PULMONARY HYPERTENSION ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION PULMONAIRE DU CANADA

CONNECTIONS

The Official Magazine of the Canadian PH Community















Special Feature:

Travel & PH

Message from the PHA Canada Team

September was a special month for our team as we gathered in Vancouver for our annual PH Community Conference. This year's theme, **Pathway of Hope**, was a beautiful reflection of what the weekend was all about: finding hope in connection, in knowledge, in new possibilities, and in one another. Bringing together patients, caregivers, healthcare professionals, and members of the PH community from across the country, the weekend was filled with learning, laughter, meaningful conversations, and plenty of opportunities to connect. Whether it was someone attending their first conference or reconnecting with friends they've known for years, it was a wonderful reminder that hope can take many forms—and that we don't have to walk our paths alone.

In this fall issue of *Connections*, we're turning our attention to **Travel & PH**—a topic that comes with questions for many people in our community, whether you're planning a big adventure, a visit with family, or simply navigating travel closer to home. For many people living with PH, travel can bring excitement and a welcome change of scenery, but it can also come with questions and extra planning. How do you prepare for a trip? What should you consider when travelling by plane? How do you manage medications, oxygen, mobility, or unexpected challenges along the way?

We've brought together information and personal perspectives to help make travelling with PH feel a little more manageable. Whether you're planning a big adventure, visiting family, taking a road trip, or simply thinking about travelling again, we hope this issue gives you practical ideas, reassurance, and the confidence to explore what's possible for you.

And as we look toward November, we're getting ready for **PH Awareness Month** and the **6-Minute Walk for Breath**. This annual campaign is a wonderful opportunity to get moving, raise awareness, honour the experiences of those affected by PH, and come together as a community. Whether you participate by walking, fundraising, sharing your story, or cheering others on, every step helps make PH more visible and brings us closer to a future where no one has to face this disease alone.

Thank you for being part of the *Connections* community and for continuing to read and share this magazine. We put a lot of care—and a lot of heart—into every issue, and we're grateful to have the opportunity to bring these stories and resources to you twice a year.

With gratitude,
The PHA Canada Staff Team



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Memo:
Inside PHA Canada

Welcome to *Connections'* message board. This is your peek into things happening inside PHA Canada, from changes in leadership to new resources, special events, and more.

Ed Rathonyi retires from the Board



At this year's Annual General Meeting in June, PHA Canada's members acknowledged the longtime service of retiring board director Ed Rathonyi. Ed became a director in 2018, bringing with him first-hand experience of being a parent and caregiver to his young daughter, who was diagnosed with pulmonary hypertension in late 2014. During the preliminary PH diagnostic procedures, Ed and his wife found PHA Canada online, and Ed soon became a committed member of the Canadian family, helping to raise awareness of PH, improve diagnosis and access to care, and raise funds to support the PH community.

During Ed's time on the board, he supported three Board Chairs as Vice-Chair and brought his keen attention to detail to the Internal Affairs Committee. Ed's contributions to strengthening PHA Canada's financial systems, digital security practices, and operational policies will leave a lasting impact on our ability to serve Canada's PH community. Thank you, Ed, from the entire PHA Canada team.

Welcome Dhaval Thanavala

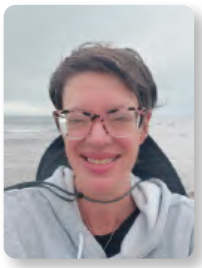
We're delighted to welcome Dhaval Thanavala as our newest Knowledge Philanthropist volunteer. Dhaval will help spotlight recent research articles and clinical breakthroughs for the pulmonary hypertension community. Extensive experience as a volunteer with Mackenzie Health's hospitals and his undergraduate work in Medical Sciences at Western University have given Dhaval a strong interest in respiratory health. He is excited to help the PH community stay fully informed and closely connected to emerging research and clinical advancements. Welcome, Dhaval!



Introducing the Patient Partner Advisory Council (PPAC)

This year, PHA Canada established the Patient Partner Advisory Council (PPAC), bringing together experienced patients and caregivers from across Canada who are trained and ready to take on leadership roles within the PH community. As patient partners, council members share their lived experience and represent community perspectives in research, advocacy, and program development, helping ensure that the voices of those affected by PH are heard where it matters most. They also advise PHA Canada on organizational priorities and initiatives, helping shape our work to better reflect the needs of the community we serve.

Meet the Council!



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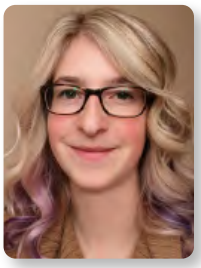

Jane Sernoskie *(ON)*

Building Leadership Across the PH Community

During this year's PH Community Conference, members of the Patient Partner Advisory Council, Indigenous Patient Council, and Peer Mentor Program came together for a full day of leadership training. Participants worked with a graphic illustrator to map the PH patient journey, explored how to share their personal stories with purpose, and developed skills to contribute as patient partners in spaces such as research, advocacy, and academic settings. The day was an opportunity to strengthen leadership skills, share perspectives, and build confidence in representing the voices and experiences of the PH community.





The 6-Minute Walk for Breath

13 Cities. One PH Community. One Big Challenge.

The 6-Minute Walk for Breath is about more than walking—it's about connection. On Walk Day, participants across Canada come together virtually before stepping out to walk in their own communities.

From coast to coast, we'll walk together with one goal: make the 2026 6-Minute Walk for Breath our biggest fundraiser yet!

