As a California local, I look forward to welcoming my PHA friends, old and new, for a real California adventure! I sincerely hope this June 25-27 will be your golden opportunity to experience “The Golden State” first-hand at PHA’s 9th International PH Conference and Scientific Sessions in Garden Grove, Calif. The International PH Conference is the largest educational and networking event for pulmonary hypertension patients, caregivers and medical professionals in the world.

This year’s Conference theme, Riding the Wave to a Cure (submitted by PH patient Melinda Schissel), was chosen for its positive, upbeat vibe. It is precisely this California attitude that makes the International PH Conference so special. Having the opportunity to hang loose with PH patients from around the world, network, share stories about living with PH and learn about the latest medical advances in research and treatments all make for an experience not to be missed. Whether you are a newly diagnosed patient or a devoted Conference aficionado, there is always something new to learn when 1,300 fellow PHA members from around the world come together in one place.

STEVE VAN WORMER’S STORY CONTINUED ON PAGE 40

Register for Conference on PHA’s NEW Website!

The easiest way to register for the 2010 International PH Conference and Scientific Sessions Riding the Wave to a Cure is on PHA’s NEW website, launching January 2010.

To register visit, www.PHAssociation.org/Conference
According to Aristotle, “The whole is greater than the sum of its parts.” PHA’s “whole” is made up of many parts — all fulfilling different parts of our wide-ranging mission to provide hope for the PH community through support, education, advocacy and awareness. Each component is essential to the difference PHA is able to make in the lives of pulmonary hypertension patients. But perhaps none is more important than meeting the support needs of patients and family members that is accomplished through our local support groups.

No one could have said it any better than our beloved Bonnie Dukart who, prior to losing her fight, was a patient, support group leader and former chair of the Board of Trustees.

When I was diagnosed after college, I lived for ten years without meeting another patient. I will never forget going from my home in Pennsylvania to the closest PH support group. It was in Chicago. When I walked in the door and I saw seven other patients, my life changed.

~ Bonnie Dukart, 1998

Since Bonnie first went to that meeting in Chicago, we have grown from a handful of groups to well over two hundred today across the entire country with new ones being formed almost weekly. That also means that there are well over two hundred people, many of whom are patients themselves, serving selflessly as support group leaders and co-leaders. It also means that thousands of individuals benefit from and give back to others by participating in support group meetings.

Although I only know a handful of support group leaders personally, each and every leader is a very special person in my book. Being a support group leader means that you have volunteered to play a key role in the lives of many who are living with pulmonary hypertension. In doing so, you not only make great contributions to their well-being, but also to that of their families.

Beyond support, these groups make so much else possible within the PH community. They hold special events, organize advocacy efforts and raise awareness in their communities. Where would we be without them? For this, and so much more, I thank each and every leader and co-leader and also every support group participant from the bottom of my heart.

Speaking of support, one of the most dedicated people I have met in our fight is PHA’s own Debbie Castro. As Director of Volunteer Services, Debbie, who recently celebrated her fifth anniversary at PHA, has lead our support group network through several years of expansion, inspiring me and hundreds of others on a daily basis. Debbie is a member of the PHA team that in my book knows no equal. They help keep hope alive by making support and education available to anyone who wants it and by empowering you, the members of our community, to get involved in advocacy and awareness-raising.

I want to close by saying that it gives me great hope and gratification to be part of an organization that is made up of such caring individuals who give so much of themselves in the fight of our lives. To meet other extraordinary people like yourself, read about PHA’s 9th International Pulmonary Hypertension Conference and Scientific Sessions in this issue and make the decision to come to this life changing event.

Empowered by hope,

Correction: PHA apologizes to David Wilson for referring to Sharon and David “Miller” in the fall 2009 Message from PHA’s Board Chair.
PHA Launches New Programs for Communities with Special Interests

This autumn, PHA held a series of focus group phone calls with community members who identified themselves in an online survey as newly diagnosed, young adults, PH patients with associated illnesses, parents of children with PH or family caregivers. Of 230 survey respondents, 55 patients and caregivers called in with ideas for resources and services to address their unmet needs.

What we heard
Members of each population said they were looking for more targeted emotional and practical support from PHA, new opportunities to connect with community members and education geared toward their specific questions and concerns. Here are some of the topics each group wanted to know more about:

Newly diagnosed patients
This population had questions about medical issues and treatment, financial and legal resources, overcoming denial and depression, talking to friends and family about PH, dealing with the “day-to-day,” finding and keeping a job and traveling with oxygen. New patients also wanted resources written in language that would be both accessible to people unfamiliar with PH terminology and sensitive to their immediate emotional needs.

“I’m so newly diagnosed that I’m still walking around in a fog. You know, it’s not even real to me yet.”
~ Susannah Black

Young adults
These patients wanted information about the medical, legal, and practical logistics of transitioning to adulthood, college and scholarships, dating and marriage, pregnancy and family planning, choosing a PH-friendly career, exercising and sports and maintaining a positive outlook in the face of their illness.

“Young adults have the potential to give hope to a generation that read about poor statistics and outcomes from a previous generation … It is my hope to have our generation see the cure for PH.”
~ Lindsay Nicol, age 26

Parents of children with PH
Parents were most interested in pediatric-specific research and treatments, side effects of PH medications in children, learning how to measure a young PHer’s pain and energy levels, recreational opportunities for children with chronic diseases, school disability laws and policies and information on individualized education plans (IEPs).

“Due to the variations in this disease, I feel alone often; people in this PH community help bring some sense of understanding of what’s ‘normal.’”
~ Melissa Keltgen, parent of PH patient Evelyn, 2 years old

Family caregivers
This group was looking for resources to help manage PH treatment from a caregiver’s perspective, explain PH to extended family and friends, avoid caregiver burnout and communicate with their loved one.

“Sometimes I say ‘when we were diagnosed.’ You know, it’s changed my life too.”
~ Patrick Gilstrap

Patients managing multiple illnesses
These patients were eager to learn more about coordinating specialists and concurrent treatment plans, educating their non-PH specialists about PH treatment, medical information about how PH interacts with other diseases and medical information about how therapies interact.

