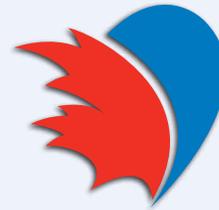


# CONNECTIONS

THE OFFICIAL NEWSLETTER OF THE CANADIAN PH COMMUNITY



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

## COUNTDOWN TO CONFERENCE 2011

by *Jennifer Gendron, Regional Coordinator, AND  
Angie Knott, PHA Canada National Manager*



*Attendees of the 2009 PH Conference made great "PHriends", learnt about PH and made many memories*

**T**he countdown to Conference 2011 has begun! Our 2011 Conference Committee is hard at work behind the scenes to bring together a truly amazing Conference that will have something for everyone!

Our 2011 "Connecting the Community from Coast to Coast" Conference will be held September 16-18th at the Delta Chelsea Hotel in downtown Toronto, Ontario. This year's conference will offer a wide variety of sessions for patients and caregivers as well as a full schedule of children's programming allowing you to attend with the entire family.

The 2011 Conference Committee consists of members of the Toronto Chapter of PHA Canada, members from HTAP Quebec as well as PHA Canada Board and staff who are working to ensure that the conference is fully bilingual and offers something that will appeal to everyone.

The Toronto Chapter invites you to help them kick off Conference on Friday night with a meet and greet event, which they will be hosting. Come partake in some appetizers, enjoy live entertainment and meet some new PH friends. The Conference continues on Saturday with a welcome breakfast and then dives right into a number of sessions on a variety of topics; including the latest in PH, information on oxygen and a variety of others, led by patients, caregivers and medical professionals. Lunch on Saturday will give us a glimpse into the lives of some extraordinary people with "Journeys" and the Saturday night keynote dinner, will leave you feeling inspired. As Conference draws to a close, Sunday morning's breakfast will energize you and the last set of sessions will continue your weekend's education.

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## A MESSAGE FROM THE PRESIDENT



Welcome to Volume Two of our Connections newsletter: what an amazing year 2010 was, and 2011 promises to be even greater for our PH community.

As you may have noticed we're starting the 2011 issues of Connections off with a bit of a change. Thank you to those who provided their feedback to the reader survey in the last issue. Based on your comments we have decided to take a different approach to the way we lay out Connections. We have now

split the newsletter into a half English and half French version: we hope that this will make the newsletter easier to follow in your preferred language. If you have any other suggestions with regards to Connections: from the layout to the content of articles you'd like to see and everything in between, we'd love to hear from you. Please send your suggestions to [connections@phacanada.ca](mailto:connections@phacanada.ca).

Although it's still about five months away, our offices are buzzing with planning for this year's National PH Conference, which will be held on September 16 – 18 at the Delta Chelsea Hotel in Toronto. You can read more about our preparations in the pages of this issue. It's going to be a great event and we hope that you will join us in making it a very memorable one.

We have many programs and projects on the go this year as we continue to connect our community, raise awareness and educate about PH. One of the major programs that we are currently working on is a campaign to educate medical professionals about PH. So often we hear about the lengthy process of getting correctly diagnosed with PH and we want to help assure that the medical professionals who are first seeing the symptoms are better informed to think about the possibility of PH. We hope to be able to share more on this exciting project in the next issue.

For me, one of the great things about serving as president is getting to see the growth and the sense of community that becomes stronger and stronger as time goes by. PHA Canada has grown so much: we moved into a larger office this January in order to accommodate a new administrative staff person, Shirley Wong. Shirley will be the one processing memberships and donations, and preparing all of the mailings that PHA Canada does, as well as keeping track of our entire inventory and keeping things organized.

It's not only PHA Canada that has grown though; it's the community as a whole. With each passing month, we have the opportunity to meet so many new community members and we get to hear some incredible stories. Our local Chapters and Support groups are growing by leaps and bounds as well; this issue features updates from some of the groups and we're so excited by the great local work being done.

There are so many PHers out there doing incredible things, and it's so inspiring to all of us. With that being said, we are always looking for new ways to help you share your story. Remember, we are here to serve our members, and it's the stories of the community that bring it to life, that help others understand what PH is and how it affects the life of those living it, that inspire those who are just starting out on their PH journey, and that help to honour those who help us. In this issue, we are introducing a new way for you to share your story on an ongoing basis, read all about it on page 6. If you prefer a more traditional way of sharing, I encourage you to submit yours for the next issue of Connections. You will find information on how to share your story, your tips on living with PH, a tribute to a caregiver that makes all the difference in your life, or a thank you to your PHenomenal PH nurse or doctor on the back page of this issue.

I hope that the beginning of this year has been kind to you and that the rest will continue to be as well. I strongly encourage you to circle September 16th – 18th on your calendars and attend this magical event, the 2nd National PHA Conference in Toronto, as I guarantee it will be an experience you will not soon forget.

Lastly, it is with enormous sadness that I pass along the news that a great leader and original founding member of the PHA Canada Board of Directors, Lynda Beriault, passed away on February 24<sup>th</sup>. Lynda's strength and conviction to help those facing their own PH journeys will be forever remembered.

Sincerely,

Darren H. Bell  
President

## COUNTDOWN TO CONFERENCE 2011 (continued from page 1)



Dr. Sanjay Mehta talking to 2009 PHA Conference attendees

Conference weekend will be a weekend of joy and tears, of friends and PHamily, of education and inspiration. It is an event not to be missed.

More information on Conference will be posted on our website ([www.phacanada.ca/2011Conference](http://www.phacanada.ca/2011Conference)) as it becomes available and registration packages will be sent out in the coming days.

The Delta Chelsea hotel is conveniently located in the center of downtown Toronto and is easily accessible from the Lester B Pearson International Airport or from the train and bus stations, as well as by car.

Look for more information on Conference 2011 coming soon and be sure to save the dates! We look forward to hosting you in the city of Toronto for this wonderful event as we continue to connect the PH community from coast to coast!

## CONNECTING THE COMMUNITY FROM COAST TO COAST

by Jennifer Gendron, Regional Coordinator and PHA Canada Board member



FROM LEFT TO RIGHT: Dr. Kim Boutet, meeting organizer Rita Hebert, Line Ducharme, and PHA Canada regional coordinator Jennifer Gendron at the Montreal Support Group meeting held in February.

One of the primary goals of the Board of Directors of PHA Canada is to bring together as many people living with pulmonary hypertension (patients and their caregivers) as possible, around the country. This goal is being accomplished through a new initiative known as the "Connecting the Community from Coast to Coast" program, which was launched in September of 2010 and will be continued on throughout 2011 and beyond. I am very happy to be a part of this project on the East Coast, while my co-worker, National Manager, Angie Knott, works her way through the West.

Our first event was held in Ottawa in November and Angie and I were both fortunate enough to be able to attend the first patient support group meeting held at the Ottawa Heart Centre spearheaded by PH patient, Jo-Anne Mainwood with the help of Nurse Coordinator, Carolyn Pugliese, and others in the Ottawa area (you can read Jo-Anne's update on the meeting in the pages of this issue). The meeting was a huge success with over 50 in attendance, the majority of whom were PH patients. Dr. Duncan Stewart presented to the group and Jo-Anne led a discussion on the future of the support group. Attendees also lined up to "Pucker Up for PH" as Jo-Anne and her husband collected lip prints from all those coming through the doors.

