



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

CONNECTIONS

The Official Magazine of the Canadian PH Community

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Message from the Board Chair: Caring for those living with PH



Hello PHriends,

As summer comes to an end, I trust you are all rested and ready to move into the hectic fall schedule of preparing ourselves and our families for back to school, getting busier at work, or the coming winter.

The fall is a busy time at PHA Canada, as we prepare for our annual November Awareness Month and many other large campaigns. Our amazing staff are already busy supporting PHA Canada chapters, small support groups, and even families and individuals across the country who are working hard to improve awareness of PH in their communities. Indeed, incredible awareness and fundraising activities are held all year round, including over this past summer, where we witnessed a walk/run for PH research in Ajax, ON., and the fantastic 'GolPH for PH' tournament in Brampton, ON.! It demonstrates immense dedication when families are dealing with the burden of an illness like PH, and still find the energy to do so much for the cause. To show caring not only for a particular individual living with PH, but towards our entire PH community of patients and their caregivers through holding an event, is truly commendable. We are fortunate to have many such individuals in our PHamily.

These PH caregivers and supporters and their work always remind me that one of the strongest human needs is to care for someone else. It is clearly what motivates many of us to initially pursue the role of a healing professional, as a physician, a nurse, a pharmacist, or a therapist (respiratory, physio, occupational, or other). Even in the absence of any formal education in healthcare, many individuals learn to care for someone else living with PH, most commonly a spouse, child, parent, friend, or neighbour. Such caregivers are a vital part of our Canadian PH community, because they often do far more than caregiving. They also advocate, fundraise, and increase awareness of PH amongst everyone they know. In this issue of Connections, you'll read about Carys Dempsey. She may be a 'junior caregiver' at only 7 years of age, but make no mistake: she's already a powerful force in the Canadian PH community! She looks after her mother and PHA Canada Ambassador, Nicole, and is becoming world-renowned for her beautiful purple T-shirts, displaying her original design of flowering healthy lungs!

At PHA Canada, we continue to educate, support, and care for PH patients and their caregivers. New and exciting programs include our first PH Counsellor, Alyson Quinn, who will soon be available by phone to anyone in Canada who needs to talk about the mental health challenges of living with PH. One of our most important concerns in the care of PH patients is ensuring the access of all Canadian PH patients to all effective, approved PH therapies, regardless of their personal financial resources, private insurance coverage, or province/territory of residence. Indeed, such advocacy on behalf of the Canadian PH community is one of the 5 key priorities in our Strategic Plan. You can also get involved: help PH patients across Canada by engaging in our new Advocacy campaign, targeted at individual Provincial/Territorial Health Ministers and the managers of the individual Drug Plans. You can advocate to these government committees easily with our special email tool – just visit www.phacanada.ca/takeaction to learn more. As well, continue to share your stories of living with PH—the frustration, the sadness, but also the victories and especially the hope - with us, with the media and with the public.

The caring we all continue to show should make us proud of what we've accomplished. Canadians affected by PH are being treated better than ever before, and living longer and better lives. Here's to looking forward to an even brighter future! With hope,

Dr. Sanjay Mehta
PHA Canada Board Chair



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Mining for answers: my road to diagnosis

My name is Quentin Mosiondz, and on August 22nd, 2014, I was diagnosed with pulmonary arterial hypertension. Before that day, I don't think I had even heard of the disease.

In the year leading up to my diagnosis, I started getting tired when walking or wrestling with my boys. It just seemed like it got harder to do regular things. I shrugged it off for the first little while, blaming myself for being out of shape and getting older. At the time, I was working in the mining industry making nickel, so I was moving throughout the day, and it could get really hot in the summer and cooler in the winter. I transitioned from surface to underground mining in the beginning of 2014, that's when it really started to bother me. At the start of a shift, we would have to walk for about 1000 yards to get to the jeeps that would take us down to where we worked. By the time I got there, I would sit in the back of the jeep and take deep breaths until I felt better because I was so tired out. As the days went by, it took me longer and longer to get my breath back.

In May, I went and saw my heart specialist in Winnipeg to tell him what I was experiencing. I live in Thompson, Manitoba, which is an 8-10 hour drive depending on the weather. It's not like I can just go and see the doc-

"A week later, the doctor called and told me that I might need a heart transplant. News like that hits you hard: after I got off the phone, I remember holding my wife and just crying."

tors: I have to take days off work, and so does my wife. I saw a cardiologist who ran some tests, and then went home to wait on my results. A week later, the doctor called and told me that I might need a heart transplant. News like that hits you hard: after I got off the phone, I remember holding my wife and just crying. I was so scared and not sure of what was in store for us. In July, I went in for more tests and changed cardiologists because mine was retiring. The new cardiologist wanted to run more tests in September, this time to look at my lungs. However, on August 5th, I ended up in the hospital with the worst chest pain that I had ever felt. I was in the hospital for 7 hours and they did blood work and chest x-rays, but still could not find out what was wrong. While all this was happening, I had been continuing to go to work.

Because of my hospitalisation, the cardiologist made arrangements for me to get the tests done earlier. On August 18th, I had an MRI, a VQ scan, exercise tests, a walking test with oxygen and without, and a right heart catheter. I learned that the pressures in my lungs were 4 times higher than they were supposed to be and that I had pulmonary hypertension. They wanted to start me on pills the next day, and also told me that the pills would only slow down the disease, and that at some point, I would need a heart and lung transplant. On August 23rd, they started me on Bosentan - 62.5mg, twice a day. The Bosentan worked great for the first few months: I had more



Quentin and his wife sharing a PH purple selfie for World PH Day on May 5th, 2015!

energy and just felt good. However, December and January came and I had to spend more days at home just lying around. Going through all this, I continued to work on days that I could work. I didn't go back underground because it had been too difficult: I'm on surface working in an office, which is easier, thankfully. On January 26th, I went in to see the lung specialist to do my 6 minute walk test: it turned out to be the worst 6 minute walk that I had done. My team decided to put me on sildenafil, so now I'm on 125mg of Bosentan twice a day and 25mg of sildenafil three times a day.

Since I have been on the sildenafil, things have been steady. There are still days where my energy is not as good, but I have a lot more days that are better. When I finally got back home, I had some rough nights with lots of crying and feeling sorry for myself. I was always wondering if the next chest pain would be the one to put me in the hospital; if I would see my boys start their own families; if I would see my grandkids; if I would make it to my next birthday or my wife's; if I would get to grow old with my wife. I started feeling sorry for my wife and my boys: there were a lot more things put on them because I could not do certain things anymore. At times, I would lie in bed or be sitting by myself and just start crying as all these different emotions and thoughts would come rushing in.

It has been a year now since I have been first diagnosed, and I take each day one at a time and avoid worrying about little things. I can always tell what kind of day I'm going to have just by putting on my clothes in the morning. There are days when just getting dressed or taking a shower makes me fatigued. On those days, I try just relax as much as possible. If I need to rest, I rest; if I can go for a walk, I go for a walk. If you were to see me on the street, you would have no idea that I have a disease: I don't use oxygen, and I can still work. I can't thank the company I work for enough for how patient they have been with me. I thank my family and friends for being there for me, and being there for my wife and boys. They say things happen for a reason, and I know I am truly blessed to have such a wonderful wife who has put so much on herself and my boys that help out so much. I'm so grateful.

Contributed by: Quentin Mosiondz, PH patient, Thompson, MB.



Article author Carys, who is wise beyond her 7 years.

My life as a junior PH caregiver

My name is Carys Dempsey and I am 7 years old. I love to draw, colour, play outside, go to the park and play with my 3 dogs. When I grow up, I want to be a Vet. I'm also a caregiver to my mom, Nicole. My mom has pulmonary hypertension. I was only 5 years old when she was diagnosed and my younger sister Paisley had just turned 4 years old. Our lives changed a bit when she was diagnosed and I remember crying and feeling scared because I didn't know what was going to happen. When my mom first came home, she had oxygen tubing and that scared me a bit, but then I got used to it. My mom explained to me exactly what PH was by drawing a picture and it helped me understand what was happening to her heart and lungs. I know that PH is a disease which makes my mom's arteries in her lungs smaller, and blood can't get through them, so her heart has to pump harder.

cont'd on next page



PH patient Nicole and her daughters, Carys (left) and Paisley (right).

I love helping my mom. I always ask if she's OK, if she's out of breath or if she needs anything. I also help with our dogs, with chores and gardening and I even like to make her coffee. Lately, I have been helping her with her Caripul supplies. When she has to prepare her cassettes, I like to get everything she needs. My sister likes to help, too. I know exactly what she needs: 1 cassette, 2 syringes, 2 needles, alcohol swabs, 2 vials of sterile water and 2 vials of Caripul. I bet I will learn how to do the mixing one day.

The hardest part of my mom having PH is that she can't do some of the things that she used to do with us, like go running, playing or chasing us. But, we can still cuddle, play games like CandyLand, read together and watch movies. Those things haven't changed.

"When my Mom has hard days of not feeling good, all I want to do is help her."

I wish she didn't have PH. I don't like it when she's tired, out of breath or sad, and I don't like it when she gets pain in her jaw (her new medicine makes that happen). I know things are hard for her and I try my best to make things better. When she has hard days of not feeling good, all I want to do is help her.

I've learned a lot about PH. I know that it's a rare disease and that we need money to find a cure. I know her medicine helps her, but it will not take the PH away. I also know that one day, she might have to get some new lungs. I hope that doesn't happen, but if it will make her feel better, then that's ok. I wear my PH bracelet every day so people know that I support my mom. Last summer, my sister and I had a lemonade stand and we made over \$300 which we donated to PHA Canada. We would like to do that again this summer. I also designed some pretty lungs which were used on t-shirts and on greeting cards. That made me feel happy and proud.

Even though my mom's PH changed our lives a bit and we have some sad moments, we always seem to get through them, because we think of happy things and because we love each other.

Contributed by: Carys Dempsey, PH caregiver, Cambridge, ON.

Travel and other perks for PHriends

Many of us attended the 4th National PH Conference in Montreal in May. In addition, many of us had to travel long distances in order to get there! I hope everybody took advantage of the various travel discounts available to us when we travel. We are disabled, however invisible this disability might be. So, if you are newly diagnosed or have been fighting this disease for a long time, there are a few things that can be done to reduce the financial burden. This is not a complete list and there might be differences from province to province, but use it as a starting point to seek those benefits.

