

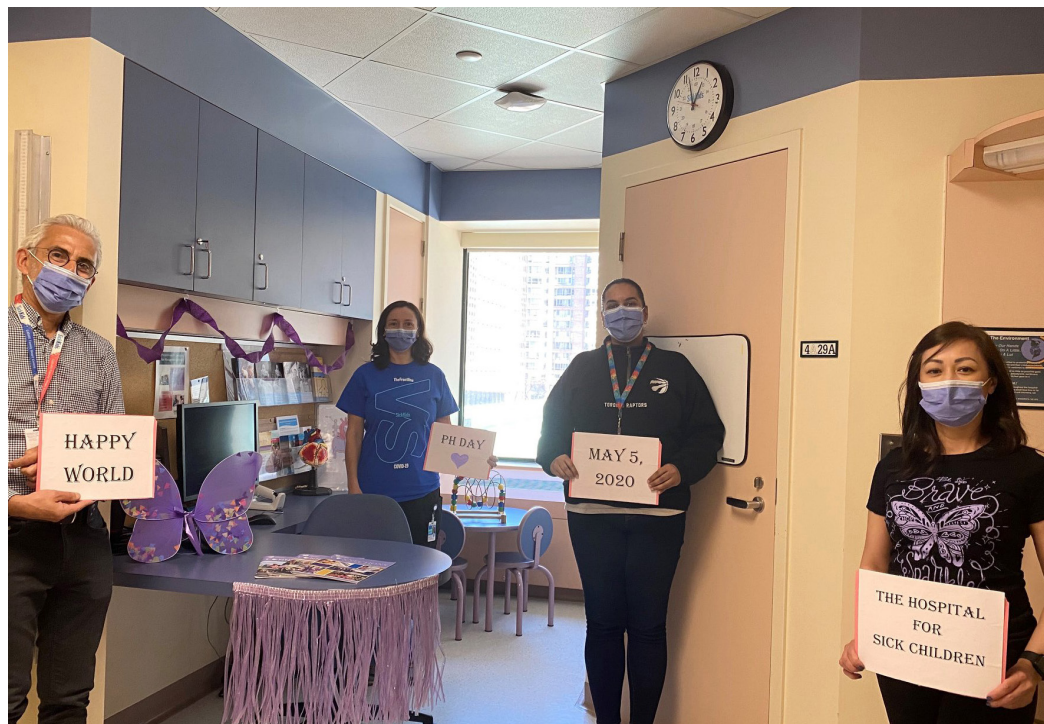


PULMONARY HYPERTENSION  
ASSOCIATION OF CANADA  
.....  
L'ASSOCIATION D'HYPERTENSION  
PULMONAIRE DU CANADA

# CONNECTIONS

The Official Magazine of the Canadian PH Community

Summer 2020 | Vol. 11, No. 1



Special Issue:  
PH & Mental Health





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

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# Message from the Chair:

## Pause, Breathe & Reach Out: PHA Canada is Always Here for You



I'm excited to be writing my first message to you as the new Chair of the Board of Directors. Although I never imagined I'd be in this role, I'm definitely honoured and looking forward to being the first person with PH to be Chair of PHA Canada. I really felt like this was a good, natural progression for me. I was diagnosed with pulmonary hypertension in 2013, became an advocate in 2014, an Ambassador in 2015, and a Board Director in 2017. So, I guess, becoming Chair seemed like the perfect next step. Over the last

three years as a Director, I've had the opportunity to observe and understand the processes of the Board and I now feel confident enough to take on this new leadership position.

I'm very fortunate to be succeeding two amazing and respected former Chairpersons, Roberta Massender and Dr. Sanjay Mehta. While I'll definitely have big shoes to fill, their phenomenal leadership, knowledge, and expertise have most definitely paved the way for me. On that note, I would be remiss if I didn't take a moment to thank Roberta and acknowledge her dedication to the organization since its inception. Roberta has devoted so much time and energy to PHA Canada. Her passion is unwavering and I'm sure she'll continue to support us, and provide guidance and insight when needed. On behalf of the whole PH community, we thank you.

**As I embark on this new journey, I'd like to continue to be a voice for all patients across the country. I want to continue to provide support and to advocate for important patient issues; access to medication is always a top priority.**

While working with the Board Directors and Executive Director, I want to continue to ensure that our objectives for the organization are met, while always keeping the care and needs of patients in mind. I'm hoping it might be reassuring to our community to know that I'm a patient, and therefore I know how it feels to live with this disease.

As Summer comes to an end and we start a new season, it certainly isn't going to be what we are used to. During these last several months, we've all been living through unconventional times, and I know firsthand that we can be easily stressed, distraught, worried, and even suffer with depression and/or anxiety. Those affected with lung disease are already at a greater risk of anxiety and to add a virus affecting the world can certainly be very stressful and isolating. I often need to remind myself to pause, breathe, and reach out when needed. Remember: be kind to yourself. I also want to tell you that PHA Canada is always here for you—in good times and in bad. I encourage anyone affected by PH to access the supports you need to be well and to stay safe.

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:

## Finding Strength & Compassion in Times of Crisis



When we started planning for this Summer issue of *Connections* at the beginning of the year, we had no idea how all our lives were about to change. In January, we decided the feature topic would be *Mental Health*, because we know it's an important topic for our community and we hoped it would serve as a useful companion to our Spring 2019 *PH & Lifestyle* issue. When the COVID-19 global pandemic arrived in Canada in March, we questioned whether we needed to change our approach and focus

entirely on COVID-19. But we quickly realized that in discussing *Mental Health*, we were indeed addressing one of the PH community's most significant needs during the pandemic.

These past months have been difficult for many—increased isolation and anxiety, delays to crucial testing and treatment (even transplant!), job losses, school and business closures. And now, as I write this, many of you are struggling with challenging decisions about returning your children to school. PHA Canada is not a public health organization; disease prevention is not our area of expertise. But because we are dedicated to the wellbeing of the PH community, we believe we have a role to play in helping you through this difficult time. This has included providing online sessions with medical experts to help answer your questions, blog posts by community members with tips for practicing meditation, mindfulness, and resiliency, and a new “PH Buddy” program to help strengthen your peer support networks (page 7).

In reality, these are the same sorts of resources and supports that PHA Canada is always here to provide. Because similar to living through a pandemic, living with pulmonary hypertension is also often marked by limitations to routine daily activities, disconnection from loved ones, and uncertainty about the future. It's no wonder that research shows that people living with a chronic disease are more likely to experience mental health challenges (page 15). Our hope is that this issue of *Connections* provides you with tools not only for managing the stresses of a global pandemic, but for facing any of life's inevitable hardships (page 22). There will always be moments of doubt, guilt, and sorrow (page 17), just as there are always opportunities for acceptance, hope, and gratitude (page 16).

**I want to thank all the community members who contributed to this important issue of *Connections*. You have shared deeply personal parts of yourself and in doing so are easing the burden for your fellow PHers. I am very grateful for your honesty and courage.**

Likewise, I thank the various experts and researchers who provided valuable insights into such complicated issues as addictions and PH (page 23), and the existential fear that can accompany a PH diagnosis (page 24).

These are not easy topics for anyone to face, but COVID-19 has truly reminded me of the amazing resilience of people with PH. Yes, these past months have been difficult, but they have also been quite beautiful. Like always, you have stepped up and truly been there for one another in a time of need. You have made extra phone calls, sent late night text messages, participated in virtual support groups, and fielded countless questions for one another. It's a privilege for us at PHA Canada to witness your strength and compassion, and to be a small part of your journey.

A handwritten signature in black ink that reads "Jamie Myrah". The signature is fluid and cursive.

Jamie Myrah  
Executive Director, PHA Canada

# MEMO: INSIDE PHA CANADA AT A GLANCE

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

## Retirements



### Roberta Massender

Roberta Massender has been involved with the PH community since her niece, Nicole Harrison, was diagnosed with PAH in November 2000. Together, they got involved with the BC Pulmonary Hypertension Society (BCPHS). Roberta's commitment to the PH community only grew when Nicole passed away in 2006. She joined the Board of Directors of the BCPHS in 2009 and also served as President. She was then elected to the Board of Directors of PHA Canada in 2012,

becoming Vice-Chair in 2013, and Chair in 2019. Roberta retired from the Board in May 2020 but will always remain a close PHriend to PHA Canada.



### Darren Bell, Eternal PHriend

A Founding Member of the organization, Darren Bell served as PHA Canada's first President/Chair from 2008 until 2011 and then as Treasurer from 2016-18. In 2018 he was honoured as an *Eternal PHriend of PHA Canada*. He has continuously provided a strong and unified voice for the Canadian PH community. Without his influence and knowledge, PHA Canada would not be where it is today. Darren retired from the Board in March 2020, shortly before the arrival of his new son James!



### Judith Moatti

Judith Moatti served as a PHA Canada Ambassador from June 2018 until June 2020. After being diagnosed with PAH in 2009, at the young age of 25, she became a strong advocate and spokesperson for those affected by PAH in Montreal, QC and across Canada. She celebrated her wedding in August 2020, just in time for new beginnings. We thank her for her many contributions to the PH community and wish her and her husband Jason a future full of happiness!

