

PHacing the Future Together



VOICE **YOUR POWER**

In the fight against Pulmonary Arterial Hypertension (PAH), your voice matters. Stop by booth 101 to be part of our audio-video experience and learn how tracking your PAH status can help you speak out.



Download the Care4Today® app and enter code PAH to unlock tracking tools, articles, and more.

Dear Friends,

Welcome to the PHA 2022 International PH Conference and Scientific Sessions. No matter how you've chosen to attend, we are so thrilled to welcome you back to Conference!

Historically, Conference has not only been a time of learning but a priceless time of connection and relationship building. We often describe Conference as a giant family reunion, as we connect with old PHriends across the globe and welcome new ones into our community with open arms.

Due to COVID-19, many of us have had to navigate the last few years in relative physical isolation. Support groups, PHA On the Road, fundraisers and even the PH Professional Network Symposium have had to meet in new and creative digital ways. While it has felt lonely at times, we have never been truly alone. PHA and our community have been there every step of the way, and I am so proud of how we continue to rally around one another, no matter what difficult situations surround us.

The theme of Conference, "PHacing the Future Together," encapsulates not only where we are headed – in what will hopefully someday soon be a post-pandemic world – but also the spirit of who we are as a rare disease community. We may be a relatively small group but together we are truly impactful.

Personally, I am watching ongoing clinical trials with great excitement, as for the first time in a while, we are hoping to see some truly breakthrough therapies become available. I'm also looking forward to getting back to in-person fundraising events and helping to support all PHA does. I can't wait to get back to my state capitol and to Washington D.C. to continue the in-person work of making our voices heard where policy is made.

However you choose to participate in this PH life, we do this together. Just as we always have. **Enjoy Conference!**

Warmly,



Colleen Brunette

Colleen Brunetti

Chair, PHA Board of Trustees

On behalf of the entire PHA 2022 Conference Planning Committee, it is our great pleasure to welcome you to Atlanta for "PHacing the Future Together," PHA's International PH Conference and Scientific Sessions.

Atlanta is home to the Braves, Coca-Cola, the Georgia Aquarium, and from June 10-12, home to the world's largest gathering of people with pulmonary hypertension, families, caregivers and medical professionals.

This year is unique in that we have been planning two conferences simultaneously – one to meet in person, in the best-case scenario; and a second to meet virtually, should we need to do so as a safety precaution during the pandemic. Our hope is that you are reading this letter in Atlanta, in the PHA 2022 program book.

The Conference 2022 Planning Committee has been dedicated to planning an event that has something to offer all attendees. We have implemented some changes to allow for more networking and socializing among attendees, as well as some "down time" to catch your breath if you are a PH patient. Breakout Sessions will focus on education related to disease state, diagnosis and treatments aimed at helping people with PH and caregivers develop the skills needed to cope and improve quality of life. Several sessions will also address the impact COVID-19 is having on the PH Community. Scientific Sessions specifically for health care professionals (but open for patients and caregivers to attend) will explore a "Vision for the PHuture: The Evolving Science and Management of PH."

We are grateful for the hard work, dedication and enthusiasm of the numerous volunteers and PHA staff who made PHA 2022 possible. We would also like to extend a very special thank you to all our sponsors who generously support this event and to our donors who help fund the scholarships that enabled many patients to attend.

We would also like to extend our gratitude and best wishes to the entire PH community for coming together and supporting each other during PHA 2022. Each attendee should take the opportunity to network with others from all aspects of the PH community. Please be an active participant, reach out to others, ask questions, and share your stories and skills. By networking with others, you will truly be "PHacing the Future Together."

Sincerely, Your PHA 2022 co-chairs



Rita Orth, R.N. Conference co-chair



Traci Stewart, R.N., M.S.N., CHFN **Conference co-chair**



Doug Taylor **Conference co-chair**

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PHA 2022 Committees

Conference Planning Committee

Doug Taylor (co-chair), adult with PH, PHA Board of Trustees member, PHA support group leader *Rita Orth*, R.N. (co-chair), adult with PH, PHA support group leader

Traci Stewart, R.N., M.S.N., CHFN (co-chair), PHA Board of Trustees member, PH Professional Network (PHPN) member

Evan Brittain, M.D., PH treating cardiologist and researcher

Nicole M. Creech, adult with PH, PHA Board of Trustees member

Michelle Liu, M.D., M.P.H., FAAOA, parent of child with PH, PHA Board of Trustees member, PHA support group leader

Diane Ramirez, adult with PH, PHA Board of Trustees member, PHA support group leader Nesha Ridings, C.M.A., PH therapy access coordinator, PHA support group leader

PHA Scientific Sessions

Evan Brittain, M.D. (chair)
Teresa De Marco, M.D.
Erin Ely, R.N.
Rebeca Greene, PharmD
Jeff Min, M.D., MSCE
Regina D. Overton-Barnes, MSN-FNP
Kurt W. Prins, M.D., Ph.D.
Michael Risbano, M.D.
Nidhy Varghese, M.D., FAAP

Scholarship Committee

This confidential committee is comprised of PH patients, caregivers, and parents of pediatric PH patients from across the United States.

Awards Committee

PHA Board of Trustees member,
PHA support group leader
Paul Finelt, spouse to an adult with PH
Frances Rogers, M.S.N., CRNP, PHA Board
of Trustees member, PH Professional
Network (PHPN) member
Oksana Shlobin, M.D., Scientific Leadership
Council member
Kelly Wiegle, parent of a child with PH

Welcome Committee

Nesha Ridings, C.M.A., (chair),
PH therapy access coordinator,
PHA support group leader
Linda Santos Morgan,
PHA support group leader
Marcie McGregor, PHA support group
leader, PHA Support Group Leader
Advisory Board
Mindy Brown, PHA support group leader
Davina Taylor, M.Ed., PH patient
Sheila Greene, M.S.A., R.R.T.

Newcomers Guide: Making the Most of Your PHA 2022 Conference Experience

Thank you for attending PHA 2022! PHA is excited to welcome you to Atlanta to learn about PH and make new friends with others on their PH journey. There are many opportunities at PHA 2022, and you can experience them in whatever way is best for you. Whether you choose to do a little or a lot, we hope this guide will help make your PHA 2022 experience a wonderful one.

Getting the Most Out of Conference

PHA collected advice from long-time Conference-goers. This is what patients who frequently attend PHA conferences suggest:

- Pace yourself. There's a lot to do at Conference, and it's easy to over-do it and lose energy. Rest and take breaks when needed. Take advantage of the wheelchair service when you need to conserve your energy.
- **Divide and conquer.** There's a lot to learn at Conference and some educational sessions overlap. If you attend Conference with a caregiver, loved one or someone else, you can each attend different sessions and take notes so you can learn as much as possible.
- **Pre-plan your day.** The Conference agenda is packed with great things to do. Don't spend time during your day planning your schedule. If possible, plan your day the night before or even before you arrive at Conference.
- Connect, connect! Don't hesitate to strike up a conversation with a stranger at a meal, in a support group, in the exhibit hall or just in a hallway. Ribbons and other "bling" can help you identify attendees with similar experiences as yours. The Saturday Night Party and other social events provide an opportunity to make new friendships that last beyond Conference.
- PHA continues after Conference. Stay connected with the PHA community after Conference. You can attend other PHA programs, follow PHA on social media, share your story or volunteer for their fantastic programs. Stay involved in a way that works best for you.

Conference Activities

- **General sessions** are open to all Conference attendees. Sessions often take place around meals and include a speaker and fun networking time.
- Breakout sessions are educational sessions with a focus on medical and lifestyle topics.
 Attendees will learn from a panel of speakers that include expert PH health care professionals,

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people living with PH and their loved ones. Several breakout sessions are scheduled at once. Attendees choose the session in each time slot they are most interested in.

- **Support groups** are a great way to connect with people who share similar experiences to yours from across the country. For example, there may be a support group for individuals who are newly diagnosed or those using a particular type of PH therapy. Depending on your interest, you can find a group of engaged people who are willing to listen and provide support.
- **Research Room** gives you an opportunity to contribute to vital PH research by participating in a study.
- The **skill building workshop** is a great way to learn about how you can get involved with PHA after Conference.
- The **Kids Room** is open to all children and teens ages 3 to 17 attending Conference. The space is hosted by a professional child care company and includes games and activities for all ages. This is a great opportunity for children and teens who are impacted by PH to meet and connect.
- The Exhibit Hall is a great place to chat with and learn from a variety of exhibitors with products and resources for the PH community. Meet with pharmaceutical companies, specialty pharmacies, associated disease organizations and more.

Navigating Conference

Program book and app. Information about PHA 2022 sessions and activities are available in this program book and via the PHA 2022 app which can be downloaded from the Apple Store or Google Play store.

Conference volunteers and PHA staff. If you get lost, need help finding something or have a question, find a volunteer or PHA staff member.

Wheelchair service. With so many people attending, the PHA 2022 space is large. Volunteers are available to provide wheelchair service from one session to another so that you can conserve your energy over the course of the event.

The **Patient Rest Stop** is a dedicated space for patients to take a rest and store their oxygen. The Patient Rest Stop is not supervised, and items are left at your own risk.

> This Newcomers Guide is brought to you by Accredo.

Navigating Pulmonary Hypertension:

A Guide for **Newly Diagnosed Patients** NAVIGATING PULMONARY HYPERTENSION



ORDER A FREE COPY NOW

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- PHAssociation.org/NavigatingPH
- Support@PHAssociation.org



A Guide for

Newly Diagnosed

General Information

PHA Resource Center

Welcome to PHA 2022!