Every Dollar Helps Advance

Support • Education • Advocacy • Awareness • Research

How Will You Walk?

Join one of 13 organized Walks across Canada, start a Walk in your community, or gather friends and family to walk in your neighbourhood.

Wherever you walk, you're part of one national PH community.

Gather your team. Set your goal. Challenge another community. Let's make every step count!

Learn more at phacanada.ca/6MW





Your Community

This edition's Community section celebrates the connections and generosity that strengthen the PH community across Canada. Guided by the theme Pathway of Hope, the 2026 PH Community Conference brought patients, caregivers, healthcare providers, and researchers together to learn, share experiences, and look toward the future. Our summer picnics offered opportunities for friendship and belonging, while Leadership Giving highlights how a shared commitment can help improve the lives of Canadians living with pulmonary hypertension. Behind each of these efforts are people who give their time, share their knowledge, and show up for one another—helping our community move forward with hope.

2026 PH Community Conference Pathway of Hope

With Pathway of Hope as this year's theme, the 2026 PH Community Conference brought together patients, caregivers, families, healthcare providers, and researchers from across Canada for three days of learning, connection, and inspiration in Vancouver. Together, we celebrated progress in pulmonary hypertension (PH) care, shared experiences, built new connections, and looked ahead with hope. With more than 300 participants joining us in person and virtually, the conference was a powerful reflection of the strength of our PH community and the partnerships that continue to move us forward.









Beginning with Intention

Before the Patient & Family Symposium began, attendees gathered for a special welcome activity led by members of PHA Canada's Indigenous Advisory Council. Through teachings about sacred medicines and the Medicine Wheel, participants were guided in creating their own medicine bags with intentions of healing, support, and self-love. It was a meaningful way to begin the conference—grounded in connection, reflection, and hope.



Where Connection Creates Hope

What makes the PH Community Conference unique is its ability to bring every part of the PH community together in one space—creating opportunities to learn, connect, collaborate, and find hope in the progress we are making together.

The conference began with the annual meetings of two professional networks—the Canadian PH Research Network (CaPH-Net) and the Canadian PH Professionals Network (CPHPN)—followed by the National PH Scientific Sessions, where physicians, researchers, nurses, and trainees from across Canada came together to explore key challenges and opportunities in PH care.

The conference concluded with the Patient & Family Symposium, empowering patients and caregivers with education, resources, and meaningful opportunities to connect with others who understand the PH journey.

Together, these events reflected the strength of a united PH community and the many ways collaboration, shared experiences, and a commitment to progress can create a pathway of hope. We extend our sincere thanks to all of the volunteers and planning committee members whose dedication, passion, and hard work helped make these events such a success.

We extend our appreciation to our Platinum Sponsor, Merck, for their outstanding leadership and generous support of the PHA Canada Conference. We are equally grateful to our other valued sponsors—Johnson & Johnson, United Therapeutics Corporation, Specialty Health Network by Shoppers, Liquidia, Pulmovant and McKesson—for their continued commitment to the PH community. Your generosity helps bring us together to share knowledge, strengthen connections, and advance hope for everyone affected by pulmonary hypertension.











What is Leadership Giving?

Leadership Giving is PHA Canada's premier annual giving program, recognizing individuals and organizations who make a significant investment in improving the lives of Canadians living with pulmonary hypertension.

Leadership isn't defined by title—it's defined by purpose.

Whether you are a healthcare provider, community supporter, corporate partner, or event organizer, every Leadership Gift helps advance support, education, advocacy, awareness, and research.

Lead by example. Inspire others. Be recognized. Together, we drive impact.

These events have already been recognized as Leaders in Action by holding an event in their community and raising over $2,500.



GolPH for PH 2026 Tournament

Organized by the Paulin Family

Raised $16,224



Kelten's Tee Time Tournament

Organized by Bernadette Duffy

Raised $4,487.50

What are you waiting for?

Raise $2,500 through a personal event or the 6-Minute Walk for Breathe or simply donate a total of $2,500 in a year to become part of our Leadership Giving circle.

2025 Donor Recognition

We are deeply grateful to everyone who supported PHA Canada over the past year. From monthly donors and major contributors to event organizers and sponsors, each of you has played an essential role in strengthening our work. Because of your generosity, we have been able to offer critical resources, support services, and education to Canadians affected by pulmonary hypertension. Your involvement in community events has brought people together, while your sponsorship has fueled important initiatives that drive progress.

Leadership Giving Circle

Dr. David Christiansen
Dr. John Granton
Dr. Sanjay Mehta
Dr. Fraser Rubens
Dr. Rhea Varughese

Major Donors

Wendy Anthony
Jeff Barfoot
Susan Barfoot
Darren Bell
Adam Blanchette
Jane Bondy
Paul Bruce
Michael Cairns
Michael Comeau
Tara Conley
Patrick Dare
Sheila Dempsey*
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Sherry Foster
Joan Gibson
Prem Gill
Gareth Gwyn
Darwin Hanofski
Robert Hargrave
Bruce Hustins
Devin Johnston
Garth Jopling
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John Pettifor*
Michael Pohanka
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James Skippen
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Mitesh Thakrar
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Heather Zloty