“Since being diagnosed with scleroderma and PH I’ve learned first-hand the importance of emotional/educational support and believe this can make a huge difference in our lives.”
~ Eileen Savell

STOrY CoNTINuED oN NExT PAGE
Looking forward

In response to the feedback collected in the focus groups, PHA is working with patients and caregivers to develop programs, networks and services to address population needs. Some of the goals of the Patient Outreach and Services Program include:

- New educational resources for each group.
- Meet-ups and additional programming at PHA’s 2010 International PH Conference.
- Population-specific programming at regional educational programs.
- A patient and family member mentorship program.
- Virtual support groups and education opportunities.
- Partnerships with associated illness organizations.
- Proactive outreach to new patients.

Get involved

To learn more about getting involved, or to receive notifications about new programs and resources for any of these five populations, contact Emma at Emma@PHAssociation.org or 301-565-3004 x777.

PHA’s Patient Outreach and Services Program is partially funded by a grant from the Medtronic Foundation.

Do you belong to any of these groups? Would you like to meet others in the same boat?

PHA has email groups to help you connect with people who understand what you’re going through!

- **PHA Community** for PH patients from all walks of life. New patients can join to ask questions, share information and meet people who understand what it’s like to live with this disease.
- **Generation Hope** for PH patients in their late teens, 20s and 30s.
- **PHA Family** for family members and caregivers of PH patients.
- **PH Plus** for PH patients managing multiple illnesses.
- **PHA Parents** for parents of children with PH.

To sign up for a PHA email group today, visit www.PHAssociation.org/EmailGroups

No Internet Access? No Worries!

With all the talk of Google, Facebook and “getting online,” we know that those who don’t have ready access to the Internet may feel left out. While PHA depends on our website for distributing information and getting people connected to others and to our programs, we want to be sure you know there are many other ways to connect with the PH community and receive information that is important to you.

- First and foremost — call our Helpline at 800-748-7274. Our friendly patient volunteers are there to lend a listening ear, answer questions and provide you with needed information and resources. Patients and family members can get help finding a doctor, get answers to insurance questions and so much more. Calls go to volunteers’ homes, so please don’t call too late.

- While you’re talking to a Helpline volunteer, find out if there is a **PHA support group in your area**. If so, give a meeting a try. You are likely to find a group of people who understand you and your concerns. These meetings also provide excellent opportunities to learn more about living with PH, treatments, coping skills and much more.

- Order PHA’s **Pulmonary Hypertension: A Patient’s Survival Guide** (call 301-565-3004 x0). You won’t find a better resource on PH. A 300-page book, written by a patient and medically reviewed, it covers everything from treatments to nutrition, dealing with emergencies, working, traveling and living with PH. The cost is only $25 ($15 for PHA members).

- Read the **PHA flier** that comes with your monthly medication mailing from your specialty pharmacy. These informative fliers tell you about what’s going on at PHA — from our insurance program, to our support groups, to ways to get involved and information on our 2010 International PH Conference.

If you still feel like you may be missing something, remember there are ways you can access online information from PHA (www.PHAssociation.org) without having a computer and Internet service at home. Local libraries and senior centers have computers and helpful staff and volunteers who can help if you are new to the worldwide web. A family member or neighbor may be willing to “log on” for you and let you know what’s going on. Computer classes offered through your local adult education or recreation department programs will put you in touch with teachers who are likely to be able to recommend other ways for you to get online.

We are here for you — whether it’s over the phone, through the mail or on the Internet. Please call on us for support, information and to find ways to get involved.
Connect from home

PHA Helpline: 800-748-7274
The PHA Helpline is answered by a group of trained patient volunteers who are there for anyone who needs someone to talk to about PH.

Call 800-748-7274 to reach a friendly voice who can help provide information and support.

Online Communities
Our discussion boards, email groups and chats help you instantly connect with other patients and family members. www.PHAssociation.org/ConnectOnline
PHA also holds frequent e-Learning Events. Take part in these monthly webinar presentations, conference call discussions and online Q&A chats at www.PHAssociation.org/Classroom

Connect face-to-face

Support Groups
Join one of our 200+ support groups nationwide to connect with people who understand what it’s like to live with PH. To find support groups in your area, visit www.PHAssociation.org/LocalSupportGroups

Conference and Patient Education Programs
PHA’s International Conference brings together over 1,000 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and coping with PH. Our 2010 Conference takes place June 25-27 in southern California. Visit www.PHAssociation.org/Conference to learn more.
PHA also hosts regional patient education conferences throughout the year. Learn more at www.PHAssociation.org/OntheRoad

Special Events and More!
Attend an event near you to meet patients and support PHA: www.PHAssociation.org/Events

Join our community of hope

Become a member to receive Pathlight, a discount on A Patient’s Survival Guide and much more. Visit www.PHAssociation.org/Join
In May 2007, I collapsed while touring in India with a church group. Except for a touch of bronchitis, I was completely healthy and had no idea why I could not breathe well. After a battery of tests in India and a visit to a pulmonologist in the United States, I was sent to Dr. Ivan Robbins, a PH specialist, at Vanderbilt Hospital. Dr. Robbins diagnosed me with idiopathic pulmonary hypertension. He and his nurse, Cindy Fink, were so helpful to me.

In 2008, I left the luxury of private health insurance when my husband left his job. We moved to St. Louis, Mo., for family support, and I began relying on my veteran’s benefits, using the St. Louis Veterans Affairs (VA) Hospital. The VA provides a medical benefits package to all enrolled veterans who are released from active duty with anything but a dishonorable discharge. This comprehensive plan provides a full range of preventive outpatient and inpatient services within the VA healthcare system.

The VA in St. Louis did not have a PH specialist, but they accepted my request to visit a specialist at Barnes Hospital at Washington University using my Medicare to cover the visits. Dr. Murali Chakinala, my new PH specialist, would make treatment recommendations to my pulmonologist. In turn, my pulmonologist continued to prescribe my costly PH medications, which the VA continued to cover.

In 2009, we moved to Jacksonville, Fla. where I began seeing the VA in Gainesville. My pulmonologist here told me I had to be treated by the VA exclusively if I were to receive medications through the VA system, and the VA refused to prescribe medications and allow me to see a specialist at a non-VA hospital using my Medicare. I did as my pulmonologist directed.