## Welcome Back Michaël Robach!



This July the Board of Directors appointed a new Director, Michaël Robach of Vancouver, BC. Michaël worked at PHA Canada between 2017 and 2019 as the Communications & Engagement Coordinator, during which time he gained a deep understanding of the issues affecting the Canadian PH community and developed a close relationship with the Canadian PHamily. To learn more, visit [phacanada.ca/Board](https://phacanada.ca/Board).

## New Staff

We are pleased to introduce you to two new permanent staff members:

### Laurence Richard

#### Marketing & Communications Coordinator

Laurence, or Lau (pronounced "Low"), joined PHA Canada as the Marketing and Communications Coordinator in November 2019. She speaks both French and English and is responsible for PHA Canada's brand management and marketing activities. This includes collaborating with the organization's team to develop and implement strategies for promoting PHA Canada amongst community members, supporters, and the general public across Canada.

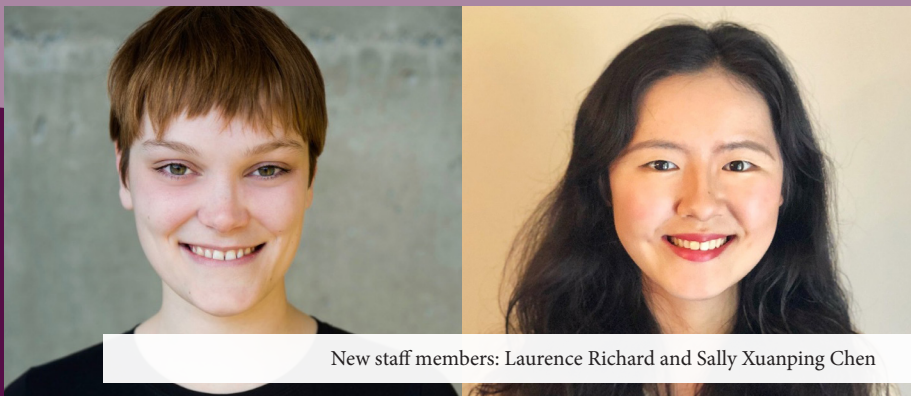
### Sally Xuanping Chen

#### Education Programs Coordinator

Sally joined PHA Canada as the Education Programs Coordinator in June 2020. Speaking both English and Mandarin, Sally is originally from China and has been living in Vancouver since the age of 16. At PHA Canada, she is responsible for leading initiatives to help the PH community manage and cope with living with PH. This includes working with community members, volunteers, and community partners to implement educational resources, events, and activities.

To read more, visit [phacanada.ca/Staff](https://phacanada.ca/Staff).





New staff members: Laurence Richard and Sally Xuanping Chen

## New Website

We launched a brand new website in February 2020! The upgraded site has been completely redesigned with more interactive features created to make the PH journey easier. We believe patients and their families should be able to find easy-to-understand information and resources that will help them stay supported and informed. Visit [phacanada.ca](http://phacanada.ca) to learn more.

Watch a live demo of the new website on our Facebook page ([facebook.com/phacanada](https://facebook.com/phacanada)): go to our “Videos” and choose *New Website Live Demo*.



## PH Buddy

Life during a pandemic can be stressful, especially for people already concerned about their health or the health of a loved one. Staying connected to others in your community—even while practicing social/physical distancing—is an important part of staying well. Could you use someone to talk to or do you want to help someone in the PH community feel less alone? Sign up to become a “PH Buddy”. Buddies will help one another stay safe and socially connected during this uncertain time. Visit [phacanada.ca/PHBuddy](http://phacanada.ca/PHBuddy).



## COVID-19 & PH

The COVID-19 global pandemic presents significant challenges for all of us, and unique challenges for those living with chronic illnesses, such as pulmonary hypertension. PHA Canada is committed to ensuring the PH community has access to trustworthy information, tools for staying mentally and physically well, and a sense of belonging in the face of increased physical isolation. Visit our dedicated webpage for trustworthy information about COVID-19, as well as education and support resources, including a special Q&A session with PH specialist Dr. Sanjay Mehta: [phacanada.ca/COVID-19](http://phacanada.ca/COVID-19).

## PH Blog

Read articles from healthcare professionals, researchers, advocates, and people living with PH about diverse subjects such as the role of inflammation in PAH, an update from Canada’s annual rare disease conference, or how to practice mediation in a few simple steps. Visit [phacanada.ca/PHBlog](http://phacanada.ca/PHBlog).

For Mental Health resources, go to page 25.

# Your Community In Action

## Community Events

In the last months, the Canadian PHamily's calendar has been filled with education, awareness, and fundraising activities, even while physical distancing measures have been in place! Here's an overview of community events that took place between October 2019 and July 2020. Thank you to all the organizers, participants, volunteers, donors, and sponsors who contributed to making each event a PHantastic success!

### 2019

OCT  
5

## Atlantic PH Forum



Thank You to the Atlantic PH Forum's Sponsors:



In October 2019, PHA Canada held its first-ever educational forum in the Canadian Atlantic region. This free event offered people affected by pulmonary hypertension the unique opportunity to learn about current research and treatment developments, to acquire skills to successfully manage life with PH, and to connect with members of the Canadian PHamily. Over 50 attendees from Newfoundland and Labrador, New Brunswick, Nova Scotia, and Prince Edward Island participated—plus some guests from Ontario & BC!

Photo: PH Caregiver Prelsey Bryson (middle) with speakers, Dr. Sanjay Mehta, MD, Eternal PHriend & Board Director; Sharon Pitre, RD; Dr. Noah Greenspan, DPT; and Emily Pinckard, PH Patient & Board Director

Fondation HTAPQ held their 2019 Conference in Longueuil, QC last October, under the theme “Together, let's hope for a better future.” PHA Canada is proud to have sponsored the event, which brings together the francophone PH community. The meeting was attended by over 75 people from throughout Québec.

Photo: The organizing committee for the 6<sup>th</sup> francophone congress in Longueuil, QC included Judith Moatti, Renée Levaque, Stéphanie Théoret, and Pierre Lachance, all members of the Fondation HTAPQ Board.

## Fondation HTAPQ 6<sup>th</sup> Conference

OCT  
18-20



NOV  
24

## 9<sup>th</sup> Annual Walk for PH JGH



The team at the Montreal Jewish Hospital worked incredibly hard this year to organize one of their most successful walks to date! The event drew many participants, including patients, their families, healthcare providers, and supporters. We wish to extend our warmest congratulations and gratitude to PH nurses Lyda Lesenko and Jessica Pinto for their inspiring support of the entire PH community.

Photo: PAH patient Kendall Tracy (middle, black t-shirt) with his family, Lynndel Tracy and her husband Dale, Collin Tracy, Wendy Bedard, and James Tracy.



NOV  
1-30

## Life in Purple: PH Awareness Month



During *PH Awareness Month* we helped people across the country better understand the daily impacts of PH on patients and caregivers through a social media campaign highlighting what “Life in Purple” looks like every day for those affected by PH. We published more than 20 posts on Facebook, which were shared more than 300 times!

## 7<sup>th</sup> Annual Ottawa Six-Minute Walk for Breath

NOV  
30

Fifty people participated in the 7th Annual Ottawa Six-Minute Walk for Breath where over **\$15,000** was raised! More than doubling the amount they have ever raised before. Thank you to the organizers of this very successful event, Carolyn Doyle-Cox, PH nurse at the Ottawa Heart Institute, with the help of her colleagues Rosemary and Julia.

Photo: One of the top fundraisers, Jane Sernoskie, with her husband Greg and niece Charlotte.



## 2020

MAR  
1

## Royal Scots Light Company Longwoods Memorial Program in Honour of Everleigh Pierce



The 2020 Royal Scots Light Company Longwoods Memorial Program in Honour of Everleigh Pierce took place on Sunday, March 1st, 2020. Kerry Pierce, Everleigh’s mother, has been a long-time supporter of PHA Canada.

Everleigh received a double-lung transplant in June 2020 after being diagnosed with PH in 2013 at the age of 2.

Photo: Members of the UTMRs marching for the cause!

MAR  
10

## Rare Disease Day Conference

This year, PH advocates gathered in Toronto and Montreal to attend events for Rare Disease Day! Here you can see members of the PH community at the Annual Disease Day Breakfast Reception hosted by the Canadian Organization of Rare Disorders at Queen’s Park in Toronto.

