PHAwareness Month November 2011: The Power of One

The story of the PH community is one of ending the isolation: When Amy Fair of Missouri was diagnosed with PH, she didn’t know anyone else with the disease. Through PHA’s online community, she met Florine Tripp and a year later they met in person for the first time. After hours of conversation about PH treatments and the challenges of living with the disease, they began to plan a support group. “Even if nobody else shows up,” Amy says. “I’ve met Florine, and Florine and I are together.”

A story of everyday heroes: Christina Rodrigues learned about PHA for the first time when her then 4-month-old daughter, Olivia, was diagnosed. This year, Olivia turned 3 and Christina set out to raise awareness of PH and funds for PH research through the inaugural Power for PH Phun Walk in Olivia’s honor. Inspired by Christina and Olivia, friends and community members pitched in to make the event a success. Power for PH received significant media coverage and raised more than $16,000!
The most valuable “currency” of any organization is the initiative and creativity of its members.

~ W. Edwards Deming in Stephen R. Covey’s Principle-Centered Leadership

**PHA** is an organization built upon vision — the vision that no one should have to face a life-threatening illness alone; the vision that one person can make a difference; the vision that together we can move (and climb!) mountains; and the vision that there will be a cure.

For over two decades, this vision has been mobilized by awe-inspiring leadership — leadership that created a vital organization from a modest kitchen table; leadership that prioritizes serving others; leadership that connects PH patients in China, Colombia and South Africa (only three of PHA’s 50 international partners) to patients living in the U.S.; leadership resulting in nine FDA-approved treatments for a rare, “orphan” disease with relatively few patients nationwide; leadership that says, “Yes we can!” even in the moments when it may feel like we can’t.

In November, we again have the opportunity to fulfill our vision through initiative and creativity during PH Awareness Month. Events will take place across the country ranging from fundraisers, media opportunities, and meetings with Congressional Members, to personal community and PHriend-gathering connections. Some of these events will be orchestrated by talented PHA staff under the keen leadership of our president, Rino Aldrighetti. However, the vast majority of these key interactions will happen because patients, family members and caregivers have the resolve and creativity to make them happen.

Here are some of the reasons why we think telling your story during PH Awareness Month is particularly important:

1. It is your story and no one has the power to tell it like you do;
2. Our collective stories create a swell of needed attention across the country and establishes urgency for our cause;
3. Although many of our Congressional Members and other policymakers have empathy for what we have experienced as individuals, they are especially interested in our joint interests;
4. In general, people truly want to help and helping those around you understand the challenges and triumphs you face living with PH can increase the support you receive within your community settings; and
5. Many individuals report that being involved in this way is an incredibly empowering experience.

You are PHA’s currency. You are the leaders who will pave the way to our future! I know that what you accomplish during our upcoming Awareness Month will be nothing short of amazing!

In partnership (with anticipation and admiration!),

Laura Hoyt D’Anna

**PATHLIGHT: A USER’S GUIDE**

Look for this icon to direct you to important information for healthcare providers.

Look for this icon throughout *Pathlight* to read news from around the world.
Email Mentors are patients and caregivers standing by to help other patients, caregivers and parents through one-on-one, email-based support. Sean Wyman is both a mentor and a co-leader of Generation Hope, PHA’s virtual support group for young adults.

What’s your PH story?

I was diagnosed on Oct. 18, 2002 (my 19th birthday). My mom and I were on vacation in Colorado Springs, Colo., and I became really symptomatic. It was as if an elephant was tap-dancing on my chest in stilettos. I blacked out twice in 24 hours. My mom brought me to the emergency room. From there it’s all a blur. I was in the ICU, then a regular room, and then transferred to Denver to see PH specialists. Since I was such a “well-behaved” patient, they gave me access to a laptop. I found PHA and read the entire site in a night.

I wouldn’t say I’ve made changes to my life; I’m just more aware of how I’m feeling. One of my school friends told me she was envious of me. When I asked her why, she said, “Because of your disease, you get to stop and admire the scenery.” I never thought of it that way when I was getting winded walking up hills, but now I do take time to “stop and smell the roses.”

When one of my doctors told me I would never be able to work or go to school, I decided to test that theory. PH hasn’t really changed my college life — I have changed college life because of my PH. I have increased awareness of PH on campus by giving presentations to classes and student organizations. My goal initially was to become a teacher (my family is full of teachers), but one of my college professors said I had a higher calling. I looked into respiratory therapy, but after taking a few of the classes, I realized I was capable of becoming a physician. I would like to think that I will stay in the world of pulmonary/cardiology medicine, but time will truly tell. After medical school, who knows what I will do. I have some ideas, but I’d like to keep a little mystery about me!

What advice would you give to other young people with PH?

The best advice I can give is, go to school and utilize all of the services! Seriously! I was scared to go back to school after my doctors told me I wouldn’t be able to. Ha, serves them right for telling me “No!” School helped me find some normality while doing something I love: learning. The most important thing is to be positive and informed. I found out about special student services and college became a breeze. Someone was always there to advocate for me, or to establish accommodations like rides around campus, special class seating (I like the front row), increased test-taking time, etc.

What does being a PH Email Mentor and a co-leader of Generation Hope mean to you?

It has given me a way to connect with other patients. There are occasions when I need to talk to someone and share an experience, and being a leader in the PH community gives me that chance. The large network being developed is amazing. Every young adult should join Generation Hope. Young adults experience a different set of trials and tribulations than older adults. Questions about relationships, marriage, education, careers and so forth are commonplace in Generation Hope. We share our experiences with each other and come up with better ways to raise awareness of PH in our communities so future friends and families understand what we go through. Being a leader and mentor has been amazing. It’s opened my eyes to other experiences, helped me better understand how to work with others and, most importantly, helped me better understand myself!

Why should someone contact a PH Email Mentor?

You should email a PH Email Mentor because we’ve “been there, done that.” Early on, I had people who acted as my mentors. Soon, I became a mentor for children and young adults. I felt that I could connect with them and tell them how to cope with PH and get a sense of normalcy back. The most important thing is to make a connection with someone who’s experienced life with PH. Some look at it as a horrible disease — I look at it as a way to be philanthropic, a lifelong learner and, of course, a lifelong PHriend.

Interview conducted by Emma Powers, Former PHA Patient Outreach & Services Intern

Email Sean at Sean@PHAMentors.org or connect with another PH Email Mentor by gender, age, associated disease or topic of interest at www.PHAssociation.org/Mentors.
Art for My Heart

It had been a long, cold winter in Colorado and even in April there were few signs of spring. I was diagnosed with class IV idiopathic PAH in 2008, and the isolation and lack of social interaction in winter gets to be a challenge for me mentally. So on one of my grocery shopping trips, I stopped by a craft store and wandered through the aisles to see what I could find. I had never been an “artist” and many of the crafts I had done in the past (knitting, needlework, etc.) were becoming difficult for me because of arthritis.

As I was walking through the paints, a little watercolor pencil kit caught my eye. It had eight pencils, a good quality brush and an instruction book. On a whim I picked it up, and that evening I started going through the first lesson. It was fun, took very little energy and didn’t make a mess. Just the right combination for me!

After going through the lessons, I bought some watercolor paper and did a few little paintings for my grandchildren. I was enjoying it so much I decided to do more studying about watercolor technique, so I checked out some books and videos from the library and watched lessons on YouTube. I bought some inexpensive watercolor paints and did my first real paintings at the end of April and first weeks of May (still snowing and cold).

Over the next weeks, I realized this was more than a passing interest to get me through until summer. I purchased better quality paints, paper and brushes and even joined a watercolor society. I now look forward to getting up in the morning and painting, even if it’s just a simple pen and ink with watercolor wash. My “studio” is a 5’x6’ space in my small condo (just a table next to a window with good natural light most of the day).

It has definitely made a difference in my outlook and mental and physical energy. When you have severe PAH, it’s easy to want to give up. Once I started painting, I began to realize that this was becoming a significant part of my legacy. I took photos of my sketches and paintings and saved them in a file so that they would outlast me.

Because of a genetic disease that keeps me from metabolizing drugs properly, I don’t tolerate any of the medications normally prescribed for PAH. Of course that pretty much seals your fate when you’re in advanced stages. Applying my background in nutrition and biochemistry, I did a lot of research and came up with a treatment plan using supplements and herbs. My right ventricular systolic pressure (RVSP) improved, and I wasn’t getting worse, but my functional capacity was still very limited and my oxygen saturation would drop into the low 80s on exertion.

At first, I thought perhaps I was imagining things, but in late spring it seemed like my heart function was improving. I could go up the stairs to my apartment instead of using the elevator all the time and I didn’t see stars when I got to the top. I ventured out on a few hikes with my husband; the first was fairly easy but quite an accomplishment. The second was much more ambitious. We were at a high altitude, and we hiked to a fishing lake on a rough trail. My husband carried my oxygen concentrator, and I was “tethered” by the tubing, walking behind him. When we got to the lake, I took out a tiny watercolor field kit and painted the beautiful scenery while he fished. It felt so wonderful to be doing something normal again!

A few weeks ago I had my first echo since I started painting. To our surprise my RVSP had dropped into the 50s. My doctor and the cardiologist thought it must have been an error in the measurements, but I know better. I can feel the difference. Is it a coincidence? I don’t think so. The American Art Therapy Association has documented the benefits of art as a healing tool for all types of mental and physical conditions, including pulmonary diseases.

I would encourage all of you who think you are artistically challenged to give it try. It’s not about producing a masterpiece or winning a show. Art is expressing your feelings, communicating with shapes and color and light, and sharing your own unique perspective of the world around you. Here are a few tips that might help you get started:

1. **Choose ONLY non-toxic materials.** I picked watercolor as my medium because you don’t need any solvents to dilute the paint or clean brushes. However, even with watercolor, some of the pigments used are considered toxic (cadmium and cobalt most notably). There are kits and tubes you can buy that are certified non-toxic. Look for the ACMI label. We need to do everything we can to protect our lungs, and unfortunately art supplies often contain VOCs.
Show Your Healthcare Who’s Boss
Introducing PHA’s Empowered Patient Online Toolkit

Studies show that patients who take the time to get and stay organized have an easier time following their medication regimens, alleviating symptoms and actually helping them feel better. This is no news to long-term PH patients and caregivers, many of whom have developed elaborate strategies for tracking medication dosages, nurses’ pager numbers, insurance plan information, appointment calendars and much more.

Drawing on the collective wisdom of the PH community, PHA has assembled some of the most useful tools, templates and checklists used by PH patients and medical professionals in our brand-new Empowered Patient Online Toolkit. The toolkit includes a range of resources that patients and caregivers can download in PDF format, personalize, and then either save to an electronic flash drive or print out to create a personalized medical binder.

The Empowered Patient Online Toolkit can help you:

- Summarize your medical and family history for new doctors
- Be prepared in case of an emergency room visit
- Track your medications and medical team contacts
- Prepare for doctor’s visits
- Record symptoms and concerns between medical appointments
- Summarize important information from appointments and hospital visits
- Keep your insurance information organized
- And more!

Get started at www.PHAssociation.org/OnlineToolkit

You can post your artwork (they welcome beginners and give helpful tips for improving), participate in monthly challenges to help you set a goal, and just chat with people of all abilities and disabilities!

5. **Share your work with others.** Art is about communicating. If friends and family laugh at your first attempts, just ignore it and keep going. Find a group of people online or in your community who understand the value of art therapy and who will encourage you, even if it seems primitive and very beginner-ish! Make sure you save at least some of your artwork and photograph or scan and file it digitally if possible.

As I write this, I’m looking forward to a few hours of painting today and a visit to a local watercolor exhibition with a friend who is also disabled and interested in art therapy. I hope you’ll give it a try — your heart may thank you in more ways than one! ♡

*By Janet Stone, PH Patient*

To read Janet’s article in its entirety, visit www.PHAssociation.org/OurJourneys/JanetStone. To view a workshop on creative expression from PHA’s 9th International PH Conference in 2010, visit www.PHAssociation.org/WordsForWellbeing.

(volatile organic compounds) and hydrocarbons that can compromise both lung and liver function. Even naturally occurring compounds like ammonia, turpentine and alcohol can be very hard on our lungs and worsen PAH.

2. **Take advantage of online learning opportunities and library resources.** As mentioned earlier, I watched many instructional videos on YouTube, and just recently got a subscription to ArtistNetwork.TV, which offers videos of workshops with well-known artists in all mediums.

3. **Look for community resources.** If you are able to get out and attend classes, community colleges and adult education programs are a great way to develop your skills. Most senior centers offer free or low-cost art classes. I just started attending a live model class once a week at my neighborhood center to get experience drawing portraits. We have a great time and everyone just chips in $3 to pay the model.

4. **Communicate with other artists.** The greatest resource for me has been a website called [www.WetCanvas.com](http://www.WetCanvas.com). There are forums for every medium and subject area. I have learned so much from this wonderful online community and made some great cyber-friends from all over the world.
Design Your Own Support Group!
A Guide for Young Adults... and the Young at Heart

Webster’s Dictionary defines a support group as “a group of people with common experiences and concerns who provide emotional and moral support for one another or sustain each other by discussing problems affecting them.”

One of the first things that my doctor advised me to do when I was diagnosed in 2007 was to get in touch with local support groups, and so I did, almost immediately. I started attending my local group’s meetings in southern Colorado as often as I could and then, in the summer of 2010, the opportunity arose for someone to take over as leader. Recognizing the physical handicaps that this disease had placed on so many, I figured that I would put my youth, energy and abilities to good use. It became my personal mission to do all that I could to support PH research and become an active member of the PH community. The support that I had experienced from my local support group made such a difference in my life and inspired me to try to give some of that support back to others.

I have 12 years of experience working with people of various age groups, ethnic backgrounds and developmental levels, and my work, volunteer experience and education have taught me that people are all unique individuals requiring very diverse forms of attention and support. With this in mind, last year I set out with some like-minded support group members to start a different kind of group. This group was designed to complement what we already had going and as an alternative to local patients whose needs weren’t met by the traditional support group. We launched an “Under 35” support group with the idea of meeting once a month, face-to-face, with younger individuals willing to talk about their struggles and challenges as a young adult — dating, school, and working with a chronic illness.

“The Front Range PHun Lungs,” as we called the group, has now become an interactive support group that meets at various locations and serves as a social club for patients, caregivers, friends and family — but also addresses specific issues of different populations when needed. It is led by a core group of patients, young mothers, teachers and counselors who offer support to members of the community in need of advice, a visitor, a social gathering, a phone call or education.

There are so many different ways that we, as patients and caregivers, can offer support to one another. All ages need support — and not necessarily the same kind. Consider school-age children who just want to fit in. They struggle with not being able to do what their friends can like exercising in PE class or playing on the playground. What about teenagers? They have to deal with peer pressure, wanting to be accepted and making positive choices for their health. There are also young adults who have questions about relationships, the future, sex, the possibility of children and being considered “disabled.” At times, patients and families just need an outlet where they can be themselves without limitation.

That is what the PHun Lungs group is all about. The group recognizes the differences in various populations’ struggles and respects them by meeting their individual needs. For example, if someone in the group needs an advocate to help deal with a difficult situation, that is what we become. If someone needs assistance organizing a fundraiser, we take on that role. We consider ourselves a stable and accepting support system, a “PHamily” without question or hesitation.

We like to base our gatherings around fun activities as often as it is appropriate. While we launched with young adults in mind, at this point the group is for all ages, not only the young but also the “young at heart.” Although it can be a challenge to coordinate, meeting in person is always the goal. And remember, support groups of all structures and sizes are important. Support can be a large community with a similar interest or issue or it can be you, just sitting at a kitchen table with three friends.

As a Generation Hope member and support group leader, I’d like to offer some ideas that have been shared with me to those who are considering starting groups geared toward young people dealing with PH:

There are so many different ways that we, as patients and caregivers, can offer support to one another. All ages need support — and not necessarily the same kind.
International Faces of PH: Huan Huang (Gloria)

“I am a slow walker, but I never walk backwards.”
~ Abraham Lincoln

My name is Huan Huang (Gloria in English); I am a 29-year-old woman from China, and you might say I’ve lived a double life. During the day, I make excuses to avoid walking or hanging out with colleagues, declining their invitations for dinners and parties. In the evening, I am cared for by my mother. I was diagnosed with pulmonary hypertension in 2005, but I’ve lived with breathlessness and fainting for years.

As a teenage girl, I was misdiagnosed with asthma and was told to hide my illness so I could attend college. In China, high school students who have been diagnosed with asthma are deprived of the right to take a college entrance exam. As a result, I began my therapies for asthma in secret, but climbing stairs remained challenging. Luckily, I completed my degree in English and worked as a project manager in a state-owned enterprise for a few years. When I’m out with my parents, we often hear, “Have a seat, ask your daughter to run errands for you.” On buses or subways, people give seats to my parents instead of me because they are in their 60s and 70s. In China, PH patients are not recognized as disabled, for the standards are highly restricted to physical appearance.

