PULMONARY HYPERTENSION
ASSOCIATION OF CANADA
2008 - 2018
L'ASSOCIATION D'HYPERTENSION
PULMONAIRE DU CANADA
A UNITED PH COMMUNITY

CONNECTIONS

The Official Magazine of the Canadian PH Community

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Special Issue:

Celebrating 10 years of PHA Canada (Part 1)!

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ACTELION

ACTELION WOULD
LIKE TO CONGRATULATE
PHA CANADA ON THEIR
10TH ANNIVERSARY.

We celebrate your commitment to the PH community.

In this Issue:

Inside PHA Canada

Your Community

Your Stories

10th Anniversary Feature

Medical Minute

Research Corner

Message from the Chair:

Living with PH: The Beauty of Today

The word “anniversary” (or anniversarium in medieval Latin) was first used in the 13th century, derived from annus (year) and vertere (to turn). In essence, it means to turn towards a particular year or date, which we do this year at PHA Canada to commemorate the 10th anniversary of our founding on April 1st, 2008 (our dies natalis, literally meaning “birthday”).

An anniversary—especially for a milestone such as the 10th—is a time to celebrate, but also to reflect on the past and, importantly, to make plans to move forward. Some people may feel quite ambivalent about anniversaries, but we can all feel fondly nostalgic about occasions, events, and people from our past. This can also harbour sadness or regret around choices and events, including the diagnosis of an illness like pulmonary hypertension (PH). Just 10 short years ago, living with PH was much more difficult: diagnosis was more often delayed because of less awareness of PH (both by the public and among healthcare providers), support and education for patients and families was minimal, and there were relatively few treatment options.

You will learn much more about the history of PHA Canada in this issue of *Connections* and throughout the year. Originating from the commitment of seven Founding Members and the hard work of initially only a single staff person, National Manager Angie Knott, we have much to celebrate after 10 years of pursuing our collective vision of a better life for all Canadians affected by PH. We have supported many patients and their families through their individual, often difficult PH journeys. We have educated patients, caregivers, and healthcare providers about PH and its treatment, and have advocated for the optimal treatment of PH patients to many committees at various levels of government. We have also built awareness of PH in the medical community, as well as the public at large. Finally, with a focus on the future of PH care in Canada, we are contributing to the training of excellent young Canadian scientists through PHA Canada’s *Paroian Family and Mohamed Family PH Research Scholarships*. PHA Canada has grown into a small team of highly dedicated and passionate staff and Board members, as well as a network of incredibly energetic and enthusiastic volunteers across Canada. PHA Canada has united this national community of patients, along with their immediate caregivers, extended families and friends, and healthcare providers, including specialized PH nurses and doctors. A diagnosis of PH today can be just as devastating and life changing as it was 10 years ago. However, patients and their caregivers have more support and resources available to them than ever before. They also have access to a network of PH expert centers across Canada, as well as a growing number of effective medical therapies.

I often reflect back on the time when I began medical practice and first started looking after PH patients 22 years ago, and am both heartened and amazed at how far we’ve come and how much more we can offer PH patients and their caregivers today. We can only have great hope and optimism for the future of PH care in Canada, including an earlier diagnosis for each PH patient, the care and support each needs in their own communities, and access to better treatments. I see a time when we can offer each patient a “normal” life such that they will live with PH, but without being affected or limited in everyday life.

For the past year, there has been a flurry of activity at PHA Canada in preparation for special events throughout the year to commemorate our history and our 10th anniversary. During this year, I invite you all to participate, to reflect on the successes of the past 10 years, and to think about what wonderful future advances are yet to come in the field of PH. Most importantly, focus on the present and where we are today in Canada: already able to support, empower, and care for PH patients, offering them longer, more fulfilling lives.

SMehta

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

Message from the Executive Director:

Facing the Future in Unison

It's a special kind of experience to commemorate a milestone anniversary of an organization when you're relatively new to the storyline. You are challenged by your personal distance from the important events and people being recognized, while also being privileged with the opportunity to hear firsthand the memories and reflections of those who have been here since the beginning. You get to take a step back, and appreciate the hard work and tenacity that has gone into building the thing that you get to celebrate, nurture, and steward each day.

When I joined PHA Canada in January 2016, three things impressed me: the dedication of the Board of Directors, the professionalism of the current and former staff, and the connectedness of the PH community (in spite of PH's rareness and Canada's vastness). It was clear that this young association had invested significant time and energy into building meaningful relationships with and between patients, families, and care providers. PHA Canada's origins (see page 20)—as a coming together of different regional groups into one united whole—had created an organizational culture where grassroots connections and actions were valued and encouraged. Staff had developed valuable tools to ensure that passionate volunteers could contribute to providing support and resources to their peers (see page 22). And the Board was working diligently to ensure that our limited resources were being used as strategically as possible.

What a gift I was given to become PHA Canada's first Executive Director on the eve of its 10th anniversary! Looking back on all that has been achieved and the very real progress being made to improve the lives of those affected by pulmonary hypertension, it is easy to feel hopeful and optimistic that our collective efforts are paying off. That is not to say that the future—like our past—will be free of hardship, only that because of the work we are doing together, I am confident we are better equipped than ever to meet the challenges of life with PH (see page 24). For this to occur, PHA Canada must continue to build on the successes of the past, learn from the obstacles we have faced, and find new sources of support in order to ensure we can keep up with the needs of the community.

For many months we've been preparing ourselves for this year's anniversary. We began by talking to the community about what PHA Canada means to you, and continued by working with our Founding Members to identify what makes this 10th anniversary particularly special. In the end, it really wasn't that hard. It seemed clear that after 10 years, one of PHA Canada's greatest achievements is that it has done what it set out to do in 2008: *unite the Canadian PH community*. The Founders understood that this unity was foundational to being able to deliver our mission and ultimately to achieve our vision of a better life for those affected by PH.

It is telling then, that as PHA Canada gets ready to embark on our second decade, we find ourselves in yet another phase of expansion. Our staff is growing, including the additions of Michaël Robach, our now-full-time Communications and Engagement Coordinator, and Vanessa Stevens, who joins us this April as our first-ever full-time Fund Development Coordinator. By expanding the skills and resources of our team, we will be better able to respond to the growing complexity of the PH landscape, and to work on your behalf to ensure earlier diagnosis of patients and more timely, equitable access to care, treatment, and support.

As I write this, we are getting ready to distribute a limited number of anniversary kits to party-planners across the country. We have been overwhelmed by the response to this fun opportunity to join in the celebrations and show your appreciation for PHA Canada. We wish we could have sent kits to all of you! We do invite everyone to join the party online, whether through our social media channels (@phacanada) or on our special edition anniversary website: phacanada10.com. On this website we are also collecting an archive of memories that honour the many people and accomplishments that have brought us to where we are today. Later in the year we look forward to commemorating some of our most important community leaders and their unique contributions to building PHA Canada.

We are especially excited for the chance to mark our anniversary at several special in-person events this year, including our anniversary party at the Vancouver PH Clinic on April 18th, our World PH Day celebrations at the Vancouver Public Library on May 5th, and at this year's regional symposium. This September, PHA Canada will once again take the lead in bringing the PH community together when we host a *National PH Medical Think Tank* (for PH specialists) to coincide with the *Western Regional PH Symposium* in Vancouver, BC (see page 31). Each of these occasions will present a special opportunity to pay tribute to how far we've come, as we set our sites on even bigger goals for the future. But more on that in our next special issue of *Connections*! Stay tuned this fall for part two of our special anniversary feature, as we explore where the next 10 years will take us.

Until then, thank you for making PHA Canada part of your PH journey. Because of your support, today no one in Canada has to face life with PH alone.

JMyrah

Jamie Myrah
Executive Director, PHA Canada

PH Awareness Month:

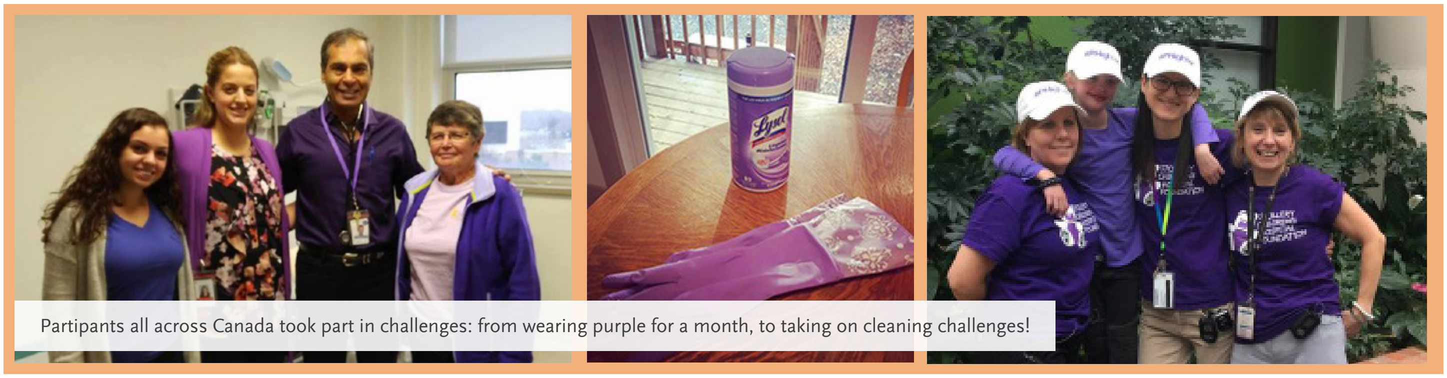
Challenge Accepted!

