

CONNECTIONS

THE OFFICIAL NEWSLETTER OF THE CANADIAN PH COMMUNITY



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

YOU CAN MAKE A DIFFERENCE WITH YOUR OWN PERSONAL FUNDRAISING PAGE

By Jennifer Gendron, Acting National Manager



On behalf of the Board of Directors and Staff of PHA Canada, I want to wish you all a Happy New Year! As we move in to 2012, PHA Canada has many projects underway and I am very excited for all that the coming year will bring.

I am very excited to share with you a fantastic new fundraising tool that PHA Canada has to offer that will allow you to join in the fight and raise funds for important projects from the comfort of your own home or office! Visit our website at: <http://personalpages.phacanada.ca> and follow the simple step by step instructions that allow you to create your very own fundraising centre and share your personal PH story. There are three different options for you or your family and friends who wish to raise funds through this system. You can set up your own personal page, set up a "Tribute" page to a loved one who has lost their battle with PH or, create an "In Honour" page for someone you wish to recognize.

This system allows you to customize your own page with your personal story, photos and a personal fundraising goal. You will receive e-notices when donations are made to your page and all of the tools you need to communicate with your sponsors have been provided. For more information contact us at personalpages@phacanada.ca

Let's come together Canada and see just how much support we can raise through this wonderful new tool. Together, we can make a difference and it starts one person at a time!

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Happy New Year everyone! I hope you all had a good holiday with family and friends and are rejuvenated for the New Year.

The past couple of months have just flown by and I'd like to take some time to recap some of the things we have had on the go.

In November, in partnership with all of our local PH support groups in communities across Canada, we ran our PH Awareness Month – Lend a

Hand campaign. Our goal for the month long campaign was to educate Canadians across the nation about PH and at the same time, help them show support for families living with this illness. We invited people across the country to sign handprints along with a message of hope for those living with the disease. We held awareness events in major cities including Vancouver, Calgary, Toronto, Montreal, and Ottawa and took to the airwaves to share our PH stories with local media outlets. I'm happy to announce that we collected well over 2000 physically signed handprints across Canada.

On November 29th, to culminate the month long campaign, we held a reception on Parliament Hill which was sponsored by the Honourable Bob Rae, Leader of the Liberal Party. Mr. Rae, along with a handful of MPs across different parties were in attendance. We were able to share patient, caregiver, and doctor perspectives of PH with them and I believe we left a lasting impression on those that attended.

I'm happy with our efforts on the campaign, and believe this year's awareness campaign built a strong foundation for the future. I look forward to building off of this campaign next year. Among other things for the coming year, we would like to tie in a national fundraising initiative to the campaign, reach a broader audience through more media coverage, and push our handprint collection goal higher as well. If you have any ideas for next November, feel free to let us know.

I'm also excited to share the wonderful news that Angie, our National Manager, and her husband Gerald welcomed their new baby, Olivia to their family in late November. Angie is currently on maternity leave until early spring. In the interim, Jennifer Gendron

is assuming the role of Acting National Manager until Angie returns. I'm extremely happy and excited for Angie and Gerald in their new journey into parenthood and wish them all the best. We are also really excited to have Angie back in the spring to lead the projects we are planning right now.

We are currently planning out our goals and initiatives for 2012 and beyond. We have grouped the areas of focus into 3 parts: Fundraising and Awareness, Patient Support and Advocacy, and Clinic Relations and Education. In Fundraising and Awareness, we have set goals such as giving our membership fundraising tools and co-ordinating national programs to help members go out into their communities to raise awareness of the disease. Within Patient Support and Advocacy, we want to reach out to newly diagnosed patients, foster new support groups in new communities, and continue to nurture and support our existing groups across Canada. In the Clinic Relations and Education section, we have goals such as building stronger relationships with PH clinics and finding effective ways to raise awareness and educate healthcare professionals (doctors, nurses, medical students, etc.) about PH to help improve early diagnoses rates.

We are always looking for more ideas for all these areas of focus but more importantly, we need volunteers to help lead these exciting projects. So I encourage all of you to lend a hand and contact us if you want to volunteer for a specific project or area of focus.

I wish all of you a wonderful start to the New Year. My door is always open, so feel free to send me an email or give me a call if you have questions, concerns, or need help with anything.

All the best,

Frank Poon
President



WHAT'S IN A NAME? CLASSIFYING AND NAMING THE DISEASES THAT CAUSE PULMONARY HYPERTENSION IN BABIES AND CHILDREN

By Ian Adatia MBChB, MRCP(UK), FRCP(C)
Professor of Pediatrics, University of Alberta,
Director Pediatric Pulmonary Hypertension Clinic
and Cardiac Critical Care Program, Stollery
Children's Hospital and Mazankowski Heart
Institute, Edmonton, Alberta, Canada

Pediatricians have known for a long time that many causes of pulmonary hypertension are different in babies and children and are not the same as in adults. Also, the ways in which we assess the symptoms and treatments of pulmonary hypertension are different in young children. For example, how do we get an idea of exercise tolerance in children too young for the 6-minute walk test? What would be the equivalent? Some have suggested humorously the 6-minute crawl test. Joking aside, these are very important questions if we are to improve the lives of young children with pulmonary hypertension. So last year a group of experts from around the world interested in improving the care of babies and children with pulmonary hypertension met in Panama. These doctors were members of a task force of the Pulmonary Vascular Research Institute (www.PVRI.com). The PVRI is an independent medical research organization devoted to increasing the awareness and knowledge of pulmonary vascular diseases around the world, and to facilitating advances in the treatment of affected people worldwide. Pediatric pulmonary hypertension experts from North and South America, Asia and Europe decided that the first place to start the work of the task force was to devise classifications, or naming systems, of disease and functional ability that would be helpful in our understanding of children with pulmonary hypertension. Well what's in a name, you might ask? Isn't pulmonary hypertension just pulmonary hypertension however old you are? The answer we believe is: NO.

Babies and young children, as all parents know, are not just small adults and this is equally true of childhood pulmonary hypertension. It may surprise you to learn that all of us are born with pulmonary hypertension. This is because the fetus living in the womb before birth does not use the lungs to breathe but receives oxygen from the mother's placenta. As the fetus does not use the lungs for breathing, there is very little need to send blood to the lungs. As a result the lung blood vessels are small and collapsed. At birth with clamping of the umbilical cord blood the baby must start to breathe and this triggers more blood to flow to the lungs. The pulmonary vessels start to expand and change into the thin walled pulmonary vessels that form a healthy lung artery. As the vessels expand or dilate, the pulmonary pressures decrease slowly over the first few days or weeks of life until the lung artery pressures normalize at a mean pressure around 10-15 mmHg. In some babies, for instance those with heart disease, trisomy 21 (Down syndrome) or premature birth, the pulmonary pressures take longer to come down to normal levels. In other babies, for reasons we do not understand always, the lung pressures may never come down to normal levels and these children will have pulmonary hypertension and eventually need treatment. In some children this may be because the process of normalization started but was interrupted because for

example of an illness at or shortly after birth. We call this maladaptation because all the signals were present for normalization or adaptation to life outside the womb but the process of lowering the pulmonary pressures was interrupted and the lung vessels did not continue to develop normally but remained small and thick walled. In the new classification system of pulmonary hypertension for babies and children the first 2 categories are pulmonary hypertension due to problems that happened before birth or shortly after birth. It seems likely that by acknowledging these types of pulmonary hypertension we can research the causes and look at more specific treatments for children with pulmonary hypertension. Understanding the events that occur at birth that allow the pulmonary pressures to decrease to normal may be very important in understanding pulmonary hypertension later in life. We are just beginning to understand that many diseases of adult life start before or just after birth for example high blood pressure in the "other" circulation or systemic hypertension or diseases of the coronary (heart) arteries. This may turn out to be the case for some causes of pulmonary hypertension in adults. For more detailed reading and a wider explanation of the categories of pulmonary hypertension in babies and children the reader is referred to www.pulmonarycirculation.org for a free download of the article.

