First Pediatric Pulmonary Hypertension Research Program Funded

In late September 2012, the Robyn Barst Pediatric Pulmonary Hypertension Research and Mentoring Fund reached its stage-1 fundraising goal of $1,000,000 to begin awarding grants. This is the world’s first research and mentoring fund established to support pediatric research in PH.

Named for Dr. Robyn Barst, a pioneer in the field of PH who provided the gifts to launch this research fund, the Robyn Barst Pediatric PH Research and Mentoring Fund will provide grant opportunities that include both clinical research and patient-care components. The fund is intended to provide young physicians with mentoring to develop clinical research skills as well as appropriate role models for patient care. Young physicians will be mentored by established pediatric PH physicians in PH centers.

Participating physicians will be trained on how to take care of children, and they will also be trained in clinical drug development intended to improve survival as well as quality of life.

“It takes a lot of exposure,” says Dr. Barst, since treatments and available drugs can change and vary rapidly over time. Clinicians and researchers must spend considerable time studying and treating the disease firsthand to reach conclusive findings regarding diagnosis and management.

Dr. Barst has seen, and often been the catalyst of, advances in the field of PH. PH treatment options have increased since the beginning of her career when the sole option was heart-lung transplantation. Now patients can be managed on one of nine FDA-approved therapies.
As I read the stories in this issue of Pathlight prior to its publication, I could see that 2013 is going to be a big year for our community.

PHA has never been an organization to rest on its laurels. Every year it strives to do more for the various communities it serves, and 2013 will be no different.

I hope you were as excited as I was when you received your Pathlight and saw on page 1 that 2013 is the year that, for the first time, PHA will offer targeted pediatric research grants through the Robyn Barst Pediatric Pulmonary Hypertension Research and Mentoring Fund.

I have had the privilege to benefit from Dr. Barst’s knowledge of this complicated field for many years, and I couldn’t be more pleased that research grants aimed at advancing the field of pediatric pulmonary hypertension — her personal passion and life’s mission — will soon be awarded. In addition to reading about the fund, you can learn more about Dr. Barst and her contributions to the field on page 15.

When you get to page 19, you’ll learn about an innovative new fundraising venture PHA is embarking on — establishing chapters in three major metropolitan areas: Chicago, New York City and San Francisco. These chapters, whose primary purpose is to advance PHA’s work through signature special events fundraising, will also raise the profile of our too-little-known disease in areas populated by millions. I am very pleased to know that running this critical program is in the good hands of Carl Hicks, one of my predecessors as chair of PHA’s Board of Trustees.

Throughout the issue you’ll find news of our early diagnosis campaign, Sometimes it’s PH, including a challenge to our younger readers to find the many zebra images that grace the pages. The zebra symbol for this campaign — used because in medical circles a zebra stands for a rare diagnosis or disease — has been widely embraced by our patient and medical communities alike.

Special events are being “zebra-fied” with participants donning all manner of zebra accessories; patients and others are sharing an array of intriguing zebra photos with us online; and the world is taking notice — our campaign video was recently translated into Spanish and the medical community has asked PHA to take this critical campaign global.

Our sincere hope is that over the coming years, those suffering from PH will not have to wait an average of 2.8 years to get diagnosed because physicians will know that “sometimes it’s PH.”

These are just the highlights of what’s in store — there’s much more to come in the year ahead, so please stay tuned.
Email Mentors are patients and caregivers from all over the world, standing by to help patients, caregivers and parents through one-on-one, email-based support. Read on to learn about BreAnn McFarland, an email mentor and transplant survivor.

**What’s your PH story?** In eighth grade, I started having chest pain and dizziness. My pediatrician referred me to a cardiologist, who diagnosed me with a hole in my heart and scheduled surgery to take place during my summer vacation. Before surgery, I had to have a heart catheterization, and the doctors discovered that I had PH rather than a hole in my heart. I was admitted to the hospital to do the testing I needed in order to be put on the transplant waiting list. Before I had a transplant, however, my doctor wanted to exhaust every other option available.

I made it through my freshman year of high school taking only a blood thinner for treatment. Then I was placed on Flolan®, which was still experimental at that point. Flolan® kept me going through high school, but the side effects were destroying my body. I finally had to accept that it was time for transplant, so on my 18th birthday, I was placed on the waiting list for a bilateral lung transplant.

In October 2002, I had seizures due to a medication interaction, and I ended up in ICU. I was struggling to breathe, and the doctors told my family that I probably wouldn’t make it ... but I did. I wasn’t on oxygen until after the seizures, but all of a sudden, I couldn’t turn the tank high enough to get enough oxygen. I felt like I was being held under water with a rock on my chest, slowly suffocating.

On Dec. 7, 2002, I lay in bed, knowing that I was out of time. We all knew that without new lungs, I would not make it through the weekend. That’s when the phone rang with the call I had waited five years for: I was about to receive my new lungs. There were some complications because my body was so debilitated, but after a few days I finally began to improve. It was not the ideal place to spend Christmas, but I had no complaints that year ... I had just been given the best Christmas gift ever, the gift of life! A gift that I am still incredibly thankful for 10 years later.

**What does being a PH Email Mentor mean to you?** As a mentor, I want to bring hope to other people living with this cruel disease. I thought I had been given a death sentence when I was diagnosed, but my doctor gave me hope. No matter how bad things got, he kept that hope alive in me. If you don’t have hope for the future, you don’t have anything to fight for ... to live for. I know my life was saved for a reason, and maybe that reason was to show others that there is always hope.

**How can a PH Email Mentor help?** As PH Email Mentors, we use our experiences and the knowledge we’ve gained from our PH journeys to guide and support other people living with PH. Being told you have a rare lung disease is one of the scariest things in the world, and everything just falls apart around you as each word sinks in. Then you hear the four little words that echo in your mind, “There is NO cure.” When you are hit with something so hard, to be able to talk to someone who has already been through the same thing is a huge comfort. You find hope in knowing that you can live with this disease, and that you can still have dreams and goals for the future. You learn that it’s not the end — not by a long shot.

Email BreAnn at BreAnn@PHAMentors.org or connect with another PH Email Mentor by gender, age, associated disease or other topic of interest at www.PHAssociation.org/Mentors.

**Contact me about these and other topics:**
- Infused medication
- Transplant
- Going to school with PH
- Gender-specific issues

BreAnn@PHAMentors.org
Videos Shed Light on How Patients Cope with Multiple Illnesses

Pulmonary hypertension is a tough disease by itself, but many patients develop PH in association with another chronic illness. To explain what life is like for these patients, PHA recently released a video series that focuses on PH in association with congenital heart disease (CHD), lupus, HIV and scleroderma. Although patients experience their PH and their associated illnesses individually, the patients and doctors who participated in the videos shared some key messages that are pertinent to all patients. Patients may find these tips, gleaned from the videos, helpful whether they have PH alone or with an associated illness:

Listen to what your body is telling you.

“Everybody has a different baseline; someone who runs every day, suddenly can’t go that extra mile or whatever they were doing before. That may be a sign that something is going on,” shares Richard Krasuski, MD, Cleveland Clinic.

Patients should be prepared to be their own advocates.

Colleen Schnell was born with congenital heart disease (CHD) and pulmonary hypertension, but wasn’t diagnosed until she was 9 months old. When you have multiple illnesses, Colleen suggests that “you really have to be your own advocate. If you’re having issues and your doctor doesn’t understand, you have to understand yourself and what is going on.”

The incidence of associated illnesses and PH varies.

Dr. Krasuski notes that epidemiologic studies suggest that 5–10 percent of patients with CHD develop PH: “To be able to recognize this requires an astute doctor and an astute patient.”

According to Robert Schilz, DO, University Hospitals of Cleveland, “Only a tiny proportion of people with lupus ever develop PAH. It is estimated to be about five in every 1,000 lupus patients.”

Virginia Steen, MD, Georgetown University Hospital, notes that 10–15 percent of patients with scleroderma go on to develop PH.

As Hap Farber, MD, Boston University School of Medicine, explains, “People who get PAH associated with HIV have been infected a long period of time, usually eight to 10 years, or longer … the median survival for someone newly infected with HIV is now 19–20 years. So if the thing that’s important as far as developing PAH is how long you’ve been infected, most people will survive long enough to at least be at risk … that’s one in 200.”

Find doctors who collaborate and understand your illness or illnesses.

“Find an HIV doctor who knows about PH; find a PH doctor who knows about HIV or is at least willing to learn. If you can’t do that, find a university or hospital where everything is under one roof, where your doctors communicate and work together,” says Jeannie Wraight, a PH and HIV patient.

“You end up with specialists for everything you have, because it’s so complex that one doctor really can’t be an expert on all of it,” says Ellen Rains Harris, a patient living with scleroderma and PH.

Support — it’s essential!

Rita Hébert has PH associated with CHD. At age 6, she says the doctors realized there was something “very, very wrong with me.” Rita is a proponent of support groups to end the isolation of living with “a very isolating disease.”

Your disease doesn’t define you — you do.

Jeannie Wraight has been HIV positive for 18 years and was diagnosed with PH eight years ago. “It is really difficult living with one life-threatening illness; living with two 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 that you did before. You’re not going to be able to do all the things you want to do … but that’s ok, because you can do other things.”

Tammy Gilbert, who has been diagnosed with both PH and scleroderma, shares, “If the sickness becomes your identity, then you don’t have a shot. You have to surround yourself with people who don’t make you feel sick.”

PHA thanks the doctors and patients who participated in making these videos: Colleen Schnell, Rita Hébert and Dr. Richard Krasuski (CHD); Jeannie Wraight and Dr. Hap Farber (HIV); Ellen Rains Harris, Tammy Gilbert and Dr. Virginia Steen (scleroderma); Anna Bower, Veronica Elaine Lobato and Dr. Robert Schilz (lupus). The production of the Associated Disease Video Series is made possible by an unrestricted educational grant from Novartis Pharmaceuticals. These videos and other resources for those living with PH and another disease are available online at www.PHAssociation.org/PHPlus.

By Kim Lamon-Loperfido, PHA Manager, Patient Outreach & Services
My name is Lorena Dávila Hernández, and my story with diagnosed pulmonary hypertension began May 29, 2006. I had already presented with almost all the symptoms. I tired easily, and I was a little short of breath, but I didn’t pay attention and simply thought it was because I was gaining weight.

Slowly my lack of air got worse. I remember very clearly going walking while on a mission trip one day. There were some light hills, and there was a moment when my heart started to beat very quickly, like it wanted to escape from my chest. After that I went back home, and I started to get inflamed eyelids, lips and legs. I got to a point where I could only walk a few steps before getting really tired. I went for a consultation at the university hospital, and there were a lot of questions and exams. At 21 years of age, my only dates were with the doctor.

One day I started to have trouble getting air, and then I couldn’t breathe. I felt like I was suffocating, and I fainted. I was taken to the doctor, and on May 26, 2006, they performed a heart catheterization. I can’t forget that my doctor looked me in the eyes and told me that I had a chronic disease called pulmonary hypertension. I didn’t get scared; I was just stunned. Everything was changing so drastically that I didn’t know what to do.

I remember going home and giving the news to my family. Everybody was sad, and I went to my room and started to cry. That day I said to God that I didn’t want an explanation; I only asked that God give me the strength and that He help me because I was going to fight. I had no intention of dying soon from pulmonary hypertension.

It hadn’t been easy, but with my family supporting me and giving me their love, everything has been more manageable. Today I say with all sincerity that this disease has changed my life in a good way; in the first place, I have continued to become closer to God, and I have learned to value the little things in life that others do not.

My doctors invited me to participate in a drug trial with oral treprostinil, and I accepted. One of my sisters said that I shouldn’t; she was scared and didn’t know why I was letting them experiment with me. I told her that to fight and find a cure, they needed brave and determined people and that I was both brave and determined. I wanted to do something for me and for others. I told her that you can’t ask for health, you can’t ask for medicine, you can’t ask for a cure if you want everything to fall from the sky for you. You must do something yourself. I told her that if she wants to help me, please don’t ask me to stop because I won’t. I’m thinking not only about myself but also other generations of people, like my nieces and nephews.

The drug trial was a big challenge for me — even more so when I found out all the secondary effects: headache, nausea, vomiting, stomachache, jaw ache, face flush. Some or all of these symptoms could present themselves.

Like always, my brother went with me the day that I signed the informed consent. The most important rule was to try to tolerate the medication as much as possible. I was to start with 1 mg in the morning and 1 mg at night, which I did. When all of the symptoms manifested themselves, I sometimes thought of giving up, but I reflected on it and continued onward. At one point I was able to tolerate up to 10 mg in the morning and 10 mg at night, although that was too much!

As I adjusted, my quality of life got better and better until I was leading a nearly normal life — climbing stairs, wearing high heels, dancing. I felt excellent and very happy. The best was that my six-minute walks were more than 500 meters without dyspnea, with good saturation and with a good heart rate.

I invite all of you to not be scared in the face of this disease. We must keep fighting to bring knowledge and awareness about it. I know and trust that the cure will be found because we have advanced so far with the medicines. Soon we will have that which all patients and our families so long for.

By Lorena Dávila Hernández, PH Patient in Mexico; translated by Julia Friederich, PHA International Program Associate

To read the full version of Lorena’s story in English or Spanish, please visit www.PHAssociation.org/SometimesItsPH/LorenaDavilaHernandezDiagnosisStory. Check out more stories from around the world at www.PHAssociation.org/PHInternational/Faces.
Breathing Fire: PH and Anger

Have you ever gotten so angry that you wanted to hit something or throw something? Have you ever been so mad that you gave a tongue-lashing to someone? Have you ever been so angry that your body felt so hot? I’m sure I’m not the only one who’s been there, but we have every right to feel angry. We have a chronic, incurable, life-threatening illness that has drastically changed our lives.

I get mad at people who just don’t get it; I’ve been mad at someone for staring at me while I’m walking with my oxygen tank. I’ve been angry at my mom when she asks me if I’m okay; I’ve been mad when I see another medical bill I can’t pay. I get mad when I can’t walk at the pace of other people; I get angry when I have to cancel plans with friends. I get mad when I can’t focus. I get mad when I don’t have any more energy left; I get angry when I have to spend a day in bed. I get mad when I can’t go to the club with friends. There are probably more than a 1,000 things that cause me to get angry about my pulmonary hypertension and how it affects my life.

But behind that anger is sadness and depression, and I’m most angry with my body and the fact that I have PH. The pressures and frustration of having a chronic illness build up inside. It’s so hard to have an illness where I can’t take an antibiotic to get rid of it in 10 days. I wake up, and I’m still in the same body that I fell asleep in the night before. I’m still sick. I get frustrated when I know that I used to be able to do something and I no longer can do it since my PH symptoms started. I have PH. It hurts my soul, and I cry out sometimes. But it’s okay to feel anger, sadness and hurt.

But just because we have PH, it doesn’t give us a free pass to explode on family, friends or complete strangers. My sister once told me that it was hard to live with me because she didn’t know how I was going to be from moment to moment. It’s hard to deal with the anger, so we need to use some of the outlets available to us to deal with it. For instance, we can post on the Generation Hope Google email group or the Generation Hope: Young Adults with Pulmonary Hypertension Facebook page or share at a local support group meeting. We can also talk to a friend, family member or professional; write in a journal; pray; listen to music; or punch a punching bag. Continue to have hope and be positive. Also, remember that we are not alone with this illness and anger. A cure is burning up!!!