Every November, PH patients, caregivers, supporters, and health care professionals across the country and around the world take part in awareness-raising activities that put a face to PH, make the signs and symptoms of the disease known, and bring attention to how PH impacts individuals and families.We are continuously amazed by, and grateful for, your dedication to bringing PH to the forefront of the global conversation year-after-year (with some events reaching their 6th year in a row!). Last November, our community put on a PHabulous demonstration of periwinkle power with awareness events and fundraisers organized throughout the country. We thank all the event organizers, volunteers, sponsors, and donors for supporting the cause and for helping us create a better life for all Canadians affected by PH. Here is an overview of PH Awareness Month 2017 events:

Life in Purple Challenge

(November, Canada Wide)

This year, for the first time, we challenged Canadians everywhere to take on the *Life in Purple Challenge* to help raise awareness of what it can mean to “walk in the shoes” of someone affected by PH. Thank you to everyone who took on challenges, and to those who shared their stories with the wider community online! From climbing 40 flights of stairs every day to nurses wearing sub-Q sites in solidarity with their patients, supporters got creative in their quest to better understand the daily impacts of PH on patients and caregivers. The community also rose to the challenge of raising a minimum of $3,000, which was then matched by another $3,000 donation by McKesson Canada. What an amazing display of Periwinkle Power by the Canadian PHamily!



Partipants all across Canada took part in challenges: from wearing purple for a month, to taking on cleaning challenges!

Fifth Annual 6-Minute Walk for Breath

(November 4th, Ottawa, ON)

For the fifth year in a row, PH patients, caregivers, and supporters gathered for PHA Canada’s *6-Minute Walk for Breath* fundraiser at the Ottawa PH Clinic. Participants walked the Heart Institute’s 6-minute walk test route, and those without PH wore masks and carried weights to help better understand how the test feels for people with PH. Big thank you to Board Member and PH Nurse Carolyn Doyle-Cox for organizing this event annually and for inspiring the community in the Ottawa region to raise funds in support of PHA Canada’s programs and services.

Those without PH wore masks and carried weights to help better understand how it feels.

The group at this year's *Annual 6-Minute Walk for Breath* having a great time!

PH Aquathon in Memory of Lynn Hawke

(November 10th, Bradford, ON)

We are so grateful to the Bradford West Gwillimbury (BWG) Leisure Centre for continuing their PHenomenal support of the PH community. Carrying on the torch from Ruth Dolan's *Annual Run/Walk, Swim or Bike/Spin PH Challenge*, this year the team at the BWG Leisure Centre led a new event, hosting 37 swimmers who took up the challenge in honour of their friend and long-time member, Lynn Hawke. Thank you to the organizers, swimmers, and donors for raising over $500 in support of PHA Canada!

The Bradford West Gwillimbury Leisure Centre hosted 37 Aquafit participants and Bradford Mayor Rob Keffer (pictured right)

Sail-o-thon Benefiting PHA Canada (November 4th, Vancouver, BC)

(November 11th, Vancouver, BC)

Our PHriend Mariane Bourcheix-Laporte (PHA Canada's previous Communications & Engagement Manager) marked PH Awareness Month by bringing together her love for sailing with her love of helping the PH community. For the second year in a row, she braved strong winds, big waves, and cold weather for a 40-km sail across Vancouver's English Bay. Thanks to the support of friends, family, and the PH community, Mariane's second Sail-o-Thon raised over $1,500!

It was chilly out on the water for Mariane's Sail-o-Thon!

Sixth Annual Montreal PH Awareness Walk

(November 5th, Montreal, QC)

Year-after-year, members of the Québec PH community come together to participate in a community gathering and fundraiser benefitting the Montreal Jewish Hospital. Thank you to PH Nurses Lyda Lesenko and Jessica Pinto for organizing this event, and for creating such wonderful memories for the community each year.

Members of HTAPQ walking with pride!

Additional Events:

Respiratory Therapy Program of the Winnipeg Health Sciences Centre Bake Sale

(October 23rd, Winnipeg, MB)

What an incredible spread the Respiratory Therapy Program at the Winnipeg Health Sciences Centre put up last fall! Led by the daughter of PH patient Joelle Rancourt, Mélodie Rancourt and her colleagues held a bake sale in support of PHA Canada. The event raised an amazing $500!

Smiles and yummy treats were abound!

10- and 20- Mile March in Honour of Everleigh Pierce

(March 3rd, Mosa Township, ON)

As spring slowly starts to arrive, we are only reminded of the cold winter months looking at pictures of the Royal Scot's *10- and 20-Mile March for PH in Honour of Everleigh Pierce*. The Upper Thames Military Reenactment Society braved the snow to recreate the journey conducted by the Royal Scots and 89th Light Companies in 1814. Now in its fourth consecutive year, we are so impressed by this group and their continued commitment to raising funds in support of the Pierce Family and our cause – thank you!

Members of UTMRS walking for the cause.

Foundation HTAPQ News:

Celebrating 10 years!

Mariane Bourcheix-Laporte representing PHA Canada.

Congratulations to our Québec colleagues at Fondation HTAPQ who celebrated their 10th anniversary on October 22nd of last year. “La Fondation Hypertension Artérielle Pulmonaire Québec” was founded in 2007 in honour of PAH patient Isabelle Cormier, by her family in Plessisville, Québec. Today, it has become a provincial nonprofit organization essential to providing support to Québécois(e) affected by pulmonary arterial hypertension (PAH).

To mark this special occasion, a celebratory brunch was organized in Trois-Rivières (QC). Speakers included Past-President Denis Cormier and current President Hugues Boulanger, both of whom spoke about the organization’s accomplishments and where it is headed in the future. We also got to hear from patients Stéphanie Théoret and Judith Ross, both of whom are patient representatives within the organization and work to improve peer support in the region. PH medical pioneer Dr. David Langleben also spoke and represented medical professionals during the event. PHA Canada’s previous Communications and Engagement Manager, Mariane Bourcheix-Laporte, attended the event to speak on behalf of the wider Canadian PH community and PHA Canada about our hopes for continued collaboration and mutual support. She also spoke about the inspiring journey that has led this unique foundation to where it is today.

Contributed by: Michaël Robach,
Communications and Engagement
Coordinator, PHA Canada

Upcoming events in 2018:

AJAX'S 5TH ANNUAL RUN/WALK FOR PH RESEARCH

JUNE 9TH 2018

Help support the event at www.phacanada.ca/ajaxwalk

Register or Donate at www.phacanada.ca/golPH2018

July 20, 2018

GOLPH for PH

REGISTER NOW!

Eastern Regional Symposium:
A place to learn, connect, and be inspired


Patients & caregivers from the *Tips & Tricks* panel


Drs Hambly & Chandy

Last year we welcomed over 220 members of the pulmonary hypertension (PH) community to our first Eastern Regional Symposium, held in Toronto, Ontario on October 13th-14th. With attendees from across Eastern Canada, we had the pleasure of reuniting with old PHriends, while also meeting many new members of the Canadian PHamily. We kicked things off on Friday night with a casual welcome reception, where a scavenger hunt helped us break the ice and get to know one another better.

Saturday began with an opening plenary on *The History of PH in Canada*, presented by Dr. Sanjay Mehta, from the Southwest Ontario PH Clinic in London, and Dr. Ali Kapasi, from the University of Alberta PH Program in Edmonton. Drs. Mehta and Kapasi explained to us how PH is defined and categorized, the different treatment pathways and options that currently exist for PAH (pulmonary arterial hypertension), and how radically the treatment landscape has changed since the first PH clinic opened in Montreal in 1986. Dr. Mehta, PHA Canada's Board Chair, also shared the original vision of our Founders (see page 18) and the strategic priorities that drive our work today.

For the rest of the morning, participants split up and attended two breakout sessions. The first set of sessions included: *Myth Busters: A Q&A Panel with PH Medical Specialists*, *Managing IV & Subcutaneous Meds*, and an intimate discussion on *Pediatrics* with Janette Reyes, nurse practitioner (NP) at SickKids Hospital, Darcy Farrell, Remodulin Nurse with McKesson's patient support program, and PH-parent Kerry Pierce. The second set of sessions included: *Tips & Tricks: A Q&A Panel with Patients & Caregivers, Mental Wellness: Strategies for Coping with Chronic Illness*, and a special *CTEPH* panel featuring Anastasia Bykova, NP at the Toronto CTEPH Program, and Patrick Himmelheber whose CTEPH was successfully treated with surgery in 2016.

During lunch we were fortunate to hear from two patients, accompanied by members of their medical team. Charlene Smith, co-leader of the Ottawa support group, shared her personal journey with PH, along with her physician (and Chair of PHA Canada's Medical Advisory Committee) Dr. Lisa Mielniczuk. Charlene stressed the significance of the relationships she's built in her support group, while Dr. Mielniczuk highlighted the importance of patients remaining in the lead, as they may not always share the same goals as their physicians. Judith Moatti, from Sainte-Clotilde, Quebec, also presented, along with her PH nurse from the Centre for Pulmonary Vascular Disease in Montreal, Lyda Lesenko. Judith spoke about some of the difficult decisions she's had to make finding the right treatment for her PAH, while Lyda helped us understand some of the medical "numbers" underlying Judith's choices.

