2016 National Patient Education Conference #unmaskthecure
Dear Conference Participants,

On behalf of the leadership of the Scleroderma Foundation we would like to welcome you to 18th Annual National Patient Education Conference. Our theme, "Unmask the Cure," could not be a more suitable backdrop for our time together. We are looking forward to forging new relationships, strengthening existing ties, robust learning, and recognizing individuals who have contributed to our success.

Our goal this weekend is to provide you with a conference experience that is educational, uplifting, inspiring and fun. With a grateful nod to the amazingly talented staff of the Foundation’s National Office, I am confident that our goal will be reached.

We are thrilled with the educational lineup we have in store for you. With support and guidance from the Foundation’s National Medical & Scientific Advisory Board and other experts, we offer a program rich in information that touches on every aspect of living with this complicated disease. There are 74 sessions, 45 of which are offered for the first time this year.

There is also a world of adventure waiting to be discovered in New Orleans. I hope you have planned some extra time in your itinerary to experience some of the local food, history and atmosphere.

I look forward to learning by your side during this conference. I hope what we learn together from our outstanding speakers, as well as through conversations with fellow attendees, helps enlighten and inspire us all. By joining together we believe we can unmask a cure for scleroderma while helping one another on our journey until it is found.

Sincerely,

Robert J. Riggs
Chief Executive Officer
Message from the Chair
National Patient Education Conference

Dear Conference Attendees,

On behalf of the National Board of Directors, it’s my pleasure to welcome you to New Orleans and the Foundation's 18th National Patient Education Conference, “Unmask the Cure.”

Although we come from all parts of the country – and some from overseas – and represent multiple backgrounds and ages, we are all bound by one important commonality: scleroderma. In my case, I'm involved with the Foundation because my wife, Ronni, has the disease. Watching her wage battle with scleroderma has inspired me to do what I can to support her, this organization, and the scleroderma community.

The National Board of Directors is comprised of dedicated, hard-working individuals from around the country who, like you and me, have been touched by this disease. Whether they have the disease themselves, or have a close family member battling scleroderma, each one of us is passionate about finding better treatments and a cure. Until then, we want to make sure that all of us have information and tools available to live the best life possible with scleroderma.

That’s why the Scleroderma Foundation’s three-fold mission, SUPPORT, EDUCATION, and RESEARCH is the guiding force behind all that we do. This conference is an outstanding example of how the Foundation seeks to fulfill its mission. Over the course of this weekend, established research experts will be mentoring the next generation of scleroderma investigators as part of the "Early Career Investigators Workshop;" the Foundation will hold an accredited Continuing Medical Education program for physicians and nurses; 74 presentations by a faculty of 58 will provide people living with scleroderma and their caregivers invaluable information about disease management and the latest information on research advances; and equally as important, the friendships made and the information shared among all of us provides an extraordinary environment of support that binds our community together.

I know I can speak for my fellow National Board members when I say that we are dedicated to advancing the Foundation's work and mission. As Chair, I’m honored to lead this dynamic organization as we work with all of our stakeholders – patients, caregivers, chapter and support group leaders, physicians and researchers, sponsors and donors. Working together, we will continue to evolve to meet the needs of the scleroderma community until we have unmasked a cure.

Sincerely,

Cos Mallozzi
Chair, National Board of Directors
NEW ORLEANS. With its richly mottled old buildings, its sly, sophisticated — sometimes almost disreputable — air, and its Hispanic-Galic traditions, has more the flavor of an old European capital than an American city. Townhouses in the French Quarter, with their courtyards and carriageways, are thought by some scholars to be related on a small scale to certain Parisian “hotels,” princely urban residences of the 17th and 18th centuries. Visitors particularly remember the decorative cast-iron balconies that cover many of these townhouses like ornamental filigree cages. One of the truly amazing aspects of New Orleans architecture is the sheer number of historic homes and buildings per square mile. Orleanians never seem to replace anything. Consider this: Uptown, the City's largest historic district, has almost 11,000 buildings, 82 percent of which were built before 1935 — truly a time warp.

Take a bike ride along the Mississippi River, feed an alligator or stroll through time as you take in the stories behind one of the many historical attractions. New Orleans has so much to offer and caters to every traveler. So whether you’re a sports fan, history buff, outdoor adventurer, aspiring chef or music lover, there’s an attraction in New Orleans to suit your every need.

NIGHTLIFE. The night never has to end in New Orleans, since bars and clubs are not required to close. In fact, many say the city is at its best under the glow of a French Quarter street lamp. But to suggest the party starts and ends on Bourbon Street sells the rest of the city short. New Orleans has many distinct neighborhoods that offer nightlife options from incredible live music on Frenchmen Street to intimate cocktails just a neighborhood away.

MUSIC. It is said that in New Orleans, culture bubbles up from the streets. Nowhere is this more evident than in the music scene. You’ll know it when you come across a street performance that rivals any ticketed show you’ve seen. Or when you find yourself inspired to sway, clap and move like never before. The city is the birthplace of jazz and a mecca for gospel, R&B and ultimately, the rock and pop we love today. It’s not an exaggeration to say that a wholly original spirit of creativity and musical magic is alive on the streets and in the clubs of New Orleans. Experience unbelievable live musical performances in venues from swank lounges to tiny honky tons to mega concerts in places like the Smoothie King Center. New Orleans is one big stage.

ART & CULTURE. New Orleans’ Old World roots have created a strong foundation and long-standing appreciation for the arts. Early residents of the city often traveled back to Europe for musical instruction or training in the visual arts. Today the scene thrives via countless galleries, performance spaces and museums. But perhaps what sets New Orleans’ cultural institutions apart from those in other cities is their ability to embody the “joie de vivre” (joy of life) mentality. So whether it is a Ralph Brennan restaurant in the New Orleans Museum of Art or Thursday night musical performances at the Ogden Museum of Southern Art, New Orleans’ unique culture and love of food, music and fun blends perfectly with the vibrant arts scene to create experiences you can’t find anywhere else.
A Special Thanks to Our 2016 Corporate Sponsors

2016 Platinum Conference Sponsor
2016 National Bronze Sponsor

2016 National Gold Sponsor

2016 Silver Conference Sponsor

2016 National Bronze Sponsor

Corporate Sponsors
#unmaskthecure

Share your experience during the National Patient Education Conference with the rest of the scleroderma community on social media channels! Find the Scleroderma Foundation on Facebook, Twitter, YouTube, Pinterest, Instagram and Inspire.

▷ It’s easy to join the conversation . . . Just use the hashtag #unmaskthecure on your posts!

Inspire is an Arlington, VA-based company with an online support community with more than 800,000 patients and caregivers, and encompassing health conditions such as cancer, chronic conditions, and rare disease. Inspire partners with the Scleroderma Foundation on a 23,000-member support group (www.scleroderma.org/inspire).
## SCHEDULE at a GLANCE

### FRIDAY, JULY 29TH 2016

<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>Napoleon Foyer</td>
</tr>
<tr>
<td>4:00 p.m. - 7:15 p.m.</td>
<td>Exhibit Hall Opens</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>5:00 p.m. - 7:15 p.m.</td>
<td>Poster Hall Open</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>6:30 p.m. - 7:15 p.m.</td>
<td>Opening Reception</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>7:15 p.m. - 7:30 p.m.</td>
<td>Please Find a seat for the Opening Keynote - Armstrong Ballroom (8th Floor)</td>
<td>Armstrong Ballroom (8th Floor)</td>
</tr>
<tr>
<td>7:30 p.m. - 8:30 p.m.</td>
<td>Welcome and Opening Keynote - Armstrong Ballroom (8th Floor)</td>
<td>Armstrong Ballroom (8th Floor)</td>
</tr>
</tbody>
</table>

### SATURDAY, JULY 30TH 2016

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:45 a.m. - 8:15 a.m.</td>
<td>Wake Up with Yoga</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>7:45 a.m. - 6:30 p.m.</td>
<td>Registration</td>
<td>Napoleon Foyer</td>
</tr>
<tr>
<td>8:30 a.m. - 5:00 p.m.</td>
<td>Exhibit Hall (Closing for Lunch from 12:15 p.m. - 1:45 p.m.)</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>7:45 a.m. - 9:00 a.m.</td>
<td>BUFFET BREAKFAST</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Grand Lecture - Shortness of Breath?</td>
<td>Armstrong Ballroom (8th Floor)</td>
</tr>
<tr>
<td>9:15 a.m. - 10:15 a.m.</td>
<td>Localized Scleroderma</td>
<td>Nottoway</td>
</tr>
<tr>
<td>10:15 a.m. - 10:45 a.m.</td>
<td>REFRESHMENT BREAK</td>
<td>Exhibit Hall</td>
</tr>
<tr>
<td>10:45 a.m. - 11:45 a.m.</td>
<td>Workshops</td>
<td></td>
</tr>
<tr>
<td>12:15 p.m. - 1:45 p.m.</td>
<td>AWARDS LUNCH - Please find a seat so the lunch can begin promptly - Napoleon Ballroom</td>
<td></td>
</tr>
<tr>
<td>2:15 p.m. - 3:15 p.m.</td>
<td>Workshops</td>
<td></td>
</tr>
<tr>
<td>3:15 p.m. - 3:45 p.m.</td>
<td>REFRESHMENT BREAK</td>
<td>Exhibit Hall</td>
</tr>
<tr>
<td>3:45 p.m. - 4:45 p.m.</td>
<td>Last Workshops of the Day</td>
<td></td>
</tr>
<tr>
<td>5:00 p.m. - 6:15 p.m.</td>
<td>BUFFET DINNER - Featuring Dr. Michael White and the Original Liberty Jazz Band - Music starts at 5:30 p.m. - Napoleon Ballroom</td>
<td></td>
</tr>
</tbody>
</table>

### SUNDAY, JULY 31ST 2016

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 a.m. - 7:30 a.m.</td>
<td>Wake Up with Yoga</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>7:00 a.m. - 1:30 p.m.</td>
<td>Registration</td>
<td>Napoleon Foyer</td>
</tr>
<tr>
<td>8:00 a.m. - 1:30 p.m.</td>
<td>Exhibit Hall Open</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>7:00 a.m. - 8:15 a.m.</td>
<td>BUFFET BREAKFAST</td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>8:30 a.m. - 9:30 a.m.</td>
<td>Closing Keynote-</td>
<td>Armstrong Ballroom (8th Floor)</td>
</tr>
<tr>
<td>9:30 a.m. - 9:45 a.m.</td>
<td>REFRESHMENT BREAK</td>
<td>Exhibit Hall</td>
</tr>
<tr>
<td>9:45 a.m. - 10:45 a.m.</td>
<td>Workshops</td>
<td></td>
</tr>
<tr>
<td>10:45 a.m. - 11:00 a.m.</td>
<td>REFRESHMENT BREAK</td>
<td>Exhibit Hall</td>
</tr>
<tr>
<td>11:00 a.m. - 12:00 p.m.</td>
<td>Workshops</td>
<td></td>
</tr>
<tr>
<td>12:00 p.m. - 12:30 p.m.</td>
<td>REFRESHMENT BREAK</td>
<td>Exhibit Hall</td>
</tr>
<tr>
<td>12:30 p.m. - 1:30 p.m.</td>
<td>Workshops</td>
<td></td>
</tr>
</tbody>
</table>

### SCHEDULE NOTE . . . NEW THIS YEAR!

We have added a 30-minute yoga class on Saturday and Sunday. The yoga class will be held in the Napoleon Ballroom and will run during the first 30 minutes of breakfast. This class will be led by certified yoga instructor, Kathy Randolph. She has specialized in developing a yoga routine designed for people with scleroderma.

