

“The rise of pulmonary hypertension patient associations and how they are shaping today’s care landscape”

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President & CEO

Pulmonary Hypertension Association



Our vision:

A world without pulmonary hypertension, empowered by hope.



Our mission:

To extend and improve the lives of those affected by PH.



It all started around the kitchen table...

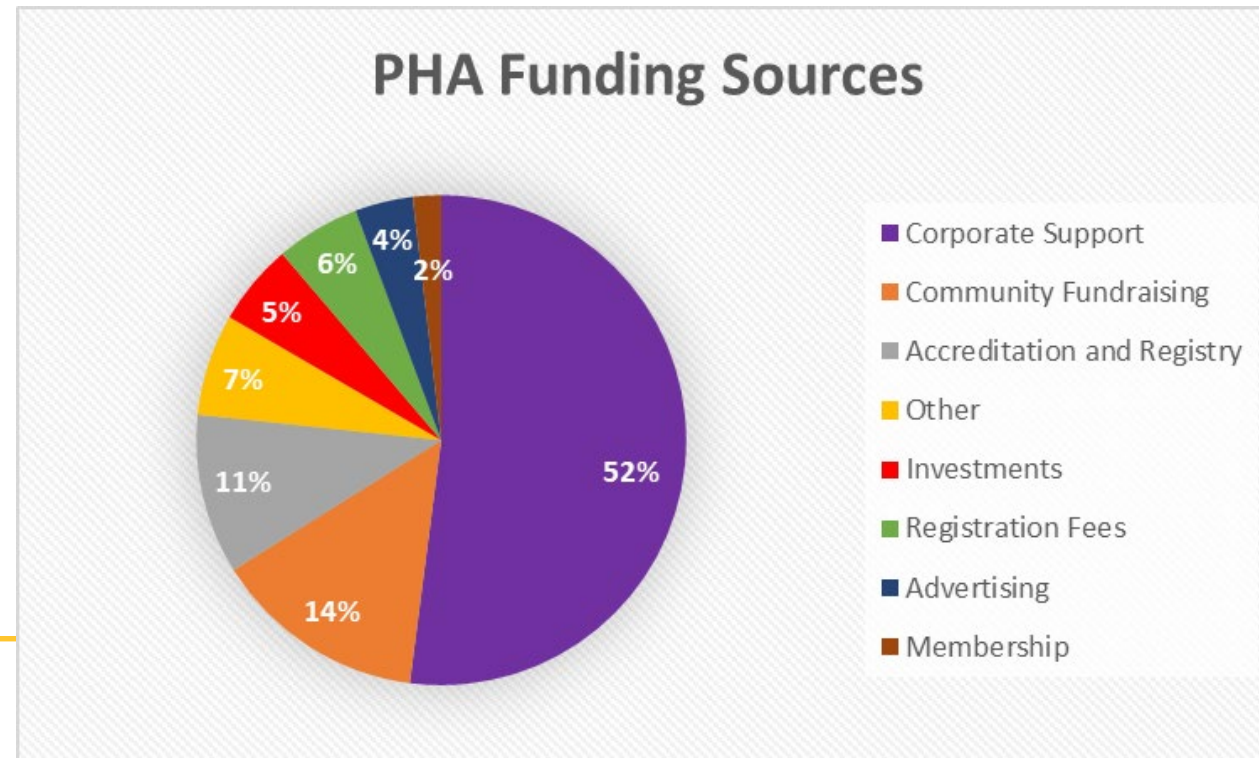
Over 30 years ago, four women met in Florida

- PHA has evolved to be the largest PH organization in the world – 501(c)(3)
- End isolation, provide education, advocate, advance science and PH research to eventually find a cure



PHA today

- Community of thousands of patients, caregivers, and HCPs – and industry partners
 - 2200 active members plus 1000s of subscribers
- Hybrid: “*patient advocacy organization*” and “*professional medical society*”
- Headquartered in Washington, DC
- 36 staff members
- \$8.9 million budget



Patients at the center



How do we Advocate?

- Legislative, regulatory, judicial pressure
 - Meetings, being present, showing up
 - Working in coalition with other affinity organizations
 - Focusing on and promoting individual stories
- To influence or effect change in the regulatory or legal field affecting PH patients
 - Access (coverage, reimbursement)
 - HCP/patient relationship
 - HCP availability, expertise



Raising Awareness: Publications

- Navigating Pulmonary Hypertension: new resource combines medical information and support
- Developed from feedback from patients and HCPs



- PH& brochures: explain the relationship between PH and different associated conditions



Raising Awareness: PH Connects Hub

Connecting the PH Community to PHA resources, information and support:

- Microsite that links to popular patient resources
- Direct mail, emails, and social media

**FACE EVERY DAY
EMPOWERED BY HOPE.**

Behind every person with pulmonary hypertension is a community prepared to help them overcome uncertainty and thrive beyond their diagnosis.

