



# **PHA** ON THE ROAD **PATIENT** AND **CAREGIVER** **WORKSHOP**

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Brought to you by the  
**Pulmonary Hypertension  
Association**

Saturday, Sept. 17, 2022  
8:30 a.m.–3:30 p.m.  
Marriott Louisville Downtown  
Louisville, Kentucky

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# WELCOME



**Kimberly Jackson, B.S.N., R.N.**  
*Nurse Cardiovascular Coordinator,  
Pulmonary Hypertension Program;  
University of Kentucky Gill Heart  
and Vascular Institute*



**J. Wesley McConnell, M.D.**  
*Director, Norton Healthcare  
Pulmonary Hypertension Center  
Pulmonologist and Critical Care  
Physician, Norton Pulmonary  
Specialists; Adjunct Professor of  
Medicine, Transplant Pulmonologist,  
University of Kentucky*

Dear Friends,

Welcome! Thank you for participating in the Pulmonary Hypertension Association (PHA)'s On the Road Workshop for pulmonary hypertension (PH) patients and caregivers. PHA is committed to providing timely information and key resources to support patients at every step of their journey.

PH is such a difficult and challenging disease for patients. The symptoms can be debilitating and the treatments complex. PHA On the Road is a fantastic opportunity for you to learn more about the disease process from experts in the field and meet others with the same condition.

There's an ongoing need to inform the PH community about disease management and timely updates on the latest advancements in PH treatment and care. This workshop aims to provide key information, support and resources that'll help empower you throughout your journey.

Today, you'll have the opportunity to learn about living with and managing PH. This will include key information on required tests for accurate diagnosis, available treatment options, current clinical trials and important lifestyle adjustments for optimal disease management. You will also have the chance to connect with other patients, caregivers, care partners and medical professionals who live in the area.

Thanks again for your participation! Together, we will make great progress in the fight against PH.

Sincerely,

**Kimberly Jackson, B.S.N., R.N.**  
*Co-chair*

**J. Wesley McConnell, M.D.**  
*Co-chair*

MARRIOTT LOUISVILLE DOWNTOWN | SECOND FLOOR



# SCHEDULE AT A GLANCE

TIME	SESSION	LOCATION
8–9 a.m.	Registration and Continental Breakfast	Marriott Ballroom Foyer VII – X
9–9:50 a.m.	<b>General Session #1: Opening and Welcome</b> <i>PH 101: The Journey through Diagnosis and Treatment</i>	Marriott Ballroom VI
9:50–10 a.m.	Break	Marriott Ballroom VII
10–10:50 a.m.	<b>Breakout Sessions #1 (concurrent)</b>	
	<i>Exercise, Cardiopulmonary Rehabilitation and Sexual Health in Pulmonary Arterial Hypertension</i>	Marriott Ballroom VIII
	<i>Balancing Sodium and Fluid Intake</i>	Marriott Ballroom IX
	<i>Pediatric PH</i>	Marriott Ballroom X
10:50–11:20 a.m.	Coffee Break	Marriott Ballroom Foyer VII – X
11:20 a.m.–12:10 p.m.	<b>Breakout Sessions #2 (concurrent)</b>	
	<i>Medication Management: The PHight Against Side Effects</i>	Marriott Ballroom VIII
	<i>Treatment Approaches in PH</i>	Marriott Ballroom IX
	<i>Communication with Emergency Care Providers in Case of PH Emergency</i>	Marriott Ballroom X
12:10–1:30 p.m.	<b>Networking Lunch, Ask the Experts Q&amp;A and Keynote Presentation</b>	Marriott Ballroom VI
1:30–1:40 p.m.	Break	Marriott Ballroom VII
1:40–2:30 p.m.	<b>Support Group Sessions (concurrent)</b>	
	<i>Patients: Support Group for PH patients</i>	Marriott Ballroom VIII
	<i>Parents: Support Group for Parents of Kids with PH</i>	Marriott Ballroom IX
	<i>Caregivers: Support Group for People Who Love Someone with PH</i>	Marriott Ballroom X
2:40–3:20 p.m.	<b>General Session #2: Presentation and Closing</b> <i>Spotlight on PH Research</i> <i>PHA at a Glance</i>	Marriott Ballroom VI
3:30 p.m.	Program Concludes	Marriott Ballroom VI