Visit us at Booth #213 to:

Pick up your PHA 2022 T-shirt

Learn about **PHA** member benefits

Find out about PHA-accredited **PH Care Centers**

- Get information about the PHA Registry
- Connect with staff and attendees
- Take part in advocacy efforts
- Get your questions answered

PHA 2022 General Information

Conference Check-in and On-site Registration



Grand Hall Foyer (Exhibit level)

Hours

Thursday, June 9 3–9 p.m. Friday, June 10 7 a.m.–7 p.m. Saturday, June 11 7:30 a.m.-noon

If you arrive after noon on Saturday, you can check in at the PHA Resource Center located in the Exhibit Hall.

Exhibit Hall Grand Hall West (Exhibit level)

Hours

Thursday, June 9 6:30-9 p.m.

Friday, June 10 8 a.m.–12:45 p.m.

2-6:30 p.m.

Saturday, June 11 9 a.m. -11:45 a.m.

1-5:45 p.m.

Continue your learning experience in the Exhibit Hall. Be sure to visit our exhibitors and the PHA Resource Center Thursday

through Saturday!

Poster Hall Regency 7 (Ballroom Level)

Hours

Thursday, June 9 4–9 p.m.

(Unopposed poster viewing and discussion – PHA

Scientific Sessions attendees only)

Friday, June 10 8 a.m.-5:45 p.m. Saturday, June 11 9 a.m.–noon

(Open to all registered attendees)

The Poster Hall features research abstracts and case studies presented by medical professionals in the field.

Research Room

Courtland & Dunwoody (Atlanta Conference level)

Hours

Thursday, June 9 3-6:30 p.m. Friday, June 10 9 a.m.-noon

2-6 p.m.

Saturday, June 11 9 a.m.-noon

2–6 p.m.



Every PHA International PH Conference includes a Research Room dedicated to helping researchers further their studies by allowing the collection of data from the largest gathering of PH patients in the world. Participation from all interested attendees – including patients, caregivers, family members and health care professionals – is vital to PH research. 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 difference.

PHA Resource Center

Exhibit Hall – Grand Hall West (Exhibit level)

Hours

Thursday, June 9 6:30-9 p.m. Friday, June 10

8 a.m.-12:45 p.m. 2-6:30 p.m.

Saturday, June 11 9-11:45 a.m.

1-5:45 p.m.

Come learn more about PHA. Volunteers and staff will be available to share information about our mission and ways you can get involved. Don't forget to pick up your Conference t-shirt and the latest PHA resources.

Patient Rest Stop

Chicago AB (Exhibit Level)

Hours

Wednesday, June 8, at 5 p.m. to Sunday, June 12, at noon.

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 (oxygen storage is at the patient's own risk - PHA will not provide security or locked storage). The Patient Rest Stop will be equipped with ice packs, distilled water and seating.

Art Gallery



Hours

Saturday, June 11

8 a.m.–6 p.m.

PHA will showcase the creative talent of our community while raising money to sustain our mission to extend and improve the lives of those affected by PH. Gallery tickets will be sold Saturday only! Winners of Saturday's drawing will be announced at the Closing Breakfast and on the Conference mobile app Sunday morning. Drawing winners may pick up their artwork on Sunday, June 12, 10:45 a.m. to 12:30 p.m. at the Art Gallery.

Memorial and Hope Wall

Centennial Ballroom Foyer (Ballroom level)

The Welcome Committee invites you to honor your loved ones who have passed away, or to share words and expressions of your hope for this community, on paper cutouts found outside the ballroom, the Welcome Table and at the Patient Rest Stop. Cutouts will be placed by volunteers on the craft boards outside the ballroom.

Refreshment Breaks

Grand Hall (Exhibit level)

Refreshment breaks will be served throughout Conference in Grand Hall.

Refrigerators/Freezers

All hotel rooms at the Hyatt Regency Atlanta contain in-room refrigerators. A limited number of freezers (that were requested during the hotel reservation process) are available to patients for medicine storage only. If you have any questions, please visit the front desk.

Special Meal Requests

If you requested special dietary meals during the registration process, you will find meal tickets in your badge holder. Please present these meal tickets to your server at the start of the corresponding meal. Please go to the registration booth at Conference if you do not have your meal tickets.

Heart Racers (Wheelchair Assistance)



Please use this free wheelchair service for transportation between sessions in the Centennial Ballroom Foyer on the Ballroom level. Volunteers will help to propel the chair and return it to the wheelchair corral in the foyer area after you arrive at your session. These wheelchairs are not to be personally claimed by attendees throughout the entire Conference, but are for use between sessions. Ask a Conference volunteer or PHA staff member for assistance.

Photography/Filming

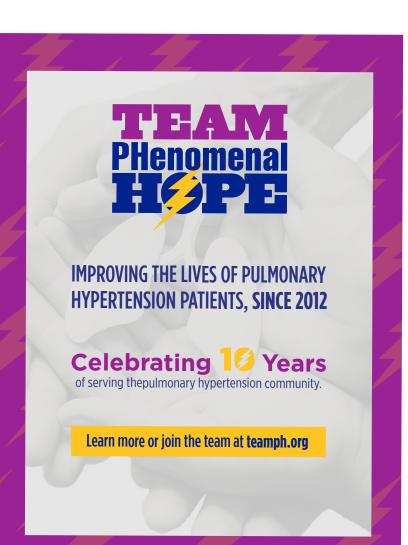
A film crew will be taping throughout Conference and conducting interviews with Conference attendees. Footage recorded will be used to capture the spirit of PHA's International PH Conference.

For those who do not wish to be filmed or photographed, please be sure to ask for (and wear) a red name badge holder at registration.

Medical Emergencies

If you are experiencing a lifethreatening medical emergency, please call 911.

If you are in distress, but it is not an emergency, please contact your home PH physician for help. PHA staff cannot offer triage services or medical advice. If you need medical supplies, prescription medication or oxygen, please contact your physician, specialty pharmacy or oxygen carrier. PHA is unable to help. For additional information, see the Guide to Local Medical Resources on Page 15.





Download the PHA 2022 Conference App

Co-sponsored by Insmed and Liquidia

Download the PHA mobile app for the most updated agenda, speaker and session information, electronic handouts and more. Turn app notifications on to receive live updates! To find the app, search for "PHA" in Apple's App Store or Google Play to download.



PHA Scientific Sessions

International Ballroom

PHA Scientific Sessions are designed for health care professionals who work in the PH field. If space allows, patients and caregivers may sit in on these sessions, however we encourage patients and caregivers to attend the patient-focused sessions which will be taking place at the same time.

Scholarships

Thanks to many generous donors PHA's scholarship program was able to honor all those who were awarded scholarships in 2020 and provided financial support for 90 adult patients and caregivers, 20 child patients and parents, 37 peer support volunteers and 41 international patients and caregivers.

Conference T-shirts

PHA Resource Center, Exhibit Hall – Grand Hall West (Exhibit level) Co-sponsored by Insmed, CVS Specialty and Synergen Rx

Please take the voucher in your badge holder to the PHA Resource Center to redeem your free t-shirt, which will be available for pickup during Exhibit Hall hours.

Chair Yoga

Rosewell (Atlanta Conference Level)
Sponsored by Accredo



Hours

Friday, June 10 7–8 a.m. Saturday, June 11 7–8 a.m. Sunday, June 12 7–8 a.m.

PHA is happy to offer chair yoga for all attendees throughout Conference. The sessions offered will be geared for everyone regardless of age or ability. Each session will include breathing techniques to enhance lung function, yoga poses for anyone and relaxation techniques. Sessions will also 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: these sessions are expected to be full.

SPHA 2022

Outstanding Member Awards **Dinner**



Saturday, June 11 | 6-7 p.m. Centennial Ballroom

Join us in recognizing award winners for:

- Outstanding Physician
- Outstanding Allied Health Professional
- Outstanding PH Citizen
- Outstanding Young PH Citizen
- Outstanding Caregiver
- Outstanding PHA Support Group Leader
- Julie Hendry Memorial Scholarship Award



General Information Guide to Local Medical Resources

Conference Evaluation

PHA Resource Center, Exhibit Hall – Grand Hall West (Exhibit level)

Your opinion matters! Let us know about your experience at Conference and how PHA can make future events better. The PHA Conference Evaluation will be available in the Conference mobile app. For those who prefer a paper version, a limited number of evaluation forms will be available at the PHA Resource Center during Conference.

Conference Activities for Kids, Tweens and Teens

Ages 3-7 Executive Conference Suite 222 (Atlanta Conference Level)
Ages 8-12 Executive Conference Suite 226 (Atlanta Conference Level)
Ages 13-17 Executive Conference Suite 223 (Atlanta Conference Level)



The Kids Room will focus on providing an engaging and entertaining experience for all age ranges through fun interactive activities. Stop by the Kids Room for the full Kids Room schedule.

The Kids Rooms will be open Friday and Saturday during PHA 2022, for children ages 3-17 (no diapers please). Children 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 for each child care required. Children must be registered to participate in the field trip to the Georgia Aquarium.

The Kids Room is managed by Elegant Event Sitters Inc. (eleganteventsitters.com). All Kids Room staff are required to be vaccinated for COVID-19 and wear masks.

Kids Room Hours

Friday, June 10

12:30–7 p.m. Kids Room Open

2–6 p.m. Field Trip to the Georgia Aquarium

Saturday, June 11

8:45–11:45 a.m. Kids Room Open (closed for lunch 11:45 a.m.–1 p.m.)