In the afternoon, participants broke off again for informal discussion groups led by their peers, before coming back together for the closing plenary session. Moderated by Dr. Mehta, the closing session featured a discussion on *The Future of PH Therapies* with Drs. John Granton (Toronto), Steeve Provencher (Quebec City), and Duncan Stewart (Ottawa). Together, these leaders in PH research in Canada introduced us to both new treatments that utilize the three "classic" treatment pathways for PAH, as well as to potential new target areas for treatment, such as inflammation, cell growth, and gene therapy. **To view videos and slides from both the opening and closing plenary sessions from symposium, please visit www.phacanada.ca/easternsymposium2017.**

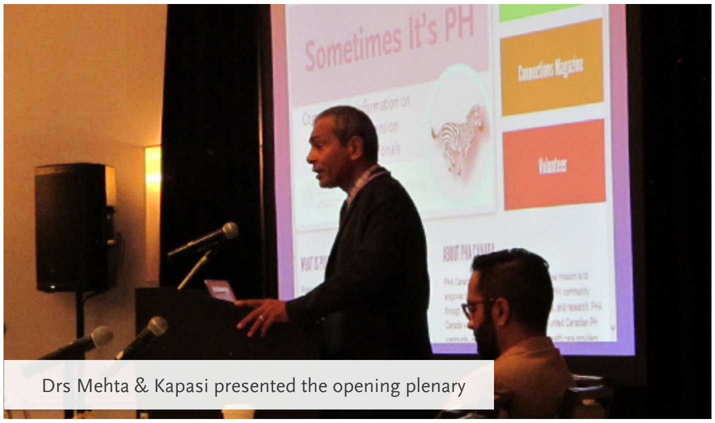
PHA Canada gratefully acknowledges the support and contributions of the many people who made this event possible, especially the participants – who came from as far away at the Ukraine! – and the speakers, for sharing their time and expertise. Thank you to our outstanding volunteer Steering Committee members – Andrea Gardner, RN; Jessica Pinto, RN; Janette Reyes, NP; and Beth Slaunwhite – who helped plan the Symposium, as well as to all our event volunteers who helped make the event run smoothly. Thank you also to Project Sunshine Canada, for ensuring our youngest attendees also had a PHun time at Symposium! And finally, a very special thanks to our sponsors for their PHenomenal support!

Contributed by: Jamie Myrah, Executive Director at PHA Canada

Check out page 31 for information about the 2018 Western Regional Symposium.

Gold-Level Sponsors:


Members of the London Support Group


Drs Mehta & Kapasi presented the opening plenary

Bronze-Level Sponsor:

In-Kind Sponsor:

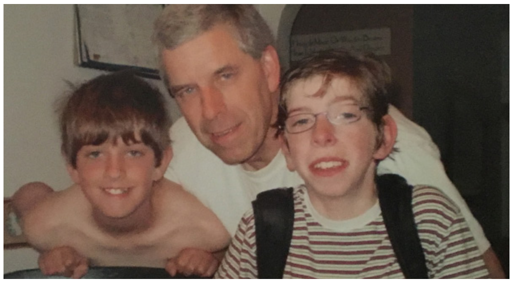
Exceptional PHighters

The Canadian PH community is made up of many exceptional individuals: patients, caregivers, healthcare providers, researchers, and supporters who individually and collectively refuse to give up in the face of the many challenges brought on by this disease. Every individual in the PH community 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.

Quinlan O'Blenis: A PH Community Hero

Tracey O'Blenis lives in Moncton, New Brunswick. Her son, Quinlan O'Blenis, was a PAH patient and a leading advocate within the PH community. In 2013, Quinlan was awarded the "PH Community Hero Award" under the category of "Young Leader" for his ability to inspire others through his own actions, his willingness to share his story, and his work raising awareness of pulmonary hypertension in Canada.


Quinlan with past PHA Canada Chair, Frank Poon, and Founding Member Jennifer Gendron



It is with a very heavy heart that I'm writing this article to tell everyone that our beautiful son, Quinlan O'Blenis, passed away at the age of 22 on May 13, 2017 from pulmonary hypertension.

Quinlan was diagnosed at 2½ years old, which is where our journey began with Dr. Robyn Barst in New York (USA). Quinlan was put on Flolan® at three-years-old and was eventually put on both Tracleer® and sildenafil. While doctors in Canada gave Quinlan one-to-five years to live, Dr. Barst gave us hope for a much longer life. After about six years we started travelling to SickKids Hospital in Toronto (ON) and the IWK in Halifax (NS). By this point, Quinlan was also diagnosed with progressive scoliosis, which was pushing on one side of his lungs and turned quite severe during the last couple of years. We did a transplant assessment at Toronto General where they told us that if he could gain weight he would probably qualify for transplant. Unfortunately, although we tried everything to help him gain weight, he would burn all of the calories just trying to breathe. We also went to visit the Shriners Hospital to see about back surgery, but that too would have probably been too much for his small body. So we kept our faith and tried to be positive that things would somehow work out.

Quinlan was such an amazing person: funny, positive, always worried about his family. We had a talk once and I asked him, "Quin are you afraid of dying?" He said, "No mom I am not afraid of dying: I am afraid for you, if I die." Well, that was Quinlan. He loved to draw and have conversations about life, loved ghost stories as well as animee. He liked his music, his video games, and taking naps. He would say, "Mom: my bed and I are one." He would enjoy spending time with his brothers Devlin, 27, and Sullivan, 18. I never knew for sure what they would be up to. He and his father both had a similar sense of humor; I thought of it as a kind of club for special people because their humor was so unique to them.

I can honestly tell you that this journey was worth every heartbreak and disappointment that happened along the way, because there was so much joy, love, and amazement at what this beautiful man gave us, and I really hope we gave all that back too. I hope he is that star in the sky running free, or that tap on your shoulder you thought you felt, or maybe that feather that fell from the sky saying *Hey! I'm okay*, or maybe that dream you had where you were laughing together at something so dumb that only you two got it. He once said to me "I don't want to die, but if I do, I'll save a place for you, dad, Dev, and Sully."

I don't know why God chose us, but my mom always says, "God doesn't give us more than we can handle Tracey." Well I saw a magnet in a gift shop on one of our hospital visits and it said, "My mom always says God doesn't give us more than we can handle, but I sure wish he didn't have so much confidence in me." I think of that and have probably felt that way many times; but I am so, so grateful that he did. Quinlan passed away in his sleep on a Friday night and while I believe he was ready, we however were not. One thing he said that I will always take comfort from was that he was happy 87% of the time. Not 85, or 90, but 87% of the time. If we could all say that we were happy 87% of the time, then I think we could say we are doing alright.

He will be forever missed and loved by many.

Contributed by: Tracey O'Blenis, caregiver, Moncton, NB

Living Life to the Fullest

Dennis Guiotto lives in Langley, BC with his children and his wife. Although diagnosed with a progressive illness, Dennis has been making the most out of his life through travel and spending time with his family. A dedicated PHA Canada volunteer and community supporter, Dennis offers up a unique perspective on being a man living with PH.

I own a 12-foot-long inflatable zodiac boat. Just a few years ago I'd fold it up, carry it up from my basement, blow it up, and take it fishing. It was really heavy but I was able to do all of that single-handedly. I'd also go dirt biking, camping, and all this other physical stuff. Then, I think it must have been about five years ago, I started noticing how out of shape I was and how heavy my breathing would get. I would tell myself, "Dennis, you're getting old!" I was 44-years-old at the time. My brother and I had a successful, growing plumbing and heating business. We had been running it for 11 years at this point. So I figured maybe I was just getting out of shape sitting at my desk all day. Then this one time, I went up to Whistler (BC) with the family to do the toboggan run. There is a series of about six flights of steps from the parking lot to the base of the hill, and I could honestly barely make it up there. I felt winded, taking breaks at each of the landings. Even then, I blamed it on my brand new oversized Sorrels. That's when my wife turned around and told me I needed to see a doctor, so I finally caved in.

The family doctor ordered a series of tests, but what caught it was the echocardiogram. That's when they saw that something was very wrong. From there, they sent me to a medical clinic where they eventually diagnosed me with PH. It didn't end there though. The doctor from the medical clinic had some CT scans done of my lungs. They found lesions on my liver. A couple of months later, a biopsy confirmed that I also have a rare form of pancreatic and liver cancer (which I would later find out was the same kind Steve Jobs had).

It's hard to find words that describe how tough a diagnosis like that can be on a person. During one of the most difficult periods of my life after the diagnosis, I met an incredible woman named Lynn-Marie Cox. She straightaway welcomed me into the PH family and helped with literally all of my questions. She really went out of her way to make sure I was okay, and spent a lot of time communicating with me. I only knew her from Facebook at first, but a couple of years later, during a visit to Edmonton for a clinical trial at The Cross Cancer Institute, she happened to be at a close-by hospital. At the time, I did not know how ill she was. They had given her three days to live the day I got to her. Only then did I find out she was actually a Board Member of PHA Canada. I had no idea that she was such an important person to the community. You have to be really grateful to people like that who can care so deeply for you in spite of their own struggles.