PHA ON THE ROAD | LOUISVILLE, KENTUCKY

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## SPECIAL CONSIDERATION TO

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## PHA ON THE ROAD | LOUISVILLE, KENTUCKY

### FACULTY PRESENTERS

**Brooke Benninger, M.S.,  
R.D., L.D.**

*Baptist Health Systems*

**Christina Benninger, M.S.N.,  
APRN, FNP-BC, AGACNP-BC**

*Norton Pulmonary Specialists*

**David C. Booth, M.D**

*University of Kentucky  
Healthcare*

**Rebecca D. Brauner, M.S.N.,  
APRN, NP-C**

*Norton Pulmonary Specialists*

**Andrew R. Kolodziej, M.D.,  
FACC**

*University of Kentucky  
Gill Heart & Vascular Institute*

**Yash Kothari, M.D.**

*University of Louisville Health*

**Gillian Leung, PharmD, BCCP**

*University of Kentucky  
Gill Heart & Vascular Institute*

**Kimberly Robinson, APRN**

*Norton Pulmonary Specialists*

**Michelle Sykes, M.D.**

*University of Kentucky,  
Kentucky Children's Hospital*

### PATIENT ADVOCATES

**Denise R. Clark**

*PH patient*

**Nicole Creech**

*Patient advocate and PHA  
Board of Trustees member*

**Evelyn Mitchell**

*PH patient*

**Kelly Wiegele**

*PH parent*

### PULMONARY HYPERTENSION ASSOCIATION

**Matt Granato**

*President & CEO*

**Katherine Kroner**

*Vice President, Advocacy  
and Patient Engagement*



# SESSION DESCRIPTIONS

## REGISTRATION AND CONTINENTAL BREAKFAST

8–9 A.M.

*Marriott Ballroom Foyer (VII – X)*

## GENERAL SESSION #1: OPENING AND WELCOME

9–9:50 A.M.

*Marriott Ballroom VI*

### Welcome

**Matt Granato, LL.M., M.B.A., PHA president and CEO; J. Wes McConnell, M.D., PHA On the Road co-chair; Kimberly Jackson, B.S.N., R.N., PHA On the Road co-chair**

## PH 101 – The Journey Through Diagnosis and Treatment

**Presenter: Christina Benninger, M.S.N., APRN, FNP-BC, AGACNP-BC**  
**Q&A Moderator: J. Wes McConnell, M.D.**

Testing for a PH diagnosis can be overwhelming. These tests can include an echocardiogram, right heart catheterization, pulmonary function testing, sleep studies, exercise testing and various other imaging techniques and laboratory tests. Understanding how the results of these tests lead to different PH diagnoses is essential to comprehending the best treatment options. This presentation will provide an overview of the diagnostic process and what information the test results provide to clinicians.

### BREAK | 9:50–10 A.M.

*Patient Rest Stop/Marriott Ballroom VII*

## BREAKOUT SESSIONS #1

10–10:50 A.M.

### Exercise, Cardiopulmonary Rehabilitation and Sexual Health in Pulmonary Arterial Hypertension

*Marriott Ballroom VIII*

**Panelists: David C. Booth, M.D.; Kimberly Jackson B.S.N., R.N.**

Exercise in World Health Organization (WHO) Group I pulmonary arterial hypertension (PAH), as for everyone, is beneficial. This session will briefly review randomized trial data demonstrating the benefit of exercise, when to consider cardiopulmonary rehabilitation in PAH and a simple plan for starting a walking program (secret: by the watch, not distance or speed). We will also discuss the importance of listening to individuals regarding sexual health. The remainder of the session will be dedicated to answering questions from the audience.