A similar event was held on the West Coast on November 20<sup>th</sup>, bringing together two groups from Calgary and Edmonton. The meeting was held at the Red Deer Lodge, in Red Deer, which is exactly half way between Calgary and Edmonton, was attended by PHA Treasurer Sharon Proudfoot as well as Angie Knott. It was the first meeting of its kind held in Alberta, and was the first time many of the members of the Southern Alberta Chapter (SAB Chapter) of PHA Canada and those of the Edmonton PAH Society (EPAHS) had a chance to meet one another. The meeting was a great success, with about 20 in attendance. It gave a chance for the group to sit together and discuss some of the issues facing patients in Alberta and the need for further gatherings. It was decided that a similar meeting should be held in Red Deer at least once per year and the two groups (the SAB Chapter, and EPAHS) will coordinate their efforts in the future to continue to organize these Red Deer meetings). We are also thrilled to announce that an Agreement of Affiliation was signed between PHA Canada and the Edmonton PAH Society at that meeting, assuring that we will continue to work together in helping to build the PH community in Edmonton.

The latest region to host a meeting was Montreal, and patient, Rita Hebert, worked very hard to bring together a group from this area for their first bilingual meeting on February 21<sup>st</sup> at the Jewish General Hospital. The meeting was a great success with about 50 in attendance.

Additional meetings are planned for 2011 in Halifax, Vancouver and talks are ongoing for northern Ontario and northern Alberta meetings. The hope is that this program will continue to take root and grow in regions throughout the Country. Our goal for the program is to help set local support in motion, that will then be carried forward by the members of the new group(s). In order to make the most of this program and have meetings continue, it is very important that a key person come forward willing to assist in the organization of meetings and identifying the direction in which the group would like to move forward. PHA Canada will assist the organizer(s) for as long as necessary and has put together materials specifically for support group leaders.

If you would like to see a similar meeting organized in your area, or you, or someone you know, would be interested in becoming involved, contact PHA Canada at [support@phacanada.ca](mailto:support@phacanada.ca). With your help, we will begin to see this big country united one PH community at a time.



PHers from Calgary and Edmonton met for the first time in Red Deer with help from PHA Canada's Connecting the Community Program



### A SMALL STEP BACKWARDS IN THE MEDICAL TREATMENT OF PULMONARY ARTERIAL HYPERTENSION AROUND THE WORLD

By **Kim Boutet, MD, FRCPC, PH Expert CHUM – Notre Dame Hospital, Montreal, AND**

**Sanjay Mehta, MD, FRCPC, FCCP, Director, Southwest Ontario PH Clinic, LHSC – Victoria Hospital, London**



The pulmonary arterial hypertension (PAH) community in Canada and elsewhere around the world suffered a setback this past December. We all learned that Pfizer, the company, which produces sitaxsentan (Thelin®), one of the medications commonly used to treat PAH, had decided to withdraw this PAH medication from the worldwide market. As a result of this decision, sitaxsentan would no longer be available for the treatment of PAH, and PAH patients currently treated with sitaxsentan would have

to stop this medication. Each patient receiving sitaxsentan had to be contacted by their healthcare team so that their individual situation could be re-evaluated, and they could be transitioned to an alternative PAH treatment.

Although this may seem like a step backward in the treatment of PAH, the decision to withdraw a drug is simply part of the ongoing process of the development and monitoring of pharmaceutical medications. We'd like to take advantage of this issue of Connections to discuss this important event.

PAH is a disease, which has been an increasing focus of the attention of the medical community over the past 10-15 years. Advances in PAH have been quite spectacular thanks to the growing interest of the medical and research communities, partnerships with the pharmaceutical industry and the involvement of patients in organizations such as PHA-Canada. Over 3500 scientific publications on PAH and related illnesses appear each month. Many effective treatments are now available, and many other potential new therapies are currently being studied in clinical trials.

On the medical scale, the progress in our understanding of PAH and in the availability of new, effective medical therapies has been staggering. On the human scale, for patients, their families and friends, as well as for their medical team who would like to offer them the best care possible, the process still seems too slow. We all feel a sense of frustration and impatience; given the length of time it takes to develop newer, better therapies. A new pharmaceutical molecule, deemed promising, can take 15 to 20 years before it is accepted for widespread clinical use in patients. First, this molecule has to be tested in the laboratory on cells and animals in which PH has been induced. The process then moves to trials on healthy humans to verify the way the medication acts in the body and to determine its safety. Next, the medication is tested on a small number of PAH patients, and, finally, on a larger number of these patients. This last step becomes more difficult when dealing with a rare disease, such as PAH, where the numbers of patients are relatively small, and these clinical studies requires a collective effort and collaboration between international PH centres, including those in Canada.

It then comes as a great disappointment when, after all these steps, a treatment is withdrawn and is no longer available for clinical use, as recently happened with sitaxsentan. After such an event, uncertainty surrounding other PAH treatments may even arise. It is important however to put this all in perspective and to be reassured. The process of developing medications available in Canada is very rigorous and strict. What's more, once on the market, all drugs continue to be monitored and constantly re-evaluated in terms of safety. The treatments we use in PAH offer great benefits to many patients, and generally with minimal risk, provided these medications are given to the right patients and monitored closely.

Indeed, it was exactly during such ongoing monitoring of PAH patients, and their PAH treatments, that a concern about sitaxsentan arose. At least four cases have been reported where sitaxsentan was associated with severe liver toxicity, which led to the patient's death. Thankfully, there were only a few cases of this fatal liver damage reported throughout the world. Although sitaxsentan remains an effective PAH treatment, Pfizer decided to voluntarily withdraw sitaxsentan for safety reasons. These cases of severe liver damage and the process of sitaxsentan withdrawal underline the ongoing importance of continuing to proceed with carefully structured clinical studies of new PAH therapies, following each of the necessary testing steps until drug approval. Moreover, PAH patients must be carefully monitored during the period of testing of new medications in clinical studies, as well as during routine clinical treatment after drug approval.

In Canada, we are fortunate that we have access to other effective PAH medications in the same class as sitaxsentan, to other complementary PAH medications, as well as specialised PH centres, who can determine the best alternative for each patient. The path towards a new medication is always followed in a safe and well-supervised manner.

On behalf of Canadian PAH patients, their caregivers, and the Canadian PH medical community who cares for these patients, we support and encourage our pharmaceutical partners to continue to commit themselves to this field, which is near and dear to our hearts, and to continue to develop new treatments in a scientific and ethical fashion for the good of our patients.

### UPDATES FROM THE TORONTO CHAPTER OF PHA CANADA

By **Ruth Dolan, parent of a PH Patient and Toronto Chapter Support Group Co-Leader**

Full 2010 was a very busy one for the Toronto Chapter. Members of our PH support group were very active with awareness campaigns, one of which was participating in the global Pucker-Up 4 PH campaign. We all participated as a group and then other members reached out to their communities to gather more "lip prints" and to spread awareness about PH. Toronto helped collect 328 lip prints to add to Canada's total count for this awareness campaign. (Ed. note: across Canada a total of 3315 kisses to help support the global effort were gathered.)

