



2024
PH COMMUNITY CONFERENCE
CONFÉRENCE COMMUNAUTAIRE SUR L'HTP
September 19-21 septembre
CALGARY

THE PULMONARY HYPERTENSION ASSOCIATION OF CANADA PRESENTS
**THE PULMONARY HYPERTENSION
COMMUNITY CONFERENCE**

THURSDAY - SATURDAY
September 19-21

CALGARY, AB

2024
CONFERENCE PROGRAM



Dear PHriends,

It is with great excitement and heartfelt gratitude that I welcome you to the 2024 PH Community Conference. This year, our theme, “Diverse Voices, Shared Experiences”, embodies the spirit of what makes our community so special. We chose this theme to celebrate the unique stories and perspectives that each of you brings, whether you are a patient, a family member, or a caregiver.

Throughout Canada, our voices are as diverse as our landscapes, yet within this diversity, we find shared experiences that connect us in profound ways. The challenges, the triumphs, and the resilience that come with living with PH are threads that weave us together, creating a tapestry of understanding and support.

This conference is more than just a gathering; it is an opportunity to meet those who truly get it—those who understand the journey of living with PH. It is a chance to share your voice and listen to others who might sound just like you. Together, we will connect, inspire, and challenge one another, forging bonds that will last far beyond these two days.

Thank you for being here and sharing your hearts, minds, and stories. Your presence enriches our community, and I am eager to meet each of you, hear what brought you here, and share the experiences that will make this conference unforgettable.

Wishing you all a wonderful and inspiring conference experience!



Kimberly Brunelle
Director, Strategic Initiatives

Welcome to the 2024 PH Community Conference



Welcome from the board

On behalf of the Board and as incoming Board Chair, I would like to welcome all of you to the 2024 PH Community Conference. I was thrilled to hear that the conference theme is “Diverse Voices, Shared Experiences” because that is our community.

My daughter was diagnosed with PAH in 2014 at the age of 24. While our journey with PHA Canada began on the day of her diagnosis, it has been the patients in our community that we have turned to during some of our toughest days. Whether it was attending an in-person support group at the beginning of our journey, joining Online Meetups during COVID or my perennial favourite, the Canadian PHriends Facebook group, we knew that you knew! And because of that, we know that we are not alone. No matter where we live or where we are on our journey, our individual voices speak to the shared experiences that only others travelling on this journey can truly understand.

My wish for all of you is that Conference provides you, whether you are the patient, the caregiver, the family member, or the friend, with the opportunity to meet, reunite, and build friendships with the people who “get you” and that you experience the sense of hope that comes from knowing that you are part of a caring, supportive community.

Thank you for being here, for sharing your story, and for listening to others’ experiences. I hope to meet many of you. Together, our diverse voices and shared experiences raise each other up!



Joan Paulin
Board Chair

Exhibits

PH Store - South Foyer

Friday 4:30 - 7:30pm - Saturday 8:00am - 4:30pm

The PH store will be available on Friday evening and throughout the day on Saturday with new t-shirts, hoodies, water bottles, and more! Proceeds from all purchases help fund PHA Canada's programs and services. Additional sizes and colours are also available anytime on our online store at phacanada.ca/store.

PH Info Table - South Foyer

Saturday 8:00am - 2:45pm

On Saturday, visit our PH information table hosted by PH medical professionals who can answer questions and provide you with resources.

Caregivers Alberta - South Foyer

Saturday 8:00am - 2:45pm

Caregivers Alberta provides resources, support and education to help people provide care to family members or friends. Their mission is to empower caregivers and promote their well-being. PHA Canada is happy to welcome them to conference this year! Be sure to visit their booth and all caregivers are invited to attend their breakout session "Caregivers Need Care Too".

