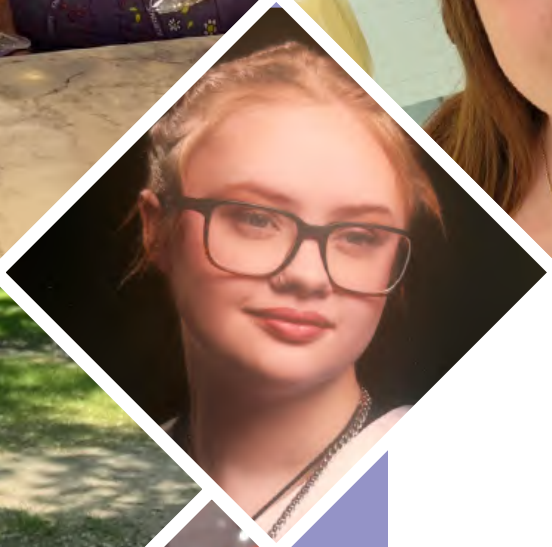
PULMONARY HYPERTENSION ASSOCIATION OF CANADA

L'ASSOCIATION D'HYPERTENSION PULMONAIRE DU CANADA

CONNECTIONS

The Official Magazine of the Canadian PH Community



Special Feature:

Transplant & PH

Message from the PHA Canada Team

As spring arrives, it brings with it a sense of renewal—longer days, brighter moments, and the promise of new beginnings. Each issue of *Connections* is a chance to reflect on what makes this community so special—the willingness to share, to support, and to stand alongside one another through every part of the pulmonary hypertension journey.

This past November, we were inspired by the incredible energy shown across the country during Pulmonary Hypertension Awareness Month. This year's theme, Heart Under Pressure, resonated deeply, highlighting the realities of living with PH and the urgency of raising awareness. So many of you helped bring this message to life by sharing your stories, starting conversations, and finding meaningful ways to get involved. These moments—both big and small—play an important role in helping others better understand pulmonary hypertension and its impact. To everyone who took part, thank you for helping amplify the voice of our community.

We're also proud to celebrate the success of our annual 6-Minute Walk for Breath. Together, we raised more than $58,000 in support of people living with PH in Canada. Your support allows us to offer programs, resources, and connections that make a meaningful difference in people's lives.

In this issue of *Connections*, we focus on an important and deeply personal topic: transplantation and pulmonary hypertension. For some individuals, transplant becomes part of their journey—bringing both challenges and new possibilities. This issue shares the voices of patients and families who have experienced transplant firsthand, offering insight into the realities of the process and life beyond it.

We chose this theme because transplant is not only a critical medical option for some, but also a profoundly human experience that impacts entire families. Whether you are navigating this path yourself or simply looking to better understand it, we hope these stories provide comfort, perspective, and a sense of connection. We are deeply grateful to the individuals who shared their experiences so openly—their voices are what make this issue so meaningful.

Looking ahead, we are excited for what's to come. This year will bring several new initiatives, including the launch of our Patient Partner Advisory Committee and our Peer Mentor Program—both designed to strengthen connections and support within our community. And of course, planning is well underway for this year's PH Community Conference, with registration opening soon. We can't wait to bring the community together once again—whether in person or virtually—for another opportunity to learn, connect, and be inspired.

Thank you for being part of this community and for supporting one another in so many ways.

With warm wishes for the season ahead,
The PHA Canada Staff Team

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Contributors

Editor in Chief
Kimberly Brunelle, Director, Programs

Contributing Editor
Shelley Grogan, Director, Fund Development
Robyn Kalda, Manager, Research & Policy

Contributing Proofreader
Robyn Kalda, Manager, Research & Policy

Translation
Jeremy Durand, Manager, Marketing and Communications

Art & Design
Jeremy Durand, Manager, Marketing and Communications

Printing
BP Media

Contributors
Lindsay Forsyth Brochu
Braden Gendron
Dr. John Granton
Izabelle Nicole Lamarre
Ella Macleod
Mahnaz Nazari
Hogan Nguyen
Tina Proulx
Elmira Safaie Qamsari
Adam Reitor
Sophia Ricci
Jane Sernoskie
Dr. Rhea Varughese
Lori Weber

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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.

Celebrating 10 Years at PHA Canada

Darren Bell, Jamie Myrah, Roberta Massender, Ethel Abiera

In 2026, we're excited to celebrate a special milestone—10 years since Jamie Myrah, our Executive Director, and Ethel Abiera, our Administrative Coordinator, joined PHA Canada. Over the past decade, they have been a constant, caring presence in our community, helping to grow programs, bring people together, and support Canadians living with pulmonary hypertension. Their warmth, dedication, and genuine passion for this community shine through in everything they do.

This milestone is not just about their individual journeys, but also about the strong, connected team we've built together over the years. We are so grateful for all that Jamie and Ethel have given to PHA Canada and to our community, and we're proud to celebrate everything we've accomplished together—with so much more still to come.

End of an Era: Thank You, Gail & Carolyn

More than 15 years ago, Gail Nicholson and Carolyn Pugliese had a vision of the great potential for coordinated pulmonary hypertension nursing care in Canada. Their devotion to their PH patients and the nursing profession led them to found what we now call the Canadian Pulmonary Hypertension Professional Network (CPHPN). The PH nursing experience they have is invaluable and they share their knowledge generously with all nurses. Creating something new never comes easily but we are incredibly grateful for their perseverance.