Another important part of caring for children with pulmonary hypertension is to be able to decide objectively how well or poorly they are doing and the need for a change in treatment. In adults, most pulmonary hypertension specialists use a system called the WHO functional classification. WHO stands for World Health Organization. Class 1 is the best and describes a person with pulmonary hypertension but whose activity levels are normal and who has no symptoms. The worst class is Class 4 and describes someone who cannot carry out any physical activity without symptoms and may even be breathless while at rest. One of the most gratifying effects of drug therapy for pulmonary hypertension is when a person improves their WHO functional class. Changes in WHO Class are one of the ways used by drug regulators and researchers to decide if a new drug is effective. But the WHO system is rather difficult to use in children because as we all know, babies and children grow and mature and as they do so the functional limitation of an illness like pulmonary hypertension will also change. In a baby and infant a key part of wellness is good feeding without breathlessness and gaining weight. In a school age child, the number of days missed from school or if they need to take a nap after school tells us how well the child is feeling. So the pediatric taskforce of the PVRI thought it was important to think up a functional classification for children of different ages so that we can objectively measure how they are doing and whether we are winning with treatment or if it needs to be changed. The details of this classification can be found as a free download from www.pulmonarycirculation.org.

Although very few drugs are specifically licensed for children with pulmonary hypertension it may come as a surprise to know that drugs like nitric oxide and sildenafil (Revatio) were first used in babies and children with pulmonary hypertension as a direct result of understanding the reasons that pulmonary hypertension does not always go away after birth. It is the hope that these new classifications of pulmonary hypertension in babies and children will lead to better understanding of the causes of pulmonary hypertension in children and lead to more specific therapies. Also, the discoveries made in babies and children may have important results in understanding why some grown ups develop pulmonary hypertension.

CONNECTIONS SUBMISSIONS

The deadline for submissions for the next issue of Connections is March 15, 2012.

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.

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.

AN ARTICLE FOR CAREGIVERS

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

Providing care for a family member in need is a centuries-old act of kindness, love, and loyalty. Caregivers, friends, and family members make an incredible difference in the lives of their loved ones diagnosed with pulmonary hypertension.

As a caregiver, you assist with many things such as: grocery shopping, house cleaning, cooking, shopping, paying bills, giving medicine, toileting, bathing, dressing and eating.

There are many rewards and challenges to providing care to a loved one.

There are times of intimacy, fun and laughter:

Research has found that caregivers report approximately three times more positive than negative emotions related to caregiving. Literature reports some of the following statistics and comments. 96% report feeling "loving", 90% report feeling appreciated, and 84% report feeling proud. Caregivers often experience increased closeness with their loved one, find it meaningful to care for someone and often report a sense of purpose. Caregiving can help clarify one's beliefs and deepen one's sense of their own values, compassion, and patience, improve their self confidence and self-esteem. It can also create a positive psychological change that is experienced as a result of the struggle with a highly challenging situation.

There are also times of sadness, frustration and exhaustion often caused by a lack of practical skills and support:

Caregivers often must travel through a health care system that, unfortunately, is not designed to manage chronic long-term illnesses. That means struggling to coordinate doctors, managing multiple prescription medications, monitoring for changes in conditions, and more. Studies have shown that caregivers are nearly twice as likely as the general population to develop multiple chronic illnesses due to stress and neglect of their own health and well-being. Caring for another person takes a lot of time, effort, and work. In addition, most caregivers juggle caregiving with full-time jobs and parenting and in the process, caregivers put their own needs aside. Caregivers often report that it is difficult to look after their own health in terms of exercise, nutrition, and doctor's visit and can often end up feeling angry, anxious, isolated, and sad.

Two take home messages that I find very important and hope you find helpful:

1. Manage PH together: Understanding how to manage PH with your loved one is an important task, such as understanding your loved ones goals, making sure you talk with not at your loved one, tag teaming appointments with others, assisting in the development of a health journal, improving your own comfort level and helping to maintain a safe home environment.

2. Take care of yourself: It is very important that you don't neglect your own needs. While it may feel selfish, it really is the best thing you can do for not only yourself but your loved one as well. If you become run down and depressed, you will not be able to provide the best care possible for them.

1. Manage PH together

UNDERSTAND YOUR LOVED ONE'S GOALS

Talk to your friends or loved ones with chronic illness to help understand their goals. Get the conversation started by discussing events or activities that they used to participate in and miss such as fishing, walking the dog, playing cards, or something in the future they would like to be a part of. You can help your friends or loved ones meet these goals by discussing it with them and their health care providers, doctors or community service agencies.

TALK WITH NOT AT YOUR LOVED ONE

Your loved one may be put off by your advice if they think that you are speaking at them and not with them. Most people suffering from a chronic illness such as PH do not want advice; they want to talk things out to come to their own decisions. At times, giving advice inhibits conversation. Try and put yourself in their shoes and talk to them in a way that's likely to encourage a positive reaction. Example "I read that some people suffering from heart failure have trouble checking their weight every day. We could make a pact to make sure we weigh ourselves every day." Keeping communication healthy is very important.

TAG TEAM

Having someone also attend doctor's appointments with your loved ones can not only be comforting to them, but can also be very helpful in terms of providing a second pair of ears to pick up on medication and other instructions from the doctor. If you accompany your loved ones to their appointments, it is a good idea to have them take all of their medications (in the containers) along to the doctor appointment. It's also helpful to write down questions for the doctor/nurse so you are ready for the appointment.

DEVELOP A HEALTH JOURNAL

Another great way to start the conversation about your loved ones' health is to help them create a personal health journal. Include vital information such as doctors' contact numbers, weight, oxygen use and symptoms to monitor like increased shortness of breath and fatigue. This tool will allow you both to remain proactive as well as have information ready for your PH team when treatment is necessary.

IMPROVE YOUR OWN COMFORT LEVEL

Some people feel that they need to be a trained health professional in order to help loved ones with a chronic condition. While it is true that you should never try to take the place of a primary care physician, gaining the trust of your loved one can be invaluable. By educating yourself about your loved ones'

conditions, you will feel more comfortable speaking with them about it and reinforcing the advice they have received from their doctors.

MAKING SURE THE HOME IS SAFE

Look for things in the environment that might cause harm to your loved one such as loose area rugs, loose steps or missing/faulty handrails that can be dangerous for someone who has trouble walking. Stairs can cause shortness of breath, so think about moving their living environment to the ground floor if it is a multi-story home. Place chairs around the house so that if your loved one needs to frequently sit, they can.

2. Take care of yourself

DEVELOP A SUPPORT SYSTEM

Find friends and family that you can lean on for emotional support or join a local PH support group composed of other people who are in your same situation. You can even visit website pages such as [cargiving.com](http://www.caregiving.com/) at <http://www.caregiving.com/> to provide support.

DON'T GO IT ALONE

Ask your doctor about what community resources are available to you, such as home care. If a friend or family member offers to give you a break, thank them and accept their offer. Or, if you are financially able, hire someone to assist you in keeping up with daily tasks. Don't feel guilty about accepting help. You will be better able to provide care for your loved one if you are not burnt out.

TAKE SOME TIME FOR YOURSELF

When you have a break from caring for your loved one, don't make it all about grocery shopping or paying bills. Get your hair done or see a movie with a friend. Listen to music and exercise. Meditation can be very helpful as well. There are a number of CD's available and websites to help such as: <http://www.mayoclinic.com/health/meditation/HQ01070>

Even a few hours away from your usual routine can make a big difference in your mental health.

GIVE YOURSELF PERMISSION TO GRIEVE

A serious illness is a life-changing event. You should not feel guilty for being sad that things are no longer how they used to be. It's okay to mourn what you all have lost.

TAKE CARE OF YOUR OWN HEALTH

As much as possible, make sure that you are eating properly, getting enough sleep and dealing with any medical needs of your own. If you are unhealthy you will be more prone to illness and depression and less able to care for your loved one. It makes sense for all parties to stay healthy.

ASK FOR HELP WITH SADNESS/DEPRESSION/FAMILY STRESS IF YOU NEED IT

Even with the best self-care, what you are going through is very stressful and may overcome your and/or the families ability to cope. Don't be afraid to ask for help if you need it. Let the healthcare team know if you require help in the home, for yourself or for your family. Your healthcare team will know the right direction to point you in and can help coordinate referrals.

OVER THE COUNTER MEDICATIONS

By **Holly Mansell, BSP, PharmD**
Pharmacist, Saskatchewan Transplant Program
St. Paul's Hospital

As a pharmacist who works with pulmonary hypertension patients, I am often asked which over the counter (OTC) medications are safe for patients to take. Over the counter medications should be used cautiously in patients with pulmonary hypertension. Many of these medications have the potential to adversely affect the heart and lungs, or to interact with pulmonary hypertension medications.