Monthly/Quarterly/Annually

Anthony Baker
Nasreen Bhalloo
Kimberly Brunelle
David Christiansen
Susan Cosenzo
Dominic Dedato
Loretta Deeter
Nicole Dempsey
Sheila Dempsey
Jill Douglas
Katherine Huisman
Doris Issa
Janine Labelle
Karen Mayner
Vanda McLean
Renae Mohammed
Lorna Mulrooney
Angela Myrah
Jamie Myrah
Cynthia Neilson
Brooke Paulin
Judith Pederson
John Pettifor
Ed Rathonyi
Garth Robertson
Jeffrey Skippen
Marilyn Stubberfield
Lynndel Tracy
Joan Yearsley

Community Events & Campaigns

6 Minute Walk for Breath (National)
Books 4 Breath (Victoria, BC)
GolPH for PH (multiple Ontario locations)
Andrew Barfoot Memorial Carwash (Owen Sound)
Personal Fundraising - Sherry Foster
Personal Fundraising - Jolene Mosiodz
Personal Fundraising - Maria Mota
Personal Fundraising - Jane Shirley
PayPal Giving (Facebook Fundraising)

Corporate & Foundation Donors

731607 Ontario Ltd
BP Media
Community Service Fund
JD Pest Control
Lucan District Lions Club
Provincial Employees
Skipton Solutions Ltd

Corporate Efforts

We are pleased to recognize corporate supporters at the following sponsorship levels, based on the total amount of funding committed during 2025:

Legends $100,000 and above: Johnson & Johnson and Merck

Champion $50,000: United Therapeutics Corporation

Partner $25,000: Gossamer

also Monthly Donors

A Summer of Connection

This summer, the PH community came together in Calgary, Dieppe, London, Ottawa, Toronto, and Vancouver for our annual PH Summer Picnics—a tradition that brings people together for friendship, connection, and a little summer fun.

From coast to coast, patients, caregivers, families, and friends gathered around picnic tables to share food, stories, laughter, and time together. For many, it was an opportunity to reconnect with familiar faces; for others, it was a chance to meet someone new who understands what living with PH can mean.

These gatherings are a reminder that community can bring hope in simple but meaningful ways. A conversation, a shared experience, or even a few hours spent together can make someone feel seen, understood, and a little less alone.

A heartfelt thank you to the incredible volunteers who brought these picnics to life, and to everyone who came out to celebrate with us. It's the people who show up for one another that make the PH community so strong.











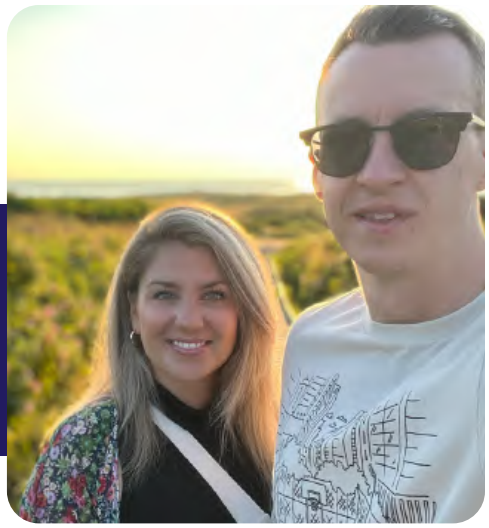


Special Feature

Travel & PH

Living with pulmonary hypertension doesn't mean you have to put your travel dreams on hold. With thoughtful planning, the right support, and a little flexibility, travel can still be a meaningful part of life with PH. In this section, we'll explore tips, stories, and practical advice to help you feel more prepared and confident when travelling—whether you're planning a weekend getaway, visiting family, or heading somewhere new. Because sometimes, the journey itself can be just as memorable as the destination.

Travel Tips from a PH Nurse



Onna White is a Registered Nurse with Nova Scotia Health Authority at the QEII Health Sciences Centre, specializing in the care and management of patients with pulmonary arterial hypertension (PAH) as the PAH Clinic Nurse.

Travel can be unpredictable, whether it is a short car ride or a trip including multiple flights. Weather, traffic, cancellations, and delays are among the most common variables while travelling. Unexpected delays can cause additional stress to those traveling with a chronic illness such as pulmonary hypertension. Advanced planning with your pulmonary hypertension (PH) team will allow you to create a travel plan that is customized to your medical requirements. Having a travel plan in place is a valuable way to both manage stress and allow you to focus on enjoying your time away.

Before You Travel

Prior to booking, please tell your PH team that you are interested in travel. They will want to learn about your destination, mode of travel, and length of stay. This will allow your PH team to determine possible medical concerns that need to be addressed prior to your departure. It is important to remember that others included within your circle of care should also be notified of your upcoming travel plans. This includes your family physician, specialists, and the Patient Support Program, if applicable. If your travel plans include an extended stay, your PH care team may connect with local health care providers to provide any necessary medical assessments while you are away. Ensure you have the appropriate travel and medical insurance depending on your destination. Discuss your vaccination status with your health care team and determine if you require any destination-specific vaccines.

Preparing To Fly

Both air travel and high-altitude destinations can worsen your pulmonary hypertension and will require careful consideration. High altitude lowers oxygen levels, causing the blood vessels in your lungs to tighten. The tightening of blood vessels in your lungs will cause an increase in pulmonary artery pressure, ultimately causing additional strain on the right side of your heart.

