PHA on the Road: Connecting Patients Through Education and Networking

PHA is hitting the road again this June when *PHA on the Road: PH Patients and Families Education Forums* visits Denver, Colo. (June 1); Boston, Mass. (June 8); Durham, N.C. (June 15); and San Francisco, Calif. (June 29). PHA is excited to embark on this fifth year of free, one-day educational forums, and we are pleased to welcome our new chair of the program, Zeenat Safdar, MD, from Baylor College of Medicine.

*PHA on the Road* depends on the eagerness of both patients and caregivers to learn and our medical professionals’ desire to share their knowledge. As we continue on our monumental journey in 2013, in this issue of *Pathlight* we reflect on the education, networking, and fun that these forums offer.

Many patients delight at the opportunity *PHA on the Road* offers for networking. For some, these forums are the only time they meet other patients. When describing a forum she attended in 2012, PH patient Melanie Kozak explains why she enjoyed the experience, “I love *PHA on the Road*, as it brings together PH patients and reminds us we are not alone.”

Lynn Bastian, a PH patient who attended *PHA on the Road* with her daughter, says that the most important thing she received from the day was a sense of gratitude: “Sometimes I feel sorry for myself, I admit it. It is a good reminder to be grateful for all the medications and options that were not available 20 years ago.”

In addition to the various opportunities to network throughout the day, the forum is also full of education on living with PH for patients, caregivers and family members. Past forums have included sessions on diagnosis, eating better, exercise and emergency situations. Because our medical doctors understand that there are so many...
As I think about the spring season, I am reminded of all that it symbolizes — new hope, new beginnings, revitalization and reinvigoration. And as I think about the PHA community, I am struck by how those phrases aptly describe what we are doing and the new challenges that we are taking on in 2013.

This year marks a turning point for PHA and our funding structure. In the winter Pathlight, we shared information about our innovative new fundraising venture — establishing chapters in the Midwest, New York City and San Francisco. As PHA’s president Rino Aldrighetti shared in his blog entry about these new chapters: “PHA has always known that it is no less complex or expensive to solve the problems of a disease state like PH, with our 20,000 to 30,000 diagnosed patients in the U.S., than it is to solve the problems of a disease like diabetes (24,000,000 diagnosed in the U.S.) or arthritis (73,000,000). In the face of that reality, we are building a system that will allow us the funding to do what we need to do.” We have even more exciting details to share this spring about our new chapters, and you can read more on page 14 in this issue of Pathlight. To read Rino’s blog about our chapters, visit www.PHAssociation.org/RinoBlog/ThreeChapters.

To help us on this financial journey, PHA is reinvigorating our Development Department, and we are pleased to welcome Damon Bradley, PHA’s new Director of Development. He is responsible for PHA’s national fundraising with an emphasis on relationship-based philanthropy.

Damon has added some subtle but refreshing changes to this issue, including a contest for children to design the new look of PHA’s bookmarks. See page 39 for details. We are excited to incorporate Damon’s ideas into PHA’s future. If you should have any questions for Damon or wish to learn more about PHA’s giving programs, you can reach him at DamonB@PHAssociation.org or 301-565-3004 x767.

As we embark on a new financial path for the organization, the PHA community remains steadfast in all of its other programs and in its support of our common goal — to provide hope for all those who have been touched by this illness. Patients like Emerald and Migdalia are moving thousands of miles away from their home countries, adding strength to the voice of our global community. Doctors like Lynn Brown, MD, are spearheading awareness of PH in the medical community through the Sometimes it’s PH campaign. Caregivers like Susan Kennedy are taking a stand to raise money through PHA special events. You can read more about their stories of hope and strength on pages 5, 17 and 27, respectively.

This spring we look ahead with renewed hope, excitement and invigoration as we step forward into PHA’s future. Enjoy this issue of Pathlight. I hope you find yourself and your experiences reflected in these pages. Thank you for standing with us as we change the future of this disease together. •

Vallerie McLaughlin, MD
Couple's Book Explores Pressures of Chronic Illness on Marriage

Editor's note: Kathy Levitt, a PH patient, shares a little of her PH journey and talks about the e-book she and her husband wrote together.

I am a PH patient, and my husband Brian and I decided to write an electronic book (e-book) last year about living with chronic illness as a married couple. In Sickness and Not Health deals with how chronic illness has altered our lives and how we deal with it on a daily basis.

I have been sick with pulmonary hypertension since 1993. I started feeling short of breath, very tired and dizzy in college, and my symptoms got progressively worse and worse. My heart would beat out of my chest, and I often would feel like I was going to pass out. In fact, I did pass out a few times. I went to several doctors, including cardiologists, and they all told me it was panic disorder. After suffering for three years with all these symptoms, fear and confusion, I finally ended up in the local emergency room and was quickly sent up to the ICU. By this point, my health had declined very rapidly and I had to be watched closely until they figured out what exactly was going on with me. I was diagnosed a week later with idiopathic pulmonary arterial hypertension. There was no known cause, they said; it just happened. I was given no more than six months to live. That was in 1997.

At that time, I had been married only two months, and I had known my husband Brian for only four months. As you can see, we had a quick romance. Over the last 16 years together, this illness has taken us both on a path neither of us expected.

There have been many trials and frightening moments, but we have managed to get through it all together. Our life as a young couple has not followed the traditional path of two healthy people, but our experiences are not unusual for many couples living with chronic illness. The illness affects all aspects of a couple's life together: finances, intimacy, childrearing, working and more.

Reading postings on Facebook and the PHA message boards over the years, Brian and I would see how an illness can have such adverse affects on a marriage. Since he and I have been together for so long, and I have been sick for the entire marriage, we thought that our experiences may help others. We take a different topic for each chapter and tell our side of things. Living with PH and dealing with the symptoms, medications, doctors, side effects, fear, anxieties and more is often discussed as they pertain to each of us; we wanted to specifically address illness within the confines of a marriage or partnership.

Our e-book is relatively short and easy to read, but it is full of personal stories and ways to cope with chronic illness (specifically PH) in the marriage realm. We share about how we first met and how we quickly began adjusting our lives when I was diagnosed just two months after we exchanged vows. We discuss how we have coped with my hospital stays, adopting our daughter and dealing with my body's physical changes. The response so far has been positive, and we are excited that we have been able to share a little something about our experiences.

You can buy the book at www.amazon.com by typing in the title or either one of our names. You can also find a link to buy the book on PHA’s website at www.PHAssociation.org/Store/RelatedProducts

By Kathy Levitt, PH Patient

Excerpt from In Sickness and Not Health

It seems I am always driving Kathy from one doctor to another. It gets tiring and repetitive, but it is necessary and part of our lifestyle. As a caregiver, you also assume the role of advocate. This means, you take an active interest in your spouse's treatment and you speak for them when they cannot speak for themselves. When Kathy goes to the doctor, I leave it up to her whether she wants me in the exam room or not; sometimes she does and sometimes she asks me to wait in the lobby. Sometimes I have questions or concerns for the doctor, so I will go in to speak with him myself. It is okay, as your spouse's caregiver, to talk to the doctor directly. You are, after all, totally involved and have a vested interest in what is going on. Also, a caregiver can answer questions that perhaps the patient cannot. For example, Kathy has sleep apnea. Therefore, her doctor might ask me about her behavior in her sleep. A caregiver needs to be more than a passing observer. Your sick spouse needs the support and needs to know you are there in all aspects of their life. It is not going to be easy all the time, but it is better to be fully aware than to be in the dark.
PHENOMENAL LIVES

For Good and Ill, I Have Learned What I Am Because of PH

The Latin proverb says, “Sickness shows us what we are.” As in the proverb, pulmonary hypertension has taught me exactly who and what I am. My life has drastically changed since the onset of PH symptoms seven years ago. I had graduated from college and started my career, and then my losses began. I lost financial stability, my friends, my home, my car and my sense of control and independence. My diagnosis of PH, however, has many positive outcomes as well as negative.

I’ve been on this roller coaster ride of loops and upward and downward slopes. Before my diagnosis, I thought I knew what and who I was: a licensed social worker, a daughter, a sister, an aunt and a friend. I exercised regularly with a trainer and ate healthy food. My plan in life was to open a private practice and focus on psychotherapy for adolescents with emotional and learning disabilities.

After my diagnosis, I had to overcome many challenges and obstacles. I slept on a futon in my mother’s living room. We moved to a bigger apartment, but then I shared a bedroom with my little sister and, later on, with my sister and nephew. My income first went from a good salary to less than half of what it had been, and then I had no income for months. But I still had to pay medical bills, an electric bill, car insurance and other costs. I was depressed, angry and felt like I was nothing. What I didn’t expect was that this PH journey would in some ways be good for me.

I learned what I am from PH. I am strong; I have the strength I need to get up every day and take medication, to deal with the not-so-good PH days and to be okay with having PH. I have the strength I gained from rebuilding my life, a different life. No more sleeping on a futon or sharing a bedroom. I moved to my own apartment, and I sleep in my own room. I receive Social Security Disability Insurance with Medicare and supplemental health insurance. I also teach as an adjunct instructor at my local community college. I may not be able to climb Mount Everest, but I have enough strength to achieve a personal goal of hiking to Stone Church in Dover, N.Y. This strength I have allows me to overcome any obstacle that PH puts in my path.

My faith deepened. I learned to rely more on God for my strength and guidance. His strength and power gives me strength and provides hope when I’m weak, tired, depressed and angry. My priorities in life have changed from self-focused to other-focused. I share my free time in service to others such as volunteering in my community, being a support group leader for PH patients, etc.

I also realized that I have more support than I thought, and I have formed stronger bonds with family and friends. My mom, sisters, nieces and nephews have been there for me through the hospital visits and doctors’ appointments, but also through the fun days of family outings. My nephews and nieces carry those heavy oxygen tanks for me and attend my PH support group meetings with me, and we spend quality time together.

Staying in contact with close friends is important to me no matter how far away those friends live; Facebook and texting help. I created new friendships, “phriendships.” I meet and talk to people with PH from all over the world through PHA conferences, support group meetings, Facebook and even focus groups. My “phriends” and I go through similar experiences, so we empathize with one another without having to explain PH.

A chronic illness changed my life, negatively and positively. What about you? What are some positive changes PH has brought to your life? Visit the Generation Hope blog at www.PHAGenerationHope.blogspot.com and share with us.

By Kiara Tatum, LMSW, PHA Support Group Leader, Generation Hope Advisory Board member, Generation Hope Blog Co-Coordinator and PH Patient

PH asked the PH community on Facebook what positive things have happened because of their PH. Some of their positives include:

- A greater appreciation for life
- Different priorities
- Stronger friendships and family ties
- Awareness of their inner strength
- Compassion for others

The following quote from a community member best summarizes the responses: "PH puts priorities in place! Non-threatening things that cause people so much stress seem foolish and shallow. You learn to live life a mile deep and an inch wide. The highs are higher and the lows are lower. You experience life at a much higher level of awareness and learn what walking in faith really means. The PHriends you meet quickly become closer than your friends that will never completely 'get it.' You become part of an exclusive PHamily and support one another, far and near, sharing the highs and offering encouragement during the lows."
Patients Move to New Countries for a Chance at Better Care

Accepting that you are vulnerable and that you suffer from a chronic disease is really a difficult situation. Psychologically, you enter states of panic which only others who have suffered the same can understand. And if you add to this that you must be connected to a machine so that you can live and that this medicine doesn’t exist in your country and that the cost is more than you can pay, well that really complicates things.

— Migdalia Denis, PH Patient

Meet Emerald. Emerald was diagnosed with PH in 2007; she was in and out of high school until finally dropping out after fainting in the halls. Two years after her diagnosis, she landed in the ICU and underwent transplant. After her transplant, Emerald became involved with the PH community in her country, China, where many PH patients were living with a very poor quality of life.

Emerald moved to Canada in 2012 to finish high school and receive better transplant follow-up care. She spent months looking for a clinic or hospital to help her. Eventually, she found care, and through her doctor, she found a post-transplant PH community in Canada and learned what life could be like for a transplant patient.

Now meet Migdalia. When she found out she had PH in 2000, her organs were in total collapse and her life was instantly changed in every way. She says she went from being an independent and successful executive and mother with thousands of plans for the future to a sick person dependent on a machine round the clock. According to her doctors, she had no apparent future.

To find treatments not available in her own country of Venezuela, she flew to the United States to meet with a PH specialist in Pittsburgh. She did not have an appointment or any clear plans. Eventually, she was seen and put on epoprostenol. Back in Venezuela, she started the Venezuelan PH Foundation to help others without access to treatment and with few resources to travel. But without easy access to her medication, she had to make the difficult decision to abandon her country, friends and family to move to the U.S. where she had some friends and a job offer.

Like Emerald, Migdalia spent months searching and eventually found doctors and nurses who would help her fight her PH and find ways to pay for her treatments. Also like Emerald, the changes to her life just kept coming. On top of dealing with her PH, Migdalia had to deal with living in a new culture, being away from everything she knew, learning a new language and navigating an unknown medical system.