Rosemary Lavery and Paul Adams, were once again the enthusiastic engine driving preparations for the second annual "Let Me Breathe" Vegas Night Fundraiser held at Brebeuf College in Toronto on Saturday, November 6, 2010. After our first successful event in 2009, our members were inspired and energized to try to make this year's event even better. They sold tickets, sought donations for door prizes and auction items and received

### AN UPDATE FROM THE OTTAWA PH SUPPORT GROUP

By **Jo-Anne Mainwood, PH Patient and Ottawa Support Group Leader**

The first ever Ottawa Support Group meeting was held on October 8, 2010. Thanks to PHA Canada's "Connecting the Community" Program, Carolyn Pugliese (Nurse Coordinator of the Ottawa Clinic), Diane Nauth (Assistant to Dr. Davies), Harry Rozakis [a former PH patient, Harry had Chronic Thromboembolic PH (CTEPH), which was cured through a Pulmonary Thromboendarterectomy (PTE) surgery, but remains a very active supporter and member of the PH community] and Jo-Anne Mainwood (who has Idiopathic Pulmonary Hypertension), were put in contact with one another and worked together to organize the meeting, which was very well attended by PH patients, and family members, from all over the Ottawa region.

The meeting was a great success with over 50 people in attendance. The guest speaker was Dr. Duncan Stewart, who has extensive expertise in the latest research in Pulmonary Hypertension. His talk, about the latest advances in PH, was very informative and provided a lot of hope for patients with the disease. The Ottawa chapter was also thrilled that both Jennifer Gendron and Angie Knott, from PHA Canada, were able to attend our initial meeting and provide excellent information about the national organization and programs and support available through PHA Canada.

Eli Lilly Canada, one of the pharmaceutical companies, which makes PH treatments, supported the meeting by providing delicious food and drinks and the PH Program at the Heart Institute provided free parking for all participants.

During the meeting we were also able to collect many kisses for the Pucker Up 4 PH campaign, which was a lot of fun and provided for some levity as people walked around with blue lips! We even managed to get some of the Heart Institute staff involved and puckering up!

The next meeting of the Ottawa Support Group will be planned for the summer when driving in Ottawa is not so challenging. Anyone who would like to be added to the list of Ottawa Support Group Members can send an email to [Jo-Anne.Mainwood@ocdsb.ca](mailto:Jo-Anne.Mainwood@ocdsb.ca) or contact her by phone (613)-824-6916.

numerous donations of money. On the afternoon of the event, many volunteers showed up to help with last minute preparations. Helen, one of our members, was especially thoughtful in that she also prepared food to keep all the volunteers fuelled as they worked.



TOP: Members of the Toronto Chapter show off prizes and educational materials at the event

BOTTOM: Brebeuf College staff volunteered to act as dealers at Toronto Chapter's Vegas night fundraiser 2010

Bradford ON. I prepared a power point presentation about PH and led a Q&A period; about 60 participants from the community, many of who were seniors, enthusiastically received the session. Information pamphlets and PH items were available for the audience, many of whom said that they would pass this information on to their doctors or respiratory clinics.

Other efforts, of the Toronto Chapter, at spreading awareness include requesting the Ontario Lung Association to have PH listed as a lung disease on their website. We were glad to hear they're currently working on a new page on PH for their website. We were also successful in our request to have the Mayo Clinic Web site add Pulmonary Hypertension to their "Symptom Checker" tool.

In conclusion, it is clear to me that our group has grown and evolved over the last 3 years, when Loretta (Chu) and Frank (Poon) and the first few members met for the first time in a coffee shop. Because of them, and what each new member brings to the group, we have gained so much from each other and now have the courage to talk openly to others and to "spread the word" about pulmonary hypertension whenever the opportunity presents itself. Over the past three years, friendships have blossomed and there is even support happening beyond the group meetings. We are welcoming new members and spreading the word about PH.

It looks like 2011 will be an exciting year for the Toronto group as well as for PHA Canada. For the first time we will be inviting guest speakers to our group; in February a Registered Holistic Nutritionist and in March a Social Worker who offers seminars in Mindful Living (with the goal of reducing stress and appreciating the lives we have). By summer we should be gearing up to help with the Canadian PH Conference being held in Toronto on Sept 16 -18th, as well as preparing for our third "Let Me Breathe" Fundraiser in November.

Our very best wishes to our sister groups across the country for a wonderful year. We look forward to hosting you in Toronto in September!

It is my great privilege to be a part of this wonderful group and the PH Association.

We owe a great debt of gratitude to the Principal of Brebeuf College, for allowing us to hold the event in this beautiful building. We are also grateful to many of Rosemary's and Paul's colleagues from Brebeuf College and St. Patrick's school, who generously donated their time to act as dealers at the gaming tables and who provided so much fun for our guests. This year with all of this enthusiastic support we were able to raise \$13,700 for PHA Canada programs.

On November 11th, I had the opportunity to be a guest speaker at a "medical information" event in

## PHENOMENAL LIVES BLOGS: A GREAT NEW WAY TO SHARE YOUR STORY

By *Angie Knott*, National Manager, PHA Canada



When I was little, like most girls my age, I kept a diary. It had a blue cover, a lock and fit nicely under my mattress. We've come a long way since then. Truthfully, I can't remember the last time I picked up a pen and paper to write down my thoughts, even if I am writing something personal, it is now always done clicking away at a keyboard (being left-handed this works much better for me as I no longer have to worry about a streak of blue pen smudge all over the side of my hand). With all this technology comes an incredibly powerful tool: instead of hiding your stories away under a mattress, you can share as much or as little of them, as you choose.

Within the PH community we very often speak about the importance of sharing stories, and although I could probably click away and fill an entire page with reasons why sharing your story is so important; I will mention only a few. Those, which, to me, are at the top of that list, are:

The first and foremost reason is: because sharing your experiences can be extremely therapeutic: One of the main rules of blogging is "write for yourself". Writing is an outlet, a way to share joy, vent anger, express frustration, or even celebrate personal triumphs. Writing out your story can be healing and can give you insight into the fact that your life, and the things you do while living with PH, are incredible.

The second reason why sharing your story is important is because sharing your experiences can be extremely therapeutic. No, this isn't a mistake; this reason is in here twice on purpose. Sharing your story, your experiences, with others can be just as therapeutic for them as it is for you. Go back in time for a moment; think of what it was like when you heard the words "pulmonary hypertension" for the first time. Likely, one of the first things you did when you or your loved one were told they had this thing about which you had never heard, was go to the internet, open a search engine and type in: pulmonary hypertension. If you heard these words spoken quite some time ago, likely what you found did not inspire much hope. If you heard them a little more recently, you may have found the website of PHA (USA) and learned that maybe there was some hope after all. That is how your story can be therapeutic: imagine you have just come back from the doctor who told you that they have to run some more tests but most likely you have pulmonary hypertension. You sit at your computer and search the words "pulmonary hypertension". You find the PHA Canada website and after learning a bit about the disease you click on the PHenomenal lives link and find yourself reading the stories of patients, caregivers, and others, whose lives have been affected by PH but who are still living normal lives. Sure, they have some ups and downs but they cope with them, they have hope

and here they are, sharing their story, showing you that there is a life with PH and, that although things will change, you will be ok.