By Kiara Tatum, PH Patient, PHA Generation Hope Blog Coordinator, PHA Generation Hope Advisory Board Member

“A Breath of Fresh Air” is a section devoted to young adult issues. To learn more about Generation Hope, PHA’s group for patients in their late teens, 20s and 30s, visit www.PHAssociation.org/Patients/YoungAdults

This article by Kiara Tatum was first published as part of the Generation Hope blog. To read more blog entries, visit www.PHAssociation.org/GenerationHope/Blog

PHA Offers Guides for Coping with Pulmonary Hypertension

In her article above, Kiara highlights how living with a chronic illness can elicit strong feelings. Although we know that strong negative feelings may not last forever, we may feel challenged to cope with them when they arise. It is important to acknowledge that life with PH can be difficult. Anger and sadness are both okay and normal. Finding an outlet for emotions, connecting with others and reflecting on your purpose are coping mechanisms that others living with PH have turned to for solace. PHA has developed new resources to help you manage the mental, emotional, social and spiritual side of living with PH. These guides are available for download from www.PHAssociation.org/Coping and may also be requested in print. However, if managing your emotions becomes too difficult, seeking professional help may be your next step.
Have You Got PHA’s Support Resources in Your Back Pocket?

Everyone needs resources and people they can turn to when they have a quick question, want to vent, share successes or just connect with others who “get it.” Are you aware of all the resources PHA offers for family members and friends of people living with PH?

Coping article series: Offered as online articles, downloadable PDFs, and in print, these recently released articles address a variety of important topics for caregivers: managing stress, caring for your relationship while caring for your loved one’s health, seeking help with everyday tasks, identifying depression and more. We also offer recorded webinars for caregivers on related topics on our website. As Chris, a caregiver for his wife, explains, “[These articles] touched on a lot of things that my wife and I have gone through over the past 3+ years and affirmed a lot of the helpful behaviors that we have adopted.” www.PHAssociation.org/Caregivers/Coping

Caregiver Email Mentors: Are you still learning your way around life with PH? Have you been handling your loved one’s PH for years but encountering new questions or concerns? Want someone you can have a supportive exchange with via email? PHA’s PH Caregiver Mentors are available to share their experience and offer guidance and support to other caregivers at any point in their PH journey. Submit a one-time question or connect for an ongoing email relationship. www.PHAssociation.org/Mentors

Caregiver Shout-Out! This Shout-Out goes from PH patient Jana Guranova to her husband and caregiver Michal.

Shout-Out to my caregiver and amazing husband Michal Guran. He has been by my side from the day I was diagnosed! He accepts my bad moods and my bad days. He is my perfect friend, and I can share my feelings with him.

Before my lung transplant, he brought me breakfast in bed every morning, and every evening he took me upstairs to bed. When I needed something, I always knew I could count on him. I was really dependent on my husband during my transplant process, and I don’t know what I would have done without him. My darling, I really thank you for everything, and I hope we will be able to face any challenges together that may appear. I love you, and you know it!

Visit www.PHAssociation.org/Shout-Out for a chance to express gratitude to your loved one in Pathlight.
Aggie Stefanelli (Hamilton, N.J.)

I was diagnosed on June 22, 2009. I’ll never forget that day. I had been telling my primary care doctor that I just didn’t feel right and couldn’t really take a nice, clean deep breath. He always said it was anxiety or menopause, so he put me on anti-anxiety meds.

My daughter was a senior in high school, and I was very committed to participating with her extracurricular activities. I was exceptionally tired but figured it was the busy schedule of working full time, attending PTA and post-prom meetings, dance recitals and competitions. At the same time, my son was applying for law enforcement positions and working towards getting accepted in a police academy.

I started to notice that I had an enormous amount of swelling in my legs at the end of the day, and again my doctor would tell me that I was eating too much salt! At the same time, people started to tell me that my lips looked blue, and I felt that my coloring was off. Once again, I went back to my doctor, and he finally said that I should have an echocardiogram done. I had no idea what he might be looking for. I figured I might have a blocked artery or something.

I was absolutely shocked to receive a letter in the mail from my test results stating that I had pulmonary hypertension. Having no idea what that was, I, of course, went online, only to discover that I basically had two to three years to live. I was absolutely devastated. I couldn’t imagine not being around for my children. I want to see them grow into adults, marry, give me grandchildren, etc. I went to a lung specialist who put me on oxygen immediately and told me to see a pulmonary specialist in Philadelphia. I called and did not get an appointment until September. It was terrible trying to work and carry on as usual and have people look at me with the oxygen attached and ask questions that I didn’t know the answers to.

THANK GOD for the wonderful nurses and doctors at the University of Pennsylvania. I had a catheterization done, and they could not believe what bad shape I was in. I was put on Flolan® immediately and, after a week in the hospital, came home to an entirely new life. It has been a struggle with a few serious infections in my Hickman line and some unwanted stays in the hospital. I am currently on Veletri® (an alternative to Flolan® that requires no ice or making more than one cassette at a time) and only have to use oxygen while sleeping. All in all, I am still able to do whatever I would like to, although I did decide to retire a few years earlier than expected.

As much as PH is devastating to be diagnosed with, I was glad that they finally found something, as I just knew that my body was not functioning correctly. I feel that it is important to be your own advocate and insist on having your doctor continue to do tests, as you are the only one who really knows how you feel. I feel that it is important to be your own advocate and insist on having your doctor continue to do tests, as you are the only one who really knows how you feel. It has been three years since I was diagnosed, and I have a much more positive attitude about PH and being able to live a long and very active life.

My son will be 25 soon and is a correction officer for the state of New Jersey. My daughter is an intern at a hair salon and is always trying out new hairdos on me, which I am glad to have done! I feel blessed to have very caring and attentive caregivers: my husband of almost 30 years and two wonderful kids. They’ve had to go through some very emotional days and changes themselves since my diagnosis.

I could sit around and say “why me” and have PH really get to me. There are days when I feel down, but it is important to look at yourself and say “why not me” and be positive and look at all that you do have in your life and enjoy every moment of it!
I am 27 years old and was diagnosed with pulmonary arterial hypertension in June 2012. I started experiencing symptoms nine months before I was diagnosed, while living in South Korea to teach English. Because I was only living there temporarily, I relied on public transit, which meant a lot of walking as well. There were a lot of stairs to climb at every subway station, and I began to notice that I was struggling to get to the top a lot more than I used to. I didn’t think too much of it. When my boyfriend and I finished our contracts in Korea, we traveled to Vietnam. I felt like I could barely keep up with him there. In my heart I knew something was wrong, but I couldn’t possibly figure out what it was, so I told myself and everyone else that I was just really out of shape.

We finished our traveling, and I came back to my parents’ place in Canada, where I grew up. I was excited to be home and began to run up the stairs to my childhood bedroom like I always did. When I had to stop halfway up the stairs to catch my breath and let my pounding heart slow down, I knew for sure that I had a problem.

Mom took me to the emergency room on Christmas Day, and we were lucky enough to see my family doctor. He couldn’t figure it out. Eventually, he referred me to an internal medicine specialist. In the meantime, I was living on my own and walking to work every day. My condition worsened, and my walk to work, which should have taken me 10 minutes, took me 25. I was stopping to catch my breath every 20 steps or so. I was afraid I would pass out while crossing the street. I was so embarrassed to be clinging to everything I could — fire hydrants, hydro poles, etc. — while people passing by in their cars stared at me, probably wondering why a young girl like me with no apparent problem couldn’t walk normally. I guess we were wondering the same thing. So many times I cried walking to work.

Finally, I saw the internal medicine specialist. After explaining everything to him and taking many tests, he told me that he didn’t know what was wrong with me but that I would have to live this way. He told me not to worry because my heart was fine, and the only way to decrease my symptoms would be to exercise more. After hearing that, I couldn’t stop crying. I left his office feeling more hopeless than ever.

I continued my life and tried my best to take his advice of exercising more. I clung to the stairway railing of my apartment building every day, pushing myself to get to my suite on the third floor. It was a daily struggle. On really bad days, my boyfriend, who also had a suite in the building, would piggy-back me up to my suite. He started to do everything for me. Suddenly, I started to retain water in my feet and ankles. I’d never had water retention before. I had a follow-up appointment to see the internal medicine specialist, so I hesitantly went back to see him and showed him my feet. He told me it was normal for a 27 year old to have water retention like that and sent me on my way.

Eventually, I was admitted to the hospital to rid my body of the extra water weight. Once the water weight was gone, my parents took me to the states to have an echocardiogram done at a mobile screening unit in Fargo, N.D. The echocardiogram showed my diagnosis of pulmonary hypertension.

Since then, I have been in the care of my amazing PH specialist. I’ve only just started treatment, but I feel amazing! I’m walking around as quickly as I want without stopping, picking things up off the floor without losing my breath, and daring to do more stairs than I have done in a long time.

I feel so blessed to be in the care of doctors and nurses who know about PH and to able to take medications that are helping me. I’m happier than I’ve been in a long time. I know that is strange because I’ve just been diagnosed with a life-threatening disease, but at least I know what I’m up against. The worst part for me was not knowing and just living with it. The diagnosis has been hard to deal with, especially not being able to carry a pregnancy. I’ve screamed and cried over this many times. But I’m happy to be where I am. God has carried me this far, and I know He’ll carry me the rest of the way. I’m excited to see the upcoming developments in PH treatments! ✧
Pathlight Volunteer Copyeditors Make Each Issue Strong

Before Pathlight reaches your mailbox each quarter, each story is read and reread to make sure everything is in the best shape possible for our readers. If you take a look at the inside back cover of this and every issue of Pathlight, you will find the names of our three volunteer copyeditors — Jodi Palmer, Amanda Martin and Edward Freundl. They provide the final check of every story before we go to print. We are grateful for their help, and in this issue of Pathlight, we’d like to tell you a little more about these three individuals behind the scenes.

Jodi Palmer is a journalist from Macon, Ga., where she and her husband own Macon Magazine. “I first became involved with PHA when my daughter, Christen, was diagnosed with pulmonary hypertension. As so often happens, she was misdiagnosed numerous times until the fall of 2000,” Jodi says. “By then the disease had progressed so far that her only choice for treatment was Flolan®. She survived with grace, strength and an incredibly positive attitude for two years. Flolan® stopped working in the fall of 2002, and Christen died in November.”

Following Christen’s death, Jodi did various volunteer projects involving writing and editing and eventually became a regular copyeditor for Pathlight. “If I can help make the information in Pathlight more readable or easier to understand, then I feel I am helping in a small way. I know it can help others who suffer with the same disease Christen had and their families, too. It is definitely a way for me to honor her memory. I know she would want me to do this.”

Jodi continues, “We all need to work together to raise money, raise awareness and educate people about PH. It takes a community to fight this, and we all have different talents to offer. The Pulmonary Hypertension Association is a blessing in so many ways to so many people. I have watched PHA grow and thrive over the last 10 years. There have been so many advances in treatment, and I feel sure part of that is due to an increased awareness and understanding of pulmonary hypertension.”

Amanda Martin lives in eastern Pennsylvania and works as an editorial assistant for a small publishing company in New Jersey. She joined PHA’s copyediting team in the fall of 2010. “While I was in college, I was living with my family near the PHA headquarters,” Amanda says. “As an English major, I was looking for a chance to work in publications, and I was interested in working with a nonprofit, so I could help to support a good cause. Happily, I was able to get involved with PHA over the summer of 2010 as a publications intern. I knew hardly anything about PH when I came into the internship, but PHA did a great job of educating me over those few months.”

When Amanda finished her internship, she wanted to keep her copyediting skills sharp and remain connected to the PH cause. Copyediting for Pathlight was the perfect fit. “I love seeing what the people in the PH community have done in just a few months: the solutions they’ve discovered to expected and unexpected setbacks, the money and support they’ve raised, the stories they’ve been able to share. The creativity and courage highlighted in Pathlight is amazing, and I know it’s just a small part of what’s going on. I’m always inspired.”

Edward Freundl is a PH patient and former newspaper editor from Michigan Center, Mich. He became involved with Pathlight when he submitted his PH journey to be published in the summer 2011 issue. When he submitted his story, he also offered his copyediting expertise. “[Copyediting Pathlight] keeps me involved in an aspect of my career in journalism that I enjoyed for almost 20 years before having to give it up due to PH. I also enjoy reading about the activities of PHA and about other patients — either individually or through their support groups — and learning about the advances in PH research,” Ed says. “If I could share anything with other patients and caregivers, it would be to try your best to maintain a positive attitude and never give up hope, especially on those days when you don’t feel particularly good. That is the best way I can think of to combat this disease.”

When Jodi Palmer edited the summer 2011 issue of Pathlight and read Ed’s journey, she was impressed with his journalistic skills. Unaware of Ed’s offer to help out, Jodi suggested that we talk to him about joining the editing team, and that’s exactly what we did.
**ASK A PH SPECIALIST**

**Q: What recommendations would you give a PH patient interested in alternative forms of exercise like yoga?**

**A:** Exercise is important and valuable for everyone, but especially for patients with PH. Of course, PH patients do have to consider exercise from a perspective of safety first. You should always talk to your PH team before starting any new form of exercise. Beginning a new exercise program is ideally done when you are stable on medical therapy and have been tested to determine whether you have oxygen requirements with exertion.

Know that there is a version of exercise that will be right for you, regardless of your physical ability. It may take some trial and error to find it, but it will be worth finding. Do your research. Get to know what is available in your area; you might be surprised. The popularity of alternative forms of exercise is increasing every year, and even your local senior center or YMCA might host a yoga class!

Set reasonable goals. The beauty of alternative forms of exercise like yoga and Tai Chi for PH patients is that they truly allow you to work at your own pace, while slowly expanding the possibility of what your body can do. The mind-body aspect with a focus on breathing allows for the calming of your nervous system, can reduce stress and improve your mood as well as your body. Just participating in the deep breathing exercises may be all you do the first time and that’s alright. Slowly building on your achievements each time is preferable to starting out too fast and then burning out.

Start slow. Read the descriptions of classes offered in your area. If you’re considering yoga, look for classes that are low intensity, involve stretching and a focus on breathing exercises rather than an advanced class. Avoid classes described as “high intensity” or “designed to make you sweat” (like hot yoga). Look instead for classes advertised as “Gentle Flow” or “Restorative.” These are designed for those looking for a gentle and serene practice. These classes will focus on balance and meditation and tend to be more appropriate for those battling chronic illness. The poses are easier on the body and would be safe for a PH patient to perform. Balancing poses help to strengthen leg muscles, increase flexibility and improve concentration. An example of a safe balancing pose for PH patients is the tree pose with the hands on the hips.

Chair yoga is a gentle way to try yoga positions while seated, which is ideal for those just getting started or those with joint issues like arthritis. Though finding a chair yoga class is more challenging, utilize the Internet or your local library to research poses and try them out with a work-out partner. Once you learn a few, you can do them at home! Just always make sure to have someone around in case you need help.

Talk to the instructor before class. Yoga teachers are accustomed to modifying poses for different injuries their students may have and conditions like pregnancy. Many yoga classes involve seated postures. If you find a class in your area, ask the teacher if you can use a chair rather than a mat.

Because you can’t expect every instructor to know which poses to avoid in every medical condition, you have to be ready to educate them. Let the instructor know that you are to avoid inversions. This way, when an inverted posture comes up, the instructor can advise you on how to modify the pose. Inversions are poses that involve having your head below the level of your heart. Examples are downward facing dog, half moon and side-angle. These poses result in more blood flow to the heart and lungs, which can cause an unsafe increase in pulmonary pressure and should be avoided by PH patients.

Know that you should also avoid poses that require the arms to be raised above the head. You can modify any pose by placing your hands on your hips or down at your sides. It’s important to know that in any yoga class, each student is encouraged to rest in child’s pose whenever they need a break. You won’t be the only one resting. Take advantage of this and listen to your body.