Whether in Venezuela, the U.S. or elsewhere, the uncertainty of being able to live can be compounded by the uncertainty of being able to obtain medicine. If people have the means to seek life-saving treatment elsewhere, they must then choose between staying with everything and everybody they know or leaving and getting treatment. And still for many, this kind of travel is not even an option.

Now post-transplant in Canada, Emerald enjoys skiing and SCUBA diving. She still stays in touch with the Chinese PH community, which is currently focused on helping patients get more information and access to treatment. And Migdalia has been living in Miami for 13 years now. She lives with her children and other loved ones, is on a treatment that works well for her and counts these years as the best of her life. Migdalia has founded the Latin PH Society with the goal of getting access to medicines and support in every country in Latin America.

Whether you leave your country or not, we have a growing international PH community that supports each other no matter where in the world you are located. Together our global community can support those who are isolated, create awareness, promote research and influence policies worldwide to improve treatment for everyone. As Migdalia says, “The integration of all is fundamental for a common fight; since this is a disease with low prevalence, we can only have the strength to fight it as a single, solid block.”

By Julia Friederich, PHA International Program Associate, with Migdalia Denis of la Sociedad Latina de Hipertensión Pulmonar and Emerald of iSEEK China

To read Migdalia’s story in Spanish, visit www.PHAssociation.org/PHInternational/Faces/MigdaliaDenis. For more information on PH associations around the world, contact International@PHAssociation.org.
People living with PH and their caregivers face daily challenges that put them at increased risk of depression. It’s important to know the warning signs and learn about the resources available should you or anyone in your family need help now or at any point down the road. Research suggests that the earlier depression is treated, the greater the likelihood of a positive outcome.

**Warning Signs of Depression**

As you watch for symptoms of depression, you are looking for changes in behavior that present themselves over an extended period of time.

- **Feelings of sadness, numbness or emptiness nearly every day.** Depression feels like a dark cloud that can make everything seem hopeless. Not everyone expresses these feelings in words. Pay attention to non-verbal cues, such as crying or shutting off from loved ones.

- **Markedly diminished pleasure in almost all activities.** Be particularly aware of a loss of interest in things you or your loved one used to enjoy.

- **Feelings of worthlessness or excessive guilt nearly every day.** These feelings are often inappropriate to the situation. Someone who is depressed might feel guilty for things they have no control over, including getting ill in the first place.

- **Diminished ability to concentrate or make decisions.** Depression can make it hard to think clearly or pay attention to conversations. Simple choices can feel overwhelming.

- **A feeling of being completely alone.** People suffering from depression frequently isolate themselves and pull away from loved ones.

- **An inability to relax.** More than half of the people diagnosed with depression also have anxiety. Someone who is depressed may find it difficult to kick back and stop worrying, even for short periods of time.

- **Thoughts of self-harm and suicide.** If you or a loved one is thinking about self-harm or suicide, visit your local emergency room or call the National Suicide Prevention Hotline at 1-800-273-TALK.

**How to Get Help**

Depression, though sometimes difficult to identify and understand, is an illness like any other, and symptoms will not go away on their own without attention and intervention.

**Seek professional treatment.** For stomach pain we can’t ignore, we go to the doctor. When depression begins to interfere with an individual’s everyday functioning, that’s a good indicator that it’s time to seek professional help. The goal of treatment is to help an individual reclaim a sense of control and rediscover pleasure and fulfillment in daily activities through therapy, lifestyle changes and sometimes medicine. Ask your PH doctor, primary care physician, support group members and insurance company for recommendations for good therapists in your area or visit [http://locator.apa.org](http://locator.apa.org). Good therapists can be psychologists, social workers or psychiatrists.

**Be supported and supportive.** Research shows that one of the most important factors in coping is maintaining caring and supportive relationships. Join a support group, make plans with your friends or connect with other PH patients or caregivers through PHA’s email and telephone groups. Similarly, it’s important to be supportive of yourself. Set realistic goals and forgive yourself when you can’t accomplish everything on your list. Make time for activities that you love. Reflect on the coping skills that help you most, and dedicate time to those coping techniques.

**Have patience.** Keep in mind that it takes time to see the benefits of therapy, medication and lifestyle changes. Don’t give up after a few weeks just because you haven’t seen dramatic changes. Keep putting effort into your recovery. Your hard work will eventually pay off.

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This article has been adapted from “Coping with Depression” at [www.PHAssociation.org/Patients/CopingWithPH/Depression](http://www.PHAssociation.org/Patients/CopingWithPH/Depression) and “Recognizing Depression in Yourself or Your Loved One” at [www.PHAssociation.org/Caregivers/Depression](http://www.PHAssociation.org/Caregivers/Depression). View coping resources for both patients and caregivers on the next page.
Getting Help: Resources for Caregivers

In a PHA survey of PH caregivers, 42 percent reported that they sometimes felt sad or depressed. To be an effective caregiver, it’s important to take care of yourself with the same intention and commitment with which you care for the others in your life. If you suspect that you may be suffering from depression, anxiety or chronic stress, it’s time to talk to someone outside your family for support.

- Find more information on identifying and seeking treatment for depression at: www.PHAssociation.org/Caregivers/Depression
- Join our Caregivers Telephone Support Group and Email Group: www.PHAssociation.org/Caregivers/Support
- Connect with a caregiver PH Email Mentor for advice and support: www.PHAssociation.org/Mentors
- Visit the Family Caregiver Alliance: www.caregiver.org
- Visit the Caregiver’s Survival Network: www.caregiversurvivalnetwork.com
- Read the books:
  » When Someone You Love Has a Chronic Illness: Hope and Help for Those Providing Support, T.M. Greenberg (Cedar Fort, Inc., 2012)
  » How to be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers, Toni Bernhard (Wisdom Publications, 2010)

Getting Help: Resources for PH Patients

Depression can be difficult to identify and understand. It is an illness like any other, and it needs to be treated in order to alleviate the symptoms. In the words of Teresa, a PH patient who sought treatment for her depression, “There are enough struggles when you have PH without struggling with your emotions. You don’t have to live with depression.”

- Talk to a long-term survivor on PHA’s Patient-to-Patient Support Line: 800-748-7274
- Find more information on identifying and seeking treatment: www.PHAssociation.org/Patients/CopingWithPH/Depression
- Connect with others at local and virtual support groups for patients: www.PHAssociation.org/Community
- Join our monthly Patient Telephone Support Group: www.PHAssociation.org/Patients/TelephoneSupport
- Connect with a patient PH Email Mentor for advice and support: www.PHAssociation.org/Mentors
- Read How to be Sick: A Buddhist-Inspired Guide for the Chronically Ill and Their Caregivers, Toni Bernhard (Wisdom Publications, 2010)
- Watch Keeping the PH Blues Away, a recorded webinar on PHA Classroom: www.PHAssociation.org/Classroom/Recording/LivingWithPH/KeepingThePHBluesAway

Contact a Patient or Caregiver PH Email Mentor Today!

When I was diagnosed with pulmonary hypertension in May 2003, my doctor told me there was no cure, very limited treatments and that PH was a fatal disease. It wasn’t until I saw a doctor who specializes in treating PH and met other patients with PH that I realized just how wrong that first doctor was. I have learned more about PH from the other patients and have been encouraged and inspired by others’ stories. The PH Email Mentor program is an incredible way for patients to share with each other and for patients to ask the questions for which they need answers.

— Doug Taylor, PH Patient and PH Email Mentor

Visit www.PHAssociation.org/Mentors to connect with Doug or any of our email mentors.
What is the difference between the terms "PH" and "PAH"?

Pulmonary hypertension (PH) and pulmonary arterial hypertension (PAH) are terms commonly used interchangeably. However, there are key differences between these two terms.

Pulmonary hypertension is often referred to as the “other high blood pressure” or “high blood pressure in the lung circulation.” Although this condition was described as early as 1891, not much was known until the early 1950s when right heart catheterization was first introduced, enabling the actual measurement of pressures in the right side of the heart and lung circulation.

It remained a mysterious condition for many decades. The reasons and mechanisms for development of this condition remained obscure. As a result, this condition was poorly classified as primary and secondary PH in the past. Primary PH referred to high blood pressure in lung circulation occurring for unclear or unknown reasons. Secondary PH referred to all other conditions that would result in PH.

Considerable strides have been made in the understanding of this condition over the last two decades. These newer concepts resulted in an improved classification of PH in 2003, which was based upon pathogenesis — the mechanism of development of PH. PH was further subdivided into five subgroups. However, it helps to have an understanding of some of the basic concepts pertaining to our blood circulation before trying to understand these key differences in classification.

The heart is a pump. The right side consists of the right atrium and ventricle and the left has the left atrium and ventricle. Ventricles are the bigger chambers that pump the blood into the vessels called arteries that carry blood to the various organs. Veins are blood vessels that help return blood to the heart from the organs. The cardiac cycle consists of the following steps:

1. The left ventricle pumps oxygen-rich blood to the various organs of the body (via arteries), such as the brain, kidneys, liver, etc.
2. The arteries branch further to many smaller branches called arterioles and capillaries, which supply tissues with oxygenated blood.
3. Next, the oxygen-poor blood is returned to the right side of the heart via blood vessels (veins).
4. The right ventricle pumps this blood into the lungs via blood vessels called pulmonary arteries that branch into small pulmonary arterioles and capillaries.
5. In the lungs, the oxygen in the air we breathe crosses over to the capillaries (a process called diffusion).
6. New oxygen-enriched blood returns to the left side of the heart through blood vessels called pulmonary veins, and the cycle is repeated.

The World Health Organization (WHO) classification introduced during the Venice convention in 2003 (and subsequently modified in Dana Point in 2008) established five forms of PH based on the mechanism of development of the disease as follows:

- **WHO Group I:** Progressive narrowing of the small blood vessels in the lungs may hinder smooth blood flow. The right side of the heart, therefore, may need to work harder to propel and squeeze the blood forward through the lungs. Due to thickening of these blood vessels, oxygen transfer from lungs to the blood vessels may not be efficient. This mechanism is referred to as pulmonary arterial hypertension or PAH.
- **WHO Group II:** Problems related to the left side of the heart could result in a “traffic jam” phenomenon (back pressure), which may be reflected as high blood pressure in the lung circulation. This type of PH is also referred to as pulmonary venous hypertension.
- **WHO Group III:** High blood pressure may ensue in lung circulation due to chronic or longstanding lung diseases such as emphysema, pulmonary fibrosis and sleep apnea, and this type is referred to sometimes by doctors as cor pulmonale.
- **WHO Group IV:** In some instances, small clots may clog up the small and medium-size branches of the pulmonary arteries over a prolonged period of time resulting in PH. This type is referred to as chronic thrombo-embolic pulmonary hypertension (CTEPH).
- **WHO Group V:** Consists of a miscellaneous combination of conditions which the mechanisms for PH are still poorly understood.

“PH” therefore is a broader term that encompasses the state of high blood pressure in the lung circulation.
The term “PAH” refers to a specific group of conditions (WHO Group I) that results in high blood pressure in the lung circulation due to progressive narrowing of the blood vessels in the lungs as mentioned in the diagram on the right. In other words, PAH is a specific subtype of PH. The entity primary pulmonary hypertension (PPH), therefore, was placed under PAH in Group I and is now referred to as idiopathic pulmonary arterial hypertension (IPAH).

PAH is the form of this illness that is a serious condition with a poor prognosis if undiagnosed or untreated. The modern therapies and the significant strides in improved outcomes and survival have been associated with treatment of PAH. I hope that this synopsis clarifies the differences between PH and PAH.

**Answer provided by Vijay P. Balasubramanian, MD, FCCP, Medical Director, Pulmonary Hypertension Program, Associate Professor of Medicine, Division of Pulmonary & Critical Care, UCSF Fresno**

**Abbreviations**

PoPH — Porto-pulmonary hypertension
APAH — Associated pulmonary arterial hypertension
CTD — Connective tissue diseases (such as scleroderma, lupus, etc.)
New Study Explores Pathology of PAH

Editor’s Note: In the following article, Brian Graham, MD, of the University of Colorado Denver, shares the research findings he and his colleagues originally published in the research article “Modern Age Pathology of Pulmonary Arterial Hypertension.”

Narrowing and vasoconstriction of the arteries in the lung is believed to be the cause of increased resistance to blood flow through the lungs, which in turn results in increased pulmonary artery pressures and subsequent failure of the right heart. Arteries have three layers (ordered from inside to outside): intima (composed of endothelial cells), media (composed of muscle cells), and adventitia (composed of fibroblasts, immune cells, and other types of cells). Past studies reported increased thickness of all three of these blood vessel layers in patients with pulmonary arterial hypertension (PAH), but the studies were limited in many respects. Possible problems with these prior studies include analysis of autopsy specimens (which are likely degraded and altered after death), sampling which was neither random nor systematic and a lack of quantification. Furthermore, there have been no large PAH lung tissue studies since the introduction of the main classes of drugs used to treat PAH — i.e., phosphodiesterase type-5 inhibitors, endothelin receptor antagonists and prostacyclin analogues.