1–5:45 p.m. Kids Room Open

Guide to Local Medical Resources

This guide to local medical resources in Atlanta offers information that you may find useful during your time at PHA 2022.

Disclaimer: PHA is providing this resource and listing of medical facilities as a convenience to PHA 2022 attendees. PHA does not represent these facilities and can't confirm the facilities listed in this document will accept your specific insurance. Please contact the facilities listed in this document directly if you have any insurance coverage questions.

What to Do in Case of a Medical Emergency



Adult Patients

Direct the ambulance to take you to Emory University Midtown Hospital (550 Peachtree Street NE, Atlanta). It is the closest hospital to the Conference Hotel (Hyatt Regency Atlanta). If you need to be admitted, you may be transferred to the PHA-accredited PH Care Center in Atlanta, Georgia at Northside Hospital (bit.ly/Northside-Hospital).

Pediatric Patients

Direct the ambulance to take you to Children's Healthcare of Atlanta, Emory Children's Center (2015 Uppergate Drive NE, Atlanta). It is the closest children's hospital to the Conference Hotel (Hyatt Regency Atlanta).

Consider completing and printing the Empowered Patient Toolkit (bit.ly/EmpoweredPatient) prior to traveling to Conference. Keep this with you at all times during PHA 2022 in case of an emergency.

After you call 911, contact your home PH doctor using the instructions your home PH health care team has given you. Though there may be many medical professionals at Conference, your home PH health care team knows you and your situation best. Involving your PH health care team will help local medical providers better care for you if you need medical assistance at Conference.

What to Do If You Are Not Feeling Well (Not an Emergency)

If you don't feel well but you don't know whether it's an emergency, approach the situation the same as you would when travelling outside of PHA Conference. Contact your home PH team using the phone numbers they gave you. If you are experiencing COVID-19 like symptoms, please take a COVID-19 test and quarantine. If the test is positive or think that you have tested positive, please follow quarantine guidelines and seek immediate medical attention. In addition, please notify your emergency contacts and PHA Staff member, Pat Reilly, at (240) 485-3803.

If your PH team didn't give you a phone number, if you can't remember your PH team's phone number or if you start to feel worse, it is always better to dial 911.

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Guide to Local Medical Resources

Guide to Local Medical Resources

Empowered Patient Toolkit

PHA's Empowered Patient Toolkit was designed by experienced PH patients and health care professionals to help you organize your own PH medical information through several worksheets and resources. The toolkit is available on the PHA website at bit.ly/EmpoweredPatient.

Before coming to Conference, you should consider completing the following components of the Empowered Patient Toolkit and keep it with you at all times during Conference in case of an emergency. These documents will help emergency medical technicians (EMTs), hospital personnel and other health care professionals who might assist you in an emergency.

- Patient Medical Summary: Use this document to track your personal information and emergency contacts and include a brief summary of your most important medication and medical information. Include any critical health information at the top of the sheet, including, "Do not stop pump," "On sildenafil No nitrates" and/or "Takes Coumadin."
- **Medication Log:** Use this log to record everything you take, both prescribed and over-the-counter medications. Medicines that you have recently stopped taking should remain on your list. Use multiple sheets if necessary. Your health care team may also be able to provide you with a list of your current medications.
- Medical Contact List: Compile a complete list of your doctors and health care providers, along with their specialties and contact information.

• Information worksheet for EMS and Emergency Department Professionals:

bit.ly/EMS-Information

In addition, PHA's Empowered Patient Toolkit contains several guides that might assist you as you plan your trip to Atlanta.

- Travel Checklist: Use this checklist to get organized whenever you are preparing for a new trip.
- Travel Contact List: Use this list to record the names and contact information of your local medical team, as well as emergency contacts at your destination location.
- Emergency 101 readiness checklist: bit.ly/Emergency-101
- Template Letters:
 - Flying with Medical Equipment: bit.ly/med-equipment
 - Permission to Fly with Oxygen: bit.ly/oxygen-permission
 - Permission to Cancel Flight: bit.ly/cancel-flight

Nearest Adult Hospital

Emory University Midtown Hospital 550 Peachtree Street NE Atlanta, GA 30308 (404) 686-4411

Nearest Pediatric Hospital

Children's Healthcare of Atlanta, Emory Children's Center 2015 Uppergate Drive Atlanta, GA 30322 (404) 785-9400

Nearest PH Care Center (Non-Emergencies)

The Pulmonary Hypertension Program at Northside Hospital/Pulmonary and Critical Care of Atlanta 960 Johnson Ferry Road., Suite 500 Atlanta, GA 30342 (404) 257-0006

Nearest Urgent Care Facility

Piedmont Urgent Care 882 Ponce De Leon Ave. NE Atlanta, GA 30306 (770) 809-3034 Monday–Sunday: 7 a.m.–7 p.m.

Local Oxygen Contacts

• MediSource Main Office: (770) 528-9559

• Lincare

Marietta: (770) 425-1229

• Apria

Forest Park: (404) 479-4922

Local Pharmacies

CVS/Pharmacy 235 Peachtree Street NE Atlanta, GA 30303 Phone: (404) 577-4054 Distance: 0.2 mi NE

Store Hours:

Monday-Sunday: 7 a.m.-Midnight

Pharmacy Hours:

Monday-Friday: 9 a.m.-7 p.m.; Saturday

and Sunday: Closed

Walgreens 25 Peachtree St SE, Atlanta, GA 30303 Phone: (404) 260-1038 Distance: 0.6 mi Store Hours:

Monday-Sunday: 8 a.m.-10 p.m.

Pharmacy Hours:

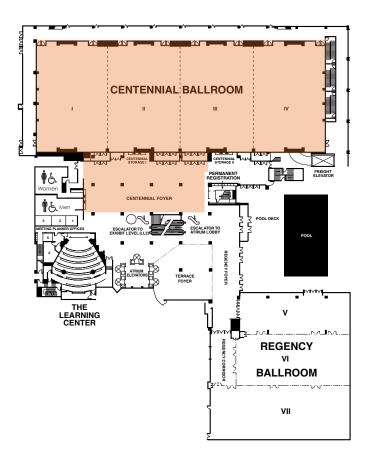
 $Monday-Sunday: 7 \ a.m.-10 \ p.m.$

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Floor Plans Floor Plans

Hotel Floor Plans

Ballroom Level



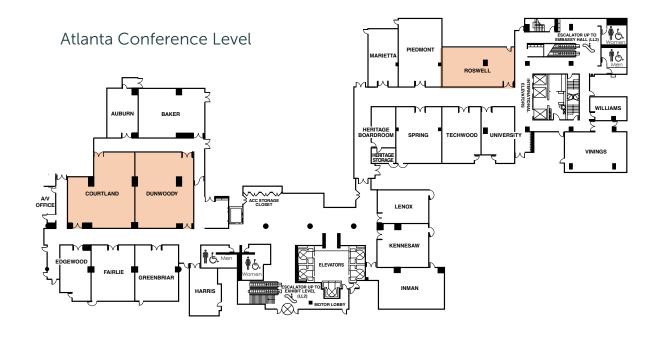
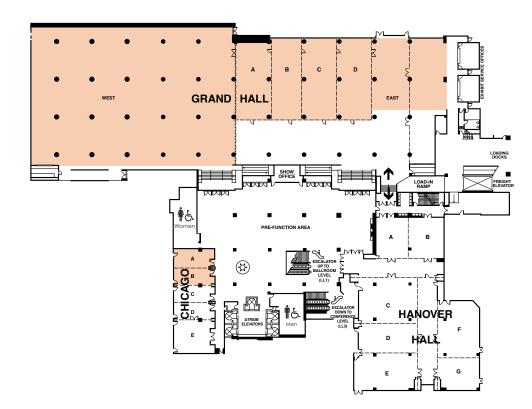
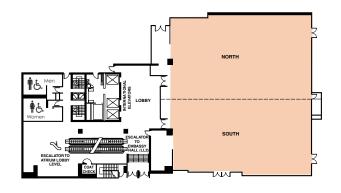


Exhibit level



International Ballroom



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Floor Plans Schedule at a Glance

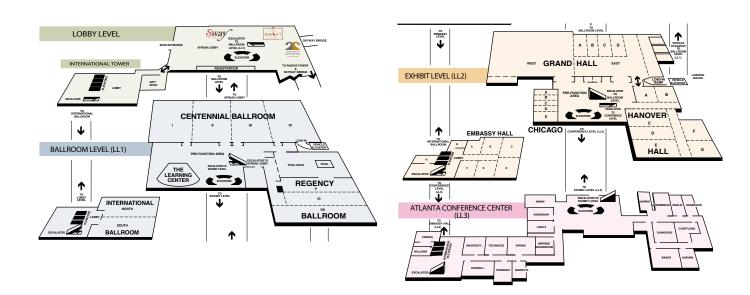
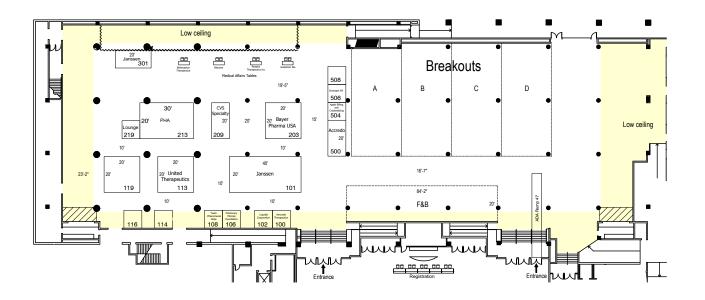