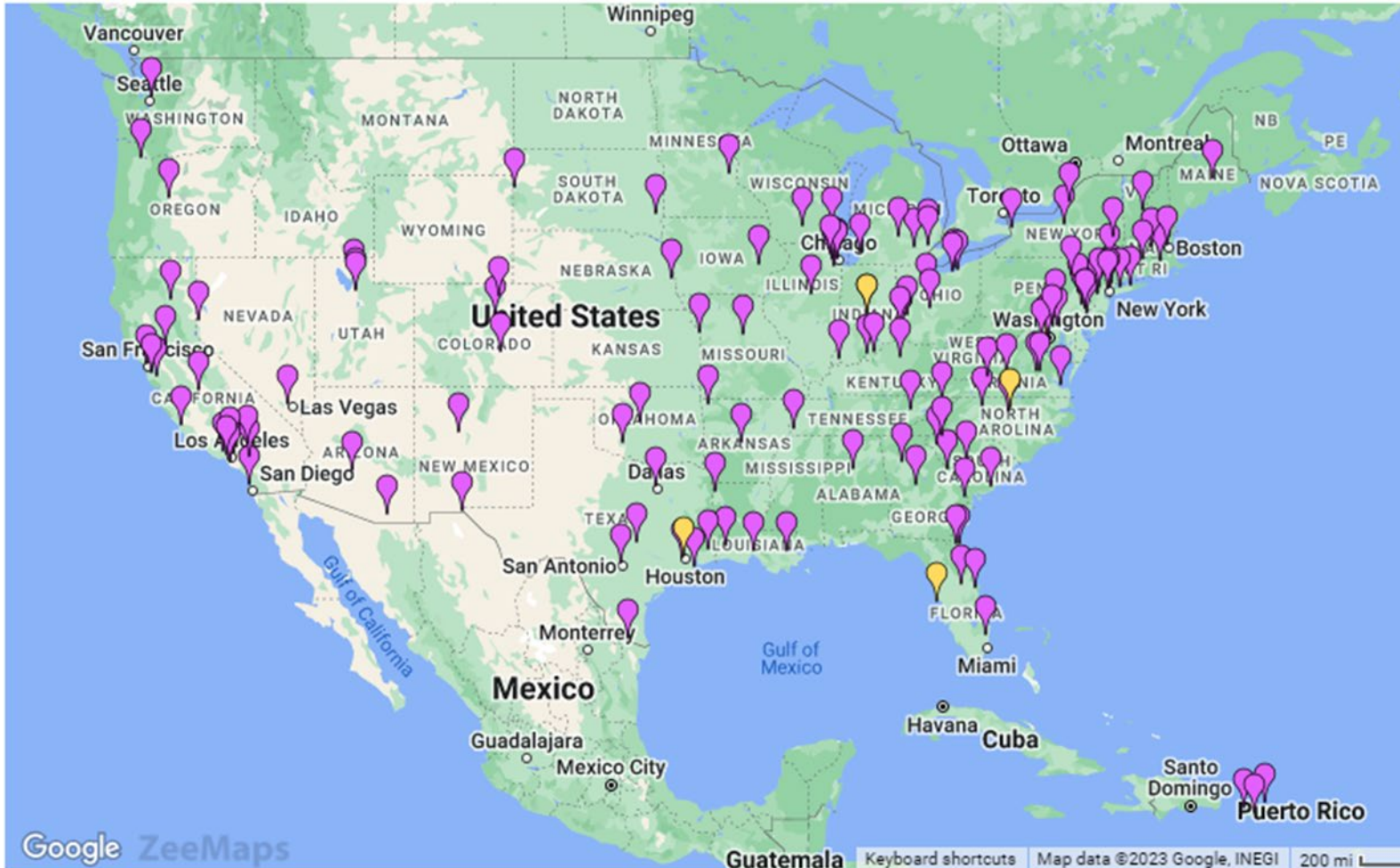
Whether you're newly diagnosed or helping someone navigate the challenges of PH, our new online **PHA Connects Hub** makes it easy for everyone to find the support they need.