My pulmonologist began taking me off Flolan™ and adding bosentan. My health began to deteriorate. I was back on oxygen 24/7, I could no longer do my exercise walks and I was feeling terrible. I asked her to request an exception so I could see a doctor outside of the VA. She said that “they” don’t approve any exceptions to see outside doctors.

At this point, I decided to fight the system. I contacted the patient advocate at the VA. The patient advocate acts as a liaison between the patient and the medical center. They help to resolve complaints and concerns of the patient in a timely manner. I wrote emails to my representative, my senators, the governor and the president in hopes of getting the VA to allow me to see a PH specialist.

About one week after I sent my emails, staff from my representative’s office (Representative Ander Crenshaw, R-FL) directed me to resubmit my request for outside treatment to the VA as fee-based. If approved, the VA would pay the fee of visiting a physician outside the system, allowing me to see a PH specialist. About two weeks after I resubmitted the request, I was approved to see Dr. Kamal Mubarak at Shands Hospital at the University of Florida.

Maneuvering through a government system can be confusing and disconcerting sometimes, but don’t give up! Here are a few words of advice for anyone going through the VA health system:

* If you were active duty in the U.S. military and were released on anything but a dishonorable discharge, you are entitled to treatment at a VA hospital.
* VA will approve fee-based visits to doctors outside of the VA if you can prove it is needed.
* Using the VA Hospital for your PH medicines (even if you have other insurance or Medicare) is a huge win since there are low co-payments and no lifetime caps. My medicines, oxygen, liquid oxygen and wheelchair are all covered by VA.
* You must work with your pulmonologist to get medications. VA requires all medications to be prescribed by their doctors.
* The patient advocate is there to help you. They will also ensure that there is no retaliation from your doctor for asking for assistance.
* Political influences can be very helpful when you hit a roadblock.
* Contact your local media for an exclusive on your story. They love a good story. I was featured in an article in the St. Louis Beacon.
* Finally, you must be your own advocate. Nobody can look out for you better than you. Get educated and be an expert in PH. Know what you are talking about, and it will carry you far. I learned so much from the PHA website, chats and message boards.

By Racheal Locklear
PH Patient

Do you have an insurance story to share? Contact Margaret at Insurance@PHAssociation.org or call 301-565-3994 x773.
On September 24, I had the unique experience of participating in the PH Resource Network Advocacy Day on Capitol Hill. I had been interested in attending, but I must admit I was a bit shy at the thought of public speaking outside familiar arenas. So, I had delayed signing up for the event. A colleague told me she had attended a number of times, and each time she came away with a sense of awe and accomplishment. She said advocating makes her feel that she is the voice and physical presence for those she works with who are unable to attend and advocate for themselves. How could I not want to participate! So, with much trepidation, I showed up on Advocacy Day to see if I could join at the last minute.

I was met with a wonderful welcome: “Sign up? Sure. Right over here!” I attended a very informative training session led by Katie Kroner and other PHA staff, and I had the opportunity to ask questions. We were given talking points and the H.R. 1030 bill (The Tom Lantos Pulmonary Hypertension Research and Education Act of 2009) for review since we would be asking our representatives to co-sponsor the bill. Each of us had an opportunity to speak either with our representative or their legislative assistant. I was pleased that everyone we spoke with had heard of the bill, and during the course of conversation, they asked specific questions related to pulmonary hypertension. I believe we did our best to answer all their questions and seek their support.

Participating was exciting for me on many levels. Being on Capitol Hill was a totally new experience and reminded me that my representative’s job is to listen to constituents and represent them at the highest levels. Without my feedback and interest in bringing specific bills to their attention, this bill may not become their priority. It felt good to network with others in bringing this disease to the forefront, while developing new friends and resources along the way. I went back to my work place with a new sense of commitment in getting the word out and being less complacent in future interactions with legislators. It is a unique opportunity for all involved in the care of those with pulmonary hypertension to be a voice with our vivid examples of patients’ PH experiences, their trials and tribulations. These examples make it all the more real to those who have never heard of the disease. I would urge all to become involved in PH advocacy and make those who represent you locally and in Washington, D.C., aware of the need for continued research and education in the fight against PH.

For more information about becoming a PH advocate, contact Katie at Katherine@PHAssociation.org or 301-565-3004 x749.

By Sherry Duveneck, BSN, RN
Dartmouth-Hitchcock Medical Center, Lebanon, N.H.
The PH family extends far and wide. We’ll take a look at patients from around the world to learn more about our friends in far places. This winter, meet Wah Wah Khin, a patient in Myanmar.

Before she was diagnosed with pulmonary hypertension, Wah Wah Khin worked as a general practitioner in Myanmar, one of the world’s least developed countries. Her diagnosis in December 2007 meant the end of her 14-year medical career and the beginning of an international search for life-saving medications. With a special needs child to care for, no health insurance and only a small pension from her work in government hospitals, Wah Wah has been reliant on her parents and siblings for help paying for as much of her treatment as possible.

“The very fact that I am unemployed, totally dependent and staying together with my parents at their house says it all,” Wah Wah told PHA when she first contacted us for help. “Whether my parents can continue to support and absorb my medical expenses in 2010 is very much open to question.”

In a country with no support for PH patients, Wah Wah must be her own assertive advocate. Like many Myanmar nationals, she purchases her medications in Singapore, where healthcare is better, and after many months of making her case, this fall she was finally able to secure a discount from Bayer Schering that will make it possible to extend her treatment.

Myanmar, previously called Burma, is a Southeast Asian country a little smaller than Texas. “It is more than likely that all the least developed countries are being faced with very, very expensive drugs for the treatment of PH,” Wah Wah explains. “Hence, they are presently unable to treat with the medications to combat this deadly disease. But with the rising tide in development, the situation may get better.” While the situation improves, however, PH patients require support today. “… Given the nature of this deadly disease, an ongoing sensitization on the need to lower the cost of the drugs should be made,” Wah Wah argues. “This is because all diseases, including PH, do not have national boundaries.”

Interested in learning more about PH patients outside the US? Visit www.PHAassociation.org/PHInternational/Faces to meet the International Faces of PH, or to submit your own story.

