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

CONNECTIONS

The Official Magazine of the Canadian PH Community

CONNECTIONS | **Fall 2016** | *Vol. 7, No. 2*

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CONNECTIONS

In This Issue:

Message from the Chair: Treatment of PH—Have We Already Done Enough?

As most of you know, tremendous research over the past thirty years has led to a better understanding of pulmonary hypertension (PH), and more importantly, the development of many new effective medications to treat patients. Indeed, Health Canada has approved ten different PH medications, an astounding number given that the first PH drug, intravenous epoprostenol, only became available in 1997. Although a diagnosis of PH can still be devastating, Canadian PH patients today are living much longer and have better quality of life—fewer symptoms and a greater ability to be active socially and recreationally. This is due to the care of expert PH physicians and nurses in a network of twenty PH Clinics across the country, as well as thanks to government and private insurance funding coverage of many PH medications. Clearly, we have accomplished much in the care of PH patients.

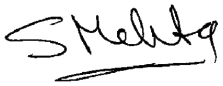
Are we satisfied that we've done enough for PH patients? PH remains a serious, usually progressive and often fatal, lung disease. Only a small number of PH patients can be cured, either through surgery for chronic thromboembolic PH (PH due to multiple or recurrent blood clots in the lungs) or by lung transplantation. However, none of our current medications cures PH, and most PH patients still suffer with their illness, experiencing symptoms and side effects of medications on a daily basis. Based on the recognition that most PH patients remain unwell and can worsen over time despite treatment, the current approach to PH treatment around the world is to be more aggressive. Many patients are now treated initially using two drugs instead of just one, and some patients are being treated with three different PH medications at once. These approaches may provide greater improvements and keep patients well over the long-term.

However, over the past few years we have started to face greater restrictions on the use of medications to treat PH patients in Canada. Regulatory bodies (e.g. CADTH) and provincial Ministries of Health have begun to refuse to provide public funding for some PH medications, especially the newest oral PH drugs, some of which have the strongest evidence for long-term improvement of PH patients. There are several reasons for this lack of funding approval. First, clinical studies do not directly compare the effects of these newest PH medications against those of older approved drugs. Second, newer medications can be more expensive than older ones, especially generic versions. Finally, the Canadian PH community may be a victim of its own success; if PH patients are indeed doing much better with the available older PH medications, governments ask: "Do we really need new ones?"

This is terribly short-sighted thinking. In science and medical research, even after progress in an illness has been made, the search continues for better understanding and new treatment approaches. Intensive research into PH continues, and indeed, has never been as strong as it is today. The goal remains the same: to better understand why patients develop PH and how they can be treated more effectively. We may one day even be able to cure PH or prevent patients from ever developing the disease.

Lack of funding of new PH medications is already limiting the ability of Canadian PH physicians to best treat their patients. There are many new potential PH medications currently being studied worldwide. I am concerned that Canadian PH patients may never have access to these in the future. Restricted funding of new PH medications will almost certainly also lead to decreased investment by pharmaceutical companies in PH research in Canada.

PHA Canada remains committed to the vital work of supporting PH patients and their caregivers and achieving our vision of a better life for all Canadians affected by PH. One of our most important roles is advocating on behalf of PH patients for access to the best care, including funding availability for all effective PH medications. However, we cannot do this alone; many voices are much stronger than just one! The voices of those directly affected by PH, including both PH patients and their caregivers, are the most passionate and the most convincing. We are not happy with the current restrictions in access to new PH medications. If you also feel this way, I invite you to help us fight to make sure that all current and future Canadian PH patients have the opportunity to benefit from the best medications, in order to live the longest, fullest, and healthiest lives they can.



Sanjay Mehta, MD, FRCPC, FCCP

Director, Southwest Ontario PH Clinic, LHSC – Victoria Hospital, London

Message from the Executive Director: Writing the Next Chapter of our Collective Story

While it's only been seven months since I joined PHA Canada, I can honestly say that I already feel quite at home in this amazing community. It's been such a privilege to begin getting to know many of you and I feel incredibly fortunate to get to work with a great team of smart, dedicated, passionate people. There is always a steep learning curve when entering a job like this and I know that my journey in understanding PH and those that it impacts has only just begun. Yet, having spent almost twenty years working to further the best interests of people with serious chronic illnesses, I am also grateful that I am able to bring a perspective to PHA Canada that makes our daily work feel familiar and our ambitious goals feel attainable.

As Dr. Mehta has already outlined, one of our most important goals is advocating on behalf of PH patients for access to better care. You may recall learning in the last issue of *Connections* some of the many ways in which we are working with the PH community to raise awareness of lack of access to optimal treatment in Canada. For instance, we have partnered with the Scleroderma Society of Canada (SSC) on a campaign calling on provincial governments to provide publicly funded access to all Health Canada-approved treatments, including Opsumit® (macitentan). PHA Canada and SSC believe that all patients in Canada—no matter their financial situation, province of residence, or private insurance coverage—should have access to optimal treatment. We invite you to participate in this campaign by visiting **takeactionPAH.ca** and sending a letter to your provincial representatives. Even if you have sent a letter before, sending another—especially when you include details of your own PH story—helps to keep this issue on the radar of decision makers. Additionally, if you or someone you love has been unable to access a treatment recommended by a PH physician due to lack of funding coverage, I encourage you to contact me directly. The more stories we are able to collect and the more voices we are able to raise up, the sooner all patients—now and into the future—will be secure in knowing that they are receiving the best care possible.

Storytelling is central to much of our work here at PHA Canada. Our members use stories to raise awareness and inspire others to give (pages 6-7); our Ambassadors use stories to educate their communities and political representatives about PH (pages 10-11); and the stories of patients and caregivers, whether shared in support groups, online, or here in the pages of *Connections*, are crucial to helping us all navigate our own PH journeys. This issue of *Connections* features a very special focus on transplant stories (pages 12-21). The bravery and hope evident in these accounts are a testament to the courage and strength I see throughout the PH community. Whether it's the struggle of deciding whether transplant is the right thing to do, waiting for the lungs that will be just right, or adjusting to a renewed life without supplemental oxygen or IV meds, but with a new mountain of pills and medical challenges; transplant is an emotional rollercoaster unlike any other. Thank you to Tina Giroux-Proulx, Valérie Plouffe, Jennifer Gendron, Carson King, Jamie Kretzschmar, and Adam Kingz for so generously sharing your transplant stories with us all.

Finally, I want to take this opportunity to thank United Therapeutics Corporation for sponsoring this issue of *Connections*; we are very grateful for the continued commitment of our corporate partners. I also want to draw your attention to something new in this issue. Inserted in your magazine you will find a pre-paid reply envelope asking you to donate to PHA Canada. Due to a lack of government funding programs for rare diseases, patient associations such as ours rely on the support of donors and sponsors to be able to deliver our programs and services. Without this support, we wouldn't be able to provide community events such as the Alberta PH Forum (page 9), seed grants for local support groups (page 29), materials for awareness-raising activities for November Awareness Month (page 29), or scholarships to young researchers (page 28). As we rapidly approach the end of the year, a time when many of us turn our attention to thoughts of giving,I ask you to consider making a financial gift to PHA Canada. Whether you use the enclosed envelope to send us a cheque or choose to donate online (including via a personal fundraising page), every contribution makes a difference. Thank you for continuing to be part PHA Canada's story.

Jamie Myrah

Executive Director, PHA Canada

Summer Events: Bringing Community Together for the Cause

Summer is synonymous with sunshine and well-deserved vacation time, but for some of our members, the last months were filled with a flurry of awareness and fundraising activities! We are happy to share highlights and photographs from these PHantastic events. Thank you to all the event organizers, participants, volunteers, sponsors, and donors for their incredible support.

Your Community

VOLLEYBALL TOURNAMENT IN MEMORY OF BRENDEN BRINKWORTH (June 11th, Long Sault, ON)

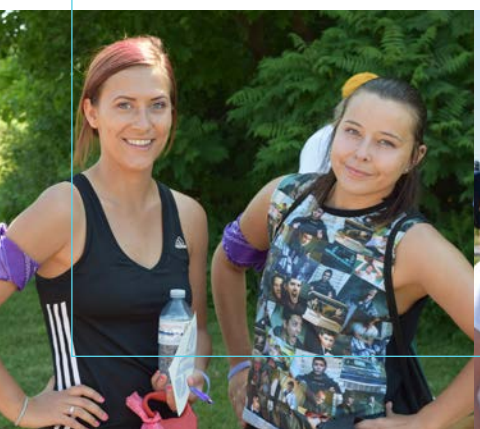
The sky was cloudy on June 11th, but that didn't stop supporters from getting their game on and having some PHun at the Volleyball Tournament in Memory of Brenden Brinkworth. With over $2,000 raised, the tournament was a great success! Thank you to Shawna Brinkworth who organized the event in memory of her brother, Brenden, who was taken away by PH in January of 2015. Shawna has organized multiple fundraisers to benefit PHA Canada and we salute her positive energy and generosity!


Far left: *Event organizer, Shawna Brinkworth, and her little helper, Parker.*

THIRD ANNUAL PHA CANADA WALK/RUN FOR RESEARCH (June 25th, Ajax, ON)

For a third year in a row, the Mohammed Family organized a walk/run fundraiser to raise funds for PHA Canada's research and support programs. This year, over 110 supporters gathered on the shores of Lake Ontario to run/walk for the cause and cheer participants along. Thanks to the efforts of organizers Renae and Joseph Mohammed, the event raised over $11,000, half of which will go towards research. We are thrilled that so many supporters gathered to raise hope for those affected by PH in Canada. Thank you to the Mohammed family for their continued support of our activities and their commitment to supporting PH research.

Center photo: *From left to right: PHA Canada Director, Ruth Dolan, Joseph Mohammed, MP Mark Holland, and Renae Mohammed.*




GOLPH FOR PH (July 15th, Brampton, ON)

For the second year in a row, the Paulin Family organized a golf tournament in support of PHA Canada's programs and services. While green may usually be a golfer's favourite colour, thanks to the efforts of the Paulin Family, periwinkle was top of mind for the 70 event participants at the Lionhead Golf and Country Club in Brampton. With over $20,000 raised, we can say that this year's tournament was definitely a hole in one! We are amazed at the success of this event and grateful for Pat, Joan, and Brooke Paulin for their passion and commitment to helping us achieve a better life for all Canadians affected by PH.

Top right: GolPH for PH organizer, Pat Paulin, with PHA Canada Board Chair, Dr. Sanjay Mehta. ***Bottom row:*** *Photos by Natalie Scuderi*

ASCENSION DU MONT-WASHINGTON (August 13th, Mount Washington, New Hampshire)

PH caregiver Geneviève Marcoux trained all summer to climb Mount Washington, the highest peak in the north-eastern United States. An avid trail runner, Geneviève used this personal challenge as an opportunity to collect donations in support of PHA Canada. Unfortunately, the weather was uncooperative on the big day and she was forced to postpone her climb. Congratulations on your efforts Geneviève, keep reaching for the top!

Far right: *Geneviève Marcoux (right) was ready to climb Mount Washington.* ***Far left:*** *Unfortunately, the weather did not cooperate.*

Left to right: The 14th BCPHS PH Symposium set a record with 140 people in attendance; A panel of Vancouver PH Clinic professionals responded to questions during the "Ask a Medical Professional" forum.

Reflections on Hope 2016: 14th BCPHS PH Symposium

Every two years, the BC Pulmonary Hypertension Society (BCPHS) organizes a Pulmonary Hypertension Symposium that convenes PH patients, caregivers, specialists, and other medical professionals in British Columbia. The PHA Canada affiliate held its 14th PH Symposium February 26 and 27, 2016 on the theme of hope. After being launched with a celebratory meet-and-greet reception, the event unfolded through a day of PH-related presentations. With a roster of guest speakers including PHA Canada staff, Vancouver PH clinic professionals, PH patients, and health care professionals from the Vancouver region, the Symposium provided the attendees with questions answered and new resources to ponder.

Enthusiastic Master of Ceremonies, Betty Ross, a retired Registered Nurse from Kelowna, BC, introduced the Symposium sessions and presenters. After a brief overview of PHA Canada resources and activities by staff members Jamie Myrah and Mariane Bourcheix-Laporte, Dr. John Swiston, Respirologist affiliated with the BC Pulmonary Hypertension program, provided an update on the Vancouver PH Clinic. Attendees then benefitted from an insightful presentation on sodium and fluids management by Vancouver PH Clinic Nurse Practitioner Lisa Lee, and were able to ask questions to a panel of PH health care providers through the "Ask a Medical Professional" forum. Finally, two sessions provided insight into managing life stages with PH. Palliative Care Physician Dr. Shalini Nayar addressed the importance of end-of-life planning and care through a presentation titled "Introduction to Palliative Care in Patients with PH," and CTEPH patient Dianne Curle, accompanied by University of Victoria Self-Management Programs Coordinator Karen Hannah, provided useful tips for PH patients to live a healthy life. Roberta Massender, BCPHS President and PHA Canada Vice-Chair, shares her perspective on the Symposium's highlights.

