



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

CONNECTIONS

The Official Magazine of the Canadian PH Community

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PH & Lifestyle



PULMONARY HYPERTENSION
ASSOCIATION OF CANADA
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PULMONAIRE DU CANADA

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Cover photos (left to right, top to bottom): Sonya Collins receiving awareness month proclamation, photo from the 2018 Montreal PH Walk, the 2018 Eternal PHFriends of PHA Canada, Jamie Myrah and Sharon Proudfoot.

Unless otherwise noted, all of the photographs in this issue were contributed by authors or by PHA Canada.

HELP US SUPPORT THE PH COMMUNITY TODAY!

By donating to PHA Canada, you are improving the daily lives of all Canadians affected by pulmonary hypertension through:

EDUCATION

PH RESOURCES

COMMUNITY SUPPORT

Donations also help provide hope for tomorrow by supporting Canadian PH research and more:

RESEARCH SCHOLARSHIPS

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Message from the Chair:

Improving the Lives of All Canadians Affected by PH



This issue of Connections marks my final chance to speak to you as Chair of PHA Canada. As I have made clear over the past little while, after five years as Chair it is now the right time for me to step back and let others take the lead.

Following PHA Canada's 10th anniversary celebrations last year, we've moved into a new decade of our history with renewed energy and purpose. We are being carried forward by our small but incredibly passionate, hardworking, and dedicated staff, a strong and diverse Board of Directors, as well as countless volunteers—each of these special people with their own personal connection to PH.

As I have emphasized, I will remain a part of PHA Canada and the Canadian PHamily. I will continue to serve on the Board as one of the Founding Members and remain a part of PHA Canada's Medical Advisory Committee (MAC), along with my PH expert physician colleagues from across Canada.

Personally, one of the key aspects of PH that I have always been concerned about is "Living with PH". It was because of this that my wife, Linda Arsenault, and I first developed and launched [\[WithPH.ca\]\(http://WithPH.ca\) more than 10 years ago, and why it was donated to PHA Canada to integrate into \[www.PHACanada.ca\]\(http://www.PHACanada.ca\).](http://www.Living-</p></div><div data-bbox=)

Helping PH patients and their caregivers "live well" everyday with PH continues to be an important focus at PHA Canada. Living with PH often requires patients to adapt to "a new normal". They must look after themselves physically through nutrition and exercise, which specific articles in this issue of Connections can help with. Other articles address the physical burden of symptoms like fatigue and lack of energy, and the importance of sleep which helps PH patients get the critical rest they need for their bodies to adapt and heal. When faced with a diagnosis of a serious illness like PH, living well also means that patients must deal with

Our work at PHA Canada continues through new educational and research initiatives, but the first priority will always remain the support of PH patients and their caregivers. This also remains very important to me personally.

the overwhelming ideas, emotions, and feelings about their illness, their bodies, and their lives that arise. An article on the importance of mental health and mindfulness may help deal with this emotional burden.

We live in an era when the Canadian PH medical community and PHA Canada have already improved and extended the

lives of many PH patients across Canada. However, we have not yet achieved our vision of "A better life for all Canadians affected by PH". Important gaps remain, including not reaching every person that we could help, as well as limited recognition and support of the vital caregivers of PH patients. Our work at PHA Canada continues through new educational and research initiatives, but the first priority will always remain the support of PH patients and their caregivers. This also remains very important to me personally. As we go forward together, I welcome the opportunity to continue improving the care of PH patients in my own community of London (ON) as well as across Canada.

Yours in PHriendship,

Sanjay Mehta, MD, FRCPC, FCCP
Director, Southwest Ontario PH Clinic
LHSC—Victoria Hospital, London, ON
Chair, Board of Directors, PHA Canada

Message from the Team:

Holding on to Hope



With PHA Canada's Executive Director, Jamie Myrah, currently on maternity leave, we are honoured to step in with a special letter from the operational team out to all of you in our PHabulous community.

At the dusk of the first decade of our association, we are still holding on to the echo of our most advantageous superpower: our United PH community. Time and time again, all of you inspire us through your endurance and courage. Even in the face of adversity, the Canadian PH community externalizes a level of stoic strength in unity that inspires us to work harder, push farther, and develop the tools and platforms our PHamily needs to live better every day.

The Canadian PH community is rich in its diversity, and we are excited to be standing at this crossroad in our journey with all of you: patients, caregivers, medical professionals, supporters, and more. That is why this issue of *Connections* works to amplify all of your voices. It doesn't matter if you are new to our PHamily (page 16), whether you're a long-term survivor of PH (page 17) or you have someone in your family who has PH (page 18). You might even be someone who has just decided to ensure a legacy for the future

PH community (page 14), or you've chosen to delve into the scientific depths of PH research (page 32), there's a place for you here. In fact, our hope is that the wide range of community sub-groups—from PH Medical Providers to parents of children living with PH—can all converge right here, on the pages of *Connections*.

Another challenge we share as a community living in this vast country is distance. Progress in online media make it a little easier to find fellow PHriends to connect with, but now and again, we are lucky to experience special moments when PHers are able to travel from across provinces to come together and learn, like at our 2018 Western Regional Symposium (page 12). No matter where you are, more and more events are taking place across Canada (page 8) and you are invited. And the further you live, the more we want you on board. PHA Canada is here to help get your event up and running, and who knows: you may have more PHers in your area than you think!

Although we are blessed in our diversity, we also have something in common. In one way or another, our lives have changed due to pulmonary hypertension (PH). And while for some of us it's easier than others, we can all relate to the challenges of having to adapt the way we live our "new normal". This may come in the form of eating better (page 24) or doing exercise (page 25). It could be sleeping in a new position to get a full night of sleep (page 23) or knowing where to ask for help (page 22). But it can also be learning to accept how you feel and being kind to yourself. None of us are immune to loneliness, and when "fear and sadness take a hold of your heart" (page 26) remember that you have an entire community here that understands and wants to help. No one should have to live through a PH diagnosis alone and there are tools and resources available to help you find support if and when you need it.

But perhaps most important of all, adapting to a new life can mean holding on to hope. Hope for young patients going to college and creating dreams for themselves (page 28). Hope for PHers pursuing their careers in spite of their illness (page 27). Hope for new and exciting research that could bring us closer to a cure (page 32). Or even hope that better and consistent PH medical care could one day lead to better and more effective treatment (page 30). Or perhaps home for patients who have lived far beyond any expectations (page 17). And hope that no matter how bad it can seem, there can always be something good waiting around the corner (page 19).

Kind Regards,



Michaël Robach
Communications & Engagement
Coordinator



Vanessa Stevens
Fund Development Coordinator

MEMO: INSIDE PHA CANADA AT A GLANCE

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

Dr. Lisa Mielniczuk joins Board of Directors



PHA Canada's Board of Directors is pleased to welcome its newest member, Dr. Mielniczuk. Having chaired PHA Canada's Medical Advisory Committee (MAC) since 2015, Dr. Mielniczuk brings with her extensive medical experience within the PH field. She is currently the co-founder and Director of the PH Program at the Ottawa Heart Institute. You can find out more about her and our other Directors by visiting www.phacanada.ca/whoarewe.

Welcoming our Acting ED, Mark Schuett



With our permanent Executive Director (ED) on maternity leave, we're honoured to welcome Mark Schuett on board as our Acting ED. Mark brings with him years of experience working within the non-profit sector, along with a specialty in strategic planning. You can find out more about Mark and our entire staff by visiting www.phacanada.ca/staff.

PHriends of PHA Canada

In 2018, PHA Canada celebrated its 10 years a national PH association. We wish to thank everyone across Canada who joined in on the celebrations and helped make it such a special milestone in our history as a strong, united community.

To mark this special occasion, PHA Canada also celebrated past and present PH leaders for their unwavering commitment to empowering and bettering the lives of all Canadians affected by PH. From past Board Directors to staff and volunteers, our association sought to ensure that those who paved the way to where we are today are captured in time and recognized for years to come for their unique and impactful contributions to the larger Canadian PH community. These are the "PHriends of PHA Canada".

We are also thrilled to have identified and recognized the first cohort of "Eternal PHriends of PHA Canada"; we express our greatest appreciation to those whose commitment, passion, and hard work have been essential to the birth and growth of the Pulmonary Hypertension Association of Canada, and the unification of our community here in Canada.

While the anniversary website may be gone, you can always revisit the memories of this unique occasion by visiting the "History" section of our website at www.phacanada.ca/history.



PHA Canada is getting a new website!

We are constantly looking for new ways to better support Canadians affected by PH. Providing easily accessible information and resources plays an important part in that. And so, after nearly a decade since launching our first site, we are finally ready to take the leap and enter the new digital age. More than just being a mobile-friendly and efficient site, it will provide clearer access to PH resources and tools, and will drive focus on key strategic goals of early diagnosis and more. Coming soon!



PHA Canada staff were joined by Board Directors Roberta Massender & Ed Rathonyi in March to send-off our Executive Director, Jamie Myrah, who has gone on maternity leave until October.

PH Parents Network (PN)

PHA Canada has launched a new support group for parents of children living with PH to share experiences and gain support in a safe space. The group, which is led by volunteer parents, meets once a month via teleconference. Working together with the pediatric committee, the PN also advises on the development of tools and resources for families. **You can find out more and join the group at phacanada.ca/ParentsNetwork.**



We want your feedback!

SURVEY

Have your say on how PHA Canada can better serve you and the wider Canadian PH community. Now moving past our first decade as a national association, the Board of Directors is thrilled to be entering a strategic planning phase that will set the path for our goals for the years to come. In order to best evaluate our priorities, we want to hear from all of you in the community who are the most affected.

Please visit www.phacanada.ca/Survey to answer a series of simple questions or call us toll-free at 1-877-774-2226 to respond verbally. **The deadline for responding to the survey is 9pm PDT on May 15, 2019.**

Upcoming Events in 2019

» **May 4:** Dolores's Heavenly Heart Dinner for PH (Winnipeg, MB)



» **May 4:** The Ottawa Support Group Masquerade Ball (Ottawa, ON)

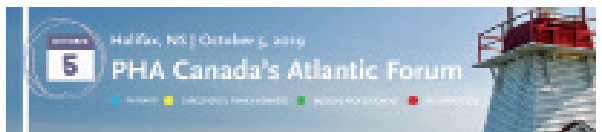
» **May 5:** Paint Canada Purple for World PH Day (Canada Wide)

» **May 16:** 5th Annual GolPH for PH (Brampton, ON)



» **June 16:** 6th Annual Ajax Run/Walk for PH Research (Ajax, ON)

» **October 5:** PHA Canada's Atlantic Forum (Halifax, NS)



» **October 18-20:** Eastern French PH Conference (Longueuil, QC)

» **November:** PH Awareness Month (Canada Wide)

* * *

Organizing an event or fundraiser is an excellent way to help raise awareness of PH in your local community all the while helping to support the national PHamily. If you have an idea or would like some help getting your event off the ground, contact us at info@phacanada.ca. We're here to help!

Your Community In Action

Community Events

Over the past few months, the Canadian PHamily's calendar has been filled with various awareness and fundraising activities! We are thrilled to share with you highlights and photographs from some of the community events that took place between August 2018 and April 2019. Thank you to all of the event organizers, participants, volunteers, donors, and sponsors who contributed to making each event a PHantastic success!

SEP 15 Baacos Bar & Grill 2nd Annual Golf Tournament in Memory of Quentin Mosiondz Thompson, MB

Ready, set, golf! Organized by PH advocate Jolene Mosiondz, the 2nd Annual Golf Tournament drew a PHenomenal \$3,000 for the Canadian PH community this year. This support is in memory of Jolene's late husband Quentin, who passed from PH

in 2016. We are so incredibly grateful to everyone who came out for the day to help raise awareness of PH in Manitoba and support the national PH community. Thank you!