Your PH care team may require updated diagnostic testing to help determine your medical stability prior to travel. For air travel, this may also include completion of medical fitness to fly forms. Depending on the severity of pulmonary hypertension or your additional medical history, you may require in-flight supplemental oxygen. Therefore, it is important to choose an airline that provides this service. If you will require in-flight supplemental oxygen, your PH care team will work with the airline to have it arranged. Your PH care team can help you coordinate renting a portable oxygen concentrator that is approved by the airline, if required. Not routinely requiring supplemental oxygen does not mean it may not be required in-flight.

Managing Your Routine

Travel frequently impacts daily routines. This includes sleep and medication schedules as well as diet and fluid intake. Meals while traveling often have a higher sodium content. This can lead to retaining fluid. As part of your pre-travel planning, your PH team may ask you to monitor your weight daily and adjust your fluid medication if necessary.

Being Prepared

Research the destination ahead of time to familiarize yourself with nearest hospital/medical centers. Always travel with information including your medical history, medication list, vaccinations, and allergies, as well as your emergency contact information. You should also travel with the contact information for your PH team as well as the Patient Support Program, if applicable. Your PH care team can provide you with a letter that outlines your diagnosis and the required medication and supplies that must travel with you.

Travelling With Your Medications

It is imperative that you keep your medication with you. Medications should never travel in checked baggage. Travel with enough medication to support you through your trip as well any unexpected trip delays. Ensure your prescription has sufficient refills prior to departure.

Travelling with a continuous medication infusion via CADD pump will require special attention when planning your trip. Always have your "to-go" bag with you that includes enough medication and supplies for 2 days in addition to the amount required for the duration of your trip. Plan for areas such as restaurants or hotels that can refrigerate your medication and store your ice packs, if applicable. Ensure you travel with a support person who can take over the care of your infusion if you are unable to do so.

Using Your Resources

Lastly, it is important for you to utilize help and resources along the way. Researching accommodations, restaurants or local events/attractions will help you learn about accessible services. Accessibility services will help you to explore while reducing stress, limiting symptoms such as breathlessness, and conserving energy. Air travel specifically can be a major point of stress, but airlines provide many accessible options to help reduce travel anxiety and provide a more seamless journey. As you begin to learn about accessible resources, your confidence surrounding travelling and exploring new areas will, hopefully, grow.

Living with a chronic illness such as pulmonary hypertension can often feel like you are continually managing appointments, symptoms, medication, and side effects. Constantly working to optimize your pulmonary hypertension can feel like a full-time job that leaves little time for yourself. Despite requiring thoughtful planning upfront, travel can provide a sense of freedom as well as an excited eagerness to enjoy life, whether it is a short trip visiting a friend or a long trip across the country to a bucket list destination. It is equally as important to prioritize your mental health as it is your pulmonary hypertension. As your PH care team, we want to support you as you navigate this journey.

Contributed by: Onna White, RN, Halifax, NS

Planning a trip? Our travel resource offers practical tips to help people living with pulmonary hypertension prepare for time away.

Visit phacanada.ca/travel-tips or scan the QR code to explore the tips and start planning your next adventure.

Have clinical trial? Will travel



How far was my desire to try sotatercept willing to take me? Apparently, to Edmonton.

Some backstory: In 2019, I was diagnosed and immediately began the IV medication Caripul. With pump life came restrictions. Travel required a medical note, and my own anxiety and fears got in my way. But a few years ago, my uncle passed away. I very much wanted to go to his funeral, so I overpacked and went to Edmonton. Then there were staycations for romance book events and the PH conference in Calgary. Those small steps helped me say "Sign me up" when the sotatercept exercise clinical trial in Edmonton opened up to those of us in Calgary.

This led to…anxiety. I was going to have to travel. My friend couldn't come. My mom couldn't come. That meant me—and a bus because I don't drive.

First, packing. I was going to be dragging my suitcase around. A lot. From the bus, I was going immediately to the U of A hospital, then the hotel. The next day, I was checking out early, and my suitcase would be with me until I got home. So, I couldn't overpack. Second, my medication cassettes need to stay cold, and my ice packs were good for 8 hours. Tops. I needed 12 hours. I put two crack 'em ice packs (room temperature until you crack them) in my bag. On my final trip home, I cracked them and added them to the cooling bag. Joy! They worked.

Trip one was a freaking success. I packed enough. The crack-and-go ice packs worked. Everything was so…easy. "I can totally do this," I thought with mental fist pumps.

Then came trip two. No lie, it was a disaster. No hotel reservation. No air conditioner. Worst of all, my sandwich froze in the hotel room fridge. Also in that fridge? My Caripul, which cannot freeze. I freaked out. Remember how I streamlined my luggage so I could drag my suitcase everywhere? Yup, I had no backup mixing supplies.

Everything worked out. Had I not had all my previous short trips, I don't know how confident I would have been, especially when things went wrong. But…here I am, home from my third bus trip to Edmonton, planning a flight to the Vancouver conference. Solo.

Sotatercept was the excuse, but the clinical trial was really about finding pieces of me I had lost: the pieces that would find a seat sale and hotel deal and go on weekend trips; that would go on trips with friends and family; that were confident and comfortable in going somewhere…anywhere.

The clinical trial has made me realize that I can go the distance for myself and for this disease. Things can go wrong, or right. A Circle K can be down the street from your hotel to reward yourself with Slurpees. You can participate in a clinical trial to see whether something will help you or someone else. You can do the scary things.

Do the clinical trials, even if it requires travel. This disease has taught us how to adapt when things suck. Do the scary things. If we can keep breathing, we can do the scary things.

