



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA
.....
L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA

CONNECTIONS

The Official Magazine of the Canadian PH Community



Special Feature:
Art & Healing

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**PULMONARY HYPERTENSION
ASSOCIATION OF CANADA**
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PULMONAIRE DU CANADA

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Message from the Chair

We Are All Capable of Self-Expression



Well, here we are! At this time last year, I was writing my first message to you as Board Chair, and we had only seen the first wave of the pandemic. Now, things feel a little different. Dare I say that we are ending Summer with renewed hope and heading towards better times? Personally, I'm hopeful for a more optimistic Fall, one where I can hopefully add travel back into my plans.

Maybe some of you are also considering travelling once again? If so, I hope you were able to take part in our first ever virtual conference in June. And, if not, hopefully you were able to watch some of the recorded sessions, like the one on PH & Travel! I've been to several PH conferences over the past seven years and, I have to say, this was quite possibly one of the best. I don't say this just because of my role in the organization. I attended many sessions as a patient, participated in discussions, and chatted with many others during the week-long event. There were so many great sessions, whether they were patient led or featured healthcare professionals. The sessions were well attended, with interesting dialogue and great questions. It was amazing to see large numbers of participation and all from the comfort of our own homes. I'm so grateful for the PH doctors and nurses who took time from their busy schedules to be with us, answer questions, reassure us, and—most of all—for showing us they care. It was remarkable witnessing everyone being Extraordinary Together: patients, caregivers, family members, doctors, nurses, and PHA Canada's staff members.

A very special part of the conference were the exhibits featuring art from members of the PH community. Those exhibits were an extension of the theme of this issue of *Connections*: Art & Healing. I have come to the conclusion over the last year and a half that many people have relied on some form of art to get through the pandemic. I've seen many posts on social media where people have taken up a new art-related hobby. I've realized just how important art—in all its forms—is to our mental health and well-being. Whether it be painting, knitting, crocheting, doing puzzles, playing music, or so many other practices, we are all creative and are all capable of self-expression.

[...] may you continue
being extraordinary.

I recently read an article by Carrie Brummer about «Why the arts matter?». She says, «...it's because the arts are a means of emotional expression for people in an increasingly stressful, busy, and confusing world. The arts allow people to channel their emotions to the benefit of themselves and others to live more fulfilled lives. It makes our world a better place to live.» This resonated for me, and I think demonstrates why so many were drawn to art-related hobbies throughout the pandemic. I hope that the art featured on the conference website and here in *Connections* leaves you feeling less stressed and more fulfilled.

As we head into Fall, I also hope that this past year and a half has allowed you to heal and grow. I hope you will continue to express yourself through art and to share your stories with us. And, of course, may you continue being extraordinary.

A handwritten signature in black ink that reads 'Nicole Dempsey'.

Nicole Dempsey
Living with IPAH since 2013
Board Chair, PHA Canada

Message from the Executive Director

Slow Down and Gaze at Something Beautiful



Like me, I hope you share in Nicole's optimism and hopefulness for the road ahead. As Summer ends, students return to school, and the weather cools, the upcoming change of season will no doubt bring with it new uncertainties for pandemic life. Yet, we are undoubtedly in a better place this year than we were last year. We know more and we have more tools at our disposal to keep ourselves and one another safe.

The PH community is also no stranger to uncertainty, and I continue to be impressed by your ability to adapt to new situations and overcome challenges. Whether it's improving your physical fitness, organizing a challenging trip, supporting your child through major surgery, or learning a new computer program so you can participate in your first virtual conference; you keep going. And life keeps unfolding before us.

This Summer I've wished more than usual that we could slow down time somehow. It's all going by so fast. It seems like World PH Day and the National PH Community Conference (pages 8-9) just happened, and yet here we are, already getting ready for PH Awareness Month in November (page 6). For me, this issue of *Connections* is an invitation to slow down a little and nurture that part of ourselves that longs to sit and gaze at something beautiful and interesting (without checking our phones). Like nature (perhaps its most famous subject), art helps us take pause. No matter what may be taking place around us, art gives us—both as creators and consumers—space to focus, reflect, and find new meaning in our everyday experiences.

Perhaps it is because of this space that art creates, that art can be so healing. The artists portrayed in this special issue (pages 14-24) show us something more profound than their talent, they show us why the practice of creating art—simply for the sake of creating—matters. It is in their personal expressions of creativity that they find freedom, relaxation, connection, and pride. The healing is in their experience of the art, not in the art object itself. And that means it's available to us all, whether we think of ourselves as artists or not.

[...] art gives us space to focus, reflect, and find new meaning in our everyday experiences.

Once upon a time I thought of myself primarily as an artist. I have always believed in the power of art to change the world! So, it's been thrilling to see the many ways that folks in the PH community have embraced their artistic sides throughout their PH journeys and during the pandemic. To all the artists featured this Summer in *Connections* and at the community conference, thank you for shining a light on the value and self-care that comes from expressing ourselves creatively. I suspect in sharing your creations with us, you will have inspired many others to consider new creative endeavours.

And speaking of creative endeavours, you will notice we've made some changes to the design of *Connections* this issue! We hope you enjoy this refresh of the magazine and, as always, we encourage you to share your feedback with us. Our new team members (page 5) can't wait to get to know you better, so please reach out to us anytime, whether by phone, email, or on social media. And in the meantime, thank you for making this summer quite extraordinary. It wouldn't have been the same without you.

A handwritten signature in black ink that reads "Jamie Myrah".

Jamie Myrah
Executive Director, PHA Canada

MEMO: Inside PHA Canada At a Glance

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

Retirements

Renee Levaque

Renee joined PHA Canada's Board of Directors in 2016 after being introduced to the PH community by her friend, former PHA Canada Director, Harry Kingston. Harry was living with PAH and knew that Renee would be an asset to the PH community, given her passionate personality and her 20 years of experience working in public health. Inspired by her experiences with PHA Canada, such as the 2015 National Conference in Montreal, Renee became a dedicated champion of the cause. In addition to joining PHA Canada,

she also joined the Board of Fondation HTAPQ in Quebec and served as a crucial liaison between our organizations. Renee also played a lead role in the development of PHA Canada's most recent strategic plan. Throughout the planning process Renee was a strong advocate for keeping PHA Canada accountable to patients by focusing on the needs of people living with PH. Renee retired from the Board in August 2021. We are grateful for her many years of compassionate service to the PH community... Merci Renee!



New Video Series

This Spring PHA Canada launched a four-part video series about pulmonary hypertension. The short, easy-to-understand animated videos explain what PH is, its types, risk factors, and treatments. Watch the videos on our website and share them with your friends and family to help spread awareness about your **Life in Purple**: phacanada.ca/videos



New Staff

PHA Canada's team is growing across the country! Welcome to our new staff members in Calgary, Toronto, and Mississauga...

Darren Fisher

Manager, Strategic Initiatives

Darren joined PHA Canada as a volunteer in January and by May we made it official when he became our first Manager of Strategic Initiatives. Darren is responsible for overseeing the planning, implementation, and evaluation of all PHA Canada's program activities, including community engagement, partnership development, and team leadership. Darren comes to PHA Canada with a long history in community-based health organizations, including many years working in respiratory health. Darren resides in downtown Toronto and is the only member of the staff team to have visited every Canadian province and territory!



Kimberly Brunelle

Coordinator, Support & Education Programs

Kimberly is the newest member of PHA Canada's team, joining us in August from Mississauga, ON. As Support and Education Programs Coordinator, Kimberly is responsible for leading initiatives that help the PH community to live better with PH. This includes working with community member, volunteers, and partners to implement support and education activities both online and in-person. Kimberly speaks both English and French and has a passion for patient care, coming to PHA Canada with many years of experience working in health promotion and patient support in Ontario.