Visit their website to learn more about their programs and services - www.caregiversalberta.ca

Meet your Ambassadors

Keep an eye out for your PH Ambassadors throughout the conference! You can easily spot them in their purple t-shirts. They're here to help guide you, answer any questions, and offer a friendly face when you need someone to talk to. PH Ambassadors include individuals living with PH, family members, and caregivers who work with PHA Canada to extend its reach nationwide and provide leadership to the PH community. Learn more about PH Ambassadors at phacanada.ca/ambassadors

Meet your PHriends

Colour-coded nametags will help you get to know your new PHriends:

Patient



Caregiver or Family



Medical Professional



PH Supporter



PHAware

Phaware® wants to share your PH and rare disease expertise with their engaged global audience. They are enlisting PAH Experts, Patients, Caregivers and Global Thought Leaders to participate in podcast interviews taking place during the 2024 PH Community Conference in Calgary, on September 20th. Please visit phaware.global/interviews to learn more and schedule an interview time.

For the Kids

The Kids Room will be open Saturday during the hours listed below. 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!

Kids Room

Location: Nakiska (lower level)

Date & Time: Saturday, September 21 – 8:30am – 4:30pm



Conference at a Glance

Thursday, September 19th

**by invitation only.*

Time	Event	Room
8:00-12:00pm	*CAPHNet Meeting	Brownlee
12:00-5:30 pm	*Medical Think Tank	Nakiska
8:00-4:00 pm	*CPHPN Meeting	Barclay

Friday, September 20th

7:00-5:00 pm	*Medical Think Tank	Nakiska
8:00-4:00 pm	*CPHPN Meeting	Barclay
11:00-4:00 pm	*Ambassador Workshop	Lake Louise
6:00-8:00 pm	Cocktail Reception	Britannia/Belaire

Saturday, September 21st

8:00-9:00 am	Breakfast & Registration	South Foyer
9:00-9:30 am	Opening Remarks	Britannia/Belaire
9:30-10:30 am	Opening Plenary	Britannia/Belaire
10:30-10:45 am	Break	South Foyer
10:45-11:30am	Break Out Sessions	Multiple Rooms
11:30-11:45 am	Break	South Foyer
11:45-12:30pm	Break Out Sessions	Multiple Rooms
12:30-1:45pm	Lunch	South Foyer
1:45-2:30pm	Break Out Sessions	Multiple Rooms
2:30-2:45 pm	Break	South Foyer
2:45-4:00 pm	PH Community Café	Britannia/Belaire
4:00-4:30 pm	Closing Remarks	Britannia/Belaire

Friday, September 20th

Registration & PH Store

4:30 pm – 7:30 pm
South Foyer

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

Cocktail Reception

6:00 pm – 8:00 pm
Britannia/Belaire

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 21st

Breakfast & Registration

8:00 am – 9:00 am
South Foyer

Hot Buffet, Registration & Networking

Sponsored by  **MERCK**

Opening Remarks

9:00 am – 9:30 am
Britannia/Belaire

Introductory Remarks

Speakers: Jamie Myrah, Executive Director & Dr. Lisa Mielniczuk, Past-Board Chair

Opening Plenary

9:30 am – 10:30 am
Britannia/Belaire



Sponsored by  **MERCK**

Bench to Bedside: Exploring the Future of PH Care & Treatment

Moderator: Joan Paulin

Speakers: Dr. Sanjay Mehta, Dr. Lisa Mielniczuk, Dr. Jason Weatherald

This session will provide an overview of the future of PH care and treatment. Attendees will gain a unique perspective on the most promising upcoming clinical trials, groundbreaking research, and other critical developments poised to impact the daily lives of those living with PH.

Break

10:30 am – 10:45 am
South Foyer

Movement Break

Conference Program

Break Out Sessions

10:45 am – 11:30 am

Managing Infusion-Based Therapies



Britannia/Belair

Speakers: Lisa Kolkman NP, Marion Roth, Kaitlyn Salonga, Jay Scraba

This session will 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 insights from experts and learn how to optimize your experience with infusion-based therapies for better health outcomes.