We performed a study systematically analyzing and comparing the blood vessels and other components of the lung in patients with PAH to lung tissue from patients without PAH. Lung tissue was collected from 62 patients with PAH who required lung transplantation. All patients were on PAH-specific treatments, and most patients were on all three classes of drugs prior to transplantation.

The tissue was collected by the Pulmonary Hypertension Breakthrough Initiative (PHBI), a consortium of 13 university-affiliated medical institutions, which is supported by the Cardiovascular Medical Research and Education Fund (CMREF). CMREF was created through the phentermine/fenfluramine/dexfenfluramine (i.e., including Phen-fen) class action lawsuit. The lung tissue was systematically sampled at the time of collection. Lung tissue was also obtained from 28 unsuccessful lung donors (lungs that were harvested with the intent of transplanting but did not end up being used). Unexpectedly, six of the control lungs had thickening of the blood vessel media layer and were excluded from further analysis.

Comparing the 62 PAH to the 22 normal control samples, the PAH samples had thicker intima and media layers. In contrast to prior reports, however, the media in PAH lungs was only slightly thicker than the media in control lungs (only 11 percent of PAH lungs had thicker media). However, the intima in PAH lungs was significantly thicker: 76 percent of PAH specimens had thicker intima compared to control lungs. The thickness of the intima and media correlated with the severity of the pulmonary hypertension as measured by pressure and pulmonary vascular resistance on right heart catheterization.

There was no correlation between the number of plexiform lesions (tortuous collections of endothelial cells) and either intima or media thickness, but female patients with PAH had almost three times more plexiform lesions than male patients with PAH. Half of the patients with PAH had small blood clots in the lungs; this percentage was decreased in patients taking anticoagulation therapies like warfarin. There was also a significant amount of inflammation in the adventitia in patients with PAH. The amount of inflammation correlated with increased thickness of the pulmonary vessels and severity of the disease as measured by right heart catheterization.

Limitations of this study include the use of systematic but not random sampling and the analysis of lung tissue from patients with end-stage disease requiring lung transplantation, which may not apply to patients with more mild disease.

What do these results mean? Similar to prior studies, we found significant disease in the blood vessels in the lung tissue from these patients with end-stage disease. However, we found most of the disease was in the intima layer, not the media layer as previously reported, and there was a significant component of inflammation in the adventitia layer which had also not previously been reported. These findings help the research community by focusing future PAH treatments on the specific parts of the vessel which are affected — i.e., potentially suppressing growth of the intima and inflammation in the adventitia. We also found smaller pulmonary blood clots in patients treated with anticoagulation, adding to the evidence that anticoagulation is of benefit in patients with PAH.

Research Article:

www.PHAssociation.org
Dr. Krasuski Specializes in Treating PH and Congenital Heart Disease

Richard Krasuski, MD, FACC, FAHA, is committed to and motivated by the complexities and challenges of treating patients who have PH in association with other diseases. “PH patients with associated conditions can be so complicated that not every guideline applies to every patient,” he says. Instead of considering the treatment of PH with an associated disease an obstacle, Dr. Krasuski sees it as an opportunity. “That’s what really drives me and what makes me excited about going to work every day: I’m not practicing from a cookbook,” he says. “Each person provides a unique set of challenges that we then have to approach and give different potential options.”

Dr. Krasuski currently treats patients who have PH and adult congenital heart disease at the Cleveland Clinic, but he began his work with PH patients in 1998 as a fellow at Duke Medical Center where he performed hemodynamic assessments for patients in the PH clinic. He describes this time as an “eye-opening experience” because in the ‘90s little was known about PH. Dr. Krasuski grew excited about the possibilities for advancement and growth in the field. He says, “Throughout my career what really guided me to different areas in cardiovascular medicine was just how challenging the patients were and what a difference we could make.”

Education is part of his prescription for every patient. That’s one of the reasons Dr. Krasuski recently participated in creating the video “PH & Congenital Heart Disease” for PHA’s associated disease video series. “Anytime I have an opportunity to become involved with something that’s going to potentially touch the lives of others, I consider that to be extremely worthy of my time,” says Dr. Krasuski. He sees these videos as an educational tool for the entire PH community, including physicians, patients and caregivers.

When patients understand more about their disease or diseases, Dr. Krasuski says, they can take greater control of their lives. He believes it is the physician’s responsibility to ensure that patients are truly educated on what is going on in their bodies. He suggests that physicians and patients must work together to create a “therapeutic alliance” that will ultimately empower patients in their own fight against PH.

Patients receiving a second diagnosis can feel extremely isolated and ask, “Why me?” Dr. Krasuski says he hopes the PHA video series will help fight that feeling by affirming to patients that they are not alone.

Patients who have one chronic illness “know their bodies pretty well, but they also have a tendency to attribute all their problems to [that disease],” says Dr. Krasuski. Sometimes something else may be going on in their bodies. While a second diagnosis can be scary, Dr. Krasuski notes that second diagnoses not only clarify the cause of patients’ noted decrease in health, they provide more opportunities for different therapies that can help enhance lives.

Above all, Dr. Krasuski has always been motivated by his patients. He became involved with PHA early in his career because he felt that he and PHA shared many of the same values, including patient education. “PHA is a wonderful organization because it originated from the patient’s perspective. Patients are at the forefront of the organization. At the end of the day, the reason we’re all doing this is for the improvement of the patient outcome. I think PHA really knows where its heart is, so to speak,” says Dr. Krasuski.

Dr. Krasuski is the Director of Adult Congenital Heart Disease Services at the Cleveland Clinic where he collaborates on a multidisciplinary program in pulmonary hypertension. Among his PHA activities, he is a member of PHA’s PH Clinicians and Researchers professional network and serves on the Editorial Board for PHA’s medical journal, Advances in Pulmonary Hypertension.

By Briana Rivas-Morello
PHA Medical Outreach Program Associate

The “PH & Congenital Heart Disease” video and all other associated disease videos — including PH & Scleroderma, PH & Lupus and PH & HIV — can be viewed at www.PHAssociation.org/PHandAssociatedDiseasesPlaylist. For more information on dealing with PH and other associated diseases, check out www.PHAssociation.org/PHPlus.
Registration is now open for the 2013 PH Professional Network Symposium, The Power of Teamwork: 10 Years of Professional Collaboration in PAH. Healthcare professionals — don’t miss your chance to register for this valuable educational and networking program! Register online at www.PHAssociation.org/PHPN/Symposium.

This Symposium will feature an extraordinary line-up of speakers and topics highlighting the latest advances and research in pulmonary hypertension. Symposium faculty will include a range of healthcare professionals, such as nurses, pharmacists, respiratory therapists, physician assistants, nurse practitioners and physicians.

The 2013 Symposium will also provide an opportunity to:

- **Earn CEUs**: Close to 30 sessions will be presented on topics that highlight the latest advances and research in pulmonary hypertension with an extraordinary line-up of speakers. Sessions will be accredited for nurses, respiratory therapists, pharmacists, physician assistants and social workers.

- **Network with colleagues**: Meet face-to-face with fellow PH medical professionals for the opportunity to share stories, experiences and ideas. Contacts made at Symposium will give you a vast array of resources to tap into!

- **Advocate for PH on Capitol Hill**: Make the most of your trip to the D.C. area for Symposium by arriving in time for Advocacy Day! Take this unique opportunity to visit Capitol Hill and educate your Members of Congress about the needs of PH patients and the medical professionals who treat them.

- **Share updates on research**: Highlight new and interesting research being conducted at your institution or learn about research being conducted by colleagues in the 2013 PH Professional Network Symposium Poster Hall.

For more information, contact 301-565-3004 x761, email Symposium@PHAssociation.org or visit www.PHAssociation.org/PHPN/Symposium.
Put a Little Spring in Your Step!
Discover the Benefits of Exercise This Season

It’s that time of year again: spring. What a motivating time to start or expand your current exercise regimen! There is no better time to get moving. The days are brighter and longer, the weather is warmer and the humidity has not yet arrived.

The greatest thing about exercise is that it is versatile. Every patient with pulmonary hypertension (PH) should be able to participate in some form of exercise. Exercise does not necessarily mean you are training for the next marathon, nor does it mean that you are competing against anyone. It does mean that you are participating in activities to support a healthy lifestyle.

And remember, while PH experts agree that exercise is usually safe for PH patients, it is important to discuss your exercise regimen with your PH provider. You should discuss your plans before you begin a new activity and update your provider on your progress as time goes on. If you start to experience lightheadedness, chest pain or severe shortness of breath, stop exercising.

Read on to find some exercise benefits and tips to help you get moving this spring.

Exercise fits your social calendar

Exercise can become a social activity if you get out there and find a partner to join you! Whether or not your buddy has PH, having someone else along can provide a nice outlet to discuss your feelings and struggles or just to chit chat about popular TV shows and exchange healthy eating tips. You can be each other’s cheerleader, often a helpful way to keep yourself on track. A great way to meet others is by participating in a community exercise program or an organized program through your local YMCA or gym.

And if you aren’t a social butterfly, that’s fine, too. If you would feel more comfortable starting an exercise regimen at home, consider watching fitness programs on TV or purchasing DVDs. You can also try searching the Internet for ideas; YouTube has some nice videos that you might enjoy.

Let’s get happy! Movement creates a positive outlook

Regular exercise causes the brain to release endorphins, which leads to a “natural high.” This high can result in better moods and lower rates of depression.

Another way to continue your positive attitude is to set small, manageable goals for yourself. By having smaller goals, you should be able to achieve them more often. It will feel so rewarding to reach each one, making you even more motivated to form a new goal.

When should you exercise? Anytime!

There is no “right” time to get your body moving. Find the best time for you to fit exercise into your life, and you will be more likely to stick to your plan.

What kind of activity should you choose?

Exercise comes in lots of different forms, and here are just a few kinds to consider:

- **Yoga:** There are many types of yoga. Some types can be done while sitting in a chair. Some types are good for people with chronic lung conditions or with shortness of breath. Check with your healthcare provider and local yoga instructor for the type that is the best fit for you.

- **Walking:** Walking is great because you can do it almost anywhere! You can walk laps at the mall or a local track at a school. You can also enjoy nature while walking through a park or on a trail.

- **Gardening:** Gardening is a very mild form of exercise that can be relaxing and fun. You could read a book or attend a class on gardening to enhance your own skills. It might be fun to ask your children, grandchildren or others to join you.

Sounds great! But how do you stay on track?

Try keeping a log of your exercise, including what you did, for how long, and how you felt during and after your activity. You might want to include your blood pressure, heart rate and blood oxygen level. This information can be very helpful for your healthcare provider to assess how you are tolerating the exercise. By jotting down this information, you can also look back to see how far you have come and any improvements made, both emotionally and physically.

Enjoy your new active lifestyle and remember to stop and smell the roses!

By Amy Kimber, APNP, PH Nurse Practitioner, Division of Pulmonary & Critical Care Medicine, Froedtert Hospital & Medical College of Wisconsin, Milwaukee, Wis.
PHA’s New Chapter Offices Are Up and Running in Three Locations

By now you’ve probably heard about the opening of our new PHA fundraising chapters in three locations across the country: the New York Tri-State Area, the Midwest and the San Francisco Bay Area. You may also know that their primary mission is to conduct cause-related special events such as walks, golf tournaments, galas and so forth. We are proud to be able to report to you that all three are fully staffed, up and running, and doing a marvelous job.

Following an intensive training and planning program, all nine new staff members are giving their all for you, our PHA family. They are meeting, planning, coordinating, scheduling and recruiting volunteers for nearly 50 nationally branded special events across the country with the charter to raise millions of dollars for the struggle against PH.

To have achieved this rapidly — having never had this sort of structure in place at PHA before — has been nothing short of a miracle. There’s lots of credit to go around. First to the home team staff at PHA — change this sweeping can be quite daunting, and our home office in Silver Spring, Md., has gone above and beyond to support the efforts of our new staff in the field. Frequently, the home team staff has been met with a request for something that we needed in the field less than 24 hours later and, time and time again, our home team did it. It’s impressive.

Just to name one of the many things our home team is doing, we’d like to send a huge thank you to Diane Greenhalgh, PHA’s Director of Web Services, and her team for building the amazing chapter websites at warp speed. Be sure to check them out at the following addresses: New York Tri-State Area (www.NY-PHA.org), San Francisco (www.SF-PHA.org) and Midwest (www.Midwest-PHA.org).

Next, we’d like to acknowledge the hard work of the field staff. We got the best of the best when we hired Bette Perez (Executive Director, San Francisco), Gina Parziale (Executive Director, New York City), and Lisa Beth Gansberg (Executive Director, Midwest). In doing so, we went a long way toward guaranteeing our success in this mission. Their leadership in any number of areas from building their own staff, rapidly integrating into their communities and helping to develop our national brand has been inspirational to watch.

Finally, we want to salute PHA President Rino Aldrighetti’s leadership and the PHA Board of Trustees’ vision, trust and confidence in directing these important steps that we are now taking. Clearly, there is risk in any new enterprise, but the greater risk would have been to take no steps in this direction. Their courage and leadership in this effort has been remarkable.