Milena Ashgedom

Coordinator, Marketing & Communications

Milena took over as PHA Canada's Marketing and Communications Coordinator at the end of May, just in time to help launch our first virtual and bilingual community conference. Talk about a learning curve! Milena jumped right in and dedicated herself to getting to know the PH community as fast as possible, especially our francophone friends. In her role, Milena is responsible for making sure PHA Canada is effectively reaching the PH community in both of Canada's official languages, including overseeing our website, social media channels, newsletters, and marketing activities. Milena currently lives in Calgary, AB and comes to PHA Canada with a background in politics, public affairs, and community relations.



Learn more about PHA Canada's entire team at phacanada.ca/staff

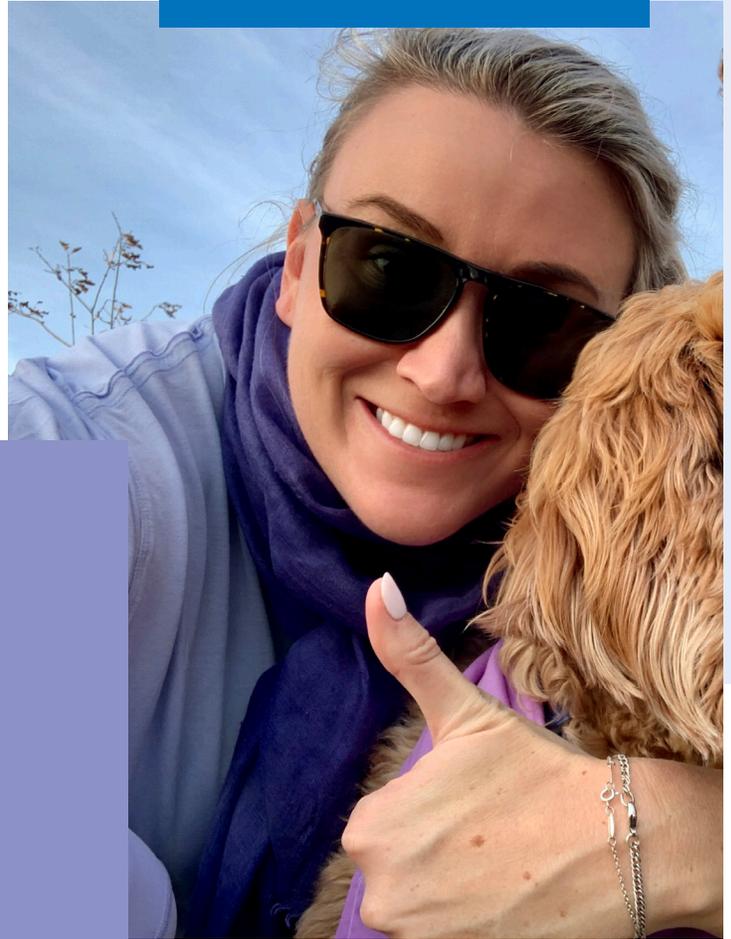
To learn more about the National PH Community Conference, go to **page 9**.

PH Awareness Month

November is PH Awareness Month!

Join us in raising awareness and
support for PH in Canada!

Learn more at
phacanada.ca/lifeinpurple



As a CTEPH patient living with residual PH and a dedicated patient advocate, I know first-hand some of the challenges that people affected by PH in Canada face. As a member of the PHA Canada Board of Directors, I also see how our programs and services are helping Canada's PH Community face those challenges. This November, I encourage you to take the opportunity to raise awareness of PH in your community, and to show your support for PHA Canada.



PHA Canada Board Director,
Emily Pinckard,

Living with CTEPH since 2017. One of our top fundraisers in the 2020 Virtual 8th Annual Ottawa *6-Minute Walk for Breath*.

Your Community

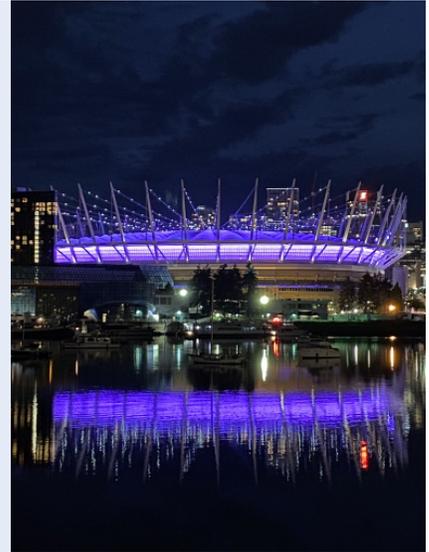
COVID-19 continues to impact our lives and challenge us to find creative ways to come together virtually. From the flood of social media posts celebrating World PH Day to being *Extraordinary Together* through our first online community conference, the PH community continues to reach out, respond, and support each other however we can.

Paint Canada Purple: A Purple Wave Crosses Canada For World PH Day 2021

PHA Canada's vision is "a better life for all Canadians affected by pulmonary hypertension". This vision guides the work of our staff and volunteers just as it reflects the hope and drive within Canada's PH community. The spirit of this vision is alive and well all year long, represented in the many ways you care for one another daily and connect with those sharing a similar journey. But each year on May 5th, something special happens when we all put our purple on to raise awareness of PH and show the strength of the Canadian PH community.



From coast to coast, some of Canada's most recognized landmarks were lit up in purple in support of World PH Day. This year, PHA Canada's #PaintCanadaPurple campaign included 17 public illuminations from Vancouver Island, BC to St. John's, NF. Each illumination raises awareness of PH and reminds local decision makers of the importance of your health and well-being. These public expressions of support also bring joy and hope to those affected by PH in communities across Canada. Thank you to all the volunteers who helped make sure Canada was shone bright in support of World PH Day 2021!



Somehow World PH Day still grabbed the attention of the media this year despite the near total domination over the media of COVID-19 and the continued limitations on in person community events. Members of the PH community Shared their journeys with the media in BC, Alberta, and Quebec. Nothing is more effective at raising awareness and making PH more visible than sharing your personal stories.



Photo Source: CTV News Calgary, Kevin Fleming, Video Journalist.

Check out more photos and stories from World PH Day 2021 at phacanada.ca/worldphday

2021 National PH Community Conference

Sessions

This year's conference featured the largest and most diverse program in PHA Canada's history! From June 12 to 19, our PH community was able to choose from over 30 educational sessions, yoga and reiki classes, and topic-specific meetups, all from the safety and comfort of home. This year's program featured over 75 panelists, speakers, and room hosts. This impressive list of healthcare providers, patients, and caregivers gave their time, expertise, and insight into a range of topics from COVID-19, emerging research, and stress management to information about treatment options or living life as a PH family.

Sponsors

The 2021 National PH Community Conference would not have been possible without the support of our sponsors. We are appreciative of the support provided by Jansen, United Therapeutics Corporation, Acceleron and Bayer. Their sponsorship allowed us to bring this amazing week-long virtual event. We are also grateful for the in-kind sponsors and supporters who gave their time to help promote the conference

and provide both Reiki and Yoga. Thank you Fondation HTAPQ, Shoppers Drug Mart Specialty Health Network, Birdeen from love.light.reiki. and Kim from Mantas Yoga. Finally, we are incredibly humbled by the time and effort given by our volunteers who sat on the advisory committee, informed our programming and planning, and who participated as speakers and meeting hosts. Thank you for helping ensure the 2021 National PH Community Conference was "more than just another Zoom meeting"!

Registration Kit

One of the things conference participants look forward to are conference registration kits. Not wanting to disappoint our attendees, we worked to provide everything necessary to give everyone that "conference feeling" despite being apart physically. Each kit contained a mini-program, PH wristband, pen, notebook made of seed paper, stickers, and some treats, just like you would normally get at a conference!

No conference would be complete with a photo booth and an opportunity to have a little bit of fun! In each registration kit we provided some photo booth props and encouraged our attendees to post some photos. From children to adults, our conference attendees did not disappoint!



Talent Show

Some of the most common feedback from every conference is how our events provide an opportunity to come together, meet new people, and have some fun with others in the PH community. In keeping with this theme, our Friday afternoon session featured a mini-talent show hosted by the very talented Jane Sernoskie. In addition to her original version of a famous rap song, the show featured up-and-coming stars Sandy and Charlotte Gibson, Ella Dorscht, and Carl Selzer. It was an extraordinary hour of music, laughter, and fun we won't soon forget!

