



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

# CONNECTIONS

The Official Magazine of the Canadian PH Community

Autumn 2019 | Vol. 10, No. 2



Special Issue:  
Caregiving



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

*Connections* is published twice a year by the Pulmonary Hypertension Association of Canada.

For subscription inquiries and information, please contact us at 1-877-774-2226 or at [info@phacanada.ca](mailto:info@phacanada.ca).

All rights reserved  
© 2019 Pulmonary Hypertension Association of Canada

**Editor-in-Chief**  
Michaël Robach  
PHA Canada  
Communications and  
Engagement Coordinator

**Translation**  
Denise Bérubé  
Mariane Bourcheix-Laporte  
Jean Dussault  
Josée Dussault  
Priscilla Hendrickson  
Isabelle Lamarre

**Art & Design**  
BP Media

**Printing**  
BP Media

**Contributors**  
Dolorès Carrier  
Paisley Dempsey  
Greg Giles  
Karima Habbout  
Teri Kingston  
Roberta Massender  
Janet McLean  
Emily Pinckard  
Vincent Pollitt  
Michaël Robach  
Vanessa Stevens  
Géraldine Vitry



*Cover photos (left to right, top to bottom): The Dempseys on World PH Day, Second Annual Ottawa Unmasking PH Masquerade Ball organizers, Fifth Annual GolPH for PH participants, and Sixth Annual Ajax Run/Walk for PH Research participants.*

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



The image depicted contains models and is being used for illustrative purposes only.

## Creating a future where disease is a thing of the past.

We are Janssen, the Pharmaceutical Companies of Johnson & Johnson. Bold thinkers. Big dreamers. Fearless advocates on behalf of patients. So that one day, the world's most daunting diseases will be found only in the pages of history books.

**Janssen Inc.**



19 Green Belt Drive  
Toronto, Ontario  
M3C 1L9

vxl90009  
© 2019 Janssen Inc.  
[www.janssen.com/canada](http://www.janssen.com/canada)



PHARMACEUTICAL COMPANIES OF  
**Johnson & Johnson**

# In this Issue:

## Inside PHA Canada

- 4** **Messages from the Chair & Executive Director: New Beginnings**  
by Roberta Massender & Jamie Myrah
- 5** **Message from the Team: Spotlight on Caregiving**  
by Michaël Robach & Vanessa Stevens
- 6** **Memo: Inside PHA Canada At-a-Glance**  
by Michaël Robach
- 8** **A New Place to Call Home: Welcome to PHA Canada's New Website**  
by Michaël Robach

## Your Community

- 9** **Your Community in Action**  
by Michaël Robach & Vanessa Stevens
- 12** **Planning for the PHuture and Leaving a Lasting Legacy**  
by Vanessa Stevens
- 12** **Donor Spotlight: Carl Selzer**  
by Vanessa Stevens
- 13** **News from the HTAPQ Foundation**  
by Dolorès Carrier

## Your Stories

- 14** **Eventually, the Good Days Will Outnumber the Bad Days**  
by Emily Pinckard
- 16** **What Message Would You Want to Share with Someone Who Has Offered You Support and Care on Your PH Journey?**  
PH Community Quotes

## Caregiving Feature

- 18** **Family Caregivers: Reach Out for Support**  
by Janet McLean
- 20** **At My Best and My Worst: Life as a Caregiver**  
by Greg Giles
- 21** **From the Point of View of a Young Caregiver: Interview with the Daughter of a PH Patient**  
by Paisley Dempsey
- 22** **Finding Your Magic**  
by Vincent Pollitt
- 24** **The End of the Caregiver Road in Three Affirmations**  
by Teri Kingston

## Research Corner

- 26** **PHA Canada PH Research Scholarships: New Scholarship Recipients**  
by Géraldine Vitry & Karima Habbout

# Messages from the Chair & Executive Director: New Beginnings



It was an honour to begin a term as Board Chair of PHA Canada in May of this year. On behalf of the entire organization, I would like to thank Founding Member, Dr. Sanjay Mehta, for his commitment, dedication, and leadership as Board Chair for the past five years. Sanjay is a passionate advocate and an inspiration to our community. We are grateful for his continued service on the Board of Directors, both as Past Chair and in his new role as Treasurer.

My personal connection to PH began when my niece, Nicole, was admitted to Vancouver General Hospital on November 6, 2000 to go on Flolan®. A month later, eight people—three of them PH patients—gathered for the first time in Vancouver. That meeting resulted in the creation of the BC Pulmonary Hypertension Society (BCPHS) in 2001 by Liz McCall. Nicole and I worked alongside Liz, the volunteer board members, and many friends to support the PH community and raise awareness of this rare disease. Nicole succumbed to her illness in March 2006. In memory of Nicole, I have stayed connected to the PH community. I joined the Board of Directors of BCPHS in 2007 and the Board of Directors of PHA Canada in 2012. It is very meaningful for me to volunteer and give back to something that is close to my heart and aligned with my core values.

It is a privilege to work with the PHA Canada Board, Jamie, and the staff. Together PHA Can-

ada has grown into a supportive and well-respected organization. It is an exciting time for the organization, as we are currently setting our strategic direction for the next three years. A key focus of PHA Canada's work will always be support; support for the patient and their caregivers—most often family—throughout their entire journey. When there is a diagnosis of PH, there are many mixed emotions. We often speak about the patient adapting to a "new normal". But it's not only the patient; families and caregivers also have to adapt to their new roles.

This issue of Connections has a very special focus on caregiving, with remarkable stories of courage and perseverance. The role of a family caregiver (or other close caregiver) is not an easy one; caring for a loved one with PH can be both challenging and rewarding. It is important for the caregiver to also take care of themselves, which can be especially hard in difficult times. This issue is part of our commitment to providing resources for caregivers. We hope it helps you in your own journey and serves as a reminder of how valued you are for the care that you provide the PHer in your life.

A handwritten signature in black ink that reads "Roberta Massender".

Roberta Massender  
Chair, Board of Directors, PHA Canada



As I return to PHA Canada from maternity leave, it seems fitting to be shining a light on the role of caregiving. To give care is central to what family life is all about. But family caregiving takes on a whole new meaning in the context of a complex condition like PH. When PH becomes part of a household, daily routines are upended, finances are destabilized, and life's hopes and dreams are called into question... for everyone, including partners, children, siblings, parents, and all those who are committed to being with us through the good and the bad.

PH caregivers are at the heart of the PH community—attending medical appointments, administering medications, reading the latest research, doing extra loads of laundry, adapting meal plans, social calendars, and personal expectations. Every day they step up to make life better for people with PH. Caregivers are determined advocates, passionate educators, fierce fundraisers, and influential change-makers. Like your family, we rely on them to get things done and keep us moving forward. Caregivers, we see all that you do and are grateful for your strength.

But in order to sustain that strength, caregivers need help too. They need tools to assist them with their new responsibilities, platforms to tell their stories and speak out on issues that matter to them, and opportunities to connect with others who understand what their lives are like. PHA Canada is here to make sure that happens. As part of our commitment to caregivers, we hope you enjoy this special issue of Connections.

Living with PH is many things, but it should never be lonely. Caregivers are living proof that we're all in this together.

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

Jamie Myrah  
Executive Director, PHA Canada

# Message from the Team:

## Spotlight on Caregiving



Dear PHriends,

Did you know that every year, nearly eight million Canadians become a caregiver to someone close to them? It would be hard to tell how many are caregivers to someone with PH, but we know for certain that every new PH diagnosis creates new caregivers. If you are reading these lines, you understand better than anyone how, when someone is diagnosed with PH, the lives of all of those around them are affected. This is why we have dedicated the special feature of this issue of Connections to caregiving.

If you are a caregiver, a family member, friend, or even the colleague of someone living with PH, then this issue of Connections is for you. Keep it with you, browse through the pages and the stories, take note of the tools that might help you navigate this chapter of your life, and know that you are not alone in this experience. In fact, you have an entire community who is on a journey similar to yours. While everyone's experience is unique, it can be helpful to learn from, and share with, others who can understand what you are going through.

Another challenge we share as a community living in this vast country is

**The connecting thread between all caregivers is their dedication to caring for someone they love.**

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!

The broad nature of caregiving makes it tricky to pinpoint who fits the role. It can be the child of someone living with PH who has grown to understand what it means to have a parent living with this illness (page 21). It can often be a partner who's assumed the role of a caregiver due to proximity and love (pages 20 and 22-23). Or it could even be someone small and fuzzy, who is there to care for you and bring you joy (pages 14-15). The connecting thread between all caregivers is their dedication to caring for someone they love. Often, this can come with difficult or negative emotions like resentment, guilt, fear, or worry. Sometimes, unfortunately, it can also come with having to mourn the person you gave so much of yourself for. Although this process is hard, it is not impossible (see pages 24-25). PHA Canada is there to help you at every step of your caregiving journey.

For the both of us—Michaël and Vanessa—this will be our last letter to you. During our time at PHA Canada, we have had

the immense honour of being welcomed into a unified community that can only be described as a PHamily. We are so grateful for the experiences we gained, the PHriends we made, and the opportunities we had to help advance the interests of the national Canadian PH community. These are experiences we will cherish forever. We also witnessed first-hand the hard work and commitment of those working behind the scenes: the incredibly dedicated members of our Board of Directors who volunteer their time and energy towards accomplishing PHA Canada's mission. The organization also counts a number of committees of nurses, doctors, and parents, and for special initiatives who act as the voices for our community. We thank each of their members for the expertise they give and passion they show for positively affecting the lives of Canadians who have, in some way or other, become affected by pulmonary hypertension.