Until we cure this terrible disease, we will continue fighting tirelessly for our cause. So, what can you do to help? If you, family members or friends live anywhere near these communities, give our chapter staff members a call and volunteer. If you can think of anyone else we might be able to contact in these communities for help or donations, let us know. These donations can be large or small, and our contacts can be corporate or individual. Your help and knowledge is invaluable to our efforts!

Finally, just call them to say hello and introduce yourself. Welcome our new chapter staff members to the PHA community. All of their contact information is below.

By Carl Hicks, PHA Vice President, Field Operations

### New York Tri-State Area
- **Gina Parziale**
  - Executive Director
  - GinaParziale@NY-PHA.org
- **Im Senephimmachack**
  - Development Director
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- **Juliette Pelletier**
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### Midwest
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- **Geoff Gephart**
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- **Lindsey Noel**
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### San Francisco Bay Area
- **Bette Perez**
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- **Michael Ehret**
  - Development Director
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- **Andrea Gia Bevilacqua**
  - Development Manager
  - AndreaGiaBevilacqua@SF-PHA.org
is working hard to ensure that a new PH-specific bill is introduced and that National Institutes of Health (NIH) funding remains intact.

**This effort will only be successful with your help!**

As a result of your advocacy for previous PH legislation, the NIH has steadily increased its PH research portfolio and the Centers for Disease Control has funded multiple PH awareness initiatives.

Be part of continued success this spring by educating your Members of Congress about the need for PH research and urging your friends and family to do the same.

Getting involved is easy! Here are two advocacy opportunities:

1. **CALL!** PHA’s National Call-In Day is Wednesday, April 24. Pledge to call your Members of Congress and share your PH story as you ask for legislative support. Visit [www.PHAssociation.org/PHANationalCallInDay](http://www.PHAssociation.org/PHANationalCallInDay) for more information.

2. **VISIT!** Your Members of Congress return to their states throughout the year to meet face-to-face with their constituents about the issues that matter to them (see calendar to the right). One visit can inspire years of support for PH research. PHA can even help you schedule your meeting! Learn more: [www.PHAssociation.org/DistrictVisits](http://www.PHAssociation.org/DistrictVisits)

For more information about how you can get involved in PHA’s National Call-Day or schedule a district visit with your Members of Congress, contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at 301-565-3004 x753 or Advocacy@PHAssociation.org.

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**By Elisabeth Williams, PHA Grassroots Campaigns Manager**

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### 2013 Congressional Recess Calendar

*It was great that I really only had to talk about what I knew — my own patient experience.*

— Colleen Brunetti on her 2012 visit with Sen. Richard Blumenthal (D-CT)

A face-to-face meeting with your Members of Congress or their staff is one of the most effective ways to build legislative support in the fight to cure PH. Call early and schedule a meeting for one of the dates below, when Members of Congress are working from local offices in their home states.

- April 29–May 3
- May 27–31
- July 1–5
- Aug. 5–Sept. 5
- Oct. 14–18
- Nov. 4–11

Get contact information for your senators and representative at [www.PHAssociation.org/CongressionalContactInformation](http://www.PHAssociation.org/CongressionalContactInformation)

### PHA Receives “Exceptional Designation” for Business Practices 10 Years Running

PHA is proud to announce that for the 10th consecutive year PHA has received the highest possible rating — 4-stars — from leading charity evaluator, Charity Navigator, for best governance and accountability practices. Only 1 percent of rated charities have achieved this distinction. According to Ken Berger, President and CEO of Charity Navigator, PHA’s “exceptional designation ... demonstrates to the public it is worthy of their trust.”

PHA’s work wouldn’t be possible without the support and investment of community members like you. Thank you for trusting us with your support and donations. Together, we will continue to make great advances in the fight against pulmonary hypertension.
Giving is personal. Its impact is far-reaching. For Laura Doria-Djenfer of Staten Island, N.Y., giving is both. Her monthly contribution to PHA is in memory of her mother, Dolores Doria.

“My mom was my best friend. I loved her so much. Even today, I don’t think there’s a day that goes by that I don’t think of her,” she explains.

Dolores was diagnosed with PH in 2003. When diagnosed, her PH was so advanced she was immediately put on epoprostenol and oxygen therapy. A year and a half later, she lost her battle with pulmonary hypertension.

“There were so many complications — with mixing the medicine at the right time and making sure we had enough oxygen tanks,” Laura shares.

PH was devastating to Laura and her family. She attributes the lack of awareness and knowledge about PH to her mother’s late diagnosis and early passing. Supporting the fight against PH is important for Laura because she doesn’t want any other family to go through the pain and challenges her family did.

Inspired by her mother’s memory and seeking a way to combat the disease, she joined PHA’s monthly giving program Sustainer’s Circle. Seven years later, she has contributed more than $12,000 to PHA and the fight against this illness.

Laura’s monthly gift helps fund important PHA initiatives and programs that help advance our cause, including PHA’s Sometimes it’s PH: An Early Diagnosis Campaign. The focus of Sometimes it’s PH is to educate primary care providers so patients can get diagnosed and treated sooner. It’s just another way PHA is taking action to fight PH through the support of individual charitable contributions.

“It’s such a great feeling to help other people. Making a monthly contribution is so easy. By doing a little bit at a time, you can really make a big impact over time. I didn’t even realize I’d given so much — more than $12,000! I feel overwhelmed but really good about it,” says Laura. Mom would be proud.

Make an Impact

You, too, can support PHA like Laura Doria-Djenfer and 140 others by contributing monthly through PHA’s Sustainer’s Circle. In the last three years, more than $139,000 in PHA donations have been made through the Sustainer’s Circle. Your monthly contribution funds hope through support, education, advocacy and awareness and PH research.

Monthly donations can be made on your credit card or directly debited from your bank account. Join PHA’s Sustainer’s Circle at www.PHAssociation.org/SustainersCircle or by filling out the remittance envelope in the center of this Pathlight.

Contact Ellen Leoni with any questions you may have about PHA’s Sustainer’s Circle at 301-565-3004 x756 or Giving@PHAssociation.org.

PHA is thankful for the support of all of our donors. PHA’s Sustainers are recognized in each issue of Pathlight. Look for donors with the ★ after their names in the back of Pathlight to see who has made a sustained commitment to PHA.

By Ellen Leoni, PHA Development Associate

Stretching the Impact of Your Donations

PHA is funded by your generosity, so it’s important to us to stretch every charitable gift further. We are beginning to send email acknowledgement letters when possible for donations below $250 received through mail. Sending emails instead of letters will provide you with immediate gift acknowledgement and a tax receipt, as well as save resources. You can also save resources by making your donation online at www.PHAssociation.org/Donate.
Expect the zebra, a symbol of PHA’s early diagnosis campaign, to appear in more and more primary and specialty care circles as PHA takes its Sometimes its PH initiative into the health community.

PHA’s five-year campaign will have its biggest impact when we reach healthcare professionals directly involved in patient care — physicians, nurses, respiratory therapists, pharmacists, cardiopulmonary rehabilitation professionals and others. Sometimes it’s PH will teach professionals to consider a PH diagnosis when symptoms warrant, to screen for PH and to team earlier on with specialized PH physicians who can confirm diagnosis and offer a wider range of treatment, clinical trials and patient support networks.

The campaign’s central message is: “Sometimes dyspnea, chest pain and other widespread symptoms may lead you to conclude it’s asthma, COPD, obesity or lack of fitness. But sometimes it’s not. Sometimes it’s PH.”

The campaign is actively working with PHA’s professional leaders to bring our issue to the attention of the healthcare community. Here’s what we’ve been doing:

- **Researching opinions and issues surrounding early diagnosis.** To truly change professionals’ knowledge of pulmonary hypertension and diagnostic practices, PHA must clearly understand the views, challenges and needs of those the campaign aims to reach. We will, therefore, conduct opinion research using a firm experienced in polling medical professionals. We will also research other factors that contribute to the “climate” around early diagnosis such as developments in the business of healthcare, relevant government policies, and trends in diseases with similar symptoms to PH. Our findings will help us better understand which ideas and action steps will have the most impact in reducing the time needed to diagnose PH.

- **Proposing professional educational opportunities.**
  David Badesch, MD, another active campaign member, has proposed an educational session to be delivered at ACCP’s convention attended by cardiologists, pulmonologists and others. Many of them have little knowledge of PH because they mainly treat other cardiopulmonary diseases. Working through ACCP’s Pulmonary Vascular Network, Dr. Badesch suggested a slate of instructors from our SLC to speak on the evidence of delayed diagnosis, the consequences of late diagnosis and approaches to earlier diagnosis.

Be sure to stay up to date on the latest Sometimes it’s PH campaign news through Pathlight and PHA’s online communications. Medical professionals can expect a regular column on the campaign from its chair Lynn Brown, MD, beginning with the next issue of PHA’s medical journal, Advances in Pulmonary Hypertension. The journal is available free at www.PHAOnlineUniv.org. You may also find information at www.SometimesItsPH.org.

*By Mollie Katz, PHA Vice President, Community Engagement*
During Pulmonary Hypertension Awareness Month this past November, PHers all over the world used their voices and shared their stories to raise PH awareness. In 30 short days, we were everywhere: in news headlines, community events, government offices and online. Your efforts united the PH community, ended isolation for PHers who’ve never met other PHers and delivered life-saving information about the disease to those who’ve been misdiagnosed.

“I found out about your support group over the radio. I’ve been having shortness of breath for over a year and a half. I’ve been to cardiologists, neurologists and pulmonologists, and they have not found a problem. There was never a mention of the possibility of pulmonary hypertension. My quality of life is impaired, and I am frustrated,” said one male listener. He had heard Ft. Worth Support Group Leader Diane Dauwalder on a radio show segment focused on PH and her upcoming special event.

PH Awareness Month would not have been a success without your hard work! Here are a few PHers talking about their Awareness Month victories in their own words.

» “I changed my Facebook photo to this one of my daughter dressed up as a zebra and posted the link with a short blurb about myself as my status at the beginning of the month. I had lots of friends comment and many more than I would have imagined post the link as their status for a day, too. Not a lot, but it’s still something!” — Aimee from North Carolina

» “I wrote several articles for CNN’s iReport in an attempt to get my message out. In the end having the article did get the word out a little easier in my hometown, and it actually assisted our local support group in getting noticed by the local news media.” — Kevin from Ohio

» “I decided to get the proclamations (declaring November PH Awareness Month) and send the photo to all of the local papers because I want people to know that we exist. We may be small in number compared to other illnesses, but we matter.” — Evette from Texas, who contributed to a record-busting 111 proclamations secured by the PH community

» “We need to spread awareness. We need to educate each other, and the Tom Lantos Pulmonary Hypertension Research and Education Act allows us to do this.” — Diane from North Carolina

Read about all of our Awareness Month victories at www.PHAssociation.org/AwarenessMonth and turn to page 26 to see photos of November special events.

By Elisabeth Williams
PHA Grassroots Campaigns Manager
As we go to press, PH advocates across the country are calling and writing to their U.S. senators and representatives about not one, but two threats to the federal programs that fund PH research, review new treatments and help ensure patient access to medication.

One threat is sequestration — an 8 percent funding cut to most federal programs that was scheduled to go into effect on March 1, 2013, unless Congress agreed on a new strategy to reduce the national debt before the deadline. For the Public Health Service, which includes the Food and Drug Administration and the National Institutes of Health (NIH), sequestration would mean a $2.4 billion budget cut in 2013.

In addition, Congress is considering additional cuts to these programs as part of the 2013 and 2014 federal budget processes taking place this year.

NIH Director Francis Collins, MD, PhD, has identified a wide range of research initiatives that would lose momentum if the cuts take place, including work on cancer treatment and rare diseases.

Don’t let Congress get so caught up in the “numbers” problem of reducing the deficit that they lose sight of the impact their choices will have on real people with PH and other illnesses.

While sequestration will (hopefully) be resolved by the time you read this article, the fiscal year 2014 budgeting process will continue throughout 2013. There is still time to make your voice heard about preserving adequate funding for federal health programs.

For more information, contact Elisabeth Williams at 301-565-3004 x753 or visit www.PHAssociation.org/Advocacy/Alerts.

By Katie Kroner
PHA Director, Advocacy & Awareness

NIH Research Finds New Clue to Cause of PH

Leaders in PH research produced one of the top findings in 2012 at the National Heart Lung and Blood Institute (NHLBI) of the National Institutes of Health (NIH). The study suggests that bone marrow-derived endothelial progenitor cells play a role in causing the vascular injury in the lung that underlies PAH. The NIH funds nearly 30 percent of the biomedical research done in the U.S., but proposed budget cuts to most federal programs put that research at risk.

In Insurance Finds: Insurance Victories Provide Support and Guidance for Fellow Patients

Have you faced an insurance challenge that was eventually resolved? If so, consider sharing your story in the Insurance Victories section of PHA’s website.

This section contains personal stories — written by PH patients or their caregivers — about how they overcame insurance challenges, including:

- Getting Medicare to cover pulmonary rehabilitation
- Appealing a denied claim
- Obtaining Supplemental Security Income (SSI) for a child with PH
- Pushing Veterans Affairs to provide appropriate PH care
- Being approved for a lung transplant

Insurance victory stories offer resources and techniques that can help other PH patients work through their own insurance challenges. Most importantly, insurance victories motivate others to advocate for themselves in insurance matters and demonstrate that persistence pays off.