Navigating Relationships with PH

Bonavista

Speakers: Sonya Collins, Brad Lynch, Joanne Schwartz MSW RSW

Living with PH presents unique challenges, especially when it comes to relationships. This session will delve into the intricacies of maintaining healthy relationships while managing a chronic illness. Whether it's with family, friends, or partners, learn strategies to navigate your relationships more effectively and strengthen your connections.

Building Successful Partnerships Between Patients and Researchers

Mayfair

Speakers: Dawn Clarke, Joan Gibson, Dr. Lisa Mielniczuk, Dr. Jason Weatherald

In 2024, PHA Canada's Patient Partners in Research program facilitated a series of conversations between patients and researchers involved in the Canadian Right Ventricular AdaptiVE (CRAVE) feasibility project. This session will share stories about the experiences, challenges, and perspectives in developing the CRAVE study, highlighting its progress and the creation of guidelines for effective communication, collaboration, and conflict resolution within the team. Learn how engaging patients as partners enhances the relevance, importance, and impact of research, and discover practical insights for building successful patient-researcher partnerships.

Beyond Diagnosis: Working with PH

Mount Royal/Rideau

Speakers: Jennifer Bryson, Don Downey, Maureen Harper, Tarya Morel

For individuals living with PH and their caregivers, maintaining employment and financial stability can be a significant challenge. The impact of PH extends far beyond the diagnosis, affecting not only health but also the ability to keep a job and earn an income. This breakout session is dedicated to exploring the real-world implications of living with PH in the workforce.

Growing Up with PH

Lakeview

Speakers: Cynthia Neilson, Janette Reyes MN NP-Paediatrics, Heather Zloty, Olivia Zloty

Growing up with PH brings unique challenges that impact not just the patients but their entire families. This breakout session brings together a diverse panel of voices, including parents of children with PH, teen and young adult patients, and pediatric healthcare professionals. Together, they will share their experiences, insights, and strategies for managing the complex journey from childhood to adulthood with PH.

Break

11:30 am – 11:45 am

Movement Break

Break Out Sessions

11:45 am – 12:30 pm

Pediatric PH: Advances in Therapies



Britannia/Belair

Speakers: Janette Reyes NP, Dr. Erika Vorhies

Join us for an insightful session on the latest advancements in therapies for pediatric PH. This session will cover cutting-edge treatments and innovative approaches designed specifically for children with PH. Experts in the field will share recent research findings, discuss the effectiveness of new therapies, and explore future directions in pediatric PH care.

“But You Don’t Look Sick?”: Communicating With Friends & Family

Bonavista

Speakers: Jas James, Brooke Paulin, Joanne Schwartz MSW RSW

Living with PH often comes with the challenge of helping friends and family understand an invisible illness. In this session, we will explore effective communication strategies to convey the realities of living with PH to your loved ones. Through shared experiences and expert advice, you’ll learn how to articulate your needs, set boundaries, and foster empathy and support from those around you.

Oxygen Therapy in PH

Lakeview

Speakers: Kathy Downey, Anila Khan RTT

Explore the critical role of oxygen therapy in managing PH in this informative session. We will discuss the benefits of oxygen therapy, how it improves oxygen levels in the blood, and its impact on reducing symptoms and enhancing the quality of life for PH patients. Join us to understand how oxygen therapy can be optimized for better health outcomes in PH.

Mythbusters: Q&A with PH Medical Experts

Mount Royal/Rideau

Speakers: Carolyn Doyle-Cox APN, Dr. Naushad Hirani, Elizabeth Tangalin RN BScN, Dr. Mitesh Thakrar

Join us for a dynamic Q&A session featuring a panel of expert PH 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.

Restoring Within: Exploring Exercise Rehabilitation

Mayfair

Speaker: Dr. Rhea Varughese

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 and tailored exercises designed to help manage PH symptoms.