One week after my diagnosis, I was mocked by my employers for telling them that I had a fatal disease, because they didn’t think moving slowly was a life-threatening condition. One year later I fell into a deadly coma in my office and was taken to the hospital. Upon my mother’s urgent phone calls, Dr. Zhi-Cheng Jing, a PH specialist in China, rushed to the hospital and recommended iloprost (Ventavis™), which brought me back to life. Dr. Jing also gave me a copy of PHA’s Pulmonary Hypertension: A Patient’s Survival Guide and told me there are many other medicines on the international market. However, in China patients must wait until therapies are approved by the government.

One year later, when my medications became available, I had to pay all of the costs, since orphan drugs are not covered by medical insurance and there is no definition for rare diseases in China. To make matters worse, shortly after I regained consciousness, I got fired by my company. One year before my diagnosis, I was awarded the title “Most Valuable Employee,” but one month after my coma, I was rendered useless. My company finally believed that PH is deadly.

After spending all of my savings on PH medicines, I was hired by another company that was unaware of my illness. If my PH came out in the open, I knew I would lose my job. Once, my colleague even invited me to buy lipstick with her because she thought my blue lips were a new fashion trend!

During my regular hospital check-ups, I was surprised to find that my experiences were better than many other patients in rural China, who are unable to afford medical care and are incapable of working. Some of them have even experienced discrimination for not having children. The more connections I made with other patients, the more problems I found. I began to organize advocacy activities, submit letters and proposals to government officials, and I formed relationships with other rare disease groups.

Since 2009, I had hoped to start a non-governmental organization (NGO), but this decision proved difficult. If I had publicized my condition and ventured into establishing an NGO, I would have had to invest funds, quit my job and live on my savings account. After facing great difficulty in NGO registration, strict government administration, and the skyrocketing cost of my medicine, I waited to move forward until 2010. That year I met director Ziye Lee, an independent documentary filmmaker. With her help in July 2011 we finally co-founded our NGO, the ISEEK PH Social Service Center, and we are currently working on a documentary on PH patients all over China.

Fighting PH and founding our NGO was tough, but there were always people who supported us with love and care and there are always new solutions ahead. During our preparation period, patients, families, doctors and volunteers from all walks of life offered their help, and this has strengthened my confidence and persistence. In the future, I do believe more Chinese patients will benefit from what we are working toward today.

By Huan Huang (Gloria), PH Patient

Visit www.PHAssociation.org/PHInternational/Faces for more patient stories from around the world. To see a video about Gloria’s NGO, visit www.PHAssociation.org/SlowWalker.
Living with PH Plus... HIV

When I look back at who I was when I was first diagnosed with HIV, it’s hard to believe I am the same person. I knew I was at risk. My boyfriend was HIV-positive and we took minimal precautions based on uneducated decisions. The only thing I can say in my own defense was that in 1995 there was little HIV education available, and syringe exchange programs, even in New York, were only open a few hours a day, a couple days a week. We could never make it there in time to collect clean syringes, but we thought we had figured out how to use them without putting me at risk. We were dead wrong. I was stupid and careless.

I have never been sick from HIV. I am what they call a long-term non-progressor. My viral load is almost nonexistent and it took 15 years for my T-cells to decline to a point of concern. I have never been on HIV medication. For the past 15 years, I have lived and breathed HIV. I’m an AIDS treatment activist, focusing on such issues as novel drugs in development for HIV, including gene therapies, immune-based therapies and therapeutic vaccine. My big focus now is cure research. With one person already cured of HIV (though his treatment cannot be replicated for most), we are closer than ever to finally ending the AIDS crisis. Even so, my biggest problem is not HIV. It is my pulmonary hypertension that is the more likely of the two to take me down.

I was diagnosed seven years ago with PH. I remember the night that I realized something was wrong. My dog, Jo-Jo, a rescued Akita, loved to take off running whenever he got the chance. He’d make me chase him around, pretending to stop and sniff a tree so I could catch up, allowing me to get within arms’ reach before running again until he’d had enough. I knew the game well, and having no choice but to let him do this ritual, I began chasing him through the streets of the Bronx. But this night was different. After a few minutes my lungs started to burn. The air seemed to be disappearing. I kept needing to stop. Jo-Jo, of course, stopped beside me each time. My heart began beating wildly and I felt like I was hyperventilating. I couldn’t catch my breath.

Even with Jo-Jo mercifully waiting for me, I could barely keep up with him. I couldn’t go home, even to get help, because I was afraid he’d run into traffic. I began crying uncontrollably. I remember walking past some kids who had been hanging out on the corner. One said, “Damn, girl, you ain’t caught that dog yet? What’s wrong with you?” I wanted to scream, “Something is wrong with me – I need help!” By the time I caught Jo-Jo, I thought I was going to die. When I finally walked through the door of my apartment, I fell to the ground, hysterical, and threw up.

Luckily, my doctor had recently seen another doctor diagnose PH, so he sent me for an echocardiogram upon seeing my symptoms. Three weeks later I was at the 16th International AIDS Conference in Bangkok, Thailand, when it was time to call in for my results. After I was given a diagnosis of pulmonary hypertension over the phone, I immediately called a cardiologist friend for an explanation. He didn’t need to say much. I knew from his voice it was bad.

I have found that stress will aggravate my sickness and symptoms. Unfortunately, stress is a major factor in my life. Today, I am trying to minimize the amount of stress I feel and improve the way I handle it. I am newly married to a wonderful man from the United Kingdom, and as soon as the U.S. government approves his visa, I can start living the life I have always wanted — a quiet life with much less stress.

I will not give up. I am surviving HIV, and I plan to survive PH for as long as superhumanly possible. I have much to live for, particularly in the form of a gorgeous Brit. I am finally learning to come to peace with myself and the world. My PH may be HIV-related, or it may not. But one thing is for sure: more HIV physicians and patients need to be made aware of the risk of PH in HIV patients. One in 200 HIV-positive people have pulmonary hypertension, but because it is normally so rare, diagnosis comes too late for too many. I was lucky and I will work until my last breath to make sure that others are lucky as well, being diagnosed early and getting the appropriate treatment. My life is not nearly over, it has only just begun! *

By Jeannie Wraight
PH and HIV Patient

*www.PHAssociation.org PATHLIGHT FALL 2011
I was diagnosed with PAH during the spring of 2005. I am fortunate to be virtually symptom-free, and I continue to work full time. Since 2005, my employer-based insurance has changed providers four times, and I was declined coverage of subcutaneous Remodulin™ after each change. The first three times took only a phone call from my PH specialist to the new insurer in order to get the drug approved. The most recent change, however, was a different story.

**The Persistent Denial:** When I learned that I would be switching insurance once again, I filled out the required paperwork for continuation of care and pre-approval of my medication. As usual, I received a standard letter denying coverage. As with previous insurance changes, I emailed my PH specialist who was already aware of the situation. My PH specialist spoke to the insurance company’s medical director, who assured my PH specialist that my medicine would be approved.

A few days later I received a letter granting me a 30-day approval pending further evaluation, but this was followed shortly thereafter with a rejection letter from the insurance company’s pharmacist. After numerous additional phone calls between my PH specialist and the insurance company, I was informed that the insurance company was still refusing to pay for my medication. At this point I was told that I might need to get a lawyer.

**The Standoff:** My insurance company picked the wrong patient and doctor to mess with. We formed what I referred to as “my army” to fight the battle. I contacted a lawyer, Caremark, Accredo, and my employer’s insurance broker to work on my behalf as a go-between with the insurance company. My PH specialist was able to pull together a team from United Therapeutics, the legal department at University of Chicago Hospitals and the leading physicians who work with PHA.

It turned out that the insurance company was basing its decision solely upon the dosing information in the package insert for Remodulin™. Since the dose that I use is higher than the dosing information listed on the package insert, they claimed that it was not medically sound; they would only approve the dose listed in the package insert, half of what I normally receive. Not only did we have to prove that the dose I received was typical for many PH patients, but we also had to prove it would be unsafe to lower my dose.

**The Road to Victory:** I worked with Caremark and Accredo to obtain copies of each prescription my doctor had written for Remodulin™ since I started on the drug in 2006. They also provided copies of every Remodulin™-related bill they had on file and proof that all my previous insurance companies had paid for the drug at the higher dosage. I also had copies of Explanation of Benefits (EOBs) from my previous insurance companies, additional evidence that insurance had covered my medication at the prescribed dosage.

My PH specialist provided my complete medical records and made all the contacts necessary to connect the different groups of people helping me. She also gave us copies of academic papers regarding Remodulin™ dosing. United Therapeutics provided additional research articles and information. Finally, PHA provided a letter signed by its president and the leaders of its Scientific Leadership Council.

My lawyer compiled all the information and submitted it to the insurance company. Within a few days, the insurance company notified my lawyer and PH specialist that insurance would pay for the prescribed dose of Remodulin™.

**Some Lessons Learned and Take-Home Tips:** The first step is always to contact your PH specialist. Often a phone call from them is all that is needed. They may also have contacts with the pharmaceutical companies and access to legal assistance. Insurance companies are big and tough, but when you get pharmaceutical companies and hospital legal departments arguing your case, they realize they can’t simply scare you away from a fight.

**Know your state’s health insurance laws** (and the terms of your health insurance contract). I am fortunate that my state has a mediation process, independent of the insurance company, which can be used when insurance companies deny claims. This would have been our next step, which gave the insurance company an incentive to treat me fairly in their internal reviews. It is essential to know how much leverage you have.

**Ask for help.** Besides my PH specialist and her resources, we involved my union’s insurance committee, my employer’s health insurance broker and a local attorney. They gave me direct support and helped ease the stress. **Don’t panic, and don’t give up!**

By Kathy Morton, PH Patient
Announcing New Resources for Caregivers

**PHA** is continuing to implement new programs and resources based on your feedback! We’ve recently launched two new offerings for caregivers:

*Resources for Family and Friends*

**Free Information Packet**

Are you or someone you know a caregiver to a PH patient? PHA now offers a free information packet, *Resources for Family and Friends*, to help caregivers plan their next steps after a loved one’s PH diagnosis, find important resources and connect with other caregivers. To order your free packet, visit [www.PHAssociation.org/CaregiverPacket](http://www.PHAssociation.org/CaregiverPacket).

**Caregivers Telephone Support Group**

PHA now offers a monthly Caregivers Telephone Support Group. Family and friends of PH patients “meet” by phone on the third Wednesday of every month to learn and share about caring for a loved one with PH.

**When:** Every third Wednesday of the month. The next three calls will be Oct. 19, Nov. 16 and Dec. 21, 2011.

**What Time:** 1:30 pm ET/10:30 am PT

**How do I join?** Join the call by dialing toll-free 1-866-740-1260. When prompted, enter access code 5653004.

**What topics?** The topic changes monthly! Check the schedule anytime at [www.PHAssociation.org/Caregivers/Support](http://www.PHAssociation.org/Caregivers/Support).

For more details or to learn about more resources for caregivers, check out [www.PHAssociation.org/Caregivers](http://www.PHAssociation.org/Caregivers) or contact Michal at Caregiver@PHAssociation.org or 301-565-3004 x800.

PHA is grateful to Gilead and the Jansen Family Foundation for their support of the Kerry Bardorf Family Support Program.

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**Caregiver Shout-Out! Graeme Warner honors his wife, Jean**

My name is Graeme Warner. I am 62, have had PH for 19 years and live in Edinburgh, Scotland. I live with my wife of 15 years, Jean (65).

I depend VERY greatly on her. I am becoming less mobile, more limited and cannot do as much now as I once did. All the same chores have to be done — the supermarket, the garden, our coal fire, all the usual domestic chores. The supplies for Flolan™ must be organized and put away in an upstairs cupboard to be retrieved throughout the month as required. The list is endless. Anyone with PH or caring for someone with PH will know what I am talking about!

It is so easy to begin to take your caregiver for granted. I try very hard not to do so. However, I realized very recently just how very much I have come to rely on — indeed depend on — Jean for my day-to-day life. She went to Australia for about six weeks to visit her younger son and his two daughters, one of whom she had only previously seen on Skype. I did not travel with her. We made an honest assessment and decided it would just be too difficult. I was, therefore, on my own for six weeks. If anything was to be done, only I was available to do it. Boy, was that ever hard work!

Let’s acknowledge with gratitude and praise what our caregivers do for us, how much we depend on them and how different our lives would be if they were not around. Let’s hear it for caregivers! ✭

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For a chance to express gratitude to your loved one in Pathlight, email submissions to Michal at Caregiver@PHAssociation.org.
Q: How should I deal with my line and pump when I’m taking a non-PH medical test like a CAT scan, MRI or mammogram?

A: In this day and age, for patients with even advanced pulmonary arterial hypertension (PAH) requiring infusion therapy such as intravenous epoprostenol (Flolan™) or treprostinil (Remodulin™) or subcutaneous treprostinil, life goes on. And that often means undergoing a variety of non-PAH related medical procedures. Among the most common of these procedures are radiographic studies such as chest x-rays, CAT scans, mammograms and MRIs.

With the exception of MRIs, these procedures are readily compatible with PAH infusion therapies, including indwelling catheters, tubing, pumps and the medications themselves. Of course, it is critical that the patient continues to be his or her own biggest advocate, taking the same meticulous care of their therapy and its delivery system during these procedures as they do in all aspects of their day-to-day life. In addition, it is a good idea to inform the staff overseeing the procedure of the importance of the therapy and familiarize them with the delivery system. This will allow them to take the proper precautions to avoid, for instance, the tubing being tugged during the procedure.

The need to undergo an MRI, on the other hand, raises a number of challenging issues. Chief among these is that the magnet lying at the heart of an MRI scanner is generally not compatible with outside metal objects. Unfortunately, there have been instances when outside metal objects have mistakenly been brought into an MRI scanner, turning the objects into projectiles capable of inflicting injury and equipment damage. Accordingly, the following steps are recommended when a patient on infusion therapy for PAH is scheduled for an MRI:

1. Ask the question: is the MRI absolutely necessary? Often a CAT scan or other imaging study is an acceptable substitute and does not carry the same risks to the therapy delivery system.

2. If the MRI is deemed necessary, the MRI department should be contacted well in advance of the scheduled procedure to make arrangements. Typically this involves fitting extra-long tubing to the patient’s pump and catheter to allow for uninterrupted infusion of the therapy with the pump being kept safely outside of the MRI room.

3. It is important that an experienced provider supervise the incorporation of the extra-long tubing to avoid inadvertent medication bolus or prolonged interruption of medication. Possible providers include a PH specialty nurse, an IV team member, a specialty pharmacy representative or an experienced floor nurse.

4. Once the scan is complete, the tubing can be changed back to its normal length.

If these simple precautions are taken, an MRI can be performed safely. As is so often the case, a little foresight and preparation goes a long way to preventing any problems. Don’t hesitate to ask your PH care team to help.

Answer provided by Michael Mathier, MD, Associate Professor of Medicine and Director of the Pulmonary Hypertension Program at the University of Pittsburgh Medical Center, Pittsburgh, Penn.
Meet Dr. Paul Fairman: Furthering PH Education on the Road

Dr. Paul Fairman is the Director of the Pulmonary Hypertension Service and a Professor of Medicine at Virginia Commonwealth University in Richmond, Va. He became interested in PH in 1991 when he met his first PH patients while working in a lung transplant program. Dr. Fairman currently serves as National Committee Chair for the PHA on the Road: PH Patients and Families Education Forums. He chaired the four PHA on the Road programs in the spring of 2011 and is looking forward to chairing, planning and attending two more programs in the fall of 2012. Dr. Fairman recently took time to talk about his involvement in spreading awareness and education about PH.

You specialize in pulmonary and critical care medicine. What sparked your interest in PH?

I enjoyed thinking about the hemodynamics (pressures and blood flow) of PH and how they created symptoms and signs that were different from other lung and heart problems. I was curious about the various disease states that lead to PH. And I was captivated by the thought that there might be ways to treat PH other than transplant. Our first success came in a group of patients with obesity-related sleep apnea causing PH. Successful surgery for weight loss resulted in resolution or substantial improvement of PH in most patients.

You’ve been working in the field of PH for a long time. Do any cases or patients really stand out to you?

There are many: Lindsey, Angela, Robert, “Pinkie,” Gwen, Melvin, Gayle, Bonnie and many more. Each of them has a unique story and has taught our team something about the disease, its treatment, and the resilience and resourcefulness of those with this disease.

One special woman taught me not to underestimate the capacity of patients to manage this disease. She was in her mid-60s when her diagnosis of idiopathic PAH was confirmed. We agonized over starting epoprostenol (the only treatment at the time). It seemed like it would be too much of a burden for her and her partner. We worried about her ability to care for her catheter and operate the pump. Despite our concerns, she thrived on the drug, had no “pump problems,” maintained her catheter without any infections and remained independent until her death nine years later. Patients can, with the help of family and friends, team up to fight PH. It is very rewarding to be a part of a patient’s team.

How did you become involved with PHA?

I stopped by PHA’s booth at an American College of Chest Physicians national meeting. I was curious: who is this group and can they really help our patients and their families? I was impressed by the enthusiasm of those at the booth and their knowledge. Their goals to connect patients, provide accurate information and lobby for additional research made sense. And when I went to a national PH meeting, I was “hooked.”

What do you enjoy most about working with PHA and the PH community?