The **Yoga for Scleroderma** session will be held in the Napoleon Ballroom from 3:45 p.m. - 4:45 p.m. on Saturday.

We have added **Using Your Voice to Advance Research and Improve Care: Tips for Effective Advocacy and Congressional Outreach** on Saturday afternoon from 2:15 p.m. - 3:15 p.m. in Endymion (8th Floor).

We will be hosting an awards luncheon rather than a traditional Saturday awards dinner so that attendees will have more time to explore New Orleans on Saturday evening. Before heading out to explore NOLA, please plan on joining us in the Napoleon Ballroom for dinner at 5:00 p.m. Music by Dr. Michael White and the Original Jazz band will begin at 5:30 p.m. We will also be simultaneously hosting a Saturday buffet dinner to provide greater opportunity for you to meet new friends and gather with old.
Keynote Speakers

Opening Keynote: Mary Woolley, President and CEO, Research!America

Turning a Moment into a Movement: Your Role in Advocacy for Research

Now is the time to turn last year’s ‘moment’ for research into a movement. The National Institutes of Health (NIH) received an additional $2 billion for FY16, the largest increase for the agency in over a decade. To maintain the momentum, especially during an election year when candidates are discussing their priorities for the nation, researchers, patients, and patient advocates must ensure that candidates, the public, media, and policymakers hear about the benefits of research from a health and economic standpoint.

At a time when Congress and the public may be taking medical progress for granted, all those who care about research for health need to be more engaged in outreach. Mary Woolley, president and CEO, Research!America will discuss the current state of federal health research agency budgets, share relevant public opinion survey data and provide insights on how to effectively communicate with the candidates, public, policymakers and the media.

Closing Keynote: Andrew Botieri, Founder of Total Peak Performance

Got Adversity?

With all the complications that arise from the many challenges people living with Scleroderma face, some days are better than others. But where do you find the strength and spirit to persevere on your bad days? No matter what adversity you face, you all possess two internal weapons - positive attitude & perseverance. As our keynote can attest, having a positive attitude and perseverance enabled Andrew to survive life threatening renal failure and a coma from Scleroderma. He is a rare male survivor. His recent book “A Celebration of Life - A Story of Hope, A Miracle & The Power of Attitude” recounts his sudden life altering ordeal and eventual triumph over this rare autoimmune disease which almost took his life. He’ll discuss the importance of finding balance in our lives, reducing stress and the power of mind/body and spirit.
Speakers and Facilitators

Sarah Aiken
Sundar Balasubramanian, Ph.D.
Jill Blitz, P.T., D.P.T., A.T.P.
Francesco Boin, M.D.
Carol Feghali-Bostwick, Ph.D.
Andrew Botieri, C.S.P., N.A.L.P.
Monica Brown, D.O.
Richard Burt, M.D.
Caroline Campion, M.D., M.P.H.
Dane Christiansen
Lorinda Chung, M.D., M.S.
Philip Clements, M.D.
Vanessa DeLisle, M.Sc.
Carole Deyoe, R.Ph.
Stephen Elrod
Jessica Farrell, Pharm.D.
Daniel Furst, M.D.
Elaine Furst, R.N., B.S.N., M.A.
Tracy Frech, M.D., M.S.
Shadi Gholizadeh, M.S., M.Sc., M.P.H.
Tammy Gilbert, P.T., D.P.T., O.C.S.
Jessica Gordon, M.D.
Karen Gottesman
Joanna Harper, Pharm.D., R.Ph.
Kristin Highland, M.D., M.S.C.R.
Laura Hummers, M.D.
Lisa Jewett, M.Sc.
Karla Jones, R.N., M.S.N., C.P.N.P
Dinesh Khanna, M.D., M.S.
Edward Lally, M.D.
David Leader, D.M.D., M.P.H.
Lauren Lucente, L.A.C.
Ginny Maril, Ph.D.
Joy Mitchell
Lara Naughton, M.P.W.
Janet Poole, Ph.D., O.T.R./L., S.W.C.
Janet Pope, M.D., M.P.H.
Arnold Postlethwaite, M.D.
Kathy Randolph
Michelle Ravenel, D.M.D.
Kevin Riemer, D.P.M.
Lauren Ruiz
Lesley Ann Saketkoo, M.D., M.P.H.
Mavis Seehaus, M.S., L.C.S.W.
Maggie Sepkowitz, L.C.S.W.
Lee Shapiro, M.D.
Richard Silver, M.D.
Michael Williams-Stark
Virginia Steen, M.D.
Brett Thombs, Ph.D.
Kathryn Torok, M.D.
Paula Erwin-Toth, M.S.N., R.N., C.W.O.C.N., C.N.S., F.A.A.N.
John Varga, M.D.
Chanel White
Mary Woolley
Michael York, M.D.
General Information

The Conference Registration/Information Booth is where you will receive your name badge that must be worn to all events, pick up your conference gift bag and program book, and for any general conference information. Registration is located in the Napoleon Foyer (map on page 6).

CONFERENCE REGISTRATION HOURS ARE:
Friday, July 29: 4:00 p.m. - 8:30 p.m.
Saturday, July 30: 7:45 a.m. - 6:30 p.m.
Sunday, July 31: 7:00 a.m. – 1:30 p.m.

MEDICAL EMERGENCIES
PLEASE COMPLETE THE EMERGENCY CONTACT INFORMATION ON THE BACK OF YOUR NAME TAG AS SOON AS YOU RECEIVE IT! If you are experiencing a life-threatening medical emergency, please call 911 or dial "0" (zero) on house phone. 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 has access to a service that has rentals available. Please contact the hotel Front Desk for more information.

SPECIAL MEAL REQUESTS
If you have requested special dietary meals in advance, this will be marked 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 for every meal.

GENERAL HOTEL OR SIGHTSEEING QUESTIONS
Please visit the hotel concierge staff or the Front Desk for any specific room needs or hotel questions. Check-out time is 12:00 p.m. on Sunday if you registered with the hotel as a conference attendee. The hotel bell staff can provide storage for your belongings at no charge.

SCLERODERMA FOUNDATION LITERATURE TABLE AND STORE
The Scleroderma Foundation literature table is located in the Exhibit Hall.

CONFERENCE SURVEYS
Please be sure to fill out the conference survey located in your gift bag (extra surveys are available at registration) and return to registration by Sunday. The survey also will be available on our website at www.scleroderma.org/conferencesurvey after the conference. Thank you! Your input is vital to making future conferences a success. We will randomly select one person to win free hotel and registration to the 2017 National Conference so be sure to complete your survey and return it to registration on Sunday.

REFRESHMENTS
Refreshments will be offered between each session (except for lunchtime) and will be near the exhibit area (see map on page 6). For morning breaks, beverages will be offered and for afternoon breaks, beverages and light snacks will be served. Sunday’s break will have more substantial snacks due to the workshops ending at 1:30 p.m. (Lunch will not be provided on Sunday.)

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 their attendance at the conference there will be photographs taken as well as audio/video recordings made of various activities, events and sessions. Each registrant grants the conference permission to photograph participants 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 PRIOR TO ATTENDING ANY SESSIONS.

The Scleroderma Foundation in no way endorses any drugs, treatments, clinical trials, or studies reference during the 2016 National Patient Education Conference. Information presented is to keep the 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.
Yes to doing all you can.

Want to find ways to get back some of the things you may have missed since your diagnosis? Living PAH can connect you to a growing community of support designed to help you get the most from your care.

Visit LivingPAH.com today. You’ll find relevant information about your condition; healthy, low-sodium recipes in our Living PAH Kitchen; and tips from other patients and caregivers who have traveled a similar path. And if you choose to enroll, you’ll receive additional tools and resources, a set of low-sodium recipes, and a monthly newsletter with helpful lifestyle tips.

Yes. It’s time to pursue your goals.

---

Poster Session

We are pleased to announce the inclusion of a poster session for scleroderma research. The scientific posters presented at this session provide an invaluable learning experience for attendees and presenters alike.

Visitors to the poster hall are able to browse the science and have one-on-one conversations with researchers in a convenient and relaxed format.

PLEASE JOIN US for this important and interactive session! Poster presenters will be available to discuss their research with you on Friday, July 29th from 5:00PM - 7:15PM in the Napoleon Ballroom.
The Youth Program

The Scleroderma Foundation is proud to announce the continuation and expansion of the Youth Program at this year’s National Patient Education Conference! Working closely with pediatric providers from across the United States, the Scleroderma Foundation has created a robust program for the entire weekend. This program is designed to let our younger attendees and their caregivers learn more about scleroderma in a fun environment that promotes making new connections. The entire weekend will be filled with engaging, fun workshops and activities. Of course you can go to any session that is offered throughout the weekend but if you are looking to focus on the youth aspect of scleroderma, there are so many options.

The Kid’s Activity Room, located in Borgne, is facilitated and staffed by Corporate Kids Events. Since 1998, Corporate Kids Events has been providing professional childcare programs. This room is for juveniles aged 5-17. The activity room is run concurrently with the other workshops. This is a great place for our younger patients, siblings, and children of patients to meet and do projects together while the parents and young adult patients attend workshops. The youth program is spilt into two rooms which will provide programming for the whole family.

In Maurepas, (see hotel map on page 6), we will run programming aimed at the older population. This room will have speakers talking to children age 13 and older about different aspects of the disease.