SEP 23 Dolores's Heavenly Heart Walk for PH Winnipeg, MB

Sisters Corrise Proulx and Samantha Roy in Winnipeg (MB) put on Winnipeg's very first Walk for PH event. The walk commemorated their mother, Dolores Rapinchuk, who passed away from PH in 2016. Through this event, their family hopes to continue

raising awareness of PH locally to make sure no one has to go through a PH diagnosis alone. Our heartfelt thank you to everyone who helped make this inaugural event an incredible success and for raising \$1,300 for PHA Canada.

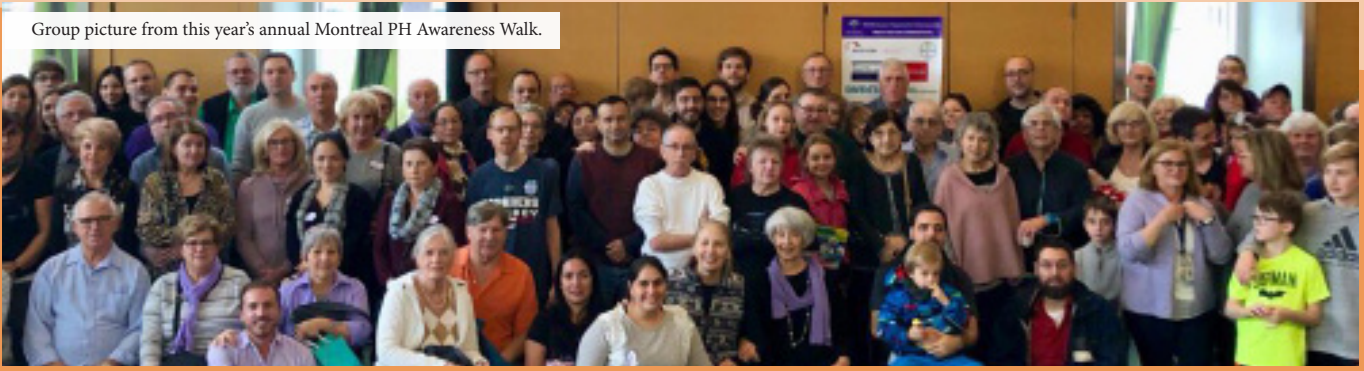
NOV 10 3rd Annual Sail-o-thon Benefitting PHA Canada Vancouver, BC

Past and current PHA Canada Communications & Engagement Coordinators Mariane Bourcheix-Laporte and Michaël Robach set sail across Vancouver's Burrard Inlet again this year in honour of PH Awareness Month! Admiring the incredible

strength that transpires from touching stories of patients and caregivers whose lives have been impacted by a PH diagnosis, these two raised an incredible \$2,225!



Group picture from this year's annual Montreal PH Awareness Walk.



NOV
11

Shawna Nicholson's Epicure Fundraiser in Memory of Brenden Brinkworth Cornwall, ON

Not only did participants get healthy and easy meal solutions at a discount, they also helped raise close to \$600 for the Canadian PHamily! This special November Awareness Month fundraiser was organized by Shawna Nicholson in memory of her beloved

brother Brenden who was taken too soon at the hands of PH in 2015. We salute Shawna for her positive energy and dedication to helping the PH community through awareness and fundraising.

NOV
17

Figo's Climb for PH Vancouver, BC

Accomplishing the relentless uphill 10.5km through the North Shore mountain backcountry, PHA Canada's Fund Development Coordinator Vanessa Stevens and her partner-in-crime, Figo, raised an incredible \$1,500 for the PH community.

Inspired by the level of endurance and perseverance that the PH community conveys day-after-day, they were able to raise awareness of the illness amongst friends and family who helped support their climb.



Vanessa & Figo pictured here at the top of Mt. Strachan. They climbed through the North Shore backcountry to raise funds and PH awareness.

NOV
25

7th Annual Montreal PH Awareness Walk Montreal, QC

From sodium reduction to face paint and raffle prizes, 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 over 225 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 PH community at large.



Members of HTAPQ along with PH nurses Lyda Lesenko and Jessica Pinto (pictured in beige) organized one of their most successful walks to date!



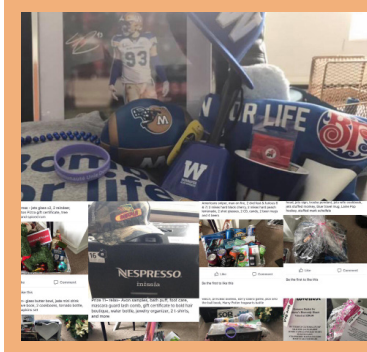
The London PH Clinic (ON) showing their support of the PH community during PH Awareness Month!

NOV
30

Dolores's Heavenly Heart Comedy Night Winnipeg, MB

To mark November Awareness Month this year, Corrise put the “FUN” in “FUNDRAISING” by organizing a special comedy night event that raised over \$800 for the PH community through

ticket sales and auction prizes. We could not be more grateful for her inspiring commitment to supporting our community and for the friends and family who came to support the event.



Corrise pictured with her friends and family enjoying a night out of comedy.

NOV
31

Adobe Canada 6-Minute Walk for PH Ottawa, ON

Adobe Canada organized its very first 6-Minute Walk for Breath after being inspired by a co-worker's journey and struggle living with PH. Thank you to the incredible organizers for taking the

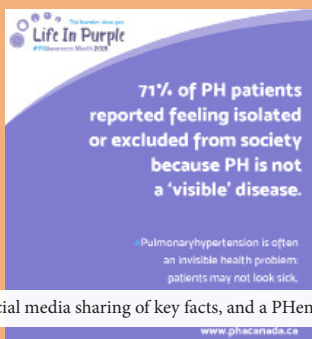
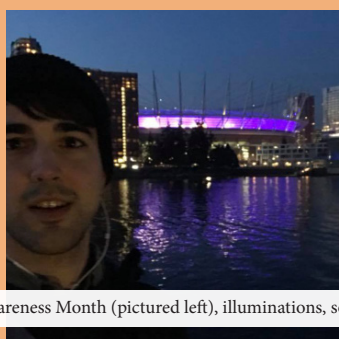
initiative of carrying out this walk, for raising funds in support of PHA Canada's programs and services, and for spreading awareness of PH.

NOV
1-30

Life in Purple (November PH Awareness Month) Canada Wide

Throughout November PH Awareness Month 2018, PHers from across the country helped show how pulmonary hypertension can change your *Life In Purple*. From sharing facts about the illness online to underlining the impact of PH on your life, we cannot thank you enough for helping to spread PH awareness!

We were also blown away by the support of numerous events listed in this issue along with special donations that helped us raise an incredible \$32,000 for the PH community thanks to matches from both Actelion Pharmaceuticals Inc. and McKesson Canada. Thank you!



Activities included proclamations of PH Awareness Month (pictured left), illuminations, social media sharing of key facts, and a PHenomenal show of purple!



It was all smiles at this year's Royal Scots 20-Mile March in Honour of Everleigh Pierce!



DEC
1

6th Annual Ottawa 6-Minute Walk for Breath Ottawa, ON

The Ottawa PH clinic held its annual 6-Minute Walk for Breath at the University of Ottawa Heart Institute. PH patients, caregivers, and supporters participated by walking the Institute's 6-minute walk route. The walkers without PH wore masks and used weights to get a better sense of what PH patients deal with

daily. Thank you to all the participants and organizer Carolyn Coyle-Cox for inspiring the PH Community across the country and supporting PHA Canada. This year's event raised over \$2,000!



The annual Ottawa 6-Minute Walk for Breath was another great success this year, thank you to all the organizers, participants, and supporters.

DEC
15

Realtors Giving Back Christmas Ball In Honour of Erica Castrillon Vaughan, ON

When Hugo Castrillon's five-year-old daughter Erica was diagnosed with PH in 2017, Lauren Parente—a colleague of Hugo's—decided to start "Realtors Giving Back", a professional group of realtors who wanted to support their fellow colleague and friend. This inaugural event was a night filled with glitz and

glamour, all the while sharing the story of this families' inspiring journey with PH. PHA Canada Board Chair Dr. Sanjay Mehta spoke about the importance of early diagnosis and was joined by fellow Board Director Janette Reyes who helped coordinate a special awareness booth at the event.



Dr. Sanjay Mehta speaking to the crowd at the inaugural event in Vaughan, ON.



MAR
2

Royal Scots 20-Mile March in Honour of Everleigh Pierce Mosa Township, ON

To commemorate the 204th anniversary of the Battle of the Longwoods, the UTMRS, which portrays the 1814 Light Company of the Royal Scots, marched from Delaware to Battle Hill, the site of the battle, a distance of twenty miles. In its fifth

year, the Royal Scots raised over \$2000 in honour of five-year-old Everleigh Pierce, for PHA Canada. PHenomenal work!

2018 Western Regional Symposium

Celebrating a United PH Community

PH Medical Think Tank

Over the course of two days leading up to the 2019 symposium, PH medical professionals from across the country came together to discuss and share progress on PH research and treatment in Canada. Led by Medical Advisory Committee Members Drs. Sanjay Mehta,

Lisa Mielniczuk, and John Swiston, the event marked PHA Canada's first time hosting Canada's medical community as part of our commitment to ensuring all PH patients have access to excellent and comprehensive care and treatment. Discussion and presentation topics

included the new national PH database tool (see page 30), current research projects/clinical trials, standards of PH medical practice, and an update from the Canadian PH Professionals Network (CPHPN). ■

Western Regional PH Symposium: Uniting the PH Community

In September of 2018, PHA Canada was thrilled to welcome 200 PH patients, caregivers, medical professionals, and supporters to the Western Regional Symposium in Vancouver, BC.

We kicked off the weekend with a special 10th anniversary celebration that reunited old PHriends while welcoming new ones to the Canadian PHamily. The party was complete with live music, food and drink, and an interactive "Tree of Hope". PHA Canada Board Vice-Chair, Roberta Massender, welcomed over 100 guests and also presented special gifts to 11 important individuals being honoured with the title of "Eternal PHriends of PHA Canada" for the integral role they've played in founding our organization and building a united PH community.

The following morning began with an opening plenary themed around Living Well with Chronic Illness. The panel included Child Life Specialist Judy Dahl, PH Patient Tarya Laviolette, and Retired PH Nurse Betty Ross. Moderated by PHA Canada's Executive Director, Jamie Myrah, the session covered topics related to finding your "new normal" and coping both emotionally and physically with the range of changes that families face because of a PH diagnosis. Next, there was a moment of silence in recognition of those lost to PH (led by Dr. Sanjay Mehta) and a networking break before participants split up and attended their choice of breakout sessions. The first set of sessions

included: Myth Busters: Q&A Panel with PH Medical Experts, Tips & Tricks: Q&A Panel with PH Patients, Caregiving: Don't Do it Alone (hosted by Janet McLean from Family Caregivers of BC), and an intimate panel discussion on CTEPH. The second set of sessions included panels on PH & Travel and Being a PH Advocate, as well as a Chair Yoga Demonstration by PH patient Sam Bowker. During the

I left the symposium heartened by the progress that has been made and hopeful for the exciting direction that research is going.

— Anonymous

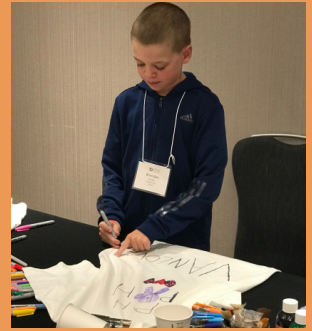
same time, parents of children with PH attended two dedicated pediatrics sessions: the first was a medical session led by Drs. Angela Bates and Erika Vorhies, and the second focused on lifestyle topics and was led by PH Nurse Practitioners (NPs) Janette Reyes and Susan Richards. As participants enjoyed a low-sodium lunch, we were honoured to hear from a very special guest speaker for a 10th Anniversary keynote presentation. Introduced by PH patient and personal friend, Tarya Laviolette, PHA Canada's

former National Manager, Angie Knott, took us on an emotional journey through the first 10 years of our association and the building of our PHamily.