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

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*Answer provided by Rana Awdish, MD, Senior Staff Physician, Department of Pulmonary & Critical Care Medicine, Pulmonary Hypertension Program, Henry Ford Hospital, Detroit, Mich.*

Want to learn more about yoga as an exercise option? On Tuesday, Jan. 22, 2013, join Dr. Rana Awdish for the live webinar “Calm, Cool and Collected: Restorative Yoga for the PH Patient.” Visit [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom) to register!
Your INR Blood Test: A Cautionary Tale

I’ve had pulmonary hypertension for 14 years. I thought I’d seen it all when it comes to PH. Boy, was I wrong. I’d like to share my story, so that other patients can avoid the recent disaster I went through that could have cost me my leg and my life.

Like many PH patients, I take a blood thinner. I know the range my PH doctor wants me to maintain, and I manage it with my primary care doctor. I’m very good about getting my monthly international normalized ratio (INR) blood test done. I may slip a week here or there, but I get it done regularly like a good patient. In July, I started to really feel awful — completely listless with zero energy, nausea and no appetite.

I had my monthly blood work done in mid July. I handed the lab tech a prescription and said, “I’m also here for my monthly standing order, an INR test.” I was feeling so awful that day I was worried about passing out. She put two pieces of paper in front of me, and I signed them both without reading them (Mistake #1). I didn’t hear from my primary doctor’s office about my INR results. That should have raised a flag for me, but I simply made the very bad assumption that my INR was probably fine (Mistake #2).

My calf had begun to ache and, after a few days, started to swell. I woke my husband up at 1:30 a.m. in a lot of pain and asked him to take me to our local hospital. “I think I have a blood clot.” Wrong again, Joanne! Someone, please remind me to turn in my self-awarded medical degree from my fantasy medical school.

An ultrasound ruled out a clot, but a blood test showed that my INR was 13.99. Normal INR is 0.8-1.2, and therapeutic INR for treatment of PAH with warfarin is 2.0-2.5. The local hospital staff contacted the blood lab and found no record of an INR test, but did see a result for a cerebral hemorrhage. I promised him I’d go home and go straight to bed (Mistake #3).

That night, I emailed my PH doctor (Mistake #4). It was a religious holiday, and my doctor was understandably out of contact and didn’t receive the email until late that night. I should have called the emergency number and spoken to the covering doctor, explained the situation and asked for guidance. Not feeling well, I was making one bad decision after another.

My friend Debbie, who is a nurse practitioner, came over to take a look at me. She did a quick evaluation and said, “Hospital. NOW.” She saw that I couldn’t bear any weight on my leg and suspected I was bleeding internally. I was admitted to the local hospital and diagnosed with compartment syndrome, a life-threatening condition where the nerves, blood vessels and muscles become compressed inside a closed space. My too-thin blood, combined with a bump to my calf (that I don’t even remember), was the perfect recipe for this disaster. Compartment syndrome is very serious, and if not treated quickly, amputation is a real possibility.

The local doctors contacted my PH doctor, and she instructed them on how to medicate me to thicken my blood back to a safe level. Debbie coordinated my transfer to the New York City hospital where my PH doctor practices. I felt such relief as soon as I saw her. I was taken directly to the CCU, seen by the vascular doctors who did an immediate evaluation and rushed me into surgery. They performed a fasciotomy to relieve the pressure and attached a vacuum device to the open wounds that would facilitate healing and be with me for two weeks.

I spent 10 days in the hospital after my surgery. I came home for one week and then had to return for a second surgery to remove the vac and close the wounds. I went home and spent the next five days in bed. The recovery time for all this takes several months (and includes physical therapy), and I’m happy to tell you that I’m almost back to normal.

I’m sharing my story in the hope that no other patient will ever have to go through this. So please, my fellow PH warriors, be diligent about your blood work. Follow up on test results, and never assume ‘all is well.’ Ask for help from your loved ones when you’re not feeling well and have to make big decisions. And lastly, know when to raise the alarm (talk to your PH specialist now, so you both agree on what constitutes an emergency). And please, don’t email your PH doctor like I did. Pick up that phone and get the guidance and help you need. Be well.

INR Management Advice from Mary Bartlett, NP

Warfarin, also known as Coumadin®, is a blood
PHA’s SLC Provides Statement on FDA’s Ruling on Revatio®

On Aug. 30, 2012, the FDA issued a safety warning on Revatio® (sildenafil) for pediatric use following the results of the sildenafil monotherapy STARTS trials. Revatio® is approved by the FDA for adults with group 1 pulmonary arterial hypertension (PAH). The ruling states, however, that Revatio® should not be used in patients 1-17 years of age. The ruling is based on a long-term extension study in pediatric PAH patients on low, medium and high doses of sildenafil. During PHA’s September Parents Telephone Support Group Session, I heard from parents of pediatric PH patients on Revatio® with questions about the study and whether or not to continue this treatment. Parents are concerned that an option for treatment is being taken away from them as some children have been on sildenafil for more than five years without a problem. PHA’s Scientific Leadership Council (SLC) has released a statement about this decision that may address some of the concerns patients and parents have. I, along with the SLC, strongly urge patients and parents to discuss this issue and their treatment regimens with their PH-treating physicians before making any changes.

By D. Dunbar Ivy, MD, Section Head of Cardiology and Director of the Pediatric Pulmonary Hypertension Program at the University of Colorado, Boulder, Colo., Member of PHA’s SLC and Board of Trustees

REVATIO® (SILDENAFIL) FOR PEDIATRIC USE
A Consensus Statement Issued by the SLC

Revatio® (sildenafil) is FDA approved for adults with group 1 pulmonary arterial hypertension (PAH). Further, sildenafil is approved in Europe by the European Medicines Agency for use in adults and children with PAH. On Aug. 30 2012, the FDA placed a safety warning on prescription of sildenafil in pediatric PAH patients. The ruling, now part of the package insert for Revatio®, states that Revatio® should not be started in patients 1-17 years of age.

This decision is based on results of the sildenafil monotherapy STARTS trials. In the STARTS-2 study, the blinded dose extension study of the 16-week double-blind placebo-controlled STARTS-1 study, patients randomized to high dose sildenafil in the 16-week STARTS-1 study had an overall increased mortality at 3 years compared to the lower dose groups (Eur Heart J (2012) 33 (suppl 1): 979).

The study included several groups of PAH patients, including those with idiopathic and heritable PAH and PAH associated with congenital heart disease (CHD). Risk factors for death included patients with idiopathic or heritable PAH and those with higher mean pulmonary artery pressure and higher pulmonary vascular resistance at baseline. Children with APAH-congenital heart disease and those weighing less than 20 kg did not appear at an increased risk with high dose sildenafil.

The safety and/or efficacy in PAH children on combination therapy is unknown as all of the children studied were only treated with sildenafil monotherapy per study protocol.

While acknowledging and respecting the FDA’s decision, the Scientific Leadership Council of the Pulmonary Hypertension Association, in response to concern expressed by PH care providers, patients and caregivers, would like to provide some perspective.

- The results from the STARTS-2 trial do not account for the differences in disease severity at the time of enrollment or subgroups of PAH children who might respond more favorably.
- With respect to long-term survival, there was no control group (untreated group) for comparison. The overall survival for the sildenafil-treated patients is very favorable compared to historical controls (untreated patients reported in previous studies). Survival is also favorable in current cohorts of treated patients despite the reported association between high dose sildenafil and increased mortality.
- The SLC recognizes the highly complex decision-making process that involves appropriate treatment of pediatric PAH when there are so few options available.
- The SLC urges patients/parents to discuss this issue and their treatment regimen with their PH-treating physician as soon as possible and warns against abruptly stopping sildenafil, as this may be associated with severe clinical worsening or death.

This situation continues to underscore the need for ongoing clinical research in pediatric PAH to identify safe, effective therapies. The PH community is currently working on how to best address this problem and will keep you informed of any updates.

Visit www.PHAssociation.org/MedicalProfessionals/ConsensusStatements/RevatioForPediatricUse to view this statement.
thinner often used in patients with pulmonary arterial hypertension. The use of warfarin is based largely on studies performed on idiopathic pulmonary arterial hypertension patients prior to the discovery of our current FDA-approved therapies for PAH. The results showed positive benefit for those patients treated with blood thinners.

Warfarin is a vitamin K antagonist. Patients on warfarin require close monitoring in order to decrease their risk of clotting, while also decreasing their risk of bleeding. Patients on warfarin should be advised to maintain a consistent diet, particularly when consuming foods rich in vitamin K, as these tend to inhibit the effect of warfarin. These include green leafy vegetables, broccoli, cauliflower, cabbage, brussel sprouts, kale, liver, as well as green tea and certain vitamin supplements. If these foods are eaten on a regular basis, the warfarin dose can be adjusted in order to maintain the desired INR level. Cranberry juice or other cranberry products may increase the INR in patients on warfarin.

Drug-to-drug interactions are many and can potentially cause an increased chance of bleeding and an elevated INR. It is important to notify your healthcare team when initiating or stopping a medication as this may impact your INR level. Antibiotics are notorious for causing INR levels to rise, making the blood thinner. Joanne’s story is a reminder to clinicians and patients alike of the serious consequences of an elevated INR level. Joanne is extremely brave in telling her story. It is a reminder that one cannot be too careful when it comes to monitoring the effects of warfarin.

By Joanne Sperando-Schmidt, PH Patient, and Mary Bartlett, NP, Winthrop Pulmonary Associates, Mineola, N.Y.

BARST PEDIATRIC FUND ARTICLE CONTINUED FROM PAGE 1

however, the management of pediatric PH remain limited with no FDA-approved treatments for children.

“Children are not small adults,” Dr. Barst explains, and should not be treated in the same way as adults. “Their response to drugs can be somewhat different. Dosing is different. Side effects are different.” The common process of prescribing lower doses of adult medications may not necessarily be the best treatment method for children.

When establishing the fund’s goals, Dr. Barst insisted that she did not intend to raise money that would be completely dispersed and depleted within a year. She wanted to create a long-lasting and hopefully life-changing endowment-like fund to improve overall quality of life and improve outcomes.

“I made it clear that this was to be an endowment-like fund. We want to be able to train physicians and, at the same time, do research and maintain a body of funds so we can do this for many years to come,” states Dr. Barst. She hopes that such extensive first-hand involvement will help expand the number of PH pediatric experts.

When the Robyn Barst Pediatric Pulmonary Hypertension Research and Mentoring Fund recently reached $1,000,000, it was activated. Its next stage will be to move to $3,000,000 when it will be able to offer more robust grants. The fund will maintain a $1,000,000 minimum balance. It is also receiving global recognition and recently received generous gifts from PHA’s sister organizations, PHA Europe and PHA Korea.

PHA is proud to launch this fund to better understand pediatric PH. Awarding will begin in 2013.

More information about Dr. Barst and the Robyn Barst Pediatric Pulmonary Hypertension Research and Mentoring Fund can be found at www.PHAssociation.org/BarstFund. View a video about Dr. Barst’s commitment to advancing care for pediatric PH patients, the development of the first PH treatment and the advancement of the understanding of the disease at www.PHAOnlineUniv.org/PHTrailBlazer-RobynBarstMD. Read our “Meet the Doctor” interview with Dr. Barst on page 15.

By Briana Rivas-Morello
PHA Medical Outreach Program Associate

INR TALE CONTINUED FROM PAGE 12

By Joanne Sperando-Schmidt, PH Patient, and Mary Bartlett, NP, Winthrop Pulmonary Associates, Mineola, N.Y.

We encourage readers to discuss their healthcare with their doctors. This newsletter is intended only to provide information on PH/PAH and not to provide medical advice on personal health matters, which should be obtained directly from a physician. PHA will not be responsible for reader’s actions taken as a result of their interpretation of information contained in this newsletter.
Meet Dr. Robyn Barst: A Pioneer in PH Medicine

Robyn Barst, MD, is Professor Emeritus of Pediatrics at the Columbia University College of Physicians and Surgeons, as well as a Professor of Pediatrics at Cornell University School of Medicine. She presently serves on PHA’s Board of Trustees and Scientific Leadership Council (former Chair).

You began in pediatric cardiology. What sparked your interest in PH? In my pediatric residency, one of the first patients I admitted was a 16-year-old girl who had primary PH. The next morning she had died, and I was devastated. I immediately went to the textbook of medicine at that point and looked up primary PH, and it said PH is an incurable disease with no treatment except investigational transplantation, which had a poor outcome. There was nothing that could be done. I thought to myself, “How can there be no treatment?” That stuck with me through my pediatric residency. I did a second fellowship in pulmonary medicine, because PH bridges cardiology and pulmonology. It convinced me that this was an area I wanted to go into.

Tell us about your experiences in PH drug research. In the mid 1980s, when there was a greater increase and potential success for heart-lung and lung transplantations and at least 40 percent of our patients listed for lung transplantation were dying on the waiting list, we thought, “Well let’s see if we can treat these patients with intravenous prostacyclins as a palliative bridge to transplantation.” In ‘91 we started the pivotal trial, which we published in 1996. There were 81 patients: 40 in the placebo group and 41 in the epoprostenol group. Over the 12 weeks, none of the patients randomized to prostacyclin died. Eight of the 40 randomized to placebos died during the 12 weeks. It was probably one of the most difficult studies for me to be involved in because we didn’t have any other therapy, and my colleagues and I were convinced that the drug worked. We had patients who were on placebo, and they had to stay in the study for 12 weeks. Probably the worst one was a 16 year old on the placebo, who had a massive episode of hemoptysis three days before the end. The bottom line: if she had not died, and we had not seen a survival benefit, the FDA never would have approved it.

What was the significance of this study? Of all the drugs I’ve been involved in with drug development, intravenous epoprostenol is the only drug I’ve worked with that works better than we ever anticipated. Studies are done; they’re published; the drugs are FDA approved; and then everyone starts using them in the field. And the results are never as good as what was published. Prostacyclin is the only drug I’ve ever used that literally works in 99+ percent of the patients. There’s a spectrum on how much better they get. Some get better in the sense that they have a slowing of their disease progression. Some get better to the point that years later we can wean them off the prostacyclins. In my mind, it’s been a miraculous drug.

What advice can you give to PH physicians? One of the problems in medical care right now is that physicians are so limited by time. It’s important to train physicians to listen to their patients. I’ve never felt that a child complains of something unless it really is true. Whenever I saw a new patient, I told them, “I’m going to waste at least an hour of your time. I need to ask the history completely myself because that’s the way I’ll remember it, and a lot of what’s written in medical records is incorrect.” What was amazing to me was that parents would say, “You’re the only doctor who’s talked to my child as if he or she was a person.” I said, “That’s very nice, and I appreciate very much you paying me that compliment. But that’s not really the main reason why I ask children questions. They’re the only ones who know how they feel; so you have to ask them.”

Describe one of your most rewarding experiences working with the PHA community. Before I went to my first PHA International PH Conference, Ken Moser, a wonderful man who has since passed, said “Robyn, I can’t really explain how you’re going to feel. But I can tell you at the end of the weekend, you will have such gratification for what you’re doing.” And he was absolutely right because you spend two and a half days nonstop with patients and their families. This is a way to educate patients and their families, let them meet others, and let them know that they are not alone. That was very eye opening to me.

It was particularly important to children because you don’t really have a chance to meet other children with PH. To be able to see kids meet other children at this meeting, whether they’re on a prostacyclin pump or not, was amazing. They didn’t feel alone. They felt they could talk to other children. That’s been a wonderful experience for me; PHA has expanded that to so many patients and families.