> "I thought for sure that I would be questioned in Mexico; I mean my two carry-on bags were packed to the brim with drugs and drug paraphernalia!"

I do my best to stay proactive in my own life. My doctor is not very experimental with me because everything is so delicate and complicated (and he's right, you can't exactly argue with a cardiologist). But you know how on holiday the first thing you want to do is drop your bags and run into the ocean? *I want to do that.* Obviously it's not so easy, what with having a central line and all of that. You have to plan for any emergency, have your portable oxygen with you if needed, the pumps, the ice cooler for the Caripul® cartridges, and a suitcase with a week's worth of mixing supplies and accessories. But that hasn't stopped me. I flew to Hawaii for Christmas with my family last year. It was a huge deal for me; I'd had to cancel the trip twice due to sickness. But I eventually made it there! I also took my mother to a resort in Mexico in March: it was our very first vacation together. I thought for sure that I would be questioned in Mexico; I mean my two carry-on bags were packed to the brim with drugs and drug paraphernalia!

Today, I spend as much time as I can with my family. You never know what'll be waiting for you around the corner, so I've learned to make the most of life—and the people around me—while I still can.

Contributed by: Dennis Guiotto, PAH patient, Langley, BC

What Really Matters After All

Andréane Mailloux lives in Sainte-Marthe-sur-le-Lac, Québec. She was diagnosed in 2017 with pulmonary arterial hypertension. Since then, she has dedicated her life to advocating on behalf of PH patients through a number of fundraisers benefiting HTAPQ. She is also speaking out in local media about the importance of early diagnosis and continued efforts to improve patient support in her region.

April 2017: I am lying on my right side. I try and gather my thoughts. My head feels heavy and I can feel my heart pounding. The nurses are working around me. They made me run on a treadmill just a moment ago, and barely two minutes in I felt myself collapsing. It wasn't the first test either; I'd been there for a while. As I try to sit up straight, I can hear them whisper something to one another. Finally, a cardiologist enters the room and briefly explains to me something about "pulmonary arterial hypertension" (PAH). I pretend to know what it means. I grab my coat and prepare to leave the hospital, the same way I have so many times before. That's right. I have been in and out of the hospital since the age of four. In 2000 I was diagnosed with acute respiratory distress syndrome along with a serious flu. I've had relapses ever since.

I don't feel so good. On top of my appointments I work at the CLSC [local community service centre]: it is my world. But all that changed when that cardiologist uttered the words "pulmonary hypertension". After seventeen years of frequent visits to the hospital, I figured this was just another vague diagnosis. Well, not this time. After Googling PH, I freeze with panic. I scroll through lists of symptoms and constraints, one of which is the ability to safely carry out a pregnancy. In the midst of my research, I manage to get in touch with two women living with PH. One of them, Judith Moatti, helps me set up an appointment with PH specialist Dr. David Langleben at the Jewish General Hospital of Montreal. I met with him soon after that. He concluded that the only thing that would help is a lung transplant and carrying around an oxygen tank. It seemed crazy to me.

Here I am now, relaxed in my home. I can no longer work, not even part-time to make ends meet. It's terribly difficult. Luckily my partner is here for me in every way. I also have my family's support. I have five sisters, three nephews, and four nieces (including a god daughter whom I love more than anything). I have always wanted children.

> "Talk about what you are going through, as much with your family as with people who might be living through something similar themselves."

In 2017, my "petite maman" (mother) was diagnosed with stage-4 lung cancer. The news came as a shock. I asked myself the question: why me? Why does she—the woman who's taught me everything, and helped me through my own diagnosis—have to suffer? Why her? Do I have something more to offer this world than she does? Hundreds of questions never answered, still today. It's a tough reality to accept, especially at 22.

Today I am doing my best to get involved with the "Fondation HTAP Québec" (HTAPQ). I am in the middle of organizing my third fundraiser for them. People are so generous. I have a good family and the best of friends. It is what's most important when finding out you're living with a rare disease: surround yourself with good people. Talk about what you are going through, as much with your family as with those who might be living through something similar themselves. HTAPQ and PHA Canada are there to help with that. If they have been so kind with me, surely they will be with you too. And then, all there is left to do, is to remain positive. Do not think about tomorrow, and rather focus on today. Every second counts and every step forward is progress. Yes, we have limitations to accept, or moments when we feel week or ill. Yes, your high school friends are out clubbing or having children of their own. My happiness will not be that. But I am able to find it within my family, and with the man of my dreams who has my back every day of the year. That's what really matters after all.

I'm eternally grateful to my partner for his patience and understanding, as he holds me tight in his arms despite my nasal cannula that makes me feel less pretty. I am also grateful for my family. *Maman*: you are a warrior. *Papa*: you are my hero. My sisters, I love you more than anything. Justin—no, we will not have the life that we had in mind, but I thank you for staying with me through all of this. Roxane, my best friend, who through struggles of her own has always stood by my side: thank you. Adele, my daughter from another mother, who always makes me smile even when I want to cry: thank you. You are my joy. You are my world. That's what really matters after all.

Contributed by: Andréane Mailloux,
PAH patient, Sainte-Marthe-sur-le-Lac, QC

PAH:
People Advocating for Hope

Ottawa advocates James Altimas (left) and Jane Gibson (right) meet with MPP Bob Chiarelli.

Since her diagnosis, Jane Gibson and her family have played an important role in advocating on behalf of the Canadian PH community for access to treatment. Most notably, their meetings with MPPs as part of the *Take Action PAH* campaign helped keep up the pressure during recent pricing negotiations for Uptravi®.

"The ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy." This quote by Martin Luther King Jr. was presented to me by my grade five teacher and has greatly shaped both my life, and how I reacted once I was told I had severe idiopathic pulmonary arterial hypertension.

For the first few months after my diagnosis I was living in shock and tried to find my bearings in living my new 'normal', all the while trying to stay positive. One of the biggest shocks came from learning that it is not recommended for women living with PH to bear children. This really took a toll on my mental health: ever since I can remember I have wanted to be a mother. I think my diagnosis was also difficult on the people around me, to the point that some took it harder than I did. My family and friends just want the best for me in life and it was very tough on them to see me go through the uphill battle of my diagnosis. Looking back, there was one good thing that comes to mind, and that is how quickly it all happened. I know of so many PH/PAH patients that have gone through the agony of waiting years to get their diagnosis. It is so important to get an early diagnosis so that treatments can start right away and the progression of the disease can be slowed down, or halted.

It wasn't until I went to a support group in Ottawa that I found the motivation to start doing something about the fact that I was living with a progressive disease. That motivation came from a man named Harry Kingston. He was an incredible PHighter, mentor, member of our support group, and an all-around amazing person. Through my discussions with him and Carolyn Doyle-Cox (our superhero nurse) it became clear to me that there was a community of people here in Canada working hard to raise awareness of this disease and that because of it, doctors were catching it quicker. It was at that moment that I felt the desire to pay it forward to others, and join the PHight. Harry introduced me to PHA Canada and all of the great work they do in order to support and advocate for the PH community, which really helped me get started. Unfortunately, he is no longer with us, but his spirit lives on in all those who he has moved. Through his actions and commitment to PHA Canada, he has led me to the conclusion that I need to do all I can to make a difference in the lives of those affected by PH/PAH in Canada. In my mind's eye I want to do all I can to improve access to treatment, better the lives of those living with PH/PAH, and perhaps most importantly, to help find a cure.

I have never done any advocacy work before, but I have come to learn it's not that difficult. There are no degrees required and you don't have to do it alone. PHA Canada has a foolproof system in place to support those who wish to approach media and/or politicians, like in their latest campaign *Take Action PAH* (in partnership with Scleroderma Canada). All it took was a Facebook post, and bam! It was enough to spark my family, friends, and myself to write letters to our MPPs, the Minister of Health, and our Premier in Ontario to advocate for accessible and affordable treatments for all. The MPPs were supportive and all those that my family encountered agreed to send letters on our behalf to the Health Minister. And you know what? All that advocacy work paid off, because in February of this year we found out that the Uptravi® pricing negotiations had been successful! Having learned this, I went to a town hall hosted in Ottawa and asked Premier Wynne what her government is planning to do to keep people with rare diseases alive and well. Wynne gave me a rather vague answer about needing a federal partner to help with funding for rare disease treatments. To this day, I am not satisfied with this answer, so I am not stopping there. I plan on asking other political parties about what their plans are to support people with rare diseases.

Even though having a chronic lung disease is not all balloons and elephants, it is a golden opportunity to show the world and myself how I can stand during "times of challenge". I have met some amazing people through advocating for fellow PH/PAH patients and found that advocacy offers us a chance to do something that matters, at a time when we might be searching for meaning in this 'new' life.

Contributed by: Jane Gibson, PAH patient, Ottawa, ON

What Does PHA Canada Mean to You?

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.

In 2018, PHA Canada is celebrating its 10th anniversary. As part of this milestone, we've been asking our community how our organization has impacted their lives. Here's a selection of quotes from members of the Canadian PHamily reflecting on what PHA Canada means to them.