Exhibit Hall



Schedule at a Glance

	Thursday June 9, 2022	
3–9 p.m.	Registration Open	Grand Hall Foyer
3-6:30 p.m.	Research Room Open	Courtland/Dunwoody
3–4 p.m.	Industry Sponsored Session (CVS Specialty)	Regency 6
4–7 p.m.	Poster Hall Session and Lightning Round Presentations	Regency 6
5:30-6:30 p.m.	Peer Support Networking Hour	Regency 5
6:30-9 p.m.	Exhibit Hall Open	Grand Hall West
6:30-7:30 p.m.	Exhibit Hall Opening Reception	Grand Hall West
7:30-9:30 p.m.	PH Professional Network Reception	Regency 5

	Friday June 10, 2022	
7–8 a.m.	Chair Yoga	Rosewell
7 a.m.–7 p.m.	Registration Open	Grand Hall Foyer
7:15 a.m.–12:30 p.m.	Scientific Sessions	International Ballroom
8–9 a.m.	Volunteer Appreciation Breakfast (by invitation only)	Hanover FG
8 a.m12:45 p.m.	Exhibit Hall Open	Grand Hall West
8 a.m12:45 p.m.	Poster Hall	Regency 7
9 a.mnoon	Research Room Open	Courtland/Dunwoody
10:30-11:30 a.m.	Industry Sponsored Session: The Echo in PAH: State of the Art in Right Heart Monitoring (PAH Initiative, United Therapeutics Corporation)	Hanover FG
Noon-1 p.m.	Conference Countdown Lunch	Centennial Ballroom
12:30 p.m7 p.m.	Kids Room Open	Executive Conference Suites 222, 223, 226
1–2 p.m.	Conference Opening General Session	Centennial Ballroom

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2–6 p.m.	Research Room Open	Courtland/Dunwoody
2-6:30 p.m.	Exhibit Hall Open	Grand Hall West
2-6:30 p.m.	Poster Hall	Regency 7
2–5 p.m.	Scientific Sessions	International Ballroom
2:30-3:30 p.m.	Breakout Sessions	Grand Hall A, B, C, D
3:30-4 p.m.	Break	
4–5 p.m.	Breakout Sessions	Grand Hall A, B, C, D
5-5:30 p.m.	Break	
5:30-6:30 p.m.	Industry Sponsored Session: A Time for Hope in PAH: New Science, Potential New Therapies and the Patient's Role in Drug Development (Aerovate Therapeutics)	Hanover FG
5:30-6:30 p.m.	Industry Sponsored Session: Established Science and a Novel Potential Therapy: Targeting Serotonin for the Treatment of PAH (Altavant Sciences)	International Ballroom
5:30-6:30 p.m.	PHacing the Future Together Through Volunteering	Regency 5
7–8:30 p.m.	Medical Update Dinner	Centennial Ballroom
9–11 p.m.	PHA LGBTQIA+ "No-host" Social	Twenty-Two Storys Restaurant and Bar, Hyatt Regency Atlanta

	Saturday June 11, 2022	
7–8 a.m.	Chair Yoga	Rosewell
7:30 a.mnoon	Registration Open	Grand Hall Foyer
8–9 a.m.	Networking with a Medical Professional Breakfast	Centennial Ballroom
8 a.m6 p.m.	Art Gallery Open	Centennial Foyer
8:45-11:45 a.m.	Kids Room Open	Executive Conference Suites 222, 223, 226
9-9:30 a.m.	Break	
9–11:45 a.m.	Exhibit Hall Open	Grand Hall West



Fighting for breath together

In pulmonary arterial hypertension, or PAH, breathing is no longer as simple as it seems, and we don't take it for granted. The needs of people with PAH are at the forefront of what Respira does.



Become a part of the clinical trial

The VIPAH•PRN trial is looking at an investigational treatment* for people living with PAH



SCAN TO VISIT





For more information on the trial and who can participate, visit: www.vipah-prntrials.com

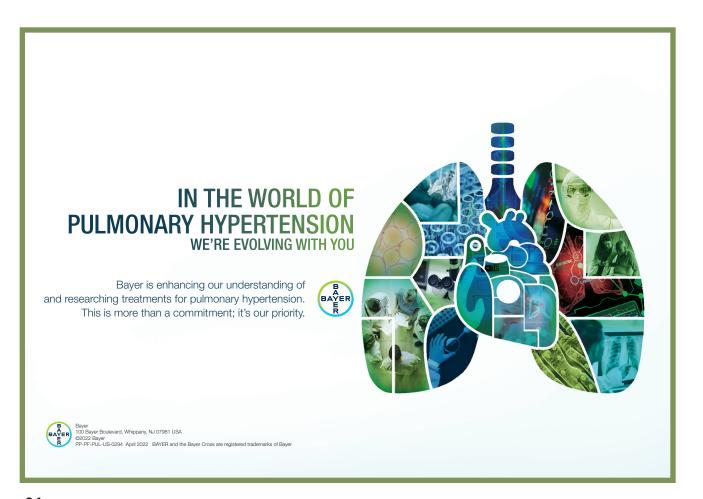


Or, join us at Respira's **Medical Affairs Table 2 Prefunction Area in front** of the Grand Hall West

^{*}The treatment that Respira is researching has not yet been FDA-approved for doctors to prescribe to people with PAH. The VIPAH•PRN trial is sponsored by the pharmaceutical company Respira Therapeutics, Inc. ClinicalTrials.gov Identifier: NCT04266197; RT234-PAH-CL202

Schedule at a Glance Schedule at a Glance

9-noon	Research Room Open	Courtland Dunwoody
9:00 a.mnoon	Poster Hall	Regency 7
9:30 a.mnoon	Scientific Sessions	International Ballroom
9:30-10:30 a.m.	Breakout Sessions	Grand Hall A, B, C, D
10:30-11 a.m.	Break	
11 a.mnoon	Breakout Sessions	Grand Hall A, B, C, D
Noon-1 p.m.	Journeys Lunch	Centennial Ballroom
1–2 p.m.	Industry Sponsored Session: Patient and HCP Perspective: A Conversation about Tracking and Self-Advocacy (Janssen)	Regency 5 and 6
1–5:45 p.m.	Exhibit Hall Open	Grand Hall West



1–5:45 p.m.	Kids Room Open	Executive Conference Suites 222, 223, 226
2-4:30 p.m.	Scientific Sessions	International Ballroom
2–6 p.m.	Research Room Open	Courtland/Dunwoody
2-3 p.m.	Breakouts Sessions	Grand Hall A, B, C, D
3-3:30 p.m.	Break	
3:30-4:30 p.m.	Support Group Meetings	Fairlie, Greenbriar, Kennesaw, Auburn, Spring, Innman, Piedmont, Baker, Edgewood, Lenox
4:30-4:45 p.m.	Break	
4:45–5:45 p.m.	Industry Sponsored Session: PHocusing on the Future: Precision Medicine, Emerging Treatment Pathways and New Molecules in Development for PAH (GossamerBio)	International Ballroom
6–7 p.m.	Awards Dinner	Centennial Ballroom
7–8:30 p.m.	Fashion Show and Saturday Night Party	Regency 5 and 6
9–11 p.m.	PHA International Attendee "No-host" Social	Twenty-Two Storys Restaurant and Bar, Hyatt Regency Atlanta

	Sunday June 12, 2022	
7–8 a.m.	Chair Yoga	Rosewell
9:30-10:30 a.m.	Closing Breakfast	Centennial Ballroom

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Session Tracks Session Tracks

Session Tracks

Living with PH



Breakout Sessions

- A Conversation for Men: Expressing Love, Desire and Affection with PH
- A Conversation for Women: Expressing Love, Desire and Affection with PH
- Get Moving: Exercise and Pulmonary Rehabilitation in PH
- Having a Career with PH
- PHacing the Future Together Through Volunteering
- Posting for PH: How to Make an Impact on Social Media
- Self-Advocacy: Get What You Need by Finding Your Voice
- Self-Care isn't Selfish: Tips for PH Patients

Support Groups

- Beginning your Journey: For people who are newly diagnosed, beginning their journey with PH or still finding their new normal
- Continuing your Journey: For people who are living with and thriving or enduring PH
- Group 1 Pump Therapy: For people with PAH to discuss pump therapy
- Men with PH: For men living with PH (patients only)
- PH and Associated Conditions: For people living with an associated condition such as scleroderma, lupus, sickle cell disease, HHT, COPD, sleep apnea, HIV, sarcoidosis

Treatments/Disease Management (§)



Breakout Sessions

- Improving Sleep Quality When You're Under Pressure
- Interventional and Surgical Therapies in Pulmonary Hypertension
- Returning to Care: Finding Normalcy After a Pandemic and Keeping the Best of What We Have Learned
- Understanding and Navigating Health
- When PH Patients Need Surgery

Pediatric Care



Breakout Sessions

- Parenting Your Child with Pulmonary Hypertension
- Pediatric PH: Types and Treatments
- The Gray Area: Navigating from Pediatric to Adult Care

Support Group

• Parents of Kids with PH: For parents of children with PH

Spanish



Breakout Sessions

- Entendiendo la hipertensión arterial pulmonar, desde su diagnóstico hasta su
- Abogando por el Paciente de HP: Perspectiva del Paciente y el Cuidador

Support Group

• Grupo de Hispanohablantes: Para las personas que hablan español

CTEPH



Breakout Session

• Group 4 PH: CTEPH - Overview and Treatments

Support Group

• Chronic Thromboembolic Pulmonary Hypertension (Group 4 – CTEPH): For people living with **CTEPH**

Caregiver



Breakout Session

• Caregivers Need Care Too

Support Group

• Caregivers: For anyone who loves and cares for someone with PH

Go Digital to Enhance Your PHA 2022 Experience





Download the PHA 2022 mobile app to:

- Check your agenda.
- Receive notifications of schedule changes.
- Conduct online chats with other attendees.
- Make new connections.
- See PHA 2022 social media posts.
- Learn about exhibitors and sponsors.