PHriends always,

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.

## Meet PHA Canada's New Board Chair, Roberta Massender



We are incredibly thrilled to introduce PHA Canada's new Board Chair, Roberta Massender. Roberta joined the PH community in 2000 following her niece's diagnosis and has since been a pillar of the Canadian PHamily. After working closely in BC with PHA Canada co-founder Elizabeth McCall, Roberta joined PHA Canada. She quickly became very involved in sub-committees and stepped into the role of Co-Chair only one year into her nomination. **For more information on Roberta, visit [www.phacanada.ca/whoware](http://www.phacanada.ca/whoware).**

---

## PHA Canada Appoints Two New Members to the Board of Directors

As we gear up for our next strategic phase for 2020-2023, we are happy to welcome two new Board Directors. Each of them brings invaluable skills and unique experiences with pulmonary hypertension. The Board of Directors wishes to extend Emily Pinckard and John Pettifor its warmest welcome to the PHamily. **You can find out more about them below and by visiting [www.phacanada.ca/whoware](http://www.phacanada.ca/whoware).**

### Emily Pinckard



Emily is a CTEPH patient who earned an LL.B. from the Faculty of Law at the University of Kent in England after completing her Bachelor of Social Sciences at the University of Ottawa where she majored in Political Science. While pursuing her law degree, Emily studied Private International Law at The Hague Academy of International Law at the Peace Palace in Den Haag, Netherlands. She later returned to the University of Kent where she earned a Master's in International Corporate/Commercial Law. Since her call to the Bar, Emily has practiced corporate and commercial litigation in Toronto, Ontario.

Emily has extensive volunteer experience, having contributed as a member of the Young Advocates Standing Committee and the Advocates' Society Juror PTSD Task Force. She was also Editor of the Advocates' Society's Keeping Tabs publication. Emily is passionate about patient and caregiver psychosocial support. In particular, she is keen to contribute to the establishment of programming to assist PH patients and caregivers with the psychological burden of a PH diagnosis. Emily advocates for an increase in social services and economic assistance programs available to PH patients. She is specifically interested in PH support programs for young adult and adolescent patients. Emily is also an active Patient Partner at the University Health Network in Toronto, Ontario. She resides in Toronto with her partner, Joshua, and her service dog, Oscar.

### John Pettifor



John, who moved to BC from the UK in 2009, brings with him a unique insight into the non-profit world. He is currently VP of Non-Profits at a Burnaby-based technology consultancy firm where he oversees a team of ~100 consultants who are implementing technology for a range of non-profits throughout North America. As a career consultant, John has led technology implementations for hundreds of companies ranging from small start-ups to global enterprise organizations in both for and non-profit sectors.

Having lost his mother to the illness in the early 90s, John has a close connection to PH. His brother was also diagnosed with PH in 2013. John is happily married and enjoys playing music, camping, and being with friends and family.

# NEW RESOURCE:

## PH & Contraception

### PH & CONTRACEPTION

Many types of pulmonary hypertension (PH) are more common in women than in men. As such, the issue of potential pregnancy and contraception is a common and important one. The effects of pregnancy on blood volume and the heart can often worsen PH and right-sided heart failure, which is associated with very high risk to the life of both the mother and baby. **That is why it is strongly recommended that those living with PH who are entering puberty and/or of childbearing age typically avoid pregnancy through continued and stable use of birth control.**

#### WHY IS IT IMPORTANT TO NOT GET PREGNANT NOW?

During pregnancy, the mother's blood volume increases by about 50%. This increase in volume causes heart rate and blood pressure to go up while decreasing the heart's ability to push blood throughout the body and lungs. During labor and delivery, there are also many issues that can occur: blood loss, uterine contractions, the body's reaction to pain, and an increased risk of blood clots. For someone living with PH, these changes are poorly tolerated and can lead to a rise in blood pressure in the lungs and right heart failure. To give you an idea, between 1997 and 2007, the maternal mortality rate amongst pregnant women with PAH was 25%. Many of the medications used to treat PAH are also harmful to unborn babies.

- Due to the risks linked with pregnancy for those with all types of PH, it is recommended that patients avoid pregnancy or consider an early termination.

Healthy Women	Women with PH
Increased blood volume and heart rate	Increased blood volume and heart rate cannot be accommodated
Decreased ability to push blood throughout the body and lungs	Rise in blood pressure in the lungs and right heart failure

All decision-making regarding birth control should include the patient and involve talking with a women's health specialist. Although it is strongly discouraged, if a PH patient decides to plan a pregnancy it is important to do so in close consultation with a PH specialist.

#### ADDITIONAL RESOURCES

- For more information on birth control and sexual health: <https://www.cpha.ca/birth-control-methods-and-sexual-health>, <https://www.sexandu.ca/>
- For more information on adoption & surrogacy: <https://www.adoption.ca>, <https://www.surrogacy.ca>

PHA Canada's latest patient tool is here! This new resource addresses the importance of contraception for women living with PH and provides an overview of available methods. This resource was developed in collaboration with CPHPN and our Medical Committee.

We encourage the community to download this new resource for free, along with our other tools, at [www.phacanada.ca/resources](http://www.phacanada.ca/resources).



As we enter a new and exciting phase for our organization, we first wish to extend our warmest thank you to three staff members who have left us in 2019. In their time with PHA Canada, Michaël Robach (Communications and Engagement Coordinator), Vanessa Stevens (Fund Development Coordinator), and Mark Schuett (Acting Executive Director) have each wholeheartedly played their part in furthering our vision of a better life for the national PH community. The Board of Directors wishes them nothing but the best in all of their future endeavours.

# A New Place to Call Home: Welcome to PHA Canada's New Website

In a day and age where information is often free and accessible to anyone with a WIFI connection, we, as a rare disease community, are particularly lucky to have the ability to find information and resources on PH in a few clicks. With this in mind, we've aimed to make PHA Canada's website the Canadian PHamily's go-to online destination to learn more about PH, find support, access tools, stay connected, and get involved.

## What?

All of us at PHA Canada are incredibly excited to share the news of our new website! Over the past year, we have worked closely alongside both community and medical committees to improve and enhance one of our community's most valuable asset: our online directory of tools, resources, and information.

So, what's new? We've upgraded various sections of the site to include better and more interactive features designed to make your PH journey easier. We're excited about our new FAQ section! Spread out across the site you will find relevant answers to common questions about both medical elements of diagnosis and life with PH. We've also redesigned our directories of PH clinics and of current Canadian PH research trials to make information easier to find. Our new community calendar will now be a lot more functional, with regular events and support group meetings being featured throughout the year. And finally, we've jazzed up the look of our site to better showcase our content and your stories.



## Why?

We've aimed to make our new website as accessible as possible. We believe that patients and their families should be able to find the information and tools they need, and in a way that they understand, so they can feel both supported and informed. This new website upgrade will also mean that folks using varying types of devices (computers, tablets, and phones!) will be able to share the same user experience of the site. We've also designed our site keeping in mind the needs of users who may require specific font sizes and/or colour adjustments.

## When?

Our goal is to deliver a new site that is as perfect as we can make it. We'll keep you in suspense by not revealing a launch date just yet... but look out for a special roll-out of the new site by year-end.

## Where?

We're giving our website a makeover, but same as before, you'll be able to access our online resources by visiting [www.PHACanada.ca](http://www.PHACanada.ca). Happy browsing!



# Your Community in Action

## Second Annual Ottawa Unmasking PH Masquerade Ball

May 4th, Ottawa, ON

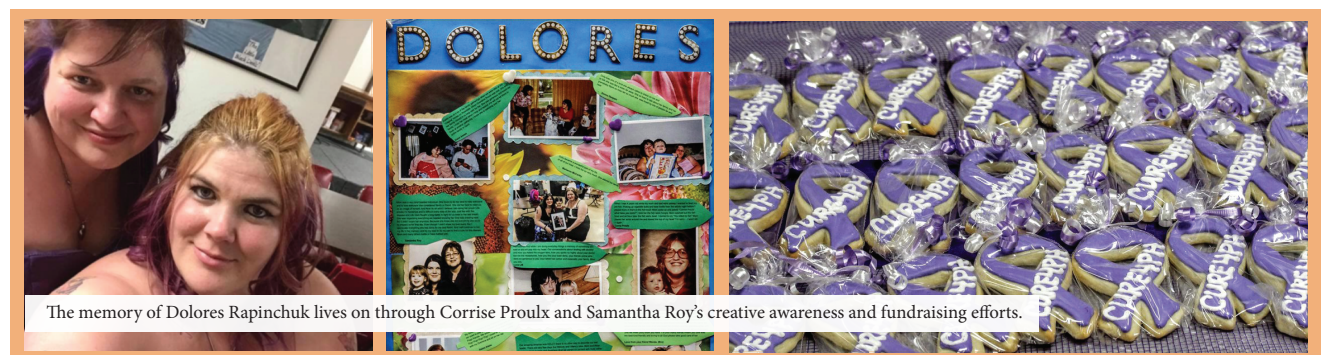
For the second year in a row, the Ottawa PH community gathered to honour Canadians affected by PH at the Ottawa Unmasking PH Masquerade Ball. By “unmasking” those hidden behind an invisible illness, the event worked to unite PHighters and raise awareness. This year’s Masquerade Ball raised more than \$11,000 for the national PH community! Guests got to hear from a number of special speakers, including medical professionals, patients, and caregivers. Congratulations to the organizers on a PHantastic event!



