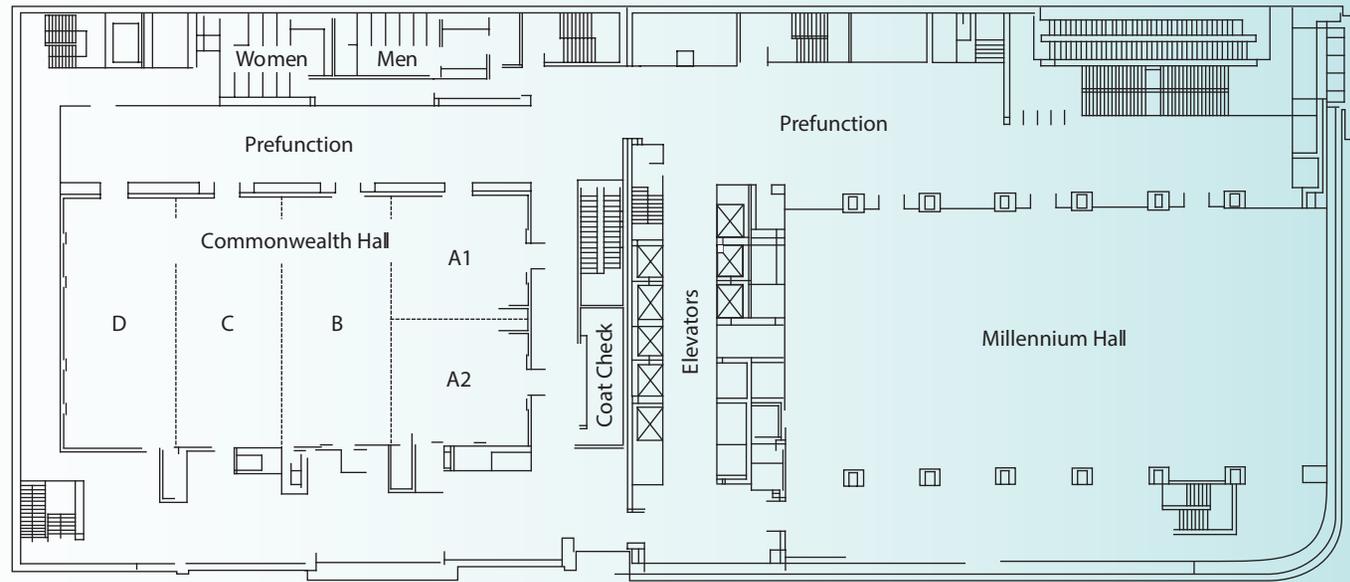
The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials, or studies referenced during the 2018 National Patient Education Conference. Information presented is to keep attendees informed. Because the manifestations and severity of scleroderma vary among individuals, personalized 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.

Hotel Information

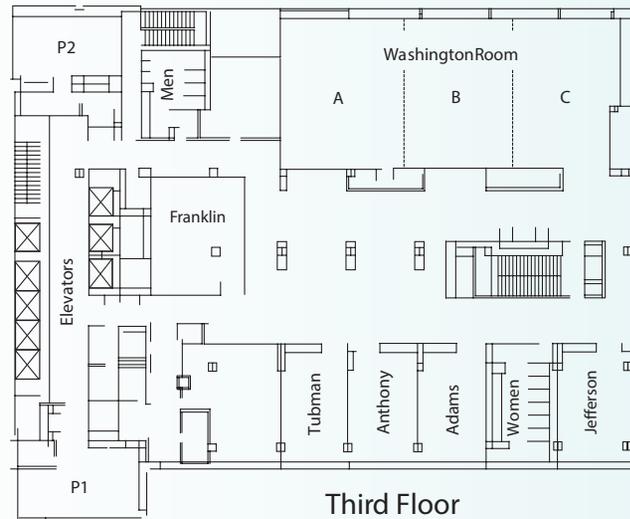
LOEWS

HOTELS

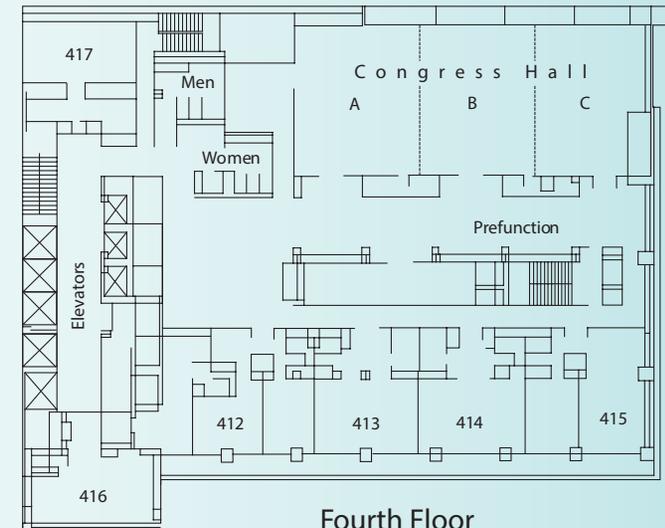
Second Floor



Second Floor Mezzanine



Third Floor



Fourth Floor

SCHEDULE NOTES

Enjoy the wide range of opportunities to learn at this conference from among the 77 workshop presentations by 69 speakers.

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

Check out the yoga room stationed in *Tubman/Anthony*. 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 (see page 13).

Schedule *at a Glance*

FRIDAY, JULY 27

4:00 p.m. - 8:30 p.m.	Registration	Millennium Hall Pre-Function Area (2nd floor)
4:00 p.m. - 8:30 p.m.	Kids & Teens Program	See full schedule page 10
4:00 p.m. - 7:15 p.m.	Exhibit Hall Open	Millennium Hall (2nd floor)
5:00 p.m. - 7:15 p.m.	Poster Hall Open	Millennium Hall (2nd floor)
6:00 p.m. - 7:15 p.m.	Welcome Reception	Commonwealth C & D (2nd floor)
7:15 p.m. - 7:30 p.m.	Please find a seat for the Opening Keynote	Regency Ballroom (2nd floor mezzanine)
7:30 p.m. - 8:30 p.m.	Welcome & Opening Keynote	Regency Ballroom (2nd floor mezzanine)

SATURDAY, JULY 28

7:30 a.m. - 8:45 a.m.	BUFFET BREAKFAST	Regency Ballroom (2nd floor mezzanine)
7:45 a.m. - 6:30 p.m.	Registration	Millennium Hall Pre-Function Area (2nd floor)
8:30 a.m. - 5:00 p.m.	Exhibit Hall Open	Millennium Hall (2nd floor; closed during lunch)
8:45 a.m. - 4:45 p.m.	Kids & Teens Program	See full schedule page 12
9:15 a.m. - 10:15 a.m.	Grand Lecture: PAH in SSc in the Current Era	Regency Ballroom (2nd floor mezzanine)
9:15 a.m. - 10:15 a.m.	Localized Scleroderma Lecture	Commonwealth C (2nd floor)
10:15 a.m. - 10:45 a.m.	BEVERAGE BREAK	Exhibit Hall (Millennium Hall, 2nd floor)
10:45 a.m. - 11:45 a.m.	Workshops	See workshop schedule for location, pages 12-15
12:15 p.m. - 1:45 p.m.	AWARDS LUNCHEON	Regency Ballroom (2nd floor mezzanine)
2:15 p.m. - 3:15 p.m.	Workshops	See workshop schedule for location, pages 12-15
3:15 p.m. - 3:45 p.m.	BEVERAGE BREAK	Exhibit Hall (Millennium Hall, 2nd floor)
3:45 p.m. - 4:45 p.m.	Last Workshops of the Day	See workshop schedule for location, pages 12-15
5:00 p.m. - 6:15 p.m.	BUFFET DINNER	Regency Ballroom (2nd floor mezzanine)