How to use:

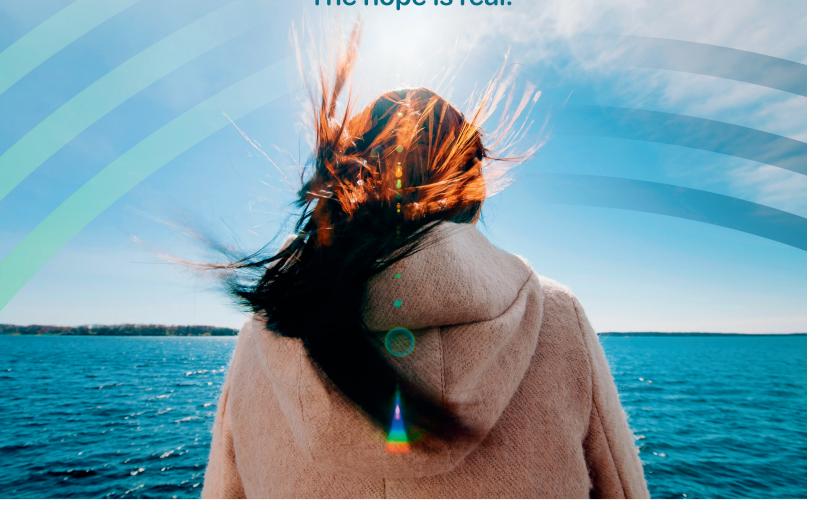
- 1. Go to the Apple App Store or Google Play.
- 2. Search for the "PHA" app.
- 3. Download the app on your mobile device.
- 4. Find the app on your screen and tap to open.
- 5. Login with the credentials you received in an email from the PHA 2022 events team.
- 6. Browse the agenda, find speakers and more!

Questions? Ask for help at the PHA 2022 registration desk.



We're aiming to take the wind out of PAH. And you're invited.

Find out more about the IMPAHCT Study today. The hope is real.



The IMPAHCT Study is looking at a potential new medication for pulmonary arterial hypertension (PAH).



Learn more about the study and if you or a loved one may qualify for the trial.

Scan QR code or visit **IMPAHCTSTUDY.COM**



Session Descriptions

- O General session
- Live Stream
- Living with PH
- **O** CTEPH

- Pediatric Care
- Treatments/Disease Management
- Spanish
- Caregiver

Thursday, June 9

Industry Sponsored Session (CVS Specialty)

Thursday, June 9, 3-4 p.m. Regency 6

Join us for an engaging session presented by CVS Specialty on a topic of great interest to the PH community. Patients and health care providers are encouraged to attend. Please visit the conference mobile app or website for session details.

Peer Support Networking Hour

Thursday, June 9, 5:30-6:30 p.m. Regency 5 (Ballroom level) (By invitation only)

PHA's vast network of peer support volunteers support group leaders, support line volunteers, email PHriends, Facebook group moderators and telephone support group facilitators - can meet for a rare chance to network with their fellow volunteers and get to know each other better.

Exhibit Hall Opening Reception

Sponsored by Liquidia

Thursday, June 9, 6:30-7:30 p.m. Grand Hall West (Exhibit level)

Come join PHA staff, sponsors and exhibitors for the first ever Exhibit Hall Opening Reception. This is your chance to get a head start on networking with peers and industry leaders. Stop by the exhibit booths to learn about new PH updates and innovations. All registered attendees are encouraged to attend, and light refreshments will be served.

PHPN Reception

Co-sponsored by Accredo, GossamerBio and

Thursday, June 9, 7:30-9:30 p.m. Regency 5 (Ballroom level)

This reception brings together members of the PH Professional Network (PHPN), nonphysician clinicians, nurses and other allied health professionals who care for patients with PH. Whether to meet new colleagues or to reconnect, this reception is a perfect way to begin your Conference journey. Come and celebrate outstanding members of the community and learn how to get more involved.

Friday, June 10

Volunteer Appreciation Breakfast

Co-sponsored by GossamerBio and Insmed

Friday, June 10, 8-9 a.m.

Hanover FG (Exhibit level) (By invitation only)

PHA has more than 450 volunteers who support our mission through Support Groups, the Patient Support Helpline, Special Events, mentoring and the PHriends program. This is a special way to say "thank you" to these amazing volunteers and celebrate their hard work and dedication to helping PHA move its mission forward.

Industry Sponsored Session: The Echo in PAH: State of the Art in Right Heart Monitoring

Sponsored by PAH Initiative, United Therapeutics Corporation

Speakers: Anjali Vaidya, M.D., FACC, FASE, FACP, Temple University Hospital and Lewis Katz School of Medicine, Temple University, Philadelphia, Pennsylvania; John Ryan, M.D., M.B., B.Ch., B.A.O., University of Utah Pulmonary Hypertension Center, Salt Lake City, Utah

Friday, June 10, 10:30-11:30 a.m. *Hanover FG (Exhibit level)*

Data shows that early identification of changes in right heart size and function are time-critical to making treatment decisions before a patient's condition worsens. Join Drs. John Ryan and Anjali Vaidya to learn about recent advancements in right heart imaging and how it may help inform treatment plans. This session is intended for health care professionals.

Conference Countdown Lunch

Friday, June 10, Noon–1 p.m. *Centennial Ballroom (Ballroom level)*

Grab a boxed lunch outside the ballroom, then head inside to network with fellow attendees prior to Conference Opening.

Conference Opening 0 0

Sponsored by Janssen

Welcome: Colleen Brunetti, adult with PH, PHA Board of Trustees chair; Matt Granato, PHA president and CEO

Emcee: Doug Taylor, adult with PH, PHA Board of Trustees member, PHA Conference co-chair **Keynote Speaker:** Linda Santos-Morgan, adult with PH

Friday, June 10, 1–2 p.m.

Centennial Ballroom (Ballroom level)

Join us as we kick off an exciting weekend of learning and connecting with community members: patients, caregivers, families, medical professionals and industry. The opening session keynote speaker, Linda Santos-Morgan, will speak about her experience from PH diagnosis to connecting with PHA, moving across the country to beautiful Savannah, Georgia, and feeling empowered by being an informed patient.

Breakout Sessions 2:30–3:30 p.m.

Get Moving: Exercise and Pulmonary Rehabilitation in PH ()

Speakers: Navneet Singh, M.D., MBA; Lindsay Thurman, PAH patient; Kaye Norlin, M.A., C.W.C., CSMC, CYT-200, R.Y.T., yoga instructor

Friday, June 10, 2:30–3:30 p.m. *Grand Hall A (Exhibit level)*

Starting an exercise regimen can be intimidating for anyone, especially if you're living with PH. However, exercise is a great way to improve breathing efficiency, aerobic capacity and overall quality of life. Learn how you can safely exercise at home and the benefits of pulmonary rehabilitation. This session will also discuss insurance coverage options for pulmonary rehab.

Group 4 PH: CTEPH: Overview and Treatments **⊙**

Speakers: Gustavo A. Heresi, M.D., M.S.; Ivan M. Robbins, M.D., D.O., Ph.D.; Summer McKesson, CTEPH Patient

Friday, June 10, 2:30–3:30 p.m. *Grand Hall B (Exhibit level)*

This session will discuss Group 4 PH, chronic thromboembolic pulmonary hypertension (CTEPH), and how it differs from other types of PH. CTEPH is a serious disease that can develop in patients who have had pulmonary embolisms. Panelists will discuss the diagnosis of CTEPH and treatment options, including both surgery and alternatives.

Posting for PH: How to Make an Impact on Social Media ()

Speakers: Nidhy Varghese, M.D.; Lauren Intrieri, PHA communications and marketing coordinator; Elise Whalen, M.S.N., APRN, FNP-C, C.P.N.; Gerry Langan, IPAH patient

Friday, June 10, 2:30–3:30 p.m. *Grand Hall C (Exhibit level)*

This session will focus on utilizing social media as a positive tool for education, empowerment and advocacy for patients, caregivers and medical teams. With various social media platforms available today, individuals can engage with others around the world and share information. The panel will discuss the importance of patient stories and how sharing them effectively can make an impact in the health care space. Speakers will also cover the potential negative effects of social media and introduce tools on how to handle them. This session will be constructive, focusing on harnessing the power of social media to make an impact in all facets of the PH community.

Self-Advocacy: Get What You Need by Finding Your Voice (§ (§)

Speakers: Diane Ramirez, PH patient, PHA Board of Trustees, support group leader, advocacy advisory board member; Nikole DuTemple-Nichols, PH patient, PHA support group leader and support group advisory board member; Colleen Brunetti, PH patient, PHA Board of Trustees and chair of the board

Friday, June 10, 2:30–3:30 p.m. *Grand Hall D (Exhibit level)*

As patients, we need to be able to speak up for ourselves and take an active part in the decision-making around our care. This session will cover practical tips and tricks of working with your medical team, insurance and specialty pharmacy, as well as address the mental and emotional challenges that can come with navigating the health care system and getting what you need. Whether you are newly diagnosed or have had PH for a while, it is important to be informed and empowered. This is your journey – find your voice to face it with confidence.

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Breakout Sessions 4–5 p.m.