## Dolores’s Heavenly Heart Night for PH Awareness

May 4th, Winnipeg, MB

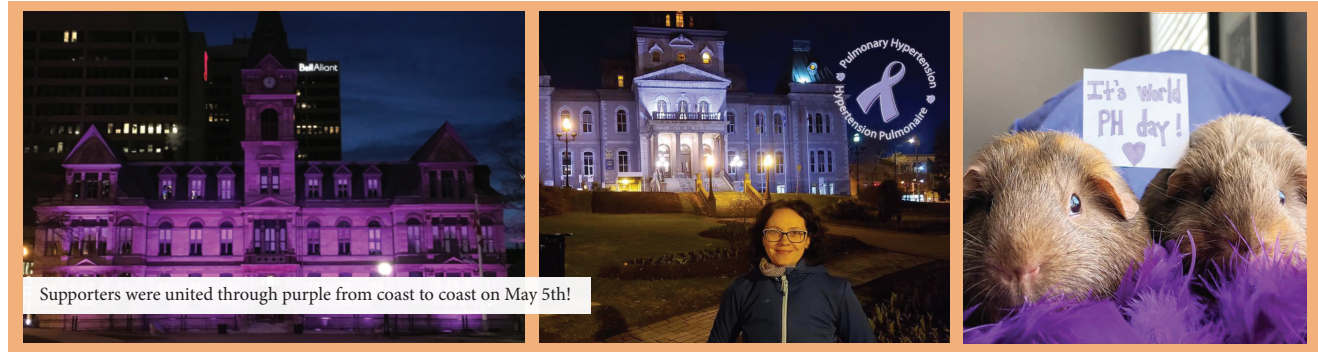
Congratulations to sisters Corrise Proulx and Samantha Roy in Winnipeg who organized a PH awareness and fundraising dinner. Attendees were able to learn about the impact of PH through special speeches and various performances all the while celebrating World PH Day. The event raised a PHabulous \$2,300 for the national PHamily! Corrise and Samantha aren’t stopping there; they are now working toward raising enough funds to establish the PHA Canada Dolores Rapinchuk PH Research Scholarship to honour their mother, who they lost to PH in 2016.



## World PH Day

May 5th, across Canada and internationally

The Eighth Annual World PH Day saw our PHamily across Canada unite to raise awareness of the many facets of PH. Our Paint Canada Purple campaign raised the bar with an incredible 21 illuminations that lit our skies periwinkle on the night of May 5th. We were also honoured to join an international collaboration online with fellow PH associations by sharing facts about the illness across social media. To everyone who contributed to making this day so impactful, thank you!



## Fifth Annual GolPH for PH

May 16th, Brampton, ON

Our favourite team of golfers celebrated the fifth anniversary of the GolPH for PH fundraiser this year and raised an amazing \$18,000! This event—organized annually by the Paulin Family—has funded an incredible total of four PHA Canada Paroian Family PH Research Scholarships. The Paulin Family have also worked tirelessly to advocate and raise awareness of PH both locally and nationally. Their work is having a deep impact on the lives of all Canadians affected by PH and we are incredibly grateful to have them as part of our PHamily. Thank you!



## Sixth Annual Ajax Run/Walk for PH Research

June 8th, Ajax, ON

A massive congratulations to the Mohammed Family whose Annual Ajax Run/Walk for PH Research broke all records and raised nearly \$39,000! These funds will directly support the PHA Canada Mohammed Family PH Research Scholarship. We are eternally grateful to everyone in the community who's helped raise the roof and crush all expectations! A BIG special thank you to Renae, Joseph, Judy, and Kam Mohammed for organizing their most successful event yet.



## PHifty4PHifty Draw for Darren Bell

June 29th, Vancouver, BC

One of PHA Canada's founding members, Darren Bell, celebrated his 50th birthday with a special 50/50 draw supporting the BC PH community. Following the loss of his son to the illness, Darren has played an integral part in supporting our goal of achieving a better life for all Canadians affected by PH. Nearly 12 years later, Darren is still a PH leader, advocate, and strong supporter of the Canadian PH community. This PHantastic initiative raised more than \$10,000! It's safe to say that PHA Canada would not be where it is today without Darren, and we are incredibly grateful that he chose to help support our PHamily at this special milestone in his life.



## Second Annual Dolores's Heavenly Heart Walk for PH

July 13th, Winnipeg, MB

and

## Second Dolores's Heavenly Heart Night for PH Awareness

July 20th, Winnipeg, MB

Sisters Corrise Proulx and Samantha Roy from Winnipeg put on the Second Annual Dolores's Heavenly Heart Walk for PH in memory of their mother, Dolores Rapinchuk, who passed away from the illness. The event was followed a week later by a PH Awareness night complete with vendors selling handmade goods, face painters, and even the Winnipeg Blue Bombers' mascot! These events raised close to \$1,000 for the national PH Community. A very special thank you to everyone who donated and helped make these events possible.



## Planning for the PHuture and Leaving a Lasting Legacy

Your legacy is your chance to create a lasting impact for generations to come and provide them with the best possible future. However, choosing how to give and whom to give to are important and personal decisions. Making these decisions can mean having to find a delicate balance between providing for your family and supporting the causes that are close to your heart.

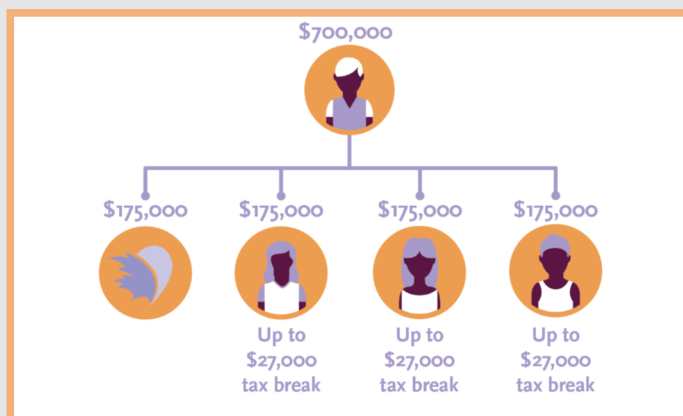
With a legacy gift, you can achieve this balance by giving to both loved ones and cherished causes.

For many, making a legacy gift means being able to make a more significant impact than they would be able to during their lifetime. Most often, a legacy gift will allow you to make a tax-effective gift, meaning that it can help reduce the tax burden falling on your family and estate. With these benefits, making a legacy gift makes your impact go even further.

When choosing to leave a legacy gift to a charitable organization like PHA Canada, you are not only helping your loved ones through tax savings. You are also making sure that future Canadians affected by PH have the best support they need, along with access to the latest treatments. Your generosity will ensure that PHA Canada can continue to empower the Canadian PH community through support, education, advocacy, awareness, and research.

### Here is a simple breakdown of how legacy giving can work:

John Smith wants to leave \$700,000 to his three kids and PHA Canada. Each child would receive a tax break of about 15% (\$27,000) when leaving a charitable gift.



*Note: The information on this page can help facilitate discussions between you and your advisor. It is not intended as legal or financial advice. We encourage you to consult a qualified professional.*

## Donor Spotlight: Carl Selzer



PHA Canada monthly donors Carl and Birdeen Selzer.

Carl Selzer was diagnosed with acute myeloid leukemia (AML) in 2017 and immediately began chemotherapy. After going through three rounds of chemo and receiving a stem cell transplant from his brother in 2018, his AML was finally in remission. Later that same year his breathing began to deteriorate; he wasn't able to walk for fear of blacking out and could hardly make it out of bed. He was readmitted to the hospital to determine what was happening to him. After undergoing many exhausting tests, he was diagnosed with pulmonary arterial hypertension (PAH) and prescribed Caripul®. Like many other PHighters, he now had to carry a CADD Pump with him 24/7.

Throughout this draining ordeal, his wife and best friend, Birdeen, was, and continues to be, by his side. Throughout countless hospital stays, Birdeen has never missed a day at Carl's bedside. She has been advocating for him when he has been unable to and has discovered her inner strength in the most challenging of times.

When they noticed the new "donate" option on Facebook, Carl and Birdeen thought this fundraising option was a great idea. After further reflection and conversation, they started to worry about the potential for this donation option to desensitize Facebook users to the needs of non-profits like PHA Canada. So, they decided instead to become monthly donors.

"You can't support every worthwhile cause or organization, but you can choose one or two you believe in and consider a \$20 or \$30 regular monthly donation. Think about it, that's only one or two restaurant meals a month! And your donation is tax-deductible. We chose to donate every month to PHA Canada and LLSC (Leukemia & Lymphoma Society of Canada). These two organizations have provided support and a lifeline when we needed it most." Carl Selzer, PAH patient and monthly donor, Vancouver, BC.

