25 YEARS OF PROGRESS:
CHANGING THE HISTORY OF PH

June 17 – 19, 2016

Omni Dallas Hotel • Dallas, Texas, U.S.A.
The Pulmonary Hypertension Association would like to thank ACTELION for sponsoring the 2016 International PH Conference Program Book.
Welcome to Conference!

Dear Friends,

Welcome to PHA's 2016 International PH Conference and Scientific Sessions here in Dallas, Texas. By joining us for this event you are part of the largest gathering of pulmonary hypertension patients, caregivers and medical professionals in the world, and we hope that throughout the weekend you will take advantage of all that Conference has to offer – time to be social and grow PHriendships, educational offerings from patients and medical professionals alike, research opportunities and so much more.

Our theme for this Conference – 25 Years of Progress: Changing the History of PH – recognizes and celebrates our community's 25th anniversary and all that we have accomplished together during this time. This Conference also marks the retirement of Rino Aldrighetti, PHA's President and CEO, and throughout this weekend, we will honor him for his contributions to our shared cause and introduce you to his successor, Brad A. Wong. When you see Rino in the hallways, be sure to say hello and thank him for all he has done for our community over the years. He has been a visionary leader and we all owe him a great debt of gratitude.

As we celebrate our past, we also look toward our future, and the amazing things that our community will do together over the next 25 years. I'll never forget my daughter Christen's revelation at the 2002 Conference when she met other PH patients for the first time and knew that she was not the only person on the planet with PH. She went home with a renewed sense of hope and a resolve to keep fighting. I hope this Conference will give you the resolve to do the same.

Celebrate with PHriends, educate and empower yourself with new PH knowledge, and find your place in our shared history. Thank you for joining us, and enjoy your Conference experience!

Sincerely,

Stephen L. White, PhD
Chair, PHA Board of Trustees
Welcome PHA Members!

On behalf of the entire 2016 Conference Planning Committee, it is our great pleasure to welcome you to PHA's International PH Conference and Scientific Sessions in Dallas, Texas. This year marks the 25th anniversary of PHA. Throughout Conference, there will be reoccurring theme celebrating 25 Years of Progress: Changing the History of PH.

PHA's Conference is the world’s largest gathering of patients with pulmonary hypertension, caregivers and medical professionals. You have the opportunity to network with attendees from all aspects of the PH community. The planning committee has been dedicated to planning a Conference that meets the needs of all attendees. The sessions are planned to provide education, develop skills, and allow time to share tips on coping. Please be an active participant, reach out to others, ask questions and share your stories and skills. By networking with others, you will leave Conference filled with hope and inspiration.

We are grateful for the hard work, dedication and enthusiasm of the PHA staff and numerous volunteers in organizing Conference. Also, a special thank you to all of the sponsors who generously support this meeting and fund the scholarships to enable many patients to attend.

We would like to extend our gratitude and best wishes to this PH community for coming together and supporting each other. PHA’s President and CEO, Rino Aldrighetti, has been instrumental in leading the PH community. Rino will transition his leadership and begin his retirement at the end of Conference. Please extend your appreciation for his direction and vision for PHA when your paths cross during Conference.

Again, the Conference planning committee welcomes you and invites you to participate in and celebrate 25 years of progress in PH.

Sincerely,

Linda Carr  
2016 Conference Co-Chair

Rita Orth, RN  
2016 Conference Co-Chair

Traci Stewart, RN, MSN, CHFN  
2016 Conference Co-Chair

2016 International PH Conference Planning Committee

- Linda Carr
- Rita Orth, RN
- Traci Stewart, RN, MSN, CHFN
- Susie Alvarez
- Eric Austin, MD
- Sonja Bartolome, MD
- Josh Belt
- Lindsey Belt
- Lynette Brown, MD
- Kelly Chin, MD
- Vinicio de Jesus Perez, MD
- Louise Durst, RN
- Jean Elwing, MD
- Mary Felkel
- Paul Forfia, MD
- Stacey Gausling, OT/L
- Mardi Gomberg/Maitland, MD
- Tiffany Gunderman
- Anna Hemnes, MD
- Wendy Hill, MSN, RN, NP-C
- Davud Ishizawar, MD
- Kim Kerr, MD
- Martha Kingman, FNP-C, DNP
- Melanie Kozak
- Tim Lahm, MD
- Sandra Lombardi, RN
- Sally Maddox
- Perry Maminjogian
- Stacy Mardras, MD
- Stephen C. Mathai, MD
- Pat Paton
- Ioana Preston, MD
- Diane Ramirez
- Erika Berman Rosenzweig, MD
- John Ryan, MD
- Jeffrey Sager, MD, MSc
- Ed Simpson
- Judy Simpson
- Doug Taylor
- Roger Towle
- Rosemary Tsacoyianis, RN, MS
- Corey Ventetuolo, MD
- Andrea White
- Roham Zamanian, MD

#PHAConference | #Heart2CurePH | @PHAssociation
April 2016

Greetings,

As Mayor of Dallas, it is my extreme pleasure to welcome attendees of the Pulmonary Hypertension (PH) Association's International Conference and Scientific Sessions, on June 17-19, 2016.

PHA is a 501(c) (3) nonprofit organization that funds many programs and research to find ways to prevent and cure PH. I commend your dedication to improving life for those with pulmonary hypertension through education and advocacy. We thank you for your efforts in fighting PH and building the PH community in Dallas and beyond.

As you descend upon Dallas, I encourage each of you to enjoy our beautiful city and the variety of things to see and do. I hope that you will discover why we love to call Dallas home.

On behalf of the citizens of Dallas, we wish you the best for a memorable 25th anniversary and a successful event.

Best regards,

Michael S. Rawlings
Mayor
General Information

Conference Check-in and On-site Registration  
*Prefunction Area (3rd Floor)*

**Hours:**
- Thursday, June 16: 3:00 p.m. – 9:00 p.m.
- Friday, June 17: 7:00 a.m. – 7:30 p.m.
- Saturday, June 18: 7:30 a.m. – 12:00 p.m.

*If you arrive after 12 p.m. on Saturday, you can check in at the PHA Store.*

Exhibit Hall  
*Dallas Ballroom Foyer (3rd Floor)*

Continue your learning experience in the Exhibit Hall. Be sure to schedule some time to visit our sponsors, partner nonprofit organizations and PHA booths on Thursday, Friday, Saturday and Sunday!

**Hours:**
- Thursday, June 16: 6:30 p.m. – 9:00 p.m.
- Friday, June 17: 8:00 a.m. – 12:30 p.m.
- 2:30 p.m. – 5:30 p.m.
- Saturday, June 18: 8:00 a.m. – 12:00 p.m.
- 1:30 p.m. – 6:00 p.m.
- Sunday, June 19: 8:00 a.m. – 12:00 p.m.

Poster Hall  
*Arts District Foyer (2nd Floor)*

The Poster Hall will feature nearly 80 research abstracts and case studies presented by medical professionals in the field.

**Hours:**
- Thursday, June 16: 5:30 p.m. – 7:30 p.m.
- Friday, June 17: 8:00 a.m. – 12:30 p.m.
- 2:30 p.m. – 5:30 p.m.
- 5:30 p.m. – 6:45 p.m.
- *Unopposed Poster Viewing and Discussion – Scientific Sessions attendees only*
- Saturday, June 18: 9:00 a.m. – 1:30 p.m.

Research Room  
*Fairpark 1 (3rd Floor)*

Patient participation is vital to PH research. Every International PH Conference includes a Research Room dedicated to helping researchers further their studies by making possible the collection of data from the largest gathering of PH patients in the world. Consider participating in studies currently underway by donating a small blood sample or cheek swab and/or filling out a questionnaire. A few minutes of your time could help make a real difference!

**Hours:**
- Friday, June 17: 8:00 a.m. – 5:00 p.m.
- Saturday, June 18: 8:00 a.m. – 6:00 p.m.
- Sunday, June 19: 8:00 a.m. – 10:00 a.m.

PHA Store  
*Prefunction Area (3rd Floor)*

Don’t forget to stop by the PHA Store to purchase many popular items!

**Hours:**
- Thursday, June 16: 3:00 p.m. – p.m.
- Friday, June 17: 8:00 a.m. – 7:00 p.m.
- Saturday, June 18: 8:00 a.m. – 7:00 p.m.
- Sunday, June 19: 8:00 a.m. – 11:30 a.m.
Conference Evaluation
PHA Store
Deadline: Sunday, June 19 at 11:30 a.m.
Your opinion matters! Let us know about your experience at Conference and how PHA can make future events even better. Please take the time to complete the evaluation included in the pocket on the tabbed divider in this program book. Upon turning in the evaluation at the PHA Store, the first 800 people will receive a small gift.

Conference T-shirts
Sponsored by Bayer HealthCare and Gilead Sciences, Inc., and Eiger BioPharmaceuticals
Exhibit Hall (PHA Booth)
Please take the voucher in your registration packet to the PHA booth to redeem your complimentary T-shirt, available when the Exhibit Hall is open.

Patient Rest Stop
Sponsored by Gilead Sciences, Inc., and Reata Pharmaceuticals
Southside 2 (3rd Floor)
The Patient Rest Stop is a quiet room for patients who need to take a break, change their ice packs and store their extra oxygen. The Patient Rest Stop will be accessible to patients starting Wednesday, June 15, at 9:00 a.m. until Sunday, June 19, at 9:00 p.m.

Refrigerators/Freezers
A limited number of in-room refrigerators, which were requested in advance of Conference, are available to patients for medicine storage only. If you have questions, please see a PHA staff member at the Check-in and On-site Registration booth.

Heart Racers (Wheelchair Assistance)
PHA recognizes that the Omni is a large property, and a lot of walking will be necessary. A number of volunteers will be available to transport attendees by wheelchair on-site. Please see a Conference volunteer or PHA staff member for assistance. This service should be utilized for assistance to and from sessions on the 2nd and 3rd floors. If you think you will need assistance renting a scooter or wheelchair throughout Conference, please visit the PHA Store for information.

Medical Emergencies
If you are experiencing a life-threatening medical emergency please call 911. Due to Texas regulations 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 call your specialty pharmacy or oxygen carrier company for assistance.

Special Meal Requests
If you requested special dietary meals in advance, you will find special meal tickets in your registration packet. Please present these meal tickets to your server at the start of the corresponding meal.
Photography/Filming
The entirety of our Conference and majority of sessions are being photographed, videotaped and/or audio recorded. Selected educational sessions will be posted on PHA’s website (www.PHAssociation.org) or PHA Online University (www.PHANlineUniv.org) to further the education of the PH community. Crews will be taping throughout Conference, and the meal sessions and conducting interviews with Conference attendees. Materials gathered will be used for the production of informational DVDs on PH and to capture the spirit of PHA’s International PH Conference. For those who do not wish to be filmed or photographed, please be sure to wear the red name badge holder you were given when you registered for Conference.

Yoga
PHA is happy to offer yoga for all attendees throughout Conference! The sessions offered will be geared for everyone regardless of age or ability/disability! Each session will be different and will include breathing techniques to enhance lung function, yoga poses for anyone, and relaxation techniques. Sessions will include a variety of poses that can be adapted to each student as needed by the yoga instructor. Attendees will learn how to connect the breath to the movement, chair/ seated poses, assisted standing poses for balance and strength, and restorative poses. Please note, this session may be fuller than expected.

Session Location: Katy Trail (2nd Floor)
Session Times:
Friday, June 17
11:00 a.m. – 12:00 p.m.

Saturday, June 18
7:00 a.m. – 8:00 a.m.

Sunday, June 19
7:00 a.m. – 8:00 a.m.

Conference Handouts
Included in the back portion of this program book are educational handouts from speakers in the Medically Led Sessions, Patient/ Family Led Sessions and Skill-Building Workshops. These handouts are your resource to many of the sessions offered at Conference. Even if you are unable to attend a specific session, you can learn more about the topic with the help of the handout.

Scientific Sessions
Our Scientific Sessions on Friday, June 17, are designed for medical professionals who work in the field of pulmonary hypertension. If space allows, patients and caregivers may sit in on the Scientific Sessions but we encourage patients and caregivers to attend the patient-focused sessions taking place at the same time. Extra Scientific Sessions program books will be available Friday at the PHA booth in the Exhibit Hall while supplies last.
Conference Activities for Kids, Tweens and Teens

Kids’ Room
Sponsored by Reata Pharmaceuticals
Kids’ Room Location: Deep Ellum A & B (2nd Floor)
Teen Room Location: Cedars (2nd Floor)
The Kids’ Room will be open Friday through Sunday during the Conference, but children (3-16 years of age; no diapers please) must be picked up by their parents for all meals. There is no charge for children’s activities, but Conference registration and Kids’ Room reservations are required. Advanced registration is required to participate in field trips.

New this year! The Kids’ Room is being managed by Accent (www.accentoca.com).
The 2016 Kids’ Room will focus on providing an engaging and entertaining experience for all age ranges through fun interactive activities. For full Kids’ Room schedule, stop by the Kids’ Room for more information.

Friday, June 17
12:00 p.m. – 7:00 p.m. (Closed 7:00 p.m. – 8:00 p.m.)
8:00 p.m. – 10:30 p.m. Night at the Movies (Trinity 5)

Saturday, June 18
9:00 a.m. – 12:15 p.m. (Closed 12:15 p.m. – 1:15 p.m.)
1:15 p.m. – 6:30 p.m.
Field Trip – Perot Museum of Nature and Science*
10:30 a.m. – 2:30 p.m.

Sunday, June 19
7:45 a.m. – 12:30 p.m.
1:15 p.m. – 6:30 p.m.
Field Trip – Perot Museum of Nature and Science*
10:30 a.m. – 2:30 p.m.

*Children participating in the Fashion Show will depart the museum at 1:30 p.m. to allow time to rehearse.
Hotel Floorplan

Omni Dallas Level Three

Omni Dallas Level Two
Exhibit Hall Floorplan

Omni Dallas Ballroom Foyer
# Schedule at a Glance

## Thursday, June 16, 2016

<table>
<thead>
<tr>
<th>Time: 10:00 a.m. – 4:30 p.m.</th>
<th>Session: International Leaders’ Summit (by invitation only)</th>
<th>Location: Trinity 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time: 3:00 p.m. – 6:00 p.m.</td>
<td>Session: PH Care Center (PHCC) Workshop</td>
<td>Location: Trinity 5</td>
</tr>
<tr>
<td>Time: 5:30 p.m. – 7:30 p.m.</td>
<td>Session: Scientific Sessions &amp; PH Clinicians and Researchers Poster Hall Reception</td>
<td>Location: Arts District Foyer</td>
</tr>
<tr>
<td>Time: 6:30 p.m. – 8:30 p.m.</td>
<td>Session: Patient and Family Meet-and-Greet</td>
<td>Location: Trinity 2 &amp; 3</td>
</tr>
<tr>
<td>Time: 6:30 p.m. – 9:30 p.m.</td>
<td>Session: PH Professional Network Dinner</td>
<td>Location: Dallas D &amp; H</td>
</tr>
</tbody>
</table>

## Friday, June 17, 2016

<table>
<thead>
<tr>
<th>Time: 7:00 a.m. – 5:30 p.m.</th>
<th>Session: Scientific Sessions</th>
<th>Location: D2/D3, Convention Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time: 9:00 a.m. – 10:00 a.m.</td>
<td>Session: International Strategy Meeting</td>
<td>Location: Trinity 4/8</td>
</tr>
<tr>
<td>Time: 10:30 a.m. – 11:30 a.m.</td>
<td>Session: Pre-Conference Patient and Caregiver Meet-ups</td>
<td>Location: Trinity 2 &amp; 3</td>
</tr>
<tr>
<td>Time: 10:30 a.m. – 12:30 p.m.</td>
<td>Session: Support Group Leaders Networking Luncheon (by invitation only)</td>
<td>Location: Trinity 5 &amp; 6</td>
</tr>
<tr>
<td>Time: 10:30 a.m. – 12:30 p.m.</td>
<td>Session: Regional International Meetings</td>
<td>Location: See page 13</td>
</tr>
<tr>
<td>Time: 11:00 a.m. – 12:00 p.m.</td>
<td>Session: Yoga</td>
<td>Location: Katy Trail</td>
</tr>
<tr>
<td>Time: 11:30 a.m. – 1:00 p.m.</td>
<td>Session: Lunch Break (on your own)</td>
<td>Location: Dallas F</td>
</tr>
<tr>
<td>Time: 11:30 a.m. – 12:30 p.m.</td>
<td>Session: Chapters Chat and Chew</td>
<td>Location: Dallas A, B, C, D &amp; H</td>
</tr>
<tr>
<td>Time: 1:00 p.m. – 2:00 p.m.</td>
<td>Session: Conference Opening: Celebrating 25 Years of PHA</td>
<td>Location: See page 14</td>
</tr>
<tr>
<td>Time: 2:30 p.m. – 3:30 p.m.</td>
<td>Session: Patient/Family Led Sessions (Group 1)</td>
<td>Location: Dallas Ballroom Foyer/Trinity Ballroom Foyer</td>
</tr>
<tr>
<td>Time: 2:30 p.m. – 3:30 p.m.</td>
<td>Session: PH Fundamentals: Continuing Education for Medical Professionals</td>
<td>Location: See page 15</td>
</tr>
<tr>
<td>Time: 3:30 p.m. – 4:00 p.m.</td>
<td>Session: Coffee Break</td>
<td>Location: See page 16</td>
</tr>
<tr>
<td>Time: 4:00 p.m. – 5:00 p.m.</td>
<td>Session: Patient/Family Led Sessions (Group 2)</td>
<td>Location: Katy Trail</td>
</tr>
<tr>
<td>Time: 5:30 p.m. – 6:30 p.m.</td>
<td>Session: Skill-Building Workshops</td>
<td>Location: Arts District Foyer</td>
</tr>
<tr>
<td>Time: 5:30 p.m. – 6:30 p.m.</td>
<td>Session: International Reception (for guests from other nations)</td>
<td>Location: Dallas A, B, C, D &amp; H</td>
</tr>
<tr>
<td>Time: 5:30 p.m. – 6:45 p.m.</td>
<td>Session: Unopposed Poster Viewing (Scientific Sessions Attendees only)</td>
<td>Location: Katy Trail</td>
</tr>
<tr>
<td>Time: 7:00 p.m. – 8:30 p.m.</td>
<td>Session: 25 Years of PH Medicine and Its Future</td>
<td>Location: Dallas A, B, C, D &amp; H</td>
</tr>
<tr>
<td>Time: 8:30 p.m. – 10:00 p.m.</td>
<td>Session: Fellow and Junior Faculty Reception</td>
<td>Location: Katy Trail</td>
</tr>
</tbody>
</table>

## Saturday, June 18, 2016

<table>
<thead>
<tr>
<th>Time: 7:00 a.m. – 8:00 a.m.</th>
<th>Session: Yoga</th>
<th>Location: Katy Trail</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time: 8:00 a.m. – 9:00 a.m.</td>
<td>Session: 25 Years without Barriers: Network with a Medical Professional</td>
<td>Location: Dallas A, B, C, D &amp; H</td>
</tr>
</tbody>
</table>

● Patients and Family Members  ■ Medical Professionals  ▲ All Attendees

#PHAConference | #Heart2CurePH | @PHAssociation
## Schedule at a Glance

### Saturday, June 18, 2016, continued

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30 a.m. – 10:30 a.m.</td>
<td>Medically Led Sessions (Group 1) ●</td>
<td>See page 18</td>
</tr>
<tr>
<td>9:30 a.m. – 10:30 a.m.</td>
<td>PH Fundamentals: Continuing Education for Medical Professionals ■</td>
<td>D1/D4, Convention Center</td>
</tr>
<tr>
<td>10:30 a.m. – 11:00 a.m.</td>
<td>Coffee Break</td>
<td>Dallas Ballroom Foyer/Trinity</td>
</tr>
<tr>
<td>11:00 a.m. – 12:00 p.m.</td>
<td>Support Group Meetings ●</td>
<td>See page 19</td>
</tr>
<tr>
<td>11:00 a.m. – 12:00 p.m.</td>
<td>PH Fundamentals: Continuing Education for Medical Professionals ■</td>
<td>D1/D4, Convention Center</td>
</tr>
<tr>
<td>12:15 p.m. – 1:15 p.m.</td>
<td>Journeys Luncheon ▲</td>
<td>Dallas A, B, C, D &amp; H</td>
</tr>
<tr>
<td>1:30 p.m. – 2:30 p.m.</td>
<td>Medically Led Sessions (Group 2) ●</td>
<td>See page 20</td>
</tr>
<tr>
<td>1:30 p.m. – 2:30 p.m.</td>
<td>PH Fundamentals: Continuing Education for Medical Professionals ■</td>
<td>D1/D4, Convention Center</td>
</tr>
<tr>
<td>2:30 p.m. – 3:00 p.m.</td>
<td>Coffee Break</td>
<td>Dallas Ballroom Foyer/Trinity</td>
</tr>
<tr>
<td>3:00 p.m. – 4:00 p.m.</td>
<td>Medically Led Sessions (Group 3) ●</td>
<td>See page 21</td>
</tr>
<tr>
<td>4:30 p.m. – 5:30 p.m.</td>
<td>Fashion Show ▲</td>
<td>Dallas F &amp; G</td>
</tr>
<tr>
<td>5:30 p.m. – 6:30 p.m.</td>
<td>Parents’ Mixer</td>
<td>Arts District 3</td>
</tr>
<tr>
<td>5:30 p.m. – 6:30 p.m.</td>
<td>Men’s Mixer</td>
<td>Arts District 1</td>
</tr>
<tr>
<td>5:30 p.m. – 6:30 p.m.</td>
<td>CTEPH Mixer</td>
<td>Arts District 2</td>
</tr>
<tr>
<td>5:30 p.m. – 6:30 p.m.</td>
<td>Long-Term Survivors Mixer</td>
<td>Arts District 4</td>
</tr>
<tr>
<td>6:30 p.m. – 8:30 p.m.</td>
<td>PHA: Change Built on Community ▲</td>
<td>Dallas A, B, C, D &amp; H</td>
</tr>
<tr>
<td>8:30 p.m. – 10:00 p.m.</td>
<td>Generation Hope After Dark Mixer</td>
<td>Katy Trail</td>
</tr>
</tbody>
</table>

### Sunday, June 19, 2016

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 a.m. – 8:00 a.m.</td>
<td>Yoga ▲</td>
<td>Katy Trail</td>
</tr>
<tr>
<td>8:00 a.m. – 9:00 a.m.</td>
<td>Coffee Break</td>
<td>Dallas Ballroom Foyer/Trinity</td>
</tr>
<tr>
<td>8:00 a.m. – 9:00 a.m.</td>
<td>Medically Led Sessions (Group 4) ●</td>
<td>See page 23</td>
</tr>
<tr>
<td>8:00 a.m. – 9:00 a.m.</td>
<td>PH Fundamentals: Continuing Education for Medical Professionals ■</td>
<td>D1/D4, Convention Center</td>
</tr>
<tr>
<td>9:30 a.m. – 10:30 a.m.</td>
<td>How Families Come Together to Fight PH ▲</td>
<td>Dallas A, B, C, D &amp; H</td>
</tr>
<tr>
<td>9:30 a.m. – 10:30 a.m.</td>
<td>Support Line and Email Mentors Training and Breakfast (by invitation only)</td>
<td>Dallas F</td>
</tr>
<tr>
<td>11:00 a.m. – 12:00 p.m.</td>
<td>Medically Led Sessions (Group 5) ●</td>
<td>See page 24</td>
</tr>
<tr>
<td>11:00 a.m. – 12:00 p.m.</td>
<td>PH Fundamentals: Continuing Education for Medical Professionals ■</td>
<td>D1/D4, Convention Center</td>
</tr>
<tr>
<td>12:00 p.m.</td>
<td>Conference Ends. We’ll see you in Orlando in 2018!</td>
<td></td>
</tr>
</tbody>
</table>

● Patients and Family Members  ■ Medical Professionals  ▲ All Attendees
Thursday, June 16

International Leaders’ Summit (by invitation only)
Sponsored by Bayer HealthCare
10:00 A.M. – 4:30 P.M.
Trinity 3
The Fourth International Leaders’ Summit brings together PH association leaders from all over the world. International PH association leaders will learn from each other, work toward solutions to common problems, and build relationships. This year’s summit will bring together patients, caregivers, and medical professionals in leadership positions in their countries to brainstorm ideas and jumpstart projects identified in 2014 as common goals for the international PH community.