In the afternoon, participants broke out again into informal peer-led discussion groups before coming back together for the closing plenary session. This year, the panel on The Future of PH Therapies was moderated by Dr. Lisa Mielniczuk from the University of Ottawa Heart Institute and included Dr. Sanjay Mehta from the London Health Sciences Centre, Dr. Duncan Stewart from the Ottawa Hospital Research Institute, and Dr. John Swiston from the University of British Columbia.

Videos of both the opening and closing plenary—along with the keynote address by Angie Knott—can be found at www.youtube.com/PHACanada. ■

Contributed by: Michaël Robach, Communications & Engagement Coordinator at PHA Canada



Gold Level Sponsors:



Bronze Level Sponsors:



Spotlight: The Gift that Keeps on Giving

New Monthly Donor, Jas James

Jas's journey to becoming a monthly donor began nearly 17 years ago when she was diagnosed with pulmonary hypertension (PH). She had developed what she thought to be a particularly bad case of pneumonia, but after noticing how long it was taking to go away, she sought out medical help and found out she in fact had PH.



As a mother to two little girls, donating monthly wasn't an option for Jas and her family at the time of diagnosis. She decided to support PHA Canada by donating only when it was the right time financially for her family. But all of this changed in 2018; with both of her girls all grown up and out of the house, Jas decided she wanted to give back to the community, one that had been standing by her side every step of her PH journey. And so, Jas became a monthly donor. In honour of the 17 years since her diagnosis, Jas gives \$17 per month and plans to increase it by \$1 for every year that goes by.

"For the same price as Netflix, why not. To me, PHA Canada means that there are people who care and are fighting for me to survive. PHA Canada has impacted my life by letting me know I am not alone in this. The most valuable service PHA Canada has offered me is support. I know I can call or email at any time if I need something and they will do their best to help me with whatever I am looking for."

Monthly Giving 101

Monthly giving can be a quick and convenient way to make a significant difference in the lives of all Canadians affected by PH throughout the year.

Donating can seem overwhelming, but monthly giving makes it easier for you to include philanthropy in your budget. For example, a one-time donation of \$300 can be kind of a big commitment for families, but a monthly donation of just \$25 is way more manageable. You only need to sign up once, pick the amount that is right for your family, and each month your gift will automatically be deducted. You can cancel your support at any time, and you'll still receive an annual tax receipt for the total amount that you've donated over the course of the year.

Becoming a monthly donor is the most powerful way you can make a difference today and create a legacy for future Canadians affected by PH. ■

Contributed by: Vanessa Stevens, Fund Development Coordinator, PHA Canada

How It Works and How You Are Making An Impact



You are helping to provide a newly diagnosed patient with education materials so that they don't have to feel alone facing their PH diagnosis. That's only 0.33 cents a day!

\$10/month



We will give patients and their families free subscription to Connections, the semi-annual PH community magazine.

\$20/month



You are helping to support research and the PHA Canada research scholarships, in hopes to one day find a cure.

\$25/month



You are helping us advocate on behalf of the community for better and equal access to affordable treatments across Canada.

\$30/month



Allows doctors to be educated so that patients can be diagnosed earlier and provided with treatments that can vastly extend and improve their quality of life.

\$50/month



You are sending families living in rural & remote communities to regional symposiums so that they can connect and acquire skills to effectively manage life with PH.

\$100/month

Fondation HTAPQ News

Formed in 2007, “La Fondation Hypertension Artérielle Pulmonaire Quebec” (Foundation HTAPQ) has approximately 500 members, of whom 160 are PAH patients and 350 are contributing members. Their mission is to improve the quality of life for anyone affected by PH through support and information. Here we share with you a short update on highlights from the past six months, contributed by their Vice-President, Dolorès Carrier.

Strategic Planning

Since the fall of 2018, our Board of Directors has been working on a strategic plan to ensure that the needs of people affected by PH and their families are met by improving the services offered by HTAPQ. To do this, we must grow financial resources but, above all, ensure that we have the necessary support system in place.

Changes to the Board of Directors

The Board of Directors had to accept the resignation of one of its founding members, Jacques Gariépy. Due to his health, Mr. Gariépy had to resign from his duties as Secretary and Head of the selection committee. His inspiring desire to help and bring comfort to those around him made an immense difference to people living with PH and their loved ones.

Mr. Hugues Boulanger also left his position in February 2019; he has been a member of the Board of Directors since the beginning, first as a Director and then as President. A key organizer of our infamous annual cheese sale fundraiser, he also involved himself in all the Foundation's activities:

conferences, book sales, fundraising, press conferences, etc. Through his empathy, kindness, and his great availability, he too has left his mark on our community.

General Activities

The three “brunch-conferences” organized in the fall of 2018 across the region were a great success. The goal was to promote the well-being of those living or affected by PH in our community. Amongst other things, we spoke about the importance of retaining your energy, “fun therapy”, and resilience. We have also decided to come back with these events in spring.

Our AGM will be held in Trois-Rivières on Sunday, May 5, which is World PH Day. We will take this opportunity to meet with our members.

A number of fundraising events took place these past few months:

- Andréane Mailloux organized another activity, this time it was a sugar shack dinner in St-Eustache on March 16. Another success!

- The annual cheese sale for Mother's Day begins in March and distribution will take place in early May. At Christmas, we sold more than 3400 boxes across the province, which is a record!

- The sale of new and used books will take place on Saturday, May 11 in Plessisville. Thousands more books will be sold at low prices under a big top.

- For the third year, Mr. Carol Fournier will present the BREATH Show in Granby, on Saturday, May 18. Renowned artists will present an exciting show. It'll be quite a show!

Good news, a Francophone Conference for Eastern Canada is being prepared, with the support of AHTP Canada for the fall of 2019, for the members of the Foundation and Francophones outside Quebec. Further details will follow. ■

Contributed by: Dolorès Carrier,
Vice-President, HTAPQ

OCTOBER

5

Halifax, NS | October 5, 2019

PHA Canada's Atlantic Forum

PATIENTS CAREGIVERS & FAMILY MEMBERS MEDICAL PROFESSIONALS PH SUPPORTERS

It's official! Mark your calendars for PHA Canada's first ever Atlantic Forum. For more information on registration & scholarships, visit www.phacanada.ca/AtlanticForum2019

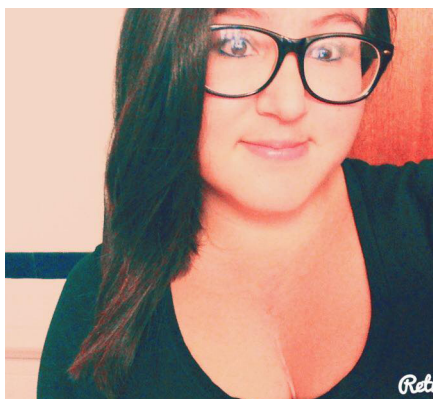


Your Stories

Every individual in our PHamily has a unique story to tell and can help make a difference in the lives of Canadians affected by PH. We are happy to feature the stories of exceptional PHighters whose unwavering commitment to the cause, unique journeys, or remarkable accomplishments deserve the spotlight.

Count Your Spoons: Taking it One Day at a Time

Alicia Thompson is a newly diagnosed PH patient who, in 2018, had her world turned upside down. In spite of this, the 24-year-old mother of three has taken it one step at a time and begun the process of adapting to her “new normal” the best she can. She is a mother of three little children and lives with her family in Strathroy, Ontario where she makes the most of her life by learning to appreciate and feel inspired by even the littlest things.



I was diagnosed with pulmonary hypertension (PH) on May 16, 2018. But my story starts much earlier than that. You see, I was born with congenital heart disease, mild asthma, and pulmonary veins stenosis. As a baby, I had to have two major open-heart surgeries and two surgeries to have a pacemaker put in. After years of stability, my body then decided to add more to my medical history.

It began last year, in 2018, when I was hospitalized for over two weeks. I met with a whole range of new medical specialists—I had up to 15 doctors trying to figure out what was going on at one point! They ran every possible test, needle after needle, and my favorite part (please note my sarcasm here) the IV Lasix. Finally, after what seemed like forever, I had a certain Dr. Mehta come in and go over my test results. He explained to me that I had something

called pulmonary hypertension and it was causing the right side of my heart to go into failure. A week later I was discharged with new meds, daily Lasix, a BiPAP machine, and home oxygen.

Since getting discharged, my life has changed so much. I've spent more time in the hospital than my own home (I had to return to the hospital once a month for a week at a time to get the IV Lasix). I've had to leave my job due to the illness and so did my fiancé since I needed 24-hour care. Doing the simplest tasks like getting out of bed, getting dressed, brushing my teeth, or even having a shower takes my breath away and sucks the energy out of me. One thing I always try to remember is to not overuse my “spoons” for the day. For those of you who don't know: The Spoon Theory is a type of disability-metaphor that visualises the amount of energy a person has in a day. It's a great way to understand your body and explain how you feel on a daily basis to your family and friends (look it up!). So now, I plan my days out to make sure to take my time and stop when needed. Each day is a struggle but I know if I push myself a little every day I'll get better at it.

As negative of a situation as this may be, a lot of positive things have come out of it too. I've had the honor of meeting a lot of great working nurses and doctors, I've gotten incredible support from my family

and friends, and I've started to appreciate a different perspective on life through just “the little things”. So my advice for someone who is just being diagnosed with PH would be to take a breath and don't rush things: take your time to get better. Do some research and keep track of what you eat, drink, and weigh. Join the Facebook

“So now, I plan my days out to make sure to take my time and stop when needed. Each day is a struggle but I know if I push myself a little every day I'll get better at it.”

support groups and reach out to others who can relate. But most importantly, talk to a counselor or someone you trust; don't hold in your feelings, it's better to let them out. And don't lose hope!

My hopes for the entire PHamily would be that we all get to live long and happy lives thanks to more research and better treatment options for both adult and pediatric patients. ■

Contributed by: Alicia Thompson, PH Patient, Strathroy, ON

Life with PAH: It Gets Easier

20 years after being diagnosed with idiopathic pulmonary hypertension, Phuc Vinh Bi still manages to feel inspired and hopeful. When he got home from a visit to the hospital earlier in 2018, his wife bought him an acoustic guitar. He captured the moment in the picture below. “The guitar reminded me of an extraordinary personal experience during my stay at the hospital: the time I switched from Flolan® to Upravi®.”

Taking medication for the rest of one’s life is a most troubling thing. But for me it wasn’t so bad, not for long anyway, because when I found out that I had a rare and incurable life-threatening disease, there was a latterly approved medicine to treat my illness. So I felt blessed to get treated, especially by the most qualified physician and health care personnel available in the city where I lived. Now, 20 years after my diagnosis with idiopathic pulmonary arterial hypertension (IPAH), I still think I’m sort of a lucky unfortunate person.

Everybody knows what it’s like to be in shortness of breath, but whereas healthy people can just huff and puff to gain extra energy while racing to catch a bus, my breathing problem was just plain horrible: I felt like there was a heavy bag of sand weighing on my chest. The difficulty in breathing worsened every day until I found such insignificant efforts like walking from the living room to the kitchen really insufferable. It took only a chest X-ray and an EKG to reveal that the breathing problem came not from my lungs, but from my heart. An ultrasound test further suggested that I could have pulmonary hypertension (PH). My cardiologist told me that he knew only one specialist in the whole city of Montreal who could treat my illness; he referred me to the Jewish General Hospital where I met Dr. David Langleben for the first time. That simple referral request is the reason I’m still alive 20 years later.