# News from the HTAPQ Foundation

The Pulmonary Arterial Hypertension Foundation of Quebec (HTAPQ) started its activities in 2007. The Foundation has over 500 members, including 160 people living with pulmonary hypertension and nearly 350 contributing members. The Foundation's mission is to improve quality of life for people living with pulmonary hypertension and their loved ones through support and information.

## Annual General Meeting

The Board of Directors presented positive results for 2018. The Board plans to continue with the roll-out of its strategic plan, which includes refreshing its website and increasing membership with people living with PH and contributing members, while remaining responsive to the needs of people living with PH and their loved ones.

Stéphanie Théoret is a new member of the Board of Directors who joined at the AGM. She is already involved in a support group and is known for her dynamic approach, energy and desire to help.

## Activities

Once again, brunch-conference sessions were held in various locations across the province to reach people living with PH in their area. Some very interesting sessions took place in Laprairie, Sherbrooke and Québec on various topics: *Making Peace with your Life* with Maïka Roy, *Cardiopulmonary Rehabilitation* with Geneviève Garant and *Research* with Dr. Steeve Provencher.

In late September, all volunteers involved in the Foundation's fundraising activities are invited to attend our *Volunteer Brunch* to honour all these people who give their time and energy to raise funds to help people living with PH. People living with PH are also invited to attend and show their appreciation.

## Conference

The HTAPQ Foundation held its 6th conference on pulmonary hypertension on October 18-20, 2019 in Longueuil, with support from PHA Canada. The conference theme was Ensemble, espérons un avenir meilleur (Working Together for a Better Future). Participants attended a number of speaker sessions and workshops, and connected with people living with PH and caregivers who share a common experience regardless of where they live.

On Saturday, we met with Dr. Steeve Provencher and members of the team of researchers at the Institut universitaire de cardiologie et de pneumologie de Québec (Quebec Heart and Lung Institute).

On Sunday, Dr. David Langleben from the Jewish General Hospital discussed changes in the understanding of risk for patients living with PH. An amazing opportunity to hear from these two specialists!

Several workshops and sessions addressed both people living with PH and their caregivers. Discussion, interesting sessions, new friendships, and great opportunity to connect! Thank you for joining us!

## Thanks

We would like to thank Michaël Robach whom we had the great pleasure of working with. We wish him all the best in the new opportunities that lie ahead.

Contributed by: Dolorès Carrier, President, HTAPQ Foundation



The HTAPQ Foundation Board of Directors: Pierre Lachance, Renée Levaque, Judith Moatti, Pierre Gagnon, Dolorès Carrier, Alain Chabot, and Stéphanie Théoret (missing: Jean-Pierre Vigneault).

# 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.

## Eventually, the Good Days Will Outnumber the Bad Days



Emily Pinckard and her PTSD service dog, Oscar. Photo by Laura Bombier.

I recall lying in a monster-sized bed in the ICU, so awkwardly large that traditional fitted sheets didn't fit. The flat sheet underneath me kept falling down, leaving the skin on my backside exposed to the crunchy maroon mattress. There were two men in brown scrubs on each side of my bed. They rolled my body like a sack of potatoes, up onto my side so my nurse could give me a sponge bath and change my ever-irritating sheets. Tons of tubes came out of my body, but I was only bothered by the choking sensation of the ventilator and OG tube protruding out of my mouth. I didn't have my glasses on, so my sight was limited. But I could hear, smell,

and feel. I could hear the hum of the machines keeping me alive, the beeping of monitors, the sounding of alarms, and the faint sound of classical music on the radio. I could smell the smell of a sterile environment and the nurse's coffee breath as she leaned close to me. My body was freezing cold but my hands felt like they were on fire, having been wrapped in oven mitt-like restraints for eight days, which were meant to keep me from tugging at my ventilator. I list these because all of those smells, sounds, sights, and feelings would later become triggers for my post-traumatic stress disorder (PTSD).

This nightmare began when I was diagnosed with bilateral pulmonary emboli in May 2017. By August, I was diagnosed with chronic thromboembolic pulmonary hypertension (CTEPH), a rare form of pulmonary hypertension (PH) that develops when your body is unable to break down blood clots in the arteries of the lungs. The clots turn to scar tissue, blocking your pulmonary arteries and, as it follows, elevating the pressures in your heart and lungs, thus putting the "PH" in CTEPH. By October, I was in complete heart failure and admitted to the ICU at Toronto General Hospital. A team of Cardiologists, Pulmonologists, Thoracic

Surgeons and Hematologists (words I've capitalized because, having saved my life, they've earned it) worked to keep me alive until my surgeon could return from Japan to perform a Pulmonary Thromboendarterectomy (PEA) to remove the scar tissue from my lungs, lower the pressures in my heart, and as it follows, save my life.

Following an urgent PEA surgery, I spent eight days in a medically induced coma. During that time, I suffered a series of microhemorrhages in my brain, a collapsed lung, and two bouts of pneumonia, further complicating my medical status and delaying my recovery. I was a woman, in the ICU, fearing for my life, and suffering unspeakable hallucinations and deliriums. I met every risk factor for PTSD, so it was no surprise when I was diagnosed with the paralyzing disorder months later.

I continued to have trouble breathing in the months immediately following my PEA. My specialists decided to flesh out the physiological symptoms from the psychiatric symptoms, so they could determine whether my shortness of breath and hyperventilation was caused by residual PH or something psychiatric in nature. As it turned out, it was both. I had both residual PH and PTSD.

I struggled for months with nightmares, night sweats, and panic attacks. I was suicidal, going so far as re-designating beneficiaries for my RRSP. If this was what life as a stroke patient with PTSD and PH looked like, I was having none of it.

My sister accompanied me to my fifth of eleven CT scans. While we sat in the waiting room, a team of nurses and porters wheeled a man in a monster ICU bed down the hall where we were waiting. I could see that the man's flat sheet was falling down, exposing the maroon mattress which must have felt as cold on his back as it did on

mine. I burst into tears. I couldn't breathe. I wanted so badly to run to this man, fix his bed sheet, hug his family, and whisper to him "I know how you feel." I felt the same feelings of sadness and hopelessness that I felt when I was in his position. That is how triggers work—they transport you in time and location to when and where your trauma took place. One glimpse of a porter in brown scrubs, and suddenly I am back in the ICU, it's October 2017, and I am dying, sad, and hopeless.

Every appointment and hospital admission (five) since then have been equally triggering. During a recent hospital admission, I was sick in the middle of the night. A nurse ran to my side and handed me the same type of sterile tin basin used to give sponge baths in the ICU. I immediately burst into tears, which fell from my face into the basin, as I was transported back to my trauma.

Hospitals are a horror house of triggers. Like a Halloween "fun house," with terrifying reminders unexpectedly popping out at you from every angle. In the outside world, triggers are also omnipresent. Subway tiles resemble the tiles on the wall of an operating room. The smell of coffee puts me right back at the mercy of my nurses. Remembrance Day poppies on the lapel of every Canadian take me back to Remembrance Day 2017, when I was wheeled out of the hospital nearly 30 pounds lighter than when I checked in, leaving my independence and identity behind.

My PTSD is manageable thanks to a combination of antidepressant and anti-anxiety medications, peer support, psychiatry, psychotherapy, and my PTSD service dog, Oscar. And while I am still waiting for the day I am cured of my PTSD, at least for now, I am coping. Over time the triggers become less triggering and the horror-house becomes less horrific.

If you have PH, you may be simultaneously struggling with some form of a mental illness such as PTSD, depression, panic disorder, or anxiety. This would be secondary to your illness, like the side effects of your medication—yet another collateral issue for you to cope with. Whether you are a caregiver, physician, or patient, and in case you have not already done so, you should recognize symptoms of mental illness, diagnose them, and treat them. No PH patient can heal, cope, or treat PH without first treating their mental health.

To the patients, know this: though treating a mental illness will not treat your physiological disease, it will help you to derive some amount of hope, happiness, and meaning from your life as a PH patient. You will have good days and bad days. But with treatment, eventually the good days will outnumber the bad days.

Contributed by: Emily Pinckard, CTEPH patient and PHA Canada Board Director, Toronto, ON

# What message would you want to share with someone who has offered you support and care on your PH journey?

Caregivers are at the heart of this special issue of Connections. What better way to recognize the ways in which they positively contribute to the lives of PH patients than to ask PHighters to share messages of gratitude for those who've provided them care and support? We've gone straight to the source and asked patients what message they would like to share with someone special in their life who's offered them support and care on their PH journey. These touching quotes from members of the Canadian PHamily testify to the multifaceted nature of the love, care, and support provided by caregivers.



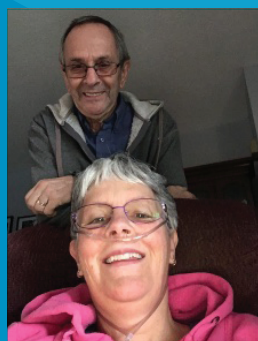
Thanks to Kaylene [my sister] for being so understanding when I need site changes and through tough times. Also, thanks to Mom and Dad for driving me to Edmonton [from West Kelowna] over the last seven years and doing site changes and all that.