Contributed by: Jennifer Howard, living with PAH since 2019, Calgary, Alberta

Why I Travel



People sometimes ask why I travel so much when I have pulmonary hypertension. The answer is simple: I refuse to let PH decide how much of the world I can experience.

Before travelling, you should get approval from your PH specialist. I have to admit that is not something I have done. Instead, I have told my PH specialist about my adventures when I returned home. I know what I do may not be appropriate for someone else with PH. Everyone is different, and over the years, I have learned what my body will and won't do.

Lately, I walk slowly. People constantly pass me. I stop, sit when I can, and give myself time to recover. I no longer worry about the people behind me or compare myself with those ahead. Their journey is not mine. Mine is measured in small victories.

I have climbed Diamond Head in Oahu, part of the Great Wall of China, part of the endless staircase at Fushimi Inari Taisha in Japan, and more than 300 steps to the Holy Monastery of St. Stephen in Meteora, Greece. I have zip-lined in Costa Rica, gone tubing in Belize and Jamaica, taken 4x4 adventures in Dubai, Mykonos and the Dominican Republic, ridden a jet ski in the Bahamas, swum with turtles in Barbados and Maui, and gotten close to stingrays in Grand Cayman. I have gone caving in Italy, slid down a salt mine in Germany, enjoyed Disney rides in Florida, California and Paris, and climbed the Leaning Tower of Pisa. Favourite adventures in Africa include safaris and cruising the west coast. And somehow, there is always another adventure waiting.

I don't do these things alone. My husband, children, and friends literally pull and push me up hills, stairs, and difficult sections. My husband has always had my back, sometimes quite literally.

Many moments, I've wondered if I could make it. I might think I have reached the top of a hill, only to discover another section waiting. Whistler, British Columbia, taught me that lesson more than once.

But then something happens: I reach the top. That feeling is difficult to describe. It isn't just the view. It's knowing how hard it was to get there and knowing my lungs made the journey with me, even if they made me work for every step.

I travel because I want memories that are bigger than my diagnosis.

Travel has given me something else: my writing. Travel gives me characters, settings, ideas, and stories, so I can take my readers along with me. During these years of travelling, I wrote *No Cure for Me*. I am writing the sequel, *Still No Cure*, and the planned third book, *The Donor List*, will complete the trilogy.

PH has taken a lot from me, but it has made my curiosity, imagination, sense of adventure, and desire to see what is around the next corner more precious. I keep travelling, because there are still places I want to see, stories I want to tell, and adventures waiting for me.

And when I reach the top, I look around, take a deep breath, and think: I'm here. I made it. And there is still so much more to come.

Contributed by: Carolyn Mathur, living with PAH since 1996, Port Perry, Ontario

A Parent's Guide to Air Travel with Pulmonary Hypertension



Our daughter (who is now 13) was born with a heart defect and was diagnosed with pulmonary hypertension as an infant. She has been fortunate to have been on several flights, and we have learned many tips and tricks for flying with oxygen along the way. It takes some preplanning, but we have had many great family trips with several different airlines. The process has several steps, and it is essential to start the process early.

Many airlines require advance notice regarding oxygen. Firstly, the person should discuss with their doctor whether flying is an option and, if so, whether oxygen is required. Some people with PH do not require oxygen regularly, but do while flying. Secondly, you should check your airline's website for policies and requirements. Every airline has different requirements and procedures. Airlines do not allow oxygen tanks, but allow portable oxygen concentrators (each airline has a list of which concentrators they allow), and some airlines allow you to purchase oxygen for use through the airline. The airline itself does not supply the oxygen concentrators; you will need to get them from an oxygen supply company.

Once you receive your oxygen concentrator from your oxygen company, I definitely recommend testing the machine and becoming familiar with it at home. I also recommend checking the batteries to make sure they are fully charged before your trip. Tip: Don't forget to also bring along oxygen cannulas.

Many airlines require a doctor to fill out paperwork in advance of the flight. Check your airline's website. If paperwork is required, provide the paperwork to your doctor. Once it is filled out, follow the instructions on the airline website to submit the paperwork. You will need to receive confirmation from the airline that you are ready to use oxygen on the plane. Some airlines require approval from their airline medical team before you fly.

Another consideration is how many batteries you will need to take with you. Your airline's website will list battery requirements. Often, you need enough to have for 1.5 times the length of your flight (for example, if your flight is 3 hours, you would need enough batteries to last 4.5 hours). How long a battery lasts depends on your oxygen concentrator and the number of litres it is set to. Remember, batteries cannot go in checked luggage, and bring a charging cord so you can charge them before your trip home. Once you are ready to fly, be sure to arrive at the airport early. You will need to check in at your airline's desk (you cannot e-check in with oxygen). I find it useful to have copies of all paperwork with you (the form your doctor filled out, the airline's approval, your oxygen prescription, any medical history, etc.). It may take you longer to go through security, as they will need to check your concentrator and batteries.

It always surprises us that many airport staff have little experience with oxygen concentrators, so you may receive many questions. It may require some advance planning, but travelling with pulmonary hypertension can be doable and a lot of fun. Happy travels!

Contributed by: Kristen Dorscht, mother and caregiver, Elmira, ON

Travelling with Pulmonary Hypertension: Tips I've Learned Along the Way



Our family loves to travel. Having lived with PH for more than 15 years, I've learned how to make travelling work for me—and for all the medication, equipment, and "gear" that comes along with it.