### Balancing Sodium and Fluid Intake

*Marriott Ballroom IX*

**Panelists: Brooke Benninger, M.S., R.D., L.D.; Rebecca D. Brauner, M.S.N., APRN, NP-C**

Being conscious of your sodium and fluid intake is an important goal for patients with PAH. The overconsumption of both fluid and sodium can exacerbate symptoms related to PAH. Education and dietary alterations can help manage these symptoms and raise awareness of what you put into your body.







## Pediatric PH

*Marriott Ballroom X*

**Panelists:** Michelle Sykes, M.D.; Kelly Wiegele, PH parent

From birth to adulthood, there are many unique concerns among parents of children with PH. Join the discussion as we dedicate time for parents and families of infants, kids and teens with PH to ask questions about pediatric PH diagnoses and available surgical and medical treatments. Other specific topics that may be discussed include advocating for your child, open communication with your child's PH care team, emotional support and managing stress as a family, coping with side effects of PH therapies and the transition from pediatric to adult care for young adults.

**COFFEE BREAK | 10:50–11:20 A.M.**

*Marriott Ballroom Foyer VII – X*

## BREAKOUT SESSIONS #2

**11:20 A.M.–12:10 P.M.**

### Medication Management: The PHight Against Side Effects

*Marriott Ballroom VIII*

**Panelists:** Gillian Leung, PharmD, BCCP; Yash Kothari, M.D.

Medications are the mainstay in the management of PH. However, your ability to take these potentially life-altering medications

are often hindered by off-target side effects of the drug products. This session covers common side effects of PH medications. Panelists will share tips and tricks on how to manage these undesirable effects so you can get the most benefits out of your PH therapy.

## Treatment Approaches in PH

*Marriott Ballroom IX*

**Panelists:** J. Wes McConnell, M.D.; Kimberly Robinson, APRN

Patients may be prescribed oral, inhaled, subcutaneous and intravenous therapies that can be used alone or in combination. It is important to understand the various treatment options available to manage the symptoms of PH. This discussion will provide an overview of these treatment approaches and how they work. Additionally, panelists will discuss questions to ask your doctor when you are choosing treatment(s).

## Communication with Emergency Care Providers in Case of a PH Emergency

*Marriott Ballroom X*

**Panelists:** Andrew R. Kolodziej, M.D., FACC; Christina Benninger, M.S.N., APRN, FNP-BC, AGACNP-BC; Nicole Creech, patient advocate and PHA Board of Trustees member

This session will discuss the important use of health information cards and smartphone applications for PH patients in an emergency. You will learn what information is needed, such as patient demographics, emergency contacts and PH provider information, when in an urgent situation. The discussion will highlight the value of communicating which parenteral medications you are on, the dosage and how important it is to avoid abrupt discontinuation. We will also discuss what vital information a caregiver, or person close to the patient, needs to know in the event you are unable to communicate.

# SESSION DESCRIPTIONS

## NETWORKING LUNCH, ASK THE EXPERTS AND KEYNOTE PRESENTATION

12:10–1:30 P.M.

### Ask the Experts

*Marriott Ballroom VI*

**Q&A Moderator: J. Wes McConnell, M.D.**

This open forum discussion will allow patients to connect with PH specialists and receive answers to questions about PH diagnosis, management and treatment.

### Keynote Presentation

*Marriott Ballroom VI*

**Keynote Presenters: Denise R. Clark, PH patient; Evelyn Mitchell, PH patient**

Hear from PH community members about their PH journey and the role PHA has played in helping them thrive.

**BREAK | 1:30–1:40 P.M.**

*Patient Rest Stop – Marriott Ballroom VII*

## SUPPORT GROUP SESSIONS (CONCURRENT)

1:40–2:30 P.M.

### PH Patients: Support Group for PH Patients

*Marriott Ballroom VIII*

**Facilitator: Evelyn Mitchell, PH patient**

Meet other patients diagnosed with PH, discuss long-term coping tips and share stories of how you have found your “new normal” in a confidential, supportive environment. This session is facilitated by a trained PHA patient volunteer and is for patients only.