The mandate of BCPHS is to advocate for those living with PH, to promote public awareness of PH through education, and to provide support to patients and caregivers affected by the disease. Organizing PH symposia allows BCPHS to achieve its mission by bringing together patients, families, friends, and health care professionals in an environment that offers support, knowledge, and hope for the future. These events are important because the PH community loves to have opportunities to get together to share experiences, renew friendships, and welcome new PHriends. A symposium is an occasion to learn about PH, hear about the latest developments in the field, have questions answered, and know that patients and caregivers are not alone.

The most successful aspect of the 2016 Symposium was to see so many people affected by PH together in one room. With 140 people in attendance we set a record! We were delighted to see 54 patients, 34 caregivers, 21 extended family members, and 31 community partners (medical professionals, presenters, and corporate sponsors) all gathered under one roof. These events are always great venues to make connections and BCPHS is pleased to provide community members with opportunities to get together.

Beyond bringing the community together, the Symposium provided attendees with useful information. Dr. Swiston made a very informative presentation on PH, providing information on the disease, current treatments, and updates on the Vancouver PH Clinic. Nurse Practitioner Lisa Lee's presentation on sodium and fluids was full of scary sodium facts. I went grocery shopping ahead of time and Lisa called on PH patients to review the nutrition content of the items I had purchased in an effort to demonstrate that labels must be read carefully, as many items that are packaged as "good choices" are in fact not that good.

Dr. Nayar's introduction to palliative care was a very thoughtful presentation dealing with a difficult topic. Living with a chronic illness is hard enough and the end-of-life discussion may not be easy, but is very important. Dr. Nayar's presentation was well received. She explained what palliative care entails and answered many questions from the audience.

Karen and Dianne presented us with tips to live a healthy life with a chronic condition. Karen provided information on self-management programs and Dianne shared her PH story and how she manages to live well on a daily basis. Dianne has participated in Self-Management BC classes and is now a program leader. She encouraged attendees to take part in the program's classes, either in person or online (for more information, please visit **selfmanagementbc.ca**).

We live in a time of hope and that is what the Symposium's title was meant to reflect. Hope sustains us through times of crisis, hope lifts our spirits, hope is eternal. We hope for a cure. Personally, I am hopeful that all patients in BC and Canada will have access to all available PH treatments no matter where they live, what their financial situation is, and what insurance coverage they have. It is not easy, but I hope PH patients and caregivers will go about living the best they can and enjoy every day.

Contributed by Roberta Massender, BCPHS President and PHA Canada Vice-Chair, Richmond, BC

Mieux Vivre: 5th Québec Conference on Pulmonary Arterial Hypertension

The 5th Québec Conference on pulmonary arterial hypertension, organized by the Fondation hypertension artérielle pulmonaire Québec (Fondation HTAPQ), took place September 23 to 25, 2016 in Quebec City. For its fifth edition, the Conference was held under the theme "better living," inviting patients, caregivers, and supporters to turn to support, resources, and information to achieve a better quality of life. Among the Conference sessions were informative presentations given by PH specialists, workshops for patients and caregivers, and peer discussion forums. Guillaume Ouellet, a Paralympian athlete diagnosed with retinitis pigmentosa, a chronic ocular disease, acted as guest of honor and gave a keynote presentation on resilience through hardship.

In the same spirit, the president of the Fondation HTAPQ, Denis Cormier, put forth an optimistic perspective as he invited members of the Quebec PH community to attend the Conference: "Although pulmonary arterial hypertension affects both patients and caregivers on a daily basis, those affected can take steps to minimize the ongoing impacts of the disease and better meet the challenges they face. It is therefore under the theme 'better living' that the Fondation HTAPQ invites you to its 5th Annual Conference in Quebec City. In addition to hearing the speakers and facilitators share their knowledge and experiences, you will have the opportunity to mingle with people whose situations are similar to yours."

Echoing his words, Fondation HTAPQ members explain why they like to attend conferences:

"I am always excited to attend congresses because there is a great spirit of solidarity and sharing. No one is there to judge and all questions and comments are welcome. We always learn new and interesting things about the disease and research, which gives us a lot of hope." —Francine Fortier, caregiver

"I like our conferences because they give me the chance to meet up with friends in the PH community and meet new patients. The sessions are always interesting and there are new things to be learned, all this with a positive twist." —Rita Hébert, patient

"I like to share with other caregivers on how to proceed to make myself available while still thinking of my needs. I view this weekend as a respite because, given that there will be several professionals present, I am less alert and this allows me to breathe a little." —Yvon Lemay, caregiver

"These meetings give us the opportunity to escape everyday life and glean information during workshops with experts." —Ginette Nadon, patient

Contributed by Mariane Bourcheix-Laporte, PHA Canada Communications Associate, in collaboration with the Fondation HTAPQ

ANNOUNCEMENT: PHA CANADA ALBERTA FORUM AND EASTERN SYMPOSIUM

PHA Canada believes in bringing the PH community together. We are committed to creating opportunities for our members to learn more about PH and to make valuable connections with one another. We also believe that such events should be made available to as many people—in as much of the county—as possible. Accordingly, instead of organizing a national conference in 2017, PHA Canada will begin hosting annual regional events in different parts of the country.

PHA CANADA ALBERTA FORUM (October 1, 2016)

The first PHA Canada Alberta Forum took place Saturday October 1st in Red Deer. Over fifty PH patients, caregivers, and supporters from Alberta attended this free one-day networking and educational event. The Forum's program was put together by a great provincial steering committee consisting of Lynn-Marie Cox, Marcin Gozdzik, Gail Nicholson, Cheryl Salvador, Stephanie Ricci, and Heather Zloty. To learn more about the program and presenters, please visit **phacanada.ca/albertaforum**.

PHA CANADA EASTERN SYMPOSIUM (Fall 2017)

We are happy to announce that the first Eastern Canada Pulmonary Hypertension Symposium will be held in Toronto in Fall of 2017. A Western Canada Symposium will follow in 2018—stay tuned for more details! PHA Canada members will continue to be eligible to receive scholarships to help them attend conferences in their region.

We are very excited to be bringing new events to new parts of the country, in addition to continuing to support the great work of our provincial partners, BCPHS and HTAPQ. We look forward to working with our members and supporters in all provinces to help give shape to these special events!

PHA Canada's first Ambassador cohort. From left to right: Ruth Dolan, Board Liaison, Tarya Laviolette, Kerry Pierce, Stephanie Ricci, Nicole Dempsey, Teri Kingston, Caroline Liu, Gail Nicholson, Sandy Vachon, and Danush Rudolph.

Recognizing PHA Canada's Ambassadors (2014-2016)

In 2014, PHA Canada initiated a new Ambassador Program in an effort to extend the organization's reach across the country and provide leadership to the PH community. We welcomed a group of talented, committed, and passionate individuals to champion awareness and advocacy initiatives, as well as inspire and facilitate collective action in support of a better life for those affected by PH. In October, the term for this inaugural cohort of Ambassadors will come to an end. We wish to take this opportunity to highlight some of their achievements and contributions by sharing a selection of quotes reflecting on their experience. On behalf of the Canadian PH community, thank you to our 2014-2016 Ambassadors! We look forward to working with a new group of Ambassadors beginning later this year.

"Some may call me a PH caregiver because my husband has pulmonary arterial hypertension... I call myself a woman who loves her husband 'in sickness and in health'! It is my mission to help all those who are caring for someone they love. PH affects the whole family, not just the patient."

—Teri Kingston, PH caregiver

"The best part of my experience with the Ambassador Program has been connecting with the other Ambassadors across Canada, learning about their journey, and witnessing how they are helping raise awareness of PH."

—Stephanie Ricci, PH caregiver

"I enjoyed being part of PHA Canada and feeling like I was someone important, providing leadership and a voice for the association. I loved being able to advocate on behalf of myself and other patients across Canada. I felt like I was able to give a voice to the disease and really educate others."

—Nicole Dempsey, PH patient

"I believe that my most significant contribution has been creating awareness of PH in the region where I live, a remote rural area, through newspapers, television, social media, as well as small and large-scale events. I never thought it would be possible and the reactions I received were of pure empathy and interest. It is an amazing feeling to be heard, recognized, and supported. It fills my heart with faith and gratitude."

—Danush Rudolph, PH caregiver

"I have had many accomplishments, big and small, as an Ambassador. ***Some accomplishments were easier to achieve than others, some were more recognized than others, but they were all in the best interest of the PH community and my daughter.*** *I am grateful I was able to play whatever big or small role in possibly making a difference."*

—Kerry Pierce, PH caregiver

"Awareness is key. I have found that, once people become aware of the disease and can put a face to it, they can relate and contribute to the cause. I have encountered this response multiple times, whether I was asking for a donation, requesting that the Calgary Tower be illuminated, or advocating for increased staffing ratios at clinics."

—Gail Nicholson, PH nurse

"Our efforts at Queen's Park in December 2015 are quite memorable for me; it was the first time I did a press conference. ***It allowed us to put the name of this disease out there and to educate MPs and other members of the House about PH.***"

—Nicole Dempsey, PH patient

"I have felt honoured to be able to use this platform to connect with other parents and families and offer my support in whichever way needed. *I think this has been my greatest achievement as an Ambassador. I have come to know some great families with amazing kids who are fighting a battle no one should have to fight. I have taken comfort in knowing that I have been able to share our journey and the things that work for my family. I have also taken many suggestions and advice from all of them and am very grateful for that."*

—Stephanie Ricci, PH caregiver

"The best part of my experience as an Ambassador has been enjoying the richness of relationships formed through the Ottawa Support Group, which I co-chair, and the awareness-raising activities we have championed, including organizing Dine for the Cause fundraising events, getting proclamations from the City of Ottawa, and building connections with the Ontario Lung Association. Together we are stronger."

—Teri Kingston, PH caregiver

"Being able to share my knowledge of PH and connect with others affected by the disease has been a great experience. ***The connections we make are what keeps this small community strong.***"

—Kerry Pierce, PH caregiver

Message from Ruth Dolan, Ambassador Program Board Liaison: Thanking PHA Canada's First Ambassadors

As a PHA Canada Board member, I appreciate and applaud the bravery and generosity of our first PHA Canada Ambassador cohort, a group of dedicated individuals—patients, caregivers, parents, and a PH nurse—who stepped forward and volunteered to give of their time and energy to spread awareness of PH and advocate for the PH community. They accepted the challenge of reaching out to provincial politicians and the media, often for the first time; they participated in awareness events big and small; raised funds to support PHA Canada; and sat on organizational committees. Our Ambassadors have been an important outspoken voice for PHA Canada as an organization and for its members across the country. The work you have done is nothing short of extraordinary!

On behalf of the PHA Canada Board, I extend our sincerest thanks to each of you and I believe that no matter where you are, you will continue to spread the word about PH.

Contributed by: Ruth Dolan, PHA Canada Board Member and PH caregiver, Bradford, ON

Transplant Focus: Life Passed On

Unfortunately, with the exception of some cases of CTEPH, pulmonary hypertension remains a disease with no cure. Yet, for many people living with PH, hope of being "cured" of the disease exists in the idea of lung transplantation, which effectively rids a person's body of PH through the replacement of the affected organs. However, transplant is a treatment option that doctors consider only when a patient reaches advanced stages of the disease and available PH therapies fail to adequately manage their symptoms. As a "last resort" treatment option, lung transplantation can ignite hope, but it can also be a source of anxiety for PH patients and caregivers. A long and challenging journey, this life-changing procedure is one that will be as unique as the individual that embarks on it.

This issue of *Connections* features a special section on lung transplantation. Not every PH patient and caregiver will go through this process, but as a community, it is a topic close to our hearts. Many of our members are in the process of being assessed for transplantation, are waiting to receive new lungs, or have undergone transplant surgery, some in recovery right now. As the closest thing we have to a cure, lung transplant is a cause we can all rally behind, and there is a lot to advocate for.

Statistics from the Canadian Organ Replacement Register (CORR) indicate that at the end of 2014, 300 Canadians were awaiting lung transplant, whereas only 220 transplants were accomplished during that year.[1] This demonstrates the clear need for increased organ donation in Canada. The Canadian Transplant Society and provincial transplant associations are raising awareness of this need through such efforts as the Canadian Transplant Games, National Organ and Tissue Donation Awareness Week, "Transplant Trots," and various provincial awareness campaigns. Thanks to such efforts, along with advances in the field of transplantation, the number of lung transplants in Canada grew 52% between 2005 and 2014.[2] Importantly, CORR also shows that 65.6% of patients who received a first lung transplant from a deceased donor survived at least 5 years.

