

CONNECTIONS

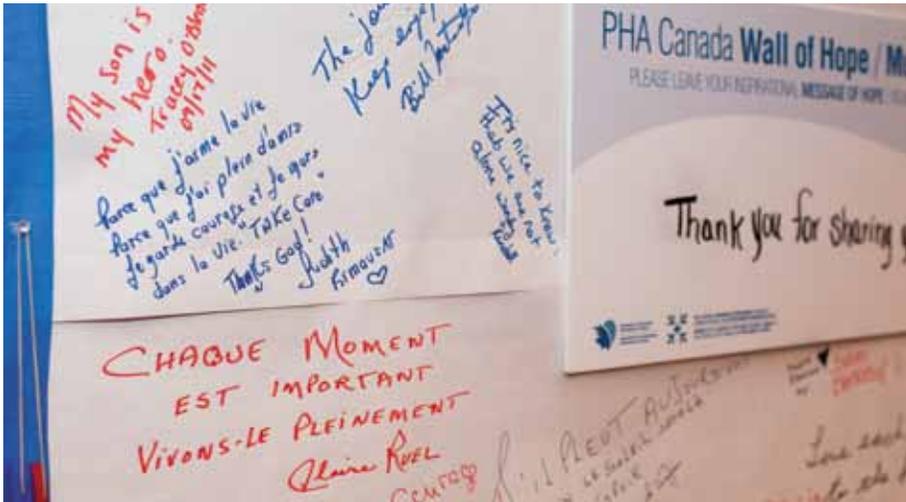
THE OFFICIAL NEWSLETTER OF THE CANADIAN PH COMMUNITY



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

UNITING THE COMMUNITY FROM COAST TO COAST AT CONFERENCE 2011

By Jennifer Gendron, Regional Coordinator



In September, approximately 250 patients, their caregivers and family members as well as medical professionals gathered in Toronto for an incredible weekend of learning, celebrating and sharing at our second biennial national conference at the Delta Chelsea. The spirit of the conference was truly captured with attendees arriving from as far away as British Columbia to the West and Prince Edward Island to the East, and special guests coming all the way from the USA.

The conference kicked off on Friday evening with a special “Meet & Greet” sponsored by the Toronto Chapter of PHA Canada. Attendees mixed and mingled while enjoying a game of “PH Bingo” followed by entertainment by special guest performer, Paul Adams who shared his special song, “Let Me Breathe”, a tribute to those living with PH.

The Saturday program included a line up of educational break out sessions on a variety of topics of interest to participants. During the noon hour meal, the “Journey’s Luncheon” was presented with three groups of health professionals and their patients sharing their PH stories. During this meal, a special presentation was also made to PHA President, Darren Bell by 16 year old Quinlan O’Blenis from Moncton, New Brunswick. Quinlan, a PH patient, raised over \$1,000 through Dragon Boat racing and presented the funds to PHA Canada. The presentation was followed by a touching tribute by Jacques Garipey of HTAP Quebec, to Isabelle Cormier, a dedicated member of the PH community who sadly lost her battle in March of this year.

Afternoon sessions on Saturday concluded with a variety of support groups for newly diagnosed and long-term patients, caregivers as well as PH parents. The sessions
(continued on page 4)

In This Issue

A Message from the President	2
A Message from the President	3
Uniting the Community from Coast to Coast at Conference 2011	4-5
Outstanding Members of the PH Community Honoured	6-8
PH Clinics Around Canada Help Spread the Word About our Community.....	8
Giving Thanks.....	9
An Interesting Educational Seminar in Quebec City.....	10
Spotlight on Local Support: The Quebec Pulmonary Arterial Hypertension Foundation (HTAP Quebec).....	11
Ask a Nurse: Pacing Yourself to Make the Most of Every Day.....	12-13
My ‘Myth of Cave’ Experience.....	13
Medical Corner: A Better Treatment for PH: the Research Continues!.....	14
We Cannot Face This Illness Alone: Line Ducharme’s Story.....	14-15
Our Local Patient Support Group is on a Mission!.....	15
Get Ready to Lend a Hand for PH this November!	16

PHA CANADA CAN BE REACHED AT:

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

Tel: 604-682-1036

Toll Free: 1-877-7-PHA-CANADA

Fax: 604-669-3688

Or via email at connections@phacanada.ca



Welcome to this issue of Connections! Having just returned home from our very successful Second National Biennial Conference in Toronto this September, I would like to take a moment to look back. When I accepted the role of President of PHA Canada in April 2008, the organization's name (formerly PH Society of Canada) and mandate was changed. The dedicated and exceptional members of our Interim Board of Directors, together with our

newly hired National Manager, Angie Knott, worked tirelessly to create an organization that could fit in and complement the great work that was already being done throughout the country by local support groups and provincial societies. As a young organization, it was critical for us to fulfill our mandate of providing support, awareness, and education of Pulmonary Hypertension while uniting this remarkable community from coast to coast. Over the past three and a half years, I strongly believe we have made great strides in achieving our objectives: we've seen many new support groups and chapters form throughout Canada and we continue to work closely and collaboratively with provincial societies who have chosen to maintain their own charitable status/mandate. We have seen patients, family members, caregivers, friends, and medical professionals all become more involved in this remarkable community. We have fought and won some important battles respecting equal access to therapies for all patients in Canada, and at the same time, raised awareness of this disease on a National level. With a new bi-lingual, national website and newsletter, we are reaching more people everyday! I truly am honoured to have been part of PHA Canada during these incredible achievements!

Having said all this, I feel like we are just at the beginning of a wonderful Journey together! Although we had just about 250 individuals attend the Conference, we are aware that there are still large numbers of patients and their loved ones throughout Canada who have not yet become part of this growing community. One of our many goals at PHA Canada is to find those that might not know about the great resources, support, and hope we offer. With the unwavering support of PH clinics across Canada, we are doing our best to spread the word by sending information to patients

about this growing family. Our pharmaceutical and specialty pharmacy industry partners have also support our initiatives from day one, and continue to assist us in spreading the word about our organization. One thing I have noticed from the beginning is how much hope and inspiration there is within our great PH Community; of which PHA Canada is proud to be a part.

The next major milestone on our calendar is the upcoming Awareness Month throughout November, about which you can read more on the following pages in this issue of Connections. I personally encourage everyone to get involved in whatever way you can (large or small) by spreading the word about PH and participating in our "Lend a Hand" National Awareness Campaign. Remember, PHA Canada is your organization; it will only be as strong and successful as you help to make it!

Finally, I want to say that after three and a half years of serving as PHA Canada's President, I am extremely pleased to introduce Mr. Frank Poon as the new President of PHA Canada. Frank was elected President by the new 2011/2012 Board of Directors immediately following the Annual General Meeting during the Conference. As I mentioned earlier, it has been an honour and privilege to serve you for these years and to work with so many individuals who continue to inspire me daily with their dedication to this community. I am also pleased to continue serving this great organization and community as a Director for the upcoming year!