Meeting the people who create the fine programs and materials we have come to depend on for our patients and their families. I am fascinated by the stories of PHA’s staff and amazed by their seemingly boundless energy.

You are currently the PHA on the Road National Committee Chair and have participated in planning a number of forums. What impact has this had on you and what have you enjoyed most?

First, I am more deeply aware of the enthusiasm and dedication of PHA staff members who plan, organize and develop these programs. Second, I learn from the experience and expertise of the speakers and leaders at each program; I hear how they teach “PH” and organize their clinical care. Third, I get to hear more stories from more patients and family members about their “walk” on the PH pathway.

What’s the most important piece of advice you give to your PH patients?

Pulmonary hypertension is a team event. You need to involve your spouse, family, friends and connect with your doctor, nurse, specialty pharmacy nurse, physical therapist, PH support group. Learn all you can about this disease and how you, and your team, can fight it together.

Interview conducted by Meghan Finney, PHA Patient Education Manager
BMP Promotes Motility and Represses Growth of Smooth Muscle Cells by Activation of Tandem Wnt Pathways

The Questions:
1. What are the molecular mechanisms behind the protective role of bone morphogenetic protein (BMP) signaling in the pulmonary circulation?
2. Is recruitment of the Wnt signaling pathways associated with the protective effect of BMP in the pulmonary circulation?
3. What are the functional consequences of disrupting BMP and Wnt signaling in pulmonary smooth muscle and endothelial cells and do they relate to the pathology of pulmonary vascular disease?

Past Studies: One of the key pathological features of idiopathic pulmonary arterial hypertension (IPAH) is progressive loss of small (<50µm) distal blood vessels and abnormal vascular remodeling characterized by accumulation of smooth muscle cells in the medial layer of affected vessels resulting in luminal obliteration and obstruction to blood flow. Since the discovery of the link between familial and sporadic PAH and loss of function mutations in the bone morphogenetic protein receptor (BMPR) 2, a key player in the BMP signaling pathway, much work has been devoted to understanding how this pathway is involved in preservation of pulmonary vascular homeostasis and how its disruption can result in PAH. However, despite its definite link with PAH, only 20 percent of those who carry mutations in BMPR2 develop the disease suggesting that other genetic and/or environmental modifiers are required for disease development.

In 2009, we published a scientific study that established for the first time that BMP, in a BMPR2 dependent fashion, can protect pulmonary artery endothelial cells (PAECs) against injury and promote regeneration of small vessels by co-activation of two different Wnt signaling pathways: the Wnt/β-catenin (βC), which promotes growth and survival, and the Wnt/planar cell polarity (PCP), which coordinates their motility and ability to assemble into vessels. The Wnt signaling pathways have been shown to regulate various aspects of cellular behavior ranging from cell fate decisions to growth and survival of cells in adult tissues, and disruption of their normal function can result in a wide variety of disorders including cancer and heart failure.

In the present work, we wanted to explore whether cooperation between the BMP and Wnt pathways is also necessary to regulate pulmonary artery smooth muscle cell (PASMC) response following vascular injury and whether disrupting this interaction could lead to increased smooth muscle cell (SMC) accumulation in a mouse model of endovascular injury.

This Study: We discovered a novel cell-signaling paradigm in which bone morphogenetic protein 2 (BMP-2) consecutively and interdependently activates the Wnt/βC and Wnt/PCP signaling pathways to facilitate PASMC motility while simultaneously suppressing their proliferation. This pattern of Wnt activation is different from that seen in PAECs where BMP mediated activation of each Wnt pathway is independent of the other. Using a combination of cell-based experimental approaches, we found that BMP-2, in a BMPR2 dependent fashion, could induce SMC motility via the βC dependent production of fibronectin (FN), an extracellular matrix component that not only provides anchorage to SMC but also serves to enhance SMC migration by the activation of Wnt/PCP signaling.

However, addition of selective antagonists of FN as well as loss of function mutations in disheveled (Dvl), a key component of the Wnt/PCP pathway, resulted not only in loss of SMC motility but also increased cell proliferation. Interfering with the Dvl-dependent Wnt/PCP activation in a murine stented aortic graft injury model resulted in extensive neointima formation and luminal obliteration as shown by optical coherence tomography and histopathology that was reminiscent of PAH vascular pathology.

The Bottom Line: Based on our findings, we postulate that, in response to injury, factors that subvert BMPR2 mediated activation of Wnt/βC and Wnt/PCP pathways contribute to obliterative vascular disease in both the
Meet the New Members of the PHPN Executive Committee

This September, the PH Professional Network (PHPN) Executive Committee welcomed three new members, who will serve as the leaders of their respective committees for the next two years. Glenna Traiger joins us as Chair of the Membership Committee, Frances Rogers as Co-Chair of the Symposium Committee, and Gerilynn Connors as Chair of the Practice Committee. PHPN is becoming a powerful resource for allied health professional education and networking within PHA.

Meet Glenna, Fran and Gerilynn!

Glenna Traiger, RN, MSN, University of California Los Angeles, Los Angeles, Calif.

1. **How did you begin working in the field of PH?** I was the Cardiovascular Clinical Nurse Specialist at USC University Hospital in Los Angeles when Dr. Shelley Shapiro came to USC to start the PH program there. I was looking for new challenges, and she needed help with that program, so we found each other. We built a strong program there and then moved across town to the Veterans Administration Greater Los Angeles Healthcare System and UCLA. I have now been working with PH patients for 12 years.

2. **What is your area of expertise?** I work with both a cardiologist and pulmonologist so we see a variety of adults with PH. We also have an active research program. My role in the research program is to teach patients and family members about research and explain any PH studies they may be candidates for. I work closely with our research coordinators at the VA and at UCLA. I am also a study coordinator for the REVEAL Registry (Registry to Evaluate Early and Long Term PAH Disease Management) and have collaborated on some investigator-sponsored studies in PH.

3. **How long have you been active with PHA, and what PHA programs or activities have you been involved in?** My involvement with PHA spans at least the last 10 years. I have served as a member of the PHPN Membership Committee for the past few years, prior to taking on this role as Chair. Over the years, I have attended and spoken at PHPN Symposia and participated in Advocacy Days on Capitol Hill. I have served as a speaker for PHA on the Road forums, PHA’s International PH Conference, and webinars for newly diagnosed PH patients. I have also helped to revise the drug chapter in *Pulmonary Hypertension: A Patient’s Survival Guide* and served on the editorial board for the medical journal *Advances in Pulmonary Hypertension*. Additionally, I have been a support group leader for more than 11 years with the USC PH Support Group and then West LA PH Support Group.

Frances Rogers, MSN, CRNP, Hospital of the University of Pennsylvania, Philadelphia, Penn.

1. **How did you begin working in the field of PH?** My interest in PH began in July 2007 when the Hospital of the University of Pennsylvania opened its own PH program under the direction of Dr. Paul Forfia. I had been working with Dr. Forfia as a nurse practitioner in the heart transplantation program there prior to that and wanted to become part of the PH program at the “ground level.” I realized this was a dynamic field and wanted to learn more about it as well as how I could use my expertise as a nurse practitioner to help PH patients and their families. I have been the Clinical Coordinator of Penn’s PH program since summer 2007.

2. **What is your area of expertise?** I would certainly say my area of expertise is in the clinical arena, as we care for PH patients both in the outpatient and inpatient settings. In my position, I am also involved in pertinent clinical research because, as an academic institution, research is a big part of what we do.

3. **How long have you been active with PHA, and what PHA programs or activities have you been involved in?** My involvement with PHA began in 2007. I have been a member of the PHPN Symposium Committee since 2009 and have attended the PHPN Symposium, including Advocacy Day on Capitol Hill. Also, I co-lead a PH patient support group with Chris Archer-Chico, CRNP, through Penn. Presbyterian Hospital (part of the University of Pennsylvania hospital system).

STORY CONTINUED ON NEXT PAGE
Gerilynn L. Connors, BS, RRT, FAACVPR, FAARC, Inova Fairfax Hospital, Falls Church, Va.

1. **How did you begin working in the field of PH?** I am a respiratory therapist and have been working in pulmonary rehabilitation for more than 25 years. I have had the privilege of working with PH patients in pulmonary rehabilitation for eight years. I worked with my first PH patient in 2003.

   In 2003, our pulmonary rehabilitation program received our first referred PPH patient being worked up for lung transplant at Inova Fairfax Hospital. At that time, there was no literature about exercise and pulmonary rehabilitation in PH patients. The only published information then was from the 1998 National PR Guidelines by the American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) which had a short paragraph on PPH and pulmonary rehabilitation, stating “no exercise prior to transplant, exercise after lung transplantation.”

   Since then, I have been fortunate to have been an editor and writer of these national guidelines and have seen the role of pulmonary rehabilitation for the PH patient gain evidence and purpose. But we still have a long way to go to show stronger evidence that pulmonary rehabilitation in PH is an adjunct therapy that can improve six-minute walk tests, activities of daily living and the patient’s quality of life.

2. **What is your area of expertise?** My area of expertise is clinical. I am a respiratory therapist working in pulmonary rehabilitation.

3. **How long have you been active with PHA, and what PHA programs or activities have you been involved with?** My involvement with PHA began in 2007. Since 2007, I have served as a member of the PH Professional Network Practice Committee and authored articles for *Pathlight* and *Advances in Pulmonary Hypertension*. I have also served as a committee member and speaker at the PHA on the Road forums, a committee member for PHA’s Insurance Program, and have presented webinars on various topics. Lastly, I’ve spoken at educational sessions and presented abstracts at PHA’s International PH Conference and PHPN Symposium.

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**Research Corner Continued from Page 13**

Systemic and pulmonary circulations. This is relevant to understanding PAH pathogenesis as the current paradigm proposes that endothelial injury may trigger endothelial cell death with subsequent loss of small vessels and increased expansion of PASMCs in the wall of the pulmonary arteries which would then increase pulmonary pressures. Our studies strongly support a collaborative role for Wnt pathways in BMP mediated protection of the pulmonary vasculature and stress the devastating impact that disruption of these pathways can have on proper vascular regeneration and healing following injury. Our future studies will center on applying genetic and pharmacologic strategies to reverse and/or prevent development of PAH in animal models with dysfunctional BMP and Wnt signaling.

**Where to find this article:** *The Journal of Cell Biology*, Vol. 192, Number 1, 171–188

*By Vinicio A. de Jesus Perez, MD, Stanford University Adult PH Clinic, Stanford University Medical Center, Stanford, Calif.*

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**Disclaimer**

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 readers’ actions taken as a result of their interpretation of information contained in this newsletter.

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**Transplant Focus Group Forming Email Group Expanding**

If you are a transplant survivor, we want to hear from you. PHA is creating a focus group of patients who have had an organ transplant to help us learn more about your specific needs. We will use this information to improve our transplant resources and our ability to support patients before, during and after transplant. To get involved in this effort, email Meghan Finney at Transplant@PHAssociation.org or call 301-565-3004 x744.

Check out PHA’s transplant email group. In this email group, members share their experiences and ask questions about transplant. The group includes patients awaiting transplant, transplant survivors, caregivers and others interested in transplant. For more information or to join the transplant email group, contact Transplant@PHAssociation.org or 301-565-3004 x744.
Looking for a Pulmonary Hypertension Specialist in Your Area? Check out PHA’s Updated Find a Doctor Directory

PH patients are encouraged to seek care from doctors with experience and expertise in PH, and PHA’s recently expanded and updated Find a Doctor Directory is designed to assist you in locating and identifying such doctors. The Directory is a database of members of PHA’s medical membership network for physicians, PH Clinicians and Researchers (PHCR).

How to Use PHA’s Find a Doctor Directory

The information included in PHA’s Find a Doctor Directory has been provided by the listed doctors, and PHA does not specifically endorse any physician listed. But to help you to make your own assessment of their qualifications, PHA’s Scientific Leadership Council* has created two tools: an instructional video and a guide to help you navigate the process of choosing a doctor that is qualified to manage your pulmonary hypertension care.

These tools reference several key questions that you should ask when evaluating a physician. Some of those questions include:

- What year did you begin caring for patients with pulmonary hypertension?
- How many patients with pulmonary hypertension do you take care of in your practice currently?
- Do you have a specific nurse dedicated to assisting in the care of pulmonary hypertension patients?
- Do you require all patients to undergo cardiac catheterization prior to prescribing a therapy for pulmonary arterial hypertension?
- Do you currently provide access to all PAH therapies including prostanoid therapy (inhaled as well as injectable) to your patients?

For a full list of questions, as well as to access the video, visit www.PHAssociation.org/Patients/FindaDoctor

*Members of PHA’s Scientific Leadership Council are clinicians and research scientists in medical centers recognized for performing outstanding research and providing excellent care for patients with pulmonary hypertension. Its members provide medical and scientific leadership and guidance to support the mission of the Pulmonary Hypertension Association and lead the development of the wide array of PHA’s medical programming.

Welcome, Rebecca Kurikeshu, MPH, Medical Outreach Program Associate!

As Medical Outreach Program Associate, Becky is responsible for serving the members and promoting membership in PHA’s PH Clinicians and Researchers medical membership network. She also works with PH medical professionals to develop and expand resources that will advance the PH community. In addition, she assists in organizing the Scientific Sessions at PHA’s biennial International PH Conference, develops the monthly Research Roundup e-newsletter, and manages PHA’s Research Program. Becky can be reached by email at Rebecca@PHAssociation.org or phone at 301-565-3004 x776.

Welcome, Alisa Goldman, Allied Health Program Associate!

As Allied Health Program Associate, Alisa is responsible for promoting membership in PH Professional Network and helping to develop the group’s knowledge and other resources in ways that will benefit the entire PH community. She provides assistance and support to each of the group’s five leadership committees as they work toward meeting their goals. Alisa also assists in organizing PHA’s biennial PH Professional Network Symposium, the largest educational event in the field for PH allied health professionals. Alisa can be reached at Alisa@PHAssociation.org or 301-565-3004 x761.
The summer issue of Pathlight included a challenge to the PH community: Get news coverage in 35 states by Sept. 1. Over the summer, PHers received 35 new media stories in 10 new states, which brought the total number of pulmonary hypertension media stories to 73 in 31 states, and as we go to press, stories are still coming in!

Sharing your story with the media is a powerful way to reach a wide audience. Educate, empower and provide hope to your community this November: Share your personal PH story with a reporter during PH Awareness Month!

Be the first to put your state on the way toward a media success (and a star on your state), contact Elisabeth at 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit www.PHAssociation.org/Awareness/50StateMediaChallenge

In the meantime, get inspired by a few of the newest media victories! The following stories showcase the creativity of PH community members who used their interviews to talk about their involvement in special events and support groups, in addition to their experience with pulmonary hypertension:

Support Group Leader Puts Focus on Special Event (New Jersey) — PH patient and local support group leader Melanie Kozak was diagnosed with PH 14 years ago. A reporter at The Sentinel interviewed her about her experience with PH and the fun walk held in honor of Olivia Marie, a young PH patient who’s been battling the rare disease since birth. After seeing her article in print, Melanie exclaimed, “Now I am going to contact another event organizer in New Jersey to see if I can try to be their media advocate!”

Art Show Held in Maritza’s Memory (New Jersey) — Alice Matiz spoke to reporters about her special event in memory of her sister, PH patient Maritza. The June 11 art show featured Maritza’s artwork and the work from three other local artists. “My sister was feisty, talented, intelligent, and believed in speaking her mind. I want to keep her memory alive,” Alice told the news organization Hudsonreporter.com.

Two PH Patients Discuss Life with PH (Texas) — PH patients Yvette Pedroza and Stuart Berwick were interviewed in their local newspaper about issues that affect most PH patients, including misdiagnosis, the expense involved in managing the disease, their medications and their relationship with their caregivers. “I think going in as a pair was really beneficial because we were able to fill in gaps for each other … Also, the article stressed the fact that I came from Dallas for the interview in Lubbock/Plainview to try and help Yvette and her family. It really showed the willingness of PH patients to help each other,” says Stuart.

Add your state to the map!
These states need stars in our media map to the right.

- Alabama
- Alaska
- Arizona
- Arkansas
- Connecticut
- Idaho
- Illinois
- Maryland
- Michigan
- Nebraska
- Nevada
- New Hampshire
- New Mexico
- New York
- North Dakota
- Oregon
- South Carolina
- Vermont
- West Virginia
- Wyoming

Join other PHers working with the media: Put your state on the map!
Giving Every Month — and Beyond — In Honor of Her Sister

As one of PHA’s newest Sustainers Circle monthly donors, Lucia Martuccio knows how important PHA’s programs and services are to the PH community: her sister, Maria, was diagnosed with idiopathic pulmonary hypertension in July 2004. Lucia’s monthly gift is just one of many ways she, along with her entire family, supports Maria’s ongoing battle with PH.

In 2003 Maria was a healthy young woman, “but all of a sudden she was short of breath with minimal exertion, she was dizzy all the time and was having problems with simple daily tasks that we all take for granted,” Lucia says. During a monthlong heart monitor test, Maria passed out for nine minutes and was immediately rushed to the hospital. The doctors kept saying, “Her condition is very interesting,” and after many, many tests and a few incorrect diagnoses, Maria was finally diagnosed with IPAH.