Photo: Allison McLean, Jeannie Tom, Esther MacLeod, Joan Linett Paulin, and Janette Reyes



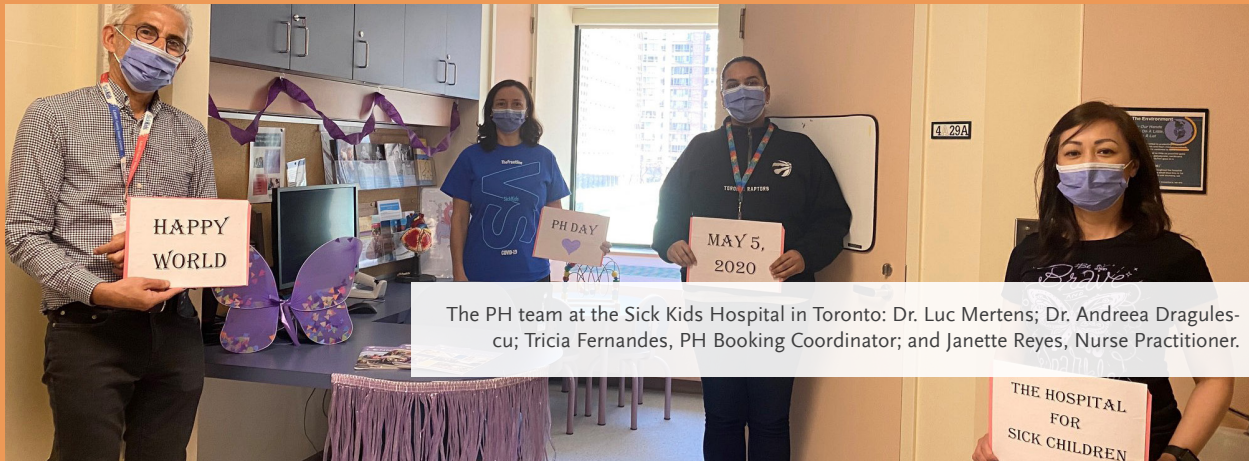
## World PH Day 2020

MAY  
5

World PH Day was very successful this year! Members of the PH community made #PaintCanadaPurple shine on social media, and we were able to reach over 20 million Canadians through media coverage. For more details, visit [phacanada.ca/WorldPHDay](http://phacanada.ca/WorldPHDay).

Photo: Niagara Falls illuminated for World PH Day 2020





The PH team at the Sick Kids Hospital in Toronto: Dr. Luc Mertens; Dr. Andreea Dragulescu; Tricia Fernandes, PH Booking Coordinator; and Janette Reyes, Nurse Practitioner.

## Celebrating Our Major Fundraisers

These three annual community fundraising events could not take place this year because of COVID-19. However, the organisers were committed to making sure that support for the PH community—including PH research—continued despite this year’s challenges. They gave their time and energy in the midst of the pandemic to keep the momentum going and have surpassed all our expectations. We are so grateful for your support and the continued generosity of your donors and sponsors. Thank you!

### MAY 2 Unmasking PH Masquerade Ball



#### Ottawa Unmasking PH Masquerade Ball

Ottawa PHERs made an unexpected gift of **\$6,000** in a show of support to the entire Canadian PHfamily during these challenging times. Amazing!

### JUN 6 7<sup>th</sup> Annual Ajax Run/Walk for PH Research

#### AJAX'S ANNUAL RUN/WALK FOR PH RESEARCH

The Mohammed family, living in Ajax (ON), took another step closer to finding a cure and raised over **\$1,800**. Way to go!

### GOLPH for PH JUL 23



Patrick Paulin and his family surprised everyone by raising over **\$10,000** without the swing of a single golf club. Outstanding!

### Fundraise Online



Make a difference for the PH community from the comfort of your home—create a personal or team fundraising page! 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](http://phacanada.akaraisin.com/FundraiseForPH)



# 2019 Donor Recognition

When you donate to PHA Canada, you are making sure that no one in Canada has to face a diagnosis of pulmonary hypertension alone. With your support, we are able to shine a light on this invisible illness, amplify the voices of the PH community, and help launch the careers of the next generation of PH researchers. We are grateful to all our donors and sponsors for their tremendous generosity. Thank you for your kindness and your commitment to creating a better life for all Canadians affected by PH.

## Legacy Gifts

The Estate of Johannes Jonk

## Major Donors

Darren Bell  
Adam Blanchette  
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Michael Cairns  
Michael Comeau  
Bryen Daly  
Dr. Desmond & Stephanie Dwyer  
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Ruthann Pierce  
Dr. Steeve Provencher  
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Birdeen & Carl Selzer  
Jacqueline Selzer  
Balakrisna Shastry  
Naveen Shastry  
Wilma Shastry  
Jeff Skippen  
Marilyn Stubberfield

## Community Events

2<sup>nd</sup> Annual Ottawa Unmasking PH Masquerade Ball (Ottawa, ON)  
5<sup>th</sup> Annual GolPH for PH (Brampton, ON)  
6<sup>th</sup> Annual Ajax Run/Walk for PH (Ajax, ON)  
7<sup>th</sup> Annual Ottawa 6-Minute Walk for Breath (Ottawa, ON)  
Dolores's Heavenly Heart (Winnipeg, MB)  
Paypal Giving Fund Canada (Facebook Fundraising)  
Phifty4PHifty Draw for Darren Bell (Vancouver, BC)  
Royal Scot's 20 Mile March for PH in Honour of Everleight Pierce (Mosa Township, ON)

## Corporate & Foundation Donors

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McKesson Canada  
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## Corporate Efforts

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Pfizer Canada Inc  
Shoppers Drug Mart Specialty Health Network  
United Therapeutics Corporation



## Postponed: PHA Canada's Eastern Regional PH Symposium & 2<sup>nd</sup> National PH Medical Think Tank



### PHA Canada's Eastern Regional PH Symposium

For the past five years, PHA Canada has been proud to host at least one educational event for the PH community every year. We have gathered in communities big (Toronto, Vancouver), medium (Halifax), and small (Red Deer), and were very excited about our plans to return to Ottawa in September 2020 for the first time since 2013.

However, the on-going and uncertain nature of the COVID-19 global pandemic means it is necessary to postpone this year's *Eastern Regional PH Symposium* and *2<sup>nd</sup> National PH Medical Think Tank*. This decision is aligned with current public health regulations, but—more importantly—is a reflection of PHA Canada's absolute commitment to the safety and well-being of the PH community.

#### Save the Date:

*Eastern Regional PH Symposium* returns June 11-12, 2021  
*2<sup>nd</sup> National PH Medical Think Tank* returns June 10-12, 2021

We look forward to welcoming PHers from across Eastern Canada (and beyond!) for a full day of learning, connection, and inspiration.

Stay safe and be well. We will continue to get through this together.

Visit [phacanada.ca/Events](https://phacanada.ca/Events) for all the updates.



# Fondation HTAPQ News

2019 was a very busy year for the Fondation de l'hypertension artérielle du Québec (Quebec Pulmonary Arterial Hypertension Foundation). Following the resignation of our president Hugues Boulanger in February, I took over the presidency so that all planned activities and financial assistance could continue uninterrupted for our members. We continued to organize meetings with speakers in different regions: La Prairie, Sherbrooke, and Quebec City. Our objective was to meet people with PAH and their loved ones where they are, so that they wouldn't have to travel long distances. We want to encourage people with PAH to organize meetings adapted to their needs in their respective regions.

## Volunteer Brunch

We also innovated by offering a brunch to thank our many loyal volunteers in September 2019. Close to 100 people attended! We took the opportunity to highlight the involvement of the Cormier and Ruel families, good-hearted people who have always been there to help the Fondation since it was created.

## HTAPQ Meeting, October 18-20, 2019

In collaboration with PHA Canada, the Fondation HTAPQ organized a meeting for all its members and all francophones outside Quebec. Held in Longueuil under the theme "Together, let's hope for a better future", the meeting was attended by over 75 people. Presentations, workshops, pleasant encounters, and a little magic were in store for the participants.

We also provided direct financial assistance to several people and celebrated the birthday of each of our members living with pulmonary hypertension. The number of members with pulmonary hypertension is on the rise, and we hope to recruit more members to increase our representation.

## Funding

To be able to carry out all these activities, we held two fundraising campaigns. To our cheese sale event, we added the sale of olive oil and balsamic vinegar box sets. This addition allowed us to make unprecedented profits. Our huge book sale was also a great success. Of course, fundraising requires a lot of time and energy, and the collaboration of many volunteers.

## The Impact of COVID-19

We had several projects in store for 2020, but due to the pandemic we had to cancel or postpone activities that were already organized. We also had to cancel two fundraising campaigns that were planned for the Spring. We hope to be able to carry out our big fundraising campaign for Christmas. On the other hand, we have turned to new technologies to continue to serve our members. Presentations and meditation sessions were offered online to all our members to help relieve the stress and anxiety brought by the pandemic.

But rest assured that we will do our best to continue to improve the quality of life for people with PAH and their loved ones.

After a year as President, I can say that the success of the Fondation depends directly on the involvement of the members of the Board of Directors. I would like to take this opportunity to thank them for their involvement, their generosity, the quality of their work, their availability, and the support they have given me throughout the year.

Contributed by: Dolorès Carrier,  
President, Fondation HTAPQ

Thanks to each of you [see photo below] and to all the volunteers who work with the Fondation. A special thank you to Judith Moatti who left her position as PH representative at the beginning of 2020, after several years of dedication to our organization.



Top row, left to right: Vice-President Pierre Lachance; Treasurer Pierre Gagnon; Director Jean-Pierre Vigneault; and Director Alain Chabot  
Bottom row, left to right: Secretary Renée Levaque; Director Stéphanie Théoret; President Dolorès Carrier; and Judith Moatti

# Special Feature: PH & Mental Health

## Mental Health with a Diagnosis of Pulmonary Hypertension

In her late 50s, Jeannette MacKeen graduated with a Master of Education degree with a Counselling specialty. She was diagnosed with systemic sclerosis (scleroderma) and pulmonary arterial hypertension with extremely high pressures in 2012 at the age of 68. She now lives in retirement in Wolfville, Nova Scotia. She introduces the subject of mental health for this edition of *Connections*, as a PAH patient and a counsellor.

**Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community.**

—World Health Organization

Mental health comes from feeling balanced, connected to others, and ready to meet life's challenges. Mental health goes hand-in-hand with physical health. When we eat well, get enough sleep, and stay active, our emotional health can improve.

When we develop an awareness of ourselves, the more in tune we are to our emotions, thoughts, and behaviours, the better we are at taking away the control they have over us. We are less likely to become overwhelmed in our everyday lives.

We need to allow ourselves to feel all of our emotions whether good or bad in order to work through them. If we acknowledge them, we are better able to deal with them. Acceptance allows us to put them in perspective. In other words, we are reframing our mindset.

When faced with adversity in my life, whether it is dealing with chronic illness, family situations, or the present situation facing our world, the COVID-19 pandemic, I try to face it by tapping into my resiliency. We all have a certain amount of resilience and need to access it when facing difficulties, whether situational or dealing with

chronic health issues such as pulmonary hypertension. It doesn't mean the situations are not difficult, but resilience provides us with the ability to deal with them reasonably.

In March of 2012, after going through much testing, I was finally given a diagnosis for what I had been dealing with for the previous 20 years: limited systemic sclerosis (scleroderma) and pulmonary arterial hypertension with extremely high pressures. My cardiologist did not mince words and told me directly what I was dealing with, finishing with: "This will likely be life-shortening". To hear that at age 68 was not encouraging news. My immediate reaction was not one that most people would expect. I was very calm, despite being a tad overwhelmed. What would the rest of my life look like? Was there any medication that would help? Was I facing doom and gloom? Should I get my affairs in order? All kinds of questions went through my mind.

Eight years have passed since this fateful day and today I can say that my life has been anything but doom and gloom. What I have learned about myself over the past 8 years is that I am a very resilient person.

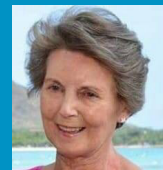
**Resilience is the ability to bounce back from most anything life throws at us, to recover quickly from difficulties, deal head-on with situations, and carry on with as little stress as possible. It's not about avoiding stress, but facing it.**

**A resilient person usually has:**

- a sense of purpose
- self-awareness
- self-confidence
- stress handling techniques
- a positive attitude
- perseverance
- problem-solving skills

Over the years I have developed ways to cope with most situations. I have always been driven in most things in my life and that has included continuing to educate and improve myself through research and courses or by attending and conducting workshops.

Attending support groups with like-minded people has been life-saving for me. I have learned much about myself and have recognized areas I needed to change to better my life. Through this, I have managed to create a positive self-image and have built confidence in my strengths and abilities. Last, but by far not the least, I have a firm faith and rely on my belief system to guide me through all areas of my life. My mental health depends on all of these factors. My suggestion to all of you is to push yourself to the very limits and enjoy every moment of your life. Tap into your resilience.



Contributed by:  
Jeannette MacKeen,  
Retired Counsellor,  
Living with PAH since  
2012



# Mental Health Statistics

By the time Canadians reach 40 years of age, 1-in-2 have—or have had—a mental illness (1).

In any given year, 1-in-5 Canadians experiences a mental illness or addiction problem (1).

Only about half of Canadians experiencing a major depressive episode receive “potentially adequate care” (2).

## Chronic Illness: Anxiety & Depression

Canadians with a chronic disease are twice as likely to experience a mood or anxiety disorder (3).

One third of people with a chronic disease experience depression (4).

Half of Canadians suffering from both a physical chronic condition and major depression report limitations to their day to day activities (3).

53% of people diagnosed with PH have experienced or been diagnosed with anxiety or depression (5).

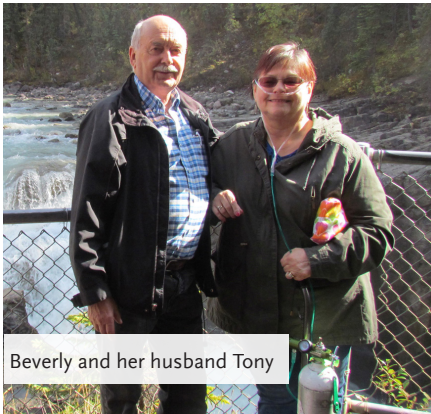
58% of people affected by PH who have experienced or been diagnosed with anxiety or depression have asked for professional help (5).

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# Making the Most Out of Life

Between 2014 and 2016, Beverly got several diagnoses: ILD, IPF, and PH. While these letters seem inoffensive, they carry a heavy load of medication, visits to the hospital, and emotional burden. Even if Beverly knows her life will be shortened, she is happy to have lived this long. She shares her story and how she makes the most out of life.



My world has taken a 180-degree turn since July 2014 when I was diagnosed with an interstitial lung disease (ILD) called idiopathic pulmonary fibrosis (IPF). I remember sitting in the doctor's office thinking: "I came to see you because of my Crohn's and you're telling me my lungs are sick!" There were difficult conversations with my husband, Tony, as well as with our four kids and their spouses. There have been tears, lots of tears. Now, there are nights when I am afraid to sleep because of chest pain. Being diagnosed with IPF is tough, and adding pulmonary hypertension (PH) to it makes life even more difficult.

In November 2016, I was referred to a specialized lung disease clinic in Edmonton, AB. My first appointment with Dr. Meena Kalluri was on December 15, 2016. Being seen so quickly made me nervous but grateful. Dr. Kalluri told me the prognosis was 3-to-5 years from diagnosis, that the only real treatment is a lung transplant, and that there are a couple of drugs that might slow down the progression of the fibrosis. I had decided against a transplant when my first pulmonologist suggested it.

In April 2017, I started using oxygen and taking Ofev® [for IPF]. In June 2018, I had an exacerbation that sent me to the emergency room. I had felt short of breath with chest pain before, but nothing like this. I was so weak and shaky, and it was hard to breathe, walk, or talk. I had no idea that my life could change that quickly: feeling well at 9 am and being barely able to walk, talk, or breathe by noon. That was an eye-opener.

I asked Tony for a mobile home to go camping with our grandchildren. We'd previously

sold our 24' mobile home and decided against buying another. A week later, Tony bought a 30' Class A with a rear bedroom. We were both anxious about me having another exacerbation, breathing difficulties, chest pain, or the oxygen concentrator having mechanical issues, but we hit the road anyway. We spent July and August 2018 traveling and camping with our grandkids. It was a very tiring time for Tony as I was not able to help him.

September 1, 2018 was our official move to Edmonton to be closer to Dr. Kalluri and live with our youngest daughter. In December 2018, Dr. Kalluri told us that my November echocardiogram test showed severe pulmonary hypertension (PH). I was dismayed to learn that there was no treatment. My PH is treated by treating the cause and my cause was IPF which was already being treated as much as we could. Dr. Kalluri decided it was time to start me on homecare/palliative care so that everything would be in place as I got sicker.

Having IPF and then adding PH was bad news for me. I thought I had accepted that I would die sooner than expected. I thought I had made my peace with dying. Turns out I hadn't. I had to accept that PH was going to add to my daily struggles. Who would think that bending over or reaching above my head could be dangerous to me? Now using both arms at the same time causes shortness of breath and tight chest pain.

**“The hardest thing to accept is knowing that all these things are going to get harder to do, that I am going to leave this world before I am ready, that I will not get to see most of my grandchildren graduate.”**

I was not ready to admit how sick I was. I had a really hard time accepting the number of drugs I needed to feel well: fentanyl, Dilaudid®, liquid hydromorphone, lorazepam,

gabapentin, isosorbide, Tecta®, furosemide, spironolactone, and so on.

My respirologist told me that treating me is uncharted territory and they will be using my experiences to treat other patients with IPF and PH. So much is unknown about IPF complicated with PH and there are no known guidelines of what to expect. I have signed documents to allow Drs. Kalluri and Janice to do a full autopsy in the hope they learn things to benefit other patients.

Usually when people are as sick as I am and on such high oxygen flows (14 to 18 lpm), they are in a hospital or bed-bound, and not planning to go camping. I am so tired of feeling sick, but I am not ready to give up yet. Dr. Janice tells me I am a warrior who has lived at least a year longer than anticipated, so that's good.

I am certain that I have lived this long because of my strong faith, the hope of a better world to come, the support of my family, friends, congregation, and my palliative care team.

I did get to see two grandsons graduate, attended one grandson's wedding, and went camping in our mobile home. Life is still good; different, but good and I am grateful for my life.

Contributed by: Beverly Mix, Living with PH since 2018



# From Sorrow to Celebration: Weathering the PH Roller Coaster as a Long-Term Survivor

Some long-time survivors may not always feel as blessed as we think. Many have self-doubts and question why they are the ones to live longer while their friends are suffering. Survivor Guilt, a significant symptom of post-traumatic stress disorder (PTSD), is a common phenomenon among long-term chronic disease survivors (1). I was fortunate enough to interview two people living with PH for more than 10 years to learn more about their emotional journey and experiences with guilt and self-doubt.