We have come a long way in such a short time, and I am confident that PHA Canada will continue to have many more successes as we face new challenges and obstacles in the future! I think back almost 14 years ago when I started my PH Journey with my son, Dylan, and how critical the support and education was that my family received. I truly can't imagine this Journey without the PHenomenal support this community provided Ariane, Dylan, Hunter and myself. In closing, I can only reiterate how much of an honor it has been to be part of this special organization and community! THANK YOU,

Sincerely,

Darren Bell



Hi everyone, I'd like to welcome you to our final newsletter issue of the year. I've had the privilege of serving on the PHA Canada board for over two years and I am honoured to now serve as the new PHA Canada President. Darren has done an amazing job leading this organization to where it is today. I have big shoes to fill but I'm extremely excited to be given the opportunity. There are definitely ambitious plans in the works to enable our organization to better serve families living with PH.

A little bit of background on myself: I was first introduced to PH over five years ago when one of my best friends Loretta Chu was diagnosed with it. It was really tough for her at the time. There was no support group in Toronto and it was difficult to find people who could relate to the situation. We felt what so many of us have felt before, a sense of helplessness, isolation, and fear for the future. So I helped her get in touch with other patients in the area and we eventually created what is now the PHA Canada Toronto Chapter. Through that support group, I've had the privilege of becoming friends with some of the strongest, most compassionate, and inspiring people I've ever met. After spending the last year in France at business school, it was wonderful to come back to see them again at the PH Conference in Toronto in September.

I'd like to share some thoughts about the wonderful weekend I had at the PH Conference. This has been my 3rd such patient conference and every time, I've had an inspiring and energizing experience. My personal favourite thing is seeing all the new friendships that get created at the dinner table, or in the foyer, when people from all parts of the country meet, share their personal stories, share words of support and begin that new friendship. I also really enjoyed the inspiring messages and call to action from our incredible speakers

Mark Black and Carl Hicks. For those of you who attended, I hope you met new friends, found strength in others fighting the same battle, and were inspired to take action to help fellow PHriends in your community.

The common thread that I found throughout the weekend was that no one does it alone: friends, family, and the support network around us give us strength and make such a huge positive impact on our lives. And that is the theme I will keep in mind as the new Board plans its activities for the coming year.

Our 2011-2012 Board is our largest ever. We have 11 passionate individuals from across the country serving this year and we are currently planning and prioritizing our programming for the coming year. We have some ambitious projects in store around fundraising, awareness, patient support/advocacy, and educating medical professionals. We've also developed a better interaction model with our corporate partners that we hope to use to find new ways to partner together to help patients. There is a lot of planning on the go right now and I hope to share more details with you in the next issue.

I am based out of Vancouver now and my door is always open. Please feel free to send me an email or give me a call if you have any questions, suggestions, or comments. Also, we have an ambitious agenda in the next year, and with that, comes a need for volunteers to help us achieve our goals. I encourage you to reach out to us if you are interested in volunteering.

I wish you all the best during the rest of the year and look forward to giving you all an update on our progress in the New Year.

Take care,

Frank Poon

2011/2012 BOARD OF DIRECTORS

Here is your 2011/2012 Board of Directors as elected by PHA Canada members at the 2011 Annual General Meeting, held in Toronto on September 18, 2011

Officers:

Frank Poon – President
Maureen Tymkow – Treasurer
Sandy Metcalfe – Secretary

Directors:

Ian Adatia, MD – Medical Advisor
Darren Bell – Immediate Past President
Lynn-Marie Cox
Jennifer Gendron
Darwin Hanofski
Rita Hebert
Sanjay Mehta, MD – Medical Advisor
Carolyn Pugliese – Nurse Liaison

PHA Canada Staff

Jennifer Gendron – Regional Coordinator
jgendron@phacanada.ca
Angie Knott – National Manager
aknott@phacanada.ca
Shirley Wong – Administrative Assistant
swong@phacanada.ca

If you would like to learn more about PHA Canada directors or staff please visit our website at www.phacanada.ca. Staff listing and bios can be found at www.phacanada.ca/staff and Board of Directors listing and bios can be found at www.phacanada.ca/BoardofDirectors.

ACTELION CELEBRATES TEN YEARS AND HELPS PATIENTS IN A BIG WAY

This year Actelion Pharmaceuticals is celebrating their tenth anniversary, and instead of expecting gifts, they've given a huge gift to PH patients and their families: a \$10,000 donation to PHA Canada to help further educational and support

resources for patients. We'd like to thank Actelion for their continued generosity and for continuing to support a better life for those living with PH. Happy 10th birthday Actelion, we look forward to many more.

were well attended and gave participants the opportunity to speak candidly and share their thoughts and experiences.

The evening meal began with the presentations of special awards to outstanding members of the PH community. Many wonderful nominations were received and you will read profiles of all nominees in [this issue] of Connections. This year's award recipients were: Outstanding PH Caregiver: Benoit Plante; Outstanding PH Medical Professional: Lyda Lesenko; and Outstanding PH Patient: Quinlan O'Blenis. Congratulations to our 2011 award recipients as well as to all those who were nominated as you have all made a difference in your own way in the fight against this rare illness. Following the presentation of awards, another special tribute was made by Dr. Sanjay Mehta in honor of PH patient, Lynda Berault who also lost her fight with PH this past year. Lynda, dedicated her life to making a difference for those living with the disease, was one of the founding members of PHA Canada and truly an inspiration to the PH community.

The highlight of the evening was a presentation by keynote speaker, Mark Black. Mark is a heart and double-lung transplant recipient turned 4 time marathon runner, best-selling author, life coach and motivational speaker. Born with a life-threatening heart defect, Mark underwent two open-heart surgeries before the age of one. He battled his condition and its limitations for 22 years quite successfully, but at 23 years old, Mark suddenly faced the biggest challenge of his life when his doctor informed him that he would require a dangerous heart and double-lung transplant. Since receiving his second chance at life in 2002, Mark hasn't wasted a moment. He shared with conference attendees his truly unique story and powerful life lessons to inspire all those in attendance to live their lives to the fullest. He captured the hearts



Our amazing team of conference volunteers!



Singer Paul Adams



Conference attendees

of all who heard him speak and received a standing ovation. His presentation was followed by a signing of his book *Live Life from the Heart: 52 Weeks to a Life of Passion and Purpose*.

Saturday evening concluded with a special a "Phenomenal Young Adults After Hours Meet & Greet" in Monarchs Lounge, which gave young PHers a chance to meet in a casual setting and share their experiences.

The Sunday morning breakfast began with the presentation of awards to our outgoing Board members: Sharon Proudfoot, Carol Storseth and Dr. Kim Boutet. A special recognition was also made to Mr. Darren Bell who served as PHA Canada's President from PHA Canada's beginning in 2008 until Conference weekend.

Programming continued with a very inspirational address given by Immediate Past Chair of the Pulmonary Hypertension Association of the USA, Carl Hicks. His speech, "The Power of One" outlined how each and every one of us can make a difference in the fight against PH.



Conference participants experience the benefits of yoga



Conference presentation

Following the presentations, the Annual General Meeting of PHA Canada was held with 100 members in attendance. Elections of our new Board of Directors was held and PHA Canada would like to welcome the following new members to our 2011-2012 Board: Dr. Ian Adatia, Rita Hebert, Lynn-Marie Cox and Darwin Hanofski.