Not long after her diagnosis, Lucia and Maria became involved in the PHA community. Lucia volunteered to participate in the Cleveland Area Pulmonary Hypertension Support Group (CAPHS) Annual Walk & Roll for a Cure and, after quickly browsing the “Get Involved” section of PHA’s website, Maria started her own Web of Friends personal fundraising page. Both sisters then started soliciting donations from family and friends in support of PHA’s programs and services.

After a conversation with a co-worker, inspiration struck again: Lucia decided to throw her own 30th birthday party and, in lieu of presents, asked for gifts to PHA in honor of her sister. “This way I knew I’d get exactly what I wanted,” Lucia says. The birthday donation trend continued with Lucia’s 31st birthday, as well as other holidays throughout the year. “Even though I wasn’t actively fundraising, my family and friends wanted to make these donations because they knew how much they meant to me and Maria,” Lucia says.

Earlier this year, Lucia had the opportunity to participate in the Dick’s Sporting Goods Pittsburgh Marathon. “Everyone who knows me knows I’m not a runner, I’m not athletic,” Lucia says. “More people than ever asked me about PH while I was training.” In just three weeks, Lucia raised $1,833 through a Web of Friends page, and she completed her first half marathon on May 15, 2011.

In recognition of “going the extra mile” for Maria by running a half marathon, Lucia also signed up to make a monthly gift to PHA through the Sustainers Circle. “It was simple — it took a whole three minutes to sign up. It is also so effortless, because I don’t have to remember to make a donation. I know my monthly gifts will help bring the greatest gift — finding a cure for Maria and her PHriends,” Lucia says.

The sisters are already brainstorming their next events: perhaps they’ll host a pasta dinner (their mom’s sauce is the best!), help their dad and brother organize a classic car show with proceeds donated to PHA, or lobby for a PH license plate in their home state of Ohio. “Maria is the inspiration for all I’ve done and all my family continues to do to raise awareness of this disease,” Lucia says.

Interested in learning more about PHA’s Sustainers Circle or brainstorming other unique ways to get involved? Contact Jennifer at Jennifer@PHAssociation.org or 301-565-3004 x756 or visit www.PHAssociation.org/Donate/SustainersCircle

By Jennifer Kaminski, PHA Development Manager

Welcome, Haley Elmers, Executive Program Associate!

As the Executive Program Associate, Haley is part of the team that supports the work of PHA’s president. Haley serves as the primary liaison to PHA’s Board of Trustees, maintains PHA’s historical archives, coordinates PHA’s internship program and assists with other projects that are of priority for the president and the organization. Haley graduated with a B.B.A. in Marketing and International Business from Baylor University. She can be reached at Haley@PHAssociation.org or 301-565-3004 x801.
When Is the Perfect Time to Support PHA at Work? Right Now!

Here are a few ways you can raise funds and awareness at your workplace:

- **Host a workplace fundraiser**
  From raffles and rummage sales to ice cream socials and potluck lunches, PHA’s *Our Workplace Has a Heart* kit offers creative ideas for hosting a fundraiser (and awareness-raiser!) at your workplace.

  When you request a copy of the kit, you’ll receive a colorful, easy-to-use binder filled with everything you need to plan a fun and successful event. The kit includes step-by-step instructions for easy fundraising events; a CD-ROM full of customizable templates; and everything you’ll need to plan PHA’s signature workplace fundraising event, *Blue Jeans for PH*.

- **Give to PHA at work**
  Many employers host charitable fund drives in the fall, and you may be able to designate PHA as the recipient of your pledge. Check to see if your employer participates in the United Way, or if it holds its own fund drive and encourage your co-workers to pledge to a charity that means so much to you. One of the country’s biggest fund drives is the Combined Federal Campaign (CFC), for employees of the federal government, postal service, and members of the military.

- **See if your employer will match your gifts to PHA**
  Some companies offer employee matching gift programs, which means every gift you give to PHA can be doubled or even tripled.

Ready to get started?
Workplace events are great any time of year, but November is the perfect time to support PHA at work because it’s PH Awareness Month! Visit [www.PHAssociation.org/Fundraise/AtWork](http://www.PHAssociation.org/Fundraise/AtWork) or call 301-565-3004 x756 to request PHA’s free *Our Workplace Has a Heart* kit or for more information.

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IN 1998, JANE COOPER HEARD NEWS THAT CHANGED HER LIFE. SHE RESPONDED BY CHANGING THE LIVES OF 30,000 OTHERS.

“This disease is not cool,” was the diagnosis her doctor delivered. They’re also the words that sent Jane and her family into action. While Jane was hospitalized for low oxygen levels, her husband Harold went to work researching PH and discovered an upcoming international conference on the Pulmonary Hypertension Association’s website that very weekend. Although her scheduled release was still days away, Jane’s response was, “We have to go.”

Follow Jane’s fight, and her family’s relentless support, at PHAssociation.org/Give/JaneCooper

Like Jane Cooper, you can strike a blow against PH by designating PHA as a legacy beneficiary. Your contribution will help shape a brighter future for all those affected by PH. For details, call us at 301-565-3004 x767, or email giving@PHAssociation.org. Visit our website for more information at PHAssociation.org/Give.
Meet ANHP (Spain) and the Israel PH Association: International Winners of Tom Lantos Innovation in Community Service Awards

The Lantos Awards, named for the late Representative Tom Lantos, a long-time advocate in the fight against PH, are awarded to members of the PH community to help them implement innovative awareness-raising initiatives, grow PH community service programs or duplicate existing programs in another area. Two global PH associations, Asociación Nacional de Hipertensión Pulmonar (ANHP) and the Israel PH Association, have used their awards to hold seminars for medical professionals who want to learn more about the disease. These awards are sponsored by Gilead.

Award Winner Profile: ANHP (Spain)
by Juan Fuertes, ANHP Coordinator
www.hipertensionpulmonar.es

The Tom Lantos Innovation in Community Service Award has been a turning point in the psychological care of pulmonary hypertension patients in Spain. We have always promoted the principle of considering the PH patient as a whole, not just as a faulty organ. After publishing the guide “Emotional Aspects of PH,” we saw the need to involve health officials in this holistic view of the disease. The Lantos Award has given us the opportunity to organize the first Seminar on Psychological Care for PH Patients, which reached out to psychologists and psychiatrists in Madrid.

On June 7, 2011, our organization brought together 12 psychologists and psychiatrists to discuss psycho-social needs in the field of PH, and this raised not only interest but real motivation and involvement on the part of the attendees. Irene Delgado, President of ANHP, says, “PH patients must get emotional support to face the fear of our prognosis, and we must have tools to reduce the challenges of this disease, which often impede access to jobs and make it hard to adjust to society. Psychological support is paramount for many patients in their struggle to make the most of their lives.”

PH patients are often placed at the bottom tier of the health system because of the small number of patients, and getting support from health officials has proved challenging. However, we found unexpected support through the Coordinator of the Regional Mental Health

Award Winner Profile: Israel PH Association
by Dr. Yosef Gotlieb, Board Member, Israel PH Association
www.phisrael.org.il

Primary care providers are often the first doctors to encounter a patient struggling with pulmonary hypertension. However, their lack of familiarity with the disease leads to misdiagnosis, delays in diagnosis and postponement in treatment for many patients. This realization prompted our conference, “PH: Profile of the Disease,” held at a Tel Aviv hotel on June 16, 2011, with nearly 100 clinicians and researchers in attendance.

The sessions, which consisted of 40-minute lectures by specialists, featured highly focused briefings on different dimensions of the disease. Following each lecture, the floor was opened for questions from the audience. Lecture topics included when to suspect PH, types of PH, treatment options, the complexity of care and research on diagnosis and treatment. The hall was so packed with attendees that extra chairs had to be brought in so attendees could listen to Israel’s top PH specialists lecture on the disease. Despite a physicians’ strike in Israel at the time, attendance at our conference was robust.

One of the sessions, a panel discussion dealing with the complexity of care, included the director of a respiratory rehabilitation unit at a Jerusalem pediatric hospital, a family physician, a support group counselor, a technician providing home care support and a patient. Everyone agreed that awareness of PH among non-specialist physicians and clinical staff was imperative and that family physicians play a critical role in coordinating treatment across the various specialties and agencies involved in patient care.

Our seminar, held on the Tel Aviv shore, also included several breaks that allowed participants, lecturers and PHA Israel board members to meet each other and network. Conversations continued over lunch, and following the meal, everyone returned for a final

Attendees and panelists at the ANHP seminar
Office of Madrid, Dr. Gustavo Petersen, who contributed to the success of the seminar.

After the seminar, we received a request from one of the public hospitals to fund research on the impact of psychological therapy in reducing morbidity and mortality of PH. One group of patients will attend group therapy while others will see psychiatrists on an individual basis. Their progress will be compared with a control group, and we expect to see a measurable difference in favor of the patients with psychological support.

There is much more to do as we encourage physicians to diagnose the whole person whose quality of life is affected by the way they experience the disease, the limitations they face, the drugs they take and changes from one functional class to another. This first seminar on psychological care for PH patients, made possible by the Tom Lantos Innovation in Community Service Award, is a milestone in the evolution of PH care. As President Delgado says, “We have opened a door for new challenges: we are small and in dire need of funds, but we have hope and a strong will.”

One important outcome of the event was the formation of an Experts Council of PH specialists who will create policy and provide guidance on the diagnosis, treatment and follow-up of PH patients. Our conference, made possible by PHA’s Lantos Grant Program, was a resounding success, and we intend to continue a series of educational programs for the medical community.

A session dealing with research horizons, including new possibilities in drug and cell therapies.

Amazing Idea but Short on Funds? We’re Here to Help!

Apply for a Tom Lantos Innovation in Community Service Award

PHA is pleased to announce the third year of the Tom Lantos Innovation in Community Service Awards program. Named for one of the true heroes of the PH community and sponsored by Gilead, these awards support members of the PH community who are making a significant impact in the following ways:

- Researching and developing innovative ways to raise awareness and foster community services in PAH;
- Extending the reach of an existing innovative program in PAH community services; or,
- Reproducing an existing program in PAH community services in another geographic region to address an unmet need.

Your amazing idea could be the perfect fit for this established grant program. As many as 10 awards of up to $5,000 each will be granted in 2012.

In addition to the international award winners featured above, visit www.PHAssociation.org/LantosAwards/2011 for a little inspiration from all of our 2011 award winners. And be on the lookout for announcements of opportunities for training on our website and in PHANews, PHA’s biweekly e-newsletter.

The application process opens on Tuesday, Oct. 11, 2011. Applications are due Friday, Jan. 6, 2012, and winners will be announced in April 2012.

For more information and to apply online, go to www.PHAssociation.org/LantosAwards or contact Jennifer@PHAssociation.org.
Imagine that your son was born with not one but two life-threatening congenital diseases, then was diagnosed with pulmonary hypertension when he was only a year old.

Martha Gonzalez knows this scenario only too well. Her son, Daniel Torres, has been living with these life threatening conditions for more than five years.

Martha has lived in the U.S. for more than 20 years, and now she is using her son’s example and all that she has learned about PH over the past five years to help other people in her native Ecuador. She is trying to convince officials in that country to add PH to the list of “catastrophic illnesses” for which the government-funded healthcare system will subsidize treatment.

Turning fear into action

When Daniel was diagnosed, rather than become immobilized by self-pity, the family met the challenges head-on and completely changed their way of life to become Daniel’s caregivers and closest allies.

“We as a family have become closer than ever,” Martha says. For example, “when we go to clinic, my oldest son Sergio takes care of my youngest, Mia. Sergio is considered a third caregiver of Daniel — knowing all about PH, always asking about it. He also knows the doses of his medications and schedule.”

Martha has maintained close ties with friends and family in Ecuador as well, which led her to launch a campaign to educate physicians about PH in that country.

“My involvement with the Ecuador government is related to an awareness project that I have planned with countries in South America,” Martha says. “I began with Ecuador because I am originally from there.”

The Ecuadorean embassy helped to arrange a visit in May with the directors of cardiology at Hospital Clínica Kennedy, Hospital Pediátrico León Becerra, and Hospital de Niños Dr. Roberto Gilbert Elizalde.

“Groups of physicians invited me to sit with them in rounds, during diagnosis of patients, and also showed me their advanced cath labs,” Martha says.

During those meetings, she was able to give the physicians informational material in Spanish regarding the disease. PHA provided her with material such as Pulmonary Hypertension: A Patient’s Survival Guide, the medical journal Advances in Pulmonary Hypertension and information on the international seed grant program.

“My impression was that all these physicians were very interested in PH,” she says. “Although some had heard of it, one hospital never had any case of it. In the pediatric centers, my visit coincided with the recent diagnosis of two children with PH.”

Martha adds that she is pleased with the response of the physicians she visited, who are interested in coming to PHA’s 2012 International PH Conference and getting actively involved in the PH journey.

Obstacles along the way

Martha says she was “amazed” to discover that the only PH drug administered in Ecuador is sildenafil. As she began working to change government policy by communicating with Ecuadorean health officials, Martha encountered a number of obstacles.

“I did my research and found that there was a list of catastrophic illnesses in Ecuador that included heart malformation and cardiac valve disease,” she recalls. “I called and emailed the authorities to inquire if PH could be included in this list, and they said only if the cardiac malformation causes PH at some point, as if it was secondary PH. I specifically asked what if it is genetic PH, and the answer was no. This disappointed me because if all cancers were included in this list, then why not PH? PH is incurable and, without treatment, is fatal.”

She presented the example that if a person was born with no heart malformation and developed cancer later in life, treatment of the illness could be subsidized by the government. However, if a person was born with no heart malformation and 20 years later developed PH due to a mutation of one of his genes, then why could this person’s care not be subsidized?

Martha is currently working with PHA on how best to approach the medical establishment and win the battle.
so PH can be included in this list.

“My goal is to put the word out there, be a mom ‘on the road,’” she says. “I will fight for my own country’s PH patients, and after that, I would love to move on to the rest of the countries in South America. I believe that the only way to have subsidized help for the expensive therapies for PH is by including PH in the catastrophic illnesses lists of these countries, especially in healthcare systems funded by governments.”

Hope for a cure

Martha says that even though her son Daniel is just beginning to comprehend what’s going on with his health, she is thankful for their private insurance and the daily medications that allow him to be just like any other 5-year-old boy who loves to run, jump, swim, play Wii and watch SpongeBob SquarePants. She wants people in other countries to experience this same care.

“We enjoy every day with Daniel,” she says. “We feel we are blessed to have found a great PH pediatric center and PHA. We feel that PHA is our security blanket; if we have any questions, we just call PHA and there is always help there for us. Not all is bad for us. PH has brought out the best of us as human beings. We no longer feel hopeless, we now feel hopeful for the cure.”

By Edward Freundl,
PHA Patient and Volunteer Writer

To read the full story of Martha’s family and her work in Ecuador, visit www.PHAssociation.org/Awareness/CommunityEducation

International Highlights:
What’s Going on Around the World?

With more than 50 PH associations worldwide, there have been some exciting developments in the global PH community. These international highlights are a testament to the hard work of PH community members everywhere!

• **In Canada...** PHA Canada’s two-day PH conference occurred on Sept. 16-18, 2011, in Toronto. The conference brought together patients, caregivers and medical professionals from around the country under the theme of “Uniting the PH community coast to coast.” Topics varied from the basics of PH to coping with the disease.

• **In Germany...** The German PH association, ph e.v., celebrates its 15th year in operation in 2011 and the Rene Baumgart-Stiftung Foundation, the PH research foundation operated by Ph.e.v., will celebrate its 10-year anniversary!

• **In Israel...** The first-ever PH special event in Israel, a Yarid Shira carnival, was held in memory of PH patient Shira Dunur on July 1, 2011, with the proceeds going to PHA Israel.

• **In Italy...** AIPI, one of the two PH associations in Italy, celebrated its 10th anniversary this year!

• **In Korea...** PHA Korea has officially been granted nonprofit status. The group began with a PAH blog in 2006, and the organization is now working toward raising awareness of PH in the medical community, the general public and the Korean health department.

• **In New Zealand...** The New Zealand PAH Trust association has become PHA’s newest MOU-holding partner! PHA’s Memorandum of Understanding program has united 26 associations in formal partnership to date.

• **In Norway...** PHA Norway, through a Lantos Grant sponsorship, held its first meeting for patients and caregivers near Oslo on Sept. 24-25, 2011. Stay tuned for more information in the next Pathlight!

• **In Paraguay...** A one-day PH conference for medical professionals was held on June 30, 2011, by the Asociación Latinoamericana del Tórax. Educational programming targeted cardiologists, clinicians and rheumatologists among other medical professionals.

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

By Meghan Tammaro, PHA International Services Manager
Insurance Finds: Five Tips for Parents of Children with PH

This past summer, Caring Voice Coalition (CVC) presented a webinar to the PHA community on how to obtain and maintain insurance coverage for your child. If you missed it, visit www.PHAssociation.org/Insurance/PediatricCoverageWebinar to see the recording. Until then, here are five tips from CVC:

1. **Keep coverage until age 26.** The Affordable Care Act now requires that dependents have the option of staying on a parent’s insurance plan until the age of 26. That means that if you have private insurance, you don’t have to worry about finding insurance coverage for your child until their 26th birthday.