SUNDAY, JULY 29

7:00 a.m. - 1:30 p.m.	Registration	Millennium Hall Pre-Function Area (2nd floor)
7:00 a.m. - 8:15 a.m.	BUFFET BREAKFAST	Regency Ballroom (2nd floor mezzanine)
8:00 a.m. - 11:30 a.m.	Exhibit Hall Open	Millennium Hall (2nd floor)
8:15 a.m. - 1:30 p.m.	Kids & Teens Program	See full schedule page 14
8:30 a.m. - 9:30 a.m.	Workshops	See workshop schedule for location, pages 12-15
9:30 a.m. - 9:45 a.m.	BEVERAGE BREAK	Exhibit Hall (Millennium Hall, 2nd floor)
9:45 a.m. - 10:45 a.m.	Workshops	See workshop schedule for location, pages 12-15
10:45 p.m. - 11:00 a.m.	BEVERAGE BREAK	Exhibit Hall (Millennium Hall, 2nd floor)
11:00 a.m. - 12:00 Noon	Workshops	See workshop schedule for location, pages 12-15
12:00 Noon - 12:30 p.m.	REFRESHMENT BREAK	Millennium Hall Pre-Function Area (2nd floor)
12:30 p.m. - 1:30 p.m.	Closing Keynote	Regency Ballroom (2nd floor mezzanine)

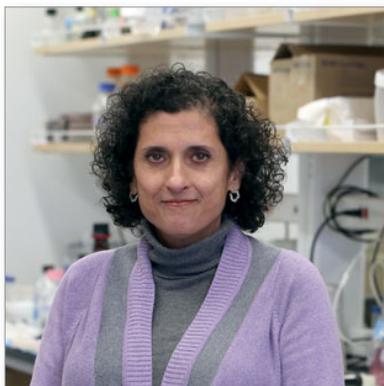
To sit together at meals, **young adults** connect at **yellow** balloons; **kids and teens** connect at **teal** balloons

Keynotes

Opening Keynote:

BACK FROM THE FUTURE

Carol Feghali-Bostwick, Ph.D.



Carol Feghali-Bostwick, Ph.D.

Dr. Feghali-Bostwick will describe what has been accomplished in the scleroderma field over the past two decades and the lessons we have learned. She will discuss advances that have been made and current efforts under way in basic and clinical research, and end the session with vision and hopes for the future.

Closing Keynote:

VOICES OF PATIENT ADVOCATES

Advocacy Committee



Reflecting on her time on Capitol Hill, a scleroderma advocate shared that “the voices of patients and family members are crucial elements in our advocacy work to advance important legislation to benefit those affected by scleroderma.” Our keynote speakers will share what motivated them to raise awareness about living with scleroderma.

Plus, we’ll meet Bill! Bill has been a champion for the Scleroderma Foundation for many years and has played a key role in the advocacy workshop and in the exhibit area.



We're united in PAH support

Our founders started United Therapeutics because their daughter was diagnosed with PAH. When we say we're united with you, it's because we've been there.

United by PAH Support is our latest initiative to ensure you receive the support you need. We partner with nurses, pharmacists, advisors, and PAH mentors who can help you on your treatment journey.



LEARN MORE
about PAH so you
can advocate for
your own care



GAIN INSIGHT
from PEER Mentors about
incorporating our treatments
into your daily routine

THESE ARE JUST A FEW WAYS WE CAN HELP.
Sign up at www.unitedbypahsupport.com/pah-support
to see how United by PAH Support can support you.



Speakers and Facilitators

Sabra Abbott, M.D., Ph.D.,
Northwestern University

Cheryl Albright, O.T.R./L., C.-I.A.Y.T.,
Soul to Soul Yoga

Sundar Balasubramanian, Ph.D.,
Medical University of South Carolina

Nancy Baldwin,
Independent Patient Advocate

Rachael Barta, *Independent Patient Advocate*

Jill Blitz, P.T., D.P.T., A.T.P.,
Children's Hospital of Los Angeles

Linda J. Bornstein Baum, O.D.,
Independent Patient Advocate

Andrew Botieri, C.S.P, N.A.L.P., *Author*

Dee Burlile, M.Ed.,
Independent Patient Advocate

Sean Burlile, Ph.D., C.V.R.C. U.S.,
Department of Veteran Affairs

Flavia Castelino, M.D.,
Massachusetts General Hospital

Dane Christiansen,
Health & Medicine Counsel of Washington

Lori Chung, M.D., M.S., *Stanford Medicine*

Philip Clements, M.D.,
University of California, Los Angeles

Talitha Cox, M.A., O.T.R./L., S.W.C., P.A.M.,
C.B.I.S., *Children's Hospital of Los Angeles*

Maria Crespo, M.D., *University of Pennsylvania*

Jacob Davila, *Independent Patient Advocate*

Jovana Desarden,
Independent Patient Advocate

Scott Dexter, M.D., *Albany Medical College*

Tracy Duvall, *Independent Patient Advocate*

Jessica Farrell, Pharm.D., *Albany College of
Pharmacy and Health Science*

Carol Feghali-Bostwick, Ph.D.,
Medical University of South Carolina

Tracy Frech, M.D., M.S., *University of Utah*

Dan Furst, M.D.,
University of California, Los Angeles

Elaine Furst, R.N., B.S.N., M.A.,
Independent Patient Advocate

Jessica Gordon, M.D.,
Hospital for Special Surgery

JoAnna Harper, Pharm.D., R.Ph.,
Pain Partners, L.L.C.

Laura Hummers, M.D.,
Johns Hopkins University

Sergio Jimenez, M.D.,
Thomas Jefferson University

John Keegan, *Independent Patient Advocate*

Dinesh Khanna, M.D., M.S.,
University of Michigan

Kelly King, *PEAL Center*

Lee Korotzer, *Independent Patient Advocate*

David Leader, D.M.D., M.P.H.,
Tufts University, School of Dental Medicine

Suzanne Li, M.D.,
Hackensack University Medical Center

Ginny Maril, Ph.D.,
California Lutheran University

Cyndy Martin, *Independent Patient Advocate*

Maureen Mayes, M.D., M.P.H.,
University of Texas, Houston

Fabian Mendoza, M.D.,
Thomas Jefferson University

Peter Merkel, M.D., M.P.H.,
University of Pennsylvania

Liz Morasso, M.S.W.,
University of California, Los Angeles

Juanita Morgan, *KiddieCorp*

David Murad, *Scleroderma Foundation*

John Novack, *Inspire*

Lisa Pappas-Taffer, M.D.,
University of Pennsylvania

Lori Pierce, R.Y.T., *Kodawari Studios*

Janet Poole, Ph.D., O.T.R./L., S.W.C.,
University of New Mexico

Janet Pope, M.D., M.P.H., *Western University*

Arnold Postlethwaite, M.D.,
University of Tennessee Health Science Center

Kathy Randolph, C.-I.A.Y.T.,
The Yoga Center Reno

Josh Rolnick, M.D., J.D.,
University of Pennsylvania

Misty Rushing, C.R.N.A.,
Independent Patient Advocate

Lesley Ann Saketkoo, M.D., M.P.H.,
Tulane University School of Medicine

Nora Sandorfi, M.D.,
University of Pennsylvania

Ron Sasso, M.S., L.P.C., *Author*

Bernadette Scarduzio,
Independent Patient Advocate

Maggie Sepkowitz, L.C.S.W.,
Children's Hospital of Los Angeles

Lee Shapiro, M.D., *The Center for Rheumatology*

Rick Silver, M.D.,
Medical University of South Carolina

Kate Silver, M.D., M.S.C.R.,
Medical University of South Carolina

Virginia Steen, M.D.,
Georgetown University Hospital

Keith Sullivan, M.D., *Duke University*

Tom Sutton, Esq., *Duke University*

Kathryn Torok, M.D.,
Children's Hospital of Pittsburgh

Richard Tosti, M.D.,
Thomas Jefferson University

John Varga, M.D., *Northwestern University*

Diane Weber, *Independent Patient Advocate*

Candace Wright, *Independent Patient Advocate*

Christina Zampitella, Psy.D., F.T.,
Integrative Psychology Group

Show Your Scleroderma Colors!



Scleroderma Awareness Items are Available at Our Literature Table and on CafePress

Come to our literature table to browse many items that feature the Scleroderma Foundation logo.

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

www.cafepress.com/sclerodermafoundation

Reata is extremely proud to partner with the Scleroderma Foundation in support of research for Scleroderma-PAH.

For more information, please visit:

CATALYSTtrial.com or clinicaltrials.gov
and search for
CATALYST NCT02657356.



THANK YOU

for raising
your voice.
And helping
others
raise theirs.