Allison Cain, Victoria, BC, & Sharon DiSanto, Savary Island, BC

Allison Cain and Sharon DiSanto share similar stories and have both gained wisdom from their PH journeys. Allison is the oldest of three girls and very close to her family. Now 38 years old, she was diagnosed with IPAH in 2010. She is currently pursuing her CPA while working for the BC Public Service. Sharon, a retired social worker in a family of 10 siblings, was diagnosed with IPAH 17 years ago at the age of 60. She has four sons and eight grandchildren who are her complete delight.

They have each sometimes struggled to tell their story to people affected with PH who may face more challenges. For instance, Allison recalls how feeling “not sick enough”—which may seem like a silly thought—was constantly on her mind when she attended her first PH conference.

However, both agree that living with PH has ultimately given them a great appreciation for their lives.

## The Diagnosis

Back in 2003, during her annual physical exam, Sharon’s family doctor noticed that her body was responding differently to the tests. A week later, through an echocardiogram, she was diagnosed with PH without having felt any symptoms. It was a big shock. Average prognosis at the time suggested that her life expectancy could be around two and a half years. Before telling her family about it, Sharon isolated herself at her cottage for three months. At the time, she didn’t process the positive aspects of being diagnosed early. Only later did she realize, “This early diagnosis was everything for me. I got on medication very quickly.”

It took Allison a year after feeling shortness of breath to see a doctor, and another year to get her diagnosis. Following this news, she spent three months alone, crying in bed. She went through very difficult feelings while processing her diagnosis. “Becoming okay with the fact that it’s not always okay, is the hardest challenge that I’ve had. What also helped me was being surrounded by the amazing team at the PH Clinic at Vancouver General Hospital. They really offered a ton of support and guidance, not only throughout diagnosis but during the long-term journey too!”

## Living With PH

For Sharon and Allison, living with PH for so long has made them normalize a lot of their limitations. They can even forget that they are sick, until they have shortness of breath, attend clinic appointments, or need to take their medication. Over the years, PH has simply become a part of their lives. They don’t go through life thinking they are sick.

But Sharon struggles telling her story because she knows other people might have it differently. “I care deeply when I see my friends affected by PH suffer.” Allison also feels guilt about the opportunity that she gets to forget she even has PH. “It’s horrible to see people suffer or pass on from this disease. It especially hits me very hard when I see kids struggle and pass away from it.”

When experiencing Survivor Guilt, it is important to acknowledge it instead of repressing it. It’s not about healing the guilt so much as it is about shifting one’s perspective (1). Knowing that PH is a degenerative disease, one never knows what tomorrow holds. So, Sharon and Allison try to live in the moment and live life to the fullest.

Allison started focusing on the things she could control, like making healthier choices to try to help her body work better than it was. It took four years for her to feel better, but she was determined not to let this diagnosis define her. “If I could give advice to myself at the time I first got diagnosed, I would tell myself to be kind and allow myself to feel sad. I really feel like getting PH—while hard to process at first—has given me a better life than I could have ever imagined,” Allison adds.

For Sharon, when asked to define her experience with PH, she recalled what Elizabeth McCall, a Founding Member of PHA Canada, told her when she was first diagnosed: “Welcome to the roller coaster ride of pulmonary hypertension!” Overall though, she thinks that Survivor Guilt plays a minimal role in her life. I mainly celebrate and enjoy my long-time survival and have complete hope for others to experience the same.

From the dark place they both entered upon diagnosis, through feelings of sorrow and guilt, to finding the strength to getting back to living their lives, Allison and Sharon remind us that the PH journey can be a beautiful one indeed.

Contributed by: Laurence Richard, PHA Canada Marketing & Communications Coordinator

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# Coping Mentally When Being a Caregiver

Alastair MacDonald has been a caregiver to his wife, Kathleen, for eight years, and has learned to do this the hard way. Hence, he attended a caregiver retreat to learn how to become a better caregiver, learn from other caregivers, and get support. Alastair offers tips to caregivers to learn how to mentally cope with the challenges of caregiving.

I am a retired Physical Education teacher and have been married to Kathleen MacDonald for 40 years. We live in Dartmouth, Nova Scotia. I am the primary caregiver for Kathie, who has always had significant health issues. Some of these include asthma, a digestive disorder, allergies, an undiagnosed neuromuscular disorder, G.I.S.T., liver cancer, and now pulmonary arterial hypertension (PAH). Needless to say, Kathie is a very vulnerable person.

Kathie was diagnosed with PH about eight years ago, in 2012. At the time, we knew nothing about PH and neither did many doctors. It was the first day of March Break, and when I went to wake her this particular morning, I was unable to rouse her. She was completely unresponsive and I had to call 911. She was so sick at this time that she almost didn't make it! It was very scary.

After they diagnosed Kathie with PH, the doctors told us that she had anywhere from two months to two years left to live. She was deemed palliative, which was very difficult to hear.

It was at this time that I retired to become a full-time caregiver. This world of full-time caregiving was new to me and I quickly became completely overwhelmed. I had to learn how to navigate the health-care system, the everyday household chores, and—of course—just caring for Kathie.

While the first two years were difficult, Kathie was demonstrating slow, steady improvement, which made life a little easier. But there were always setbacks and hospital stays, which I always dreaded. Hospital stays for Kathie ranged anywhere from one week to possibly months. But she always seemed to bounce back.

When Kathie was told that she was palliative and possibly had only two years left, it was very discouraging. That two-year timeframe was always in the back of our minds and we thought that if we could just get past those two years, it would lift our spirits and give us hope for the future. That was about eight years ago! So, it sure did give us some incentive to keep moving forward and work hard to improve.

## Coping as a Caregiver

1. Understanding the situation you find yourself in and accepting it will help promote a positive attitude toward the care that you need to provide. Your loved one did not ask to have PH, and feels very frustrated about being so dependent upon others. Remember they used to be able to do everything for themselves. Maintaining a positive attitude will help you and the person you are caring for.

2. Don't be afraid to accept help from others or to ask for help when you need it. Try to build a network of friends and family who can help out. It has been my experience that close friends and family love to help when possible. However, they don't always know when or how they can provide assistance. That is when you need to reach out to them.

3. Keep in contact with your friends. While my circle of friends has certainly shrunk since Kathie's PH diagnosis, it is much easier to stay in touch with others through social media. So, take full advantage of this and use it!

4. Look after yourself. Try to keep fit. Exercise and eat well. If you feel good physically, looking after someone else is a lot easier and will promote well-being for both parties.

5. When things get overwhelming, don't let that overwhelming feeling build up. Reach out for help. There are caregiver groups to join for guidance and support. A PH support group in our area has started up thanks to Beth Slaunwhite who is involved with the PH community across Canada. Kathie and I find this support group extremely helpful.

6. Celebrate small victories! Some of ours include:

- When Kathie's O<sub>2</sub> requirement went from 4 litres to 2
- When she was able to walk around the block!
- No hospital stays for one year

7. Count your blessings often! Here are some of ours:

- Being able to see our daughter get married
- Being there when our granddaughter was born and watching her grow into a little girl
- Having our children close to us
- Having wonderful support from family and friends
- Having each other!

Even though the prognosis for PH is not good, the progress that research has made has been remarkable. I hope this article has given some helpful hints and built awareness of the complexities of caregiving! Even after eight years, my caregiving is still a work in progress. I continue to learn more and more every day—especially so in this COVID-19 pandemic—which has forced us to suspend most of our supports. This has certainly created new challenges but we have adapted and we keep moving forward.

Contributed by: Alastair MacDonald, PH Caregiver since 2012



Alastair and his wife Kathleen



# PH Community Quotes:

What has helped you on your PH journey and during this time of COVID-19 to stay mentally well?

CTEPH: chronic thromboembolic pulmonary hypertension

PAH: pulmonary arterial hypertension

IPAH: idiopathic pulmonary arterial hypertension



“I am definitely using counselling to help me come out the other end. I am trying to be happy and make fun of my new life, by laughing and joking. I also give out support when I can to people in my circle of friends and PHamily who need it to learn our new way of enjoying life with all the hurdles we have to face on a daily basis.”

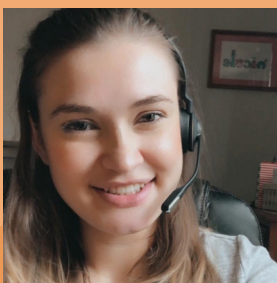
—Dianne Curle, Living with CTEPH since 2013, Richmond, BC

“I am well enough to be able to go to work! That is one of my happy places! Also, my family, friends, and especially our health care providers have helped to keep me sane. We have the



most awesome and amazing team behind us! They have not only seen me at appointments but have kept in contact through phone calls and Facebook. Knowing that I have all these people standing behind me sure makes a big difference!”

—Kendall Tracy, Living with PAH since 2010, Mansonville, QC



“I'm lucky enough to be working from home, which has enabled me to spend the time I would normally use for a commute to start lots of healthy habits. I go for a run in the

park next door every morning, very early when no one else is awake.”

—Nicole Mary Bridget, Living with PAH since 2017, Waterdown, ON



“One of the biggest things that has helped me during COVID-19 is staying in touch with some of my PH friends. It's really great to talk to them and just catch up. Even a quick text can help people feel thought of. It

certainly makes me feel connected and feel like I'm doing something normal. We've formed some pretty amazing friendships and I want to nurture that.”

—Robyn Ashmore, Living with scleroderma associated PAH since 2013, Victoria, BC

I keep reminding myself that I have overcome darker days, and each time, I come out stronger. I meditate, do reiki, stay in touch with family and friends.