The third reason why sharing your experience is so important is: it helps raise awareness of PH. Nothing touches more than a personal story. Nothing explains how a disease, especially one that is rare, and relatively unknown, affects the life of a patient, a caregiver, or a family member, like the story that person tells. When you tell your story it puts a face to the disease and brings home the importance of knowing about it. Raising awareness helps to assure that others will be diagnosed and treated earlier, allowing them a better prognosis and quality of life. It assures that more funding for research is made available and it helps people to understand that just because someone doesn't look sick that doesn't mean they are not struggling.

This month PHA Canada is introducing PHenomenal Lives Blogs: these personal blogs give you the opportunity to share your day-to-day PH experiences: the good and the bad.

Here is your chance to create and maintain your very own PH blog within our website. What we offer you:

- ◆ A pre-designed (it will look like the PHA Canada website) space for your blog
- ◆ A blog page only you can access and edit, using the same user name and password you use for the PHA Canada site (discussion forum, etc).
- ◆ You can set who can read your blog - Anyone visiting the PHA Canada website or only registered website users (choosing this option will significantly limit the number of people who can view your blog)
- ◆ A really simple and user friendly way to edit your blog – you can add posts, images, really whatever you wish
- ◆ The ability to control comments – comments can be turned completely off, can be on and post immediately or can be on but have to be moderated by you before they post, it's your choice
- ◆ A way to share your PH story with the world, to connect with other PH bloggers, to inspire others, raise awareness and make some new PHriends.
- ◆ Your own blog url that will look like this: [www.phacanada.ca/nameofyourblog](http://www.phacanada.ca/nameofyourblog)
- ◆ Tips and ideas on how to create a blog that others will want to read

Getting started is really simple: visit [www.phacanada.ca/PHenomenalLivesBlogs](http://www.phacanada.ca/PHenomenalLivesBlogs) and follow the instructions on getting your own blog set up today.

Want to share your story but not sure if a blog is the right platform for you? Don't forget you can submit your story to the PHenomenal Lives website section, or to be published in the next issue of Connections.

Remember, every PH story is important and worth sharing, No matter the medium you choose to share your story, we want to hear it!

## PHENOMENAL YOUTH: CREATING HOPE THROUGH RESILIENCE

By *Emily Dolan*, PH Patient, PHenomenal Youth Blogger

“It's easy to become hopeless. So people must have hope: the human brain, the resilience of nature, the energy of young people and the sort of inspiration that you see from so many hundreds of people who tackle tasks that are impossible and never give up and succeed.”

– Jane Goodall

This quote is a commentary on global struggle, and the plight of so many facing adversity in a stark world, though as I came across it, it articulated what I wanted to convey with this article. My original thought was to write about youth and Pulmonary Hypertension from a perspective of struggle and resilience as it pertains to dealing with illness, treatment, and pain (both physical and emotional). This topic is not so narrow as to only speak to young people, but that is what drew me to it. Let me explain: I am a firm believer that to live is to struggle. And it is how we frame, cope, and respond to struggle that defines our strength. To learn this at a young age is a privilege of sorts, as so many go through life not able to grasp their own ability to thrive.

For me, this has been a life lesson learned with many pitfalls. In itself, falling flat on my face metaphorically when life threw me curveballs and I not always bouncing back with a smile on my face was a lesson; we are human after all! But the majority of days I am resilient. I have consciously chosen to treat my PH as a strength: an opportunity to grow and give back. I see this attitude as my only alternative as I refuse to be miserable and negative; after all, I have to live with myself! Taking this perspective is also helpful in putting my dark days and moments into perspective. I know that they will pass; I also know that I can handle pretty much anything that is thrown at me! Being aware of this ability has helped me, not only to deal with my PH, but with other life situations as well.

Like the quote says: It is easy to give up our hope. But, through resilience we can create hope where there is struggle by changing how we see it. Another poignant point that Jane makes is that young

people have an energy that is truly remarkable. This is why youth living with PH have such an incredible opportunity to change the face of this disease. Energy (not physical energy necessarily) is the will to overcome adversity with a strength and consistency that resists boundaries and sees hardship as an opportunity to grow. Youth harness this capacity in a way from which others can learn. It is their gift to the world.



FROM LEFT TO RIGHT: Toronto Chapter's Young PHers: Loretta, Kathy and Emily

I am no guru, just a young woman with a passion. I am eager to share my thoughts, musings and occasional rants. I also encourage dialogue, feedback and general interesting conversation. That being said, please visit Loretta and me, PHA Canada's youth bloggers, at <http://phenomenalyouthcanada.blogspot.com/>. Be sure to also visit the youth page on the PHA Canada website: [www.phacanada.ca/YoungPHers](http://www.phacanada.ca/YoungPHers), where we are working towards putting together an entire information section devoted to young adults living with PH.

## MY PHENOMENAL CAREGIVER, RON

By *Michelle Andrews*, PH Patient



Ron Andrews



Michelle Andrews

His name is Ron. He will tell you that he is not a nurse. He has a scientific, mathematical, logical mind. He is a MacGyver. But, as he says, he is not a nurse and wouldn't choose to be one. However, you wouldn't know it from observing him.

When I am at a meeting and have been standing too long, I almost always feel a chair being slid in under me. When I brush my hair (long, tangly and tiring), two strong arms hold up my arms. If I forget to put on my O2 and bounce into a task, which most likely necessitates it, he quietly brings it to me.

He's the person who designed a special flow meter right into my handheld shower, so that I do not have to struggle with the taps of the very old heritage house that we are renting. And he's also the one who put a hook for my O2 hose just at the right height beside the kitchen table that is my desk, entertainment center, laundry table... where I spend a good deal of time. Also, he made sure that I have a very

**MY PHENOMENAL CAREGIVER, RON (continued from page 7)**

comfortable office chair that travels me around the kitchen on bad days.

He adjusts his work schedule so that he can drive me to my many doctors' appointments: besides my PH team, I have eight other specialists. We seldom have a week that does not include a full day at Credit Valley Hospital or Toronto General. Often, it stretches to two days a week.

He even helps me when I am adjusting to a new dietary restriction: low sodium (of course), low calorie, low fat, low sugar, low potassium, and now low purine. As I said: nine specialists for 7 medical conditions besides PH. He either takes his portion of food restricted to me into his study or foregoes it all together.

Washing my hair is not his favorite thing, but when I have the flu or some other bad spell, wash it, detangle it, and condition it he does.