PH Care Centers (PHCC) Workshop
3:00 P.M. – 6:00 P.M.
Trinity 5
This workshop will bring awareness to key PHCC criteria, help identify ways to organize the site visit day, and provide a basis to coordinate meetings with key facility staff and patient care area tours. Careful attention will be given on how to develop and present your center PAH/CTEPH roster for review and how to prepare for the coordinator and director interviews through staging of a mock site visit interview.

Scientific Sessions & PH Clinicians and Researchers Poster Hall Reception
Sponsored by Actelion Pharmaceuticals US, Inc.
5:30 P.M. – 7:30 P.M.
Arts District Foyer
Please see the Medical Education program book for details.

Patient and Family Meet-and-Greet
Sponsored by Actelion Pharmaceuticals US, Inc.
6:30 P.M. – 8:30 P.M.
Trinity 2 & 3
Cowboy fare and line-dancing anyone? Hosted by the local Dallas and North Texas PHA Pulmonary Hypertension Support Groups, this homecoming-themed event provides an energetic and fun way for patients and caregivers to make new connections prior to the official start of Conference programming on Friday. Hundreds of patients, caregivers and supporters are expected to participate in all of the activities, games and light refreshments at this fun Meet-and-Greet!

PH Professional Network Dinner
Sponsored by Accredo Health Group and SteadyMed Ltd.
6:30 P.M. – 9:30 P.M.
Dallas D & H
Please see the Medical Education program book for details.

Friday, June 17

Scientific Sessions
7:00 A.M. – 5:30 P.M.
D Ballroom, Convention Center
Please see the Medical Education program book for details.

International Strategy Meeting (by invitation only)
Sponsored by SteadyMed Ltd.
9:00 A.M. – 10:00 A.M.
Trinity 4/8
This one-hour meeting will facilitate discussion among the various international associations to identify and discuss possible areas of collaboration and/or mutual support. Topics include global treatment access and coordinated research.

Pre-Conference Patient and Caregiver Meet-ups
10:30 A.M. – 11:30 A.M.
Trinity 2 & 3
Mix and mingle with patients and caregivers of all ages and backgrounds, as well as community leaders who volunteer as members of PHA advisory boards, at the Pre-Conference Meet-ups. By the end of these meet-ups, you will recognize a bunch of friendly faces. By Sunday, you might just count them as lifelong friends!

Caregivers
Connect with other caregivers, family members and friends of adult patients. This is an opportunity to meet the Caregiver Advisory Board.
CTEPH (Chronic Thromboembolic Pulmonary Hypertension) Patients
Get together with your fellow CTEPH patients! Trade experiences with others just like you, whether you’ve had PTE surgery, are exploring alternatives due to not being a surgical candidate, or are living with residual CTEPH. Share your stories, tips, and experiences with others managing this special blood-clot related type of PH, and meet the members of the CTEPH Advisory Board, too.

Facebook and PH Online Communities
Stop by to finally meet your online friends from PHA online communities and Facebook in-person. Members of the Social Media Advisory Board will be on-hand.

Families of Children and Teens with PH
Children and young people living with PH and their families can play, chat, and start making friends before the Kids’ Room opens. This is your chance to meet members of the Parents (of PH Patients) Advisory Board.

Generation Hope
Mingle with young-adult patients living with PH, aged 18 to 40. You will have the chance to meet members of the Generation Hope Advisory Board.

Long-Term Survivors
Mingle with other patients who have been living with PH for the long haul. Also, join a conversation with members of the Long-Term Survivors Advisory Board.

Men with PH
Get together with fellow men who are living with PH. You can also meet the members of the Men’s Advisory Board.

Newly Diagnosed Patients and First-Time Conference Attendees
Many Conference attendees are new to PH or to PHA. Stop by this gathering of first-timers to meet someone else looking for a friendly face. You can also meet members of the Newly Diagnosed Advisory Board.

Patients with Associated Illnesses
Living with an associated condition? Scleroderma, lupus, CHD, COPD, HHT, liver disease, sleep apnea, sickle cell disease, HIV? Chat with others who understand the complexities of juggling multiple illnesses. You can also meet members of the PH Plus Advisory Board.

Transplant
Meet up with fellow organ transplant recipients, donors and their family members. You can also get to know the members of the PH Transplant Advisory Board.

Support Group Leaders Networking Luncheon (by invitation only)
Sponsored by Gilead Sciences, Inc., and United Therapeutics Corporation
10:30 a.m. – 12:30 p.m.
Trinity 5 & 6
PHA Support Group Leaders, Co-Leaders and their caregivers are invited to this very special two-hour networking session. This session will provide an opportunity for leaders to share ideas, celebrate successes, troubleshoot challenges and meet other leaders of PHA-recognized, in-person support groups which actively meet in the United States and Puerto Rico.

Regional International Meetings
11:30 a.m. – 12:30 p.m.
The Regional International Meetings bring leaders and PH patients together to discuss topics important in their geographic region. The following regions will be hosting meetings:

Canada
Arts District 1
PHA Canada will host a meet-and-greet for PH patients, families and medical professionals visiting from Canada (for Canadian attendees only).

Latin America
Arts District 2
The Sociedad Latina de Hipertensión Pulmonar will host a networking event for PH patients, families and medical professionals visiting from Latin America (for Latin American attendees only).

Chapters Chat and Chew
11:30 a.m. – 12:30 p.m.
Dallas F
Saddle up and mosey on down to join the PHA California, Lone Star, Midwest and Northeast Chapters at the Rodeo Roundup Reception. This event will give attendees an opportunity to learn about exciting chapter events and how you can join in the fun. It’s also a great opportunity to network and meet new friends from your chapter area! Light bites and beverages will be available and we will have fun activities and giveaways for all attendees.
Conference Opening: Celebrating 25 Years of PHA

Sponsored by Bayer HealthCare

1:00 P.M. – 2:00 P.M.
Dallas A, B, C, D & H

PHA has brought together patients, caregivers, families, medical professionals, researchers and industry in a strong and vibrant community. To honor the past 25 years and to launch into the next, PHA create a video montage celebrating PHA’s 25th anniversary and giving our more than 16,000 members the opportunity to reflect on how PHA has given hope to so many.

Patient/Family Led Sessions (Group 1)

2:30 P.M. – 3:30 P.M.

Doctor, Doctor. Gimme the News!

Panelists: Barbara Benningfield (Chair); Marla Olitsky Atkins; Gabriela Nguyenphouc

Do you find it difficult to talk to your doctor? Are there things you forget to ask during your visits? This session is all about preparing for your appointments, staying organized, and coordinating with healthcare providers from PH specialists to Primary Care and everything in between. Come discuss how to ask the right questions when you meet with your healthcare team! (Session handout on page 56)

Having a Family with PH

Panelists: Monica Penaranda (Chair); Jessie Kohler; Brandon Penaranda; Kellie Tasto

From surrogacy to adoption to fostering and step-parenting: When a young woman receives a diagnosis of PH, she and her partner may also learn the disheartening news that pregnancy with PH is a “high risk.” Yet, many couples may still want to have a family someday. In this session, panelists and attendees will discuss the emotional aspects of diagnosis and pregnancy, alternatives to high-risk pregnancies and what to expect as a parent with PH. (Session handout on page 57)

Insurance: a Maze or Amazing?

Panelists: Lauren Ruiz (Caring Voice Coalition); Nikki Blake (PHA)

Insurance can either be incredibly confusing or a lifeline to PH patients, but very often it’s both. Our PHriends from Caring Voice Coalition bring their expertise to help you navigate the maze of selecting the best available program for you to get the most from your insurance coverage. Attendees will also learn about the insurance resources offered by PHA’s Treatment Access Program. (Session handout on page 58)

It's a Man's World

Panelists: Kevin Burger (Chair); Shelby Anders; Javier Estevez; Mike Peters

Men with pulmonary hypertension are in a minority that can be doubly isolating. Generally, men respond differently to a PH diagnosis than women. This session gives panelists and attendees the opportunity to discuss issues for men related to developing or maintaining relationships, job loss, and the changing role a chronic and often debilitating disease has on men. This session is open to men with PH and to men who are primary caregivers to someone with PH. (Session handout on page 59)

Life Hacks

Panelists: Donna Ard Head (Chair); David Bardwell; Tammy Lewis; Valerie Papineau

Life goes on after diagnosis. PH patients and caregivers share their tips for conserving energy to get the most out of each day from making “me time” to simplifying daily tasks. Come learn a few tricks from the panel and share a few tricks of your own. (Session handout on page 60)

Living a PHit Life

Panelists: Jen Cueva (Chair); Marvin Acuna; Kaye Norlin

The constant quest to eat right, manage fluids and exercise well can get cumbersome and confusing. Your doctor will tell you what you need to do. Our panelists will lead a discussion on how to do it. Come discuss and share realistic tips and tricks on staying healthy while living with PH from others who have been there, too! (Session handout on page 61)
The Ride of Your Life

_Dallas F_

**Panelists:** Josh Belt (Chair); Heather Hebert; Matt Hebert; Billie Jo Thompson; Brooke Thompson

Walking with a child through PH can often feel like riding a roller coaster. The twist and turns and ups and downs can take a PH family on the ride of their life. In this session, parents and PH teens will discuss how to process through the emotional, social and mental challenges that come with PH. Topics will include how to: overcome depression, resolve family dynamics, work as a team, build a support system, and much more. (Session handout on page 64)

Vive saludablemente con HP

_Trinity 7_

**Panelistas:** Erika Prieto (Chair)

Podría ser confuso y dispendioso estar siempre intentando comer las cosas correctas, manejar tu consumo de líquidos y hacer los ejercicios adecuados. Un doctor te contará qué se debe hacer y nuestros panelistas te contarán cómo realmente hacerlo. Ven a conversar y compartir consejos con otros pacientes sobre cómo mantenerte saludable y vivir con la HP al mismo tiempo.

PH Fundamentals: Continuing Education for Medical Professionals

2:30 p.m. – 3:30 p.m.
_D1/D4, Convention Center_

Please see the Medical Education program book for details.

**Coffee Break**

Sponsored by Actelion Pharmaceuticals US, Inc.
3:30 p.m. – 4:00 p.m.
_Dallas Ballroom Foyer / Trinity Ballroom Foyer_

Patient/Family Led Sessions (Group 2)

4:00 p.m. – 5:00 p.m.

Building Your Ark: How to Create Your Own Support System

_Trinity 5_

**Panelists:** David Grady (Chair); Tammy Sue Flores; Laurie Johannsen; Cathy MacLeod

Many medical professionals say that PH is a disease that cannot be managed by one person alone — so how do you find the support you deserve when it feels like it’s all on you? This session is for PHers living alone or without the privilege of willing and able support networks. Learn about communicating your needs to friends and family effectively and reaching out to others through church, support groups, online networks and PHA. You are not alone in this journey! (Session handout on page 53)

Decisions, Decisions, Decisions

_Dallas F_

**Panelists:** Lindsey Belt (Chair); Jennica Clasby; Martha Gonzalez; Dwayne Johnson; Jessica Johnson

How do I ensure my child’s needs are met at school? Which infusion method is best? Should I go to a PH specialist or pediatric cardiologist? As a parent of a child with PH, you have to make decisions everyday on behalf of your child. Some decisions are easy, but some are down right difficult. In this session, parents of PH kids will share real life experiences and practical tips on how to work through some of life’s most difficult moments. (Session handout on page 54)

Do You Think I’m Sexy?

_Trinity 4_

**Panelists:** Kathleen Scheiffer (Chair); Lane Benningfield; Michelle Figueras

Pump up the volume despite the challenges of pills, pumps and the dreaded oxygen tanks! Find confidence in dealing with new friends, new social situations, and even new romantic interests. Discuss with the panelists and other attendees what to tell, when to tell, and how to tell about your PH diagnosis. (Session handout on page 55)

Making Choices

_Trinity 1_

**Panelists:** Jan Janus (Chair); Nichole Holland Bardwell; Marcie McGregor; Gary Pederson

Choosing happiness is something that is possible to learn to do even with PH. Our panelists will help you learn to relieve the stress in your life and the life of your caregiver by sharing the techniques they use. They will help you understand how to move beyond the “grief” most of us experience when we or a family member are diagnosed with PH. (Session handout on page 62)

Puedes ser Feliz aún Viviendo con HP

_Trinity 7_

**Panelistas:** Carmen Lozada-Brun (Chair); Alma Berber; Omar Estevez

La vida puede continuar después de que te diagnostican HP. En esta sesión, pacientes de HP y cuidadores comparten sus consejos sobre cómo vivir y lidiar con una enfermedad como la HP.
The Power of Partnership

*Trinity 3*

**Panelists:** Mike Alsman (Chair); Jim Gausling; Stacy Gausling; Brandon Griffin; Darrell Randolph

How do caregivers renew themselves when exhausted? How can patients positively communicate their needs? What if the PH patient has to become the caregiver, too? Discuss with other patients and caregivers ideas and practices for a deeper trust and overall closeness. Ask questions and share your ideas and concerns with this inclusive panel who will enable us to learn how to give and receive better care. (Session handout on page 63)

Trains and Planes and Boats: Oh My!

*Trinity 2*

**Panelists:** Julie Scott (Chair); Ornah Levy; Daniela Moritz; Trent Tracey

Does the thought of traveling with PH seem overwhelming? Join our panelists to discuss how all types of travel — even travel abroad — can be safely navigated. Panelists will lead a discussion on travel, including having a plan of action in case of emergencies while away from home. (Session handout on page 65)

Working and Higher Education with PH

*Trinity 6*

**Panelists:** Kevin Mayhood-Paskawych (Chair); Dr. Farng-Yang Foo; Shannon O’Donnell; Betsy Wilson

Find a way to continue working on a job or on a degree while keeping up your health. Our jobs and careers make up such a large part of our identity that few of us want to give them up — not to mention the need for income and access to health insurance. Hear how other PH patients manage to work or attend school. Join this discussion of workplace and educational rights and what you should or shouldn’t tell your employer and fellow employees. (Session handout on page 66)

Skill-Building Workshops

**5:30 p.m. – 6:30 p.m.**

Fundraising 101: Create Your Own Event for PHA!

*Trinity 1*

**Panelists:** Donna Head, PH Patient; Nichole Holland Bardwell, PH Patient; Sally Maddox, PHA Board Member and PH Patient

Thinking about taking on a bigger role in your PH community involvement? PHA fundraisers are a great way to help support research, drive patient programs and increase public understanding of PH, while allowing others the opportunity to support you and the entire PH community. In this session, learn about the various ways to create your own fundraising special event. Panelists will share their own experiences and tips on being a first time event organizer to help you get started. (Session handout on page 50)

Fundraising 201: Take Your Event to the Next Level!

*Trinity 2*

**Panelists:** Colleen Connor, PHA Board Member and PH Patient; Bonnie McGoon, PHA Periwinkle Pioneer; Debra Watkins, Portland Support Group Leader and PH Patient

Looking for ways to kick it up a notch at your next PH community event? This session will offer examples and ideas of how to maximize the success of your fundraising event year over year. Community events are a great way to raise awareness and funds in the fight against PH. There are many resources available to help you increase participation, sponsorship, media coverage, excitement and much more. Hear from the experts, a panel of PH event organizers, about their event experiences and how they work with PHA to keep their events growing. (Session handout on page 50)

Media Matters

*Trinity 3*

**Panelists:** Kelly Williams, VP, Communications & Marketing, PHA, a former TV news reporter and corporate communications and advertising executive whose team launched Heart2CurePH; Jordan Jennings, Associate Director of Communications, PHA, a nonprofit new media guru who is helping PHA raise unprecedented awareness; Jason Roberson, Managing Supervisor, FleishmanHillard, Dallas, former award-winning healthcare business journalist

In the era of social media, a PH patient’s social media page or blog can play a powerful role in PHA’s public awareness and advocacy efforts. Learn how you can join PHA’s communications team. (Session handout on page 51)
Networking: Connecting at Conference, Online and In Your Own Backyard

Trinity 6

Presenters: PHA staff and patients and caregivers active in the community

How do I connect meaningfully with others during Conference? When I go back home, how can I find more patients or caregivers like me? Where are good places to find others with PH online or in my home town? This community-led “skills building” session will help you maximize your time at Conference to connect with patients or caregivers who can help you in your journey with PH. We will also help you find ways to connect online and in person, at support groups. We will also share tips on starting a support group in your area, too!

Yes We Can!: Turning Elected Officials into PH Advocates

Trinity 5

Presenters: Angelia DiGuiseppe, Grassroots Campaign Associate, PHA; Dane Christiansen, PHA’s Washington Representative

Does your Member of Congress have the #Heart2CurePH? Learn how to turn your elected officials into PH allies during this interactive workshop. You will hear from PHA’s Washington Representative with an update on the PH bill and other legislative priorities. Then you’ll learn how PHA can support you in small and large advocacy efforts. You can make a difference by sharing their story with Members of Congress. (Session handout on page 52)

International Reception (for guests from other nations)

Sponsored by SteadyMed Ltd.
5:30 P.M. – 6:30 P.M.
Katy Trail

This reception is an opportunity for global leaders, medical professionals, and other guests from the international PH community to network with each other. In doing so, the hope is that attendees will discuss projects and common goals, working together as patients’ associations and medical infrastructure develops internationally.

Unopposed Poster Viewing

5:30 P.M. – 6:45 P.M.
Arts District Foyer

25 Years of PH Medicine and Its Future ▲
Sponsored by Actelion Pharmaceuticals US, Inc.
7:00 P.M. – 8:30 P.M.
Dallas A, B, C, D & H

The Conference opening dinner on Friday evening is the first meal that the PHA community shares together. Patients, caregivers and medical professionals connect, and old friends renew acquaintances, forming bonds and friendships that will last throughout the Conference and beyond. During this dinner, a member of PHA’s medical community will provide an overview on how individuals like you, participating in research, have contributed to the growing number of treatments and better understanding of the disease over the first 25 years of PHA. In addition, the Award of Excellence in PH Care recipient will be honored at this dinner.

Saturday, June 18

25 Years without Barriers: Network with a Medical Professional ▲
Sponsored by Reata Pharmaceuticals
8:00 A.M. – 9:00 A.M.
Dallas A, B, C, D & H

Speakers: Traci Houston, RN, MS, Johns Hopkins University; Amy Kimber, RN, APNP, Froedtert and the Medical College of Wisconsin.

This Saturday morning breakfast gives patients and caregivers the unique opportunity to interact with medical professionals in a non-clinical setting. Medical professionals specializing in various areas of interest in the PH field will be seated at specific tables for discussion with patients and caregivers over breakfast.
Medically Led Sessions (Group 1) ●
9:30 A.M. – 10:30 A.M.

Coping with Chronic Illness
Trinity 7
Panelists: Bela Patel, MD, University of Texas Health Science Center at Houston (Chair); Ben Lippe, PhD, UT Southwestern; Landra Slaughter, RN, CCRC, University Hospitals Case Medical Center; Aaron Waxman, MD, PhD, FACP, FCCP, Brigham and Women’s Hospital

This session will focus on coping with chronic illness over the long term for caregivers and patients. Caregivers can be family members, friends or healthcare professionals. Long term exposure to the challenges and stress of providing care and/or living with a chronic illness can lead to physical and emotional symptoms. Caregivers and patients may experience difficulty coping, compassion fatigue, burnout and survivor’s guilt. Strategies to identify and address these issues will be discussed. (Session handout on page 71)

Debunking PH Misperceptions I
Trinity 4
Panelists: Jeffrey Sager, MD, MSc, Santa Barbara Pulmonary Consultants (Chair); David Badesch, MD, University of Colorado, Denver; Abby Poms, RRT, Duke University Medical Center

Have you heard tips and advice through the grapevine, social media or from your PHriends that you’re not sure are reliable? Talking to others about PH can be a great way to learn new information, but that information is not always medically accurate. In this session we will discuss and debunk common PH myths, rumors and misperceptions. Feel free to bring myths that you’ve heard or questions you have, as this session will be very interactive. (Session handout on page 73)

Diagnosing PH – Is Your PH Diagnosed Correctly?
Trinity 5
Panelists: Lana Melendes-Groves, MD, University of New Mexico (Chair); Todd Bull, MD, University of Colorado Denver; Adaani Frost, MD, Houston Methodist Hospital; Charles Gallegos, CNP, UNM Health Sciences Center

This session will review the current classification/definitions of pulmonary hypertension (PH), as well as standard testing methods used to fully diagnose patients. Diagnostic tests such as echocardiography, cardiac catheterization, pulmonary function tests, sleep studies, exercise tests and other lab and imaging modalities will be discussed. (Session handout on page 74)

Disability Benefits
Trinity 1
Panelists: Nikki Blake, Pulmonary Hypertension Association (Chair); Lauren Patrizio, Caring Voice Coalition; Tonya Zeiger, RRT, Mayo Clinic in Florida

Those with chronic illnesses such as PH often have to make the difficult decision to stop working before reaching full retirement age. If you are no longer able to maintain substantial work, Social Security disability benefits can provide continued income and health insurance options. Like many government benefits programs, however, the pathway to receiving disability benefits can be confusing and time consuming. Join us to gain a better understanding of what benefit type you’re eligible for, how the Social Security Administration (SSA) will analyze your claim, what evidence to compile, how to prepare the strongest argument for your case and where you can turn to for help! (Session handout on page 75)

Informacion General Sobre Hipertension Pulmonar: Conceptos Basicos, Examenes y Opciones de Tratamiento
Trinity 6
Panelistas: Hector Cajigas, MD, Northwestern University Feinberg School of Medicine (Chair); Tomas Pulido, MD, Instituto Nacional de Cardiologia; Fernando Torres, MD, UT Southwestern

En esta sesión se explicará la función cardíaca y pulmonar y lo que sucede a estos sistemas en pacientes con HP. Esta visión general acerca de los diferentes tipos de hipertensión pulmonar, le proporcionará las bases educativas necesarias para luego enfocar su atención en otras sesiones.