—Brendan Ritchie,  
West Kelowna, BC



Thank you to my husband, Charles, for your quiet and loving support over the past two years, through my diagnosis—first lupus, and then PH this spring—treatment. Thanks for your gentle humour that helps me not take myself too seriously.

—Julie Mikuska,  
Winnipeg, MB



I feel very blessed to have such a supportive husband.

—Vanda McLean,  
Orillia, ON



To my spouse, Pascal: The help you gave me throughout the most difficult time of my life has been a blessing. I feel lucky to have you by my side, and I am deeply grateful for it. From the bottom of my heart, thank you for all that you do for me on a daily basis.  
I love you xxx.

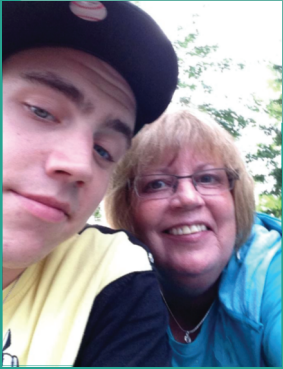
—Stéphanie Théoret,  
Montreal, QC



To my husband, Rod: I wouldn't be where I am today without your love and support. You helped me to never give up the PHight.

—Carol Doyle  
Ploughman,  
Erin, ON





I want to pay tribute to my (then) 12-year-old son, Scotty. Throughout his teen years, he did groceries by bus transportation, cooked, and cleaned the house as best he could. No 12-year-old should have had to do that, but I had no one in my crisis years. He has since accidentally passed away. He was my rock, and it makes me so happy to honour him for all his caregiving.

—Susan Cosenzo,  
Ottawa, ON



I have the best team behind me. My family and friends for the emotional support, and the Peter Lougheed Centre superheroes for my medical support. I told my mom I wasn't sure I'd be this positive in my fight if it wasn't for the amazing support I have.

—Jennifer Howard,  
Calgary, AB



I have a phenomenal caregiver, my husband, James. He comes to every medical and dental appointment and there are many. He does our groceries, usually does our laundry, cleans the house, takes care of yard work, runs many errands, and surprises

me everyday with his care and compassion. He also participates on the committee for a masquerade gala as he knows how much the event means to me. I would wish for everyone to be blessed by someone who loves and cares so much.

—Susan Hambrook Bailey, Ottawa, ON



Thank you to my husband Craig and my parents, Joan and Ian. You are the best support team a PHighter could ever ask for. Thank you for helping me in many ways, such as taking tasks off my plate, listening to me, loving me unconditionally, and just showing up everyday. Thanks also to my rascally black lab pup who literally makes me get out of bed everyday to go outside for some exercise.

—Jane Sernoski, Ottawa, ON



Being my own caregiver works very well for me. I have been living on my own for many years. If I feel that I cannot do something, then I don't do it. Save it for another time. I have no qualms about living alone at this point. Perhaps that will change and I will deal with it at that time. I tend to live one day at a time. I do have friends who would be there for me if I needed them, as has happened on a couple of occasions, such as my recent fractured foot!

—Jeannette Cormier MacKeen,  
Wolfville, NS

# Special Feature: Caregiving

## Family Caregivers: Reach Out for Support Invisible and Invaluable



Close to one in three Canadians is an unpaid family/friend caregiver, which translates into over eight million caregivers across the country. 89% of caregivers provide care to a loved one for over a year, with the average span being six years. For every hour of paid care provided to a loved one, family caregivers put in ten hours of unpaid care, which amounts to up to 80% of care in the home. What more, 60% of family caregivers assume their roles while holding down a job. Despite these statistics, caregivers' compassion and commitment go largely unacknowledged and unsupported.

Why is this? In part, lack of recognition is due to the fact that caregivers don't "self-identify." Family caregivers come into the caregiving role through their relationship with the person they care for, so they define themselves primarily through that relationship—as a daughter, son, spouse, relative, or friend. A recent Ontario report found that only 42% of caregivers self-identified as such, that 35% didn't understand they were caregivers until the role was explained to them, and that 24% still didn't see themselves as caregivers after the role was explained.<sup>1</sup> Some people use different labels—like "care partner" or "care provider"—or they may prefer not to label their care work at all. This might not seem like it should matter, but it does. No matter what caregivers call themselves, they take on a role that is separate and distinct from their primary relationship with the person for whom they provide care. It is an important distinction.

At Family Caregivers of BC, we define a family caregiver as a family member or friend who gives *unpaid* care to an adult, either at home or in a facility, who has a physical or mental health condition, chronic illness, or frailty due to aging. Examples of caregiving include: helping with transportation and errands, attending health care appointments and being an advocate, scheduling and coordinating appointments, assisting with medical treatment and personal care, and providing emotional support. The role of caregiver is emotionally, psychologically, spiritually, physically, and financially taxing, and if someone doesn't recognize they are caregiving, they are not likely to reach out for support. The evidence is very clear: caregivers who identify as caregivers and reach out for support early in their caregiving journey are much more likely to manage their caregiving role without endangering their own health.<sup>2</sup>

While many caregivers feel deeply satisfied with the care and support they provide to others,<sup>3</sup> they struggle to maintain their own well-being in the process.<sup>4</sup> In fact, family caregivers are at greater risk of suffering from chronic illness, isolation, and depression than the general population. There is support available for caregivers, but if they don't understand their role and how support can benefit them, they are going to miss out. In turn, this can lead to caregiver burnout and inability to continue caregiving.

Depending on where you live in Canada, various types of support are available. British Columbia, Alberta, and Nova Scotia have provincial non-profit organizations 100% dedicated to supporting caregivers. Local support organizations are also active in other parts

of the country. A summary of the programs and services available through Family Caregivers of BC is included at the end of this article. One of the most important aspects of support for caregivers is its focus on caregivers.

Caregivers who understand that there are resources available to help them and things they can do for themselves stand a better chance of meeting the needs of their care recipient while safeguarding their own wellbeing. For example, when caregivers call our Caregiver Support Line, we often refer them to our online education module *Staying Healthy While Caregiving* and our two flipbooks, *Information, Tips and Tools for Family Caregivers* and *Building Your Personal Resilience: Strategies for Family Caregivers*. These resources expand upon the following topics:

**Understanding the importance of staying connected:** A primary factor in caregiver resiliency is having strong connections with family and friends who are supportive and caring.

**Practicing self-compassion:** Seeing yourself in a positive light, believing in your abilities and knowing your strengths. This will help you bounce back from stress and challenging situations.

**Finding ways to adapt to change:** Caregivers often reflect on the fact that being a caregiver wasn't in their life plan and has required a significant shift in perspective and expectations. Resilient caregivers often provide the advice: "Accept circumstances that can't be changed. Then turn your attention to those that can be changed and focus on them."

**Trying not to dwell too long on the negatives:** It's important to be mindful of your feelings, especially the painful and negatives ones. It's also important to acknowledge that life is imperfect and to hold space and comfort for yourself in the face of difficult times. However, this requires a fine balance. Research shows the importance of not staying too long with negative thoughts, whether that means focusing on living in the moment or working towards a long-term perspective.

**Creating meaning in your caregiving role:** Finding positive meaning (even if it seems small) in your role adds to positive overall health. Having and holding a sense of purpose in caregiving is also associated with resiliency. For some, it's knowing they are strengthening the relationship between themselves and their care recipient or giving back to a loved one. For others, their caregiving role can fulfill a sense of greater purpose in life by taking pride in their skills and their desire for a better outcome for the person needing care.

**Making a plan for "self-care":** It is common for caregivers to become caught up in the daily grind if they don't recognize the warning signals of burnout, which can include extreme fatigue, isolation, lack of rest, irritability, and frustration over lack of free time. When this occurs, caregivers can get stuck in an unhealthy

cycle of hopelessness and depression without seeing a way forward. At Family Caregivers of BC, we encourage caregivers to make a plan to improve some aspect of their situation. No matter how small the goal, making a plan can help you feel more confident about doing something positive for yourself.

- The research on goal setting suggests listing as many goals as you want. Don't worry if the list is too long or too short, or the goals seem lofty. Just start by writing them down. Then, choose the one that is most important to you, or choose the one that you want to work on first. Self-care is not to be confused with self-improvement; your goal can be anything you want it to be!
- Let's say your goal is to "read for pleasure." Start by listing options for how you can do this, e.g. reading something you otherwise wouldn't make time for (either from your own collection, from the library, or from other sources). Focus on a single step or a short-term action that can be accomplished in a week. Then make a very specific plan, for example:
  - Q: What you are going to do? A: Read a book for pleasure.
  - Q: How much will you do? A: 30 minutes at a time.
  - Q: When you will do it? A: After lunch.
  - Q: How often will you do it? A: Three times a week.
- Research on action planning suggests a key ingredient for success is to ask yourself: "on a scale of zero to ten, with zero being totally unsure and ten being totally certain, how sure am I that I can complete this entire plan?" If you answer seven or more, chances are good that you've set a realistic goal. If the answer is less than seven, go back to your action plan and see if there is anything you can do to make the goal feel more achievable.

Finally, research continues to show that peer support can be one of the most valuable resources for caregivers. There is nothing like connecting with others who have first-hand experience of what you are going through. If you live in a community with a caregiver support group, consider joining. From our experience, support group relationships can become lifetime friendships that remain long after the caregiving journey has ended.