Connects.PHAssociation.org

Support Groups

- Largest community of patients and caregivers:
- 200+ support groups led by 260 volunteer leaders
- During COVID-19 virtual meetings with 250 attendees/month
- PH “PHriends”
English/Spanish online and telephone support: 3,000+ people/year



📍 General support groups
📍 Pediatric support groups

Patient and Family Education



Self-paced learning modules



Understanding Sickle Cell Disease and PH

Published Thursdays alternating with PHA News

WHAT'S YOUR PH?

WORLD SYMPOSIUM ON PULMONARY HYPERTENSION
Pulmonary Hypertension Group Classifications

There are five distinct classifications of pulmonary hypertension (PH). Across these groups, there are more than 30 different, specific causes of PH and people can have more than one type of PH.

GROUP 1 Pulmonary Arterial Hypertension	GROUP 2 PH Due to Left Heart Disease	GROUP 3 PH Due to Lung Diseases	GROUP 4 Chronic Thromboembolic Pulmonary Hypertension (CTEPH)	GROUP 5 PH Due to Unclear Mechanisms
Hereditary Idiopathic (Bosnian, Drug and toxin induced (e.g., methamphetamine, amphetamine)) New-onset disease Diseases associated with PAH: Connective tissue (e.g., scleroderma, Scler., etc.), HIV, portopulmonary, congenital heart disease, liver-related, and/or pulmonary hypertension of the newborn	Left heart failure (heart failure with preserved or reduced ejection fraction) Heart valve disease	Chronic lung disease conditions (e.g., obstructive lung disease, chronic obstructive pulmonary disease, emphysema) Restrictive lung disease (e.g., interstitial lung disease, sarcoidosis) Obstructive sleep apnea Alveolar hypoventilation disorders Developmental lung disease Exposure to high altitudes for extended periods of time	Pulmonary embolism (blood clotting disorders in the lungs)	Hematologic disorders (sickle cell anemia, chronic hemolytic anemia, paroxysmal nocturnal hemoglobinuria, splenomegaly) Systemic disorders (sarcoidosis, pulmonary fibrosis, neurofibromatosis, neurofibrominosis and neurofibrosis) Metabolic disorders (e.g., Gaucher disease, phenylketonuria) Other diseases (e.g., thoracic aortic aneurysm with dissection, fibrosing mediastinitis)
TREATMENT OPTIONS Medications may include pills, intravenous (IV) infusions and subcutaneous (SC) injections and supplementary oxygen (indicated for specific type of PH). Depending on the severity of the PH, lung transplantation may be an option. Managed by treating the underlying heart condition. Depending on the severity of the PH, a heart-lung or lung transplantation may be an option. Surgery such as balloon pulmonary angioplasty or pulmonary thromboendarterectomy surgery can remove blood clots and eliminate PH. For CTEPH patients who are not eligible for surgery, PH targeted therapy can be prescribed. Depending on the severity of the PH, lung transplantation may be an option.				
DIAGNOSTIC TESTS TO DETERMINE YOUR SPECIFIC PH GROUP Multiple diagnostic studies are conducted including: echocardiogram, electrocardiogram, right heart catheterization, pulmonary function tests, lung ventilation/perfusion scan, blood tests – HIV, antinuclear antibody test and liver function studies. Additional testing may be required if the above tests fail to identify your PH type. Other testing may include cardiac stress tests, cardiopulmonary exercise tests, CT scans, pulmonary angiogram, cardiac MRI, sleep study or nighttime oximetry, immunology and abdominal ultrasound scans.				

Large washable poster for clinics distributed to PHCCs in November for PH Awareness Month



Don't Miss Our PHA Live 'Caring for a Child with Pediatric PH'

7 live webinars & 18 pre-recorded videos including 8-part pediatric series.



Patient Education 2024 Priorities

Content

- Associated conditions
 - ILD
 - Sleep apnea
- CTEPH
- Drug pipeline and disease modifying therapy
- Genetics
- Grief
- Open enrollment
- Oxygen access
- Pediatrics, tweens and teens
- Prior authorization
- Reproductive health/women's health
- Spanish language resource translation
- Titration education & support
- Transplant

Distribution Channels

- PHA 2024 breakout sessions
- Community Workshops
- PHA Classroom (self paced)
- PHA Live (webinar)
- Newsletters/Pathlight
- Podcasts
- Print and downloadable content