Nutrition and Diuretics
Trinity 3
Panelists: Jean Elwing, MD, University of Cincinnati Medical Center (Chair); Katherine Beich, MS, RD/LD, CNSD, Baylor University Medical Center; Steven Kawut, MD, MS, Hospital of the University of Pennsylvania; Joel Wirth, MD, Maine Medical Center

Panelists will discuss how a patient’s diet can improve living with pulmonary hypertension. Attendees will learn how to optimize the body’s water balance with good salt and water habits, learn the importance of maintaining a proper diet and a healthy weight, and learn tricks to better deal with the side effects of water pills. (Session handout on page 84)
PH Simplified – The Basics of PH, Treatment and Tests  
*Trinity 2*

**Panelists:** Martha Kingman, FNP, UT Southwestern, Dallas, Texas (Chair); Harrison Farber, MD, Boston University School of Medicine; Marlena Fox, PharmD, BCPS, Orlando Health; Scarlett Harden, ACNP, UT Southwestern; Michael McGoon, MD, Mayo Clinic

This session will cover the basics of pulmonary arterial hypertension (PAH), explaining how the heart can be affected by high lung pressures. We will also discuss the different types of pulmonary hypertension and the rationale for the extensive testing recommended by recent guidelines. Finally, we will review the available therapies to treat PAH and how they may be used in combination. This session will provide an overview of basic pulmonary hypertension knowledge. (Session handout on page 88)

**PH Fundamentals: Continuing Education for Medical Professionals**

* 9:30 a.m. – 10:30 a.m.  
  *D1/D4, Convention Center*

Please see the Medical Education program book for details.

**Coffee Break**

10:30 a.m. – 11:00 a.m.  
*Dallas Ballroom Foyer / Trinity Ballroom Foyer*

**Support Group Meetings**

11:00 a.m. – 12:00 p.m.  

**Adult PH Patients with Children**  
*Trinity 5*

**Associated Conditions: PH & Autoimmune Conditions (e.g. scleroderma, lupus, HIV, etc.)**  
*Trinity 1*

**Associated Conditions: PH & Non-Autoimmune Conditions (e.g. liver disease, HHT, sarcoidosis, ILD, etc.)**  
*Arts District 4*

**Beginning Your Journey: For those diagnosed 0-7 years**  
*Dallas G*

**Bereavement: For those who have lost someone to PH**  
*Arts District 6*

**Caregivers: For friends and family members of PH patients**  
*Arts District 7*

**Chronic Thromboembolic Pulmonary Hypertension (CTEPH)**  
*Trinity 2*

**Combination and Transitioning Therapies: For PH patients on two or more therapies and/or transitioning therapies**  
*Trinity 6*

**Familial PH: For those with two or more family members diagnosed with PH**  
*Art District 3*

**For Men Only**  
*Trinity 4*

**Grupo de Hispanohablantes: For Spanish-speaking PH patients**  
*Trinity 3*

**Long-Term Survivors: For those diagnosed eight years or more**  
*Dallas E*

**Parents and Siblings of PH Patients (All ages)**  
*Arts District 1*

**PH Patients on “Pump Therapy”**  
*Dallas F*

**Teen & Pre-Teen PH Patients: Ages 10-18**  
*Arts District 5*

**Transplant Recipients: For PH patients who have undergone or listed for transplant**  
*Arts District 2*

**PH Fundamentals: Continuing Education for Medical Professionals**

* 11:00 a.m. – 12:00 p.m.  
  *D1/D4, Convention Center*
Journeys Luncheon ▲
Sponsored by Bayer HealthCare
12:15 P.M. – 1:15 P.M.
Dallas A, B, C, D & H
Presenters: Daniela Brady, FNP, Columbia Presbyterian Medical Center, and Collin Wickizer; Kelly Chin, MD, UT Southwestern Medical Center, and Caroline Roberts; Vinicio de Jesus Perez, MD, Stanford University Medical Center; and Martha Gonzalez
Initiated at the first Conference in 1994, Journeys is PHA’s longest tradition. The Journeys Luncheon highlights the experiences that patients and their care teams share together, from diagnosis, to treatment, to hope for the future. Join us as three patient/medical professional pairs share their stories of breaking down barriers and building partnerships ... the partnerships that make the PH community both unique and successful.

Medically Led Sessions (Group 2) ●
1:30 P.M. – 2:30 P.M.
Adult Congenital Heart Disease, Blood Disorders and Liver Disease with PH
Trinity 5
Panelists: Zeenat Safdar, MD, Houston Methodist (Chair); Michael Krowka, MD, Mayo Clinic
The goal of this session is to address the clinical management approaches of three different disorders that can be associated with pulmonary artery hypertension. Diagnostic criteria and special concerns for each disorder will be reviewed. Treatments options (medical and organ transplant) will be discussed. (Session handout on page 67)

Changing Treatments
Trinity 7
Panelists: Karen Fagan, MD, University of South Alabama (Chair); Wassim Fares, MD, MS, Yale University Department of Medicine; Elizabeth Stone, RN, BSN, CHFN, Baptist Health South Florida; R. James White, MD, PhD, University of Rochester
Changes in therapy are usually considered when therapeutic goals are not reached or when medications are causing difficult side effects. Changes are also sometimes considered for other reasons, such as a desire to change route of delivery or to take fewer treatments per day. In these situations, we will discuss ways in which this may be accomplished and the monitoring that is often required before and after the changes are made. (Session handout on page 69)

Connective Tissue Diseases and PH
Trinity 6
Panelists: Stephen Mathai, MD, MHS, Johns Hopkins University. (Chair); Christine Archer-Chicko, MSN, CRNP, Penn Presbyterian Medical Center; Colleen McEvoy, MD, Washington University in St. Louis
In this session, we will describe the spectrum of connective tissue disease and define the different types of pulmonary hypertension (PH) encountered. We will focus the discussion on systemic sclerosis (scleroderma) because PH is particularly common in this connective tissue disease and because PH has a profound impact on the course of the disease. A multidisciplinary approach to screening scleroderma patients for PH will be addressed; we will highlight the importance of early diagnosis and early treatment intervention in these cohorts. Further, we will examine the unique features of PH in scleroderma, emphasizing the many ways in which PH can develop in the setting of scleroderma. Finally, we will discuss treatment strategies for patients with connective tissue disease-associated PH. (Session handout on page 70)

Familial Genetics and PAH
Trinity 1
Panelists: Eric Austin, MD, MSCI, Vanderbilt University (Chair); Micheala Aldred, PhD; Cleveland Clinic; Gregory Elliott, MD, Intermountain Medical Center; Lisa Wheeler, MT, Vanderbilt University Medical Center
The purpose of this session is to discuss what is known about the inheritance of pulmonary arterial hypertension (PAH), with special emphasis on familial PAH, which is a type of heritable PAH (HPAH). We will provide an overview of the way that the disease may be inherited and how individuals and families can deal with the risks and the knowledge that PAH may be a familial disease. We will discuss the possibility that a genetic basis of disease may be present in persons who have no other known family member with pulmonary hypertension. We will discuss the percentage of patients who carry the known genes that are associated with PAH. We will discuss the benefits, risks and limitations of genetic testing. (Session handout on page 78)
PH from Left Heart Dysfunction: The Great Pretender

Trinity 2

Panelists: Austin Thompson, MD, University of Nebraska Medical Center (Chair); Robert Frantz, MD, Mayo Clinic; Judy Lane, BSN, University of Nebraska Medical Center; Myung Park, MD, Houston Methodist Hospital

The goal of this session is to introduce the concept of pulmonary hypertension (PH) in the setting of left heart disease, particularly associated with diastolic dysfunction of the left ventricle. We will discuss the typical patient profile seen with this condition, which is one of the most common causes of PH. Similarities and contrasts with pulmonary arterial hypertension (PAH) will be emphasized. Treatment options will be described, as well as types of treatment which might not be best suited to this condition. (Session handout on page 87)

WHO Group 3 – Lung Diseases

Trinity 3

Panelists: Franck Rahaghi, MD, Cleveland Clinic (Chair); Abubakr Bajwa, MD, FCCP, University of Florida College of Medicine; Denise Lewis, RN, BSN, Inova Fairfax Hospital; Paresh Giri, MD, Loma Linda Medical Center

The goal of this session is to discuss how lung diseases are associated with pulmonary hypertension (PH). We will discuss how various forms of lung disease cause PH and how they should be evaluated and treated. We will also cover the use of devices in treating PH related to lung disease, including continuous positive airway pressure (CPAP) and supplemental oxygen. (Session handout on page 96)

WHO Group 4 – Chronic Thromboembolic Pulmonary Hypertension

Trinity 4

Panelists: Terence Trow, MD, Yale University School of Medicine (Chair); William Auger, MD, University of California, San Diego; Janice Napoletano, RN, Yale School of Medicine; Fran Rogers, MSN, CRNP, Temple University

Chronic thromboembolic pulmonary hypertension (CTEPH) is a serious complication of a common disorder, venous thromboembolism. CTEPH and pulmonary arterial hypertension (PAH) share many similarities and yet critical differences including the potential for a curative surgery in the case of CTEPH. This session will review diagnostic considerations and the latest treatment options for CTEPH. (Session handout on page 97)

PH Fundamentals: Continuing Education for Medical Professionals

1:30 p.m. – 2:30 p.m.
D1/D4, Convention Center

Please see the Medical Education program book for details.

Coffee Break

2:30 p.m. – 3:00 p.m.
Dallas Ballroom Foyer / Trinity Ballroom Foyer

Medically Led Sessions (Group 3)

3:00 p.m. – 4:00 p.m.
Exercise and Rehabilitation Programs

Trinity 5

Panelists: Roxana Sulica, MD, UCLA School of Medicine; Daniel Fox, MD, University of Colorado Denver; Michael Lewis, MD, Cedars-Sinai Medical Center

Specific foci of discussion will foster an appreciation and understanding of how drugs in development will complement the currently approved therapies for PAH and what the therapeutic potential and current limitations of gene therapies currently are. While few gene and cell therapy clinical trials have yet been undertaken for PAH, these technologies have shown promise in other diseases. We will conclude with an overview of translational research now underway in PAH, and a discussion of timelines to clinical trials for select gene and cell therapy strategies. (Session handout on page 77)

Infused Therapies

Trinity 2

Panelists: Lynette Brown, MD, PhD, Intermountain Medical Center (Chair); Deedre Boekweg, RN, BSN, Intermountain Medical Center; John Ryan, MD, University of Utah Health Care; Namita Sood, MD, Ohio State University

Prostacyclins are among the most potent and effective treatments for patients with advanced pulmonary arterial hypertension (PAH). However, there are unique challenges and potential complications of these therapies, mainly related to their delivery systems. This session will review currently available infused prostacyclin therapies, pros and cons of different modes of infusion systems, as well as their unique side effects. Emerging prostacyclin therapies will also be discussed. (Session handout on page 80)
Preparing for Emergency Situations

*Trinity 1*

**Panelists:** Harold Palevsky, MD, Temple University (Chair); Charles Burger, MD, Mayo Clinic in Florida; H. James Ford, MD, University of North Carolina School of Medicine; Anne Lovig, RN, BSN, University of Iowa Hospitals and Clinics

Patients with pulmonary hypertension are at risk for experiencing medical emergencies. This session will discuss common emergency situations, avoiding emergencies, recognition of emergencies, and emergency preparedness. (Session handout on page 89)

Preparación de Emergencia

*Trinity 3*

**Panelists:** Adolfo Kaplan, MD, Pulmonary and Sleep Center of the Valley (Chair); Vinicio de Jesus Perez, MD, FCCP, FAHA, Stanford University; Margie Rodríguez, FNP, Sleep Center of the Valley

Esta sesión abordará situaciones en las que la hipertensión pulmonar se convierte en una emergencia. Se centrará en quién llamar, qué medida inmediata a tomar, y a dónde ir.

The Teenage PH Patient

*Trinity 4*

**Panelists:** Felix Shardonofsky, MD, University of Texas Health Science Center at Houston (Chair); Daniela Brady, NP, Columbia Presbyterian Medical Center; Beth Coleman, RN, CPNP, Children’s Hospital Colorado; Delphine Yung, MD, Children’s Hospital Seattle

The goal of this session is to discuss the special needs of 12–18 year olds with pulmonary hypertension. Specifically, panelists will focus on changing medical and lifestyle topics of particular relevance to adolescents. (Session handout on page 93)

Transplantation for PH

*Trinity 7*

**Panelists:** Deb Levine, MD, University Health System in San Antonio (Chair); Monica Esquivel, ACNP-BC, University of Texas Health Sciences Center San Antonio; Ivan Robbins, MD, Vanderbilt University Medical Center

The goal of this session is to discuss surgical and/or interventional therapies that may be performed in particular patients with pulmonary hypertension (PH). Therapies to be discussed will be atrial septostomy, pulmonary endarterectomy, lung transplantation and heart-lung transplantation. This session will specifically focus on the description of these procedures and how and when they are performed in patients with PH. (Session handout on page 95)

Women’s Reproductive Health and PH

*Trinity 6*

**Panelists:** Wendy Hill, FNP-C, Cedars-Sinai Medical Center, (Chair); Patricia Santiago-Munoz, MD, UT Southwestern; Corey Ventetuolo, MD, MSCI, Brown University; Melissa Wilson, ARNP, ACNP-BC, Orlando Heart Institute

The goal of this session is to discuss the importance of reproductive health issues in pulmonary hypertension (PH), including recommendations for pregnancy prevention, routine well-woman health care, gynecological procedures, etc. A panel of PH experts and an OB/GYN specialist will discuss important issues regarding reproductive health for women with PH. PH patients are strongly advised to avoid pregnancy, so this session will also focus on various birth control methods available to women with PH. The session is meant to be interactive so bring your questions! (Session handout on page 91)

Fashion Show ▲

Sponsored by Gilead Sciences, Inc., and United Therapeutics Corporation

4:30 p.m. – 5:30 p.m.

*Dallas E, F & G*

Parents Mixer

Sponsored by Actelion Pharmaceuticals US, Inc.

5:30 p.m. – 6:30 p.m.

*Arts District 3*

Meet fellow parents of children with PH for conversation and cocktails.

Men’s Mixer

Sponsored by Actelion Pharmaceuticals US, Inc.

5:30 p.m. – 6:30 p.m.

*Arts District 1*

CTEPH Mixer

Sponsored by Bayer HealthCare

5:30 p.m. – 6:30 p.m.

*Arts District 2*

Join fellow CTEPH patients for conversation and drinks.

Long-Term Survivors Mixer

Sponsored by Actelion Pharmaceuticals US, Inc.

5:30 p.m. – 6:30 p.m.

*Arts District 4*

Mix and mingle over cocktails with others who have been living with PH for the long-haul.
PHA: Change Built on Community
Sponsored by Gilead Sciences, Inc.
6:30 p.m. – 8:30 p.m.
Dallas A, B, C, D & H
Presenter: Rino Aldrighetti, PHA President & CEO

PHA’s foundation has and always will be the PH community. Since the first meeting of our founders around the kitchen table, PHA has seen tremendous growth and progress in support, awareness and treatment. This Saturday evening program is a Conference signature event, and we invite you to join us in saluting Rino Aldrighetti, PHA’s first employee and President, as he addresses the PH community for the final time as PHA’s President. The dinner will also feature a screening of the Conference highlight video and the presentation of the Outstanding Member Awards: Julie Hendry Memorial Scholarship, Outstanding Caregiver, Outstanding PH Citizen, Outstanding Support Group Leader, and the Outstanding Young PH Citizen.

Generation Hope After Dark Mixer
Sponsored by Actelion Pharmaceuticals US, Inc.
8:30 p.m. – 10:00 p.m.
Katy Trail
Join your Generation Hope peers for conversation and cocktails.

Sunday, June 19

Coffee Break
8:00 a.m. – 9:00 a.m.
Dallas Ballroom Foyer / Trinity Ballroom Foyer

Medically Led Sessions (Group 4)
8:00 a.m. – 9:00 a.m.

Ask a Pediatrician (Infant – Age 11)
Trinity 3
Panelists: Erika Berman Rosenzweig, MD, Columbia University (Chair); Anna Brown, CPNP, Monroe Carell Jr. Children’s Hospital at Vanderbilt; Jeffrey Fineman, MD, University of California San Francisco

The goal of this session is to discuss the challenges facing infants and children up to age 11 and their families. Specific focus will be on how medications approved for adults may be used “off-label” in children. (Session handout on page 68)

Coping with PH and the Role of Palliative Care
Trinity 1
Panelists: Tim Williamson, MD, University of Kansas Medical Center (Chair); Traci Housten, RN, MS, Johns Hopkins University; Timothy Lahm, MD, Indiana University; Traci Stewart, RN, MSN, CHFN, University of Iowa Hospitals and Clinics

Day-to-day life with a chronic disease is a challenge to patients, caregivers and their families. The goal of this session is to provide tools for coping with the “good days” as well as the “bad days,” and provide some new options for improving quality of life. (Session handout on page 72)

Drug Development, Treatments on the Horizon and Stem Cells
Trinity 5
Panelists: Kelly Chin, MD, UT Southwestern (Chair); Patricia George, MD, UPMC; Vallerie McLaughlin, MD, University of Michigan

During this session, the panel will provide an overview of how drugs are developed, how newer drugs may impact drug selection as well as an overview of various active and recently completed clinical trials. The panel will also discuss stem cells as a potential novel therapy for PAH, particularly for patients with advanced disease who are unresponsive to currently available therapies. (Session handout on page 76)

Los Tratamientos que están en Proceso de Desarrollarse
Trinity 4
Panelists: Fernando Torres, MD, UT Southwestern (Chair); Vinicio de Jesus Perez, MD, FCCP, FAHA, Stanford University

Durante esta sesión, el panel proporcionará una visión general de cómo se desarrollan los medicamentos, cómo los nuevos fármacos pueden afectar la selección de medicamentos, así como una visión general de los diversos ensayos clínicos en proceso y los que han sido concluidos recientemente. El panel también discutirá acerca de las células madre como una nueva alternativa de terapia para la HAP en particular para los pacientes con la enfermedad avanzada que no responden a las terapias disponibles actualmente.
Oral Therapies

*Trinity 2*

**Panelists:** Anna Hemnes, MD, Vanderbilt University (Chair); Richard Channick, MD, Massachusetts General Hospital; Kimberly Farmer, RN, BSN, Vanderbilt University Medical Center; Matthew Lammi, MD, LSU Health Sciences Center

This session will review phosphodiesterase inhibitors, endothelin receptor antagonists, soluble guanylate cyclase stimulators and oral therapies in the prostacyclin pathway. Panelists will review these drugs’ roles in the treatment of PAH and how novel oral agents are being developed which will further advance the field and hopefully improve long-term outcomes in patients who suffer from PAH. (Session handout on page 85)

PH Associated with Another Condition – Coping with Second Illness

*Trinity 6*

**Panelists:** Stacy Mandras, MD, Ochsner Medical Center (Chair); Keri Djupstrom, RN, Cottage Health; Veronica Franco, MD, MSPH, Ohio State University Medical Center

As treatments for pulmonary hypertension (PH) allow patients to enjoy longer life, patients with PH are then susceptible to the problems of ‘regular’ people as they age. Problems like diabetes, systemic (ordinary) hypertension, chronic kidney disease, cancers (like lymphoma), coronary artery disease, and osteoporosis become more prominent as people age, and PH does not ‘protect’ you from developing other serious medical problems. Unlike some of the other sessions (e.g., genetics or treatment), there is not too much for the panel leadership to talk about without questions from the audience. Your participation will end up defining the topics in real time, and we look forward to an informative and supportive session. (Session handout on page 86)

Preparing for Travel and Oxygen Use

*Trinity 7*

**Panelists:** Glenna Traiger, RN, MSN, University of California (Chair); Bradley Maron, MD, Brigham and Women’s Hospital; Kerri Akaya Smith, MD, Hospital of the University of Pennsylvania; Tonya Zeiger, RRT, Mayo Clinic in Florida

Patients with pulmonary hypertension (PH) need careful planning to have a wonderful travel experience. This session will explain how to prepare for travel in order to have a safe and uneventful trip. The presenters will review practical considerations as well as determining oxygen requirements for travel and how they can be met with various devices. (Session handout on page 90)

**PH Fundamentals: Continuing Education for Medical Professionals**

*8:00 a.m. – 9:00 a.m.*  
*D1/D4, Convention Center*

Please see the Medical Education program book for details.

**PHA is Family: How Families Come Together to Fight PH**

*9:30 a.m. – 10:30 a.m.*  
*Dallas A, B, C, D & H*

A community united in common cause is the force that has helped the PH community – with a small patient population – grow far beyond its numbers and become what is truly a family. During this session, PHA will highlight the families of PHA challenge the norm and fight together to end this terrible disease. This brunch will celebrate the past, present and future families of PHA.