As you will see in the following stories, the issue of access to lung transplant continues to impact many Canadians. With only a handful of hospitals across the country able to perform lung transplantation surgeries, it is not uncommon for patients to have to relocate in order to be listed for transplant. Patients who do not live in proximity to a lung transplant hospital must move—sometimes relocating to a different province—in order to be within easy reach in the period leading up to and following their surgery. For many, this represents a significant financial burden, which may impact patients' ability to access this type of treatment. In such cases, community support is essential and our members have demonstrated time and again how supportive the Canadian PHamily can be.

The following pages present touching stories of PH patients who have undergone the dramatic process of receiving a new pair of lungs and caregivers who have accompanied loved ones on the rollercoaster ride that transplant represents. Patient stories testify to incredible strength and resilience: Tina Giroux-Proulx recounts her CTEPH journey, explaining how in the span of a few years, she went from seeking an accurate diagnosis to adjusting to life post-transplant; Adam Kingz, who has undergone not one but two double lung transplants, shares how his unique experience has changed his outlook on life; and Jamie Kretzschmar's story provides insight on how the many challenges encountered on a patient's transplant journey can be overcome. Caregiver stories afford us a glimpse of what it is like to stand by a loved one through thick and thin: Valérie Plouffe's story testifies to the challenges her family went through following her spouse's diagnosis; PHA Canada Founding Board Member, Jennifer Gendron, shares her family's journey in an article about her son's double lung transplant; and Carson King's inspiring story demonstrates how essential community support is to ensuring a patient receives the care they need. Finally, thanks to collaboration from Dr. Charles D. Poirier, Medical Director of the Lung Transplant Program at the Université de Montréal and Head of the CHUM Pulmonary Department, these stories will be prefaced by some interesting medical information on how lung transplantation works.

Whether you and your loved ones are at the beginning of your PH journey and contemplating the possibility of one day facing lung transplant, in the process of being assessed for transplant, or waiting for the call that will change your life, we hope that this special transplant section of *Connections* leaves you with a clearer idea of what lung transplantation entails. May we all draw strength from the inspiring accounts of these courageous members of our community.

OVERVIEW OF LUNG TRANSPLANT IN CANADA:

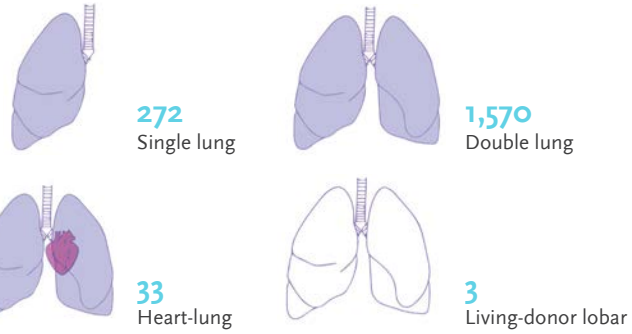
Between 2005 and 2014 PAH patients made up:[3]

4.4% of **double lung** transplant recipients

1.1% of **single lung** transplant recipients

17.6% of **heart-lung** transplant recipients

Number of lung transplants in Canada between 2005 and 2014: [4]



272 Single lung

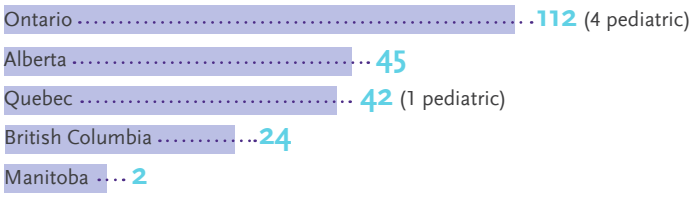
1,570 Double lung

33 Heart-lung

3 Living-donor lobar

1,878 Total

2014 Lung transplants accomplished by province: [5]



Contributed by: Mariane Bourcheix-Laporte, PHA Canada Communications Associate

REFERENCES

1–4 Source: Canadian Organ Replacement Register
5 Source: Canadian Institute for Health Information (CIHI)

Insight on Lung Transplantation

In people with pulmonary hypertension, lung transplantation may be an option if medical therapy is not enough to control the illness and the heart begins to weaken. At that point, transplant may present the sole option for relieving pressure in the pulmonary arteries through a change of lungs.

There are three types of lung transplantation: the replacement of one lung (single or unilateral lung), replacement of both lungs (double lung or bilateral), or the replacement of the lungs and heart (heart-lung). A heart-lung transplantation is considered when, at the time of evaluation, the patient's heart is too weak to undergo double lung transplant. This may be the case in people with pulmonary hypertension because the disease can lead to heart failure. The heart must therefore also be replaced at the time of the transplant or else the patient is at high risk of cardiac complications (including death) during the postoperative period.

PATIENT ASSESSMENT

There are important criteria to be met for all patients requiring a lung transplant, and unfortunately not all patients with pulmonary hypertension will be eligible. These criteria exist to maximize chance of a successful transplant; all patients must meet them in order to be eligible. Indeed, after the operation, patients who are able to lead a relatively active lifestyle are more likely to survive, and this requires some strength and endurance capabilities. To qualify, a patient must first be sick enough to be considered, but also well enough to undergo a transplant. In addition, they must meet the following criteria: be less than 65 years of age for lung transplantation and less than 55 years of age for heart-lung transplantation; survival is estimated at less than two years without transplantation; deterioration in the quality of life; and increased incidence of disease complications.

To determine whether a patient is eligible for transplantation, the lung transplant team will conduct a comprehensive examination of the patient as well as interviews. The process to register a patient on the waiting list takes several months: one to two months of waiting are needed before the transplant team meets with the patient; full assessment lasts between seven and ten days, during which examinations and consultations are carried out; and finally, a period of four to six weeks is needed for the transplant team to make a decision whether or not to list the patient. Patient evaluation includes tests in areas such as hematology, biochemistry, respiratory physiology, radiology, and cardiology, as well as consultations with a pulmonologist, cardiologist, thoracic surgeon, social worker, nutritionist and physiotherapist.

REGISTRATION AND WAITING

When a patient is placed on the waiting list, they are followed every three or four months by the transplant team to assess whether they are still a good candidate for transplant. In preparation for a transplant, the patient should follow the recommendations of the transplant team in order to maintain an overall stable condition, similar to the one at the time of their evaluation. The patient must follow a physiotherapy program to maintain their physical condition and adapt their diet to ensure their weight is constant. In some cases, tube feeding will be used to provide the patient with necessary dietary supplements.

Once the patient is registered on the waiting list, the standard wait time to undergo a transplant is between twelve and sixteen months, or can be between one day to three months for the emergency transplant list. It all depends on the patient's blood type, height, weight, and compatibility between the donor and the recipient. Moreover, since the lungs of potential donors are very sensitive, they can deteriorate rapidly and it is estimated that only twenty to twenty-five percent of donated lungs can be used for transplantation. Compatibility between a donor and a recipient is assessed with blood samples; there is always recipient blood on reserve and the donor's blood is sampled to assess the compatibility of their respective antibodies.

TRANSPLANTATION

The surgical procedure varies depending on the type of transplantation being done (unilateral, bilateral, or heart-lung). In the case of the transplantation of a single lung (unilateral), an incision will be made along the side of the chest, next to the lung to be replaced. For the double lung transplant (bilateral), a horizontal incision under the chest will be made. The incision will be vertical in the case of a heart-lung transplant. After opening the chest cavity, the surgical team proceeds with the organ replacement, removing the lung(s) or the heart-lungs and sewing the new organ(s) in place. In the case of a bilateral lung transplant or heart-lung transplant, and if necessary during a unilateral transplantation, the patient can be put on a heart-lung machine that circulates and oxygenates the blood during the operation. Chest tubes are inserted to drain the excess blood and air, and the rib cage is closed with sutures. The surgery can take between three and eight hours, depending on the type of transplant and other related factors.

After the surgery, the patient is immediately transferred to intensive care for a few days and later stays in the transplant unit for two to three weeks depending on their recovery. The risks related to lung transplantation include death and major complications; the mortality rate after the operation is one to two percent and the rate for major post-operative complications is eight to twelve percent. There are many complications a patient may face, including within the the neurological, cardiac, renal, and intestinal systems. Rejection is relatively rare in the days following the operation and can be effectively treated with anti-rejection drugs. After receiving a transplant, a patient is monitored regularly and must undergo many tests, including chest X-rays, blood tests, pulmonary function tests, and bronchoscopies with pulmonary biopsies in order to exclude organ rejection.

Resuming to a normal life after surgery varies from patient to patient. The process can take between two to six months, depending on the patient's fitness level before transplantation, post-operative complications, and their ability to do enough physical therapy to get back in shape quickly. In addition to taking anti-rejection drugs, patients should remain vigilant about protecting themselves against infections, in addition to maintaining a healthy diet and good dental hygiene. For women, pregnancy is strongly discouraged due to the medications taken. Exposure to the sun and travel are possible if certain precautions are taken.

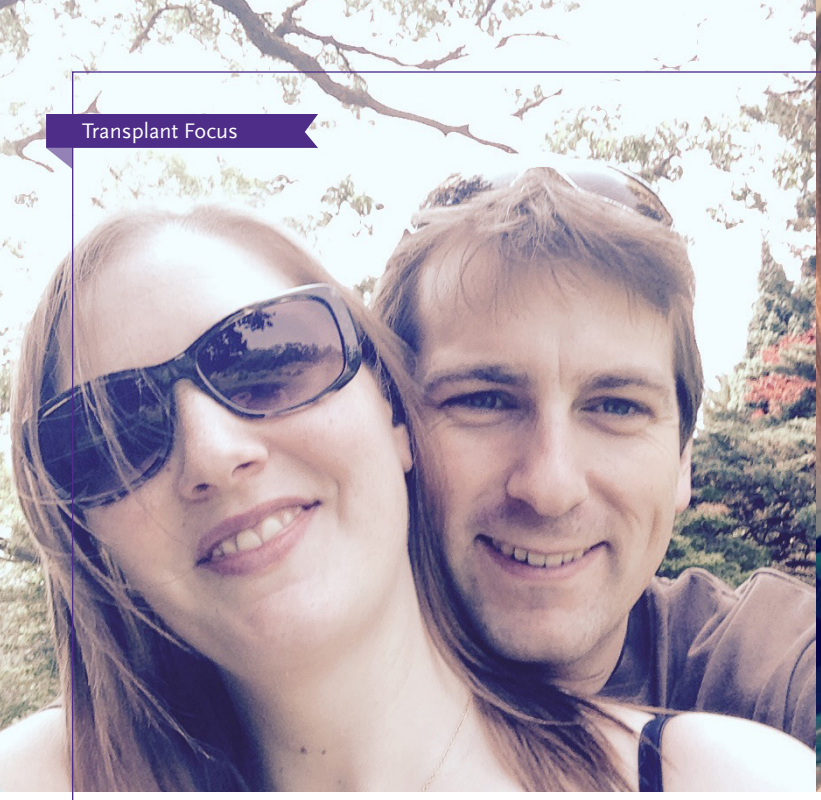
We have seen several advances in lung transplantation in recent years. In particular, advances in surgical techniques and the development of new immunosuppression molecules to prevent organ rejection are encouraging to professionals working in the field and provide a source of hope for patients. With a growing rate of lung transplantation in Canada, those awaiting transplants have something to look forward to.

Contributed by: Dr. Charles D. Poirier MD, FRCPC, in collaboration with Mariane Bourcheix-Laporte, Communications Associate, PHA Canada.

ABOUT DR. CHARLES D. POIRIER:

Dr. Charles D. Poirier is a Clinical Associate Professor in the Faculty of Medicine of the University of Montreal and Associate Professor at the Faculty of Medicine of McGill University. He is also the Medical Director of the Lung Transplant Program at the University of Montreal, Head of the Pulmonary Department of the CHUM, Co-Manager of the Allergy, Respiratory and Digestive Medicine Cientele Group, and researcher at the CHUM Research Centre.

Please note that some information in this article is drawn from ***Transplantation pulmonaire : conseils et directives à l'intention du patient et de ses proches****, a resource written by the Lung Transplant Program team at the CHUM's Notre-Dame Hospital, 2006.*



Left to right: A photo of Tina and Joel taken before Tina's transplant, when they were waiting for "the call" in Toronto; Now that she has resumed a "normal life," Tina's motto is: live life to the fullest!

Not Just Another Bump in the Road: From Being Diagnosed with CTEPH to Receiving New Lungs

I was first diagnosed with PH in September of 2003; I was twenty years old at the time. However, the process of getting to that diagnosis started a year before that when I noticed that my 15-minute walk to school was getting more and more difficult to do. My husband, Joel, trying to be an optimist, thought that I must just have been out of shape and so he suggested I go for a jog. I didn't even make it out of the parking lot of our building, when I had to stop because I could not breathe. This was my tipping point and I questioned whether there was something seriously wrong with me, so I made an appointment to see my family physician. After an X-ray was done, he diagnosed me with a mild case of asthma and sent me away with puffers to treat it.