Being very "techy", he has ensured that even with all the old, gleaned electronics we have, I can start a DVD or music in the kitchen and click it on instantly when I enter another room. So if I get tired in one room, I can just stay there. That's also why he made sure that I have a phone in every room, and an intercom. My fatigue is also the reason that he has placed everything I need within my reach, not too high, and never below the waist. He bought a small freezer chest so that the side-by-side fridge/freezer wouldn't get too crowded, allowing me to handle it with ease. Only things that he needs to retrieve are in the chest freezer. My washer, dryer and treadmill have all been placed in my kitchen, so I don't have to travel far.

If he comes home and sees the laundry unfinished, dishes not done, things out of place, things dropped on the floor and just left there, he just quietly does it all, knowing that I am having a bad day.

On my bad days before he leaves for work, he leaves me all set up with ice water, meds, pen, paper, remote, phone and laptop. He makes sure all the supplies I need are on hand.

And when my ridiculously high heartbeat (120 BMP) won't let me sleep, he gives me a back rub until I fall asleep, event though he has very painful arthritis in his hands.

This fellow does countless other things for me, including sacrificing some of his own hobbies so that funds can stream into all things medical. Until five years ago, when my Mom passed, he bathed her feet daily, put her support hose on, and helped me change her diapers.

He is a great guy, a gem. All the women I know have made clear note of this. I have been married to him for 32 years.

His name is Ron and he is not a nurse.

**THE LIFE OF A "PHER"**

By Rita Hébert, PH Patient



What might it feel like to skip 30 or 40 years of your life in the space of 3 to 5 years? Imagine for a moment what your life would be like if you turned 89 a mere four years after your 45th birthday! Sounds like a horror out of a sci-fi movie doesn't it? However, that is one of the "hidden truths" behind Pulmonary Hypertension. And, our little sci-fi tale doesn't end there. Friends, family and co-workers wouldn't especially notice, as outwardly you looked only 49! They may however have noticed that you seem a little short of breath, and perhaps a little more moody, but think it must be due to hormonal changes.

Let us imagine what life might be like for this 89 year-old; who for the sake of this article, we will call "PHer". After an appointment or running regular errands, PHer is feeling exhausted and frail. He embarks on a crowded bus – no one offers him a seat because of his youthful appearance. So PHer stands, with swollen ankles and/or abdomen, dizzily hoping that the ride won't be too long. Upon arriving at his destination, PHer realizes that he hasn't eaten in several hours but is too tired to prepare a meal. PHer's budget is rather tight since going on disability, but hopes to find a lunch counter that offers reasonably priced meals. Unfortunately, this proves to be very challenging as most take out meals are laden with salt. Disheartened and feeling isolated PHer goes home, grabs a handful of low sodium crackers then breaks into tears!

Pretty dismal picture isn't it? However, what I just described is only a small portion of the challenges pulmonary hypertension patients face on a day-to-day basis.

Here, in Quebec, we "PHer's" are fortunate to have some of the best healthcare professionals looking after us. However, we, the patients, all have something in common with PHer: whatever stage we have reached within this "orphan" disease, we have all shared, at some time or other, PHer's feelings of being misunderstood and sense of isolation. It is by holding regular patient meetings that we can help each other cope and deal better with these daily challenges.

I am proud to add that with the help of PHA Canada, and the support of our healthcare professionals, we were able to organize the first bilingual support meeting for Quebec patients! The meeting was held on February 21, 2011 and I am pleased to report that we had over 50 in attendance and, so far, patients' enthusiasm and feedback (Francophone and Anglophone) has been most favourable.

**Ask a Nurse**

The Connections "Ask a Nurse" feature allows you to submit your general questions about PH to be answered by a specialised PH nurse. Submit your question via email to [askanurse@phacanada.ca](mailto:askanurse@phacanada.ca). Please keep in mind that nurses can only address general topics that are not specific to individuals. If you have specific questions pertaining to your care you should speak to your PH team.

**DISCLAIMER:**

We encourage readers to discuss their healthcare with their doctors. The information contained in this newsletter is intended only to provide information on PH and not to provide medical advice on personal health matters, which should be obtained directly from a physician. PHA Canada will not be responsible for reader's actions taken as a result of their interpretation of information contained in this newsletter.

**TIPS ON TRAVELING WITH PH**

By Carolyn Pugliese, RN, MSN, Nurse Coordinator  
Ottawa Pulmonary Hypertension Clinic

Travel can be stressful. For individuals with pulmonary hypertension, there are several important factors to be considered, especially when flying. Preparing in advance, for your trip, will make your holiday travel more enjoyable.

Below are some tips and information that will make planning your trip, and traveling, a little less stressful:

**A Preflight Checklist:**

- ▶ Talk to your doctor to see if any pre-flight testing may be warranted to assure that your condition is stable enough for travel
- ▶ Carry a letter from your doctor to show Security and Customs Officials, if needed, that provides not only a medical history but also provides a list of the medications you are taking/carrying with you
- ▶ Carry adequate supplies of prescribed medicine in your carry-on luggage
- ▶ Carry your emergency contact phone numbers with you at all times, these should include a list of your doctors (including your PH specialist) and next of kin
- ▶ During the flight, consider wearing compression stockings, pass on the alcohol, exercise your legs and feet every chance you can to avoid blood clots
- ▶ If you are traveling by air, you can order special meals such as low-sodium, low fat, and diabetic, assuming meals are being served on your flights. Special meals must be ordered at least 24 hours before each flight
- ▶ Order a wheelchair for the airports. This can be done at any time. If you are going to an unfamiliar airport, it is especially important because the walks can be very long. Security, Immigration and Customs lines are often quite long and slow. If you are in a wheelchair, you can handle such lines much faster and with less stress.
- ▶ Ask your PH coordinator to help you locate the closest PH centre to where you will be staying, in case you have an emergency during your trip.

- ▶ Before deciding whether you need trip cancellation insurance and how much, figure out how much of your trip's cost would be non-refundable if you had to cancel
- ▶ The risk of contracting a contagious illness is heightened when we travel within any enclosed space, especially during the winter months; when most respiratory viruses thrive: sanitize your hands often.

**The Need for Oxygen:**

Traveling to high altitude cities as well as air travel itself poses a significant concern because hypoxia (oxygen depletion) at high altitude will trigger the narrowing of pulmonary blood vessels and cause further increases in pulmonary artery pressure. This may rapidly worsen how you feel. Planning this type of trip always requires a conversation with your PH doctor and while you may be given the ok to travel to a high altitude city and or in a plane, you may require a careful pre-trip assessment, including high altitude simulation testing to assess low oxygen conditions. If travel is necessary or strongly desired, you will most likely be required to use supplemental oxygen.

An important first step when given the green light by your doctor is to contact the airline you plan to be flying on to determine their policies on portable oxygen for travelers suffering from pulmonary hypertension.

Different airlines have different rules about oxygen. The rules can differ depending on where you are flying.

The following is adapted from the Canadian Lung Association ([www.lung.ca](http://www.lung.ca)):

**AIR CANADA RULES ABOUT MEDICAL OXYGEN**

**Portable oxygen concentrators (POCs):** Air Canada allows POCs on all flights.

**Oxygen tank rental:** Air Canada allows you to rent oxygen tanks through a third party supplier. They charge \$17 per flight. They give you the oxygen once you are seated on the plane. They do not supply oxygen to use while you are in the airport or while you are on stopovers (transferring planes, etc.). You must arrange your own supply of oxygen for all the time you will spend in airports, going through security, etc. You need to order the oxygen 48 hours in advance and get medical approval for travel.