Interview conducted by Briana Rivas-Morello, PHA Medical Outreach Program Associate
2013 PH Professional Network Symposium Call for Abstracts

The 2013 PH Professional Network Symposium Poster Hall is the perfect opportunity to highlight your institution’s important work.

Healthcare professionals in all areas of practice related to pulmonary hypertension are invited to submit an abstract for poster presentation. While not required, PHA encourages the submission of original abstracts. Abstracts also do not need to be fully executed in practice. Abstracts may include, but are not limited to, the following:

- Guidelines for specific clinical situations, implementation of a process to improve patient outcomes or innovative use of technology in clinical practice;
- Development or implementation of a performance improvement program;
- Patient safety initiatives;
- Patient satisfaction improvement initiatives;
- Identification and implementation of PH allied health educational needs; and
- PH nursing orientation programs, role implementation or development of practice guidelines.

Deadline to Request a Mentor: April 1, 2013
Submission Deadline: May 15, 2013
Notification Date: June 15, 2013

The first author will be notified via email regarding presentation of the abstract.

To view abstract resources and submission guidelines, visit www.PHAssociation.org/PHPN/Symposium/Abstracts.

2013 PH Professional Network Symposium
The Power of Teamwork:
10 Years of Professional Collaboration in PAH

September 26 – 28, 2013
Crystal Gateway Marriott — Arlington, Va.

Educational session topics include:
- Diagnostic and Treatment Options
- Encouraging Patient Adherence to Treatment
- Palliative Care Options
- Complex PH Case Studies
- Clinical Advances and Research Updates

Registration opens March 2013!

Visit www.PHAssociation.org/PHPN/Symposium for more information about session times, topics and speakers in the coming weeks. Questions? Contact PHA at Symposium@PHAssociation.org or 301-565-3004 x761.
From “Me” To “We”: Communicating with Your Medical Team

When you are dealing with an illness like PH, it is important to talk often and comfortably with your healthcare team. SPEAK UP to help the team understand your needs and discuss options; the PH team does not know what you are experiencing or what questions you have until you tell them. Empowered patients allow the PH team to partner with them in their care and know that taking charge of their health is an ongoing process. The following tips will make it easier for you and your team to cover everything you need to talk about during your appointments.

List and Prioritize Your Concerns: If you have several items, put them in order and group similar topics together. Don’t put off the things that are really on your mind — bring them up right away!

Bring Information with You: Some PH teams suggest bringing all medications and supplements to your appointment. Others recommend you bring a list of everything you take. Find out your team’s preference and try to meet their request. Have copies of your medical records, a current medication list, PH history, other recent health history and immunizations and remember to update them regularly. Don’t forget to bring your insurance information and medical ID numbers, including contact names and phone numbers.

A helpful resource for managing this information is PHA’s Empowered Patient Toolkit. Learn more about the toolkit at www.PHAssociation.org/OnlineToolkit.

Consider Bringing a Family Member or Friend: Let your family member or friend know in advance what you want from them at your visit. Your companion can remind you what you planned to discuss with the doctor if you forget, take notes for you and help you remember what the doctor said.

Plan to Update the Team: Be honest with your healthcare team when you answer their questions. Provide points of reference; keep a journal or calendar of symptoms and issues and note the impact on your daily activities and what makes symptoms better or worse. If family or friends are with you, be sure to include them in the conversation and ask them to provide examples.

Your team may ask you how your life is going, as this may be useful medically. It’s okay to ask family and friends to leave the room so you have some time alone to talk to your team. Let the doctor know about any major changes or stresses in your life, but don’t forget to talk about the good things as well!

Ask Questions: If you don’t ask questions, your team may assume you already know the answer or that you don’t want more information. If you don’t understand something, say so. You should not leave until you comprehend what is being communicated. If you have a family member or friend who helps you take medicine, make sure to sign a release and ask the team to talk to him or her. If you have a power of attorney and/or healthcare directive, carry a copy with your medical records and update them as appropriate.

When it comes to your treatment, instructions from your team are important. Tell them what you think the instructions are and let them know if they need to write them down. Ask about different treatment options. You will benefit most from a treatment when you know what is happening and are involved in making the decisions. Make sure you understand what your treatment involves and what it will or will not do. Ask for prescriptions to be renewed at your appointments. If you need to call your team for a prescription renewal, try to give them at least two weeks’ notice.

Know when to call your team and when to head for the emergency room. Does your team want you to call with a 2–3 lb. weight gain over two days? What are your team’s specific instructions related to the PH therapy you are on? If you wonder if your question is one you should ask your team, please call; they are there to help you and can talk through any issues you are having.

If You Go to the Emergency Room: Make sure to bring your prepared collection of medical information and contacts. While in the emergency room, ask questions if you don’t understand tests or procedures that are being done. Make sure to notify your PH team on your way to the hospital even if your visit is not PH-related and contact them with an update after your visit.

Keep Contact Information Accessible: Always have your center’s phone number available in your phone under DOCTOR, on your medical alert bracelet and in your medication box. Have a list of important phone numbers and an up-to-date medication list on your refrigerator; this is usually the first place EMS will look for it.

Always remember that you are your own best advocate. Communicating openly and honestly with your PH team is essential to your PH journey.

By Louise Durst, RN, Research Nurse and Study Coordinator, Mayo Clinic Medical Center, Rochester, Minn.
Race, Sex Differences May Affect Response to PAH Drugs

No two people are alike, and similarly no two patients with pulmonary arterial hypertension (PAH) are the same (even identical twins!). Different types of PAH can act differently; patients may be more or less sick, may feel differently and may respond to medicines differently. Even within each type of PAH, patients of various ages, men and women, and different races and ethnicities may have individual responses to treatment. In other more common heart and lung diseases, there are commonly distinct effects of treatment between men and women and patients of different races. To see if this is true in PAH, we performed a study of 1,130 patients with PAH who enrolled in one of the original clinical trials of endothelin receptor antagonists (ERAs) (e.g., bosentan, ambrisentan and sitaxsentan) to determine if men and women and non-Hispanic white and black patients with PAH responded similarly to these medicines.

We used data from the studies submitted to the Food and Drug Administration during the process to receive approval for these medicines. In these studies, patients were assigned to receive an active medicine for their PAH or a sugar pill (placebo) without knowing what they were receiving. Of the participants, 773 patients received the active medicine and 357 received a placebo. We separated the patients by whether they were male or female and whether they were white or black. (We didn’t have enough patients of other races and ethnicities in the trials to perform similar analyses.)

When we compared the change in the six-minute walk distance between men and women in these trials, we found that women had a larger improvement in the walk distance in response to ERAs compared to men (difference between the two sexes of 30 meters), which was statistically significant. When we compared white and black patients, we found that white patients seemed to have a greater response to ERAs compared to black patients (difference between the two races of 44 meters). These findings were not explained by patients having different types of PAH, different walk distance at baseline, age, or other factors. When we performed similar analyses in the clinical trials studying other medications (such as phosphodiesterase-5 inhibitors), we did not see these differences in six-minute walk response.

What do these results mean? Patients of different sex or race may have distinct responses to PAH treatments. This likely comes as no surprise to patients, who already know that each person may have more or fewer benefits or side effects in response to medicines compared to others. Since people are not the same, their treatment effects may also vary, even with drugs that work overall for PAH.

Why would men and women and white and black patients have a different response to ERAs? It is possible that the biology of PAH may differ between the sexes and races, and the effects of treatments which target that biology may differ as well. It is possible that the hearts and lungs of men are in some way different (or less responsive) compared to those of women. Men and women have different body size, composition and metabolism which could be an explanation. Variability in genetics between whites and blacks could explain the results. The environment, diet, exercise habits, and other aspects of daily life could also play a role.

There are several questions which this research does not answer. It is not known whether these or other drugs used for PAH act differently on more important outcomes, such as quality of life, time to worsening of the disease, or survival. The six-minute walk distance is only one measure of how well a patient is feeling. Other symptoms or limitations may not have been differentially affected between individuals.

At the current time, the results of this research should not lead to changes in treatment for patients with PAH. The best medicine or medicines for an individual can be identified only by a specialized medical team with extensive experience in caring for patients with PAH and the patient him- or herself. Oftentimes, it takes trial and error to identify the right therapy. The results of this study cannot replace the interaction of doctors, nurses and patients in determining the best individual treatment regimen.

Our study does provide some evidence that medicines for PAH may be more or less effective in certain groups. We should continue to work towards the goal of evidence-based, cost-effective “personalized medicine” in pulmonary hypertension, that is, providing the most effective treatment with the least side effects and cost for each patient.


By Steven Kawut, MD, MS, Associate Professor of Medicine and Epidemiology, Director, Pulmonary Vascular Disease Program, Perelman School of Medicine, Univ. of Pennsylvania, Philadelphia, Pa.
Over the years, PHA has been generously supported by individuals and individual fundraisers, foundations, the federal government and our corporate sponsors. We are indebted to each group for making the wide variety of programs and services PHA offers — the majority at no cost — available to the patient, caregiver and medical professional communities we serve.

PHA continues to grow, with broader education and networking for our targeted patient and caregiver populations, an ever-increasing expansion of groups and programs for our support group network, and medical projects and structures like Centers of Comprehensive Care, new research programs and international licensing of our medical journal *Advances in Pulmonary Hypertension*.

With this growth and an increasing need for diversification of our funding sources, in early December PHA launched our first three fundraising chapters — modeled after a very successful program at the Cystic Fibrosis Foundation — that will point us in a new and innovative direction.

This model reflects a different approach for PHA. We have experienced much success through a grassroots system strongly supported at the national level. To maintain what has worked so well for us, we will thoroughly integrate these new chapters into our community. In the first year, our plan is to open three chapters — in Chicago, New York City and the San Francisco Bay area — with more chapters being established each year over the next five years.

The chapters will be staffed by professional fundraisers who are expert in planning and conducting nonprofit special events and who are fearless about seeking financial support for their endeavors in support of PHA’s patient-serving and medical programs. At the same time, our own successful and unique special events — planned by energetic volunteers in communities across the country — will remain as important as they are today with the full support of PHA staff at the national office.

We see great things arising from this new model — and have hired a great person to lead this new initiative. Carl Hicks — a former Chair of PHA’s Board of Trustees, who many of you have had the privilege to meet and know at our International PH Conferences, support group meetings, special events and elsewhere — has honored us by agreeing to serve as PHA’s first-ever Vice President of Field Operations. Carl is the first Board member in history to take on a staff role.

As you read this, Carl has been on board with us for several months and has shown extraordinary gifts in understanding how to put this new complex program into place. With a background in the military and business, and having been the loving father of Meaghan, a PH patient who lost her fight but continues to motivate and inspire Carl and others, we are confident that we have the right person for the job.

For those of you who live in the targeted communities, we will welcome your help to ensure our early success. As we launch these chapters, the field staff may reach out to you, asking you to help make connections and get the word out about the importance — and the necessity — of our work. And for our entire community — we will continue to look to you for your support, engagement and commitment to our shared cause.

It is no less expensive to fight a disease like PH with 20,000 to 30,000 patients than it is to fight one like diabetes with 24,000,000. Our goal, as always, remains never to be limited by our size in meeting the needs of our community. The purpose of this new structure is to sustain our ability to meet that goal.

We look forward to this new phase in PHA’s evolution with much anticipation and the hope that you will be with us on the journey.

*Late-Breaking News:* PHA’s first chapter directors have been hired. We’ll introduce you to Gina Parziale (N.Y.), Lisa Beth Gansberg (Chicago) and Bette Perez (San Francisco) in the next issue. You can also read more at [www.PHAssociation.org/RinoBlog/ThreeChapters](http://www.PHAssociation.org/RinoBlog/ThreeChapters).

*By Rino Aldrighetti, PHA President*
Sometimes it’s PH Goes Global

Zebra fever is now a pandemic! People around the world have incorporated the Sometimes it’s PH campaign and its mascot — the zebra — into their fundraisers, November PH Awareness Month activities, and PH meetings and conferences. The message of early and accurate PH diagnosis resonates even more clearly in places like Latin America and Asia that often do not have the same treatment options that we have in the United States. To show support for this message, 18 associations from each of the six main continents have officially endorsed the Sometimes it’s PH campaign. Read on to see how the zebra is making tracks around the world.

Translation Projects

This past fall, November was embraced as Awareness Month by many more nations around the world. PHA Board member Steve Van Wormer and his media team, Lyle Such and Ryan Demaree, helped make Awareness Month activities a success in China with Chinese versions of the Sometimes it’s PH video spots he created for PHA. An image of the Chinese video is featured here, and you can view the English version of the video at www.SometimesItsPH.org.

As a gift to Latin America on Latin PH Day, Steve also created a Spanish version, which was shown at the Latin PH Day celebrations in San Jose, Costa Rica.

Facebook Hype

Sometimes it’s PH gained immense popularity in Latin America as the Facebook user known as “Concientización De La Salud” created an online event to show support and gain awareness for the campaign. This user held contests for the best zebra-related picture and designated special days in honor of patients we have lost, patients still fighting, caregivers, PH associations and support groups, and the health professionals who fight PH every day. To help bolster awareness and support in the rest of the world, PHA hosted an English-language version of the online event as well.

Media Attention

The popular campaign has even garnered support in local media around the world. The Dolan family (pictured below) of Bradford, Ontario, Canada, held a yard sale on Aug. 25 with a few friends from the Toronto Chapter Support Group to raise money to create a local PH support group in Simcoe County and to spread awareness about PH. A Bradford Times reporter was on site to interview Ruth Dolan, whose daughter has PH, about her zebra pin and the importance of diagnosing PH early. “That’s our campaign — to try to get doctors to think ‘zebras,’” Ruth told the reporter.

International Representation

All of this popularity is also evident on the Sometimes it’s PH website itself. Roughly half of both the diagnosis stories and the zebra pictures submitted to the website are from people outside of the United States! So as you scroll through Facebook or the Sometimes it’s PH website, keep your eyes open for new international PHriends. Around the world, PH patients and caregivers face so many of the same issues.

Have you submitted your photo or story to the campaign site yet? For more information on the Sometimes it’s PH early diagnosis campaign or to get involved, visit www.SometimesItsPH.org.

By Julia Friederich
PH Association International Program Associate

How many zebras can you find in this issue of Pathlight? See page 43 for details.
Early Diagnosis Campaign Focused on Communications, Planning

Communications and planning have been the central activities of PHA’s Sometimes it’s PH early diagnosis campaign in the past several months.

Building on the zebra theme that has been added to many local fundraising events and media coverage, PHA has tapped into some popular new ways of communicating within the community of PH patients, families and caregivers. We staged a successful Facebook event culminating on Labor Day, inviting supporters to post a message on our Facebook page or change their Facebook portraits to a zebra image. Our event keyed off a similar Facebook event started by a PH family, drawing U.S. and international PH patients and their loved ones.

The Facebook event also kicked off our continuous efforts to add strength to our campaign through testimonials on our Sometimes it’s PH website, www.SometimesItsPH.org. Your personal stories of misdiagnosis show the urgency of early diagnosis, and your zebra-related photos reflect the commitment of individuals in our PH community to better care. We were pleased to receive dramatic stories and diverse pictures from across the U.S. and around the world, and we welcome additions at any time. To learn how to post, contact Mollie Katz at 301-565-3004 x774 or email MollieK@PHAssociation.org.

Embracing the Internet-driven trend of communicating ideas visually, Ellie Ganelin, PHA’s Design & Publications Manager, created an eye-catching infographic depicting key statistics about the need for early diagnosis (pictured at right). The image initially was published in the fall issue of Caring Voice Coalition’s magazine, Community, and it will have many future uses with media, legislators and potential partners in our campaign.