Any drug that is contraindicated in patients with high blood pressure should be avoided in patients with pulmonary hypertension.¹ Decongestants cause vasoconstriction (narrowing) of the blood vessels, which can increase blood pressure and heart rate, and may worsen pulmonary hypertension symptoms. They are found in various OTC medications marketed for flu, cold, sinus, allergy or headache. Some examples of oral decongestants are pseudoephedrine (Sudafed™, NeoCitran™), or phenylephrine (Sudafed PE™, Dristan™, NeoCitran™). Some examples of nasal decongestants are oxymetazoline (Dristan™, Dristoral™), phenylephrine (Neo Synephrine™), or xylometazoline (Otrivin™). These are just a few name brands - be sure to check with your pharmacist or carefully read the product label as there are many more.

The Non-steroidal anti-inflammatory drugs (NSAIDs) are a class of medications used to treat a variety of conditions and are available both by prescription and OTC. Ibuprofen (marketed under the trade names Motrin™ or Advil™), ASA (Aspirin™, Anacin™) and naproxen (Aleve™) are a few examples available OTC in Canada. These ingredients are typically used to relieve pain and inflammation, but they are often found in cold or sinus medications. NSAIDs may promote sodium and water retention, which may result in an increased blood pressure and/or an exacerbation in congestive heart failure.² Furthermore, this class of medications may increase the risk of bleeding when taken concurrently with warfarin (Coumadin™). Medications in the NSAID family should be used with caution and only under the advice of a physician.

Acetaminophen (Tylenol™) is another analgesic, unrelated to the NSAID family. It appears to be safer in patients taking warfarin; although large doses have been found to interact with warfarin and increase the risk of bleeding.³ Large doses of acetaminophen also have the potential to cause liver damage. It is currently not known whether acetaminophen taken in combination with bosentan (Tracleer™) or ambrisentan (Volibris™) could increase the risk of liver damage in patients with pulmonary hypertension¹.

Caffeine is a stimulant which is sometimes found in a variety of OTC medications for headache or menstrual cramps (Mido™, Excedrin™). Over the counter medications containing caffeine should be avoided, as in large doses they may increase blood pressure, or cause palpitations or an abnormal heart rhythm.

Ingredients that possess stimulant-like properties have also been found in many herbal products. (Ma huang). Unfortunately, there is often a lack of scientific data regarding the safety and efficacy of most herbal products. Herbal products have adverse effects similar to conventional medications and may adversely affect the heart, lungs or liver. Many herbal products have been found to interact with medications commonly used in pulmonary hypertension, such as warfarin, digoxin, or calcium channel blockers. Even though a product is touted as natural, it should not be assumed to be safe.¹ Herbal products should therefore be avoided unless approved by your pulmonary hypertension specialist.

When choosing an OTC product, always be sure to read the product label paying special attention to the active ingredient section. Selecting

(continued on page 6)

an OTC medication can be confusing. Familiar brands often market multiple products, each potentially containing different ingredients. For example, Robitussin DM™ contains the active ingredients guaifenesin and dextromethorphan, while Robitussin Cough and Cold™ additionally contains pseudoephedrine. The latter product therefore should be avoided in patients with pulmonary hypertension. If you are unsure which products are safe, be sure to check with your pulmonary hypertension team. Your pharmacist will also be an excellent resource to help navigate the way through the often overwhelming multitude of choices in a pharmacy's OTC section.

While this article addresses the safety of OTC medications in pulmonary hypertension, it is also important to remember other individual disease considerations. Certain OTC medications should be avoided in conditions such as diabetes, glaucoma or asthma, and may interact with other classes of medications. It is also important to consider individual dietary considerations. Patients on a low salt diet will want to consider the sodium content of the chosen product. A sodium-restricted diet (less than 2400mg/d) is generally recommended for all pulmonary hypertension patients⁴, while other patients may be on a more severely restricted diet. Likewise, individuals with diabetes should consider the sugar content when choosing an OTC product.

In conclusion, caution should be used when choosing an OTC product for the patient with pulmonary hypertension. Certain drug classes such as decongestants and NSAIDs, as well as herbal products, may cause harm and generally should be avoided. Also, individual disease and dietary considerations should be taken into account. Careful reading of labels is advised for safe selection of products, and when in doubt, consult with your healthcare provider.

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Meet Your Medical Professional

AN INTERVIEW WITH LYDA LESENKO, RN

By Jennifer Gendron

This column marks the start of a new feature that will highlight one of the amazing medical professionals working within the PH community in each issue of Connections.

For this issue, I have had the pleasure of interviewing Lyda Lesenko, RN who works in the pulmonary hypertension clinic at the Jewish General Hospital in Montreal. Lyda was the recent winner of the 2011 Outstanding Medical Professional Award which was presented at the National Pulmonary Hypertension conference in September.

Lyda is truly an inspiration in her field. She gives countless hours

of her time to assist her patients in connecting with one another and finding the support that they need. She has been instrumental in the creation of the Montreal Support Group and continues to offer her time and energy to many projects including clinic mail outs and events such as the recent "Walk for Breath" held in Montreal in November in support of the Jewish General Hospital.

It is obvious from the wonderful comments that we have received from Lyda's patients and co-workers, just how much they value her support and what a difference she has made in the lives of so many.

Thank you Lyda for all you do and for being willing to share a little bit of yourself with our readers!

PHA Canada: What initially influenced you to join the nursing profession?

Lyda: I grew up being a caregiver first – caring for a Dad who passed away with ALS and a Mom who had CHF from congenital malformations. I went to Nursing school knowing that I should learn more to become a better caregiver. Neither parent survived to see me become an RN.

PHA Canada: Where did you begin your nursing career and in what field?

Lyda: After obtaining my nursing licence in 1984, I started my nursing career at the Jewish General Hospital and I have now been practicing here for over 27 years. I have worked 16 years in the Emergency Department; followed by 3 years in the Operating Room.

PHA Canada: How long have you worked in the pulmonary hypertension field?

Lyda: In 2003, I had the privilege to join Dr. David Langleben and Eileen Shalit BN and begin a thoroughly rewarding experience at the Center for Pulmonary Vascular Disease – or more commonly the Pulmonary Hypertension Clinic.

PHA Canada: What do you enjoy the most about your current role?

Lyda: I recognize that I work with the two of the most knowledgeable individuals working to treat and care for patients suffering from pulmonary hypertension. It is an experience that enables me to care for my patients now and look into how my patients can be cared for in the future – including my involvement with the ongoing clinical trials in PAH. In this dual capacity, I feel that I have a more rounded knowledge base and this enables me make a significant contribution in caring for my patients while collaborating with the "genius" of my colleagues.

PHA Canada: Who would you say is your greatest mentor?

Lyda: My greatest mentor without any pause for thought is Mrs Eileen Shalit, BN. This woman is a pioneer when it comes to research into every single treatment now available and offered to patients with pulmonary hypertension – from the earliest studies involving the prostacyclins; followed by those for the ERA's then the PDE5's. She has been involved with implementing policy and procedures within the hospital for these therapies, has been on many advisory boards, and is a truly valuable resource person to all the North American PH Coordinators. I find myself indeed blessed to be working and learning from Eileen.

PHA Canada: Is there anything else about yourself you would like to share?

Lyda: I enjoy the work that I do tremendously and, if I can make a difference in the life of just one patient suffering from PH – then I have done well and will continue to strive to do better in my career.

2012 INTERNATIONAL CONFERENCE ON NEONATAL & CHILDHOOD PULMONARY VASCULAR DISEASE

By Jennifer Gendron



On March 9-10, 2012, the 5th International Conference on Neonatal & Childhood Pulmonary Vascular Disease will be held in San Francisco, California at the Hotel Nikko. While this is the 5th year for this event, it is the first year that the conference will hold sessions specifically targeted to children and families living with PH. This symposium will bring together international experts to explore the current understanding of the basic pathobiology as well as new and future therapies for neonatal, pediatric, and adult pulmonary vascular diseases.

The conference line up will feature presentations on a variety of topics from specialists in their respective fields but will also include a series of family's perspectives as several parent and child pairs share their own personal journeys with PH. A breakout session will also be held for families that will include discussion on the issues specific to families dealing with PH including: unique challenges faced by families dealing with this illness, whether adequate supports are in place for families at the time of diagnosis and what further supports are needed to assist families living with PH.