Find more insurance victories or contribute your own victory story. Visit www.PHAssociation.org/Patients/Insurance/Victories or contact PHA at 301-565-3004 x773.

By Daniela Maristany
PHA Insurance Program Associate
In working to improve life for pulmonary hypertension patients and their loved ones, PHA collaborates with and learns from many other organizations. We mention a few of them frequently, like the Caring Voice Coalition and the National Heart, Lung, and Blood Institute at the National Institutes of Health (NIH). Now we’d like to introduce you to some additional organizations in the broader health community that PHA engages in our fight against PH.

**National Organization for Rare Disorders (NORD)**

NORD connected PHA’s founders in 1987. Now we support one another’s efforts to advance rare disease awareness and treatment. Each year, PHA and the PH community participate in NORD’s Rare Disease Day (the last day in February) by spreading the word that 30 million Americans are living with rare diseases. In addition, PHA staff join leaders from other rare-disease organizations at NORD-hosted symposia around the country. Recently, NORD and the Drug Information Association presented a three-day conference on rare disease treatments and advocacy, which PHA’s Advocacy & Awareness team attended. We’re using the information we gathered to guide our partnership-building efforts with organizations like the Food and Drug Administration.

**American Thoracic Society (ATS)**

ATS is an association dedicated to advancing clinical and scientific understanding of pulmonary diseases, critical illnesses and sleep-related breathing disorders among specialty physicians. PHA co-founder Judy Simpson was the chair of ATS’s Patient Advisory Roundtable (PAR), and our President, Rino Aldrighetti, is now a PAR member. Nick Hill, MD, who treats PH, is the immediate past president of ATS. Many other physicians active in PHA are also members of ATS.

Each year, ATS hosts a series of lung disease awareness weeks. Its PH week coincides with our Pulmonary Hypertension Awareness Month in November.

**American Association for Respiratory Care (AARC)**

AARC is a membership organization for respiratory care professionals. PHA is proud to support AARC’s advocacy efforts, particularly the *Medicare Respiratory Therapist Access Act*. This bill seeks to increase access to respiratory therapy for Medicare recipients living with PH and other chronic respiratory diseases. In 2012, PHA began joining AARC members on their visits to Capitol Hill offices during AARC’s annual advocacy day.

**National Center for Advancing Translational Science (NCATS) and Patient-Centered Outcomes Research Institute (PCORI)**

NCATS, which is part of the NIH, brings together researchers, patient organizations and industry to increase the number of scientific discoveries that eventually become new medicines or medical devices available to the public. NCATS includes the Office of Rare Disease Research at the NIH.

PCORI’s research is intended to give patients and healthcare providers a better understanding of prevention, treatment and care options available along with the science that supports those options.

In the coming months, members of PHA’s medical leadership will meet with representatives from NCATS and PCORI to determine how we can best work together to improve the lives of those living with PH.

To learn more about PHA’s partnerships or to become involved, contact Katie Kroner, PHA’s Director of Advocacy & Awareness, at KatherineK@PHAssociation.org or 301-565-3004 x749.

By Katie Kroner, PHA Director, Advocacy & Awareness

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**Experiential Learning Opportunities at PHA!**

Are you — or someone you know — looking to enhance your academic experience beyond classroom walls?

PHA offers a variety of internships year-round. From Medical Services to Marketing & Communications to Fundraising, there is something to meet your educational and professional goals.

For more information, visit www.PHAssociation.org/Internships or contact Internships@PHAssociation.org.
**Insurance Roundup: Improving Access to PH Treatment**

PHA’s Insurance Advocacy and Education Program, in conjunction with PHA’s Scientific Leadership Council (SLC) Insurance Advocacy Committee, is always working on issues of concern to PH patients and providers. Read on for a snapshot of our recent initiatives.

**Essential Health Benefits**

In late 2012, PHA joined 150 other patient advocacy groups in signing a letter to Health and Human Services (HHS) Secretary Kathleen Sibelius about Essential Health Benefits (EHBs). EHBs are a set list of benefits that individual and small group insurers will be required to provide starting in 2014. The Affordable Care Act (i.e., healthcare reform) requires that EHBs determine the standard of care offered by insurance plans in the health insurance marketplaces that open in 2014. This is important because many small plans have big benefit holes; for example, HHS estimates that 62 percent of plans lack coverage for maternity care.

The letter to Secretary Sibelius recommended, among other things, that EHBs include increased coverage of drugs in each class and outline how new drugs on the market should be covered. For example, if a new PH drug were to come onto the market, there are currently no standards dictating how soon insurance plans in the marketplace would have to determine whether or not they would cover the new drug. The letter urges HHS to set 180 days as the time by which plans must determine their coverage of a new therapy.

**Medicaid Treatment Access**

After several state Medicaid programs removed PAH medications from their formularies in 2012, PHA’s SLC Insurance Advocacy Committee wrote a letter to these states’ Medicaid administrators stressing the importance of all PAH treatments being available for patients. The letter was converted into a template letter so that patients encountering problems with access to their PAH treatment can include it when appealing or requesting an exemption. The template letter can be found at www.PHAssociation.org/Patients/Insurance/Letters.

**Compassionate Allowance for Social Security Disability**

As many PHers know, applying for Social Security Disability (SSD) benefits can take a long time. Some conditions, however, are given a “compassionate allowance” designation, which significantly speeds up the approval process. Last year, PHA’s Insurance Program and the SLC Insurance Advocacy Committee met with Social Security Administration (SSA) representatives to discuss a compassionate allowance designation for Stage IV PAH. The SLC’s Insurance Advocacy Committee has compiled the evidence for compassionate allowance requested by the SSA and will submit its proposal this spring.

**Palliative Care and Nursing Homes**

The concerns voiced by PH patients and families drives the advocacy work of PHA’s Insurance Program. Over the past few years, we’ve received many calls and emails from PHers being denied access to nursing homes or palliative care services because they are on prostacyclins. In response, the SLC Insurance Advocacy Committee drafted a statement of guidelines for palliative and hospice care providers about continuing prostacyclins for PH patients. The final statement will be available on PHA’s website and will guide a long-term effort to improve patient access to prostacyclins in palliative care and a variety of other settings.

What should the Insurance Program be working on that can help you with your PH care? Let us know by emailing Insurance@PHAssociation.org or calling 301-565-3004 x773.

*By Daniela Maristany, PHA Insurance Program Associate*
This year 24 states plus the District of Columbia will enact changes to their delivery of Medicaid coverage. The stated purpose of the change is to give patients better, more effective care while saving money by eliminating unnecessary tests, doctor’s visits and hospital stays. However, many in the healthcare field believe that the new delivery mechanisms are not equipped to deal with the complex medical problems that many dual-eligibles, those eligible for Medicare and Medicaid, face. While the lessons learned in California, which first began the change two years ago, should help the upcoming transitions go more smoothly, PHA encourages PHers to learn more about what to expect in their states.

Over the past two years, many California residents who are eligible for both Medicare and Medicaid were transitioned to a new type of Medicaid plan. Instead of being covered by traditional fee-for-service plans, dual-eligibles in California were switched to Medicaid Health Maintenance Organizations (HMOS), or managed care plans. Unfortunately, this transition was not handled smoothly, and many Californians living with PH continue to face challenges getting the care they need.

The dual-eligibles were supposed to receive packets informing them that they would be placed in a managed care plan. While there was an exemption option available for those with complex medical conditions, it was confusing and not well advertised. As a result, many people missed the deadline to apply for an exemption.

Some people never received a packet informing them of a switch. At the beginning of the month, they were moved to a new managed care network and a new specialty pharmacy without their knowledge. PH patients found themselves unable to see their PH specialist because the specialist was not part of their new HMO’s network. In fact, some of the new HMOS did not have any in-network PH specialists and PHers were forced to see general pulmonologists. In addition, the changes caused delays in medication because the new specialty pharmacies were not always familiar with PH.

Ron Oudiz, MD, the chair of PHA’s Scientific Leadership Council (SLC) Insurance Advocacy Committee, met with California Medi-Cal representatives to discuss the importance of allowing PH patients to remain in traditional fee-for-service plans.

Massachusetts and Washington began implementing versions of the Medicaid HMO program on April 1, with 22 other states plus the District of Columbia to follow. Learn whether or not your state is planning Medicaid HMOS at http://tinyurl.com/7yfjad or contact PHA’s Insurance Program at Insurance@PHAssociation.org or 301-565-3004 x773.

If managed care is coming to your state, be prepared by following these steps:

- Determine whether you will be affected. Are you a dual-eligible?
- Contact your PH nurse and your provider’s billing department for information and advice. Work with them to answer important questions, such as:
  - When will the switch begin?
  - Will my PH specialist be contracting with an HMO? If so, which one?
  - Is there an exemption option to stay in a traditional fee-for-service plan? If so, how do I go about obtaining this exemption?

By Daniela Maristany
PHA Insurance Program Associate

One sentence. Including the statement below in your estate plan empowers hope for thousands. Make brighter the eternal flame of PHA’s Legacy of Hope Society by sharing your intent to join today.

“I, [name], of [city, state, ZIP], give, devise and bequeath to Pulmonary Hypertension Association, Tax ID: #650880021 [written amount or percentage of the estate or description of property] for its unrestricted use and purpose.”
Dealing with PH and Something Else? PH Support Groups Can Help!

“It’s really difficult living with one life-threatening illness. Living with two [diseases] is extremely hard, but it doesn’t have to be. Life is probably going to change. It’s going to be different. You’re not going to be able to do the same things as before ... But that’s okay because you can do other things. And you can change your life to revolve around your needs and diseases.”

— Jeannie Wraight, PH and HIV Patient

**PH** is challenging even if you do not have an associated medical condition; however, PH frequently occurs in the setting of connective tissue diseases (e.g., scleroderma, sickle cell and lupus) as well as other conditions such as HHT, HIV and liver disease.

If you are getting weary of juggling the symptoms, specialists and medications that accompany each of your multiple conditions, rest assured that you are not alone. Many patients and caregivers in our community understand the uncertainty and stress that go hand-in-hand with a diagnosis of PH related to another disease.

PH support groups provide education, hope, empowerment and support for all patients — including those who have PH caused by another disease.

We asked patients to tell us why it’s important for someone with PH and an associated condition to attend support groups. Dozens of patients shared stories and good reasons why support groups are helpful. We share a sampling of their voices below:

1. **Support groups make the world seem a little smaller:**

   “I am really fond of PH support groups because it’s a very isolating disease. People get in a better and better frame of mind as they exchange [information].”
   
   — Rita Simone Hébert, PH and Congenital Heart Disease Patient

   “If you come into the PHA Chat Room almost any night there will be one or two of us in there who will have scleroderma or lupus or Sjogren’s [syndrome] ... We’re all in there, and we’re all chatting up, and we learn from each other.”
   
   — Ellen Harris, PHA Online Chat Leader

2. **Knowledge is power, and support groups provide education for all patients:**

   “[Support groups] can give you access to doctors, dieticians, yoga teachers, acupuncturists, chiropractors and healthcare facilities so you know where you want to go when you are not feeling good.”
   
   — Gail Bucci, Sarasota, Fla., PH Support Group Leader

   “I have a friend who runs a support group for another chronic, serious illness, and we share ideas for speakers. We have used drumming as meditation for one meeting, had a Medicare specialist come in and talk about yearly changes for Medicare, brought in specialists for pulmonary exercise in addition to the more obvious doctors ...”
   
   — Matty Heenan, Tucson, Ariz., PH Support Group Leader

3. **If you have PH and an associated condition, you have a story to tell:**

   “I have scleroderma, but I believe strongly that I need to be in a PH support group. Others with PH can understand part of what I am dealing with ... It’s about support and community for me. I also can help someone else in the group with information if they want to learn more.”
   
   — Leona Welker, as shared on Facebook

   “I have idiopathic pulmonary arterial hypertension (IPAH) and learning of the secondary causes has made me understand this ‘PH world’ all the more.”
   
   — Linda Santos, San Diego, Calif., PH Support Group Leader

**STORY CONTINUED ON NEXT PAGE**
4. If you have pulmonary hypertension — regardless of an associated condition — you can always depend upon a PH support group to help you manage that aspect of your health.

“Here we have several patients with associated diseases. We do what we can to accommodate them or help them find information about other groups. But our focus as a support group is PH.”
— Mark Arellano, Santa Fe, N.M., PH Support Group Leader

“[Support groups are] the best place to meet people face-to-face who are dealing with similar circumstances. The first time I met someone else who was dealing with PH along with interstitial lung disease (ILD) and a patent foramen ovale (PFO), we went to coffee after the meeting, and I cried the whole time we talked. I was not so unique. We are still great friends. Although our underlying diseases are different … we still have in common the challenges that come with multiple diagnoses. It is always complicated, and no one understands what I go through like she does and vice versa … Our main focus is PH, and I feel more at home in that support group than any other I have attended.”
— Jeannie Kendrick, as shared on Facebook

5. People with associated conditions and PH will have allies and support in their group.

“I don’t have any other disease such as lupus or scleroderma. I can be supportive of those people with those conditions.”
— Theresa McKeon Talmage, as shared on Facebook

Did you know…

- 30 percent of scleroderma patients develop PH
- 20 to 40 percent of sickle cell patients develop PH
- 1 out of every 200 HIV patients develop PH
- About 5 in 1,000 lupus patients develop PH
- About 15 to 20 percent of people with hereditary hemorrhagic telangiectasia (HHT) have at least mildly elevated pulmonary artery pressures, which means they either have or are developing PH.
- There is a strong association between selected stimulants and PAH. Individuals with IPAH were 10 times more likely to have used stimulants than individuals with PAH associated with other known risk factors.