In Estherwood (4th floor), scleroderma experts will run educational workshops for adults who have a younger scleroderma patient in their life. Come join other parents, guardians and caregivers to learn about the disease, as well as different ways to deal with it.

As part of this year’s event, Corporate Kids Events (CKE) will be supervising an off-site field trip to the Audubon Aquarium of the Americas on Saturday, July 30, 2016! Offsite field trips give children a safe and enjoyable way to explore New Orleans. Parents can enjoy workshops knowing that their kids are having a great time and are well looked after. CKE Managers and staff will attend and supervise the trip. Check in on the day of the trip is simple. Simply sign them in to their staff member and leave the rest to us. Our consent form incorporates permission to attend the trip. If you would like to send along some spending money for your child/children feel free. If you would like to check in with your child via text or cell phone you are welcome to, you can also check in with the Manager or staff as well.

In order to participate, parents or guardians must sign a liability release and children will need to be signed in and out of this room by a parent or guardian. All attendees associated with the youth program, whether child or adult, MUST come to the orientation/check-in session on Friday evening. Orientation/check-in is located in Borgne and will run from 5:00-8:30 pm.
## 2016 YOUTH WORKSHOP SCHEDULE - SATURDAY

<table>
<thead>
<tr>
<th>Time</th>
<th>FRIDAY - Corporate Kids Events All Kids Registration/Check-in/Various Activities – Borgne/Maurepas Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>5:00PM - 8:30PM</td>
<td>FRIDAY - Corporate Kids Events All Kids Registration/Check-in/Various Activities – Borgne/Maurepas Room</td>
</tr>
</tbody>
</table>

### SATURDAY

<table>
<thead>
<tr>
<th>Time</th>
<th>YOUTH ROOM: 5 - 17 YEARS OLD BORGNE</th>
<th>OLDER YOUTH ROOM: 13 - 17 YEARS OLD MAUREPAS</th>
<th>PARENT/CAREGIVER ROOM ESTHERWOOD (4TH FLOOR)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:45AM - 9:00AM</td>
<td><strong>BUFFET BREAKFAST</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9:15AM - 10:15AM</td>
<td>Corporate Kids Events</td>
<td>Light, Camera, Action! - Part 1</td>
<td>An Overview of Localized and Systemic Juvenile Scleroderma</td>
</tr>
<tr>
<td></td>
<td><em>Sarah Aiken</em></td>
<td><em>Maggie Sepkowitz, L.C.S.W.</em></td>
<td><em>Monica Brown, D.O.</em></td>
</tr>
<tr>
<td>10:15AM - 10:45AM</td>
<td>Let’s Get Moving!</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Jill Blitz, P.T., D.P.T., A.T.P.</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:15PM - 1:45PM</td>
<td>After buffet lunch in Maurepas, please join us for an exciting off-site field trip to the Audubon Aquarium of the Americas – New Orleans. The bus will depart at 1:00PM. We will return to the hotel by 4:30PM.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Jill Blitz, P.T., D.P.T., A.T.P.</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Sarah Aiken, Corporate Kids Events</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2:15PM - 3:15PM</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3:15PM - 4:45PM</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Refreshments for parents/caregivers will be served in the exhibit hall*

At the completion of the last workshop, please come pick up your child. Kids Programming is done for the day.
<table>
<thead>
<tr>
<th>Time</th>
<th>Youth Room: 5 - 17 Years Old Borgne</th>
<th>Older Youth Room: 13 - 17 Years Old Maurepas</th>
<th>Parent/Caregiver Room Estherwood (4th Floor)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM - 8:15 AM</td>
<td>BUFFET BREAKFAST</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:30 AM - 9:30 AM</td>
<td>Confidence Through Play</td>
<td>Adjusting to Your Chronic Illness</td>
<td>Medications Used in the Treatment of</td>
</tr>
<tr>
<td></td>
<td><em>Michael Williams-Stark</em></td>
<td><em>Lauren Lucente, L.A.C.</em></td>
<td>Pediatric Scleroderma</td>
</tr>
<tr>
<td>9:30 AM - 10:45 AM</td>
<td>Corporate Kids Events</td>
<td></td>
<td><em>Monica Brown, D.O.</em></td>
</tr>
<tr>
<td></td>
<td><em>Sarah Aiken</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10:45 AM - 11:00 AM</td>
<td>Lights, Camera, Action!</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Part 2 Maggie Sepkowitz, L.C.S.W.</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00 AM - 12:00 PM</td>
<td>Corporate Kids Events</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Sarah Aiken</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12:00 PM - 1:30 PM</td>
<td>At 12:00 pm, please meet and pick up your child. Enjoy a snack with them in Borgne as we wrap up the weekend with them.</td>
<td>JUVENILE CONFERENCE WRAP-UP WITH A SNACK!</td>
<td>Maggie Sepkowitz, L.C.S.W. and Karla Jones, R.N., M.S., C.P.N.P.</td>
</tr>
</tbody>
</table>
YOUTH WORKSHOP DESCRIPTIONS ➔ ➔ ➔

*ADJUSTING TO CHRONIC ILLNESS
This session will provide adolescents with psychoeducation regarding struggles commonly reported by children with chronic illness. In addition, the speaker will provide children with tools that they can utilize to help themselves adjust to their illness and maintain a better quality of life. Further, participants will learn how to identify when they may need professional help, such as counseling, to help them with their current difficulties.

AN OVERVIEW OF LOCALIZED AND SYSTEMIC JUVENILE SCLERODERMA
This session will define pediatric scleroderma. The speaker will also discuss the subtypes of scleroderma in children. Other topics covered will include the pathogenesis of disease, treatment used in this disease and prognosis.

*CONFIDENCE THROUGH PLAY
In this session, the presenter will focus on Making Faces workshops. These workshops are all about play and using improvisational comedy/acting exercises to develop life skills and self-confidence. You are the greatest you there is! You bring your own unique gifts to the world. Through play we discover just what great communicators we truly are. “Never underestimate the power of fun!”

*FOSTERING SELF-MANAGEMENT SKILLS IN YOUR CHILD TO ENSURE SUCCESSFUL OUTCOMES
This session will focus on learning the skills necessary to help your child gradually gain independence in managing their health with the long term goal of successful transition to adult health care.

*HEALTH RELATED QUALITY OF LIFE (QOL) IN PEDIATRIC SCLERODERMA
Pediatric localized scleroderma (LS) and systemic sclerosis (SSc) have unique health-related issues impacting their day-to-day perception of quality of life, such as skin thickness, joint contractures, and gastro-intestinal issues.

This session will review data obtained from patients enrolled in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry with LS and SSc and highlight the areas of particular impact, such as physical function and emotional health.

Additional attention will be focused on common themes obtained from patients themselves with LS and their families during focus group sessions conducted through the National Registry of Childhood Onset Scleroderma.

*HELPING YOUR CHILDREN COPE WITH AND ADJUST TO THEIR CHRONIC ILLNESS
This session will provide parents with psychoeducation regarding the types of mental health concerns that are commonly comorbid with chronic illness. The speaker will explore common presentations of mental health concerns and will teach parents how to identify when their child may need help adjusting to his or her illness. In addition, participants will learn about preventative techniques that they can utilize to guide and support their child with adjustment to living with a chronic illness. Further, this session will provide parents with information about mental health services that are available for their children, as well as ways to advocate for their children’s needs.

*KEYS TO EFFECTIVE SCHOOLING- PLANNING ACCOMMODATIONS AND ADVOCATING FOR YOUR CHILD
This session will focus on understanding the difference between a “504 Plan” and an Individualized Educational Plan (IEP). The speaker will also identify adaptations and accommodations that are beneficial for your child, understanding the process for transition to college and successfully advocating for your child within the educational setting.

*LET’S GET MOVING!
Come join us for a fun filled hour of games, music and activity to get our bodies moving. By the end you won’t even realize you have been exercising!

*LIGHTS, CAMERA, ACTION!
Calling all adolescents (ages 13-21)! What is Scleroderma to you? Do you want to be part of something creative that will leave a lasting impression? Then this is the workshop for you! This two day project will culminate in the creation of a unique video for the Scleroderma Foundation/YouTube. On Day 1, participants will get to know one another, brainstorm ideas/Layout/Props and work on and write your story in under 2 minutes. Day 2 will consist of making the video! We will have volunteers who will help us with the camera/lighting, etc.

*MEDICATIONS USED IN THE TREATMENT OF PEDIATRIC SCLERODERMA
This session will focus on the most common medications used to treat patients with childhood scleroderma. The speaker will also discuss the side effects that may be seen with these drugs.

*denotes a new session for the 2016 Conference
YOUTH WORKSHOP DESCRIPTIONS → → →

*UPDATES IN RESEARCH IN PEDIATRIC SCLERODERMA*

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. This session will review research updates including a general summary of results of clinical data obtained from patients enrolled in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) registry with LS and SSc and highlight the areas of interest, such as organ involvement in SSc, and extracutaneous (non-skin) manifestations in LS. The speaker will cover CARRA consensus treatment plans that have been developed and carried out in pediatric LS, which is the ‘stepping stone’ for future clinical trials and will review the latest updates in immune markers of interest in pediatric SSc and LS and overview of current study to evaluate similarities and differences between biological markers in pediatric LS and SSc.

*denotes a new session for the 2016 Conference*
We believe in more than the big breakthroughs. And more than the next big thing.

We believe in the day-in day-out work of making science happen. And the millions of little victories — and failures — in between the breakthroughs. Because to us, it’s the daily effort of everyday people that changes the future. So we don’t stop. We keep working. Every day.

---

The Scleroderma Foundation is providing a place for conference attendees to take a break. The “Scleroderma Rest Stop” is located in the Zulu Room on the 8th Floor and will be open from 8:30 a.m. - 4:45 p.m. on Saturday and from 8:00 a.m. - 1:30 p.m. on Sunday.

Complimentary wheelchair service will be available to conference attendees again this year. Volunteers will be available to assist individuals move between the conference area and their hotel room. If you are in need of a lift, just look for the “TAXI” sign to flag down a ride!
2016 Exhibitor List

- Actelion Pharmaceuticals US, Inc.
- Bayer Healthcare
- Andrew Botieri, Author of - “A Celebration of Life” and Male Scleroderma Survivor
- Caring Voice Coalition
- Cytori Therapeutics, Inc.
- Gilead Sciences, Inc.
- Hawaiian Moon
- TOSS: A internet self-management program for scleroderma
- Laclede Inc.
- NeilMed Pharmaceuticals Inc.
- Pulmonary Fibrosis Foundation
- Pulmonary Hypertension Association
- Reata Pharmaceuticals, Inc.
- Scleroderma Foundation Advocacy Program
- Scleroderma Patient-centered Intervention Network (SPIN)
- Tulane Lung Center
- United Therapeutics
- Waterblocker Skin Cream
- Welmedix Consumer Healthcare
- Wristies, Inc.