My health condition greatly improved after I received a prostanoid analogue called Flolan®. Almost overnight I felt much better and I was soon thereafter able to walk around the hospital corridors and even climb stairs. What saved me was a quick diagnosis, Dr. Langleben’s decision to put me on Flolan®, and the innumerable assistance provided to me by his colleagues Dr. Hirsch, Eileen, and Lyda. The low incidence of a disease usually means there are fewer medical specialists available to deal with such problems, and I happened to have access to a specialist who was also a medical researcher.

Even so, Flolan® presented a challenge for me: it had to be perfused intravenously and continually with a pump, because it had a short half-life of a few minutes. I learned techniques of preparing the Flolan® cassettes, dressing, and sterilizing the equipment at the hospital. The mechanism of a drug perfusion is tricky because it’s susceptible to bacterial infections of the central catheter, the skin insertion site, and more importantly the blood. On top of that, I developed skin irritation and dermatitis at the insertion site, and because of this skin rash I was unable to apply proper dressing designed to minimize infections. With that said, this treatment worked well for me; during those early years I rarely showed any signs indicating a worsening of my cardiac functions. I also benefited from a second drug, Revatio®, which worked to alleviate



my PH via a different pathway and was administered orally. On average, I was hospitalized once every two years because of bacterial infections or leaking catheters. Dr Langleben then one day decided to put me on Upravi®, a pill to be taken twice a day. This treatment, again, worked nicely for me, with similar but much lessened side effects compared to the previous intravenous medication. I also no longer had to worry about the skin problems and catheter infections or malfunctions.

I can’t say enough how much easier and less worrisome life has been since taking this new medication. I used to keep a bag packed with clothes, books, a toothbrush, and more in case of an emergency admission to the hospital. Now, I no longer have to prepare medicine cassettes, nor clean and change my dressings. Without the pump, I can take a shower or use a bathtub easily, or even go to the swimming pool. Travel no longer requires careful planning and meticulous preparation. Just thinking about these new experiences infuses me with pleasant feelings. Thinking back on what I have gone through after all these years, I have learned to appreciate such small mundane pleasures of everyday life.

I’m grateful for the fruitful work done by the pharmaceutical companies because they developed and brought not just one but a whole series of orphan drugs into use to treat this rare illness. I’m especially indebted to all of the advocates who helped make this new drug available to us PH patients. It’s heart-warming to think that medical science can now treat systemic hypertension, a common illness, and PH, a much rarer disease, with pills. Since the pathophysiology of hypertension is very different between these two circulatory systems, it’s not obvious that many recent, newer drug discoveries targeting systemic hypertension would also lead to breakthroughs in treating PH. But I’m delighted to know that modern medicine can now manage both diseases. ■

Contributed by: Phuc-Vinh Bi, PH Patient, QC

Becoming a Caregiver

Learning New Things Everyday

Garnet Heffernan lives in Calgary, Alberta, along with his wife and their teenage son. Although they never saw what was coming, they've slowly begun adapting to their new PH reality. As a caregiver to his wife, Garnet is learning new things everyday and taking it as it comes. There are countless folks in the community who, like Garnet, are thrown into the role of caregiving and he's thrilled to share with you a glimpse into what that world can be like.

It's not easy being a caregiver. It's not easy and it's not something you sign up for. The same way that no one wants to get PH, it's just something you get thrust into. But we do it out of love. It's a big bump in the road is what it is. Life sends us all kinds of bumps, but most of them are liveable and manageable. But this one is a big one that I'm still working to figure out.



Our lives were thrown into shock in early 2014 when my wife started feeling incredibly tired to the point that she could barely walk at work. She couldn't complete simple tasks without needing to rest half-way and stuff like that. After some initial trips to the hospital, they thought it might be a cardiac issue. We were referred to the Rocky View Hospital where she was hospitalized for a week. She was eventually discharged and went through a couple of different internal medical specialists until we finally got referred to the PH clinic at Peter Lougheed Centre. A couple more tests and finally, in December of 2015, a heart catheterization showed that she in fact had pulmonary hypertension (PH). In a way, it was actually a relief to find out what was wrong. But the more we learned about the illness, the more we realized how bad it could get and that there is no cure for it (not yet, at least).

Things kind of went from bad to worse at this stage. After returning to work from her first hospital stay, Joette's employer gave her an ultimatum: go part-time or lose your job. Obviously, she needed the job. But what we didn't realize at the time was that it meant Joette would go on to lose all of her health benefits which threw our family into some serious financial hardship. Joette has, since then, had to quit her job.

My caregiving duties kicked in pretty quickly as Joette's health began deteriorating. And let me tell you: it's made me a lot busier!

She used to do all of the cooking at home. I'm not a very good cook and what I do cook has directions on it, so for a long time we would eat take-away food. I'm finally starting to figure it out though, so we're eating at home a lot more again. I also had to start changing around my work hours to take her to the three or four appointments we have every month. Right now, I do night shifts so I can be home during the week with her and with our son. Our son has struggled a lot through all of this. He got thrust into the caregiving role with me and, following a serious concussion in 2014, he's only now getting back on track. Even though he's about a year-and-a-half behind with school he's on track to graduate, which we're thrilled about.

Quick tip for other caregivers out there: reach out to your local homecare services. We didn't know anything about homecare until about two years after Joette's diagnosis, but it's made life so much easier for the three of us. We have someone come in regularly and help out with bathing and with little bits of tidying, which gives us much needed time to rest and be with ourselves. In fact, a while ago now, Joette was placed on IV Lasix which she needed almost daily. But going to the hospital isn't easy: it entails getting my wife dressed, the oxygen tank going, the wheel chair, etc. But they have this new thing where community paramedics will come out to your house and deliver the IV Lasix at home. It's such a helpful service!

“But we do it out of love. It's a big bump in the road is what it is. Life sends us all kinds of bumps, but most of them are liveable and manageable. But this one is a big one that I'm still working to figure out.”

Things haven't been easy, but we are starting to get things handled. We're taking it one day at a time and learning as we go. One good thing that's happened through all of this is getting to know our PH Nurse, Gail. She's the nicest person and we're so grateful to her and the PH clinic for everything they do. ■

Contributed by: Garnet Heffernan, Caregiver, Calgary, AB

Participating in Clinical Trials

High Hopes, Realistic Expectations

Sandra Diebel is living testament of hope and perseverance. Since being diagnosed with pulmonary hypertension over a decade ago, she has invested herself in engaging with the PH community and values the importance of research in our quest for a cure. And if not for her own benefit, then for future generations of patients like herself. Although Sandra took part in a clinical trial that was terminated early, she hasn't let it break her down. In fact, she's standing taller than ever.



months, but having an INOpulse delivery device attached to me 24/7. I was told that I was the best patient for following the protocol of the studies.

An early heart catheterization report showed that there was substantial improvement in my pulmonary pressures so I felt ecstatic to enroll in a study that could actually help me. My doctors had all hoped that the INO would normalize my pressures and it did! I was clinically stable and went from having severe PH to mild PH.

It has been 15 years since I first realized something was terribly wrong with my health. It took four years of tests, specialists, poking, and prodding before I was diagnosed with pulmonary hypertension (PH). In the years since then, I have had the ongoing tests, clinic visits, and changes in PH medications—not to mention the lifestyle changes that come with living with a chronic illness.

For the past five years I have been participating in Inhaled Nitric Oxide (INO) studies. The first study I took part in was from 2013 to 2016, and the second right after that was a “long term extension” of the first study. This study was terminated as of August 8, 2018.

I participated in these studies even though I “may or may not receive any direct benefit” from them. I chose to take part not only in the hope that it would help me, but because the information from these studies may help others with PAH or may contribute to a better understanding of the illness in future. I complied with the study requirements for five years which entailed not only numerous initial visits to my study site and ongoing visits every four

However, abrupt termination of the study on August 8 was like having the rug pulled out from under me. I didn't see that coming. I found myself grieving the loss of something that was an integral part of my life for five years. Something that brought my pulmonary pressures down to almost normal. I was anxious about the ramifications of my pressures going back up to where they were before the INO and I was just plain scared of what this meant for the progression of my PH after being clinically stable for so long. The PH community is always looking for new therapies that slow down disease progression, improve quality of life, patient function, and survival. We need these studies and we need to participate in them not only for our own benefit, but for the possible benefits for future patients and research. As a matter of fact, a dear PHriend of mine participated in a study which enabled me to be on Macitentan® now.

I certainly don't regret participating in this study. It normalized my pressures for five years. My concern for future participants is that they be aware of the possibility of clinical trials being terminated unexpectedly.

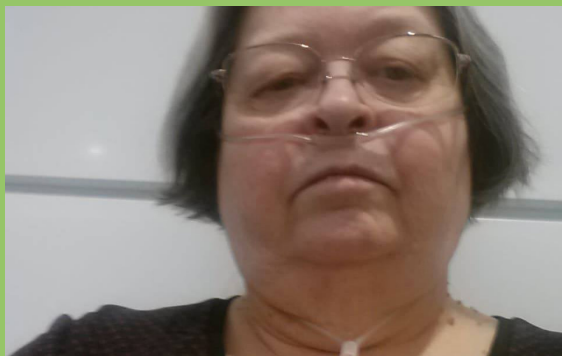
“I certainly don't regret participating in this study [...] My concern for future participants is that they be aware of the possibility of clinical trials being terminated unexpectedly.”

As a PH survivor of 15 years, I will never give up hope. Not for myself and not for the PH community and our quest for a cure. When the INO study was terminated, I had a feeling that something good was around the corner. As the saying goes, “when one door closes, another one opens.” Over the past few months I have gone through a multitude of tests and am happy to announce that I am now participating in another study. The SAPPHERE study is a new and exciting study that is testing gene-enhanced endothelial progenitor cells (EPCs). I'm beginning a new leg of this journey filled with excitement, hope, gratitude, and a wonderful sense of purpose. ■

Contributed by: Sandra Diebel, PH Patient, Durham, ON

What is something that has helped you manage life with PH better?

PHA Canada's mission is to empower the Canadian pulmonary hypertension community through support, education, advocacy, awareness, and research. To fulfill this mission and achieve our vision of a better life for all Canadians affected by PH, we offer a variety of programs and services to the PH community. Acting as a resource hub, our organization empowers community members to become educated about PH, as well as to support one another and advocate on behalf of the PH community.



“The biggest support in my life with PH would be my doctor, Dr. Weatherald, whom I could talk to, and my wonderful nurses Gail and Erin who helped me a lot!”

— Gloria Lowry, PH Patient, AB



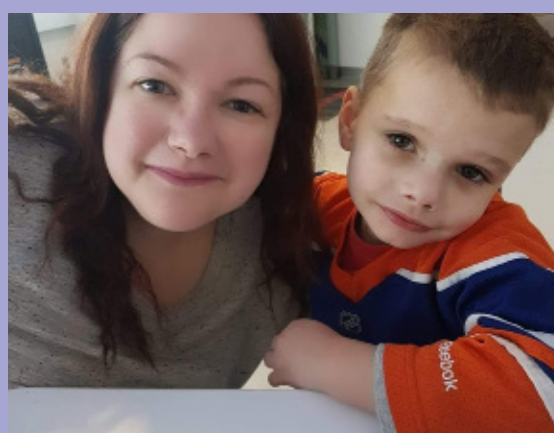
“Accepting that I have limitations. I was in denial when I was first diagnosed, but with the help of therapy I've come to realize that my life isn't over, it's just changed. Learning to rest when I need to, and not apologizing for it. Explaining my limitations to friends, but not getting upset when they don't understand. Acceptance. For me, that's the key.”