Carolyn Pugliese and Gail Nicholson

CPHPN is more than a resource for PH education and nursing research: it is a network of peer support, knowledge sharing, and a community of encouragement to all the members to keep doing this challenging but important work. It is impossible to imagine how we could continue caring for this special patient population without CPHPN as a resource. As Gail and Carolyn now take a much-deserved break from the daily responsibilities of CPHPN leadership, we are thankful for their ongoing support as we move into a new era of PH nursing which is rapidly increasing in complexity. We need CPHPN now more than ever and it is an absolute honor to be trusted to carry this work forward. Thank you again, Gail and Carolyn!

Contributed by the CPHPN Executive: Andrea Gardner, Kelly Kerwin & Janette Reyes

Welcome Lisa

Lisa Harder,
Knowledge Philanthropist

We are pleased to welcome Lisa to our volunteer team as a Knowledge Philanthropist. Bringing both professional expertise and lived experience, Lisa is a psychologist with 10 years in the mental health field who was diagnosed with PAH in 2024. In her new role, Lisa will work closely with us to develop meaningful mental health resources for the PH community. Her unique perspective allows her to translate complex information into compassionate, accessible support for those navigating life with pulmonary hypertension.

PH Peer Mentor Program

We're excited to introduce PHA Canada's new Peer Mentor Program, created to provide extra support for people living with pulmonary hypertension (PH) and their families. Navigating life with PH can feel overwhelming, especially after a diagnosis, and sometimes it helps to speak with someone who truly understands the journey.

Our program connects you with trained volunteer peer mentors—people living with PH or caregivers of someone with PH—who offer encouragement, understanding, and practical insights from their own experiences. Peer mentors provide emotional support, share what they've learned about managing daily life with PH, and help patients and families feel less alone.

This program is open to everyone in the PH community, whether you're newly diagnosed or have been living with PH for years. It's a safe, welcoming space to connect, learn, and be supported by someone who really gets it.

Learn more at www.phacanada.ca/peermentors

Ask a PH Doc

Living with pulmonary hypertension often comes with questions — about symptoms, treatments, daily life, and what the future may hold. Ask a PH Doc is a new way for our community to get trusted answers directly from Canadian pulmonary hypertension specialists. Every question submitted will receive a response from PHA Canada. Some questions will be answered directly by email, while others may be selected to be featured on our website with a video response from a PH Doc.

Learn more at www.phacanada.ca/ask-a-ph-doc

2026 PH Community Conference & Scientific Sessions

Pathway of Hope

September 24-26 in Vancouver - in-person or virtual

Learn more at
phacanada.ca/conference

Join us this September in Vancouver for PHA Canada's PH Community Conference and Scientific Sessions, inspired by this year's theme, Pathway of Hope. This unique event brings together healthcare professionals, researchers, patients, and caregivers along a shared journey—one grounded in learning, connection, and progress. The conference begins with two days dedicated to healthcare professionals, featuring in-depth scientific sessions, research updates, and collaborative discussions. The Patient & Family Symposium begins with a Friday evening welcome followed by a full Saturday focused on education, empowerment, and meaningful connection. Together, these moments create a powerful continuum—from science to lived experience—lighting the path forward with hope for everyone impacted by pulmonary hypertension.

"Attending the PH Conference was a turning point for me. I realized that I was no longer alone in this journey."

Junaid Naeem
Living with PAH, Ottawa, ON

Your Community

This edition's Community section celebrates the passion, creativity, and collective strength of the PH community across Canada. From the impact of last year's 6-Minute Walk for Breath and the powerful Heart Under Pressure campaign during PH Awareness Month, to the many community-led fundraisers that continue to bring people together in support of a shared cause, your efforts are driving meaningful change. We are also proud to highlight new initiatives like the Leadership Giving Circle, while ongoing advocacy through the Time Matters PAH campaign shows what is possible when we raise our voices together. Each of these moments reflects a community united in purpose—working toward better care, greater awareness, and hope for all those affected by pulmonary hypertension.

The 6-Minute Walk for Breath

The 2025 6-Minute Walk for Breath was our biggest and most inspiring yet—raising an incredible **$58,744** nationwide in support of people living with pulmonary hypertension.

This year truly captured the spirit of a growing national movement. With 12 walk locations across Canada, including eight new communities and five additional walk teams, the 6-Minute Walk for Breath reached farther than ever before. From coast to coast, volunteers, patients, families, and supporters came together to raise awareness, share their stories, and take meaningful steps toward better support and research.

Top Fundraising Teams

Team Ottawa took the top spot, raising an incredible $15,797! Led by PH patient Jane Sernoskie, this unstoppable team continues to show unwavering dedication to the PH community. Close behind, the new **Team Toronto** rallied together to raise an impressive $15,007. Your support is truly inspiring! Rounding out the top three, the **Team Vancouver** raised an outstanding $8,655—a powerful show of commitment and strength.

A heartfelt thank you to these incredible teams and to everyone who participated. Your efforts make a real difference!