Gaining the attention of physicians and allied health professionals is a critical part of our campaign, which has now reached an active stage. Our journal for those treating PH, Advances in Pulmonary Hypertension, devoted its summer 2012 issue to this theme. The issue included documentation of the problem and commentary on solutions by leaders in our campaign such as chairperson Dr. Lynn Brown along with Dr. Greg Elliott, both of Intermountain Health and the University of Utah School of Medicine. The issue, which is also available online at www.PHAonlineUniv.org, also offered information on screening for PH and on clearly explaining the many medical tests for PH to patients.

We have also been taking important steps to raise funds for the campaign and to bring more healthcare professionals into the planning process for our in-depth communications and education activities for primary and specialty care providers. Our three committees of health professionals are forming detailed plans to target professional societies that are influential in healthcare practice and relevant patient-oriented disease groups. In concert with them, we will work to assure that more healthcare providers understand PH, when to screen for it and the importance of referring patients to highly specialized care.

By Mollie Katz, PHA Vice President, Community Engagement
International Highlights: What’s Going on Around the World?

With more than 60 PH associations worldwide, there is always something PHenomenal happening in the global PH community. These international highlights are a testament to the hard work of PH community members everywhere!

- **In Argentina…** HIPuA (Hipertensión Pulmonar Argentina) hosted two PH Days for patients and family members in October. The meetings, held in Buenos Aires and La Plata, provided information on PH, treatments and resources available in Argentina.

- **In Bulgaria…** PHA Bulgaria held its First National Conference on PH on Oct. 13–14. The meeting, partially funded by a Tom Lantos Innovation in Community Service Award, brought together patients, families and health professionals across Bulgaria to discuss patient rights, treatment, disability prevention, and the development of support groups.

- **In Canada…** PHA Canada celebrated PH Awareness Month with a campaign of “6-Minute Walks for Breath.” Routes of six minutes were set up with accompanying information sheets that taught participants about PH and PH symptoms along the way. Participants could walk the routes as many times as they wanted to raise money for the PH cause. The walks were held in Vancouver, Ottawa, Edmonton, Montreal and Toronto.

- **In China…** iSEEK PH Hope Center hosted an event in Shenyang on Sept. 9 to promote changes in the national health insurance system; patients in Shenyang can now pay a lower cost for bosentan. iSEEK also held its Inaugural Conference for the iSEEK Medical Council at the beginning of November and held several educational events in honor of PH Awareness Month.

- **In Costa Rica…** Members of the Sociedad Latina de HP helped to host Latin PH Day meetings and celebrations in San Jose on Nov. 24 and 28. PHA attended the meetings on Nov. 24 where attendees discussed the importance of cooperating among Latin PH organizations as well as building new social resources.

- **In Europe…** PHA Europe held its General Annual Meeting in Castelldefels, Spain, on Sept. 12–16. Leaders of 39 PH patient groups from 20 countries attended.

- **In Korea…** PHA Korea held its First International Conference and Scientific Sessions on Oct. 13 in Seoul. More than 200 people attended, including patients, caregivers, health professionals and industry representatives. See article on page 23.

- **In South Africa…** PHSA (PH South Africa) hosted a PH Awareness seminar in Johannesburg on Nov. 3. The seminar featured many guest speakers, including several doctors, and focused on PH and PH management in South Africa.

For more news from around the world, visit www.PHAssociation.org/PHInternational

*By Julia Friederich, PHA International Program Associate*

**PHA Thanks Eva McCaffrey, Volunteer Services Intern for Fall 2012**

Eva found PHA through her cousin Mim Farley. Mim’s daughter Katie was diagnosed with PH in 2009, and Katie is now 7. Eva and her children started to attend PHA’s weekly volunteer nights on a few occasions. “I saw all the interns at PHA and was envious of the time they got to spend learning valuable skills and information about how to go about helping to cure this illness. I needed to do it, too,” Eva says. Eva joined the Volunteer Services team, assisting with various projects, including reaching out to PH advocates prior to PHA’s Congressional Luncheon. Eva also attended many PHA events such as the *PHA on the Road: PH Patients and Families Education Forum* in Chicago. “My internship has opened my eyes to all the possibilities of how I can participate in making a difference.” Eva says. “I wouldn’t have missed this opportunity for the world, and I’d do it again in a heartbeat. Speaking of hearts, the PH patients I have met truly have the biggest and bravest hearts I’ve seen.”
Approximately 200 patients, caregivers, physicians, allied healthcare professionals, researchers, industry representatives and medical students came together on Oct. 13, 2012, for the first-ever PHA Korea conference in Seoul, South Korea. Carl Hicks, former PHA Board Chair and current PHA staff member (see story on page 19), attended at PHA Korea’s invitation.

PHA Korea has had trouble taking advantage of volunteerism, that all-important ingredient to our success here in the U.S. Three patients and a caregiver getting together around a kitchen table in Korea would have likely ended at just that, but most of us know how the coming together of those four in Florida back in 1990 was the beginning of PHA. What followed changed the face of the illness around the world largely through the efforts of volunteers. The folks at PHA Korea, founded in only 2010, wanted to learn how to harness this untapped power for their organization. Carl’s mission was to illustrate that.

Leading with an inspirational video produced by Colleen Brunetti, PH patient and member of the PHA Board of Trustees, Carl expanded on her theme of the importance of volunteerism and how it impacts the lives of so many patients. He detailed many of the ways that volunteers from all walks of life in our PH community fight back daily through advocacy, fundraising, awareness-raising and many other ways. These activities in turn support PHA’s mission to find ways to prevent and cure pulmonary hypertension and provide hope for the PH community through support, advocacy, education and awareness.

The day-long program was conducted at the Severance Cardiovascular Hospital, part of the Yonsei University College of Medicine, in downtown Seoul. It included many of the same topics that we include at our International PH Conferences such as “Combination Therapy,” “Pulmonary Hypertension in Pediatrics” and “Working with Insurance.” This shouldn’t have come as a surprise: it is the same illness and Korean patients face many of the same problems and challenges that patients face in the U.S. That’s why engaging volunteers in the struggle in Korea is as critical there as it is in the U.S.

PHA is grateful for the generosity of PHA Korea. This fledgling organization covered all the expenses associated with Carl’s visit and proved to be warm and appreciative hosts. Beyond that, prior to embarking on the 19-hour return trip to Washington, D.C., Carl was presented with a $500 donation to the Robyn Barst Pediatric PH Research and Mentoring Fund by the people of PHA Korea, who are solidly our allies in this struggle.

PHA MEMBER SPECIAL!

Save 40% on PHA’s Awareness Ribbon Keychain!

Show your support for the fight against PH and raise awareness every time you reach for your keys!

Only PHA Members are eligible for this special, limited-time offer. Order now through April 2 at the PHA Online Store, www.PHAssociation.org/Store, or give us a call.

Not a member? Visit www.PHAssociation.org/Join to become a member of PHA today! Questions? Call the PHA Office at 301-565-3004.
Sally Mackey of Sumter, N.C., has made some changes in her life because of her pulmonary hypertension, but she’s never given up her passionate hobby, quilt-making. Now thanks to a 2012 Tom Lantos Innovation in Community Service Award from PHA, her craft is bringing beauty and comfort to people touched by PH. What’s more, it is contributing to the success of PHA special events, providing attractive handmade items for fundraising raffles.

Sally, along with members of her quilting club, are creating 12 quilts this year to be given away in the PH community. One, raffled off at a PHA fun walk in Baltimore last fall, set black triangles alongside bright colors on one side, with solid periwinkle on the other. Other quilts feature stars, a patriotic heart and various improvised patterns. Each one has a periwinkle ribbon on the back and a label noting it was created with a Tom Lantos grant.

Sally regards the Lantos grant as an opportunity to use her skills to create quilts that lift the spirits of people with PH by providing an artistic, warm and comforting wrap. Through her quilting she has also been able to educate others about PH. Her quilting club members have become knowledgeable about the illness, and Sally uses the group’s quilt shows as a forum to tell her PH story as she displays a quilt decorated with periwinkle ribbons.

Message on a Coffee Cup

While travelling this past year, Ron Oudiz, MD, a member of PHA’s Scientific Leadership Council, bought a cup of coffee and, to his surprise, found an awareness message about PH on the cardboard insulation ring around his hot cup. These informational “hot holders” were developed with a Lantos grant by New Jersey residents Ryan Juntti, who has PH, and his mother Bonnie Patricelli, a support group leader and caregiver. Ryan and Bonnie opted to promote awareness among people with shortness of breath. Their brief message includes these words: “Breathlessness is no small matter. If shortness of breath is part of your daily life, ask your doctor about pulmonary hypertension.”

The insulated ring also carries the PHA name, logo and contact information.

Ryan and Bonnie chose the hot holders to carry their message based on information they found that said the average hot drink consumer spends 45 minutes with the drink and that the sleeve is seen by approximately six others who may be sitting or walking nearby.

They worked with a printer to design and produce the hot holders and distributed them through the printer’s network to coffee shops around the country on college campuses, in airports and train and bus stations, in city centers and near tourist attractions.

For the past three years, the Tom Lantos Innovation in Community Service Award program, funded by Gilead, has provided grants of up to $5,000 to PH community members to act on their own ideas to help promote awareness, develop new services, educate or otherwise bring new benefits to those touched by PH. Learn more about this grant program at www.PHAssociation.org/TomLantosAwards.

By Mollie Katz
PHA Vice President, Community Engagement

Webinar Recording Helps You Shine the Media Spotlight on PH!

Would you like to see more stories about pulmonary hypertension in the media? With advice and materials from PHA, you and PH can make the news! During this informative one-hour webinar, you’ll hear PH patient Jeannette Morrill and Mollie Katz, PHA’s Vice President of Community Engagement, share strategies for catching journalists’ attention and getting media coverage.

View the webinar recording at www.PHAssociation.org/Classroom/ShineTheMediaSpotlightOnYourPHStory.
PHA Extends a Huge Thank You to Our 2012 Awareness Month Sponsors

**Platinum Level**
Actelion Pharmaceuticals US, Inc.

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United Therapeutics Corporation

**General Sponsors**
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Every November PHers around the world collectively spread PH awareness in their communities, and this year was no exception! As we go to press, we’re hearing from you about the creative ways you’re raising PH awareness. Here is a visual representation of the entire community’s exciting November activities. We’ll have a full wrap-up in the spring edition of *Pathlight*!

You can also look back at our community’s efforts at www.PHAssociation.org/AwarenessMonth

There is still time to support PHA’s End of Year Campaign

A new year has begun, and PHA is continuing to raise funds to support our important programs and services, including *Pathlight*, through PHA’s End of Year Campaign. It’s never too late to make a difference! The dedication and passion of the PHA community make it possible for PHA to carry out our mission to find ways to prevent and cure PH and provide hope to the entire PH community. Please support PHA’s mission by making a generous gift today at www.PHAssociation.org/E0Y2012

If you’ve already given, please accept our gratitude and know that your gift is working hard to make life better for the entire PH family.
We spoke with Daniela Maristany, PHA’s Insurance Program Associate, about insurance advocacy, webinars and her first days on the job.

What are the goals of PHA’s Insurance Advocacy and Education Program?

Our goals are a lot like our name — to advocate for pulmonary hypertension patients in the insurance realm and to educate patients and providers about insurance. These goals translate into a wide array of projects, from creating online and print materials to working with insurance companies and government to resolve policies detrimental to PH patients.

How do you hear about insurance challenges that the PH community is facing?

We hear about issues from patients, physicians and our contacts in the pharmaceutical industry. For example, we heard from patients when Blue Cross Blue Shield (BCBS) of North Carolina began eliminating coverage of combination therapy for oral PH therapies. Recently, we learned from several PH specialists that patients at some Veterans Affairs clinics are being limited in their access to more advanced PH therapies.

How does the Insurance Program respond to these challenges?

We partner with medical professionals who are the leaders in their fields through the Insurance Advocacy Committee of PHA’s Scientific Leadership Council (SLC). The Committee includes PH physicians, a respiratory therapist and a social worker. We work with the Committee to write letters to or meet with the insurance company or state program whose policies prevent PH patients from accessing their medications. Having these expert medical professionals as our spokespersons brings tangible, positive change for our patients.

What insurance advocacy issues have you been working on lately?

Two of our big projects right now are the Veterans Affairs clinics issue mentioned above and coverage of palliative care for PH patients.

Furthermore, earlier in 2012 the Insurance Advocacy Committee met with representatives from the Social Security Administration (SSA) to discuss approval of PH for Compassionate Allowance, meaning that PH patients applying for disability benefits would receive expedited approval.

Recently, we have seen several state Medicaid programs limit the number of brand-name prescriptions allowed to each patient per month. This poses a risk for PH patients on combination therapy, so we are working to prevent these and other states from enacting such limits.

When I submit a question on the website, who answers?

If you ask a general insurance question, I’ll answer, but if you ask a question about Social Security, you’ll hear from our Social Security expert, Alan Harder, a PH caregiver and former employee of the SSA with more than 30 years of experience. Since PHA is a national organization, we don’t always know the specific details for each state. That is why we often refer patients to the Caring Voice Coalition (CVC), as they have the resources to do individual case management. You can contact the CVC at www.caringvoice.org or 800-267-1440.

Even though we may not be able to answer every question, we like hearing from patients because it helps us stay connected to the insurance needs of the PH community.

PHA has an Insurance Advocacy and Education Program. Tell me more about your educational projects.

We host webinars about insurance topics — recently, we had a webinar on disability benefits and an online chat on Medicare Part D. Almost all of our information is online at PHA’s website. Additionally, anyone can get our insurance print materials for free — you just have to ask me! You can contact me at Insurance@PHAssociation.org or 301-545-3004 x773.

What are some of the most common insurance questions people ask you (and what are the answers)?

I often get asked about what to look for in an insurance plan. This is a tough question because individual needs vary widely. I encourage patients to
Michael McGoon, MD, a PH-treating physician and member of PHA’s Scientific Leadership Council and Board of Trustees, has been inspired by PHA’s work and the stories of its members. “PHA is a unique organization,” Mike says. “From a medical perspective, it’s amazing to see a group of patients, caregivers, researchers, physicians and allied health professionals all working toward a common goal.”

His wife, Bonnie, has been just as involved.

To read how Mike and Bonnie continue to devote their efforts to defeating PH, visit www.PHAssociation.org/Give/McGoon
As the New Year rolls in, many of us will sit down to write self-improvement lists. This year, don’t forget to think about how you can become a better insurance consumer. Consider making one of the following resolutions part of your new year.

**Keep a wellness journal**
- A wellness journal can help you see the progress you’ve made fighting PH, but it can also demonstrate the daily activities that you are no longer able to perform. Such changes serve as important evidence when compiling an application for Social Security Disability (SSD) benefits. Record doctor’s visits, medications, diet, exercise, energy level and how you feel mentally and physically.

**Stay organized**
- Organization is key, whether you are appealing a denied insurance claim or applying for SSD benefits. Keep all your paper insurance records together. Record the names of the insurance representatives you speak with and the dates of your conversations.

**Use your resources to learn something new**
- Insurance is complicated, but there are resources to teach you what you need to know. Sign up for PHA’s Coverage Connection e-newsletter or read about health insurance laws and important terms on PHA’s website. Contact PHA’s Insurance Program Associate, Daniela Maristany, at Insurance@PHAssociation.org or 301-565-3004 x773 for information or advice.

- Ask questions. If your doctor or insurance representative says something that you don’t understand, ask them to clarify. You have the right to understand your healthcare!