**PHA PHriends Training and Breakfast (by invitation only)**

Sponsored by Gilead Sciences, Inc., and United Therapeutics Corporation  
*9:30 a.m. – 10:30 a.m.*  
*Dallas F*

**Medically Led Sessions (Group 5)**

*11:00 a.m. – 12:00 p.m.*  
*Debunking PH Misperceptions II*  
*Trinity 7*

**Panelists:** Brandy McKelvy, MD, The University of Texas Health Science Center – Houston (Chair); Bruce Brundage, MD, St. Charles Medical Center – Bend; Darren Taichman, MD, PhD, Penn Presbyterian Medical Center

Have you heard tips and advice through the grapevine, social media or from your PHriends that you’re not sure are reliable? Talking to others about PH can be a great way to learn new information, but that information is not always medically accurate. In this session we will discuss and debunk common PH myths, rumors and misperceptions. Feel free to bring myths that you’ve heard or questions you have, as this session will be very interactive. (Session handout on page 73)

**Goal-Directed Combination Therapy**

*Trinity 5*

**Panelists:** Victor Test, MD, Duke University (Chair); Victor Tapson, MD, Cedars-Sinai Medical Center

The goal of this session is to discuss how combination therapy is used in pulmonary arterial hypertension (PAH). Recent
studies have demonstrated that patients may benefit from early combination therapy. The balance between benefit and risk of multiple agents affects the decision process for a specific patient. The specific focus will be how drugs are chosen for patients with PAH, and the rationale for, and timing of adding more PAH medications. The concept of “goal-oriented therapy” will be discussed. (Session handout on page 79)

Inhaled Therapies
Trinity 1
Panelists: John Wesley McConnell, MD, Kentuckiana Pulmonary Associates (Chair); Eric Fenstad, MD, IHA Pulmonary, Critical Care and Sleep Consultants; Nimaijeet Tarango, RN, MS, NP, UCSF Medical Center; Debra Zupancic, FNP BC, University of Colorado, Denver

This session will discuss how inhaled therapies are used to treat some patients with pulmonary arterial hypertension (PAH). An overview of the two FDA-approved inhaled prostacyclins will be provided, along with a discussion of appropriate patient selection and management of side effects. (Session handout on page 81)

Intimacy Issues – Women Only
Trinity 6
Panelists: Ioana Preston, MD, Tufts University, Boston (Chair); Amy Kimber, NP, Medical College of Wisconsin; Kristen Kruczek, RN, MSN, Massachusetts General Hospital

The goal of this session is to discuss the impact of a pulmonary hypertension (PH) diagnosis on one’s personal life. We will focus on dealing with changing relationships, a changing body image, and maintaining emotional and sexual intimacy in the face of medical illness. In an effort to allow free communication on these personal topics, this session is for women only. (Session handout on page 82)

Men with PH
Trinity 4
Panelists: Robert Schilz, DO, PhD, Case Western University School of Medicine (Chair); Roblee Allen, MD, MSc, University of California, Davis Medical Center; Jeff Voner, PA-C, Brigham and Women’s Hospital

During this session, panelists will facilitate a discussion about the ways that men experience living with pulmonary hypertension, and the ways that PH can impact one’s personal life. This session will provide a space for men with PH to share their stories with others who understand their situations. In particular, panelists and attendees will discuss changing relationships, changing body images and maintaining emotional and sexual intimacy in the face of PH. In an effort to allow free communication on these topics, this session is for men only. (Session handout on page 83)

Surgery and Anesthesia in PH Patients
Trinity 3
Panelists: Sonja Bartolome, MD, UT Southwestern (Chair); Jocelyn Havener, RN, BSN, University of Kansas Hospital; Kim Kerr, MD, University of California – San Diego Medical Center.

The purpose of the discussion will be to review the potential risks of anesthesia and surgical procedures in patients with pulmonary hypertension, define the various components of perioperative management, and adequately prepare for elective surgery in the event it is determined that the procedure is important for your health. (Session handout on page 82)

Transitioning from Pediatric to Adult Care
Trinity 2
Panelists: Jackie Szmuzkovicz, MD, Children’s Hospital of Los Angeles. (Chair); Beth Coleman, RN, CPNP, Children’s Hospital Colorado; Donna Guadiz, RN, Children’s Hospital Los Angeles; Dunbar Ivy, MD, Children’s Hospital Colorado

This program is designed to support teens and their families as they transition their care from a pediatric to an adult medical center. Discussion will include topics such as: understanding your diagnosis, managing your medications, planning for insurance changes, understanding reproductive health needs, and ensuring open communication with your healthcare providers. (Session handout on page 84)

PH Fundamentals: Continuing Education for Medical Professionals
11:00 a.m – 12:00 p.m.
D1/D4, Convention Center
Please see the Medical Education program book for details.

Conference Ends
12:00 p.m.
We’ll see you in Orlando, Fla., in 2018!
Every patient is unique.
We are one PAH community.

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Choose a message of hope and pose for a souvenir photo. Stop by the Actelion booth to add your pledge to the wall.

Greet YouTube sensation and award-winning singer/songwriter Chloe.

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Learn about her personal pledge and take a photo with Chloe.

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DEDICATED TO THE SEARCH FOR A CURE, WE SALUTE THE MANY FACES OF PH. YOUR STRENGTH, COURAGE, AND DETERMINATION IS AN INSPIRATION TO US ALL.
PHA’S EMPOWERED PATIENT ONLINE TOOLKIT

The Empowered Patient Toolkit can help your patients:

- Summarize medical history for new doctors
- Prepare for emergency situations
- Track medications and medical contacts
- Get the most out of doctors’ visits
- Record symptoms and questions between appointments
- Keep insurance information organized
- Plan for travel
- And more!

Any help that a patient or a caregiver can get for tracking their medical documents is great, because it can get overwhelming.

Available online at: www.PHAssociation.org/OnlineToolkit
**PHA Outstanding Member Award Recipients**

**Outstanding Allied Health Professional**  
Glenna Traiger, RN, MSN  
Awarded to an allied health professional (nurse, physician assistant, technician, therapist, etc.) for contributions to the PH community through any combination of the following: raising awareness, participation in advocacy efforts, fundraising, service to PHA, and providing kind and compassionate care to PH patients.

Glenna Traiger began caring for pulmonary hypertension patients in 1999 with Dr. Shelley Shapiro at USC. She served as a support group leader for 10 years before transitioning the group to two patient co-leaders. In 2005, Glenna and Dr. Shapiro moved their private practice to UCLA. The UCLA Pulmonary Hypertension Program now includes three physicians, a nurse practitioner and manages several hundred PH patients. Glenna has published in the field of PH and speaks nationally to patient/family and healthcare professional groups. She has actively supported PHA over her long career serving on the Membership Committee (committee chair for one term), Publications Committee and currently Communications Committee of PHPN. She was the first HCP to serve on the Advances in Pulmonary Hypertension editorial board. Glenna regularly participates in several Southern California support groups. Glenna is a member of the Review Committee for the PHCC Initiative. She is a PHPN Mentor, has contributed to several editions of the Patient Survival Guide, webinars, PHA Online University, PHPN Pulse, Pathlight and has spoken at several International Conferences and PHPN Symposia.

**Past winners:** 2014 – Abby Poms, RRT, RCP; 2012 – Mary Bartlett, NP; 2010 – Deborah McCollister, RN, BSN; 2008 – Christine Archer Chicko, MSN, CRNP; 2006 – Daniela Brady, RN; 2004 – Eileen Shalit, RN, BSN; 2002 – Traci Houston, RB, MS; 2000 – Beth Vogel, RN; 1998 – Cathy Anderson-Severson, RN, BSN

**Outstanding Caregiver**  
Martha Gonzalez  
Awarded to a PH patient who exemplifies dedication to the PH community through any combination of the following: raising awareness; participation in advocacy efforts; fundraising; service to PHA and helping to provide the public with a voice and face of the PH community.

Martha Gonzalez is a caregiver and activist who was inspired to fight pulmonary hypertension when her son, Daniel, was diagnosed at barely a year old. He already had two open heart surgeries and a liver transplant, but Martha knew PH, an incurable and debilitating disease, would be Daniel's greatest challenge yet. She knew she would never let him fight it alone and has dedicated all her energy, time, and talent to making the world better for all PH patients nationwide and worldwide. Some of Martha's accomplishments include winning two Tom Lantos grants from PHA to start her outreach to the PH communities of Latin America. She put together an international team and created a website (hpaqui.com) to help connect patients with medical professionals, patient organizations and information in Spanish and Portuguese. She also was able to bring PH to the attention of the Vatican and Daniel was blessed by Pope Francis in a special Mass in Philadelphia last fall. Martha has also been bringing the voices of PH patients to Capitol Hill, urging representatives to support Bill H.R 3520. However, her greatest achievement has been to be a caregiver and mom to her son. She fights to ensure that Daniel lives a normal, happy life and she spreads the message of PH to everyone who hears Daniel's story.

PHA Outstanding Member Award Recipients, continued

**Outstanding PH Citizen**

Nicole Stafford

Awarded to a PH patient who exemplifies dedication to the PH community through any combination of the following: raising awareness; participation in advocacy efforts; fundraising; service to PHA and helping to provide the public with a voice and face of the PH community.

Nicole was born with a congenital heart defect, and on Thanksgiving morning, when she was in third grade, she had emergency open heart surgery. After the surgery, Nicole’s childhood included gymnastics, track, volleyball and cheerleading. She never had difficulties with these activities, except running distance, and in the winters she noticed that her fingers and toes would turn bluish purple while outside in the cold. She thought nothing of it at the time. After the birth of her second child, Nicole started having shortness of breath during cleaning and also after carrying laundry up from the basement. A trip to the ER, and a follow-up at the Cleveland Clinic confirmed a PH diagnosis on July 28, 2011. After coming to the realization of her diagnosis and overcoming the fact that she could not work anymore, Nicole decided to dedicate her time to fundraising and spreading awareness for PH. She hosts an annual Nicole’s PHriends golf outing in June and also have other small fundraisers throughout the year. To date, Nicole has donated more than $100,000 over the last 4 years to PHA, and she plans to continue to help raise funds and awareness.


**Outstanding Physician**

Richard Channick, MD

The Outstanding Physician Award recognizes a physician who has been most notable in his or her service to PHA and in promoting excellent clinical care, research, education and advocacy on behalf of PH patients.

Richard Channick, MD, is director of the Pulmonary Hypertension and Thromboendarterectomy Program at Massachusetts General Hospital and associate professor of medicine at Harvard Medical School. Dr. Channick received his medical degree at Temple University Medical School, where he was elected to the Alpha Omega Alpha Medical Honor Society. He did his residency and was chief resident at University of Massachusetts Medical Center. He did a Pulmonary and Critical Care Fellowship at University of California, San Diego Medical Center. Dr. Channick has been caring for pulmonary hypertension patients for 27 years and has served on the steering committees for several pivotal clinical trials in pulmonary hypertension. He has published more than 150 original articles, chapters and reviews focused on all aspects of pulmonary hypertension. He serves on many national and international leadership committees including the American Thoracic Society Pulmonary Circulation Program Committee and the Board of Directors of Pulmonary Hypertension Care Centers, Inc. He has served as Chair of the Scientific Leadership Council for the Pulmonary Hypertension Association and lectures nationally and internationally.

PHA Outstanding Member Award Recipients, continued

Outstanding Support Group Leader
Diane Dewaulder

Awarded to a support group leader who provides a welcoming environment for patients, families and friends of PH patients; champions and serves PHA by leading local efforts to raise awareness; leads and participates in advocacy efforts and acts as a PH ambassador to the general public.

In 2004, after a trip to the ER, Diane was diagnosed with severe sleep apnea. Many tests were done and fortunately for her, the pulmonologist overseeing her care was aware of pulmonary hypertension and was 99.9% sure that she had IPAH. Her PH diagnosis was confirmed in February 2005. Being new to Texas, Diane didn’t know anyone as her family and friends were all in Arizona. While in a clinic visit, Diane was told about the Ft. Worth Support Group – and she no longer felt alone. Six years later, Diane stepped up to lead the group. Diane aims to provide her group with knowledge, resources, understanding and hope – and to give patients the opportunity to meet others dealing with PH. In addition to leading the group, she has conducted various fundraisers to raise awareness and to raise money for PH research. Diane was involved in the early planning stages of the North Texas 1 Mile PHun Walk (now Zebra PHest 5K and 1M PHun Walk) which is in its 10th year.


Outstanding Young PH Citizen
Eliana Elderete

Awarded to a PH patient, under 30 years of age, who exemplifies dedication to the PH community through any combination of the following: raising awareness; participation in advocacy efforts; fundraising; service to PHA and helping to provide the public with a voice and face of the PH community.

Eliana was diagnosed with PH when she was only 6 months old and has been kicking PH butt ever since! She is full of life, spunk and a desire to help others understand what PH is while showing them that anything is possible with faith, hope and love. She is on IV Remodulin and was the first PH patient to undergo the non-traditional Potts Shunt in New Mexico. She got through it with flying colors and once again showed the world her strength and courage. She is a light and a true inspiration to so many, from children to adults and continues to PHight with grace and determination. Once told she wouldn’t live to see her first birthday, she will be celebrating her 13th birthday in July.

PHA Outstanding Member Award Recipients, continued

Julie Hendry Memorial Scholarship Award
Julie Paton Hendry, daughter of PHA founding members Pat and Jerry Paton, was the first full-time, non-patient PHA volunteer. Every two years, she looked forward to the PHA Conference as an opportunity to meet the PH patients and families she talked with by telephone and email. Sadly, Julie passed away in 1998. Her family established the Julie Hendry Memorial Scholarship Award in her memory to help a non-patient volunteer attend Conference.

Don Stevenson
Don Stevenson, accompanied by his wife Loretta, dedicated nearly 6 months to walking across America and throughout his home state of Washington to raise funds and awareness for the Pulmonary Hypertension Association. After walking more than 4,000 miles and raising nearly $7,000, Don continues to offer support to the PH community. Being a U.S. Marine Corps veteran, a former pastor, teacher, author, poet, truck driver, firefighter and EMT, Don is no stranger to life’s challenges. He believes the greatest calling any man can receive is the call to serve others. With strong conviction, he often says, “The most peaceful people on earth are those who give their lives to help others. The most miserable people on the planet are those who think only of themselves.”

Jack Nino
Jack’s girlfriend, Heather, passed away from pulmonary hypertension just before PHA’s 2002 Conference. Since Heather had been so excited about Conference, he decided to attend anyways and was overwhelmed by what a great event it was. Jack has been back to every Conference since, volunteering. A few years after his first Conference, Jack decided he could do more for PHA and created the Las Vegas Scramble For A Cure Golf Tournament to raise funds. The event just celebrated its eighth year in April.


PHA Impact Awards

Steve and Debra Abraham Family – JFK Tower Golf Scramble
The Abraham Family has been organizing the JFK Tower Golf Tournament in Westchester, N.Y., for the past 13 years. Steve and Debra Abraham created the tournament with the idea of raising funds and awareness while honoring their daughter Rachel, a PH survivor. Raising well into six-figures for the struggle against PH, Steve and his FAA colleagues that provide air traffic control at JFK International Airport have set a superb example of fighting back through fundraising with their efforts.

Debra Watkins – Thirsting for a Cure in Portland
Debra and Dale Watkins, along with their Portland Support Group, originated their “Thirsting For a Cure” winetasting event in order to put the Robyn Barst Pediatric Research Fund over the one million dollar mark, activating the fund for proposals. They did it, and have subsequently conducted the event three more times in addition to the Shamrock Shuffle multiple times in Portland raising hundreds of thousands of dollars for PHA. Join them in fighting back through fundraising at their next “Thirsting for a Cure” event in Portland, Ore., on September 30, 2016.
PHA Impact Awards, continued

Matt and Jayna Wall – Driving Fore a Cure Golf Tournament
For the past three years, Matt and Jayna Wall have been hosting their annual “Driving Fore a Cure for PH” Golf Tournament in honor of their son, Jackson. The Walls have gone on to raise more than $100,000.00 to support PHA in our fight against pulmonary hypertension. Join them in fighting back through fundraising at their event in Raleigh, N.C., on October 15, 2016.

Amy Lovercamp Family – Kansas City Denim and Diamonds Dinner and Auction; Higginsville Denim and Diamonds; Kansas City O2 breathe 5K; Alma, Mo., O2 breathe 5K
Amy Lovercamp and her family joined the Midwest Chapter in planning three inaugural events in 2015, and have added an additional event for 2016, hosting the “Kansas City Denim and Diamonds,” “Higginsville Denim and Diamonds,” “Kansas City O2 breathe 5K,” and “Alma O2 breathe 5K.” Amy chose to fight back in memory of her sister-in-law, Carolyn Lovercamp Niederjohn, and in honor of her husband, Steve. The effort of both Amy and her family have brought the entire community together to raise thousands of dollars in support of PHA’s mission and she has laid the groundwork to fight back through fundraising for many years to come.

Mike and Sharri Caffrey – Taylor’s Wish
Following the loss of their daughter, Taylor, in 2009 to PAH, the Caffrey’s decided to fight back through fundraising for PHA. Since that time, they have conducted their immensely popular “Taylor’s Wish” 5k, seven years running, raising hundreds of thousands of dollars and awareness in the SoCal area for PHA.

Mike and Bonnie McGoon – Rochester PHA Gala
Bonnie and (Dr.) Mike McGoon are legends in their service of our community and the fight against PH. Their Rochester “Reach for the Stars” Gala for PHA has been one of the most successful galas produced by our community for years, and they have raised hundreds of thousands of dollars and immense awareness for the struggle against pulmonary hypertension. The ninth iteration is scheduled for September 30, 2017. Plan now to join them to fight back through fundraising at their magnificent event.

Melinda Grubich – DeWitt Take a Breath for PH Race
Melinda Grubich has been racing to put an end to PH each year in memory of her daughter Mackenzie. As co-director of the annual “DeWitt Take a Breath for PH and Get Moving for MS” event in DeWitt, Mich., Melinda has raised thousands of dollars for PHA. She finds inspiration through the community as well as competing in triathlons. She is a driving force and continues to encourage others to get out and run, get fit and stay healthy, all while growing this annual event to fight back through fundraising for PHA.
PERIWINKLE PIONEERS

At PHA’s 2016 Conference, we will celebrate our Periwinkle Pioneers, individuals and groups responsible for advancing care for pulmonary hypertension patients and helping to change the history of this disease.

PHA opened its Periwinkle Pioneers selection to the public in October 2015 with the expectation that its judging committee would select 25 winners. However, the decision was a lot more difficult than anticipated. As a result, the final 25 Periwinkle Pioneers represent individual and group category winners. Committee members all said this was one of the most difficult tasks they’ve undertaken because so many have given so much to this organization.

PHA’s Periwinkle Pioneers include the following people (listed alphabetically):

1. Rino Aldrighetti  
2. Gail Boyer Hayes  
3. Bruce Brundage, MD  
4. Bonnie Dukart  
5. Alfred Fishman, MD  
6. Teresa Knazik  
7. Sally Maddox  
8. Michael McGoon, MD  
9. Dorothy Olson  
10. Jerry Paton  
11. Pat Paton, RN  
12. Ed Simpson  
13. Judy Simpson, RN, EDS  
14. Barbara Smith  
15. PHA Early Global Leaders  
   • Iain Armstrong, RN (United Kingdom)  
   • Sharon Chetty (South Africa)  
   • Migdalia Denis (Latin America/Venezuela)  
   • Pisana Ferrari (Europe/Italy)  
   • Gerry Fischer (Europe/Austria)  
   • Juan Fuertes (Europe/Spain)  
   • Melanie Gallant-Dewavrin (France)  
   • Bruno Kopp (Germany)  
   • Noriko Murakami (Japan)  
   • Tomas Pulido, MD (Mexico)  
   • Annie Whitaker (Australia)  
   • Kay Yeowart, MBE (United Kingdom)  
   • Jing Zhi-Cheng, MD (China)  
   • Julio Sandoval, MD (Mexico)  
16. PHA’s Early Medical Transformation Pioneers  
   • David Badesch, MD  
   • C. Gregory Elliott, MD  
   • Vallerie McLaughlin, MD  
   • Victor Tapson, MD  
   • Carol Vreim, PhD  
17. PHA Scientific Leadership Council  
   • Richard Channick, MD  
   • Karen Fagan, MD  
   • Erika Berman Rosenzweig, MD  
18. PH Care Centers and PHA Registry  
   • Murali Chakinala, MD  
   • Steven Kawut, MD, MS  
   • Ron Oudiz, MD  
   • Abby Porns, BS, RRT  
   • Joel Wirth, MD  
   • Roham Zamanian, MD
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   • Beth Vogel, RN
   • Crystal Weber, RN
   • Melisa Wilson, ARNP, ACNP-BC

20. Board Leadership
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    • Carl Hicks
    • Roger Towle
    • Steve White, PhD

21. Early PHA Leaders
    • Candi Bleifer
    • Linda Carr
    • Shirley Craig
    • Laura D’Anna
    • Jim Wilson
    • Betty Lou Wojciechowski

22. Awareness
    • Kevin Burger
    • Tom Linnen
    • Diane Ramirez

23. PH Medical Trio
    • Robyn Barst, MD
    • Stuart Rich, MD
    • Lewis Rubin, MD

24. PH Genetic Researchers
    • James Lloyd, MD
    • Jane Morse, MD
    • John Newman, MD
    • Richard Trembath, MD

25. PHA Superstar Support Group Leaders/Volunteers
    • Ann Arnott
    • Evelyn Crespo
    • Diane Dauwalder
    • Angie Eldam
    • Kim Ford
    • Amanda Harvey-McKee
    • Julie Hendry
    • Steph Layer
    • Bonnie McGoan
    • Linda Pall
    • Rick and Delores Peacy
    • Merle Reeseman
    • Joanne Sperando-Schmidt
    • Jack Stibbs & Family
    • Doug Taylor
Research Grant Award Recipients

Barst Fund Award Winners

2015
David Brian Frank, MD, PhD
“Wnt Signaling Progenitor Cells in Late Lung Development, Regeneration, and Repair”
The Matthew and Michael Wojciechowski Pediatric PH Research & Mentoring Grant
December 1, 2015 – November 30, 2016
Instructor/T32 Grant Trainee, Cardiology
The Children’s Hospital of Philadelphia, University of Pennsylvania

Vitaly Oleg Kheyfets, PhD
“The Cause and Effect of Decreased Wall Shear Stress in Pediatric Pulmonary Arterial Hypertension”
Cordelia’s Pediatric PH Research and Mentoring Grant
December 1, 2015 – November 30, 2016
Assistant Research Professor, Medicine
University of Colorado Denver | Anschutz Medical Campus

Kara Nicole Goss, MD
“Right Ventricular-Pulmonary Vascular Interactions Following Postnatal Hypoxia Exposure”
The Joel Belt Pediatric PH Research and Mentoring Grant
December 1, 2015 – November 30, 2016
Assistant Professor, Pulmonary and Critical Care
University of Wisconsin

PHA Proof of Concept Award

2015
Ke Yuan, PhD
“The Role of Lung Pericytes as a Source of Occluding Pulmonary Artery Smooth Muscle Cells in PAH”
December 1, 2015 – November 30, 2016
Instructor, Pulmonary Critical Care Medicine
Stanford University

Soban Umar, MD, PhD
“Y Chromosome Confers Protection Against Pulmonary Arterial Hypertension”
The Jerry Wojciechowski PH Proof of Concept Grant
December 1, 2015 – November 30, 2016
Resident Physician, Molecular Medicine
University of California Los Angeles

2014
Daniel L. Fox, MD
“SSc-PAH Risk Score: Early Identification of Scleroderma-associated PAH by RV Strain, GDF-15 & IL-8r”
December 1, 2014 – November 30, 2015
University of Colorado Denver

Frances S. de Man, PhD
“A New Tool to Obtain Novel Insights in PAH-Induced Right Heart Failure”
The Jerry Wojciechowski Pulmonary Hypertension Proof of Concept Grant
December 1, 2014 – November 30, 2015
VU University Medical Center Amsterdam

Fiona Murray, PhD
“A Novel G-Protein Coupled Receptor (GPCR) Target in Pulmonary Arterial Hypertension”
American Thoracic Society Foundation/Pulmonary Hypertension Association Proof of Concept Research Grant
University of Aberdeen, UK

Marc de Perrot, MD, MSc
“Photodynamic therapy for the Treatment of Pulmonary Arterial Hypertension”
December 1, 2014 – November 30, 2015
University of Toronto, Canada
Research Grant Award Recipients, continued

**PHA/ATS Research Fellowship in Pulmonary Arterial Hypertension**

### 2015

**William M. Oldham, MD, PhD**

“Metabolic Flux Analysis in Pulmonary Arterial Hypertension”

December 1, 2015 – November 30, 2017

Associate Physician, Pulmonary and Critical Care

Brigham and Women’s Hospital

### 2014

**Ankit A. Desai, MD**

“Enhanced Risk Profiles of Sickle Cell-Related Pulmonary Hypertension – Integrating Genomics & Imaging”

American Thoracic Society Foundation/Pulmonary Hypertension Association Research Fellowship


University of Arizona

**PHA/NHLBI K08/K23 Award Winners**

### 2015

**Laura Mercer-Rosa, MD, MSCE**

“Right Ventricular Remodeling and Outcome in Tetralogy of Fallot”

September 1, 2015 – November 30, 2019

Assistant Professor, Cardiology

The Children’s Hospital of Philadelphia

### 2014

**Tien Peng, MD**

“The Role of Hedgehog Signaling in Pulmonary Arterial Hypertension”

July 1, 2014 – June 30, 2019

Postdoctoral Fellow, Pulmonary Care Division

Hospital of the University of Pennsylvania

### 2013

**Bradley A. Maron, MD**

“Aldosterone Impairs Endothelin B-Dependent Synthesis of Nitric Oxide to Promote Pulmonary Arterial Hypertension”

July 1, 2013 – June 30, 2018

Division of Cardiovascular Medicine

Department of Medicine

Brigham & Women’s Hospital

**Vinicio A. de Jesus Perez, MD**

“The Role of the Wnt/Planar Cell Polarity Pathway in Pulmonary Angiogenesis”

Oracle Corporation Community Grant

July 1, 2012 – June 30, 2017

Division of Pulmonary and Critical Care Medicine

Department of Medicine

Stanford University Medical Center

**Edda Spiekerkoetter, MD**

“Modulating BMPRII Signaling in Pulmonary Arterial Hypertension”

September 1, 2011 – August 31, 2016

Division of Pulmonary and Critical Care Medicine

Department of Medicine

Stanford University Medical Center
With Gratitude

Thank you, 2016 Conference Scholarship Fund Contributors for helping to build the largest non-profit Scholarship Fund!