—Ola Gudat, PH Patient, BC



“First and foremost, my amazing support system, my husband and the rest of my awesome family. Without them, things would have most definitely been harder. And second, my positive attitude, which has always helped me see the good things in life, and has always been one of the driving forces that gets me through the things life throws at me.”

—Tina Giroux-Proulx, PH Patient, ON



“As a parent it was connecting with other parents and families who get it.”

—Nicole Klassen, Parent of Child with PH, AB



“I would have to say as a parent what has helped me, is learning to cross one bridge at a time and living in the now. As well as each day is different. If one day happens to be a crappy one, we deal with it and move onto tomorrow. When it’s a good day for Sophia, we do our best to make the most of it!”

We also have great friends and family and an incredible medical team.

— Stephanie Ricci, Parent of Child with PH, AB



“Having my support person. I know my family is always there for me, but my “other” person always understands me even when I don’t say a word. Whenever I have a decision to make, I can just give him a call and we’ll both list the pros and cons. He is the one who helps me with switching my infusion site every month. I am so grateful to him. I just feel lucky to have him. He is my pharmacist and my boss, Hardeep Khabra.”

—Sukhpreet Kaur Sidhu, PH Patient, BC



“I try to start my day as positive as possible. Don’t let the disease define you!! Living life to the fullest for me, means to find pleasure in all that I do and make memories everywhere I can while daring to dream!!”

— Lynette Chambers, PH Patient, AB



“For me it would be my rollator, Betsy. It’s great to have a seat right there anytime I need a break and she helps steady me as I walk. My world keeps getting smaller, but Betsy allows me to expand those boundaries a little.”

—Kaarina Klutz, PH patient, ON



“The staff and doctors at St. Paul’s Hospital in Vancouver extended and protected the quality and duration of my wife’s life long past what we could have expected.”

—Barry William Millar, Caregiver, BC

Special Feature: PH & Lifestyle

A new PH diagnosis is—for many of those in our community—a shock to the system. It comes with a flurry of medical pamphlets, treatment information, health jargon, and more. It also comes with having to adapt to a “new normal”. By this, we mean re-adjusting the way you lead your life, because PH is an illness that can — depending on the severity of your PH — affect your body’s ability to function the same way it has your whole life. This is not an easy thing to accept, in fact for many it takes a certain period of adaptation. But if there was just one thing we would wish for you to take away from this special “lifestyle” issue, it is that you are not alone.



For this Lifestyle feature, we will be focusing on the first two of PHA Canada’s strategic pillars: support and education. While a lot of the work we do is around advocating for better and equal access to treatment, raising awareness amongst medical providers, and of course helping to advance PH research in Canada, the empowerment of those in our community living with PH every day is a significant objective. As treatments improve, so does quality of life. And we want to help you live through this “new normal” the best we can. We are committed to informing PH patients and their loved ones throughout their PH journeys by providing free access to educational resources and events developed in collaboration with experts—specialized physicians, PH nurses, and experienced PHers.



PH Education

Did you know that PHA Canada has over 25 free resources tailored for anyone ranging from PH patients to caregivers, that you can easily access both online and offline? Topics include how to take oral medications, low-sodium recipes, and how to emotionally manage life with

PH better. These resources are developed collaboratively by the Canadian PH Professionals Network (CPHPN) and our Medical Advisory Committee (MAC). You will also find a number of articles written by experienced PHers who are able to speak from their first-hand experience. So if you’ve ever wondered about traveling with PH or wished there was a pamphlet you could share with friends so you didn’t have to explain what PH is to them every time, be sure to visit www.PHACanada.ca/Resources. You can also give us a call at 604-682-1036 or toll-free at 1-877-774-2226 to order printed versions.

“Did you know that PHA Canada has over 25 free resources tailored for anyone ranging from PH patients to caregivers, that you can easily access both online and offline?”

PH Support

Living with a rare disease like PH can be very lonely. In Canada, where people are spread out and sometimes live in very remote areas, patients often feel isolated. Remember, you are not alone: there is a strong community available to connect with you. By reaching out to others who live with the same issues every day, you will find a world of support, information, hope, and some incredible friendships. There are many ways to connect: through support groups, on the phone, and online.



Support Groups

There is often a miss-conception that support groups are “depressing”. That is absolutely not the case; support groups are a fantastic and fun way to meet and mingle with folks who can relate with you on many levels. Canadian PH Support Groups are independently managed and led by local community members. To find the nearest group to you, simply visit www.phacanada.ca/support-groups.



Facebook Groups

Social media has become an excellent platform to connect with others affected by PH in Canada. Facebook offers a free group feature through which users are able to join private message boards to talk and share things with one another related to life with pulmonary hypertension. To join the national Facebook group, simply visit www.Facebook.com/groups/CanadianPHriends. ■

Tips & Tricks for Everyday Living

Living with pulmonary hypertension (PH) can often make simple day-to-day activities a challenge. The simplest of tasks often require colossal amounts of energy and, due to the often-invisible nature of the illness, those around you might not always be able to fully understand nor relate to what you may be going through. That does not mean you are alone. In fact you have an entire community of patients across Canada who—like you—experience the daily struggles of coping with a chronic illness, all the while trying to get through their day. So, we asked folks in the community what their tips and tricks are for everyday living, and here is some of what they had to say about it:

Managing Your Stamina

A key indicator for PH is the lung's inability to effectively funnel oxygen to the heart, meaning it works at double speed a lot of the time. Because your body is working so hard, it drains much of your energy and makes even the simplest tasks an uphill battle. So what things can you do to cope with this better? While resting intermittently throughout your day helps preserve stamina, taking it slow and easy can extend your ability to complete activities at home or outside. It's important to listen to your body and accept your limitations. Remember that it is in no way a sign of weakness, but rather one of perseverance.



Jill M. I STILL struggle with overdoing things and paying for it for several days. Now I set alarms on my phone to limit task times and write errands for the week (spread out over several days) on the calendar.



Beth S. When tackling stairs, face them, take a deep breath in, and when you breathe out, take your first step or even two. Blow this out through pursed lips like you are cooling soup. I could only do this one step at a time at first, but now, after much practice, can do three steps before pausing to inhale again.

Sleeping Better

A full night of uninterrupted sleep can give the body an opportunity to heal damage all the way to the cellular level. A human growth hormone (HGH) is released into the body to repair and recharge organs and tissues. Unfortunately, struggling to sleep is a fairly common problem for many people living with PH. That is why talking to your PH specialist about any problems with sleep is an important factor in improving your quality of life.



Miriam K. Elevate your head above your heart when you sleep, it keeps the heart from pounding hard for hours (and keeps the sound of your heart out of the ears too). Another one is to use a humidifier and air purifier in your room (I also do deep breathing exercises before bed every night).



Tina K. I bought a 15 pound anxiety blanket from Amazon that works like a charm.



Donna P. Lots of outside fresh air helps me and if I can't get a good sleep at night and it's cool enough then an afternoon nap beside my fireplace can give me an additional two hours.

Relationships

All of us develop patterns in relationships we have with those around us. This is as much true with family as it is with friends and colleagues. A diagnosis of PH can sometimes affect those patterns as roles and responsibilities change, and adjustments get made in your routine. It is vital that those living with PH adapt and maintain healthy and strong relationships with those around them, as they will play an integral role in helping you through the difficult journey ahead.



Rebecca A. The more having to wear the oxygen, having your body be slowed down, having to use a scooter bothers YOU, the more that you will reflect those feelings out and anticipate that that's what others are thinking and feeling when you get those glances and "stares". But you've got this, you are a PHfighter and you have better things to worry about!



Jesse N. No relationship is immune to stressors and PH is a big one. Just remember that your disease doesn't make you unworthy of love. I met my husband after diagnosis on Tinder of all places. I was upfront about my diagnosis and symptoms so that I could create an environment of realistic expectations, and that's exactly what I have.

Travel

Whether you're going on a day trip by car or flying down to Mexico, travel can be a stressful thing for individuals with PH. Carrying around treatments and/or oxygen can be tough on the go. But with some careful preparation, travel is absolutely an option. It's important to always discuss any travel plans with your medical team so they can give you the tips and tools that will make it easier on you. Also remember to check with travel companies to see how they can alleviate the stresses of travel through special support programs. Visit www.phacanada.ca/travel for some useful tips.



Allison C. I'm not on Caripul but I traveled to Europe for two months last summer. It was amazing and unforgettable. Don't let PH stop you from living your life. You won't regret it :)



Millie K. I must travel on two separate flights to go and see my Drs in Edmonton. Each flight is 1.5 hrs. Your fear is real, but you can train yourself to manage. Breathing exercises work. And if your on oxygen the airline can provide you with it. Other than that it becomes routine.

Maintaining a Healthy Diet

Maintaining a balanced and healthy diet provides your body with the nutrients it needs to function at its best. But this is often easier said than done. A healthy diet consists of looking at the big picture: long-term dietary decisions that can help improve overall quality of life. Being more selective about what you eat can require more cooking at home and involvement in the foods you are buying. And finally, nausea and side-effects from PH treatments can have a big impact on appetite. But there are certain simple things you can watch out for that will make all the difference (and you'll feel better for it too!).

The Big Things to Watch Out For

The two most important things to consider when thinking about PH and nutrition are sodium and fluid intake. As tells PHA Canada's scholarship recipient, Sylvia Rinaldi—a PhD studying nutritional status on PH patients—lower sodium and fluid intake can have a direct impact on reducing swelling or edema in the body (a common issue in PH) thus reducing blood pressure in the body and lungs.

While reducing the amount of salt you put into your food is a great first step, it's important to watch out for hidden sodium in common food products like bread, packaged meals, and processed foods. Sport drinks and sodas often contain sodium too! Restricting fluids helps avoid or decrease swelling and fluid retention. **Each patient is different, so your PH specialist can give you guidance on whether you need a fluid restriction and if so how much.** Easy ways to mitigate risks is measuring the amount of fluid you're drinking every day (including fluids in your food if you can, such as soups) and spacing out your liquids throughout the day. Weight gain is often one of the first signs that you are retaining fluids, so keep an eye out for any big changes in very short amounts of time.

Foods to Focus On

While we want to be careful of certain foods that should be limited with PH, specifically high salt and fat items, don't forget there's a ton of great products you're encouraged to consume when living with PH. First, trying to replace less heart healthy fats known as trans or saturated fats which are most commonly found in animal products with heart healthy fats such as omega-3 fatty acids such as plant oils, nuts and seeds. Second, a diet rich in fibre can help manage bowel health. Include plenty of fruits and vegetables in your diet and choose whole grain bread or pasta products to boost your fibre intake.

Lean on your support system

Healthy eating isn't always an easy thing to do depending on how you're feeling on any given day. But getting your support system to help you prep and cook ahead of time on "good days" can help ensure you have ready-made meals next time you're hungry or are feeling too tired to cook. ■

Contributed by: Sylvia Rinaldi, PH Researcher (London, ON)

Reading Labels: Quick Tips

Always check the serving size!

Checking the % Daily Value (DV) of sodium:

- < 5% is considered a little.
- > 15% is considered a lot.

Ingredient list

Sodium isn't always listed as 'salt'. Look out for these words in ingredient lists which can indicate hidden sources of sodium:

- Disodium phosphate (MSG)
- Baking powder & soda
- Celery salt, garlic salt, or onion salt
- Brine
- Soy sauce
- Monosodium glutamate

Front of Packaging

There are lots of front-of-package labels, like 'low-fat' or 'no salt'. But what do these actually mean? "Salt-free", "zero salt", or "no salt" mean that each serving will contain less than 5mg of sodium. The term "low salt" means the product has less than 140mg of sodium (<6% DV) per serving. Phrases like "reduced", "less", or "lower" indicate that the product contains at least 25% less sodium than the original product. Similarly, "lightly salted" means there is at least 50% less sodium when compared to the original product. Beware, because even products labelled as "reduced" or "low sodium" can still have %DVs greater than 15%.