### PH Parents: Support Group for Parents of Children With PH

*Marriott Ballroom IX*

**Facilitator: Kelly Wiegele, PH parent**

Meet other parents of kids with PH and discuss coping tips, shared challenges and share experiences in a confidential, supportive environment. This session is facilitated by a trained PHA parent volunteer and is for parents only.





## PH Caregivers: Support Group for People Who Love Someone with PH

*Marriott Ballroom X*

**Facilitator: Nicole Creech, PHA Board of Trustees member, PH patient**

Meet other caregivers, discuss coping tips and share your experience in a confidential, supportive environment. This session is facilitated by a trained PHA caregiver volunteer and is for caregivers only.

**BREAK 2:30–2:40 P.M.**

*Patient Rest Stop – Marriott Ballroom VII*

## GENERAL SESSION #2: PRESENTATION AND CLOSING

**2:40–3:20 P.M.**

### Spotlight on PH Research

*Marriott Ballroom VI*

**Speaker: J. Wes McConnell, M.D.; Q&A moderator: Kimberly Jackson, B.S.N., R.N.**

Treatment options for PH continue to expand because of scientists' commitment to advancing PH research. This session will explain the research process and how it leads to promising clinical trials that discover new therapies and patient registries that advance PH. You will also learn about current regional clinical trials and how patients can participate.

## PHA at a Glance

*Marriott Ballroom VI*

**Speaker: Katherine Kroner, PHA vice president, advocacy and patient engagement**

At the PHA at a Glance presentation, learn about PHA's vision of a world without PH empowered by hope, the resources we offer and how you can become part of the PHA community.

## PROGRAM CONCLUDES

**3:30 P.M.**

# ABOUT PH AND THE PULMONARY HYPERTENSION ASSOCIATION

## What Is the Pulmonary Hypertension Association?

Founded in 1991 by patients, for patients, the Pulmonary Hypertension Association (PHA) is the oldest and largest nonprofit patient association in the world dedicated to the pulmonary hypertension community. Our mission is to extend and improve the lives of those affected by PH. To achieve our mission, PHA engages people with PH and their families, caregivers, health care providers and researchers worldwide who work together to advocate for the PH community. We provide support to patients, caregivers and families, offer up-to-date education and information on PH, improve quality patient care and fund and promote research.

## What Is Pulmonary Hypertension?

Pulmonary hypertension (PH) is an umbrella term used to describe a group of complicated, 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 can also 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.

## Who Is Affected by Pulmonary Hypertension?

Adults and children of all ages can develop PH. Women develop PAH (pulmonary arterial hypertension) more than three times as often as men, and people of color have disproportionately poorer health outcomes.

## 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 multiple 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.

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

## 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.

► **Support Groups:** Attending one of PHA's 200+ support groups in your area puts you in touch with patients, families and health care professionals who know and understand what it is to live with PH. These groups meet in-person, virtually, or both. Visit PHA's interactive support group map and calendar at [PHAssociation.org/SupportGroups](http://PHAssociation.org/SupportGroups).

► **Telephone Support Groups:** PHA hosts topical telephone support groups including those for patients, caregivers, parents, young adults, individuals with chronic thromboembolic pulmonary hypertension (CTEPH) and bereaved family members. For more information on how to register for a PHA Telephone Support Group, contact [Support@PHAssociation.org](mailto:Support@PHAssociation.org).

► **Facebook Groups:** PHA currently hosts eight Facebook groups, each focused on a specific group or individual affected by PH. The groups are: CTEPH, Teens with PH, PH and Associated Conditions, Generation Hope: Young Adults with PH, Long-term Thrivers: Living with PH for Several Years, PH Caregivers, Parents of Kids with PH and

Newly Diagnosed with PH. Find a list of our Facebook support groups at [PHAssociation.org/support/social-media](http://PHAssociation.org/support/social-media).