**Ask for help and get support**
- Take the advice of these PH patients who have successfully fought to insurance victories:
  - “My biggest words of advice ... are don’t do it alone and don’t wait to make the call for assistance! There are many organizations (like PHA and Caring Voice Coalition) that want to help you. You just need to ask.” — Hada Monahan, PH Patient
  - “Some days, you just can’t do it anymore. It feels like the insurance companies have won and you just want to give up. Don’t! This is the time to ask for help. Whether it’s from a spouse who can contact an HR group, a parent, sibling, child or a doctor who can work out next steps with an insurance company, sometimes just a short break can give you the stamina to pick up the ball next time around.” — Jennifer Tahmoush, PH Patient

**Speak up for others by sharing your story**
- Your voice and knowledge can make a difference in the lives of others. Tell others in the PH community about your insurance experience through your support group, Facebook or PHA’s message board and email groups. You can also tell your story as an insurance victory in Pathlight. To do this, contact PHA at www.PHAssociation.org/Patients/Insurance/ContactUs.

By Daniela Maristany, PHA Insurance Program Associate

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**Insurance Q&A continued from Page 26**

Comparison shop prospective plans by asking questions like these: What are the co-pay and deductible? Are my PH medications on the formulary? Are my physicians covered or are they out-of-network?

I also get asked about what to do if you can’t afford your insurance. The CVC can often help; they have co-pay assistance for those who qualify.

**Tell us about yourself. What’s your background, and why did you join PHA?**

After college I worked with uninsured patients at a community health clinic. At that job I had a lot of wonderful on-the-ground patient contact. I joined PHA because I wanted to see how things worked on the other side of health, with education and policy.

**What is your favorite part of the job?**

My favorite part is talking to patients because I rarely have a conversation where I don’t learn something new. So give me a call!

**PHun PHact?**

I had a pretty neat introduction to PHA — my fourth day on the job was the first day of PHA’s 10th International PH Conference and Scientific Sessions in June 2012!
Thanks to a new law, the Food and Drug Administration (FDA) will expand the way it uses patient input during its review and approval of drugs and devices. The FDA plans to select 20 specific disease communities to focus on in 2013. As a first step, they took testimonies in October from representatives of more than 50 disease communities. The FDA nominated PAH as part of this group.

PH patient and PHA Board Member Colleen Brunetti travelled to Washington, D.C., to speak to an FDA panel, arguing for the inclusion of both PAH and organ transplant in the pilot year of the FDA’s new initiative.

Rino Aldrighetti, PHA’s President, submitted written comments as well as letters of support from several of PHA’s partner organizations encouraging the FDA to include both PAH and organ transplant in the program’s first year.

The goal of the patient-focused initiative is to help the FDA understand how its approval processes can better meet patients’ needs. For example, the FDA will seek input on the way it assesses risk versus benefit during the approval process for new drugs and devices. After working with 20 disease communities in the program’s first year, the FDA will expand the program in the future. (Watch the next issue of Pathlight for an update!)

We will continue to work closely with the FDA through this and other initiatives to improve the drug and device approval process for the PH community.

Sneak Peek: PH Advocacy in 2013

The two years of the 112th Congress ended in December, and the first session of the 113th Congress began in January 2013. The start of a new Congress “resets” the legislative clock, which means that any proposed legislation that had not become law by the end of 2012 will now be reintroduced and begin the process from scratch. In the coming year, PHA looks forward to promoting regulation and legislation that benefit the PH community, including:

- Introducing a PH-specific bill aimed at increasing funding for PH research;
- Building our relationship with the Food and Drug Administration (FDA) and increasing the PH patient voice in FDA processes;
- Collaborating with the National Organization for Rare Disorders to advance legislation that benefits the entire rare disease community;
- Working in coalition with other organizations to preserve funding for the National Institutes of Health and Centers for Disease Control;
- Following the Affordable Care Act (healthcare reform) implementation process and sharing information about its impact on the PH community.

Join us in 2013! Contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at 301-565-3004 x753 or ElisabethW@PHAssociation.org to get involved.
Working Up a Sweat: Spotlight on Marathon Fundraisers

Fundraising for PHA is a great way to raise awareness and fight PH. In 2012, a number of community members ran half, full or relay marathons and fundraised for PHA. Altogether, PHA’s grassroots fundraisers raised nearly $40,000 for important PHA education and support programs and pulmonary hypertension research.

To raise funds for PHA, all you have to do is ask family and friends to support a cause that is important to you: supporting PHA’s mission to find ways to prevent and cure PH and to provide hope through education, support, advocacy and awareness.

Pairing a fundraiser with an existing community event, like a marathon, is a great idea because it allows you to focus on asking for donations to support PHA without worrying about event details or expenses.

The commitment and dedication it takes to train for and run a marathon is a wonderful way to honor your loved ones. It’s also a great way to motivate family and friends to support your fundraiser!

On these two pages, you will find three inspirational stories of people running for the PH cause, spreading awareness and raising funds along the way.

Not everyone can run a marathon, but everyone can raise funds! To get tips and learn more about ways to fundraise, visit www.PHAssication.org/Fundraise.

Fighting for the Future: A Mother Raises Funds in Honor of Her Daughter

Mimi McNiff, age 5, was diagnosed with PH in early 2012. Her mother, Britt, turned to running to help cope with the changes and challenges of managing Mimi’s PH. A friend told her about the Smuttynose Rockfest half marathon, and when Britt learned she could raise funds for PHA, she decided to run in honor of Mimi.

Britt and her husband, Sean, decided to begin fighting back by raising as much money for research as possible. As we go to print, Sean and Britt have raised more than $12,600 for the Robyn Barst Pediatric PH Research and Mentoring Fund.

Britt used Facebook and emails to get the word out about Mimi, her PH and the fundraiser. “A few people took the mission on and gave enormous sums of money and wrote letters to local newspapers and our town listserv, which brought in additional funds and, more importantly to us, awareness,” she says. The McNiffs regularly updated their supporters about Mimi and the fundraiser and even created a Facebook group called “Team Mimi” to keep supporters in the loop.

Britt says, “Fundraising for us has been so cathartic. It certainly has helped us work through our greatest fears, and we learned how to communicate about this disease and about Mimi in general.”

One way Britt and Sean motivated friends and family to donate was to use shock value. “We gave details we were uncomfortable giving, but we knew we had to bring about some real emotion in people.”

Britt’s advice to others is to “take your tears, confusion, sadness, depression, heartbreak, sleepless nights, worry, fear, panic, anxiety — all of it, and throw it into a big bag of empowerment. Do something, anything that resonates within you and with love. You will be consoled in knowing you are moving forward when this disease wants you to go nowhere but back.”

Read Britt McNiff’s full fundraising story at www.PHAssication.org/Fundraise/McNiff

The McNiff family created this informational card to help raise PH awareness.
The McMullens’ Rally to Relay

Mary McMullen lost her battle with PH in August 2012. As a special education teacher, she had dedicated her life to helping others. The McMullens say they feel a strong responsibility to carry on Mary’s legacy. Her family — husband, Tim, and children, Erin, Timmy and Eddie — ran the Baltimore Running Festival marathon as a relay team in her memory. A second relay team of extended family members also ran and helped raise funds in Mary’s memory.

For the McMullens, fundraising was very rewarding: “It gave our family and friends something we could rally behind in a time when we were grieving.” In a few short weeks, the McMullens exceeded their original goal of $5,000, and as we go to print, they’ve raised more than $10,500 for PHA.

Through email and Facebook posts, the entire McMullen clan was able to reach family, friends, co-workers and even former classmates, some of whom they hadn’t spoken to in years. The McMullen children say, “The nice thing about Facebook is our friends would repost our updates, spreading the word to other people we may not have reached.”

Erin, Timmy and Eddie say, “Fundraising gave us perspective of what a large support system we have. And it gave us the opportunity to learn more about our mother through all of the people’s lives she touched. “We would definitely recommend fundraising to anyone. It helps educate individuals about PH. PH is a real-life issue, and we wish we were more educated about it prior to our mother suffering. If you are thinking about fundraising, go out and do it. People are more willing to lend support than you think. Never underestimate the kindness of strangers, and don’t hesitate to reach out to those you may have lost touch with.”

With 26.2 Miles, a Son Honors His Mother’s Battle

Anthony Piatek ran the Chicago Marathon in October in honor of his mom, Mary Jo, who has PH. This was Anthony’s second year running in honor of his mother, and he plans to continue to run the marathon each year. As we go to print, Anthony has raised more than $2,500 in honor of Mary Jo. Anthony says, “I admire [my mother’s] strength in battling pulmonary hypertension each and every day. She is a warrior. If she can go on each day fighting this battle, then I can easily run 26.2 miles.”

Anthony enjoyed seeing his family, friends, co-workers and even friends of the family he doesn’t know personally support his fundraiser. “I know that looking at the list of people who have donated makes my mother feel more comforted and blessed knowing that she’s not alone in this battle. We are all here to fight with her, whether it be running 26.2 miles or donating $20,” he says.

Anthony emailed family and friends and posted the link to his fundraising page on Facebook every week throughout his 16 weeks of training. Anthony encourages others to consider fundraising for PHA and says, “Coming together shows solidarity and strength and tells the disease that it is not bigger than the circle of friends and family of those who suffer from PH. Fundraising, especially during these economic times, can be intimidating, but you will be surprised at how many people will step up and help because they believe in the cause.”
Congressional Luncheon Reaches Legislators from Coast to Coast

“In 2012, PHA added a new twist to our annual Awareness Month Luncheon on Capitol Hill — we invited support group leaders from different regions of the country to come early for a training and stay for the Luncheon. As a result, this year’s event boasted the most diverse group of PHers and their loved ones ever.

Luncheon attendees from the PH community mingled with legislative staff, sharing stories about life with PH and listening to remarks from leaders in the fight against the disease. Speakers included Dr. Gary Gibbons, Director of the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health; Sen. Bob Casey (D-PA), the sponsor of PH-specific legislation in the Senate; Dr. John Berger, a PH-treating physician from Children’s National Medical Center-D.C.; and Diane Ramirez, a PH patient and PHA Board Member.

“When you come here as advocates … you should never underestimate the value and impact of these visits,” Sen. Casey told the crowd.

After lunch, more than 30 PH community members from 12 states met with legislative staff in their senators’ offices to request co-sponsorship of the Tom Lantos Pulmonary Hypertension Research and Education Act and to seek support for the National Pediatric Research Networks Act.

Making a Difference One Legislative Visit at a Time!

Visiting Capitol Hill is just one of many ways to connect with your elected officials about the issues that matter to the PH community. District visits — visiting your Members of Congress while they are working at home in your state — combine the power of a face-to-face meeting with the ease of dropping in on a neighbor.

When Nicole Cooper visited Rep. Sarbanes’ (D-MD) district office this fall to thank him for co-sponsoring the Tom Lantos PH Research and Education Act, she expected a quick visit. She discovered that Rep. Sarbanes didn’t know as much about PH as she’d thought. He was eager to learn, and they spent 30 minutes talking about life with PH and what his support meant.

Diane Ramirez (left) and Monica Peters asked Rep. Howard Coble (R-NC) to co-sponsor the Tom Lantos PH Research and Education Act during a visit to one of Rep. Coble’s North Carolina offices.
How many couples have vowed on their wedding day to care for each other “in sickness and in health?” When a couple is confronted with the struggles of pulmonary hypertension, this commitment can be challenged. Regularly attending support group meetings with your partner is one of the simplest, most practical and rewarding ways to demonstrate your commitment.

According to many support group leaders, caregivers have five good reasons to attend a group:

1. **To Offer Support**

   Stephanie Layer, a PH patient and Minnesota support group leader, says, “I feel that it is so important for a caregiver to attend support group meetings to show support for the patient. The love and support that caregivers give is the extra strength that helps the patients move forward.”

   Living with a chronic illness can often be as much of a mental challenge as it is a physical one. Accompanying a spouse to a support group meeting shows you consider being part of the PH community important. Caregivers who show such understanding and empathy are invaluable.

2. **To Receive Support**

   “Our approach to pulmonary hypertension is that if one person in the family has PH, then the whole family has it,” explains Doug Taylor, a PH patient and South Carolina support group leader. “Caregivers need to hear what other caregivers see and do and how other caregivers cope.”

   As a caregiver, it’s easy to spend all of your time focusing on your loved one while neglecting your own needs, yet PH is life-changing for the caregiver as well as the patient. By attending a support group, you will meet others who are going through the same things you are. You will have the chance to share your PH-related hopes, fears, struggles and victories with fellow caregivers. When your needs are being met, you will feel more energized to be a better friend, a better caregiver, a better spouse.

3. **To Be Educated**

   Learning more about PH helps caregivers cope.

   Although living with PH can be an overwhelming experience, a general knowledge of the disease, available treatments and current research can allow both patients and caregivers to embrace hope. A well-informed spouse is better prepared to ask good questions, help evaluate options and assist in making decisions.

4. **To Connect with Other Caregivers**

   Barbara Thompson, a PH patient and support group leader from Tennessee, says that one of the most important reasons for caregivers to attend support groups is to speak with other caregivers.

   PH can be a lonely disease for both patients and caregivers. Many tend to withdraw from social situations for emotional reasons or because of physical limitations. However, socializing is healthy, and a support group is a safe place to interact with people on a similar journey.

5. **To Be Appreciated**

   A PH patient and Florida support group leader, Pat Murphy, claims that “a caregiving-centered meeting brought to light to PH patients that, although we appreciate the care, we don’t always realize the needs of the caregiver.”

   Many support group leaders are beginning to understand the importance of caregiver recognition. Heather Kirkland, a PH patient from Idaho, claims that “people are shy about getting personal, but we should be comfortable and happy to honor our caregivers in a significant way.” The acknowledgement of a job well done can encourage caregivers to rededicate themselves to their important roles.

In our culture, it is easy to relinquish support group participation to the sick, but caregivers also benefit greatly. If you are married to a PH patient, think about joining your spouse at a support group meeting to give and receive support, socialize, be appreciated and learn all you can about PH. The experience will allow you to act on your promise to stand together “in sickness and in health.”

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By Joshua Griffis

PHA Volunteer Services Coordinator
What Are PHA Support Groups Up To? LOTS! Check It Out ...

Alabama Support Group Leader Donna Head (center) secured a state proclamation and can be seen here proudly displaying the official document with members of her PH community: Dr. Karen Fagan (left), Chair-Elect of PHA’s Scientific Leadership Council; Barbara Cheatham (right) and Paiton Cale (front, holding the proclamation).

The first meeting of the Bay Area Alabama PH Support Group was a great success! Four patients and two caregivers came together to learn from each other’s stories. What a relief for those meeting a patient for the first time! They enjoyed it so much that they plan to meet every month at the same time and place.

This Fresno, Calif., Support Group meeting welcomed two newly diagnosed members and also said farewell to the group’s founder and leader, Josh Daniels, RN, CCN. Josh was a dynamic leader, and while we’re sad to see him go, we’re happy for his success as he starts a new chapter in his life.

Nicole Cooper, support group leader of the Charm City Exhalers (Baltimore, Md.) and PHA’s 2012 Outstanding Support Group Leader, told us her fall meeting was “AWESOME — the best support group meeting ever! Three new members were greeted with a warm welcome from the rest of the group. Not sure what was in everyone’s cup, but there was so much laughter going on, and everybody was having such a good time. The meeting was over, and patients continued the conversation for another hour.”

The Houston PH Support Group brought together 22 patients and community members, including Ellen Harris, an online chat leader who used to run a support group in Northern Virginia.

Joy Gore, the Bullhead City, Ariz., Support Group Leader, received a present from a member that she proudly displays here.
Advocacy, Education, Celebration, Friendship and Much More!