Nutrition Facts	
Serving Size 4 oz. (113g)	
Servings Per Container 4	
Amount Per Serving	
Calories 280	Calories from Fat 130
% Daily Value*	
Total Fat 14g	22%
Saturated Fat 3.5g	18%
Trans Fat 2.5g	
Cholesterol 120mg	40%
Sodium 640mg	27%
Total Carbohydrate 13g	4%
Dietary Fiber 1g	4%
Sugars 0g	
Protein 24g	

It's All About Balance

Fill ½ your plate with vegetables and fruit. These give us lots of antioxidants which help with inflammation, something that plays a role with PH. Eating a variety of fruits & veggies also provide a range of important minerals and vitamins.



Fill ¼ of your plate with lean proteins. Be sure to watch out for saturated & trans fats here. If eating meat, choose lean cuts.

Fill ¼ of your plate with a good balance of starches, pasta or grains. Choose whole grain options to keep you feeling full and satisfied longer and to help meet your fibre needs.

What Kind of Exercise Works for You?

Everyone is different. What makes PH so complicated are the many forms that it comes in (whether you're group 1, 2, 3, or 4) and/or the associated conditions attached to it. This is why it is important—when thinking about PH and exercise—to first and foremost know your limits and always consult with your PH team before starting any new form of exercise.

Research has shown that exercising improves short-term function and quality of life in people living with mild to severe PH. This can seem a little counter-intuitive; why exert yourself when the main struggle is breathing in general? The key is to never exert yourself to a point of discomfort. In fact, the simplest of activities can be enough to slowly build up endurance and, in many cases, you'll see improvement in how far you can walk or how much you can lift over a longer period of time.

What are the benefits?

Exercise can do a lot for your PH, but it can do even more for you. By engaging different parts of your body and mind, you're not only increasing your fitness and reducing your weight, you're also improving your mood and decreasing feelings of depression, anxiety, and stress (all of which are common in people living with PH). This is partly because it produces changes in the parts of the brain that regulate stress and anxiety, and is also known to increase the production of "endorphins" in your brain which are known to help produce positive feelings and reduce the perception of pain.

Another important benefit is the social aspect that exercise can have. Social interaction can do wonders for your mental health and

yet becomes much more limited when living with an illness like PH. So inviting your family, friends, or loved ones to participate in your activity (no matter how small) can be an excellent way of positively engaging them and building relationships.

Listening to your body

It can be both difficult and a little scary to start any form of new physical exercise, especially when living with a chronic illness. But remember: you're only meant to do as much as you feel comfortable with and always listen to your body; pacing yourself and setting reasonable targets can go a long way in getting you started. This is especially true in PH where patients can become short of breath even at rest or mild exertion. But even then, be kind to yourself by focusing on achievements rather than failures. A short walk or a few minutes of arm-lifting can be plenty to feel good about. ■

Contributed by: Michaël Robach, Communications & Engagement Coordinator at PHA Canada

There is a whole range of exercise activities that can be adapted to the limitations of someone with a lung and heart disease. But here are three examples of popular activities that are commonly practiced amongst those in the PH community. The key is to remember that it doesn't necessarily take much to reach a point where you are in fact "working out". So the real question is, what type of exercise works for you?



Walking (Cardiovascular)

Cardiovascular exercise (or "cardio") improves the way your body uses oxygen and has the most impact on your heart health. Depending on the severity of your PH, walking short to medium distances (with lots of breaks!) can have a great impact on your overall health and can actually help improve your 6-minute walk test results over time.

- Start slow by taking regular intermittent breaks every 3 to 5 minutes, and work your way up.
- Avoid inclines and carrying weights/bags so as to save energy and relieve blood pressure.
- Don't walk alone. Find someone to do it with you. It's more fun that way!



Chair Yoga (Flexibility & Breathing)

Yoga is a very popular option for people living with PH as it can be practiced in a seated position and can be adapted very easily to your needs and limitations. In fact, anyone can practice it regardless of how much or how little exercise-experience they have.

- If you are able to, try to connect your rhythm of breath to the movements you're making in simple patterns.
- Do not place your heart below your waist, as this will put strain on your heart and blood pressure.
- Find a series of movements that work for you, and then repeat the same sequence every time you practice to start seeing progress.



Weights (Strength)

Strength training is a simple and accessible way for PHers to maintain muscle, balance, and posture. This is especially important when mobility and activity in daily life becomes more limited due to the illness progression.

- Never use weights heavier than 15 pounds. Quick tip: using your own arm weight is a great place to start!
- It's important to keep your arms below your head, so as to limit increase in blood pressure.
- Do not try and over exert yourself, simple counts of 5 reps at a time with lots of intermittent breaks will do the job of slowly building up your muscles.

How to Cope with Tough Days:

PH & Mindfulness

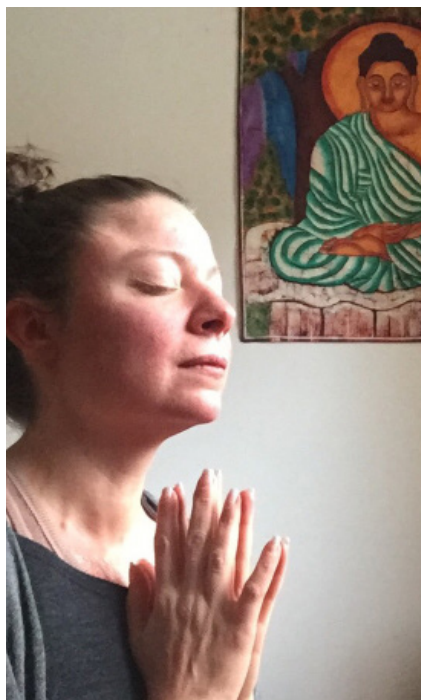
Since her PH diagnosis in 2015, Sam Bowker has not let PH get in the way of achieving her goals of staying active. In fact, she completed a 10-km walk as part of the Oak Bay Half-Marathon in her hometown of Victoria (BC) in 2017. Sam has since then continued to grow as an avid yogi and hosted a workshop for PHers looking to practise yoga during the 2018 Western Regional PH Symposium.

I was already crying when I walked into the yoga studio.

Some song on the radio had gotten me thinking—not hard when my clinic visits are approaching. I suddenly felt incredibly sad, overwhelmed, worn out. My instructor looked at me with concern; I muttered something about a hospital visit that week. “I know hospital visits are uncomfortable,” she said, “but doesn’t this seem a bit excessive?” I stopped and thought about past appointments, the coming visit, the conversations I have with my doctor, and how life changing they can be. I shook my head. “No.” I found a spot and rolled out my mat. Then I took out my phone and messaged a fellow PH patient. I explained where I was, what was happening, how embarrassing it was. They answered quickly, telling me about how many times the person in the car next to them had looked over in great concern as they’d been bawling at the steering wheel.

The truth is, we’ve all been there. When fear and sadness take a hold of your heart, it feels like wolves sniffing around, waiting to lead you down a dark, scary path.

When I was asked to write this article I answered with a ready yes. But every time I would sit down to write, I’d quickly become overwhelmed. What did I have to say that could help others cope better with their PH? “Live life to the fullest”. How? When you look down at the pump you’re attached to, thinking about the oxygen tank you might need to schlep around or dealing with the side effects of the meds you take, it can seem overwhelming. I get it. What about “stay positive?” It sounds good, but it’s not easy to do when you’re in the specialist’s office and they’ve uttered the word ‘transplant’ 16 times. You know this because you’ve been so busy counting the number of ‘transplants’ and haven’t heard anything else they’ve said. How



about, “have hope”. I’ve seen the Internet. I know what it says.

None of these clichés seemed to fit. So this is what I did. Sitting on the floor of that yoga studio, I began thinking of PHriends I saw as mentors and about what they’d say; I knew I had to “find a way to be with it.”

For me, this means mindfulness and yoga practice. I sit in meditation and stand on my mat almost every day. The point is not just to relax, although that can be a positive side effect of both practices. Instead, ‘being with it’ is to learn to be present, to be with what is, to pay attention to what my mind is thinking and what my body is feeling, and to observe. When I practice this, I have more resilience when things are hard and I’m paying more attention and being more present when it is not. What I intrinsically discovered was something that research tells us is true: mindfulness practices are

incredibly helpful for patients with critical and chronic illnesses.

There is something else that is so important for us PHers. It is a sense of belonging.

In my experience, the PH community is one the greatest assets we have. Yes, there are sad stories and losses, but this is true in all parts of life. Our community is one of incredible resilience and speaks to the strength of the human spirit. You always know that when you are scared, you can reach out to connect with someone who has been there and is standing with you now. When you lose hope, someone is there to tell you their story of coming through transplant or that they were diagnosed forever ago and are here to support you.

“The truth is, we’ve all been there. When fear and sadness take a hold of your heart, it feels like wolves sniffing around, waiting to lead you down a dark, scary path.”

If you want to live life to the fullest and have thought of some crazy adventure you want to go on, someone is out there to tell you how they did it with their pump and their oxygen in tow. Or if you are sitting on the floor of a yoga studio crying, someone is there to tell you they’ve been there too. ■

Contributed by: Sam Bowker, PH Patient, Victoria, BC

Balancing Work and PH

For many of those in our community living with PH, maintaining a professional career becomes incredibly difficult or often impossible, depending on their PH. But there are those who uniquely manage to balance their work and their illness. We share here three perspectives on why staying at work has been important to them and how they've managed to maintain a certain rhythm of work.

Carol Ploughman

Operations Analyst

I was diagnosed a week after my daughter was born, so I had a year of maternity leave to figure out how I was going to handle going back to work and raise two small kids. I was doing okay and went back to work but it didn't take too long before my body was telling me something had to give. I knew I couldn't keep up the pace and my family needed me more than my employer. So I started looking into disability options. It was hard to stop working. I felt I lost a lot of my independence when I gave up my job. But I took a year and a half to concentrate on my health and my family. After that, I was at a better place and my health was stable.

My PH doctor recommended that I work no more than 20 hours a week. With that in mind, we worked out with my employer coming back part-time. I was very lucky in that my employer worked with us to come to an arrangement that worked for everyone. I started working a few days a week for the first couple of months and then worked up to 18 hours. To ensure my body gets the rest it needs I work Mondays, Wednesdays, and Fridays so I can rest in between. If I have a really bad day and can't make it to work, my employer is flexible enough with me that I can switch days. I also return the favour if they need me to swap days to attend a meeting or other work-related items. This new schedule works well for me and it gives me satisfaction on both a personal and professional level. I'm not saying it's always easy. Living with PH never is. I listen to my body and if I need more rest—which happens every few months—then I take that time. One day I could be back to having to work less but for the present, I take it one day at a time. ■

Jane Gibson

Kindergarten teacher

Along with “PHighting the good PHigh” against PH, I also work as a full-time Kindergarten teacher. Right now my health is stable and teaching is my passion. Somedays working with kids proves to be more effective than my medicine as they bring me lots of laughter and learning opportunities. That's what motivates me to keep getting out of bed every morning.