First of all a disclaimer: I am not an expert, nor

do I give advice about taxes or the other topics I write about in this article. This is intended for general information only and is in part based on my own personal experiences. All of this information is available on various government and business websites. You should seek out professional advice from the appropriate people if you can't navigate through the information on the web or have more detailed questions.

The Disability Travel Card

The Easter Seals Canada (easterseals.ca) has a Disability Travel Card. With this discount card, the disabled person pays the fare and one com-

panion/caregiver can travel free on VIA Rail, Greyhound Bus, Coach Canada, and all Motor Coach Companies of Canada. When applying for this card, also apply for the Access2 card. With this card, one companion will get free entry into participating movie theaters and many attractions and museums across the country. The travel card is free and for life, while the Access2 card has a small fee and will have to be renewed every five years. There are as many other discount programs across the country as there are rail and public transit systems. For example, when traveling by GO transit in Ontario, all you have to ask for is a companion ticket at the ticket counter.



Article author Juergen, diligently reading his Spring 2015 issue of Connections magazine!

There are no passes or special ID-cards needed. Again, one companion rides free with you. The Toronto Transit Commission requires their own special TTC Support Person Assistance Card. A quick check on Google reveals requirements for other public transit systems: please investigate what is available in your specific region.

Flying

WestJet has a "One Person One Fare" (OPOF) program where an additional person can fly for no charge. This program applies only to flights (not vacation packages) within Canada, and there are limitations and certain requirements and forms to be dealt with. The WestJet website (WestJet.com) will again be your starting point for this information.

Handicap Parking Permit

This is a must for all of us, since at times, we need to park as close as possible to where we want to go. These permits are issued by the province you live in and the process will be different for each. Feel free to investigate what is needed in the jurisdiction you live in.

The Disability Tax Credit

Since about 2007, there has been a Disability Tax Credit available to us individuals with disabilities. It requires that you get a form filled out by your physician and submit it to approval to Revenue Canada. The form can be retroactive, which means that you can apply for the tax credit

for previous years if you were disabled in those years and your physician can attest to that. Once (and if) Canada Revenue approves the request, the tax credit can easily be applied retroactively to all years in which you have been qualified as having a disability. These forms are available on the web and with a little time investment, they can be filled by the individual. If you don't have income or a low income, these credits can also be transferred to a spouse. Just a little bit of advice: be careful if you want to use some of the Disability Tax Credit promoters. They do all the work for you, but charge a steep amount off the top of the tax credit when it gets paid out. The government is working on limiting the amount they can charge.

The Registered Disability Savings Plan

For individuals under age 59 and parents of disabled children, there is also the Registered Disability Savings Plan (RDSP). The RDSP also accesses the Canada Disability Savings Grant and Canada Disability Savings Bond. Depending on the income level of the individual or the family, the government matches RDSP contribution up to 300% or pays into the plan on behalf of the plan holder. This is free money, so educate yourself or obtain advice! Start here: www.cra-arc.gc.ca/tx/ndvdlis/sgmnts/dsblts/menu-eng.html
I hope my message motivates you to take advantage of these programs if you are not already doing so. Living with PH is hard enough, so let's welcome anything that can make it easier.

REFERENCE RESOURCES USED:

Easter Seal Disability Travel card:
easterseals.ca/english/disability-travel-card

Access2 card:
www.access2card.ca

GO:
www.gotransit.com/public/en/fares/tickettypes.aspx#PassengerCategory

TTC Support Person Assistance Card:
www.ttc.ca/Fares_and_passes/Support_Person_Card/index.jsp

WestJet:
www.westjet.com/guest/en/travel/special-arrangements/special-needs/one-person.shtml

Handicap Parking Permit Ontario:
www.ontario.ca/driving-and-roads/get-accessible-parking-permit

Disability Tax Credit:
www.cra-arc.gc.ca/E/pbg/tf/t2201/README.html

Registered Disability Savings Plan:
www.cra-arc.gc.ca/tx/ndvdlis/tpcs/rdsp-reei/menu-eng.html

Canada Disability Savings Grant and Savings Bond:
www.cra-arc.gc.ca/tx/ndvdlis/tpcs/rdsp-reei/cdsg-eng.html

Contributed by: Juergen Buttemeyer, PH patient, London, ON.

Living with PH Secondary to a Congenital Heart Defect: Eisenmenger's



Article author Carolyn.

I originally wrote my story for the book "The Heart of a Mother" which is about mothers either raising a child with a congenital heart defect (CHD), or having a heart defect themselves. However, my pulmonary hypertension played a huge part in my life. My PH was never given a name, but after learning about it, I realized it was the PH that affected my life more than the CHD.

My name is Carolyn, and I was born in Toronto, Ontario, Canada on April 23, 1948. I was diagnosed with a ventricular septal defect when I was about nine months of age. Dr. John Keith performed a catheterization at the Hospital for Sick Children in Toronto when I was about ten years old. My parents were told that I had developed Eisenmenger's syndrome when my heart defect caused damage to my lungs. Although surgery could correct the heart defect, the pressure in my lungs had caused irreparable damage, thus heart surgery would actually endanger my life. I did not have surgery and was left to try to lead a normal life.

This was difficult, because I was never able to keep up with the other kids. They did not understand how much it hurt me to be left behind. I was never able to take part in sports, and I always felt like a fifth wheel sitting on the sidelines. Even when there was a sport that I could participate in, I was always the last one chosen because I was never good enough. I was not allowed to go outside at recess during the cold Canadian winters. Although some children envied that, I was still left feeling different.

As a youth, I always felt rather homely, being tall and awkward and having "four eyes" and mousy brown hair. But, in the eleventh grade, I blossomed. I got contact lenses and coloured my hair blonde. What a change: there was no holding me back! Lots of boyfriends, dances, and fun!

Later, having married and adopted two children, I was very fortunate to have been able to be a stay-at-home mom. I know that I would not have had the physical stamina to work full-time and raise a family. I feel very fortunate in that my CHD and PH did not have a profound effect on the way I was able to raise my children, nor did it adversely affect the lives of my children. Luckily, my children were very well-behaved, and did not wear me out physically. But, I was not able to do some of the things other parents were able to do with their children. Winter sports were probably the most difficult. As a teenager, I had given skating a try but never learned to skate; however, when they had free skating for preschoolers, I got myself a pair of skates and did the best I could skating with my children. It was like we were all beginners. And, in time, when they learned to skate, off they went by themselves. I would have loved to have taken my kids tobogganing or skiing, but was not able to take part in this type of winter sport. Summer was not so difficult. Every summer, we would head off to the provincial parks with our camper. We did some hiking, but I avoided the big hills because I couldn't breathe. As long as I had my husband by my side, I was not afraid of getting into a situation with the children that I could not handle.

I became a Brownie leader, but was always careful about the kinds of activities chosen. The winter season has always been difficult for me, because I tire much more quickly when exerting myself in cold weather. I remember when the Brownies would have a winter activity day, I just would not go because I could not take part in some activities, and I did not want to have to explain why. I was always afraid of getting myself into a situation that I could not handle. The most memorable of those for me was when we took the girls on a cookout at the beach. We had to go down a big incline to get to the beach, which was fine. But, as you can guess, the return trip was terrible for me. I had to keep stopping to rest - I was so out of breath. Another time we took the Brownies and Beavers (five-year-old boys) up to Ottawa and walked the cold, windy streets. But, I trudged onward because I would not give in! I continued being a Brownie leader for seven years.

I was always the first parent to volunteer on class trips. I was fearful that I would get myself into a

"Although my CHD and PH caused me to miss out on a few things in life, the truth is, I have not missed out on any of the really important things."

difficult situation; however, that never happened! I was also a parent volunteer in the special education classroom of our school for two years, working two mornings a week with children with learning and behavior problems.

Sadly, in 1988, my marriage of nineteen years ended, leaving me to raise my two teenagers on my own. Those were difficult and stressful years, but I am proud to say that we made it! Being a grandmother is a little more difficult for me physically than being a mom was. I find that over the years, my physical stamina has decreased and that I suffer from a lot of joint pain due to my heart condition. However, I continued to push on—to refuse to let my CHD and PH bring me down. If anything, my health issues have taught me to appreciate every day and to enjoy life to its fullest. My heart may not be perfect, but the love I have inside it helps me to achieve more than I ever thought possible.

I am truly thankful that I have been able to lead a fairly normal and active life. Although my CHD and PH caused me to miss out on a few things in life, the truth is, I have not missed out on any of the really important things. I am so happy that I was able to experience motherhood and all the joys that go with it. I continue to keep very active with many volunteer activities and organizations. I have retired from work, my two grandchildren have grown up, and I have remarried (thus giving me 3 more children and 7 more grandchildren). The PH still affects my life, although the new medications have kept me stable. I will continue to push on for as long as I can.

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Contributed by: Carolyn Robinson, PH patient, Sarnia, ON.



Article author Lise Demers.

Beating the odds: living with PH for 46 years!

I couldn't tell you how I had felt when I first heard about PAH, because it happened during my early childhood. I was born with PAH secondary to a congenital heart defect called Eisenmenger syndrome. So I can't really say how I felt about facing these diagnoses, but I have learned over the years to live with my conditions and to accept them, even if it hasn't always been easy.

I had a heart attack at three weeks old. It was during those medical tests that my parents learned that I had PH. When I was born, I weighed 8.5 pounds, and when I was 4 months old, I weighed 5. No-one could tell what my prognosis would be, but I'm still alive today! Because I have lived with my conditions since birth, they never changed my life. I've grown up with them, so I don't have a reference for 'before PAH' and 'after PAH'. As I often say, "I'm normal in my own version of 'normal'." I live day to day without thinking too much of the future!

One of the impacts that PAH has had and continues to have on my life is that the disease prevents me from living an active lifestyle. In one instance, I had to abandon my work because it was causing me too much stress and fatigue. I was often sick and being hospitalized. My cardiologist at that time therefore strongly suggested that I quit my job. As a child, I had to learn to be different from other kids my age, and to not be able to be involved in several activities. Of course, my parents also had to choose family activities around my limitations and conditions, which my sisters weren't always happy about, but they understood.

The hardest thing for me was having to put some of my dreams aside, especially the dream of having children. I had to have my tubes tied when I was 18 years old. I also had to put aside the idea of travelling without worry-

ing about what could happen. Despite these difficulties, the most positive thing for me has been continually beating the odds and defying the doctors who had often told my parents that I wouldn't live beyond 5 years old, then 10 years old, then 20 years old. I'm now 46 years old and look forward to continuing to beat the odds for years to come!

