

Patient & Family Symposium Agenda

**subject to change*

Friday, September 25th

Registration & PH Store

3:00 pm – 7:00 pm

Grab your nametag and check out the PH store!

Welcome Reception

5:00 pm – 7:00 pm

Join us for an inspiring evening of PHriends, food, a fundraising raffle, and the opportunity to connect and meet others in the pulmonary hypertension community

Saturday, September 26th

Breakfast & Registration

8:00 am – 9:00 am

Opening Remarks

9:00 am – 9:30 am

Introductory Remarks

Speakers: Jamie Myrah, Executive Director & Joan Paulin, Board Chair

Opening Plenary

9:30 am – 10:30 am



Exploring the Future of PH Therapies

Presenter & Moderator: Dr. Mitesh Thakrar

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Change is underway in pulmonary hypertension care, bringing renewed hope to patients and families. In this forward-looking opening plenary, a panel of leading PH medical experts will explore what's coming next—from cutting-edge research to emerging treatments and new approaches to care. Learn how ongoing advancements pave the way for meaningful change and offer hope for a brighter future. Don't miss this chance to hear directly from the experts shaping what's ahead for the PH community.

Break

10:30 am – 10:45 am

Movement Break

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Break Out Sessions

10:45 am – 11:30 am

PH Basics: The 5 Groups and How We Treat Them



Pulmonary hypertension (PH) is a complex condition with different causes, symptoms, and treatments depending on the type. In this session, we'll break down the five WHO groups of PH in simple, understandable terms. You'll learn what sets each group apart, how they are diagnosed, and what treatment options are available. Whether you're newly diagnosed or just looking to better understand the basics, this session will give you a solid foundation to navigate your PH journey.

Restoring Within: Exploring Pulmonary Rehabilitation

This breakout session will delve into the importance of exercise rehabilitation for individuals living with PH. Participants will learn about the benefits of pulmonary rehabilitation, including how it can improve quality of life, enhance physical endurance, and support overall heart and lung health. An expert instructor will guide attendees through a series of safe, tailored exercises to help manage PH symptoms.

The Pediatric PH Journey: From Diagnosis to Treatment to Transition

Navigating pulmonary hypertension (PH) in children is a journey filled with unique challenges and milestones. This session will explore the full pediatric pulmonary hypertension experience—from the initial diagnosis and treatment options to the transition from pediatric to adult care. Medical experts and patient families will share insights into managing symptoms, supporting development, and planning for the future. Whether you're a parent, caregiver, or a young person living with PH, this session offers guidance, support, and hope every step of the way.

Breaking the Silence: Conversations That Support Wellbeing

Living with pulmonary hypertension can bring difficult thoughts and conversations—both within ourselves and with those closest to us. This session will help patients and caregivers navigate these moments with greater confidence and care. We'll explore how to approach tough conversations about fears, boundaries, changing roles, and emotional needs, with practical tools to support more open, honest, and compassionate communication.

Break

11:30 am – 12:00 pm

Movement Break

Break Out Sessions

12:00 pm – 12:45 pm

On the Move: Travelling Safely with PH



Living with pulmonary hypertension doesn't mean you have to stay close to home. This session will explore how to plan and travel safely with PH, whether you're heading out for a weekend getaway or a longer journey. From managing oxygen and medications on the go to navigating airports and finding travel insurance, we'll cover practical tips and share real-life experiences to help you feel confident and prepared when you're on the move.

Mythbusters: Q&A with PH Medical Experts

Join us for a dynamic Q&A session featuring a panel of expert pulmonary hypertension medical professionals. This interactive session provides a unique opportunity for participants to ask questions about PH. Our experts are ready to debunk myths, clarify misconceptions, and provide evidence-based answers to help you better understand PH.

Tips & Tricks: Practical Tips for Daily Living with PH

Join a panel of experienced PH patients and caregivers who have been living with and supporting loved ones with PH for more than 20 years. This session offers a unique opportunity to learn firsthand practical advice and strategies for navigating daily life with pulmonary hypertension. From managing fatigue and nutrition to navigating oxygen therapy, symptom tracking, caregiving responsibilities, and adapting to the challenges of chronic illness, these seasoned community members will share valuable tips and insights gained through decades of lived experience. Whether you are newly diagnosed, have been living with PH for years, or are caring for someone with PH, come hear from people who truly understand the realities of life with PH — and the many ways to adapt, cope, and thrive together.

You Don't Have to Do This Alone: Building Your Support System

Living with PH can feel overwhelming at times—but having the right support can make a meaningful difference. This session will explore the many forms a support system can take, from family and friends to healthcare teams and peer connections within the PH community. Together, we'll look at how to identify the support you need, how to ask for it, and ways to build and strengthen a network that works for you—so you can feel more connected and supported.

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Lunch Break

12:45 pm – 1:45 pm

Buffet & Networking

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Community Connection Block

1:45 pm – 2:45 pm

Take a break from presentations and connect with others in the PH community through guided small-group conversations. This interactive session is designed to create space for meaningful discussion, shared experiences, and new connections in a welcoming and supportive environment.

Break

2:45 pm – 3:15 pm

Movement Break

Break Out Sessions

3:15 pm – 4:00 pm

Your Heart and PH: Understanding the Connection



The heart plays a critical role in pulmonary hypertension, but the ways PH affects the heart can look very different from person to person. In this session, a PH physician will explore the biology behind PH and the heart, explain why heart function is so important in all types of PH, and share insights into current research and care. Alongside the medical perspective, several individuals living with PH and heart-related complications will share their personal experiences, offering real-world insight into the many different ways the heart can be involved in PH.

Managing Side-Effects of Treatments

Living with PH treatments can come with challenges, but patients often develop practical and creative ways to manage side effects in their daily lives. In this discussion-based session, medical professionals and patients from the PH community will share insights into common treatment side effects, along with real-world experiences and coping strategies. Attendees will leave with practical tips, shared experiences, and a better understanding of how others navigate treatment while maintaining quality of life.

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Caregivers Need Care Too (session open to caregivers only)

Caregivers provide important support, including physical and emotional assistance, in various settings. But caregivers need support, too. This breakout session will allow caregivers to connect with each other, share their experiences, and gather some practical tips and strategies to help support their well-being.

Closing Remarks

4:00 pm – 4:30 pm

Closing Remarks

Speakers: Jamie Myrah, Executive Director &
Joan Paulin, Board Chair



Sessions will be livestreamed for virtual participants