By Christine Dickler
PHA Associate Director of International Services

Maleen Fischer was diagnosed with PH when she was just three years old. That’s when her dad knew he needed to start a group in Austria to ensure patient support and research for a cure. This year, PHA Austria held a number of hugely successful events, including the Charity Circus Roncalli Gala. Pictured to the left are Maleen and celebrity magician, Tony Rei. Both Maleen and Tony Rei appeared as special guests for this awareness event. The Charity Circus Roncalli Gala took place on October 11 in front of the Vienna City Hall. With 1,450 people in attendance, the event raised € 22000 (about $33,000 USD) for PH research with a specific emphasis on PH research to help child patients.
**Travel? Yes, I Can! Young PH Patients Offer Tips for Hitting the Road**

“I can’t do everything, but I try anything.”
~ Robert Ngo, PH patient

Many young PH patients have followed their dreams — and their hearts — to all corners of the earth. When day-to-day living feels more like moving mountains, traveling might seem impossible. It’s not. Here are a few tips from young PHers:

1. **Start planning early:**
   - Talk to your doctors. Have them write a letter explaining your illness, your treatments, the equipment you will need and a list of your medications. If you’re planning to fly, ask about taking an altitude test.
   - Get the name, address and contact information for the PH center nearest to where you are traveling. Go to www.PHAssociation.org/Patients/FindADoctor and carry that information with you. Give a copy to your doctor.
   - Carry written prescription refills with you.
   - Bring enough medications and supplies for the length of your trip plus a few extra days.
   - If appropriate, have emergency instructions translated, especially if you use a pump.
   - Most insurance plans don’t provide international coverage. Always buy your own policy before your trip. Go to www.insuremytrip.com
   - Call your cell phone provider to find out if your phone will work overseas. If it won’t, you can rent an international phone for the vacation.
   - Scan all your recent medical records, including heart catheterization results, lab work, medications and dosages, etc., onto a flash drive and put it on your key chain. That way, hospital personnel will have instant access to your file.
   - Register your trip with the U.S. Embassy in the countries you’re traveling. Tell them you are a PH patient and will need special medical treatment if any problems arise. Go to www.state.gov

2. **Contact the airline early and remember:**
   - ALWAYS carry all your medications and supplies on board with you.
   - Ask for bulkhead seating so you will have more room for your medications and supplies during the flight. These bags do not count as your carry-on luggage and are allowed at no extra charge.
   - Bring an insulated lunchbox with ice packs rather than a hard plastic cooler to store your medications.

They’re not as heavy and take up less space.
   - Tell the airline you have a medical condition and need extra time to board the plane. They will let you on early to get settled.
   - Ask about oxygen use while on board. Virgin Atlantic provides oxygen for free on all transatlantic flights.
   - If you bring your own concentrator, make sure the floor in front of your seat is flat. The more room you have, the better. You will also need a letter from your doctor stating that you are allowed to fly, listing what your liter flow is and stating that you know how to operate it yourself. Be sure you have enough battery power for the length of the flight plus one hour.
   - Look into buying or renting the Inogen One®, especially if you need oxygen all the time. It’s a portable, battery-operated oxygen concentrator. Ask your oxygen provider about a backpack to carry your oxygen in. The beach is possible!
   - Wheelchairs are available at all airports. Use them.

3. **Plan for the hotel:**
   - If your medications require it, request a mini-fridge with a freezer to keep your medications cool.
   - Ask all the (seemingly) obvious questions. Without an elevator, you’re sunk. Try to get a room close to the elevator. Save your energy for the fun stuff.
   - To avoid any dosage mix-ups when you are in a different time zone, take your medications at the same time you would back home.
   - Don’t underestimate the time change, either. Rest when you need to!
   - Bring a plug adapter when you go overseas.

Our diagnosis is a string of words, not heavy metal chains holding us captive. PH cannot imprison our spirits. It may deprive our bodies of oxygen, but it cannot keep us from dreaming. In fact, this new way of life may be just the push we need to live life to its fullest. Make PH fit into your life, not the other way around. Always be prepared but never afraid. Don’t leave for tomorrow what could be the experience of a lifetime. As Ellen Rains Harris, PH patient, explains, “If you let fear stop you, the disease wins. That’s not what I’m about.”

By Katie Tobias

PH Patient

*Special thanks to Donna Pederson, Robert Ngo, Ellen Rains Harris, Lindsay Nicol, Luz Batista, Cindy Wangerud, Pammie, Doug Taylor, Tara Suplicki, Laura Thaisen, Colleen Brunetti, Anthony Roe, Camille Frede and Emine Çayiroğlu for their contributions to this article.
David Sisk, as told by his wife Mary (Savannah, Ga.)

It’s that time of year again. November 1st marked the beginning of Pulmonary Hypertension Awareness Month — something that is near and dear to my family. My husband has PH, and this is our story.

We first noticed a problem with my husband four weeks after I gave birth to our second child. We were raking leaves in the yard, and for some reason, David could not keep up with me. He began to blow the leaves off the roof, and within minutes he was drenched in sweat and looked like he was going to pass out. I knew something was wrong. This man teaches whitewater kayaking, runs around with my son and rock climbs. He should have no trouble blowing leaves off a roof.

I made the doctor’s appointment for David, and initially he was diagnosed with having asthma, but his doctor had enough good sense to realize maybe there was something else going on and scheduled a stress test a week later. David used his little inhaler for a week with no improvement in his ability to “catch his breath.” He was so tired and slept a lot. David left for his stress test, and I stayed home with our two-year-old and the new baby. I thought nothing of it. My world changed that afternoon, and we have never looked back.

David collapsed during his stress test and was rushed to cardiac intensive care and had a left-sided heart catheterization. I rushed to the hospital after finding friends to take the babies. We sat in intensive care for three days and were discharged with a vague diagnosis dealing with the endothelial tissue in his heart valves.

A few days later, on July 3, the doctor called us back and said he looked at David’s chest echo and noticed that his heart was extremely enlarged. He wanted us to come back in on July 5 for more tests. We frantically searched for the words “enlarged heart” on the Internet. These words kept coming up — pulmonary hypertension. Then we clicked the link. “No cure … continuous IV drug therapy … heart and lung transplant … five years to live after initial diagnoses.” Our world came crashing in.

On July 5, 2007, the doctor met with us and confirmed our suspicion, and he told us to find a specialist at either Mayo or Emory.

We had our first meeting with the doctors at the Mayo Clinic (Jacksonville, Fla.) two weeks later. David went through a series of tests to try to determine the cause of his PH. We learned it is usually secondary to a number of other diseases. They found nothing and diagnosed him with idiopathic PH, which means there is no known cause. One in a million, they say.