Following breakfast, another round of educational sessions were held with a variety of topics.

Throughout the weekend, conference attendees were asked to leave their inspirational messages and signatures on our "Wall of Hope", a large mural that served as our conference guest book. Some of the messages and quotes that were left will be used in the materials produced for our upcoming November Awareness Campaign.

Overall the conference was a huge success. Many old friends were able to reconnect and many new friendships were made. Attendees had the opportunity to learn and share and everyone left feeling more connected to their community.

A camera crew was also present all weekend and attendees took the time to stop and chat with the friendly crew who were gathering footage and having attendees share their experience and story for a conference video we will be putting together. All mealtime presentations were also video taped and smaller breakout sessions were audio taped. Look for post-conference materials such as videos, and the audio recordings to be up on our YouTube channel (www.youtube.com/phacanada) and on our website in the near future.



Kids programs at conference



Conference attendees

More conference photos as well as session presentations and handouts will also be available on the post-conference website soon.

We look forward to seeing everyone again at our 2013 National Conference! We welcome your stories and photos of your conference experiences for our next issue of Connections.



Conference attendees applaud keynote speaker, Mark Black



Conference attendees

OUTSTANDING MEMBERS OF THE PH COMMUNITY HONOURED

By *Jennifer Gendron*, Regional Coordinator

Every year, outstanding individuals across Canada make wonderful contributions to the PH community in a variety of ways through their projects and accomplishments. This year, PHA Canada called for nominations for awards for outstanding members of the PH community in three separate categories. The categories for nominations included: Outstanding PH Caregiver, Outstanding PH Medical Professional and Outstanding PH Patient. The Conference Committee received many wonderful nominations and was charged with the difficult task of selecting the winning recipients in each category. Each and every one of the nominees deserves very special recognition and we congratulate you one and all!

Outstanding PH Caregiver

The outstanding caregiver award is given to someone who makes an incredible difference in the life of someone living with PH. Without this caregiver the life of the patient would be much more difficult and not at all enjoyable. This person can, but does not have to be directly involved with the PH community.

2011 Award Recipient: Benoit Plante

What the nominator(s) said about Benoit:

For me, my husband, Benoit, helps me so much to live with this disease; he is very compassionate and understanding. I do not know what I would do without him, he drives me where I need to go and he attends to my needs without ever having a bad word to say.



Frank Poon, PHA Canada; M. Benoit Plante; Denis Cormier, President, HTAP Quebec

Felicitations M. Plante!

Outstanding PH Medical Professional

The outstanding medical professional award is given to a medical professional (physician, nurse, respiratory therapist etc.) who makes a tremendous difference in the life of PH patients. This medical professional goes above and beyond for their patients and is actively involved in the PH community.

2011 Award Recipient: Lyda Lesenko, RN, Nurse Coordinator Pulmonary Hypertension Program, Jewish General Hospital

What the nominator(s) said about Lyda:

We met Lyda in January 2010 at my first visit to Dr. Langleben's office. She made herself very accessible to us. She is an endless vat of information and if she doesn't know she will find out. She calls to make sure everything is going well. She helps to set up and organize PH meetings at the hospital. We can't thank her enough; she has helped make the transition to life with PH easier.

All her patients know her as Lyda not "Nurse Lesenko" or "Mrs. Lesenko"; it's Lyda, your nurse and your friend. I don't know the words that would put Lyda on enough of a pedestal, but she would be too modest to stand there anyway. She thinks that what she does is nothing, just her job, but it is so much more to me, to all of us, her patients.

Over the course of the last year, I have gotten to know Lyda through my role as Regional Coordinator. During this time, I have seen how much Lyda truly cares about each and every one of the patients she sees at the Jewish. She gives so much of herself to the PH community and is always willing to lend a hand whenever she is asked. Lyda is a true inspiration in her field.

Lyda is not only an outstanding nurse, caregiver and coordinator, but in the last 6+ years I have been a PH patient at the JGH she has always been involved in organizing a local support group. She has also shown her support by attending every patient support meeting. Her generosity of spirit is exemplary!



Lyda Lesenko, RN & Dr. Sanjay Mehta

Congratulations to all of our Outstanding PH Medical Professional Nominees!

Dr. David Langleben

Director Pulmonary Hypertension Program, Jewish General Hospital, Montreal

What the nominator(s) said about Dr. Langleben:

With Dr. David Langleben I first and foremost appreciate the way he cares for his patients. He also informed me that this association exists and with that he helped me to feel less isolated and have fewer negative thoughts, that's a lot for us patients.

Dr. Dale Lien

Director Lung Transplant Program, University of Alberta, Edmonton

What the nominator(s) said about Dr. Lien:

I am nominating Dr. Dale Lien as the outstanding Medical Professional. Dr. Lien is quite simply the reason that I, and others like me, am alive! He has been a practicing Respirologist for over 30 years. He started the first Flolan patient in Alberta 15 years ago in Sept. He has been the head of the Lung Transplant Program at the U of A, Hospital since it started 14 years ago in Aug. He has been involved in the care and development of PH protocols at a local, national, and international level for the past 15 years. PH patients are referred to him from all over Alta, Sask, the NWT, and parts of BC. Dr. Lien is very gifted. He is knowledgeable, calm, and compassionate and caring and a strong advocate for us all. Although he is extremely busy, he remains hands on and approachable. He is a skilled educator. I am so grateful that he is my physician. He makes this PH journey as uncomplicated as he can.

Carolyn Pugliese, RN

Nurse Coordinator, Pulmonary Hypertension Program, Ottawa Heart Institute, Ottawa

What the nominator(s) said about Carolyn:

The Ottawa Support Group is nominating Carolyn Pugliese, as she was instrumental in getting the group started. She took it upon herself to contact the pharmaceutical companies, to obtain food and free parking for the first meeting, and she contacted Dr. Davis to come and speak at that meeting. It was through her tremendous efforts that the Ottawa area patients were able to get together and not feel so alone with the disease. When an email went out to the Ottawa Support Group about nominating Carolyn many patients responded with comments of how kind, comforting and informative she is. She always has time for the Pulmonary Hypertension patients. When I was first diagnosed I had never heard of the disease and Carolyn told me to call her at the clinic if I had any questions or needed reassurance. This was the common experience of all patients who have come in contact with her. I did call her and she always took the time to call me back and answer any questions I had in detail. If she was not sure of an answer she always got back to me with the correct information promptly. The Ottawa PH community is so blessed to have Carolyn as our clinic nurse. She has constantly gone above the requirements of her job by being available to patients and getting involved in the community by assisting with the start up of the support group. She is such a compassionate person who has gone out of her way to advise, support and care for people dealing with the challenges of Pulmonary Hypertension.

Outstanding PH Patient

The outstanding PH patient award is given to a member of the PH community, living with pulmonary hypertension, who, despite life's daily challenges, is working to make a difference in the lives of others. This person is involved in the PH community through a support group, PHA Canada Chapter or affiliate PH organization (BCPHS, EPAHS or HTAP Quebec), or is working to help spread the word about PH through raising PH awareness, working with the media, advocating on behalf of the PH community or educating others about PH.