I stay in touch with the PH community, because even after almost 18 years, I can still learn some things from people. Also, PH patients sometimes reach out to me privately when they need someone to talk to. When I can help them, it always makes me feel better and I get a sense of purpose. PH is not the best thing that has ever happened to me, but in some ways, I've never been happier.

—Sonya Collins, Living with IPAH since 2003, PHA Canada Ambassador, Paradise, NL



After four and a half years post diagnosis, something changed. I realized that PH wasn't going to magically disappear, and that I still had a life worth living! My whole mindset shifted

to wanting to become an advocate for myself and others, and to get involved with my health journey because it was now more important than ever! COVID-19 has rocked everyone. I believe that we will come out of this better than we were before; more aware, more loving, more kind. We will continue to slow down and take the time to appreciate what we have in front of us: our family, friends, and elders.

—Jennifer Bryson, Living with IPAH since 2012, Oshawa, ON



These are strange times which are allowing us to be creative with time. It's important to keep the mind and body sharp. My activities include short walks with my husband, trying out new

recipes and reworking old ones, completing jigsaw puzzles, playing cribbage, staying in touch with loved ones regularly, and reading. I am also soaking in the quiet, the lack of bustle in society, and the peace that it brings. Finally, being acutely aware of our vulnerability as PH patients and all that it entails, I am in no hurry for things to go back to normal and will be patient as that unfolds.

—Susan Hambrook Bailey, Living with IPAH since 2016, Ottawa, ON

My Elders taught me to never over think and worry about things, so we don't bring the concerns to ourselves and make them happen to us. With that in mind, it helps me to be confident and think smarter to limit stress. The power of positivity helps mind and body to remain strong. Using best practices to avoid any risk of contact with viruses and all illnesses, by staying isolated and by the use of services to your door. I had promised my new lungs that I would take the best care of them, as a gift to me, which means that I must be determined to avoid getting sick. After all, I'm responsible for the both of us—my donor and me.



—Millie Kuliktana, Diagnosed with IPAH in 2010, Received double-lung transplant in 2019, Kugluktuk, NU





“When I was first diagnosed and had to deal with grieving my “old life”, I turned to using a gratitude journal and sessions with a psychologist to help me stay mentally well. Now that three years have passed, I find that

staying physically active has played a large role in maintaining a positive outlook on life. I also find working and keeping busy with activities helps give me a sense of purpose and keeps my mind off of focusing on my IPAH. Last but not least, being surrounded by such a loving and supportive team that consists of my family, friends, medical professionals, and the Ottawa PH support group has been vital to keeping me going strong.

—Jane Gibson, Living with IPAH since 2016, Ottawa, ON

“After nine years of living day to day with PH and doing everything I can to see the next day, I was well prepared for the lockdown. Since PH is a chronic disease, we have to be very careful with infections like colds and flus. So I was already very careful when I was around other people in general. I always tell my friends, “If you care about me, don’t come see me when you’re sick.”



—Réjean Dupont, Living with PAH since 2011, Shawinigan, QC

“COVID-19 has been challenging for all of us but I’ve kept busy doing things I love, including playing the guitar and singing. I post short



songs to social media, huffing and puffing the whole time, to keep in touch with family and friends. I think it’s important to keep yourself busy doing things you love to do. It doesn’t matter what level we’re at. Sing, dance, paint, write, read, and let’s not be so critical of ourselves. The important thing is to have fun!

—Carl Selzer, Living with PAH since 2018, Vancouver, BC



“We believe that the best thing to do to preserve your mental health is to never give up hope and to do whatever the caregivers tell you to do. Dr. Provencher told us that no two people are the same, therefore it’s best not to compare yourself to others. The most important thing is to be surrounded by good people who offer psychological support. We also have pets and believe that nothing beats pet therapy.”

—Richard Poirier, Living with PH since 2014, waiting for a double-lung transplant, and his caregiver, Lyne Devarenes, Quebec City, QC

# How to Cope Mentally with Pulmonary Hypertension

Joanne Schwartz has a Master's degree in Social Work from the University of British Columbia and a degree in Conflict Resolution from the University of Winnipeg. She has 18 years of experience in a variety of roles working with people with complex needs. Joanne is a counsellor in private practice trained in Cognitive Behavioural Therapy, mediation, and Motivational Interviewing. She works at St. Paul's Hospital, has taught at Vancouver Community College, and has supervised and mentored graduate-level students. She has worked with clients with mental health and physical health challenges and, more recently, specifically with the pulmonary hypertension community at the Pulmonary Hypertension Clinic at Vancouver General Hospital (VGH).

Inevitably in life, we all deal with change, loss, or major disruption to our routine. Some setbacks can be minor like your favorite coffee shop closing down, while others are disastrous on a much larger scale (pandemics, floods, hurricanes, etc.). While we cannot control these life events from occurring, we can control how we cope with them. The following 10 tips are my ways of coping and staying strong and resilient in the face of adversity.

## Coping and Staying Strong and Resilient

- 1 Practice self-compassion.** Recognize that what you are going through is hard, and you are struggling. Give yourself permission to struggle and sometimes resort to things that bring you comfort. Talk to yourself as if you were a small child and need reassurance. This tactic can be a big shift from our usual inner critic and can be very soothing. If you saw a small child crying or a puppy in distress, you would be kind and compassionate and do your best to comfort them. Try applying this kindness to yourself.
- 2 Maintain a routine.** Even in the most difficult times, get out of bed at a regular time, shower, or do your usual morning routine; get dressed even if you have nowhere to go. I know I feel better when I have gotten out of my pyjamas and am ready to face the day.
- 3 Eat sensibly.** Stressful times make people lean on caffeine and alcohol. Drink water and things that will hydrate you instead. Be sure to check-in with a healthcare professional if they have restricted your fluid intake.
- 4 Get regular rest.** Going to sleep at the same time each day and waking up at the same time each morning is ideal but may be challenging in times of stress. Sleep is rejuvenating and helps us heal. If you cannot sleep at night, try a short nap in the daytime.
- 5 Reach out to people who can help, and tell them how.** Depending on your situation, others might be willing to help. Giving people direction on how to assist you can make them feel useful and can help you meet some of your needs. "Help" might be a friend bringing you a prepared meal, picking up your groceries, assembling your new IKEA bookshelf, or even being available for a 20-minute phone chat.
- 6 Be active as best as you can.** We all have different abilities, but I call exercise "Nature's Prozac." Try a new Tai Chi video from YouTube or a yoga stretching video. Move your body in whatever way you can to get the blood flowing.

- 7 Get outside.** I have read studies that suggest even as little as five minutes near the water or in a forest can be rejuvenating. Try it if you can. Sit in your yard or on your patio; listen to the birds, and notice the leaves and the vegetation around you.
- 8 Listen to music 24 hours a day.** Music is magical; it can lift your mood and spirits. Have a radio station playing in the background, make a mix of your favourite songs, consider playing an instrument if you have the ability.
- 9 Try to build self-care into your schedule.** Self-care is a big buzz term, but it can be as simple as taking five minutes for journaling your thoughts and feelings, taking a bubble bath, or learning to meditate. Try and figure out what soothes you. Is it peppermint tea? A cozy blanket and your favorite book?
- 10 Reflect on how you have managed other challenges in the past.** What worked? What didn't work? What can you learn from those previous experiences?

Trying to incorporate some of these techniques into your daily routine will generally help you cope with difficult times; however, if you feel you are really struggling to sleep, function, or cope, it might be time to reach out to your team of healthcare professionals. Whether it is your counsellor, nurse, or doctor, it is always important to ask for help when you need it.



Contributed by: Joanne Schwartz, MSW RSW, [Joanneschwartz.com](http://Joanneschwartz.com)



# Addiction & Pulmonary Hypertension

Lisa Lee is a nurse practitioner at the Pulmonary Hypertension Clinic at Vancouver General Hospital (VGH). Before obtaining her Master's degree at the University of British Columbia, she worked as a registered nurse for over a decade in a variety of intensive care units in Canada and the United States. Along with providing direct patient care, Lisa manages the Prostacyclin Program and is responsible for the pulmonary hypertension database at a provincial level. She also supports genetic testing and counselling for PH patients.

## What is addiction?

Addiction is a mental illness, a disease of the brain that results in an individual compulsively using a substance, despite harmful consequences to themselves and those that they love. Addiction is not a moral failing, but results from changes to the brain that makes it difficult for an individual to stop using drugs, even if they want to. Addiction is more common in people who are genetically predisposed, have a history of psychological or emotional trauma, who are raised in environments where drug use is common, who are poor, or who experience abuse, discrimination, or oppression (1). People that struggle with addiction should not be dismissed as inherently bad or weak. While poverty, criminal behaviour, and homelessness can be associated with addiction, it is important to recognize that individuals with addiction issues can be high functioning and are present in all levels of society.

## Addiction and Pulmonary Hypertension (PH)

It is possible to become addicted to a variety of substances including alcohol, marijuana, caffeine, hallucinogens, stimulants, pain killers, sedatives, and tobacco. Stimulants, particularly crystal meth (methamphetamine), are the most commonly reported drugs of addiction in people who have no other risk factors for PH (2, 3, 4). This makes sense, as there are similarities between amphetamines and certain diet pills that were known to cause PH before they were removed from the market (4).