We learned at Mayo through the wonderful doctors and respiratory therapists that this is not a death sentence. There are new drug therapies being discovered and new drug trials. David is currently taking up to ten medications a day including his continuous drug therapy through a catheter in his chest. We have had a few setbacks, but for the most part, he is doing better. We had good news at our last visit to Mayo. He is no longer being considered for a heart and lung transplant because his heart function is starting to get better.

David has had to stop working and now runs the house and takes care of the kids. On the flip side, I have taken on all the other responsibilities. I have gone back to work as a full-time speech therapist, and I have traded in my house slippers for work boots. I never thought I would use a jack hammer to tear up concrete in the yard!

So, if you see me running through the hallways with purple in my hair — yes, purple — it’s my way of spreading awareness for PH Awareness Month. David and I wanted to say thank you to our huge network of friends and family. We cannot do this without you.
Jaimie Love (Midvale, Utah)

My name is Jaimie Love, and technically, I’m no longer a PH patient. This terrible disease almost took my life last year. On July 1, 2008, I received a double lung transplant that saved my life.

I was diagnosed with idiopathic PH on June 30, 2006. I remember that day so vividly. I had never heard of PH before, and I thought it was no big deal — just something I would have to take some pills for. Well, after Tracleer™ and Flolan™ and about a million hospital visits, I knew better.

Pulmonary hypertension changed my family’s life and my life in every way possible. I ended up losing so many friends, not going to school and just being completely depressed. I had no hope. With the support of the people around me and the people on the PH message boards on PHA’s website, I found hope. I looked at life so much differently. So what people say is true: life really is short.

I eventually got too sick for any medication to help me and had to be put on the lung transplant list. I couldn’t believe this was happening. I live in Utah, and the transplant team there turned me down, so I had to move to Seattle and live away from my family while I awaited a double lung transplant at the University of Washington. I was at the very top of the transplant list and waited for four months until I finally got the call I had been waiting for — the call that saved my life.

It’s weird how things happen at exactly the right time. If I hadn’t had my transplant then, I would not have been alive the following day. Now over a year later, I am healthy and alive!

I know how so many PH patients feel: the doubt, the fear and the lost hope. I want to tell you to hang in there; there is hope. We all were dealt a nasty hand, but we can all handle it. Things will get better. Pulmonary hypertension is where my heart is, and my greatest dream is that there will be a cure found for it.

To all of you out there suffering from this awful disease, you are my heroes.

A Terminally Positive Experience by Ellen Smith (Bloomington, Ill.)

The air was still as the doctor inhaled to say what my parents and I weren’t prepared for: “A terminal lung disease; pulmonary hypertension.” I was 13 when I received the diagnosis. The shock ran deep. Further tests were ordered, and a life expectancy was given: two years. My family went into survival mode. My aunt’s blood ran cold: “Why Ellen?” According to my grandmother, “Ellen’s strength has brought our family together and taught us to live one day at a time.” Although people usually think of my lung disease as a negative experience, it has also been a positive experience, influencing my personality, family relationships, friendships and my dreams.

Following the diagnosis, I have had yearly cardiac catheterizations to monitor the pressure in my heart. The prep rooms for surgery are always cold. I hear the doctors talking about me, but I cannot talk. Tears run down my cheeks as fear fills my empty stomach. The PH nurse always takes my hand reassuringly.

As I was being diagnosed, my life changed very rapidly. I went from being a typical new teenager — school dances, first boyfriend and make-out parties — to an adult learning how to monitor my oral medications and inject myself with a needle to receive my continuous medication. Along with all these changes came a change in my personality.

Perseverance is the quality in which I take great pride. Everyone always tells me how strong I am. When given a full plate of responsibilities, I just take one bite at a time to help me pull through. Loving, caring and understanding also became a part of my life. I love being there for my friends, and I understand how tough life can get. My family and friends play a huge role in making my lung disease a positive experience.

Without my friends or family, I would have never made it through these seemingly insurmountable obstacles. As a result of my experience, I make sure to call my parents, grandparents and aunts regularly to tell...
them I love them. Friends have also been there for me, and I cherish these relationships.

As a result of my experience with PH, I began to dream of becoming a physician’s assistant so I would work with patients faced with possibly terminal illnesses. I want to look at patients as more than just a source of revenue but as individuals — understandably fearful and anxious. I have a lot of empathy to share with patients. I know that I will achieve this dream because of my personal determination and the continuing support of family and friends. I am confident that given my personal experience, I can make a difference for others in what can be the most difficult and challenging times of their lives.

A chronic disease can bring a person down or ruin a person’s life. Now after twelve years, I have chosen to let PH shape me and help me grow in a positive direction. The whole experience has low points, but it ultimately made me into who I am today and I am a better person for the experience.

Eight years ago, my wife Laura and I took Shannon to Children’s Hospital Boston. Shannon was having fainting spells. After one of these spells, we took her to the local emergency room. Something did not look right on her EKG. Her pediatrician scheduled an appointment for her with cardiology three weeks later. When asked if the appointment should be sooner, he said it was probably nothing and three weeks would be fine. On May 30, 2001, we found out why Shannon was fainting. She has pulmonary hypertension. We were told we were lucky because there is a doctor, Dr. Mary Mullen, who treats PH and a treatment is available. The only FDA-approved treatment at that time was Flolan™. Without treatment, they told us, Shannon would be dead in a year.

Now, here is the dilemma. You bring your child to a hospital to see a specialist. Your child has had syncope and fainting spells and from time to time has been short of breath. Doctors, including other non-cardiac specialists, have told you there is nothing to worry about. It is a vasovagal response, the lightheadedness you feel when you jump out of bed. You are also told the shortness of breath is in her head. You are totally unprepared to hear the words, “She could die from this. She may not wake up if she faints again.” This is five days prior to kindergarten graduation. The doctor wants to admit her immediately, and if admitted, there is no way she will be out of the hospital for graduation. What would you do?

It was probably the toughest decision I ever had to make. We asked the doctor to leave the room. I looked at Laura and said, “I do not want the last memory of Shannon to be that we took her to the hospital.” Somehow Laura understood what I was saying, and we decided to take Shannon home. On that day we discovered what a special place Children’s Hospital is. No one tried to change our minds, and while we were discussing all of this with the doctors, and also by ourselves, someone played with Shannon.