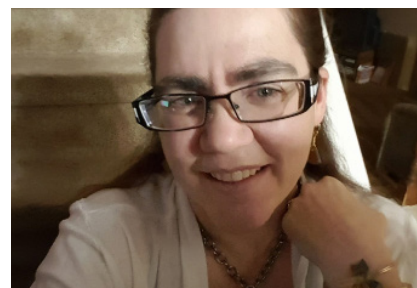


Of course, it has its challenges. When I come home from a full day, I am wiped! It's hard to tell whether it's the job that I find exhausting, the effects of my idiopathic PAH (IPAH), or both. I find that once I get home, I have to lay low in order to have enough energy for the next day. Low key nights can be a challenge on my spirits too but I make sure that I try to do different things (e.g., walk/play/dance party with the dog, play games, read, watch TV, etc.) to keep things interesting. I am always questioning myself, “Why work when I am fighting for my life?” It really comes down to my need to feed my passion for teaching as long as I physically can. For those wondering the same question, I would say, do what makes you happy. Eventually staying at home may become my reality and I will have to find ways to manage. In the meantime, let me stay and play in the wonderful world of KINDERLAND! ■

Maureen Harper

Registered Pharmacy Technician

Two years ago, my cardiologist discovered that I had multiple pulmonary embolisms and sent me to a Pulmonologist, which is when I was diagnosed with PH.



I have worked in pharmacy for almost 20 years and I love my job. I worked hard to become a pharmacy technician so it never really crossed my mind to quit. There are days when I'm exhausted and I can barely get out of bed, but days like that I just remind myself to keep moving (waking up and getting ready every day makes you feel better than if you stay in your pajamas all day). I do one or two things, then rest for 10-15 min, and then do another couple of things until I'm ready to go to work. Once I get to work, I'm good to go all day as most of my fatigue is early morning and later evening. At the pharmacy, I usually have to walk quickly, which wasn't a problem before, but as symptoms change, I am having to do things a little differently. I try to save steps whenever possible and I avoid looking up at shelves when I'm turning a corner because the medications I'm on make me dizzy. Sometimes I just stop what I'm doing and take a moment to catch my breath. If making a prescription takes an extra couple of minutes to fill, it'll still be faster than if I pass out. ■

Studying while Living with PH

Things I learned along the way

Rebecca Andre is currently in her second Undergraduate year at Carleton University in Ottawa (ON) where she is studying Applied Linguistics and Discourse Studies. In 2013, Rebecca was diagnosed with Group 4 PH—called CTEPH—but she hasn't let it define her life. In fact, she is making the most of it by taking things head-on and constantly looking for ways to accomplish her goals no matter the difficulty.



My name is Rebecca and I have CTEPH. Like many of my fellow PH friends, my life was filled with years of doctor appointments and tests before I finally got my PH diagnosis and began treatment. I started on Adcirca and despite the side-effects, I was getting back to a sense of self I hadn't felt in YEARS! I was suddenly able to play with my nieces outside, to take

a shower without fear of passing out mid-way, and to generally just make it through the day better. About six months into the treatment, it stopped working for me and I started taking bigger steps back than I was taking forward. That's when Adempas was brought in and my life really started to change again. A combination of Adempas, rehabilitation at the Heart Institute, and weight loss really helped push me forward to where I am today.

I am currently in my second Undergraduate year at Carleton University and am loving every single minute of it. I am engaged on such an extraordinary level that I still have moments where I sit and ask myself "is this really my life?", and the answer is always "yes, yes it is". With a little help and support I am moving mountains, and it's an incredible feeling.

SO! I wanted to share with you all some of the things that I've learned in my first two years of University as someone with CTEPH and a slew of other chronic illnesses.

1 Get a locker—for real—if you have any kind of chronic illness, having a locker on campus will save your life!

- I didn't have one in my first year and the amount of times I said "I wish I had a locker" was astronomical. I have one this year and it has saved me! I have extra medication stored in there, a blanket for "those days", a change of shoes, a change of clothes, and a place to store all my winter stuff so I don't have to lug it around.

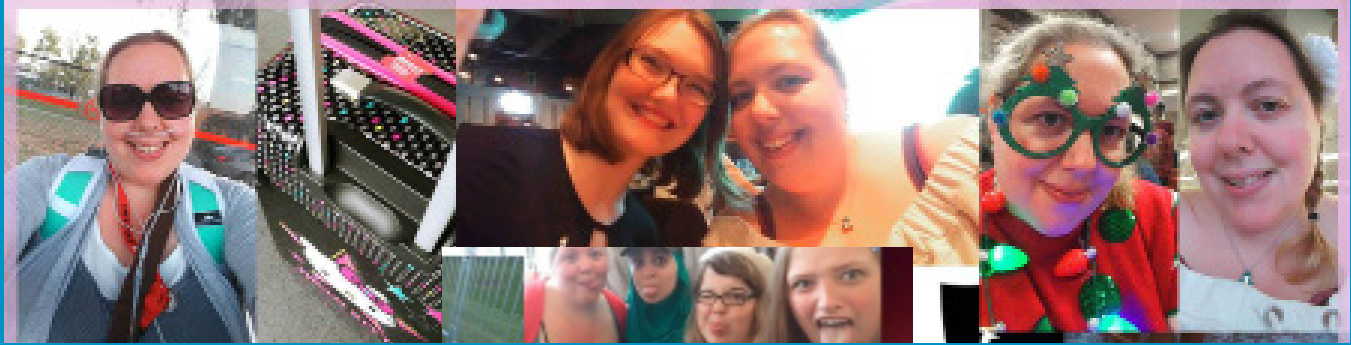
2 Get to know your Professors; the better your connection is the better their understanding will be when you run into bumps.

- In my first year would get pretty sick nearly every six weeks or so. I had pneumonia and lung infections; I ended up with fluid on my lungs that just would not leave me alone and so I did have to miss some classes. Ultimately, because I had made those connections with my professors and had accommodations in place, I was absolutely fine academically and still made it through the semesters with ease.

3 Use your accommodations: they will save your academic life. And if something isn't quite working for you, just change them!



- Can I just say: BRAIN FOG! This is a real thing and can hit at the worst times! So find your campus accessibility department and explore your options. Things like having your classes recorded or having access to a notetaker can make or break a semester when you are struggling through things like extreme fatigue and brain fog. Use the accommodations, you do not have to do this alone!
- I did get sick in my first year, nearly every six weeks or so. I had pneumonia, and lung infections. I ended up with fluid on my lungs that just would not leave me alone and so I did have to miss some class. Ultimately, because I had made those connections with my professors and had accommodations in place, I was absolutely fine academically and still made it through the semesters with ease. Having accommodations in place at the beginning of the semesters is really important!



4 Be comfortable! Seriously, no one cares what you are wearing. Long days studying can be longer if you're not comfy!

- During exam time, it is not a strange sight to see people walking around in onesies. No one cares; be as comfortable as you need to be. Do you need to dress up to feel functional? Awesome—do it! Do you need to wear a sparkly unicorn dress to make it through the day? Amazing! I have one in my closet that I pull out on occasion.

5 Don't be afraid to ask for help: this is one that I didn't have to learn but have had to impart a few times: do not be afraid to ask for help. There is so much help available if only you reach out for it.

- This goes for all students, not just us. Do not be afraid to seek out the student success center or whatever that looks like on your campus. There will be services available to help you figure out time management, exam prep, plotting your next year in courses. All of these things should be available on campus, you just have to ask. If you don't know WHO to ask, start at the Registrar's office and they should be able to direct you to a better starting point for student services.

6 Get involved.

- A very important leader of the Carleton Community often tells us that “you get out what you put in” and this is so true. If you just go to class, study, eat, and sleep you will be missing out on some of the most amazing experiences of your life. Check out the clubs, ask about the involvement. Some meet once a month throughout the year, some require even less commitment than that. No matter what you do, I suggest that you do something! Volunteer somewhere, find a cause that you believe in and give some of your time. A little bit goes a long way and you can look back and think “hey, I did that”.

7 Know when to say no, but don't be afraid to say yes.

- This was an important lesson in balance for me. It started out slow with agreeing to a few things here and there, and suddenly I had a very full plate! I had to learn when to say

no to helping and over-extending, and even reaching out to offer my help, no matter how much I wanted to. When you put yourself in a position to say YES to opportunities though, so many doors will open for you, and that is an amazing thing.

8 Naps. Take that nap. Set your alarm clock but take that nap.

- Fatigue is a real thing, and sometimes we need to just take that half hour to take a nap. I have learned to not take the two-hour nap that I would rather, and cut it down to 45 minutes so I don't wake up feeling like a zombie. Find your perfect “short nap” time and try and stick to it so you can still get some studying done.

9 Take care of yourself.

- This is more than just self-care: make sure you stay on track with medical appointments, your meds, and eating well. Something I also learned was how impactful stress and anxiety are on PH symptoms, so please be mindful of that. If you start feeling overwhelmed with studies, with assignments, with academic life in general – talk to someone, ask for help!

10 Finally – have the time of your life!

- Going to school with PH or any other chronic illness is an amazing thing. We are challenging the notion of “able” and showing the world that we are amazing rockstars. Remember, you fight every day to breathe. What's a little academic challenge?

I hope you all go off and do amazing things, and I can't wait to hear about them! ■

Contributed by: Rebecca Andre, CTEPH Patient, Ottawa, ON

A National Registry for Canadian PH Patients (Part 2)

We learned in our Fall 2018 issue of *Connections* about a new National Registry for Canadian PH Patients that has been in the works for quite some time and that it is now launching at various clinics across the country. The first interview was held with two members of a committee that's getting this project underway, Lisa Lee (NP) and Lena Legkaia. You can read this first interview at www.phacanada.ca/databasePart1.

Now, with a better sense for what a registry is, we were honored to speak to Dr. Jason Weatherald at the Calgary PH clinic—who has been involved with this project for a few years—about some specific goals for this registry and how he hopes it may impact PH patients directly.

Could you start by introducing yourself and how you began working within PH?

My name is Dr. Jason Weatherald, I'm a respirologist at the PH clinic in Calgary. I got interested in PH pretty early on in my career when I was a resident; I did an elective year with a PH group and I found it really interesting and loved the physiology, so I always sort of intended on pursuing that. I came to Calgary to finish my training and then I went to France for a year to do research with a group there. I've been back in Calgary now for two years and I spend about half my time treating patients and the other half doing research.

So how did you get involved with this registry?

There had been talk [in Canada] of doing a national registry for many years, so the Vancouver group got this database going at their center. At the same time, when

“We're trying not to bite off more than we can chew. There's lots of information we'd love to collect and look at, but we always have to balance sort of feasibility of things”

I was in France, I was working with the same program, so I got a lot of experience working with it and also using it to do research. I was excited when I came back to team up with Vancouver and try to get at least the Alberta clinics on board as well. There was a lot of enthusiasm from them and other sites across the country so that's sort of how I got interested in using this registry and moving it forward.

Could you talk a little bit about some of the key data you're hoping to track as part of this registry?

We're trying not to bite off more than we can chew. There's lots of information we'd love to collect and look at, but we always have to balance feasibility of things and the time it takes to gather and enter data into the registry. A lot of the things we're collecting are variables which have to do with patients' characteristics like the cause of their PH, their sex, and their age. This is because those are factors that are related to prognosis. But then we also collect information about how they're doing at each visit, such as their symptoms and their exercise capacity. Usually we measure that by how far they can walk in six minutes. Another thing we're interested in is getting a more detail on associated conditions [comorbidity] that patients have and how those conditions interact with their PH in terms of either causing similar symptoms or making it more difficult to optimize treatment. And then one of the other routine tests we do for these

patients is a blood test called the BNP or Brain Natriuretic Peptide. It's a test that looks at how stressed out the heart is due to pressure and/or fluid overload. It's one of the tests associated with prognosis so we're interested in collecting that at all the sites.

And then the two more common tests for patients are ultrasounds of the heart, or echo-cardiograms, and heart catheterizations which is the gold standard for telling us how the PH is doing. We're following patients over time—many years, in fact—and looking at things that are important to patients, like hospitalization, how often patients need lung transplants, and of course, the number of patients who die to their PH is associated condition. And then after a couple of years we can do an analysis that looks at which of these factors are most likely to predict good or bad outcomes, so that we can identify patients who are at higher risk and potentially treat them more aggressively or figure out other strategies for those patients.