To rent oxygen equipment or to use a POC, you need to make arrangements with Air Canada at least 48 hours in advance. Your doctor must complete a medical form and fax it to Air Canada. Visit the Air Canada website ([http://www.aircanada.com/en/travelinfo/before/specialneeds\\_medical.html](http://www.aircanada.com/en/travelinfo/before/specialneeds_medical.html)) to find out how to get medical approval for travel on Air Canada, and links to the form for your doctor to fill out. For more information and updates on Air Canada rules about medical oxygen, call 1-888-247-2262.

**WESTJET RULES ABOUT MEDICAL OXYGEN**

**Portable oxygen concentrators (POCs):** WestJet allows POCs on all flights. You must use a model of POC that's on their list of approved models, and follow other rules. You must also have a signed physician statement.

**Bringing your own oxygen tanks:** WestJet allows passengers to bring their own oxygen aboard flights in Canada (domestic flights only), if they meet certain conditions. WestJet will permit up to two guests with up to two oxygen cylinders each for personal use onboard the aircraft. Visit the WestJet website (<http://www.westjet.com/guest/en/travel/special-arrangements/special-needs/portable-oxygen.shtml>) to find out more about WestJet regulations regarding oxygen.



For more information on travelling with oxygen on WestJet, call 1-888-937-8538 or visit WestJet's web page on travelling with special medical needs (<http://www.westjet.com/guest/en/travel/special-arrangements/special-needs/index.shtml>).

#### TRAVEL TO THE USA AND OTHER COUNTRIES

If you plan to travel outside of Canada, talk to your local oxygen provider and ask for help to plan oxygen for your entire trip.

**In general, there are 3 possible ways to get medical oxygen while you fly:**

1. The airline lets you bring your own oxygen tank with gaseous oxygen.
2. The airline lets you rent oxygen equipment from them.
3. The airline lets you carry a portable oxygen concentrator (POC)

#### IF YOU ARE SUPPLYING YOUR OWN OXYGEN

- ◆ Make sure your oxygen tank(s) is approved by your airline. Ask your oxygen supply company to look at your oxygen prescription, your travel plans and calculate how much oxygen you will need.
- ◆ When figuring out how much oxygen you will need, your oxygen supplier will have to consider:
  - The oxygen rate you are prescribed (you may use a higher rate when you are in the air)
  - The time it will take to get through airport security areas
  - Time in the air
  - Time on the runways, taxiing
  - Time in airports between flights, if you have a stopover
  - Possible flight delays
- ◆ Ask your oxygen supplier to make sure you have an oxygen supply waiting for you once you reach your destination. If your supplier doesn't supply oxygen at your destination, they may be able to tell you about a company that does.

#### MAKE SURE YOU BRING:

- ◆ Your nasal cannula
- ◆ Your written prescription for oxygen
- ◆ A physician's statement, if your airline requires it
- ◆ Contact information for the oxygen supply company in your hometown and in the place you are visiting.

**If you plan to use the airline's oxygen supplier, talk with this company. The airline will give you their contact information.**

- ◆ Tell them how much oxygen you need (your doctor or respiratory therapist has told you).
- ◆ Make sure they will supply oxygen from the moment you arrive at the airport until you get to your destination – this must include time to go through security checks, time in the air, stopover time, plus any possible delays.
- ◆ If they do not supply oxygen from the time you arrive in your departure airport until the time you clear customs in your destination, you must arrange for a separate oxygen supply for use in your departure airport, any stopover airports, and your arrival airport.
- ◆ Make sure you know how to use the oxygen tank they will supply.
- ◆ Bring your written oxygen prescription and a physician statement, if required.
- ◆ Ask if you need to bring nasal cannula.

**If the airline lets you carry a portable oxygen concentrator (POC):**

1. Portable oxygen concentrators (also called portable concentrators or POCs) are similar to home oxygen concentrators, but they're smaller and easy to carry. Portable oxygen concentrators supply you with a higher amount of oxygen than what's found in the air around you. With a POC, you don't actually carry around a tank of oxygen. Instead, the POC draws oxygen from the air around you, concentrates it (builds it up), and then sends you the oxygen-enriched air.
2. If your airline allows POCs, you are responsible for bringing your own. You can buy a portable oxygen concentrator or rent one from an oxygen or medical supply company. The airline does not charge you for bringing the portable oxygen concentrator, but it will ask you to follow certain rules and bring a signed note from your doctor saying you are fit and able to use the POC. WestJet and Air Canada allow portable oxygen concentrators on domestic flights and international flights. Many U.S. airlines also allow you to carry portable oxygen concentrators.
3. Always prepare for the unexpected such as delays or unplanned layovers. What will you do for oxygen if your trip is longer than expected? Will the battery life for your equipment last long enough, and how will you recharge batteries, if you have cancellations or unexpected delays. If you plan things in advance, you'll have enough oxygen to stay safe and healthy.
4. Before you book any flights, learn about the rules for oxygen on that particular flight on that particular airline. Allow at least a few days to talk with the airline and let them know that you require oxygen on a particular flight. Don't book your flight until you have arranged your oxygen supply.

**When you talk with the airline about medical oxygen, tell them your planned destination and ask:**

1. What are your rules about using medical oxygen? Can you show me a written policy?
2. Can I bring my own oxygen tank? If so, what are the rules?
3. Do you supply medical oxygen? If so, what is the cost?

4. Do you allow me to carry a portable oxygen concentrator (POC)? If so, what are the rules? What sizes and brands are allowed?
5. Can I bring oxygen tanks? How many tanks can I bring?
6. Do I need a physician's (doctor's) statement proving my medical need for this device?
7. Will you provide emergency oxygen if I need it?
8. How much advance notice do I need to give you that I require oxygen?
9. What's your company policy on batteries in carry-on luggage?
10. Can I bring other medical devices, like a humidifier?
11. What is the security procedure for medical oxygen?
12. What is the airport procedure for medical oxygen?

#### What To Do About the Sodium, While You Are Traveling:

##### HEALTHY SNACKS:

Avoid snacks that are pre-packaged, as many are high in sodium. Whole fruit and unsalted nuts are a great snack during the day.

**Read Nutrition Labels:** If you need to purchase pre-packaged foods, read nutrition labels to understand their sodium content. First, look at the ingredient list. MSG, baking soda, baking powder, disodium phosphate, sodium alginate, and sodium nitrate all represent sodium. Secondly, look at the sodium percentage on the Nutrition Facts label. Choose foods that represent less than 10% of your daily value of sodium.

##### GENERAL SODIUM TIPS:

**Ordering at Restaurants:** Ask a lot of questions to understand how food is prepared. Ask about spices, rubs, marinades, dressings and finishing sauces. All of these can be high in sodium.