Five days later, Shannon graduated from St. Raphael’s kindergarten. It was the best graduation I have ever attended. It was also the toughest graduation I have ever attended. I was on the edge of my seat. Not like most proud parents because my little girl was graduating kindergarten, but because I was praying that nothing would go wrong with Shannon. I do not think I ever took my eyes off her. In fact, even though I was physically present at the graduation ceremony, I would remember very little if it was not for the videos. Shannon did a great job at graduation. For many people, she stole the show.

Shannon recently graduated from McGlynn Middle School. Eight years ago I never imagined I would see this day. I was the proudest dad in the audience. Once again, I was on the edge of my seat. This time it was not because I was worried something would go wrong, but because my little girl was graduating from middle school!

If I have learned one thing these past years it is to celebrate the little things, so celebrate with me. Sing your favorite song at the top of your lungs or get up and dance around the room. If people look at you funny, share the joy with them. Have your favorite meal, drink or dessert. You can go back on your diet tomorrow. Just do something to celebrate. Most importantly, do not forget to say a prayer of thanksgiving for eight wonderful years.
An Active Voice in the PH Community: Meet Dr. Michael Mathier

“We are what we repeatedly do. Excellence then is not an act, but a habit.”
~ Aristotle

Excellence is a way of life for so many PHA members and volunteers, and for Dr. Michael Mathier, it’s no different. Dr. Mathier recently took the time to talk about his involvement in the fight against pulmonary hypertension and the work he’s been doing with PHA.

You specialize in cardiology. What initially sparked your interest in PH?

When I went into cardiology, I became interested in congestive heart failure, specifically the mechanics of the heart: WHY it weakens and what we can do to either treat or prevent it from weakening. As I learned more, I became more interested in the right heart in part because it remains less studied. I wanted to find out why the right heart struggles with pressure build up. And when you’re interested in the right heart, many of your patients have PH. I began to do some collaborative work with the PH docs at Massachusetts General Hospital, where I did my residency and fellowship. The rest, as they say, is history.

Over the years, you’ve treated a lot of PH patients. Are there any cases that really stand out?

Oh yes, a lot, but the most rewarding was a young woman born in Mexico who had a septal defect that had gone undiagnosed, and she developed severe PH. She came to the U.S. in the late 90’s. She had no health insurance, but we were able to enroll her in a study with subcutaneous Remodulin™, and she improved dramatically. She went on to adopt two children and is now an incredibly active mom, a force in the community and a real spokesperson to how far PH patients can come when on the right treatment.

What advances in the treatment of PH patients have you seen since you first started practicing?

I remember when I was a trainee as recently as the mid-90s, and there were no treatments available before Flolan™ was approved. Too many young people’s lives were cut short. That’s such a contrast to where we are now with eight FDA-approved treatments. Of course, none of us who treat this disease are under the illusion that our work is done. Until we really have a cure, we don’t think for a moment that we can rest on what we’ve accomplished. But it’s helpful to think back to what the disease state used to be like and see how far we’ve come.

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

Keep your spirits up. PH can be very successfully managed. Longevity and a high quality of life can be achieved, but it takes real effort. Patients must be seen by experts and they must be fully committed: using their medications properly, maintaining a good diet, engaging in appropriate physical activity and setting aside time each day for personal enjoyment. Outcomes in the face of this difficult diagnosis can be really outstanding.

You’re currently a member of PHA’s Scientific Leadership Council (SLC) and Chair of the Medically Led Sessions Committee for the upcoming 9th International PH Conference. How did you become involved with PHA?

In 2000, I joined the faculty at the University of Pittsburgh with Dr. Srinivas Murali. Through Dr. Murali, I began to meet a number of physicians and other caregivers across the country, including Dr. Vallerie McLaughlin. Both Dr. Murali and Dr. McLaughlin suggested that I become involved in PHA, and my first real PHA experience was the 2004 International PH Conference.

The Medically Led Sessions Committee is hard at work preparing for the 9th International PH Conference. What’s in store for Conference attendees?

The Medically Led Sessions are a true highlight of Conference. The idea that a group of patients and family members can get together with healthcare providers is unique in medicine, and it’s my favorite part of the meeting. Our goal has been to take all the good parts from previous Conferences and build on those, preserving the successes and finding new topics that are pertinent given the changes in the field. Past attendees will see old favorites, but we’ve added some new sessions. We’ve

STORY CONTINUED ON PAGE 19
**HEALTH MATTERS**

**ASK A PH SPECIALIST**

**Q:** At a recent visit, my physician mentioned involving a palliative care specialist. What is palliative care, and how does it differ from hospice care?

**A:** What palliative care means and what it involves are often misunderstood. Palliative care is active, total care of patients whose diseases are not fully responsive to curative therapy. Though this type of care is often thought of for cancer patients, palliative care has been applied to several other chronic illnesses including heart failure, emphysema, kidney disease, dementia and liver cirrhosis. In addition, many healthcare providers now advocate palliative care plans for patients with pulmonary hypertension. The main goals of palliative care are to achieve the best quality of life for patients and enhance comfort and dignity. This often involves symptom control and trying to best understand patients’ goals of care.

Physicians, nurses, social workers, spiritual ministers and others may work together as part of the palliative care team. Palliative care allows for current therapies to continue if they are helping you to live well. This may include, but is not limited to, your PH medications or oxygen. Symptoms addressed by palliative care include difficulties with side effects from IV PH medications (like Flolan®), pain, shortness of breath, fatigue, depression, fluid issues and several others that may or may not be related directly to your PH. Palliative medicine doctors may also be able to help you with clarification of issues like advanced directives, living wills and determining if hospice is right for you.

Hospice is a specific type of palliative care that is provided to seriously ill patients near the end of life. In general, life expectancy is six months or less on average in order to enroll. Hospice can be provided in a variety of places, including your home, nursing homes, hospitals or free-standing hospice facilities. The rules are generally modeled after the Medicare hospice benefit, even if you have private insurance. If a patient lives longer than six months, they may “re-enroll” in hospice for an indefinite number of three-month periods, as long as they still meet the criteria in a physician’s best judgment.