Unfortunately, after several weeks had gone by, it was clear to me that the medicine was not helping. And so, when I had what I thought was an asthma attack while working outside and my Ventolin® inhaler didn't give me any kind of relief, I knew there was more to my symptoms. I mentioned my concerns to my family doctor, who advised me to stop taking the medication, but did not do any further investigations. This was surprising to me and I now know I should have questioned him on that, but I was a young adult still learning the ways of adulthood and didn't feel comfortable doing so.

In the weeks following this episode, I started experiencing a lot of chest pains. One night, the pain was so terribly unbearable that anytime I tried to lie down to sleep, it felt like a sharp knife was being stabbed into my chest. My husband and I decided it was time to go to emergency. There, the doctors discovered that I had an overinflated lung. This meant that my lungs were being irritated by something; they just had no idea what. They immediately referred me to a respirologist for a consultation on the matter who, after several tests, discovered that I had pulmonary hypertension. However, Dr. Born was convinced that my PH was secondary to another disease and his bets were on a cancer called mesothelioma—commonly referred to as the "asbestos cancer." This seemed strange to me as I had never been in contact with asbestos, but stranger things had happened. An appointment for a biopsy was made to confirm this, but the surgeon had some doubts about the diagnosis and wanted to explore a theory of his own. He decided to send me for one more test before doing an invasive surgery: a CT scan with dye. This test revealed what he had suspected; I had multiple micro blood clots sitting in my lungs. Alas, this gave me a final diagnosis of chronic thromboembolic pulmonary hypertension (CTEPH). All in all, it took over a year to reach this diagnosis.

At the time, I didn't know how severe PH was. I was not educated on the matter and felt mostly like it was just another bump in the road that I would soon adapt to and move on from. I was immediately put on blood thinners to control the clotting so I felt like everything was under control. It is not until I was finally referred to Dr. John Granton at the Toronto General Hospital PH Program that I started to understand what PH was all about. Although my new reality was difficult to swallow, I've never been one to look at the glass half empty and so I thought: "life has thrown this awful disease your way, you can either allow it to get the best of you or you can show it who's boss." And I am always the boss in my life! I completely understood that there would be some adjustments to make and that I wouldn't be able to do everything, but I intended to at least try.

When I lived with PH, physically demanding activities were obviously a challenge, but I always tried to adapt certain activities to my situation. For example, pulling up a chair on the dance floor at a wedding so that I may have a

seat while friends and family danced around me, or being the drummer on a work-related dragon boat team instead of a paddler. I always tried to find ways to join in on the fun somehow, but not all activities were as adaptable and it sometimes was difficult to pass on certain things. But if you had to ask me what the most challenging aspect of living with PH really was, it was facing the reality of not being able to have children. Growing up, I was never truly sure where my place was in the world. I didn't know what kind of career I wanted or what city I should live in, but if there was one thing I was sure of, it was that I was going to be a mother one day. So when the doctors told me that it wasn't the best idea, I was heartbroken. Joel and I considered adoption, but we both knew that I was not healthy enough to take care of children. Not having children was the right choice, but I still feel at times like there is something missing in my life, a feeling that I am sure will stay forever in my heart.

The years following my diagnosis were a roller-coaster ride of ups and downs, but I did the best I could to live a fairly normal life for more than 10 years with CTEPH. Unfortunately, the unpredictability of the disease caught up with me and by June 2014, my health started to take a turn for the worse. It was discovered that my pulmonary pressures had gone up. My PH doctor decided to try me on a new medicine called Adempas®,the only medication approved to treat CTEPH. I was also re-evaluated for pulmonary thromboendarterectomy (PEA) surgery, but as was the case in the past, I did not qualify because my blood clots were too small and too far to reach. And so by September 2014, my journey towards a double-lung transplant began.

I received my double-lung transplant on December 2, 2015, but that's not where the story of my transplant starts. The very first chapter was a meeting with a respirologist from the lung transplant program in Toronto. During this discussion, my family and I were informed on the program itself and we talked about what it meant to get a transplant. The doctor gave us all the details of what it is like to be on the wait list, their expectations of me as a patient and of my husband as a support person, and the grueling facts of the surgery along with the recovery that follows. Basically, we received an overwhelming amount of facts and information, but when I was asked if I still wanted to pursue transplant, my answer was a resounding "yes." From there, my health team started making arrangements for the next step: the week of assessment. A week filled with tests, consultations, and evaluations all to determine if I qualified for transplant. It took around 8 weeks before I was notified that my team was ready to move forward and I was finally accepted into the program. After a few complications related to the blood thinners I was taking, I was officially put on the transplant list on June 22, 2015.

As my husband and I lived in Ottawa, this meant we had to relocate to Toronto to be closer to the Toronto General Hospital. Although we had previously lived in Toronto for our college years, moving was still quite a stressful ordeal. As Joel and I both had to take unpaid leaves from work, finding an apartment without any income was quite the challenge. But we managed with the help of a real estate agent. However, actually living there without any income was a whole other ball game and was probably the biggest challenge of all. With no money coming in and not a whole lot of help from the government, Joel and I were in what felt like an impossible situation. How were we supposed to pay for rent and daily living without jobs? How were we suppose keep our brains sane and ready for transplant when all we could think about was whether or not we would have a home next month or enough money to buy food? This is the unfortunate reality of most transplant patients. Lucky for us, we received an amazing amount of support from friends, family, and even strangers who collected funds through events and online. It made all the difference in the world! But still, not knowing how long we were going to stay in Toronto meant that we were constantly worrying about having enough money to make it through.

Although my new reality was difficult to swallow, I've never been one to look at the glass half empty and so I thought: "life has thrown this awful disease your way, you can either allow it to get the best of you or you can show it who's boss."

Waiting was actually a lot different than what I was expecting. I had imagined that my life would be suddenly filled with all this spare time, but the truth is the hospital keeps you on a pretty tight schedule and you're actually quite busy. Between tests, bloodwork, clinic appointments, and physiotherapy, I was at the hospital an average of four days a week. Truthfully, my husband and I felt like this was a blessing in disguise as it got us out of the house and kept our minds busy. While on the list, your thoughts can sometimes drift towards the fear of what is to come or whether or not you will even make it to that point, and so having a full schedule helped with that. Although I was terrified at times, I generally tried to keep a positive attitude. I believe that this is what has gotten me through not only the transplant chapter of my life, but my entire PH journey.

By November of 2015, my PH had unfortunately progressed to an unmanageable stage and I was hospitalized and put on extracorporeal membrane oxygenation (ECMO), a sort of life-support that gave my heart the well-deserved break that it needed. I was on this machine for six days when the surgeon walked into my hospital room with the best news: that they may have found a matching set of lungs for me. From that point forward, they started the process required to see if the lungs and I were compatible. It took a full 12 hours of testing and waiting before I was told that surgery was a go and I was finally going to get my double lung transplant.

Recovering from transplant was one of the hardest things I have ever had to do. It is a very slow process that takes time, patience, and determination. I was definitely determined, but unfortunately I have never been a very patient person so I got frustrated often, especially when it came to learning how to walk again. I also ran into a few complications, which slowed down my progress, but in the end I got through it. Once released from the hospital, my recovery gradually picked up speed and it felt amazing! Each and every day got better. Since then, the plan has been to lead a "normal life" as best as I can. Of course, I will always have to take a lot of medications and I am certainly required to be more germ-aware as I am now immunosuppressed, but I have a much better quality of life. There will always be challenges and I have had to adapt my life slightly, but in the end it is well worth it.

And so you ask, how has transplant changed my life? Transplant is the reason why I have a life today and so it has changed everything including my perspective on life. Although I was grateful for the things that I had before, I am much more grateful now. I cherish every waking moment with friends and family because I know how close I came to losing that. I appreciate the small things in life like going for walks or dancing in the middle of my house while singing at the top my lungs. Most importantly, I am determined to work harder on my passions and my dreams, and less on the things that don't matter. I want to do all of this in honor of my hero: my donor. Life is unpredictable and way too short to take for granted. I know this more than ever now because of transplant.

Contributed by Tina Giroux-Proulx, transplant recipient, Ottawa, ON

Two Transplants Strong: Adam Kingz's New "New Set of Lungs"

Adam surrounded by his loved ones: wife Ashley, daughter Emmalynn, and son Abel.

I was diagnosed with pulmonary arterial hypertension (PAH), which was then called primary pulmonary hypertension, when I was about twelve years old. One of the main reasons I initially went to see a doctor was because I was passing out in gym class all the time. From there, the process of receiving my diagnosis was long and doctors had no idea what I had. They later said they thought I had had PH for about two years before I received my diagnosis.

The day I was diagnosed, I was sent to Sick Kids Hospital in Toronto. I pretty much lived in the hospital after that. It was hard being twelve and having PH. As my friends played, I sat. They continued in school, but even that was too much for me. I was in a wheelchair and on oxygen; the oxygen was a pain to carry with me and being stuck in a wheelchair was difficult. The doctors put me on Flolan®. I was the first child in Ontario to be put on the medication so it was a little nerve-raking. The fact that the medicine had to stay cold and be changed daily was quite taxing on my family. To add to the challenge, I developed an allergy to all tapes so they could only use gauze on me. My health continued to decline and I was able to do less and less.

I got the call for my transplant August 23, 1999. I was now thirteen. I was home (one of the few times!), it was 3:00 in the morning, and I was whisked away to Sick Kids. After my surgery things became amazing! I could breathe, run, play! It was truly wonderful! My life was no longer on pause and this allowed me to grow up! I got to meet my beautiful wife and become a father to her daughter. At the time, I was only taking anti-rejection medication, which wasn't too bad (besides my face being swollen from prednisone!).

After thirteen amazing years post-transplant, I developed a cough. After a few tests, the doctors found out that I suffered chronic rejection. This was heart-breaking and terrifying! I was so happy and my life was going to slip away right through my fingers. But then the doctor gave me a glimmer of hope as I was told they could do a re-transplantation. This thought was scary, but it was something. I would be able to keep my family; my life wasn't over.

After my surgery things became amazing! I could breathe, run, play! It was truly wonderful! My life was no longer on pause and this allowed me to grow up!

Shortly after, my wife and I decided to try and have a child. I was already a father to a little girl that may not have been mine by blood, but she was, and still is, a huge light in my life. So why stop living? A few months later, we were blessed with a son! Throughout my wife's pregnancy however, I got worse. Every day it was getting harder and harder for me to breathe, but when I saw my son, I forgot about it all. He was perfect, and just one more reason I had to survive! My wife and I also got married during this time. To see how beautiful she was walking down the aisle was incredible! She truly is my other half.

While my life was moving forward, my health was getting incredibly bad. While you wait for your transplant, you have to do physiotherapy to stay as strong as possible and be able to recover fast after transplant. The exercise routine consists of lifting some light weights, stretching, and walking on a treadmill. By the end, I was barely doing five minutes on the treadmill and had difficulty walking up two or three steps. I used a walker and refused to use a wheelchair; I never wanted to go back in one again. My breathing was so bad that I was burning too many calories and was down from about 210 lb to 105 lb. Every breath I took reminded me of having PH again. It hurt so bad. Every minute of every day it hurt.

After one false alarm, the day finally came and I got my new new lungs on September 22, 2014! Twelve days in the hospital and I got to go home. I pushed hard and recovered fast. I am now healthy and able to breathe once again and I will never forget how lucky I am. I love my life! I am extremely thankful to both my donors. Organ donation is incredible! I get to be a dad, husband, son, and friend. What I would tell other PH patients is that it will get better. Transplant is a frustrating thing, but it is so worth it! Listen to your body.

Contributed by: Adam Kingz, transplant recipient, Beamsville, ON

Living Life Without Regrets: Lessons Learned from Transplant

I was diagnosed with pulmonary hypertension around 2009, when I was twenty-three years old and living in Oshawa, Ontario. I was diagnosed very late and, as a result, I was diagnosed with stage IV PH associated with left-sided heart disease.

As with most individuals diagnosed with PH, the four years that I had the disease were riddled with complications. I started on Tracleer®, which I took for the first six months after diagnosis, but unfortunately it did not work for me, so doctors switched me over to Remodulin®.

Remodulin® was not covered by the government of Ontario for patients whose pulmonary hypertension is caused by a heart murmur, and United Therapeutics provided the medication on a compassionate basis—their the Executive Director became one of my heroes. I was on the subcutaneous version for about a year, but unfortunately as my illness progressed, my body began to reject that form of medication delivery. As a result, I was always in pain, I could never find a proper site for the medication, and my skin hardened so it was impossible to have a site last for longer than a day or two. For these reasons I started receiving Remodulin® intravenously.