To learn more, visit: www.PHAssociation.org/PHPlus

Check Out PHA’s Support Group Welcome Brochures Today!

Have you recently attended a PHA support group for the first time? If so, you may have received a special welcome from PHA. As a benefit for finding the courage to step out of your comfort zone and attend a support group meeting, we created a “welcome” brochure.

Your support group is backed by the power of PHA. Your local support group can connect you to diverse resources from PHA — everything from phone and online support to our resource book Pulmonary Hypertension: A Patient’s Survival Guide and ways to get involved and fight back. In addition, this brochure lists resources and support outside of the group.

If you are a support group leader and would like to request these brochures or print them from your home computer, visit the free materials section of PHA’s online store (www.PHAssociation.org/Store) or call 301-565-3004 x0.
Support Groups Paint, Learn and Party All Across the Country

SaWanda Cornette, a member of the Houston, Texas, Support Group, turned a painting party with friends into an awareness event. SaWanda worked with Houston Support Group Leader Shirley Craig to add an educational component to the event with brochures, pins and bracelets. SaWanda says it was a lot of fun, and she feels pleased to be able to share information about PH with others.

Each Houston Support Group member celebrated November Awareness Month by sending at least two PHA postcards to educate friends and family about PH and the affect it has on their lives.

Two major groups in Arizona hosted a joint end-of-year party to welcome 2013. The Phoenix Valley of the Sun Support Group joined forces with the neighboring Tucson Support Group at the Holiday Hoe-Down. According to Valley of the Sun Support Group Leader Mack McCarthy (pictured front, center), “We all had a wonderful time, and it was a way to meet in a nonclinical setting: [the] meal was wonderful!” Pictured here with Mack are the leaders of the two groups.

The Fresno, Calif., Support Group held its first meeting of 2013 with a presentation from Dr. Vijay Balasubramanian on PH clinical trials. Thirty-four people attended and previewed a demonstration of a new trial for an inhaled nitrous oxide system.

The Ft. Myers PH Support Group in Florida kicked off 2013 with Pat Paton, PHA Board Emeritus and Founder, as the featured guest speaker. Pat (pictured fourth from left) spoke about her work in the PH community and the history of the Pulmonary Hypertension Association.

The San Diego PH Support Group hosted a kickoff party for 2013. Linda Santos, the group leader, told us that everyone enjoyed the food, gift exchange and door prizes. Members wrote their predictions for 2013 to put in a time capsule and open during their 2014 party.
SPECIAL EVENTS

Six-Minute Marathon Engaged Communities During Awareness Month

Some of 2012’s successful Awareness Month events included the Six-Minute Marathon (6MM), the perfect activity for beginner or expert volunteer fundraisers. A concept based on the six-minute walk test, this fun and easily managed event raised awareness and funds for PH research and services throughout the country in 2012. Unlike other special events, the 6MM is versatile by design, allowing the coordinator discretion over the logistical intricacies of the event. As 6MM coordinator Paul Stracke puts it, “Go for it! Get your feet wet on something like a 6MM. It will give you the confidence to move on to bigger events. Once you get started you won’t want to stop.” Check out some of the 6MM events below. To host your own 6MM, contact PHA at Events@PHAssociation.org or call 301-565-3004 x765.

Bullhead City, Ariz.
A 6MM doesn’t have to be a solo project; the Bullhead City/Laughlin Support Group worked together. “It is a fun experience, and it helps bond the group by working for the same goal,” says Support Group Leader Joy Gore.

Harker Heights, Texas
New connections are forged! The 6MM coordinated during Awareness Month brought PHers Michael Lane and new PHriend Hannah together while educating the community.

Puyallup, Wash.
You can find inventive ways to make a 6MM your own just as co coordinators Charlotte McCabe and Paul Stracke did. According to Paul, “We used straws to help explain what it is like for people with PH to breathe on a day-to-day basis. Our theme was red, white and blue: the straw was red, the paper to hold the straw in place was white, and blue illustrated the shade of a PH patient’s lips. The people that walked with a straw said it was difficult to breathe (that was the idea) and that was for just six minutes.”

Fresno, Calif.
Support group leader and first-time PHA special event coordinator Perry Mamigonian shares an exciting element of the 6MM, “The actual day of the event was my favorite part. Since it was our first try at an event, I had no idea what to expect.”
Zebras in the Park! North Texas Zebra PHriends Raise PH Awareness Through 5K Race and One Mile PHun Walk

A herd of zebras was spotted at Andy Brown Park in Coppell, Texas, from morning until noon on Nov. 3, 2012. Some ran, some walked, some rolled, but all came to raise awareness and benefit PHA.

The North Texas Zebra PHriends 5K & 1M PHun Walk was the 6th annual event for the North Texas support groups of Dallas and Fort Worth. “Last year was the first time we included a 5K race with the annual walk and picnic,” says Diane Dauwalder, Fort Worth PH Support Group Leader. “Last year’s event raised $9,000, but we only had 10 runners for the 5K race. We wanted to do better this year.”

Enter Lesli Witte, who races in events from 5Ks to ultra marathons. Lesli lost her father Ken Butler to PH in 2012, and she wanted to help raise awareness and honor his memory. “Lesli came forward just when we needed her. We were so sorry for her loss and, at the same time, inspired by her commitment,” says Dallas PH Support Group Leader Marcia Beverly.

PH patient Honey Kennedy also attended the 2011 5K race. “My husband Karl Sall was one of the 10 runners that year. We decided we had to help in 2012. I volunteered my mom Susan Kennedy and myself, and off we went.”

Our group formed a core team of Marcia, Diane, Lesli, Honey and Susan. The team was supported and encouraged by Dallas co-leader Stuart Berwick, representatives from UT Southwestern and various pharmaceutical companies and others.

We decided to expand the event to increase attention. Ideas were tossed around within the team. We selected the new PHA zebra theme and created a fun new logo, website and Facebook page.

Activities included a 5K with 30 prizes, a live band (the FinishLine), zebra face painting and kids’ games, free breakfast and a local celebrity race starter, Ben Moturi. We held a silent auction and bake sale and offered vendor booths. Old favorites included the one-mile walk, PHA information booth, picnic, raffle and balloon release. Online fundraising pages generated additional donations.

Our team did a media blitz, which included distributing a press release and contacting local stations. As a result, we landed a TV spot on Good Morning Texas the week before the race. A local radio station created 10 public service announcements. A newspaper ran a full-page story on Honey and PH awareness. Members of our team donned a zebra costume and plastered cars with race flyers and received proclamations from four city councils.

The results? Even real zebras would have been surprised. “When we arrived at the park that morning, the lot was already filling to capacity,” says Lesli. “We were stunned with the turnout. We had 230 runners, 220 walkers and an incredibly beautiful day.”

“We are thankful for what we raised, but what will stay with us for years to come are the stories of hope,” says Honey. “The week before the race a man contacted us who had PH symptoms, but doctors did not know what was wrong. After a year and a half of guessing, he is now able to ask to be evaluated for PH.”

“We met so many new members of our PH community, and we look forward to building relationships with them,” says Marcia. “We were also able to honor those who have passed on and let the ones closest to them know we have not forgotten them,” says Diane Dauwalder.

At the end of the day, our group raised more than $27,000 in net donations to PHA. “We are thrilled with the results, and we’re already talking about how to make it better next year,” says Susan Kennedy.

“PHers Stuart Berwick (left) and Shaye Wallace at the 5K & 1M PHun Walk”

For more information, visit the group’s Facebook page ZebraPHriends or check out www.zebraphriends.com.

By Susan Kennedy, PH Caregiver
Five Tips for Gaining Media Coverage for Your Special Event

As a special event coordinator, you have already committed to making a difference and raising awareness of pulmonary hypertension. One way to multiply the impact of your event is to work with reporters to get your event covered by local media.

Getting publicity isn’t terribly complicated, but it does require advance planning and some persistence. Your story is already attractive because it highlights a local event, local community members and a good cause! But when and how you approach the media can influence whether your event gets coverage. These tips will help by showcasing your event in ways that are appealing and helpful to the media.

1. **Start early.** Plan at least six to eight weeks ahead of your event. Remember that some places your story could be mentioned are seen only once a week — such as weekend event calendars. This means journalists plan farther ahead and need more advance notice to publish your information. Always have dates, times, costs, phone numbers and other essential information ready to share before you contact any media.

2. **Tie the event to a larger theme about PH** that can become the basis of stories in the media. This will help you differentiate your event from the many others media could choose to cover. Some examples of themes might be: pediatric PH, early diagnosis, inspiring stories of how PH patients cope and adapt, caregiving, the impact of PH on the family and long-term survivors. The theme will be especially strong if it relates to something newsworthy because it is just happening — the anniversary of a patient achieving a health milestone, for instance, or something people in the community are doing in honor of a patient.

3. **Line up medical professionals** such as physicians, nurses, or respiratory therapists who can explain PH to the media. Have their contact information ready to share with journalists.

4. **Use PHA materials** and resources including PHA’s press kits or online press room (www.PHAssociation.org/Press) to share with reporters, public service announcements for radio and TV, the “Understanding PH” informational DVD, etc. Many of these add a visual and/or sound component which will be of interest in print, TV and online media.

5. **Approach a variety of news outlets** including print, radio, television and online. Online media may include local bloggers and highly localized news websites such as Patch.com in some communities. Print and broadcast news organizations also have their own websites. Sometimes these sites carry additional content beyond what was in the paper or on the news broadcast. Some of these sites also allow you to post your own community information. When working with media, remember that several news organizations can carry the story on the same day, so if you can, don’t just stop at one.

Find more advice on gaining media coverage at www.PHAssociation.org/MediaAtPHEvents.

We love seeing the results of your hard work and letting others in the PH community know of your successes, so share your victories with PHA! Contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at PHAware@PHAssociation.org or 301-565-3004 x753.

*By Elisabeth Williams, PHA Grassroots Campaigns Manager*

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**Spring into 2013 with a Special Event!**

It’s never too early to start planning your summer or fall fundraising event! You can help bring us one event closer to a cure. To help get the ball rolling, check out PHA’s Special Events Planning Guidebook at [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook)

And don’t forget to subscribe to our quarterly e-newsletter, **Event-ful Times**, at [www.PHAssociation.org/SpecialEvents/Newsletter](http://www.PHAssociation.org/SpecialEvents/Newsletter)
Saturday, April 27, 2013  
Philadelphia’s Hope for a Cure  
DETAILS: Colleen Connor at 610-429-0118 or connor_colleen@comcast.net

Saturday, April 27, 2013  
PH on the Prado Luncheon  
WHERE: San Diego, Calif.  
DETAILS: Linda Santos at Santos.linda.m@gmail.com or 619-847-1899

Saturday, May 4, 2013  
Pray PH or a Cure for Pulmonary Hypertension  
WHERE: Vinton, Iowa  
DETAILS: Trudy Seidel at 319-640-5674 or buggabooboutique@hotmail.com

Saturday, May 5, 2013  
Chicagoland Stride for the Cure  
WHERE: Glencoe, Ill.  
DETAILS: Erin Kholodovsky at Erin.Kholodovsky@gmail.com

Saturday, May 11, 2013  
2nd Annual Take a Breath for PH/Get Moving for MS  
WHERE: DeWitt, Mich.  
DETAILS: Melinda Grubich at grubich@msu.edu or 517-281-6197

Saturday, May 11, 2013  
4th Annual Race 2 Cure PH: Taylor Caffrey Memorial 5K  
WHERE: Anaheim Hills, Calif.  
DETAILS: Shari Caffrey at 714-200-8322 or shari@TaylorsWish.org; www.TaylorsWish.org

Saturday, May 18, 2013  
N.C. Cure PH Golf Tournament  
WHERE: Pudding Ridge Golf Club, Mocksville, N.C.  
DETAILS: Cindy Pickles at 336-978-1668 or cpickles50@gmail.com

Saturday, May 18, 2013  
Walk in Memory of Heather Wilson  
WHERE: Wilmington, Del.  
DETAILS: Ashley Wilson at ashleywilson302@gmail.com

Sunday, May 19, 2013  
Father-Daughter Benefit Dance  
WHERE: West Chester, Pa.  
DETAILS: Lisa Waxman at lisa@alittlesunshine.com or 484-680-6405

Friday, May 31, 2013  
Annual Fred Astaire Golf Tournament, Benefitting PHA  
WHERE: Kingwood, Texas  
DETAILS: Annette Nino at 281-655-0069 or anino5@yahoo.com

Friday – Sunday, May 31 – Jun 2, 2013  
Bluegrass at the Fair, Benefitting PHA  
WHERE: Pueblo, Colo.  
DETAILS: Margaret Thornburg at margaret.thornburg@state.co.us

Sunday, June 2, 2013  
3rd Annual Power for PH: New Jersey’s PHun Walk  
WHERE: Edison, N.J.  
DETAILS: Christina Lapatka at powerforph@gmail.com

Saturday, June 8, 2013  
Ashley PHun Walk for PH  
DETAILS: Vicky Turner at 989-717-1499 or turnerv10@gmail.com

Saturday, June 15, 2013  
PHun Walk for Shelley  
WHERE: Wanaque, N.J.  
DETAILS: Katherine Bryan at 973-634-0671 or katherinejanex3@gmail.com

Saturday, June 15, 2013  
Steps for Stripes: A Fun Walk for Pulmonary Hypertension  
WHERE: St. Francis, Wis.  
DETAILS: Kristen Wieneke at 414-727-5046 or klr9773@yahoo.com

Monday, June 24, 2013  
2013 JFK Tower Golf Tournament  
WHERE: White Plains, N.Y.  
DETAILS: Steve Abraham at sjahome@optonline.net

Visit www.PHAssociation.org/Calendar for complete and up-to-date special event information and listings.
Persistent Voices

Welcome to another issue of Persistent Voices. As winter winds down and signs of spring emerge, I hope PH patients and their loved ones will shed their winter selves and look forward to a new season of growth and warmth. Our two featured submissions rely on creative writing to convey their stories, and the themes of both are familiar to the PH community. Enjoy, and I hope you’ll consider submitting your story, poetry or artwork to share with fellow PHers very soon.