The optimal time to see a palliative care specialist is different for each patient. Typically, consults happen when there is a change in your health status, when PH therapies are not tolerated or when lung transplant is not an option. The misconception that hospice and palliative care are only available when there is “nothing more to do,” or that talking to a palliative care physician is like “giving up” often prevents earlier involvement of a palliative care team. However, palliative care is a life-affirming service that aims to shift some focus to not only your PH-related issues, but all symptoms that may be negatively affecting your quality of life. Together, you and your physician can determine the appropriate time for palliative care to become part of your healthcare plan to promote the best quality of life possible.

Answer provided by Keith M. Swetz, MD, Associate Program Director (Practice), Palliative Medicine Program, Mayo Clinic

“...palliative care is a life-affirming service that aims to shift some focus to not only your PH-related issues at hand, but all symptoms that may be negatively affecting your quality of life.”
PH Resource Network Symposium Encourages Cooperation in PH Care

The 2009 PH Resource Network Symposium — Leading Progress, Creating Partnerships: Empowering the Interdisciplinary PH Team — was our best Symposium ever. Nearly 400 attendees, including nurses, doctors, respiratory therapists and physician assistants — some from as far away as the U.K. and South Korea — came together for three days of learning, sharing and networking on September 24-26 in Arlington, Va. The excitement was palpable and infectious throughout the Symposium.

We had outstanding meal session speakers like Dr. Mike McGoon and Rev. Stephen White, speaking on such topics as current PAH research and caring for the caregiver.

Michael Petty, PhD, RN, delivered his talk, Exerting an Influence, during the welcome dinner. He reminded us that not only do health professionals hold a great influence on their patients’ well-being, but this influence can and should be extended to benefit everyone in the workplace. His talk was an affirmation to all of us who work behind the scenes, and it gave many of us a new sense of purpose in caring for our patients.

Donna Cardillo, RN, spoke Friday, September 25, on the topic YOU Make It Happen. She gave attendees hope and motivation to continue furthering our education, and she encouraged us to share our work with others through writing. I left her inspiring talk with a desire to begin to author articles. She made me feel like I could do anything that I put my mind to.

This year, the breakout sessions were divided into dual tracks. Those who were new to PH could begin the journey of learning about a complicated disease and its treatments, while others like myself who are veterans in the PH field could benefit from more detailed topics.

The poster session, a new addition for this Symposium, provided a boost to our shared PH knowledge. The posters stimulated conversation, and they were an important learning resource for all involved. The posters are a way to empower the members of our professional community to conduct their own research projects, continuing development as investigators in their own right.

I left the 2009 PH Resource Network Symposium rejuvenated and ready to tackle the many difficulties that our PH patients face. Sharing stories with so many diverse people gave me a sense of belonging. Furthermore, my membership in PH Resource Network gives me a lasting connection with all healthcare professionals working with PH, including those who attended Symposium as well as those who were unable to make it this year. I plan to fully take advantage of that connection this year and well beyond.

Barbara Smithson, RN, MSN
Rhode Island Hospital, Providence, R.I.

PHA Online University Goes Live

PHA Online University — www.PHAOnlineUniv.org — launched in October 2009. A website for medical professionals at all levels of experience and expertise, PHA Online University provides physicians and allied health professionals the ability to access the latest information on pulmonary hypertension, engage in networking and discussion with their colleagues and earn free continuing medical education (CME) credits and continuing education units (CEUs). This site is also the new electronic home for Advances in Pulmonary Hypertension, PHA’s scientific journal. Pass the word to your doctors and nurses!
Meet the Nurse: Shiela Bostelman, RN, MSN, CPNP, CCTC

Medical professionals share a commitment to the patient which, together with clinical skill, significantly benefits those under their care. This is particularly important in the field of pediatrics, where the patient-professional interaction extends to the entire family. Shiela Bostelman at Children’s National Medical Center in Washington, D.C., has experience caring for young PH patients and knows how to build relationships with both patient and parent.

Shiela started out as a nurse in the cardiology unit at Children’s National in 1993. Over the next five years, she occasionally found herself caring for children with PH.

“It was a difficult assignment,” she recalls. “During that time, pediatric PH patients had a very poor outlook, with survival in months rather than years.” Flolan™ was developed during her term at Children’s, but at the time, it was only being tested on adults. Shiela left Children’s National in 1998 to work at other hospitals in Florida and Maryland.

In 2007, Shiela received an invitation to return to Children’s National as a nurse practitioner and work with Dr. John Berger to care for pediatric PH patients. She recalls her initial reluctance giving way to excitement: “My encounters with PH a decade earlier were less than encouraging, but I soon learned about the many advances in PH treatment over the past ten years.” She took the job.

“Now in my second year back at Children’s National, I work closely with Dr. Berger and others to treat a wide variety of PH cases,” Shiela says. “Congenital heart defects are the cause of a majority of the PH diagnoses, though we see everything from idiopathic PH to PH associated with Down’s syndrome and scleroderma.” In addition to making rounds with Dr. Berger twice a week, the nature of her work requires tying in with several departments, including neonatal intensive care, cardiac intensive care and heart and kidney unit staff. When treating PH, “collaboration with the whole team is the goal,” Shiela emphasizes.

Interacting with children demands a very different approach than working with adults, and Shiela delights in the challenge. A pediatric patient can be an infant, an adolescent, or anyone in between, and Shiela stresses the need to understand the patient’s level of physical and mental development. “You have to be able to relate to whatever stage they’re in,” Shiela says. She lets young children draw pictures or play with her stethoscope, observing the child’s responses in the process. Tickling and playing with a toddler, for example, allows a child to become comfortable with her and reveals useful information such as palm flushing, fingernail clubbing and shortness of breath. Likewise, getting an adolescent to open up to Shiela requires building rapport with the patient, and a knowledge of teenage slang can be crucial for this step.

Beyond clinic duties, Shiela spends much of her time helping patients, parents and medical professionals learn the ins and outs of managing PH. For school-age kids, she helps parents “educate teachers about the infusion pump, write notes to teachers asking permission to carry water in class and giving warnings about staying hydrated, addressing physical exercise demands and being careful in the heat.” As medical issues arise, such as a routine checkup with the primary physician or a tooth needing to be pulled, Shiela makes sure everyone involved is aware of any special considerations when treating a PH patient.