Author: Jane Sernoskie

'Twas the night before the Virtual PH conference when all through the house.

Tech devices were charging, including the wireless mouse.

Plenaries and discussion sessions were selected with care,

In hopes that we would all become more PHaware.

The discussion boards were active with comments streaming in,

A sense of excitement was starting to begin.

Adorned in purple garments and some with purple hair,

We all felt ready to take on this virtual affair.

When all of a sudden there arose a big chatter,

I sprang to my laptop to see what was the matter.

Opening Plenary had commenced, welcoming one and all,

The Doctor's followed thereafter and answered the call.

Now Dr. Granton! Now Dr. Mehta! Now Dr. Bonnet and Dr. Brunner!

On Dr. Mak! On Dr. Mielniczuk! On Dr. Stewart and Dr. Provencher!

Relaying emerging research info and tips about taking good care,

Now enjoy your week and we invite you to participate and share!

2020 Donor Recognition

As we all know, 2020 was a year unlike any other. Yet support for people affected by pulmonary hypertension persisted despite job losses, business closures, event cancellations, and community lockdowns. The PH community rallied to donate thousands to virtual events and campaigns, our monthly donors stuck by us through all the uncertainty, and our corporate supporters were there to ensure our programs and services would not be interrupted by the pandemic.

When you donate to PHA Canada, you are making sure that no one in Canada faces a diagnosis of pulmonary hypertension alone. With your support, we are shining a light on this invisible illness, amplifying the voices of the PH community, and helping launch the careers of the next generation of PH researchers. We are grateful to all our donors and sponsors for their tremendous generosity, especially during a year filled with so much hardship. Thank you for your kindness, compassion, and commitment to creating a better life for all Canadians affected by PH.

Major Donors

David Anthony
Darren Bell
Michael Cairns
Dr. Ryan Davey
Ine Doorman
Rosemary Dunne
Dr. Desmond & Stephanie Dwyer
Patti Guminny
Greg Hunt
Bruce Hustins
Mani Jafari
Garth Jopling
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Jolene Mosiondz
Jamie Myrah
Jodi Paulin
Patrick & Joan Paulin

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Naveen Shastry
Betty Short
Jeff Skippen
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Renaë Mohammed
Angela Myrah
Ed Rathonyi

Michael Robach
Birdeen Selzer
Jacqueline Selzer
Balakrishna Shastry
Jeffrey Skippen
Marilyn Stubberfield

Community Events & Campaigns

Ajax Run/Walk for PH (Ajax, ON)
Dolores's Heavenly Heart (Winnipeg, MB)
GolPH for PH (Milton, ON)
Ottawa 6-Minute Walk for Breath (Ottawa, ON)
Ottawa Unmasking PH Masquerade Ball (Ottawa, ON)
PayPal Giving Fund Canada (Facebook Fundraising)
Royal Scot's 20 Mile March for PH in Honour of Everleigh Pierce (Mosa Township, ON)



What a great session we had on Managing Stress for PH Patients. I just wanted to say that I truly felt like I wasn't alone, and it was nice to meet everyone. I felt a bit emotional for a bit, but only because I could relate to what we discussed. Thank you so much to the organizers. Well Done!

2021 PH Conference attendee



Corporate & Foundation Donors

Chicago Title Insurance Company
 JC Weatherald Prof Corp
 JK Berg Services
 New Melbourne United Church
 Sunday School
 Provincial Employees Community
 Service Fund
 RBC Foundation
 Shylo Victoria Fragrance
 Sisters of Providence of St Vincent de Paul
 St Peter Catholic High School

Corporate Efforts

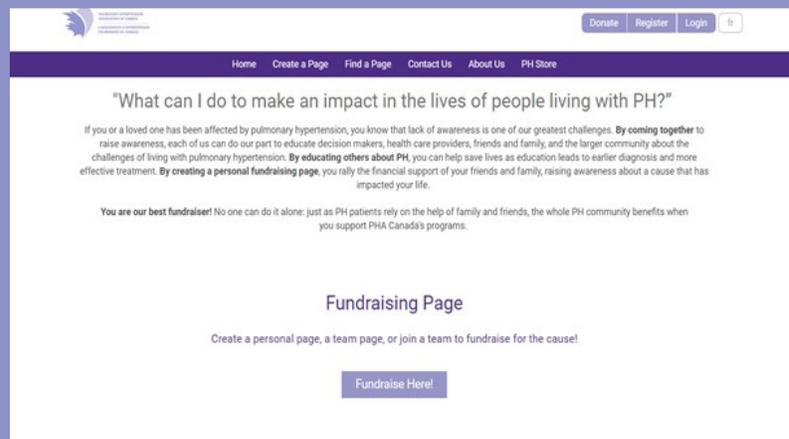
Bayer Inc.
 Janssen Inc.
 McKesson Canada
 Upjohn Canada
 Shoppers Drug Mart Specialty Health
 Network
 United Therapeutics Corporation

Fundraise Online

You can make a difference for the PH community from the comfort of your home! Create a personal or team fundraising page from PHA Canada's website. It's easier than ever to share your passion and commitment for helping Canadians affected by PH.

Start a Personal Campaign: Create your own online fundraising page and collect donations from your personal network. It's a quick, easy, and free way to start fundraising.

phacanada.akaraisin.com/FundraiseForPH





Feel Good Meetings

The HTAPQ Foundation continues to organize Zoom meetings with individuals living with PH. HTAPQ hosts monthly meetings called “Coffee with friends”. Conferences are also presented and offered to members diagnosed with PH and to PH caregivers.

The first “Coffee with friends” was held in January. During this meet-up, those diagnosed with PH introduced themselves to get to know each other better; it was a simple conversation among friends.

In February, we celebrated Valentine’s Day and most of our participants wore red. The theme of this meet-up, which was hosted by Ms. Lyne Ducharme, was “Let’s update each other”.

In March, we discussed what made us happy. What made us feel good? Some people said having grandchildren was a great feeling. Others shared their pastimes like knitting, crocheting, painting, and playing the piano. Some enjoyed doing puzzles, and many love writing and reading. As you can see, we have a few artists on our team. Despite everything, finding a pastime helps individuals enjoy life. This exceptional meet-up was animated by Ms. Judith Ross who is diagnosed with PH.

Our April meet-up was hosted by Ms. Lyne Ducharme who is diagnosed with PH. We asked the following questions: How did you feel when you received your diagnosis? How do you live with the disease? We received positive feedback. One after another, every participant shared how they received their diagnosis. We were all receptive, and we felt a sense of resilience among the group. It was a great meeting.

Our last meeting was held before summer vacation. Each of us shared our summer plans. We did not discuss time off because PH never stops; it’s always with us.

The Foundation also hosted conferences including the one hosted by Maïka Roy on “Recentring Amidst Fear”. During this hour meeting, Maïka Roy taught us how to master our fears, how to be better acquainted with them, and provided us with tools that we could use to tackle our fears in our lives to regain peace regardless of our circumstances.

We received, lawyer, Alexandra Bertrand who informed us on wills, protection mandates, power of attorney, and anticipated notarised medical directives. She answered all our questions; it was an interesting meeting.

Since March, we had six Essentrics classes led by Ms. Julie Bolduc. Essentrics is designed to increase our mobility, improve our flexibility, and tone our bodies. This exercise helps relieve chronic pain, alleviate stiffness, and improve our balance. Our participants enjoyed the classes so much that the Foundation offered six additional classes for those interested and diagnosed with PH.

This year, HTAPQ celebrates its 15th anniversary. To highlight the Foundation’s milestone, Ms. Dolorès Carrier proposed to publish a book highlighting the Foundation’s history. This book is written in collaboration with over 30 people diagnosed with PH who have accepted to share a glimpse of their lives with the disease.

We thank Ms. Dolorès for her involvement with those diagnosed with PH.