2011 Award Recipient: Quinlan O'Blenis

What the nominator(s) said about Quinlan:

My son has been struggling with his pulmonary hypertension for over 13 years. He has carried a backpack for those 13 years and he is 16 now. He has always been willing to be interviewed or photographed whenever articles were being written about him. He has kept a positive and amazing attitude throughout all these years.

He always finds something positive to turn things around. Quinlan has been diagnosed with scoliosis in the past year and will need surgery for that sometime soon and his attitude is, well I'll worry about that then. He is desperately waiting for his voice to change and always looking for those first whiskers. He is funny, kind, loving, and awesome. He is my hero and everyday he makes me so proud. I have had parents come up to me at different times and tell me how my son inspired there's.



Frank Poon, PHA Canada, Quinlan O'Blenis & Jennifer Gendron

They may have watched him play basketball and they would see him and figure if he can do this, they sure can to. He has taught so many including his own family about being brave, heroic, and incredible. Congratulations of all of our nominees for Outstanding PH Patient!

Lynn-Marie Cox

What the nominator(s) said about Lynn-Marie:

I am nominating Lynn-Marie Cox for the Outstanding PH Patient Award. Lynn-Marie was diagnosed with PH in May 1998 and started her career with Flolan in May of 1999. She is a wife and the mother of two sons and proud grandmother of Madison. While her work life was curtailed, it has opened up her new career-that of everything to do with the PH Community. She was one of the driving forces behind the formation of the Edmonton PAH Society! She knew a group was needed for support, teaching, and advocacy. Initially, while the Secretary, she was the force that ensured the Society was incorporated, received their charitable status, became an Affiliate member of PHA Canada, and is working towards adding a support group for parents of children with PH with the main Society as supporters and helpers. Lynn-Marie is simply our energizer bunny with respect to anything PH related in our area. We would be lost without her. Her PH status does not hold her back. Our Society is proud of her involvement at the National level.

OUTSTANDING MEMBERS OF THE PH COMMUNITY HONOURED (continued from page 7)

Rita Hébert

What the nominator(s) said about Rita:

Rita has shown amazing initiative and has been a wonderful support to other patients in her area. She has been very instrumental in forming a bilingual support group for patients in the Montreal area. She has organized a wonderful schedule of meetings and has arranged for guest speakers to attend. She has inspired other patients to get involved as well and has established a very active group. Rita is always positive and has a very optimistic outlook. She continues on despite adversity and obstacles that may come along the way. I feel that Rita is a very positive role model and is an inspiration to all those she encounters!

Jo-Anne Mainwood

What the nominator(s) said about Jo-Anne:

As a member of the Ottawa PH Support Group, I would like to nominate Jo-Anne Mainwood as an outstanding PH patient because, in spite of the limitations placed on her capabilities by PH, Jo-Anne has worked tirelessly for awareness of PH. Jo-Anne was diagnosed with Pulmonary Arterial Hypertension two years ago. A middle school teacher, foster mother and wife, she has managed to continue her work in spite of many challenges. She is handling these challenges, and still finds time and determination to work at educating and building public awareness of PH as well as making an effort to bring the local PH community together. After joining PHA Canada and discovering that there was no support group in Ottawa, Jo-Anne decided to take on the task of organizing an Ottawa PH support group. With assistance from the PH team at the Ottawa Heart Institute and others, the first meeting of the group was held on October 8, 2010 with over 50 people in attendance. Jo-Anne has worked very hard to spread the word about PH through the “Pucker Up for PH Campaign” at several schools in Ottawa as well as among many friends, acquaintances and the general public. Jo-Anne was also interviewed by the local media about the “Pucker Up for PH Campaign”, an article about PH with illustrations showing blue-lipped children was featured on the first page of the Orleans Star, a local Ottawa newspaper. Jo-Anne organized a family dance at her school for “Family Day” where half the funds collected through admission and drink sales were donated to PHA Canada. Jo-Anne is a deserving candidate because she has found the time and energy to build public awareness and support for PH, in addition to holding a demanding full-time job and raising a family.

Elizabeth McCall

What the nominator(s) said about Liz:

I feel that Liz is the perfect candidate for this prestigious award. Liz has had PH for over 10 years, is the founder and President of BSPHS (PHA Canada affiliate organization) and was an instrumental contributor in the formation PHA. Despite life's incredible daily challenges that are associated with PH, Liz continues to make a difference in the lives of others and their battle with Pulmonary Hypertension. She coordinates annual PH Symposium's in BC, facilitates monthly support group meetings, organizes PH picnics, promotes awareness and is a continuous advocate for anything associated with PH. Liz is editor/producer of the PH Way, a bi-annual newsletter, which keeps the PH community connected. She constantly amazes me how driven she is despite her struggle to catch a breath! Liz is held in high regard by the medical professionals associated with PH, for all of

her accomplishments to advocate on behalf of patients with this disease called “Pulmonary Hypertension”.

She truly gives a voice of hope and a source of inspiration to all those associated with PH, and I am proud to call her “my sister and my friend”

PH CLINICS AROUND CANADA HELP SPREAD THE WORD ABOUT OUR COMMUNITY

By *Angie Knott*, National Manager, PHA Canada

One of the most challenging things in uniting the PH community from Coast to Coast in a country as large, spread out, and with as many remote areas as Canada, is making sure that those affected by the disease know that there is a community here to support them.

At PHA Canada we try to do this in as many ways as possible to make sure the word about the supportive community you have created is out there: we do this through the website, through our Facebook page and twitter and with the help of each and everyone of you.

Starting in November 2010 we also began partnering with the PH clinics around the country to spread the word about PHA Canada and about the amazing PH community that you have helped to build.

Our administrative staff has been busy putting together thousands of information packages, which include information about PHA Canada, the PH community and any local support groups/chapters etc., if they exist in the area served by the clinic. These packages are put in envelopes, sealed, and have the clinic's return address printed on them (to protect privacy of those whose packages may be returned) and even have postage affixed to them. We then send boxes of these envelopes to clinics who have agreed to do mailings for us – the clinic staff has been kind enough to volunteer their time to print out address labels for all clinic patients and stick them to the envelopes and mail them out for us.

It's another way we're assuring everyone's privacy while spreading the word about PHA Canada and the community of support available to all patients and families.

We would like to take the time to thank all of the staff at the clinics that have participated in this mailing program so far: Montreal PH Clinic;

Toronto PH Clinic; Toronto Sick Children's Clinic; London PH Clinic;

Hamilton PH Clinic; Halifax PH Clinic; Calgary PH Clinic; Saskatoon PH Clinic; Ottawa PH Clinic; and Quebec City PH Clinic.

An extra special thank you also goes to Lyda Lesenko, RN, Research Coordinator at the Montreal Clinic at the Jewish General Hospital, who was the one to suggest this program and who was the first to mail out over 800 packages.