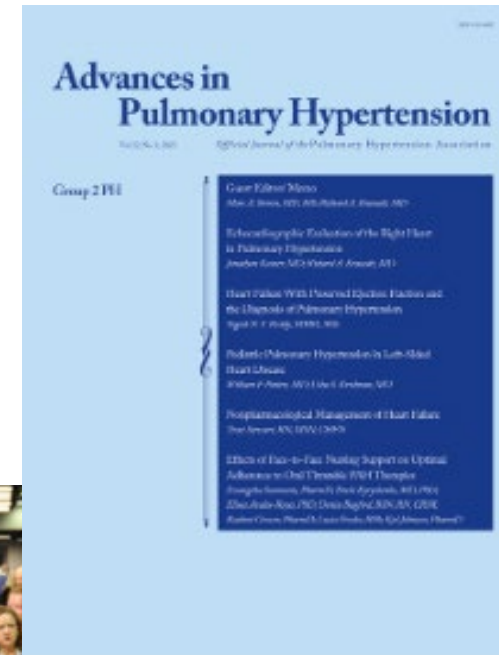
2024 PHA International PH Conference & Scientific Sessions

- Indianapolis, August 15-18, 2024
- Call for proposals will open early in 2024, registration and scholarship applications opens 3/2024
- Focus in 2024 on re-engaging international community
- Spanish translation options for all sessions, not just Spanish track
- Scientific Sessions to include recap from **World Symposium**



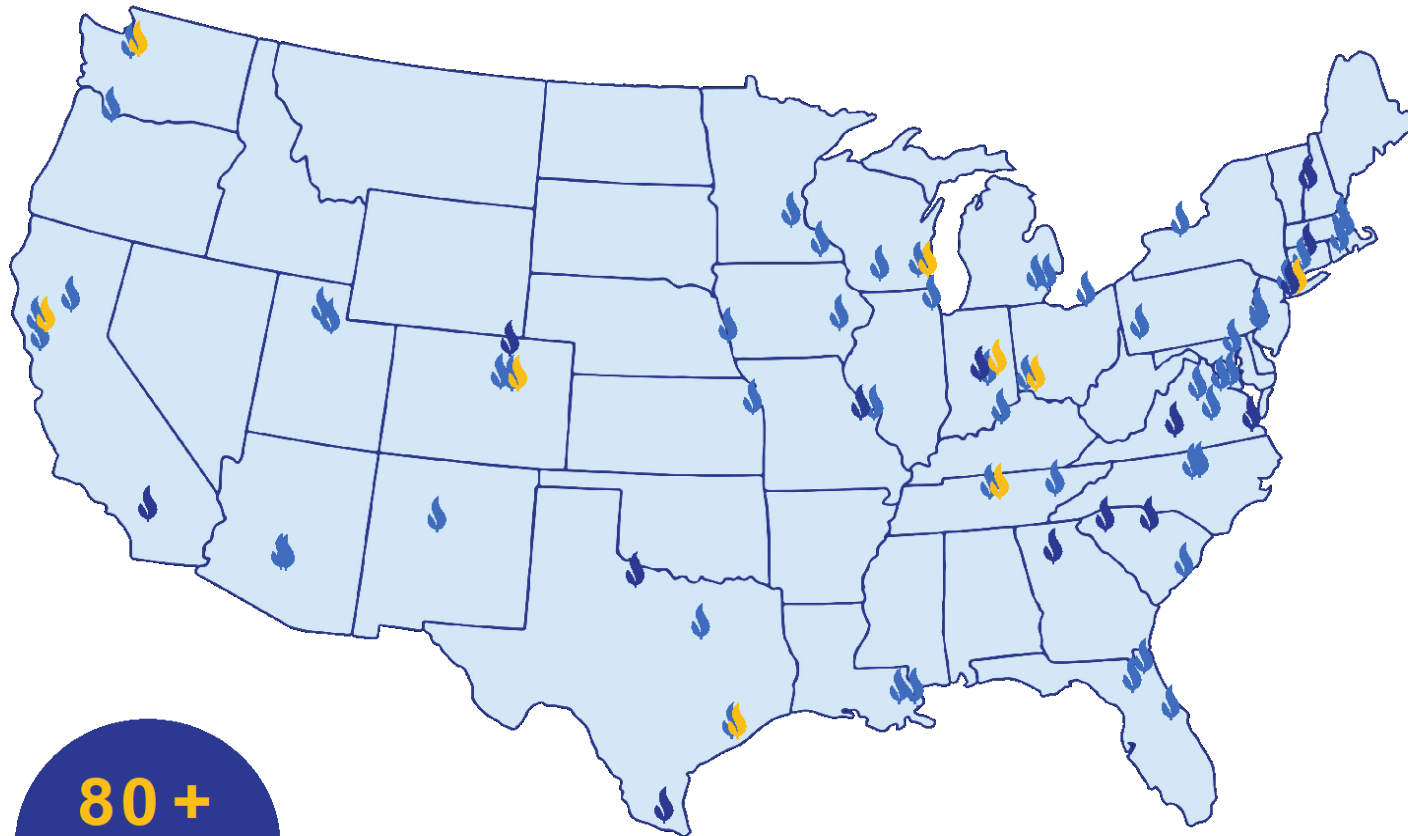
Comprehensive PHA Professional Education Programming