Lyne Ducharme
Living with PH and Administrator
HTAPQ Foundation

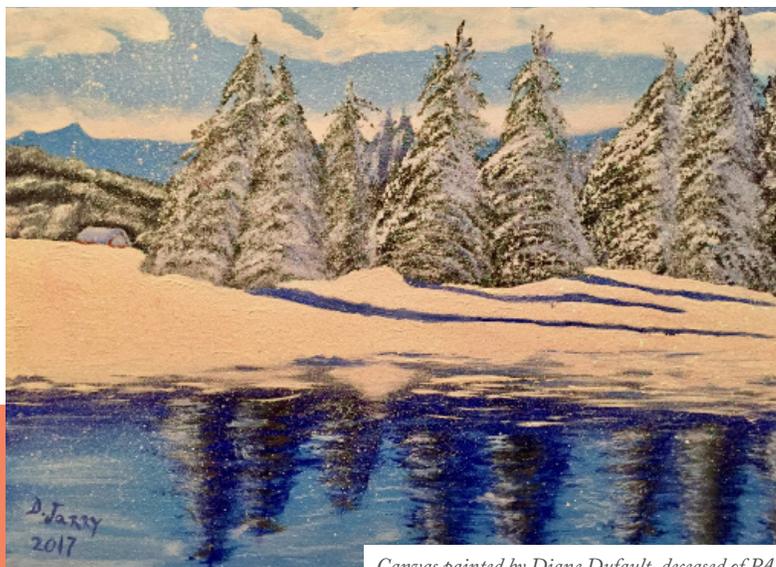
Special Feature

Art & Healing

Being diagnosed with PH usually comes with many life changes that can impact our mental health. In this special feature, you'll meet different artists from the PH community and learn some of the ways they benefit from their creative practice. These artists explore how creativity can be therapeutic, give us pleasure, help us feel connected to the world, and provide us with a sense of meaning and purpose.

A Beautiful Memory

Despite the fatigue, painting brought cheerfulness to my mother, **Diane Jarry Dufault**, throughout her illness



Canvas painted by Diane Dufault, deceased of PAH

It has been almost 10 years since we learned of the diagnosis from my mother, Diane Jarry Dufault. The diagnosis was confusing at first, heart failure, fatigue, loss of voice. He was given three months to live when diagnosed with PAH. However, she was part of a research program with the Jewish General Hospital in Montreal, and this gave her nearly five years of life.

The canvas represents life and positive energy despite the ups and downs of illness. My mother spoke a lot about her illness and her suffering. I asked her what she would like to leave my children with, other than talking about her illness, if she wanted to leave them with a positive memory of her presence in their lives.

She was already taking painting lessons for fun. To leave a positive memory, she had my daughter choose a model and she painted it ... over the span of several months. She was helped by her sisters to finalize the canvas since towards the end she was lacking a lot of energy. It was a time of special moments. Despite the fatigue, painting brought joy to my mother throughout her illness, as well as the desire to leave a memory for my daughter who greatly appreciates her canvas.

The canvas was given to my daughter before my mother died. This is the last and most personal gift she gave my daughter. I did not know my mom had this talent; it is a beautiful, positive memory. It also represents a beautiful reconciliation and a beautiful

mutual aid with her sisters. So, it's a unifying and happy feeling that I get to have the canvas. The disease did not defeat her, which is what warms my heart the most.

Painting allowed my mother to think about more than illness. It allowed her to focus on the beautiful and the positive. To see that she was still capable, despite the respiratory loss as well as the difficulty in her other daily habits.

Certainly, when I see my mother's paintings at my house or at my father's, it allows me to think of my mother and to keep fond memories of her and lessen the heaviness of the disease in our life. For the past few months, we couldn't do any activities with my mom. Just eating was breathless for her, but the painted canvases left a trace and a memory of the relationship we had with her. Discovering her talent so late also brought a feeling of gratitude: without the disease, maybe I would never have been able to see this talent born.

Contribution from: Patrick Dufault, caregiver of Diane Dufault, deceased of PAH

The canvas represents life and positive energy despite the ups and downs of illness.



Canvas painted by Diane Dufault, deceased of PAH

Painting by the Water

Jill hasn't let PAH get in the way of living life to the fullest, especially when it comes to her many hobbies, including gardening, felting, and painting

—
There are no mistakes
in painting, things
can just end up taking
a different path.
—

Jill was diagnosed with idiopathic pulmonary arterial hypertension in August 2019 and has also dealt with multiple sclerosis (MS) since 2001. She's done her best not to let her diagnoses slow her down.

When it comes to her many hobbies, including gardening, felting, and painting, Jill takes inspiration from nature and farming as she lives by the Bay of Fundy in Hampton, Nova Scotia. "I love living by the water," she says, "I love the sunsets no matter the season. It's peaceful and soothing."

She started painting seriously in 2009 after an MS relapse, as a means of getting the dexterity back in her hands. Here, the first painting is of a yellow warbler perched on an apple tree limb. Jill painted it from a photo that was taken at Bunchberry Nurseries in Nova Scotia. She's also painted bumble bees, and all sorts of flowers. The poppies, the second painting, was donated to a silent auction fundraiser for a friend with cancer. There are all sorts of subjects she paints, some water scenes, cedar wax wings on power lines at dusk, birch trees, ocean waves, and row boats, sail boats, and fishing boats.



Painting of a yellow warbler by Jill Taylor, living with PAH since 2019

She also shares her love of painting with anyone who'd like to give it a try. Jill says there are no mistakes in painting, things can just end up taking a different path.

She says that anything that's pleasing to you is art. "There's no right or wrong and it should make you happy when you're doing it," she says. "It can become work if there's no enjoyment in it. IPAHA changes your social group in many ways, but if you can create something, you can be content when you're alone doing what you like. You can also learn how to modify and adapt how you take on tasks so you can still do most of them but in a different manner."

Her other artistic hobbies include felting 3D animals, resin work, and driftwood dioramas. But what Jill is working on at the moment is a resin window for her pergola.



Painting by Jill Taylor, living with PAH since 2019

Contributed by: Jill Taylor, living with PAH since 2019

Art Helps Me Express Myself and Fulfill Myself

Sandy learned to crochet from a friend and made all kinds of toques for her kids before she started making amigurumi

I am a person with stage three idiopathic pulmonary arterial hypertension (or PAH). I was diagnosed in 2013, following my second pregnancy.

I started crocheting with a friend. She had brought her bin of yarn to the house and we started exploring YouTube videos and trying to emulate what we found there.

Art helps me relax and pass the time, it's true. But more than anything, art helps me express myself and fulfill myself!

At the beginning, I made all kinds of toques for my children: I would crochet them sets of neck warmers and toques that matched with their winter or spring clothes, depending on the season. I then started to make amigurumis, or little stuffed animals. I also made several baby comforters and slippers for my nephews and nieces and for the children of my friends.

I have always liked to write. Throughout my illness I wrote down my feelings, my fears, my anxieties. I wrote down every appointment and procedure, I wrote letters for my children ... Then one day I started to collect everything that I have accumulated over the years, and I made a manuscript of it that is taking more and more shape. The more time passed and with my health improving, the more it became like a life



A photo of the children, nephews, and sister-in-law of Sandy Vachon, living with PAH since 2013



A photo of the creations crocheted by Sandy Vachon, living with PAH since 2013

project. I don't know yet on which note I want to finish the manuscript, probably something like: life goes on even if you have a serious and degenerative illness.

Art helps me relax and pass the time, it's true. But more than anything, art helps me express myself and fulfill myself!

Contributed by: Sandy Vachon, living with PAH since 2013

Seeing the Joy in People's Eyes

Nicole lives in Sherbrooke, Québec, and learned to crochet to pass the time and grew proud of her creations and happy she could spark some joy in the people around her

Nicole started crocheting about five years ago after she was diagnosed with PAH in 2015 and had to take a sick leave from work. Needing to pass the time and keep busy, she soon taught herself how to crochet by watching videos online. At first, she started crocheting small dolls of all nationalities, where no two were the same, for friends and family. She would create them as she crocheted without a set plan in mind, so each one ended up being unique. She soon moved on to making one-of-a-kind stuffed animals, bookmarks, cup cozies, bags, and clothing, including shirts, vests, sweaters, and especially, Christmas stockings! She also created big stuffed animals called “amigurumis”. Her designs are always fun and colourful.