One significant event in my journey took place when I was 20. For my 18th birthday, a family friend gave me a book by Diane Hébert, the first Quebecoise who received a heart and lung transplant and who had practically the same condition that I did. As soon as I finished reading the book, I closed it while saying to myself that I would never want to go through that. I told myself, then and still do now, "I was born with my illnesses, and I'll die with them." Two years later, I was at the Royal-Victoria Hospital for a period of three weeks to have an evaluation for a heart and lung transplant with Dr. Levy and Dr. Fletcher. What a shock! I was evaluated on two other occasions for transplant.

Over the years, I learned that my PAH is different from others who have recently received their diagnoses. I don't have the same symptoms, because my heart and lungs developed together. It makes it so that I don't really experience the same thing. I would have a lot of difficulty communicating with and understanding someone who is newly diagnosed.

My family and my partner have always supported me through difficult moments, and are still here for me. I know that I can count on them! They experience the same pain and stress as I do whenever a challenge arises, and they encourage me a lot as well. I am a pretty strong person, and this is what helps me overcome the obstacles along my path.

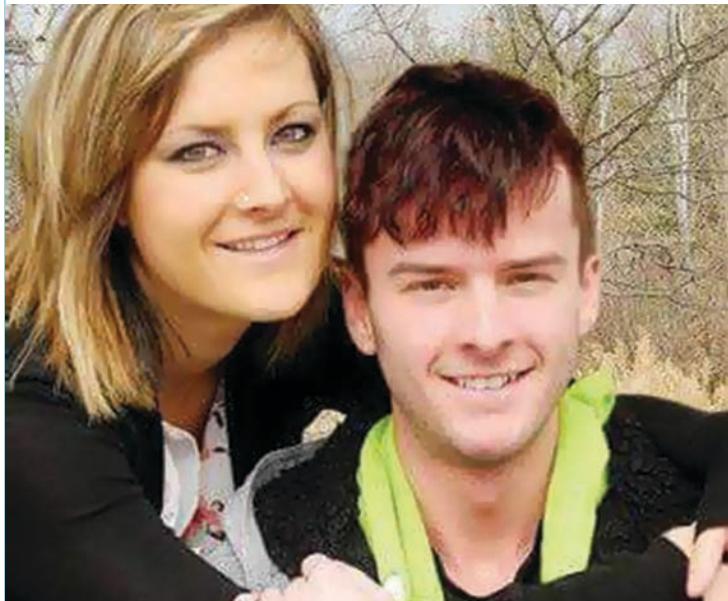
Contributed: Lise Demers, PH patient, St. Nicolas, QC.

Summer Events Special

Summer is a ‘PHantastic’ time to host an awareness or fundraising event. The weather is warmer, kids are out of school, and people often have more time to organize and attend different types of events. At PHA Canada, we’re dedicated to supporting community members in raising money for PH research or planning an awareness event. We were so excited to witness these three summer fundraisers! While each event was different in activity and motivation, what unites them was their dedication to supporting all people living with PH. We’re honoured to feature the stories of each of these events below.

Your Community

Stride for Brenden – a tribute to my brother



Shawna and her beloved brother Brenden.

I was first introduced to pulmonary hypertension 5 years ago when my little brother, Brenden Brinkworth was diagnosed, and had happily been one of his main caregivers ever since. I decided to start holding an event three years ago when I met another woman, Kriss Ross (who is also a PH patient) and the Mullin family at a walk for PH at the Ottawa Heart Institute. Hanna Mullin and I began discussing how our small town knew nothing about this illness and how great it would be to raise awareness, as well as funds, for our family member and for others suffering.

When thinking about what kind of event to hold, originally Hanna Mullin and I talked about our own interests, such as running and hiking. However, I also wanted to do something that would cause us to become out of breath. Completing a 5k is tough and hot, and you are left tired and out of breath. But for those of us without PH, that feeling of being out of breath goes away. For my brother, Hanna’s dad Sean Mullin, Kriss Ross and everyone else with pulmonary hypertension, that feeling never ever goes away. For Brenden, Kriss and Sean to see us all cross that finish line for them, and to see their smiles is part of what makes it so worth it.

My main motivation to do this run was my little brother, Brenden. Despite being 15 years old at the time of his PH diagnosis, he never, ever complained. He smiled and managed to laugh while the rest of us tried to come to terms with what the doctors were telling us. His motto was that he couldn’t change it, so he had to learn to live with it. If he could get through the challenges of his disease each and every day, there was no excuse that the rest of us couldn’t run a small 5km on just one day.

In organizing any event, there are always the nerves about things not going as planned or not reaching our goals. However, this year there was a much different feeling while planning. The last two years I had my little brother to vent to: you would swear sometimes that he was the older sibling! However, this year, January 11th at 11:20pm we had to say goodbye to the man who literally shed light on us every single day. Brenden lost his battle with pulmonary hypertension after catching mono, which caused his liver to fail, leading to cardiac arrest and days later, his passing. Because of losing Brenden, the emotions planning this year’s event were overwhelming at times. I didn’t have Brenden to call when I needed, and this year, he wasn’t going to be there. There was anxiety, sadness, and a very overwhelmed feeling. However, I knew that if Brenden were here and I could call him, he would say what he always had: “you can’t change the past, move on to the future and do what you can.” And so as hard as it was this year, I knew that Brenden would have wanted us to push forward.

So, for Brenden and for everyone struggling with PH, this year we held two small events. The first (which we will continue every year, as it was such a hit) was a Volley for Brenden Tournament which we held on June 6th at 10AM. On June 20th, we held the 3rd annual Stride for Breath – but this year, it was Stride for Brenden.

This year, we did not have a specific fundraising goal. Our main goal was to keep Brenden's name going and raise awareness. To have so many people at each event asking questions and taking flyers showed that we achieved our goal. We also were proud to raise \$4300 for PH thanks to the amazing family and friends who became involved.

One extremely memorable moment took place at the event when I spoke to a man who had lost his niece not long ago to PH. Her story was identical to Brenden's and a lot of other patients. Until our event, he hadn't known anyone else in this area who was affected by the disease. Connecting with him made it very clear that by holding an event, big or small, we were making a difference.

At the end of the run, we decided to release purple balloons in memory of Brenden and others struggling with this illness. To see kids, adults and seniors come together, shedding tears as we watched the balloons float up into the sky, gave

"If he could get through the challenges of his disease each and every day, there was no excuse that the rest of us couldn't run a small 5km on just one day."

me such a profound sense of accomplishment. I remember getting chills, and somehow I felt like my baby brother was by my side and that he was proud of me.

All in all, I would recommend the experience of holding an event to anyone. In the end, it doesn't matter how big or small the event is. It doesn't matter if you raise \$50 or over \$5,000. What mat-

ters is bringing people with PH, friends and family together to raise awareness so that others can have earlier diagnosis and don't have the same experience as my brother. Every cent helps, and having one more person who knows about PH is one more person to help spread the word. The larger our number, the stronger we are.

I believe one of the main lessons for myself and others is that life is short. We have to live it to the best of our ability, because we never know when that chance will end. Brenden was only 21: he was strong; he had a job; he had an amazing fiancé, Scott Thibaut, who he loved dearly. He had a bright future and a family that adored him. His life was taken from him so suddenly - we did not know he had mono, we just assumed it would be another regular hospital visit. That he is now gone is such an eye opener about how fragile life is.

The main hope I have is that my brother's name will never ever go forgotten. He was such an amazing young man, who we love and miss so much. If spending time organizing events will have people remember who he was as a person, while at the same time raising awareness that could help other families, this it is something we will always do for him.

Contributed by: Shawna Brinkworth, PH caregiver, Cornwall, ON.



Some runners proudly showing off their t-shirts!



Above: the entire group celebrating a fantastic first 'GolPH for PH' fundraiser!

Opposite page: some moments from the incredible golPH tournament!

GolPHing for PH!

"I would absolutely recommend organizing an event to anyone considering it. It's a ton of work, but knowing you are doing a good job for a fantastic cause is very gratifying."

Our daughter Brooke was diagnosed with PH in March of 2014. She was my motivation to choose to hold a fundraising event. When I began planning, I was the lone organizer and was trying to do it all myself. I was quickly convinced to reach out and get others involved.

Our event was called GolPH for PH: a golf tournament fundraiser. It took place on Monday, July 13th at Lionhead Golf and Country Club in Brampton, Ontario. Why a golf tournament? I thought of some activity that I could raise funds through, and since I have been to countless golf fundraisers, I thought it would be a good avenue.

Because it was the first year we'd organized something, our goal was to raise \$10,000. That goal was based on having 120 golfers. We end-

ed up having 73 golfers and raised just under \$8,400. We were very pleased with that, as it was our first event!

One memorable moment during the day occurred when I was chatting to one of our generous sponsors, the Brampton Beast Hockey Club. Explaining PH, what it was and how it affects patients, to the two staff, stood out to me. Like most people (including myself before Brooke was diagnosed) they hadn't heard of PH, because it's a very little known disease. Hopefully with events like this, we can spread the word and help people to get diagnosed earlier.

I was the event's main organizer, but I couldn't have done it without the fantastic help of the team at PHA Canada (Angie Knott and Shir-

ley Wong), and our very generous sponsors (Actelion, Unither, Bayer, Pepsi, Starbucks, Sobeys, Brampton Beast). I was also grateful for the help of family like my wife Joan, daughters Brooke and Jodi, niece Carolyn Anthony, and friends of family, TK and Jackie. Reagan Carnegie was very helpful in instructing us on how to run a tournament, Rob Faultley secured the Pepsi donation and graciously printed the hole sponsorship signs, and Frank Rooke secured various donations. Finally, I couldn't have done it without Bruce Hustins at Hanson, Tony Reda at Rampower, Loreto Capobianco who worked the dona-

tion of the Weber BBQ, and our good friends Steve and Marie Granger who generously provided some raffle prizes.

I would absolutely recommend organizing an event to anyone considering it. It's a ton of work, but knowing you are doing a good job for a fantastic cause is very gratifying. I think the major impact of this event was that it raised awareness. Through the 80 or so people attending and affiliated with the event, there are now more people that know about PH and are willing to help at a moment's notice. Wow!

Contributed by: Patrick Paulin, PH caregiver, Brampton, ON.





Event organizer Renae (rightmost) with PH patient Marion Roth (centre) and her daughter Whitney.