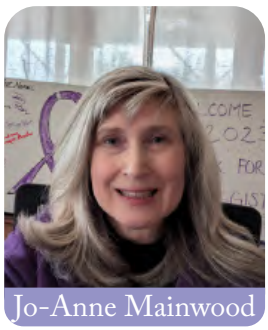
Top Individual Fundraisers

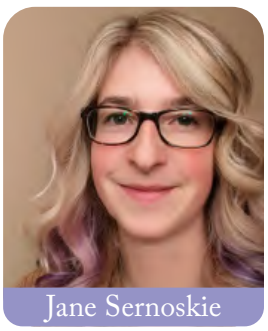
1. Donna Downes – $5,315
2. Michael Pohanka – $4,600
3. Jo-Anne Mainwood – $3,947
4. Jane Sernoskie – $3,075

We express our heartfelt appreciation to the incredible individuals and teams who have fueled our efforts in the fight against pulmonary hypertension.


Donna Downes


Michael Pohanka


Jo-Anne Mainwood


Jane Sernoskie

A huge thank you to everyone who walked, fundraised, volunteered, and supported the event. Because of you, the 6-Minute Walk for Breath continues to grow stronger every year.

We can't wait to see what 2026 will bring—and we hope even more of you will join us on November 21 to help take the next steps for pulmonary hypertension.

Dieppe, NB

Hamilton, ON

Ottawa, ON

Toronto, ON

Vancouver, BC

Winnipeg, MB

More than anything, 2025 was about reaching across the nation—connecting communities and building hope. People came together in parks, community centers, patients' homes, clinics, and shopping malls to show the power of walking together for a cause that matters.

Thank you to all 12 of our participating locations:

Calgary
Edmonton
Halifax
Hamilton
London Purple Power
Moncton
Ottawa
Regina
St John's
Toronto
Vancouver
Winnipeg

Celebrating Our Community Fundraisers

Fundraising events help raise awareness about pulmonary hypertension while bringing communities together to support patients and families. Beyond fundraising, they spark conversations, build connections, and support education, advocacy, and patient programs across Canada.

Recent Events

Terri Gower's **Books for Breath** in Victoria, BC was a wonderful success!

Many people stopped by the table to learn more about pulmonary hypertension during PH Awareness Month, while others shared their appreciation for the fundraiser and the awareness it brings. Through book sales and generous donations, the event raised $900 to support the cause.

The book sale continues to be a fun and meaningful event, and there is already excitement about bringing it back again in 2026.

Upcoming Golf Tournaments

Kelten's Tee Time - May 23, 2026 - Whisky Run Golf Club, Port Colborne, ON
In memory of Kelten Duffy Delaney, Kelten's Tee Time brings people together for a day of golf, connection, and giving back—raising awareness and vital funds for the PH community.

GolPH for PH - May 28, 2026 - Glendale Golf Club, Hamilton, ON
Organized by the Paulin family in support of their daughter Brooke, who lives with pulmonary hypertension, GolPH for PH brings people together to raise awareness and funds for the PH community.

Learn about upcoming fundraisers and how to host one at phacanada.ca/fundraise

Leadership Giving

The generosity and leadership of the physicians of the PHA Canada Leadership Giving Circle helps strengthen the PH community and demonstrates they are standing with patients in the exam room as well as the broader PH community. Their gifts help us advance patient programs, advocacy, and awareness—bringing us closer to a future where everyone living with PH has access to timely diagnosis, effective treatment, and support.

Thank you for leading the way:

Dr. David Christiansen, Winnipeg, MB
Dr. John Granton, Toronto, ON
Dr. Sanjay Mehta, London, ON
Dr. Fraser Rubens, Ottawa, ON
Dr. Rhea Varughese, Edmonton, AB

To learn more about how you can become a part of our Leadership Giving Circle, contact Shelley Grogan, Director, Fund Development, at sgrogan@phacanada.ca.

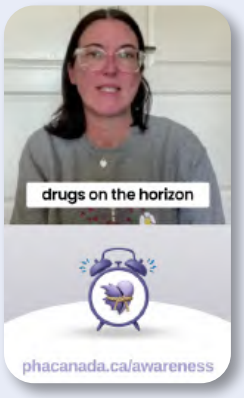
PH Awareness Month: Heart Under Pressure

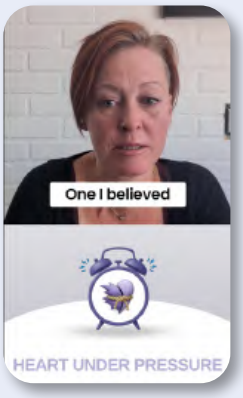
This past November, the PH community came together once again to raise awareness of pulmonary hypertension and what it means to live a with a heart under pressure. This year's theme reminded us that every heart under pressure deserves relief, and inspired our community to take action—by raising awareness, sharing their stories, and advocating through our Time Matters PAH campaign. Together, we showed that every voice can help take the pressure off.

PHA Canada Eternal PHriend Jas James and her family raising PH awareness in Cobble Hill, BC by showing off matching purple t-shirts for PH Awareness Month

During PH Awareness Month, Carolyn Mathur found these beautiful giant lungs at the Magical Gardens in Dubai

Brad Lynch showing off his purple sweater and hat in celebration of PH Awareness Month. Designed by PH community PHriend, Kayley Cowger, the purple iris stands for courage, wisdom and strength





The Heart Under Pressure campaign was supported by the launch of several patient stories highlighting the importance of access to life-saving drugs, like sotatercept.

Watch the videos at www.phacanada.ca/advocate

Time Matters PAH

Over the past few months, we've seen incredible progress in the Time Matters PAH campaign. We are proud to congratulate **Québec**, **Nova Scotia,** and **British Columbia** for listing sotatercept on their public drug formularies—an important step forward for people living with pulmonary arterial hypertension across Canada. These decisions reflect what is possible when patients, caregivers, and advocates come together to make their voices heard.