— Joanne Sperando-Schmidt, Persistent Voices Editor

James Grea, Knoxville, Tenn.

My name is James Grea. I write stories for children with a magical fountain pen named Solomon J. Inkwell. I spend a great deal of my time writing about Boogey Men and things that go bump in the night. I love spooky tales. They are my favorite. My monsters are harmless and even quite fun because they are imaginary. But there are times when monsters can be real, and sometimes they can even live inside of you.

I arrived at outpatient registration at the hospital at 5:30 a.m. with my sister and my best friend. I was surprisingly calm. I swear to you, I don’t know why. Maybe I had convinced myself that I was going to receive good news. The mind has an odd way of masking the unimaginable, especially when it is standing right in front of you. We sat in the lobby waiting to be called. My sister patted my leg and smiled at me. My uneasiness wasn’t apparent to those who didn’t know me, but she knew I was shivering on the inside. Soon they called my name and my chest tightened at the sound. I took a deep breath and followed the nurse who showed me to my curtain-walled preparation area.

Two older gentlemen were on either side of me hidden behind their own curtain walls. They were apparently having the same procedure as I that morning. I tried my best not to listen to the questions the nurses were asking them. “When did you have your first heart attack?” “Do you have a living will?” I stared at the ceiling tiles trying to think of other things, things I would do after I received the good news, movies I would see, food I would eat.

Right heart catheterization — it is a fairly simple and relatively painless procedure where a measuring device is inserted into the right femoral artery of the leg. It travels to the heart where pressures are measured and dyes are injected. It’s a common test that can locate blockages in the arteries. It’s also the only exact method of diagnosing pulmonary arterial hypertension (PAH).

There are instances where this disease is inherited. I come from a fairly large family consisting of eight children in total, of which I am the youngest. By the time I was 21 years old, I had lost my oldest brother (diagnosed age 24, passed age 27), my nephew, who was 10 months younger than
myself (diagnosed age 11, passed age 12), and my mother (diagnosed age 60, passed age 61) — all of them victims of PAH. You could say that the disease has stalked my family and me all of our lives. We all spend a great deal of time praying it doesn’t catch us. My new adventure had begun with a routine EKG that had shown an abnormality, which led to further testing. They eventually found mild enlargement on the right side of my heart. I heard the word “right” and immediately knew what was happening to me.

The orderly wheeled me into the catheterization laboratory and began to prep for the procedure. I welcomed the sedative and tried to focus on its feeling. Through my wooziness, I could see the large monitor above me. On the screen was my beating heart, and I watched as the thin cath line traveled into its chambers. I took a deep breath and tried to relax myself. Moments later it was over. The rather abrupt cardiologist I had been working with had no experience with PAH. So, he thought nothing when he rounded the table and said nonchalantly, “Well, it looks like pulmonary arterial hypertension.” Stunned, I asked, “How high was the pressure?” “It’s 110 over 44,” he said. I sank into tears. Yes, the Boogey Man under my bed had found me at last.

I continued to cry for three solid days. To me, my life was over. I wondered how much time I had left. How long would it be before I couldn’t walk to the bathroom without passing out? I was no longer James Grea. I no longer wrote scary stories. I was now a zombie who wandered around my house sobbing. Finally, I decided to reach out to PHA. I began reading everything I could on PHA’s website, trying to find any sign of hope. I obtained the Envelope of Hope, which contained a wealth of information. I went one step further and called PHA’s support line where I spoke with some great people who were living with PAH. I learned that in today’s world I have great chances, far better chances than others in my family had.

In the past, there was nothing at all that could treat PAH. But today I learned it is very different. Then, I began to do things I hadn’t done in a while. I began to talk more with God. I began to see the value in little things in my life that I had taken for granted. I began to realize that not one of us is guaranteed to see tomorrow. At any moment we could receive that test result that could drastically alter our lives forever, or even get hit by a moose. And I’ve never said, “Why me?” Why not me? What makes me better than anyone else? Absolutely nothing. So, I began to have hope. For the only other alternative is to lose hope, and that is unacceptable.

So, why am I telling you this? I’m really not sure. Maybe I want you to come along with me. Maybe I want us to be like old friends, sitting in a room, drinking coffee, and talking about the frailty of life. Maybe I just want you to listen. I’m not certain. I only know that I am moved to tell you these things because a writer must write. It could be possible that you, too, are afraid — for yourself, or someone you love — and maybe it will make you feel just a tad less lonely to know that somewhere out there I am here, being afraid along with you.

I got to see my specialist today. I felt quite blessed to be placed with him. I am going to be trained on how to use the pump that administers my medication next week. Who knows what tomorrow holds. Miracles happen every day, and my miracle could be right around the corner. Ironically, being diagnosed with this disease could very well prove to be my miracle. So, I will look toward today and value what I have in my present world, my present health, and my present life. For today, I am alive — we are alive. And what could be better than that? And yes, I am finding my identity again. My name is James Grea. I write stories for children with a magical fountain pen named Solomon J. Inkwell. And I just happen to have pulmonary arterial hypertension.
Even when we have good support from our loved ones, we sometimes wonder if they truly understand how we feel and what PH does to us. Sometimes we even experience breathlessness when we speak. Stella is caregiver to her mom, Pauline, and has written a simple but direct poem that illustrates that symptom and lets her mom know that she’s there for her and doing her best to understand.

A Poem by Stella Kamakaris, Bloomfield, N.J.

narrowing of arteries, leading from the heart to the lungs, causes shortness of breath, fatigue, lightheadedness, loss of consciousness, and, what is technically known as heartache.

— Joanne

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— Joanne

Keep the Creativity Going!

Persistent Voices is a place for creativity and sharing, and we invite you to continue sharing online anytime in the new Creative Expressions section of Our Journeys on PHA’s website. Check out artwork, poetry, creativity webinars and more at www.PHAssociation.org/OurJourneys/CreativeExpressions

Submit and share your own creative endeavors right now!

Your story is going to touch the heart of someone who reads it, so don’t think it isn’t worth telling.

— Jerry Wojciechowski

The purpose of Persistent Voices is to allow patients and their families and friends to share their personal experiences and coping strategies with one another. It is not to provide medical advice on personal health matters, which should be obtained directly from a physician. Persistent Voices assumes no responsibility for readers’ actions taken as a result of their interpretation of information contained in the publication. Please submit your stories, with contact information and appropriate photograph, to: Megan Mallory, “Persistent Voices,” Pulmonary Hypertension Association, 801 Roeder Rd., Suite 1000, Silver Spring, MD 20910 or as an attachment (.pdf, .doc or .rtf) to Print@PHAssociation.org. (Submissions may be edited for length and clarity.)
topics to talk about, they offer question-and-answer time so attendees are able to make the most of their experience.

PH patient and past PHA on the Road attendee Carmen Lozada recommends participating as much as possible. “The question-and-answer sections clarify all your doubts and concerns about life with PH,” she says.

When these patients were asked what advice they would give future attendees, their recommendations were unanimous. “Just go! Even if you don’t learn anything new, you get the chance to meet people who share this disease and talk to them. You don’t feel so alone,” says Lynn.

PH patient Dianne Reed, who not only attended a past forum but also volunteered, agrees. “Go! Enjoy! You might learn something new or meet someone you just connect with. I found it to be one of the best days I had in 2012.”

Carmen found that she took home more than just a broadened knowledge of the disease, she also found a friend. “I met an Hispanic New Jersey patient who offered support. We got to share lunch at the same table with other Hispanic patients.”

PHA on the Road is a forum that is as unique and exciting as those who attend it. For more information about PHA on the Road or to register, visit www.PHAssociation.org/OnTheRoad, contact OnTheRoad@PHAssociation.org or call 301-565-3004 x763.

PHA on the Road launched in 2009 as a way to help fulfill PHA’s mission of finding ways to prevent and cure pulmonary hypertension. This program is sponsored by the Pulmonary Hypertension Association Medical Education Fund.

By Rebecca Gifford, PHA Meeting Planning Associate
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Building Medical Education in PH (BME) events are designed to foster partnerships between PHA, PH Centers and medical professionals. The program supports continued education in the PH field through CEU/CME educational events. Participating in PHA’s BME program can benefit your educational event by providing one-time use of PHA’s medical professionals mailing list, advertising support, educational materials for distribution to attendees and more.

To partner with PHA in Building Medical Education in PH for your upcoming CME event, please contact 301-565-3004 x776 or BME@PHAssociation.org.

To learn more about this partnership, visit www.PHAssociation.org/BME

Upcoming BME events:
7th Annual Pulmonary Hypertension Symposium
June 6, 2013
Yale School of Medicine – New Haven, Conn.
Register at: www.cme.yale.edu

6th International Conference on Neonatal and Childhood Pulmonary Vascular Disease
June 21 - 22, 2013
University of California, San Francisco – San Francisco, Calif.
Register at: www.KidsWithPHSymposium.com

NYC PH Symposium:
Shining A Light on Pulmonary Hypertension
May 10, 2013
Beth Israel Medical Center – New York, N.Y.
Register at: www.chpnet.org/cme

To view a full list of education opportunities for medical professionals, visit: www.PHAOnlineUniv.org/Calendar

It’s About Time You Picked Up the Phone!

PHA offers free monthly telephone support groups for busy patients, caregivers and parents. Join us for the hour, or join us for less — we’ll be here!

Sign up to receive monthly email alerts. You can also order or print your own reminder postcards. Just visit our website at www.PHAssociation.org/TelephonePostcards or call 301-565-3004.

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Order now through July 1 at the PHA Online Store, www.PHAssociation.org/Store, or give us a call.

Want a discount on the Phineas PHriend, but not a member? Visit www.PHAssociation.org/Join to become a member of PHA today!

Questions? Call the PHA Office at 301-565-3004.
Are you getting ready for summer and wishing that PHA’s biennial International PH Conference and Scientific Sessions was just around the corner? Not to worry! You can revisit PHA’s 10th International PH Conference and Scientific Sessions with PHA’s online resources for patients and medical professionals.

The patient and medically led sessions from PHA’s 10th International PH Conference and Scientific Sessions provide patients and caregivers with the opportunity to learn about living with pulmonary hypertension from experts and medical professionals as well as their fellow patients and caregivers. In the words of one attendee: “I benefitted from every session I attended. They were educational, inspiring, caring, and allowed the development of longer-term supporting friendships.”

PHA Classroom (www.PHAssociation.org/Classroom) will be the home for all patient and medically led sessions from the 2012 Conference. If you missed a session or need a refresher, head over to PHA Classroom, PHA’s e-learning hub for patients and caregivers, to watch the latest recordings.

Medical professionals have several ways to catch up on the proceedings of the 2012 Conference. First, the latest issue of Advances in Pulmonary Hypertension, PHA’s quarterly clinical journal, provides summaries of many of the talks as well as a roundtable discussion about the recent meeting. It also includes abstracts from the most promising young investigators in the PH field. These articles and discussions highlight many of the areas where our understanding of PH is heading toward more effective treatments and eventually a cure. Read this issue at www.PHAOnlineUniv.org/Journal/Conference2012.

Medical professionals particularly will want to check out the Conference Scientific Sessions recordings on PHA Online University at www.PHAOnlineUniv.org/2012ConferenceRecordings.