Conference Program

Lunch Break

12:30 pm – 1:45 pm
South Foyer

Buffet & Networking

Sponsored by



Break Out Sessions

1:45 pm – 2:30 pm

Managing Side-Effects of Treatments



Britannia/Belair

Speakers: Kelly Gould RN BN CCN(C), Dr. Krista Kemp

This breakout session will provide invaluable insights into managing the side effects of common medications prescribed for PH. Led by two experienced medical professionals, the session will cover strategies for recognizing, understanding, and alleviating the side effects associated with PH treatments. Attendees will gain practical tips for managing symptoms, improving comfort, and maintaining quality of life while on these medications.

Breathing New Life: Advances in Lung Transplantation

Mayfair

Speakers: Sophia Ricci, Stephanie Ricci, Natalie Roy, Dr. Rhea Varughese

Join us for an enlightening breakout session on lung transplantation, where medical expertise meets real-life experiences. Led by a seasoned medical professional, this session will explore the latest advances in lung transplantation for PH patients. You will hear firsthand accounts from individuals who have undergone the procedure as they share their journeys from transplant to recovery and beyond.

Navigating the Emotional Challenges of Chronic Illness

Bonavista

Speakers: Joanne Schwartz MSW RSW

Living with PH can be a journey filled with uncertainties and challenges. This session focuses on the concept of radical acceptance, a powerful approach to embracing change and finding peace amidst the difficulties of a chronic illness. We will explore practical techniques for accepting reality as it is, reducing emotional suffering, and enhancing your quality of life.

*Caregivers Need Care Too

Mount Royal/Rideau

Speakers: Vance Collins, Jessie Cullum, Karen Cuthbertson, Garnet Heffernan

In this breakout session, we focus on those who provide care and support to loved ones with PH. This session will feature a panel of dedicated caregivers who will share their personal journeys, discussing the challenges, rewards, and emotional toll of caregiving. The session will highlight the importance of self-care and community support, offering practical tips and resources to help caregivers maintain their well-being while continuing to care for others. ***For caregivers only**

Mythbusters: Q&A with PH Medical Experts

Lakeview

Speakers: Andrea Gardner RN, Dr. Sanjay Mehta, Gail Nicholson RN

Join us for a dynamic Q&A session featuring a panel of expert PH 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.

2024 PH Community Conference

Break

2:30 pm – 2:45 pm

Refreshments & Networking

Sponsored by



PH Community Café

2:45 pm – 4:00 pm

Britannia/Belaire

As the closing session of our conference, The PH Community Café offers a space for reflection, connection, and forward-thinking. This plenary invites participants to come together in small, interactive groups to discuss the day's insights and experiences. Through guided questions, you'll have the opportunity to share what you've learned, exchange perspectives with fellow attendees, and consider how you can apply these insights moving forward in your journey with PH. Join us as we wrap up the day with meaningful conversations and community-building.