Exhibitor List

Actelion Pharmaceuticals
Arena Pharmaceuticals
Bayer Healthcare
Boehringer Ingelheim
Pharmaceuticals
Andrew Botieri, Author: "Total
Peak Performance"
Corbus Pharmaceuticals
Gilead Sciences
Juice Plus
Laclede
Pain Partners, LLC/
Pain to Peace, LLC
Protexgloves
Pulmonary Fibrosis
Foundation
Pulmonary Hypertension
Association

Reata Pharmaceuticals
Scleroderma FM
Scleroderma Foundation
Advocacy Program
Scleroderma Hope House
Scleroderma Lung Study III
ScleroMen
United Therapeutics
UPMC Transplant Services
Welmedix Consumer
Healthcare

Exhibit Hall

Enhance your conference learning experience with a visit to the interactive exhibit hall! Eat delectable treats and 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 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 2018 Conference. Support from our sponsors and exhibitors helps make this conference possible. Please show your gratitude by visiting their booths.

Friday Kids & Teens Schedule & Program Information



FRIDAY SCHEDULE:

4:00 p.m. - 6:00 p.m. - Registration

6:00 p.m. - 8:30 p.m. - Carnival

The Kids and Teens Program of the National Patient Education Conference 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.

The kids and teens program is divided into two rooms that provide programming for the whole family.

The Kids' Activity Room, located in *Congress A/B* (see map, page 4), is for **youth ages 5-17**. The activity room, managed by *KiddieCorp*, provides programming that

runs concurrently with the other workshops. *Congress A/B* 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 young adult patients attend workshops.

Congress C (see map, page 4) is home to programming aimed at the older youth population. In this venue, speakers talk to children *ages 13 and older* about different aspects of the disease.



In Room 417 (see map, page 4), scleroderma experts run educational workshops for adults who have a younger scleroderma patient in their life. Join other parents, guardians and caregivers to learn about and cope with the disease.

To participate in the kids and teens program, parents or guardians must sign a liability release and will need to sign their child or children in and out. All attendees associated with the kids and teens program,

whether child or adult, should come to the orientation/check-in session Friday evening. Orientation/check-in is located in *Congress C* and will run from 4 to 6 p.m.

Carnival. Also Friday evening, in *Congress C*, the carnival starts at 6 p.m. and a magic show starts at 6:15 p.m. Additionally, there are Nintendo Wii games, carnival games, a caricature artist, prizes, and carnival food.

Zoo Trip & Lunch. Saturday's lunch is followed by a visit to the *Philadelphia Zoo*, leaving at 1 p.m. and returning by 4:30 p.m.

Parents can attend the Awards Luncheon and other afternoon workshops knowing that their kids are having a great time and are well looked after.

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 or Foundation staff.

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



Friday Schedule

4:00 p.m. - 8:30 p.m.: Registration, Millennium Hall Pre-Function Area

4:00 p.m. - 7:15 p.m.: Exhibit Hall Open, Millennium Hall

5:00 p.m. - 7:15 p.m.: Poster Hall Open, Millennium Hall

6:00 p.m. - 7:15 p.m.: Welcome Reception, Commonwealth C&D

(Young adults, look for yellow balloons at welcome reception and in meal rooms to sit together.)

7:30 p.m. - 8:30 p.m.: Welcome & Opening Keynote, Regency Ballroom

Welcome Reception:

Reconnect with the friends you made at conference last year and make new ones while you enjoy light refreshments.



Poster Hall:

MEET THE RESEARCHERS

Meet the researchers who are working on the next advances in scleroderma treatment. A poster session provides a relaxed format that

allows an up close view of the scientists' work and a chance to ask one-on-one questions about what they are investigating.

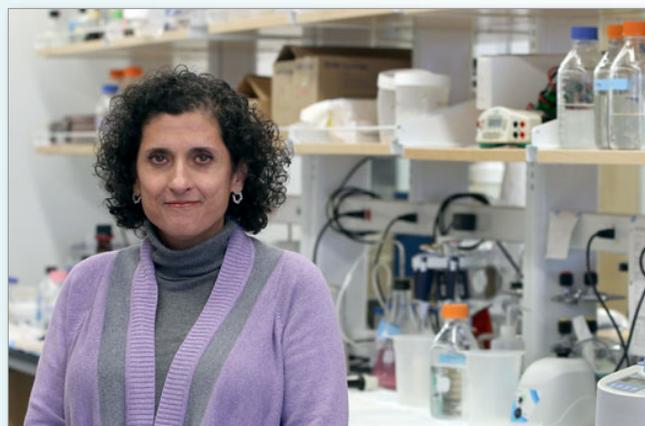
The poster session provides an invaluable learning experience for attendees and presenters alike.

Please join us for this important and interactive session! Poster presenters will be available to discuss their research with you on Friday, July 27 from 5 p.m. to 7:15 p.m. in *Millennium Hall* on the second floor.

Opening Keynote:

BACK FROM THE FUTURE

Carol Feghali-Bostwick, Ph.D.



Dr. Feghali-Bostwick will describe what has been accomplished in the scleroderma field over the past two decades and the lessons we have learned. She will discuss advances that have been made and current efforts under way in basic and clinical research, and end the session with vision and hopes for the future.

Win a Trip to the 2019 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 check-in. 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 2019 national conference.

Be sure to attend Sunday's Closing Keynote to find out where the 2019 National Patient Education Conference will be!

*RULES AND REGULATIONS APPLY. THE PRIZE IS NOT REDEEMABLE FOR CASH AND IS NON-TRANSFERABLE. IT MAY ONLY BE USED TO ATTEND THE 2019 NATIONAL PATIENT EDUCATION CONFERENCE.

Saturday Kids & Teens Schedule

	Kids Room 5-17 Year Olds Congress A/B	Older Kids Room 13-17 Year Olds Congress C	Parent/Caregiver Room 417
7:30 a.m. - 8:45 a.m.	BUFFET BREAKFAST - Regency Ballroom <i>(Kids & teens look for tables with teal balloons to sit together)</i>		
9:15 a.m. - 10:15 a.m.	Yoga for the Special Child® Congress A/B Kathy Randolph, C.-I.A.Y.T. and Sundar Balasubramanian, Ph.D.		Everyday Advocates Q & A Panel Facilitator: Sean Burlile, Ph.D., C.V.R.C. Diane Weber, Candace Wright, and Tracy Duvall
10:15 a.m. - 10:45 a.m.	REFRESHMENT BREAK - Congress Pre-Function Area, Fourth Floor		
10:45 a.m. - 11:4 a.m.	Cupcake Art Congress C <i>Leader of Cupcake Decorating:</i> Talitha Cox, M.A., O.T.R./L., S.W.C., P.A.M., C.B.I.S. Kate Silver, M.D., M.S.C.R., Maggie Sepkowitz, L.C.S.W., Liz Morasso, M.S.W., and Jill Blitz, P.T., D.P.T., A.T.P.		Overview of Scleroderma in Children and Adolescents: What Is It and What are the Concerns? Suzanne Li, M.D.
12:15 p.m. - 1:45 p.m.	KIDS' LUNCH Congress Hall, Fourth Floor Philadelphia Zoo Trip Board bus for the zoo at 1:00 p.m. Return to the hotel by 4:30 p.m.		AWARDS LUNCHEON Regency Ballroom
2:15 p.m. - 3:15 p.m.			Intersections of Health Care and Education for Children and Young People with Scleroderma Kelly King, M.S., L.B.S.C.
3:15 p.m. - 3:45 p.m.			REFRESHMENT BREAK Congress Pre-Function Area, Fourth Floor
3:45 p.m. - 4:45 p.m.			Your Child Has Been Diagnosed With Scleroderma. Now What?* Kate Silver, M.D., M.S.C.R. <i>*filmed session</i>
5 p.m. - 6:15 p.m.	DINNER - Regency Ballroom <i>(Kids & teens look for tables with teal balloons to sit with each other)</i>		
At the completion of the last workshop, please pick up your child promptly as kids programming and supervision is done for the day.			