2. **Utilize COBRA and Mini-COBRA.** If you lose your employee-based insurance, the Consolidated Omnibus Budget Reconciliation Act (COBRA) gives workers and their families the right to choose to continue group health benefits provided by their health plan for limited periods of time under certain circumstances. If you don’t qualify for COBRA because your employer has fewer than 20 workers, some states offer a Mini-COBRA plan, a state version of regular COBRA.

3. **Explore CHIP eligibility.** If your family makes too much money for your child to qualify for your state Medicaid, your child may still qualify for your state’s Children’s Health Insurance Program (CHIP). Most state CHIP programs cover children in households with incomes up to 200 percent of the federal poverty level. Some states coordinate their CHIP enrollment separately from their Medicaid enrollment, so don’t assume your child doesn’t qualify for CHIP just because he or she is denied Medicaid.

4. **Apply for Supplemental Security Income (SSI).** Children under the age of 18 can apply for SSI, an income-based benefits program administered through the Social Security Administration. A child who gets SSI benefits can also get Medicaid to help pay medical bills. When they turn 18, your son or daughter will need to reapply for SSI as an adult.

5. **Caring Voice Coalition can help!** Whether it’s counseling about your child’s SSI application or financial assistance for increased COBRA premiums, CVC provides free assistance to the pulmonary hypertension community. Call 1-888-267-1440 or visit www.caringvoice.org.

Visit www.PHAssociation.org/Patients/Insurance for more insurance information. Or, contact 301-565-3004 x773 or Insurance@PHAssociation.org with general insurance questions.

By Margaret Beardsworth
PHA Insurance Manager

Can’t wait another three months for more insurance news?

Sign up for PHA’s Coverage Connection and get your regular insurance fix with monthly email updates. To subscribe, visit www.PHAssociation.org/EmailSubscriptions

Get PH community updates delivered straight to your Inbox!

Sign up for PHANews, PHA’s biweekly e-newsletter. To subscribe, visit www.PHAssociation.org/PHANews
Advocating Across the Country

The PH community continues to educate Congress and build support for the Tom Lantos PH Research and Education Act. Here are just a few highlights since our last issue:

PHA on the Road Attendees Send 1,100 Letters to Congress

PHA on the Road brings together a cross section of the PH community, each with a personal connection to the disease. This year, at each of four PHA on the Road forums, attendees wrote letters to their Members of Congress educating them about PH and requesting co-sponsorship of the Tom Lantos PH Research and Education Act. When PHA gathered all the letters to deliver them to Capitol Hill, we had more than 1,100!

In one of those letters, a nurse practitioner talked about her patients: “I see their struggles and their fights with this chronic and terminal illness. ... We can make a difference by funding research opportunities.” The PH journeys of patients, caregivers, loved ones and medical professionals may be different, but together they paint a powerful picture of how this rare disease affects thousands of people.

Visit with Health LA Pays Off

I never thought I could make a difference!

~ Joy Gore, PH Patient

When Joy Gore attended PHA’s Congressional Luncheon in November 2010, she talked with Dvora Lovinger, Rep. John Sarbanes’ health legislative assistant, about what it’s like to live with PH. In June, Joy followed up with Dvora and requested that Congressman Sarbanes (D-MD) become a co-sponsor of the Tom Lantos PH Research and Education Act of 2011. Within a few days, he did!

Perry Mamigonian Hosts Legislative Staff at Support Group Meeting

Perry Mamigonian hosted a special guest at his August Support Group meeting: Anthony Ratekin, legislative staffer to Rep. Devin Nunes (R-CA). Perry’s group helped Anthony better understand what it’s like to live with PH and asked for Rep. Nunes’ co-sponsorship of the Tom Lantos PH Research and Education Act. Perry is just one of many PHers who took advantage of the August congressional recess to build co-sponsorship of our PH bill. Watch for more in the next Pathlight.

Inspired by these stories? Share your story with your Members of Congress and build support for the PH bill. Contact Elisabeth Williams at 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit www.PHAssociation.org/Advocacy/ConnectLocally
Welcome, Bob Gray, Director of Development!

As Director of Development, Bob is responsible for increasing contributed income benefitting PHA programs by working closely with volunteers and staff to implement techniques such as direct mail, individual and foundation gifts, special events and cause marketing. He also works closely with PHA’s Development Committee and president to research and design funding techniques for new PHA programs. Bob can be reached at Bob@PHAssociation.org or 301-565-3004 x767.

Welcome, Ellie Falaris Ganelin, Design & Publications Associate!

As Design and Publications Associate, Ellie assists in designing, editing and writing PHA’s many print and online publications. She is also the primary contact for *Pulmonary Hypertension: A Patient’s Survival Guide*, PHA’s resource book for patients and caregivers. Ellie works with volunteer contributors to update and publish the *Survival Guide* on a yearly basis. She can be reached at Ellie@PHAssociation.org or 301-565-3004 x812.

A story of one person’s power to bring about change: When Colleen Connor attended PHA’s Congressional Luncheon during Awareness Month 2009, she and her family were still learning about the details of the *Tom Lantos PH Research and Education Act* and why it is so important in promoting PH research and awareness. Nonetheless, Colleen went out on a limb to share her story with staff in Sen. Bob Casey’s (D-PA) office and request sponsorship of the PH bill in the Senate. Twenty minutes later, the staffer called to say that Sen. Casey had agreed to sponsor the bill in the Senate. Since then, his office has provided invaluable support in advancing the PH community’s cause.

This November, make the PH community’s story your story. You’ll find more information about making a difference during Awareness Month throughout this issue of *Pathlight* and at www.PHAssociation.org/AwarenessMonth2011.

Alone, we are powerful. Together, we are unstoppable. ♦

By Katie Kroner, PHA Director of Advocacy and Awareness

**INVITE YOUR MEMBERS OF CONGRESS TO PHA’S CONGRESSIONAL LUNCHEON!**

I made my phone calls, and it sure felt good to be doing something positive for PH!

~ Laurie Johannsen after PHA’s National Call-In Day

Even Members of Congress appreciate a free lunch. That makes PHA’s Congressional Luncheon the perfect way for us to educate them about PH and secure their co-sponsorship of the *Tom Lantos PH Research and Education Act*.

How do senators and representatives learn about the Congressional Luncheon? **You invite them!** Call Katie at 301-565-3004 x749 or visit www.PHAssociation.org/GetInvolved/CongressionalLuncheon to:

- See current event details;
- Find a sample script for inviting your senators and representative;
- RSVP to attend this free luncheon on Capitol Hill.

PH patients Conchita Watson (left) and Kimberlee Ford at PHA’s 2010 Congressional Luncheon

**WELCOME, BOB GRAY, DIRECTOR OF DEVELOPMENT!**

As Director of Development, Bob is responsible for increasing contributed income benefitting PHA programs by working closely with volunteers and staff to implement techniques such as direct mail, individual and foundation gifts, special events and cause marketing. He also works closely with PHA’s Development Committee and president to research and design funding techniques for new PHA programs. Bob can be reached at Bob@PHAssociation.org or 301-565-3004 x767.

**WELCOME, ELLIE FALARIS GANELIN, DESIGN & PUBLICATIONS ASSOCIATE!**

As Design and Publications Associate, Ellie assists in designing, editing and writing PHA’s many print and online publications. She is also the primary contact for *Pulmonary Hypertension: A Patient’s Survival Guide*, PHA’s resource book for patients and caregivers. Ellie works with volunteer contributors to update and publish the *Survival Guide* on a yearly basis. She can be reached at Ellie@PHAssociation.org or 301-565-3004 x812.
Two Community Members Use Social Networks to Raise Awareness

This summer, PH community members Kim Ford and Brenda Reynolds took advantage of social networking websites to encourage others to raise PH awareness. The PH community responded in a BIG way! Read our interviews with both women to find out how Kim’s PH Awareness Day and Brenda’s PHAmerica Honors Ambassador Awards spurred PH awareness raising.

Kim Ford Launches PH Awareness Day

What was PH Awareness Day? PH Awareness Day on July 8, 2011, was a day I wanted everyone in the world, regardless of their physical capabilities, to do something to spread pulmonary hypertension awareness.

What was the response? The PH community responded in an overwhelmingly positive way. My goal was to get as many people involved as possible and for them to share the event with their friends and so on. First, I created an event page on Facebook; then I reached out to support group leaders, PHA email groups and lots of PH Facebook group pages. I think Facebook made it easy for everyone who wanted to participate to share the event with their family and friends.

On the event page, 1,136 people confirmed their participation. I found out later that many more worldwide participated.

The PH community was excited about this event, and they had so many great awareness-raising ideas. One caregiver’s sister gave a speech about PH to her class. One gentleman painted a chair and told people his PH journey as they walked by it. Another person went on a local TV show to talk about PH Awareness Day. Two people got tattoos! I was amazed at how many phoned their congressional leaders and emailed friends.

How can tools like Facebook help the PH community raise awareness? PH Awareness Day was very successful because of Facebook. In the days leading up to July 8, so many people posted a link to the event page and used their Facebook status updates to share what they were planning to do for PH Awareness Day. On the day of, Facebook was flooded with people sharing what they were doing. People who did not have PH also helped to spread awareness.

If more people are willing to use Facebook and other social networking sites to help spread PH Awareness on a daily basis, we can educate the world about pulmonary hypertension. Hopefully, this will lead to more funding and soon a medical cure. The PH community has to continue to empower each other to spread PH awareness.

Brenda Reynolds Creates the PHAmerica Honors Ambassador Awards

What is the PHAmerica Honors Ambassador Awards? It is an online awards competition. An ambassador is chosen to represent their peers in a specific category. Those ambassadors must then help promote our mission and be a voice for the PH community.

How did you come up with the idea? I had a friend who was organizing a beauty pageant to help raise awareness for seat belt safety in honor of her daughter who passed away in a car accident. I always wanted to do something positive in memory of my niece, Kayla Marie Hosea, who lost her battle with PH in 2009. I also wanted an activity that was easy for the winners to do even if they were having a “PH” kind of day. That’s when I came up with the pageant, and PHAmerica Honors was born!

What was the response? The PH community’s response was fantastic! It has been wonderful to use the Honors to help direct PHers to the awesome resources from PHA. Approximately 100 people participated. I received a ton of support from everyone, even those who did not enter. Lots of people went online and voted, wrote encouraging notes to the participants and were excellent examples of positivity, working together and understanding. The essays that were submitted were phenomenal. The judges had a very hard time choosing winning essays because each was strong in its own way. A big thanks to the judges for doing such a great job, and thank you to everyone who entered and supported this new venture!

Who are the winners? PHAmerica Honors Ambassadors for 2011 include Jane Northrop, Sylvia Creach, Jhenna Pacelli-MacDonough, Nicole Northrop, Melanie Kozak, Jeannie Kendrick, Dave Rider and Joshua Griffis.

Online Tools to Help You Build Awareness

- Kick off Awareness Month! Join the PH community on Nov. 1 for Online Awareness Day. www.PHAssociation.org/AwarenessMonth2011
- Use Facebook to Advocate to Congress! Visit www.Facebook.com/PulmonaryHypertensionAssociation and click “Take Action” on the left of your screen.
- Join PHA Online Messengers! Join our online activists and commit to spreading the word about PH through social networking sites. http://groups.google.com/group/PHAonlinemessengers
Awareness Month is Just Weeks Away:
*But Time Remains for You and Your Support Group to Get Involved!*

When you hear the phrase “PH Awareness Month,” you may immediately think of large campaigns to raise PH awareness both nationally and internationally every November, but that’s not always the case. Awareness month activities can be grand and national or international in scale, but they can also be local, homegrown and easy to organize. Rest assured, even though we are only a few short weeks away from Awareness Month 2011, there are many things you can do to make an impact, especially when you link up with others to make your project happen.

**Work with your support group**

PHA’s network of support groups is the ideal place to start if you have a great idea about ways to educate those in your community about PH. In the past year, many support groups have worked together on awareness projects.

Many awareness efforts require minimal preparation, but can still be very effective. Creative support group leaders and members consistently come up with ideas that pack a punch and can be carried out quickly. In 2010, the Kentuckiana Support Group, which serves those living in and around Louisville, Ky., decided to educate people living in the region by setting up informational displays around the city. In preparation for Awareness Month, the leaders of this group hosted a craft night where members helped assemble and decorate the displays that would be placed around the city. Not only was this meeting productive, but as the group glued and decorated boards, the casual atmosphere allowed them to have fun conversations and get to know one another.

You don’t even need to create a new event or display to get the word out about PH; if you keep your eyes open, you might be able to find community events that are already taking place and would be ideal for your awareness efforts. For example, every year the Omaha and Western Iowa Support Group participates in the University of Nebraska, Omaha Health Fair, sending volunteers to represent the group with a pulmonary hypertension education booth.

**Do something during November or after!**

The key to awareness raising is getting the word out. If you can’t put together a large awareness campaign this fall, think about doing something small. Even when your PH keeps you at home and steals your energy, you can still reach out to others through Facebook, email, letters or the phone. November is the perfect time to spread the word about PH, but you can also spread awareness all year through. Give it a try!

*By Sophie Klein

PHA Volunteer Services Associate*

*Joan Stevenson, leader of the Lehigh Poconos Support Group in Pennsylvania, educates people at a local community center about PH.*

*Dedra Richardson, sister of PH patient Kim Ford, shows how easy it is to do a small awareness project. She set up this informational candy basket on her desk at work. For 25 cents, co-workers got a piece of candy and some information about PH.*
There's Always a Place for You at the Table

No doubt about it. Many patients are living a long time with pulmonary hypertension and, while previously active in their local support group, may find their need to participate wanes. Others may have a change in their PH status through transplant or other surgery. If this describes you, we want you to know that there’s a place for you at the table — whether it’s to get help for yourself or to help others.

I’m not newly diagnosed. Are support groups for me?

It’s no surprise that many people flock to support groups when they first find out they have PH. Over time, a patient may acclimate to the disease and, ultimately, learn to live with a “new normal.” At this point, many patients stop attending meetings for support. But your presence can be a huge comfort to patients who are just coming to understand their diagnosis, and you might be just the one to motivate and inspire those who need your support at a fragile time.

Enliven your group with a youthful perspective.

It’s easy to find the under-40 crowd online, keeping in touch with friends though email, Facebook and Twitter, but there aren’t usually many younger patients at support group meetings. A number of support group leaders buck this trend by creating activities for the young and young at heart. Mid-Hudson Valley, N.Y., support group leader Kiara Tatum, a member of PHA’s Generation Hope, an email group for patients in their 20s and 30s, was encouraged by her doctor to attend a support group. Now she not only attends a group, but leads it. This year she led the group in making a float for a local parade and has invited children and grandchildren to the meetings.

For more ideas on adding a youthful perspective to your meetings, read the story on p.6.

Post PH?

Whether the result of pulmonary thromboendarterectomy (PTE) surgery, transplant, or eventually diagnosis with a different condition, some people may no longer have PH health concerns to draw them to meetings. But they still can contribute much to local support group activity. Anyone who has experienced PH can relate to those living with PH. These patients bring hope to others by sharing their stories. This was the case for the Newport Beach Support Group in California when one of the group’s members, Monica Sifuentes, a post-transplant patient, spoke to the group this past year. Members were thrilled to listen to the story of how her life had changed since her lung transplant. They also had many questions for her about her path to transplant.

For more information about support groups and getting involved, contact Debbie, PHA’s Director of Volunteer Services, at Debbie@PHAssociation.org or 301-565-3004 x755 or visit www.PHAssociation.org/LocalSupportGroups

By Sophie Klein
PHA Volunteer Services Associate

Welcome, Chanda Causer, Patient Outreach and Services Manager!

As the Patient Outreach and Services Manager, Chanda works with members of the PH community to expand programming among special populations of PH patients and caregivers. She builds pathways between these populations and PHA to help identify and prioritize the interests of these groups, and creates resources and services to meet identified needs. Chanda can be reached by phone at 301-565-3004 x777 or email Chanda@PHAssociation.org or. Chanda’s predecessor in this position, Emma Bonanomi, has transitioned into the role of Health Education Specialist where she writes and edits PH education materials and develops psychosocial resources for patients and caregivers.
With more than 235 support groups nationwide, we’ve got some great stories from their meetings to share. Read on to find out what’s going on across the country!

• “What is... a right heart catheterization for $500, Alex?” Ever think you would hear those words during a PH support group meeting? PH support groups across the nation are starting to play games at meetings, including “PH Jeopardy!” South Riverside County Support Group Leader, Alex Flipse, brought the idea to her group and shared it with other leaders; now Dallas and other groups — including Treasure Valley (Idaho) and Hawaii — are testing out their patients’ knowledge on PH trivia and educating members in the process.

• Feeling crafty? The southern Colorado group “Colorado Springs Wheezers” organized “Crafts for the Cause,” a meeting with an opportunity for creative hands and minds to create crafts to uplift, raise awareness and educate.