Closing Remarks

4:00 pm – 4:30 pm

Britannia/Belaire

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

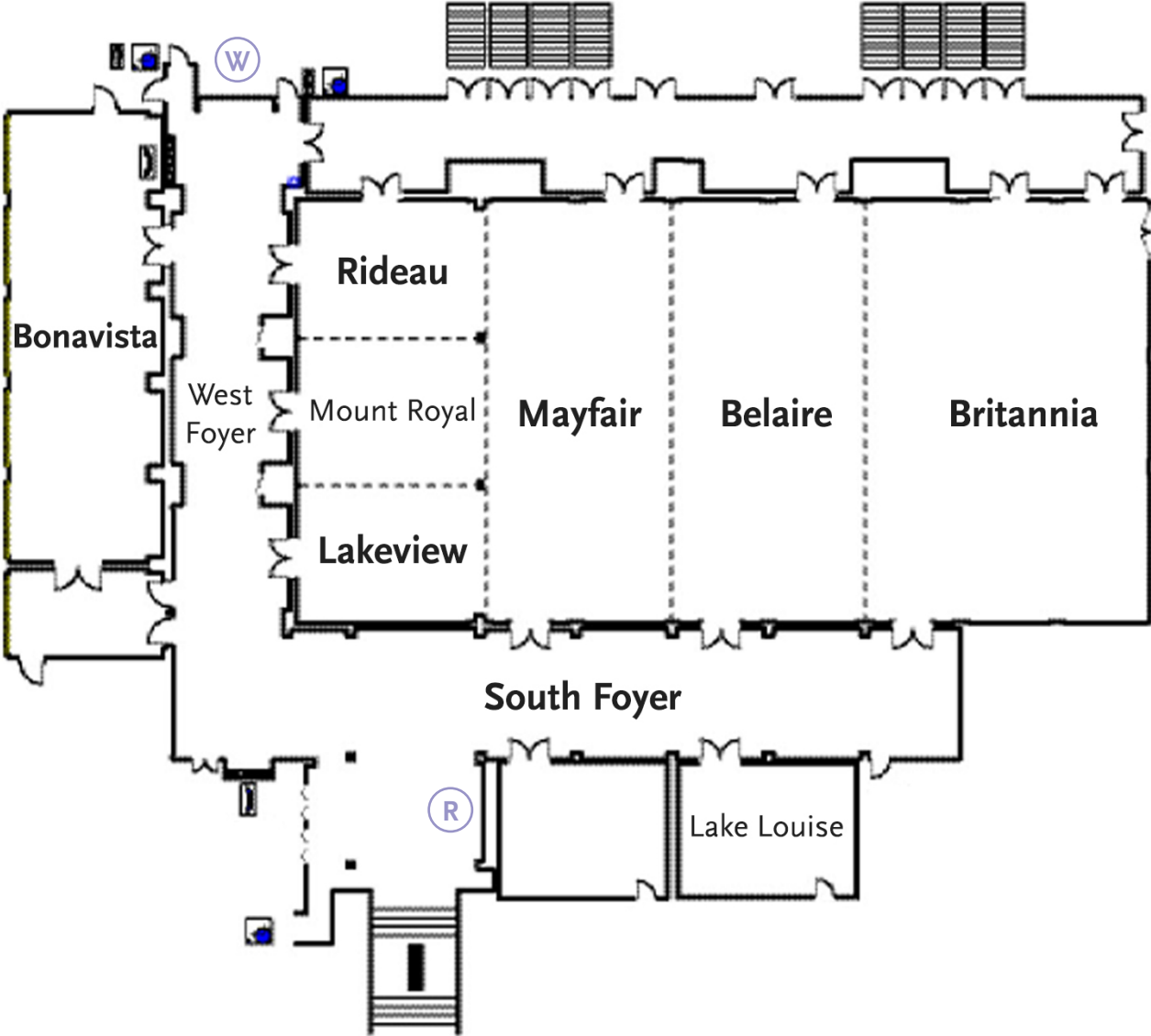


Sessions will be livestreamed for virtual participants



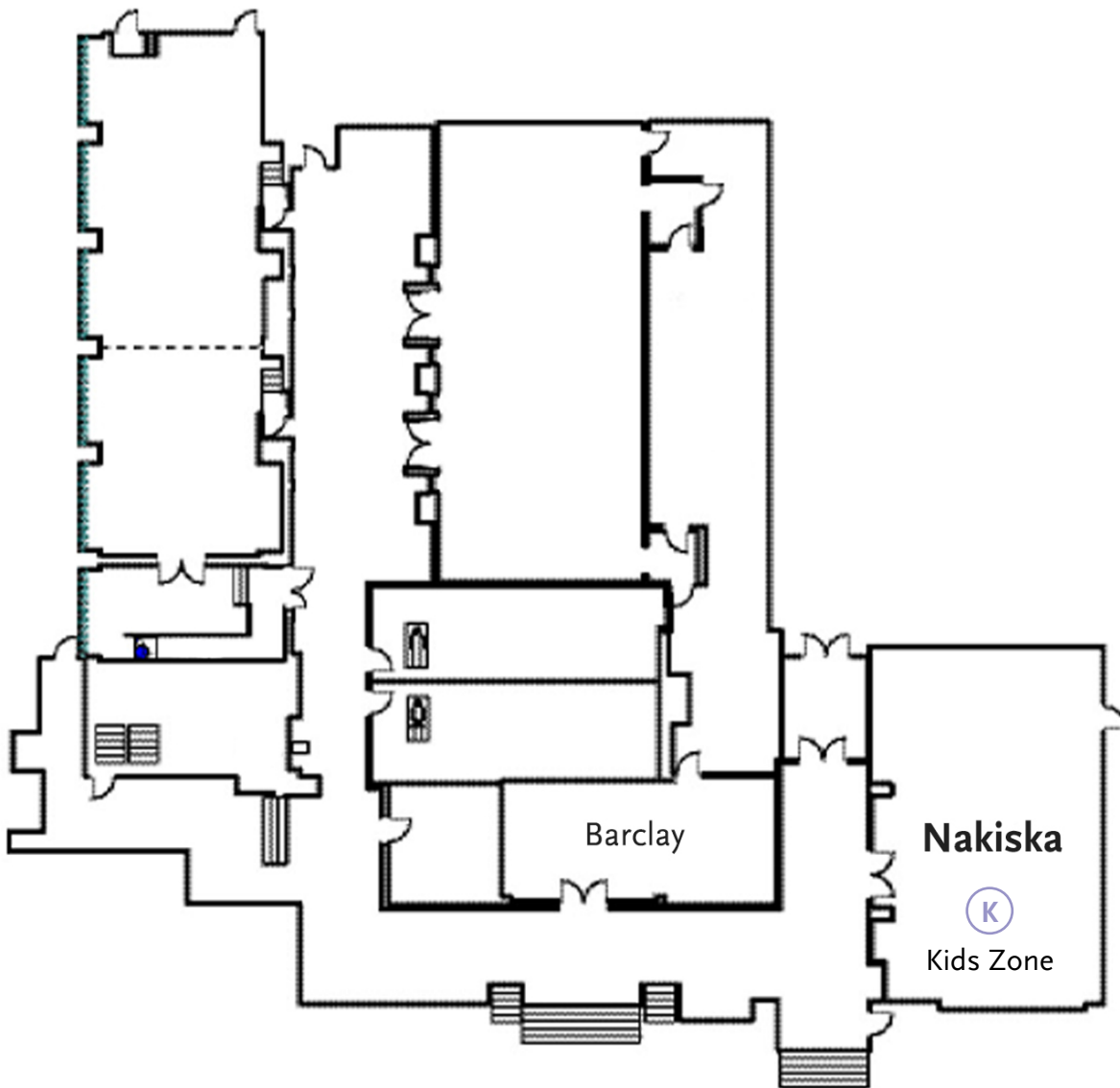
Conference Floor Plan

Conference Level



- R Registration
- W Washrooms

Lower Level



Community Support

Thank You to Our Volunteers

PHA Canada gratefully acknowledges the support and contributions of the many people who have made this event possible. We wish to take this opportunity to thank the following volunteers:

PH Medical Think Tank Programs Committee

Dr. Angela Bates
Dr. George Chandy
Andrea Gardner RN
Dr. John Granton (Committee Chair)
Dr. Paul Hernandez
Lisa Kolkman NP
Dr. Luc Mertens
Janette Reyes NP
Dr. Rhea Varughese

Community Conference Program Committee

Dawn Clarke
Sonya Collins
Don Downey
Kathy Downey
Jas James
Tarya Morel
Gail Nicholson RN
Brooke Paulin

Event Volunteers

Jennifer Bryson
Dawn Clarke
Sonya Collins
Karen Cuthbertson
Don Downey
Kathy Downey
Lindsay Forsyth-Brochu
Joan Gibson
Kelly Kerwin

Kyla Murray
Cynthia Neilson
Joan Paulin
John Pettifor
Michael Pohanka
Janette Reyes
Bob Roth
Marion Roth
Whitney Roth

Kaitlyn Salonga
Allison Shaw
Jay Scraba
Jane Sernoskie
Susan Silver
Darlene Vatcher-Thomas
Andrea Toews

Speakers

Thank you also to our speakers for sharing their time and expertise. Scan the QR code to learn more about this year's fabulous conference speakers or visit phacanada.ca/speakerslist.