[...] seeing the joy in children's eyes when they saw her creations was priceless.

Wanting to contribute to the PH community, Nicole sold her cuddly creations at craft fairs, where she donated 100 percent of her sales to Fondation HTAPQ in Québec.



A unicorn crocheted by Nicole Rodrigue, living with PAH since 2015

When thinking back to those craft fairs, Nicole says seeing the joy in children's eyes when they saw her creations was priceless. She recalls feeling proud of her creations and happy she could spark some joy in the people around her. Having such a positive influence really increased her self-confidence, and she was glad to feel useful.

Nowadays, Nicole prefers to read to keep busy. Her favourite books are suspense and crime thrillers, as well as historical romance novels written by Québec authors.

Contributed by: Nicole Rodrigue, living with PAH since 2015



A snowman crocheted by Nicole Rodrigue, living with PAH since 2015



Nicole Rodrigue and her unique crocheted creations. Nicole has been living with PAH since 2015



Captain Jack

Antoinette Webb, living with PAH since 2011,
British Columbia



Trying to Fly

Artwork by **Jamie Kretzschmar**, double lung transplant
recipient, diagnosed with Eisenmenger's and PAH in 2009,
Ontario



Judith Ross, living with IPAH since 2010, Québec



**Lyne
Ducharme**,
living
with PAH
since 2000,
Québec



Réjean Dupont, living with PH since 2011, Québec



Anne Fagan-Wood, living with PAH since 2019, New Brunswick



The Old Boat

Painted by **Manon Desrosiers**, living with pulmonary veno-occlusive disease caused by scleroderma since 2015, Québec

A Book Fold

Created by **Terri Hamm**, living with IPAH since 1997, Alberta



Saving Positive Moments

Sarah's photography helps her remember the positive happy moments in her life, even when things seem bad

My name is Sarah Joudrey, I'm 16 years old, and I live in Brechin, Ontario. I was diagnosed with idiopathic pulmonary arterial hypertension on August 28, 2020, as well as Von-Willebrand disease shortly after.

I started photography in seventh grade. I started using my phone to take pictures of sunsets and my assorted animals, then for Christmas the next year, my dad bought me a little digital camera. In grade eight, I was chosen for a special program at my school, which taught us how to budget and do taxes. But the program also offered field trips/courses that were tailored to our interests, so I decided on the photography course taught by an experienced photographer.



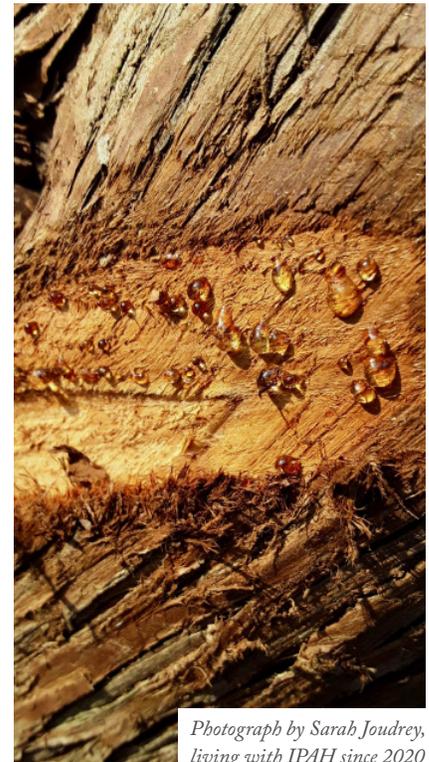
Photograph by Sarah Joudrey of her cat, Oscar. Sarah has been living with IPAH since 2020

My favorite photos are definitely the ones of my assorted animals. It seems like they see the camera and strike a pose like Madonna. Besides that, I love looking at the moment when my cat, cow, horse, or dog is doing something odd or cute. It's important for me to remember that I have positive things all around me in my life, even when things seem bad.

It's important for me to remember that I have positive things all around me in my life, even when things seem bad.

The photo that I submitted is a picture of a cedar fence post that my dad had just finished that day. I'd spent almost all day with him, and when I was following him to the barn, I saw the sap beading up from where the bark had been ripped off. I thought it looked pretty, so I took a photo of it. I never thought it would be featured in *Connections!* But that day I spent with my dad was a really good day for both of us.

Photography has greatly changed the way I see things. To me, taking a photo of something is like saving a moment that you can always go back and experience by looking at it and remembering where you were, what you were doing, and how you felt. Even though it seems cliché to say this, having a near death experience with PAH makes me want to go back to happy moments and cherish life.



Photograph by Sarah Joudrey, living with IPAH since 2020

Although cherishing life during a pandemic—when you have a lung disease, anxiety, and depression—is difficult, I did meet my therapist through all of the commotion, and things do seem to be looking up in my life right now. My family and I also received our first shot of the coronavirus vaccine in May, and my second dose is approaching quickly.

I try to see being diagnosed in the middle of a pandemic as a blessing, because this way, I'm not the only one who can't go to school or hang out with my friends, so I'm not missing as much as I could have. I hope everyone is finding ways to stay happy!

Contributed by: Sarah Joudrey, living with IPAH since 2020

An Inspiring Photograph

David aimed to capture the strength and the hopefulness these crocus flowers growing near his home in Amherstburg, Ontario

“They have a great type of energy, and they bring your mood up right away,” says Dr. David Coates, who took this photograph of wild crocus flowers in his yard. “The way they capture the sunlight is amazing.”

He was diagnosed with CTEPH and had pulmonary thromboendarterectomy (PEA) surgery at the University of Ottawa Heart Institute in 2007.

Though photography started out as a means to an end for David, it’s now one of his hobbies. “I started taking photographs with my phone to document unusual things in the environment as part of my job as a coroner,” he says. “But my wife, Patricia, is a professional artist, and she needed someone to take photos for her, and so my training began. She provided feedback on my photos and on how to improve their composition, and eventually I got better.” Over the years, this artistic duo’s photographs have been featured in exhibits, with a recent submission set to be featured in an upcoming art exhibit in Berlin, Germany.

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Every spring, they are the first flowers that come up in March, and it’s an energetic type of thing—they have strength.

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“I don’t consider myself an artist, but certainly if I keep following in my wife’s footsteps, I won’t end up too far off,” he says. When asked why he chose to photograph these crocus flowers, David says that he finds them amazing: “Every spring, they are the first flowers that come up in March, and it’s an energetic type of thing—they have strength.” David hopes people will feel the energy and the hopefulness the flowers represent to him.



Photograph of crocus flowers by Dr. David Coates, diagnosed with CTEPH and had PEA surgery in 2007

Before becoming a doctor, David studied biology. He mostly photographs nature and has also been involved in conservation projects. He and Patricia have planted thousands of trees on their acreage, which used to be farmland, as part of a restoration project, and David has photographed meadow crayfish that live in ponds created to rejuvenate aquatic ecosystems in the area. And when a new housing development threatened ecosystems, he testified on behalf of local conservation efforts at a hearing.

“But taking photos all the time can detract from your enjoyment of nature,” he says, sometimes it’s nice to venture out in nature without it, even if sometimes, you end up coming across something unusual that you wish you could photograph!

Contribution by: Dr. David Coates, diagnosed with CTEPH and had PEA surgery in 2007



Collage by Tina Giroux-Proulx, diagnosed with CTEPH in 2003 and received a double-lung transplant in 2015

Getting Through a Difficult Time with Art

When Tina and her husband, Joel, were working on this piece, they were entirely immersed in it, allowing their creativity to shine.

My name is Tina, and I live in Ottawa, Ontario. I am a CTEPH warrior and a double-lung transplant recipient.