**Avoid Foods Naturally High in Salt:** Avoiding foods such as cheese, olives, pickles, cured or smoked meats and deli meat will help to keep sodium intake down.

**Keep it Simple:** The more complicated a dish, the more likely the sodium content is high. Avoid casseroles, "pot pies" and other dishes that have a lot of "mystery" ingredients. Instead, opt for entrees that are grilled, baked, or roasted. When it comes to side dishes, choose fruits and vegetables that are prepared simply, such as steamed vegetables with no sauce. Ask for lemon to season vegetables (it is great on steamed broccoli!).

**Go Local:** When dining out, look for locally owned restaurants. More likely than not, food is prepared to order which may make it easier for them to accommodate low sodium requests.

**Dressings, Sauces and Condiments:** All of these are high in sodium. To eat well, ask for any and all sauces to be served on the side and lightly dip your fork into the sauce before spearing your food. Also, steak, teriyaki and barbecue sauces, as well as ketchup, are high in sugar, sodium and calories. If you use them, do so sparingly.

Remember to limit fluid intake (1.5 liters-2 litres of ALL fluids per day) if you happen to suffer from fluid retention

#### Traveling With Remodulin/Flolan:

Inform your clinic/nurse/pharmacy/CCAC of any and all traveling plans whether it is 1 day or 30 days. Discuss your travel plans as early as you can. The specialty pharmacy will need to know where supplies will be shipped for you and for how many days.

Keeping Flolan cold is a big factor if taking a long trip. Airlines, restaurants and hotels will keep ice packs in their refrigerator, freezer for you. Hotels will supply a refrigerator with the small freezer section.

Consider purchasing a small backpack on wheels to carry your pump, 2 days (discuss number of days with your PH team) of supplies, letters (indicating supplies needed to carry on the plane) and other things needed for trip. Other patients, who are seasoned travelers, recommend carrying a small thermos/cooler for ice and the medication cassette: small lunch bag ice packs last for about 6 hours.

Shoppers Drug Mart also suggests taking a 3rd pump as a back up for the back up. Patient and clinics will need to discuss taking a 3rd pump with CCAC if they are involved with paying for the supplies and pump rentals.

#### A Preflight Checklist (as listed on page 9):

- Talk to your doctor** to see if any pre-flight testing may be warranted to assure that your condition is stable enough for travel
- Carry a letter from your doctor** to show Security and Customs Officials, if needed, that provides not only a medical history but also provides a list of the medications you are taking/carrying with you
- Carry adequate supplies** of prescribed medicine in your carry-on luggage
- Carry your emergency contact phone numbers** with you at all times, these should include a list of your doctors (including your PH specialist) and next of kin
- During the flight, consider wearing compression stockings**, pass on the alcohol, exercise your legs and feet every chance you can to avoid blood clots
- If you are traveling by air, you can order special meals** such as low-sodium, low fat, and diabetic, assuming meals are being served on your flights. Special meals must be ordered at least 24 hours before each flight
- Order a wheelchair for the airports.** This can be done at any time. If you are going to an unfamiliar airport, it is especially important because the walks can be very long. Security, Immigration and Customs lines are often quite long and slow. If you are in a wheelchair, you can handle such lines much faster and with less stress.
- Ask your PH coordinator to help you locate the closest PH centre** to where you will be staying, in case you have an emergency during your trip.
- Before deciding whether you need trip cancellation insurance** and how much, figure out how much of your trip's cost would be non-refundable if you had to cancel
- Sanitize your hands often:** the risk of contracting a contagious illness is heightened when we travel within any enclosed space, especially during the winter months, when most respiratory viruses thrive.

By *Kate McGoey-Smith*, PH Patient and Southern Alberta Chapter Co-Leader

At the November 30th educational meeting held in Calgary, Alberta, Dr. Douglas Helmersen addressed members and their families of the Southern Alberta Chapter of the PH Association of Canada. Dr. Helmersen is head Pulmonologist for the Peter Lougheed Centre's Respiratory Clinic serving patients with pulmonary hypertension. At this meeting, Dr. Helmersen suggested that it was preferable to keep a bag packed and ready for the hospital.

As a patient with Pulmonary Arterial Hypertension, who, in the past year, has been admitted to hospitals four times, one stay lasting 58 days, I have some information to share with you to empower you and to make your hospital stay more comfortable.

Below you will find a checklist of items to take with you as well as information of what not to take as well as some additional information that may make your hospital stay a little more pleasant.

#### Packing Your Suitcase:

- Pillow:** your own will help with the transition to different bed
- Personal Quilt or throw:** becomes a "talking point" with staff and feels less like you are a patient
- Pajamas / night gown**
- Bathrobe**
- Slippers with rubber soles**
- Hair care:** shampoo, conditioner, brush/comb, hair dryer
- Oral care:** toothbrush, toothpaste, floss, mouth rinse and any other dental needs
- Skin care:** soap, lotions
- List of Medications.** Make sure to include the following information:
  - Name of Drug;
  - Dosage;
  - Frequency;
  - Time of day taken;
  - Prescribing Doctor; and
  - Reason for prescription
- List of Allergies.** Make sure to include: Name of Drug, Date of Reaction; Description of Reaction and include negative reactions to bandages
- If you are an insulin-dependent diabetic:** bring in your own meter, strips and needles/pens (these tools are often less painful than what the hospital supplies)
- If applicable:** pressure treated hosiery and latex gloves
- Reading materials** (if needed, remember reading glasses)
- Music resources:** iPod, etc.

- Cell phone,** unless hospital room is equipped with a phone (be prepared for rental fee)
- Hard candies (sugar or sugar-free):** it tends to be very dry in hospital rooms
- Tissues:** hospitals provide the basics not the soft kind
- Note book and pen** (helpful to keep track of questions and communications with consulting doctors and to make notices to state where you are when out of the hospital room, e.g. "Walking on the ward." So you can be paged and not miss a consultation)
- Calendar,** to keep track of the days of the week and record any tests that occur and/or are planned
- Personal Pictures.** Plastic frames with plexiglass keep things safer

#### Add your own items to the checklist here:

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#### What not to bring to the hospital:

- ◆ Medications from home
- ◆ All removable jewelry
- ◆ Remove all nail polish unless translucent
- ◆ Wallet (except Health Card and small amount of change)

#### Being an Assertive Patient:

If not given, ask for an "orientation" to your room and the floor, and speak up about any other needs. Here are some of the items you may want to ask about:

- ◆ Patient bell
- ◆ Room lights
- ◆ How the bed operates and use of guard rails



- ◆ The location of bathroom, lights, emergency bell
- ◆ Inquire as to who, if needed, will help you with bathing needs, i.e. Role of nursing assistant
- ◆ Check schedule of drug dispensing. Often a computer sets times, which may not work for you, e.g. pain drug at 2:00 am, this can be changed by your primary nurse
- ◆ Meal times
- ◆ Meal plan: does it meet your dietary needs? Check type of meal plans available. Write down on the menu if you want a double portion of an item and/or addition of an item, e.g. tomato slices (it is worth a try)
- ◆ Allergies? If not given a special allergy alert band, request one be given to you

#### CONNECTIONS SUBMISSIONS

*The deadline for submissions for the next issue of Connections is June 1, 2011.*

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, or anything else you'd like to share. 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 etc. for consideration in the newsletter. If you're not comfortable writing your story, contact us, we'll interview you and write the story for you. If you are interested in becoming a Connections reporter, or conducting interviews with other members of the community, let us know. This is Canada's PH community's newsletter; let your voice be heard!