Eternal PHriend Recognition



In 2018, PHA Canada established the “Eternal PHriend” title to honour individuals whose dedication has been vital in uniting Canada’s PH community. This year, we are proud to recognize Jas James with this distinguished honour.



Jas James

“Jas’s journey with PH spans over two decades, during which she has exemplified resilience, compassion, and unwavering dedication to supporting others facing similar challenges. Whether it be stuffing envelopes, participating on conference committees, volunteering at registration tables, speaking on educational panels about her experiences, meeting up with hospitalized PH patients, advocating for drug coverage with politicians, contributing to PHA Canada’s magazine *Connections*, you can always count on Jas to lend a hand.”

Beth Slaunwhite, PAH Patient and Board Director

We are honoured to name Jas James as an Eternal PHriend of PHA Canada. Her enduring commitment to the PH community stands as a testament to the power of resilience and compassion.



Welcome to Calgary

When you arrive in the city for the **2024 PH Community Conference**, you'll quickly discover why Calgary was recently chosen by Condé Nast Traveller readers as the 'world's friendliest city'. Calgary's people, places and stories are its biggest strengths, making Calgary a diverse and welcoming destination for all.

From its bustling downtown to character-filled neighbourhoods, Calgary boasts an exploding culinary, arts and culture scene, along with an impressive list of attractions.

- **EXPLORE** over 200 restaurants in Calgary's downtown core, where you can indulge in a diverse array of culinary delights.
- **EXPERIENCE** North America's most extensive urban pathway and bikeway network with approximately 1000 km of region pathways and 96 kms of trails.
- **DISCOVER** Calgary's many attractions. From the polar bears making a splash at the Wilder Institute/ Calgary Zoo to the sky-high views of the Calgary Tower, the city provides an experience you won't forget.
- **VISIT** Calgary's diverse neighbourhoods. From the shops and restaurants of 17th Avenue to the live music venues of Inglewood, there is no better way to immerse yourself.

Unlock savings with the Calgary 'Explore More' 2024 Pass

Access exclusive discounts at over 50 restaurants, attractions, shops, and more with the mobile -exclusive **Calgary 'Explore More' 2024** Pass, designed for you to enjoy during your downtime. This complimentary pass is reserved exclusively for delegates. Sign up today and prepare for your visit!

Sign-up: www.visitcalgary.com/calgary-explore-more-2024-pass

Promo Code: **YYC2024**

Start planning your visit to Calgary at - www.visitcalgary.com/PHA2024

We look forward to seeing you in Calgary!



PH Awareness Month and the 6-Minute Walk for Breath

What is PH Awareness Month?

Each November, the global PH community unites for PH Awareness Month, a time to raise awareness about PH and highlight the need for earlier diagnosis, better treatments, and a cure. Patients, families, and advocates come together to emphasize the importance of recognizing and addressing this serious condition.

The 6-Minute Walk for Breath

Since 2012, the PH community has participated in the 6-Minute Walk for Breath during PH Awareness Month. This event raises funds for PHA Canada and educates the public about the challenges of living with PH. Participants walk for six minutes while wearing a mask and holding weights, simulating the physical strain that PH patients experience, and fostering greater understanding.



The Power of 6

This year, we're using the "Power of 6" to spread awareness further. Join a local PH clinic team or create your own for the 6-Minute Walk for Breath. The idea is simple: tell 6 people about PH and the 6-Minute Walk, and ask them to share it with 6 more people. This ripple effect will help us reach more people and raise more awareness. Together, we can make a significant impact this November, raising awareness and funds for those affected by PH.

Let's walk, share, and make a difference!

Learn more about PH Awareness Month and the 6-Minute Walk for Breath at: www.phacanada.ca/NAM

THANK YOU TO OUR SPONSORS

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