As of March 31, 2026

This progress didn't happen by chance. Since the campaign began in 2024, our community has sent thousands of letters, met with elected officials, and shared powerful personal stories. These collective efforts helped lead to a national pricing agreement in late 2025 and, more recently, to three provinces listing sotatercept in just a few short months. It's clear: advocacy works, and your voice is making a real impact.

Now, we are in the final stretch. While momentum is strong, several provinces and territories are still reviewing sotatercept. Decision-makers need to continue hearing from the people most affected—patients and caregivers. You can help by sending a letter through our website, requesting a meeting with your local representative, or sharing your story with our community. Every action helps keep the pressure on and brings us closer to equitable access across Canada.

Keep up to date and take action now at phacanada.ca/advocate

Special Feature

Transplant & PH

For many people living with pulmonary hypertension, the possibility of lung transplantation brings both hope and uncertainty. In this special feature, we explore the basics of transplant by speaking with a PH physician about who may need a transplant, when it is considered, and how people can begin preparing. We also share stories from members of the PH community whose lives have been touched by transplant—from those who are waiting, to those who are living well after transplant—highlighting the diverse experiences, challenges, and hope that transplant can bring.

Lung Transplant and Pulmonary Hypertension: The Basics

For many people living with pulmonary hypertension (PH), lung transplant can feel overwhelming. When does it become an option? Who needs it? What does the process involve?

Dr. John Granton walked us through the basics.

Does everyone with pulmonary hypertension need a transplant?
"No," Dr. Granton explains. "We don't really know the exact number."

Modern PH therapies have significantly changed the timeline of disease progression, delaying—and sometimes preventing—the need for transplant. However, some patients still require transplant, especially those who do not respond to therapy or who have higher-risk forms of PH.

Not everyone who needs a transplant is eligible for one, and not everyone who is eligible chooses to have a transplant. Severe deconditioning (when someone loses physical strength through being ill, injured, or not active), high body mass index, smoking, substance use, or other medical conditions may make transplant too risky.

When is transplant discussed?
Dr. Granton believes transplant should be discussed earlier rather than later. Earlier conversations should occur (e.g. shortly after diagnosis) in some forms of PH that are less likely to respond to treatment. Conversations should also occur when patients either progress or fail to respond to maximal medical therapies.

Having the conversation does not necessarily mean immediate referral to the transplant assessment team, but it gives patients and families time to process the option and prepare.
It also allows time for people to:

- Stop smoking
- Address substance use
- Lose weight
- Improve their physical conditioning
- Strengthen their support systems

"If you suddenly, in the final hour, start having that conversation, there's no way they're going to be able to lose weight or become conditioned," he says.

How do patients react?
"It is going to be a difficult conversation for patients" he says candidly.

Some patients are shocked that their doctor is raising transplant as a possibility. Others are relieved to discuss it openly.

Avoiding the conversation, however, can be harmful. "I think you're doing an injustice if you don't have that conversation."

What happens during transplant assessment?
The transplant assessment process is thorough — and can feel exhausting. Patients undergo scans, blood work, heart catheterization, and extensive evaluation, meeting:

- A transplant physician and surgeon
- Nurse coordinator
- Social worker
- Psychiatrist or psychologist
- Physiotherapist
- Nutritionist
- Anesthesiologist

The social worker evaluates the patient's support systems. Transplant isn't the sort of thing you can go through without help. "It takes a village," Dr. Granton says.

The physiotherapist assesses strength and prescribes exercise. Nutritionists prepare patients for steroid-related dietary changes.

The assessment timeline can range from a week (for critically ill patients) to several months. Once the patient has finished the evaluations, the transplant team meets to review their case.

Patients may be:

- Added to the transplant waiting list
- Conditionally listed (pending weight loss or other changes)
- Deferred, if they do not need a transplant yet but may need one in future.

What happens if someone is approved?
If someone is listed, their priority for a transplant depends on their illness severity. The time to getting a transplant also depends on their blood type, body size, and antibody status.

The average wait time for a transplant is about six months, (again depending on urgency and other factors) though it varies widely.

What is life like on the waiting list?
Patients must stay ready to come to the hospital at any time. Their ability to travel is limited.

"People often feel like they're being held hostage, putting their lives on hold, for whatever time it takes," Dr. Granton says

At the same time, people are encouraged to stay active and improve their physical conditioning. "Prehabilitation" improves transplant outcomes.

What happens during surgery?
Most PH patients receive a double lung transplant in a surgery lasting 8–12 hours.

Afterward, patients have a breathing tube in their airway and are attached to a ventilator until they are ready to breathe for themselves. Some may require temporary ECMO (heart-lung machine) support. Chest tubes are placed to allow air, fluid, and blood to drain away.

If all goes well, people stay in ICU for about a week and stay in hospital for about a month. Rehabilitation begins early.

What does life look like after transplant?
Transplant requires lifelong follow-up. Patients return to the hospital regularly for breathing tests, CT scans, bronchoscopies, and biopsies.

Immunosuppressive medications, taken to prevent rejection of the new lungs, must be continued for life, but they increase infection and cancer risk.

Chronic rejection—called chronic allograft dysfunction—remains the biggest long-term challenge. After transplant, people survive 7.5 to 8 years on average, though many live longer.