Exhibitor Mardi Gras!

Your conference learning experience will be enhanced with a visit to the interactive Exhibit Hall this year! Eat delectable treats, and engage in informative discussions with our many exhibitors.

Located in your name badge lanyard will be an “Exhibitor Mardi Gras” card. “The Exhibitor Mardi Gras” is an activity developed to encourage all attendees to visit the exhibit hall during the 2016 Conference. Our sponsors’ and exhibitors’ support make this conference possible. Please show your gratitude by visiting their booths.

Just have each exhibitor stamp in the appropriate box on the card. Once your card is complete, sign and turn into the registration booth for a chance to win a $50 Barnes and Noble gift card! The drawing will be held at the end of the conference and the winner will be notified within one week.
If you’ve been diagnosed with connective tissue disease-associated pulmonary arterial hypertension (CTD-PAH), you may qualify to participate in CATALYST, a clinical research study evaluating the safety and effectiveness of bardoxolone methyl. Bardoxolone methyl is an oral medication taken once daily, and researchers believe it may improve several aspects of your CTD-PAH; however this hasn’t been proven.

If you qualify to participate in CATALYST, you’ll see your study doctor and research team throughout your participation in the study, which should last approximately 7 months. You may be compensated for your time and travel.

For more information on the CATALYST study, visit www.clinicaltrials.gov and search “Catalyst PAH”

Reata Pharmaceuticals is proud to partner with The Scleroderma Foundation
At conference check-in, you received a gift bag that included the conference evaluation. The conference evaluation is an important planning tool. We use your feedback to make improvements for future conferences. Please remember to write your name and contact info 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 that your feedback will remain anonymous. After the conference has ended, we will randomly select one person to win free hotel and registration to the 2017 National Conference.

Be sure to attend Saturday afternoon’s Awards Lunch to find out where we will hold the 2017 National Conference!

*Rules and regulations apply. Prize is not redeemable for cash. This prize is non-transferrable and must be used for the 2017 conference.

Scleroderma Awareness Items . . .

Help raise awareness of scleroderma! Come to our literature table at the conference 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 CafePress. Proceeds of these sales will benefit the Scleroderma Foundation.

www.cafepress.com/sclerodermafoundation

Win a Trip to the 2017 National Conference!

Just Fill Out and Return Your Conference Evaluation!
# 2016 Workshop Schedule - Saturday

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:45AM - 8:15AM</td>
<td><strong>Wake Up with Yoga</strong></td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td>7:45AM - 9:00AM</td>
<td><strong>Breakfast</strong></td>
<td>Napoleon Ballroom</td>
</tr>
<tr>
<td><strong>Workshop Room</strong></td>
<td><strong>Armstrong (8th Floor)</strong></td>
<td></td>
</tr>
<tr>
<td>9:15AM - 10:15AM</td>
<td><em>Grand Lecture - Shortness of Breath? Evaluation and Management in Scleroderma</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Richard Silver, M.D.</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Localized Scleroderma - Diagnosis and Treatment</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>Michael York, M.D.</strong></td>
<td></td>
</tr>
<tr>
<td>10:15AM - 10:45AM</td>
<td><strong>Speaker</strong></td>
<td></td>
</tr>
<tr>
<td>9:15AM - 10:15AM</td>
<td><strong>Refreshment Break</strong></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:45AM</td>
<td><strong>Workshop Room</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Oak Alley</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nottoway</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bayside A</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bayside B</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bayside C</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Southdown</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gallier</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Edgewood</td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>I am 10-15 Years After Diagnosis of Scleroderma, Now What? Janet Pope, M.D., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>How Do We Screen for and Prevent Scleroderma Complications? Laura Hummers, M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Pain has Many Causes and Many Cures Daniel Furst, M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Systemic Sclerosis: Oral Findings and Suggested Treatments Michelle Ravenol, D.M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Gastrointestinal Tract Procedures Vs. Empiric Treatment for Symptoms: Risks and Benefits Tracy Fretch, M.D., M.S.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Balancing Work, Life and Your Diagnosis Andrew Bolieri, C.S.P., N.A.L.P., Moderator Karen Gottesman, Joy Mitchell</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Body Image and Scleroderma Lisa Jewett, M.Sc., Shadi Gholizadeh, M.S., M.Sc., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Scleroderma: A New Diagnosis Jessica Gordon, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>12:15PM - 1:45PM</td>
<td><strong>Awards Lunch - Napoleon Ballroom</strong></td>
<td></td>
</tr>
<tr>
<td>2:15PM - 3:15PM</td>
<td><strong>using your voice to advance research and improve care: tips for effective advocacy and congressional outreach</strong></td>
<td>Endymion (8th Floor)</td>
</tr>
<tr>
<td></td>
<td><em>Skin Care and Wound Management in System Sclerosis Alexandra Crowe, R.N., (E.C.), B.Sc.N., M.N. - N.P.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Science Cafe: The Ugly Side of Collagen Carol Feghali-Bostwick, Ph.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Let Your Passion Overwhelm Your Fear Michael Williams-Stark</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>What Scleroderma Antibodies Mean for You Laura Hummers, M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Proton Pump Inhibitor (PPI): How to Digest the News Jessica Farrell, Pharm.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Young Adult Panel Ginny Marli, Ph.D., Moderator Stephen Elrod, Chanel White, Joanna Harper, Pharm.D., R.Ph.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Clinical Trials: Why Are They Important and Why Should I Participate? Dinesh Khanna, M.D., M.S.</em></td>
<td>Endymion (8th Floor)</td>
</tr>
<tr>
<td></td>
<td><em>Navigating Insurance Options: Understanding Available Insurance Options and What Choosing the Right Insurance Can Mean For Your Health and Your Finances Lauren Ruiz</em></td>
<td>Endymion (8th Floor)</td>
</tr>
<tr>
<td>3:15PM - 4:15PM</td>
<td><strong>Refreshment Break</strong></td>
<td></td>
</tr>
<tr>
<td>3:45PM - 4:45PM</td>
<td><strong>Yoga for Scleroderma - Kathy Randolph - Napoleon Ballroom</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Scleroderma Vascular Disease: Much More Than Raynaud’s Lee Shapiro, M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Practical Tips to Manage Fatigue Janet Poole, Ph.D., O.T.R./L., S.W.C.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Laughing at Tigers Carole Deyoe, R.Ph.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Dietary Supplements in Scleroderma Arnold Pastlethwaite, M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Pulmonary Hypertension as Seen in Scleroderma Philip Clements, M.D.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Young Adult Panel Continued Ginny Marli, Ph.D., Moderator Stephen Elrod, Chanel White, Joanna Harper, Pharm.D., R.Ph.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Caregiving 101 Shadi Gholizadeh, M.S., M.Sc., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td></td>
<td><em>Self-Compassion for Healthy Living Lara Naughton, M.P.W. Caroline Campion, M.D., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td>5:00PM - 6:15PM</td>
<td><strong>Dinner Buffet with a performance by Dr. Michael White and the Original Jazz Band</strong></td>
<td>Napoleon Ballroom</td>
</tr>
</tbody>
</table>

*Session will be filmed*
# 2016 WORKSHOP SCHEDULE - SUNDAY

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00AM - 7:30AM</td>
<td><strong>WAKE UP with YOGA</strong> <strong>BREAKFAST</strong></td>
<td>NAPOLEAN BALLROOM</td>
</tr>
<tr>
<td>7:00AM - 8:15AM</td>
<td><strong>WORKSHOP ROOM</strong></td>
<td>ARMSTRONG (8TH FLOOR)</td>
</tr>
<tr>
<td>8:30AM - 9:30AM</td>
<td><strong>CLOSING KEYNOTE</strong> - <strong>GOT ADVERSITY?</strong> - <strong>Andrew Botieri, C.S.P., N.A.L.P.</strong></td>
<td>NAPOLEAN BALLROOM</td>
</tr>
<tr>
<td>9:30AM - 9:45AM</td>
<td><strong>WORKSHOP ROOM</strong></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td><strong>REFRESHMENT BREAK</strong></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td><strong>REFRESHMENT BREAK</strong></td>
<td></td>
</tr>
<tr>
<td>11:00AM - 12:00PM</td>
<td><strong>REFRESHMENT BREAK</strong></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td><strong>REFRESHMENT BREAK</strong></td>
<td></td>
</tr>
<tr>
<td>12:30PM - 1:30PM</td>
<td><strong>REFRESHMENT BREAK</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Room</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:45AM - 10:45AM</td>
<td><em>Hematopoietic Stem Cell Transplantation for Scleroderma</em> <em>Richard Burt, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td><em>Yogic Breathing for Symptom Management in Scleroderma</em> <em>Sundar Balasubramanian, Ph.D.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td>What Your Dentist Wants to Know About You and Scleroderma <em>David Leader, D.M.D., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td>Gaining a “Foot Up” on Scleroderma <em>Kevin Riemer, D.P.M.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td>The Gastro-intestinal Tract in Scleroderma: Common Problems <em>Daniel Furst, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td>Recent Progress in Scleroderma Research - Overview of Clinical and Laboratory Advances <em>John Varga, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td>Renal Involvements As Seen In Scleroderma <em>Philip Clements, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>9:45AM - 10:45AM</td>
<td>What About Sex? <em>Elaine Furst, R.N., B.S.N., M.A.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td><em>Posture into Health: Breath into Life</em> <em>Tammy Gilbert, P.T., D.P.T., O.C.S.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td><em>Can or Should I Eat This?</em> <em>Arnold Postlethwaite, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td>The Skin You’re In: Scleroderma and Fragile Skin Care <em>Paula Erwin-Toth, M.S.N., R.N., C.W.O.C.N., C.N.S., F.A.A.N.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td>Scleroderma Hands and Their Care <em>Francesco Boin, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td>Mind Body Strength for Symptom Management when Living with Scleroderma <em>Lesley Ann Sakelkoo, M.D., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td>Insights Into Scleroderma Associated Interstitial Lung Disease <em>Kristin Highland, M.D., M.S.C.R.</em></td>
<td></td>
</tr>
<tr>
<td>10:45AM - 11:00AM</td>
<td><em>Men Only:</em> Issues in Male Scleroderma Patients <em>Edward Lally, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td><em>Musculoskeletal Manifestations of Scleroderma</em> <em>Jessica Gordon, M.D.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td><em>Hand and Face Exercises and Management of Daily Skills: An Occupational Therapy Perspective</em> <em>Janet Poole, Ph.D., O.T.R., S.W.C.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td>Raynaud and Digital Ulcers <em>Janet Pope, M.D., M.P.H.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td>Novel Insights Into Calcinosis in Connective Tissue Diseases <em>Lorinda Chung, M.D., M.S.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td>Making Tough Healthcare Decisions to Optimize Your Health and Well-Being: A Toolkit <em>Brett Thoms, Ph.D.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td>Coping With The Emotional Impact of Scleroderma <em>Mavis Seehaus, M.S., L.C.S.W.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td>The Scleroderma Support Group Survey: Understanding People’s Experiences with Scleroderma Support Groups <em>Vanessa DeLisle, M.Sc.</em></td>
<td></td>
</tr>
<tr>
<td>12:00PM - 12:30PM</td>
<td>African Americans and Scleroderma <em>Virginia Steen, M.D.</em></td>
<td></td>
</tr>
</tbody>
</table>

*Session will be filmed*
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.