"This widely unknown disease took my mother from me, leaving behind a father and his three children. Many years later, their son found out that he also has it. Today, thanks to PHA Canada and HTAPQ, he lives with the hope that the treatments available to him will allow him to live a full life and see his two sons grow up living normal lives."

—Sylvie Ouimette, Saint-Jean-sur-Richelieu, QC

"I was immediately referred to PHA Canada upon diagnosis and was so grateful for the soft landing. Today, wrapped in the arms of a united PH community, I feel stronger, more empowered, and so well educated on PH. Without PHA Canada so many of us would still be struggling for answers."

—Marion Laird-Roth, Milverton, ON

"What does PHA Canada mean to me? It means friends, family, support, connections, and an amazing community."

—Nicole Dempsey, Cambridge, ON

15 years ago when I was diagnosed I felt so alone. There was nobody to turn to for help or support. The disease was so unknown back then, I would have to explain what I had to most medical staff that I encountered. So happy PHA Canada came along to change all of that!

—Sonya Collins, Paradise, NL

PHA Canada's symposiums helped us meet other PH patients going through similar things as we are presently. This has allowed us to make new contacts and not feel so lonely.

—Rejean and Francine Dupont, Shawinigan, QC

It is the cornerstone for finding connections in my area. I also love the knowledge that you are fighting for me when I don't have the energy to do it myself. Thank you!!

—Grace Wickenheiser, London, ON

PHA Canada to me means community, knowledge, support, and understanding.

—Carolyn O'Connor Mathur, Toronto, ON


Darren Bell, PHA Canada Founding Member

Dear PHriends,

It is with great pride that I welcome you to the first of two special issues of *Connections* this year dedicated to celebrating the 10th anniversary of the Pulmonary Hypertension Association of Canada (PHA Canada). Before gazing ahead to the horizon of pulmonary hypertension in our fall issue, we will first take time to remember and acknowledge the many milestones we have reached over the past 10 years. We have come a long way in bringing together those affected by PH in Canada, thanks to your support and commitment. And it fills my heart with joy to see how together we are empowering Canadians affected by this terrible disease more than ever before.

First, it is important to remember that the history of PH in Canada started much earlier than just 10 years ago with the founding of PHA Canada. The World Health Organization (WHO) first categorized the types of PH in 1973, and most recently again this past February in Nice, France. The first dedicated expert PH clinic to open in Canada wasn't until 1986, in Montreal (QC). While it was groundbreaking for a specialty clinic to offer medical care to those living with PH, the reality for those diagnosed back then was a difficult one. This was of course in large part due to the minimal treatment options that were available, which meant poorer quality of life and shorter life expectancy. However, a significant part of the challenge was also how lonely it was living with such a rare and unknown illness. Finding others going through the same thing could be next to impossible. This was also true for families, including many who lost a loved one to something they never even had a chance to

PHA Canada Anniversary Feature
Part I of II:

Celebrating 10 years of A United PH Community

understand. And so, in the 1990s, patients and their families started reaching out to one another for support, taking the first steps towards creating a "PH community" in Canada.

It is here that the story of PHA Canada begins to take shape. In the years that followed, PH groups emerged in different areas of the country. While initially most were focused on providing peer support to local patients and their families, Ontarian lawyer Leon Paroian created the Pulmonary Hypertension Society of Canada (PHSC) in 1999 with the mandate of funding research in the hope of finding a cure. By 2006, leaders in the PH community had identified the need for a broader national organization, one that would unite the thousands of Canadians affected by PH and work to improve their lives through support, education, advocacy, and awareness, in addition to research. In 2008, the Board of Directors of PHSC resigned, making way for a new Board of elected representatives from across Canada, and the organization was renamed the Pulmonary Hypertension Association of Canada (PHA Canada). PHA Canada's first Board of Directors included: Lynda Beriault (QC), Jennifer Gendron (NB), Elizabeth McCall (BC), Sharon Proudfoot (AB), and myself, Darren Bell (BC). Very soon after, two medical advisors also joined the Board: Dr. Sanjay Mehta, Director of the Southwest Ontario PH Clinic in London, and Carol Storseth, registered nurse at the PH clinic at Vancouver General Hospital. These leaders—representing patients, caregivers, and health care providers—brought Canada's PH community together, uniting us in a common vision of a better life for all Canadians affected by PH.

In the following pages, you will learn more about some of the many accomplishments we have achieved as a PH community over the past 10 years: expanding support and education resources, raising public awareness, educating health care providers and decision makers, funding research scholarships, and more.

I remember writing the opening letter for the first issue of *Connections* back in 2010. In it, I wrote that "the path taken by all those affected by PH has, until now, been an individual stream, flowing on its own. And now, all those streams have merged into one powerful rapidly flowing river; all the parts have joined to make one strong whole". These words resonate with me as much today as they did then. I am pleased to see that our PHamily is more united now than ever before. Our collective ability to provide timely support and credible information to newly diagnosed patients in Canada reminds me of how powerful we are when we work together. It is fitting then, that as we celebrate our many accomplishments, we focus on perhaps the most important one of all: "A United PH Community".

Regards,

Darren Bell
Treasurer, Board of Directors
PHA Canada

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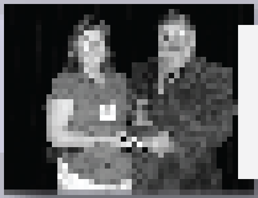
2000 - 2007



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PHA CANADA

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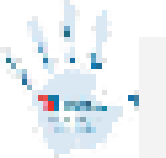

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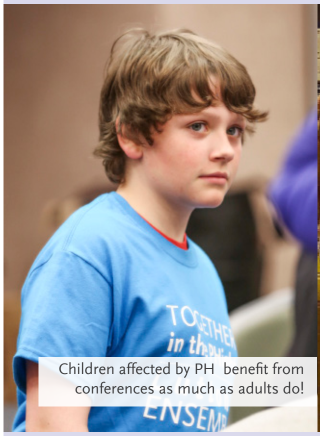
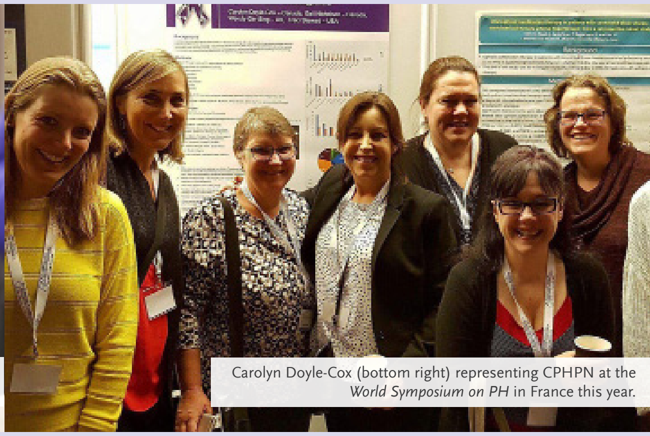
Leading the Way to a Brighter PHuture

PHA Canada is incredibly proud to work with and alongside various community leaders, volunteers, committees, and partners to better serve and empower all Canadians affected by pulmonary hypertension. We are eternally grateful to all those who have helped advance our cause through their tireless commitment to delivering more effective resources, better healthcare, and immediate peer support wherever it is needed. Thank you to the following volunteer groups for being an instrumental part of PHA Canada and for helping us become the organization we are today.


Children affected by PH benefit from conferences as much as adults do!


Carolyn Doyle-Cox (bottom right) representing CPHPN at the *World Symposium on PH* in France this year.

Pediatrics Committee

Authors: Sarah Platnar & Janette Reyes

The Pediatrics Committee was founded in 2012 by three special PH leaders: Dr. Ian Adatia, Pediatric Cardiologist at Stollery Children's Hospital (retired), Janette Reyes, Nurse Practitioner (NP) at SickKids Hospital, and Jennifer Gendron, PH-parent and Founding Member of PHA Canada. Made up primarily of parents of children with PH, along with pediatric medical providers, the Committee was created to provide support and resources for children living with PH and their families. The Pediatrics Committee works to advocate for the needs of the pediatrics community within the larger PHamily, ensuring that this special group of little patients has a voice within all of PHA Canada's programs and initiatives.

> "The Pediatrics Committee [...] is ensuring that this special group of little patients has a voice within all of PHA Canada's programs and initiatives."

Over the years, the Pediatrics Committee has developed valuable resources for families of children living with PH in Canada, starting in 2013 with a *To-Do Checklist* for newly diagnosed families and PH information sheets for schools. In 2015, the Committee developed a more comprehensive *School Resource Package* that includes a series of resources on PAH medications. In 2016, the Committee developed another new resource—*Tips for Staying Active and Preventing Fatigue*—in addition to helping create a custom *New to PH Kit* for pediatric patients. The Committee has also provided important insights into the planning of PHA Canada's conferences and symposia, assisting with program topics, recruiting speakers, and providing kids programming. Most recently, the Committee set out to empower and support young people living with PH in Canada through a video entitled "*PHighters PHeelings: Kids Living with Pulmonary Hypertension*". This project provided young PHighters with the chance to share their personal stories and raise awareness of what life with PH looks like for them.