• The Hawaii PH Support Group worked with a very talented local artist to create special postcards (pictured above) from the group to send in sympathy and support of Japanese earthquake and tsunami victims. The group members signed the cards, and the cards will be hand-delivered or placed on a collage board at several different Tsunami Evacuation Shelters in Japan.

• Food. We love it, you love it, but what does a heart-healthy diet consist of? Did you know that spinach might be good for most, but not necessarily for a PH patient? Step away from the greens, Popeye! PH support groups in York, Penn., and Newark, N.J., hosted special cooking health classes in local kitchens. The Albany, N.Y., and Kentuckiana groups hosted meetings on nutrition and diet, too. In Lehigh-Poconos, Penn., and Twin Cities, Minn., patients came together to for special summer picnics and potlucks. Support groups in the Dallas area hosted their 8th Annual North Texas Picnic.

• Downward-facing what? PH support group leaders are stretching more than just their imaginations at support group meetings. The support group at Penn Presbyterian in Philadelphia brought a certified yoga instructor to their meeting and the Long Island group introduced the benefits of ki yoga to their members.

• You want me to pay HOW MUCH? PH support groups are helping to share untapped resources and unlock the mystery of insurance support by hosting meetings on the cost of medicine and insurance matters. Groups in Inland Empire, Calif., Greater Kansas City and Everett, Wash., all brought insurance to the forefront of their meetings.

• Oh, the teenage years! One of our oldest groups, the Milwaukee PH Support Group, marked its 14th year with a celebration at a restaurant for their members.

• Some hesitate to attend support groups out of fear that they will be downbeat. Many groups deal with the fact that yes, PH can be depressing, but they respond with inspirational speakers and social workers who can help members fight back against depression with real tips and tools for making the best of this disease. Groups in Charleston, W.Va., Milwaukee, Wisc., and New Orleans, La., hosted meetings on coping, emotions and depression.

• This Lilac City group also hosted a meeting focused
PHA Welcomes New Support Line Volunteers

Every week, the PHA Patient-to-Patient Support Line switches to a different volunteer, the majority of whom are long-term patient survivors. We also have a parent of a teenage patient waiting to answer your calls! We eagerly welcome three new volunteers to our support line team: Marcia Beverly, Stuart Berwick and Melanie Kozak.

These three are all support group leaders, have been involved in past PHA International PH Conferences and work closely with PHA staff members on a variety of campaigns. In other words, they are very experienced in the community and are a good resource for support.

Call our Patient-to-Patient Support Line at 1-800-748-7274 and chat with them or any of our attentive, trained and understanding volunteers.

We are always looking for future Support Line Volunteers! Contact Debbie Castro for more information and to apply: Debbie@PHAssociation.org or 301-565-3004 x 755.

PHA Welcomes New Support Line Volunteers

Marcia Beverly Stuart Berwick Melanie Kozak

The Fresno Support Group in California hosted the staff aide for local Congressman Devin Nunes at its August meeting. They educated him on the Tom Lantos PH Research and Education Act.

Diane Ramirez, the advocacy chair for her support group in South Carolina, traveled to Asheville, Greensboro, Piedmont and now Lexington to give talks on “Making Your Voice Heard” in the political process.

By Debbie Castro
PHA Director of Volunteer Services

“A BREATH OF FRESH AIR” CONTINUED FROM PAGE 6

- Field trips to the aquarium, museum, movies, zoo or park
- Happy hour or karaoke
- PH Jeopardy or game night (card tournaments, casino parties, etc.)
- Raising awareness about PH at health fairs and schools
- Road trips and seasonal activities (caroling, pumpkin picking, trips to the farmers market, etc.)
- Mommy and me/daddy and me activities
- Bowling, pool tournaments, video game challenges
- Birthday and diagnosis anniversary parties
- Concerts and sporting events
- Monitored exercise group/Chair yoga/therapeutic recreation activities
- Cooking classes
- Mentoring or volunteering in the community
- Luncheons, BBQs, picnics and potlucks
- Photography, music and other shared interests

Find more great ideas from Lindsay at www.PHAssociation.org/YoungAdults/SupportGroups.
Generation Hope is an email group for PH patients in their late teens, 20s and 30s.

By Lindsay Collins, PH Patient & Support Group Leader
Coast to Coast: Veteran Event Planners Make November "Event-ful"

During PH Awareness Month, PH community members do their best to spread the word about PH. For certain veteran event planners, these efforts take shape in their Awareness Month Special Event.

Throughout the month of November, Special Events will be held all across the U.S. to raise PH awareness and funds for research and programming. On Saturday, Nov. 5, crowds will gather in Baltimore, Md., for the 3rd Annual Pulmonary Pints: Pubcrawl for PH. The very next day, on the other side of the country, runners will take to the streets of Stanford, Calif., during the 11th Annual Race Against PH.

On Nov. 12, Sheila Williams and Diane Dauwalder will rise before the sun to set up and arrange the 5th Annual North Texas Walk. At the same time, 692 miles away, Cindy Klein and Carol Lindstrom will be up early, prepping for the 6th Annual PHenomenal Hope for a Cure Brunch in Omaha, Neb. Later that day, residents in St. Louis will embark on a culinary journey at The Greater St. Louis Area PHA Dinner & Wine Tasting Fundraiser.

This November will also bring people to Pompano Beach, Fla., for the 4th Annual South Florida PH Fun Walk, and hundreds will gather on Long Island to cap off the Awareness Month momentum and the 2011 Special Events calendar at the 7th Annual New York Funwalk.

These hallmark events have set the framework for PH Awareness Month Special Events by creating a nationwide impact from the local level. Integral to each of these events is the opportunity to raise awareness and greater public understanding of PH. Through guest speakers, information tables and handouts, event participants learn more about PH and its impact on patients and families.

Amanda McKee, who coordinates the St. Louis Dinner & Wine Tasting with her support group, stresses the importance of the educational aspect of events: “People need to know why they are donating. When they have a better understanding of PH, they feel more connected to the cause.”

With the help of these veteran event planners, people all across the U.S. will be celebrating PH Awareness Month by walking, running, sipping, tasting or dancing for a cure!

Make your plans to attend an event this November by visiting PHA’s online events calendar: www.PHAssociation.org/Calendar.
Raising Funds for PH Research: "Wojo" Style!

Those of us who have been affected by PH understand the emptiness this disease can cause. In these life-altering moments, we have been faced with the challenge of continuing to live life with meaning. Few of us, however, are able to do this with the energy, grace, and exuberant love that Betty Lou Wojciechowski ("Wojo") and her family have exhibited — this is "Wojo" Style!

On June 27, 2011, I had the opportunity to gather with 180 friends of the Wojo family for the 4th Annual Swing 4 the Cure Wojo Golf Classic at Tustin Ranch Golf Club in Southern California. This event is a labor of love to honor the memory of Betty Lou’s two sons, Matthew and Michael, and her husband Jerry Wojciechowski by raising funds to support pulmonary hypertension research.

In addition to participating in a fun event complete with 18 holes of golf, a helicopter ball drop, a silent auction, and a live auction by an auctioneer who could talk at lightening speed without ever pausing (really!), this year’s event featured live entertainment by Diamond Tom (a compliment to Neil Diamond), who survived a PH-caused double-lung transplant. We also learned more about the amazing PH journeys of many other “PHers” local to the area.

During this year’s event, I also had the pleasure of being able to recognize Betty Lou’s accomplishments, a moment I want to share with all of you:

Betty Lou, it is not enough to simply thank you for spearheading this successful event. I want to also thank you for giving those of us who have lost a loved one to this disease the proof that something meaningful can come from something so tragic. … Thank you for allowing us to know Matthew, Michael and Jerry by telling their stories. … Thank you for raising more than a hundred thousand dollars over the past several years to push PH science forward. And, thank you for being an amazing role model and friend.

For more information about the Swing 4 the Cure Wojo Golf Classic, log on to www.swing4thecure.us. And, think about joining us next year for what is sure to be another fun, memorable and inspirational event!

By Laura D’Anna
Chair, PHA Board of Trustees

Find PHA Special Events on YouTube!

Our Special Events community is comprised of dedicated volunteers who devote their time and talent to organize, host and run phenomenal fundraisers. All of these volunteers have personal connections to pulmonary hypertension and the Pulmonary Hypertension Association — connections that drive them to make a difference in fighting this disease.

Now you can watch video testimony of these Special Events organizers and event attendees on PHA’s YouTube channel! There is also event footage to give you a look at the day-of excitement that makes these events truly special. Browse these videos by visiting www.youtube.com/phassociation, and navigate to the “PH Special Events” playlist.

Our Fall 2011 featured videos come from the participants and organizers of the Race Against PH in North Carolina. This June 25 inaugural event was the talk of the town with hundreds attending to learn more about pulmonary hypertension, participate in a PH-friendly six-minute walk, and build community. These videos capture the journeys and stories of those affected by the illness. The walk raised more than $17,000 to directly support PHA’s mission and programs.

We now have a FlipCam loan program for your special event! If you are a Special Events organizer and are interested in recording video footage of your upcoming event, contact Events@PHAssociation.org or call 301-565-3004 x765.
June 2011 saw the most special events ever in the history of PHA’s special events program with 10 fundraisers! Many of these events were held for the very first time. Walks, golf, an arts festival and a bunco tournament all made the season’s roster. Thanks to our inaugural event planners for hosting fun, creative and successful fundraisers to kick off those dog days of summer in style.

**Inaugural Events Make a Summer Splash!**

**Event:** James A. Martin Memorial Walk for PH  
**Location:** Southern California  
**Attendance:** Approximately 100 participants  
**Pictured Above:** Walkers pass under a balloon arch and “JAM for PHA” — the walk’s chosen theme.  
**Amount raised for PHA:** More than $13,000

**Event:** Miles for Mallory PHamily PHun Walk  
**Location:** Minneapolis, Minn.  
**Attendance:** Approximately 90 participants  
**Pictured Above:** Each registered walker received a specially designed event T-shirt.  
**Amount raised for PHA:** More than $9,000

**Event:** Race Against PH — North Carolina  
**Location:** Research Triangle Park, N.C.  
**Attendance:** More than 350 participants  
**Pictured Above:** Participants race toward the 5K finish line. Race Against PH — North Carolina also featured a community-friendly “Six-Minute Walk” option.  
**Amount raised for PHA:** More than $17,000

**Event:** Rolling PHor a Cure Bunco Tournament  
**Location:** Ormond Beach, Fla.  
**Attendance:** 25 participants  
**Pictured Above:** At this casual event, the first of its kind to benefit PHA, participants play bunco, a popular luck-based dice game.  
**Amount raised for PHA:** More than $3,000
Fri., Oct. 28, 2011
A CURE FOR FIVE PENNIES
WHERE: Schaumburg, Ill.
DETAILS: Denise DeGuzman at avdeguzman@comcast.net or 847-697-2934 or www.firstgiving.com/phassociation/4th-annual-cure-for-five-pennies-gala

Sat., Oct. 29, 2011
RUN FOR LUNGS
WHERE: Jackson, Miss.
DETAILS: Tonya Moss at CapitoCityPHSG@aol.com or 601-914-9503 or www.firstgiving.com/PHAssociation/RunforLungs

Sat., Nov. 5, 2011
3RD ANNUAL PULMONARY PINTS:
PUBCRAWL FOR PH
WHERE: Baltimore, Md.
DETAILS: Katy Hayes at keboehk@hotmail.com; Ashley Boehk at Ashley.boehk@gmail.com or 703-607-4360

Sat., Nov. 5, 2011
“SARAH SMILES” INAUGURAL
FUNWALK FOR PH
WHERE: Camillus, N.Y.
DETAILS: Michelle Peek at mpeek@twcnr.rr.com or 315-672-5690

Sat., Nov. 5, 2011
DINING FOR PH 2011
WHERE: New York, N.Y.
DETAILS: Edith Morales at 212-942-0017 or ediesquest@hotmail.com

Sun., Nov. 6, 2011
2ND ANNUAL ABBY’S ROAD PHUN WALK
WHERE: Albuquerque, N.M.
DETAILS: Jen Anderson at jen.anderson241@gmail.com

Sun., Nov. 6, 2011
11TH ANNUAL RACE AGAINST PH
WHERE: Stanford, Calif.
DETAILS: www.raceagainstph.org or Kristy Kerivan at kerivan@stanford.edu

Sat., Nov. 12, 2011
4TH ANNUAL SOUTH FLORIDA PH FUNWALK
WHERE: Pompano Beach, Fla.
DETAILS: Pat Hellyer at 561-737-8000 or phellyer@wxel.org

Sat., Nov. 12, 2011
2ND BIENNIAL GREATER ST. LOUIS AREA PHA DINNER AND WINE TASTING
WHERE: St. Louis, Mo.
DETAILS: Amanda McKee at mharv78@hotmail.com or www.firstgiving.com/PHAssociation/GreaterStLouisDinner

Sat., Nov. 12, 2011
5TH ANNUAL NORTH TEXAS FUN WALK
WHERE: Grand Prairie, Texas
DETAILS: Diane Dauwalder at special.d@scglobal.net or www.firstgiving.com/PHAssociation/TexasFunWalk

Sat., Nov. 12, 2011
VISION OF HOPE PH GALA
WHERE: Hunt Valley (Balt.), Md.
DETAILS: Nicole Cooper at schlease@hotmail.com or 443-677-3729 or www.firstgiving.com/PHAssociation/VisionofHope

Sat., Nov. 12, 2011
ORLANDO PH CHILI COOK-OFF & BAKE SALE
WHERE: Orlando, Fla.
DETAILS: Tina Waldman at tina1dev@yahoo.com or 407-914-9748 or www.firstgiving.com/PHAssociation/orlando-chili

Sat., Nov. 12, 2011
6TH ANNUAL PHENOMENAL HOPE FOR A CURE BRUNCH
WHERE: Omaha, Neb.
DETAILS: Cindy Klein at cklein1058@aol.com or Carol Lindstrom at imq Litn4u@aol.com

Sat., Nov. 19, 2011
2ND ANNUAL UNMASK PH: A MASQUERADE BALL
WHERE: Wilkes-Barre, Penn.
DETAILS: Lisa Granahan at clgran@ptd.net

Sat., Dec. 10, 2011
7TH ANNUAL NY FUNWALK FOR PH
WHERE: Long Island, N.Y.
DETAILS: Joanne Schmidt at NYFunWalkforPH@gmail.com or 631-427-4586 or Mary Bartlett at mbartlett@winthrop.org

December 2011
Look for the winter issue of our Event-ful Times e-newsletter!
SIGN UP: Leslie Mahaney at Eventful@PHAssociation.org

December 2011
Start making plans to host a spring event fundraiser in YOUR community!
DETAILS: Jessica McKearin at Events@PHAssociation.org or Leslie Mahaney at Eventful@PHAssociation.org

December 2011
Special Events training webinar — learn more about PHA’s special events program!
DETAILS: Jessica McKearin at Events@PHAssociation.org or Leslie Mahaney at Eventful@PHAssociation.org

For more special events coverage visit www.PHAssociation.org/SpecialEvents
To view a complete, up-to-date listing visit www.PHAssociation.org/Events
Thank you, Interns!

PHA extends a huge thank you to our summer 2011 interns, whose amazing contributions have made a real impact on the programs and services PHA is able to provide.

Danielle Doubt, Advocacy & Awareness Intern
As the summer intern for PHA’s Advocacy and Awareness department, Danielle focused on raising awareness of the disease and supporting the PH community in advocating for the Tom Lantos PH Research and Education Act of 2011. Danielle organized and promoted the webinar, “Lobby Locally: Fighting PH through District Visits” and worked with the Advocacy and Awareness team to collect and deliver letters to Members of Congress requesting co-sponsorship of the PH bill. She also assisted with preparations for the PH Professional Network Advocacy Day in September. Danielle returns this fall for her senior year at St. Mary’s College in Maryland where she will complete an English major and Women’s Studies minor.

Emma Powers, Patient Outreach & Services Intern
Throughout her internship, Emma sought to improve patients’ ability to receive information and support immediately after diagnosis. She managed Envelope of Hope requests, assisted in the design of new patient materials, and developed resources to help PHA’s staff better understand each population’s needs and concerns. Emma also completed a thorough indexing of Our Journeys, the section on PHA’s website where patients and caregivers share their stories, and helped with a detailed overhaul of the section’s navigation. For the last two years, Emma studied creative writing at the University of North Carolina at Wilmington, and she plans to study psychology at the University of Virginia this fall.

Glenda Lopez, Medical Services Intern
During her internship, Glenda helped with several English-Spanish translations in PHA Online University and PHA Classroom and assisted in editing the monthly PH Research Roundup e-newsletter for PH Clinicians and Researchers and PH Professional Network. Additionally, she assisted in mailing welcome packets, letters, copies of Pulmonary Hypertension: A Patient’s Survival Guide and current issues of Advances in Pulmonary Hypertension to PHA’s medical community.

“My favorite part of this internship was discovering that there is a vast and diverse community of PH professionals committed to understanding and treating this disease,” says Glenda. This fall, Glenda will finish her B.A. in Biology at Grinnell College in Iowa.

Experiential Learning Opportunities at PHA!
Are you — or someone you know — looking to enhance your academic experience beyond classroom walls for the spring semester or summer?