*BALANCING WORK, LIFE AND YOUR DIAGNOSIS*
Balancing work, life, and a diagnosis of scleroderma can be challenging. A panel of patients will share their experiences on how they have successfully manage their diagnosis. This session is conversational and geared to be interactive with attendees.

*BODY IMAGE AND SCLERODERMA*
For many individuals coping with body image distress because of changes in appearance related to scleroderma can be challenging. This session will include topics such as why body image distress occurs. The speaker will also highlight relevant research and types of interventions that may be helpful in coping with body image distress.

*CAN OR SHOULD I EAT THIS?*
This question is in the “back of the mind” of most patients with scleroderma. The types of abnormalities that can develop in patients with scleroderma in all parts of the gastrointestinal (GI) tract [including gastroesophageal reflux disease (GERD)] and impaired function of the GI tract (in parts or the entire GI tract) are a major contributor to malnutrition and intolerance to specific types of foods in many patients. Several other factors likely contribute to intolerance to certain foods, including abnormal bacteria and other microorganisms that reside in the GI tract and sensitivity to gluten and gluten-like ingredients in certain grains and other foods.

*CAREGIVING 101*
Providing care to a loved one with scleroderma can be both very gratifying and challenging. Similarly, being the care recipient can have its own challenges. Caregiving 101 will describe common impacts on family caregivers and identify signs of caregiver burnout. This session will also discuss personal experiences of those caring for a loved one with scleroderma.

*CLINICAL TRIALS—WHY ARE THEY IMPORTANT AND WHY SHOULD I PARTICIPATE?*
In this session, the speaker will discuss the importance of participating in clinical trials and how to interpret them. Specifically, you will learn different phases of clinical trials, what questions to ask when approached to do a clinical trial and how clinical trials can help find an effective treatment for scleroderma.

*COPING WITH THE EMOTIONAL IMPACT OF SCLERODERMA*
Coping skills are considered to be the most helpful way of managing the stress of chronic rheumatic illness, such as scleroderma. Participants will discuss coping skills they have utilized, what has worked, and on what they might want to additionally focus. This session will discuss the importance of social support and how to use it effectively. Techniques for handling distressing emotions in the moment will also be discussed.

*DIETARY SUPPLEMENTS IN SCLERODERMA*
Abnormalities of the gastrointestinal (GD) tract in scleroderma contribute to malnutrition, which is common in patients with scleroderma. Studies show low levels of several important vitamins, minerals, and certain types of fatty acids in patients with scleroderma. Studies also show that local application of vitamin E gels promotes healing of digital ulcers, and antioxidants may have anti-fibrotic effects. Concentration of deficiencies of vitamins, minerals, and certain types of fatty acids may improve overall health status.

*GAINING A “FOOT UP” ON SCLERODERMA*
This session will review common foot problems that arise with scleroderma. The speaker will also present self-care measures to identify potential foot problems.

*GASTROINTESTINAL TRACT PROCEDURES VS. EMPIRIC TREATMENT FOR SYMPTOMS: RISKS AND BENEFITS*
This session will review commonly ordered procedures to investigate gastrointestinal complaints in systemic sclerosis. The speaker will also discuss common side effects of medications used for empirically treating gastrointestinal tract symptoms.

*GRAND LECTURE - SHORTNESS OF BREATH? EVALUATION AND MANAGEMENT IN SCLERODERMA*
In this lecture, the presenter will review the mechanism of breathing and the multiple potential causes of breathlessness in patients with scleroderma. The lecture will also focus on the two major causes of breathlessness, namely pulmonary fibrosis and pulmonary hypertension. The approach to diagnosis and management of these major complications of scleroderma will be discussed.

*denotes a new session for the 2016 Conference
EDUCATION WORKSHOP DESCRIPTIONS

HAND AND FACE EXERCISES AND MANAGEMENT OF DAILY SKILLS: AN OT PERSPECTIVE
In this session, participants will learn about modalities and exercises to improve movement and function in the hands, face and mouth. The presenter will provide suggestions about the use of assistive devices and alternate techniques to accomplish the tasks of daily living to increase independence, protect the hands, or when patients have limited finger movement.

*HEMATOPOIETIC STEM CELL TRANSPLANTATION FOR SCLERODERMA
Come listen as the speaker talks about hematopoietic stem cell transplants as it relates to scleroderma. The speaker will also discuss transplantation for autoimmune and immune mediated diseases.

*HOW DO WE SCREEN FOR AND PREVENT SCLERODERMA COMPLICATIONS?
All patients with scleroderma have a different array of manifestations of their disease. An important part of care, therefore, is to make a plan for each patient on how we will assess each area for possible involvement or progression so treatment may begin at the earliest stage possible if needed. The goals of this session is to review ways we can assess each area possibly involved in scleroderma to allow for minimization for complications and choose appropriate treatment regimens.

I AM 10 TO 15 YEARS AFTER DIAGNOSIS OF SCLERODERMA, NOW WHAT?
In this session, find out answers to what happens in long standing scleroderma. 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.

*INSIGHTS INTO SCLERODERMA ASSOCIATED INTERSTITIAL LUNG DISEASE
This session will review of risk factors, evaluation for and treatment of scleroderma associated interstitial lung disease.

*LAUGHING AT TIGERS
This session will discuss the negative effects of stress on our health and the link between stress and illness. Through personal experiences, the presenter will highlight the positive effects of humor on our health and wellbeing. This session will also explore proven ways to add laughter into your daily life.

*LET YOUR PASSION OVERWHELM YOUR FEAR
Put aside your doubts and do what you love! This session will teach participants that despite setbacks, you can make a difference. This speaker will discuss personal experiences that taught them how to overcome their differences. Perhaps you’re perceived “difference” is your greatest gift. Let others say you can’t. That is their problem.

LOCALIZED SCLERODERMA - DIAGNOSIS AND TREATMENT
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. There also will be a discussion about the multidisciplinary approach to the disease that is used at Boston University Medical Center in the Rheumatology-Dermatology Clinic.

*MAKING TOUGH HEALTHCARE DECISIONS TO OPTIMIZE YOUR HEALTH AND WELL-BEING: A TOOLKIT
In scleroderma, some medical decisions are pretty clear-cut, whereas others may require more careful thought before making a decision. One example might be a risky or expensive treatment like surgery. Another might be weighing whether to begin a new medication that could address an important symptom, but may also come with unpleasant side effects or pose a serious risk. This session will focus on how you can develop and carry out a plan to work with your healthcare provider to make the best possible decisions for you.

MANAGEMENT IN SCLERODERMA
In this lecture, the presenter will review the mechanism of breathing and the multiple potential causes of breathlessness in patients with scleroderma. The lecture will also focus on the two major causes of breathlessness, namely pulmonary fibrosis and pulmonary hypertension. The approach to diagnosis and management of these major complications of scleroderma will be discussed.

MEN ONLY: ISSUES IN MALE SCLERODERMA PATIENTS
Participants will explore issues unique to men living with scleroderma including sexual dysfunction, work-related issues and psychological problems encountered by men. Workshop attendees are encouraged to share their experiences and problems with the group to engage in a meaningful dialogue.

*denotes a new session for the 2016 Conference
MIND BODY STRENGTH FOR SYMPTOM MANAGEMENT WHEN LIVING WITH SCLERODERMA
Scleroderma is a multi-system and multi-symptom disease ranging from varied types of severe pain, nausea, difficulty breathing, weakness, extreme cold and fatigue as well as the psycho-social impact of the condition on daily and long-term living. Rooted in mindfulness, this session plants practical seeds for immediate and long-term symptom self-management in scleroderma. Touching upon important discussions of sleep, nutrition and exercise as central mindful strategies for better health outcomes in scleroderma.

MUSCULOSKELETAL MANIFESTATIONS OF SCLERODERMA
Scleroderma affects the joints, bones, and muscles in ways that lead to pain and disability. In this session learn about the different ways scleroderma can affect the musculoskeletal system and what can be done to improve pain and function related to joint, nerve, and muscle disease.

NAVIGATING INSURANCE OPTIONS: UNDERSTANDING AVAILABLE INSURANCE OPTIONS AND WHAT CHOOSING THE RIGHT INSURANCE CAN MEAN FOR YOUR HEALTH AND YOUR FINANCES
Deciding which health insurance is best for your needs, as well as affordable, can be overwhelming. This session will discuss how to find and obtain insurance that meets your health and prescription needs and doesn’t break the bank.

NOVEL INSIGHTS INTO CALCINOSIS IN CONNECTIVE TISSUE DISEASES
This session will summarize recent advances in the understanding of calcinosis, medications currently used to treat calcinosis and potential novel therapeutic strategies. The speaker will also present illustrative cases of patients with calcinosis and lead a discussion of potential causes.

*PAIN HAS MANY CAUSES AND MANY CURES
Find out where the pain of scleroderma comes from and what you can do about it. In this session, the speaker will discuss the sources of pain and different strategies for managing pain depending on the cause.