Dr. Granton describes transplant as "trading one disease for another." PH is replaced with the chronic management of the transplant. For many patients, however, the trade is worth it. They experience less breathlessness and greater independence. Most, he says, would choose to do it again.

Contributed by: Dr. John Granton, Director of the PH program at the Toronto General Hospital, Toronto, ON, as interviewed by Kimberly Brunelle at PHA Canada

Community Quotes

"What has transplant allowed you to do that once felt out of reach?"

Transplant gave me back the sacred simplicity of life: managing my personal hygiene without stopping to catch my breath, eating without exhaustion, and holding the one I love without fear.

Most of all, it gave me the gift to watch my children grow, to hear their laughter, and to be present for the moments I once feared I'd miss.

Hogan Nguyen, diagnosed with PAH in 2014, two-time transplant recipient 2022 & 2024, Toronto, ON

Transplant gave me back the ordinary things that once felt out of reach like going up a flight of stairs without mapping out where I'd need to stop and breathe, being able to travel freely without measuring how much oxygen tanks I would need, and spending time with my family being present for moments I once feared I would miss.

Izabelle Nicole Lamarre, diagnosed with PAH in 2017, two-time transplant recipient 2020 & 2024, Ottawa, ON

From not being able to walk up stairs on my own, to being able to play hockey, lift weights and maintain an active lifestyle—the power of transplant has not only given me independence but a chance to experience life like a normal person. Without the power of transplant I would not be here today. Someone's decision to donate gave me the opportunity to live.

Braden Gendron, diagnosed with PAH in 2003, double lung transplant recipient 2009, Hampton, NB

It allows me to walk to places I couldn't otherwise walk to.

Adam Reitor, diagnosed with PH in 2010, transplant recipient 2022, Edmonton AB

Transplant has given me many gifts: experiences and people that I would not have had in my life had I not been gifted a second chance. The people I have met have taught me what resilience and strength mean. The patients, doctors, and nurses who have been part of my transplant journey inspired me and also kept me thriving. The most important experience I have had because of transplant was time. Time to see my son grow up. I was able to be a healthy mom to my son, one who can ride a bike, hike, paddle board, and kayak. I am forever grateful for time and the people who have enriched that time.

Lori Weber, diagnosed with PH in 2002, transplant recipient 2016, Edmonton, AB

Since my transplant, I've been able to interact more freely with my children and my grandson. We've traveled, gone swimming, and enjoyed simple outings like walking around the Assiniboine Zoo. It has also allowed me to care for my parents instead of them caring for my kids and me—especially important since they were both diagnosed with dementia in November 2023.

Ella Macleod, diagnosed with PH in 2015, transplant recipient 2022, Winnipeg, MB

For so long, there was a part of me aching to come out, held back by my health. My transplant changed everything, turning "impossible" adventures like whitewater rafting, rollercoaster riding, zip-lining, and the CN Tower EdgeWalk into my new normal. Setting "Adventurous Tina" free hasn't just changed my life…it has finally let me be my true genuine and whole self, and it's truly a magical and beautiful thing.

Tina Proulx, diagnosed with PH in 2003, transplant recipient 2015, Orleans, ON

PHighting for Time: Why I'm Not Ready for New Lungs Just Yet

Hearing the words "It is time to discuss having a double lung transplant (DLT)" gets a person's attention. When I was diagnosed with idiopathic pulmonary arterial hypertension (IPAH) in 2016, I knew that a DLT might be an option, but I thought I had many more good years ahead with my own lungs.

My doctor explained I would need a "workup," a battery of tests by the transplant team at Toronto General Hospital (TGH) to determine my candidacy and priority level. He urged me to start the process now so my condition wouldn't progress to the point where I risked being ineligible.

I decided to go ahead, considering it a "safety net" in case my condition declined. The workup took months, as I was also recovering from two strokes and already had a packed medical calendar. The tests were extensive: bone density scans, an echocardiogram, a right heart catheterization, a transesophageal echocardiogram, pulmonary function tests, and more. Finally, I travelled five hours to TGH to sign the listing papers.

Making that trip made the safety net real. I wasn't excited or scared; I just felt I had to do it. I have a little guy at home who needs his Mommy, and I will do anything in my power to make that happen. Until that point, I had pushed the beach ball that was my emotions underwater.

That changed during the meeting with the thoracic surgeon. Hearing about the operation—the physical harm of cutting the body open—was difficult, even knowing it could save my life. But the biggest shock was the possible timing. I went to Toronto to set a safety net in place, not to take immediate action. When the surgeon said I could be transplanted in a few months, the beach ball of emotions I had been submerging broke loose, dampening my eyes. I wanted to try the new PAH treatment, sotatercept, and hopefully buy time before living with someone else's lungs.

My case manager called to tell me I was listed as Priority 2. I was expecting to be listed at Priority 1, the lowest urgency. At a physio session, a lady had asked when my husband had been transplanted, assuming he was the patient. When I walked at a good speed on the treadmill, it had shocked the patients around me and added to my disbelief about the urgency of the transplant. Being considered a more urgent case was an unwanted surprise.

Thankfully, after advocacy from doctors, family, friends, politicians, Merck, and PHA Canada, I accessed sotatercept early, and it began helping me live better and longer with my own lungs. I pray that continues for me and my "PHellow PHighters." I am so grateful to have this chance. While I know I will one day need donor lungs, for now I am going to "PHight" my hardest with my own lungs.