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Thank you, Volunteers!

Thank you to the several hundred volunteers who took time out of their busy Conference schedules to help in planning, speaking, facilitating and representing PHA and the PH community.

Every job is important and our Conference would not be such a success without our volunteers!

PHA is founded on volunteerism and while we have grown, 25 years later we still depend on you to get the job done and make magic happen.

From all of us at the Pulmonary Hypertension Association, and from the bottom of our hearts, we thank you.
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Reata is a clinical-stage biopharmaceutical company located in Irving, Texas, and is conducting a phase 2 study of bardoxolone methyl in patients with PAH (The LARIAT Study). Bardoxolone methyl directly targets the bioenergetic and inflammatory components of PAH. Visit www.reatapharma.com.

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Accredo Specialty Pharmacy’s mission is to provide specialty-focused care and monitoring that can help patients maximize the effectiveness of their medication to enjoy an improved quality of life. To learn more, visit www.accredo.com.

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<td>Vallerie V. McLaughlin, MD</td>
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Note: Staff listing is current as of May 11, 2016.
Calendar of Events

Educational Events

PHA on the Road: PH Patients and Families Education Forum
www.PHAssociation.org/OnTheRoad

2017 PH Professional Network Symposium
October 4-8, 2017 – North Bethesda, Md.
www.PHAssociation.org/PHPN/Symposium

2018 International PH Conference and Scientific Sessions
June 29 – July 1 – Orlando, Fla.
www.PHAssociation.org/Conference

Special Events

4th Annual Nicole’s PHriends Golf Outing Scramble
June 25, 2016 – Girard, Ohio
Contact: Nicole Stafford at 330-2402483 or niokesphriends@aol.com

RideJonahRide
June 25, 2016 – Murfreesboro, Tenn.
Contact: Sheri Guider at guiderr@bellsouth.net

Ragnar Relay Northwest Passage
Contact: Katie Werner at KatieWerner@PHAssociation.org

San Francisco Marathon – a Team O2 breathe Marathon
July 31, 2016 – San Francisco, Calif.
Contact: PHA California Chapter at 415-361-8700

Quad Cities O2 breathe Fun Walk
August 13, 2016 – Moline, Ill.
Contact: PHA Midwest Chapter at 855-932-7255

4th Annual Steps for Stripes O2 breathe Fun Walk
August 21, 2016 – Brookfield, Wis.
Contact: PHA Midwest Chapter at 855-932-7255

Colorado PH in the Park
August 28, 2016 – Denver, Colo.
Contact: Deb Zupancic at deb.zupancic@ucdenver.edu

3rd Annual Greater Detroit O2 breathe 10k, 5k and Fun Walk
Contact: PHA Midwest Chapter at 855-932-7255

Soul Jam
September 10, 2016 – Woodstock, Ill.
Contact: PHA Midwest Chapter at 855-932-7255

Dance Your Heart Out
Contact: Gary Pederson at garypeders@comcast.net

RCP Tiburon Mile
September 11, 2016 – Tiburon, Calif.
Contact: PHA California Chapter at 415-361-8700

4th Annual O2 Glow Night Walk – an O2 breathe Night Walk
September 17, 2016 – Palatine, Ill.
Contact: PHA Midwest Chapter at 855-932-7255

3rd Annual Indianapolis O2 breathe 10k, 5k and Fun Walk
September 24, 2016 – Carmel, Ind.
Contact: PHA Midwest Chapter at 855-932-7255

2nd Annual Alma Denim & Diamonds Dinner
September 24, 2016 – Higginsville, Mo.
Contact: PHA Midwest Chapter at 855-932-7255

Thirsting for a Cure
September 30, 2016 – Portland, Ore.
Contact: Debra Watkins at gatheringgrace@gmail.com

Southern California O2 breathe Walk
October 1, 2016 – Anaheim, Calif.
Contact: PHA California Chapter at 415-361-8700

O2 breathe Walk of Philadelphia
Contact: PHA Northeast Chapter at 646-568-2068

Bank of America Chicago Marathon Charity Team – a Team O2 breathe Marathon
October 9, 2016 – Chicago, Ill.
Contact: PHA Midwest Chapter at 855-932-7255

“Swing PHor a Cure” O2 breathe Golf Tournament
October 14, 2016 – Houston, Texas
Contact: PHA Lone Star Chapter at 281-363-8122

Driving “Fore” a Cure for PH
October 15, 2016 – Clayton, N.C.
Contact: Matt Wall at mattwall67@gmail.com

Puyallup Six Minute Marathon
October 15, 2016 – Puyallup, Wash.
Contact: Gary Pederson at garypeders@comcast.net

Note: Event listed are as of April 26, 2016. For more events, please visit www.PHANews.org/Events.
The Pulmonary Hypertension Association (PHA) is a community of thousands of patients, family members and medical professionals working together to improve the lives of people affected by pulmonary hypertension. Here's a quick guide to PHA's patient resources.

**Be Prepared**

**Find a PH Doctor:** Look here for a list of PH-treating physicians from around the world: www.PHAssociation.org/FindaDoctor
- To find a PH-treating pediatrician, visit: www.PHAssociation.org/Pediatricians
- To find a PHA-accredited Care Center, visit: www.PHAssociation.org/PHCC

**Treatment Access Program:** Find answers to questions about Social Security Disability, Medicare and more with our online insurance guide: www.PHAssociation.org/Patients/Insurance

**Empowered Patient Online Toolkit:** Find templates, checklists and tips to help you manage your healthcare: www.PHAssociation.org/OnlineToolkit

¿Habla español? www.PHAssociation.org/Espanol

**Connect with others**

**PHA PHriends:** Connect with experienced PH patients, parents and caregivers available to offer support: www.PHAssociation.org/PHAPhriends or 800-748-7274

**Support Groups:** Find one near you: www.PHAssociation.org/SupportGroups

We also offer telephone support groups for patients and caregivers: www.PHAssociation.org/TelephoneSupport

**myPHA:** Join an online social network exclusively for the PH community. It’s free and easy to register – all you need is an email address: www.myPHAssociation.org

**Caregiver Resources:** Find support and information for family and friends of PH patients. www.PHAssociation.org/Caregivers/Support

**Expand Your Knowledge**

**Newly Diagnosed? New to PH?:** www.PHAssociation.org/Patients/EnvelopeofHope

**Pulmonary Hypertension:** A Patient’s Survival Guide: Our comprehensive guide to understanding and coping with PH. Order online at www.PHAssociation.org/SurvivalGuide

**Living with PH:** Tips for emergency situations, living and working with PH, traveling with oxygen and more. www.PHAssociation.org/Patients/LivingwithPH

**PHA Classroom:** Participate in live webinars or watch recordings on a wide range of topics such as PH diagnosis, treatments, living with PH, pediatric PH and more at www.PHAClassroom.org

**Looking to Help? We’re Looking for You!**

**435 Campaign:** Share your story with elected officials to advance legislation that improves lives for PHers. PHA can help you share it: www.PHAssociation.org/AdvocacyActionCenter

**Specialty Pharmacy Feedback Form:** Share your compliments or concerns so that specialty pharmacies can continue to improve their service: www.PHAssociation.org/SpecialtyPharmacyForm

**Media Action Network:** Your story is a powerful tool. Share it with the media to raise awareness of PH: www.PHAssociation.org/MediaActionNetwork

**Stay in the Loop**

**PHANews:** Up-to-date information about pulmonary hypertension, news from PHA, community events listings, and more – easily accessible on a mobile-friendly website and delivered to your inbox every Wednesday. www.PHANews.org
In this section you will find handouts from the Skill-Building Workshops, Patient/Family Led Sessions and Medically Led Sessions that were provided by the session speakers.

Use this section throughout Conference to formulate questions prior to the sessions you are attending, to follow along with the speakers during the sessions and to take notes. This section will also come in handy for those sessions you are unable to attend. Many handouts include website links and suggested resources for follow-up after Conference.

Please refer to the Program Book section for session dates, times and locations. The handouts that follow are presented by type of session in alphabetical order by session title.

**TIPS FOR MAKING THE MOST OF THE HANDOUTS**

1. **Browse ahead of time.** You may not know exactly what a session is about. After looking over the handouts, you might find something that piques your interest or adds clarity to a topic.

2. **Take notes.** Write down interesting comments during the presentation or questions to ask the speakers afterwards. Taking notes during the session presentation is a lot easier than trying to remember the key points afterwards.

3. **Sessions are being recorded.** Many sessions are being recorded and you will have the ability to tune in to the presentation again after Conference on PHA Classroom. This will let you catch information you might have missed. The bonus of these recorded sessions is that you will be able to experience and gain valuable information from a session you were unable to attend with the help of the handout. It will almost be like you were there!
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For Spanish-language handouts, please see the Spanish-language Conference Program Book

#PHAConference | #Heart2CurePH | @PHAssociation
Fundraising 101: Create Your Own Event for PHA!
Fundraising 201: Take Your Event to the Next Level!

*PHA fundraisers help support cutting-edge research, drive patient programs and increase public understanding of PH, while allowing others the opportunity to support you and the entire PH community. There are several ways to fundraise for PHA!*

**Plan your own Special Event**

- **Where do I start?** Call or email PHA using the contact info below. PHA’s here to provide you with the tools and resources you’ll need along the way.

- **What type of event should I plan?** What types of events would best attract your audience? What are their interests? Would they enjoy a family event such as walk-a-thon or a sophisticated event such as a wine tasting? Would they prefer an athletic event like a race or something all can do like a bowl-a-thon?

- **Who is my “audience”?** Friends, family, neighbors, co-workers, everyone in your social media circles, the school your children attend or at which you or a friend or family member works, your place of worship, your athletic club, social organization or fraternal order…everyone you know!

- **How will the event raise funds?** Think again about who will be attending. Would they be more likely to raise funds or make a donation? How much would they be able to contribute? What will the event cost?

**Create a webpage to collect donations for PHA**

- **How do I start?**
  - For HQ Special Events: Visit www.crowdrise.com/PHAssociation and select “Fundraise for Your Charity.” Follow the simple instructions to set up and personalize your page.
  - For PHA Chapter areas, please visit www.O2Breathe.org to contact your local Chapter for further instructions.

- **Then what?** Send your story with link to your page to everyone in your address book and post on your social media sites. Make it personal and help your contacts understand why their support is important.

**Join an existing event**

- PHA hosts more than 100 events across the country each year. To find an existing event near you, visit www.PHANews.org/Events.

**Team O2 breathe – PHA’s National Endurance Program**

- **Who can join Team O2 breathe?** Anyone who would like to represent our PH community by participating in an endurance event, such as a race, swim, bike or triathlon, while raising awareness and funds to fight PH, can join the team.

- **Do team members need to participate in a specific event?** No! There are events such as the Ironman North American Championship Texas, for which PHA has a team, but anyone who is participating in any event can join the team by registering online, creating a page, sharing their story and collecting donations. For a list of events where PHA has a team or to join the team for participation in separate event, visit www.TeamO2Breathe.org.

**What else can I do to help?**

- PHA is also looking to expand support from local and national corporations to help fund research and services. You don’t need to be the owner or executive of a company. You can help by providing the PHA with an email introduction to the appropriate person.

- If you know someone in the media – television, radio, newspaper, magazine, online – please let PHA know so we can ask them to help us increase awareness.

**Contact**

- Events@PHAssociation.org or 301-565-3004 x765
- www.PHAssociation.org/Fundraise
- For PHA members who live in Chapter regions, please go to: www.O2Breathe.org.
Media Matters

Raising Awareness through Traditional & Social Media

Overview of the Issue
In the era of social media, a pulmonary hypertension (PH) patient’s social media page or blog can play a powerful role in the Pulmonary Hypertension Association (PHA)’s awareness and advocacy efforts. Integrated messaging through multiple channels makes for a cohesive, compelling story. Learn how you can join PHA’s communications team as a social media ambassador. Together we are an impressive force in the fight against PH.

Why are patient and caregiver stories important to PHA’s work?
This session provides case studies from PHA communications and advocacy experts and one of the nation’s leaders in the field of public relations. Learn how your story can advance PH care so that more patients are diagnosed sooner rather than later and help PHA expand its reach to deliver programs and services for patients/caregivers/families, medical professionals and researchers.

What is #Heart2CurePH and how can I get involved?
Heart2CurePH is a multi-media integrated marketing and advertising campaign that uses donated and social media to raise awareness about PH and PHA. Its goal is to advance patient care, inform the public about PHA’s work and garner support in the fight against PH.

How can I use social media to raise awareness about PH and PHA?
Sharing your story in social media can make you an ambassador in the fight against PH. Integrating PHA’s messaging with your story and vice versa strengthens our collective efforts to raise awareness and advocate for support.

Resources
Like PHA’s Facebook page: facebook.com/PulmonaryHypertensionAssociation
Follow PHA on Twitter and Instagram: @PHAssociation
Sign up for and share PHA’s weekly PHANews e-newsletter: phanews.org/subscribe
Join PHA and get Pathlight magazine quarterly: phass ociation.org/Join#Levels
Join PHA’s Media Action Network: phassociation.org/MediaActionNetwork
Yes We Can!: Turning Elected Officials into PH Advocates

The PH Research and Diagnosis Act H.R.3520

Send Email
Just fill in your information and click send! Use our email templates that let you send a personalized message directly to your Members of Congress. www.PHAssociation.org/Advocacy/Alerts

Set Up Phone or In Person Meeting
Following up on your email with a personal conversation multiplies the chances that your Members of Congress will co-sponsor the PH bill. PHA will even set up a phone or in-person meeting for you and provide all the information and materials you need. Contact PHA to get started! Contact: Advocacy@PHAssociation.org or call 301-565-3004 x753

Learn More About H.R. 3520
The Pulmonary Hypertension Research and Diagnosis Act, H.R. 3520 would bring together representatives of several federal agencies working on PH to:

- Advance the full spectrum of PH research from basic science to clinical trials
- Increase early and accurate diagnosis of PH
- Educate medical professionals and the public

Want to know more about the bill?
Go to: www.PHAssociation.org/Advocacy/Toolbox

Take action today! Visit PHA’s booth, ask about signing the H.R. 3520 petition this weekend and get a FREE 435 campaign button.
Building Your Ark: How to Create Your Own Support System

Overview of the issue
How do you deal with your PH if you’re single or alone where you live?

Are you a quiet or reserved person who doesn’t like to ask for help?

This is a panel that can help PH patients learn how to manage their needs under the circumstances of limited caregivers or family support.

Important Considerations
- It’s ok to ask for assistance. This doesn't mean you’re weak or not self sufficient
- How to ask for help from your family, friends, co-workers, etc.
- If new to a city/town meet new friends at a local PH support group
  - Offer to carpool to meetings and medical appointments

Take-away Messages
- Living alone doesn't mean that you ever have to be alone
  - There are plenty of resources available for you
- Have to put yourself out there to meet people. Groups that meet on topics you enjoy book clubs animal groups, or donating time to kids at local schools etc.
- Doctors and nurses can connect you with other PH patients near you
- It is absolutely important to constantly build your self-esteem and feel confident with yourself

Additional Resources
- PHA’s Resource for “Living with PH” includes tips on simplifying day-to-day living, health and medication management, working with PH and coping with PH: www.phassociation.org/Patients/LivingWithPH
- Connecting with the PH community - www.phassociation.org/Community
Decisions, Decisions, Decisions

Overview
How do I ensure my child’s needs are met at school? Which infusion method is best? Should I go to a PH specialist or pediatric cardiologist? As a parent of a child with PH, you have to make decisions everyday on behalf of your child. Some decisions are easy, but some are downright difficult. In this session, parents of PH kids will share real life experiences and practical tips on how to work through some of life’s most difficult moments.

Important Considerations
- Learn how to become your child’s advocate for special accommodations at school.
- Find IEP and special education program trainings for parents in your state.
- Deciding which infusion method is best takes careful considerations.
- Specialists are extremely valuable because pulmonary hypertension is such a rare disease.
- PH is a part of your family’s life, but only a part of it.

Take-away Messages
- A parent needs to be prepared to appeal any decision not in favor of the child.
- Gaining insight from fellow PH parents is vital in the decision making process.
- When considering an infusion method, considerations include: side effects, delivery method, life style adjustments and risks.
- Help your child focus on what they can do, not what they can’t.
- Your family’s “new normal” includes, but isn’t defined by, your child’s diagnosis.

Additional Resources
- PHA Families Website
  - www.PHAssociation.org/ParentResources
- www.PHAassociation.org/PHCareCenters
Do You Think I'm Sexy?

Overview of the Issue
Building and maintaining relationships is one of the most important things that we do, yet something that we are rarely formally taught. It can be especially challenging to manage various relationships while also managing a life-changing disease like pulmonary hypertension. For some couples, an important component of intimacy is their sexual relationship. It can be intimidating for either member of the couple to initiate intimacy if the patient is frequently short-of-breath or on intravenous medication. The caregiver may be concerned about hurting the patient. Both partners may begin to feel alienated, distant and unsupported.

By taking the time to identify some potential challenges, it is possible to find ways to ensure that you’re getting the support you need in high stress situations and feeling the love you.

Important Considerations
- Confidence in Relationships (Social, Work, Personal)
  - When and how to talk about PH
    - Be honest.
    - Work it in naturally into early conversations.
    - Give more information gradually.
    - Express positive aspects.
  - Fear of rejection
    - You are not “damaged goods.”
  - Self-confidence Hacks
    - The power of posture.
    - Showcase your best assets.

- Sexual Activity
  - Benefits
    - Endorphins released improve your mood and relieve stress.
    - Natural pain reliever.
    - Improves your stamina and muscle strength.
  - Challenges
    - Fatigue
    - Pumps and oxygen tubing
  - Strategies for success
    - Accept your body.
    - Talk to your doctor about what is safe for you.
      - Contraception: avoidance of STIs and for female patients of child-bearing age, pregnancy.
      - Know the side effects of your medications.
      - Keep your head above your heart to avoid dizziness.
      - Be aware of your body’s physical limitations. Sex is exercise and may cause stress to the body.
      - Make your partner aware of the location of your pump and other assistive devices. Put them in a safe location out of the way.

Take-away Messages
- You can have sex with PH! You can feel sexy with PH! Own it until you become it!

Additional Resources
- www.butyoudontlooksick.com
- https://www.ted.com/speakers/amy_cuddy
- http://PHAssociation.org/LivingWithPH/Coping/MaintainingHealthyRelationships
Doctor, Doctor. Gimme the News!

**Doctor, Doctor, Gimme the News!**

**Overview of the Issue**

Ready, Set, Go – it is time to meet with your doctors are you ready? Doctor appointments and testing are part of all PH patients and their caregivers’ lives so make sure you are getting what you need from this time. Join us for a discussion about the tips and tools necessary to get the most out of your time with your doctor.

**Important Considerations**

**Preparing for the Appointment**

- Write down all concerns and questions – have a notebook
- Arrive 15 minutes early to review your plan for the appointment
- Bring someone with you – two sets of ears are better than one!
- Have a list of all medications and dosages
- Have doctors contact information – PCP, Cardiologist, Pulmonologist
- Understand your insurance – referrals, co-pays, prior authorizations

**The Appointment**

- Be prepared
- Be honest with your doctors
- Inform doctors of any supplements or alternative treatments

**Take Away Messages**

- This is YOUR time – USE it well!
- Don’t be afraid to ask questions if you don’t understand something
- Be educated – stay up to date with the latest information on the disease
- Get a second opinion if you feel you need one

**Additional Resources**

- [www.PHAssociation.org - Empowered Patients ToolKit](http://www.PHAssociation.org)
- [PHA Support Groups: www.PHAssociation.org/LocalSupportGroups](http://www.PHAssociation.org/LocalSupportGroups)
Having a Family with PH

Overview of Issue
In this session, panelists and attendees will discuss the emotional aspects of being a PH patient who wants a family, alternatives to high-risk pregnancies, and what to expect as a new parent with PH.