Saturday Workshop Schedule

7:45 a.m. - 8:45 a.m.	BREAKFAST - Regency Ballroom (Young adults look for tables with yellow balloons to sit together)								
7:45 a.m. - 8:15 a.m.	Wake Up with Yoga - Tubman & Anthony Rooms								
9:15 a.m. - 10:15 a.m.	Pulmonary Arterial Hypertension in Systemic Sclerosis in the Current Era* Lori Chung, M.D., M.S. - Regency Ballroom *filmed session					Localized Scleroderma* Lisa Pappas-Taffer, M.D. - Commonwealth C *filmed session			
10:15 a.m. - 10:45 a.m.	BEVERAGE BREAK - Exhibit Hall (Millennium Hall)								
10:45 a.m. - 11:45 a.m.	<p>Current State of Research in Scleroderma. What a Difference 20 Years Makes!</p> <p>Peter Merkel, M.D., M.P.H. Commonwealth A1</p>	<p>Fibromyalgia-Scleroderma Link</p> <p>Arnold Postlethwaite, M.D. Commonwealth A2</p>	<p>Scleroderma 101</p> <p>Maureen Mayes, M.D., M.P.H. Commonwealth B</p>	<p>Medications in Scleroderma*</p> <p>Jessica Farrell, Pharm.D. Commonwealth C *filmed session</p>	<p>Esclerodermia: Conceptos Fundamentales Para Entender la Enfermedad. (Español)*</p> <p>Fabian Mendoza, M.D. Commonwealth D *filmed session</p>	<p>In Sickness and In Health</p> <p>Ginny Maril, Ph.D. Washington A</p>	<p>What Your Dentist and Your Rheumatologist Want to Know About Scleroderma and Oral Health 2018!</p> <p>David Leader, D.M.D., M.P.H. Washington B</p>	<p>Young Adult Panel</p> <p>JoAnna Harper, Pharm.D., R.Ph., Jovana Desarden, Jacob Davila, Rachael Barta Washington C (PANEL ROOM)</p>	<p>Yogic Breathing</p> <p>Sundar Balasubramanian, Ph.D. Tubman/Anthony (Yoga Room)</p>
12:15 p.m. - 1:45 p.m.	AWARDS LUNCHEON - Regency Ballroom (Young adults look for tables with yellow balloons to sit together)								
2:15 p.m. - 3:15 p.m.	<p>Emergency Preparedness for Caregivers</p> <p>Sean Burlile, Ph.D., C.V.R.C. Commonwealth A1</p>	<p>Musculoskeletal Manifestations of Systemic Sclerosis</p> <p>Jessica Gordon, M.D. Commonwealth A2</p>	<p>Newly Diagnosed: Feeling Like a Deer in Headlights</p> <p>Ron Sasso, M.S., L.P.C., C.B.I.S.T. Commonwealth B</p>	<p>Health Care Maintenance and Systemic Sclerosis*</p> <p>Tracy Frech, M.D., M.S. Commonwealth C *filmed session</p>	<p>Taking Care of Your Hands and Face: The Importance of Stretches, Assistive Devices and Protection*</p> <p>Janet Poole Ph.D., O.T.R./L., S.W.C. Commonwealth D *filmed session</p>	<p>Yes, You Can Help Cure Scleroderma</p> <p>Flavia Castelino, M.D. Washington A</p>	<p>Understanding the Grieving Process in Adults with Chronic Illness</p> <p>Christina Zampitella, Psy.D., F.T. Washington B</p>	<p>Stem Cell Transplant 2018</p> <p>Dinesh Khanna, M.D., M.S., Keith Sullivan, M.D., Cyndy Martin Washington C (PANEL ROOM)</p>	<p>How to Go to a Yoga Class</p> <p>Kathy Randolph, C.-I.A.Y.T., Cheryl Albright, O.T.R./L., C.-I.A.Y.T., Lori Pierce, R.Y.T. Tubman/Anthony (Yoga Room)</p>
3:15 p.m. - 3:45 p.m.	BEVERAGE BREAK - Exhibit Hall (Millennium Hall)								
3:45 p.m. - 4:45 p.m.	<p>Renal Issues in Scleroderma</p> <p>John Varga, M.D. Commonwealth A1</p>	<p>Pregnancy and Scleroderma</p> <p>Scott Dexter, M.D. Commonwealth A2</p>	<p>African Americans and Scleroderma</p> <p>Virginia Steen, M.D. Commonwealth B</p>	<p>How Are New Treatments Discovered?*</p> <p>Lee Shapiro, M.D. Commonwealth C *filmed session</p>	<p>The Hand and Wrist in Scleroderma: What Are the Care Options in 2018</p> <p>Richard Tosti, M.D. Commonwealth D</p>	<p>What Happens to My Scleroderma After 15 Years?</p> <p>Janet Pope, M.D., M.P.H. Washington A</p>	<p>Why Does My Scleroderma Make Me Itch So Much?</p> <p>Arnold Postlethwaite, M.D. Washington B</p>	<p>Transplants from the Inside Out: A Panel of Experiences</p> <p><i>Facilitator:</i> Elaine Furst, R.N., B.S.N., M.A., Linda J. Bornstein Baum, O.D., Nancy Baldwin, John Keegan Washington C (PANEL ROOM)</p>	<p>Yogic Breathing</p> <p>Sundar Balasubramanian, Ph.D. Tubman/Anthony (Yoga Room)</p>
5:00 p.m. - 6:15 p.m.	DINNER - Regency Ballroom (Young adults look for tables with yellow balloons to sit together)								

Sunday Kids & Teens Schedule

	Kids Room 5 - 17 Years Old <i>Congress A/B</i>	Older Kids Room 13-17 Years Old <i>Congress C</i>	Parent/Caregiver Room <i>417</i>
7:00 a.m. - 8:15 a.m.	BUFFET BREAKFAST - <i>Regency Ballroom</i> (Kids & teens look for tables with teal balloons to sit together)		
8:30 a.m. - 9:30 a.m.	Scleroderma 101: L-E-A-R-N Maggie Sepkowitz, L.C.S.W. <i>(geared toward non patients)</i>	Tackling Transition Liz Morasso, M.S.W. <i>(patients only)</i>	What's Happening in Juvenile Scleroderma Research? Kathryn Torok, M.D.
9:30 a.m. - 9:45 a.m.		REFRESHMENT BREAK - <i>Congress Pre-Function Area, Fourth Floor</i>	
9:45 a.m. - 10:45 a.m.	The Big Reveal! Liz Morasso, M.S.W.	Penny For Your Thoughts: Questions from the Jar are Answered <i>Congress C</i> Facilitator: Maggie Sepkowitz, L.C.S.W. Kathryn Torok, M.D. and Jessica Farrell, Pharm.D.	
10:45 a.m. - 11:00 a.m.		REFRESHMENT BREAK - <i>Congress Pre-Function Area, Fourth Floor</i>	
11:00 a.m. - 12 Noon	Play, Fun, Move Talitha Cox, M.A., O.T.R./L., S.W.C., P.A.M., C.B.I.S. and Jill Blitz, P.T., D.P.T., A.T.P.	Talking to Your Peers About Scleroderma Ginny Maril, Ph.D.	Medical Information Toolkit: How to Find Reliable Medical Information on the Internet* Jessica Farrell, Pharm.D. <i>*filmed session</i>
12 Noon - 12:30 p.m.		REFRESHMENT BREAK - <i>Congress Pre-Function Area, Fourth Floor</i>	
12:30 p.m. - 1:30 p.m.	Kids attend beginning of Closing Keynote to announce 2019 conference location, then return to Congress Hall	Closing Keynote: Voices of Patient Advocates Advocacy Committee - <i>Regency Ballroom</i>	