Intravenous Remodulin® is a wonderful and dangerous drug. Within two days of switching over I felt immediately better, but within three weeks, a clot broke off my Hickman line, which caused a heart attack. This occurred one month before I moved to Ottawa, Ontario, and caused no small amount of grief for my family. After moving to Ottawa, my symptoms continued to worsen, but my ability to deny the severity of my illness knew no bounds. After just six months of living in Ottawa, while waiting to get my Hickman line replaced, I started to get major chest pains and ended up texting Ottawa PH Clinic nurse Carolyn Pugliese, who urgently told me to go to the emergency room. After running a few errands and stopping by my school, I checked into the hospital. I was almost immediately flown to Toronto General Hospital, where I was told I had 48 hours to live if I didn't get a transplant. Amazingly, I was transplanted shortly after, on January 26, 2012.

Being so sick when I made it to Toronto General Hospital and not having time on my side, doctors feared that I would crash, so I was heavily sedated and not allowed to move. I wasn't completely aware of what was going on because of the sedation so my spouse ended up signing my transplant consent form. When I became lucid again, I felt incredibly guilty and started attending transplant support meetings. I had been denying how sick I was for so long, that when I finally did get listed, I was listed at the very top, whereas many others had waited years to get their transplant.

Jamie has come a long way since receiving her PH diagnosis in 2009.

On the 25th of January, I vaguely remember a lot of buzzing around the hospital, which seemed odd to me. Eventually a nurse came in and told me that they possibly had lungs available for me. I was obviously quite excited and asked her to inform my spouse and my parents. The hospital called them around 10 p.m. and they all came rushing over from the hotel next door. I was also told throughout the night by many different staff members to not get my hopes up because they often had "dry runs." Amazingly however, the lungs were perfect for me and, after what felt like the longest wait of my life, I went into the operating room and was put under.

The recovery process in the actual hospital was brutal. It was the hardest and most surreal time of my life. I hallucinated badly for the first three weeks. I was allergic to the medication that is generally used to calm a person's hallucinations, and was paralyzed for three days. I was so out of sorts that the nurse who was on duty called my wife at 11 p.m. and asked her to come the hospital to calm me down because she thought I was going to hurt myself. Amy sang to me, which was the only way I became semi-normal again.

It also took me a very long time to be able to breathe on my own and, as a result, I was diagnosed with ventilator-induced pneumonia. While in the hospital, I coded because secretion was stuck in my ventilator. I actually pulled out the ventilator while I was sleeping because it was bothering me so much and, when I finally started breathing through a tracheostomy, I was unable to eat or talk, and remained that way for almost the entire six weeks I was in the hospital.

After leaving the hospital I soared in terms of health. I had forgotten what it was like to be able to breathe and spent the first six months walking, biking, and living life. I got a bit too brash unfortunately and thought I could do anything without getting sick. I was wrong on this point and ended up getting pneumonia again, which catapulted me going into chronic rejection and losing 40 % of my lung function. I learned quickly that the way to live with a transplant is to aim for everything to be as sterile as possible. I started working from home and learned to have fun and keep it simple. I can live an almost completely normal life without sacrificing anything as long as I make sure to adapt to my new normal.

Transplant has changed my life in so many positive and amazing ways. The fact that I wasn't supposed to live past 2012 is reason enough to be thankful. I have adapted to my new "sterile" life and am currently working and going to school from home. My wife and I adopted a dog named Wally and he and our other animals are the light of our existence. I keep up my exercise by walking him in the forest five kilometers every day. I really can't overstate the importance of watching out for germs because every time someone near me gets a cold, I end up in the emergency room.

I would tell a person considering being listed for transplant that they have to do what is right for them. I personally had a great experience with my transplant, but I have also had two friends pass away from complications after transplant. The most important thing to do is listen to your PH team and, when they think it is time for surgery, you have to really listen and decide if it is a journey you would like to embark on. The individual should learn the pros and cons of the surgery, the medications, and the lifestyle they will live post-transplant.

Again, I was really lucky with my transplant, and personally would encourage anyone to safely go through the process, but it is an individual decision that should be made on a case-by-case basis.

Contributed by: Jamie Kretzschmar, transplant

Side by Side in Hardship:

Transplantation is a Journey for Two

Valérie and her partner Francisco, who have become inseparable once again.

My partner, Francisco, was diagnosed with pulmonary hypertension in 2010. He began experiencing symptoms of this degenerative disease in 2009 and it took a year before he received a proper diagnosis. Everything changed in our life at that moment. At the time, he was treated for right-heart failure and, after several hospitalizations at the Hull Hospital, he was finally transferred to the Jewish General Hospital in Montreal for more advanced tests. This is where we learned the bad news.

Initially, when the doctor told me that my partner was suffering from PH, I did not know what it was. This disease is so rare that few people know about it. However, when I learned of all the implications of the disease, my world collapsed and I was devastated. The doctor explained to me that even with the drugs, the disease would continue to progress and as a last resort, Francisco would need a lung transplant. His life expectancy then was between four and six years.

Learning to live with PH was difficult, both for him and for me. Our lifestyle changed completely. Physical activities and family walks, those were over for us. The disease was about to take away what is most essential to Francisco's life: breathing. Seeing my partner always sick and losing his breath at the slightest effort made me feel helpless. It was a difficult reality to live with and I often had to hide so he wouldn't see me cry in front of him. He often had to be hospitalized and the idea that I could lose him at any moment was very stressful. I was overcome by fear. The children asked me a lot of questions because they saw that their father was not in very good condition. In order not to worry them, I simply told them that he was suffering from a nasty flu.

During my experience as a caregiver, there was a particularly touching moment. It was December 2015, and Francisco was then hospitalized at the Ottawa General Hospital. When I went to see him, he was very ill and the doctors told me that he had reached the last stage of the disease and could leave us at any time. He took my hand and said: "Do not worry, everything will be fine. I'll get through it. I will stay strong for the kids and for you. I refuse to let myself go." These words touched me deeply. It was a hard and very painful moment. But on the other hand, it was wonderful to see his strength and his will to fight in order to survive.

The best part is that he was right. Francisco received a lung transplant on January 5, 2016. Before receiving his transplant, he was connected to a n ECMO machine, which provides oxygenation through an extracorporeal membrane. This machine kept him alive because the oxygen level in his blood was very low and he had trouble breathing by himself. Transplant became his only option to survive and we had to fill out consent forms to start the process.

We are residents of Gatineau, where there is no lung transplantation program, so my partner had to be relocated to Toronto to wait, receive, and recover from his lung transplant. We were separated for three months, during which I had to learn to live differently and manage my loneliness because normally we are inseparable. However, the most difficult thing was to see my children, who were eight and five at the time, suffer from his absence. Even though we talked to him every day via teleconference, they asked me regularly when Daddy would come back home. At their age, they had no sense of time and three months for them could seem like only a few days.

I was very moved when I learned that lungs were available for Francisco. I was surprised and happy, and I jumped around like a child. My partner was admitted to Toronto General Hospital on December 28, 2015 and I got the news the morning of January 5th. For me, it was a miracle; he finally had two good lungs in perfect health! A precious gift of life.

Throughout this ordeal, I was surrounded by my family and friends, this is what helped me get through it. I must particularly thank my sister-in-law, Tanya, and my brother-in-law, Roberto, who greatly helped and supported us. I was lucky to receive a lot of moral support and encouragement from them. Without their help, it would have been much more painful. Talking to my partner every day and learning of his progress also gave me the strength to move forward and smile along this journey.

To a family in a situation similar to ours, I would say to not get discouraged and stay strong! We must never lose hope. I also believe that it is important to educate people to sign their card for organ donation, because life is the biggest gift we can give. It is thanks to Francisco's transplant that a new life began for us. His health now allows him to live a normal life. We resumed a few of our activities such as taking walks and doing other exercises. He can finally be active without suffering from breathing difficulties. What a change! We are enjoying life to the fullest and are making plans for the future. This ordeal has brought us closer than ever and we want to get married. My partner will resume his studies and eventually return to work. We would like to travel and enjoy all the beautiful moments of life. It is so important.

Contributed by: Valérie Plouffe, PH caregiver, Gatineau, QC

Shoot to Score: Braden's Transplant Story

Left to right: Jennifer (far right) and her son at a PHA Conference a year after Braden's double-lung transplant; Braden is now a young man who bites into life and proudly promotes organ donation awareness.

I have been involved with the PH community since 2003 when my oldest son, Braden, who was five years old at the time, was diagnosed with idiopathic pulmonary arterial hypertension, after years of unexplained health problems.

Looking back, Braden exhibited symptoms of PH early on; however, they were so subtle that diagnosis took several years. He was initially diagnosed with asthma but his health continued to decline to the point where he experienced some heart failure, which led to his diagnosis of PH in September of 2003. He struggled with the disease for a number of years after that time and went through a variety of treatments, beginning with sildenafil, followed by the addition of Tracleer®, and then eventually Flolan® in January of 2008. After a bout with pneumonia later that year, his health deteriorated to the point that transplant assessment became necessary. We travelled to Toronto in June of 2009 for the assessment and it was determined that he would be a good candidate for the surgery. At that point, since we lived in New Brunswick, we were required to relocate to Toronto before he could be listed for transplant. In August of 2009, we packed up our entire family, including our two younger boys and our two dogs, and made the temporary move.

We were incredibly lucky with the waiting process, as Braden had been listed for barely a month when we received the call. It was a shock to all of us to get the call that quickly and we were all very scared and nervous, and wondered if we had made the right decision. This was the hardest decision we have ever had to make and we were all terrified of what would happen next.

We were actually at a Leafs game in downtown Toronto when we got the call! We had been brought there by a local union who had heard of Braden's story. They were very good to us and helped us get to the hospital. My husband Dan had family in the area and they looked after our two younger boys while we rushed to the hospital to await the surgery. It took several hours after the call came in to find out if the lungs were suitable and it was the wee hours of the morning before we got final confirmation that the surgery would take place.

Braden's life has been completely transformed since the surgery. He has been able to do things we would never have dreamed possible for him. Within a few weeks of surgery, Braden was rollerblading with his brothers! Within just a few months of the surgery, he was playing hockey (which terrified me but he had been begging the doctors to let him play from the day he could stand!), and he has just continued on from there! He has continued to try new things and live life to the fullest from the day he came out of surgery. His first words to me when they took out his tubes were "I told you I could do it!"... and boy was he right!

There have been many challenging moments along the way. Making the decision of whether or not to go ahead and list him for transplant was the hardest one of all. It was the scariest decision we have ever had to make because, knowing that there was so much risk involved with the surgery, we knew we were taking a gamble. From a purely logistical standpoint, we faced challenges specific to the pediatric transplant process, such as determining how much involvement to give a child in making the decision. There were also difficulties associated with the actual listing and in our case, being forced to move away from our home because we did not have access to the required services while having two other children was particularly challenging.

I would like to tell parents of a child with PH being assessed for transplant that this experience was definitely a positive one for our family and I would encourage them to investigate it fully. Transplant is certainly not for everyone however. The process of evaluation is very thorough from both a physical and mental health standpoint and, by the end, you will know if it is a good fit for your family. Trust your instincts and watch for signals from your child. In our case, Braden's response to the whole process showed us we were making the right decision so we trusted it and took the step forward.

When Braden was initially diagnosed with PH back in 2003, there were little to no resources available in our area. We were given an extremely poor prognosis and found little help or support, so I went searching for it and found the Pulmonary Hypertension Association (PHA) in the U.S. and attended a conference in Miami, Florida the summer following Braden's diagnosis. From there, I found an entire community of support and so much hope for Braden's future. I connected with Liz McCall who had founded the British Columbia Pulmonary Hypertension Society (BCPHS) on the opposite side of the country and with Liz's help I went on to found the New Brunswick Pulmonary Hypertension Society (NBPHS) to connect with others from our area and create a support network. We worked with Liz and many others throughout Canada to bring together a strong group from across the country and eventually went on to found PHA Canada. I have remained involved since that time in many different roles: sitting on the Board of Directors, working briefly as Regional Coordinator, and now once again sitting on the Board as a Founding Director. In recent years, I have also become very actively involved with the Canadian Transplant Association (CTA) and in raising awareness about the importance of organ donation. I have recently taken a seat on the Board of Directors of the Atlantic Chapter of the CTA and am actively involved in organizing events, such as the "Transplant Trot," which promote organ and tissue donation awareness.

Contributed by: Jennifer Gendron, PH caregiver and PHA Canada Founding Board Member, Hampton, NB

It Takes a Village: A Community Coming Together to Support a PHighter in Need

Wendy King, a PH patient from Grand Falls-Windsor, Newfoundland, received a double lung transplant on July 20, 2016 in Toronto, where she had to relocate to be listed for the surgery. The relocation put financial strain on Wendy's family as she and her husband had to move close to two-thousand kilometers away from home to be within reach of one of the few hospitals in Canada where lung transplants are done. Thankfully, they have benefitted from incredible support from their community, which has taken on the challenge of ensuring the King family is able to get through these difficult times. Wendy's father-in-law, Carson King, shares insight into the community fundraising efforts he has spearheaded.