Contributed by: Jane Sernoskie, living with PAH since 2016, Ottawa, ON

Choosing Life Through Transplant, Twice

Transplant is a word I never thought I would hear in my lifetime—especially at such a young age. For patients with pulmonary hypertension, transplant is the last option, reserved for when oral medications, pumps, and IV therapies are no longer enough.

In 2018, I was diagnosed with Pulmonary Veno-Occlusive Disease. No medications could slow its progression, and in June 2020—during the height of the COVID-19 pandemic—I underwent a double lung transplant. Just one year later, I was re-listed due to chronic rejection. Learning that I would need a double lung transplant not once, but twice, was something I could never have prepared for. After waiting four and a half years, on November 27, 2025, I received a Christmas miracle: a new set of lungs—and a second chance at life.

They often say that a transplant trades one disease for another, and in many ways, that's true. I take multiple immunosuppressant medications and vitamins every day to prevent my body from rejecting my lungs. Exercise is no longer optional—it's essential to keeping my lungs strong and healthy. Masking, avoiding germs, and being vigilant during cold and flu season are now a part of everyday life, especially when spending time in public or with loved ones. Transplant is a life-altering decision—but even so, it is one I have never regretted.

Before being re-listed for my second double lung transplant, I was terrified. I had already been through one transplant and didn't have the best outcome. What would a second transplant bring? Would it be worth it? Would I endure all of that again only to face the same struggles?

Ultimately, I chose quality of life over quantity, and that decision brought me peace. I knew what kind of life I wanted, and I knew a transplant was the only way to get there.

The transplant journey is long and demanding. From extensive pre-testing to being listed to waiting by the phone for that life-changing call, it requires patience, perseverance, and an incredible amount of trust. Having a strong support system—family, friends, or both—makes all the difference, especially on hard days. Recovery takes time, but each day gets easier.

This time, my recovery has been remarkable. I spent only three weeks in the hospital, compared to six weeks after my first transplant. My body has accepted these lungs beautifully, and for the first time in years, I feel hopeful about the future. I hope to return to work after eight years on disability—a milestone I once thought impossible.

My dreams about hiking, skating, downhill skiing, and travelling will finally become a reality. I look forward to returning home to my husband and our puppies and truly living the life we've waited so long to have.

Transplant has given me my life back. If I ever had to make the same decision again, I would—without hesitation—because this time, the possibilities truly are endless.

Contributed by: Lindsay Forsyth Brochu, double lung transplant recipient 2020 & 2025, Ottawa, ON

The Morning Everything Changed: Sophia's Transplant Journey

Before transplant, how did pulmonary hypertension affect you?
"I missed a lot of school because of Remodulin," Sophia says. "Every site change was 10 days of absolute torture. I wouldn't be able to move my arms for like two weeks." Friendships required extra effort. "I have one friend with asthma who would get notes for me, and we would just talk and text all the time while I was in hospital."

Her parents shielded her from earlier conversations about transplant. She says, "I prefer that my parents were protecting me because I don't think an eight-year-old can handle that."

What was it like when you finally got the call?
"I waited a little under four years for my call for lungs. So it was a really long wait."

When the call came, "It was probably the funniest call ever," she laughed. "I was asleep and my brother barged into my room holding his phone up like it's a weapon, saying 'You have lungs, you need to get up and get ready.' I was annoyed because I wanted to sleep in. Then I heard my mom and I'm like, 'Oh my God.' I told a couple of friends, 'Hey, I'm not gonna be talking for a little while. I'm getting lungs.' It was surreal."

What do you remember about waking up after transplant?
"The first thing I remember was probably the breathing tube. It's the worst feeling ever."

She spent five weeks in hospital. "The hospital food is absolutely disgusting." Her dad stocked her room with snacks. "Goldfish mostly. Some things I could snack on."

What changed after transplant?
"The first couple of weeks were just filled with appointments," but after about three months, she returned to school.

"I've never been able to do phys ed before. I passed with a 90 my first year, which was insane to me. I've learned how to run. I've been swimming a lot more and I've picked up snowboarding." She's still coaching basketball and can do more with her siblings. "I can actually play with my little sister."

She doesn't miss Remodulin. "No Remodulin. That's the best part."

Has anything been different than you expected after transplant?
Before transplant, eating was a struggle. "I always felt sick," Sophia explains. "My doctors said, 'Feed her whatever as long as she's eating.'"

After transplant, that changed dramatically. Now, she jokes, "My parents like to say I'll bite your hand off if you come near my food — which is probably true."

What would you say to another young pulmonary hypertension patient facing transplant?
"There are risks, but you can't really avoid it. It's going to improve your life by a long shot. It's gonna suck for a while, but it does get easier." She adds, "In the end, it's always worth it."

Sophia is thoughtful about her donor. "I'm thankful for them. It sucked, but it's changed me for the better. I'm happy that they signed up to be an organ donor."