Sunday Workshop Schedule

7:00 a.m. - 8:15 a.m.	BREAKFAST - Regency Ballroom (Young adults look for tables with yellow balloons to sit together)								
7:00 a.m. - 7:30 a.m.	Wake Up with Yoga - Tubman & Anthony Rooms								
8:30 a.m. - 9:30 a.m.	<p>Research Progress: New Directions</p> <p>John Varga, M.D. <i>Commonwealth A1</i></p>	<p>Why Advocacy Matters in the Legislative Process</p> <p>Dane Christiansen, Dee Burlile, M.Ed. <i>Commonwealth A2</i></p>	<p>Pulmonary Hypertension in Systemic Sclerosis</p> <p>Philip Clements, M.D. <i>Commonwealth B</i></p>	<p>Pain Management: How to Empower Yourself Without Reliance on Opioids, Part 1*</p> <p>JoAnna Harper, Pharm.D., R.Ph. <i>Commonwealth C</i> <i>*filmed session</i></p>	<p>Scleroderma FAQ*</p> <p>Maureen Mayes, M.D., M.P.H. <i>Commonwealth D</i> <i>*filmed session</i></p>	<p>Applying for Social Security Disability</p> <p>Tom Sutton, Esq. <i>Washington A</i></p>	<p>Sjögren's Syndrome and Scleroderma</p> <p>Nora Sandorfi, M.D. <i>Washington B</i></p>	<p>Lung Transplantation in Patients with Scleroderma; Controversies and Outcomes</p> <p>Maria Crespo, M.D. <i>Washington C</i></p>	<p>Yoga for Your Hands</p> <p>Cheryl Albright, O.T.R./L., C.-I.A.Y.T. <i>Tubman/Anthony (Yoga Room)</i></p>
9:30 a.m. - 9:45 a.m.	BEVERAGE BREAK - Exhibit Hall (Millennium Hall)								
9:45 a.m. - 10:45 a.m.	<p>Overview of Living Wills and Other Advance Care Planning Documents</p> <p>Josh Rolnick, M.D., J.D. <i>Commonwealth A1</i></p>	<p>Exciting Data from the American College of Rheumatology, the World Scleroderma Conference, and the European League of Rheumatology: 2017-2018</p> <p>Dan Furst, M.D. <i>Commonwealth A2</i></p>	<p>Novel and Promising Biomarkers for Systemic Sclerosis: Addressing an Important Unmet Need for Diagnosis and Therapy</p> <p>Sergio Jimenez, M.D. <i>Commonwealth B</i></p>	<p>Pain Management: How to Empower Yourself without Reliance on Opioids, Part 2*</p> <p>Ginny Maril, Ph.D. <i>Commonwealth C</i> <i>*filmed session</i></p>	<p>Sleep and Chronic Disease*</p> <p>Sabra Abbott, M.D., Ph.D. <i>Commonwealth D</i> <i>*filmed session</i></p>	<p>An Introduction to Functional Medicine</p> <p>Misty Rushing, M.S.N.A., C.R.N.A. <i>Washington A</i></p>	<p>Scleroderma and Undifferentiated Connective Tissue Diseases</p> <p>Virginia Steen, M.D. <i>Washington B</i></p>	<p>Understanding & Living with Scleroderma as a Man</p> <p>Andrew Botieri, Lee Korotzer, Rick Silver, M.D. <i>Washington C (PANEL ROOM)</i></p>	<p>Keep Your Scleroderma Body Moving with Yoga</p> <p>Lori Pierce, R.Y.T. <i>Tubman/Anthony (Yoga Room)</i></p>
10:45 a.m. - 11:00 a.m.	BEVERAGE BREAK - Exhibit Hall (Millennium Hall)								
11:00 a.m. - 12 Noon	<p>What to do About Raynaud's and Skin Ulcers?</p> <p>Janet Pope, M.D., M.P.H. <i>Commonwealth A1</i></p>	<p>What is a Biologic Drug and Can They be Used in Scleroderma?</p> <p>Dan Furst, M.D. <i>Commonwealth A2</i></p>	<p>What My Doctor Should Have Told Me About Scleroderma (Systemic Sclerosis)</p> <p>Philip Clements, M.D. <i>Commonwealth B</i></p>	<p>Understanding the Link Between Scleroderma and Cancer*</p> <p>Laura Hummers, M.D. <i>Commonwealth C</i> <i>*filmed session</i></p>	<p>Nutrition in Systemic Sclerosis: Pathways to Increasing Quality of Life</p> <p>Lesley Ann Saketkoo, M.D., M.P.H. <i>Commonwealth D</i></p>	<p>GI Issues in Scleroderma</p> <p>Tracy Frech, M.D., M.S. <i>Washington A</i></p>	<p>Scleroderma and Interstitial Lung Disease (ILD)</p> <p>Rick Silver, M.D. <i>Washington B</i></p>	<p>Going Online with Impact: How to Get More Out of Healthcare Social Media</p> <p>John Novack, Misty Rushing, M.S.N.A., C.R.N.A., Bernadette Scarduzio <i>Washington C (PANEL ROOM)</i></p>	<p>Yogic Breathing</p> <p>Sundar Balasubramanian, Ph.D. <i>Tubman/Anthony (Yoga Room)</i></p>
12 Noon - 12:30 p.m.	REFRESHMENT BREAK - Millennium Hall Pre-Function Area								
12:30 p.m. - 1:30 p.m.	<p>CLOSING KEYNOTE - Voices of Patient Advocates</p> <p>Advocacy Committee - Regency Ballroom</p>								

Kids & Teens Workshops

Cupcake Art

Who likes cupcakes?! We all love to eat cupcakes, but half the fun is decorating. In this session you will learn some simple cupcake decorating techniques, get creative, and make your cupcakes a piece of art. We will also learn how to adapt cupcake decorating for all abilities. Don't forget this is a great exercise for your hands...and your mind.

Everyday Advocates Q & A Panel

As parents or caregivers of children with scleroderma, we need to develop skills in everyday advocacy. This panel consists of mothers of children with scleroderma. They have heard the news that their child has scleroderma. They have had to advocate for specialized medical care. They have worked with schools to ensure that appropriate accommodations are made on behalf of their children. And they have navigated the complex insurance systems. They are the everyday advocacy experts who have been diligent in ensuring the care of their children. Learn what these moms have done to develop skills as everyday advocates.

Intersections of Health Care and Education for Children and Young People with Scleroderma

We will explore how a student's education may be impacted by their condition, ways that family can work with educational institutions to meet their child's needs, and tools through which that can be done such as a 504 service plan and an Individual Health Care Plan. We will touch on the roles of key school personnel, the responsibility of the young person to advocate for themselves as they reach their college years, and steps to

prepare the individual to take responsibility for their own care as they grow toward adulthood.

Medical Information Toolkit: How to Find Reliable Medical Information on the Internet

Are you overwhelmed by the amount of medical information on the Internet? Did your Google search result in thousands of results? Are you unsure if a site is trustworthy and providing accurate health information? This presentation will provide you with an overview and "Toolkit" for finding reliably health and medical information on the Internet.

Overview of Scleroderma in Children and Adolescents: What Is It and What are the Concerns?

- What scleroderma is and the normal body processes that can go wrong during scleroderma
- The two main forms of scleroderma, systemic and localized, and what is similar and different between them
- The main problems associated with each form of scleroderma and differences from adult disease

Penny For Your Thoughts: Questions from the Jar Are Answered

We are so happy you are joining us for the unique session. Place your questions in the jar throughout the conference and we will come together for an open Q and A with discussion. This panel includes a doctor, a pharmacist, and a clinical social worker to help facilitate an open dialogue.

Play, Fun, Move

Come join us for a fun filled hour of games and activities to get you moving. Wrap up the weekend with some silliness and a quick review of what you have learned. By the end you will get to know each other a little better and feel energized.

Scleroderma 101: L-E-A-R-N

Come play and learn about the basics of scleroderma while playing BINGO. 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.

Tackling Transition

Transition to young adulthood and transfer to adult care can seem super scary! Let's work together on how to make your transition the smoothest it can be. This workshop will be led by a licensed clinical social worker and young adult patient living with rheumatic disease, Liz Morasso. It will include discussion of teen/young adult's concerns around transition as well as take-away tools for building the ultimate "Transition Toolbox."

Talking to Your Peers About Scleroderma

Scleroderma, at a younger age, comes with other challenges that are often difficult to navigate. This is a guided discussion of cool Scleroderma teens (that is you!) to allow you time to talk about these challenges, to help each other through individual concerns, and to experience the togetherness that Scleroderma provides.

The Big Reveal!

We've been keeping a secret and need your help letting it out! Join us as we use art and fun to share where next year's Scleroderma Foundation conference will be. This workshop is designed for younger patients and siblings and will use art therapy techniques to debrief from the weekend and generate excitement around next year's conference.

What's Happening in Juvenile Scleroderma Research?

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):

- Registry updates - CARRA SSc and International Inception cohort summary data
- Genetic studies - HLA findings and newer studies
- Other smaller clinical observational studies
- SCORE CARRA study

Juvenile Localized Scleroderma (jLS):

- Outcome measures update – Ultrasound, MRI, Durometer
- Quality of Life measures updates – CARRA CTP findings, LoSQI development
- Treatment – CARRA jLS CTP findings, case series reports
- SCORE CARRA study

Yoga for the Special Child®

Yoga for the Special Child® is an innovative and effective approach to early intervention. Founded in science, enriched with compassion, yoga provides children and their parents with a pleasurable way to improve the quality of their lives. A yoga session includes:

- Singing with hand motions to improve attention and imitation skills
- Eye exercises to improve ability to control movements and scan smoothly
- Breathing exercises – a great coping skill
- Yoga poses to improve strength, flexibility and balance
- Guided deep relaxation to relieve stress and calm body and mind

Your Child Has Been Diagnosed With Scleroderma. Now What?