PHA offers a variety of internships year-round. From Web Development to Volunteer Services to Special Events and more, there is something to meet your educational and professional goals.

To learn more about our internship program and see which internships are currently available, visit www.PHAssociation.org/Internships or contact Haley at Internships@PHAssociation.org.

Be part of the team that is changing the future of this disease: apply for a PHA internship.
EDITOR’S CORNER

Hello, PH Community, and welcome to a special edition of Persistent Voices!

We all have a toolbox that we draw from to help us cope with this journey called pulmonary hypertension. Using a creative outlet can be a powerful way to help us deal with the ups and downs of our everyday life with illness. Some people sculpt; some people paint. Some folks use a favorite craft or hobby to relieve stress (I make cards to help me relax). Studies have shown that writing as an outlet can ease symptoms, boost the immune system and improve emotional and physical health. In the lines below and on the following pages, you’ll find five PH patients (Jode, Carol, Mack, Yunena and Susan) who use creative writing to express their feelings and share their experiences. After reading their poignant poetry, I may give it a try myself. I’m always looking for a new tool to add to my “Coping with PH” toolbox. Why not consider giving it a try too?

Today, here’s to expression and its benefits!

Joanne Sperando-Schmidt, Persistent Voices Editor

A Poem by Carol Lindstrom, Bellevue, Neb.

Carol, a PH patient and former Nebraska/W. Iowa Support Group Leader for five years, wrote this poem to represent PHA in a nonprofit poetry contest. The goal of the contest was to celebrate a non-profit of your choice with an original poem (four to eight lines long) that highlights the organization’s mission. Here’s how Carol celebrated PHA.

The Heart and Soul of PHA

An organization that cares is the one that stands out
One who is active and gets out and about.
A cure for pulmonary hypertension is PHA’s goal
To prevent it from damaging the core of our soul.

They support, advocate, educate and make people aware
Of this dreadful disease because they do care.
And because of this mission to which they adhere
The prevention and a cure is definitely near!

Carol Lindstrom
A Poem by Jode Cox, Auburn, Wash.

Jode wrote this poem in 2009, the year she was diagnosed with PH.

This Hill

The road keeps getting longer
The farther that I walk
A headwind seems to push me back
I don’t have the breath to talk

My lungs they burn, my heart it pounds
My throat is getting dry
I see a looming hill ahead
And now I want to cry

To you this hill may seem small
To me it is a mountain
I don’t want to ask for help
I keep going as fast as I can

I slow with every footstep
Until I have to stop
I find a way to busy myself
To pretend there is nothing wrong

To admit this trouble to you
Is to admit it to myself
I don’t want to ask of others
I want to do this by myself

I feel this is all my fault
If only I could heal
The shame I feel at every gasp
This journey has become too real

If only I was stronger
This disease I could have fought
It silently crept up to me
The illness I don’t want

Each day I am able to do less
No matter how hard I try
For now I can only do my best
You don’t even understand why

I used to run and jump and play
Nothing too hard to do
Now the smallest task I take
I must ask for help from you

You think I don’t see the resentment
The bitterness in your face
You think I choose to be sick
To give up my life in this place

This hill is not enormous
The one you gave to me
I will make it to the top
I will do it just for me
A Poem by Yunena Morales, Brurien, Wash.

Yunena is the leader for the Seattle/Des Moines Support Group.

Lady PHTN

I took a walk at early dawn years ago.
I woke up full of glee, anticipation and dreams of greater achievements.
The rays of sunshine met me at every turn.
I held my father and mother’s hands and flitted away like a sun bright yellow butterfly.
It was exciting with hope at every turn.
I met a lady,
I smiled and glided down the road.
She chased after me, a beaming smile.
She said,
Young lady,
I am taking you on a most intrepid trip you could ever dream of.
My name is pulmonary hypertension.
My first name is Idiopathic.
They call me IPAH for short.
You will be introduced to some doctors who will confuse you.
You cannot imagine, little one,
Life will never be the same again.
Off balance, you will almost fall dead,
Caused by those to make you whole.
Twelve inconclusive diagnoses and more to come.
All an impact to put you on a dance spin 360 degrees.
A turn by all these confused beings that will stir every emotion one can evoke in the universe.
God stepped in just as I was about to go out of control in anger.
He said, my child, there is a reason.
Choose to celebrate every moment;
Do not die before you are dead.
Life is much more than health.
The world needs a heart like yours to advocate for those who are so judged,
So underestimated and belittled by a system which is crammed with the proud and the haughty.
Here lies the path;
I said I am ready.
Go for it, Lady, He said.
When a doctor gives you a diagnosis of an incurable disease, your life seems to stop at that point, not knowing where to turn for help, guidance and someone to listen to you. You think you are the only one and then you find out you are not.

I knew I had a long battle ahead of me, but I was willing to do anything to make it better. I asked my doctor if he could get me into pulmonary rehab. Now mind you, I thought this would be really easy, but it wasn’t. Doctors’ offices get so busy and sometimes they forget you. Well, I kept pushing and pushing (but nicely) and finally got it.

Rehab turned out to be a little harder than I thought. Around the beginning of June, they asked me if I had some long-term goals for the therapy. Well, you know how you get these questions and think, “Hmmmm, go ask the next person.” But I didn’t say that. I told them that I wanted to climb the side of a mountain to spread some of my brother’s ashes there. He always got a kick out of me talking to him about mountains while he was sick, and when he passed, I thought about him and about doing this.

The ladies at pulmonary rehab were awesome. They worked with me and gently

A Piece by Mack McCarthy, El Mirage, Ariz.

Mack wrote this description in the spring of 2011 to explain what PH does to him every day. After first sharing it on Facebook, his friends encouraged him to share it with the wider PH community.

As I lie upon my pillow at peace like a baby lamb in no pain, my PH lies in wait like a tigress waits for her prey. I stir; she twitches in anticipation. I wake; she strikes like a bolt of lightning and thunder at the same time. She tears at my lungs like nails down a chalkboard and roars out at me to say I am still here; you cannot escape my wrath. I stand and cringe; then, when done with my bathroom visit, I weigh myself and she slaps me so that I am dizzy and nearly fall. I slowly go to the kitchen table as she takes my morning breath away. I sit, and with her still tearing at my lungs, I am nauseous from the pain. I eat to calm my stomach. I take my morning medication, and she slowly releases her death grip on me as the medication takes effect. I pray I can make it through another day. She stays with me throughout the day like a cat playing with a mouse. The day is ended, it is time to rest. I take my sleeping pill and fall into a restful sleep as she waits, grumbling in her throat like a purring kitten waiting for another day.

A Personal Story and Poem by Susan Gould, Christmas, Fla.

When a doctor gives you a diagnosis of an incurable disease, your life seems to stop at that point, not knowing where to turn for help, guidance and someone to listen to you. You think you are the only one and then you find out you are not.

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The ladies at pulmonary rehab were awesome. They worked with me and gently

STORY CONTINUED ON NEXT PAGE
pushed me along. Well, I want to tell you that last October, I climbed the side of that mountain, took my brother’s ashes and spread them around a glen where we stopped to rest. Truthfully, I was crying when I did it.

Then we climbed a little higher to the top, and I yelled out, “Thank you, pulmonary rehab.” I know it wasn’t just the rehab, but it was me too. I worked very hard to get this done.

On another trip, I was able to make the trek to see a beautiful waterfall. It was a long climb, but I did it. People on the way up were telling me that I was their hero. My hero was next to me, carrying my oxygen tank up the steps as we went.

A Poem by Susan Gould

They tell you there’s no cure.
It’s all spelled out for you but the world now goes silent as those words are said to you.
Pulmonary hypertension is the name of the game; high blood pressure in the lungs ... are they really insane?

Where did it come from? Why is it here?
I guess I really now have something to fear.
I’m scared, I’m lost, I don’t know what to do.
I cry, I scream, I think now I’m through.

But the sound comes back on;
the head now thinks straight as you search for knowledge to not seal your fate.

It’s surprising to know how many people like you have this terrible disease and don’t know what to do. But knowledge is power and the name of the game is to find out all you can, so you can remain in charge of your life, your fate rests with you.

There are doctors, support groups and friends who have come in to your life, and there they will stay; forever in your heart for now and always.

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

The purpose of Persistent Voices is to allow patients and their families and friends to share their personal experiences and coping strategies with one another. It is not to provide medical advice on personal health matters, which should be obtained directly from a physician. Persistent Voices, Pathlight and PHA assume no responsibility for readers’ actions taken as a result of their interpretation of information contained in the publication. Please submit your stories, with contact information and appropriate photograph, to: Megan Mallory, “Persistent Voices,” Pulmonary Hypertension Association, 801 Roeder Rd., Suite 1000, Silver Spring, MD 20910, or as an attachment (.pdf, .doc, .docx or .rtf) to Print@PHAssociation.org. (Submissions may be edited for length and clarity.)
 Twice as Nice: Meet the Conference Theme Contest Co-Winners

This summer, the International PH Conference and Scientific Sessions Planning Committee turned to the PH community once again to help generate a theme for PHA’s 10th International PH Conference. As a special anniversary Conference, many ideas reflected PHA’s roots in Florida with the historic meeting of PHA’s founders around a kitchen table in 1990. With more than 50 theme ideas submitted, one theme idea stood out … TWICE! Marilyn Mears, a PH patient diagnosed in 1997 from Canton, N.C., and Stephanie Layer, a PH patient diagnosed in 2000 from Maplewood, Minn., are our co-winners with the theme The Power of One: From a Kitchen Table to Around the World. Read on to learn about Marilyn and Stephanie and the Conference 2012 theme.

How did you feel when you found out that you were a Conference theme contest co-winner?

Marilyn: Since I rarely win anything, I was surprised and very pleased!

Stephanie: When I got the phone call from PHA, I really couldn’t believe it. It took about an hour to sink in and then I called back to thank them again and say how excited I was about this.

Why did you choose the theme you submitted?

Marilyn: I was thinking about how PHA started with four women around the kitchen table and how far and wide we have grown over the years.

Stephanie: Of course it is Florida where it all started — the four women sitting around a kitchen table. How could I not think of them? They are our heroes! They truly opened the door for hope and for a cure.

What are you looking forward to most about Conference?

Marilyn: Meeting new PHriends and learning about new therapies. Always holding out hope of learning of a cure for myself and others.

Stephanie: Updated PH and treatment information to take back to our patients in Minnesota. I can’t wait to meet PH patients from around the world. Just being with everyone from the PH community, it gives us all hope to move forward.

Both winners will receive a complimentary registration to PHA’s 10th International PH Conference taking place June 22-24, 2012 in Orlando, Fla.

By Suzanne Flood, PHA Marketing & Communications Manager

Available Online: Recordings from Conference 2010 Plenary Sessions

Want a glimpse of what’s in store for the 10th International PH Conference in 2012? Recordings of the general sessions from the 2010 International PH Conference are available on PHA’s website. Experience highlights including the Climbing for a Cure: Opening and Keynote Address, Journeys Luncheon and more. You will see why you won’t want to miss this historic Conference in 2012!

View recordings at www.PHAssociation.org/Conference/2010Recordings
SAVEn THE DA TeE!

PHA’s 10th International Pulmonary Hypertension Conference and Scientific Sessions
The Power of One: From a Kitchen Table to Around the World

June 22-24, 2012
Renaissance Orlando at SeaWorld®
Orlando, Fla.
www.PHAssociation.org/Conference

Registration opens January 2012!
PHA’s International PH Conference is the largest gathering for pulmonary hypertension patients, family members and medical professionals in the world. Attendees have the unique opportunity to come together for three days of education and networking.

Conference highlights include:
• Networking opportunities including pre-Conference meet-ups, Support Group meetings and an exciting Meet-and-Greet on Thursday evening!
• Education sessions led by leading medical professionals in the field as well as patients and caregivers living with PH day-to-day.
• Dedicated education sessions for medical professionals including a daylong Scientific Sessions and newly added CME Sessions throughout the three-day Conference.
• Opportunities to volunteer.

Don’t forget to sign up for the Conference Early Alert Email list to stay up-to-date on the newest Conference developments! Sign up at www.PHAssociation.org/Conference

Learn About PHA's Conference Scholarship Program

Through the Conference Scholarship Program, PHA is committed to helping as many patients as possible achieve their goal of attending our International PH Conference in Orlando, Fla. Applications for patients in need will be made available online starting Nov. 15, 2011. Please visit www.PHAssociation.org/Conference/Scholarships for more information. If you would like a Conference scholarship application mailed to you, please email Scholarships@PHAssociation.org or call 301-565-3004 x764.

In 2010, PHA provided 186 patients with more than $175,000 in scholarship awards. The number of patients we are able to help through the Conference Scholarship Program is entirely dependent upon the generosity of our donors. To make a donation to PHA’s Conference Scholarship Fund, please visit www.PHAssociation.org/Donate/ConferenceScholarships or call 301-565-3004 x764.
PH Professional Network Symposium: Furthering PH Education Thanks to Attendees and Speakers

On Sept. 22-24, PHA hosted the 2011 PH Professional Network Symposium Inspiring Hope: New Directions in PAH in Arlington, Va., bringing together close to 400 PH-treating allied health professionals for three days of education, networking and awareness-raising. Attendees came from all over the United States and as far as Vancouver, B.C., to attend the Symposium.

PHA thanks all those who attended and participated in the 2011 PH Professional Network Symposium. More than 60 speakers, all medical professionals working in the pulmonary hypertension field, presented at nearly 30 different educational sessions throughout the Symposium. Educational session topics included “A New Dimension of Hope: Virtual Catheterization Lab,” “The Holistic Side of PH Management: Nutrition and Pulmonary Rehabilitation” and “Don’t Mess With My Meds: Smooth Transitions between Inpatient and Outpatient Care.” Without the speakers’ participation and willingness to educate, the Symposium would not have been such a success!

PHA also thanks Melisa Wilson, APRN, BC, who served as Symposium Chair, as well as the entire 2011 Symposium Planning Committee for their dedication and hard work in helping to make this Symposium possible. The Planning Committee consisted of 15 allied health professionals across various professions in all corners of the country, working together to plan sessions, choose speakers and guide the execution of Symposium.

Look for a full recap of the 2011 PH Professional Network Symposium in the Winter issue of Pathlight.

PHA Thanks the Sponsors of the 2011 PH Professional Network Symposium

Diamond Sponsors:
Pfizer, Inc. — General support

Actelion Pharmaceuticals US, Inc. — Gathering Knowledge, Fostering Hope: The REVEAL Registry (Saturday breakfast) • Team Hope: A Multidisciplinary Approach to PAH Care (Saturday luncheon) • Advocacy Day • Registration subsidy program • Registration brochure • T-shirts* • Room keys

Gilead Sciences, Inc. — Inspiring Hope: One Medical Professional’s Climb to a Cure (Thursday dinner) • A New Dimension of Hope: Virtual Catheterization Lab (Friday luncheon) • “Who’s who?” contact book and name badge holder • Poster session and networking reception • Save-the-date postcards • Symposium recordings DVD • General support

Gold Sponsor:
United Therapeutics Corporation — Hope in 2011: Top 10 Clinical Advances (Friday breakfast) • Audience response system • In-room wireless access • Continuing education credit • Welcome awareness materials* • Daily Pulse newsletter* (Thursday, Friday, Saturday)

Silver Sponsor:
Lung Rx — PH Professional Network committee meet-ups • Morning coffee breaks • Speaker ready room • Program book • T-shirts* • Notebook and pen • Daily Pulse newsletter* (Friday)

Bronze Sponsors:
Accredo Health Group, Inc. — Evaluation gift • Symposium flash drives • Welcome awareness materials* • Symposium giveaway

General Sponsors:
CVS Caremark — Daily Pulse newsletter* (Thursday, Friday, Saturday)

CuraScript — Internet stations

*co-sponsorships
**PHA on the Road: Three Years of PHenomenal Education!**

This past June, PHA marked the third year of the **PHA on the Road: PH Patients and Families Education Forums** by visiting four new cities in three weekends. The 2011 **PHA on the Road** cities included Seattle, Wash. (June 4), Pittsburgh, Penn. (June 11), St. Louis, Mo. (June 11), and Minneapolis, Minn. (June 18). More than 800 patients and family members attended the 2011 forums, making this the third successful year in a row for **PHA on the Road**.

General sessions for each forum covered topics including how PAH is diagnosed, long-term management and eating better. One new general session topic this year featured insurance issues and alternative means for getting treatment covered.

Breakout sessions at the 2011 forums included topics on Emergency Situations, Pediatric PH – for Parents, Understanding Transplant Options, Exercise and Yoga, PH and Connective Tissue Disease, Traveling with PH and Women’s Issues. The St. Louis forum also hosted an additional breakout session called the Nuts and Bolts of Being a Research Subject.

“My favorite part of this conference is interacting with all of the people. From the doctors and nurses to PHA staff to meeting other people with the same disease I have. Thank you for a wonderful day!” says Lisa McConnaughhay, a PH Patient from Iuka, Ill.