Similar mailings have gone out through McKesson Specialty Pharmacy and Shoppers Drug Mart Specialty Health, and we would like to extend our thank you to these two partners for helping us spread the word as well.

by *Rita Hebert*, PH Patient, PHA Canada Board Member

Another Thanksgiving has come and gone and before we know it Jack Frost will be back nipping at our noses. I always get a sense of joy and excitement when I see the first snowfall. Why is that? I don't like cold weather and I certainly prefer spring or summer. Perhaps when I look cozily through my window at those magnificent snowflakes, I am temporarily brought back to childhood days. Creating my first lopsided snowman, or helping my older brothers fabricate an igloo (we used to have plenty of snow way back when). Yes, memories also come and go: some good, some ... well, let's just say ... not so happy.

The year was 2006, prior to the inception of PHA Canada. I had been communicating and sharing some of my poetry with another PHer, through a PH website. It is through that website that I learned of my PHriend's passing. It was Thanksgiving here in Canada and I felt truly isolated and “downright” miserable. True to my nature, I had to get a quick fix of “please help me feel better” fast!

As I was too low on energy to go out and just do something to change my mind, I called my sister in Ottawa with the full intention of having a good old-fashioned cry on her shoulder. My nephew answered and said, “Hi auntie Rita, sorry can't talk. Mom's just served the turkey broth”. I mumbled something about wanting to wish them a Happy Thanksgiving and hung up. I don't think I need to elaborate on how the rest of the evening progressed ...

Please don't get me wrong. It is not that my family members don't care. But it is so very difficult for loved ones to understand the full implication of how Pulmonary Hypertension can affect our lives. PH being such an orphan disease can make us (PHer's) feel like abandoned orphans, at times. However, I digress, as this article is really about giving thanks and recognizing the things we are grateful for.

Since that tearful Thanksgiving two great means of support were formed by, and for, patients and caregivers: One is the Quebec based foundation (HTAPQ) that was conceived by the family and friends of a PHer, in order to assist patients financially and emotionally. The other is our very own national PHA Canada. Through this Canadian Association I am now able to voice my feelings by writing articles such as this one. I am also thankful that as a recently elected Board of Directors member I will be able to participate in its future direction.

A special thank-you to our local coordinator! Through her kind assistance I was able to establish a local Support Group. I am thankful that from this group we, patients and caregivers, were able to found a committee. I am also grateful for the synergy and great ideas that developed through this committee. On behalf of this committee, I am very excited to announce that this November we will be hosting our first annual Pulmonary Hypertension Awareness Walk for Breath.

Amazing what can be achieved with a little support from our PHriends!



AN INTERESTING EDUCATIONAL SEMINAR IN QUEBEC CITY

By Line Ducharme, PH patient, Support Group Leader, patient representative HTAPQ



On the 4th of June, the Quebec PAH Foundation (HTAPQ), in collaboration with the staff of the pulmonary hypertension department at Laval Hospital in Quebec City, held a very interesting educational meeting.

The organizing committee, comprised four patients, was very happy with the success of the meeting. The committee consists of Line Ducharme from Trois-Rivières, patient representative for HTAPQ, Judith Ross from Rimouski, Nathalie Chabot from Quebec City and Josée Morneau from St-Nicéphore.

The meeting started around 10:15 AM; a bit behind schedule, after waiting for some late arrivals who did not end up coming. Despite the no-shows, seventy-three (73) people were in attendance. It was Line Ducharme, the new HTAPQ patient representative, who welcomed attendees on behalf of the HTAPQ Board of Directors and who chaired the meeting throughout the day.

Dr. Steeve Provencher gave a lecture about pulmonary hypertension and what the disease involves. He also spoke about the medications used and new treatments on the horizon. Those in attendance really appreciated his presentation. Thank you doctor!

Nurses Jacinthe Poirier and Johanne Houde spoke about the side affects of medications and who to call in case of emergency: your nurse or 911. They also answered some questions asked by the patients. Johanne Houde even took the time to look after one of the guests who was not feeling well and also demonstrated to certain patients the function of Flolan and Remodulin. Thank you for your great generosity.

Thierry Tremblay, chef, prepared an excellent lunch. Thanks to the generosity of HTAPQ the meal was free for patients and was in part subsidized for those accompanying them. HTAPQ president, Denis Cormier, then addressed the attendees regarding the history of the foundation, its goals and objectives and strongly invited

all those in attendance to take part in the next annual general meeting of the organization. Dolorès Carrier, HTAPQ administrator, was also in attendance and assisted the organizers of the event in many ways.

This was followed by an interesting presentation by doctor and researcher Sébastien Bonnet. Dr. Bonnet was accompanied by several members of his team who often work in the background. He shared some interesting discoveries that will probably lead to new medications.

Attendees were then very interested in the excellent presentation given by nutritionist, Maxime Bernier. Very soon you will be able to view the information she presented, which will be posted on the HTAPQ website.

Finally, researcher and medical student, Vincent Mainguy spoke on the importance of research on pulmonary hypertension. He mentioned that exercise is also important but must be done under medical surveillance. His presentation and suggestions were very much appreciated.

In summary, it was a very good day for all those who attended.

You can reach HTAPQ on our website at: www.htapquebec.ca or on our Facebook page at: <http://www.facebook.com/HTAPQ>.



TOP LEFT: Meeting organizer Line Ducharme with HTAPQ president Denis Cormier, Dr. Steeve Provencher and a meeting attendee

BOTTOM LEFT: PH nurses Jacinthe Poirier and Johanne Houde at the June 4 seminar

TOP RIGHT: The meeting's organizing committee

BOTTOM RIGHT: HTAPQ president Denis Cormier speaks at the June 4 seminar.

SPOTLIGHT ON LOCAL SUPPORT: THE QUEBEC PULMONARY ARTERIAL HYPERTENSION FOUNDATION (HTAP QUEBEC)

By Dolores Carrier, HTAPQ Administrator

La Fondation HTAPQ » (HTAP Quebec) was founded in Plessisville in November of 2006. The members of the Board of Directors work very hard to realize the foundation's mission, which is to allow the people of Québec suffering from pulmonary hypertension to meet, share, inform themselves and receive financial aid whenever it is necessary. The Board hopes that those suffering from PH feel less alone knowing that they can get some moral and financial support whenever it is needed.

HTAP Quebec has organized many fundraising campaigns such as a romantic evening and supper for Valentine's Day, two large sales of boxed cheese – one before Christmas and another before Easter, and also a huge garage sale on the Saturday before Mother's Day. The goal of all of these activities is to raise funds in order to assist their members.

We are also organizing support groups in Quebec City and the surrounding areas. Line Ducharme, the HTAP Quebec patient representative for PH patients, has created support groups and has organized a mini symposium for patients from Laval Hospital in Quebec City. This symposium took place on the 4th of June and those in attendance heard from various speakers including doctors, researchers and nurses. This mini symposium was presented in partnership between Laval Hospital and HTAP Quebec.

Rita Hébert, a patient from Montréal, is organizing monthly meetings for the patients of the Jewish General Hospital in Montréal. The list of upcoming topics includes: living with a chronic illness, low sodium meals, etc. Besides offering helpful information, these sessions allow patients the opportunity to get together, to share their stories and to develop friendships.