The Pediatrics Committee is continuously growing and planning new initiatives. In 2018 they look forward to welcoming new members, as well as developing a new resource on nutrition in children with PH. Thank you to all members of the Pediatrics Committee—past and present—for their time and expertise, and especially for giving a voice to Canada's youngest and bravest PHighters.


The first cohor of Ambassadors pictured in 2014.


Volunteers at the 2015 *National PH Conference.*


Dr. Stewart (left)and MAC member Dr. Provencher (right) speaking at the 2017 *Eastern Regional Symposium.*

Ambassadors

Authors: Nicole Dempsey & Ruth Dolan

The Ambassador Program was launched in the fall of 2014 with an initial team of 10 Ambassadors, recruited from across Canada and made up of patients, family members, and care providers. Although the program has evolved and developed through a number of advancing phases, the core mission has remained the same over the past four years: to empower Canadians affected by PH through advocacy, education, and peer support. All of the Ambassadors who have given of their time and expertise—whether for months or for years—have done so in the service of accomplishing this mission. And whilst each of them left their unique mark on our community, all of them have been champions of a better life for Canadians affected by PH.

> "Ambassador are essential to extending PHA Canada's reach across the country and for keeping us connected to the daily issues faced by the PH community. They inspire their peers, supporting them to share their stories and raise their voices. "

Ambassadors are essential to extending PHA Canada's reach across the country and for keeping us connected to the daily issues faced by the PH community. They inspire their peers, supporting them to share their stories and raise their voices. Since 2014, Ambassadors have provided leadership in educating both decision-makers and the public about PH, and have been critical in helping us reach new audiences and grow our presence in the community.

Medical Advisory Committee

Authors: Dr. Sanjay Mehta & Dr. Lisa Mielniczuk

Created to provide medical advice and support to PHA Canada's Board of Directors and staff, the Medical Advisory Committee (MAC) is made up of physicians specialising in the field of PH across Canada. Led initially by Dr. Sanjay Mehta, Director of the Southwest Ontario PH Clinic in London, Dr. Lisa Mielniczuk of the Ottawa PH Clinic stepped in as Committee Chair in 2015.

The MAC provides expert advice and guidance related to the diagnosis and treatment of PH. The MAC also supports PHA Canada in educating health care providers about early diagnosis, raising public awareness of PH, and advocating for the needs of PH patients. Importantly, the MAC also promotes PHA Canada's PH research scholarship program and helps review applications submitted by up-and-coming young Canadian research trainees pursuing PH-related research topics.

Canadian PH Professionals Network

Authors: Carolyn Doyle-Cox, NP & Gail Nicholson, RN

Collaboration between PH nurses in Canada began around 2005, when a group from across the country were able to get together and learn from each other. It was soon realized that a more formal approach should be undertaken to develop advanced practice guidelines, nurture research participation, and support each other. By 2009, the need for meetings of PH registered nurses (RNs) became more necessary; in 2014, the adoption of a formal "Terms of Reference" and vote-in of the first Executive set the course for what would become the Canadian PH Professionals Network (CPHPN).

Today, the Network is made up of dedicated PH medical professionals spread across Canada who work collaboratively to develop comprehensive and detailed expert care protocols/guidelines for the patients they serve. Examples of some of the work to have come from the group's collaboration include: CVC care management guidelines, heart failure management guidelines (including fluid and sodium management), and most recently, a series of oral medication info-sheets, which were made available at the start of 2018.

Looking ahead, CPHPN hopes to move towards participating in work that can be developed and shared internationally in a collaborative effort. Most recently, members of CPHPN helped develop and present an abstract for an international environmental scan of specialized PH programs at the *6th World Symposium on Pulmonary Hypertension* in France, Nice (a collaborative project between Canada, the United Kingdom, and the USA). It is our mission to keep improving and furthering our practice as nurses, using the latest in ongoing research and development.

You can find out more about PHA Canada's committees and volunteer opportunities at www.phacanada.ca.

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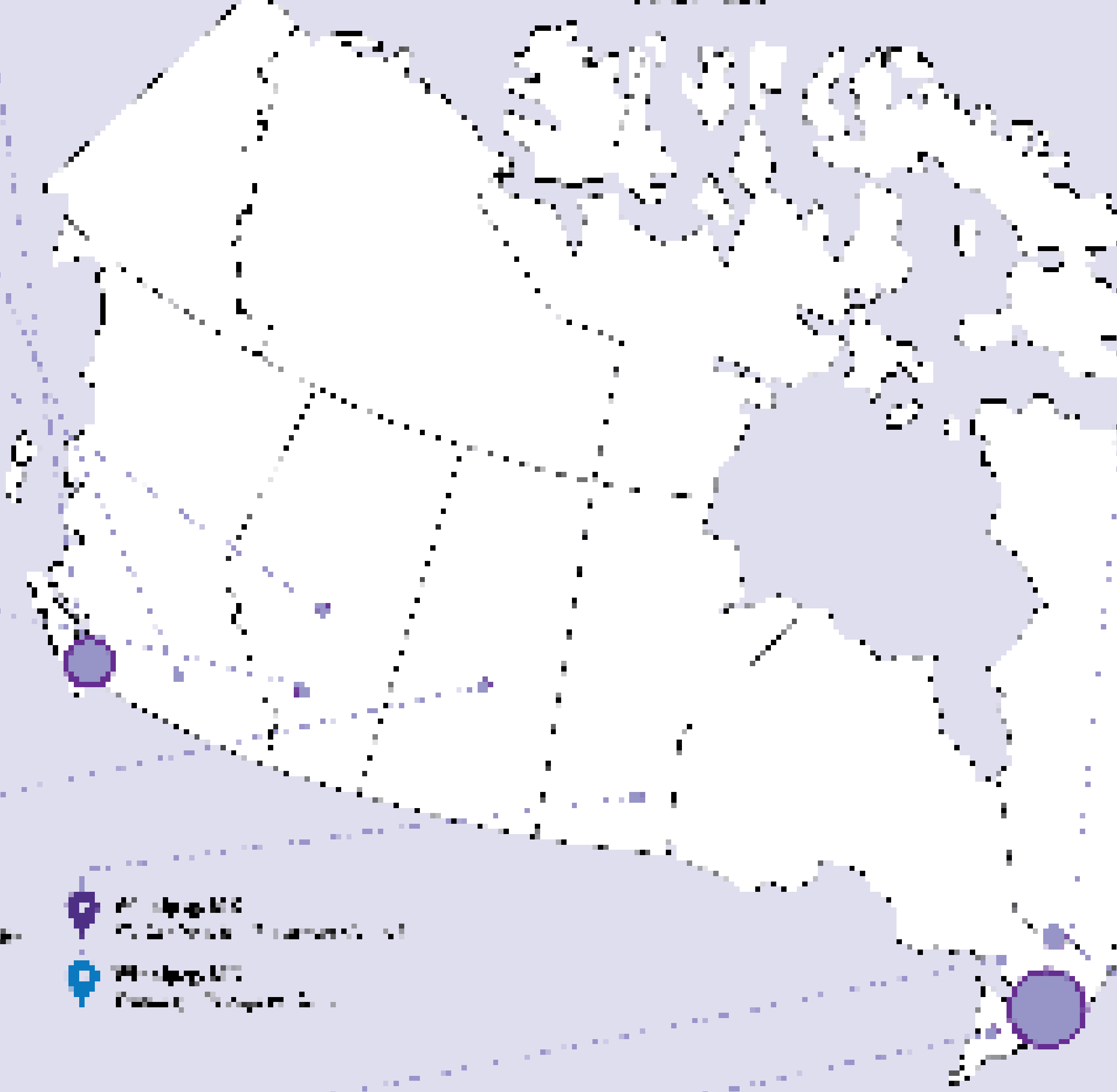

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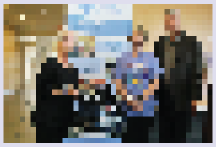

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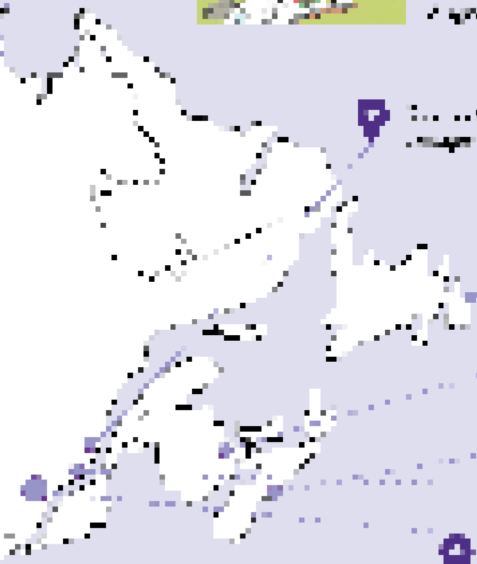

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Jennifer Gendron, PHA Canada Founding Member

Dear PHriends,

It is hard to believe that we are already celebrating 10 years of PHA Canada, and even more so that my family's journey with pulmonary hypertension began almost 15 years ago. It was 2003 when our oldest son Braden was diagnosed with this rare condition. He was only five years old. PH was virtually unheard of at the time, but we certainly learned a lot about it in the subsequent years going through a variety of therapies to try and slow down the progression of the disease. At the time, I was quick to reach out to anyone I could find who knew anything about PH and am very grateful for the many wonderful and caring people I met along the way, many of whom I've had the pleasure of working with as a Founder and Board Member of PHA Canada.