While the specifics of each caregiving journey are unique to the care recipient and the caregiver, there are common themes that connect caregivers. Hopefully, some of this article will resonate with your situation. We encourage you to search for resources that may be available to you in your province/community. If you live in British Columbia, all of our services are free to caregivers across the province and we invite you to take a look at our website for more information: [www.familycaregiversbc.ca](http://www.familycaregiversbc.ca). If you live in Alberta, you can go to: [www.caregiversalberta.ca](http://www.caregiversalberta.ca) and if you live in Nova Scotia, go to [www.caregiversns.org](http://www.caregiversns.org).

### Family Caregivers of BC (FCBC) is ready to help

There are a number of ways FCBC offers support.

#### Caregiver Support Line

Family, partner, and friend caregivers are welcome to call our toll-free Caregiver Support Line, Monday to Friday, from 8:30 am to 4:00 pm, at **1-877-520-3267**. We understand that reaching out for help can be difficult, but we are always grateful when a caregiver takes that step and trusts us enough to call. When a caregiver calls our Caregiver Support Line, we respond by:

- Listening to understand the caregiver's unique situation and to provide emotional support.
- Providing information and referrals. We also encourage caregivers to seek support from their local community services wherever possible.

- Helping to navigate BC's medical and social services systems.
- Providing one-on-one caregiver consultation sessions for complex caregiving situations, a service that includes problem-solving and developing action plans for follow-up.

#### Online Resources

Over the years, we have learned that while caregivers experience unique caregiving situations, there are common concerns. Our website ([www.familycaregiversbc.ca](http://www.familycaregiversbc.ca)) has links to handouts, webinars, and learning modules that explore the common themes of caregiving. A *Top Tips and Tools* link encourages caregivers to explore topics such as caregiver well-being, communication skills, and financial assistance ([www.familycaregiversbc.ca/for-family-caregivers/welcome-to-top-tips-and-tools-caregivers/](http://www.familycaregiversbc.ca/for-family-caregivers/welcome-to-top-tips-and-tools-caregivers/)).

We often refer caregivers to our self-assessment tool ([www.familycaregiversbc.ca/caregiver-self-assessment/](http://www.familycaregiversbc.ca/caregiver-self-assessment/)) and to one of our most popular webinars, *Where to Draw the Line: Boundary Setting for Caregivers*. By exploring their own boundaries, caregivers can be supported to identify their needs and set limits on the care they provide to others so they don't lose themselves in the process.

#### Caregiver Support Groups

Coming together to speak with other caregivers can be helpful and can reduce the feeling of isolation that many caregivers experience. As one facilitator frames it, a caregiver support group "is where a caregiver can come to remember themselves." In this community support space, caregivers have the opportunity to reflect on, and express, their own inner feelings and needs. FCBC works with communities across the province to increase caregiver support through our free caregiver support group facilitator training. Across BC there are close to 50 non-illness-specific caregiver support groups that run on a peer-led model. Formats vary depending on what the groups want.

#### Know That You Are Not Alone

More than anything, FCBC is committed to showing caregivers that they are not alone. To stay informed about new developments in caregiving, sign up for our *Caregiver Connection* newsletter and our monthly eBulletin, *Caregiver News You Need*, at [www.familycaregiversbc.ca/caregiver-connection/](http://www.familycaregiversbc.ca/caregiver-connection/).

Contributed by: Janet McLean, Education and Engagement Lead, Family Caregivers of BC

#### References

1. The Change Foundation. (2018). *Spotlight on Ontario's Caregivers*. [https://www.changefoundation.ca/spotlight-on-caregivers/?utm\\_source=TOM+Fall+2018&utm\\_campaign=TOM%3A+Summer+2018&utm\\_medium=email&utm\\_source=HQC+Subscriptions&utm\\_campaign=9ae2c684e7-EMAIL\\_CAMPAIGN\\_2018\\_11\\_16\\_12\\_25&utm\\_medium=email&utm\\_term=0\\_ebb90af4d2-9ae2c684e7-86745889](https://www.changefoundation.ca/spotlight-on-caregivers/?utm_source=TOM+Fall+2018&utm_campaign=TOM%3A+Summer+2018&utm_medium=email&utm_source=HQC+Subscriptions&utm_campaign=9ae2c684e7-EMAIL_CAMPAIGN_2018_11_16_12_25&utm_medium=email&utm_term=0_ebb90af4d2-9ae2c684e7-86745889)
2. Betini, Raquel. (2017). *Caregivers in Distress: Using InterRAI Assessments to Target and Evaluate Community Based Interventions*. UWSpace. <http://hdl.handle.net/10012/11213>.
3. Sinha, M. (2012). *Spotlight on Canadians: Results from the General Social Survey: Portrait of Caregivers, 2012*. Statistics Canada. <https://www150.statcan.gc.ca/n1/en/pub/89-652-x/89-652-x2013001-eng.pdf?st=zmAbvHvx>.
4. Mackenzie, I. (2015). *Caregivers in Distress: More Respite Needed*. Office of the Seniors Advocate British Columbia. <https://www.seniorsadvocatebc.ca/app/uploads/sites/4/2015/09/CaregiversReport.pdf>.

# At My Best and My Worst:

## Life as a Caregiver



**PHA Canada:** Can you tell me a little about the first time you found out your wife, Alicia, had PH?

**Greg:** To be honest, it was terrifying. In the weeks leading up to getting a diagnosis, she kept passing out and falling over from the tiniest amount of exercise. She generally just struggled to stay conscious. We didn't know what was wrong with her, and, being the stubborn girl I know and love, she refused to go to the hospital. But it got to a point where I decided to call her parents to help.

The whole time, her health was deteriorating and eventually it got so bad we had to call the ambulance. After that, she was in the hospital for over two weeks because they couldn't tell what was wrong with her. There was a moment there when I feared I was going to lose her and it still lingers with me, the fear I mean.

**PHA Canada:** What's been the most challenging thing about caregiving?

**Greg:** My wife is the strongest woman I have ever met, and I would be completely lost without her. So please know that what I'm about to say is honestly irrational, because I know it's not right and that she's sick. But the toughest thing has been not being angry, bitter, or resentful towards her. I know she's sick, but there are times when, just like anyone, I have an "off" day. Trying to stay levelheaded is tough. You can't help but think: "she's home all day, why do I have to go home now and do the dishes?" But then, I remind myself that she can't and that she needs me to be there for her.

Then there are other people who don't understand her condition, and so I get angry at friends around me. They don't understand the extent to which she needs my help and even though I have to bail on things a lot, it's not like I have an option not to. This can drive me a little crazy sometimes and even though I try to make sure it doesn't, it often trickles down into friendships.

Finally, and this is a big one, it's also very frustrating that there isn't anything I can do to help her. I feel weak and hopeless. And I hate that! I wish there was more I could do.

**PHA Canada:** How has your experience as a caregiver changed from diagnosis to now?

**Greg:** In some ways, I've relaxed a bit more. I just kind of do what I have to do now. When she first received the diagnosis, it totally consumed me. I'd sit around and think about it anxiously. I'd drive myself nuts thinking about how our life was changing and the amount of work I was going to have to step up and do. But now I stop sitting around thinking about it, and just get on with it. I think I've gotten a little calmer.



I think what's helped me get there is joining a PH support group in London (ON), which has been just, so incredibly helpful. And I've even attended some workshops for caregivers in my local community, to help with my mental health.

**PHA Canada:** What is one good thing to have come from it?

**Greg:** The fact that we've gotten so much closer, my wife and I. And it's not just because we spend so much more time with each other now than we did before, but because we've seen each other at our worst. When something like this happens and we actually manage to survive and get through it together, it validates the fact that we could get through anything life throws at us. That feels good.

**PHA Canada:** What is some advice you would give others who are new to caregiving?

**Greg:** Oh, that is a difficult one! I guess I would say you have to try and be patient. And also, try to be clear minded at doctor appointments. You can get so worked up by the shape of your partner that you miss things, like important information your medical team will give you that you should actually be writing down so you don't miss anything. Also, don't hesitate to ask questions and push for answers. And finally, find support wherever you can.

Contributed by: Greg Giles, Caregiver, London, ON

# From the Point of View of a Young Caregiver:

## Interview with the Daughter of a PH Patient

**PHA Canada:** Why don't you tell us a little bit about yourself?

**Paisley:** My name is Paisley and I am nine and a half years old. When I'm not at school, I like to play with my sister and go onto my electronics if I'm allowed. My other favorite thing is sleeping in in the mornings; sometimes my mom lets me sleep until noon! But then she'll wake me up.

**PHA Canada:** Do you remember when your mom got sick?

**Paisley:** Well I think I was about three years old when it happened, so I only remember parts of it. I remember that my mom was having a lot of pain before they knew what was wrong. My sister and I were sitting in the front room watching TV one day and we heard crying from the other room. So, we went over and our mom was saying that her back hurt and she didn't really want anyone touching her. Then, the next thing I remember was going to the hospital to visit her. When we walked into her room, I didn't know what was going on. And I didn't understand why there was a tube going inside her. That's when dad and mom both explained to us what was happening and that made me feel better.

**PHA Canada:** How does it affect you knowing your mom has PH?

**Paisley:** Compared to back then, it all feels different. I feel better now that I understand what's going on and I feel good that I can help her with things.