To become a member of HTAP Quebec, you need only complete the registration form found on the HTAPQ website at: www.htapquebec.ca. Or, you may call the Foundation at 1-819-362-6275. Membership is free for all patients and their caregivers may become members also for only \$10. Please note that all members of HTAP Quebec automatically become members of the Pulmonary Hypertension Association of Canada as well.

HTAP Quebec is currently offering financial assistance to its members if they are registered to attend the upcoming Toronto Conference – contact them for more information. They are also planning their Annual General Meeting, which will take place in October. The seven members of the Board of Directors presided over by Denis Cormier and the numerous volunteers of HTAP Quebec work very hard as they are here to help you!

LOVE RECEIVING CONNECTIONS, BUT WISH YOU COULD GET PH RELATED INFORMATION MORE OFTEN?

INTRODUCING: THE PULSE, PHA CANADA'S MONTHLY ELECTRONIC NEWSLETTER

The Pulse is published at the beginning of each month and features PHA Canada stories and updates, a low-sodium recipe of the month, a monthly PH resources tip, upcoming PH events around Canada as well as the latest in PH news. It's a quick glimpse into the PH community delivered to your email inbox once a month.



TOP: An HTAP Quebec banner at the annual garage sale "thanks everyone from the bottom of our hearts"

MIDDLE: HTAP Quebec's annual garage sale raises funds to support patients

BOTTOM: 26 generous people volunteered their time to make the 2011 garage sale a huge success. Thank you so much.

If you are a member of PHA Canada, you should automatically receive The Pulse, if you have not yet received an issue, check your junk mail folder and make sure you add thepulse@phacanada.ca to your safe contacts list.

If you have not received The Pulse, you may subscribe to it by going to www.phacanada.ca/ThePulse (here you will also find any past issues you may have missed).

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. 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.

PACING YOURSELF TO MAKE THE MOST OF EVERY DAY

By Carolyn Pugliese, RN, MSN, APN, Ottawa Pulmonary Hypertension Clinic, University of Ottawa Heart Institute, Ottawa, ON

In my experience over the past 4 years caring for patients with pulmonary hypertension, I have noticed a similar response in "doing too much one day has me lose the next 2-3 days on my couch/bed", to my days as a heart failure nurse caring for patients with left heart disease, or congestive heart failure. This leads to the "learn to pace yourself" conversation.

Often, the patient and I come about this discovery in clinic when we begin to discuss how they are doing. When the conversation leads to weeks filled with good and bad days, we can usually make the case for doing too much on Tuesday leads to Wednesday and/or Thursday spent on the couch or even in bed.

So I hope to spread the word in this article about how regular exercise, with careful attention to what is too much for you, can help. I would also like to share with you the experiences of two patients in our clinic.

Every one of you will respond differently to exercise based on where you are to start with, so please talk with your physician and nurse before starting any regular routine.

What does the research say?

Well, it is very well documented that regular physical exercise improves exercise capacity in patients with chronic heart failure (left heart disease). Randomized, controlled exercise trials designed to measure many functions (endothelial function, inflammatory markers, sympathetic neural activation, skeletal muscle metabolism and structure), have confirmed the benefit of exercise therapy by improving function and quality of life.

For PH, even though not as well documented, in 2006, Mereles et al published an impressive study; "Exercise and respiratory training improve exercise capacity and quality of life in patients with severe chronic pulmonary hypertension". In a highly structured 15-week program of daily exercise, patients with PH experienced a mean increase in the 6-minute walking test from a baseline. The increase in the 6-minute walking distance after exercise training was greater than that achieved with prostacyclin medications such as Flolan and Remodulin, endothelin receptor antagonists such as Tracleer and Volibris, and phosphodiesterase inhibitors such as Revatio and Adcirca.

So, even though we would like to see more trials study exercise in PH, we now know that carefully designed exercise is safe and useful in the short term in PH. The benefits are likely to be similar to those found with exercise in left heart failure, including improvement in strength and endurance in non-cardiac muscles, as well as reduced anxiety and increased confidence during physical activity. So, the next step is to find out what that means for you. How much exercise or activity can I expect to do every day without losing a day or two afterwards?

Make sure you:

- ◆ Discuss your ability to exercise with your PH physician.
- ◆ If possible, exercise in a clinical setting, such as a cardiac rehabilitation program or a pulmonary rehabilitation program, where you can be monitored closely. Speak to your physician about this and if this is not possible for you, have a family member or friend present for the first several times or even better, have a partner to walk with daily.
- ◆ Start slow. If you have not exercised or been active at all for many years, it will take time to build up your stamina as with anyone who has not exercised for many years.
- ◆ Duration of exercise should include an adequate warm-up period. The warm-up should usually be a period of 10 to 15 minutes. The exercise duration most frequently used is 20 to 30 minutes at the intensity that works for you
- ◆ Don't push too hard. You never want to exercise to the point where you are so short of breath that you can't talk, you begin to have chest pains, and/or feel light-headed. Stop exercising immediately if you begin to feel this unwell. The end result is a not so great a work out and a day or 2 spent in bed.
- ◆ When you begin a program, you do not want to work your upper and lower body at the same time (such as a rowing machine). Strengthening your upper body and lower body are fine, just don't do them at the same time, and I would say to avoid any exercises that require your arms to be raised over your head as this makes the heart work harder, however always speak to your doctor for the final word on this.
- ◆ Avoid exercising out-of-doors if the temperature is either too hot or too cold. As a matter of fact, stay in air conditioning when the temperature is too hot and humid outside. Instead do leg lifts or walk on a treadmill in your home.
- ◆ If you have a pulse oximeter for home use, test yourself often. Choose a pace that keeps your blood saturation in the 90's

(The above points were adapted from PH central)

To give you an example of the importance of pacing yourself and exercising when you have PH, I would like to share the stories of two patients from our clinic with you:

One of my IPAH patients was discouraged that she was always fatigued and breathless. She is in her mid 40's and a full-time teacher with a busy family life. At one point, she decided with her spouse that she would take time off from work around the Christmas holidays (6 weeks in total). During that time, she walked every day and rested when she needed to. When she came to clinic around the end of that time off, she had improved her 6-minute walking distance by 100 meters... that's right...100 meters. That is far better than any increase in the 6-minute walking distance achieved with any drug trial!

Another of our patients decided to stop working altogether, rest every day, exercise regularly, and lose weight. He has also improved not only his functional class to functional class II, but now uses less oxygen. He can now tell that when he does too much one day, he needs to rest extra the next day. The experience of this patient also proves that is you are overweight; losing weight can be a huge benefit to improved breathing.

There are many benefits to exercise: your physical and mental well-being depends on it. It can improve your mood, improve your sleep and help your condition by improving muscle strength and overall improve your quality of life. Again, speak to your physician and set realistic goals for yourself so as not to get discouraged. You want to do enough to improve your quality of life, and not add to more days in bed.