There is no magic formula for fundraising, but the tips I can give are: use a variety of sources, never turn down a kind offer, pull from local resources (including service organizations and people who can donate their time and talent), and start with a positive approach from the very beginning.

I knew Wendy long before she was diagnosed. She was very active and seemed to never run out of energy, both in her teaching career and lifestyle. She worked many hours beyond what was required of her at school, was active bicycling, walking, and swimming, and had lots of energy to take care of her son Kenneth. When she was first diagnosed, I didn't know enough about the disease to understand how serious it was. I knew she was having issues and had to alter her routine to go to doctor appointments, but I didn't realize how ill she was. It is only after I researched the disease that I understood how serious it is and realized that not many people know of PH, including medical professionals.

I became involved in raising funds to support Wendy's relocation because I knew that it would be a financial burden on her and my son Stephen. They couldn't possibly finance the move with the resources they had. By the time we learned they would be going to Toronto, Wendy had already given up her job due to her illness. Stephen then also had to give up his work to be her primary caregiver and support person in Toronto. This meant that, in addition to their regular financial obligations, including a mortgage and care of their seven-year-old son, they also had to face extra costs associated with moving to Toronto without the safety net of their salaries.

I had heard of a number of individuals and groups wanting to hold fundraisers to help Wendy and Stephen, among them many of their friends and past co-workers. I decided

to invite a number of those interested individuals to form a committee to discuss fundraising activities and to pool our efforts to make sure everyone was on the same page and events would not conflict. The committee held its first meeting early in February of 2016 and has since actively initiated or approved multiple fundraising events. From the beginning, we set out to get media exposure, raise awareness of the disease, and start raising money for the cause, which we named "Wendy's PH Journey." Acting as the committee chair, my role has mainly been to provide support to the many individuals and groups who have come together for Wendy and Stephen. The community has been amazing and my job has been made easier by the fantastic support of the communities of Grand Falls-Windsor and the Exploits Valley Region.

To date, many fundraisers have been held and through our collective efforts we have raised over $40,000 to support Wendy and Stephen's transplant journey. We held our first major fundraiser one month after the committee was formed and the success of this "dinner and dance event" went beyond our expectations! The support was phenomenal and tickets sold out fast—there was even a wait list! It was an amazing night. The venue was decorated using different shades of purple, several local bands volunteered their time and talent to provide music for the dance, a local photographer offered his services for individual or group photos during the evening, raffles were organized, and PH and transplant awareness information was distributed. This was a great example of how community efforts can come together to raise over $12,000 in one night!

Other fundraisers that took place in the last months include: a "Trek to Toronto" stationary bike-o-thon held at a fitness centre, which Stephen and Wendy were members of; an Easter egg hunt that families in Grand Falls-Windsor took part in; another "dinner and dance" event organized in a neighbouring community during Organ Donation Awareness Week; a live auction; a zumba fundraiser; and a talent show at the school where Wendy taught. The committee has also taken the initiative of placing donation jars in local businesses and selling purple t-shirts designed by Wendy and purple bracelets. There is no magic formula for fundraising, but the tips I can give are: use a variety of sources, never turn down a kind offer, pull from local resources (including service organizations and people who can donate their time and talent), and start with a positive approach from the very beginning. It's also important to acknowledge and be thankful of people's generosity and to get the local media involved in promotion. While raising awareness for the cause and the condition, it's important to make sure people understand both the medical and financial implications because many people don't realize the enormous costs of relocating for medical reasons. Most of all, good organization and public relations are key. Letting people know how successful an event was is a good way to thank people for their efforts. It's also important to keep the community aware of the patient's progress. When Wendy finally moved to Toronto, the community didn't give up.

People know that she and Stephen are still waiting for the next stage in their journey so we try to keep them informed.

It can be devastating for families to find themselves in a situation like Wendy and Stephen's. Giving up your employment, your home, and the things you worked for can reduce your will to fight and make things seem hopeless. I am sure that, at times, they felt that way, but the support of friends and hope for a return to a more normal life can also create the will to combat all odds. Wendy bravely set out on this journey because she wanted to be able to ride her bicycle again. She might even dare to hope to return to her teaching job, which she loved. She has faced adversity with the positive ambition that she could return to a "normal life" and my advice to anyone in a similar situation is to have that same outlook. Be an advocate for your health and seek whatever help you can—in Wendy's case a double lung transplant—and look to your family and friends to help make it happen.

My hope is that Wendy recovers well from her double lung transplant. Like many in the community, I am looking forward to her return to Grand Falls-Windsor and to the family being able to settle back into "normal life." Wendy and Stephen are so well-loved by friends and colleagues and it is my hope that they will soon be home, close to their family and friends, and that we can help them start over.

Contributed by Carson King, supporter and community leader, Grand Falls-Windsor, NL

Photos:

Opposite page, from top: Supporters at the "Trek to Toronto" bike-o-thon surround Wendy (center) and her family with love.
Carson King and his daughter-in-law, Wendy.

This page, from top: Supporters come in all shapes and sizes!
Wendy has been able to count on the support of close allies. From left to right: Wendy's father-in-law, Carson King; sister-in-law, Amy King; son, Kenneth King; husband, Stephen King; and Carson's partner, Lynne Allan.

Meet Your Medical Professional: Dr. Nathan Hambly

Dr. Nathan Hambly, MD, FRCPC, is Assistant Professor of Medicine at the Firestone Institute for Respiratory Health and Clinical Lead of the Pulmonary Hypertension Program at McMaster University in Hamilton, Ontario. Dr. Hambly only recently became a member of the Hamilton PH Clinic, but he has already had the opportunity to be involved in key issues affecting the Canadian PH community. We have the pleasure of introducing him to our members through this interview.

PHA Canada: *Where did you begin your medical career, and in what field?*

Dr. Hambly: I completed medical school training at the University of Ottawa, where I worked with several excellent general internists who mentored me and shaped the way I approached patient care. They encouraged me to treat each person as a whole, instead of picking apart the body's separate systems. Later on, as an internal medicine resident at McMaster University, respirology caught my attention. I was particularly drawn to pulmonary hypertension given the strong link between the complex pathogenesis of disease and its clinical manifestations. Understanding and treating PH challenged me to build on my previous interest in working with multiple systems and has to date been extremely rewarding.

PHA Canada: *How were you first introduced to pulmonary hypertension? What drew you towards developing a specialization in the field of PH?*

Dr. Hambly: During my respirology rotation as an internal medicine resident, I was involved in the care of an extraordinary patient with scleroderma who was admitted to hospital with shortness of breath. She had many features of scleroderma, including advanced PH, lung fibrosis, and ulceration of her fingers. It struck me just how crippling autoimmune diseases like scleroderma could be—that our body is capable of attacking itself so effectively and with such detrimental results. I was amazed by this patient's fearlessness, fortitude, and poise as she faced her disease head on. She was a strong advocate for the Scleroderma Society of Ontario and an incredible patient advocate. In many ways, she sparked my interest in interstitial lung disease and PH.

PHA Canada: *Can you describe your involvement with PHA Canada, PH awareness, and access to treatment initiatives?*

Dr. Hambly: I have been involved with PHA Canada and the Scleroderma Society of Ontario in advocating for increased access to disease-modifying treatments for patients suffering from PH. This has involved being a part of roundtable discussions with members of parliament and patient advocacy groups, and performing interviews through local media outlets. Outreach is incredibly important for a disease as rare as PH, and for which treatments, although expensive, can be transformative for the patient. Recent initiatives by PHA Canada have increased the number of available and accessible treatments in Canada and have had a direct impact on the lives of many Canadians with PH and their families.

PHA Canada: *What do you enjoy the most about your work as a PH Specialist? What has been the most inspiring part?*

Dr. Hambly: Cookie-cutter medicine cannot be applied to PH due to the uniqueness of each patient and their circumstances. When I first meet a patient with suspected PH, I consider his or her symptoms and problems and correlate them with an often-complex medical history. Then I study any physiological assessments and imaging to create an individualized treatment plan that fits the uniqueness of the patient. One person alone, however, cannot manage such a complex disease. It requires a multidisciplinary approach that involves expert nursing care, psychological support, patient advocacy groups, medical specialists from a wide variety of fields, and our pharmaceutical industry partners. These people make up a team that works together to achieve the common goal of improving patient health. Playing a role in this collective and being a part of the collaboration is one of the aspects of working in the field of PH that I find most exciting.

PHA Canada: *What do you find most challenging about working in the field of PH?*

Dr. Hambly: Without a doubt, the hardest aspect of working in PH is the relentless struggle to obtain support for clinical and research initiatives from private and public sources. PH is a severe and progressive disease that warrants investment. Negotiating the obstacle course of local and provincial medical politics often detracts from the ultimate goal of advancing patient care.

PHA Canada: *If you could sum up everything you've learned about PH into a couple of sentences that you would want to share with someone who is newly diagnosed or newly affected by PH, what would those be?*

Dr. Hambly: I like to provide a roadmap for what the next twelve months will likely look like. This involves understanding the natural progression of the disease, which effective therapies are available to control the natural rate of progression and improve quality of life, and the hurdles that will likely be encountered. I also try to reassure the patient that a multidisciplinary team of experts will be available to help navigate the obstacles ahead. Patients usually have many questions and want to know where to look for more information. Since there is so much misinformation out there, I try to direct them to reliable resources that paint an accurate picture of the current PH landscape, the treatment resources that are available, expert centres where such services are provided, and contact information for patient advocacy groups such as PHA Canada.

PHA Canada: *What advances have you seen in the treatment of PH patients since you started practicing? What do you find to be the most encouraging advances currently taking place?*

Dr. Hambly: I am incredibly fortunate to be starting my practice at a time when we have ten approved therapies for the treatment of PH. These treatments have caused a dramatic change in the clinical landscape and the natural history of the disease. The near explosion of options can be attributed to the hard work and dedication of many of my mentors, industry partners, and others—and the thousands of Canadians suffering from PH who have pushed for advancements for a disease, which as recently as 1992, had no targeted therapies. The emphasis now is on pushing even more as PH remains a disease without cure.

Contributed by Dr. Nathan Hambly, Clinical Lead of the Pulmonary Hypertension Program at McMaster University, Hamilton, ON

A Closer Look at CPHPN: Interview with Gail Nicholson, RN

The Canadian PH Professionals Network (CPHPN) is a PHA Canada committee that brings together PH nurses from across the country to enhance nursing care of pulmonary hypertension through leadership, education, and professional development. Working with patients on a daily basis, CPHPN members are on the front lines of PH health care, but they also work behind the scenes to better the lives of all Canadians affected by the disease. CPHPN Secretary, Gail Nicholson, RN, brings us up to speed on the group's activities.

PHA Canada: *Let's get to know you a little better before we discuss CPHPN's work. You became involved in the field of PH in the mid-1990s and have been working as PH Coordinator at the Calgary PH Clinic since 2007. What prompted you to specialize in the treatment of PH?*

Gail: It was a natural transition for me. My experience with PH started when I was working in ICU at the time when Flolan® was introduced and protocols were being developed to treat PH. Witnessing the impact that PH had on patients from all walks of life and ages kept me engaged and wanting to learn more.

The Calgary Transplant/PH Program was born in 2004. It started off with two doctors (MDs), one registered nurse (RN), and a part-time clerk. As the program grew, so did the need for another RN to join the team. I was excited to apply and then happy to be hired! The Calgary PH Program now stands alone, and we have five dedicated MDs, one RN, and a part-time clerk. We also have a dedicated unit within our hospital with RNs that are certified to care for the complex IV/SQ medications our PH patients may require.

PHA Canada: *What do you find most rewarding in your work as a PH nurse?*

Gail: As you can imagine being a nurse to people that have this devastating disease can take a toll on your heart. In my role, I am there for patients at diagnosis, for medication starts and changes, and through all the ups and downs.

I get satisfaction from my career in two ways. First, by knowing that I participate actively in patients' lives—I hope to make a difference as their advocate. Second, by raising awareness of PH in as many ways as I can: by educating and certifying nurses with the medications; creating teaching materials for staff, patients, and the public; and speaking to crowds and individuals—anyone who will listen. For the last three years, I have also organised a Masquerade Ball fundraiser, which raises awareness by engaging Calgary businesses and media.

PHA Canada: *You currently act as secretary for the Canadian PH Professionals Network (CPHPN). Can you explain what the mandate of CPHPN is and how the committee works towards achieving it?*

Gail: CPHPN is a national network of PH RNs. We work together not only to provide support to each other, but also to develop best practice tools that we can take back to our programs/clinics.