At the November meeting of the Mid-South Tennessee Support Group, every attendee received a zebra-striped bottle of water. Patients, caregivers and medical professionals came together to hear from speakers about the latest in PH research and education.

In honor of Emergency Preparedness Month, the Washington, D.C., Pulmonary Hypertension Support Group came together in October for a talk on PH emergencies given by a nurse educator. Group leaders Kim Ford and Conchita Watson also worked with a local patient, Alex Flipse, to organize a memorial bubble-making tribute to a young PH patient who passed away.

The Northern Virginia PH Support Group met in the fall after a brief hiatus when their long-time leader, Ellen Harris, moved out of state. The new group met in co-leader Betsie Miklos’s office to enjoy lunch and a talk by Debbie Castro, PHA’s Volunteer Services Director. This was the first time several patients met others with PH, and conversations were emotional and uplifting.

In honor of Emergency Preparedness Month, the Washington, D.C., Pulmonary Hypertension Support Group came together in October for a talk on PH emergencies given by a nurse educator. Group leaders Kim Ford and Conchita Watson also worked with a local patient, Alex Flipse, to organize a memorial bubble-making tribute to a young PH patient who passed away.

The Minn-la-Kota PHA Support Group in South Dakota celebrated National Caregiver Appreciation Month in November with a “Salute to Caregivers” meeting. Patients honored their caregivers with cards and handmade Caregiver Survival Kits. “It was enlightening and gratifying to honor our caregivers who give so much of themselves day to day,” says Jan Howd, support group leader.

Top: The Zebra PHriends of North Texas PH Support Group was featured on television on Good Morning Texas to talk about the group’s fun walk in November! They had a member dressed up like a zebra, and everyone was wearing zebra print for the Sometimes it’s PH early diagnosis campaign and periwinkle for PH.

Bottom: The North Texas group also brought patients, caregivers and PHfriends together at a recent meeting. Group Co-Leader Marcia Beverly excitedly told us, “I’m flying high with the definition of success. … We had our monthly meeting, and I estimated 30, expected 45 and had 59 PHolks at the meeting!” Patients learned about traveling with PH at a restaurant that donated 15 percent of the proceeds to the group’s fun walk. Education and fundraising in one!
Colorado Run for PHun Celebrates Fourth Year

The 4th Annual Colorado Run for PHun took place Sept. 16, 2012. PHA spoke with two of the event organizers — Beth Coleman, RN, CPNP, and Deb McCollister, RN, BSN — about the event and its history.

How did the idea for the Colorado Run for PHun come about? Our very first Colorado fundraiser was a gala held in 2008. Our two hospitals, Children’s Hospital Colorado and University of Colorado, had recently moved to one campus; it was a logical choice to work together toward a PH fundraiser since both our organizations are so involved with taking care of PH patients. We wanted it to be a joint effort between our hospitals and PHA, and this has really laid the foundation for how we’ve conducted all future Colorado fundraisers.

How did you decide on a run/walk? Although the gala idea was our first foray into PH fundraising, we wanted to draw more patients and families into the event, as well as create more awareness in the broader community. We also wanted to showcase our new campus, so we decided to hold our next event, the run/walk, on the Anschutz Medical Campus.

Who helps you coordinate the event? It started as a grassroots effort and has remained this way for the most part. Having the race on campus taught us that it is almost a full-time job to coordinate an event like this, working with all the campus personnel to nail down the logistics and all the details! So for our 2012 event, we decided to utilize a race coordinating company and hold the event in City Park in Denver. The company took on many of the finer race details that can really bog one down and enabled us to do our regular jobs of being nurses!

The registrants’ feedback was very positive about the new venue, and the race drew 470 registrants, a 20 percent increase over last year. After four events, we think we might finally have a pretty solid idea of how to move forward with our event without too much change from prior years. In terms of coordinating the event, the entire PH community comes together to make it a success, including nurses, physicians, patients, family members, volunteers and pharmaceutical representatives. It truly takes a village!

The sense of community your walk creates is evident from how much people look forward to it every year. What do you think contributes to that? A key element in organizing the event is to include patients and support group leaders who can provide guidance and suggestions and who will tell others about the event. PHA has also helped us immensely in spreading the word. Additionally, each and every one of the patients we treat in Colorado receives a race brochure. It has really built on itself year after year. Also we try to infuse entertainment, fun and education into the day by holding a silent auction, a kids’ play area, and a brief educational session provided by our expert physicians. It’s not just about the race.

What is the most important part of the event for you? While the tangible goals are clearly evident in funds raised for research and visibility to create awareness of this rare disease, the intangibles are what we take away each year — creating a venue for adults and children to connect with others affected by this difficult disease, to realize they are not alone, to bring hope in a shared fight for a cure and inspiration from all that our patients achieve despite their limitations.

What advice do you have for anyone thinking of hosting a special event? Don’t try to do it as a “one-man show.” This will lead to exhaustion, and your event will not be sustainable over the long term. Enlist members of your community, medical center and PH support groups. Delegate and empower members of your event planning committee to take ownership of specific aspects of your event: advertising, registration, silent auction, food, giveaways, education and sponsorship — to name a few. Plan to secure your event venue a year out, and start your monthly planning meetings six months prior to the event. Sponsorship and advertising can be ongoing throughout the year as opportunities present themselves. The more years you successfully host an event, the easier it gets — truly!

The event organizers put together a slideshow this year to generate even more interest before the event. View the slideshow at www.PHAssociation.org/2012CORunForPHun •
Special Events Across the Country Make Fall 2012 Event-ful

Mallory Hicks’ family (Lois Piper, far left; Tim Hicks, far right; Brandon Hicks, front) pose for a photo with PHA Board and Scientific Leadership Council member Dr. Michael McGoon and his wife Bonnie at the 2nd Annual Miles for Mallory PHamily PHun Walk in Minneapolis, Minn. This event took place Oct. 20 to remember the life of PH patient Mallory Hicks.

**Highlights include:** Approximately 150 attendees raised nearly $16,000 directly for PHA. Dr. McGoon was presented with a governor’s proclamation citing November as PH Awareness Month, and a personal letter of support from U.S. Sen. Amy Klobuchar was read at the event.

An enthusiastic Team Lehosky hits the track in honor of Sean Lehosky, a pulmonary hypertension patient, at the 8th Annual New York Fun Walk for PH. This team was one of at least 20 additional teams that participated at this Long Island, N.Y., walkathon held at Fireman’s Memorial Park in Lindenhurst on Oct. 6.

**Stats include:** This year’s event promoted a theme of “Supporting the fighters, admiring the caregivers, honoring the taken.” Together, walkers raised more than $61,000 to help benefit PHA’s research program.

From left: Cindy Gotlib, Bridie Halbach and Debra Watkins work the registration table outside the beautiful Alexana Winery in Newberg, Ore., at the inaugural Thirsting for a Cure wine-tasting fundraiser on Sept. 22. This instrumental fundraiser, led by Carl Hicks with the support of the Portland Metro PH Support Group and many others, raised more than $110,000 to directly benefit the **Robyn Barst Pediatric PH Research and Mentoring Fund** at PHA.

**Making history:** As a direct result of Thirsting for a Cure’s success, the **Robyn Barst Fund** reached its first $1,000,000 goal, opening the doors to the first-ever pediatric research fund for PH. Read more about the **Robyn Barst Fund** on page 1 in this issue of Pathlight.

Members of the 2014 Race Across America (RAAM; [www.RaceAcrossAmerica.org](http://www.RaceAcrossAmerica.org)) “Team PHenomenal Hope” are all smiles at the inaugural Pittsburgh Walking PHor a Cure on Sept. 9. The team, led by Dr. Patricia George (second from left), a lung transplant physician at the University of Pittsburgh Medical Center’s Comprehensive PH Clinic, partnered with the local support group to raise about $8,000 for PH research and patient-serving programs at PHA. Approximately 90 attended.

**In her own words:** As walk attendee and PH patient Deanna M. explains, “[My husband and I] were so happy to see so many patients, families and healthcare workers walking to support this disease and raising money for PH education and research. We were pleased to be a part of it and [are] looking forward to next year!”
**January 2013 — Happy New Year!**
What better way to kick off 2013 than to plan a springtime special event fundraiser!
GET STARTED: [www.PHAssociation.org/SpecialEvents/OrganizeAnEvent](http://www.PHAssociation.org/SpecialEvents/OrganizeAnEvent)
Contact us at Events@PHAssociation.org

**February 2013 — Attention, Spring Event Organizers!**
Time to finalize your event date/time/location and begin securing sponsors! MORE INFORMATION: [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook)

**March 2013 — Attention, Spring Event Organizers!**
Get the word out about your fundraiser and begin your media outreach! MORE INFORMATION: [www.PHAssociation.org/SpecialEvents/Publicize](http://www.PHAssociation.org/SpecialEvents/Publicize)

**March 2013**
First Event-ful Times e-newsletter of the New Year is distributed. Make sure that you’re on the list to receive this PHA Special Events publication! Sign up at [www.PHAssociation.org/SpecialEvents/OrganizeAnEvent](http://www.PHAssociation.org/SpecialEvents/OrganizeAnEvent)
QUESTIONS: Leslie Mahaney (PHA) at Eventful@PHAssociation.org

**Sunday, March 17, 2013**
PHA Team at Shamrock Run
WHERE: Portland, Ore.
CONTACT: Bridie Halbach at 360-694-6135

**Saturday, March 23, 2013**
The Woodlands CrawPHish Festival
WHERE: Town Green Park along the Woodlands Waterway, The Woodlands, Texas
CONTACT: Matacha Saul at 281-367-2222 or msaul@stibbsco.com

**April 2013 — Attention, Spring Event Organizers!**
Monitor registration and coordinate on-site fundraising (for example: a silent auction). DETAILS/QUESTIONS: Jessica McKearin (PHA) at Events@PHAssociation.org

**Saturday, April 20, 2013**
5th Annual Scramble for a Cure
WHERE: Las Vegas, Nev.
CONTACT: Jack Nino at Jack.Nino@igt.com or 702-250-2214

**Saturday, April 27, 2013**
PHA on the Prado Dinner
WHERE: Balboa Park — The Prado, San Diego, Calif.
CONTACT: Linda Santos at Santos.linda.m@gmail.com or 619-847-1899

**May 2013 — Attention, Spring Event Organizers!**
Your big day is almost here! Confirm last-minute details and coordinate day-of volunteers and tasks. Thank you for your efforts and have a fun and successful event! MORE INFORMATION: [www.PHAssociation.org/SpecialEvents/EventVolunteers](http://www.PHAssociation.org/SpecialEvents/EventVolunteers)

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

**Saturday, May 11, 2013**
4th Annual Race 2 Cure PH:
Taylor Caffrey Memorial 5K
WHERE: Anaheim Hills, Calif.
CONTACT: Shari Caffrey at Shari@TaylorsWish.org or 714-200-8322; [www.TaylorsWish.org](http://www.TaylorsWish.org)

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

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For complete and up-to-date special event information and listings, please visit PHA’s online calendar at [www.PHAssociation.org/Calendar](http://www.PHAssociation.org/Calendar)
Patients Learn and Network at PHA on the Road

Just as our 10th International PH Conference and Scientific Sessions ended in June, PHA headed back out “on the road” to bring PHA on the Road: PH Patients and Families Education Forums to two new areas of the country. The fourth year of the PHA on the Road program brought the day-long education and networking forum to New Brunswick, N.J., (Sept. 8) and the Chicago, Ill., area (Oct. 13). More than 500 people registered to attend the 2012 forums, rounding out another successful year!

“This was an informative session, an awesome and phenomenal experience,” says Carmen Lozada-Bruno, a PH patient from Brooklyn, N.Y., who attended the New Jersey forum. “I’m so glad that I had another opportunity to meet other people with PH like me and to know that I’m not alone.”

The 2012 PHA on the Road forums covered a variety of popular PH-related topics in both general and breakout sessions. General sessions designed for all attendees covered PH basics including how PAH is diagnosed, initial PAH treatment options and long-term PH management. The last general session of the day in both cities covered the topic of clinical trials and what new advances are on the horizon in PH treatment.

Breakout sessions throughout the day allowed attendees to choose topics that were most interesting to them — from emergency situations and pediatric PH to exercise, yoga and eating better. Having multiple breakout session options gave attendees at all levels of their PH journey the chance to learn new and interesting information.

PHA on the Road not only provided educational information for attendees but also created opportunities for networking and meeting other members of the PH community. Each forum kicked off with pre-forum networking sessions which targeted specific populations — including newly diagnosed patients, veteran patients, family and friends of patients, as well as parents of pediatric PH patients. This time allowed for sharing of stories, tips and questions among friends, old and new!

“This was our first conference … I came back home with positive thoughts that I am more in charge of my PH than I thought!” says Carol Zencka, a PH Patient from Crown Point, Ind., who attended the Chicago forum.

PHA will be coming to four new cities in 2013, and we hope to see you there! Stay tuned to our website, www.PHAssociation.org/OnTheRoad, to find out where we will be coming next.

By Suzanne Flood, PHA Event Marketing Manager

I am very happy that I attended the forum. I learned a wealth of information and know I am not alone.

— Anna Borup, PH Patient, Parlin, N.J.
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Building Medical Education in PH events are designed to foster partnerships between PHA and PH centers to promote continuing education in the field of pulmonary hypertension through CEU/CME educational events.

PHA extends its thanks to our 2012 Building Medical Education in PH partners:

- Duke University, Durham, N.C.
- Keystone Symposia, Monterey, Calif.
- National Jewish Health, Denver, Colo.
- Perelman School of Medicine at the University of Pennsylvania, Philadelphia, Pa.
- School of Medicine, University of Colorado, Denver, Colo.
- The University of California, San Francisco School of Medicine, San Francisco, Calif.
- The University of North Carolina at Chapel Hill, Chapel Hill, N.C.
- Tufts University School of Medicine and Tufts Medical Center, Boston, Mass.
- Yale School of Medicine, New Haven, Conn.

Visit PHA’s online education resources to get the latest PH information. All you need is an Internet connection, and you can participate from anywhere.

Highlighted Recordings
- “PH Treatments: What’s on the Horizon” led by Michael McGoon, MD
- “Newly Diagnosed? What You Need to Know” led by Maribeth Duncan, ANP-BC

To view a schedule of upcoming events or watch previous recordings, visit www.PHAssociation.org/Classroom

PHA Online University is PHA’s premier educational site for medical professionals. With course offerings, PHA’s quarterly medical journal (Advances in Pulmonary Hypertension) and webinars, you will find many ways to learn more about PH.

Highlighted Recordings
- “Working with a Social Worker” led by Allyson Rupp, MSW, LCSW
- “Caveolin-1” led by Rajamma Mathew, MD
- “Understanding Compassion Fatigue” led by Crystal Weber, RN

Learn more about our upcoming webinars at www.PHAonlineUniv.org/UpcomingWebinars
Be prepared.

**Find a PH Doctor.** View for a list of PH-treating physicians from around the world. [www.PHAssociation.org/FindaDoctor](http://www.PHAssociation.org/FindaDoctor)

**Insurance Guide.** PHA’s insurance guide answers questions about coverage and benefits, including disability, Medicare, Medicaid, Social Security and unemployment. [www.PHAssociation.org/Patients/Insurance](http://www.PHAssociation.org/Patients/Insurance)

**Empowered Patient Online Toolkit.** Templates, checklists and tips to help you manage your healthcare. [www.PHAssociation.org/OnlineToolkit](http://www.PHAssociation.org/OnlineToolkit)

¿Habla español? [www.PHAssociation.org/Espanol](http://www.PHAssociation.org/Espanol)

Expand your knowledge.