The Second Annual PHA Canada Run/Walk for Research: Running for our Mother

My brother Joseph and I are children of a parent with idiopathic pulmonary arterial hypertension. Our mom was diagnosed with IPAH 6 years ago, when I was 15 and Joseph was 13. Throughout the years, we have witnessed the devastating impact PH has on the lives of patients as well as their family members.

Last year, Joseph and I chose to hold our first ever event for PHA Canada, a 5km run/walk fundraiser to raise money for PH research. This year was our Second Annual PHA Canada Run/Walk for Research. We did this because there is not yet a cure for PH. We see firsthand how PH affects our mom and others like her. It is important to us to contribute to a research fund, to hopefully one day find a cure for PH, and in the meantime, to hopefully increase the quality of life and life expectancy for people living with PH.

“Holding an event is a great way to bring members of your home community, as well as the PH community together in unity.”

We chose to do a 5km run/walk event for our fundraiser because walking and running are activities that most people don't think twice about doing. People living with PH experience difficulties in these activities most of us take for granted. Our mom experiences varying degrees of shortness of breath when she walks, and is not able to run as a result of her PH. We chose a run/walk to remind ourselves, and others just learning about PH, of how lucky we are to be able to breathe properly while walking and running.

Prior to organizing both of our events, we felt very excited about raising funds for PH research! But for the first year of our fundraiser, that excitement also came with nerves. It was the first time our family had put on an event this size, let alone a fundraiser for a rare lung disease which most people have never even heard of. We had no idea what to expect for turn-

out and funds raised. This year, we had a better idea of roughly how many people would come out to support the cause, and were blown away by the generosity of our family, friends and people within our community. We learned that your community will pull through for you.

The Second Annual PHA Canada Run/Walk for Research took place on Saturday, June 27, 2015, at 9:00AM on the Ajax Waterfront. While it was a hectic day, the most memorable moment was when I crossed the finish line and finished my run. For me, this run was significant because I did not just run for myself, but for my mom too. I was thankful that I was able to run, thankful that the weather held up, and thankful that so many people came out to support the cause.

While Joseph and I were the main organizers of the Run/Walk, we wouldn't have been able to pull it off without our family members and close friends, who volunteered their time, helped us obtain prizes to raffle off, helped us with registration, donated prizes of their own and helped to set up and take down tents, decorations, etc. We are also very grateful to the several people and companies that donated amazing prizes for us to draw off to lucky winners – it was nice to give back to our community who had been so generous.

It's hard to believe now, but our goal for our first fundraiser last year was to raise \$500. We ended up raising \$5,995! This year, we aimed to raise \$6,000, and were ecstatic to have raised \$11,434.50 and counting! It just goes to show what you are capable of when you commit to something.

Without a doubt, we would recommend the experience of holding an event to others. It is such a great feeling to know that you are contributing to a cause that will positively alter the lives of people living with PH. Holding an event is a great way to bring members of your home community, as well as the PH community together in unity.

Our events have done exactly what we wanted them to. Regardless of the amount of money we raise, we feel successful due to the fact that every participant leaves the event aware of what PH is, and how it affects the lives of patients. Acknowledging that PH exists is the first step towards finding a cure, which is our end goal.

Contributed by: Renae and Joseph Mohammed, PH caregivers, Ajax, ON.

An update on the HTAPQ Foundation



Some of the HTAPQ Foundation's members!

The HTAPQ Foundation, which is based out of Plessisville, QC, has existed for 8 years with the goal of providing direct financial support to individuals living with PH. PH patients are generally

unable to work, which means they are faced with a significant loss of income.

The largest fundraiser that the HTAPQ Foundation holds is the bi-annual sale of cheese from the Abbey in Saint-Benoit-du-Lac, which takes place during the weeks before Christmas and before Easter. For the 2014 Christmas sale, our volunteers sold more than 3100 boxes of cheese! Many PH patients also help out with this sale.

As another fundraiser, we organize a yearly romance-themed Gala Supper for Valentine's Day, which is held at the motel Phare in Plessisville. For this evening, we have a PH patient or someone who has received a transplant give a short presentation to help raise awareness of the disease and its symptoms, as well as the challenges of daily living. This year, PH patient Sandy Vachon delivered a very touching personal account of her own life with the disease. The event helped us to raise over \$6000 in funds.

Anyone who wishes can also become a member of the HTAPQ Foundation for a fee of \$10 per year. The advantages of being a member include receiving 4 issues of our community newsletter "Le Virevent d'Isabelle" per year, and being able to participate in the conference that we organize every 2 years. At these conferences, we discuss recent discoveries in the treatment of PH and share ways to make living with PH, which is still an incurable disease, a little easier.

All year long, and particularly in November (which is PH Awareness Month), PH patients and their families can organize fundraisers in their areas with the support of the Foundation, to help us to collect funds to help patients. We encourage you to visit our website htapquebec.ca to learn more about our organization.

*Contributed by: Hugues Boulanger, Director,
HTAPQ Foundation*

Conference Focus

Honouring our Conference volunteers

"Without volunteers, a Conference cannot take place."

– Jas James

Volunteer support has been an integral part of Conference preparation and execution since PHA Canada's first Conference, held in Montreal in 2009. This year's 4th National PH Conference, also held in Montreal, was no exception. Our volunteers did everything from stuffing and distributing our Conference bags, to supporting registration, to setting up session rooms, to counting session attendance and distributing evaluation forms, to setting up and taking down signage, as well as countless other tasks. Dedicated volunteers are the people who make Conference such a wonderful gathering, so we want to express our deep gratitude to each volunteer who lent their support. This article features just a few of our Conference volunteers, and explores what they love about giving back to the PH community.

VOLUNTEER SPOTLIGHT ➤ Sarah Platnar, Pickering, ON.

Relationship to PH: My daughter Isabelle, who's 9 years old, has PH. I'm also the Chairperson of PHA Canada's Pediatric Committee.

How I helped at Conference: I worked with a team of pediatric committee members who organized and ran the children's programme at Conference. I also facilitated a parent support group session.

First PH Conference: Ottawa, 2013

What I learned: I learned that there are so many amazing patients and families in the PH community and that everyone is there to help.

The best part of Conference was: The best part about attending for me personally was to see my daughter Isabelle finally meet and interact with kids like her, who wear oxygen. When I asked her what she thought about the Conference, she said "The kids' room was awesome, and the best part was meeting kids like me. No one stared or asked me 'what is that on your face?'" Hearing this from my daughter was a true gift!

cont'd on next page



Above left: Conference Volunteer and PHA Canada Pediatric Committee member Sarah Platnar, surrounded by her family.

Above right: Sarah's daughter Isabelle is 9 years old and a PH patient. She loved the fun activities at Conference and meeting other young PHighters.

Above: Volunteer Bill (in green) with his wife PH patient Lenore (in blue) enjoying a session at our 2013 Conference.

Page centre: Volunteer Jas, having a silly moment with her periwinkle purple blanket!

VOLUNTEER SPOTLIGHT ▶ Bill Cook, Victoria, BC.

Relationship to PH: I'm a caregiver to my wife Lenore, who has PH.

How I helped at Conference: I provided session support and helped with set up, take down, and wherever else I was needed. Volunteers are always needed at a big event like this, and patients should be saving their energy for learning and connecting.

First PH Conference: Ottawa, 2013

What I learned: I'm always interested in medical progress (therapies and research), but more important is connecting with other patients and caregivers.

The best part of Conference was: I find that volunteering helps to enable interactions with others. This is what really enhances the Conference experience.

utting information to tables, packing and taping boxes with supplies. I had decided to volunteer at the 2015 conference because I want to be involved wherever I can.

First PH Conference: This was my first PHA Canada Conference.

What I learned: That there are many people who have been living well with PH for a long time, and that there are many amazing people who are dealing with PH from all sides. I also gained insight into lab research and clinical research studies, and learned that the options for treating PH are expanding relatively quickly. My biggest challenges in dealing with PH result from my own expectations. I also learned about options for medications, concerns for travelling with PH, being an advocate, and ways to better communicate to improve awareness around PH.

The best part of Conference was: Meeting so many inspiring people sharing their diverse knowledge and experience around PH.

VOLUNTEER SPOTLIGHT ▶ Jas James, Cobble Hill, BC.

Relationship to PH: I've been a PH patient for over 12 years.

How I helped at Conference: I helped to prepare and fill the Conference bags, and supplied the bags to the registration desk volunteers. I also hosted a breakfast table, moderated a session and volunteered in the kids' room. My experience as a volunteer was great: without volunteers, a Conference cannot take place, and it always feels good to give back.

First PH Conference: Montreal, 2009

What I learned: I learned to focus on what you can do, and not what you can't do. This was also an important lesson for the kids at Conference. I also learned lots at the 'Ask a Health Care Professional' session, where you can ask questions that are less common and you have more time to get them answered.

The best part of Conference was: Reuniting with everyone and meeting new attendees.

VOLUNTEER SPOTLIGHT ▶ Melissa Hutchings, Whitby, ON.

Relationship to PH: My twin sister, Amanda, was diagnosed with PH in 2010. I am her cheerleader.

How I helped at Conference: I was a volunteer in the Kids' Room. Amanda, along with a team, planned all of the events and activities. These included a "minute to win it" challenge, Teddy Bear Clinic, banner painting and t-shirt decorating, along with many other fun activities for the children. I helped to carry out what took this team countless hours to plan! Everything was so well planned that there was never a shortage of something for the children to do.

What a rewarding experience this was. It is always enjoyable to watch children engaged in play and to help facilitate this, but this environment made it even more special. Friendships and bonds were formed and strengthened during the time there, both for the children, parents, and volunteers.

Why I decided to volunteer at the 2015 Conference: Play is a very valuable thing, and parents having the time to learn and connect with others also dealing with PH is also so valuable. Having a children's program at a Conference allows both of these things to happen. I volunteered to help make this happen. Also, when you have a family member who is going through such a challenging time health wise, you are always looking for a way to help. Amanda's career involves working with children, and it is one of her many talents. PH has limited her ability to do this work that she loves, so I wanted to be her hands and body to carry out

VOLUNTEER SPOTLIGHT ▶ Ed Rathonyi-Reusz, Coquitlam, BC.

Relationship to PH: My three year old daughter received a preliminary diagnosis of PH in December 2014 with the diagnosis confirmed mid-January 2015.

How I helped at Conference: I assisted with setting up signage, setting up/distrib-



Volunteer Melissa (left) with her twin sister and inspiration, PH patient Amanda. These women light up the room, and their commitment to the cause of PH is so beautiful.