PHA also expanded family programming at the 2011 **PHA on the Road** forums. This year, the forums included both a support group networking session for parents of children with PH and an informational session led by a medical professional. PHA also continued to provide free child care and activities in the Kids’ Room the day of the forum for those children who accompanied their parents to **PHA on the Road**.

“My favorite part of this conference is interacting with all of the people. From the doctors and nurses to PHA staff to meeting other people with the same disease I have. Thank you for a wonderful day!” says Lisa McConnaughhay, a PH Patient from Iuka, Ill.

PHA is looking forward to continuing the **PHA on the Road** forums next year and hopes to see you “on the road” in the future! Visit [www.PHAssociation.org/OnTheRoad](http://www.PHAssociation.org/OnTheRoad) for photo highlights from the 2011 forums.

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**Welcome, Kimberly Demirhan, Meetings Planning Associate!**

As a Meetings Planning Associate, Kimberly manages the logistics of the PH Professional Network Symposium and is also responsible for planning aspects of PHA’s International PH Conference, including the Scientific Sessions and the Research Room. She is responsible for assisting with the meeting coordination of the PH Professional Network Executive Committee, the Scientific Leadership Council and the **Advances in Pulmonary Hypertension** Editorial Board meetings that take place biannually. Kimberly also oversees the marketing and communications for the **Building Medical Education in PH** program. She can be reached at Kimberly@PHAssociation.org or 301-565-3004 x763.
Final Daylong California PH Forum Paves Way for New Format

California PH Forum 2011 accomplished its goal of educating patients and the community about the challenges of pulmonary hypertension. Held every two years since 1999, this year’s event took place June 25 at the Hotel Sofitel in Redwood City, Calif., on the southwest shore of San Francisco Bay.

“It went well,” says Forum Committee member Kelli Danner. “We got really great feedback, they liked the speakers we had, and we covered a lot of topics connected with PH."

With topics such “PH Basics,” “The Psychological Impact of PH,” “Right Heart Failure,” “Research and New Therapy Options” and even “Yoga to Take with You,” the Forum appealed to a wide range of interests.

Presenters included healthcare professionals from the University of California Los Angeles, Stanford University Medical Center and the California Pacific Medical Center.

Kelli was one of four women to plan this full day of PH education. The other committee members included patients Rita Orth, Judy Vucci and Jeannine Hart.

“One of our goals is to make sure people get the right information, that patients know about new medicines coming down the pipeline and the new choices they have,” Kelli says.

According to Forum Committee member Judy Vucci, the Forum was originally set up to offer an informative educational and networking resource for PH patients in the years between the larger PHA International PH Conferences. With grant funding from pharmaceutical companies, they began in San Diego, but since 2001 have been hosting forums in the San Francisco Bay Area.

Originally a three-day forum, this year’s forum was pared down to one full day. “Gradually our patients’ committee decided our health issues required that we step back to a smaller event with less preparation needed, so Forum 2011 was a one-day format,” explains Judy.

In coming years the California Forum will continue to evolve as the Pulmonary Hypertension Association sponsors more events for PH patients, caregivers and physicians on the West Coast and nationwide, such as transition to doing luncheons with maybe one or two speakers. It’s easier on the patients, and with the economy it’s easier because not as many people can afford to travel."

Judy invites those not already on the California PH Forum mailing list to send their contact information to info@caphforum.com if they would like to receive notice of these future events.

PHA thanks the members of the California PH Forum Committee and all those involved in making the Forum a success over the past decade. We look forward to seeing the continuation of patient education through the new luncheon format.

By Edward Freundl, PH Patient and Volunteer Writer

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PH on the Road: PH Patients and Families Education Forums in major cities across the United States.

“PHA has begun to offer educational programs in the years in between its big conferences, so we feel that it is not as necessary as it once was to offer our regional alternative,” Judy says.

Kelli adds, “We will transition to doing luncheons with maybe one or two speakers. It’s easier on the patients, and with the economy it’s easier because not as many people can afford to travel."

Judy invites those not already on the California PH Forum mailing list to send their contact information to info@caphforum.com if they would like to receive notice of these future events.

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By Edward Freundl, PH Patient and Volunteer Writer
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

8th Annual Pulmonary Hypertension Summit —
Cleveland Clinic
InterContinental Hotel and Bank of America
Conference Center
Nov. 6-8, 2011
Cleveland, Ohio
www.ccfcme.org/pulhyper11

3rd Annual UNC-Duke Research Triangle Pulmonary Hypertension Symposium
Sheraton Imperial Hotel
Nov. 11, 2011
Durham, N.C.
www.med.unc.edu/cme

Pulmonary Hypertension: How to Recognize It, How to Treat It
Lansing Community Center
Nov. 15, 2011
Lansing, Kans.
Call: Linda MowBray at 785-267-6003

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 CME/CEU educational events. The Building Medical Education in PH program is a benefit to members of PH Clinicians and Researchers and PH Professional Network.

To partner with PHA in Building Medical Education in PH for your upcoming CME event, please contact Kimberly Demirhan at 301-565-3004 x763 or BME@PHAssociation.org.

Find Free Medical Education at PHA Online University

PHA Online University (www.PHAOnlineUniv.org) is a cutting-edge source for free CME-accredited education and other resources about PH for medical professionals. It provides medical professionals from all disciplines the opportunity to learn about PH by taking courses authored by the foremost experts in the field.

Highlighted Courses:

Course: Diagnosis of Pulmonary Hypertension in Children
Faculty: Dunbar Ivy, MD, University of Colorado School of Medicine, Denver, Colo.
This course explores the clinical presentation and diagnostic evaluation of both neonates and children with PH and discusses the different uses of diagnostic testing in children with PH.

Course: Physical Assessment of the PH Patient
Faculty: Juliana Liu, MSN, ANP-C, Stanford University, Stanford, Calif.
This course teaches the health professional to identify the physical signs related to PH as well as signs of some of PH’s associated diseases. It also discusses the physical signs of PH disease progression and the findings associated with treatment.

Course: PH and Scleroderma from a Nursing Perspective
Faculty: Barbara Smithson, MSN, RN, Rhode Island Hospital, Providence, R.I.
This course on scleroderma discusses the different levels of the disease as well as the function and importance of various testing methods

Recent Webinars*:

Title: The Role of the Respiratory Therapist in the Treatment of Pulmonary Hypertension Patients
Faculty: Gerilynn Connors, BS, RRT, RCP, Inova Fairfax Hospital, Falls Church, Va.

Title: Design and Validation of an Endothelial Progenitor Cell Capture Chip and Its Application in Patients with PAH
Faculty: Georg Hansmann, MD, PhD, Children’s Hospital Boston/Harvard Medical School, Boston, Mass.; Shashi Murthy, PhD, Northeastern University, Boston, Mass.

* Recordings of webinars can be found in the PHA Online University Library under “Abstracts and Presentations.”
INTERVIEW WITH PH PATIENT JADYN PHILIPPS

Where do you live?
I live in Naperville, Ill.

How old are you?
I’m 12 years old. My birthday is August 17.

When were you diagnosed?
I was diagnosed two and a half years ago.

When did you first start having PH symptoms?
I started having symptoms when I was in second grade.

What were your symptoms?
My main symptoms were fatigue, shortness of breath and passing out.

What are your favorite activities to do?
My favorite activities are horseback riding, crafts and softball.

Have you ever felt unable to do something because of PH?
Yes, I cannot always participate in P.E. or running activities.

How has your life changed since you were diagnosed with PH?
It hasn’t changed too much. I have to take pills four times a day and go to lots of doctor appointments now.

What message would you like to pass on to other kids with PH?
There have been some hard times, but I am doing really well! You just learn to live with the changes … and I am blessed!

Interview conducted by Isaac Kruger
PHA Pathlight Volunteer

Jadyn with her horse Fire

TALK BACK! This is your space.
Submit your jokes, cartoons, drawings, poems, questions, comments or ideas for future articles to PH Kids at www.PHAssociation.org/PHKids/Submit! For questions, you can reach Michal by phone at 301-565-3004 x800 or email at Kids@PHAssociation.org.
Talking with Your Teachers About Your PH

Hi, I’m Danielle Epstein and I have idiopathic pulmonary hypertension. I was diagnosed in May 2005 and take calcium channel blockers. Having PH in school was at first very hard because my teachers didn’t understand my PH or how my PH might affect my school year. When I was in middle school, my guidance counselor would send my teachers an email explaining my PH and that I might not feel well and have to go to the nurse. I felt like many of my teachers never really read the email, and whenever something did happen that was PH-related, they didn’t handle it very well.

When I got to high school, my parents and I decided to change that. We told my new guidance counselor that we wanted to meet with my teachers at the beginning of the year. Six out of eight teachers showed up to the meeting after school as well as my guidance counselor and my mom. My dad participated, too, by speakerphone. I explained PH to my teachers and told them that if I feel lightheaded or faint, I should go to the nurse and have someone accompany me. I also said that I might be out of school sometimes and that I would work with them to try to finish my schoolwork as soon as possible. A few teachers asked me questions and made some comments, but the whole meeting was probably only 15 minutes. Two of my teachers couldn’t attend, so I talked to them separately.

Throughout the year, whenever I needed to go to the nurse, my teachers would always ask if I needed someone to walk with me, even if it wasn’t PH-related. I was so happy that they remembered our talk and were taking extra precautions.

I think the meeting and talking to my teachers after class really helped. They got to hear what they needed to know about my health from an actual person instead of just breezing through the information in one of the many emails they get at the beginning of the year. I hope that speaking to my teachers showed them that I knew what I was talking about and that I was capable of handling things. Personally, I felt empowered talking to my teachers because I felt in charge of my PH and my situation at school.

To all those who are struggling to get their needs across to teachers, I highly recommend having a meeting with your teachers when school starts. Don’t be intimidated about talking to your teachers after class because if they know about PH and what they should expect during the year, they will be able to help when a situation comes along. I hope this helps all those starting a new year of school and my best of luck!

By Danielle Epstein, PH Patient

Have tips of your own for coping with school and PH? Log on to PHA Teens and share! PHA Teens is a secure social network for teens age 13-18 who have PH: http://PHATeens.ning.com

Can you find all eight differences between the two pictures to the right?

Find more activities for kids at www.PHAassociation.org/PHKids

Drawing by Nicole Northrop,
PH Patient, age 16
Denial isn’t just a river in Egypt. It’s also something you run up against when someone doesn’t want to believe, or simply can’t understand, that a loved one is suffering from a life-threatening disease.

I got my first taste of denial when my daughter Lily was diagnosed with a ventricular septal defect and I was told that she would need surgery. My boyfriend would not acknowledge how serious the situation was; he believed that if he didn’t think about Lily’s upcoming surgery, then it didn’t exist.

When Lily was in post-op after her surgery, my boyfriend asked me, “Was there a chance she couldn’t make it?” When I replied yes, he said that he’d thought so, but hadn’t asked the question because he was afraid of the answer. I was frustrated with him, but I thought that since Lily was going to be healthy after her surgery, I wouldn’t need to worry about his denial. But Lily’s pressures in her heart didn’t go down, and she was diagnosed with pulmonary hypertension.

My boyfriend went to some of Lily’s doctor appointments. He would nod, agree, ask a few simple questions, and when we got in the car, he would ask me to explain what the doctor had said. He is very intelligent, but he felt like the doctors were speaking in a foreign language. I learned to use simple terms when relaying information about Lily’s health to my boyfriend and other family members.

Even when my boyfriend understood Lily’s condition, he didn’t “get it.” When Lily began having blue spells, her doctor prescribed 24-hour oxygen. My boyfriend would put her on oxygen in the house, but refused to put her on oxygen when they went out. He didn’t seem to comprehend that 24-hour oxygen meant oxygen all the time. It was frustrating.

I tried talking to him about keeping Lily on oxygen when they went out, and he told me that he’d never noticed her turning blue. In the same breath, he also told me that he never looked for it. That blew my mind. He knew Lily had a life-threatening disease that affected the heart and lungs, but he wasn’t on the lookout for her to have blue spells? He said that the babysitter had never mentioned Lily turning blue. I pointed out that just that day, the babysitter had said Lily was turning ashy, and that “turning blue” didn’t mean she went Smurf-like. I was at the end of my rope with him. Whenever I tried to explain Lily’s condition in depth, he brushed it off. I even gave him the scary statistics. Nothing seemed to work. He recognized how important it was that she have her medicine on time, but he didn’t see why oxygen mattered so much.

I finally turned to the PH Family group on Facebook (a private Facebook group for members of the PH community), and asked for suggestions. The group helped me find another way to relay information about 24-hour oxygen. One night, I casually mentioned that I had read that when someone turns blue, it means their oxygen levels are already really bad, and I explained some of the other effects that can go along with turning blue. That got the message across! I didn’t realize I’d made a breakthrough until the next day when he took Lily to the store with him and put on her oxygen for the trip. I don’t know if I wore him down with all the information, if he needed time to accept it, or if he really hadn’t understood that when Lily is turning blue, she is already in real danger. From then on, I saw steady improvement in his attention to making sure she was on oxygen.

I’m still dealing with this problem of denial when I try to explain the severity of Lily’s disease to other people. What I have discovered is that the same thing does not work for every person. With some people, I need to describe pulmonary hypertension as scientifically as I am able to. For others, I have to give examples of how it affects her. Some people don’t “get it” until I lose my temper.

My boyfriend and I still run into bumps whenever Lily’s doctors give us new information, and I still have to explain things to him, but I’m glad we finally overcame this one particular hurdle. It gives me more energy to concentrate on all the other ones!

By Dianna McGlone, Parent of a Child with PH
I have found a wonderful resource for parents of a child with PH. *Extreme Parenting: Parenting Your Child with a Chronic Illness* (Jessica Kingsley Publishers, 2008) covers many important topics that parents need to navigate while raising a family with a chronically ill child. Sharon Dempsey wrote this book based on her experiences parenting her son, who had a terminal brain tumor, along with input from other parents of chronically ill children. Although it isn’t written specifically for families of PH children, the information fits easily into situations we encounter.

The book is written in an easy-to-understand format that leaves the reader feeling empowered to be his or her child’s advocate. It completely validates the experiences of the parents, the ill child and the other family members. It also takes into account different responses and needs based on the age of the child (infant through teenager). This book covers situations including diagnosis, treatments/hospitalizations, school experiences, communicating with others, sibling dynamics, support systems, day-to-day living, and end-of-life issues. Sharon writes, "Owen taught me how to parent to the best of my ability. He showed me how, in the face of adversity, to be brave and courageous and to strive to overcome what seem like insurmountable difficulties." This is a must-read for parents of PHers!

I found the thoughts and emotions of the parents in the book to be my own. There were numerous times when I would stop and think, "I could have written that paragraph!" I particularly connected with the chapter "The Diagnosis Disclosure," and since this was the first chapter, I was instantly engaged in the book.

This book made me feel that I wasn’t alone. At the time I was reading it, I was pregnant with my second child and very interested in how to balance the needs of my PHer with another child in the house. I found information in this book on ways to approach future family dynamics. It was a good refresher to read about the things I was already navigating, and it reaffirmed how I was handling them. It gave a detailed glimpse into a variety of aspects that we, as parents of a PHer, have to cope with daily. If I ever need to explain the extra stuff I need to think about as a parent of a PHer, I will recommend this book.

*By Melissa Keltgen, Parent of a Child with PH*

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**Check Out This Book:** *Extreme Parenting: Parenting Your Child with a Chronic Illness*

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**2011 Member Appreciation: Magnet Mania!**

**Fall Member Special**
Raise awareness on the go with a PH Car Magnet!

Only PHA Members are eligible for this special, limited-time offer. Order now through January 5 at the PHA Online Store, [www.PHAssociation.org/Store](http://www.PHAssociation.org/Store) or give us a call.

Not a member? Visit [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join) to become a member of PHA today!

Questions? Call the PHA Office at 301-565-3004.

**Now Only $3, Will Be $5 After January 5**

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**Special Offer: October and November Only**
Receive a “PH Resources at Your Fingertips” magnet when you join or renew.

Any new or current PHA members who join or renew during the months of October and November 2011 will receive a “PH Resources at your Fingertips” magnet in the mail. This newly revised magnet features PHA’s Patient-to-Patient Support Line number, as well as specialty pharmacy helplines and medication information phone numbers.

**Join or Renew Today to Get Your Magnet!**

Produced through an unrestricted education grant from Curascript
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.

Donations Listed were received between June 1, 2011, and August 31, 2011. PHA is deeply grateful to the PH community for its extraordinary support.

Take a Look! Sustainers Circle Members Recognized

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

In Memory Of

Donations listed were received between June 1, 2011, and August 31, 2011. PHA is deeply grateful to the PH community for its extraordinary support.

The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x756 or Jennifer@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

For those for whom it would be helpful, PHA has developed a resource, Mourning a Loved One: A Guide to Grieving, which is available at www.PHAssociation.org/Caregivers/Bereavement. For more information, or to request a print version of this guide, please contact Bereavement@PHAssociation.org or 301-565-3004 x800. We welcome all loved ones to remain a part of our community for as long as it is beneficial.
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Learn more about medical identifiers for PH on PHA’s website, at www.PHAssociation.org/MedicAlert

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The new 4th Edition features five revised chapters, including:

- Diagnosis
- PH drugs
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