This conference will be an excellent opportunity for families living with PH to come together to learn, share and connect and we encourage you to consider attending. The cost of registration for patients, family members and caregivers is \$10/person. Medical professionals wishing to attend may visit www.cme.ucsf.edu for registration information and pricing. For more information, please contact Jennifer Gendron, Acting National Manager, PHA Canada at jgendron@phacanada.ca or (506) 832-4898.

PHA'S 10TH INTERNATIONAL PH CONFERENCE AND SCIENTIFIC SESSIONS, THE POWER OF ONE: FROM A KITCHEN TABLE TO AROUND THE WORLD

By Meghan Tammaro

PHA's 10th International PH Conference and Scientific Sessions, The Power of One: From a Kitchen Table to Around the World provides the PH community with the opportunity to look back at the progress that has been made in the PH field over the years. Our first conference brought together 100 patients and family members. The 10th anniversary Conference, taking place June 22-24, 2012 in Orlando, Florida, USA, will bring together almost 1,400 PH patients, caregivers and medical professionals for three days of education, support and networking. Our conferences offer opportunities for every attendee: Scientific Sessions for medical professionals seeking to enhance their knowledge of the disease, Patient/Family Led and Medically Led Sessions for patients and their families, and Meet-Ups for the community. Our 10th International PH Conference will feature 15 Patient/Family Led Sessions, 40 Medically Led Sessions, and 15 Support Group meetings focused on a variety of topics.

As the demand for pediatric PH education and resources has grown, we've proudly taken on that challenge and are excited to offer new opportunities for children and their families at our 2012 Conference. Parents of PH patients can find all of the support and information they seek through Pediatric Sessions focused on Medical and Psychosocial Issues, Parent Support Group Sessions, Meet-Ups for Families of Children and Teens with PH, and a brand new PH Parent mixer! Children also have the opportunity to take part in Conference through a "Kids-Only Ask-a-Pediatrician Session", participation in the "Hide the Pump" fashion show, a Teen PHers Support Group, My Parent/Sibling has PH (for kids under 21) Support Group, field trips, and the Kids' Room. The Kids' Room is a supervised space for children and teens (3-16 years of age) who accompany their parents to Conference. Games, crafts and organized activities will be available in the Kids' Room.

In addition to new programming for families, we are pleased to offer networking opportunities specifically for our global audience. During the afternoon of Friday, June 22 regional international meetings will take place where global guests can come together to meet patients and families from their region. During this time, PHA Canada will be facilitating a Meet and Greet for the Canadian PH community. On that same day, PHA will be hosting an evening International Reception for all global guests. We hope you will join us June 22-24, 2012 for our 10th International PH Conference and Scientific Sessions. Registration opens on January 11 and more information can be found online on our website: www.PHAssociation.org/Conference.

2011 NATIONAL PULMONARY HYPERTENSION CONFERENCE

Toronto, Ontario
September 16 – 18, 2011



“Uniting The Ph Community From Coast To Coast”

By Gaynor Hale

This was my first attendance at a national PH conference and proved to be far beyond my expectations.

The Conference began on Friday evening with the meet and greet for all attendees hosted by the Toronto chapter of PH Canada. It was a fun and happy setting; a great way to meet new people and renew friendships. Everyone enjoyed the evening of music, food and games. There was also a meet and greet for the young adults later in the evening.

I met patients and caregivers from all walks of life, as well as medical personnel, from almost every province. Most of the educational sessions were offered in either English or French and all common events were bilingual, with audio translating devices provided for personal use. The organizers thought of everything, leaving no one out of the experience!

The educational sessions were very well done and informative, covering everything from new treatments and therapies, drug therapies, current trial studies on the horizon and genetic profiling, to the importance of proper breathing techniques, specifically formulated to help PAH patients using the Iyengar Tradition of yoga.

November is PH month and getting the word out and raising awareness through the media was the topic of another great educational session. Providing ideas and advice on just how to do that, using various methods like contacting local and neighbourhood media or community calendars, just to name a few.

The advice on the use of oxygen, as well as the various methods in which oxygen can be provided, was very informative. A little planning can make your travelling safe and pleasant. The clear message of this session was, don't let PH take over your life and don't let it define you. Live your life. I found it very reassuring that so many PH patients do travel, whether across Canada or the world and seem to be already following that advice and living their lives as fully as they can.

One of the highlights for me was inspirational speaker and motivator, Mark R.W. Black, author of “Live Life from the Heart – 52 Weeks to a Life of Passion and Purpose”, who was our

speaker at the Saturday evening dinner. Mark, a double lung and heart transplant survivor, discussed his life and health challenges and how he lives each day to the fullest, while encouraging others to do so. Facing the possible challenge of: What if you only had one year to live? How would you live that year? His message of making the choice to be positive, setting goals for yourself, not letting your diagnosis control you and refusing to quit was loud and clear.

There were many more highlights of the entire event, from the first evening meet and greet, to the great food served every day, the wonderful ambiance and friendship, the PHA Canada volunteers, instructors, professionals and attendees, all made this Conference truly an enjoyable and memorable time for me and I hope for everyone.

Thank you PHA Canada and well done!

Always, Live Life to the Fullest

By Lynn Williams, PH patient, VP of EPAHS

I was diagnosed with idiopathic pulmonary hypertension in July 2004. I started getting short of breath in March and by May 27; I was no longer able to walk. I was a Nurse Manager of a 30-bed long-term care unit. My diagnosis was done in a relatively short time. I was started on Bosentan, Viagra was added and in May 2005 I was started on Flolan. In the spring of 2010, I had very painful debilitating joint pain. By December my PH was diagnosed to be secondary to inflammatory arthritis. I was also diagnosed as having low antibodies. You all know and understand the many difficulties and cumulative side effects all the medications can bring. It was discouraging. My family is very aware of my ups and downs. To help, my daughter sent me a copy of the following poem. She said this was the poem I gave her when she was diagnosed with MS 18 years ago. I don't recall where I found it, nor have I ever known who the author is. I would like to know the author's name so that I could send my thanks. This poem is taped onto my bathroom mirror and I read it everyday as I mix Flolan. I hope it works for you as it does for me.

Always, Live Life to the Fullest

Don't let go of hope,

hope gives you the strength to keep going.

When you feel like giving up,

don't ever quit believing in yourself.

As long as you believe you can,

you will have a reason for trying.

Don't let anyone hold your happiness in their hands.

Hold it in yours, so it will always be within your reach.

*Don't measure success or failure by material wealth,
but by how you feel;*

Our feelings determine the richness of our lives.

Don't let bad moments overcome you;

be patient and they will pass.

Don't hesitate to reach out for help,

we all need it from time to time.

Don't run away from love but towards love,

because it is our deepest joy.

Don't wait for what you want to come to you.

Go after it with all that you are,

knowing that life will meet you halfway.

Don't feel like you've lost

when plans and dreams fall short of your hopes.

Anytime you learn something new

about yourself or about life,

you have progressed.

Don't do anything that takes away

from your self-respect.

Feeling good about yourself

is essential to feeling good about life.

Don't ever forget how to laugh

or be too proud to cry.

It is by doing both that we live life to its fullest.



My PAH and Me

By Marthe Poulin, Trois-Rivières, Quebec

It was only many years after the manifestation of the first symptoms that I had realized that those were my first experiences with PAH. In 2002, I was in Quebec City to see my grandnephew in an auto racing competition. On our way back, we had to go up a pretty steep hill and I was completely out of breath after a few steps. I didn't understand why I felt this way as I had been doing sports for years and was in great shape for someone my age (I was 47 years old). That same year, I was vacationing in Turkey and it was overbearingly hot. I love the heat but not when it's that intense. Our cottage was located on top of a hill and the ocean was – naturally – right at the bottom of it. During the whole trip this hill was my nemesis and I climbed it as if it were the Everest – slowly and out of breath, kneeling down every 20 steps to take a deep breath. I told myself that my body would adapt after a few days and that the hike would get easier. I thought that the heat was the reason that my body was reacting this way but on Day 14 I was struggling just as much as on the first day. I also noticed that I had put on some weight in the past few weeks and that my legs were swollen to the point that I had trouble bending them because my skin was so stretched out. Still, I thought that it was the Turkish summer heat and humidity – that was just bad as Quebec – or the effects of the atmospheric pressure from the flight, etc. In short, I wasn't as concerned as I should have been. I have to say though that I had always had health problems (scleroderma, lupus, lumbar osteoarthritis, severe Raynaud's disease) and I had never stopped to

focus on symptoms related to those diseases. On top of that, I was going through pre-menopause and I thought this to be the biggest culprit. Today, I realize that it was the beginning of PAH. At the end of summer of 2007, I had realized that I was just as out of breath cycling than I was at the beginning of the summer. That's when I decided that it was time to take things seriously and I set up an appointment with my rheumatologist. My doctor was aware that a certain percentage of people suffering from limited scleroderma (CREST) could develop into PHA so he made me take cardiac ultrasonographies and for the past few years has made me do a pulmonary function test every 6 months. That is why I was quickly referred to Dr. Provencher of the Hôpital Laval (who specializes in the treatment of cardiorespiratory diseases) and I did not have to spend many years consulting different doctors to figure out what I had. A few tests later – walk test, echocardiogram, right heart catheterization – the diagnostic was in and I immediately got a prescription for Bosentan and diuretics. A year later, a second catheterization indicated an improvement in my right intracardiac pressure that went from 28 to 23 (the diagnosis is confirmed at a pressure of 25). I was lucky to get an early diagnosis which has allowed me to carry on a normal life despite a few situations that left me breathless and brought on intense fatigue. I continue to practice sports (volleyball, racketball, cycling) but at a lighter intensity than someone who is healthy (I often have to stop to catch my breath whereas my partners breathe normally).