Our ultimate goal is to create a template to accredit PH centres based on criteria of excellence and best practices. To achieve this goal, we participate in research both nationally and internationally. However, I feel that our work will never really be done given that we will always strive for excellence to the benefit of our patients!

PHA Canada: *What are the advantages of being part of a network like CPHPN? How do members share information and support one another's work?*

Gail: Having such an accessible resource at my fingertips is absolutely invaluable. We are a team of experienced professionals and it comforts me to know that I have access to like-minded RNs to bounce ideas off of. With a simple email out, I get answers from my peers that can help in my decision-making processes. We are all here for each other and all understand what it is like to go through new experiences.

PHA Canada: *What are examples of projects or programs that CPHPN has developed over the years?*

Gail: Once CPHPN was officially formed, the team set out to review what, in our opinion, was needed by the community. Good examples of what came out of this process are the medication sheets that we created for patients. These easy-to-understand one-page documents don't replace the detailed information and teaching that nurses provide in one-on-one sessions, but they constitute good go-to resources for patients to reference. We have also contributed to the creation of resources to help patients monitor their sodium intake and are also excited to create an outline for the Canadian PH Centre Accreditation Program in the near future.

PHA Canada: *One of the projects CPHPN is currently involved in is All4PH, through which an international environmental scan of PH clinics has been accomplished. Can you speak to the objectives of this project and how CPHPN plans to further develop this initiative?*

Gail: This project is an extension of our plans for the Canadian PH Centre Accreditation Program. Collaborating with PH centres in other countries, our goal is to see what best practices are out there and evaluate what is working well and what still needs to be developed. Our goal is to outline criteria of excellence to accredit PH centres on an international level. We have completed Phase 1, through which we accomplished a scan of practices in centres specialized in the treatment of PH worldwide. We have presented the project to the international PH community and it has sparked increased interest for participation, which we are very excited about!

PHA Canada: *Can you speak to the international relationships that CPHPN fosters and to the work being done with the U.S. PH Professionals Network?*

Gail: Through *All4PH*, CPHPN has established a collaborative relationship with the U.S. PH Professionals Network and its equivalent in the U.K. We anticipate that, in the near future, several other international groups will want to participate. With our U.S. and U.K. colleagues, we are currently working on a literature search for similar case-management programs that will allow us to develop a report and recommendations to move forward.

PHA Canada: *Apart from the projects you have told us about, are there other exciting initiatives in the works for CPHPN?*

Gail: We are currently developing a "New PH Coordinator" manual that each clinic will be able to customize. This guide will include a template for the Canadian PH Centre Accreditation Program as well as educational materials for patients, caregivers, and families.

Contributed by: Gail Nicholson, RN, Calgary, AB

The Medical Team Approach: A Shared Responsibility

Arnold Hull is a scleroderma and PAH patient who resides in London, Ontario. His medical journey began in 2008 when he was hospitalized for pancreatitis, which led to the discovery of initial signs of scleroderma. However, it was not until 2013 that he was diagnosed with both scleroderma and pulmonary arterial hypertension, after securing an initial appointment with Dr. Sanjay Mehta at the London Pulmonary Hypertension Program. Thanks to the joint efforts of medical professionals affiliated with the London Health Sciences Centre (including a PH specialist, a rheumatologist, and a cardiologist) and his family doctor, Arnold's quality of life is much improved since he was first introduced to pulmonary hypertension over four years ago. Below, Arnold shares the strategies he has adopted to actively take part in the management of his treatment plan.

Being aware of symptoms affecting your health, being informed of the resources available to you, and taking shared ownership over the therapy suggested by your medical team enables you to develop a partnership with the members of this team to enhance your overall wellness. Here are a few tips to facilitate the development of a proactive relationship with health care professionals:

We all know when we are not feeling well. It is advantageous to track any ailment by keeping notes of dates and times of any reoccurring symptoms. These notes help when discussing a medical problem with your doctor. Always take a pen and paper to your appointments, so that you can record what you learn from your doctor and refer back to these notes when needed.

Resources available to you include: information on your diagnosis provided by medical practitioners and other health care providers; attending workshops, local support group meetings, and conferences; and subscribing to publications produced by organizations such as the Pulmonary Hypertension Association of Canada and other patient groups like provincial/regional Scleroderma Societies. Be mindful of the source of your information to ensure its quality and reliability.

Ensure members of your medical team communicate with each other, including your family doctor. For each appointment, provide a list of current medications, updates from appointments with other members of your medical team, and any questions you have.

For me, taking these steps has resulted in better communication and shared ownership of my treatment plan with my medical team. I feel informed and empowered. Accordingly, I would also like to share a series of questions you may consider asking in relation to a new proposed drug therapy program:

- *What is the name of the drug? With the name, you can search Health Canada's Drug Product Database (PDP) to review the Product Monograph. Although quite technical, this document includes a "Consumer Information" section, which is written for the public. You can access Health Canada's PDP through this link:* ***hc-sc.gc.ca/dhp-mps/prodpharma/databasdon/index-eng.php***
- *What would be the added benefits of taking the medication?*
- *What is the evidence that the drug is effective? In other words, how well does it work?*
- *What side effects and/or unique risks may be associated with the drug?*
- *What testing procedures are necessary when using the drug (e.g. blood work) and at what frequency are they required?*
- *Is the proposed medication compatible with other medications taken?*
- *Will the proposed medication be funded by provincial/territorial Public Drug Plan?*
- *How is the new medication taken (e.g. orally, intravenously, or subcutaneously)? How many times a day is it necessary to take the medication?*
- *Does the medication have a bearing on any restrictions imposed by a private (group or individual) health plan you are currently enrolled in (e.g. your ability to travel out of province)?*

Be aware, be informed, and be active. Learn as much as you can about your condition and treatment, keep a written diary or record of your health, and adhere to your treatment plan with a positive and supportive attitude, knowing you were an integral participant in its development!

Contributed by: Arnold Hull, MEd, Scleroderma and PAH patient, London, ON

Jeannie volunteered at PHA Canada's 2015 National Conference, where she first met PHA Canada's Communications Associate, Mariane.

How to Establish Effective Communication with Your Professional Medical Team

In the last issue of Connections, scleroderma and PAH patient Jeannie Tom (pictured above) shared goal-setting tips for people living with chronic illnesses and explained how she achieves the objectives she sets for herself. Here, she shares strategies she has developed to ensure fluid communication with her medical team and be empowered as a patient.

When I meet a new physician or health care provider, I take the approach that a new partnership will develop. My goal is for them to understand my complex condition so that they can treat it properly. First, it is essential to be prepared for consultations with medical professionals and prioritize concerns needing to be addressed to show respect for their schedule. If necessary, request a follow-up appointment to discuss additional concerns.

At home, I prepare a set of anecdotal notes. I make a list of my current medications (names, dosage, and name/title of who prescribed them). I also make notes related to my current health status and prioritize facts/concerns in relation to the specialist being consulted. Next, I make a list of up to five specific questions or comments that I prioritize in order of importance. Finally, I write a list of all my health care providers, to whom copies of medical reports could be faxed, making sure that their contact numbers are listed.

When I meet Fellows or Residents at clinic, I provide them with a copy of my notes and keep a personal copy to record new information. If family or friends accompany me, they too receive copies of my notes. For future reference, I have clinicians write their names at the top of my notes and, if they have business cards, I collect them in a folder noting dates and reasons for a particular visit.

After completing my history and exam, Fellows take my notes along with theirs to discuss my condition with specialists. Seeing that I have written down my primary concerns, they realize that I respect their limited time and want to make the best of my consultation. Copies of my anecdotal notes are usually filed with my health chart. Many specialists have complimented me on my organizational skills and my focus during visits. In addition, I am constantly learning related medical lingo, which helps with effective communication and facilitates my understanding of conveyed information. Using my health literacy skills, I ask doctors if I can restate the key points they want me to know, or I ask them to explain in clearer terms what treatment(s) or tests they want to order.

It is important that we work side by side, as partners in care. We patients are key players in doctor-patient relationships. Networking with the medical team helps to ensure that we receive the most current and best possible treatment. We know our bodies best and are our own best advocates!

Contributed by: Jeannie Tom, Scleroderma and PAH patient, Willowdale, ON

Mohamad Taha is a PhD student and PH researcher under the supervision of Dr. Duncan Stewart at the University of Ottawa. Mohamad contributes a bi-monthly Research Corner article to our Pulse e-newsletter. We are glad to have Mohamad's contribution and the opportunity to provide our community with insight into the PH research process.

The Role of the Prostacyclin Pathway in PAH and the Drugs Targeting this Pathway

In this issue, we will address some questions regarding PH therapy, more specifically, the role of the prostacyclin pathway in PAH and the drugs targeting this pathway.

What is the prostacyclin pathway composed of?

This pathway is one of the crucial pathways controlling blood vessel relaxation/tightening in the lungs. A crucial molecule called prostaglandin H2 is produced within our cells. This molecule can either be converted into prostacyclin, one of the molecules leading to blood vessel relaxation (vasodilation), or thromboxane, one of the molecules leading to blood vessel tightening (vasoconstriction). Prostacyclin is usually produced in endothelial cells—the cells lining the inside of blood vessels—but then is taken up by smooth muscle cells—the cells constituting the second layer of a blood vessel, which is important for vessel contraction. To function, prostacyclin has to bind to its receptor on the cell surface, leading to relaxation of the blood vessels (vasodilation). Thromboxane has an opposing effect to prostacyclin on blood vessels and can lead to the increased formation of blood clots.

How does this pathway work?

High levels of prostacyclin/low levels of thromboxane lead to blood vessel relaxation.

Low levels of prostacyclin/high levels of thromboxane lead to blood vessel tightening and can lead to the formation of blood clots.

Why is this pathway important in PAH?

In PAH, there is a dramatic decrease in prostacyclin levels and higher levels of thromboxane production. This results in low blood vessel relaxation, and constant constriction, leading to the narrowing of blood vessels in the lungs. The effect of this is increased pressure in the pulmonary arteries. Furthermore, thromboxane can lead to the formation of blood clots in blood vessels, which can contribute to chronic thromboembolic pulmonary hypertension (CTEPH), known as WHO Group 4 pulmonary hypertension.

What treatments target this pathway in PAH and how do they work?

Some therapies attempt to enhance the prostacyclin pathway in order to increase blood vessel relaxation. The first class of drugs is pure prostacyclin (epoprostenol, beraprost). The other class of drugs consists of prostacyclin analogs, which act to stimulate blood vessel relaxation (iloprost, treprostinil). Prostacyclin receptor activators have also recently been developed (selexipag). These therapies all attempt to increase blood vessel relaxation and reduce chances of blood clot formation.

Currently, which therapies targeting this pathway are approved for PAH in Canada?

The use of intravenous Epoprostenol (Flolan®, Caripul®) is approved in Canada. Treprostinil (Remodulin®) is also approved for both intravenous and subcutaneous delivery. Selexipag (Uptravi®), taken orally, was approved in 2016 by Health Canada. For the full list of PH treatments, please visit: **phacanada.ca/learnmore**.

What does research show about these drugs? Which one is better?

Unlike other PAH treatments, prostacyclin pathway targeted treatments are complex therapies with some adverse side effects (including headache, nausea, rash, and diarrhea). Furthermore, many of the drugs are unstable at room temperature and degrade rapidly. Thus, treatments require administration by a center with expertise in the delivery systems (intravenous, subcutaneous, or inhalation) and the management of side effects. One cannot say that one drug is definitely better than another since each patient is affected differently by the disease and will have a different response to each drug. Thus, it is very important to talk with a PH specialist to determine which drug is most appropriate for a patient.

References: Irene M. Lang and Sean P. Gaine. "Recent Advances in Targeting the Prostacyclin Pathway in Pulmonary Arterial Hypertension." European Respiratory Review Journal.

Please always keep in mind that while I can provide you with a small insight into PH research, you should always be able to get answers from your pulmonary hypertension Specialist, who is more familiar with your specific case and your treatment history.

Contributed by: Mohamad Taha, PhD Candidate under the supervision of Dr. Duncan J. Stewart, Department of Cellular and Molecular Medicine, Faculty of Medicine, University of Ottawa

Accessibility of PAH Therapies in Canada Part II

INTERVIEW WITH DR. SANJAY MEHTA BY SERENA LAWRENCE, PH PATIENT

This is the second installment of a two-part interview with Dr. Sanjay Mehta by PAH patient Serena Lawrence. The first part of this interview, published in the Spring 2016 issue of Connections Magazine, focused on accessibility of PAH therapies through public funding. Here, Dr. Mehta answers Serena's questions regarding PAH therapies that are not currently approved in Canada.