The type of PH caused by stimulants is identical to other forms of pulmonary arterial hypertension (PAH). Methamphetamine affects serotonin and norepinephrine levels, which can narrow and thicken the blood vessels in the lungs (4). Over time, the right side of the heart starts to fail from having to pump blood through the damaged vessels.

Individuals with drug addiction and PH can have shorter lifespans than patients with other forms of PH (5, 6, 7). A PH centre in California determined that PH patients who used methamphetamine had an estimated survival rate of 35% at five years (6). Ongoing stimulant use makes PH worse and can make medications less effective. In addition, having an addiction can make it difficult for people to remember to take medications or stay in contact with their health care providers. Individuals with an addiction may delay seeking treatment and are often not diagnosed until the disease is severe.

## How common is PH in addiction?

It is not known what percentage of people who use crystal meth develop PH. Not everyone who uses stimulants will develop PH.

In British Columbia, 20 of the 350 PAH patients in our registry were heavy and frequent users of methamphetamine at the time of diagnosis. In the remaining patients with PAH, five had more remote or recreational methamphetamine use (8). This form of PH is likely underdiagnosed due to the socio-economic challenges of providing health care to this often-marginalized population.

## Treating Patients with Drug Addiction and PH

Some people faced with a life-threatening diagnosis like PH will be able to use this as motivation to end their addiction. For some of these people, their PH will get markedly better and, in a few cases, disappear completely. Others will go on to have a similar disease course as those who have idiopathic PAH, and will be treated with the same medications. They will eventually need intravenous or other infusions to treat their PH, and can go on to have a lung transplant.

Others will continue to use drugs, although they often attempt to cut back or have periods of stopping followed by relapse. These people more commonly struggle to take their medication and follow up with tests and appointments. Unless patients overcome their drug use issues, they tend to become sicker over time and have a shorter lifespan. Additionally, advanced (prostacyclin infusion) therapies for PH are often not a good option for current users, as the risks outweigh the potential benefit.

It is important to treat the addiction along with PH for the best chance of a good outcome. This can involve counselling to better understand causes and behaviours related to addiction, improve self-esteem, and manage stress. It could also involve formal drug treatment programs or referral to a psychiatrist to manage withdrawal symptoms. A psychiatrist can also assess for other mental health issues that make individuals more susceptible to addiction, such as ADHD, depression, or anxiety. Many people find it helpful to connect with or create a support group or network of other individuals who are committed to living healthier lives.

## Communicating Your Struggles with Addiction to your Health Care Team

It is important to be honest with your PH specialist if you are using stimulant medication or are struggling with addiction. Your specialist will then be better able to provide you with information and advice specific to your health condition. The information will stay confidential and will not have any legal or treatment implications. We are here to support you and encourage you, even if you have relapsed.

Contributed by: Lisa Lee, Nurse Practitioner (NP), Pulmonary Hypertension Clinic at Vancouver General Hospital (VGH)

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# Facing Life's Most Difficult Questions

## Talking Through the Unique Psychological Challenges of Living with PH

Living with pulmonary hypertension has psychological and social challenges in addition to physical ones. In 2013, a PHA Canada patient and caregiver survey found that over 70% of patients who responded experienced social isolation and relationship issues—dramatic life changes that impact mental health and quality of life. Some research estimates that up to half of people with PH experience mental health challenges, but these conditions often go unrecognized by healthcare professionals. (1,2)

Since 2017, a team of researchers examined the psychological impacts of PH, in particular patients' thoughts and worries about their mortality and the meaning or value of life. This team is led by Dr. Christopher Lo, an assistant professor in the Department of Psychiatry at the University of Toronto. The team also includes Vanessa Martin, a research assistant working with the University Health Network pulmonary hypertension group in Toronto at the time.

"[PH] is a rare condition, but there's a lot going on there," says Martin. "It functions differently than other illnesses because it's a different type of progression. It's much more of an uncertain diagnosis and there's a lot of variability in what a patient experiences."

When faced with the uncertainty of a life-limiting illness, existential questions are natural—Do I know who I am? Do I have close relationships? Have I made a difference? Has my life been meaningful? (3)—but sometimes it's difficult and painful to talk about them openly.

To gain a better understanding of the psychological impact of a PH diagnosis, Martin and Lo gave patients the opportunity to explore their feelings and share their experiences (4,5). They found that many had existential concerns every day, namely:

- Loss, including loss of independence and meaningful activity, and loss of time;
- Social changes, related to struggling to be understood by others and feeling disconnected;
- Identity and self-worth, such as feeling inadequate and lacking a clear direction in life. (4)

"A lot of our patients expressed that they were grateful to have this opportunity to get things off their chest and that it was helpful for them," says Martin. "It gave them the chance to realize what they were feeling."

### A Balancing Act

Not everyone is ready to open up, and some avoid talking about existential concerns by changing the topic of conversation (5). But

Martin believes this avoidance plays an essential role in processing complex emotions. "You can't expect someone to go ahead and catastrophize and ruminate on all these feelings that they're experiencing because that becomes overwhelming," explains Martin. "But we also know that avoidance long term is not effective or sustainable and can lead to denial."

Martin explained that successfully coping with difficult existential issues is like walking on a balance beam: "You're going to lean back and forth between approaching your fears and avoiding your fears," says Martin, "by maintaining this balance, you'll be able to move forward and keep going with your everyday life while maintaining emotional stability." Mental health workers play a key role in sustaining this balance by helping them safely explore and process their experiences.

### Creating Community

While speaking to people with PH, Martin also found that many weren't able to share their thoughts with the people in their lives. Patients said that they wanted to stay positive around family and friends and didn't want to burden them, so having someone else to speak to is helpful, including reaching out to other patients to cultivate a sense of community and purpose (3,4). This may be especially true during a pandemic.

While grappling with existential questions can be uncomfortable, it can help patients cope with the unique challenges of a progressive illness. "Even though we were asking people to tell us about their worst moments in life and their biggest fears, it was an overall positive experience," emphasized Martin. "Giving people the opportunity and the space to do that can be really helpful."

It's encouraging to see researchers focus on the psychological aspects of PH. Hopefully, this will lead to improved mental health support and treatment for all PH patients.

Contributed by: Miriam Bergeret, Living with PAH since 2017, PHA Canada Knowledge Translator

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# Mental Health Resources

It is important to find resources to help manage mental health, especially with the stress of the pandemic. This stress can exacerbate negative emotions and have an impact on mental health. Below are three different resources to help with mental health that are tailored to those with PH.

*Disclaimer: This article does not present an exhaustive list of mental health resources and is intended for informational purposes only.*

## 1 Emotional Wellness Handbook for PH Patients

Written for PHA Canada by Counsellor Alyson Quinn, this handbook contains short, easy to read chapters about the emotions that can accompany being diagnosed and living with a serious condition such as PH. Whether it be anger, courage, compassion, shame, fear, or loneliness, it is extremely common to have an emotional reaction to the day-to-day realities of living with PH. While sometimes it may seem easier to repress these feelings, it is more physically and mentally healthy to try to acknowledge and accept how we feel, and to learn how to work through our emotions. Although this process is far easier said than done, the *Emotional Wellness Handbook* provides a guide based on the experiences of other PH patients and the professional expertise of its author.

To utilize this resource, go to [phacanada.ca/WellnessHandbook](https://phacanada.ca/WellnessHandbook)

## 2 Meditation for PHers

Numerous studies have shown that meditation can be a useful tool for relaxation and can even improve mental and physical health. While it may seem time consuming, modern meditation can be as short as 15 minutes per day while still having a positive effect (1). Given that there is quite a variety of types of meditation, it is important to find what works for you. This blog post serves as a starting point to explore different styles of meditation, such as mantra meditation, mindfulness meditation, or guided meditation, either in person or using an app.

Read the blog post at [phacanada.ca/Meditation](https://phacanada.ca/Meditation)

## 3 Chronic Illness Counselling

We all need help when it comes to our emotions and mental health, whether this comes from our community, friends and family, or a therapist. Living with PH can be challenging and at times it may be invaluable to seek out professional help for emotional support. Professional counselling is often covered by employer/private insurance plans. There are counsellors who specialize in chronic disease in every province in Canada.

Try a specialized search engine like *Find a Chronic Illness Therapist* at [psychologytoday.com/ca/therapists/chronic-illness](https://psychologytoday.com/ca/therapists/chronic-illness)

## Other Resources

**CARD System for Coping with Anxiety** – For Caregivers, Parents, and Patients

Patient or caregiver, child or adult, everyone feels anxious or afraid sometimes. Use this CARD (Comfort, Ask, Relax, Distract) game to reduce your fear and anxiety. It provides strategies to cope with stressful situations.

To start playing, visit [phacanada.ca/CARD](https://phacanada.ca/CARD).

## For Health Care Providers

The pandemic has significant impact on healthcare professionals' mental health. The Canadian Medical Association (CMA) provides a support line for high-quality and tailored mental health services.

Visit [cma.ca/supportline](https://cma.ca/supportline).

## Government of Canada

*Taking care of your mental and physical health during the COVID-19 pandemic*

Visit [canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html](https://canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/mental-health.html).