My sister and I get along most of the time as well, so it's good when I'm feeling scared about something, I have someone I can share that with.

**PHA Canada:** What are some ways you help out your mom?

**Paisley:** Well, I do dishes sometimes. I try and make sure to clean my room every day. I help carry things like groceries and

heavy stuff that she can't carry herself. Sometimes I help her do the laundry and hang up some clothes. And I even know how to change the cassettes on her pump, so I could if I needed to. I also make sure she keeps her cassettes close at night in case she needs to change them.

**PHA Canada:** Do your friends at school ask about your mom at all?

**Paisley:** No, I don't really tell them about it because I think it's personal. But at the end of the day at school, we have these pray circles where we get to share intentions. So that is when I like to think about mom and her getting better.

**PHA Canada:** What advice would you give to someone your age who just found out their mom (or dad) has PH?

**Paisley:** I would say that your mom [or dad] might be in pain sometimes when something goes wrong with the pump or the site, and they might get a bit upset. And even though it might be a little scary at first, your mom [or dad] will be okay eventually. And you can help her [or him] with getting things done so she [or he] doesn't have to do everything alone.

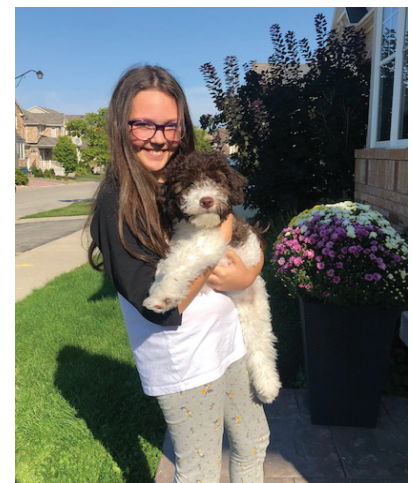
**PHA Canada:** What is something you'd want to tell your mom, that you don't tell her enough?

**Paisley:** That I love her.

Contributed by: Paisley Dempsey, Cambridge, ON



Paisley and her mom Nicole at a Blue Jays game.



Paisley also takes good care of her dog Beans.



When she's not busy with school or caregiving, Paisley likes to do a bit of shopping!

# Finding Your Magic

Do what you can  
When you can  
For whom you can  
And know when you can't.



A prescription for self-care that doesn't come in a pill bottle.

This bit of pithy wisdom rests boldly framed on our bathroom wall. It was written as a prescription by one of my wife's (Robyn) myriad of medical specialists; a not so subtle reminder of the imperative need for self-awareness and self-care. Robyn and I both have great difficulty saying no, often at the expense of our own health. With both of us negotiating longstanding medical minefields, the good doctor simply reminded us that we are unable to help others if we don't look after ourselves first.

Ours is a cute medical tale of love. I offered my assistance after my not-yet wife had severely rolled her ankle. The rest is history. Since then, I've battled my own neurological health demons, with symptoms resembling strokes and intense migraines. I've had the easy end of the stick. My wife's world came crashing down on September 11, 2013. Her hands stopped functioning. She couldn't move her head and she had lost all strength in her limbs.

It was a very dark and very long time until we finally had a diagnosis: mixed connective tissue disease encompassing four auto-immune diseases, including scleroderma. Secondary diagnoses of pulmonary arterial hypertension (PAH) and interstitial lung disease followed. Needless to say, we had our hands full. So, the question is, how do we manage and still maintain a joyful outlook on life?

Perspective is crucial. As a teen, after my first exposure to primary caregiving with a high-maintenance grandparent, it was suggested that I was talented and should pursue caregiving as a career. I responded with the repugnant look that only a teen can muster. Caregiving was a dirty word. The irony is, I have been in the profession of wellness in one form or another for almost 40 years now. I find the term caregiver to be harsh and pedestrian. We are all at some point, either individually or in our community, offering to lift up children, siblings, parents, friends, or strangers. It is the human experience; one of grace and the support of quality of life. I can't imagine a more important role. Dr. Bruce H. Lipton said: "the moment you change your perception is the moment you rewrite the chemistry of your body."

One of the things that became immediately clear in the early stages of my wife's illness was that my wife and I absolutely had to live one day at a time. It took my wife getting sick to truly bring this lesson home. Live for today. One day at a time. Sometimes, it's one hour at a time. We diligently map out our appointments, especially the medical ones and we endeavor to keep our calendars clear. This is a survival tactic. Big hopes and painted dreams, as

fun as they are, fade quickly in the face of a disease flare ups. Our friends and family are aware that if we say yes to going out, it's contingent upon us having the energy, and that we may cancel at the last moment. Keep your "social circle" in the loop, they are part of your team. You are not alone. Build a team. That team should include doctors, specialists, counselors, pharmacists (very helpful), family friends, and even relevant groups on social media to bounce ideas and problems off of. They all sit at the boardroom table looking out for our welfare, not just their patient.

Meditation has been a lifesaver for me on multiple levels. There are so many kinds. I focused on rigorous Japanese Zen, but I recommend very simply to find time to sit quietly, preferably in nature. Watch your breath... gently. Allow your thoughts to come and go like clouds. One of the key things we all forget is the power of release found in a full exhalation: not just breathing out, but letting it all go. Preferably, multiple times a day. I go weeks forgetting this trick, and the tension that is immediately released is huge. It provides a much-needed surge in power as well. Nature has become my respite. I meditate by the ocean and in the trees every night. A highly recommended resource book is simply called *Burnout: The Cost of Caring*, by social psychologist Christine Maslach. Finding opportunities for respite are challenging, and even when they are available, leaving a loved one for even a few days can lead to huge feelings of guilt. However, respite is crucial for one's long-haul stability in caregiving.

Another life saver has been the Spoon Theory. For those unfamiliar with this

theory by Christine Miserandino, we all start our day with a limited number of “spoons” that represent available energy. As a caregiver, it is very easy to deplete these spoons rapidly. Various factors come into play making every day unique: fatigue, weather, family, work, etc. Some days, just getting out of bed and taking a shower can use half your spoons. Work and domestic chores take more. Perhaps you have parenting demands, and suddenly you can have only one or two spoons left for caregiving and nothing left for yourself. So many times, my wife and I arrive at dinnertime devoid of spoons/energy and we end up ordering in. Often, we decline social invitations due to our exhaustion. We learned very early on in the survival process to save a few spoons for enjoying those aspects of life that keep us sane. Spoon Theory is also a handy way to explain to friends and family why you may not be as present as they may like.

I strongly believe that being open to simple, spontaneous, beautiful moments that arise when you least expect them can make this existence worth living, even when faced with the illness of a loved one. Looking for magic keeps us young and graceful in the face of adversity. Robyn and I take turns “Driving Miss Daisy.” Generally, it comes down to whoever is safe to drive, and the experience is one of renewal and rest. We bumble into the countryside with no specific point of destination, and more often than not we are blessed by magic.

On one particular occasion, when I wasn't well, Robyn assumed caregiver/chauffeur duties. As the farmlands slid by, I drifted along with the scenery: beautiful farmhouses and graceful trees. I was never fully present on these adventures, but on this day, I spied a huge red balloon bobbing over a distant field. As we drove past Mitchell's “arm” Market (the F in Farm had fallen off the year before) I pointed and grunted. Robyn translated as only a wife can, and within minutes we were face to face with the world's second

fastest bird, the gyre falcon. The trainer was in the middle of a session using the balloon as a beacon for the falcon, and Robyn was permitted to hold one of the birds. It completely re-energized her and she carried that energy into the following week. Magic. Kismet and amazing, much needed magic.

For any caregiver, finding magic is essential to maintaining one's long-term sanity, and avoiding the dreaded burnout. Watch for Magic. It doesn't need to cost anything; it arises when we least expect it and only requires us to be aware.

Contributed by: Vincent Pollitt, Victoria, BC



Vincent and his wife Robyn.



A magical encounter on one of Vincent and Robyn's country drives.

# The End of the Caregiver Road in Three Affirmations

When someone you love gets diagnosed with an incurable disease, life changes. You find yourself on a road in a strange land, with an undesirable destination, and many obstacles along the way.

When my husband, Harry, was first diagnosed in November 2012 with pulmonary arterial hypertension (PAH), we were actually relieved. He was feeling so awful by then that just learning what we were dealing with made a huge difference. We had a name for the all those symptoms and a highly dedicated team of professionals at the Ottawa Heart Institute PH Clinic to help us navigate the new road that was opening up before us.



The first three to four years were filled with hope and a determination to learn, adapt, adjust, and somehow live life as fully as possible. Harry's mantra was that this disease would not define him, nor dictate the terms on which he lived his life. He believed that we would face this together and stay strong, and that love, hope, faith, and trust would get us through.

Eventually though, in spite of a huge amount of personal courage and

determination, we could see the disease gaining the upper hand. Visits to the clinic increased. Admissions to ER and the Heart Institute increased. The need for transfusions and ways to deal with stubborn fluid retention increased. Some have described this as "suddenly being on a slippery slope" and that is exactly what it felt like.

The term "caregiver" never sat comfortably with me at the time. I was simply a wife who loved her husband deeply and hated seeing him suffer in any way. However, looking back now at our journey together throughout the years he lived with the disease and at my own solitary journey over the last two years since his death, I do see that it was care I was giving in so many ways, especially emotionally.