- Continuing medical education (CME) through multiple modalities
 - Online, self-paced learning – *PHA Online University*
 - In-person or virtual – *PHA On-Demand*
 - PHPN Symposium
 - Scientific Sessions at PHA Conference
 - Journal *Advances in Pulmonary Hypertension*



PHCC Network

PHA-Accredited PH Care Centers



PHCC program growth to 83+ accredited centers:

- 59 CCC programs
- 15 RCP programs
- 9 Pediatric CCC programs

New PH centers continue to apply for accreditation



80+
ACCREDITED
SITES



Adult RCP programs



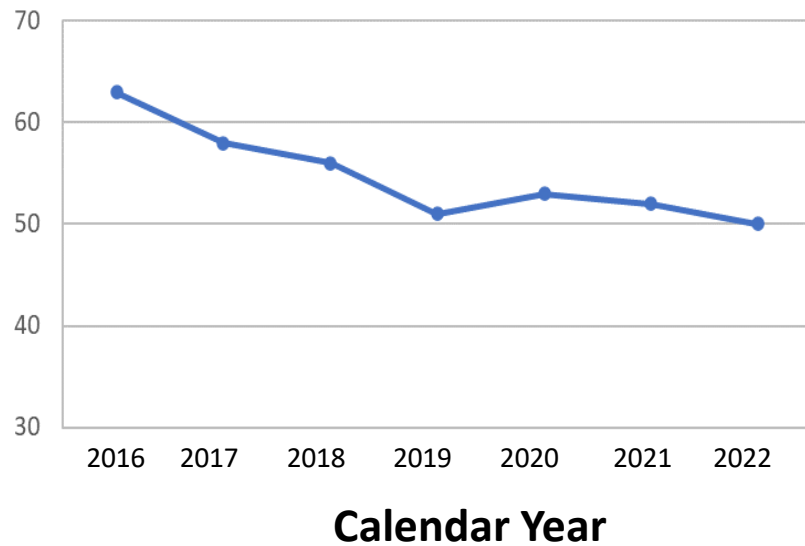
Adult CCC programs



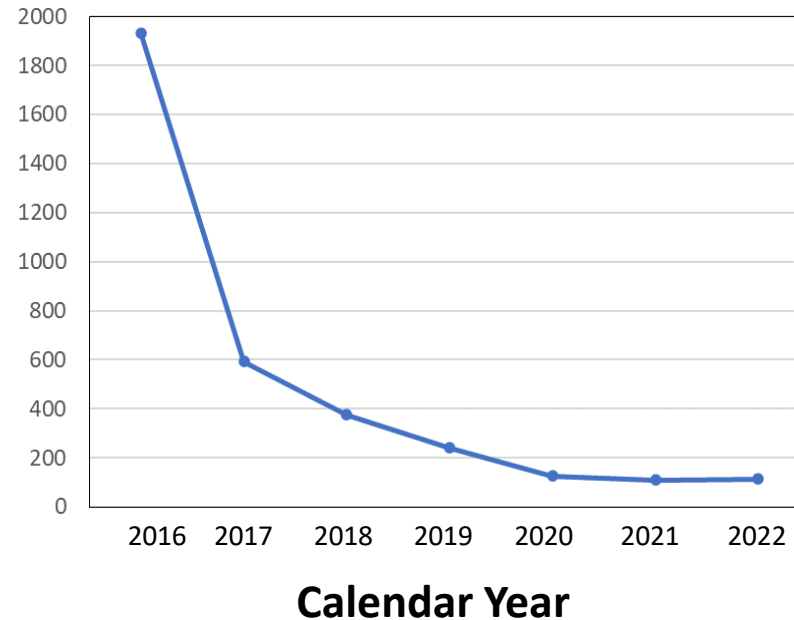
Pediatric CCC programs

Signs of Success: Favorable Trends Towards Improving Patient Outcomes

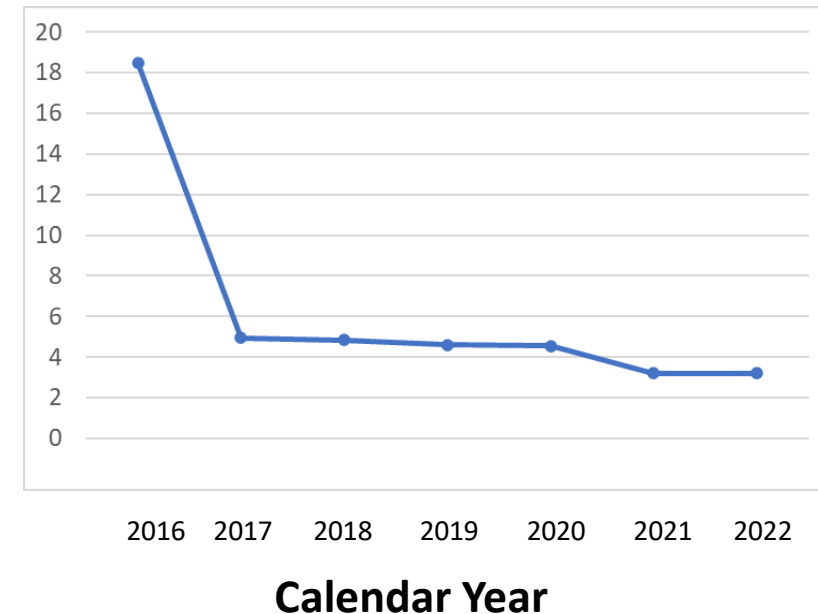