References:

Downing, J. Balady, G.J. *The Role of Exercise Training in Heart Failure (2011). Journal of the American College of Cardiology. 58:561-569*

Mereles D, et. al. *Exercise and Respiratory Training Improve Exercise Capacity and Quality of Life in Patients with Severe Chronic Pulmonary Hypertension (2006). Circulation. 114: 1482-1489.*

Xing-Guo Sun et.al. *Exercise Pathophysiology in Patients With Primary Pulmonary Hypertension (2001). Circulation. et.al. 104: 429-435*

Switzer, C. *Exercise and Pulmonary Exercise and Pulmonary Hypertension. PH Central. Retrieved August 25, 2011 from <http://www.phcentral.org/features/exercise-and-pulmonary-hypertension>.*

Piña, I.L. et.al., *Exercise and Heart Failure: A Statement From the American Heart Association Committee on Exercise, Rehabilitation, and Prevention (2003). Circulation. 107: 1210-1225.*

MY 'MYTH OF CAVE' EXPERIENCE

By Jacquelyn Mathur, Daughter of PH Patient

ED note: This story was sent to Connections editors by PH patient Carolyn Mathur, here is her brief introduction to the story:

"I found my daughters religion homework assignment on the computer as I was shutting it down. It touched my heart and made me cry to see what a wonderful daughter I have. If you would like to share it with others in "Connections" that would be very nice. Hope you enjoy."

My 'Myth of the Cave' Experience

When I was about 3 years old my mother was diagnosed with a rare and potentially deadly lung and heart disease called PPH (Primary Pulmonary Hypertension), now called PAH (Pulmonary Arterial Hypertension). The information about this disease was very limited at this time and even today not many doctors study, or have even heard of this disease.

When she was first diagnosed they had told her she wouldn't make it through the night, the next day she woke up and they told her she wouldn't make it through the week, that week passed and they told her she wouldn't make it through 2 months. The doctors and specialists have now stopped telling her, her limit because they know she will pass it. Currently she is on a lethal dose of many drugs including coumadin, which is a blood thinner to stop the forming of blood clots in the arteries. She takes 6 pills every night: these 6 pills would instantly kill any other person.

Being so young, when she was at her worst stage, I didn't understand why we had to make frequent trips to the hospital to visit her or why my dad had to do the tasks my mom used to do around the house. As I grew older I realized what was really happening and began to understand these things.

My 'myth of the cave' experience was the realization that my parents weren't always going to be around and how short and precious life is. The experience for me is ongoing and very hard, although everyone knows that one day their parents pass on, the reality and hardships of it are never really present until you get this kind of news.

The person who has helped me through this experience the most would be, in fact, my mother. She is truly my best friend and someone I confide in no matter what the situation. She is the most positive, loving and caring person I have ever met. She is so involved in many programs, loves to go out with friends and continues to live her life as if she is perfectly healthy. I think it is important that I had this experience and would not like to go back to my state of ignorance because now I know to treat her with the highest respect that every single mother deserves.

This experience has also taught me to live my life to the fullest I can because of how short it is. This experience proved to me how strong my mother is, it makes me proud to be her daughter and I love telling her story because it gives me hope and strength to carry on through any hardship with the same positive and energetic attitude she carries.

Helping around the house is put to a new meaning when having a mother with a lung disease; it is very hard for her to lift and carry things like laundry. Since she is so positive, and continually trying to exceed her limits, she always tries to carry heavy things up the stairs or do things that are challenging for her heart to handle. I love to help her with little tasks like this because I see how much of a difference it makes on her health. Although housework is annoying and boring at times my whole family contributes so my mother has a limited amount of weight bearing duties. I am glad I have this experience because I now understand what a fair and functioning family is like when it comes to chores and tasks around the house.

Although living with the fear for my mother daily is extremely hard, I am thankful for this 'myth of the cave' experience. It has made me a stronger and more spiritual person throughout these 14 years, during which she has continued to prove so many doctors wrong.



Jacquelyn Mathur and her mom, Carolyn Mathur



A BETTER TREATMENT FOR PH: THE RESEARCH CONTINUES!

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

Every month, over a hundred scientific publications on pulmonary hypertension are published. The medical and scientific communities in Canada and internationally are working hard to discover new ways to help those who suffer from PH. The world of PH is constantly changing and clinical research is in perpetual progression. We have therefore decided to share the hope and enthusiasm that inspires us by reviewing the new PH treatments currently in clinical trials.

There are three families of medications which have already been studied and are currently

available in Canada for the treatment specifically of pulmonary arterial hypertension (PAH): Endothelin receptor antagonists, administered in oral form [ambrisentan (Volibris), bosentan (Tracleer)]; PDE-5 inhibitors, administered in oral form [sildenafil (Revatio), tadalafil (Adcirca)], and prostacyclin analogues, administered in intravenous or subcutaneous forms [epoprostenol (Flolan), treprostinil (Remodulin)]. The newest approach to PAH treatment, which is still being studied, is a combination of 2 or 3 PH medications from different families, as they may act in a complementary fashion. Most PH physicians already believe that there is an advantage to combining several PH drugs, but larger and better-quality studies will, in the near future, provide better evidence in order to be able to obtain government reimbursement for this type of combination PH therapy more easily.

In addition, several other medications are currently in clinical research trials.

There are some medications that are currently already being used to treat PH, and that are now being studied in different forms in order to determine their effects. For example, treprostinil in both oral and inhaled form is currently being studied. Indeed, the method by which we administer a medication can impact its effect. The absorption and the duration of the effects are varied. Therefore, we must verify whether the benefits still exist, whether the medication is well tolerated, whether the stability is acceptable and whether the administration is truly made easier for patients. A second example of such drug development research are the efforts to improve the stability of intravenous epoprostenol, in order to eliminate the need for icepacks and to reduce the frequency of cassette changes, and therefore reduce the amount of handling required. The pharmaceutical companies are also working to develop new medications that work like those already available but in better and more efficient ways. For example, a new endothelin receptor antagonist (Macitentan) is presently in clinical trials.

Another way to address the development of new medications is to find new angles for attacking the disease. Three new classes of medications are being studied: antagonists that

directly stimulate cGMP (Riociguat), agonists of the prostacyclin receptors (Selexipag), and inhibitors of tyrosine kinase (Imatinib, Nilotinib). These three new classes of medications work in different ways and we hope that they will contribute to advance the fight against PH, while being well tolerated, meaning that they do not have too many undesirable side effects or complications. These medications have already been tested in the laboratory and are now being studied in patients suffering from PH. This means that if we demonstrate that they bring benefits, they could be available to patients within a few years. Medications like tyrosine kinase inhibitors are already approved and available to treat patients with other illnesses, and we are now studying their actual effects specifically for PH. All of these new medications aim to at least improve exercise tolerance, to reduce symptoms and to increase survival with a better quality of life.

Another important and active component of research is into the treatment of other types of PH, as all current PH treatments are only approved for PAH. For example, the treatment of PH associated with cardiac disease (eg. Heart failure, valve disease), or with lung disease (eg. pulmonary fibrosis, COPD), must be approached differently. Now that much progress has been achieved with idiopathic and other types of PAH, we are starting to look more seriously at the other forms of PH and studies are finally emerging.

Sometimes the drug development and research process may seem long, especially when a patient is sick or dying. However, it is vitally important to carefully pursue all of the required steps in developing a new medication, in order to avoid giving patients medications that may be ineffective or worse, that expose patients to undesired or even dangerous side effects. We must remember that a treatment that was effective, sitaxsentan (Thelin) was pulled from the worldwide market this year due to deadly risk of hepatitis. We must therefore maintain our hope and stay focused on the future.