Today, I am retired (I am 56 years old) and I can enjoy life without overexerting myself like when I used to work (as an educator at workshops for adults with intellectual disabilities). I participate in PAH research at the Hôpital Laval and I must say that this allows me to keep up to date with my symptoms and the progressions of my disease.

Don't Give Up

By Gina Gravel

Suffering from an illness is quite a challenge. What's obvious, is that it sends quite a serious message to your body. It's a sign revealing that you have to slow down, change something. But does that mean you have to stop living? The day I learned that my health was stable enough I decided to fulfill my dream, that of travelling.

I thought that I couldn't take a place so I decided to give myself an altitude test and I packed my bags. Nothing complicated, really – a one week all-inclusive to Cuba. People had recommended this country because of the accessibility to health care and the quality of the medical specialists. On top of that, there is bottled water on the hotel premises and the food is very good. For obvious reasons it would be preferable to choose a hotel that is rated 4-stars or more and to be careful when eating off-premises foods. But a short week of luxury and rest that allows us to completely escape our worries always does wonders on one's morale.

Thanks to this short escapade, I was able to feel like other people. In the eyes of all the other vacationers around me, I was not a sick person. I took advantage of the beach, the good restaurants, short excursions; and I met many nice people with whom I spent great evenings. This year, we went to the Dominican Republic.

Too often, we forget our wants. Let's learn about the information that is missing and organize our outings according to our needs; and we'll be able to have small dreams come true safely. Whether they be big or small, let's stay open to Life...

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Conference Participants Share Their Stories
(continued from page 9)

My Conference Experience

By Michelle Andrews

Wow...what a whirlwind!

I just got back from PHA Canada's 2011 conference, held at the Delta Chelsea Hotel in Toronto, Ontario. Yes, I am tired...but it was much more than worth it. The medical information, O2 therapy, what's in the future for treatments for us, support groups for everyone, transplant, exercise, diet, yoga, fundraising, connecting with the media, "Ask a Nurse"... so many great experiences. And then of course there were friends, new and old.

The impression I came away from the conference with was, more than anything, a sense of community. The conference is really a place where we can feel like we belong. There was so much mutual concern, so much positive energy radiating from everyone... the organizers, the volunteers, the patient participants, the pharmaceutical reps, everyone! Among all the people that I met, in all the sessions I attended, in all the meals we shared, I did not hear one negative comment, tone, or expression. An outsider would be hard put to know that this was a group of people directly affected by a rare and life threatening disease, (well maybe the O₂ tanks would give us away!)

To our delight, we had children among us this year. One young man presented his story at the "Journeys" lunch and did very, very well indeed. Excellent job, Braden! Another young man received a much-deserved award for Outstanding PH Patient. Congratulations Quinlan O'Blenis! Children's programs were provided through both the hotel and PHA Canada.

The event was packed with opportunities for learning, for getting answers to daily living problems, and for connecting with patients and caregivers from all over Canada. It's a chance to learn what works for so-and-so and to share what works for us. We had speakers: Mark Black on Saturday evening was very engaging and at breakfast on Sunday, Carl Hicks invited us all to the U.S. conference in Orlando, Florida next year. The French and English translators were great, and the hotel was an excellent choice for the needs of our group.

At this year's conference, I learned new things about O2 product delivery, met my specialty pharmacist (who up until conference was just a kind voice on the phone), was given a boost of hope by the "What's on the Horizon" presentation by Dr. John Granton, Dr. Duncan Stewart, and their associates, learned how to approach the media and where to go for help to do so, and was affirmed to continue my use of seated Yoga. And I met so many wonderful people. My husband and I met a couple from another province who are truly "kindred spirits" (in actual fact we two "girls" sat up sharing stories until a ridiculously late hour while our caregiver husbands sank, bleary-eyed, deeper and deeper into the sofas.)

Hats off to the PHA Canada Board and the Conference Committee for a hard job very well done!

To those of you who have not yet come to conference, it really is worth the effort. My plan is to start saving my pennies now for next conference, and to get my backup caregiver lined up (I think I will ask my family and friends to forego any Christmas and birthday gifts for me and instead donate to the "Get Michelle to Conference 2013" fund.) I have a whole list already made of what to take next time and what to leave home, and what to do differently to maximize my experience and those of the people I meet (And, I should make note that I did not have to be tired...there was a hospitality room to rest in, two really good pools and a gym, and there was no need to try to attend as many sessions as possible, because all the sessions were audio taped).

I could go on and on about all the good things that happened at Conference, but for now I will share my email address, for anyone wanting to know more.

Michelle Andrews
Patient - Toronto Chapter
amarthahopingtobecomeamary@rogers.ca

Living with Pulmonary Hypertension

By Sandra Diebel

I'm unique. At least that's what all of my doctors tell me... unique, a puzzle, I don't add up. I've had numerous doctors and specialists consult on my case from my family doctor to a respirologist, pulmonary hypertension specialist, cardiologist and an HHT specialist. They all agree – I'm unique.

It was 8 years ago in 2004 when I first realized something was wrong. Then the tests began. My health took a drastic downturn in 2006, I had an open lung biopsy done in 2007 and was diagnosed with pulmonary hypertension in 2008. Then I was told I really didn't have pulmonary hypertension, not the typical pulmonary hypertension. Mine is even more unique because it's exercise induced. I've been told that I'm fortunate!!

I'm fortunate. It's a daily ritual to remind myself of that. I've gone from a healthy, independent, self-sufficient single mother of 3 who owned her own home, was financially independent as an office manager and power walked on a daily basis to an unhealthy dependent person living on disability in low-income housing who has financial as well as physical limitations.

Life has indeed changed. I try not to schedule anything for my mornings as it takes most of that time for me to what I call "reboot". I have a couple of hours of prime energy time in the afternoon of a good day and then by late afternoon my body starts into shutdown mode. So, I've had to adjust my lifestyle, modify my activities and re-evaluate my priorities so that life is more manageable.

My mother is in her 90's. She's a very spry and active 93 year old who has her own energy limitations caused by age and a certain level of fatigue. For a number of years now, I have jokingly explained to people that my mother and I are on the same energy level. It's the best way to explain it. I went from a healthy active 46 year old to a retired 50 year old who feels like she's in her 90's. The comment I get all the time is "Well, you look good". I'm so glad. I would hate to look as bad as I feel!!

So, with PH as part of my life, I take each day as it comes, do whatever I can with each day and try not to do too much or push myself too hard. I have found that by accepting my PH and its limitations, I have the freedom to live my life in whatever way I choose. I choose to appreciate every day that I have and enjoy every little thing that comes my way...the birds singing in my yard, the squirrels chasing each other, the sound of the river cascading over the falls, the beauty of the leaves changing color in the fall, the small incidents of the day that put a smile on my face, bring me laughter or put joy in my heart. PH has given me a new appreciation for life. I am so grateful for my sense of humour that helps get me through and I am so blessed to have the love and support of family, friends, and fellow PHers.

LEND A HAND FOR PH CAMPAIGN A SUCCESS THANKS TO YOUR SUPPORT!