POSTURE INTO HEALTH: BREATHE INTO LIFE
Do you want to breathe easier and have more energy? Discover how simply changing your posture can improve your breathing as well as decrease your fatigue levels. Do you have neck, shoulder or back pain? This lecture will teach you how bad posture may contribute to your chronic pain levels. Are you stressed out? Come learn the simple technique of diaphragmatic breathing to help you relax. Does the word exercise immediately prompt fear and anxiety in you? Then come learn simple ways to incorporate exercise into your daily life and overcome the challenges that scleroderma patients face when trying to exercise.

*PRACTICAL TIPS TO MANAGE FATIGUE
This interactive session will review strategies to manage fatigue including diaries to see patterns of fatigue. The speaker will also discuss ways to save and budget energy such as prioritizing, pacing, and changing postures, activities, and the environment.

*PROTON PUMP INHIBITOR (PPI): HOW TO DIGEST THE NEWS?
Recent news reports of studies published in the last year related to safety issues associated with proton pump inhibitor (PPI) use have dramatized study results. News reports have stated that PPI use may be associated with dementia and kidney disease. This lecture will review and critique recently publicized studies which examine safety concerns associated with PPIs. This data will be extrapolated to discuss the risk versus benefit associated with PPI use in patients with scleroderma.

PULMONARY HYPERTENSION AS SEEN IN SCLERODERMA
About 10-15% of people with SSc may develop an elevation of blood pressure in the pulmonary circulation (pulmonary hypertension). The best known process is one that is called pulmonary artery hypertension. In this circumstance the blood flow through the lung is decreased because of narrowing of the pulmonary blood vessels that move blood into the lung circulation. In this session, the speaker will discuss the several processes that can be associated with pulmonary hypertension and how to recognize and manage them.

RAYNAUD AND DIGITAL ULCERS
This session will help patients learn about the frequency of digital ulcers and how they impact patients. The speaker will also help patients understand treatment of digital ulcers and Raynaud’s in Systemic Sclerosis. Evidence-based treatment algorithms for Raynaud’s and digital ulcers will also be covered.

---

*denotes a new session for the 2016 Conference
RECENT PROGRESS IN SCLERODERMA RESEARCH - OVERVIEW OF CLINICAL AND LABORATORY ADVANCES
Scleroderma remains a challenging disease: unknown cause, not well understood, and to date no approved therapy. Obstacles to development of effective therapies include the complex, multifactorial pathogenesis, lack of clear etiologic agent, uncertain role of genetic risks; patient-to-patient variability in clinical manifestations and disease outcomes; variable rates of disease progression in different organs in the same individual; lack of validated biomarkers, and lack of consensus regarding optimal clinical trial design. Each of these obstacles is being addressed by current research. A large number of plausible drug targets have been identified and are being validated in preclinical models. Innovative clinical trial designs and increasingly more robust outcome measures allow more effective drug testing. Molecular approaches further facilitate patient stratification, and matching drugs to patients in an increasingly personalized precision approach to management. This session will present some highlights from very recent research studies of interest.

RENAL INVOLVEMENTS AS SEEN IN SCLERODERMA
There are several types of kidney involvement. This session will discuss the different types of involvement as well how each can be managed. Scleroderma renal crisis (kidney failure usually with new onset hypertension) is the most recognizable involvement and fortunately can usually be treated successfully. Although the majority of SSc patients develop a subclinical mild decline in kidney function, it rarely needs treatment and rarely is associated with kidney failure.

*SCIENCE CAFÉ - THE UGLY SIDE OF COLLAGEN
This session will describe features of abnormal collagen deposition in the fibrosis that is the hallmark of scleroderma. The speaker will also cover studies designed to identify the underlying cause of fibrosis and potential approaches to improve it.

*SCLERODERMA: A NEW DIAGNOSIS
This session is a crash course on what you need to know when you are first diagnosed with systemic sclerosis (SSc).

SCLERODERMA HANDS AND THEIR CARE
Everything you need to know about what causes damage and dysfunction of the hands in scleroderma. This session will also provide tips on how to take good care of your hands.

*SJOGREN’S AND SCLERODERMA
This session will review making the diagnosis of Sjogren's in the setting of systemic sclerosis. The speaker will give management tips, including both behavioral and medication aspects of therapy. Patients should leave the session with a comfortable understanding of how to advocate for themselves with regards to sicca symptoms.

*SELF-COMPASSION FOR HEALTHY LIVING
The goal of this workshop is to directly experience self-compassion and to learn practices that can enrich your life, even (especially) when it’s difficult. Cultivating self-compassion can help reduce stress, anxiety and negative judgment, while increasing your strength to face the suffering in your life and in the lives of those around you. It can improve your personal and professional relationships, bolster your ability to respond to challenges, and increase joy.

*SKIN CARE AND WOUND MANAGEMENT IN SYSTEMIC SCLEROSIS
In this session, the speaker will help patients understand what is happening to their skin as Systemic Sclerosis progresses. The speaker will also include evidence-based therapies to consider. These include certain things patients should avoid, certain things that patients can do on their own and finally what medical therapies are recommended. The speaker will also briefly discuss Calcinosis and Raynaud’s as a lead into the management of wounds that are associated with Systemic Sclerosis, including digital ulcers and leg ulcers.

*THE SCLERODERMA SUPPORT GROUP SURVEY: UNDERSTANDING PEOPLE’S EXPERIENCES WITH SCLERODERMA SUPPORT GROUPS
Support groups are an important resource for many people living with scleroderma. Most scleroderma support groups are led by people who have been diagnosed with scleroderma and face many of the same challenges as other group members. Support group leaders play an important role in determining the success of a group. In order to develop training and support resources for support group leaders, we conducted a survey to understand the challenges that leaders face, as well as the reasons why people attend or do not attend these groups. This session will focus on the results of the Scleroderma Support Group Survey.

SCLERODERMA VASCULAR DISEASE: MUCH MORE THAN RAYNAUD’S
Microvascular disease is more ubiquitous in scleroderma than commonly appreciated. Pulmonary hypertension, Raynaud’s, and scleroderma renal crisis are all well recognized vascular complications of the disease. This talk will build a case for vascular disease as the basis of many other manifestations,

*denotes a new session for the 2016 Conference
EDUCATION WORKSHOP DESCRIPTIONS

SCLERODERMA VASCULAR DISEASE: MUCH MORE THAN RAYNAUD’S (continued)
including gastrointestinal disease and calcinosis, and will discuss promotion of angiogenesis as another possible treatment approach.

*SYSTEMIC SCLEROSIS: ORAL FINDINGS AND SUGGESTED TREATMENTS
The lecture will review some of the more common oral complications associated with Systemic Sclerosis. The presenter will also cover suggested treatments and strategies to maintain good oral health.

THE GASTRO-INTESTINAL TRACT IN SCLERODERMA: COMMON PROBLEMS
In this session, participants will learn about the common problems you may encounter. The speaker will also cover treatments that may help you get through them.

THE SKIN YOU’RE IN: SCLERODERMA AND FRAGILE SKIN CARE
This session will address how scleroderma affects your skin. The speaker will also offer tips to care for skin changes associated with scleroderma. Special skin care needs associated with incontinence will also be discussed.

USING YOUR VOICE TO ADVANCE RESEARCH AND IMPROVE CARE: TIPS FOR EFFECTIVE ADVOCACY AND CONGRESSIONAL OUTREACH
The federal government has many programs that fund medical research and manage and patient access to care and therapies. Members of Congress make decisions on these issues each year and they are influenced by the people they represent (you!). Learn how you can join the Foundation’s nationwide advocacy effort and work with others to educate elected officials about scleroderma and the challenges facing the community.

*WAKE UP WITH YOGA!
A short morning program with breathing for increased circulation, stretching and hand work for improved range of motion, and a deep relaxation for stress relief. On the spot adaptations by Kathy Randolph ensure the practice works for you. All the poses can be done standing or seated in chairs, so come as you are!

WHAT ABOUT SEX?
People living with chronic disease have to adapt to many changes. One of these changes is their sex life: Should we? Can we? What about getting pregnant? This workshop will discuss these and other concerns of people affected by scleroderma. Couples and singles are welcome.

*WHAT SCLERODERMA ANTIBODIES MEAN FOR YOU
One of the most important ways physicians assess scleroderma at the onset of disease is by determination of what scleroderma-related autoantibodies being produced by a patient. These antibodies may tell us something meaningful about what complications may arise in the future. In this session, the speaker will review what is known about each specific autoantibody in scleroderma and what this may mean for how we screen and monitor for complications.

WHAT YOUR DENTIST WANTS TO KNOW ABOUT YOU AND SCLERODERMA
Dentists are experts on how medical conditions may affect oral health, but many do not know about scleroderma. You can work with your dentist to educate them on scleroderma. Your dentist will feel more knowledgeable. They will be able to treat you more effectively. You will have a higher level of satisfaction with your treatment.

YOGA FOR SCLERODERMA
A therapeutic program of yoga poses and breathing techniques selected for their benefit to symptoms of scleroderma. This practice consists of a sequence of seated and reclining exercises with special emphasis on breathing techniques. All can be performed with the assistance of a caregiver, with complete instruction for both the individual and the caregiver. This session will include new material for hands and wrists, and lots of focus on symptom relief for Reynaud’s. The whole practice can be done seated in a chair, so come as you are!

*YOGIC BREATHING FOR SYMPTOM MANAGEMENT IN SCLERODERMA
This session is designed for participants from all levels including patients and caregivers. This session will also cover the basics of Yogic breathing both theory and practice. Participants will learn powerful Yogic Breathing exercises from a traditional Yoga practitioner/researcher. Discover the wonders of breathing right. The speaker will also help you understand the scientific reasons behind Yogic Breathing. No mat or special apparel required. Wear anything that would allow you to breathe well. Available to all ages. No large meal 2 hours prior is suggested and please drink adequate water.

*YOUNG ADULT PANEL
Young adults who suffer from a chronic illness face tremendous obstacles related to intimacy and relationships. This interactive double session will be moderated by a panel of young adults. Topics covered by the panel include diagnosis, pregnancy and balancing work and life.

*denotes a new session for the 2016 Conference
Letairis and tadalafil do more together than either alone

Letairis is a prescription medicine used to treat pulmonary arterial hypertension (PAH), which is high blood pressure in the arteries of the lungs.

Letairis, when taken with tadalafil, is indicated to:

- Improve your ability to exercise
- Reduce the risk of your disease progressing
- Reduce your risk of hospitalization due to worsening PAH

IMPORTANT SAFETY INFORMATION

What is the most important information I should know about Letairis?

Letairis can cause serious birth defects if taken during pregnancy.