A Conversation for Men: Expressing Love, Desire and Affection with PH

Speakers: R. James White, M.D., Ph.D.; Marco V. Reinoso, PAH patient

Friday, June 10, 4 – 5 p.m. *Grand Hall A (Exhibit level)*

This session, geared toward men and male-identifying PH patients, will explore all aspects of PH and the expression of love, affection, desire and sex. Symptoms like pain and fatigue, side effects from treatment (especially a pump-based treatment) and the emotional drain of a chronic disease can weigh heavily on these areas. How can you feel attractive and desirable with PH? We'll provide a space to share stories and advice from those who have walked this road.

This session is geared toward masculine-of-center PH patients. A parallel session for women and femme-of-center patients is offered at the same time. Conference attendees should choose the session that best meets their needs. This session will not be recorded.

A Conversation for Women: Expressing Love, Desire and Affection with PH

Speakers: Angela Michelle, B.A., A.C.S., RYT-500; Pat Ofori, PH patient, PHA support group leader and advisory board member; Ioana Preston, M.D., D.O., Ph.D.

Friday, June 10, 4–5 p.m. *Grand Hall B (Exhibit level)*

This session geared toward women and femaleidentifying PH patients will explore all aspects of PH and the expression of love, affection, desire and sex. Symptoms like pain and fatigue, side effects from treatment (especially a pump-based treatment) and the emotional drain of a chronic disease can weigh heavily on these areas. How can you feel attractive and desirable with PH? We'll provide a space to share stories and advice from those who have walked this road. This session is geared toward feminine-of-center PH patients. A parallel session for men and masculine-of-center patients is offered at the same time. Conference attendees should choose the session that best meets their needs. This session will not be recorded.

Understanding and Navigating Health Insurance **©**

Speakers: Katie Kroner, PHA vice president of advocacy and patient engagement; Laura Nowicki, R.N.; Danielle Burkett, C.M.A.

Friday, June 10, 4–5 p.m. *Grand Hall C (Exhibit level)*

When living with a chronic illness, navigating the world of insurance is often cumbersome and confusing. During this session, panelists will review common insurance terms and frequently asked questions. The session will provide tips on overcoming treatment access obstacles, including ways your health care team can help.

The Gray Area: Navigating from Pediatric to Adult Care ()

Speakers: Sandeep Sahay, M.D., FCCP; Anna Brown, D.N.P., CPNP

Friday, June 10, 4 – 5 p.m. *Grand Hall D (Exhibit level)*

In this session, panelists will guide you through the good, bad and confusing when transitioning yourself or your teen from pediatric to adult care. Patients and caregivers will hear firsthand experience from a PH patient on the challenges and successes of the process and from clinicians on ways to minimize potential pitfalls. Industry Sponsored Session: A Time for Hope in PAH: New Science, Potential New Therapies and the Patient's Role in Drug Development

Sponsored by Aerovate Therapeutics

Speakers: Ioana Preston, M.D., Tufts Medical Center; Hunter Gillies, MBChB., chief medical officer, Aerovate Therapeutics, Inc., PAH patient

Friday, June 10, 5:30–6:30 p.m. *Hanover FG (Exhibit level)*

This program is intended for both clinicians and patients attending PHA 2022. A multi-disciplinary panel, including a PAH expert, an industry scientist and a PAH patient, will explore this important time in PAH. This session will cover perspectives on new science, potential new therapies, novel approaches to drug development and the patient's role in moving science forward.

Industry Sponsored Session:
Established Science and a Novel
Potential Therapy: Targeting
Serotonin for the Treatment of PAH
Sponsored by Altavant Sciences

Speaker: Lana Melendres-Groves, M.D., University of New Mexico, Albuquerque, New Mexico

Friday, June 10, 5:30–6:30 p.m. *International Ballroom (Lobby level)*

This session is intended for both patients and health care professionals. Scientists and PAH expert will discuss a potential new therapy in development, the ELEVATE 2 study, and the importance of patient participation in research.

PHacing the Future Together Through Volunteering •

Speakers: Abby Sickles, PHA Patient and Caregiver Programs; Jaeger Spratt, M.S.W., PHA advocacy and treatment access coordinator; Tonya Hall, PHA director of fundraising events; Linda Busche, director of content strategy and development

Friday, June 10, 5:30–6:30 p.m. *Regency 5 (Ballroom level)*

Whether it is through advocacy, fundraising or peer support, raising awareness for the PH community can be a unique journey for everyone. Join PHA staff and volunteers as they help you discover the right style of volunteerism for you. Navigating fundraising, legislative advocacy, telling your story and peer support will be discussed.

Medical Update Dinner 00

Sponsored by Bayer

Welcome: Anna Hemnes, M.D., PHA Board of Trustees member, PHA Scientific Leadership Council chair-elect, Vanderbilt University Emcee: Murali Chakinala, M.D., PHA Board of Trustees member, PHA Scientific Leadership Council chair, Columbia University Medical Center/New York-Presbyterian Hospital Moment of Remembrance: Mary Felkel, bereaved parent of PH patient, Dr. Sally Maddox Speaker: Todd Bull, M.D., PHA Scientific Leadership Council, Research Committee chair, University of Colorado Keynote Speaker: Stephen Mathai, M.D.,

M.H.S., Johns Hopkins Pulmonary Hypertension

Friday, June 10, 7–8:30 p.m.

Centennial Ballroom (Ballroom level)

Program

We have made remarkable strides in our understanding of PH and available treatments, enabling patients to live longer and have a

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better quality of life. This year's Medical Update Dinner will feature Stephen Mathai, M.D., M.H.S., an associate professor of medicine and part of the Johns Hopkins Pulmonary Hypertension Program. You'll learn more about the PVDOMICS study, a multi-center study to improve understanding of pulmonary vascular disease through phenomics and the way our physical and biochemical traits change in response to genetic mutation and environmental influences.

Saturday, June 11

Networking with a Medical Professional Breakfast ()

Sponsored by Janssen

Welcome: Kim Jackson, R.N., PHA Board of Trustees, PH Professional Network past chair, University of Kentucky

Emcee: Cheri Abbott, R.N., CCRP, PHA Board of Trustees member, PH Professional Network chair-elect, University of Colorado

Saturday, June 11, 8–9 a.m. *Centennial Ballroom (Ballroom level)*

Kick-start your Saturday with a special opportunity to interact with PH experts in a casual setting before the day's breakout sessions. Medical professionals specializing in various areas in the PH field will be seated at tables organized by PH topic. This gives patients and caregivers the opportunity to have discussions with PH experts over breakfast.

Art Gallery

Saturday, June 11, 8 a.m. to 6 p.m. *Centennial Foyer (Ballroom level)*

View the creative talent of our community at the PHA Art Gallery while raising money to sustain our mission to extend and improve the lives of those affected by PH. Gallery tickets will be sold Saturday only! Winners of Saturday's drawing will be announced at the Closing Breakfast and on the Conference mobile app Sunday morning. Drawing winners may pick up their artwork on Sunday, June 12, 10:45 a.m. to 12:30 p.m. at the Art Gallery.

Breakout Sessions 9:30–10:30 a.m.

Parenting Your Child with Pulmonary Hypertension ()

Speakers: Edward (Ted) Kirkpatrick D.O.; Kelly Wiegele, parent and caregiver of child with PH, moderator of the PHA Parents of Kids with PH Facebook Group; Mitzi McIver-LaBarge, caregiver and parent of child with PH

Saturday, June 11, 9:30–10:30 a.m. *Grand Hall A (Exhibit level)*

From birth to adulthood, parents of children with PH have many unique concerns. Join this discussion on school accommodations, planning for hospital visits, emotional support, managing stress as a family, and related topics.

Improving Sleep Quality When You're Under Pressure •

Speakers: Mary Jo Farmer, M.D., Ph.D.; Tonya Zeiger, R.R.T., CPFT

Saturday, June 11, 9:30–10:30 a.m. *Grand Hall B (Exhibit level)*

Find out how PH patients with sleep apnea should be evaluated and treated. Panelists will provide a brief overview of devices and nonpharmacologic therapies used in treating and managing PH due to lung disease. This includes continuous positive airway pressure (CPAP) for sleep apnea, supplemental oxygen therapy, additional breathing equipment and monitoring technology. Take-a-ways from this session include knowledge "pearls" to promote sleep at home and on the go so you can sleep soundly wherever you are.

Equilibrar la ingesta de sodio y líquidos, asuntos prácticos llevados a la vida real ()

Speakers: Lilia Andrea Buitrago Malaver, R.N., M.N.S., Ph.D., Universidad Libre Pereira; Ricardo Restrepo-Jaramillo M.D., University of South Florida

Saturday, June 11, 9:30–10:30 a.m. *Grand Hall C (Exhibit level)*

Es de vital importancia para los pacientes con HP tomar un papel activo en el manejo de sus hábitos de nutrición y alimentación. Una dieta equilibrada, a veces con especial atención a las restricciones de sal y líquidos, es esencial para mantener la salud, mejorar los síntomas y vivir su mejor vida con HP. Los panelistas revisarán los escollos dietéticos comunes, los alimentos que debe sordecir y cómo limitar los líquidos Ingesta. Además, compartirán estrategias dietéticas y de estilo de vida para asegurar el éxito a largo plazo.

When PH Patients Need Surgery **O**

Speakers: Fran Rogers, M.S.N., CRNP; William Auger, M.D.; Ronald Oudiz, M.D.