The goal of this session will be to educate parents and caregivers on pediatric scleroderma. Specifically, we will focus on distinguishing between the two major types of pediatric scleroderma, localized scleroderma (or morphea) vs. systemic scleroderma. We will discuss each type in detail with a focus on what tests need to be done and how to interpret the results of these tests as well as review some of the different treatment options. The hope is for parents and caregivers to leave this session feeling armed with knowledge so that they can be the best advocates for their children.

Don't Forget Your Free T-Shirt!



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

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2018 National Conference
T-Shirt



Education Workshops

African Americans and Scleroderma

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.

An Introduction to Functional Medicine

An introduction to functional medicine focuses on expanding knowledge and therapies around the interconnected roles of gut health, genetics, and various environmental triggers and mediators that coalesce to create autoimmune disease such as scleroderma.

Applying for Social Security Disability

Mr. Sutton, an attorney specializing in social security issues, will discuss the process involved in applying for Social Security disability and the qualifying medical criteria for Scleroderma and related autoimmune diseases such as Lupus, Sjögren's, and Inflammatory Arthritis.

Back From the Future

Dr. Feghali-Bostwick will describe what has been accomplished in the scleroderma field over the past two decades and the lessons we have learned. She will discuss advances that have been made and current efforts under way in basic and clinical research, and end the session with vision and hopes for the future.

Current State of Research in Scleroderma: What a Difference 20 Years Makes!

Dr. Peter Merkel, Chief of Rheumatology and Director of the Penn Scleroderma Center at the University of Pennsylvania, has been part of the international scleroderma research community for over 25 years. He will review the current state of research in scleroderma with an emphasis on clinical trials of new therapies for scleroderma. Dr. Merkel will highlight the significant advances made in the research landscape in the past two decades and discuss the exciting future for the field of scleroderma research. He will leave ample time for questions and discussion with the attendees so the group can explore the many issues surrounding research in scleroderma.

Emergency Preparedness for Caregivers

Natural disasters and other emergencies affect everyone, and they can be particularly distressing for people with medical conditions. First responders and caregivers aren't always prepared to meet the unique needs of people with scleroderma. First responders may not even be familiar with scleroderma. The goal of this presentation is to provide useful information that will enable people with scleroderma (and caregivers) to help others to help them. Being prepared for an emergency will not only ease the burden of the emergency, but it could also save a life!

Esclerodermia: Conceptos Fundamentales Para Entender la Enfermedad. (Español)

Revisaremos la causa de la enfermedad, características clínicas de la enfermedad temprana (y tardía) y estrategias de tratamiento. El propósito de esta sesión es ayudar a pacientes y familias hispanohablantes a entender y manejar la enfermedad y sus complicaciones.

Exciting Data From the American College of Rheumatology (ACR), the World Scleroderma Conference (WSC) and the European League of Rheumatology (EULAR): 2017-2018

There were over 7,000 abstracts submitted to the ACR, WSC, and EULAR. Among those, of course, there were many interesting and important findings. A select few will be discussed, including data on what might cause scleroderma, how to follow it, and how to treat it.

Fibromyalgia-Scleroderma Link

Fibromyalgia is a chronic condition with widespread pain in certain locations in the body. It occurs in women more frequently than in men (3.4% vs. 0.5%, respectively). Fibromyalgia is often accompanied by other symptoms including fatigue, stiff joints, disturbed sleep, depression, and impaired mental function. It occurs in 20-30% of patients with systemic sclerosis (scleroderma) and is associated with greater disability and pain intensity. Since patients with scleroderma can have body pain from other causes such as tendonitis, bursitis, arthritis, and muscle inflammation, it is important

(continued)

Up to 15% of people living with scleroderma may be diagnosed with pulmonary arterial hypertension (PAH)¹

An online resource designed for people living with PAH

InsightsOnPAH.com

InsightsOnPAH.com was developed to help you learn more about Pulmonary Arterial Hypertension (PAH), including its signs and symptoms, how PAH is diagnosed, options for treatment, and useful tips for living with PAH. A variety of materials are available to download—visit InsightsOnPAH.com to learn more about PAH.

Insights
Your PAH Resource



Insights is an educational program designed exclusively for individuals with PAH and those who care for them—brought to you by Gilead Sciences, Inc.



Reference: ¹Khanna D, Gladue H, Channick R, et al. Recommendation for Screening and Detection of Connective-Tissue Disease Associated Pulmonary Arterial Hypertension; *Arthritis Rheum.* 2013 Dec;65(12):3194-201.

Education Workshops

not to confuse these other conditions with fibromyalgia because treatments are different for these conditions than for fibromyalgia.

GI Issues in Scleroderma

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.

Going Online With Impact: How to Get More Out of Healthcare Social Media

Patient advocates Misty Rushing, CRNA, and Bernadette Scarduzio, social media coordinator at the Hereditary Neuropathy Foundation, join John Novack, communications director at the healthcare social network Inspire, to examine how patients and caregivers can better navigate online information to help manage a condition and to network with others, while being able to evaluate the value and the source of the information. For those looking to become more active in patient advocacy, the speakers will offer practical tips on blogging, Facebook groups and Twitter.

Health Care Maintenance and Systemic Sclerosis

How can my rheumatologist and primary care physician best work together? In this session, you will learn about important age-appropriate health care maintenance issues. Immunizations, cancer screening, bone health, Raynaud's phenomenon management, and capillaroscopy will be discussed.

How Are New Treatments Discovered?

A discussion of some of the great advances in the treatment of scleroderma to find out how good ideas are born, tested, and put to use. We will look at the history of discovery of the most helpful agents used today, and look forward to how new ideas are likely to arise.

How to Go to a Yoga Class

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?"

In Sickness and In Health

So many things can change when a partner in a relationship is diagnosed with scleroderma. This session focuses on what can change and on what to do when the challenges of a partnership are amplified by diagnosis. Join a licensed psychologist, to learn more about maintaining a healthy relationship in sickness.

Keep Your Scleroderma Body Moving with Yoga

Lori Pierce teaches the morning yoga routine that keeps her body moving! Lori will share her own journey with scleroderma and yoga, from a dismal prognosis and being unable to dress herself, to becoming a travelling yoga teacher living on her own. Tips and tricks, adaptations and modifications, inspiration and hope, Lori will take away all your excuses!

Localized Scleroderma

Discussion of the different subtypes of localized scleroderma (morphea) and what clinically differentiates it from scleroderma (systemic sclerosis).

Lung Transplantation in Patients with Scleroderma: Controversies and Outcomes

Systemic sclerosis is a chronic autoimmune collagen vascular disease which often leads to life threatening visceral involvement. Lung transplantation is a treatment option in patients with end-stage lung disease. However, patients who had a diagnosis of systemic sclerosis have been considered suboptimal candidates for lung transplantation in many transplant centers. Recent studies have shown that lung transplantation is an acceptable treatment option in patients with advanced lung disease as a complication of systemic sclerosis offering them a good quality of life and survival. Early referral to a lung transplant program is key so that the patient can be evaluated before the disease is too advanced.



Medications in Scleroderma

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.

Musculoskeletal Manifestations of Systemic Sclerosis

Many of the symptoms that patients with scleroderma feel, like pain, stiffness, and weakness, relate to the way SSc affects the musculoskeletal system. These aspects of scleroderma can decrease quality of life and contribute to depression, anxiety, and disability. In this talk, Dr. Gordon will describe how scleroderma affects the joints, muscles, tendons, and bones. She will review some approaches to improving the musculoskeletal manifestations of this illness.

Newly Diagnosed: Feeling Like a Deer in Headlights

Are you newly diagnosed? Have you just added a new diagnosis to an existing assortment of diagnoses? Do you feel overwhelmed? This session will explore ways to help you cope with the change, be proactive, and keep it in perspective. This session will also cover some simple relaxation

techniques that you can use to help manage stress and diminish your feelings of being overwhelmed.