By Edelman



The Honourable Bob Rae lends his hand for PH

With the support of PHA Canada members across the country, last November we launched the LEND A HAND for PH campaign as part of Pulmonary Hypertension Awareness Month. As in previous years, the goal of the campaign was to generate public awareness around PH, but this year we also wanted to invite Canadians to get involved by signing a handprint to show their support for people living with PH.



We held four major events across the country to kick-off PH Awareness Month. In Vancouver and Calgary, events were held in high-traffic locations that engaged local community members. In Toronto and Montreal, the events were done in conjunction with local PH fundraisers. For those who couldn't make it to the events, there was also an opportunity to leave a "virtual" message of hope by signing and sharing a handprint on the PHA Canada website or Facebook page.

We concluded our campaign in Ottawa, on Parliament Hill, with the support of the Honourable Bob Rae, Leader of the Liberal Party. A large group comprised of PH patients, caregivers, physicians and politicians attended a breakfast to celebrate LEND A HAND for PH and

witness the unveiling of more than 2,000 handprints and messages of hope that were collected across the country.

Throughout the campaign, media relations activities were executed to increase PH awareness by profiling patients and physicians in different markets. With stories appearing in papers such as the Toronto Sun, Calgary Sun and La Nouvelle Union, television programs such as LCN TV in Quebec, CHCH-TV in Ontario and Shaw TV in Alberta, and national websites like canoe.ca, the campaign has generated nearly 12 million media impressions across Canada to-date – more than any of our previous awareness campaigns!

Thank you to our members for all of your support, and special thanks to our campaign spokespeople and those who collected handprints individually. We were able to raise awareness about PH, bringing it to the forefront of the minds of Canadians and the federal government. We look forward to future campaigns!

"LET ME BREATHE" VIDEO RELEASED BY J. PAUL ADAMS

By Ruth Dolan – Dec. 12, 2011



Ruth Dolan and brother, Paul Adams

About Paul:

He is my younger brother. Our mother recognized at a very early age, before he could even speak, that Paul was very aware of music and rhythm, jumping up and down in his crib in perfect time to music on the radio and trying to "sing". He started music (piano) lessons at the age of 5 and it became clear that he had perfect pitch. If he heard a piece, he could play it back on the piano, which frustrated our music teacher, Sister Louise, to no end. (I mention Sister Louise, because of the place where both Paul and I took our piano lessons; it was in a convent in Toronto, and as it turned out, that now former convent was the very music studio, (Coalition Music Recording Studio) in what had been the nun's chapel, is where Let Me Breathe was recorded some 50 years later! Boy, did that bring back memories for Paul and me.

Paul became an accomplished musician and as many teens have done in the past and do now, he started a band at the age of 12, put himself through University by playing 5-7 nights per week, and to this day continues to play music in a group. His music company is called "Music Machine". He became a high school teacher and taught music for over 30 years and was heavily involved in musical theatre at his schools and in fundraising for his schools, so his students could go on music and band trips which he organized. He has written and produced many albums and CD's throughout his career and was nominated for a Juno for one of his many children's albums.

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“Let Me Breathe” Video Released by J. Paul Adams
(continued from page 11)

Our (Edward’s and my) youngest daughter Emily, had symptoms of PH as early as 9 years old but was not diagnosed until the age of 27 when she was a student, working on her second degree at Dalhousie University in Halifax, Nova Scotia. She was diagnosed in January of 2007 and no treatment was started as they also discovered another “mystery lung disease” and were afraid to try conventional PH drugs. She became sicker and sicker until in late Aug. 2007 I received a call from a cardiologist in Halifax at my home telling me to “come and get my daughter, as she could no longer live on her own”!

I tell you that little part of Emily’s story, because that is where my brother went into action and became one of Emily’s “team” of supporters. It was he, along with his friend and colleague Rosemary Lavery, who were waiting at the airport when we brought our daughter home, or rather, to Toronto General Hospital. Paul took me and Emily to the hospital and Rosemary took Edward, all of our baggage and Emily’s cat to Bradford, where we live. As with most families who’s loved one is diagnosed with PH, there are the periods of being in shock, of being bewildered, overwhelmed and frankly terrified, not to mention lost, alone, helpless and just not knowing where to turn.

I can’t recall the exact date that we learned about the newly formed Toronto PH support group from another patient while waiting to see the specialist at the hospital PH Clinic. I just remember that Kathy, another PH patient, was the first other PH patient any of us had met and I remember the smile on Emily’s face to meet someone her age who had the same illness.

Shortly after that encounter, we too joined the Toronto PH Support Group, where so much of our stress and fear dissipated and we found support and remarkable friends, as time has gone on. We had made some Awareness efforts but no one had had any experience with fundraising in a big way. In the summer of 2009, I invited Paul (and his fundraising experience) to come to our group; and he brought along his teaching and school fundraising colleague Rosemary. The idea of the Vegas Night was born at that meeting.

Paul (the creative musician, the “ideas” guy) left that first group so completely blown away by the energy of our PH members, by their zest for life and their joy of living, that before he even got on the road to go home, he had the title of a song that he felt compelled to write, for his niece (Emily) and for all of these incredible people he had just met; the title was, and is “Let Me Breathe”!!

It took a few days for him to flesh-out the song and within a week or so he had written the words and the melody and burned the first CD in his home music studio. Our group members were over the moon!

He and Rosemary Lavery have been the driving force behind each of our 3 annual PH Let Me Breathe, Vegas Night fundraisers, which to date have raised over \$36,000 for PHA Canada.

The Toronto PH Support Group hosted this year’s National PH Conference in Toronto on Sept. 16-18, 2011, “Uniting the PH Community Coast to Coast”. My brother was invited to perform “Let Me Breathe” for our opening night reception. It was thus heard by many PH guests from across the country and a few from the USA, for the first time. It was also at that conference, that he shared an idea he had been quietly working on for several weeks, with me and with Darren Bell, the president of the Board of Directors of PHA Canada. Paul thought, to help spread awareness about PH in a very powerful way, he wanted to make a “Let Me Breathe” music video. He had always loved the concept of the “We are the World” video which helped raise awareness about the plight of people in Africa in 1985. He envisioned creating a

choir of PH patients, supporters, and friends to lend their voices to the song and to send a strong visual and vocal message that PH Patients and their families are “thrive-ers”, strong and joyful, and indeed hopeful. What better way to do this than through the use of a music video.

What I have said above is just the tip of the iceberg when it comes to the lengths to which my brother will go to make things happen. Paul had given an enormous amount of his (free) time to the folks at Coalition Music, doing a project for them to help grow their business. He accepted no payment. The studio donated their facilities, technicians, engineers, and even loaned the musicians a Gibson guitar for the recording of our video. He also worked with the videographer, and his friend, Scott Brown (a professor at Ryerson) and Ryerson University’s RTA Programme (Radio and Television Arts) to see what he might be able to do for us, re: making the video. He learned from Scott that RTA had just requested and was granted the opportunity to do charitable work/projects for small, unknown and underfunded, charitable organizations such as PHA Canada. This would also provide hands-on experience for the students in the RTA’s Programme). We were their first project! The sax player and guitar players and many of the vocalists are Paul’s friends and colleagues in the music business or from school. He only has to ask and they are there to help him, and that happens because he is one of the most generous and caring people I know!

I am sure you can put things together, the recording studio, the sound engineers, the videography and still photography and all of the musicians you see in the video and in the choir, all gave their time to create Let Me Breathe, the video. See the credits at the end of the film.

Paul has been working on our (my family and ALL families dealing with PH) behalf from the moment we returned with Emily from Halifax both behind and in front of the scenes. He is the best brother a woman could have!

The video “premiered” at our PH Fundraiser on Nov. 5th. This fall, PHA Canada sponsored our first Nationwide PH Awareness campaign this year called Lend a Hand. Banners bearing 2000 small, paper hands with messages of support came from Vancouver, Calgary, Toronto, Ottawa and Montreal. We took these to Parliament Hill in Ottawa on Tuesday, November 29, 2011 to display at a reception hosted by the National Opposition Leader, Liberal Member of Parliament, the Honourable Bob Rae. The video was shown at this event. There were several guest speakers including the (Newly Elected) President of the Board of Directors of PHA Canada, Mr. Frank Poon. Two PH patients shared how PH has affected their lives, Mr. Rae offered his ongoing support for persons with rare diseases and Mr. Don Bell (Darren Bell’s father, and a former MP who worked tirelessly to get a bill passed in parliament to recognize Rare Diseases. Darren founded PHA Canada as we know it in Canada today.)