As the oldest and largest PH association in the world, PHA takes part in global initiatives such as the annual World PH Day campaign and PH Awareness Month. Because PH is often caused by another underlying condition such as chronic obstructive pulmonary disease (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 up to 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.

# PH RESOURCES



- Subscribe to **PHANews** to get weekly updates about the latest research, community events and PHA offerings delivered straight to your inbox: [PHANews.org](http://PHANews.org)
- **Pathlight** is PHA's quarterly print magazine for members and donors that provides in-depth information on medical updates, tips on living with PH and stories from the community.
- Visit **PHA Classroom**, PHA's free video library with informative videos of PH experts discussing types of PH, insurance, medications, research and more. [PHAClassroom.org](http://PHAClassroom.org).
- **Find a Doctor** – Find a doctor who treats PH at [PHAssociation.org/Patients/DoctorsWhoTreatPH](http://PHAssociation.org/Patients/DoctorsWhoTreatPH)
- **Research** – Learn about research and find a clinical trial at [PHAssociation.org/Research/Participating-in-Research](http://PHAssociation.org/Research/Participating-in-Research)
- **PHAssociation.org** – Informational pages and downloadable PDFs cover disease overview, treatments, types of PH, testing, grief, lifestyle issues for caregivers and more.

## Join Our Community of Hope

Membership at PHA is more valuable than ever. As the largest patient-centered pulmonary hypertension (PH) organization, PHA proudly offers a unique combination of education, patient and caregiver support and valuable resources designed for the PH patient and caregiver community.

Become a part of our dedicated community of patients, caregivers and health care providers by joining or renewing your membership today. [PHAssociation.org/Join](http://PHAssociation.org/Join).

### FIND US ON:

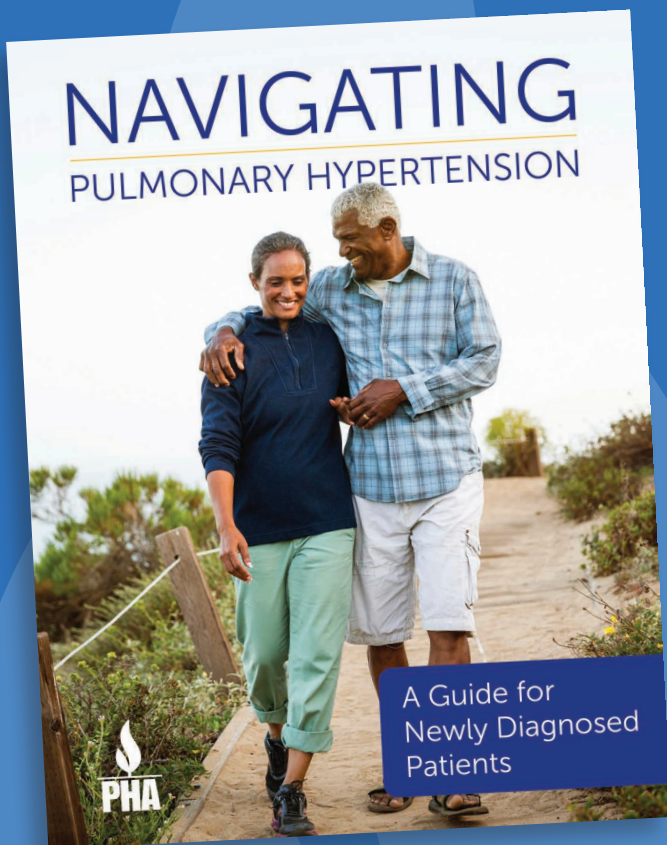
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# Navigating Pulmonary Hypertension:

A Guide for  
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 **Pulmonary Hypertension Association**  
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# PHA 2024

INTERNATIONAL PH  
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**SAVE  
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Make plans to join us  
June 27-30, 2024, for the  
PHA 2024 International PH  
Conference and Scientific Sessions  
in Indianapolis, Indiana