Start with your PH team. Make sure you are stable and medically able to travel. I ask for a letter approving travel, my most recent medical report, and an up-to-date list of medications, including dosages and supplies.

Let your specialty pharmacy know. They may be able to help troubleshoot medication, dosage, or supply issues while you're away.

Keep your documentation with you. I carry paper copies of my important information. Phones can be lost, damaged, or run out of power—and that has actually happened to us while travelling!

A few years ago, I realized, after arriving in San Juan, that I had forgotten my one diuretic medication. Once I was on the cruise ship, I saw the ship's doctor. They were concerned about my vitals, but once I showed them all my paperwork from my PH doctor, they were comfortable that those numbers were okay for me. It also allowed them to easily provide me with a comparable medication.

Plan for the unexpected. Travel delays happen, so I pack one-and-a-half times the medication and supplies I expect to need. I organize each line change separately in a resealable bag, which makes everything easy to find when I need it. If you use an infusion pump, ask about backup pumps in case of a malfunction.

Keep medications and medical supplies with you. Everything I medically depend on stays in my carry-on.

If you fly, plan ahead. I request a hand inspection rather than going through security scanners, and I keep my backup pumps with me. Policies can vary, so check with your airline and airport security ahead of time.

Think about the little things, too. Showering with an infusion pump can be tricky. A waterproof pouch or even a simple coat-hanger setup can make things easier. For time near the water, an AquaPac or similar waterproof pouch can provide more freedom to enjoy the beach, lake, or pool.

Stick to your routine. Overdoing it one day can mean missing out the next. I try to pace myself, get enough rest, and take my medications as prescribed, even when travelling across time zones.

After more than a decade of travelling while managing triple therapy with tadalafil, macitentan, and Remodulin, along with oxygen for flying and sleeping, I can honestly say it gets easier.

Cruising has become one of my favourite ways to travel. I love that I can unpack once and visit different countries and ports from a comfortable home base. There are activities for every energy level: sightseeing, entertainment, relaxing, or simply enjoying time with family.

For me, the key is simple: **plan for what you know, prepare for what you don't, pace yourself, and then give yourself permission to enjoy the journey.**

Contributed by: Marion Roth, living with PAH since 2011, Milverton, Ontario

Community Quotes

What does travelling look like for you and your family since your PH diagnosis?



Disney was always something my boys and I shared, especially after my diagnosis. Our first family trip in 2024 became one of our most magical memories. As my PH has worsened, those memories have carried me through difficult days. We aren't guaranteed tomorrow—live fully, make the memories, and cherish the good days.

Casey Clow, PAH patient from Alberta, travelled with her two children to Disneyland in 2024

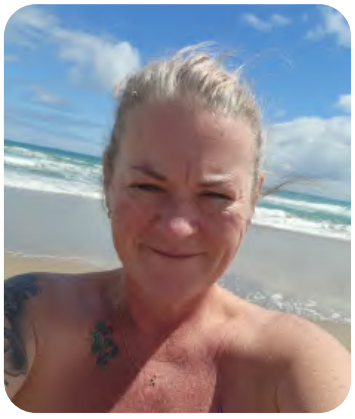


Last summer, my family and I travelled to Ireland for 2 weeks. Even though travelling is a little more complicated since being diagnosed with PH, it's very important to travel for my mental health. It gives me something to look forward to. We do, however, have to adapt some of our outings and day trips to accommodate my limitations. We also lower our expectations, we don't have itineraries set in stone and we take more breaks than the average person. We loved this trip and bonded with many, many sheep!

Nicole Dempsey, PAH patient from Ontario, travelled with her family to Ireland in 2025

Traveling with PH isn't as easy as it was before I was diagnosed, many more bags, a little more explaining at the secondary security search, but being prepared ahead of time made it so much smoother. I have been on 8 flights since my diagnosis and many road trips. Being prepared is my best advice. Having explanation letters for your supplies and CPAP if you have it, bringing more than you need in the event something changes with your itinerary. Take advantage of the accessibility options available, they made the world of difference. Check with your travel insurance to make sure you are covered. Be prepared for every situation you could possibly be in. Don't let this disease take travel away from you.

Kirsty McGeown, PAH patient from Ontario, travelled to New Zealand for her son's wedding in 2025



Research Corner

In this section, Dr. Sanjay Mehta discusses his recent paper on the history of pulmonary hypertension in Canada, and Knowledge Philanthropist Dhaval Thanavala explores an article on air travel and PH. We also look back at this year's PH Scientific Sessions and celebrate the recipients of the Wilma Shastry PAH Research Awards. Finally, previous scholarship recipient Yongneng Zhang shares insights from his recent publication.

The great history of PH research, diagnosis, and management in Canada



The Canadian Thoracic Society has launched an initiative, led by Professor Louis-Philippe Boulet of Laval University in Quebec City, to capture and celebrate the excellence, innovation, and high-level research productivity in the "History of Respiratory Medicine in Canada." They asked me to capture the history and excellence of Canadian contributions to the field of pulmonary hypertension (PH), and I invited PH colleague Dr Namisha Singh (Western University, London), Executive Director of PHA Canada Jamie Myrah, and my first PH mentor at McGill Dr. Robert Levy (now University of BC, Vancouver) (https://doi.org/10.1080/24745332.2025.2555848).

There has been a strong focus on PH basic science and clinical research globally since the 1950s, with many important contributions by clinicians and scientists in multiple Canadian institutions. Indeed, the first reports on PH in Canada were by cardiologist George Manning from Victoria Hospital in London, Ontario! He headed the electrocardiogram (EKG) lab of the Royal Canadian Air Force, and first reported using EKGs to screen for PH.