Above left: Volunteers Dale (second from right) and Lynndel (leftmost) with Wendy and PH patient Kendall. This fantastic foursome has volunteered together at Conference for years, and we don't know where we'd be without them!

Above right: Volunteer Craig with his daughter, PH patient Everleigh, at their first PHA Canada Conference in 2013.

what she would no doubt be doing herself, if she could. Volunteering was my way of being a help to both her and the other parents and children dealing with PH.

First PH Conference: Ottawa, 2013

What I learned: I learned what courage and a community of friends and professionals can do to help you PHight.

The best part of Conference was: Meeting the other resilient and tough PHighters and family members was definitely a highlight. Spending time with my sister (my best friend) was pretty good too.

wonderful people, to catch up with some old friends, and to make some new friends. We would do it again in a heartbeat.

Why I decided to volunteer: Wendy – I decided to volunteer at this Conference because it was our third and I just want to give back a little, for all that the Conferences have given us. Why wouldn't you give back? When someone you love hugs you, you hug back! Kendall – Why did I volunteer? Well it was more like Wendy told me that I was doing it!

First PH Conference: Toronto, 2011. This was our 3rd PHA Canada Conference and definitely not our last.

What we learned: Wendy – My biggest emotional problem when Kendall was diagnosed was the feeling of being alone, and the very first Conference we went to in Toronto changed all that. Kendall – I've learned that there are others like me, and thanks to our doctors, there are always new medications on the horizon to help us. I also learned that volunteering for clinical trials benefits us and others.

The best part of Conference was: Seeing old friends and meeting new ones, and listening to others' stories. The best part of this Conference was meeting a very special couple: they know who they are. I hope that we helped them know that there is hope. If we touch the lives of just one person at a Conference, like our lives were touched in Toronto, then we can go home happy.

VOLUNTEER SPOTLIGHT Dale Barnes and Lynndel Tracy, East Bolton, QC.

Relationship to PH: Lynndel's brother Kendall has pulmonary hypertension, and her mother died from it more than 30 years ago.

How I helped at Conference: We helped with putting the Conference bags together using an assembly line; at the registration desk; and wherever else we were needed. We had a blast, lots of fun!

First PH Conference: Toronto, 2011

What we learned: We always learn so much, it's hard to pinpoint just one thing!

The best part of Conference was: Getting to meet new people, and seeing old friends.

VOLUNTEER SPOTLIGHT Wendy Bedard (Conference Committee member) and Kendall Tracy, Mansonville, QC.

Relationship to PH: Wendy – I'm a caregiver to my husband: I live with him and love him. Kendall – My mom was diagnosed almost 40 years ago, and fought for 8 years before she lost her battle. Now I have a battle of my own to fight: It's been five years since I was diagnosed.

How I helped at Conference: Wendy sat on the Conference Committee to help plan the event. In addition, we helped with Conference bag packing, the store, moving tables and chairs, and registration. Whatever Angie or Bronwyn asked, we tried our best to help. Our experience was AWESOME: we got to meet many

VOLUNTEER SPOTLIGHT Craig Pierce, West Lorne, ON.

Relationship to PH: Our four year old daughter Everleigh is a patient.

How I helped at Conference: I helped out in the kids room, and also floated around, trying to help out wherever I could. I consider anything related to finding a cure, or helping victims and victims' friends and families cope with this devastating disease, a more than worthy cause to dedicate my efforts toward.

First PH Conference: Ottawa, 2013

The best part of Conference was: For me, it was the seminar with Dr. Duncan Stewart pertaining to research. Despite the lack of funding holding back research, he indicated that there is still hope in finding a cure for PH.

Thanks to each and every Conference volunteer for their dedication to our community. We can't wait to see you in 2017!



CONFERENCE 2015





Our 4th National Conference was held in Montreal from May 1st to 3rd, and was PHA Canada's largest community gathering to date. We welcomed 231 attendees and 55 speakers, and witnessed so many new and renewed connections. While we always present the latest in PH research, provide opportunities to speak in depth with medical professionals, and discuss ways to live better with PH, it's the togetherness of Conference that we love the most. To watch patients and caregivers share their experiences with the disease and gain understanding is nothing short of magic. The power of the Conference experience needs to be seen to be believed, so we're excited to share these beautiful 2015 Conference photos for the first time here in Connections magazine.

Opposite page (clockwise from top left): 1) Volunteers Rick James and Melissa Hutchings, getting the job done! 2) PH patient Pacienza Santos (right) from the Toronto chapter, accompanied by a family member. 3) Conference attendees having a light moment draped in their periwinkle purple blankets! 4) An emotional Dianne Curle (right) tells her CTEPH PEA surgery story as part of the Journeys' presentation. 5) Pediatric PH patients Sophia and Everleigh, having fun on terrace during the Meet and Greet Conference opening. 6) Volunteers going through the registration process at the volunteer orientation. 7) PH nurse Janette Reyes from Sick Kids hospital in Toronto, reuniting with another Conference attendee.

This page (clockwise from top): 1) Teri Kingston, Jamie Kretzschmar and Amy Pike-Kretzschmar from the Ottawa PH support group. 2) PH patient Harman from Brampton, ON, attended this year's Conference with his entire family. He told us that he learned a lot and loved meeting other kids with PH! 3) Joan Nemeth, Lynda Cooper, Wanda Saunders, Jimmy Doyle and Shirley Wong at registration. 4) A group of the youngest attendees at our 2015 Conference. Each of these children's lives has been touched by PH in some way, and we loved watching them connect together in the kids room.



What attending Conference means for PH parents

Many PH patients and caregivers say that the very best part of a PH Conference is meeting and connecting with others who understand. This is very important for pediatric patients, who may have never met another child with PH or seen someone else their age wearing an oxygen cannula. It's also especially true for PH parents, who can experience empathy, care, togetherness and relief through knowledge sharing with other parents. We at PHA Canada believe that these connections are critical for people affected by PH, and that just knowing others who understand is priceless. These anecdotes feature the experiences of two PH parents at our 4th National PH Conference.



"OUR DAUGHTER OLIVIA IS THREE AND A HALF."

When she was diagnosed with PH 11 months ago, our world was turned upside down. We felt like we were spiralling out of control, and as any other PH parent knows, we felt very helpless with our situation. Once we were released from the hospital, we started researching the healing power of food. By applying my background as a holistic nutritionist, we came up with a plan of attack. The only thing we had any control over was what we put in front of our daughter to eat, so we wanted to make sure we were making her body healthy and strong as could be. We also focused on our own health, as PH caregivers, so that we could fight PH as a team. We all began following a plant based diet, which gave us more energy and made facing Olivia's day-to-day challenges easier for all of us. The cooking demonstration at the PHA Canada Conference was the first time that I was able to learn about this diet, used specifically for PH patients. It was one of my favourite sessions. Conference was also a truly amazing experience for my daughter Olivia. Be-

Photos (from left to right):

Heather's daughter, PH patient Olivia, had a wonderful time at her first Conference.

PH parent Heather and her lovely family.

Genevieve's purple ribbon photograph became a viral sensation within the PH community for World PH Day 2015. She shared this photo and requested that others use it as their profile picture, and her campaign was adopted across the globe!

cause she was more recently diagnosed, this was the very first time that she got to meet incredible other PHighters who were close to her own age, and going through the same experiences. We are grateful to PHA Canada for providing us with this opportunity at a time where we truly needed to come together with the PH community."

Contributed by: Heather Zloty, PH caregiver, Chestermere, AB.

"LAST JANUARY, MY SON HAD AN OPERATION FOR A CARDIAC CATHETERIZATION."

It was then that I learned that he was suffering from pulmonary arterial hypertension, and that his stage was advanced. At that moment, I experienced an intense mix of emotions. Hearing the doctor telling us that our son had a progressive and incurable disease was not easy. A few weeks later, I randomly stumbled across the HTAPQ Foundation. Through it, I met some very kind people, and they told me about the upcoming PHA Canada National PH Conference. I hesitated for a while, but my partner and I finally decided to attend. It ended up being a very lovely weekend which permitted us to meet others who truly understood our situation. The sessions that we attended were very interesting. We learned a lot more about the disease and how to learn to live with it every day. We would recommend the experience to everyone: thanks to the PHA Canada National Conference, we feel a lot less alone."

Contributed by: Geneviève Marcoux and Patrick Champagne, PH caregivers, St- Valère, QC.

PHighting against a one-size-fits-all approach to PAH treatment



"We all must fight to ensure that treatment decisions for this disease be left in the hands of PAH specialists who are best able to assess their patients' individual needs, and make therapeutic choices that will benefit their patients' long-term health."

– Dr. Sanjay Mehta, MD, FRCPC, FCCP,
Board Chair of PHA Canada.

In March 2015, the PAH community received disturbing news when CADTH (the Canadian Agency for Drugs and Technologies in Health) released its Therapeutic Review Recommendation Report for Drugs for PAH. This report may seriously impact members of our community, especially those receiving a new PAH diagnosis. The report recommends that, in the case of a new PAH diagnosis for patients in functional class II or III, physicians would have to prescribe one type of therapy first, even if that therapy may not be the best choice for that patient. Physicians would have to wait for the therapy to fail (that is, for a patient's PAH to progress) to try any other treatments.

PHA Canada believes that patients should have access to the treatment plan that's right for them, and that PH-treating specialists are best positioned to determine what that treatment plan is. Because every PAH patient needs an individualized treatment plan, we are PHighting against the approach that CADTH recommends. **This is why we need to let provincial governments know that a one-size-fits-all approach will put the lives of PAH patients at risk, and we need your help making our message come across loud and clear!**

Our message to government decision-makers across the country is this: All PAH patients should have immediate, publicly funded access to any and all Health Canada-approved PAH medications, as prescribed by their physicians.

In June, we launched an advocacy campaign and have been working with our Ambassadors and others interested in participating. These advocates have been meeting with their provincial elected representatives and have made appearances in local media to tell their stories

and to explain why it's critical that PH specialists be the ones making decisions when it comes to treatment.

Together we are stronger! Together we speak louder!

Our PHight is not over, and we need your help to ensure that these recommendations are not implemented. There are many ways you can get involved:

By email:

- Send an email to your Premier and Health Minister in a few clicks. Go to PHACanada.ca/takeaction to fill out our email form.