Important Considerations: Surrogacy/Fostering/Adoption
- Social Emotional Factors
  - Making the decision to pursue parenting and choosing the best route
  - The need for support from your doctor to sign off on your health status
  - Wait times (i.e. application to adoption; finding a surrogate to birth)
  - Risk of adoption or surrogacy plans that fall through and emotional stress on your well-being
  - Chance your health may decline and you may be unable to care for the child
  - Spouse/partner emotions: fear of being sole provider or single parent
- Alternatives to High-Risk Pregnancies
  - Adoption through agencies or a private lawyer
  - Social Services fostering/adopting
  - Surrogacy*

Take-away Messages
- What to Expect and Tips for Coping as a New Parent with PH
  - Kids take a lot of energy, be prepared to adjust to new routines
  - Be prepared to ask for help
  - Surround yourself with supportive people who can lend a hand
  - Schedule play dates
- Tips From The Spouse of a PH Parent
  - Patience, understanding and ways to reduce stress
  - Additional support when my spouse is not well & setting expectations

Additional Resources:
- PHA’s Scientific Leadership Council Consensus Statement on Pregnancy: https://www.PHAssociation.org/MedicalProfessionals/ConsensusStatements/BirthControl
- PHA’s Family Planning Resource: https://www.phassociation.org/Patients/YoungAdults/FamilyPlanning
- For adoption financial assistance by state: http://www.childwelfare.gov/adoption/adopt_assistance/
- Parenting with a Chronic Illness: http://www.parents.com/parenting/better-parenting/advice/parents-and-chronic-illness/
  Parenting while in pain: http://www.m.webmd.com/pain-management/features/parenting-children

*Please consult with your PH-treating specialist as surrogacy poses health risks to PH patients.
Insurance: A Maze or Amazing?

Overview of the issue
Understanding the benefits associated with your insurance is important to maximizing your coverage and knowing the options available to pay for your needed services. This session will discuss what insurance options may be available to you as well as how to make the most of your insurance coverage. It will also provide a brief overview of resources available to help you defray the cost of pulmonary hypertension treatment.

Important Considerations
- Coverage varies from state to state, between insurance providers, between policies, based on insurance type and changes year to year – not “one size fits all.”
- Insurance benefits can be difficult to understand. Check out the resources below for help
- Patients and caregivers must be diligent in ensuring coverage for doctors and needed services; if coverage is denied, learn why and understand your options for appeal
- Limitations on coverage are just as important to be aware of as covered benefits

Take-away Messages
- Shop around to find the policy with the best fit for your particular needs
- Everyone, including insurance personnel and patients make mistakes. If you believe an error has been made, don’t be afraid to request to speak to a supervisor to get answers
- Never miss an Open Enrollment opportunity to re-assess your needs
- Take charge of your healthcare. Familiarize yourself with insurance terminology, know your plan’s benefits and document all communication with your insurance company

Additional Resources
- Caring Voice Coalition
  - Provides a variety services such as assistance with coverage and appeals, Social Security benefits and financial assistance
  - Contact information: http://www.caringvoice.org/contact-us/, (888) 267-1440
- PHA resources
  - Treatment Access Program: www.caringvoice.org
    - General information on a variety of topics (types of insurance, choosing a plan, financial assistance options, applying for disability and more)
  - Supplemental oxygen guide: www.PHAssociation.org/Patients/Insurance/Oxygen
  - PHA Classroom: www.PHAClassroom.org
    - Healthcare and insurance webinars available
  - Contact information: Insurance@PHAssociation.org, (301) 565-3004 x773
- Medicare Rights Center:
  - Direct assistance to older adults and people with disabilities
  - Contact information: www.medicarerights.org, (800) 333-4114
- Medicare:
  - Information about coverage for eligible elderly and disabled individuals
  - Contact information: www.medicare.gov, (800) 633-4227
It's a Man's World

Overview of the issue
So it’s been bred into our DNA that “the man of the house brings home the bacon” but what happens when we’re unable to be the bread winner? What and how do we over come the stigma attached to this way of thinking and what can we do to compensate for now having to stay at home?

Important Considerations

- Having to work while dealing with PH
  - Dealing with the issues associated with this illness while trying to perform the tasks of our required job duties
  - Not all patients are married and can depend on a spouse/partner financially.
- “ Dating” with PH: how do patients handle the dating aspects with this illness?
  - When do you tell that special person you have a incurable illness and you may not be around for very long, or how do explain the oxygen tank your carrying?
- These issues make it very difficult to become accepting of this illness
  - Should we ever become accepting of this illness?

Take-away Messages
When ALL of this is just TOO much when do know when to ask for help and who do we ask for help from?

1. How do you deal with not being able to be the bread winner in the family?
2. Working with PH
3. Being single with PH ( dating)
4. Accepting our diagnosis or not
5. When to ask for help

Additional Resources

- Coping with Chronic Illness – http://www.alpineguild.com/COPING WITH CHRONIC ILLNESS.html
- Invisible Disability Newsletter – https://invisibledisabilities.org
- Coping with Chronic Illness and Depression – http://www.m.webmd.com/depression/guide/chronic-illnesses-depression
- Support resources – www.PHAssociation.org/Community
Life Hacks

Overview of the Issue
How do you do everyday tasks with your limited energy or mobility when you have your family to take care, the house to clean, or even buying groceries? Join us to learn how other PH patients have found ways to live their lives to the fullest with modifications.

Important Considerations
- Explaining different ways to go about your daily life
- Building and maintaining strong support systems
- Realizing and understanding your "new normal"

Take-away Messages
- You can live a fulfilling life with PH
- Surround yourself with a strong support network: family and friends.
- Keep negative people/issues away and staying positive

Additional Resources
- Join a local PH Support Group or start one! – www.PHAssociation.org/FindASupportGroup
- PHA Classroom webinar on "Emotional Well-Being "and more! – www.PHAClassroom.org/LivingwithPH/
- Coping with PH guides (for newly diagnosed, long-term survivor, teens, parents and caregivers) – www.PHAssociation.org/Patients/CopingWithPH
Living the PHit Life

Overview of the issue
Eating right, exercising, and maintaining a sodium/fluid balance can be overwhelming, to say the least. Knowing which foods are healthier and making those choices is not always easy. Exercise is beneficial to our health, and helps maintain flexibility builds muscles, and enhances quality of life. Maintaining our sodium and fluid balance can be challenging and crucial to our health.

Always talk with your PH doctor regarding any exercise and food plan.

Important Considerations
- Eating Issues
  - Dietary habits can play a big part in the management of your PH.
  - Eat more fruits and vegetables, as well as whole grains to add fiber to your diet.
  - Avoid eating out as often as these meals are often of fat, cholesterol, and sodium.
- Exercise
  - Stretch, breathe right, maintain your bones and muscles.
  - Yoga improves your overall health and can be done by anyone, regardless of their disability (e.g. Chair Yoga).
  - Low dose exercise: walk short distances; it all adds up to a healthier you!
- Sodium/Fluid Balance
  - Be sure and take all diuretics that your PH doctor has ordered.
  - Weigh daily, as instructed per PH doctor.
  - You can cut sodium by limiting processed foods in your diet.

Take Away Messages
- Eating
  - Use spices and fresh herbs to add more flavor to foods. Try new things!
  - Small steps can lead to big changes. Your body will thank you.
  - Learn to cook more at home so you know what you are eating.
- Exercise
  - Use your hospital’s rehabilitation centers if possible.
  - Stay in the present and listen to your body. Don’t exercise alone!
  - Find a good yoga therapist/certified teacher who can meet your physical limitations.
- Sodium/Fluid Balance
  - Maintain the proper fluid intake; additional fluid can make it much harder to breathe.
  - Small changes in your diet such as limiting processed and packaged foods can help.

Additional Resources
- Cleveland Clinic – https://my.clevelandclinic.org/health/treatments_and_procedures/hic-your-sodium-controlled-diet
- Yoga for PH – http://www.phaclassroom.org/LivingWithPH/content.cfm?ItemNumber=5026
- PHA Classroom: E-Guides and Webinar recordings – http://www.phaclassroom.org/LivingWithPH/index.cfm?navItemNumber=4522
Making Choices

Overview of the issue
What is grief? How can you overcome the grief? How do you maintain happiness when dealing with your diagnosis? Will I always be fearful of this disease and my Happiness? We welcome all the “PHriends” and “PHamily” coming to this session, where we explore the different areas that have helped us achieve and maintain happiness in our lives while dealing with PH.

Important Considerations
• Do not let PH control your life
• Be open to talking about your diagnosis
• The only thing to Fear, is Fear itself
• Take me time: hobby or activity

Take-away Messages
• Don’t stop living
• Set aside time to grieve
• Be positive
• Encourage yourself
• Have faith

Additional Resources
• Join a local PH Support Group – www.PHAssociation.org/FindASupportGroup
  PHA Classroom webinar on “Emotional Well-Being” and more! – www.PHAClassroom.org/LivingwithPH/
  Coping with PH guides (for newly diagnosed, long-term survivor, teens, parents and caregivers) – www.PHAssociation.org/Patients/CopingWithPH
• Read: Happiness: The best guide to becoming a happier you and reducing depression and anxiety by finding success and fulfillment in life By: The Fulfilled Life Project
The Power of Partnership

Overview of the issue
How do caregivers renew themselves when exhausted? How do patients positively communicate their needs? Join patients and caregivers to discuss ideas and practices to build trust and overall closeness. There will be an opportunity to ask questions and share your ideas and concerns with the panel to learn how to receive and give better support and understanding of each other’s needs.

Important Considerations
- Openly and honestly communicate about your needs
- Building a bond between caregiver and patient
- Importance of stress relief for patient and caregiver
- Importance of building support outside the partnership
- Discovering and accepting the strengths and weaknesses of each partner

Take-away Messages
- You can grow even stronger as partners with PH
- Find new activities you can do together to relive stress and have fun.
- Build communication skills and learn to “listen” to your partner
- Dealing with “new-normal” in your partnership.

Additional Resources
- Passages in Caregiving, Author Gail Sheehy
- National Patient Safety Foundation: www.npsf.org
- Join a local PH support group:
  www.PHASociation.org/LocalSupportGroups
- PHA Caregiver Resources: www.PHASociation.org/Caregivers
The Ride Of Your Life

Overview
Walking with a child through PH can often feel like riding a roller coaster. The twist and turns and ups and downs can take a PH family on the ride of their life. In this session parents and PH teens will discuss how to process through the emotional, social and mental challenges that come with PH. Topics will include how to: overcome depression, resolve family dynamics, work as a team, build a support system and much more.

Important Considerations
- Keep in mind that stress looks different in everyone.
- PH can cause extreme loneliness and isolation so it is vital to connect with people who understand what you are going through.
- A brief mental break can help you get through the toughest of days.
- When it comes to friends and activities think ahead to potentially difficult situations and how you might handle them.
- Parents set the tone for their children.
- PH is a full-family diagnosis.
- It’s important to remember that people have different coping mechanisms, so what works for one person might not work for another. In the end, you have to find what works for you.

Take-away Messages
- Isolation decreases quality of life. Togetherness increases quality of life.
- Help children focus on what they can do, not what they can’t.
- In order to help a depressed family member, you need to stay healthy and positive yourself, so don’t ignore your own needs.
- Being a teen with PH can be extremely hard. It’s important to remember is that there is always someone out there going through the same thing as you.
- Pulmonary Hypertension is something you have, not who you are.
- Routine and structure help children cope.
- Finding ways to process feelings is important.

Additional Resources
- Pulmonary Hypertension Association website:
  - www.PHAssociation.org/Parents
  - www.PHAssociation.org/Teens/CopingAsATeenagerWithPH
  - www.PHAssociation.org/Parents/Support
- http://www2.ed.gov/about/offices/list/ocr/transition.html
Trains and Planes and Boats: Oh My!

Overview of the issue:
An increasing number of available medication for PH provides a better prognosis for patients and enables them to lead a more active life, including travelling. Travelling with PH can require a little planning ahead for certain patients but is basically possible. Typical obstacles for PH patients can be the determination if you need additional oxygen when you want to use a plane, taking medication across international borders including syringes, taking diuretics while you are travelling, crossing high-altitudes with your RV/car, as well as securing oxygen supply at your destination. This session will provide some practical advice on how some of these obstacles can be resolved.

Important considerations:
- Travelling can be exhausting, allow enough time to rest once you get to your destination; you may need a full day, especially if your oxygen drops during travel to recuperate.
- Consider that a different climate can have an impact on your breathing ability.
- Take spare medication with you and distribute it across different pieces of luggage in case some luggage gets lost or stolen.
- If you take e.g. Marcumar, Coumadin, consider that with different food your INR level can vary, therefore increase your intervals to check the INR level.
- Cabin pressure in planes simulate an altitude approximately equivalent to the pressure of 6,500 to 8,600 ft above sea level resulting in less oxygen levels in your blood which strains your body, 40% less than normal. The longer the flight, the more stress your body has. Hence, check your need for additional oxygen.

Take away messages:
- Travelling with PH is possible, you just need plan ahead.
- Not all forms of travelling are suitable for all patients. Talk to your doctor to find out what is ok for you.
- If you like to travel by plane, check if you need additional oxygen and make according reservations. You will need to check with airline as some need a prescription written on their letterhead with your doctor’s signature in order to bring on an approved POC.

Additional resources:
- Thamm M, Voswinckel R: Air travel can be safe and well tolerated in patients with clinically stable pulmonary hypertension (2011) http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3198644/
- Shrikrishna D, Coker RK. Managing passengers with stable respiratory disease planning air travel: British Thoracic Society recommendations (2011) http://thorax.bmj.com/content/66/Suppl_1/i1.extract
Working and Higher Education with PH

Overview of the issue
Pulmonary Hypertension is itself a challenge to patients. If a PH patient chooses to go to college, or try to work, the issues can be further complicated. Like many other aspects of living with pulmonary hypertension, working and higher education can still be accomplished.

Important Considerations
- PLANNING for both college and work are important to success with either.
  - Recognize your limitations and plan ways to work them into your schedule.
  - Structure your day so that work and school obligations have minimal impact on your medication schedule whether you are on oral meds, inhaled therapy or a medical pump.
- Advise appropriate people at work or school of your condition, limitations, and emergency procedures. Everyone doesn’t need to know, but supervisors, professors, close friends, etc. need to be aware.
- Don’t be too proud or get embarrassed. Always ask for help if you need it.
- Find out if provisions in the Americans with Disabilities Act (ADA) or having an Individualized Education Program (IEP) or 504 Plan can help you achieve your work and education goals, or help protect you if someone tries to circumvent your rights.

Take-away Messages
- Many pulmonary hypertension patients can continue to work or go to school after their diagnosis.
- There are alternatives to traditional work and school experiences such as working for yourself or working from home or on flex schedules.
- PH patients can pursue higher education with online courses at many reputable colleges and universities.
- If you try to continue to work or go to school, plan, plan, plan, and then plan some more.
- Experiment to see what works if you have to. If something doesn’t work, try to modify or change it so that it can work out.
- “Remember: You call the shots.” (PHAssociation.org)

Additional Resources
- http://www.phassociation.org/Patients/WorkingWithPH
- http://www.phassociation.org/Patients/YoungAdults/College
- http://www.phassociation.org/Patients/EmergencySituations
- http://www.ada.gov/ada_intro.htm
- http://www2.ed.gov/parents/needs/speced/iepguide/index.html
- http://www2.ed.gov/about/offices/list/ocr/504faq.html
Adult Congenital Heart Disease, Blood Disorders and Liver Disease with PH

Session Description
The goal of this session is address the clinical management approaches of three different disorders that can be associated with pulmonary artery hypertension. Diagnostic criteria and special concerns for each disorder will be reviewed. Treatments options (medical and organ transplant) will be discussed.

Learning Objectives

- **Congenital heart disease (CHD)**
  Attendees will be able to:
  - Define Eisenmenger syndrome
  - Review expectations when treating PAH associated with CHD
  - Distinguish volume versus pressure overload in CHD-related PH
  - Identify which CHD patients can safely undergo shunt closure if PH present

- **Blood disorders**
  Attendees will be able to:
  - Explain why PH occurs in sickle cell disease (SCD) and thalassemia
  - Discuss the various forms of PH that can occur in SCD or thalassemia
  - Recognize the possible importance of splenectomy (spleen removal)
  - Summarize clinical trials in SCD – associated and thalassemia-associated PH

- **Liver disease**
  Attendees will be able to:
  - Contrast the 3 distinct types of PH associated with liver problems.
  - Describe disorders that can cause liver disease and PH
  - Debate PAH treatment options in the setting of liver disease
  - Determine which patients can proceed to liver transplant and possible outcomes

Additional Resources

- Adult Congenital Heart Association (ACHA): www.achaheart.org
- Sickle Cell Disease Association of America (SCDAA): www.sicklecelldisease.org
- American Association for the Study of Liver Disease (AASLD): www.aasld.org
Ask a Pediatrician (Infant – Age 11)

Session Description
The goal of this session is to discuss the challenges facing infants and children up to age 11 and their families. Specific focus will be on how medications approved for adults may be used “off-label” in children.

Learning Objectives
Attendees will be able to:

- Know PH medications approved for use in adults that are used in children
  - Endothelin Receptor Antagonists
    - Bosentan
    - Ambrisentan
    - Macitentan
  - Type 5 Phosphodiesterase Inhibitors
    - Sildenafil
    - Tadalafil
  - Soluble guanylate Cyclase stimulators
    - Riociguat
  - Prostacyclins
    - Epoprostenol
    - Treprostinil (SQ/IV/Inhaled/oral)
    - Iloprost

- Discuss findings of the Pediatric Task Force of the World Symposium of Pulmonary Hypertension
  - Treatment
    - Responders treated with Calcium Channel Blockers
    - Low Risk Nonresponders initially Treated with Oral Medication
    - High Risk Nonresponders treated with more aggressive medical therapies, such as IV/SQ prostacyclins

Additional Resources
- www.PHAssociation.org/Parents
- www.PHAcclassroom.org
Changing Treatments

Session Description
Changes in therapy are usually considered when therapeutic goals are not reached or when medications are causing difficult side effects. Changes are also sometimes considered for other reasons, such as a desire to change route of delivery or to take fewer treatments per day. In these situations, we will discuss ways in which this may be accomplished and the monitoring that is often required before and after the changes are made.

Learning Objectives
Attendees will be able to:

- Know when to consider changing therapy
  - Clinical worsening
  - Stabilization or slight improvement with a failure to reach therapeutic goals
  - Intolerable side effects
- Describe information and tests that may be conducted prior to changing therapy
  - Symptoms
  - Functional class
  - Laboratory tests
  - Six minute walk distance
  - Echocardiogram or cardiac MRI
  - Possibly a right heart catheterization
- Know what to ask before changing therapy
  - Side effects
  - Required monitoring (LFTs, pregnancy tests, other labs)
  - Route of delivery
- Identify potential changes
  - Switching therapy
  - Add-on therapy: continuing current therapy, but adding a second or third medication
  - Changing route of delivery (same medication or not)
- Identify what to monitor after changes are made
  - Dose-titration monitoring (if required)
  - Early follow-up (1-6 weeks depending on medication)
  - Testing – what types of tests (same as those done prior to switch)
    - Early testing: symptoms, functional class, walk distance
    - Later (3-12 months): echocardiogram, possibly catheterization

Take away messages
- Changing therapy can be an important part of optimizing your overall treatment plan. This can usually be accomplished safely, but it requires an organized and careful plan.

For reference
Approved therapies include:
1. Endothelin-1 receptor antagonists: (Letairis, Opsumit, Tracleer)
2. Phosphodiesterase-type-5 inhibitors: (Adcirca, Revatio)
3. Soluble guanylate cyclase activators: (Adempas)
4. Prostacyclins: oral (Orenitram), inhaled (Tyvaso, Ventavis), subcutaneous (Remodulin) and intravenous (Flolan / Veletri, Remodulin)
5. Prostacyclin receptor agonist: (Uptravi)

Additional resources
- www.phassociation.org/Treatments
Connective Tissue Diseases and PH

Session Description
In this session, we will describe the spectrum of connective tissue disease and define the different types of pulmonary hypertension (PH) encountered. We will focus the discussion on systemic sclerosis (scleroderma) because PH is particularly common in this connective tissue disease and because PH has a profound impact on the course of the disease. A multi-disciplinary approach to screening scleroderma patients for PH will be addressed; we will highlight the importance of early diagnosis and early treatment intervention in these cohorts. Further, we will examine the unique features of PH in scleroderma, emphasizing the many ways in which PH can develop in the setting of scleroderma. Finally, we will discuss treatment strategies for patients with connective tissue disease-associated PH.

Learning Objectives
Attendees will be able to:

- **Recognize the multi-system nature of the various connective tissue diseases**
  - The spectrum of “connective tissue disease” encompasses a diverse group of chronic, systemic diseases characterized by immune-mediated organ damage, a variety of clinical features, and usually the presence of circulating antibodies.
  - Lung disease is common in patients with connective tissue disease, and certain of these disorders are more likely to develop PH.

- **Define the different types of PH encountered in patients with connective tissue disease**
  - There are 5 primary groups of PH. Group 1 PH – also called *pulmonary arterial hypertension* (PAH) – is the only category with multiple and targeted treatment options. Approximately 25% of all Group 1 PH is due to connective tissue disease and the vast majority of these cases are scleroderma-associated PH. Given the prevalence of scleroderma in the US and the expected prevalence of PH in scleroderma, PH is likely significantly under-recognized and under-diagnosed.
  - Patients with connective tissue disease are also potentially at risk for developing Groups 2, 3 or 4 PH.

- **List the specific connective tissue diseases most often associated with PAH**
  - Patients with systemic sclerosis (scleroderma) are at highest risk of developing PH.
  - Patients with mixed connective tissue disease and a subset of those with systemic lupus, Sjogren’s syndrome, rheumatoid arthritis, and dermatomyositis are also at risk of developing PH.

- **Appreciate the importance of a multi-disciplinary and collaborative approach to the screening and evaluation of patients with connective tissue disease and PH**
  - Due to the heterogeneity of the connective tissue diseases and due to the diverse types of PH encountered in these patients, a multi-disciplinary and collaborative approach is often needed.
  - At-risk patients with connective tissue disease (i.e. scleroderma patients) should be screened yearly for the presence of PH.