**About PH: An Online Guide.** Learn about the basics of PH, diagnosis and treatment. [www.PHAssociation.org/Patients/AboutPH](http://www.PHAssociation.org/Patients/AboutPH)

**Pulmonary Hypertension: A Patient’s Survival Guide.** Our comprehensive guide to understanding and coping with PH. Order your copy online at: [www.PHAssociation.org/SurvivalGuide](http://www.PHAssociation.org/SurvivalGuide)

**Living with PH.** Tips for emergency situations, living and working with PH, traveling with oxygen and more. [www.PHAssociation.org/Patients/LivingwithPH](http://www.PHAssociation.org/Patients/LivingwithPH)

**PHA Classroom: e-Learning. Anytime. Anyplace.** Learn about diagnosis of PH, treatments on the horizon, and other popular topics at: [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

Stay in the loop.

**PHANews** and **PHA Daily Beat.** Get the latest news about research, our community and PHA offerings sent straight to your Inbox or RSS feed. [www.PHAssociation.org/News](http://www.PHAssociation.org/News)

**Pathlight.** PHA’s quarterly print newsletter for members and donors provides medical updates, tips on living with PH, support group news and much more. [www.PHAssociation.org/Pathlight](http://www.PHAssociation.org/Pathlight)

Looking to help? We’re looking for you.

**The 435 Campaign** can help you reach out to Members of Congress to advocate for PH research and education. Request information and sample letters at: [www.PHAssociation.org/Advocacy](http://www.PHAssociation.org/Advocacy)

**Our Journeys.** Submit your story online to inspire others and help raise PH awareness. [www.PHAssociation.org/OurJourneys](http://www.PHAssociation.org/OurJourneys)

**PHAware Campaign.** Contact your local media outlets to spread the word about PH. PHA provides a step-by-step media guide, press kits and an email group to make it easy to do. [www.PHAssociation.org/PHAware](http://www.PHAssociation.org/PHAware)

Join our community of hope.

**Become a member.** Receive *Pathlight*, a discount on *A Patient’s Survival Guide* and much more. [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join)
Parents — Need Support?

Speak to other parents of pediatric patients on our monthly call.

“There’s just something reassuring about having a phone conversation, getting to know people, knowing you’re not the only one going through this ... Sometimes you get to feeling that there’s not a whole lot of hope out there, but there is.”

— Jody, mom to 8-year-old Taryn

The Parents Telephone Support Group is your chance to connect with other family members of pediatric PH patients for tips, brainstorming and support. The group meets the third Thursday of every month.

Upcoming topics include:

- Sibling Issues
- Clinical Trials: Process and Interpretation
- Preparing for School: 504s, IEPs and Day-to-Day Strategies

Check the schedule any time at www.PHAssociation.org/Parents/Support or call 301-565-3004 x800.

Calling All Volunteers!

☑ Do you want to make a big difference in the lives of others?
☑ Do you want to help fund cutting-edge PH research?
☑ Do you want to improve the quality of life experienced by those living with PH nationwide?
☑ Do you want to be able to say, “I helped find a PH cure”?

If you answered “Yes!” to any of the above, help bring your PH community one event closer to a cure by coordinating a special event fundraiser. PHA’s looking for motivated volunteers to host Fun Walks, Fun Runs, Six-Minute Marathons, fundraising meals and more during the spring and summer of 2013. No prior fundraising experience is necessary, and our Special Events program staff will support you each step of the way!

To begin your “PHund”-raising and awareness-raising experience, contact 301-565-3004 x765 or Events@PHAssociation.org. Learn more about PHA’s Special Events program at www.PHAssociation.org/SpecialEvents.

Support Line

PHA’s Patient-to-Patient Support Line is staffed by friendly patients who are long-term PH survivors. They are available to answer your PH questions, lend a sympathetic ear or help you solve issues relating to living with PH. Recently diagnosed patients, caregivers or anyone looking to find PH-related support will find this a great resource.

800-748-7274

Email Mentors

PH Email Mentors are caring and knowledgeable members of the PH community, ready to share what they’ve learned along the way, point you in the direction of information and resources, and work with you to develop strategies for coping with PH in your own life. Contact an Email Mentor today!

www.PHAssociation.org/Mentors
INTERVIEW WITH PH PATIENT
MIMI MCNIFF AND HER MOM BRITT

How old are you? Mimi: I just turned 5 on October 16!


When were you diagnosed with PH?
Mimi: Thirty-nine years ago or 30; no, really that’s what it feels like to me.
Mimi’s mom, Britt: Mimi was diagnosed on February 17, 2012.

If you were a superhero, what kind would you be?
Mimi: Iron-Woman, because I have the broviac in my chest. (Pictured right: Mimi’s drawing of herself as Iron-Woman in a periwinkle super suit.)

How is your family helping fight PH?
Mimi: Finding a cure.
Mimi’s mom, Britt: I ran a half marathon and raised $12,500 in pledges for the Robyn Barst Pediatric Fund. My sister’s Brownie troop (“007”) raised almost $1,000 with a lemonade stand, craft sale at town day and a school ice cream social. Mimi’s dad and I are hoping to organize a fun run and a benefit concert in the upcoming year all in hopes of finding a cure and, in the meantime, better and less invasive therapies. (Editor’s note: Read more about Britt’s half marathon on page 30.)

What message do you want to pass on to other kids who have PH?
Mimi: It’s a stupid disease, but it’s okay, it’s not really that bad.

ZEBRA CHALLENGE!

How is PH like a zebra? Sometimes it takes patients two or three years before the doctors figure out they have PH. This is because when doctors look at your symptoms, they are taught to think of diseases that a lot of people have before they think about a disease that is rare. It’s like expecting a horse when you hear hoofbeats — because how often do you run into a zebra? But PH is like a zebra — it sounds like a horse, but it isn’t. PH “sounds” a lot like other diseases, and that’s why it can take a long time for a doctor to realize a patient has PH.

People across the world are getting involved in helping others see the zebra and learn about PH. We have a challenge for you: Find the hidden zebras in Pathlight! We’ve hidden this zebra throughout this edition of Pathlight — can you find them all?

Have you told people about PH and the zebra?
We want to hear about it! Email us at Kids@PHAssociation.org or call us at 301-565-3004 x800 to tell us how you’re helping others around you learn about PH.
Teen Talk: Teens Share Their Thoughts about Living with PH

We asked teens at PHA on the Road: PH Patients and Families Education Forum in the Chicago, Ill., area and on PHA Teens, our teen social network, their thoughts on living with PH. See some responses below. Join PHA Teens at www.PHAssociation.org/TeenSocialNetwork!

Most people assume …

Most people assume I’m a normal teenager until they see my pump or my central line. Then they think that I can’t participate in physical activities, but I know I can. It just takes more time. ~ Courtney, age 14, diagnosed July 2012

Something I never thought I could do with my illness that I did is …

Something I never thought I could do with my illness that I did was graduate high school. When I was born, I was given a 13 percent chance of living to the age of 5. But after four open heart surgeries, over 20 heart caths, taking 45 pills a day and having a pacemaker/defibulator put inside of me, I was finally able to walk across that stage and prove once and for all that miracles do happen. ~ Becca, age 19, diagnosed at birth

A new hobby I have taken up since my diagnosis is …

Since I’ve gotten PH, I’ve taken up competitive cheerleading. I take breaks as needed, but PH is a hard thing to live with. If you control the disease instead of letting it control you, you can live your life more if you don’t always think about it. ~ Brooke, age 14, diagnosed at age 8

I was born with PH, but it wasn’t until I was 9 that I really started to feel lonely at recess. All the other kids were able to play kickball and soccer together while I just had to sit and watch. I started helping out in the school’s pre-school during lunch to give me something to do, and while I was there, the teacher was teaching the students basic sign language. I caught on fast, and she told me about a choir where we sign to music, and I’ve been doing sign language ever since. Sign language was something I could do, even when I had to stay inside because of a bad air pollution day or if I was too tired to get out of bed. I could put my headphones on and move my hands to help get out all of my emotions. I will always be grateful for that teacher’s gift to me. ~ Becca

My illness has taught me …

My illness has taught me to be thankful for each day that you’re given and to appreciate my family — like my brothers. When I was in the hospital, I missed them a lot. I never thought I would, but I missed them a lot. ~ Courtney

My illness has taught me a lot of things about life. Just because you have something that not everyone has, don’t get down on yourself. You need to have more of a drive to do things. Like in gym, let’s say your friend is running. Okay, it’s like five times harder for you to run — you just have to have that drive to do it. But you also have to make sure that when enough is enough, you stop. Living with PH is hard at times, but you also need to know that there are other people out there for support and to help you get through this disease, and you’re not alone. ~ Brooke

When someone is diagnosed, I’d like to tell them …

When someone is diagnosed, I’d like to tell them they can keep their head up and stay strong, and they should try to do what they usually do and take it one day at a time. I thought I could never be happy again, knowing that I had this illness, but my family was there and they were very supportive. They understood how I felt, and they helped me with it. ~ Courtney

When someone is newly diagnosed, I would tell them that just because you have PH, PH doesn’t have you. You can either control the disease or let it control you. You just have to know your limitations. That doesn’t mean you can’t go on to be a doctor or nurse because you’ll be standing all day. You just have to listen when your body tells you it’s enough. ~ Brooke

The nicest thing someone did for me when I wasn’t feeling well was …

I’ll never forget when my friend William called up the hospital and asked to buy a teddy bear from the gift shop and have it delivered to me. I’ll also never forget when my family had my little sister’s birthday party in the hospital cafeteria so I could be a part of it and not miss out on her special day. ~ Becca

When I wasn’t feeling well, my mom stayed in the hospital with me for all four weeks I was there. She brought me food I wanted because I don’t like hospital food and she was my support system — she and my father and my grandmother. They all helped me get used to having PH, telling me everything will be okay and helping me believe in it. ~ Courtney

Watch a video of Courtney and Brooke on PHA’s website!
www.PHAssociation.org/Teens/TeensTalkPH
Balancing Act: Parents Weigh in on Sibling Issues

It can be hard to balance the needs of all your kids — especially when one of your children requires intensive medical care. We asked parents to share their tips for helping children cope with a sibling’s PH diagnosis.

Having Time for Everyone

- **Support network.** Everyone can play a role in helping kids cope with PH in the family. When Britt’s 4-year-old daughter was diagnosed with PH, Britt and her husband were concerned about helping their 8-year-old cope. “We notified Gracie’s Brownie troop, teachers, our friends, neighbors, and family and asked that they give any time they could to Grace,” Britt shared. “Read, take her places, play dates, movies, sit and talk — anything that would make her feel loved, especially during the times Mommy and Daddy couldn’t be around.”

- **Celebrate accomplishments.** If you can’t be there in person, find ways to let children know you’re thinking of them and celebrating with them. “I missed Sydney’s last day of elementary school because Brooke was having heart surgery hours away,” Billie told us. “I had a limo pick up Sydney and her friends from school and take them out for pizza and ice cream.”

- **Turn medical trips into vacation opportunities.** “Since we no longer can afford to travel very far for family vacations, I usually ask if either of the kids wants to go on the medical trips to New York,” said Billie, who has two kids in addition to her daughter with PH. “All three kids have been able to take turns bringing a friend to New York. There is usually plenty of time for some fun before and after the tests.”

Life Lessons

- **Offer broader lessons.** “I think it’s important that [our 10-year-old son] learns that people are sick and have challenges,” Mitzi said. “I want him to be accepting of all people and not to look the other way when people need help. Empathy is an important quality!”

- **Bring perspective.** “We have been very open and honest with [our kids],” commented Billie. “They have asked if their sister is going to die. I always say that we are all going to die and none of us knows when. She could live longer than any of us. It’s not for us to decide or worry about. We should just be happy for today and that we have each other!”

Responsibility, Sacrifice and Sibling Rivalry

- **Remind them how much they contribute.** When Pam’s daughter Julie was diagnosed with PH, Pam wanted to find a way to use her son’s interests to help him feel good about his role as a caregiver to Julie. “We talked to our son about what it is to be an unsung hero,” Pam told us. With a father in the military, Pam’s kids understand that heroes often sacrifice their needs for the greater good of others. “You are a hero to Julie,” Pam explained to her son. “You have to help out every day and you often go without so that she can be treated at the hospital. Perhaps we should focus on your strengths and weakness so we know what kind of super-hero you are.” Pam bought her son a “how-to-draw-a-super-hero” book and some tracing paper. “It was a good beginning for him to discover who he would become,” Pam shared. “It helped him focus on why he was important and less on ‘why does Julie have more?’

- **Be fair when you can.** “We make sure that both of our kids have an allowance they earned,” Pam advised. “They can spend within their limits on treats. This helps us cap the spoilage and keeps both children feeling it was a fair deal. If my son thinks my daughter is getting more than him, we will look at the receipts and compare expenditures.”

- **Acknowledge that sometimes it’s unfair.** “One of the hardest things is the inequity in chores and work levels,” Christina admitted. “Emily does get jealous [of her sister with PH] at times. The key to it all is communication and sometimes just telling Emily that life is unfair. I know as she gets older she’ll understand more.”

PHA thanks all of the parents who offered input on issues and tips for this article. For more recommendations, visit [www.PHAssociation.org/SiblingsandKids](http://www.PHAssociation.org/SiblingsandKids).

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Join the conversation! Connect with other parents of PH kids by phone, email or Facebook. For the Parents Telephone Support Group schedule, visit [www.PHAssociation.org/Parents/Support](http://www.PHAssociation.org/Parents/Support) or call 301-565-3004 x800. To join the PHA Parents email group, visit [www.PHAssociation.org/EmailGroups](http://www.PHAssociation.org/EmailGroups). To get connected to the Families of Kids with PH Facebook group, contact PHA on Facebook!
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.

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The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x800 or Passages@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@PHAAssociation.org or 301-565-3004 x756. You may also use the remittance envelope enclosed in this issue of Pathlight.

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IN MEMORY OF

TAKING A LOOK! Sustainers Circle Members Recognized
PHA now recognizes members of our Sustainers Circle in the donations list. 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.PHAssociation.org/Donate/SustainersCircle or call 301-565-3004 x756. You may also use the remittance envelope enclosed in this issue of Pathlight.

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To honor those who have included PHA in their estate plans or whose legacies have been realized, PHA created the Legacy of Hope Society. PHA is pleased to recognize the following members.

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You may also submit a change of address online at www.PHAssociation.org/ContactUs.
PATHLIGHT AND PERSISTENT VOICES

Submissions

The Spring issue deadline is February 4, 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:

“Newsletter Submission”  or  “Newsletter Submission”
Print Services Department  Print@PHAssociation.org
Pulmonary Hypertension Association
801 Roeder Road, Ste. 1000
Silver Spring, MD 20910

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

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PATHLIGHT WINTER 2013
Pulmonary hypertension is a difficult disease on its own, but many patients develop PH in association with another chronic disease. PHA recently released a video series focusing on PH in association with adult congenital heart disease, lupus, HIV and scleroderma.

Check out page 4 in this issue of Pathlight to read more about these videos, and be sure to view the videos online at www.PHAssociation.org/PHPlus.

View PHA's New Videos on Coping with Multiple Diseases

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To subscribe, visit www.PHAssociation.org/PHANews

PHA Welcomes New Staff Members!

From time to time, PHA welcomes new staff members as former staff transition to graduate school, move out of the Washington, D.C., area, or take on new professional challenges. We are pleased to welcome new faces, and we wish our former colleagues well in their future endeavours. For a current list of PHA staff members, please visit www.PHAssociation.org/Staff.