On your social networks:

- Don't just "like" PHA Canada's posts; share them with your networks!
- Use the hashtag **#patientsPHirst** when you post about PH advocacy issues.
- Tweet at your Governmental representatives.
- Tag PHA Canada in your posts: we're on Facebook, Twitter and Instagram at "@PHACanada"

In person:

Ready to take the next step as a PH advocate and meet with your provincial government representative? We've prepared an advocacy package that will take you through all the steps, from requesting a meeting to preparing for it. For those interested, advocacy training is also available! Visit PHACanada.ca/advocacy to get the info you need.

Every action counts. The more we speak up, the more decision-makers will have to listen. Together, we can and will make a difference!

*Contributed by: Mariane Bourcheix-Laporte and Bronwyn McBride,
PHA Canada Communications Associates*

Meet your medical professional: Dr. Anne Fournier

We had the pleasure of hosting Dr. Anne Fournier as part of a 'Journeys' presentation at our 4th National PH Conference. Dr. Fournier presented her experiences as a pediatric cardiologist and PH specialist and the story of 5 year old PH patient Riley, alongside Danush Rudolph, who is Riley's mother and a PHA Canada Ambassador. We are grateful for Dr. Fournier's work in the lives of young PH patients. Her story of becoming a pediatric cardiologist and PH doctor is below.

Where did you begin your medical career, and in what field?

I graduated in medicine in 1980, and completed residencies in pediatrics and pediatric cardiology at the Centre hospitalier universitaire (CHU) Sainte-Justine from July 1980 to June 1984. I started to practice as a pediatric cardiologist in January 1987 at the CHU Sainte-Justine after having finished a fellowship in pediatric cardiac electrophysiology in Miami and Houston.

How did you first learn about PH? What drew you towards the field of PH: why did it interest you?

As a pediatrician, you hear about PH early on in your first internships, especially in neonatology. The patients are the motivation for my involvement in PH: I had to treat some young children with pulmonary hypertension, and had no choice but to be interested in the field of PH because I wanted to offer them the best possible care. PH is a complex medical problem that has seen major advances in diagnosis and treatment over the past few years, which makes it interesting and attractive for a medical professional who is curious and cares for the wellbeing of their patients.

How long have you worked in a health-related field, and how long have you worked with individuals affected by PH?

I've been in the field of health since my admission into the faculty of medicine in 1976, and have been significantly involved in treating PH since the arrival of the first oral PH therapies in the early 2000s.

How did you become involved with PHA Canada?

Through my patients!

What do you enjoy the most about your work as a PH Specialist?

The contact with children and with their families.

What do you find most frustrating?

When I am not able to help a child who has an incurable disease.

What has been the most inspiring part?

Witnessing patients and their families fight their illness and go beyond it.

What advances have you seen in the treatment of PH patients since you started practicing?

The arrival of PH therapies, first intravenous and then oral, changed the prognosis for PH patients. In the beginning of my practice, there wasn't a single treatment to offer patients. Now, children survive, and are even transferred into adult clinics.

What would you find to be the most encouraging advances currently taking place?

The pursuit of research into therapies intended not only to treat PH patients, but developed with the hope of curing them.

As you know, early diagnosis of PH is an important strategic priority for PHA Canada. Why do you think early diagnosis is important? What measures can we take to ensure an earlier diagnosis for PH patients?

The earlier that a patient receives medical attention and a treatment plan, the better their chances of survival and good health. The dissemination of knowledge with scientific presentations across all possible forums is a good way of raising awareness of PH amongst physicians.

Can you recall one specific memorable moment or conversation with someone affected by PH that was particularly meaningful to you? Can you describe it?

At PHA Canada's National Conference in Montreal last May, an old patient who I had followed when he was child and who is now an adult came to say hello. He's doing well and has finished his studies in engineering. It's very touching to know that you've been able to make a difference in a child's life, and that he's gone on to become an adult and live a mostly normal life.

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?

There is hope. The journey may be chaotic, but there will be many options for patients to take charge of the disease. Finally, patients won't have to be alone on their journey.

Contributed by: Dr. Anne Fournier, Pediatric Cardiologist, Cardiology department, CHU Sainte-Justine, Montreal, QC.



Dr. Fournier (left) with Danush Rudolph, telling the story of Danush's son Riley as part of the 'Journeys' presentation at our recent Conference.

A PH patient's step-by-step guide to getting (and staying) active



Dr. Rana Awdish is a senior staff physician at the Department of Pulmonary and Critical Care Medicine at Henry Ford Hospital, and has a passion for educating pulmonary patients about safe ways to engage in exercise. At our 4th National PH Conference in May, 2015, she co-presented a session called 'Breathing your way to calm' with Lynn-Marie Cox, and presented two mini sessions on chair yoga for PH patients, and breathing exercises. We are grateful to Dr. Awdish for sharing her expertise in this article on getting active the safe way.

When a patient with PH makes the decision to change aspects of their life and embrace a healthier lifestyle, they encounter challenges that are unique and often daunting. Despite hearing from the medical community that physical exercise is especially valuable for PH patients, too often little guidance is provided as to how to actually become more active. Everyone has busy lives, but add in doctor's appointments, medication mixing, and fatigue and suddenly making time for physical fitness can seem an unreachable goal. In this article, we will address ways in which you can set yourself up to succeed, to give you the best possible chance of making a change

that will be sustainable and benefit you for years to come.

STEP 1: SAFETY FIRST

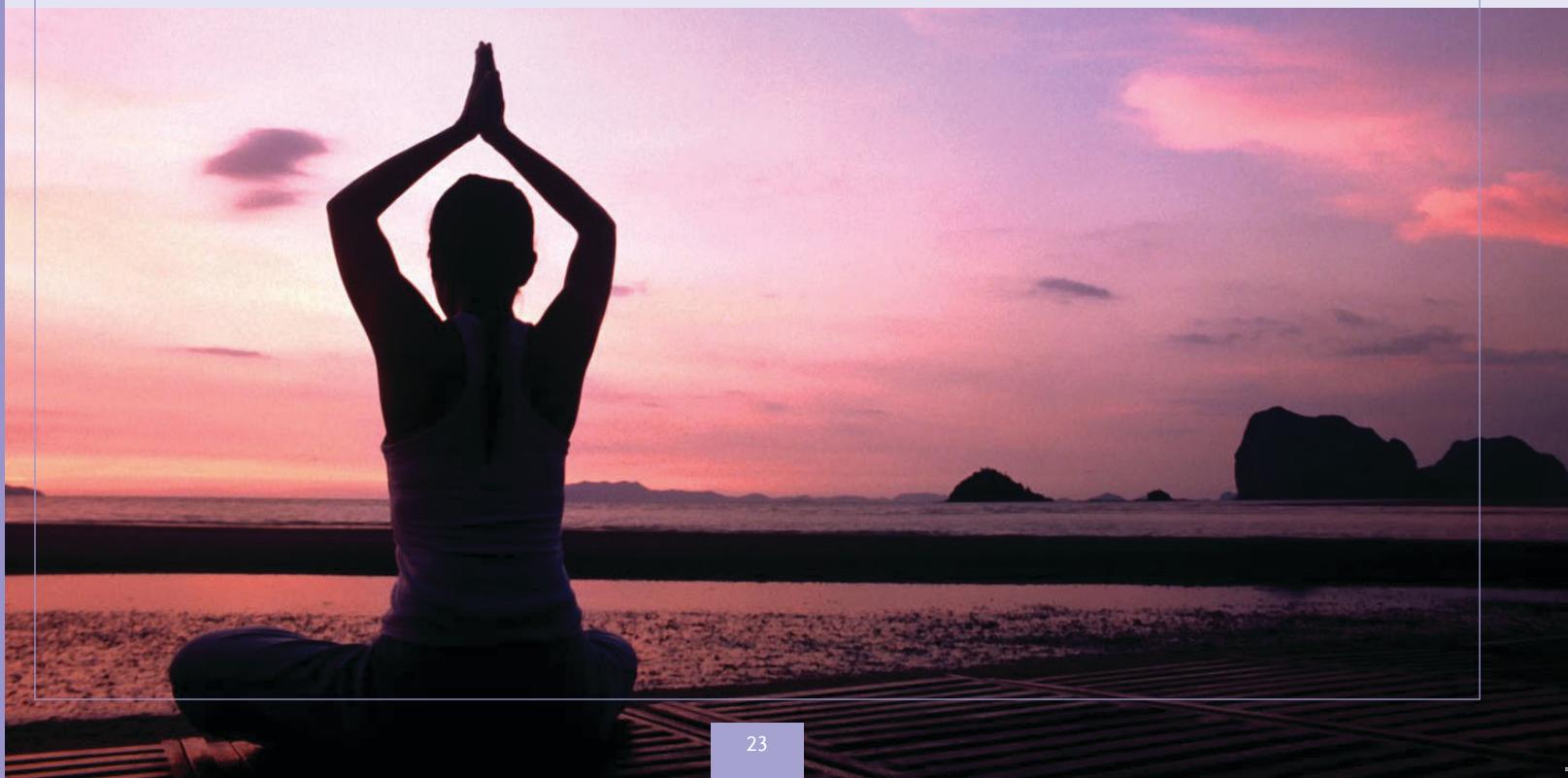
The surest way to feel safe while exercising is being secure in the knowledge that you are safe. This means discussing your plan with your PH team before starting any new form of exercise. Beginning a new exercise program is ideally done when you are stable on medical therapy, and have been tested to determine whether you have oxygen requirements with exertion. If you have the option of attending pulmonary

rehabilitation, it can be a wonderful structured way to learn what your exercise tolerance is and to gain a level of comfort. If you want the convenience of exercising at home, make sure you have someone watching out for you. This may be someone who lives in your home, or a friend who is willing to Face Time with you. Make sure your exercise partner knows whom to call in case of an emergency.

STEP 2: ACKNOWLEDGE YOUR FEARS

Maybe you're afraid to see how little you can actually do without becoming short of breath,

cont'd on next page



and that worry has kept you from trying to exercise. Maybe you're afraid exercise will make you sicker. Whatever your fears are, try to articulate them either out loud or in writing. Sort out which questions are medical issues to discuss with your PH care team, and which are conquerable fears. Once you can name your fears, you can start to reframe them into positive messages. For example, "I'm afraid of feeling more short of breath," can become "I may have more of a sensation of breathing hard while I am working to make myself stronger, but over time if I work at it the exercises will become easier, and my breathing will improve."