There were times in those early years that I would have to get away by myself (sometimes while Harry was at work!) to wrap my head around the fact that this man, my "second chance" husband, this huge-hearted man who loved me to the depth of his bones, was not going to be around into our golden years. Anticipatory grief—grieving the future we would not have, knowing I would be heading into my 60s, 70s, and on without him—was almost more than I could bear at times. As hard as it was for me to see him in physical pain or discomfort, it was harder still for him to see me break down. So, I found time away from him to cry, storm, rage, and weep for what we would not have.

Six months before Harry died, my father was admitted to hospital with a sudden, severe case of double pneumonia. He lasted five days in intensive care. It was during those days of saying goodbye to my dad that I learned that there are three things that people need to hear when they can see the end of life coming:

- Promise #1: They are not going to be alone.
- Promise #2: They will not be in pain.
- Promise #3: We (the ones they are leaving behind) will be ok.

It was those conversations that helped me so much when Harry decided it was time to ask the palliative team to step in and help.

There is a certain harsh beauty to the time we spent together in his last year. We knew that we had started on the path to the inevitable a good six months or so before he died. I had already left my job the year before as I could see that our time together was rapidly disappearing. Nothing was as important as being with him to keep him company and to care for him. I would call our time in hospital for various appointments and procedures our "quality time" or "date time." And, over and over again, I found myself promising him and reassuring him that he would not be alone, that he would not be in pain, and that somehow, I would be ok.

People ask me how I coped in his last days, how I was able to stay so calm and peaceful especially on his final day when it was clear he was slipping away. It is hard to explain, but the quality of the air changes when the one you love is dying. Everything unessential falls away and you become hyper-focused on them and what they need. My answer is simple. Those final days of someone's life belong to them. It really is all about them. I had had my days of grief and I knew I would have days, weeks, months, and years to continue to grieve. I could face my last hours and minutes with Harry by focusing on saying to him over and over, you are not alone, we have a whole team here making sure you are not in pain, and yes, maybe not right now, maybe not today, but I will be ok.

The fact is that whether we have a diagnosed disease, a sudden accident, or are blessed enough to die after a full and wonderful life well lived, we are all going to die someday. It is part of life. What I hope for anyone reading this is that you understand the power of those three promises. When you can help someone you love to have a "good death," when



you have done all you can to ensure their final weeks, days and hours are filled with comfort and peace, you are smoothing the way to cope with your own long journey with grief.

Don't get me wrong, the day Harry died was, and remains, the hardest day of my life. But, that day, in those final moments with him, it was not the time for me to be weighing down his final hours with my pain. I sat there next to him for hours with the sunshine flooding in through the window of the hospice and his doctor and the PSW checking in from time to time. It was a time for me to flood him with as much love as I could, with as much peace as I could, and with as much courage as I could. It was a sacred time filled with prayer and light. It was his time, and, in the end, at his end, that was all that mattered.

In my darkest moments of grief since June 27, 2017, when Harry drew his last breath, I draw my courage and determination, my peace and my strength, from the deep well of knowing that I made sure we met the first two of those promises that day and continue to work on number three.

The road we walk on when someone we love dies is never the same. My ways of coping may not be yours. However, sometimes it helps to hear from someone who is further down the road than you are now. If, by reading this, you get a sense of the path you want to take, or you can see how to navigate around some of the painful bumps and obstacles in the path, then I will have fulfilled my purpose in writing this.

I wish none of us had to walk this road but, since we all will at some point, I offer you these words: may your journey be filled with grace, light, and love.

Contributed by: Teri Kingston, PH  
Supporter, Ottawa, ON



Teri and Harry's last holiday was filled with bliss.

# PHA Canada PH Research Scholarships: New 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.

## Géraldine Vitry



Pulmonary Arterial Hypertension Research Group, Centre de recherche de l'Institut universitaire de cardiologie et de pneumologie de Québec, Laval University, Quebec City, QC.

Under the supervision of:  
Dr. Roxane Paulin, Laval University, Department of Medicine, IUCPQ Research Centre

Vitry obtained a degree in Life Sciences in Cellular Biology and Physiology and a master's degree in Therapies and Technologies with a special mention from the University of Paris 13 in France. In this context, she had the opportunity to work on the cystic development of the kidney in Renal Cyst and Diabetes (RCAD) pathology during a two-month internship, then to study telomeres and their potential as a therapeutic target in cancers for seven months. These experiences confirmed her passion for research.

In 2016, she enthusiastically joined the Québec pulmonary hypertension research group, led by Drs. Sébastien Bonnet and Steeve Provencher, to study the molecular and cellular mechanisms involved in the pathogenesis of pulmonary arterial hypertension. She is completing her doctorate at Laval University under the supervision of Dr. Roxane Paulin.

Vitry's Project: Involvement of NUDIX proteins in the pathogenesis of pulmonary arterial hypertension

Pulmonary hypertension is characterized by high blood pressure in the pulmonary arteries due to obstruction of these vessels (imagine closing your fist on an inflated balloon). The heart must then put more effort into moving the blood in the bloodstream and in ensuring the oxygenation of all tissues in the body. Patients with PAH die of heart failure in less than 5 years if left untreated. We must therefore improve our understanding of the disease in order to develop better treatments.

The cells that make up the wall of the small pulmonary arteries of PAH patients, the PAH CMLAPs, survive and proliferate abnormally despite hostile conditions (hypoxia, inflammation, mechanical stress), causing their accumulation and contributing to the progressive obstruction of these vessels. This suggests that they have acquired molecular mechanisms to adapt, strongly reminiscent of the characteristics of cancer cells. The loss of these mechanisms should make these cells vulnerable and lead to their death. We have identified NUDIX proteins as a potential shield for CMLAP-HTAP because they are involved in DNA protection and metabolism optimization (availability and mobilization of energy resources).

Our project aims to highlight the role of NUDIX proteins in the survival of pulmonary artery cells and to evaluate the therapeutic potential of their inhibition by (S)-Crizotinib (already in clinical study in cancer) in different animal models of PAH and cell lines from PAH patients. This study examines a new therapeutic strategy for patients and will improve our understanding of the disease at the cellular and molecular levels.

## Karima Habbout



Pulmonary Arterial Hypertension Research Group, Centre de recherche de l'Institut universitaire de cardiologie et de pneumologie de Québec, Laval University, Quebec City, QC.

Under the supervision of:

Dr. Olivier Boucherat, Researcher and Assistant Professor, Laval University, Department of Medicine, IUCPQ Research Centre

Throughout her university studies, Habbout specialized in the field of human pathophysiology. After a bachelor's degree in general physiology, she oriented her master's degree in this field.

Understanding the mechanisms that cause pathologies in humans has always intrigued her. To be able to understand what is not working and then be able to find a solution is a stimulating challenge in which she wanted to be involved.

To date, she has had the opportunity to learn more about pulmonary arterial hypertension in order to be able to advance research and find treatments that will allow to treat patients. The understanding of this disease and the need to develop new therapeutic strategies are a source of motivation for her.

Habbout's Project: Implications of EZH2 in PAH

Pulmonary arterial hypertension (PAH) is a progressive disease affecting the lungs and hearts of patients and can often lead to heart failure. Inside the arteries of the lungs, vessels undergo a deep remodeling that obstructs the arteries, preventing proper blood flow from the heart to the lungs.

PAH is similar to cancer, in that the cells inside the pulmonary arteries continue to multiply due to a resistance to cell death. This similarity makes it possible to observe that some molecules involved in cancer are also involved in PAH. This is the case of a protein called EZH2, which is involved in cancer and is documented as promoting the multiplication of cancer cells.

We found that EZH2 was more abundant in the pulmonary arteries of PAH patients than in healthy people. In addition, it appears that when EZH2 is inhibited, cells stop multiplying uncontrollably. These preliminary results show that the EZH2 protein is most certainly involved in the development of the disease. Our project here is to understand how EZH2 influences cell multiplication and how it may be possible to develop a treatment on animal models of the disease. The goal of our study is to try to discover treatments that could cure patients with the disease. Indeed, current treatments do not stop or reverse the disease, they only relieve patients. This underlines the need to develop new therapeutic strategies.

FREE for PH patients  
& primary caregivers!

# CONNECTIONS

Subscribe to the Canadian PH Community's Official Magazine!

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

## Subscribe

- **Lifetime subscription** — FREE for PH patients & primary caregivers (limit one per household)
- **1-year subscription (two issues)** — \$25.00
- **2-year subscription (four issues)** — \$40.00

To learn more & subscribe online, visit [www.phacanada.ca/connections](http://www.phacanada.ca/connections).

## 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!

Send your contributions to: [info@phacanada.ca](mailto:info@phacanada.ca)

## 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.

**ALMOST 1 IN 3  
PEOPLE DIE FROM  
CARDIOVASCULAR  
DISEASE** | **OUR  
SCIENTISTS  
WON'T  
ACCEPT THAT**



According to the World Health Organization (WHO), cardiovascular diseases are the number one cause of death throughout the world. That's why we're investigating treatments to manage heart failure, as well as prevent myocardial infarctions and strokes. Which heart patient wouldn't love to benefit from that?

To find out how our innovations are helping to change lives for the better, visit [www.bayer.ca](http://www.bayer.ca)