I received my incredible gift of life on December 2, 2015, but the time leading up to that day did not come without its fears, worries, or anxieties for not just me, but my husband as well. The move to Toronto to wait for a surgery that may or may not have happened was difficult, and the seemingly endless wait for that very important call was

stressful. And so, we tried to fill our time with things that allowed us to escape the regular flow of life on the waitlist. This is where our first art piece came into play.

We had initially seen an art piece in a store made up of newspaper and magazine clippings that we thought looked really cool, but it was expensive and with a closer look, we immediately thought (like many people do), “Well, we can make that!” And so, we did.

The piece itself is made up of mostly magazine clippings, which we got from family and friends who gave us their unwanted magazines, and by grabbing any free magazines or pamphlets we could find in hospital waiting rooms, street corner stands, junk mail, and even blue boxes. We spent hours turning pages, looking for corky sayings, inspirational words, phrases that made us laugh or cry, and pretty much anything that felt uniquely us. Each piece was strategically placed on the canvas with glue and was chosen for a specific spot based on its colour, shape, and size.

It was a surprise to us how therapeutic this turned out to be. We were looking for something to pass the time, but we ended up finding something that helped us both cope with the stresses surrounding transplant. When we were working on this piece, we

were entirely immersed in it. Our minds would fall into a place that allowed our creativity to shine, and it gave us something different to focus on.

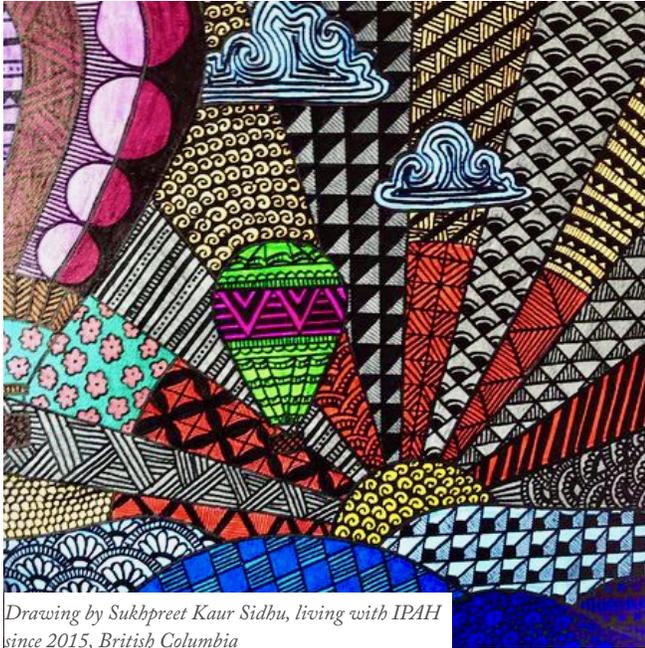
We enjoyed making this piece so much that when my one-year post-transplant anniversary came about, we decided to make another one as a thank you gift to the incredible group of people that played a role in saving my life—the transplant team at the Toronto General Hospital. In addition to magazine clippings, this ribbon shaped art piece also contains quotes from people whose lives have been affected by organ and tissue donation, such as organ recipients, recipient family members, and donor family members. I am proud to say that this piece now hangs in the Ajmera Transplant Centre’s patient waiting area.

Although we have since made a few more of these cool art pieces, nothing will compare to that very first one that helped us get through a difficult time. This piece now hangs over our bed, as a constant reminder that even in the hardest times we still managed to find fun, laughter, peace, and positivity.

Contributed by: Tina Grioux-Proulx, diagnosed with CTEPH in 2003 and received a double-lung transplant in 2015



Tina and her husband Joel in front of their collage, now displayed at the Ajmera Transplant Centre in Toronto, ON



Drawing by Sukhpreet Kaur Sidhu, living with IPAH since 2015, British Columbia

Life Is Colourful

Drawing and colouring helps **Sukhpreet** stay positive and cope with PAH while showing people that life is beautiful and colourful despite bad days

I was diagnosed with idiopathic pulmonary arterial hypertension in 2015, and when it started it was pretty severe. I was put on the subcutaneous infusion pump of Remodulin that same year. It helped for a while, but the pulmonary artery pressure wasn't going down, so my pulmonary hypertension team decided to add Bosentan, and then Adcirca. But I wasn't getting better, so I was sent for a lung transplant assessment in 2016. I knew that day would eventually come because my family doctor had told me from day one that I would need a lung transplant.

It was a tough journey. I travelled from my home in Victoria, British Columbia, to Toronto, Ontario, in October 2019 for the assessment, and I got on the active list for transplant in December 2019 and started physiotherapy three times a week. The year 2020 started as a good year for me. I got my first call for transplant on January 4, but that surgery was cancelled. When I got my second call, I didn't get my hopes up because anything could change at the last minute. But I was lucky and got my transplant on February 8.

As a kid, I had an artistic side. I remember I used to love drawing and won a few competitions too, but never pursued it because I was busy with school and then college. I started to pay more attention toward my artistic side whenever I was hospitalized. I started drawing in adult colouring books to keep myself busy and to keep my mind off everything.

But last year when I came back to British Columbia at the end of May 2020, I was not allowed to work and was bored and stressed because I was dependent on my family most of the time. So, I decided to order some canvas and start my passion again. I started with a small canvas (the first canvas that I made were lungs, heart, kidney, liver) then slowly I created on medium sized canvas for my family. My inspiration is nature as it's so colourful, so most of my drawings are flowers, sky, birds, etc. My sister gifted some of my work to her

business colleagues with my story on the back; they really appreciated it. When her colleagues responded with an email, my sister sent me screenshots of the messages and they made me cry because I lacked self-confidence and never trusted my work.

Currently, I am working on creating more canvas for my Instagram, which is Rtistik45. I usually upload some work once a week. I have posted most of my artwork and canvas on the page.

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Colouring really helped me cope with my condition and helped me stay positive. It also helped me to see life in a new way, just like the colours on the page: so beautiful and bright.

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Colouring has changed me a lot. It has made me so happy, and it gives me peace of mind. Whenever I finish a canvas, I feel I have accomplished something—I feel I did something good. I like to make my canvas colourful to show people that life is really colourful; even though we have some bad days, they will end because there's always a rainbow after the rain. I have started to stay positive now with my work. It inspires me to do more now every day.

Contributed by: Sukhpreet Kaur Sidhu, living with IPAH since 2015

Something for the Next Sick Girl to Read

By Terri Gower

My name is Terri, and I live in Victoria, British Columbia. I started writing because I had a lot of free time during the pandemic. I wrote this poem because it was hard to find poetry, fiction, or creative non-fiction about living with pulmonary hypertension. The poem is a kind of guide to getting diagnosed and all the fear and grief that can come with it, but also a way to remind people that your illness doesn't define you.

Ultimately, this is the poem I wanted when I was diagnosed, so writing it was very cathartic. My nurses and doctors were amazing, but there was a lack of shared experience and emotions that I really craved, so I hope this poem can fulfill that for someone else.

Contributed by: Terri Gower, living with IPAH since 2019

Walking
But also
heaving and streaming and wheezing
blood flows through rigid branches to
oversized clockwise cavities.

your heart's hollow echos
Climp clamp of ventricle's contracting
Rán's call to home.

A balloon sailing on crimson tide
Between groin and pulmonary artery
Norns' numbers passage back.

Start collecting compact clams
No crashing curls captured in their crevices
Soft-hued and smooth
swallow them swiftly to stay alive.

Storms start with more wind
Than your exhaling breath
But waves crash with less force
than takes to break your heart.

Something for the next sick girl to read.

Time for Selfcare

My name is Lisa, and I live in Toronto, Ontario. I had started taking a few watercolour courses here and there, but really delved into watercolours during the pandemic. It gave me something creative and fulfilling to do. I dedicated every Wednesday to my art and trying to find my style. I finally came up with a style that I enjoy creating and viewing and have stopped worrying what others think.