STEP 3: IDENTIFY BARRIERS

You may feel that with the limited energy reserves you have, that exercise should come last in your To Do list. Recognize that exercise done properly will give you more energy to accomplish the day's tasks, and reward you with a sustained sense of well-being and accomplishment. Set yourself up to succeed. Maybe this means laying a Yoga mat on the floor of your bedroom, so that as soon as you wake, while the house is quiet you can sneak in some gentle stretching. If your joints are stiffer in the morning, make a quiet bedtime practice your routine. Work within the truth of your body, and you'll be more likely to stick to your intentions.

STEP 4: ACCEPTANCE OF TODAY

When living with a chronic disease like PH, you have to be aware of your body and the messages it sends you. Before any exercise, take time to check in with yourself, surveying your body for changes from day to day. You may find a breathing exercise or guided meditation helpful here. This will allow you to be attuned to what your truth is each day. By noticing changes in your body while they are still small, they are more likely to be easier to manage.

STEP 5: SET REASONABLE GOALS

The surest way to self-defeat is by setting unreasonable goals. Make sure the goal you set is attainable. Maybe a goal when you are first starting is simply to spend 10 minutes researching any local classes that are offered that fit with your ability level. The beauty of alternative forms of exercise like yoga and Tai Chi for PH patients is that they truly allow you to work at your own pace, while slowly expanding the possibility of what your body can do. The mind-body aspect with a focus on breathing allows for the calming of

your nervous system, can reduce stress and improve your mood as well as your body. Just participating in the deep breathing exercises may be all you do the first time. Slowly building on your achievements each time is preferable to starting out too fast and then burning out.

STEP 6: KNOW WHAT TO WATCH OUT FOR

When starting a new exercise program, you should pay close attention to your body and how becoming slowly more active may change how you feel. Watch out for the following symptoms: feeling lightheaded or dizzy, feeling unable to catch your breath, heart fluttering in your chest, chest pain traveling to your jaw, arm or back, or feeling confused.

STEP 7: REWARD YOUR SUCCESSES

Feeling stronger each day is of course its own reward, but be sure to acknowledge your successes. Select a reward that will keep you motivated, and isn't defeating (think new walking shoes, not chocolate cake). If you enjoy listening to music while you exercise, then a new playlist can be rewarding.

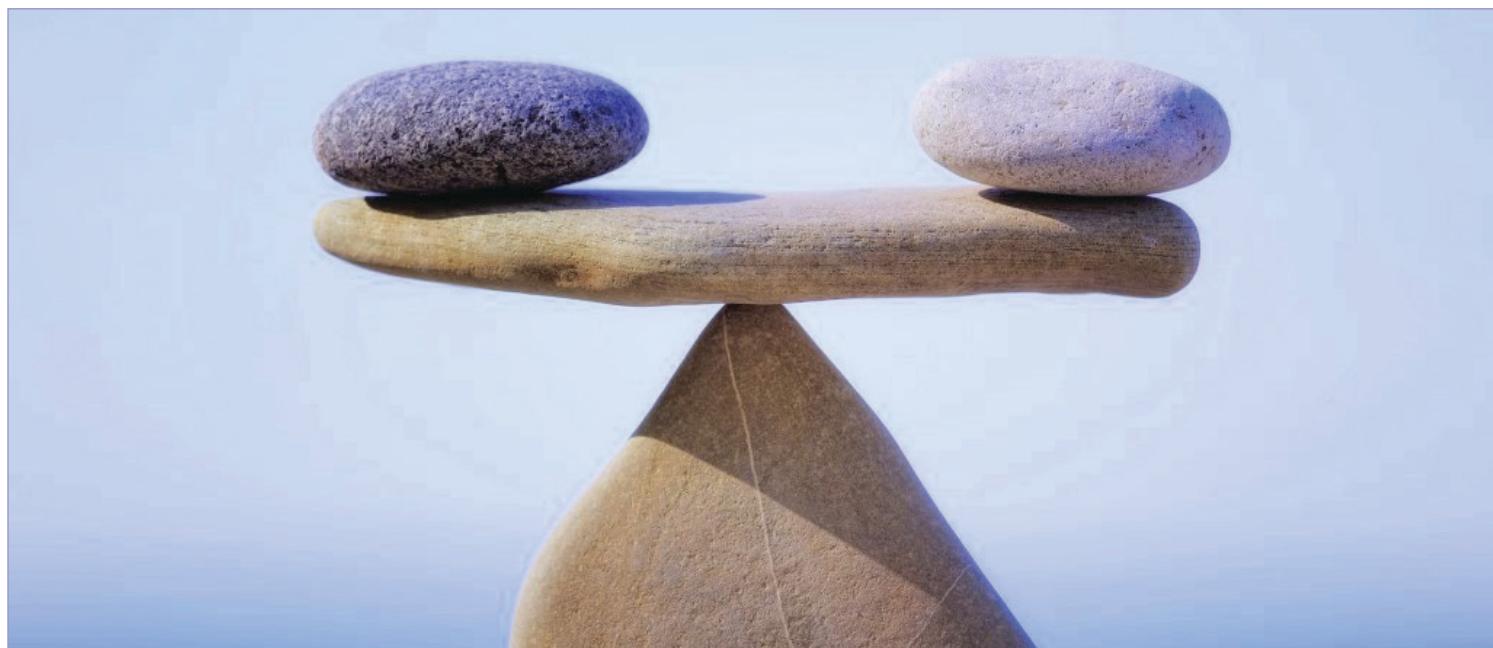
With these tips in mind, you'll soon find yourself engaged in a safe, restorative and rewarding practice.

STEP 8: KNOW YOUR RESOURCES

Yoga and meditative breathing exercises have been shown to be helpful for PH patients. Breathing exercises with accompanied stretching can help those with PH feel less breathless, reduce stress and slowly help patients be able to do more activity in their daily lives. Not all yoga poses are safe, however, for PH patients. Our team worked with an experienced yoga therapist to design a Yoga program with three levels (beginner, intermediate and advanced) appropriate for patients of all physical abilities. They also have been designed as progression to help patients slowly improve their skills in performing the exercises and safely challenge their abilities.

If you are interested in receiving a copy of the Yoga for PH DVD that was made possible by a Lantos Grant awarded to our Pulmonary Hypertension Nurse Coordinator Patricia Fantuz at Henry Ford Hospital in Detroit, please contact Sue Docherty at Sdochert1@hfhs.org.

Contributed by: Rana Awdish, MD; and Bronwyn Small, MD; Pulmonary Hypertension Program, Henry Ford Hospital, Detroit, MI.



Ask a Nurse: How to PHight against fatigue and shortness of breath

The fear of increasing your shortness of breath, or experiencing greater fatigue, prevents many PH patients from being as active as they once were. This fear also prevents patients from participating in special family events, or engaging in daily activities and chores that provide satisfaction. I have written up these tips to help you PHight against shortness of breath and fatigue while doing your daily activities.

PHighting fatigue means conserving your energy when you can, and simplifying tasks so that they're easier to do. To save your energy, you can find different ways of doing your daily activities with as little effort as possible. With some planning and tips, you can streamline your tasks and events in order to PHight against fatigue and breathlessness.

GENERAL TIPS

- Plan ahead so your tasks are spaced throughout the day. As you make this plan, keep in mind the times of day you tend to have the most energy. Everyone is different.
- Alternate activity days with rest days.
- Do not feel bad if you have to say no to an outing with friends or family if you are too tired to attend. You can also make it known ahead of time that you can be there for a short period of time: this allows you to exit without feeling guilty.
- Do only 1 thing at a time. Finish 1 task before starting another. If you are the type of person who is type A, or a multi-tasker, you should not feel guilty that you are now doing 1 thing at a time. You are being good to yourself!
- Assemble everything you need before you start a task (do this slowly to not get out of breath and energy before the task is started). This cuts out unnecessary steps while you're working.
- Think about what you really need to do. Be realistic about what you can get done in a day.
- Alternate between hard tasks and easy ones throughout your day.
- Give yourself plenty of time for each task, so you don't have to hurry.
- Take 20 to 30 minute rest breaks after meals and multiple times throughout the day to recharge. These are amazing recharge minutes!
- If an activity takes a lot of energy, break it into smaller parts. For instance, fold the laundry first. Then take a 20 to 30 minute break before putting it away.
- Avoid exerting yourself in extreme cold or heat.
- Avoid early-morning doctor's appointments. The pressure of getting up, bathing, eating breakfast and getting to the doctor on time can create a stressful scenario, so try to schedule appointments later in the day when possible.

GETTING DRESSED IN THE MORNING

- Gather all of your clothes before you start getting dressed.
- Sit to dress and undress. When you're sitting, choose a firm surface with arm rests. Soft couches and chairs, although tempting, are hard to get out of.
- Dress your lower body first, as this takes more energy.
- Put your underwear on, then pull it up to your knees; put your pants on, then pull them up to your knees; stand once and pull both up at the same time.
- Choose front-opening, loose-fitting clothes.
- Choose clothes with elastic waistbands, because they're easiest to manage.
- If you can't use slip-on shoes, consider elastic shoe laces. Bring your feet up to your tie laces; footstools are helpful for this. Use long-handled shoe horns to avoid bending.
- In the winter months, wear boots and coats that are lighter, but still keep you warm in the extreme cold weather.

IN THE BATHROOM

- Use a raised toilet seat and/or toilet safety rails.
- Sit on a bench to shower. Use warm water, not hot: steam can make breathing harder.
- Use a long-handled bath brush for your back and feet.
- Dry off by wrapping yourself in a terry-cloth robe—this uses no energy.
- Sit to groom and brush teeth
- Choose an easy hairstyle that requires little arm-raising.

IN THE KITCHEN

- Use a cart with wheels to move groceries, laundry, and other items around the house. Some carts have seats so you can rest when you need to.
- Consider leaving your most-used items out on the counter.
- Use energy-saving appliances, such as an electric can opener.
- Plan one-dish low sodium meals. Consider using a Crockpot or other slow cooker, and try low sodium prepared mixes and low sodium frozen foods.
- Slide filled pots, mugs, and other containers along countertops or the stove rather than lifting them.

IN THE WORKPLACE

- Plan your workload around your best times of day.
- If available, have an ergonomic assessment.
- Make sure to take rest breaks, because this will allow you to better focus while you're working.

FINAL WORDS

PHighting fatigue is about making choices on where and when to spend your energy. Make sure to balance activity and rest, because when you're tired, your activities will take longer. Allow yourself always to stop and rest when you need to. Don't wait until you're overtired because you will then be on the couch exhausted for the next few days, or unable to get out of bed. Finally, remember the importance of perspective. You may have limited energy, but you can apply your energy in the ways that you choose. This perspective brings the power back to you, rather than the disease.