As you know the Video was launched into the You Tube world on Friday, November 25, and to date has over 1,100 views. Just the other day, a family who lost a loved one to PH and had heard Paul’s song at the conference in Sept. requested to have it played at her funeral. How bitter sweet! The family said that when the video came out she had played it every day.

Sorry for all the detail here, but we have been on such an exciting journey during the past 4 years and are so energized by all the caring and compassionate people we have met along the way, just like so many of our PH friends around the world. I love to hear their stories and I hope that there is something in this one that will speak to others and encourage them in some way.

A VEGAS NIGHT FOR PH 2011

By Loretta Chu



The Toronto Chapter of PHA Canada held their 3rd annual fundraising event: “Let Me Breathe” – A Vegas Fundraiser for Pulmonary Hypertension on November 5, 2011 at Brebeuf College.

With over 200 guests in attendance, the night featured casino game favourites such as blackjack, roulette and the ever popular spinning wheel. Each participant is provided with 25 “PH dollars” to start playing on the casino games. At the end of the evening participants can use their “winnings” to bid on the Live Auction.

This year we had amazing live auction prizes such as: LG Plasma 50” TV, Toshiba 10” Netbook, CN Tower Edgewalk experience, Ruby & diamond pendant, a pair of Leafs vs Rangers hockey tickets, beautiful handmade quilt and many others! All our prizes were donated by members from the PH community so a huge thank you to you generous folks!

Guests also “Lend a Hand” for PH by signing a hand print for the National Campaign. We collected over 200 hand prints this evening!

The evening featured a live musician, Martin Traynor who played an amazing set during the break of the casino gaming. There were also cupcakes donated by Sisterly Sweets and pizza for people to keep their bellies happy, along with the cash bar. Another big hit for the evening was our Raffle draw for the “booze buckets”. People at the fundraiser also got to watch the world premiere of the “Let Me Breathe” video by Paul Adams.

In the end, we were able to raise over \$11,000 for PHA Canada. Thanks again to event coordinators Paul and Rosemary, Fundraising Committee and the volunteers for a fun and successful evening!

WALK FOR BREATH

by Judith Moatti

My name is Judith Moatti, I was diagnosed with Pulmonary Hypertension in 2009 when I was 25 years old.

A few months ago, I met Rita Hébert. Since then we formed the Patient Support Group and organized a fundraiser walk in Montreal.

At the time of the organization of the walk, the members were: Rita Hébert, Lyda Lesenko, Lucie Gratton, Lena Bergevin, Jean-Kathleen Rioux, Michèle Moatti and Judith Moatti. I mention this because since then the committee has grown.

Through facebook I had discovered that the PHA association in the U.S. were having a walk, and I thought that it would be a good idea to organize one here also. I discussed the idea with Rita and the Committee. From there, it was team work that made this event such a success. We had a few challenges along the way, but it was nothing that we could not overcome.

The day of the walk, the volunteers and the Support Group were at the venue to get ready for the event. The downtown YMCA was generous to provide us with the perfect indoor venue to hold our walk, aptly named the “Walk For Breath”. We were hoping to host at least 100 participants for this our first walk, but we welcomed 250 instead. That’s when we realized that all the hard work that was put in, the walk was an enormous success – beyond even our expectations.

Amongst our friends, families and supporters, were our healthcare providers and their families. This was truly special occasion. After the opening speeches, we got ready for the walk. The first row at the starting mark was lined with children that were patiently waiting to commence the walk. It was heart-warming to see family and friends walking in solidarity with a loved one afflicted with pulmonary hypertension.

We walked for a couple of laps at the indoor venue (participants were free to walk for as many laps as they felt comfortable doing) and we closed our event with a raffle. The three winners received stained glass work that was created by Nicholas Tanguay, himself a patient at the Center for Pulmonary Vascular Disease at the Jewish General Hospital. We have raised approximately 19 000\$. We are still receiving donations as of this writing.



The First Annual Pulmonary Hypertension Walk for Breath in Montreal was born and will hopefully live on for a long time.

That evening, I was asked to be interviewed for “TVA nouvelles”, which was an unexpected but opportune moment to broadcast our walk as our ultimate goal for the walk was to create awareness for the little known disease of Pulmonary Hypertension. Our walk coincided perfectly with the campaign that the Pulmonary Hypertension

Association of Canada was holding throughout the country to promote awareness of this rare disease. November is Pulmonary Hypertension Awareness Month throughout the nation.

First and foremost, we would like to thank Rita Hébert for all her efforts since the onset to make this event come to life. This special project could not have had a better organizer.

I would like to thank the Support Group Committee, everyone gave their 100%.

We would like to thank everyone that made The Walk For Breath possible: Mary Metzitan from the Jewish General Hospital Foundation, the volunteers, the YMCA, PHA Canada (and its representative Jennifer Gendron), HTAPQ, Catherine Pouliot from the PR firm Edelman, and to fellow patients, the Tracy's, who provided us with water bottles and fruit that their grocer so generously donated.

Our heartfelt thanks to everyone who took this walk by our side.

MY DREAM IS FOR ORGAN DONATION TO BECOME AUTOMATIC

By Dolorès Carrier, HTAPQ Foundation



I've been dreaming of this for a few years... Ever since one of my friends required new lungs. In fact, my friend had a rare disease called pulmonary arterial hypertension. This young woman was healthy and practiced many sports: swimming, golf, etc. Shortly after giving birth to a beautiful girl, she started having health problems: dizzy spells, shortness of breath, extreme fatigue and trouble taking care of her young daughter. Because of her deteriorating health, she was hospitalized. It was only after her trip to the third hospital that they told her that she suffered from pulmonary arterial hypertension. Her condition required a very invasive treatment that caused a lot of side effects. Her health worsened to the point where the only solution was a lung

transplant, and then a heart and lung transplant. Sadly, she died before getting a transplant. She was 38 years old and the mother of a young 8 year old girl.

I also met a young 13 old who had cystic fibrosis who died while waiting for a lung transplant.

I have a young friend who just turned 20 et whom I love very much. She has pulmonary arterial hypertension and a heart disease. She has been in Toronto for the past 6 months waiting for a heart and lung transplant.

This is why I dream of organ donation becoming automatic; for the loss of someone close to save the life of someone else. In the meantime, I urge you to sign your health card to authorize organ donation.

CHEESE SALE

By Denis Cormier, President, HTAPQ

If money is the sinews of war, it is safe to say that for the Fondation HTAPQ, cheese is what keeps us alive!

We also organize many fundraising campaigns but our main source of revenue is the sales of the products from Abbaye St-Benoît-du-Lac before Easter and Christmas.

I am sure that what was just said was already expressed because the number of boxes sold keeps on increasing every year.



The secret to our success is that we believe in the cause for which we work and, without being too humble, we know that we are a great organization.

At Christmas alone, over the past six years, our statistics are the following (in terms of boxes sold) – 270 in 2006 ; 614 in 2007 ; 1640 in 2008 ; 2090 in 2009 and 2350 in 2010. This year, in 2011, we have set a new record of 2841 boxes sold. Added to that, it is interesting to mention that Easter sales represent only half that of Christmas sales.

Many people have contributed to our success: members of the Board of Directors – obviously – as well as several people who suffer from PH and who wish to help their loved ones.

Here is how our campaign works: we sell, we go get the boxes from Juvénat Notre-Dame of St-Romuald, we bring all these boxes to Plessisville and we organize the distribution.

Deliveries were made to Trois-Rivières, Drummondville, St-Hyacinthe, Granby, Rimouski, Varennes, Victoriaville, Boucherville, Longueuil, Montreal, Ste-Julienne, Sherbrooke as well as other

cities within the province of Quebec.

Essentially, cheese is what allows us to help people. Since our existence, \$150,000 have been donated to people in need.

The Fondation HTAPQ would like to thank all the people who have bought, sold and delivered these boxes.

ONE WOMAN'S QUEST TO MAKE A DIFFERENCE!

By Jennifer Gendron

Ruth Dolan's adventure in to the world of requesting proclamations began as a way to garner some support for PH Awareness on a local level when the thought occurred to her to go to her local Mayor's office in Bradford a couple of weeks ago. Ruth, co-leader of the Toronto Chapter of PHA Canada, visited the Mayor's office to request a proclamation to declare November PH Month with the hopes that she could then take the proclamation to her local paper and encourage them to write an article. When things went smoothly in her local town, she decided to try other towns and municipalities in her area and the proclamation project was born! One of the biggest challenges that Ruth faced in having the proclamations passed is that some areas requested that a local representative from their town accept the proclamation in person and she has had to do a lot of work to explain what a rare disease this is and in fact there are only two support groups in Ontario at present. This did not deter Ruth and she continued to pursue additional areas. She was able to enlist the help of her co-leader and PH patient, Loretta Chu to share her personal story with local media in the Toronto area and PH patient, Michelle Andrews to act as the local representative in the Brampton area and accept the proclamation in person.