Contributed by: Lisa Noonan, living with systemic scleroderma and PAH since 2018



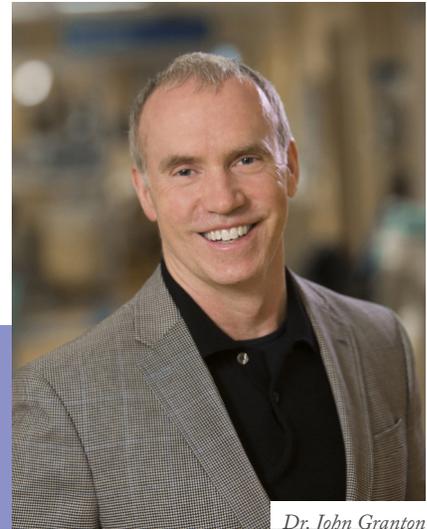
Watercolour painting by Lisa Noonan, living with systemic scleroderma and PAH since 2018

Research Corner

This section highlights Canadian research presented at PHA Canada's National PH Medical Think Tank and National PH Community Conference in June, as well as Canadian research that focuses on the benefits of regular movement and breathing practice.

Being Extraordinary Together: An Overview of the 2nd National PH Medical Think Tank

PHA Canada is proud to collaborate with PH health care providers across the country to support the timely and accurate diagnosis of pulmonary hypertension and the most effective care and treatment of patients.



Dr. John Granton

Before the National PH Community Conference began on June 12, Canadian PH health care professionals came together remotely on June 10 and 11 for PHA Canada's 2nd National PH Medical Think Tank. The event was organized by Dr. John Granton and the Programs Subcommittee of the Canadian PH Medical Committee to share knowledge and foster collaborations within the PH community.

The more than 60 registered attendees included physicians, researchers, nurses, social workers, and more, all eager to learn about new research and treatment approaches that they could bring back to their PH patients.

The first day of presentations covered ongoing research on understanding the pathology of PAH, as well as research around diagnosis and treatments, including advances in treating CTEPH with balloon artery angioplasty (BPA), potential avenues for treating interstitial lung disease (ILD), as well as advances in lung transplantation for PAH. Dr. Stephen Archer presented a plenary session on the effect of coronavirus disease on the lungs.

With the intention of fostering potential collaborations, the second day began with updates on the SAPPHERE, OPTION, and APPROACH trials, as well as the Canadian PH Registry. Dr. Marc De Perrot in Toronto provided an update on CTEPH patient outcomes after PEA surgery, while Dr. Jason Weatherald led the second half of the day with his project around setting priorities for future PH research in Canada.

The result was a lively discussion around ideas such as establishing a Canadian PH clinical trials network to evaluate and improve PH research across the country. Such a network could also provide resources to help smaller PH centres join multi-center trials, which would benefit patients and researchers alike. The mood was hopeful, and attendees were motivated and committed to meeting more often using a virtual format. Frequent meetings between PH doctors, nurses, and health care professionals to discuss new ideas and initiatives will only benefit the PH community.

The group agreed that in order to identify new treatment pathways and new effective therapies for patients, we need to prioritize more PH research.

Lastly, PHA Canada's Executive Director, Jamie Myrah, provided an update on the organization's 2021–2024 Strategic Plan, including its goal of establishing standards of excellence for PH care in Canada. Ultimately, the group of PH health care professionals agreed that to identify new treatment pathways and new effective therapies for patients, we need to prioritize more PH research in Canada.

Contributed by: Miriam Bergeret, living with PAH since 2016, PHA Canada Knowledge Translator

Why should PH clinicians care about patient quality of life?



Dr. Jason Weatherald

On the last day of the PH conference, Dr. Jason Weatherald spoke about the importance of patient-centered care and quality of life (QoL) in the PH community. According to Dr. Weatherald, PH is a complex disease that significantly impacts QoL, more so than other diseases. But why should clinicians care about it? Dr. Weatherald set out to answer this question. Clinicians should care about QoL because it is the most important expectation from treatment and is directly related to survival—people with better QoL tend to live longer and do better.

However, disease management strategies for PH often do not take patient experiences and quality of life into account, explains Dr. Weatherald. Current treatments largely only treat the underlying disease and fall short of addressing things that improve QoL, such as mental wellbeing and relationships with friends and family.

Incorporating QoL measurements in future PH research can ensure that in addition to treating the underlying disease, new interventions and therapies also have a positive effect on patients' daily lives, says Dr. Weatherald. A shift to a patient-centered care model where patients are engaged in the decision-making process around their own care can empower patients and could lead to better overall care and patient outcomes. "In a practical sense, patients should be able to discuss their symptoms and experience of their illness, including the psychosocial impact of PH," says Dr. Weatherald, "and clinicians should be receptive to this input and be able to apply it to the patient treatment models."

Contributed by: Miriam Bergeret, living with PAH since 2016, PHA Canada Knowledge Translator

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In a practical sense, patients should be able to discuss their symptoms and experience of their illness, including the psychosocial impact of PH...

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Being Extraordinary Together: An Overview of National PH Community of Conference Plenary Sessions



Dr. Sanjay Mehta



Dr. Steeve Provencher

Addressing the questions on every PH patient's mind

On Saturday, June 12, the Canadian PH community gathered online for the opening plenary session of the 2021 National PH Community Conference. Presented by Drs. Sanjay Mehta and John Granton, the session focused on a topic that has been on all our minds for over a year—COVID-19.

Dr. Granton opened the session and spoke about what health care workers experienced during the pandemic. He described the extraordinary measures taken to support those who have been critically ill with COVID-19, including using ECMO, or extracorporeal membrane oxygenation, an advanced life support technique. Dr. Granton also talked about some of the unintended effects of the pandemic, with Dr. Mehta detailing its impact on the PH community specifically, where a decrease of in-person clinic visits and testing has led to significantly fewer diagnoses over the past year.

Both physicians also spoke of the observed overlaps between PH and COVID-19, and the different lessons the health care community has learned during the pandemic that may one day help those living with PH. Dr. Mehta's presentation addressed some of the key questions particularly concerning PHers: Can COVID-19 cause PH? Are people living with PH more susceptible to infection with the coronavirus? What happens if someone with PH is infected with the coronavirus? Is that person more susceptible to severe COVID-19?

A key message of the opening plenary session was made clear—vaccination is the best defense against severe COVID-19 and both PH experts assured attendees that in general, COVID-19 vaccines are safe for those with PH.

To learn the answers to these questions and more, watch the recordings of the plenaries online at www.youtube.ca/phacanada

PH experts are optimistic about PH research

After a week of online seminars, exhibits, and discussions, the PH conference ended with a final presentation and Q&A panel discussion about new and emerging PH research. Dr. Steeve Provencher, the panel moderator, began with a talk about how patient outcomes have significantly improved as the result of research in Canada and around the world. New research is helping to better understand the disease and has already led to the discovery of new treatment pathways that are being tested in clinical trials.

Dr. Provencher then opened the discussion to a panel of PH experts who answered audience questions: Dr. Sebastien Bonnet, Dr. Nathan Brunner, Dr. Susanna Mak, and Dr. Duncan Stewart.

A key message from the panel was that there is reason to be optimistic about PH research, both for new treatments already being tested, as well as for the potential that a cure may be discovered some day. Dr. Bonnet affirmed, “It’s only a matter of us working all together and I’m sure we will cure PAH one day.”

The experts emphasized that there are many ways for PHers to get involved. For instance, patients can help researchers better understand what endpoints and outcomes are important to them when designing a trial. Patient enrollment is invaluable for developing new techniques, care models, and treatments.

The Q&A discussion also delved into other topics, such as the effects of the pandemic on PH research, updates on the SAPPHIRE trial and nitric oxide studies, and the Canadian PH Registry.

Contributed by: Miriam Bergeret, living with PAH since 2016 and PHA Canada Knowledge Translator, and Ashok Pandley, Marketing & Communications Assistant, PHA Canada



Dr. Sebastien Bonnet



Dr. Duncan Stewart

PH & Exercise: Taking an Active Role

Increasing evidence shows that exercise has benefits for people with PH, and some PH centers are beginning to recommend it.