Novel and Promising Biomarkers for Systemic Sclerosis: Addressing an Important Unmet Need for Diagnosis and Therapy

In this session, we will discuss the application of novel, state of the art, molecular approaches for the identification of promising biomarkers for systemic sclerosis (SSc). The identification and validation of disease-specific biomarkers is a powerful tool in the design of personalized disease management and treatment of SSc.

Nutrition in Systemic Sclerosis: Pathways to Increasing Quality of Life

Nutrition and issues of the gastrointestinal (GI) tract are intricate players in quality of life, survival, and peace of mind. Every part of the GI tract, from beginning to end, can be affected in SSc, impairing essential mechanisms of digestion, motility, and nutrient extraction; challenging our comfort and freedom. Nutrition and GI difficulties are an extremely individualized experience from person to person. With important building blocks of SSc nutrition knowledge and well-deserved attention to ourselves, over time we can augment insight and strategy to a much healthier, happier GI experience.

Overview of Living Wills and Other Advance Care Planning Documents

Advance care planning is the process of planning for your medical care at a future time when you may be too sick to make decisions for yourself. This talk will provide

an overview of living wills and other legally recognized documents to record care wishes. It will describe the forms, discuss general legal requirements and summarize the different options to create care documents. Finally, it will provide more general guidance on how to make sure that your wishes for care are understood and followed by your health care providers.

Pain Management: How to Empower Yourself without Reliance on Opioids. Part 1

Do you experience pain with scleroderma? Have you been affected by the "opioid epidemic?" Do you want to be more empowered to better manage your pain and communicate with your providers? This session is designed to give you an insider's view of a pain management clinic, provide ideas for how to effectively treat your pain with fewer medications, and how to use your medications most appropriately.

Pain Management: How to Empower Yourself Without Reliance on Opioids. Part 2

Learn about non-pharmacologic coping strategies for pain management. Attendees will not only learn about various methods, but will also practice employing them in session.

Pregnancy and Scleroderma

We will discuss the impact of pregnancy upon scleroderma. In addition, the risks associated with undertaking pregnancy in patients with various manifestations of systemic sclerosis will be reviewed. Steps to take prior to a

(continued)

Education Workshops

planned pregnancy and health care providers you would want on your health care team are important considerations. Recommendations for pregnancy management will also be discussed.

Pulmonary Arterial Hypertension in Systemic Sclerosis in the Current Era

Definition and frequency of pulmonary hypertension in systemic sclerosis. Risk factors for and symptoms of pulmonary arterial hypertension in SSc. Screening and diagnosis of PAH in connective tissue diseases. Treatment options and response to therapies in the current treatment era.

Pulmonary Hypertension in Systemic Sclerosis

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?

Renal Crisis and Scleroderma

About 5-10 percent of scleroderma patients are at risk for kidney involvement, which can occur suddenly and unexpectedly. If undiagnosed, this complication of scleroderma, called "scleroderma renal crisis" or SRC, can lead rapidly to kidney failure and irreversible damage. There are biomarkers that can potentially predict who is at highest risk, allowing for close monitoring and early aggressive treatment. Additionally, genetic

and other research are underway to identify the genetic risk factors and other predictors for this severe complication of scleroderma. While treatment, if started early, can be effective in limiting kidney damage, the hope is that ultimately we can prevent acute kidney damage in scleroderma.

Research Progress: New Directions

Research from a number of fronts contributes to a better understanding of scleroderma. In particular, genetic studies are pointing out new molecules and pathways that seem to go awry in individuals, increasing their disease susceptibility. An on-going genetic study is currently analyzing the entire genome of 1,000 individuals with scleroderma; this is the most ambitious genetic undertaking in scleroderma to date. In addition, results from a multi-center trial of autologous stem cell transplantation are shedding light on how resetting the immune system might ameliorate the disease in patients with scleroderma. These and other advances are helping to identify novel treatment strategies and bring us closer to precision medicine in scleroderma.

Scleroderma and Undifferentiated Connective Tissue Diseases

The names that are given to connective tissue diseases by different doctors can be very confusing. Doctors have specific criteria for specific diseases, but the individual patient doesn't always fit the specific criteria. This session will try to explain the terms that are used to describe these diseases. It will help you understand how these diseases interrelate and how treatment is generally

focused on individual symptoms rather than on the NAME of the disease.

Scleroderma 101

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 FAQ

A discussion of the different kinds of scleroderma (localized versus diffuse systemic versus limited systemic forms); the epidemiology of scleroderma in terms of prevalence and incidence; plus research efforts and current and future therapies.

Scleroderma and Interstitial Lung Disease (ILD)

The lungs are often affected in patients with scleroderma. Interstitial Lung Disease (ILD) leading to pulmonary fibrosis is the



most common lung complication. When ILD is progressive, patients may experience shortness of breath and cough. In this session, we will discuss the diagnosis and approach to management of scleroderma ILD.

Sleep and Chronic Disease

In this session, we will cover the basics of normal sleep and why sleep is important for your health. We will then touch on common sleep disorders with a focus on aspects of these disorders that are unique to patients with scleroderma. Finally, we will discuss strategies that everyone can use to improve their sleep quality.

Sjögren's Syndrome and Scleroderma

Having an autoimmune condition increases the chance of the development of an other autoimmune disease in a person. This is true for the rheumatological autoimmune diseases as well. Sjögren's Syndrome, which targets the secretory glands, is the most common that can develop in conjunction with many of the connective tissue diseases. During this presentation, we will discuss the features of Sjögren's Syndrome and its unique characteristics in systemic sclerosis. We will also discuss the every day care and potential medical therapies.

Stem Cell Transplant 2018

Stem cell transplants for scleroderma have come a long way in the past few years. This panel will include a rheumatologist, bone marrow transplant physician and a recipient patient each presenting the topic from their unique perspective. Learn the most current

information on this treatment option for rapid or aggressive cases of scleroderma.

Taking Care of Your Hands and Face: The Importance of Stretches, Assistive Devices and Protection

In this session, participants will learn about the importance of taking care of the hands and face. Participants will be taught stretching exercises to improve movement and function in the hands, face, and mouth. Suggestions will be also be provided on modalities such as heat to warm up tissue before stretching, the use of assistive devices, and alternate techniques to accomplish tasks of daily living to increase independence, and to protect the hands.

The Hand and Wrist in Scleroderma: What Are the Care Options in 2018

Scleroderma often involves the hand and wrist. Its manifestations range from joint stiffness and contracture to Raynaud's Phenomenon and digital ischemia to CREST syndrome. New research has led to an improved understanding of the pathophysiology of these issues and to better treatment options such as contracture releases, joint replacements, and limited fusions. Medications, Botox injections, and microsurgical sympathectomy have prevented ischemic hand infections and digital amputation. In conclusion, an algorithmic approach to hand care in scleroderma has proved consistently successful in alleviating pain, preserving and improving function, enhancing esthetics, and avoiding amputation.

Transplants from the Inside Out: A Panel of Experiences

Transplants are done for many different reasons. Individuals with scleroderma have been in the forefront of stem cell transplantation since 1996 when the first patient underwent one in Seattle. Furthermore, scleroderma patients have had good experience with organ transplantation even though they were thought not to be able to heal as well. This panel features a patient who had a lung transplant and a patient who underwent a type of stem cell transplant. In addition, we will have a caregiver present the family's point of view.

Understanding and Living with Scleroderma as a Man

As we know, scleroderma affects men, woman, and children; however, only around 20% of those affected are men. In this "men only" session, we'll have open discussions on what some of your issues and concerns might be. The session will be facilitated by Lee Korotzer and Andrew Botieri with Dr. Silver available to answer medical questions. This session is presented by ScleroMen.

Understanding the Grieving Process in Adults with Chronic Illness

Often the grieving process associated with chronic illness is disenfranchised, leading people with scleroderma, their families, and loved ones without the social support they need to cope with the complicated nature of this progressive disease. Losses may not be readily apparent or even recognized as being "grievable." This presentation will help the attendee identify what is considered "normal"

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grief, understand the often misunderstood grieving process, and learn to cope with grief and communicate needs to those in one's support system.

Understanding the Link Between Scleroderma and Cancer

While studies have suggested that the risk of cancer might be increased in scleroderma patients, the reason for this association has not been well understood. Possible reasons for the connection will be explored in this session. Specifically, however, we will focus on more recent data suggesting that cancer is the source of the autoimmune response in scleroderma, suggesting that it may be part of what may cause scleroderma in a subset of patients. Implications this may have for treatment and screening for cancer amongst patients with scleroderma will also be discussed.