Do you hope to compare all this Canadian data with registries in other countries?

For the time being, we'll just be looking at the Canadian data as aggregated. For example, comparing how far in progression is a patients' PH when they show up and how long they live on average compared to the United States. The problem with comparing to other



countries is that it might take us five years to get that survival data in Canada and then we're comparing us to US studies that are already three or four years old now. So other things might have changed in that time period that would explain any differences. It'll be hard to compare them directly, but we'll want to see that we're at least doing as good.

“We’ve shown that it at least predicts survival in these other registries but it hasn’t actually been done looking forward or prospectively, which is really where you find out whether a risk assessment tool works. It’s sort of like getting better at predicting what might happen so that we can act on it before patients get worse.”

There is an interesting subject that’s been brought up around this, which is multi-national registries. That has already happened in CTEPH for instance, and other types of PH. There’s no reason

why we couldn’t pool all of the patient data together—without any identifiable or personal information of course—and just look at thousands of patients across the world. That’s very powerful. I don’t think we’re quite there yet but I know there’s interest in doing that.

This opens up some really exciting opportunities for researchers to go in and make sense of the data and the patterns. Are there some specific projects that you’re excited about?

There’s one project I’ve been involved with quite a bit in the last couple of years which is this concept around “risk assessment” for patients. When I first started-out we generally made treatment decisions just based on symptoms. Some of the work we did in France in the last two years was looking at what we call “multi-dimensional risk assessment”, which is where we look at multiple factors or risk scores and put them into a low-risk profile-oriented strategy through which we try to increase treatment to make the patient as good as we can. We’ve shown that it at least predicts survival in these other registries but it hasn’t actually been done looking forward or prospectively, which is really where you find out whether a risk assessment tool works. It’s sort of like getting better at predicting what might happen so that we can act on it before patients get worse. Traditionally we treated PH as: you start a medication, then you wait until they get worse, and then you add another one when they are already getting worse. But we think that the horse is out of the barn already by the time they get worse, and it’s maybe too late. So, if we could have better ways of identifying someone’s risk and our target becomes getting that patient to low risk, then maybe we can try and prevent those episodes of worsening from happening.

I think Canada is ideally set up to be the first country in the world to do this and that’s one of our main objectives in the next two to three years; to see how risk assessment tools actually work in the real world prospectively. That’s the final step to say “yeah, this is the way we should do these things in practice”.

How can patients help support this initiative? Is going to their clinic and talking about this with their doctor a good idea?

Going to your doctor directly and saying that you’re interested in participating in the registry is a great idea. The thing about this research is that it doesn’t take much extra effort from the patients. It’s not like being in a clinical trial, which is much more complicated and often restricted to just certain types of patients. There’s lots of reasons why all of our patients can’t get into clinical trials, but everyone can participate in this type of study. We’re hopefully getting information that could help them out within their lifetime or at least help out future patients.

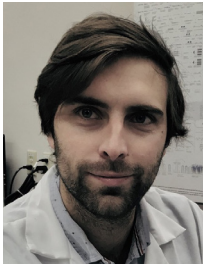
“The thing about this research is that it doesn’t take much extra effort from the patients. It’s not like being in a clinical trial, which is much more complicated and often restricted to just certain types of patients.”

We have multiple steps to protect patient information in terms of privacy and confidentiality, and in terms of the security of their information. There’s very minimal risk to the patient and we’re not putting them in potential harm’s way during any step of this research. I think it just empowers them to participate in improving knowledge of their disease. ■

Research Corner:

Meet the 2018 Scholarship Recipients

One of the ways that PHA Canada promotes Canadian research in the field of PH is by offering scholarships of up to \$10,000 to outstanding trainees in support of their research. Through our research program, we provide a financial stipend to emerging PH researchers whose projects will contribute to the better understanding or treatment of PH. We currently support up-and-coming Canadian researchers pursuing scientific investigations that will help better the lives of Canadians living with PH through two PH research scholarships: the Paroian Family PH Research Scholarship and the Mohammed Family PH Research Scholarship.



Dr. François Potus
Queen's University, Department of
Medicine (Kingston, ON)

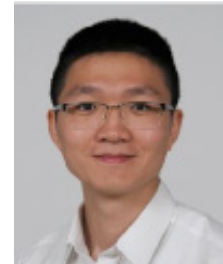
Under the supervision of:
Dr. Stephen L. Archer, Head of the
Department of Medicine, Queen's
University, Faculty of Health Science
(Kingston, ON).

Dr. François Potus obtained a Master's Degree with distinction in Molecular Biology and Genetics at the Université Claude Bernard Lyon 1, in France, and completed his PhD in Molecular and Cellular Biology at Laval University in Québec, Canada. Dr. Potus is a Physiologist and Molecular Biologist with expertise in cardiovascular research and genetics. His main work currently focuses on the epigenetic regulation of gene expression in pulmonary arterial hypertension (PAH). More specifically, he is interested in exploring the role that DNA methylation plays in pathological regulation of gene expression in pulmonary arterial hypertension.

Dr. Potus's Project: Linking inflammation and the progression of pulmonary arterial hypertension

We have identified special modifications to DNA ("epigenetic changes") that alter the way genes are expressed in PAH lungs. This study will investigate the role of a critical regulator of this epigenetic mechanism—called ten-eleven-translocase (TET2)—in the development of PAH. We will determine if artificial modulation of TET2 worsens or improves disease outcomes in an animal model of PAH. We will then investigate lung inflammation, cell proliferation, and TET2 expression to understand how this factor contributes to the disease. Finally, using an animal model of PAH, we will investigate which section(s) of DNA are targeted by epigenetic changes and determine the link between TET2, the identified genes, inflammation, and cell proliferation.

This project aims to increase basic knowledge of PAH etiology and investigate TET2 modulation as a potential cure for PAH. ■



Dr. Ping Yu Xiong
Queen's University, Department
of Medicine & Biomedical and
Molecular Sciences (Kingston, ON)

Under the supervision of:
Dr. Stephen L. Archer, Head of the
Department of Medicine, Queen's
University, Faculty of Health Science
(Kingston, ON).

Dr. Ping Yu Xiong completed his Undergraduate Degree at the University of British Columbia in 2010 and Doctor of Medicine at the University of Ottawa in 2014. Subsequently, he went to Queen's University to continue his post-graduate medical training in Internal Medicine. After doing a research elective in Dr. Archer's lab, Ping decided to pursue a research career in the PH field through the Clinician Investigator Program where Ping is now pursuing a PhD degree in addition to his residency training. He spends 80% of his time doing research and 20% doing clinical work.

Dr. Xiong's Project: Significance of Elevated Right Ventricular Systolic Pressure on Echocardiogram

Echocardiograms can estimate right heart pressure, which can in turn be used to calculate pulmonary pressure, but the results may not be very accurate. Indeed, to accurately measure blood pressure in the pulmonary circulation, a right heart catheterization needs to be performed. This is an invasive procedure involving passing a catheter through the right atrium and ventricle into the pulmonary artery. If the mean pulmonary arterial pressure is ≥ 25 mmHg, the diagnosis of PH can be made. As a result, PH is difficult to diagnose and the process can take months, if not years.

Our project examines PH patients who have had an echocardiogram done between 2013 and 2016. By studying these patients' echocardiogram results, their clinical history, and laboratory investigations, we are hoping to gain a better understanding of the echocardiographic, clinical, and laboratory profile of patients with PH vs. patients without PH. Knowledge gained from this study could improve clinicians' ability to recognize the presence of pulmonary hypertension, thus speeding up the diagnosis and treatment process for this illness. ■

2018 In Memoriam

While our community holds enormous hope for the future, the reality is that pulmonary hypertension still takes loved ones away from us. In 2018, our community has sadly lost the persons listed below. Our hearts go out to their families and friends.

Wendy Burnie
Frederick Dyck
Amanda English
Donna Fess
Sonya Gall
Diane Jarry
Mary Patricia Kerrivan
Pirkko Koutsombos

Caroline Laforest
Serena Lawrence
Patrick Lockhead
Pauline McCrum
Doreen Millar
Ayan Warsame
Marie Zinken

Please note that this list was created to the best of PHA Canada's knowledge at the time of printing. Please contact our office at info@phacanada.ca to have recently deceased loved one's listed in future or to report an error or omission.

2018 Donor Recognition

2018 saw PHA Canada celebrating our 10th Anniversary and each day we are able to see the incredible impact your support has made possible. Your generosity has made it so that we can continue on our mission to improve the lives of all Canadians affected by PH. It is truly remarkable how far we've come. So, we couldn't think of a better way to say thank you other than celebrating our donors—people like you—who are helping to write the next chapter of PHA Canada.

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Anonymous
Bell Family
Cheryl Dewson

\$1000-\$4999

Dr. Nathan Brunner
Dr. George Chandy
Dr. Marc de Perrot
Dr. John Granton
Jon Johnson
Dr. Sanjay Mehta
Jolene Mosiondz
John Murray
Paulin Family
Gemini Waghmare

\$500-\$999

Samantha Adams
David Anthony
Susan Barfoot
Andrew Christopher
Michael Comeau
Dr. Ryan Davey
Dr. Desmond & Stephanie Dwyer
Brent Fripp
Patti Gumenny
Dr. Naushad Hirani
Patricia James
Margaret Lacroix
David Marno
Jamie Myrah

Dr. Steeve Provencher

Rathonyi-Reusz Family
James & Kathy Reinhardt
Gwendolyn & John Reischman
Dr. Erika Vorhies

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Gibson Family
Deborah Hunter
Mani Jafari
Jasbir James
Timothy Loder
Karen Mayner
Naveen Shastry
Wilma Shastry
Marilyn Stubberfield

Community Events

6th Annual PHA Canada Ottawa 6-Minute Walk for Breath (Ottawa, ON)
5th Annual Ajax Run/Walk for PH (Ajax, ON)
4th Annual GolPH for PH Tournament (Brampton, ON)
Dolores's Heavenly Heart (Winnipeg, MB)
*multiple events over the year
3rd Annual Sail-o-thon Benefitting PHA Canada (Vancouver, BC)
The Royal Scot's 20 Mile March for PH in Honour of Everleigh Pierce (Mosa Township, ON)
Figo's Climb for PH (Vancouver, BC)
Ottawa Support Group Unmasked Masquerade Ball (Ottawa, ON)
Baacos Bar & Grill 2nd Annual Golf Tournament in Memory of Quentin Mosiondz
Adobe Canada's 6-Minute Walk for Breath (Toronto, ON)
Shawna Nicholson's Epicure Fundraiser for PH in Memory of Brenden Brinkworth (Cornwall, ON)
PHA Canada's Personal Page Fundraisers

Corporate Efforts

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FREE for PH patients
& primary caregivers!

CONNECTIONS

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Published twice a year, *Connections* is a bilingual publication that brings together the Canadian pulmonary hypertension community to inform, support, and celebrate one another.

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Contribute

Connections is your publication. Tell us about your support group or recent event; share your story or tell us about a phenomenal caregiver in your life; or let us know how you cope with PH on a daily basis. If you're not comfortable writing your story, contact us, we'll interview you and write the story for you. Let your voice be heard, that's what *Connections* magazine is all about!

Content Disclaimer

The content featured in *Connections* magazine is created by members of our community, and the information is checked for accuracy to the best of our ability. However, each person's PH story is unique, so what works for one individual may not work for everyone. If any information in *Connections* doesn't seem correct to you, please let us know so that we can verify it. Most importantly, always check with your PH team before making any lifestyle or treatment changes.

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