Saturday, June 11, 9:30–10:30 a.m. *Grand Hall D (Exhibit level)*

Learn about what to consider when you need surgery, including the types of anesthesia and how to navigate the risks of surgery. Considerations for medical teams such as the condition of the right side of the heart, exercise capacity/fitness of the patient, the type of surgery and what PH therapies a patient is receiving will be discussed. Panelists will describe the various components of preparing PH patients for elective surgery such as asking the right questions, involving your PH health care team(s) and safety precautions.

Breakout Sessions 11 a.m.-noon

Having a Career with PH ()

Speakers: Darrell Randolph, PAH patient; Aisha L. Woods, Psy.D., LPC-S; Dorothy Watts, M.B.A., PH patient; Jessie Kohler, PH patient, PHA board member

Saturday, June 11, 11 a.m.—noon Grand Hall A (Exhibit level)

Get insight into finding ways to pursue a job or degree while maintaining your health and managing PH. Relationships, higher education and careers can make up a large part of our lives and identities. Hear from other people with PH who have successfully managed work and/or pursued higher education.

Pediatric PH: Types and Treatments

Speakers: Russel Hirsch, M.D.; S. Melissa Magness, APRN-CPN-AC

Saturday, June 11, 11 a.m.–noon *Grand Hall B (Exhibit level)*

This session will explain PH and the treatments that are specifically geared towards the pediatric patient population. Speakers will help you understand your child's PH diagnosis, the causes of pediatric PH, treatment and therapeutic options and how to manage PH as your child grows.

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Entendiendo la hipertensión arterial pulmonar, desde su diagnóstico hasta su cuidado ()

Speakers: Maritza Brenes Castillo, PH patient; Ricardo Restrepo-Jaramillo M.D.; Martha Torres, caregiver

Saturday, June 11, 11 a.m.–noon *Grand Hall C (Exhibit level)*

En esta sesión los panelistas revisarán los conceptos básicos de la HP, por ejemplo; la interacción entre el corazón y los pulmones, cómo el corazón se ve afectado por la presión arterial alta en los pulmones, la diferencia entre la presión arterial alta en los pulmones y la presión arterial alta en todo el resto del cuerpo, También conocerán acerca de las vías patológicas que originan la enfermedad y los síntomas comunes de la HP. Los panelistas discutirán los diferentes tipos de HP, la clasificación actual y las razones detrás de las extensas pruebas que se requieren para un diagnóstico preciso y elegir el mejor plan de tratamiento. Se brindarán recomendaciones a pacientes recién diagnosticados y sus cuidadores para su convivencia con esta condición.

Returning to Care: Finding Normalcy After a Pandemic and Keeping the Best of What We Have Learned

Speakers: Karen A. Fagan, M.D.; Nick Fox, M.D.; Lori Reed, N.P., APRN; Thenappan Thenappan, M.D., D.O., Ph.D.

Saturday, June 11, 11 a.m.–noon Grand Hall D (Exhibit level)

In this session, panelists will review the hardships and obstacles of navigating health services during and after a pandemic. Learn about the differences between in-person and virtual care visits and receive guidance on navigating appointments while maintaining safety.

Journeys Lunch () ()

Welcome: Tony Lahnston, PHA Board of Trustees member, chair-elect, Windemere, Fla. Panel Host: Betty Lou Wojciechowski, bereaved family member, caregiver, past PHA Board of Trustees member, Southern California Panelists: Michelle Liu, M.D., M.P.H., FAAOH, parent of a child with PH, Walter Reed Military Medical Center, Bethesda, MD; Stephen H. Walker, M.S., CRNP, Children's Hospital of Philadelphia; Allison Dsouza, B.S.N., R.N., patient with PH; Elizabeth Colglazier, M.S., N.P., University of California-San Francisco, San Mateo; Kimberly Jackson, R.N., PHA Board of Trustees member, University of Kentucky; Evelyn Mitchell, adult with PH, PHA support group leader, Lexington

Saturday, June 11, Noon–1 p.m. *Centennial Ballroom (Ballroom level)*

A tradition since PHA's first Conference in 1994, the Journeys Lunch highlights the experiences that patients and their care teams share. The Journeys Lunch focuses on the personal and medical journey of being diagnosed with PH, including how patients and their teams determined the most effective treatment plan and found hope for the future. Patient/medical professional pairs will share their stories of building partnerships, breaking down barriers and planning for patients' futures together.

Industry Sponsored Session: Patient and HCP Perspective: A Conversation about Tracking and Self-Advocacy

Sponsored by Janssen

Saturday, June 11, 1–2 p.m. *Regency 5 and 6 (Ballroom level)*

Pulmonary arterial hypertension (PAH) is a complicated disease and affects each patient differently. Your PAH status reflects your unique journey. Janssen invites you to join a PAH health

care provider and someone living with PAH to learn about how changes in your PAH status can inform treatment decisions and your overall care plan. Discover how understanding your PAH status helps create a more informed conversation with your healthcare team. Learn about the benefits of and tools for tracking your PAH, the importance of returning to care since COVID-19 and how this all helps you to be a powerful self-advocate.

Breakout Sessions 2-3 p.m.

Interventional and Surgical Therapies in Pulmonary Hypertension **©**

Speakers: Oksana A. Shlobin M.D., FCCP; Erika Berman-Rosenzweig, M.D.; Donna Hershey, PH patient

Saturday, June 11, 2–3 p.m. *Grand Hall A (Exhibit level)*

The goal of this session is to discuss surgical and/or interventional therapies that may be performed in patients with all forms of PH. Atrial septostomy, lung transplantation, heart-lung transplantation, pulmonary thromboendarterectomy (PTE) surgery and balloon pulmonary angioplasty will be discussed. Panelists will describe each procedure and how and when they are performed in patients with different forms of PH.

Self-Care Isn't Selfish: Tips for PH Patients ()

Speakers: LaKeshia Orr, PH patient; Patrick Mellin, PH patient; Elyse Lundberg, PH patient

Saturday, June 11, 2–3 p.m. *Grand Hall B (Exhibit level)*

Our panelists will define self-care and offer insights on managing your self-care with PH. This session will empower you to perform your own self-care to improve your overall well-being.

Abogando por el Paciente de HP: Perspectiva del Paciente y el Cuidador ()

Speakers: Evelyn Crespo, PH patient; Marco V. Reinoso, PAH patient; Maribel Rosario-Lopez, M.D.

Saturday, June 11, 2–3 p.m. Grand Hall C (Exhibit level)

En esta sesión, los panelistas revisarán las preguntas importantes que se deben hacer a los médicos. Los pacientes de HP y sus cuidadores aprenderán a aprovechar al máximo las citas con el médico y mejorar su interacción con las instituciones que brindan atención médica. Esta sesión también tratará sobre la importancia de defender sus derechos como paciente y la forma en que el cuidador puede apoyarlo.

Caregivers Need Care Too O

Speakers: Michelle F. Liu, M.D., M.P.H., PHA board member; Michele Freeman, MSMHC, N.C.C., L.P.C., LCSW

Saturday, June 11, 2–3 p.m. *Grand Hall D (Exhibit level)*

Learn about the importance of caregiver resilience and wellness through simple practices such as mindfulness, laughter and body-centered techniques.

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Support Group Meetings 3:30-4:30 p.m.

Beginning Your Journey: For people who are newly diagnosed, beginning their journey with PH or still finding their new normal *Seairlie (Atlanta Conference Center)*

Bereavement: For people who have lost someone to PH.

Innman (Atlanta Conference Center)

Caregivers: For anyone who loves and cares for someone with PH (e.g., spouse, child, friend) *O Piedmont (Atlanta Conference Center)*

Chronic Thromboembolic
Pulmonary Hypertension (Group 4:
CTEPH): For people living with CTEPH

Auburn (Atlanta Conference Center)

Continuing your Journey: For people who are living with and thriving or enduring PH *Baker (Atlanta Conference Center)*

Group 1 Pump Therapy: For people with PAH to discuss pump therapy **O** *Lenox (Atlanta Conference Center)*

Grupo de Hispanohablantes: Para las personas que hablan español () *Greenbriar (Atlanta Conference Center)*

Men with PH: For men living with PH (patients only) **Spring** (Atlanta Conference Center)

Parents of Kids with PH: For parents of children with PH • Edgewood (Atlanta Conference Center)

PH and Associated Conditions: For people living with an associated condition such as scleroderma, lupus, sickle cell disease, HHT, COPD, sleep apnea, HIV, sarcoidosis *(Sennesaw (Atlanta Conference Center)*

Industry Sponsored Session:
PHocusing on the Future: Precision
Medicine, Emerging Treatment
Pathways and New Molecules in
Development for PAH

Sponsored by GossamerBio

Friday, June 10, 4:45–5:45 p.m. *International Ballroom (Lobby level)*

Reflecting on the past, present and future of therapeutics developed for the treatment of PAH, this session will lead attendees through the evolution of PAH treatments. The speakers will introduce some investigational drugs in mid-to-late stages of clinical development, including agents designed specifically for the treatment of PAH. Attendees will learn about new treatment pathways in PAH and ongoing research advancing the reality of precision medicine in PAH. Following the presentation, a moderated panel discussion will explore efforts to advance our scientific understanding of PAH and where future PAH therapies may be heading for patients.

Outstanding Member Awards Dinner



Presenters: Doug Taylor, adult with PH, PHA Board of Trustees member, PHA Conference Committee co-chair; Matt Granato, PHA president and CEO

Saturday, June 11, 6–7 p.m. *Centennial Ballroom (Ballroom level)*

This dinner brings us together to celebrate community members who have raised awareness and given a voice to the PH community through advocacy, philanthropy, peer support, patient care and efforts to advance PH research. Join us in recognizing award winners for Outstanding Physician, Outstanding Allied Health Professional, Outstanding PH Citizen,

Outstanding Young PH Citizen, Outstanding Caregiver, Outstanding PHA Support Group Leader and the Julie Hendry Memorial Scholarship Award.