Voices of Patient Advocates

Reflecting on her time on Capitol Hill, a scleroderma advocate shared that "the voices of patients and family members are crucial elements in our advocacy work to advance important legislation to benefit those affected by scleroderma." Our keynote speakers will share what motivated them to raise awareness about living with scleroderma. Plus, we'll meet Bill! Bill has been a champion for the Scleroderma Foundation for many years and he played a key role in the advocacy workshop and in the exhibit area.

Wake Up with Yoga

A short morning program with breathing for increased circulation, stretching and hand work for an improved range of motion, and

a deep relaxation for stress relief. On the spot adaptations by the instructor ensure the practice works for you. All the poses can be done standing or seated in chairs, so come as you are!

What Happens to My Scleroderma After 15 Years?

This workshop discusses some of the problems that increase in people with long standing scleroderma and what to do about them. These include worsening blood vessels in the fingers, on the skin and possibly in the pulmonary arteries. The gut may have more problems in people with 15 or more years of scleroderma. Hand contractors do not improve even though the skin may soften. Dry mouth is more common.

What is a Biologic Drug and Can They Be Used in Scleroderma?

Biologic drugs are highly targeted proteins that have completely changed the face of treatment for rheumatoid arthritis. Can they be useful in scleroderma? The answer is yes, and what is the evidence that they can help. On the other hand, you must never forget that "you never get something for nothing," so what is the downside?

What My Doctor Should Have Told Me About Scleroderma (Systemic Sclerosis)

When I first went to the doctor and my doctor thought I might have scleroderma, she/he should have told me about what to expect from scleroderma. He/She should have told me about: How do we know that I do have scleroderma? If I have scleroderma, how long have I had it? What to expect about the

swelling/tightening of my skin. How will my heart, lungs, kidney, and gastrointestinal tract be involved? And, importantly, how do I treat scleroderma and its varied complications?

What to do About Raynaud's and Skin Ulcers?

Raynaud's is a spasm of blood vessels. It is common and often very severe in people living with scleroderma. There are several treatments including drugs that have been used in erectile dysfunction (PDE5 inhibitors). Ulcers can be from severe Raynaud's and also from calcinosis and trauma. Ulcers from ischemia (poor blood flow) have treatment, whereas calcinosis is more difficult to treat. This workshop will discuss how these problems are diagnosed and managed.

What Your Dentist and Your Rheumatologist Want to Know About Scleroderma and Oral Health 2018!

Scleroderma affects oral health in a myriad of ways. Your dentist may not have experience with scleroderma, but they know how to treat you. You can help to improve your dentist's knowledge and confidence to treat



all patients who have scleroderma. Similarly, your rheumatologist may help improve your oral health and advise your dentist. This year's presentation is updated with additional information on medications, dental implants, and more.

Why Advocacy Matters in the Legislative Process

Separate policy from politics with an overview of current activity on Capitol Hill and how you can add your voice to the conversation. Learn about ongoing and emerging efforts that have potential to impact healthcare coverage and access as well as treatment development and medication costs. This workshop also includes a review of medical research and patient care priorities. Hear about recent advocacy success stories at local and federal levels, and take home practical ideas that will help you share with your elected officials how scleroderma affects you and your family.

Why Does My Scleroderma Make Me Itch So Much?

Itching skin (pruritus) can be associated with a variety of conditions or diseases including psoriasis, allergic conditions, kidney failure, liver failure, insect bites, some forms of cancer, and reaction to medications. These conditions should be looked for in scleroderma patients complaining of itchy skin. How itchy skin develops is not well understood, but recent studies suggest several cell types and factors found in scleroderma skin might play important roles in producing itchy skin.

Yes, You Can Help Cure Scleroderma

This session will discuss the importance of patient participation in clinical trials and clinical registries in scleroderma. We will review the different phases of clinical trials and aspects of a clinical registry, and how your participation can help develop effective treatments for scleroderma. We will also review questions or concerns that may arise if you are approached to participate in a clinical trial or registry, so that you may make an informed decision.

Yogic Breathing for Symptom Management in Scleroderma

Yogic breathing is a form of yoga technique practiced with ease and with much less physical involvement and therefore could be a useful tool for symptom management in scleroderma. Research from our lab shows that molecules associated with stress and inflammation are reduced with yogic breathing. This talk will describe the science behind key yogic breathing techniques and how to practice them.

Yoga for Your Hands

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's. This program is done seated in chairs, so come as you are!

Young Adult Panel

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.



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 2018 conference. Thank you!

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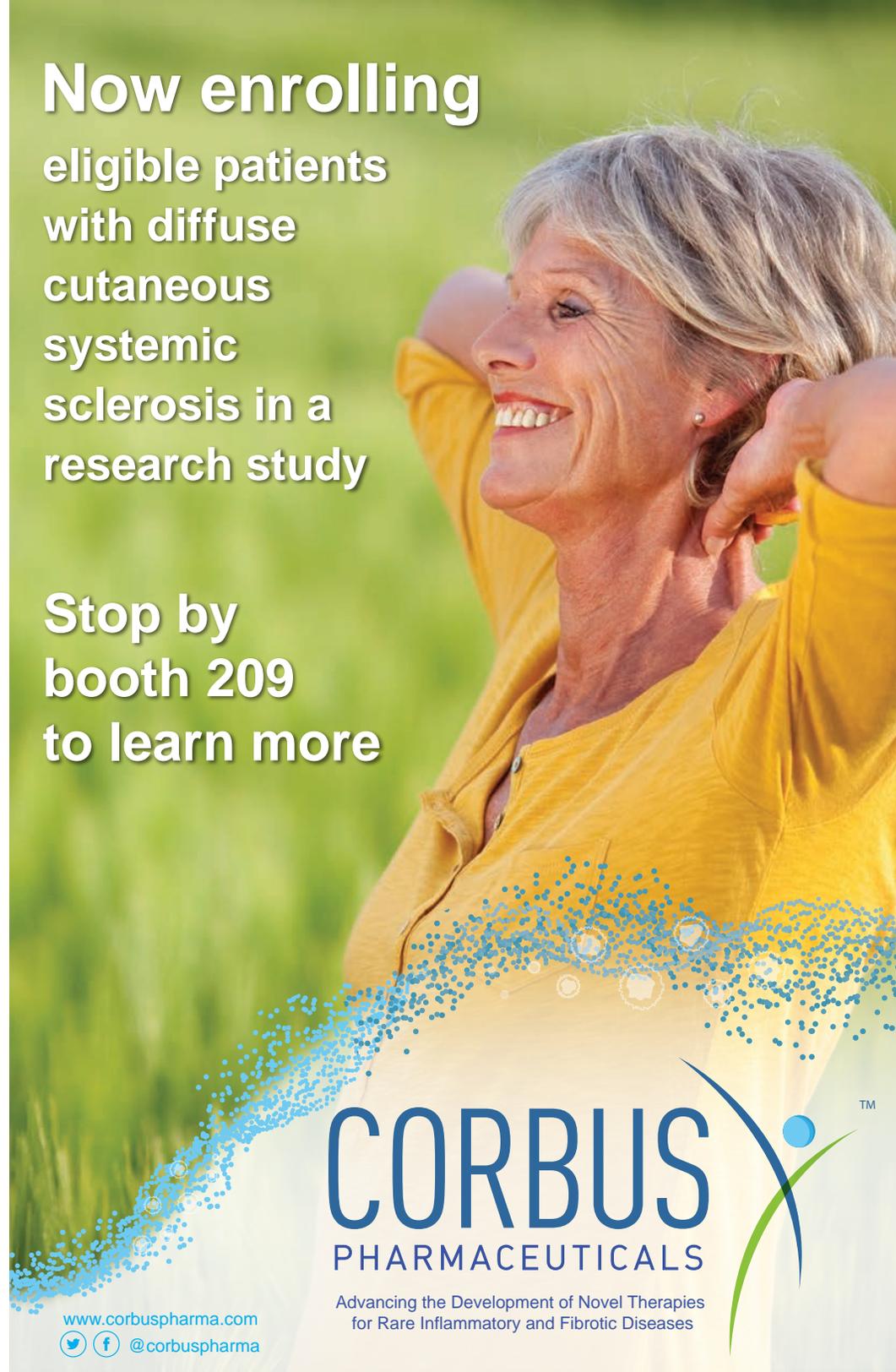
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