Contributed by Sophia Ricci, living with PAH since 2009, lung transplant recipient 2023, Edmonton, AB, as interviewed by Kimberly Brunelle at PHA Canada

Research Corner

First, we summarize a couple of journal articles that talk about pulmonary hypertension and transplant: one finds pulmonary rehabilitation safe for PH patients awaiting transplant, and the other compares transplant outcomes for people with Group 2 and Group 3 pulmonary hypertension. Next, we present our 2025 Pulmonary Hypertension Research Scholarship recipients and their projects. Last but not least, we take a brief look at results from our new Clinical Trials report

Research Update: Pulmonary Rehabilitation in Lung Transplant Candidates with PAH

Maha Munawar, Lisa Wickerson, Chaya Gottesman, Aislinn Braun, Sahar Nourouzpour, Marc de Perrot, Lianne G. Singer, Shaf Keshavjee, John Granton, and Dmitry Rozenberg. Pulmonary rehabilitation in lung transplant candidates with pulmonary arterial hypertension. Respiratory Medicine 2024, 234:107816.

Background. We know supervised exercise training is safe and effective for people with mild or moderate pulmonary arterial hypertension (PAH), and we know that pre-transplant exercise capacity is associated with better outcomes and shorter hospital stays after lung transplants. But is pulmonary rehabilitation safe and effective for lung transplant candidates who have severe PAH? This study looked at how pulmonary rehabilitation affected people with severe PAH who were listed for lung transplants.

Findings. Researchers studied 40 lung transplant candidates with PAH who attended a mandatory supervised outpatient pulmonary rehabilitation program three times per week for 90 minutes while awaiting transplants. These exercise sessions involved aerobic exercise on a treadmill or stationary bike and weight training for both upper body and lower body muscles.

Participants increased their six-minute walk distance (6MWD) by an average of 18 metres while they were waiting (half waited more than 225 days, half for fewer) for a transplant. Measures of oxygen uptake, muscle volume, and the amount of oxygen people were able to use when exercising compared to the oxygen they used when sitting still all showed small but significant improvements. Measures for shortness of breath and leg fatigue did not change. Most participants' hearts remained unable to fully compensate for exercise and participants were unable to increase their heart rates enough with exercise.

There were no major safety incidents related to the exercise training.

Implications. This study established that participants listed for lung transplant and who participated in pulmonary rehabilitation safely maintained or improved their exercise capacity despite the significant symptoms associated with severe pulmonary arterial hypertension.

A 6MWD increase of 18 metres was not statistically relevant. However, other studies found decreases in 6MWD in similar participants over shorter time periods, so researchers in this study felt that participants ability to maintain their 6MWD while awaiting transplant was positive.

Future studies should look at post-transplant outcomes. They should also examine at-home and hybrid exercise programs as well as in-person programs and should look at the best ways for participants to resume pulmonary rehabilitation after a hospitalization.

Contributed by: Robyn Kalda, Manager, Research & Policy
Reviewed by: Dr. Rhea Varughese, University of Alberta Pulmonary Hypertension Program, Edmonton, AB

Research Update: Lung Transplant Outcomes in Patients with Groups 2 & 3 PH

Mora-Cuesta, V. M., Martínez-Meñaca, A., Iturbe-Fernández, D., Tello-Mena, S., Izquierdo-Cuervo, S., García-Camarero, T., Gil-Ongay, A., Alonso-Lecue, P., Cifrián-Martínez, J. M., Rodríguez-Chiaradia, D. A., Escribano-Subías, P., & Barreiro, E. (2025). Lung transplant outcomes in patients with preoperative catheterization indicating Group 2 pulmonary hypertension. Pulmonary circulation, 15(2), e70107. https://doi.org/10.1002/pul2.70107

Background. In recent years, better survival after lung transplantation has led to more flexible transplant criteria. Transplant patients are now older and more likely to have conditions such as pulmonary hypertension (PH). This study looked at 412 transplant patients from one hospital in Spain to see how many had Group 2 PH (pulmonary hypertension associated with left-sided heart disease), Group 3 PH, (pulmonary hypertension associated with lung disease) or no PH, and to compare how the various groups did during and after their lung transplants.

Findings. About one in ten of the transplant patients had Group 2 PH. About six in ten had Group 3 PH, about a quarter did not have pulmonary hypertension, and a few were excluded from the study because they had other conditions (including pulmonary arterial hypertension).

There were no significant differences in outcomes among the Group 2 PH, Group 3 PH, and no-PH groups. During the transplant surgeries, patients in the three different groups had similar complication rates. After their transplants, they had similar rejection rates, needed additional surgery, diuretics, or other interventions in similar proportions; and spent about the same length of time on ventilation, in ICU, and in the hospital in total.

Most importantly, there were no significant difference in long-term survival after transplant.

Because this study looked at patients who had already had lung transplants, the researchers noted that many patients who might have done poorly after transplant were already excluded. They also noted that it is possible that Group 2 PH patients who also show signs of Group 3 PH might not do as well.

Implications. Previously, there was little information about Group 2 PH and lung transplantation, but it was thought that Group 2 PH patients had worse outcomes after transplant. This study's patients are highly selected as they received lung transplants; it is uncertain how these results would reflect on those with more severe Group 2 PH and Group 3 PH. This study's results might help guide future research. More practically, it provides useful information for assessing potential transplant patients with Group 2 PH: mild Group 2 PH may not need to be a contraindication for lung transplant.

Contributed by: Robyn Kalda, Manager, Research & Policy
Reviewed by: Dr. Rhea Varughese, University of Alberta Pulmonary Hypertension Program, Edmonton, Alberta

2025 Bell Family Pediatric PH Research Scholarship Recipient

PHA Canada is proud to support the growth of the pulmonary hypertension research community by awarding scholarships to outstanding trainees. The Bell Family Pediatric Pulmonary Hypertension Research Scholarship, funded through the generous donations of Darren Bell in memory of his son Dylan, specifically aims to advance research that will improve the lives of children living with pulmonary hypertension.