At the time of Braden's diagnosis, oral therapies were relatively new and still quite experimental. We were given a very grim prognosis and told that our son's chances of survival beyond two to three years were minimal. The two choices we were given were to either place Braden directly on to Flolan® via IV therapy, or to attempt to use sildenafil to treat his condition. The latter was very much an experimental drug at the time, but given the

Paving the Way: PH Community Quotes

"Liz (pictured bottom right) had a dream of a national organization and the dream turned into a reality. Liz would be so pleased to see a strong united PHA Canada fighting the good fight to make a difference in the lives of those affected by PH."

—Roberta Massender, Vice-Chair of PHA Canada's Board of Directors and President of the BC Pulmonary Hypertension Society, speaking about PHA Canada & BCPHS Founder Elizabeth McCall

"PH is a complicated disease which is evolving rapidly with new scientific discoveries and treatments. It is very important that Canada's PH expert physicians provide their support and input in order for PHA Canada to stay up-to-date! I am profoundly grateful to all of my colleagues who kindly volunteered their time and commitment to the MAC for the past 10 years."

—Dr. Mehta, London PH Clinic, speaking about the MAC

"I like to refer to this team of highly motivated individuals as my 'work family' because together we can problem-solve and encourage each other despite the vast distances."

—Carolyn Doyle-Cox, Ottawa PH Clinic, speaking about CPHPN

"It is an exciting time in PH medicine, and we are glad to help support PHA Canada in sharing some of that with our community across Canada. It is an honour and a privilege to be part of PHA Canada, and all that has been accomplished by this organization in the past few years."

—Dr. Mielniczuk, Ottawa PH Clinic, speaking as the Chair of the MAC options it seemed like the best route to take. From that point on, we paid close attention to what was happening in the world of PH research and kept up-to-date on any ongoing trials in the field. Although Braden initially responded somewhat well to the sildenafil, he deteriorated quickly, which meant additional therapies. He was placed on Tracleer® next. Again, he saw improvement for a short time before things took another turn for the worse. We eventually had no other choice but to begin IV Flolan® therapy. At the time, he was still only nine years old.

Over the years since this time, it has been incredible seeing the number of therapies that have come onto the market. I think it is safe to say the outlook for newly diagnosed patients continues to improve. We are so grateful for the time we have had with our son, and feel rejoiced knowing other parents will share this relief. And we are only at the start: new treatments continue to emerge, patient care continues to improve, and a diagnosis of PH has a much more promising outlook than it did back in 2003. Our family's journey with PH ended in 2009 when Braden's health deteriorated to the point where he required a double-lung transplant. He is doing incredibly well and will celebrate his ninth "lungiversary" this coming September.

Looking back at our journey offers us so much perspective, and helps us remember to appreciate how far we have come. Knowing first hand how difficult it is to manage IV therapies, I am amazed reading about emerging therapies that offer huge improvements to the quality of life of patients living with PH and their families. This is why organizations like PHA Canada are so important, not only for patient support, but to continue to advocate and raise awareness of PH. In doing so we can continue to push for more treatments, research, and ultimately—one day—a cure.

Regards,

Jennifer Gendron

Jennifer Gendron
Board of Directors
PHA Canada

"Creating Canadian content as a team to outline standard-of-care is the cornerstone for developing tools for best practice and ultimately enhancing the lives of PH patients."

—Gail Nicholson, Calgary PH Clinic, speaking about CPHPN

"We are so incredibly grateful to the members of this Committee for contributing their valuable time in ensuring our objectives are met year-after-year."

—Janette Reyes, SickKids PH Clinic, speaking about the Pediatrics Committee

"I joined because I was interested in doing what I could to help with advocacy, especially surrounding drug access. I also was eager to educate everyone about a disease that is rare and often unheard of."

—Nicole Dempsey, PHA Canada Board Director, speaking about the early days of the Ambassador program

"The first Ambassadors recruited were on a very steep learning curve as each experience was new to us. They were so brave and innovative and generous and willing to share with and learn from each other."

—Ruth Dolan, former PHA Canada Board Director, speaking about the Ambassadors

Meet Your Medical Professional

Dr. Angela Bates, MD, FRCPC

Dr. Angela Bates, MD, FRCPC, is a pediatric pulmonary hypertension specialist in Edmonton (AB). After a long journey through various areas of pediatrics and medicine, she recently joined the team at the Stollery Children's Hospital in the PH Clinic, following Dr. Adatia's retirement in 2017. We recently had the pleasure of interviewing this new figure of the Canadian pediatrics PH world to find out a little bit more about her journey.

PHA Canada: Can you tell me a little about your journey: how did you first decide you wanted a career in medicine and what drew you to specializing in pediatrics?

Dr. Bates: I always knew I enjoyed working with people, and found both biology and physiology fascinating. So during my second year of university, when I realized medicine brought all of these things together, it became pretty clear that's what I wanted to do. I took a somewhat unorthodox journey to arrive at pediatric cardiac critical care and pulmonary hypertension (PH) though.

Initially, I completed my pediatrics residency in Saskatoon through the University of Saskatchewan and was torn between whether I was the right fit for a critical care career, and whether I really enjoyed a resident role. While figuring that out, I finished a pediatric infectious disease (ID) sub-specialty fellowship through the University of Calgary and worked as an ID consultant and pediatric hospitalist in Saskatoon. I love working with children and their families, so pediatrics was a natural fit and I felt drawn back to the pediatric critical care field. It was really during the two years of my pediatric critical care fellowship at the Stollery, when I met Dr. Ian Adatia, that I became particularly interested in the patients he was following both in the community and in the pediatric cardiac ICU.

I then also started to learn about how special these little people were, how important it was to be involved in every aspect of their health and care (which brought me back to general pediatrics), and how challenging their physiology can be to manage. I did one more year at the Children's Hospital of Philadelphia (CHOP) where I spent time in their large pediatric PH program. Since that time, the world of PH has brought me together with amazing patients and families, colleagues around the world, and the fantastic team I get to work with at the Stollery!

PHA Canada: What made you decide to go back to Stollery?

Dr. Bates: Dr. Ian Adatia's passion for this field was infectious! He was patient with all of my questions, always shared so much knowledge when we worked together, and really advocated to build the Stollery PH program from the ground up. It was during these early months that I knew with his support, I would come back to the Stollery as a pediatric PH specialist. I have only grown to love what I do more and more every day since!

PHA Canada: How is it going so far?

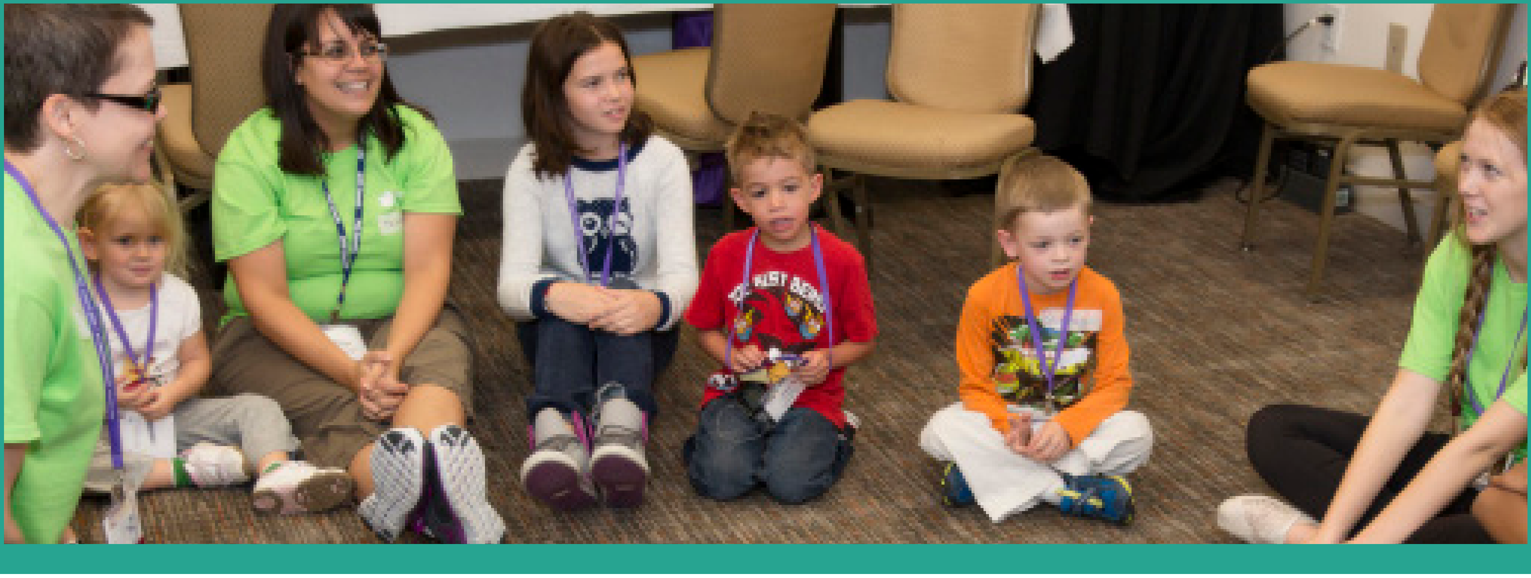
The Stollery covers a very diverse group of patients with PH, including the idiopathic pulmonary arterial hypertension (IPAH) patients, those born with congenital heart disease, and the ever-growing developmental lung disease group. We are involved with all of them and see patients from all over Western Canada.