*Contributed by: Carolyn Doyle-Cox, APN
Ottawa Pulmonary Hypertension Clinic,
Ottawa, 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 to our Pulse e-newsletter. We are glad to have Mohamad's contribution to provide our community with insight into the PH research process.

The role of Endothelin-1 in PAH

In this issue, we will address some questions regarding PH therapy. More specifically, we will examine the role of endothelin-1 in PAH and drugs used for blocking its function.

What is endothelin-1?

Endothelin-1 (ET-1) is a small secreted protein, which can bind the surface of the blood vessel cells. There are two main “receptors” on the cell surface that ET-1 can bind. The first is ET-A, which is abundant on smooth muscle cells. The second is ET-B, which is present on both endothelial cells (the cells lining the inside of blood vessels) and smooth muscle cells (the cells making the second layer within a blood vessel).

Why is ET-1 important in PAH?

In PAH, there are dramatic increases in ET-1 production and secretion, as well as increased levels of receptors on the surface of smooth muscle cells. This results in constant vasoconstriction and in the division of smooth muscle cells. This process leads to the narrowing and blockage of the blood vessels in the lungs. The effect of this is increased pressure in the lungs and pulmonary arteries.

What treatments target ET-1 in PAH, and how do they work?

Starting in the 1990s, several studies implicated ET-1 in PAH and suggested that blocking its function might be therapeutic. Drugs that inhibit ET-1 binding to its receptors called Endothelin Receptor Antagonists (ERAs) were developed. The first dual receptor blocker, Bosentan, was approved to treat PAH in North America in 2001.

Currently, which Endothelin Receptor Antagonists (ERAs) are approved to treat PAH?

ERAs currently approved for PAH patients are Bosentan, Macitentan/Opsumit and Ambrisentan. Bosentan and Macitentan bind and inhibit both ET-1 receptors (ET-A and ET-B). Ambrisentan inhibits mostly the ET-A receptor. Bosentan is the oldest ERA approved for PAH, after which came Ambrisentan. In 2013, Macitentan was approved to treat PAH as well.

What does research show about ERAs? Which one is better?

Each of these therapies has some side effects. These could include mild liver toxicity, mild edema (fluid in the extremities) or mild anemia. 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 drugs. Thus, it is very important to discuss with a PH specialist which drug is most appropriate for each patient.

Reference: Aversa M, Porter S, Granton J. (2015). Comparative Safety and Tolerability of Endothelin Receptor Antagonists in Pulmonary Arterial Hypertension. Drug Saf. 38:p419.

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.



PH Veteran Wilna and her husband Gordon pictured at our 2013 National Conference in Ottawa, ON.

Celebrating Wilna: a Canadian PH hero

In May 2015, the PH community lost one of its brightest stars. Wilna Toombs was a PH veteran, a wife and mother, a resourceful and hard worker, and an inspiration to PH patients across North America. Dr. David Langleben was Wilna's PH-treating physician for her entire journey with PH. We are grateful to Dr. Langleben for sharing this beautiful tribute to a Canadian PH hero. Breathe easy, Wilna.

I first met Wilna about 25 years ago. She was in a foreign city, in a foreign hospital, facing strangers, and had been given 3 months to live. What I saw was a bright, resourceful, frightened and defiant young woman. Her thoughts were to her family. There was no question in her mind of giving up her life to the disease and, in her very Wilna way, she was being politely aggressive with it. In the coming weeks, she was to learn that she would require therapy to be delivered by wearing a pump, possibly for the rest of her days. She mastered the complex care of that pump and her medication with acceptance and ease. She still, by many years, holds the record for the longest continuous use of a Broviac catheter. Thankfully, her breathing improved and her heart failure resolved and she gained strength by the day. Thankfully too, there would be many many more days, although never enough for any of us who knew her.

Courage is not an absence of fear. Rather, it is the ability to move forward despite the fear. Wilna gained mastery of her disease and, with only a few constraints, resumed the life she chose to lead. But her control of the disease did not stop there. I knew her as an incredibly generous person. She gave of her time and of her strength and courage to advise and support other patients suffering from pulmonary hypertension, and they valued it so much.

Wilna was clearly the matriarch of the family. And what a family. Incredible Gordon, the boys, the girls, and everyone around her. They

gave her life and she gave everything of herself to them. In the midst of everything, she always seemed to be working 24/7. Almost every time I would call the Toombs, she would be cheerfully answering "Toombs Plumbing". I think that knowing she was supporting the family effort was a great source of comfort and distraction for her.

Wilna suffered what could have been many setbacks over the years, each of them potentially life threatening. It's not that she scoffed at them but that she faced each of them calmly and head on and with the faith that she somehow would make it through, and she always did. It was nightmarish for me to try and care for her from such a large distance, but she and her family were so astute about her condition that we always managed to arrive at the right choice of care. It was remarkable for me to be able to deal with someone so clear-headed.

I enjoyed her warmth, her wisdom, her wit and her carefully considered advice. She was beloved by all the PH Clinic staff and the staff on the hospital floor, and in many ways took each one under her wings. So, in addition to having lost an exceptional patient, I have lost a dear friend. We and her family have had the great fortune to have shared our lives with such an exemplary individual.

Contributed by: Dr. David Langleben, PH-treating physician, Montreal, QC.

Early Diagnosis – Getting PH on physicians' diagnostic radar



Early diagnosis Practicum student
Jennifer Grewal

Last year, we at PHA Canada hosted our first Practicum student, Russell Bonaguro. Russell developed the framework for PHA Canada's

Early Diagnosis program, as early diagnosis is our top strategic priority. This summer, Practicum student Jennifer Grewal has been continuing to develop the program. This is an update from Jennifer.

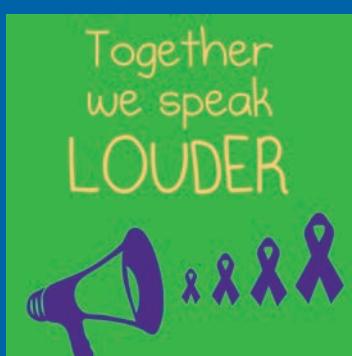
Over the summer, I have been working alongside the staff at PHA Canada to take action on an Early Diagnosis Program for pulmonary hypertension. The program aims to increase awareness of PH among the medical community. This includes physicians, specialists, nurses, and everyone else who works within the screening for and diagnosis of PH. The goal is to have PH become part of the regular "checklist" that physicians consider when diagnosing patients, in order to decrease the delay in diagnosis of PH and extend the quality of life of our PH patients and their families. After much planning and consideration, an Early Diagnosis Task Force was created. This group is comprised of health professionals that share a connection with pulmonary hypertension and are committed to Early Diagnosis. This task force has been working hard to network with organizations within and outside of our community

that would be interested in supporting our Early Diagnosis Program.

I have been working with medical schools across Canada that have programs such as the Health Mentors Program at UBC, which allows patients with rare or chronic diseases to meet with medical students throughout the year and share their stories and struggles with their disease and the health care system. Our goal is to have PH included in the curriculum topic of rare diseases in medical schools across the country, and have new medical professionals have first hand experience with PH patients while still studying, to further raise PH awareness.

The Early Diagnosis program is in the initial action phase. With continuous and active support, the Early Diagnosis Program will flourish and reach our goal of Early Diagnosis of pulmonary hypertension for our PH patients and their families!

*Contributed by: Jennifer Grewal, B.Sc, MPH
c.2016, Surrey, BC.*



Why membership matters

Our members make change possible: we call on them whenever rights of PH patients are under attack. The actions of our members help to put pressure on governments and decision-makers to do the right thing.

Currently, the right to access treatment of choice for newly diagnosed patients is being threatened. In spring 2015, the Canadian Agency for Drugs and Technology in Health (CADTH) released a final recommendations report, which provided recommendations to provinces on how drugs for pulmonary arterial hypertension should be funded. It recommended that for all newly diagnosed patients who are diagnosed in functional class II or III, only one type of therapy should be tried first. Only if that therapy fails (that is, if the person starts getting worse) would a different therapy be funded. This is not acceptable. PH doctors need to be able to treat patients with the medications they believe will provide their patients the best long-term outcomes. Taking these decisions out of expert physicians' hands is dangerous and potentially life threatening.

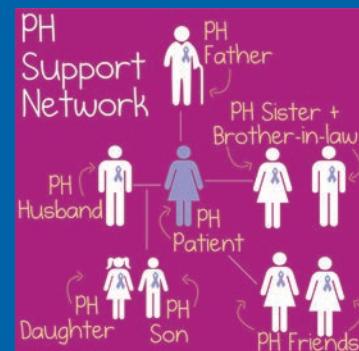
What now?

It is now up to the provinces to decide if they will implement these recommendations. PHA Canada has undertaken a campaign to encourage the provinces to not adopt these recommendations, but we need your help.

When more individuals demonstrate that they care about an issue, the government and media are more likely to respond to that group's requests. You don't have to have PH to be affected by it. The PH community is made up of those who have been affected by pulmonary hypertension in a variety of ways: they are patients and caregivers, but they are also brothers, sisters, friends, grandparents, parents, in laws, children, grandchildren, medical and healthcare professionals, researchers, and many others. They have all been touched by PH: they are all PH supporters.

In order to make an impact, and show the government that treatment choice belongs in the hands of doctors, we need a strong voice. This is where you come in. PHA Canada is encouraging anyone who has in some way been touched by PH to become a member. We have created a new PH supporter category especially for these individuals, and we are offering them free membership in PHA Canada throughout the months of September, October and November.

Help to make the voice of the PH community extra loud by encouraging all of the PH supporters in your personal network to extend their support to the whole PH community by joining PHA Canada today. Visit www.phacanada.ca/phsupporter to learn more.



Connections submissions guidelines

The deadline for submissions for the next issue of Connections is January 15th, 2016. **Connections is your publication.** Tell us about your support group, recent event, share your story or tell us about a phenomenal caregiver in your life. Let us know how you cope with PH: how you live and work every day. We'll accept articles, personal PH stories, quotes, photos, tributes, poems, drawings and more for consideration in the magazine. If you're not comfortable writing your story, contact us, we'll interview you and write the story for you. This is Canada's PH community's newsletter: let your voice be heard!

Please send submissions including your contact information (phone and/or email) to:

Connections submission
PHA Canada
Suite 208, 1311 Howe Street
Vancouver BC V6Z 2P3

Or email it to "Connections submission" at info@phacanada.ca!

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.