- Females must not be pregnant when they start taking Letairis or become pregnant while taking Letairis
- Females who are able to get pregnant must have a negative pregnancy test before starting Letairis, every month while taking Letairis, and 1 month after stopping Letairis. Your doctor will decide when to do the tests, and order the tests for you depending on your menstrual cycle
  - Females who are able to get pregnant are females who have entered puberty (even if they have not started their period), and have a uterus, and have not gone through menopause (menopause means that you have not had a period for at least 12 months for natural reasons, or that you have had your ovaries removed)

Please see additional Important Safety Information and Brief Summary of full Prescribing Information, with important warnings, on adjacent pages.
IMPORTANT SAFETY INFORMATION (continued)

What is the most important information I should know about Letairis? (continued)

Females who are able to get pregnant must use two acceptable forms of birth control while taking Letairis and for 1 month after stopping Letairis because the medicine may still be in the body. See the Letairis Medication Guide for acceptable birth control options.

- If you have had a tubal sterilization or have an IUD (intrauterine device) or progesterone implant, these methods can be used alone and no other form of birth control is needed.
- Talk with your doctor to find out about options for acceptable forms of birth control that you may use to prevent pregnancy during treatment with Letairis.
- If you decide that you want to change the form of birth control, talk with your doctor to be sure that you choose another acceptable form of birth control.
- Do not have unprotected sex. Talk to your doctor or pharmacist right away if you have unprotected sex or if you think your birth control has failed.
- Tell your doctor if you think your birth control has failed.
- Tell your doctor if you are pregnant, plan to become pregnant, or become pregnant while taking Letairis. Letairis can cause serious birth defects. (See “What is the most important information I should know about Letairis?”)
- You have Idiopathic Pulmonary Fibrosis (IPF)

What should I avoid while taking Letairis?

- Do not get pregnant. If you miss a menstrual period, or think you might be pregnant, call your doctor right away.
- Do not breastfeed. It is not known if Letairis passes into your breast milk.

What are the other possible side effects of Letairis?

Serious side effects of Letairis can include:

- Swelling all over the body (fluid retention) can happen within weeks after starting Letairis. Tell your doctor right away if you have any unusual weight gain, tiredness, or trouble breathing while taking Letairis. These may be symptoms of a serious health problem. You may need to be treated with medicine or need to go to the hospital.
- Decreased sperm counts have happened in some men taking a medicine that is like Letairis, which may affect your ability to father a child. Tell your doctor if being able to have children is important to you.
- Low red blood cell levels (anemia) can happen during the first weeks after starting Letairis. If this happens, you may need a blood transfusion. Your doctor will do blood tests to check your red blood cells before starting Letairis. Your doctor may also do these tests while you are taking Letairis.

The most common side effects of Letairis when taken with tadalafil are swelling of hands, legs, ankles and feet (peripheral edema), headache, stuffy nose (nasal congestion), cough, low red blood cell levels (anemia), indigestion (dyspepsia) or upper respiratory tract infection (bronchitis).

Some medicines that are like Letairis can cause liver problems. Tell your doctor if you get any of these symptoms while taking Letairis: loss of appetite, nausea or vomiting, fever, achiness, generally do not feel well, pain in the upper right stomach (abdominal) area, yellowing of your skin or the whites of your eyes, dark urine, itching.

What should I tell my doctor before taking Letairis?

- All your medical conditions. Be sure to tell your doctor if you have a low red blood cell level (anemia) or liver problems.
- All the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements. Letairis and other medicines may affect each other causing side effects. Do not start any new medicines until you check with your doctor.
- Especially tell your doctor if you take cyclosporine (Gengraf, Neoral, Sandimmune). Your doctor may need to change your dose of Letairis.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see Brief Summary of full Prescribing Information, with important warnings, on adjacent page.

Talk to your doctor to see if Letairis + tadalafil is right for you. Visit www.letairis.com for more information.
Letairis® (le-TAIR-is) (ambrisentan) tablets

Brief Summary of full Prescribing Information. For more information, please see the full Prescribing Information, including Medication Guide.

What is Letairis?

• Letairis is a prescription medicine used to treat pulmonary arterial hypertension (PAH), which is high blood pressure in the arteries of your lungs.
• Letairis can improve your ability to exercise and help slow down the worsening of your physical condition and symptoms
• When taken with tadalafil, Letairis is used to reduce the risks of your disease progressing and hospitalization due to PAH and to improve your ability to exercise.
• It is not known if Letairis is safe and effective in children.

What is the most important information I should know about Letairis?

Serious birth defects

• Letairis can cause serious birth defects if taken during pregnancy.
• Females must not be pregnant when they start taking Letairis or become pregnant while taking Letairis.
• Females who are able to get pregnant must have a negative pregnancy test before starting Letairis, each month while taking Letairis and 1 month after stopping Letairis. Talk to your doctor about your menstrual cycle. Your doctor will decide when to do a pregnancy test, and will order a pregnancy test for you depending on your menstrual cycle.
• Females who are able to get pregnant are females who have entered puberty (even if they have not started their menstrual period), and have a uterus, and have not gone through menopause.
• Females who are not able to get pregnant are females who have not yet entered puberty, do not have a uterus, or have gone through menopause or are infertile for any other medical reason and the infertility is permanent.
• Menopause means that you have not had a menstrual period for at least 12 months for natural reasons, or that you have had your ovaries removed.
• Females who are able to get pregnant must use 2 acceptable forms of birth control, while taking Letairis and for 1 month after stopping Letairis because the medicine may still be in the body.
• If you have had a tubal sterilization or have an IUD (intrauterine device) or progesterone implant, these methods can be used alone and no other form of birth control is needed.
• Talk with your doctor or gynecologist to find out about options for acceptable forms of birth control and how to prevent pregnancy while you are taking Letairis.
• If you decide that you want to change the form of birth control that you use, talk to your doctor to be sure that you choose another acceptable form of birth control.
• Do not have unprotected sex. Talk to your doctor or pharmacist right away if you have unprotected sex or if you think your birth control has failed. Your doctor may tell you to use emergency birth control.

• Tell your doctor right away if you miss a menstrual period or think you may be pregnant for any reason.
• If you are the parent or caregiver of a female child who started taking Letairis before reaching puberty, you should check your child regularly to see if she is developing signs of puberty. Tell her doctor right away if you notice that she is developing breast buds or pubic hair. Her doctor should decide if she has reached puberty. Your child may reach puberty before having her first menstrual period.
• Females can only receive Letairis through a restricted program called the Letairis Risk Evaluation and Mitigation Strategy (REMS) program. If you are a female who can get pregnant, you must talk to your doctor, understand the benefits and risks of Letairis, and agree to all of the instructions in the Letairis REMS program.
• Males can receive Letairis without taking part in the Letairis REMS program.

Who should not take Letairis?

Do not take Letairis if:

• You are pregnant, plan to become pregnant, or become pregnant while taking Letairis. Letairis can cause serious birth defects early in pregnancy. See “What is the most important information I should know about Letairis?”
• You have a condition called idiopathic pulmonary fibrosis (IPF).

What are the possible side effects of Letairis?

Letairis can cause serious side effects including:

• See “What is the most important information I should know about Letairis?”
• Swelling all over the body (fluid retention) can happen within weeks after starting Letairis. Tell your doctor right away if you have any unusual weight gain, tiredness, or trouble breathing while taking Letairis. These may be symptoms of a serious health problem. You may need to be treated with medicine or need to go to the hospital.
• Decreased sperm counts have happened in some men taking a medicine that is like Letairis, and may affect the ability to father a child. Tell your doctor if being able to have children is important to you.
• Low red blood cell levels (anemia) can happen during the first weeks after starting Letairis. If this happens, you may need a blood transfusion. Your doctor will do blood tests to check your red blood cells before starting Letairis. Your doctor may also do these tests while you are taking Letairis.

The most common side effects of Letairis include:

• Swelling of hands, legs, ankles and feet (peripheral edema); stuffy nose (nasal congestion); inflamed nasal passages (sinusitis); hot flashes or getting red in the face (flushing)
• Some medicines that are like Letairis can cause liver problems. Tell your doctor if you get any of these symptoms while taking Letairis:
• Loss of appetite, nausea or vomiting, fever, achiness, generally do not feel well, pain in the upper right stomach (abdominal) area, yellowing of your skin or the whites of your eyes, dark urine, itching
• Tell your doctor if you have any side effect that bothers you or that does not go away.
• These are not all the possible side effects of Letairis. For more information, ask your doctor or pharmacist.

What should I tell my doctor before taking Letairis?

Tell your doctor about all your medical conditions, including:

• Low red blood cell level (anemia)
• Liver problems

Tell your doctor about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements. Letairis and other medicines may affect each other causing side effects. Do not start any new medicines until you check with your doctor.

Especially tell your doctor if you take the medicine cyclosporine (Gengraf, Neoral, Sandimmune). Your doctor may need to change your dose of Letairis.

How should I take Letairis?

• Letairis will be mailed to you by a certified pharmacy. Your doctor will give you complete details.
• Take Letairis exactly as your doctor tells you to take it. Do not stop taking Letairis unless your doctor tells you to stop.
• You can take Letairis with or without food.
• Do not split, crush or chew Letairis tablets.
• It will be easier to remember to take Letairis if you take it at the same time each day.
• If you take more than your regular dose of Letairis, call your doctor right away.
• If you miss a dose, take it as soon as you remember that day. Take your next dose at the regular time. Do not take two doses at the same time to make up for a missed dose.

What should I avoid while taking Letairis?

• Do not get pregnant while taking Letairis. (See the serious birth defects section of “What is the most important information I should know about Letairis?”) If you miss a menstrual period, or think you might be pregnant, call your doctor right away.
• It is not known if Letairis passes into your breast milk. You should not breastfeed if you are taking Letairis.

Keep Letairis and all medicines out of the reach of children.

This Brief Summary summarizes the most important information about Letairis. If you would like more information, talk with your doctor. You can also ask your doctor or pharmacist for information about Letairis that is written for health professionals, or call 1-866-664-3327 or go to www.Letairis.com or www.gilead.com.