You can always follow the research being done in PH clinics in Canada by visiting our website: www.phacanada.ca/ClinicalTrials.

You can also have the opportunity to join our discussion on this subject at the National Pulmonary Hypertension conference coming up in Toronto from September 16 to 18th. We look forward to seeing you there!

WE CANNOT FACE THIS ILLNESS ALONE: LINE DUCHARME'S STORY

By **Line Ducharme, PH Patient, Patient Representative HTAP Quebec**

My name is Line Ducharme. I am originally from La Tuque but I have been living in Trois-Rivières for the last 20 years. I worked for Caisses Populaires Desjardins for almost 20 years and then for five years for the Registry of automobile insurance for Quebec.

I was born on February 23, 1961 and in 1979, an automobile accident turned my life upside down. I had to relearn how to walk, how to eat and even to recognize my family. All that I know of the first 18 years of my life are things that my family has told me. I cannot put any images to these events.

What I do know is that life is worth living right up to the end of the road.

I have suffered from pulmonary hypertension since 2000. It took four years before a name was given to the illness that I was suffering. In the beginning, I was treated for my nerves and then

for asthma. When I started having many fainting spells in 2004, I was referred to Laval Hospital in Quebec City where they finally discovered the disease that was haunting me. Bosentan was my first medication. As my condition was deteriorating, I was then put on Flolan.

When I returned home, in my region, I was feeling very alone in the world without anyone who really understood me. But I learned while searching the web that there was a site in France where patients could chat amongst themselves. I signed up for this group and it was there that I first met Isabelle Cormier who became my best friend. She was a great comfort for me. I quickly learned that like her, I wanted to help others to feel less alone in the face of this terrible diagnosis. I started sharing my own story, first with little meetings in restaurants, and now on Facebook (visit Line at: www.facebook.com/HTAPQ).

I am honoured to have been asked, by the Board of Directors [of the HTAP Quebec Foundation], to succeed Isabelle [as the Patient Representative]. I will work hard [in this position] to put into practice my motto: "We can not remain alone facing this illness, we need to share!"

OUR LOCAL PATIENT SUPPORT GROUP IS ON A MISSION!

By **Rita Hebert, PH patient, Montreal PH Support Group Leader**



Members of the Montreal Support Group

Yes! We are on a mission!

Our mission is to facilitate supportive communications between patients and raise awareness locally, nationally as well as globally!

It has been a mere five months since the initial patient support meeting was held here in Montreal. A lot of water has gone under the

bridge since that initial meeting but I'm happy to say that we are now getting together on a monthly basis.

However, the path, or shall I say the water we had to tread under that bridge, was not always an easy one. How do you relate information to 800+ patients without breaking any confidentiality rules? Add to the formula the fact that although the Quebec population is predominantly Francophone, almost a quarter of our clinic's patients are Anglophones.

For starters, I wanted the meetings to be bilingual so I created the initial invitations in English and my sister translated them to French. Then we had them proofread by a third party.

What about the cost of printing? Lyda Lesenko, our local nurse coordinator, approached her husband, Peter Rollitt, who had them printed by Pazazz, his printing company.

We also wanted to avoid any breach of confidentiality, therefore Lyda provided us with pre-addressed labels, which we stuck on Dr. Langleben's personalized envelopes. This was done within the cardiology department in a spare examining room, courtesy of our coordinator. And, thanks to patients who volunteered their time, the 800+ flyers were folded and stuffed in the labelled envelopes. These were promptly shipped out from the hospital mailroom.

A lot of teamwork wouldn't you say?

Such teamwork is of utmost importance when you're suffering from an orphan disease such as ours, because there's no accounting for the sense of isolation, not to mention the general lack of energy one encounters on a daily basis. And as you know, we patients need all the help we can get!

Such teamwork has recently led us to form a committee whose purpose is to continue and improve what has already been set in motion. The initial vision could not have become a realistic mission without the dedication and involvement of our local coordinator!

Thank you Lyda!!!

Yes! ... We are on a mission and that mission is to facilitate supportive communications between patients ...

CONNECTIONS SUBMISSIONS

The deadline for submissions for the next issue of Connections is December 15, 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!

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

NEWSLETTER SUBMISSION

PHA Canada
Suite 308, 1311 Howe Street
Vancouver BC V6Z 2P3

Or email it to "Newsletter Submission" at info@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.

GET READY TO LEND A HAND FOR PH THIS NOVEMBER!

By *Angie Knott*, National Manager, *Jennifer Gendron*, Regional Coordinator

As you are probably already aware, November is “Pulmonary Hypertension Awareness Month”. This year PHA Canada, with the help of Edelman PR, is very excited to be launching what we hope will become a yearly ever-growing National Awareness Campaign.

The “Lend a Hand for PH” campaign will launch at the beginning of November with kickoff events in Toronto, Montreal, Vancouver and Calgary.

The main objective of the “Lend a Hand for PH” campaign is to raise awareness about PH and its symptoms by engaging the PH community, media and the general public. The campaign will be represented by a memorable symbol: a blue handprint where each of the five fingers will represent a symptom of PH and spell out the acronym **BLUES**

BLUISH HANDS, FEET AND LIPS

LIGHTHEADEDNESS (especially when climbing stairs or standing up)

UNABLE TO BREATHE (shortness of breath/breathlessness, especially with activity)

EEDEMA (swelling of ankles, legs and abdomen)

SYNCOPE (fainting)

Canadians will be invited to “lend a hand” for PH by signing a blue handprint and posting a message of hope. Banners where participants will be able to attach their blue hand will be available at these locations.

The Toronto event will be held in conjunction with the Toronto Chapter’s annual “Let me Breathe” Vegas night fundraiser. This fun-filled event is in its third year and is a great way to support the PH community. We encourage those in the area to attend this fantastic evening of music, gambling and PH awareness. To learn more about the event visit the event listing on our calendar page www.phacanada.ca/letmebreathe or by visiting the Toronto Chapter’s website at www.phatoronto.ca/?p=801.

Other launch events are currently being planned in the other cities. Look for more information in upcoming issues of the Pulse as well as on our website.

Not located in one of the launch cities? No problem!

This campaign is designed for anyone to be able to participate.

We will have “lend a hand” kits which will contain all the materials you need to run a campaign in your own city – the kits include: hand prints, PH info sheets, and template letters to help you organize the campaign at your workplace, a school or other venue in your community, as well as some campaign related goodies. Get yours early so you can get your campaign planned. To preorder your lend a hand kit or for more information about email us at lendahand@phacanada.ca or call the office at 1-877-7-PHA-CAN.

The campaign will wrap up at the end of November with an event on Parliament Hill, where the murals as well as handprints from all over the country will come together to form one large mural. Members of parliament will be invited to add their handprints to the mural and learn more about PH. An official count of number of handprints collected will be announced at the event.

For more information on how you can “Lend a Hand” for PH, please visit our website at www.phacanada.ca/lendahandforph