“The 2012 Scientific Sessions marked the seventh time scientists and medical professionals have gathered at the International Conference to hear the latest scientific advances in the field. Under the leadership of Dr Todd Bull, the theme was Genetics of Pulmonary Hypertension, with talks focused on continuing efforts to understand BMPR2 mutations in PAH, other genetic contributors important in development of PAH such as microRNAs, genes that cause HHT, and PAH as a systemic disease,” says Karen Fagan, MD, chair-elect of PHA’s Scientific Leadership Council. “I think that it really allowed us to focus in on a lot of different, creative ideas related to pulmonary hypertension and future directions.”

The 2012 Conference included a record-breaking number of abstract submissions by researchers presenting their current research in the field of pulmonary hypertension. These abstracts are also available on PHA Online University.

Stay tuned in the coming months for information about PHA’s 11th International PH Conference and Scientific Sessions in Indianapolis, Ind., in June 2014. It’s just one short year away!

By Caitlin Flewellen, PHA Online Education Associate
When Katie Grace was 5 and her sister Savanha was 9, Katie Grace was diagnosed with pulmonary hypertension. We asked Katie Grace and Savanha to share their experiences living with PH.


How old are you both now? Katie Grace is 10, and Savanha is 14.

How has PH impacted you and your family?

Savanha and Katie Grace: We had to move away from our home, friends and family to be closer to Katie Grace’s pediatric PH specialist. But now we have made a lot of friends here. We have a new home, and we have had opportunities to do things we never would have if we hadn’t moved.

Tell us about some of the things you’ve done to raise awareness of PH.

Savanha: I run in races, write papers for science class and have worked with friends on local news articles explaining PH and the people it affects. Each year I have dedicated my birthday to raising both money and awareness.

Why is fundraising important to you?

Katie Grace: I want a cure for all my PHriends. I want to keep other kids from having to do the things I have to do to stay healthy.

Savanha: I had a friend who I met when my sister was diagnosed who lost her battle with PH three years later. I know other PHers, and I want to do all I can to keep this from happening to my sister and them.

What message do you want to share with other kids who are interested in raising awareness of PH?

Katie Grace and Savanha: It is really very easy. Find out if your school will let you announce PH Awareness Month in November. Choose that month to write a science paper, send a letter to your mayor and ask him or her to sign a proclamation, invite your local town paper to write about PH Awareness Month. We like to fundraise, but more importantly we want people to know the signs and causes of PH so that they can be educated enough to help others.

What’s the most important thing you think other kids should know about PH?

Katie Grace and Savanha: PH is not contagious and does not prevent us from being a normal family. Living with PH has made us stronger.
I'm (Almost) 18. So What?

You’re in high school. You’re juggling that stressful midterm and school projects, maybe thinking about where your friends want to go to college and whether you’ll go to the same school. Maybe there’s a guy or girlfriend; maybe there’s an internship or summer plans to make. And there’s your mom or dad, reminding you to take your meds, and now they want you to meet some new doctors because you’re almost 18.

I’m (almost) 18. So what?

Many hospitals require adult-age patients — usually meaning you’re 18 — to be treated by adult healthcare teams. This means that even if you’ve been treated by the same team since you were born, hospital policy might require you to transition to an adult healthcare team when you become an adult. When that happens, the doctors will want you to be the active one in making decisions — not your parents.

As you approach age 18, if you have plans — to move out, go to college, start your own life — you need to be ready, and a big part of that is managing your PH on your own.

But I’m not 18 yet. When do I need to start thinking about this?

Think about how much time your parents put into helping you manage your PH and how many things they had to learn — all the medical and technical stuff. You have a head start because you probably know most of that just from growing up with it. But there is probably still a lot for you to learn, and taking on your own healthcare all at once — remembering to call the pharmacies, mixing your meds, knowing your full health history to explain to your new doctors, making insurance decisions — could be overwhelming. If you take it in steps, you’ll feel more comfortable when it’s time to take over your own healthcare. Researchers recommend starting to prepare, in small steps, for your transition to adult healthcare as early as age 12.

But can’t my parents still help with that stuff?

Some of it. Because of laws about healthcare privacy, you must sign legal forms to allow your doctors to talk to your parents, and you can ask your parents to help you with pharmacy refills and the like. But if you go to college away from home or move out, then your parents won’t be around all the time.

Okay, I get the message. Now what? Where do I start?

Your hospital may already have a transition program in place. But whether or not this is the case, check out PHA’s Teen Transition Guide at www.PHAssociation.org/Teens/Transition. The Transition Guide offers suggestions as to what responsibilities you should take on for your own healthcare depending on your age. We’ve also provided forms that will help you gather all the information you will need to comfortably discuss your PH care with your healthcare team when you switch to an adult healthcare setting. We also have Young Adult PH Email Mentors who can answer any questions you have along the way.

Check out the Teen Transition Guide on your smart phone!

PHA's Teen Social Network is now on Facebook!

If you are:

• Ages 13-18
• Living with PH
• Interested in connecting with other PH teens

Join us at www.facebook.com/groups/PHATeens
A medical crisis can be a frightening experience for both you and your child who has PH. During an emergency, being able to communicate with your child about symptoms and help them stay calm are especially important. Handling an emergency begins long before the emergency happens: advance preparation can make all the difference. Read on for advice on communicating about symptoms and helping your child — and their siblings — cope during and after a crisis.

**Communicating About Symptoms**

**Happy Face, Sad Face.** Smiley face pictures can be a great way for kids to indicate how they are feeling: a smiling face means they feel well, a face with a flat mouth means not great, and a frowning face means they are in pain. Families might prefer to use different symbols that their child associates with being happy or sad — for instance, foods your child likes and dislikes.

**Stand-In.** When your child is under stress, it can be more difficult for them to tell you what’s wrong. Using their doll or action figure as a stand-in for them to point out “where it hurts” can be a great technique — and the toy may be comforting to your child in the midst of a crisis, so it’s great to bring it out anyway.

**Be Consistent.** Each family has its own words for symptoms, treatments and medical equipment. When the Emergency Medical Technicians arrive, let them know what names you and your child use when talking about these things. It will facilitate their communication with your child, and the familiar names will be less frustrating, and more reassuring, for your child.

**Helping Your Child Keep Calm During a Medical Crisis**

**Breathe In, Breath Out.** Focusing on a breathing exercise helps children in two ways: it distracts them from the crisis, and deep breathing helps the body de-stress. Practice breathing exercises regularly so that your child is comfortable using them, and then guide them through the exercises during a crisis.

**Use Imagination.** Children have wonderful imaginations, which can be great for practicing guided imagery relaxation exercises. Take some time each week to practice imagining yourselves somewhere calming, like the beach. Ask your child questions to help them focus on what they are imagining — “What are you wearing? Who else is at the beach?” Then during a crisis, help your child go to their “happy place.”

**Comfort Objects.** Most children have a comfort object — a blanket, toy or doll — they want with them during unsettling moments. Make sure you bring along your child’s comfort object during a crisis.

**If You’re Not There.** If your child is on medication, you’ve probably trained your childcare providers in administering the treatment and being on the lookout for any side effects. Similarly, you want any adult caring for your child to know how to help your child stay calm if a crisis occurs. Along with your other instructions, show them any breathing exercises, relaxation techniques or coping tools you practice with your child.

**Don’t Lie.** You want to build your child’s feeling of safety and trust in you and their medical professionals. Don’t make promises, and don’t tell your child, “It won’t hurt.” Broken promises will be more damaging in the long run.

**Stay by Their Side — and Let Them Know It.** An unplanned visit to the hospital can be frightening, and your child will take reassurance from your presence. Make sure they know that you’re aware of how they are feeling and that you’re going to stay by their side. For instance, you might say, “I know you’re having a hard time breathing right now. The doctor is going to help, and I’m going to stay with you.” If you’re required to leave the room for a procedure, explain to your child where you’re going, why, and when you’ll be back.

**Helping Your Child — and Their Siblings — Cope**

**It’s No One’s Fault.** Children, particularly around ages 3 and 4, often believe that their thoughts, feelings and actions significantly impact the reality around them. This means that they may blame themselves for events in their lives. Young children could easily believe that their medical crisis is their fault, and you may need to reassure them. Let them know that the crisis is NOT their fault. This is an additional reason to stay by your child’s side in the ambulance and hospital: it will reassure your child that you don’t blame them for what’s happening and that you love your child just as much as you did before the crisis occurred.

**Brothers and Sisters.** In the midst of a crisis, your focus is understandably on your child who has PH.
Remember to take some time after things settle down to talk to your other children about how they felt during the crisis. Let them know you’re proud of them for being brave and thank them for any help they gave you — whether it was by staying in their beds, helping pack for the hospital or comforting their sibling.

Additional Resources

Books You and Your Child Can Read About Visiting the Hospital:

- Franklin Goes to the Hospital (2000) by Paulette Bourgeois and Brenda Clark
- Going to the Hospital (2009) by Anne Civardi
- Clifford Visits the Hospital (2000) by Norman Bridwell

For additional book suggestions, visit the Boston Children’s Hospital website at:
http://childrenshospital.org/patientsfamilies/Site1393/mainpageS1393P442.html

Resources for Parents:

- Read Your Child in the Hospital: A Practical Guide for Parents (1999) by Nancy Keene and Rachel Prentice for tips from other parents
- Read Helping Healthy Children and Siblings Cope for additional tips on helping your healthy children cope: www.PHAssociation.org/SiblingsandKids
- Read Helping Children with PH Cope for additional tips: www.PHAssociation.org/Parents/HelpingYourChildCope

Sample Guided Imagery Relaxation Scripts:

- “Kid’s Meditation Guided Imagery Script for Childhood Stress” by Shambala Kids & Teens www.KidsMeditationCDs.net/guidedimageryscript.htm

PHA is grateful to Patricia Dwyer, MSW, LCSW, of the Lucile Packard Children’s Center at Stanford Hospital and Clinics for her contributions and review.

Announcing a Contest for Kids:

Help us raise awareness and support work for a cure! Art from the Heart bookmarks are one of the many ways that PHA thanks people who donate money to help find a cure for PH. PHA wants to use your design for our Art from the Heart bookmarks! Kids ages 15 and under can enter the PHA Art from the Heart contest. The contest is open to both kids who have PH and kids who have a family member or friend with PH. Artwork should show the strength it takes to fight PH or your hope for finding a cure. The contest deadline is July 31, and winning artists will be profiled in the October 2013 issue of Pathlight!

Look below to find a template you can cut out and trace on a plain white piece of paper for a bookmark design. For the full entry form and complete instructions, visit www.PHAssociation.org/ArtFromTheHeart.

Don’t have access to Internet? Contact Ellen Leoni, PHA’s Development Associate, to receive a paper entry form: 301-565-3004 x756.

PHA Art from the Heart bookmarks will be produced in memory of Christen White Cranford through the generosity of Jodi and James Palmer.
PASSAGES is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x800 or MichalR@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

For those for whom it would be helpful, PHA has developed a resource, Mourning a Loved One: A Guide to Grieving, which is available at www.PHAssociation.org/Caregivers/Bereavement. For more information, or to request a print version of this guide, please contact Bereavement@PHAssociation.org or 301-565-3004 x800. We welcome all loved ones to remain a part of our community for as long as it is beneficial.
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DONATIONS LISTED WERE RECEIVED BETWEEN DECEMBER 1, 2012, AND FEBRUARY 28, 2013. PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

TAKE A LOOK! Sustainers Circle Members Recognized

PHA now recognizes members of our Sustainers Circle in the donations lists. Look for a symbol to see who has made a sustained commitment to donate to PHA on a monthly basis. If you are not a member of our Sustainers Circle but are interested in joining, visit www.PHASassociation.org/Donate/SustainersCircle or call Ellen Leoni at 301-565-3004 x756. You may also use the remittance envelope enclosed in this issue of Pathlight.

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x777, EOH@PHAssociation.org

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x756, Membership@PHAssociation.org

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952-380-4999

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Patient-to-Patient Support Line Coordinator
Pat Paton, pjpaton1@gmail.com
772-597-4962

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1-866-FIGHT-PH
for Veletri
1-866-344-4874

for Remodulin
1-866-FIGHT-PH
for Tracleer
1-877-483-6828

for Ventavis
1-877-483-6828

Caring Voice Coalition
1-888-267-1440
Curascript Helpline
1-866-4PH-TEAM

CVS Caremark Helpline
1-877-242-2738
(Remodulin, Tracleer and Flolan)

GlaxoSmithKline Patient Assistant Programs
www.gskforyou.com

Letairis
1-866-664-LEAP

NeedyMeds
www.needymeds.org

Partnership for Prescription Assistance
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The Summer issue deadline is May 6, 2013.

Pathlight is your publication. Tell us about your support group, recent event, phenomenal PHer 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, quotes, photos, tributes, etc. for consideration in the newsletter. We also accept submissions of personal PH stories, pictures, poems and quotes for publication in the next issue of Persistent Voices. If you’re not comfortable writing your story — or if you just can’t find the time — contact us and we’ll interview you about it and write it for you. If you are interested in reporting for Pathlight or conducting interviews with other members of the community, let us know. Please contact us with your input and stories! Send submissions, with your phone number, to:

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To get started now, visit www.PHAssociation.org/PHReady