Mahnaz Nazari

In 2025, Mahnaz Nazari was awarded the Bell Family Pediatric Pulmonary Hypertension Research Scholarship for the second time. Mahnaz joined Dr. Bernard Thébaud's laboratory at the Ottawa Hospital Research Institute in 2021 to pursue a Ph.D. in the Cellular and Molecular Medicine program. Her research is dedicated to developing treatments for extremely premature babies suffering from pulmonary hypertension, with the ultimate goal of developing a cell-free, off-the-shelf product with the potential for clinical trials.

Project: Investigating the therapeutic potential of endothelial progenitor cell-based therapy for neonatal pulmonary hypertension

Extreme preterm birth complications, including neonatal pulmonary hypertension, are the main cause of death in children under 5. In babies with neonatal PH, the loss of blood vessels forces the right side of the heart to work harder and grow larger. This doubles the risk of death, and unfortunately, no cure exists for neonatal pulmonary hypertension. Our lab is working to change this. We previously found that blood from the human umbilical cord (hUCB), normally discarded at birth, contains special cells called endothelial colony forming cells (ECFCs), which can build new blood vessels. We also found that ECFCs in the lungs of babies and rats are impaired when exposed to high oxygen levels, which are often needed in neonatal care.

Encouragingly, we showed that hUCB-ECFCs help newborn mice grow more lung vessels and prevent pulmonary hypertension. We are now testing a new type of reprogrammed stem cell derived vasculogenic progenitor cells which behaves like hUCB-ECFCs but can be produced in unlimited supply. We showed that these cells improved blood vessel growth and reduced pulmonary hypertension in mice, showing promise as a regenerative approach for babies with this life-threatening condition.

Learn more about PHA Canada's scholarship recipients and their research projects at phacanada.ca/researchscholarships

2025 Paroian Family PH Research Scholarship Recipient

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.

Elmira Safaie Qamsari

In 2025, Elmira Safaie Qamsari was awarded the Paroian Family Pulmonary Hypertension Research Scholarship. With a Master's degree in Medical Immunology, she aims to leverage her immunology background to harness immune cells in developing novel therapies for pulmonary arterial hypertension. She began her PhD journey in Dr. Duncan Stewart's lab at the Ottawa Hospital Research Institute in 2022 and is now investigating immunotherapeutic approaches using natural killer T (NKT) cells and chimeric antigen receptor–engineered natural killer (CAR-NK) cells to prevent and reverse the disease.

Project: Targeting Endothelial Cell Growth in Pulmonary Arterial Hypertension Using CAR-NK Cell Immunotherapy

We identified a molecule, called TM4SF1, which is on the surface of some of the abnormal cells that form the inner lining of blood vessels in patients with pulmonary arterial hypertension. These TM4SF1-positive cells have uncontrolled growth, leading to the blockage of small lung arteries.

This discovery opens the door to two new ways to fight pulmonary arterial hypertension.

First, we will engineer immune cells that target TM4SF1-positive blood vessels. These engineered cells will seek out and destroy the abnormal blood vessel cells that drive pulmonary arterial hypertension.

Second, we will use powerful gene-editing technology to remove TM4SF1 from these abnormal cells, thus restoring normal control of blood vessel cell growth. Unlike today's treatments, which mostly only manage symptoms, these approaches could change the course of pulmonary arterial hypertension and give patients new hope for a healthier future.

Interested in funding a scholarship?
Write researchscholarship@phacanada.ca to ask about our Donor Directed Gift Policy

Clinical Trials: What Matters to You?

In 2024, PHA Canada, in collaboration with Principal Investigator Dr. Jason Weatherald from the University of Alberta, conducted a survey to better understand why people living with pulmonary hypertension choose to participate—or not participate—in clinical trials. The survey was adapted from one first conducted by Pulmonary Hypertension Association UK. The findings will help researchers better understand the needs of patients and their loved ones, supporting the design of clinical trials that are as straightforward as possible to participate in and that measure aspects of health that reflect participants'

"By taking part in clinical trials, patients play a vital role in researching new treatments for pulmonary hypertension - and it's important their voices are heard when it comes to designing them" - PHA UK

What did we find?

84% of those who have taken part in a clinical trail that involved taking a drug for pulmonary arterial hypertension would definitely or probably do so again

67% had a good or very good experience

The top 3 reasons people gave for **wanting to take part** in clinical trials were:

1. To help other people with pulmonary hypertension in the future
2. Because the drug treatment I would get in the trial may help me
3. To advance science

Top 3 reasons people gave for **being discouraged** from taking part in clinical trials:

1. I would be worried about side effects from medication
2. The cost that may be associated—e.g. travel to hospital, parking, or time off work
3. It wouldn't be worth it if I ended up getting a 'dummy' or placebo treatment instead of the drug being tested

"For me being part of a study would depend on how much work I would miss. As well, I live in the country so winter months are more difficult to travel (never know when a storm will hit)" – a survey respondent

"These results will help researchers design new clinical trials that are more relevant to patients and that minimize the burdens of participating. " – a survey respondent

"The more trials that are opened up to more of us, the more data can be compiled. You can't test for trials for PH on healthy people. You need PH / PAH patients to do the trials." – a survey respondent

Look for the full report soon on our website.

CONNECTIONS

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