Revised: October 2015

©2016 Gilead Sciences, Inc. All rights reserved. LETC0226 06/16
Letairis, the Letairis logo, GILEAD and the GILEAD logo are registered trademarks of Gilead Sciences, Inc., or its related companies. Other brands noted herein are the property of their respective owners.
Special Thanks

Scleroderma Foundation Conference Planning Team
Kerri A. Connolly, Conference Director
Ryan Burrill, Venue Logistics Coordinator
Shenna Gianetta, Exhibits/Scholarship Coordination
Laura Koumarianos, Accounting Support/Sales
David Murad, Chapter Liaison/Volunteer Management
Linda Norris, Data Support
Deborah Pearce, Team Support
Robert J. Riggs, Team Leader
Irena Shuruyeva, Accounting Support
Jillian Scola, Program Book/Communications
Angel Soto, Administrative Support
Maureen Zuluaga, Registration Support

Thank You To Our 2016 Corporate Sponsors:
Actelion Pharmaceuticals, US, National Gold Sponsor
Bayer Healthcare, Platinum Conference Sponsor/National Bronze Sponsor
Boehringer Ingelheim, Corporate Sponsor
Genentech, Corporate Sponsor
Gilead Sciences, Silver Conference Sponsor
Reata Pharmaceuticals, National Bronze Sponsor
United Therapeutics, Corporate Sponsor

Additional Thanks To:
Carol Feghali-Bostwick, Ph.D., Vice-Chair, National Board of Directors
Justin Burrill
Fibrocell Science
Foxgloves, Inc.
The Fyke Family
Joi and Bill Goodbread
Health and Medicine Counsel of Washington, D.C.
LaPlume & Sons Printing
Louisiana Support Groups
Robb Cohen Photography and Video
Ryan Lovelace
The Management and Staff of the Sheraton New Orleans
Magnus Media Group
New Orleans Convention and Visitors Bureau
John Novack, Director of Communications for Inspire.com
Christina Relacion, Account/Project Manager | Cathexis Partners
Scleroderma Foundation Advocacy Committee
Scleroderma Foundation National Board of Directors
Scleroderma Foundation National Medical and Scientific Advisory Board
Tracey O. Sperry
The Seed Agency Graphics
The Weber Family

Special Thanks to Our New Orleans Conference Volunteers and Coordinators
A special debt of gratitude is owed to volunteer coordinators Joy Mitchell and Del Anselmo. We also owe a big thank you to the wonderful group of volunteers who have given countless hours and talent to help with the logistics of this conference. While you are in NOLA, you can find the volunteer staff wearing purple t-shirts. On behalf of the conference attendees, we thank you!

We would also like to thank Lesley Ann Saketkoo, M.D., M.P.H. for all of her help and support during the planning process.
Boehringer Ingelheim ranks among the world’s 20 leading pharmaceutical corporations. Our vision drives us forward. It helps us to foster value through innovation in our company and to look to the future with constantly renewed commitment and ambition.

For more than 125 years, Boehringer Ingelheim has been committed to the research and development of innovative medicines that help make more health for patients and their families.

Visit us online at us.boehringer-ingelheim.com
The work of the Scleroderma Foundation could not reach the people who need our assistance most without the tireless efforts of our volunteers and staff in chapters across the country.

**Colorado Rocky Mountain Chapter**  
(303) 806-6686  
www.scleroderma.org/colorado

**Delaware Valley Chapter**  
Delaware, Eastern Pennsylvania, Southern New Jersey  
(866) 675-5545  
www.scleroderma.org/delawarevalley

**Georgia Chapter**  
(770) 925-7037  
www.scleroderma.org/georgia

**Greater Chicago Chapter**  
Illinois, Indiana, Iowa, Wisconsin  
(312) 660-1131  
www.scleroderma.org/chicago

**Greater Washington, D.C. Chapter**  
District of Columbia, Maryland, Virginia  
(571) 291-1480  
www.scleroderma.org/dc

**Heartland Chapter**  
Iowa, Nebraska, South Dakota  
(515) 661-8089  
www.scleroderma.org/heartland

**Michigan Chapter**  
(248) 595-8526  
www.scleroderma.org/michigan

**Minnesota Chapter**  
(877) 794-0347  
www.scleroderma.org/minnesota

**Missouri Chapter**  
(417) 887-3269  
www.scleroderma.org/missouri

**New England Chapter**  
Maine, Massachusetts, New Hampshire, Rhode Island, Vermont  
(888) 887-0658  
www.scleroderma.org/newengland

**Northern California Chapter**  
(800) 722-4673  
www.scleroderma.org/norcal

**Ohio Chapter**  
(866) 849-9030  
www.scleroderma.org/ohio

**Oklahoma Chapter**  
(405) 596-3786  
www.scleroderma.org/oklahoma

**Oregon Chapter**  
(503) 245-4588  
www.scleroderma.org/oregon

**Southern California Chapter**  
(877) 443-5755  
www.scleroderma.org/socal

**South Carolina Chapter**  
(864) 617-0237  
www.scleroderma.org/southcarolina

**Southeast Florida Chapter**  
(954) 798-1854  
www.scleroderma.org/sefl

**Tennessee Chapter**  
(800) 497-5193  
www.scleroderma.org/tennessee

**Texas Bluebonnet Chapter**  
(866) 532-7673  
www.scleroderma.org/texas

**Tri-State Chapter**  
Connecticut, Northern New Jersey, New York  
(800) 867-0885  
www.scleroderma.org/tristate

**Western Pennsylvania Chapter**  
(800) 722-4673  
www.scleroderma.org/wpenn

**Washington Evergreen Chapter**  
253-381-9654  
www.scleroderma.org/washington
National Leadership

BOARD OF DIRECTORS
Cos Mallozzi - Chair
Carol Feghali-Bostwick, Ph.D. - Vice Chair
Bruce Cowan - Secretary
Greg Marion - Treasurer
Mary Blades
James Evans
Katayun Jaffari
Lee Roy Jones
Robert Kacick
Bill Martin
Robert Slappey

NATIONAL STAFF
Robert J. Riggs
Chief Executive Officer
rriggs@scleroderma.org

Kerri A. Connolly
Director of Programs and Services
kconnolly@scleroderma.org

Ryan Burrill
Programs and Services Manager
rburrill@scleroderma.org

Laura Koumarianos
Senior Accountant
lkoumarianos@scleroderma.org

Shenna Gianetta
Executive Assistant
sgianetta@scleroderma.org

David Murad
Director of Chapter Relations
dmurad@scleroderma.org

Linda Norris
Database Administrator
lnorris@scleroderma.org

Deborah Pearce
Chief Operating Officer
dpearce@scleroderma.org

Jillian Scola
Communications Manager
jscola@scleroderma.org

Irina Shuruyeva
Accounting Assistant
ishuruyeva@scleroderma.org

Maureen Zuluaga
Database Manager
mzuluaga@scleroderma.org

MEDICAL AND SCIENTIFIC ADVISORY BOARD MEMBERS
John Varga, M.D. - Chair
Lorinda Chung, M.D.
Philip Clements, M.D.
Aryeh Fischer, M.D.
Tracy Frech, M.D.
Daniel Furst, M.D.
Jessica Gordon, M.D.
Laura Hummers, M.D.
Sergio Jimenez, M.D.
Dinesh Khanna, M.D., M.S.
Robert Lafyatis, M.D.
Maureen D. Mayes, M.D.
Janet Pope, M.D.
Arnold Postlethwaite, M.D.
Richard Silver, M.D.
Robert F. Spiera, M.D.
Virginia Steen, M.D.

MEMBERS EMERITI
Frank Arnett, M.D.
Carol Black, M.D.
Michael Ellman, M.D.
Thomas Medsger, Jr, M.D.
Frederick Wigley, M.D.

CONTACT US
Contact the National Office by phone at 800-722-HOPE, by fax at 978-777-1313,
or visit www.scleroderma.org. You may also email sfinfo@scleroderma.org.

OUR MAILING ADDRESS IS:
300 Rosewood Drive, Suite 105 • Danvers, MA 01923
© 2016 Actelion Pharmaceuticals US, Inc. All rights reserved. ACT-01236 0616
Up to 1 in 4 people living with scleroderma may have PAH.¹

People living with scleroderma may be at risk for another condition called PAH, or pulmonary arterial hypertension.¹ The most common symptom of PAH is shortness of breath during daily activities.¹

What is PAH?

- PAH—high blood pressure in the arteries of the lungs—is a serious and progressive condition that may develop in patients with scleroderma.¹
  - Annual PAH screenings are recommended for all patients with scleroderma.¹

Treatments for PAH

- Although there is currently no cure for PAH, treatments are available. If you have PAH, your doctor will decide which therapy is right for you.

Be PAH proactive.

Ask your doctor about annual PAH screenings.

For more information about PAH, visit www.scleroderma.org or www.phassociation.org.

Brought to you by Actelion—a proud sponsor of the Scleroderma Foundation.
Getting to Know:
Dr. Michael White and the Original Jazz Band

We are excited to announce that Dr. Michael White and the Original Liberty Jazz band will be providing entertainment at our buffet dinner on Saturday, July 30th starting at 5:30 p.m. Dr. Michael White and his Original Liberty Jazz Band take a little bit o’ New Orleans with them wherever they go. Their goal is to “both preserve and expand the authentic New Orleans jazz tradition.”

Dr. Michael White is one of today’s primary exponents of classic New Orleans jazz. He was born and raised in New Orleans, Louisiana. He is a jazz clarinetist, bandleader, composer, jazz historian, and musical educator. Scott Yanow, a jazz critic, said that Dr. White “displays the feel and spirit of the best New Orleans clarinetists.”

Dr. White is a classically trained musician who began his jazz career as a teenager playing for Doc Paulin’s Brass Band in New Orleans. He was a member of an incarnation of the Fairview Baptist Church Marching Band, established by banjoist Danny Barker. He was discovered by Kid Sheik Colar, who heard him performing in Jackson Square in the French Quarter. He began working with the musician regularly following the encounter. A staunch jazz traditionalist, Dr. White can be heard on the 1989 album The Majesty of the Blues by Wynton Marsalis.

In 1981, he founded The Original Liberty Jazz Band with the express intent of preserving the musical heritage of New Orleans.
I am very impressed with the wealth of knowledge and support provided by this community.

This site is a Godsend.

Visit us online at Scleroderma.Inspire.com.

Complete the registration process. (It’s free and just takes a minute!)

Connect and share with others like you!

Join today!

Scleroderma.Inspire.com

The Scleroderma Foundation and Inspire have partnered to help you get valuable information and support from others who understand what you are going through.
Science For A Better Life

Bayer is committed to advancing the science of systemic sclerosis through ongoing research.

Bayer is proud to be a Platinum Sponsor of the 2016 Scleroderma Foundation National Patient Education Conference

For more information:
Phone: 1-888-842-2937
Email: clinical-trials-contact@bayerhealthcare.com