I am very fortunate to have an amazing nurse practitioner (NP), Susan Richards, as well as an equally fantastic research coordinator, Cathy Sheppard. Both of these women go above-and-beyond for our patients and have strong backgrounds in the pediatrics critical care world. We also have a very engaged multidisciplinary team including our child life specialist, social worker, nurses, physicians, and respiratory therapist colleagues in cardiology, critical care, pulmonology, ENT, and other subspecialties. We also receive a huge amount of support from our Subcutaneous (SC) Remodulin nurse, Karen Janz, which has been truly invaluable when dealing with patients who come from so far away.

All of these factors foster an incredible working environment and allow us to provide amazing care to even the sickest of our patients.

PHA Canada: The Stollery Children's Hospital has a mandate to serve all of Western Canada: how does this impact your work?

Dr. Bates: It's certainly difficult to cover such a large area. I think being flexible in working around other appointments has made the biggest impact. As Sue (our NP) is always thinking ahead, we are often able to batch appointments, procedures, and tests to minimize the impact on our families. Social workers are also very resourceful in helping these families meet the needs of getting to and from appointments. The SC Remodulin program, with the support of United Therapeutics and their Remodulin Nurse, Karen Janz, has also really improved our ability to support families in their communities.



PHA Canada: Are there differences in how PH can affect children and adults, and if so what are some examples?

Dr. Bates: The biggest difference, I think, is that kids really don't look as sick as they are. This makes it challenging when advocating for extra services for them in their communities and at school. In fact, most kids don't complain or accept limitations in what they can do, so judging how limited a little child is by their illness can be tricky. That's why we often lean on the families to help guide us. On top of that, kids are always growing and developing, so fostering this in a child with a chronic illness certainly has its challenges.

PHA Canada: What are some of the main challenges you face working with children?

Dr. Bates: I think the biggest challenge is finding ways to minimize the invasiveness of our testing, exams, and lab work. It is also challenging that children are the last to get approvals and access to treatment.

PHA Canada: And what are some of the rewards and positive aspects of it?

Dr. Bates: All you have to do is come in to the clinic to see the reward: children are amazing, they teach me something every day! We feel incredibly fortunate that we get to work with all our child patients and their families. And although living with a serious illness has its limitations on children, working with groups to make things like holiday-camp and other activities possible, as well as minimizing their time in hospital, has huge impacts on their quality of life.

PHA Canada: Are there any current research programs or clinical trials within the field of pediatric PH that you are watching out for?

Dr. Bates: Approval for oral pulmonary vasodilators in children, especially in those with fewer side effects, is something I am very excited for right now. Also, for our patients, improving our non-invasive testing to minimize cardiac catheterizations is something we need to continue working on.

Another one is the importance of understanding the genetics and phenotypes of pediatric PH through international registries (such as PPHnet). I think the more we're able to delve into this area, the more we will be able to understand the origin of the disease and hopefully focus efforts on early diagnosis, modification of disease progression, and eventual cures. Many of our PH diseases are very different in their aetiology and may have specific interventions or treatments that are more effective in one group of patients over another. We still have so much to learn!

PHA Canada: What is the most important information you would want to share with parents of a child who has been newly diagnosed with PH?

Dr. Bates: You are not alone: we are here for you and your child, and will be there every step of the way. It can be scary and as a parent you might feel helpless, but we are here to advocate, educate, and push the envelope on how we treat PH: we will always work to do better for our patients in the services and treatments we provide.

Research Corner:

How your diet can help control inflammation from PH

In both 2016 and 2017, Sylvia Rinaldi was awarded PHA Canada's *Paroian Family PH Research Scholarship* for her study on the *Nutritional Status of Patients with Pulmonary Hypertension*, under the supervision of Dr. Janet Maditt, PhD RD. Her project is associated with the Southwest Ontario PH Clinic where she is working closely in collaboration with PHA Canada's Board Chair, Dr. Sanjay Mehta, MD, FRCPC, FCCP. She is a Registered Dietitian and PhD candidate in the Department of Health and Rehabilitation Sciences at the University of Western Ontario, with a focus on health and aging. Sylvia earned her Bachelor's in Biochemistry at the University of Windsor and a Bachelor's and Master's in Foods and Nutrition at Brescia University College. This article was co-authored by Jessie Leduc - BSc in Foods and Nutrition at the Brescia University College.

Disclaimer: It is important to talk to your doctor if you are considering supplementation or drastic changes to your diet, as such decisions may increase or decrease the effectiveness of some drugs.

Inflammation is a protective process used by the body to defend against acute injury, irritation, or infection. However, long-term chronic inflammation can be harmful, as the body's immune system will begin to attack healthy cells. Chronic inflammation has been associated with various diseases such as heart disease, diabetes, obesity, and pulmonary hypertension (PH). Medical management may be used to help treat chronic inflammation associated with PH; however, certain environmental or lifestyle factors can both promote or inhibit inflammation.

Factors such as physical activity, smoking, alcohol consumption, as well as diet can all play a role in regulating inflammation. Certain foods can be anti-inflammatory while others can be pro-inflammatory. For example, nutrients such as trans fats and saturated fats, which are often found in commercially prepared baked goods, pre-packaged foods, and animal fats have been associated with increased inflammation. Consuming large amounts of foods that are high in trans and saturated fats may also lead to weight gain, which is a risk factor for further inflammation. So, being mindful of the amount of trans and saturated fat in your diet and maintaining a healthy weight can help you counteract inflammation.

Alternatively, there are plenty of opportunities for your diet to help combat inflammation. Two key nutrients have shown anti-inflammatory effects, including omega-3 fatty acids and antioxidants. There are three types of omega-3 fatty acids: α-linolenic acid (ALA), eicosapentaenoic acid (EPA), and docosahexaenoic acid (DHA). ALA is most commonly found in plant oils such as canola and olive oil, as well as chia seeds, walnuts, and ground flaxseed. EPA and DHA can be found in anchovies, salmon, mackerel, and fish oils. They can also be found in fortified products such as eggs or in supplement form. Omega-3 fatty acids can suppress metabolic pathways that produce inflammatory molecules. These are important in decreasing inflammation because they can help replace other fatty acids in the diet, such as omega-6 fatty acids, which often don't have the same anti-inflammatory effects. It is important to talk to your doctor if you are considering supplementation, as large amounts of omega-3 fatty acids may increase or decrease the effectiveness of some drugs, such as blood-thinning medications, blood sugar lowering medications, and statins.

Antioxidants have also been studied for their anti-inflammatory effects. Vitamin E, Vitamin C, selenium, carotenoids, and polyphenolic compounds all have antioxidant properties that are associated with lowering inflammation. The wonderful thing about these antioxidants is that they can be found in a number of whole foods. For example, food sources of Vitamin E include nuts, green leafy vegetables, and olive oil. Food sources of Vitamin C include citrus fruits, kiwis, and strawberries. Food sources of selenium, carotenoids, and polyphenols can be found in a variety of whole foods such as fruits, vegetables, nuts, and fish. Interestingly, polyphenols in particular target your gut microbiota, or the bacteria in your gastrointestinal tract, to moderate inflammation. Talk to your doctor before considering an antioxidant supplement, as large doses found in supplements may interfere with other treatments you are receiving.

All nutrients have an impact on our immunity and overall health. But, by focusing on consuming a balanced diet made up of colourful fruits and vegetables, whole grains, legumes, fish, and low fat dairy products you will be well on your way to an overall healthy diet, while helping your body to best manage inflammation from PH.

Contributed by: Sylvia Rinaldi and Jessie Leduc, London, ON

PHA Canada's Western Regional PH Symposium

PULMONARY HYPERTENSION
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Vancouver | Sept. 28-29, 2018

● PATIENTS ● CAREGIVERS & FAMILY MEMBERS ● MEDICAL PROFESSIONALS ● PH SUPPORTERS

It's official! Mark your calendars for PHA Canada's *Western Regional PH Symposium*, which will take place September 28-29, 2018 at the Sheraton Vancouver Airport Hotel in Richmond, BC. Find out more by visiting **www.phacanada.ca/westernsymposium2018**.

The event will offer Canadians affected by PH a unique chance to come together, share tips and resources, and empower one another in a safe and interactive space. The Symposium will feature educational sessions presented by medical experts, along with opportunities for peer-led discussion and networking.

- Our Western Regional Symposium will be free for people affected by PH. More information on this event will be announced in the coming months, including further details on scholarships, registration, volunteer opportunities, and program updates. Stay up-to-date by joining the event on Facebook *(www.facebook.com/PHACanada)*.

- Online registration (along with scholarship applications) will open on June 1st, 2018.

- PHA Canada has limited funds to help cover participants' travel and/or accommodation costs. Patients and primary caregivers living in, or west of, Manitoba can apply for travel assistance scholarships (some restrictions apply).

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Deadline for submissions for the next issue: July 15, 2018.
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