- **Recognize the importance of early diagnosis and early intervention in patients with connective tissue disease-associated PAH**
  - Effective screening of scleroderma patients should lead to an earlier diagnosis and earlier intervention strategy.
  - Because PH can have such a profound impact on the course of disease, timely referral to PH treating specialists is needed.
  - Multiple therapies are now available for treating Group 1 PH; these options offer the potential of improved quality of life, improved heart function, and longer survival.
Coping with Chronic Illness

Session Description
This session will focus on coping with chronic illness over the long term for caregivers and patients. Caregivers can be family members, friends or healthcare professionals. Long term exposure to the challenges and stress of providing care and/or living with a chronic illness can lead to physical and emotional symptoms. Caregivers and patients may experience difficulty coping, compassion fatigue, burnout and survivors guilt. Strategies to identify and address these issues will be discussed.

Learning Objectives
Attendees will be able to:

- **Define concepts of compassion fatigue and survivor’s guilt**
  - Compassion fatigue: gradual indifference to appeals from those who are suffering as result of frequency or number of appeals.
  - Survivor’s guilt: perceiving that it was wrong to survive a traumatic event that someone else did not survive.

- **Identify symptoms associated with compassion fatigue, burnout and stress of living with chronic illness**
  - Examples: difficulty sleeping, isolation, poor self-care, illness, depression, anxiety, difficulty concentrating, denial

- **Recognize that awareness is the first step to change and wellness**

- **Associate being a caring person with caregiving**

- **Describe strategies for coping and self-care to survive the journey**
  - Take time to understand how being a caregiver affects you.
  - Be kind to yourself, be patient, eat healthy, exercise.
  - Practice self-management, focus on most important tasks, be proactive.
  - Develop a support system, ask for help, speak up with what works for you and what does not.

Additional Resources

- www.compassionfatigue.org
- www.proqol.org
- www.e4healthinc.com
Coping with PH and the Role of Palliative Care

Session Description
Day-to-day life with a chronic disease is a challenge to patients, caregivers and their families. The goal of this session is to provide tools for coping with the “good days” as well as the “bad days,” and provide some new options for improving quality of life.

Learning Objectives
Attendees will be able to:

- **Describe two ways to control stress**
  - Energy levels vary from day to day…pace yourself accordingly
  - Be realistic about what you can do.
  - Take time to rest, relax and exercise on a daily basis.
  - Do activities you enjoy such as listening to music, walking in a park or zoo, knitting, crossword puzzles, jigsaw puzzles – you decide.
  - Watch old comedies, cat or dog videos on the internet, or TV. Laughter is the best medicine.
  - Be especially patient with yourself on “bad days” and rejoice on the “good days.”
  - Spiritual belief can be a great comfort, regardless of religious tradition.

- **Describe the goals of palliative care**
  - Palliative care focuses on:
    - Relieving symptoms (from fatigue, shortness of breath, worsening right heart failure, mood issues, pain, and whatever else one may experience)
    - Defining and discussing goals of care, advanced directives, honoring your wishes
    - Affirmation of life by working towards the best quality of life for patients and their families
  - Palliative care begins with the symptoms of an incurable disease
  - Hospice care is a specific type of palliative care that occurs when a patient is terminally ill (less than 6 months to live).

Additional Resources

- National Hospice and Palliative Care Organization: www.nhpco.org/palliative-care-0
- www.getpalliativecare.org
- www.PHAssociation.org/Patients/CopingWithPH
Debunking PH Misperceptions

Session Description
Have you heard tips and advice through the grapevine, social media or from your PHriends that you’re not sure is reliable? Talking to others about PH can be a great way to learn new information, but that information is not always medically accurate. In these two sessions we will discuss and debunk common PH myths, rumors and misperceptions. Feel free to bring myths that you’ve heard or questions you have, as this session will be very interactive.

Discussion Notes
During this session, please feel free to use the worksheet below to organize your thoughts, questions and myths. Record the facts on the right hand of the worksheet to take back to your PHriends, loved ones or support group. Example myths to be discussed and dispelled are included below to get the conversation started.

<table>
<thead>
<tr>
<th>MYTHS</th>
<th>FACTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s impossible for me to lose weight because I can’t exercise.</td>
<td></td>
</tr>
<tr>
<td>If I am treated for PAH with medications, I will no longer need supplemental oxygen.</td>
<td></td>
</tr>
<tr>
<td>Oral prostacyclins can be used in place of IV prostacyclins.</td>
<td></td>
</tr>
<tr>
<td>Transplant should only be discussed during the final stages of disease.</td>
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</tr>
</tbody>
</table>
Diagnosing PH – Is Your PH Diagnosed Correctly?

Session Description
This session will review the current classification/definitions of pulmonary hypertension (PH), as well as standard testing methods used to fully diagnose patients. Diagnostic tests such as echocardiography, cardiac catheterization, pulmonary function tests, sleep studies, exercise tests and other lab and imaging modalities will be discussed.

Learning Objectives
Attendees will be able to:

- **Recognize the updated 2013 Pulmonary Hypertension Classification System**
  - 1. Pulmonary arterial hypertension (PAH)
  - 2. Pulmonary hypertension (PH) due to left heart disease
  - 3. Pulmonary hypertension (PH) due to lung diseases and/or hypoxia
  - 4. Chronic thromboembolic pulmonary hypertension (CTEPH)
  - 5. Pulmonary hypertension (PH) with unclear multifactorial mechanisms

- **Distinguish the terms “PH” and “PAH”**
  - PH is defined as an elevated pulmonary arterial pressure (> 25 mm Hg at rest) as measured by right heart catheterization (RHC).
  - Normal pulmonary arterial pressures are below 20 mm Hg at rest. The prognostic and therapeutic implications of pulmonary arterial pressures between 21 and 24 mm Hg are currently unknown.
  - Patients with PAH are characterized by:
    - Pre-capillary PH (increased pulmonary arterial pressure, normal left heart pressures (pulmonary arterial “wedged” pressure or left ventricular “end-diastolic” pressure) and elevated pulmonary vascular resistance.
    - No significant lung disease or chronic thromboembolic disease

- **Summarize the testing required to differentiate PH and PAH**
  - Transthoracic echocardiography continues to be the most important noninvasive screening tool to assess the possibility of PH.
  - The diagnosis of PAH requires the exclusion of other causes of PH. This evaluation includes tests for lung disease (Pulmonary Function Tests and Chest Imaging) and chronic thromboembolic pulmonary hypertension (ventilation-perfusion scanning).
  - A right heart catheterization (RHC) is considered mandatory to diagnose PAH.

- **Review the recommendations on screening of high-risk populations for PAH**
  - Annual screening for PAH is recommended in asymptomatic patients with limited scleroderma with both echocardiogram and pulmonary function testing.
  - Screening of asymptomatic scleroderma patients should include a multi-step approach using clinical assessment followed by echocardiography. A RHC should be considered in patients with abnormal findings.
  - Patients with SSc and other CTDs with clinical signs and symptoms of PH should be evaluated by RHC.

Additional Resources
- [http://www.phassociation.org/Patients/Diagnosis](http://www.phassociation.org/Patients/Diagnosis)
Disability Benefits

Overview of the issue
Those with chronic illnesses such as PH often have to make the difficult decision to stop working before reaching full retirement age. If you are no longer able to maintain substantial work, Social Security disability benefits can provide continued income and health insurance options. Like many government benefits programs, however, the pathway to receiving disability benefits can be confusing and time consuming. Join us to gain a better understanding of what benefit type you’re eligible for, how the Social Security Administration (SSA) will analyze your claim, what evidence to compile, how to prepare the strongest argument for your case and where you can turn to for help!

Important Considerations
• While the approval rates are not in your favor, you can achieve a disability approval with the right tools! Stay encouraged!
• You cannot apply for benefits until you have cut work back to gross earnings below $1130/month for non-blind individuals

Take-away Messages
• What might you be eligible for?
  o Supplemental Security Income (SSI) – based on financial need
  o Social Security Disability Insurance (SSDI) – based on work credits
• Tips before applying for SSA disability benefits:
  o Be mindful and honest in speaking to your physicians – don’t undermine symptoms!
  o Gather your work history and medical history for the last 15 years
• If you have been denied SSD or Supplement Security Income (SSI), you still have the right to make an appeal

Additional Resources
• Caring Voice Coalition
  o Has a team of Patient Advocates dedicated to representing you from the initial filing through the Administrative Law Judge hearing
    ▪ Contact information: Sr. Patient Advocate, Lauren Patrizio, (804) 417-0273
  o Provides a variety of other services such as financial assistance, finding and selecting health insurance and more
    ▪ Contact information: www.caringvoice.org, (888) 267-1440
• PHA resources
  o Treatment Access Program: www.PHAssociation.org/Insurance/Disability
    ▪ General information on a variety of topics including applying for disability, types of insurance, choosing a plan, financial assistance and more
  o PHA Classroom: www.PHAClassroom.org
    ▪ Webinars on disability available
  o Contact information: Insurance@PHAssociation.org, (301) 565-3004 x773
• Social Security Administration:
  o SSA has official Information on how to apply for disability, check your application status, contact your local SSA field office and all things related to disability
  o Contact information: www.ssa.gov/onlineservices, (800) 772-1213
Drug Development, Treatments on the Horizon and Stem Cells

Session Description
During this session, the panel will provide an overview of how drugs are developed, how never drugs may impact drug selection as well as an overview of various active and recently completed clinical trials. The panel will also discuss stem cells as a potential novel therapy for PAH, particularly for patients with advanced disease who are unresponsive to currently available therapies.

Learning Objectives
Attendees will be able to:

- Understand the process of drug development and clinical trials
- Describe the current therapies under development
- Understand the various methods for gene delivery in humans
- Understand the theorized mechanisms of therapeutic gains from stem cell transplantation
- Understand the current limitations of gene and cell therapy, and where current research is focused

Additional Resources
- http://clinicaltrials.gov/
Exercise and Rehabilitation Programs

Session Description
The goal of this session is to discuss how exercise and pulmonary rehab may affect pulmonary hypertension (PH) and how to incorporate regular exercise and rehab into your lifestyle. Specific focus will be on sharing the latest evidence of exercise benefit for PH, and tips on how to get started and stick with a regular exercise program for maximal benefit.

Learning Objectives
Attendees will be able to:

• **Describe how exercise can affect PH**
  - Research on exercise for PH is limited, but current evidence suggests that it may:
    - Improve ability to perform physical activities of daily living
    - Improve quality of life
    - Improve some indicators of disease progression, such as:
      - Performance in Six Minute Walk Test
      - Peak aerobic capacity
      - World Health Organization (WHO) functional class or New York Heart Association (NYHA) class
    - Help prevent or minimize other conditions that are associated with excessive weight and can limit function for patients with PH, such as: diabetes mellitus; sleep apnea; and increased work of breathing.

• **Describe and provide examples of different types of exercise that may benefit patients with PH, such as**
  - Aerobic exercise at low to moderate intensity
  - Aerobic interval training
  - Resistance training
  - Yoga and Pilates

• **Describe the types of assessments and activities that will be performed in an outpatient cardiopulmonary rehabilitation program**
  - Exercise testing
  - Exercise training
  - Nutritional counseling
  - Psychological counseling and/or group support
  - Education on PAH and strategies to manage it in daily life

• **Define the role of an organized cardiac-pulmonary rehab program in the management of PH**
  - Cardio and pulmonary rehab programs can help define a safe and reasonable exercise program for patients with PH.
  - These programs can then be continued at home for long-term benefits.
  - Although it is likely that a combination of both strength and endurance training is helpful in PH, the optimal program is not yet known.

Additional Resources
- www.nhlbi.nih.gov/health/health-topics/topics/pulreh/during.html
- www.PHAssociation.org/Patients/ExerciseAndPH
Familial Genetics and PAH

Session Description
The purpose of this session is to discuss what is known about the inheritance of pulmonary arterial hypertension (PAH), with special emphasis on familial PAH, which is a type of heritable PAH (HPAH). We will provide an overview of the way that the disease may be inherited and how individuals and families can deal with the risks and the knowledge that PAH may be a familial disease. We will discuss the possibility that a genetic basis of disease may be present in persons who have no other known family member with pulmonary hypertension. We will discuss the percentage of patients that carry the known genes that are associated with PAH. We will discuss the benefits, risks and limitations of genetic testing.

Learning Objectives
Attendees will be able to:

- Define the words used to describe inheritance of genetically-related disorders
- Describe the risk of inheritance and of disease development to an individual in a family with known mutations that cause PAH
- Discuss methods of health surveillance if a mutation exists
- Discuss the benefits and risks of genetic testing in family members with idiopathic disease, and in their family members
- Discuss preliminary scientific studies designed to understand mutant PAH genes, and efforts to use this knowledge for novel therapies

Important Considerations

- Heritable: a condition which can be passed on to a person’s children
- What is heritable pulmonary arterial hypertension (HPAH)?
  - More than one family member diagnosed with pulmonary arterial hypertension
  - Identification of a disease causing mutation in a patient diagnosed with PAH
- What tests are available, who should be tested, who pays, and what do the results mean?
  - Genetic tests are available with appropriate genetic counseling
  - Immediate family members (brothers, sisters, children, parents) are candidates for tests
  - Genetic testing is not for everyone. Pretest counseling is necessary.
  - Health Insurance Companies may not pay for genetic testing.
  - A disease causing mutation increases the likelihood to develop HPAH
    - If the mutation is not found, PAH almost never will develop
    - If the mutation is found, the risk over a lifetime to develop PAH is:
      - About 40% for females
      - About 15% for males

Take-away Messages

- Pulmonary arterial hypertension (PAH) is sometimes a heritable condition
  - Researchers have discovered gene mutations which associate with PAH
  - Not all people with the concerning mutation will develop PAH
  - Genetic tests are available and may help some individuals. Counseling is important.

Additional Resources

- www.phassociation.org/AboutPH/Genetics
Goal-Directed Combination Therapy

Session Description
The goal of this session is to discuss how combination therapy is used in pulmonary arterial hypertension (PAH). Recent studies have demonstrated that patients may benefit from early combination therapy. The balance between benefit and risk of multiple agents affects the decision process for a specific patient. The specific focus will be how drugs are chosen for patients with PAH, and the rationale for, and timing of adding more PAH medications. The concept of “goal-oriented therapy” will be discussed.

Learning Objectives
Attendees will be able to:

- State the different “pathways” that different PAH therapies target

- State the different medications that work via these pathways
  - Endothelin pathway (bosentan, ambrisentan)
  - Prostanoid pathway (epoprostenol, treprostinil)
  - Nitric oxide pathway (sildenafil, tadalafil, riociguat)

- List the common parameters used to determine the need for additional PAH therapy
  - Patient’s symptoms and physical examination
  - Exercise test such as 6 minute walk test
  - Oxygen level and requirement
  - Lab testing such as BNP test
  - Right-heart catheterization (performed at least once, before any PAH therapy)
  - Echocardiogram

Additional Resources:

- www.nhlbi.nih.gov/health/health-topics/topics/pah/
- www.PHAClassroom.org
Infused Therapies

Session Description
Prostacyclins are among the most potent and effective treatments for patients with advanced pulmonary arterial hypertension (PAH). However, there are unique challenges and potential complications of these therapies, mainly related to their delivery systems. This session will review currently available infused prostacyclin therapies, pros and cons of different modes of infusion systems, as well as their unique side effects. Emerging prostacyclin therapies will also be discussed.

Learning Objectives
Attendants will be able to:

- **Know the differences among the infused prostacyclin treatments and indications for use**
  - Epoprostenol (Flolan)
    - Half-life ~ 4-6 minutes
    - Not stable in room temperature
  - Thermostable epoprostenol (Veletri)
    - Stable in room temperature
  - Treprostinil (Remodulin)
    - Half-life ~ 3-4 hours
    - Stable in room temperature

- **Know the possible side effects associated with prostanoid infusion treatments**
  - Potential acute side effects
    - Hypotension, nausea, flushing, headache, diarrhea, jaw pain
  - Potential chronic side effects
    - Jaw pain, diarrhea, flushing, headache
    - Thrombocytopenia (decrease in platelet count), increase risk in bleeding
  - Side effects often diminish over time and the improvement in symptom with therapy often outweigh the side effects of treatment

- **Know the pros and cons of different routes of delivery**
  - Intravenous route
    - Direct delivery of drug via Hickman catheter
    - Risk of line infection, malfunction
    - Patients must learn the sterile preparation of the medication, operation of the ambulatory infusion pump, and care of the central venous catheter.
  - Subcutaneous route
    - Avoid need of central line
    - Site infusion pain / discomfort for some – varies among individuals

- **Learn important information regarding therapy with infused prostacyclins**
  - Infused prostacyclins are effective but complex treatments
  - Optimal dosing varies among individuals and must be monitored closely with your pulmonary hypertension team for continued evaluation and to assess for changes in therapy / titration of dose
  - Abrupt cessation of infused prostanoids can be life threatening

Additional Resources
- www.phassociation.org/Treatments
Inhaled Therapies

Session Description
The goal of this session is to discuss how inhaled therapies are used to treat some patients with pulmonary arterial hypertension (PAH). An overview of the two FDA-approved inhaled prostacyclins will be provided, along with a discussion of appropriate patient selection and management of side effects.

Learning Objectives
Attendees will be able to:

- Define the differences between the two inhaled prostacyclin options
  - Iloprost (Ventavis™) overview
  - Inhaled treprostinil (Tyvaso®) overview

- Describe the rationale for the use of inhaled prostacyclins.

- Describe some potential patient scenarios that may be appropriate for inhaled prostacyclins
  - When inhaled therapy may be appropriate and when IV therapy may be more appropriate
  - Patient selection: inhaled therapies require a high level of compliance

- List measures that may control common side effects of inhaled therapies
  - Cough – the most common side effect can be lessened in a number of ways
  - Headache or other prostacyclin side effect management may require temporarily reducing the dose until side effects are tolerable

Additional Resources
- www.4ventavis.com
- www.tyvaso.com/hcp/for-nurses/patient-education
Intimacy Issues – Women

Session Description
The goal of this session is to discuss the impact of a pulmonary hypertension (PH) diagnosis on one’s personal life. We will focus on dealing with changing relationships, a changing body image, and maintaining emotional and sexual intimacy in the face of medical illness. In an effort to allow free communication on these personal topics, this session is for women only.

Learning Objectives
Attendees will be able to:

- **Describe the impact of a medical diagnosis on their personal relationships**
  - Parental relationships
  - Sibling relationships
  - Children
  - Romantic relationships

- **Discuss communication strategies to use in restoring the balance in relationships**
  - Making Connections
  - Communication strategies
  - Caring for oneself

- **Identify body image issues which may occur after a medical diagnosis and affect relationships**
  - How to mourn what “once was” but find the good about “what is”

- **Discuss the impact of a PH diagnosis on a woman’s sex life**
  - The physiology involved
  - What is safe and what is not
  - Medical problems and a woman’s libido

Additional Resources
- [www.psychologytoday.com/blog/communication-success/201205/are-you-poor-communicator-how-improve](http://www.psychologytoday.com/blog/communication-success/201205/are-you-poor-communicator-how-improve)
- [www.PHAssociation.org/LivingWithPH/Coping/MaintainingAPositiveSelfImage](http://www.PHAssociation.org/LivingWithPH/Coping/MaintainingAPositiveSelfImage)
- [www.PHAssociation.org/LivingWithPH/Coping/MaintainingHealthyRelationships](http://www.PHAssociation.org/LivingWithPH/Coping/MaintainingHealthyRelationships)
Men with PH

Session Description
During this session, panelists will facilitate a discussion about the ways that men experience living with pulmonary hypertension, and the ways that PH can impact one’s personal life. This session will provide a space for men with PH to share their stories with others who understand their situations. In particular, panelists and attendees will discuss changing relationships, changing body images and maintaining emotional and sexual intimacy in the face of PH. In an effort to allow free communication on these topics, this session is for men only.

Learning Objectives
Attendees will be able to:

- Describe obstacles to physical and emotional Intimacy
  - We will explore how disease affects the relationship of PH patients and their partners
  - Discuss the physical limitations to intimacy, sexual and emotional
  - Discuss the effects of chronic disease on sex

- Describe the impact of a medical diagnosis on their personal relationships
  - Parental relationships
  - Sibling relationships
  - Children
  - Romantic relationships

- Discuss communication strategies to use in restoring the balance in relationships
  - Making Connections
  - Communication Strategies
  - Caring for oneself

- Identify self-image issues which may occur after a medical diagnosis and affect relationships
  - How to mourn what “once was” but find the good about “what is”

Additional Resources
- www.psychologytoday.com/blog/communication-success/201205/are-you-poor-communicator-how-improve
- www.PHAssociation.org/LivingWithPH/Coping/MaintainingAPositiveSelfImage
- www.PHAssociation.org/LivingWithPH/Coping/MaintainingHealthyRelationships
Nutrition and Diuretics

Learning Objectives
Attendees will be able to:
- Differentiate healthy from unhealthy eating habits in PH
- Recognize how salt and water intake affects PH
- Demonstrate how proper diet, correct use of diuretics and keeping track of daily weights can improve general well-being and parameters of PH
- Identify strategies to better deal with side effects of water pills

Nutrition: The Basics
- Eat a balanced diet of all 3 sources of calories: carbohydrates, protein and fat.
- Eat plenty of fruits and vegetables. Fish and chicken are preferable over red meat.
- Account for the total calories ingested and compare that to your activity level. Men and very active women may burn 2500 calories a day and less active women 2000 daily. Severe PH may cause you to be sedentary burning only 1500 or so calories daily. If the caloric intake is greater than the calories burned, weight gain will occur and vice versa.

Salt and Water: The Basics
- The body regulates its fluid balance based on both salt concentration and water content in the blood.
- Normally, any extra water or salt intake can be handled by the kidneys to keep the balance even. Many PH patients however are unable to keep up, and end up retaining water. This makes them gain weight and swell up; this makes them more short of breath, and makes their PH worse.
- Although we often hear that it is good to drink a lot of fluids, when you have PH, drinking a lot of fluids can actually hurt you and could land you in an emergency room.

How to Manage Your Fluid Intake
- If you are retaining water, your doctor may instruct you to cut back on your fluid intake. This means less liquid of all kinds: water, juice, coffee, etc. Your doctor may also tell you to cut back on sodium. This means no added salt (you might do well to start trying salt substitutes, but beware if you have high potassium problems and/or kidney failure). This also means less canned and prepared foods, and less eating out since most restaurants salt their food so people will like the taste and patronize their business (if eating out, try low-salt choices).
- If you are taking a water pill like furosemide (“Lasix”, “Bumex”, etc), this usually means that your doctor has determined that you are retaining fluid. The things to remember with water pills are:
  o Whenever you are on water pills, you also have to watch your salt intake (salt “sucks” water into your body).
  o Weigh yourself and record your weight daily; changes of more than two pounds up or down per day or 4 pounds per week mean that your water weight is changing.
  o Bring your daily weights with you to the doctor’s and/or nurse’s visits.
  o You may need to take potassium (KCl) pills because water pills can deplete potassium from your system, which can cause muscle cramps, irregular heartbeats, and even death.
  o Water pills make you thirsty. We understand, however drinking too much will put the water that we are trying to get out of you right back into your system. Try gum, candy, etc.
- If you get sick and stop eating or drinking, you may need to temporarily lower your water pill dose or even stop taking it until you recover. Notify your physician in those situations. When in doubt, ask.