- ◆ Ask about how to rent a TV and/or phone (if wanted)
- ◆ Location of "comfort station" a.k.a. a mini kitchen for patients and their families (usually equipped with a fridge, microwave, toaster, kettle, water and ice dispenser and assorted jams, peanut butter and bread)
- ◆ Location of a "family room" where family members and visitors can gather to avoid a crowded hospital room
- ◆ Location of public washrooms for visitors
- ◆ Visiting hours (check if it is different for family than friends). Let staff know if you require any restrictions
- ◆ Check if you are permitted to be off the floor, where you can go, whom do you tell
- ◆ Inquire about spiritual support, if so desired
- ◆ Always ask the name of your "primary nurse" so you can tell the front desk if you need medication, etc.
- ◆ Ask your primary nurse who his or her "buddy" is for the shift (for paging necessities)
- ◆ If your room has a white board on the wall, request that developments in your care are recorded there, so you can refer to it when talking to those on the next shift or your consulting doctors. This saves lots of questions and answers: instead just point to the board
- ◆ If assigned a student nurse, remember you can refuse this, however when a student nurse is looking after you, you often have the benefit of not only one-to-one care as well as the care of the supervising practicum nurse and a staff nurse
- ◆ You may request your curtain be pulled and/or room door be closed (this helps at night to cut down on extraneous noise)
- ◆ Need additional support? Request to speak to a social worker
- ◆ Being discharged soon? You will often be assigned a "Transitions" worker who will contact community resources, e.g. Home Care, if such support is needed
- ◆ Remember to be courteous: "please" and "thank you" create good will and cooperation

No one wants to be in the hospital. Hopefully the information given to you in this article will make your stay more comfortable. May you remain a visitor and never a guest!

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

#### NEWSLETTER SUBMISSION

PHA Canada  
Suite 303, 1311 Howe Street  
Vancouver BC V6Z 2P3

Or email it to "Newsletter Submission" at [connections@phacanada.ca](mailto:connections@phacanada.ca)

Work submitted will be printed as space permits. Please let us know if you'd like anything returned. We cannot be held responsible for any materials lost.

## BRADEN'S JOURNEY CONTINUES AT THE 2010 NATIONAL TRANSPLANT GAMES

By **Jennifer Gendron**, parent, PHA Canada Regional Coordinator and Board Member

The week of August 9th, 2010, my son, 12 year old Braden Gendron of Hampton, was one of only two athletes from New Brunswick to represent our Province at the 5th Canadian National Transplant Games in Quebec City. This was an amazing accomplishment, as Braden, a former pulmonary hypertension patient, received a double lung transplant less than a year prior to the Games, on September 23rd, 2009 at Sick Kids Hospital in Toronto.

We first learned of the Games through Braden's physiotherapist, while he was recuperating in Toronto. The Games are a unique opportunity for transplant recipients from all over Canada to gather in a friendly and warm atmosphere. The goal of the Games is to increase public awareness on organ and tissue donation by showing that not only does transplantation save lives, but that the recipients can return to full and active lives post-transplant. Aside from promoting organ donor awareness, the Games give the transplant recipients and their families the opportunity to meet organ donor families and to share moments with them and express their gratitude. Preparing for the competition encourages the participants to improve their fitness level and lead a more active life. Braden was one of almost 100 transplant recipients competing at the Games.

During the Games, we had the opportunity to meet a number of other lung transplant recipients, several of whom had also suffered from pulmonary hypertension. Braden was thrilled to attend the Games for the first time and represent our home Province along with fellow New Brunswicker, Mark Black, a double lung and heart transplant recipient from Moncton who also underwent his surgery at Sick Kids many years ago. Braden made the most of the opportunity by competing in badminton, table tennis, and several track and field events bringing home one gold and two bronze medals. His next goal is to represent Canada at the World Games in South Africa in 2013.

As a parent who has watched their child sit on the side lines for many years unable to participate in any form of physical activity let alone compete in an athletic event, it was a truly amazing and heart warming experience. Our entire family was moved by the experience and we met many incredible people who made lasting impressions on our lives. If you or someone you know has undergone transplant, I strongly urge you to consider attending the Games.

To learn more about the Games and how you can support organ donation, visit [www.organ-donation-works.org](http://www.organ-donation-works.org) or contact Jennifer Gendron at [jgendron@nb.sympatico.ca](mailto:jgendron@nb.sympatico.ca)

## In memory of...



### LYNDA BERIAULT

We are saddened to report that Lynda Beriault passed away on February 24, 2011. Lynda lived with PH for 19 years. She was a pioneer in the PH community in Quebec and in Canada: she was one of the first patients in Canada on Flolan, and participated in the clinical trial, which contributed to Flolan being made available in Canada.

Lynda was a tremendous contributor to the PH community: she organized the first patient meetings in Montreal and led the Montreal PH support group (in English and French) for many years. She was one of the founding Board members of PHA Canada and was very passionate and involved with the organization. Lynda spoke to PH groups and conferences in Canada and the United States, and communicated with PH groups across Europe, Central and South America. She was an example, an inspiration, and a source of hope to other patients and the PH community as a whole. She will be greatly missed.



### ISABELLE CORMIER

We are saddened to report that Isabelle Cormier passed away March 18, 2011, at the age of 38.

Isabelle was an extremely active member of Quebec's PH community. She fought tirelessly on behalf of patients and acted as a patient spokesperson. She will be greatly missed.

We would like to share with you a few words written by Isabelle's father, Denis Cormier, president of the Quebec Pulmonary Arterial Hypertension Foundation (HTAPQ):

*"After an eight-year long battle with pulmonary arterial hypertension, your tired, and spent body, went to sleep peacefully on March 18, 2011: you were surrounded by your family.*

*No amount of suffering could calm your appetite for life and your biggest dream was to see your daughter Elizabeth, aged 9, grow up. You were just 38 years old.*

*You managed to find unbelievable strength to overcome all the difficulties placed before you. You leave behind an example of extraordinary courage and determination.*

*Isabelle, only the thought that your suffering is over can help us to accept that you are no longer with us. We will remember your generosity, your love of life, the cuddles that you were so good at giving. You are already extremely missed by all those who loved you so much.*

*The family would like to thank, from the bottom of our hearts, Dr. David Langleben, from the Jewish General Hospital in Montreal, who was available to Isabelle 24 hours a day. He and his team did everything possible to allow you to continue your life. Aside from the amazing quality of care you received, all those who cared for you sincerely liked you.*

*Rest in peace, dear Isabelle, you've certainly earned it."*

Isabelle was the representative for PH patients on the Board of Directors of the HTAPQ Foundation; her last wish was that donations be made in her memory to the cause that was so dear to her.