Fashion Show and Saturday Night Party

Sponsored by Accredo. Additional support provided by Aerovate Therapeutics

Hosts: Nicole M. Creech, PHA board member and Doug Taylor, PHA board member

Saturday, June 11, 7–8:30 p.m. *Regency 5 and 6*

What better way to celebrate all the friendships, connections and triumphs of the weekend, than with a one-of-a-kind party! Come join the party and cheer on fellow PHA 2022 attendees who will proudly flaunt or cleverly conceal the accoutrements of life with PH as part of the Saturday night Fashion Show. Participants will transform oxygen cannulas, mobility devices and medication pumps into symbols of strength and hope.

Immediately following the Fashion Show, you are invited to the first-ever PHA 2022 Saturday Night Party which will feature a DJ, dancing, games and a ton of fun. This exciting, vibrant party is not to be missed!

Sunday, June 12

Closing Brunch ()

Emcee: Colleen Connor, adult with PH, PHA Board of Trustees member

Gavel Passing: Colleen Brunetti, adult with PH, PHA Board of Trustees chair; Tony Lahnston, bereaved family member, PHA Board of Trustees chair-elect

Keynote Speaker: Stephen Carter-Hicks, adult with PH

Sunday, June 12, 9:30–10:30 a.m. *Centennial Ballroom (Ballroom level)*

Join Stephen Carter-Hicks as he shares his journey from starring on Broadway to being diagnosed with PH. Hear how he is courageously facing and creating ways to cope with the limitations he was presented with and his determination to live a full and rewarding life.

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At Janssen, we're working to create a future where disease is a thing of the past. Our research efforts are focused on helping transform pulmonary arterial hypertension (PAH) into a long-term manageable disease, with the hope of one day finding a cure. We at Janssen understand that the PAH community is more than only data and science. We want people living with PAH to feel understood, supported and prepared to manage their lives with PAH. To support and empower people living with PAH, Janssen launched Breathe In, Speak Out About PAH – an educational and informational resource for patients, caregivers and advocates to help support and empower them throughout the PAH journey. Learn more at www.pahbreatheinspeakout.com.

Gold Sponsor





Bronze Sponsors

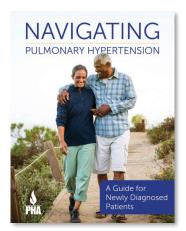








PHA PATIENT RESOURCES



Navigating Pulmonary Hypertension

"Navigating Pulmonary Hypertension: A Guide for Newly Diagnosed Patients" is designed for individuals with pulmonary hypertension (PH) and their loved ones to find answers, support and hope during the first few weeks, months or years after a PH diagnosis. The resource provides an overview of diagnosis, treatment, symptoms and quality of life, as well as checklists, resources and questions to ask doctors.

Order online at no cost or download at PHAssociation.org/Newly-



What You Need to Know After a Pulmonary Embolism

Between 0.5% and 5% of people who experience a pulmonary embolism (PE) later develop chronic thromboembolic PH (CTEPH). If you or someone you care for have had a PE, learn about the risks for CTEPH as well as its signs, symptoms, diagnostic tests and treatments in this brochure.

Available for download at PHAssociation.org/CTEPH2020.



Living with PH: A Guide to Intimacy

PHA's intimacy guide is designed to help people living with PH talk about sensitive subjects and start conversations about intimacy and sex when it may not be easy to do. This guide has been created for adult members of the PH community interested in or engaged in physically intimate and/or sexual activity and contains sexually explicit information including references to sexuality and sex both written and in images. This resource was originally developed by the Pulmonary Hypertension Association, U.K., and revised for the U.S. audience with the help and support of health care professionals, patients, caregivers, young adults, parents and staff.

Available for download at PHAssociation.org/a-guide-to-intimacy.

Free video resources 24/7 at PHAssociation.org/Classroom



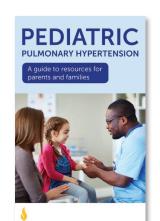
PH & ... 15 Related Conditions

To help people with pulmonary hypertension and people who may be at higher risk for PH learn more about their specific disease, these 15 brochures provide information about each condition, how it is connected to PH, how it is diagnosed or how people are screened for it, and how it is treated. These resources have been medically reviewed.

Available for download at PHAssociation.org/PHAfree-materials-store.

- PH & Congenital Heart Disease
- PH & Chronic Obstructive Pulmonary Disease (COPD)
- PH & Chronic Thromboembolic Disease (CTEPH)
- PH & Hereditary Hemorrhagic PH & Methamphetamine Use Telangiectasia (HHT)
- PH & HIV
- PH & Idiopathic Pulmonary **Fibrosis**
- PH & Liver Disease
- PH & Lupus

- PH & Sarcoidosis
- PH & Scleroderma
- PH & Sickle Cell Disease
- PH & Sjögrens
- PH & Sleep Apnea
- PH & Left Heart Disease



Pediatric Pulmonary Hypertension: A Guide to Resources for Parents and Families

This pediatric resource guide, created with the help of a task force of parents, health care professionals and teens with PH, helps connect parents and families with resources and support, and provides:

- An overview of pediatric PH
- Ways to locate specialized pediatric PH care
- Opportunities to connect with other families
- Emotional support opportunities for all family members
- Information on how to work with a child's school

Available for download at PHAssociation.org/PHA-free-materials-store.



In Your Time of Sorrow

"In Your Time of Sorrow" explains that bereaved family members – those experiencing the death of a loved one – are not alone and that they remain a welcome part of the PHA community. This resource also lists ways in which a bereaved person can memorialize their loved one through PHA, for example by having their loved one's name listed in Pathlight magazine's Passages section or volunteering for PHA in their memory. Readers will also find other PHA support resources and information about other organizations which specialize in grief and

Available for download at PHAssociation.org/PHA-free-materials-store.

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ABOUT PH AND THE PULMONARY HYPERTENSION ASSOCIATION

WHAT IS PULMONARY HYPERTENSION?

Pulmonary hypertension (PH) is an umbrella term used to describe a group of complex, potentially fatal lung conditions. PH is characterized by high blood pressure in the vessels of the lungs and can lead to right heart failure.

PH can occur in relation to left heart disease, lung disease, blood clots in the lungs and other conditions. Genetics also can play a role. In some cases, there is no known cause.

Symptoms of PH include shortness of breath, fatigue and chest pain.

Since PH often mimics symptoms of asthma and other less threatening illnesses, many people go months or years without an accurate diagnosis. As a result, they might not get the full benefit from available therapies once they are diagnosed.



Adults and children of all ages can develop pulmonary hypertension.

Women develop PAH more than three times as often as men, and women of color have disproportionately poorer health outcomes.

*Benza RL, et al. Chest. 2012;142(2):448-456

PH RESOURCES AT PHASSOCIATION.ORG

PH Resources at PHAssociation.org

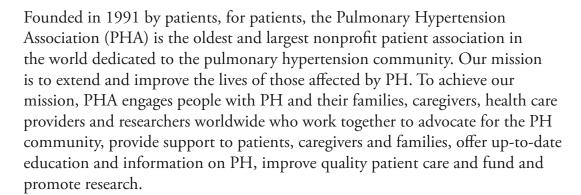
- Learn about research and find a clinical trial at PHAssociation.org/Research/Participating-in-Research
- Watch videos about PH, living with PH and various insurance and treatment access issues at PHAssociation.org/Classroom
- Find the resources you need at PHAssociation.org/Patients/Living-with-PH
- Find a doctor who treats PH at PHAssociation.org/Patients/DoctorsWhoTreatPH/

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

Pulmonary arterial hypertension (PAH) is one type of PH. Without treatment, people with PAH live 2.8 years past diagnosis on average.

Fortunately, there are 15 FDA-approved targeted PAH treatment options for adults and one FDA-approved drug for children. Although life expectancy has more than doubled,* these drugs are complex and expensive. Currently, there is no cure for PH.

WHAT IS THE PULMONARY HYPERTENSION ASSOCIATION?



HOW DOES PHA CONNECT THE PH COMMUNITY?

PHA's 200 support groups serve patients, caregivers, medical providers, parents, children, bereaved families and anyone whose life is touched by PH. Along with telephone support groups, a toll-free Support line, Facebook groups and an email mentor program, PHA's support programs serve thousands of patients and caregivers each year.

As the oldest and largest PH association in the world, PHA takes part in global initiatives such as annual World PH Day campaigns, convenes dozens of leaders at a biennial summit and creates communication channels for nearly 80 PH associations worldwide.

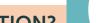
Because PH often arises from another underlying condition such as COPD or blood clots, PHA partners with organizations that represent associated diseases to offer support and provide information about the risks, symptoms and screening for PH.

PHA's International PH Conference and Scientific Sessions unites 1,400 patients, caregivers and medical professionals every two years to learn about the latest research and lifestyle advice, and to connect and network. Other events such as PHA on the Road provide patient and caregiver education.

DOES PHA PROMOTE QUALITY PATIENT CARE?

PHA has provided more than \$8 million for PH research and provides continuing education for medical professionals through PHA Online University and inperson CME programs.

Since 2014, PHA has accredited more than 80 hospitals and clinics as Pulmonary Hypertension Care Centers (PHCCs). Many of these PHCCs participate in the PHA Registry (PHAR), which has enrolled more than 2,022 patients to help advance research.









Don't Forget:
orget;

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