To date, Ruth has contacted 53 towns, cities and municipalities and received some very positive responses and was been encouraged to continue on her quest. She has been successful in many areas and has even been granted a proclamation by the City of Toronto! Ruth received many of the proclamations by email but also had several originals mailed to her. In Brampton and several other cities and towns, she received requests for a local representative of the Toronto Chapter to receive the Proclamation in person. In total, Ruth was able to gather 22 proclamations.

Ruth's amazing story shows just how much of a difference one individual can make when they have the drive and motivation to make a difference. Congratulations Ruth on a job well done! We can't wait to see where this project takes you next!

MY DREAM

By Laurence-Émilie Mainville

I've had this dream for the past 20 years. Recently, my life drastically changed. I had a choice to make: live or die! At the age of 7, I was diagnosed with a rare and serious degenerative illness called pulmonary arterial hypertension. Out of a million people, only 2 are affected by this disease. The decision I had to make was to fight for life. I know that many have lost their battle against what we call "The Robber". But I have determination and I've made the choice to fight by moving to Toronto with my mother since June 14th. My life depends on a heart and lung transplant which can be performed in Quebec. I've decided to add years to my life and, at the same time, life to my years. Had I not chosen so, I would have stayed in Quebec fighting a losing battle. Not a single day goes by without me shedding a tear



Josée Morneau, Micheline Richard and Laurence-Émilie Mainville

for all those I've left behind et all those who have lost the battle against this illness. I would like this chapter of my life to be heard and known. I want to go back home healthy very soon.

HOW TO CARE FOR YOUR CAREGIVER

By Michelle Andrews

Let me begin by informing you all that Ron and I are not the perfect couple, with the perfect care-giving solutions; and I will be the first to admit that many of the suggestions listed below I learned from doing things the wrong way.

Here are some tips I can offer:

- ◆ Be patient with yourself and your caregiver as you both come to realize that this diagnosis is not going away.
- ◆ Reset your priorities: in doing so, many of us come to know that we have to lower our standards to allow energies to go where they are most needed. I have found that having Ron reasonably rested beats a clean floor any day.
- ◆ For some of us (our household included) financial priorities will need major overhauls. Our family sold our two story townhouse to enable me to live on one level. I know of another family in the process of doing this and I am sure there are many others who have done the same. Most of us can't afford chairlifts. This also makes life easier for my caregiver.
- ◆ Inform yourself and your caregiver as much as possible about PH. In my "career" life I was an R.N. but I have no fear of feeling embarrassed by some of the questions that I pose to my nurse, our doctor or my pharmacist. I don't care if anyone thinks I'm dumb. It is just too important to know the ins and outs of PH.
- ◆ Try to do as many tasks as you can yourself, without taxing your self! Find out from your PH team what activities you as an individual should restrict and which things you can try. There are a lot of tasks that can be done sitting down!
- ◆ Put a lot of effort into scheduling appointments, social outings, shopping etc. Many of us have found that one day out then requires one day home to rest. Think of all the tasks that your caregiver must do to actually get you from A to B. I have postponed and vetoed outings that sounded to the planners like a lot of fun, but actually would create a lot of extra work for Ron. All the people that I said "Thanks but no thanks" to understood.

- ◆ Of course each of my several specialists all thinks their speciality takes precedence. I am not above calling the secretary of a specialist and rescheduling—just this week I declined an appointment with my diabetes specialist. I had the lab work faxed to my GP, so I knew my values were fine and I could put this off for another week. I just tell the secretary that I have to pace myself. (I do use that one sparingly.) Ron does need a break from all the driving—if it is not crucial, I “space” the appointment as much as possible. Also, sometimes with enough hours in between to allow for doctors “running late”, I can see 2 doctors on the same day, in the same hospital.
- ◆ Besides spacing active days with rest days, I have learned how much I can actually accomplish in a day and try diligently to plan accordingly. And I have learned to tune in to my body when I have moved to another level of ability (up or down).
- ◆ At our house, we keep lists of daily routines as reminders. On the porch door we keep a list of all the things that should be in the car for a usual day out. This way Ron doesn't have the added task of remembering everything. Sometimes we even remember to read it!
- ◆ Besides the hospital bag, we keep an emergency room bag, for Ron. Long before I had PH, my mother had a fairly complex cardiac condition and we often found ourselves in the ER in the wee hours of the morning. In the ER bag we keep -granola bars, coffee money, bottled water—depending on what is wrong with the patient, the patient may not be allowed to eat but the caregiver needs to eat—cash for when the cafeteria does open, change of socks etc., and a sweater—it gets cold in the middle of the night and they don't give him a blanket. I also add a book for each of us, a note pad, a pen and my PH doctor's emergency number.
- ◆ If you don't get the flu—there is less work. We make an effort to avoid as many flu germs as possible by hand washing, keeping masks on hand for possible encounters with coughing and sneezing people and we ask people not to stop by if they have a cold or the flu. We also ask our adult daughter and her husband and the girl who helps me for 2-4 hours a week, to get their flu shots.
- ◆ Ensure that your caregiver takes her/his medications, vitamins, exercise and rest.
- ◆ Respite! Make sure that your caregiver has some regular down time. At times when I have been ill with the flu or just on a bad stretch, I found that our local V.O.N. has someone who will visit me for a few hours a week. They are volunteers, who can't do medical care, but they can play cards with me, chat, read and hand me things I can't reach, get herself and I water and tea and of course call 911.
- ◆ Watch for signs of fatigue. When I see them, I call my son-in-law and tell him Dad needs a little extra R and R. We plan a day ASAP for the two of them doing some of his favourite things. I don't need someone with me if I am at my “PH normal”—but if my daughter can't stay with me there is a kind neighbour-friend across the street who will if I give enough notice. *All caregivers need regular respite (I know that too well—I was my Mother's 24/7 caregiver for many years.) And I do realize how difficult it is to arrange for respite—money often being a key factor. It does take a lot of imagination and often “thinking outside the box” for it to happen.
- ◆ Try to keep your house and equipment you need in an organized way, so that it can be located easily when needed. Keep detailed records of which med is due for renewal when and keep a close eye on your O² supply. (It can be so stressful when you run low at a hectic time.)

These are most of the things that work at our house—most of the time. When they work, life is just easier for everyone.

QUINLAN'S CREW FUNDRAISER 2011

By Tracey O'Brien (Quinlan's mom)

As we braved the frigid waters of Jones Lake in Moncton, NB, on our 21 seated Dragon Boat to raise money for PHA we laughed, cried and prayed. We laughed at how much pain we were in from paddling making us realize how out of shape we really were. We cried because we were so wet and cold. We prayed that we wouldn't tip our boat as we would probably all drown trying to get to Quinlan.



Quinlan O'Brien pictured with his grand-mother, Ivy

Our boat was filled with twenty-one family and friends to help us race against twenty-seven other boats for the title of champions. Quinlan who is 17 years old and has had PPH since he was 2 1/2 was the drummer on our boat. He sits on this tiny seat up front and beats the drum while we paddle to his beat. It is a good thing he has a tiny behind.

It was rainy on the race day which was in May and not real warm but we brought our tent and raincoats and good spirits to get through the day. Quinlan waddled around in his “Lifesaver” costume, the theme being Lion's Club Sick Kids and PHA Canada having been his lifesaver. Quinlan's brother, our son, Sullivan paddled with us for the first time.

It is a big job getting 21 people together to commit to practice as well as the race day but the pure exhilaration and joy these people all take with them is an incredible feeling. This was our third time in the races and everyone who has helped Quinlan's Crew started out doing it to help us fill our boat, but ended the races so caught up in the wonderful feeling of so many people coming together for a cause that now we have to promise that they can be on our boat again the next year.

We raised \$1,006.00 for PHA Canada as well as money for the Sick Kid's Fund. Oh, and we did finish 10 out of 27 boats so I guess we weren't as out of shape as we thought. We are looking forward to the 2012 races with the hopes of raising lots more money for PHA.