For many PH patients, the first symptoms they noticed were feeling breathless or lightheaded when exercising. As a result, many people diagnosed with PH feel anxious about exercising for fear of worsening symptoms. In fact, exercise has traditionally been discouraged. But increasing evidence shows that exercise has benefits for people with PH, and some PH centers are beginning to recommend it.

“[People with PH] shouldn’t be afraid to exercise with the counsel of their PH specialist once they are treated. And in fact, exercise or some activity is usually good for people with all kinds of cardiovascular and pulmonary vascular conditions,” says Dr. Susanna Mak, a clinical cardiologist and heart failure specialist who is the director of the Anna Prosserman Heart Function Clinic, as well as the director of the Harold & Esther Mecklinger and the Posluns Family Cardiac Catheterization Clinical Research Laboratory at Mount Sinai Hospital in Toronto. “For most of our cardiovascular and pulmonary diseases, we know that a structured exercise program does help people become more confident and increases their stamina, and in some cases, actually improves outcomes like hospitalization.”

Dr. Mak has recently launched a clinical research program to study the relationship between cardiovascular function and shortness of breath, known as the BREATH (Breathlessness Revealed using Exercise to Assess the Hemodynamic response) program.

What happens to the heart and lungs during exercise with PH?

When we exercise, blood flow from the heart to the lungs increases, increasing the pressure in the lungs. This puts stress on the heart and lungs to keep up and supply our body with enough oxygen. To meet the increased demand, our lungs divert more blood to the small blood vessels (arterioles); however, in PH, these small vessels are damaged, which restricts blood flow through the lungs and to the rest of the body, resulting in exercise intolerance.

This exercise intolerance also limits our ability to participate in daily activities that put stress on the heart and lungs, such as climbing the stairs, carrying heavy groceries, bending over to pick something up, etc.

Understandably, when you have chronic fatigue, shortness of breath, and pain, it can be difficult to see the benefits of regular exercise, especially when those benefits aren’t immediate. You may also have safety concerns related to exercising and worry about overdoing it.

However, when we stay in one position for a long time, we’re not giving our body the movement that it needs. It’s important to change positions and move frequently to improve circulation and help our tendons, muscles, bones, and ligaments remain healthy.

What does the research say?

A number of studies have examined the role of exercise training in PH. One 2016 review of different clinical trials that evaluated aerobic, resistance, and inspiratory muscle training for six to 18 weeks in people with PAH found the training improved their six-minute walk distance by 17 to 96 metres, as well as their oxygen capacity.¹ Some participants even improved by one functional class and reported a better quality of life with very few adverse events related to exercise.

Since then, more studies have found that a regular exercise routine can lead to increased quality of life for PH patients.^{2,3,4}

In a 2020 survey, a number of PH patients said that walking or supervised exercise in the gym made them feel good and helped them feel more independent.⁵ In fact, one home-based walking program had beneficial effects on six-minute walking distance, quality of life, and WHO functional class.⁶

These results are encouraging, and researchers continue to investigate the effects of exercise in PH in order to develop specific and clear exercise guidelines both for patients and healthcare professionals.

Where to start with exercise?

In an ideal world, you may want a team of physiotherapists, exercise physiologists, nurses, and dieticians to help support an exercise routine. But even without a team of professionals, you can speak to your PH specialist and set some goals. “We still tell people that it is safe to exercise if they’re not feeling lightheaded, and if they follow some general guidelines for safe activity,” says Dr. Mak.

“It’s important to be smart about it and exercise sensibly. Take longer to warm up and listen to your body.” Don’t push yourself to the point where you’re either unable to speak two words together or feel lightheaded, she advises.

One useful goal may be to focus on functional training to start; for example, practicing exercises that can help make everyday activities easier. This may be practicing standing up from sitting in a chair (an adapted squat exercise), step training to improve capacity to climb stairs, etc.

Aim to move every hour or so for a few minutes. You can do some gentle stretches while sitting or standing or take a short five-minute walk. Even just regularly exercising your respiratory muscles, like your diaphragm, through deep breathing can increase respiratory capacity, making it easier to breathe with practice.

Some general guidelines:

- Choose an activity you enjoy
- Go slow
- Make sure you warm up
- Consider using a heart rate monitor
- Take regular breaks
- Be aware of your limitations
- Make sure someone is nearby in case you need assistance

For most of our cardiovascular and pulmonary diseases, we know that a structured exercise program does help people become more confident and increases their stamina, and in some cases, actually improves outcomes like hospitalization.

- Adapt exercises to your needs, such as doing them while sitting (e.g., chair yoga)

Contributed by: Miriam Bergeret, living with PAH since 2016, PHA Canada Knowledge Translator



Dr. Susanna Mak

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Breathe In, Breathe Out: Improve Your Breathing Through Practice

Many PHers, if not all of us, experience difficulty breathing, whether it's taking shallow breaths, physical discomfort when breathing and fear of taking a deep breath, or breath holding. Having PH also often means we don't get to exercise our muscles, causing muscle inflammation and damage, which leads to decreased muscle function.¹ This loss of function includes the muscles we use to breathe—our respiratory muscles—which can contribute to shallow breathing.

For those with PAH, there's the added challenge of fewer pulmonary blood vessels being available for oxygen exchange in the lungs.

So, what happens when we take shallow breaths? Less oxygen reaches the areas deep in the lungs where oxygen is exchanged, leading to less oxygen entering the circulation, known as hypoxemia. Hypoxemia can affect our organs and our muscle function by causing inflammation and damage, including to the respiratory muscles, further contributing to breathing impairment in PH.

You may think the muscle impairments in PH are permanent, but the good news is that, to a certain degree, they are reversible through exercise training. This includes the respiratory muscles—we can improve our breathing through practice.

Inspiratory muscle training

Inspiratory muscle training can be as simple as following a regular schedule to deliberately practice your breathing. For example, a basic schedule may be concentrating on taking 20 to 30 pursed lip or deep breaths twice a day over a period of a few weeks while monitoring your oxygen levels with a pulse oximeter.

- Sit or lie in a comfortable position and close your eyes
- Focus on the rise and fall of your chest
- Inhale through your nose and focus on breathing deeply into your belly
- Exhale through your mouth
- Repeat

As you progress and you exercise your respiratory muscles, breathing should get easier week by week. Sustaining this type of breathing practice can help maintain respiratory muscle health and function. This simple type of exercise can be done almost any time and any

You may think the muscle impairments in PH are permanent, but to a certain degree, we can improve our breathing through practice.

place and can easily be stopped if you need to take a break—always listen to your body and ask your PH doctor before starting any exercise or respiratory training.

Adding movement

For those with higher respiratory function, research has shown that combining carefully monitored low-dose exercise and respiratory training as an additional intervention to medical therapy improved exercise capacity and quality of life in patients with PH and right heart failure.²

You may think the muscle impairments experienced in PH are permanent, but the good news is that, to a certain degree, they are reversible through exercise training, including for the respiratory muscles.

Some of us may want to combine a breathing practice with less rigorous movement. One such approach is yoga therapy, which takes a person-centered one-on-one approach that focuses specifically on improving breathing and function through movement. It's less about body form and exercise, and instead embraces the idea that breathing is connected to body movement, to muscle movement. "We use simple movements to enhance the natural breathing movements of the body," says Cassandra Prus, a Toronto-based yoga teacher and therapist. "We build that practice slowly over time to make some space for the heart and lungs to expand inside the body, making space for the physical organs to move." Improved function can happen on a muscular level through inspiratory muscle training, and it can also happen through improved blood flow through body movement, says Cassandra. But let's not forget the nervous system.



Kassandra Prus

Improving anxiety

Many of us also experience anxiety that leads to physical symptoms like tense muscles and shallow breathing. But the mind is not passive—how you think can also change how the brain is organized. Research shows that having a deliberate and conscious breathing practice can strengthen neural connections between the brain and lungs and help alleviate anxiety.³ This type of mindfulness practice also contributes to better mental health and wellbeing by fostering new neural circuits related to controlling our attention and focusing our mind on our breathing.

Contributed by: Miriam Bergeret, living with PAH since 2016, PHA Canada Knowledge Translator

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