In parallel, many children born with congenital heart disease (CHD) were found to develop PH, which greatly reduced survival. They required medical management and surgical interventions, leading to development of expert multidisciplinary clinics, including the first in 1938 at SickKids Hospital in Toronto. Landmark PH surgical approaches were developed, including various shunts and eventually lung transplantation.

As children with PH were living longer into adulthood, and PH was being more often recognized in adults, increasing numbers of patients led to a need for expert care by cardiology and respiratory specialists. Canadian PH expert clinics were established, initially in Montreal, Edmonton, and Calgary, and now there are 24 PH centers across Canada. Community resources to support and educate patients with PH and their families emerged in the 1990s, with initial PH peer support groups in British Columbia, Alberta, Ontario, Quebec, and New Brunswick. These PH leaders worked to unify the Canadian PH community, leading to the founding of PHA Canada in 2008.

The larger number of patients and expert clinics across the country supported increasing PH clinical and basic science research. Advances in our understanding of PH identified new chemical pathways, leading directly to development of 11 different PH-targeted medications approved by Health Canada and now largely available to patients with PH across the country.

In summary, the pioneering work of numerous Canadian clinicians and scientists has contributed to our greater understanding of the science of PH. Moreover, Canadian initiatives have advanced our ability to diagnose, assess, and treat patients with multiple innovative PH-targeted medications and surgical approaches across a network of PH expert centers across Canada. Most importantly, these novel therapies have helped to significantly prolong and improve the lives of many Canadian patients affected by PH.

Contributed by: Sanjay Mehta, MDCM FRCPC, Founding Board Member, Past Chair, and Eternal PHriend of PHA Canada, Professor of Medicine and Medical Director, Southwest Ontario PH Clinic, LHSC, Western University

Improving the quality of life of patients with PH: PH doesn't rule out air travel



Yogeswaran A, et al. Air travel in patients suffering from pulmonary hypertension—A prospective, multicentre study. Pulm Circ. 2024; 14:e12397. https://doi.org/10.1002/pul2.12397

Background. Air travel has been a concern for patients living with pulmonary hypertension (PH). As the air is thinner (including less oxygen) at high altitudes, airplane cabins are pressurized for comfort and safety, but passengers still have less oxygen available than at ground level. Consequently, lower oxygen levels could theoretically worsen PH, strain on the right ventricle (RV) of the heart, and clinical wellbeing in patients with PH during air travel. Given minimal prior research and lack of clear guidelines, these researchers investigated whether flying poses significant health risks in patients with PH by assessing a cohort of European patients with stable, mild-to-moderate PH (WHO functional class II and III) before, during, and after air travel.

Findings. Of 239 patients with PH, 72 travelled by air during the study period, half for less than 3 hours and half for more than three hours. Of note, 30% of all patients did not travel because of concerns about flying (17%), and medical advice discouraging air travel (13%). During the flight, nine travellers (13%) reported symptoms of mild discomfort, including chest pressure, dizziness, breathlessness, or palpitations. After arrival, 12 participants (20%) experienced worsening symptoms, with most occurring within one hour of landing and only one passenger required medical evaluation following the flight.

None of the participants experienced any severe medical effects related to air travel. Notably, the study found that patients who received supplemental oxygen during the flight maintained higher blood oxygen levels (92% compared to 89%) and reported fewer symptoms compared to passengers who did not receive oxygen therapy.

Implications. This study suggests that air travel is generally safe for patients with stable, mild-to-moderate PH. Approximately 1 in 3 patients suffered worse symptoms during or after the flight due to lower oxygen levels in-flight, which place additional burden on the already strained RV. These findings reinforce current recommendations to consider in-flight supplemental oxygen to maintain higher oxygen levels and reduce severity of symptoms, PH and RV strain during air travel.

Further research is still needed to evaluate the risks of longer flights and air travel in patients with more advanced PH. Nevertheless, for many patients with stable PH, this study offers reassuring evidence that, with appropriate planning and medical guidance, they can still safely enjoy air travel.

Contributed by: Dhaval Thanavala, Knowledge Philanthropist, and Sanjay Mehta, MDCM, FRCPC, Founding Board Member/Past Chair/Eternal PHriend of PHA Canada, UWO, London, ON

2026 National Pulmonary Hypertension Scientific Sessions

The 7th National Pulmonary Hypertension Scientific Sessions took place September 24–25, 2026, in Vancouver, BC. Co-developed by PHA Canada and the Canadian Thoracic Society, this national interdisciplinary meeting brought together healthcare professionals, researchers, and trainees to learn from leaders in the field and connect with colleagues from across Canada. A panel discussion on Thursday evening was followed by an intensive full-day program on Friday comprising two keynotes, nine presentations, and two student presentations.



The sold-out Connect and Learn opening panel on Thursday evening, Transitioning from Pediatric to Adult Care, was a lively discussion moderated by Dr. Sanjay Mehta, featuring Brinley Marks (patient partner), Dr. Jason Weatherald (Brinley's adult PH specialist), and Dr. Angela Bates (Brinley's pediatric PH specialist).

