

# Patient & Family Symposium Agenda

*Draft version subject to change*

## Friday, September 12<sup>th</sup>

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### Registration Open

4:30 pm – 7:00 pm

Come early to collect your nametag and conference kit and purchase your PH swag!

### Cocktail Reception

6:30 pm – 8:30 pm

Join us for an inspiring evening of PHriends, food, and entertainment, as well as a special program honouring the newest Eternal PHriend of PHA Canada. Family friendly.

## Saturday, September 13<sup>th</sup>

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### Breakfast & Registration

8:00 am – 9:00 am

Registration & Networking

### Kids Room

8:30 am – 4:30 pm (closed for lunch)

A room dedicated to the little ones

### Opening Remarks

9:00 am – 9:30 am

Introductory Remarks

### Opening Plenary

9:30 am – 10:15 am



### Living Well with Pulmonary Hypertension

In this opening plenary, a panel of patients and caregivers will share personal reflections on what it means to live well with pulmonary hypertension. Through stories of resilience, daily strategies, and hard-earned insights, they'll explore the supports that have helped them thrive, the challenges they've faced, and what needs to change to help others live their best lives with pulmonary hypertension.

### Break

10:15 am – 10:30 am

Movement Break

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## Break Out Sessions

10:30 am – 11:15 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 newly diagnosed or just looking to understand the basics better, this session will give you a solid foundation to navigate your PH journey.

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### **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.

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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.

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### **Walking the Transplant Path:** Voices from the PH Community

For some people living with pulmonary hypertension, lung transplantation becomes a necessary part of their treatment journey. In this powerful session, you'll hear from individuals who have undergone transplant surgery, as well as from others for whom transplant may become a life-saving option in the future. They'll share their personal experiences—what led them to this point, how they prepared, and what life has been like after surgery. With honest reflections on the challenges, hopes, and lessons learned, this session offers real insight and support from those who have faced, or are facing, the possibility of this life-changing procedure.

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## Break

11:15 am – 11:30 am

## Movement Break

## Break Out Sessions

11:30 am – 12:15 pm

### **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.

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### **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.

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### **Managing Infusion-Based Therapies** (Panel with patients + nurse)

Delve into how therapies like Caripul and Remodulin work in the body and the benefits they offer to patients with PH. A panel of patients will also discuss practical strategies for managing pain and other side effects associated with these treatments. Gain valuable expert insights and learn how to optimize your experience with infusion-based therapies for better health outcomes.

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### **Stepping Into Research:** The Patient Experience in Clinical Trials

Clinical trials are essential to advancing pulmonary hypertension (PH) treatment, but what is it really like to participate in one? This session brings together researchers and patients to explore the clinical trial experience from both sides. Panellists will discuss the goals and design of PH clinical trials, what participation involves, and how patient voices are shaping the future of research. Patients will share their firsthand experiences—why they chose to participate, what they learned, and what they wish they had known. Whether you're curious about getting involved in research or want to better understand how clinical trials work, this session offers an honest, human-centred look at the path from study to breakthrough.

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## Lunch Break

12:15 pm – 1:30 pm

Foyer

Buffet & Networking

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## Break Out Sessions

1:30 pm – 2:15 pm

### Mythbusters: Q&A with PH Medical Experts

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### Take Charge of Your Finances: How to Access the Benefits You Deserve

Living with pulmonary hypertension can bring financial challenges, but you don't have to face them alone. This practical session will help you understand and access the financial support available to you. Experts will break down government benefits, disability programs, tax credits, and other resources that can ease the burden. You'll also hear tips on navigating application processes and advocating for yourself when systems get complicated. Whether you're newly diagnosed or looking to maximize your support, this session will empower you to take control of your financial well-being.

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### Navigating the Emotional Challenges of Chronic Illness

Living with PH can be a journey filled with disruptions, uncertainties and challenges. This session focuses on concepts from the psychology of adjustment including ways of coping with stress and acceptance. In this facilitated discussion with 2 clinical psychologists, we will explore practical and evidence-based techniques for coping, reducing emotional suffering, and enhancing your quality of life.

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### CTEPH 101: What Patients Need to Know

Chronic thromboembolic pulmonary hypertension (CTEPH) is a type of PH caused by blood clots that don't clear from the lungs. This session is a great opportunity to learn more about CTEPH, its diagnosis, and available treatment options, including medications and surgical procedures. Whether you live with CTEPH or want to understand this condition better, this session will provide clear, practical information to support your journey.

## Break

2:15 pm – 2:45 pm

Refreshments & Networking

## Closing Plenary

2:45 pm – 4:00 pm



## Next Steps: Exploring the Future of PH Therapies

Change is underway in pulmonary hypertension care, bringing renewed hope to patients and families. In this forward-looking closing 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.

## Closing Remarks

4:00 pm – 4:30 pm

Closing remarks



Sessions will be livestreamed for virtual participants

## Kids room

The Kids Room will be open all day Saturday. Kids must be picked up by their parents for lunch. All youth who will be participating in the kids' program must be pre-registered before the conference begins. The program for the day will include fun-filled games and activities to keep even the littlest PHighters happy. All children between the ages of 4 and 16 are welcome to join!