*Mental health and COVID-19 for public servants: Protect your mental health*

Visit [canada.ca/en/government/publicservice/covid-19/protect-mental-health.html](https://canada.ca/en/government/publicservice/covid-19/protect-mental-health.html).

*Caregiving While Working*

Visit [canada.ca/en/government/publicservice/covid-19/caregiving-working.html](https://canada.ca/en/government/publicservice/covid-19/caregiving-working.html).

Contributed by: Ashok Pandey, PHA Canada Education Programs Assistant

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# Research Corner

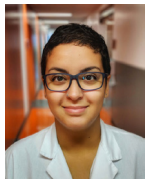
## Meet the 2019 PHA Canada Research Scholarship Recipients

You may have heard back in high school biology that DNA (deoxyribonucleic acid) is the basis of genetics; in other words, the specific sequence of the DNA code in each of the trillions of cells in your body make you, you! You can think of your DNA like series of blueprints, containing tons of information about everything about you. For example, some parts of your DNA are related to your hair or eye colour, while others might be related to your risk of getting specific diseases, including pulmonary hypertension (PH). DNA codes are similar to recipes that can be used to produce proteins, which are the workhorses of the cell. Proteins have many different functions. For example, hemoglobin carries oxygen in your red blood cells and keratin is a key structural component of your nails and hair. Diseases can arise when there are abnormal amounts of a specific protein (i.e. too much or too little) or abnormal mutations or modifications to proteins, causing them to behave differently than normal.

While the molecular biology of underlying diseases like PH is incredibly complex, Canadian researchers are hard at work tackling this problem with the hopes of better understanding PH in order to develop treatments to help patients. Here, we profile the incredible work of three emerging PH scientists and PHA Canada scholarship recipients.

### **Karima Habbout**

2019 PHA Canada Mohammed Family PH Research Scholarship recipient, Karima Habbout, MSc, is conducting ground-breaking research at the Université Laval



in Québec City. She is investigating the role of the protein EZH2 on pulmonary arterial hypertension (PAH). EZH2 is an important protein involved in epigenetic regulation, which can regulate how specific DNA codes produce proteins. For example, epigenetic regulation may silence regions of your DNA so that they are not read anymore, reducing the amount of proteins produced. You can think of it like a black pen that crosses out sentences in a book. Alongside her team at Laval, Habbout is researching how EZH2 may play a role in PH by regulating pulmonary arterial vasoconstriction and vascular remodelling. Now, the research is shifting towards examining whether inhibition of EZH2 may alter physiological parameters like hemodynamics by using a drug called EPZ-6438 (catchy, right?).

### **Géraldine Vitry**

2019 PHA Canada Paroian Family PH Research Scholarship recipient, Géraldine Vitry, MSc, is part of the Pulmonary Hypertension Research Group at Laval University, Québec City, led by Drs. Sébastien Bonnet and Steeve Provencher. Like Habbout, Vitry is studying molecular and cellular mechanisms

underlying PAH. The team previously found that one family of proteins, called NUDIX, was much more abundant in the cells lining pulmonary arteries (known as PASMCs) in patients with PAH compared to people without. In PAH patients, the smooth muscle cells (which form the pulmonary artery lining) have adapted to become abnormally resistant to dying and can sometimes accumulate, which causes obstruction of pulmonary arteries. The team is now trying to study whether the NUDIX family of proteins may be responsible for this change and whether inhibiting these proteins could be a viable therapy.



### **Dr. Ruaa Al-Qazazi**

Dr. Ruaa Al-Qazazi also received a 2019 PHA Canada Mohammed Family PH Research Scholarship and is studying the molecular and cellular science of PH. Her research is based in Kingston, Ontario at the Translational Medicine graduate program at Queen's University where she is working under Dr. Stephen L. Archer. One important consequence of PAH is right ventricular failure due to the backed-up pressure, which can cause blood to back up even further,



resulting in swelling in the legs, liver, and gastrointestinal tract. Dr. Al-Qazazi is studying how inflammation might play an important role in

this process. One focus of her research is the role of the NLRP3 inflammasome, a massive complex of proteins that initiate inflammatory pathways, and the effects of its targeted inhibition.

These three passionate researchers are part of a global network of scientists working diligently to help improve the lives of patients using innovative techniques in molecular and cellular biology. Only two or three decades ago, this type of research would not have been possible! It can be challenging at times to see how complicated names like EZH2, NUDIX, or NLRP3, can ultimately impact the lives of PH patients. The molecular pathways underlying human disease are very complicated, and PH is no exception. Taking on a challenge like this requires scientists to come at it from different angles, with the hopes that novel break-through treatments will one day make it into the hands of PH patients around the world. While this research is still at a very preliminary stage—and much more investigation and rigorous clinical trials are needed to determine whether something like this could help PAH patients—these innovative research projects are certainly very exciting!

Contributed by: Arjun Pandey, PHA Canada Knowledge Translator



# How PH Patients Can Make a Difference in Future Canadian PH Research

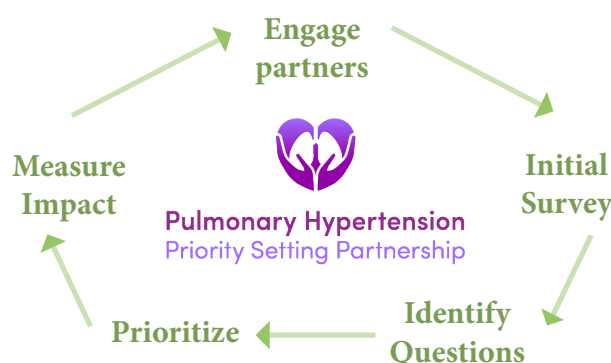
Dr. Jason Weatherald is a respirologist with the Southern Alberta Pulmonary Hypertension Program at the Peter Lougheed Centre in Calgary, Alberta. He is a founding member of the Canadian PH Registry (CPHR) that was described in the Fall 2018 and Spring 2019 issues of *Connections*.

Dr. Weatherald has launched a new project called the *Pulmonary Hypertension Priority Setting Partnership (PSP)*. Here he describes the PSP project and how the PH community can help shape the future of PH research in Canada.

The past months have been truly extraordinary. The global COVID-19 pandemic has changed the world as we know it, possibly for many years to come. People with chronic diseases like pulmonary hypertension (PH) may feel particularly anxious about how their lives and medical care have changed. Even before COVID-19, many questions and anxieties have likely lingered in the minds of people with PH and their caregivers. These questions may not always get addressed during specialist appointments. Some people may also have difficulty expressing all their questions about PH during routine follow-ups with their care team. Some of these questions don't even have a known answer, yet.

Knowledge about PH has greatly evolved over the past few decades. Recent medical advances in the diagnosis and treatment of PH have improved the length and quality of life for most patients. However, the new ideas that have led to groundbreaking PH research have mostly been driven by scientists and pharmaceutical companies. Patient-oriented research is an approach to health research where the patients are involved throughout the process in a meaningful way. Patient-oriented research is about engaging patients, caregivers, and families as partners in the research process. This helps to ensure that health research focuses on patient-identified priorities, hopefully leading to research that is relevant to patients and improves their outcomes. The patient-identified priorities for future PH research have yet to be established.

To identify these research priorities, we launched a new project called the Pulmonary Hypertension Priority Setting Partnership (PSP). The PSP is supported by the Canadian Institutes for Health Research (CIHR), the Pulmonary Hypertension Association of Canada (PHA Canada), the Fondation d'hypertension artérielle pulmonaire du Québec (HTAPQ), and the Libin Cardiovascular Institute in Calgary, Alberta. This project will be the first of its kind for PH research worldwide. The PSP will give patients, caregivers, and clinicians an opportunity to ask questions that they would like answered by future research. This could include questions about the causes, diagnosis, or treatment of PH, questions about mental health, or about how COVID-19 has affected people with PH. There are no limits on the types of questions that can be asked.



The PSP project will begin with a national survey in Summer 2020 (See Figure above). The survey will be available online, through PH clinics across Canada, and through emails from PHA Canada and HTAPQ. Participation will be voluntary and anonymous. The survey will be available in English or French and will ask for some basic information about who you are and what questions you would like answered by future research. In collaboration with PH patients, we will then review and combine the questions into a smaller number of related topics or “research uncertainties”. Then, we will search the available research to find out which of these topics have already been adequately answered by research and which topics remain unanswered. The final stage of the PSP project will be to bring a group of patients, caregivers, and clinicians together in a one-day workshop. At the end of the workshop, we will have a prioritized list of the top 10 uncertainties for future PH research.

This PSP project will provide people living with PH an opportunity to shape the research agenda for years to come. Engagement of patients to identify and prioritize the problems that matter most to them is just the start. Our long-term goal is to have patients and caregivers embedded into all aspects of PH research in Canada. We also hope to engage a broad and diverse group of patients and caregivers to carry out new research studies that address these priorities. Your input matters. It always has.

**To participate in the national research survey, please visit [phpsp.ca](http://phpsp.ca).**

Contributed by: Jason Weatherald, MD, MSc, FRCPC, Pulmonary Hypertension Specialist, University of Calgary

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## The Pulse

PHA Canada's monthly newsletter, received a makeover in June 2020!

*The Pulse* will keep you updated on what's happening in the world of PH in Canada and beyond.

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