% WHO Functional Class III and IV at Enrollment



Hospitalizations Per 100 Patient Years



Deaths Per 100 Patient Years

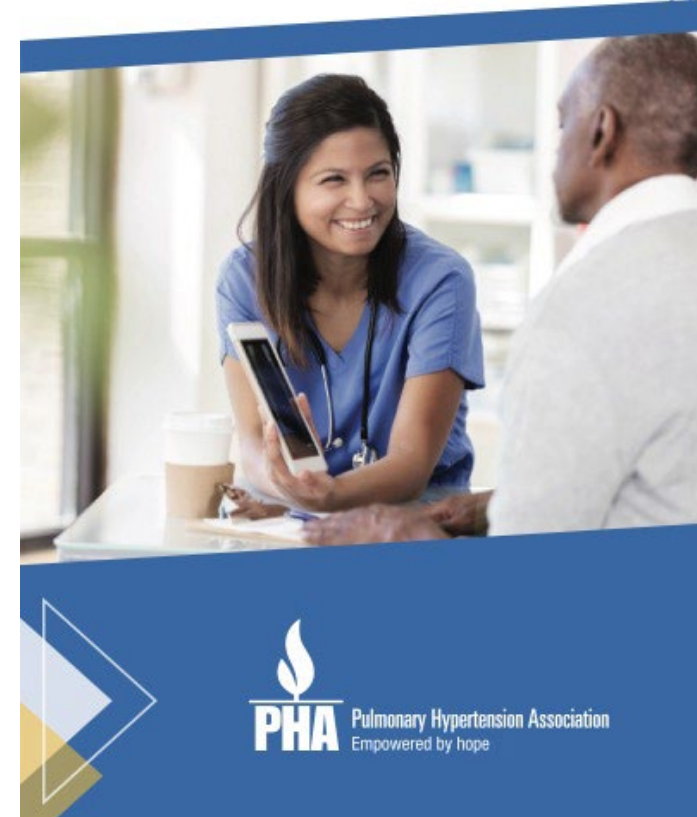


PHA Registry (PHAR)

>2,700 PH patients enrolled in 70 participating centers

U.S. based, prospective, longitudinal, observational patient registry

- Only patients with PAH, CTEPH and pediatric PH due to developmental lung disease
- Participating sites are PHA-accredited PH Care Centers (CCCs & RCPs)
- Measure and improve quality of care
- Understand risk factors for patient outcomes
- Determine clinical effectiveness
- Facilitate clinical trials for new therapies
- Support collaboration with PH community (HCPs, patients and caregivers)
- Support PHCC reaccreditation



Thank you!
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