Take-away Messages
- Eating habits and fluid (water) balance are important for keeping your heart healthy.
- Controlling fluid and salt intake alone may be enough to keep you from needing water pills.
- If you are prescribed water pills, be careful about becoming dehydrated, but DON’T jump to the conclusion that you are dehydrated just because you are thirsty.

Additional Resource
- www.phassociation.org/Patients/DietAndNutrition
Oral Therapies

Session Description
This session will review phosphodiesterase inhibitors, endothelin receptor antagonists, soluble guanylate cyclase stimulators and oral therapies in the prostacyclin pathway. Panelists will review these drugs’ roles in the treatment of PAH and how novel oral agents are being developed which will further advance the field and hopefully improve long-term outcomes in patients who suffer from PAH.

Learning Objectives
Attendees will be able to:
- Review the nitric oxide, endothelin and prostacyclin targeted pathways in PAH
- Review data from the pivotal studies that led to approval of the oral agents
- Highlight newer outcome measures (morbidity and mortality) for future studies in oral agents and PAH
- Review expected side effects of oral therapies
- How to monitor patients while on oral therapies
- How to use oral therapies in combination with each other and with inhaled, subcutaneous and IV therapies

Additional Resources
- www.PHAssociation.org

PH Associated with Another Condition – Coping with a Second Illness

Session Description
As our treatments for pulmonary hypertension (PH) allow patients to enjoy longer life, patients with PH are then susceptible to the problems of ‘regular’ people as they age. Problems like diabetes, systemic (ordinary) hypertension, chronic kidney disease, cancers (like lymphoma), coronary artery disease, and osteoporosis become more prominent as people age, and PH does not ‘protect’ you from developing other serious medical problems. Unlike some of the other sessions (e.g., genetics or treatment), there is not too much for the panel leadership to talk about without questions from the audience. Your participation will end up defining the topics in real time, and we look forward to an informative and supportive session.

Learning Objectives
Attendees will be able to:

- Describe (mainly in response to specific audience questions) how the treatments for PH and chronic right heart failure complicate the diagnosis and/or management of a new problem unrelated to PH

- Review the role of the PH treatment team in assisting other physicians with the evaluation and/or management of a new problem unrelated to PH

- Explore in a group setting strategies which more experienced PH patients have used when they’ve encountered new medical problems –to talk about the strategies that worked and especially the times when things went badly (so that the group can benefit)

- Reinforce with attendees the healthy habits that can reduce the risk of new medical problems, especially those that have a ‘lifestyle’ or behavioral component

Additional Resources

- www.PHAClassroom.org
PH from Left Heart Dysfunction – The Great Pretender

Session Description
The goal of this session is to introduce the concept of pulmonary hypertension (PH) in the setting of left heart disease, particularly associated with diastolic dysfunction of the left ventricle. We will discuss the typical patient profile seen with this condition, which is one of the most common causes of PH. Similarities and contrasts with pulmonary arterial hypertension (PAH) will be emphasized. Treatment options will be described, as well as types of treatment which might not be best suited to this condition.

Learning Objectives
Attendees will be able to:

- **Distinguish the difference between PAH and PH associated with left heart disease**
  - Definition depends on wedge pressure and PVR
  - PH/LHD probably the most common form of PH
  - PAH relatively rare

- **List the types of left heart disease which may cause PH**
  - Left ventricular systolic dysfunction
  - Diastolic dysfunction (HFpEF)
  - Valve disease

- **Describe the typical features (age, weight, gender, other medical problems) of a patient with PH related to diastolic dysfunction**
  - Older patients, female, metabolic syndrome, A Fib

- **Understand the role of heart catheterization in diagnosing PH related to left heart disease**
  - Right heart catheterization required for accurate diagnosis

- **Describe the role of PAH drugs in the medical treatment of PH with left heart disease**
  - Treatment with PAH drugs may yield disappointing results

Additional Resources

- [www.PHAssociation.org/PHPlus](http://www.PHAssociation.org/PHPlus)
- [www_PHAClassroom.org](http://www_PHAClassroom.org)
PH Simplified – The Basics of PH, Treatment and Tests

Session Description
This session will cover the basics of pulmonary arterial hypertension (PAH), explaining how the heart can be affected by high lung pressures. We will also discuss the different types of pulmonary hypertension and the rational for the extensive testing recommended by recent guidelines. Finally we will review the available therapies to treat PAH and how they may be used in combination. This session will provide an overview of basic pulmonary hypertension knowledge.

Learning Objectives
Attendees will be able to:

- Explain what happens to the right side of the heart with progressive PAH
- Answer the question, “What are the types of PH?”
- Know what medications are available to treat PAH

Important Considerations
- The role of the right heart is to pump blood to the lungs so that the blood can be oxygenated.
- The segment of flow of blood from right heart to lungs and back to left heart is referred to as the “pulmonary circulation”
- Pulmonary hypertension (PH) = elevated pressure in the blood vessels of the lung “PH” can result from many different mechanisms:
  - Over-growth of cells lining the blood vessel wall resulting in progressive narrowing of the small blood vessels in the lungs. The right heart needs to pump harder to ‘squeeze’ the blood in to the lungs. (PAH – Group 1)
  - Problems in the left side of the heart causing high left heart pressures can be transmitted to the pulmonary circulation (PH – Group 2)
  - Lung conditions causing low oxygen can elevate pulmonary pressures (Group 3)
  - Chronic blood clots in the pulmonary blood vessels can raise pulmonary pressures (Group 4)
- The right heart catheterization is required to diagnose PAH.
- The right heart may eventually enlarge and sometimes start to fail if the pressures are not lowered.
- The main function of the PAH medications is to dilate the pulmonary arteries allowing more blood flow to the lungs.
- There are now 14 FDA medications to treat PAH affecting 3 different pathways: Endothelin, nitric oxide and prostacyclin.

Take-Away Messages
- PAH must be carefully distinguished from other forms of PH
- The diagnostic work up includes multiple tests including the right heart catheterization to make the diagnosis.
- The emergence of multitude of medications over the last decade has dramatically changed the way patients are treated with PAH and most patients are feeling better and living longer.
Preparing for Emergency Situations

Session Description
Advance planning can help avoid the stress of a health emergency. During this session, presenters will cover preparation for emergency situations and provide helpful strategies for responding to emergencies.

Overview
Recognizing a medical emergency:
- Any situation that is serious or life-threatening
- Any big change in condition, worsening breathlessness, chest pain, fainting/near fainting are usually an emergency until proven otherwise.
  - Examples include severe bleeding, loss or malfunction of central line, malfunctioning IV pump, or sudden worsening of PH symptoms, such as chest pain, increased shortness of breath, fainting/passing out and coughing up blood.
- When in doubt, call 9-1-1
- If time allows, best to go to the hospital connected with your PH center
  - Can be transferred after stabilized in the local Emergency Department

Preparing for an emergency
*Items to have available at all times*
- Emergency contact list
  - List of people you want notified in case of an emergency
  - Contact information for your PH physicians, nurses, specialty pharmacies, etc.
    - Have emergency providers contact your PH provider. Do not let important medicines be stopped.
    - Inform PH provider of ALL elective procedures not ordered by them.
    - Family members should be aware of your wishes in advance for certain situations (e.g. mechanical ventilation, CPR)
- lists of your medications and medication allergies—wallet, refrigerator, other
- list of medicines/supplies you need to bring with you to hospital/ER Advanced directives

Important Considerations
Education of nearby EMS/Hospitals. *EMS and ER staff may not be familiar with PH or your medications.* Give emergency providers clear/concise explanation of your diagnosis and situation. Be an advocate for yourself. Ask ER staff to contact your PH physician directly if they have questions.
- Wear a medical alert bracelet
- Know your infusion dose and keep a copy in writing as well
- Keep extra supplies and bring them to the hospital.
- If on a clinical trial:  
  - Bring medication with you
  - Notify research coordinator

Additional Resources
- www.PHAssociation.org/Patients/EmergencySituations
Preparing for Travel and Oxygen Use

Session Description
Patients with pulmonary hypertension (PH) need careful planning to have a wonderful travel experience. This session will explain how to prepare for travel in order to have a safe and uneventful trip. The presenters will review practical considerations as well as determining oxygen requirements for travel and how they can be met with various devices.

Learning Objectives
- List elements to include in your preparations for travel within and outside the country.
- Discuss planning for oxygen needs during travel, especially at altitude.

Overview
Discuss your travel plans with your PH team well in advance. Tell them where you want to go, what you plan to do and how long you plan to stay.

Specific Vacation Plans
- Write down travel questions and bring to your clinic visit
- Discuss your travel plans with your doctor. Are there certain activities that should be avoided?
- Request a letter from your doctor explaining your medical condition and need for specialty medications including infusion pumps, nebulizer devices and oxygen use during travel. You will need this to get your equipment through TSA.
- Ask for recommendations for PH centers or tertiary care hospitals close to your vacation spot or along your travel route. Check the "Find a Doctor" page on PHA's website.
- Plan activities to avoid fluid overload or dehydration, overexertion (standing in long lines or walking long distances in the airport) and rushing from place to place.
- Plan for a stroller or wheelchair with ample cargo space to manage your equipment.
- Be able to trouble shoot all of your equipment or travel with a capable, trained companion.

Oxygen Needs
The FAA has approved several POCs (Portable Oxygen Concentrators) for in-flight use for passengers requiring oxygen:

- Inogen One, AirSep Lifestyle and AirSep Freestyle, SeQual Eclipse, Respironics EverGo
- Often your oxygen prescription may be different during air travel than when "on the ground." Please verify exactly what your doctor recommends prior to travel. Should you have a HAST?
- Many airlines have their own specific medical form for your Doctor to fill out
  - Remember to allow ample time for form completion turn around – give minimum two week notice
  - Be sure to have accurate information for the airline to contact your doctor easily

Traveling with oxygen usually incurs an additional expense for each leg of air travel even if you are bringing a POC with you.

If you are on BiPAP or CPAP, you should bring your machine and associated supplies with you in your carry-on luggage.
Reproductive Health and PH

Session Description
The goal of this session is to discuss the importance of reproductive health issues in pulmonary hypertension (PH), including recommendations for pregnancy prevention, routine well-woman health care, gynecological procedures, etc. A panel of PH experts and an OB/GYN specialist will discuss important issues regarding reproductive health for women with PH. PH patients are strongly advised to avoid pregnancy, so this session will also focus on various birth control methods available to women with PH. The session is meant to be interactive so bring your questions!

Learning Objectives
Attendees will be able to:

- Identify the need to attend to reproductive health needs after diagnosis of PH
  - A diagnosis of a chronic illness frequently focuses attention on only that health need often resulting in neglect of other health concerns. To be discussed:
    - Routine well woman health care in PH
    - Common gynecological concerns in PH – bleeding, diagnostic procedures, etc.
    - Menopause symptom treatment

- Describe pros and cons of several popular methods of pregnancy prevention
  - Pregnancy prevention is vital to PH care. To be discussed:
    - Types of pregnancy prevention
    - Interactions of PH medications with contraceptives
    - Importance of discussing these issues with your whole health care team (PH physician and primary care / women’s health care provider)

Additional Resources
- http://www.womenshealth.gov
- http://www.acog.org/For_Patients
Surgery and Anesthesia in PH Patients

Session Description
The purpose of the discussion will be to review the potential risks of anesthesia and surgical procedures in patients with pulmonary hypertension (PH), define the various components of perioperative management, and adequately prepare for elective surgery in the event it is determined that the procedure is important for your health.

Learning Objectives
Attendees will be able to:

- Define the potential risks associated with anesthesia and surgery in patients with PH.
  - PH places a significant stress on the right-side of the heart which can worsen during or immediately after surgery resulting in heart failure or even death.
  - The medications given for anesthesia can lower blood pressure and create additional challenges for the right heart.
  - Blood loss and shifts in fluid can aggravate the situation further.
  - Patients with severe PH e.g. functional class III and IV, have the most difficulty tolerating anesthesia and surgery.

- Discuss with the medical team the plan for management before, during and after the surgical procedure.
  - There should be a clear goal of optimizing your treatment of the PH prior to elective surgery to minimize the risk.
  - Your medical team should work together with your surgeon and anesthesiologist to plan the best strategy to control your PH during and after the surgery.
  - Risks vary with the different types of anesthesia; therefore, the choice of anesthesia may be influenced by the severity of your PH.
  - For severe PH, particularly those on infusion PH therapy, the question must be asked: “Should the surgery be performed at a PH Center?”

- Prepare for surgery
  - Understand the instructions for your PH medications prior to and after surgery.
  - Bring your medications to the hospital.
  - After discussion with your doctor, discontinue blood thinners and/or use injections to bridge before and after surgery.
  - Have a plan for assistance if your recovery is prolonged.
  - Discuss a plan with your doctor and bring your Living Will to the hospital just in case you have major problems with your surgery.

Additional Resources

- www.phassociation.org/AskAPHSpecialist/GeneralAnesthesia
- www.phassociation.org/MedicalProfessionals/ConsensusStatements/ElectiveSurgery
The Teenage PH Patient

Session Description
The goal of this session is to discuss the specific needs of teenagers, including interpersonal issues, communication issues, transitions, changes, reproductive health and more.

Learning Objectives
Attendees will be able to:

- Demonstrate ways to empower adolescents and young adults to take responsibility for their own health and lifestyle
  - Key areas that adolescents should know prior to transition to adult care:
    - Diagnosis – symptoms, risks, diagnostic procedures
    - Medications – names, purpose, dosages, side effects, interactions with other medications
  - Encourage the adolescent patient to:
    - Make own medical appointments
    - Manage and prepare own medications
    - Know what regular tests are done and what their results mean
    - Know their insurance and associated obstacles of care and reimbursement
    - Interact with their pharmacy and order their own medications
    - Make their own medication schedule and work towards taking their medications without reminders
    - Self-report their medical history without help from parents

- Review special issues facing the adolescent patient
  - General health, nutrition, body image
  - There is no health without mental health: anxiety and depression in teenagers and their family members
  - Sexuality: pregnancy risks, contraception, physical involvement, STDs, medication side-effects
  - Risk taking behaviors: drugs, alcohol, smoking, violence: consequences and effects on health.
  - Lifestyle choices: healthy habits, school, employment, violence, travel
  - End-of-life issues

Additional Resources
- www.PHAssociation.org/Teens
Transitioning from Pediatric to Adult Care

Session Description
This program is designed to support teens and their families as they transition their care from a pediatric to an adult medical center. Discussion will include topics such as: understanding your diagnosis, managing your medications, planning for insurance changes, understanding reproductive health needs, and ensuring open communication with your healthcare providers.

Learning Objectives
Attendees will be able to:

- **Describe the difference between transition and transfer**
  - Transfer ≠ Transition
  - **Transition** is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult orientated health care systems.
  - **Transfer** defines an event or series of events through which adolescents and young adults move their care from a pediatric to an adult health care environment

- **Demonstrate ways to empower adolescents and young adults to take responsibility for their own health and lifestyle**
  - Key areas that your adolescent should know prior to transition to adult care:
    - Diagnosis – symptoms, risks, diagnostic procedures
    - Medications – names, purpose, dosages, side effects, interactions with other medications
    - End of life issues – advanced directives
  - Encourage the adolescent patient to:
    - Make own medical appointments
    - Manage and prepare own medications
    - Know what regular tests are done and what their results mean
    - Know their insurance and associated obstacles of care and reimbursement
    - Interact with their pharmacy and order their own medications
    - Make their own medication schedule and work towards taking their medications without reminders
    - Self-report their medical history without help from parents

- **Review special issues facing the adolescent patient**
  - Sexuality: pregnancy risks, contraception, physical involvement, STDs, medication side-effects
  - Drugs, alcohol, and smoking: consequences and effects on health
  - General health: nutrition, dental care
  - Lifestyle choices: appropriate activities, exercise, travel, school, sports, employment

Additional Resources
- [http://www.phassociation.org/Teens](http://www.phassociation.org/Teens)
Transplantation for PH

Session Description
The goal of this session is to discuss surgical and/or interventional therapies that may be performed in particular patients with pulmonary hypertension (PH). Therapies to be discussed will be atrial septostomy, pulmonary endarterectomy, lung transplantation and heart-lung transplantation. This session will specifically focus on the description of these procedures and how and when they are performed in patients with PH.

Learning Objectives
Attendees will be able to:

- Define atrial septostomy and describe when this procedure may be performed in PH patients
  - Atrial septostomy is a procedure in which a small hole is created between the upper two chambers of the heart (the atria). This procedure is considered in only a very limited number of patients with refractory or worsening PAH despite aggressive medical therapy. It is difficult to predict which patients will benefit and which will deteriorate after this therapy. It is used many times as a bridge to lung or heart lung transplantation. This procedure should be performed only by centers with experience in this method.

- Define pulmonary thromboendarterectomy and describe when this procedure may be performed in PH patients
  - Pulmonary thromboendarterectomy is the surgical procedure of choice for patients with Group 4 PH [chronic thromboembolic pulmonary hypertension (CTEPH)]. The decision to proceed with this operation is based on strict criteria based on an extensive evaluation. This procedure is best done at a center of excellence with surgeons experienced in this field.

- Describe lung and heart lung transplantation, and when these procedures may be performed in PH patients
  - Transplantation is performed in patients with Group 1 PH (PAH) and is considered to be an effective treatment for selected patients who are refractory or have failed medical therapy. Bilateral lung or heart–lung transplantation are the types of procedures most often performed.

Additional Resources
- www.PHAssociation.org/Transplant
WHO Group 3 – Lung Diseases

Session Description
The goal of this session is to discuss how lung diseases are associated with pulmonary hypertension (PH). We will discuss how various forms of lung disease cause PH and how they should be evaluated and treated. We will also cover the use of devices in treating PH related to lung disease, including continuous positive airway pressure (CPAP) and supplemental oxygen.

Learning Objectives
Attendees will be able to:

- Define PH and describe the difference between pulmonary arterial hypertension (PAH) and PH related to lung disease
  - PH is defined as a mean pulmonary artery pressure ≥ 25 mmHg.
  - PAH is defined as a mean pulmonary artery pressure ≥ 25 mmHg with a pulmonary capillary wedge pressure ≤ 15 mmHg in the absence of underlying left heart disease and lung disease.
- List the lung diseases commonly associated with PH and how they can cause PH
  - Lung diseases commonly associated with PH include:
    - COPD (chronic obstructive lung disease)
    - ILD (Interstitial lung disease)
    - OSA (Obstructive sleep apnea)
    - Chronic thromboembolic disease (chronic pulmonary embolism)
  - Lung diseases typically cause PH through a combination of damage to the lung tissue and low oxygen levels.
    - Lung tissue damage can affect the surrounding blood vessels, leading to narrowing of these vessels and PH.
    - Low oxygen levels cause the pulmonary vessels to constrict. This leads to increased pressure in the lungs and worsens PH.
- Describe the proper evaluation of patients with lung disease who may have PH
  - Patients with suspected PH should undergo specific tests to evaluate for underlying lung diseases. These tests include:
    - Full pulmonary function tests
    - High resolution computed tomography (CT) of the chest
    - Ventilation-perfusion scan of the lungs
    - Overnight oximetry or sleep study where indicated
- Explain treatment options for PH related to lung disease
  - Except for chronic thromboembolic disease related PH, there are no FDA approved therapies for PH related to lung disease
  - Use of supplemental oxygen may improve pulmonary pressures and PH
  - Optimal Treatment of underlying lung diseases may improve overall symptoms and PH, especially for OSA

Additional Resources
- www.PHAClassroom.org
- www.PHAssociation.org/SleepApnea
WHO Group 4 – Chronic Thromboembolic Pulmonary Hypertension

Session Description

Chronic thromboembolic pulmonary hypertension (CTEPH) is a serious complication of a common disorder, venous thromboembolism. CTEPH and pulmonary arterial hypertension (PAH) share many similarities and yet critical differences including the potential for a curative surgery in the case of CTEPH. This session will review diagnostic considerations and the latest treatment options for CTEPH.

Learning Objectives: at the conclusion of the session attendees will be able to:

- **Describe what causes CTEPH and describe how this differs from PAH**
  - PAH is a narrowing of the smaller, more down-stream pulmonary arteries
  - CTEPH is caused by chronic blood clots that scar over instead of being dissolved in the more central or larger pulmonary arteries.
  - In most patients the body has a system to dissolve clots but in a minority (1-4%) they cannot be dissolved and remain and form scars in the pulmonary arteries resulting in PH.
  - Not all patients with CTEPH have had a previous diagnosis of an acute blood clot (about 40% do not!)
  - If left unaddressed these chronic clots can cause right heart failure and in some cause changes in the smaller vessels resulting in PAH

- **Describe how CTEPH is diagnosed**
  - All patients with unexplained PH should be screened for CTEPH
  - Screening is best done with a ventilation-perfusion (V/Q) scan.
  - If the V/Q scan is abnormal, further imaging is needed (CT scan, pulmonary angiogram, MRA) to confirm the presence of clots.

- **List treatment options for CTEPH**
  - Surgery is the recommended treatment of choice for CTEPH and is potentially curative!
    - The surgery is called a pulmonary endarterectomy (PEA), or pulmonary thromboendarterectomy (PTE).
    - Centers with expertise in surgery for CTEPH should be consulted to assist in determining surgical candidacy
    - Surgery is best performed early in the diagnosis rather than waiting until pulmonary hypertension is severe
  - Medical therapy should be reserved for patients who are not candidates for surgery or in those with persistent PH after surgery (about 5-10% of patients after PEA).
  - Riociguat (Adempas®) is the only FDA approved medical therapy for the treatment of CTEPH and again is used only after failed surgery or in those who are not candidates to undergo the surgery.
Up to 15% of people living with scleroderma may be diagnosed with pulmonary arterial hypertension (PAH)\(^1\)

An online resource designed for people living with PAH

InsightsOnPAH.com

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

Pulmonary hypertension puts unbearable stress on the heart. We’re putting our heart into finding a cure.

Pulmonary hypertension (PH) narrows arteries in the lungs. This puts pressure on the right side of the heart as it works extra hard to push blood through those arteries. It can cause death from heart failure, and there’s no cure. At first glance, PH can look like asthma or other less threatening diseases. And undiagnosed and untreated, the average survival time with PH is 2.8 years. But with early diagnosis, new treatments are extending life expectancy and improving PH patients’ quality of life. The Pulmonary Hypertension Association, PHA for family members and medical professionals through support, education, research and until we find a cure. Learn how you can help at www.PHAssociation.org