As someone with Pulmonary Hypertension, I was very surprised to learn that a number of potentially life-altering medications have already been available for many years in the United States, but have yet to be approved in Canada. I assumed that because Canada offers free "universal" health care, it also had the best interest of its patients in mind. Needless to say, I was completely shocked to learn that some prostanoid-family medications like Tyvaso® (inhaled treprostinil), Ventavis® (inhaled iloprost), and Orenitram® (oral tablet form of treprostinil) are not available here in Canada. Given that these medications are less invasive than intravenous prostanoids such as epoprostenol (Flolan®, Caripul®) and intravenous or subcutaneous treprostinil (Remodulin®), I asked PH specialist Dr. Sanjay Mehta to answer some questions I have regarding the accessibility of PAH therapies in Canada.

Serena: *Could you explain the benefits of inhaled and oral versions of treprostinil over the intravenous and subcutaneous prostanoid treatments? Do you believe that medications like Tyvaso® and Orenitram® should be available to Canadians with PH? Could you briefly explain why these medications are not currently available here in Canada? Is there anything that we can do as a community to have these medications available here?*

Dr. Mehta: Treprostinil is a very effective treatment for PH. It is currently approved and available in Canada both for intravenous and subcutaneous administration as Remodulin®. Both of these approaches require an external pump and a cassette or syringe to be filled regularly, usually every one or two days.

Treprostinil has been modified for patients to be able to take it by either breathing it in (inhaled Tyvaso® in the U.S.) or by taking a pill (oral Orenitram® in the U.S.). Both of these approaches have been shown to be effective in treating PAH. Moreover, the inhaled and oral routes of drug administration clearly simplify the treatment compared with much more complex intravenous/subcutaneous treprostinil administration. However, inhaled and/or oral treprostinil are not the best treatments for all PAH patients. Inhaled treprostinil may not be as effective as intravenous/subcutaneous treprostinil and is typically only used as an addition to other oral PH therapies in the U.S. Oral treprostinil is effective, but side-effects of nausea, abdominal pain, and diarrhea can be difficult for some patients.

Ultimately, both inhaled and oral treprostinil are not available to Canadian PAH patients because the pharmaceutical manufacturer never submitted an application for Health Canada approval. This is largely because of business reasons, as the PH market in Canada is much smaller than in the U.S., and it is expensive to launch a new medication in Canada. Moreover, many PH medications cost less in Canada than in the U.S. because of government regulations. As such, the cheaper price for a new PH medication in Canada could put pressure on a company to reduce its cost in the U.S., which would lead to the manufacturer making less money in the much bigger American market.

Serena: *Are you able to speak to a trial for and the benefits of having Remodulin® administered through an implantable pump, as opposed to subcutaneous or intravenous methods? Do you foresee this implantable pump being available in Canada?*

Dr. Mehta: There was an exciting trial in the U.S. that studied whether Remodulin® could be administered via an implantable rather than external pump. Such an implanted pump has a reservoir of medication that can last for a prolonged period, such as a month, and be refilled regularly in the PH clinic. As a result, patients with this pump no longer have to look after preparing medication every day or every second day at home and changing tubing, cassettes, and needles, which clearly improves their quality of life. This implantable pump for Remodulin® may become available in the U.S. in 2016, and then hopefully one day in Canada.

Serena: *This concludes our two-part interview. Are you able to share insight on any exciting and promising treatments on the horizon in Canada?*

Dr. Mehta: Despite all the advances we have seen in the last years in regard to PH therapies, PAH is still a progressive and often fatal illness for which we have no cure. Tremendous research, both in Canada and around the world, continues to better understand the disease and what exactly is happening to the blood vessels of the lungs to cause PAH. There are many ideas for new treatment approaches, including both pharmaceutical therapies and potentially gene-therapies. This is a very hopeful time because PAH patients will continue to benefit from this research and the development of new therapies. I am hopeful for a time when we can say to a patient: "You have PAH, but we can treat you so that it will not affect you in everyday life and will not shorten your lifespan."

PHA Canada PH Research Scholarships

In 2016, PHA Canada awarded its first two research scholarships, named in recognition of the Paroian Family's instrumental initial contribution to our research program. PHA Canada's research scholarships are intended to provide a financial stipend to emerging PH researchers involved in projects related to the better understanding or treatment of the disease. By supporting the work of young Canadian researchers pursuing scientific investigation in the field of PH, we hope to foster the development of professionals who will remain committed to bettering the lives of Canadians living with PH throughout their careers.

Thanks to the incredible fundraising efforts of our members, the generosity of our donors, and the continued support of our corporate sponsor Actelion, we have been able to provide two $10,000 scholarships this year. Recipients are: Sylvia Rinaldi, PhD candidate in the Department of Health and Rehabilitation Sciences at the University of Western Ontario (London, ON) and Virginie F. Tanguay, post-doctoral fellow in Medicine at Laval University (Quebec, QC). We are excited to publish their research outlines in this issue and to share the development of their projects in the coming months.

Description of Sylvia Rinaldi's Project: Nutritional Status of Patients with Pulmonary Hypertension

Pulmonary hypertension (PH) is a serious lung disorder resulting from the narrowing of the pulmonary arteries that carry blood from the heart to the lungs. The goal of this study is to determine the nutrition profile of PH patients with various disease subtypes and disease severity. The first objective is to determine the percentage of patients who have higher or lower than normal calorie needs. The second objective is to determine if there are specific nutrients of concern in these populations. The third objective is to measure body composition and nutritionally relevant functional markers such as hand grip strength.

Participants will be recruited from the Victoria Hospital PH Clinic in London, Ontario and will be asked to collect data on their food, beverage, and supplement intake using a 24-hour food recall (asking participants to remember food ingested) and a three-day food intake journal. Data collected will include, but is not limited to: body composition data, such as body fat percentage and amount of muscle mass measured through bioelectrical impedance analysis (a method used to estimate body composition); the amount of calories used by the body at rest using indirect calorimetry (a way to estimate energy expenditure from measures of carbon dioxide production and oxygen consumption); and functional measures such as hand grip strength. Additionally, patients' charts will be reviewed for relevant data such as disease severity, disease subtype, and relevant blood work such as levels of vitamin D.

As minimal information is available in the literature on the nutritional status of PH patients, the knowledge gained from the study will provide new and novel evidence to help guide health professionals, including Registered Dietitians, to provide better care to PH patients. This research has the potential to improve the lives and outcomes of PH patients through inter-professional collaboration in the management of the disease.

About Sylvia Rinaldi *(pictured above on the left)*

Sylvia Rinaldi is a registered dietitian and PhD student in the Department of Health and Rehabilitation Sciences at the University of Western Ontario (London, ON) with a focus on health and aging. Sylvia earned her BSc in Biochemistry at the University of Windsor and a BSc and MSc in Foods and Nutrition at Brescia University College. Her research interests involve maintaining and improving the nutritional status of patients with chronic respiratory disorders including pulmonary hypertension and interstitial lung disease. As a Registered Dietitian, she values evidence-based and research-driven clinical practice. These values guide her research into the links between nutrition and disease and how improvements in nutrition may have the potential to improve disease outcomes and quality of life.

Description of Virginie F. Tanguay's Project: Metabolic Syndrome and Pulmonary Hypertension

Researchers: Virginie F. Tanguay, Simon Malenfant, Sandra Breuils-Bonnet, Olivier Boucherat, Sébastien Bonnet, and Steeve Provencher, Centre de recherche de l'Institut universitaire de cardiologie et de pneumologie de Québec (UCPQ).

Increasing scientific evidence supports the idea that metabolic syndrome, a cluster of conditions such as obesity, high blood pressure, diabetes, and high cholesterol, may play a role in the development of pulmonary hypertension. The goal of this project is to evaluate the impact of metabolic syndrome in pulmonary hypertension patients (WHO Group 1—pulmonary arterial hypertension and WHO Group 2—PH associated with left-sided heart disease). More specifically, the project will study the accumulation of fats in different organs and the relationship to cardiac and pulmonary functions, muscular strength, and medium-term prognosis. This innovative research will shed light on the clinical pertinence of metabolic disorders, thus increasing our understanding of pulmonary hypertension and its treatment.

About Virginie F. Tanguay *(pictured above on the right)*

Virginie F. Tanguay began her doctorate in medicine in 2012 at Laval University (Québec, QC). Her internship with the IUCPQ Research Group in Pulmonary Hypertension and Vascular Biology solidified her interest in pursuing research in this area and led her to begin a master's degree in experimental medicine in 2015. Virginie believes that her master's degree will enable her to better invest in her patients in the future: "I am convinced that this course of study, in parallel to the pursuit of my doctorate in medicine, will equip me with tools to better face future clinical and research challenges and will make me a more well-rounded clinician." Virginie will continue to pursue her objective of bettering the quality of life of patients when she undertakes PH research as part of her postdoctoral studies.

SUPPORTING PHA CANADA'S PH RESEARCH SCHOLARSHIP PROGRAM

Research into pulmonary hypertension is a crucial source of hope for our community and PHA Canada is committed to fostering its development through these scholarships. We will be awarding a third research scholarship in 2017 and look forward to continuing our support of young researchers into the future. For members looking to make a tangible impact on the future of PH, donating to and fundraising for our research program presents an exciting way to get involved. To find out more, please contact our Executive Director, Jamie Myrah, at **jmyrah@phacanada.ca** or at 1-877-774-2226 x101.

Get Ready for November PH Awareness Month

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 view the month of November as a 30-day challenge that all our members and supporters can get involved in, so that together we can create a better life for all Canadians affected by PH. There are many ways in which you can participate in November Awareness Month activities and we have designed tools to help everyone reach out to their networks and show the world what periwinkle-power is all about!

JOIN OUR *LEND A HAND* CAMPAIGN

The *Lend a Hand* campaign makes it easy for anyone to get involved in raising awareness at work, school, or among family and friends. When you order a *Lend a Hand* kit, you receive everything you need to inform those around you about PH, collect tokens of support, and even raise funds for PHA Canada. Our kits have been completely redesigned so if you have taken part in *Lend a Hand* in the past, we invite you to renew the experience with brand new materials! Visit **phacanada.ca/lendahand** to learn more and order your kit before October 20th.

HOST AN AWARENESS EVENT IN YOUR COMMUNITY

Thinking of hosting a special awareness event in your community? PHA Canada staff are here to provide support, materials, and guidance. There are countless ways in which you can make an impact: host an awareness table, request a PH Awareness Month proclamation from your municipality, give a presentation at a local community centre, or organize a *6-Minute Walk* event. Get inspired by visiting **phacanada.ca/novemberawarenessmonth** or contact us at 1-877-774-2226 x102.

FOLLOW US ON SOCIAL MEDIA

Social media presents an important opportunity to make a big periwinkle splash for November PH Awareness Month! Follow our Facebook and Twitter feeds (@PHACanada) throughout the month to stay connected and share posts with your networks.

RAISE FUNDS TO SUPPORT PHA CANADA

PH Awareness Month is the perfect time of year to raise funds to support PHA Canada's programs and activities. As a registered charity serving the PH community, we rely on donations to maintain our programs and develop new initiatives to support all Canadians whose lives are affected by pulmonary hypertension. One way you can help us raise necessary funds is by creating a personal online fundraising page, through which you can ask your family and friends to make a donation to PHA Canada. Creating your own personal page is quick and easy. It's also a great way to raise more awareness as you reach out to all your contacts for support! Visit **phacanada.ca/pledgesforph** to build your fundraising page or contact our Communications Associate, Mariane Bourcheix-Laporte, for assistance at **mblaporte@phacanada.ca**.

REQUEST A PHA CANADA SEED GRANT

PHA Canada has a limited amount of money available to support member-driven events such as support group meetings, special community gatherings, educational forums, and awareness and fundraising activities. Our seed grants are designed to help our members organize events that will benefit the PH community. If you're planning an awareness event for November, preparing a special support group gathering, or have big ideas for projects to come, we invite you to fill out a Seed Grant Request Form. To discuss your ideas or obtain more information, please contact Jamie Myrah at **jmyrah@phacanada.ca** or 1-877-774-2226 x101.

Connections submissions guidelines

The deadline for submissions for the next issue of *Connections* is November 15, 2016. ***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. We'll accept articles, personal PH stories, quotes, photos, tributes, poems, drawings, and more for publication in the magazine. 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 about!

Please send submissions including your contact information to:

Mariane Bourcheix-Laporte
connections@phacanada.ca
Subject: Connections submission

We look forward to reading your stories!

Work submitted will be printed as space permits.

Imagine Canada Standards Accreditation

In May 2015, PHA Canada became accredited as part of the Imagine Canada Standards Program. This is a big step for PHA Canada, who has now joined the ranks of Canada's most trusted charities and non-profits! To receive this accreditation, organizations must demonstrate excellence in the areas of Board Governance, Financial Accountability and Transparency, Fundraising, Staff Management, and Volunteer Involvement. To learn more about this accreditation, visit **phacanada.ca/accountability**.

Connections 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.