Friday morning, the accredited program began with a keynote by Dr. Stephen Archer and Dr. Patricia Lima, both from the Translational Institute of Medicine at Queen's University, talking about the *Role of Inflammation in Pulmonary Arterial Hypertension*. Participants heard emerging evidence that immune mechanisms drive PAH, with details about inflammatory processes that contribute to right ventricular failure. Inflammation, they noted, could be a significant alternative therapeutic target for PAH.







After lunch, Dr. Yogesh Reddy from the Mayo Clinic presented our second keynote session on *Disentangling the Central, Peripheral and Hematological Mechanisms of Benefit from Sotatercept*. Dr. Reddy discussed how changes in heart function and in the blood after treatment with sotatercept may improve physical function by affecting tissues and organs beyond the heart and lungs. These findings, too, may reorient PAH treatment and care.

The 2026 program specifically included slots for students. Elmira Safaie Qamsari, 2025 PHA Canada Paroian Family PH Research Scholarship recipient, who is working on her PhD in Dr. Duncan Stewart's lab at the Ottawa Hospital Research Institute (see p.23 in Connections 2026 #1), and Dr. Yongneng Zhang, a postdoc at the University of Alberta and 2023 Paroian Family PH Research Scholarship recipient (see p.24), presented their work.

Many thanks to our sponsors for supporting the 2026 Scientific Sessions: Merck (Platinum), Johnson & Johnson (Gold), Specialty Health Network by Shoppers (Silver), Liquidia (Bronze), and Eitan Medical, Inhibikase, Pulmovant, and United Therapeutics (Supporters).

Plans for next year's PH Scientific Sessions are already underway. We hope you'll join us September 23-25, 2027, in Halifax!

See phacanada.ca/researchupdates for short summaries that give a sense of the breadth and depth of other topics covered during Scientific Sessions this year and in past years. Many thanks to Knowledge Philanthropist Miriam Bergeret for contributing summaries!

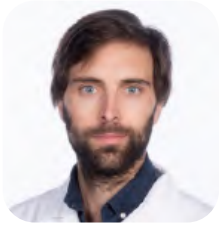
Wilma Shastry Pulmonary Arterial Hypertension Research Awards

The Canadian Lung Association and PHA Canada congratulate Dr. Antenor Rodrigues and Dr. Francois Potus, the recipients of the 2026 Wilma Shastry PAH Research Awards. The objective of this award is to build Canadian research capacity to address pulmonary arterial hypertension (PAH) in Canada.



Dr. Rodrigues, an associate professor in the School of Rehabilitation at Université Laval in Sherbrooke, Quebec, will study activin inhibition and skeletal muscle adaptation in PAH. The goal of the study is to improve understanding of why patients continue to experience exercise limitations despite advances in treatment and to improve exercise capacity, physical function, and quality of life for people living with PAH.

Dr. Potus, an associate professor of medicine at Université Laval, and his team will test whether sotatercept, a recently approved drug for PAH, relaxes lung blood vessels and acts directly on the heart muscle. This would help explain why some patients improved faster than expected, even though the drug did not improve how well their hearts pumped.



These one-year, $40,000 grants are funded primarily by generous donor contributions in support of respiratory and PAH research. See phacanada.ca/research-grants for more information.

Contributed by: Robyn Kalda, Manager, Research & Policy

Scholarship Recipient Research Update

PHA Canada is proud to support the growth of the pulmonary hypertension research community by awarding scholarships to outstanding trainees. The Paroian Family Pulmonary Hypertension Research Scholarship was founded by Phil Paroian in honour of his sister, Sherry Paroian, and is supported by the Paulin family's annual GolPH for PH Tournament. In 2023, PHA Canada awarded a Paroian Family PH Research Scholarship to Yongneng Zhang. Dr. Zhang presented this work at the PH Scientific Sessions in September 2026.

Gene variant affects heart muscle support cells in PAH

Researchers are working to identify pulmonary arterial hypertension patients at higher risk of right heart failure, so treatment can be adapted for them. One theory was that muscle cells in the heart ran out of energy as the right side of the heart enlarged and there weren't enough new blood vessels to supply energy to the heart muscle. This would lead heart muscle cells to die, forming scar tissue and changing the heart's structure. But this theory didn't explain why the right side of the heart could recover after, for example, lung transplantation, so researchers kept looking for other causes.

Recently, 2023 PHA Canada Paroian Family Pulmonary Hypertension Research Scholarship winner Dr. Yongneng Zhang, together with his supervisor, Dr. Evangelos Michelakis, at the Cardiovascular Research Institute (CVRI) at the University of Alberta, and in collaboration with Canadian pulmonary hypertension specialists Dr. Sébastien Bonnet and Dr. Steeve Provencher at IUCPQ and other collaborators, found that heart failure accelerated when certain support cells (myofibroblasts) became overactive, rather than when the heart muscles were not receiving enough energy to pump. They identified a particular variation of the UCP2 gene in about 30% of patients with severe pulmonary arterial hypertension—a variation which led to lower levels of the UCP2 protein in those support cells. People with this form of the UCP2 gene experienced heart failure sooner, compared to pulmonary arterial hypertension patients with other variants of the UCP2 gene.

Testing patients for this gene variation could help identify those at higher risk earlier, allowing care teams to tailor monitoring and treatment more proactively. These patients might require "more intense PAH/ supportive therapies, frequent follow-ups, earlier referral for transplantation, and anticipating slower recovery after transplantation."

Contributed by: Robyn Kalda, Manager, Research & Policy

Reviewed by: Dr. Yongneng Zhang, past Paroian Family PH Research Scholarship recipient (2023)



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