For further education, and to give patients and families the chance to connect with others, Shiela turns to PHA. “We hook everyone up with PHA right away,” she says. “We get on a computer in the clinic and show what’s available on the website, or we tell parents to go to a nearby library and visit the site and write down any questions they have. By the end of the day, they’re calling or emailing and thanking us.”

Shiela believes that the greatest benefit of her work in PH is the personal growth that her own patients have helped her achieve. “It blows me away. I get paid to play with kids every day, and I love it,” she says. “These kids have given so much back to me. I see so much more hopefulness in these patients that I never saw as a cardiology staff nurse.”

Her parting advice: “Don’t lose that hope.”

By Roice Fulton
PHA Medical Services Program Associate
Prepare Yourself for Emergency Situations

Because pulmonary hypertension is a rare disease, many hospitals, physicians, nurses and emergency medical technicians (EMTs) may not fully understand your condition. Being educated and prepared is your first line of defense in preventing emergencies. Here are a few tips and resources to help you stay a step ahead of an emergency and to help you cope if one does occur.

WHEN IS IT AN EMERGENCY?

Potential Emergencies

Some situations are “potential emergencies” and may not require you to go immediately to the hospital. However, it is important that you call your doctor or clinic and talk to someone as quickly as possible. Give brief and concise information, and answer all questions carefully.

A few examples of potential emergency situations include:

- High or prolonged fever, especially if you have a central line catheter
- Fainting/near-fainting
- Coughing up blood
- Coughing up colored mucus
- Chest pain
- Rapid or irregular heartbeats
- Unusual (for you) shortness of breath
- Unusual (for you) fluid retention
- Dark, tarry stool (if you are on blood thinners such as Coumadin™ or warfarin)

Based on the information you give them, the medical professional may call in a prescription, refer you to another doctor, ask you to come to the hospital, or ask you to hang up and call 911.

Remember — the most important part of dealing with any potential emergency is timely communication of the problem.

Immediate Emergencies

If you are a patient on intravenous medication and your catheter comes out/is cracked or your pump stops working, this is an immediate emergency. Call 911 and indicate that you have a life-threatening emergency.

While waiting for help to arrive, minimize physical activity and put oxygen on if available. For detailed information on what to do while waiting for the ambulance, familiarize yourself with our Emergency Situations tips at www.PHAssociation.org/Patients/WhenIsItAnEmergency or contact PHA by email at Medical@PHAssociation.org. Keep this information on hand in case an emergency does arise.

Keeping a Step Ahead

Help your emergency team and yourself by contacting your EMT/ambulance provider before you have a problem. Most emergency call centers have a database of local individuals with medical conditions, so they can advise EMTs of any special conditions while the ambulance is on the way. Call your EMT/ambulance provider’s non-emergency phone number, which in many areas is 311. Visit www.911dispatch.com/info/311map.html to find out if this service is available in your area.

When you call, share the following information with your emergency responders:

- Diagnosis (PAH) and any other related illnesses/conditions
- Specialty medications you are taking and how you infuse, inject, inhale or ingest the medicine
- Oxygen needs
- If on a central line IV medication:
  - Tell them that you are on a life-sustaining medication with a very short half-life administered by a constant (24/7) infusion pump.
  - EMTs cannot turn off or remove the pump.
  - An EMT may need to start an emergency IV line in your arm if there is a problem with your catheter or pump.
  - Stress that a delay of a couple of minutes can be the difference between life and death.

Make sure to obtain a confirmation of your entry into the system, and keep it on file. Ask how often you need to update the information, and then make those updates whenever you move or change your phone number or whenever your medication changes.

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

DISCLAIMER
The study
The PHIRST (Pulmonary Arterial Hypertension and Response to Tadalafil) trial was a 16-week, double-blind, placebo-controlled study of 405 patients with idiopathic or associated pulmonary arterial hypertension (PAH). These patients were randomized to receive either placebo or tadalafil (2.5, 10, 20 or 40 mg) once per day. Tadalafil (Adcirca™) is a long-acting, phosphodiesterase type-5 (PDE-5) inhibitor that can be taken once daily. Phosphodiesterase is an enzyme that breaks down cyclic GMP. Cyclic GMP (cGMP) is the active agent of the nitric oxide pathway. By inhibiting PDE-5, cGMP builds up, resulting in more vasodilatation of the pulmonary arteries.

Tadalafil was either the first treatment for PAH (treatment naïve) or added to bosentan (Tracleer™) (stable dose of 125 mg twice a day for at least 12 weeks). About half of the patients were already on bosentan. Treatment with any prostanoid (Flolan™, Remodulin™ or Ventavis™) was prohibited.

The primary endpoint of the study was a change in the six-minute walk distance from baseline to week 16. In addition, the researchers looked at changes in World Health Organization Functional Class (WHO FC), clinical worsening and health-related quality of life. At the end of the 16-week study, patients could enter a long-term extension study. To help determine the best dose of tadalafil, patients were randomly assigned to receive either 20 or 40 mg (blinded) during the first year of the extension trial. After the first year was complete, all patients who could tolerate the higher dose were given 40 mg.

Conclusions
The increase in six-minute walk distance with tadalafil was dose dependent, the 40 mg dose reaching the prescribed level of statistical significance (p<0.01) (44 m in treatment naïve patients). A “p” value of 0.01 means that there is less than a 1 in 100 chance that the findings are random (due to chance) and not due to the effects of the drug. Generally, “p” values of <0.05 are considered significant, i.e. the results are not due to chance. Overall, in all patients on 40 mg, the average placebo-corrected treatment effect (treatment group six-minute walk distance and placebo group six-minute walk distance) was 33 meters. Patients on 20 mg increased their walk 27 meters more than those on placebo (p=0.028). For patients who were not on bosentan, the placebo-corrected treatment effect was 44 meters. In patients where tadalafil was added to bosentan (53% of the patients), the placebo-corrected walk distance increased by 23 meters. Patients who were WHO FC III or IV improved more (36 meters, p=0.02) compared to FC I and II patients (24 meters, p=0.04).

Treatment naïve patients taking 40 mg of tadalafil were less likely to get worse (clinical worsening) compared to those in the placebo group. Clinical worsening meant death, hospitalization for worsening PAH, adding a new PAH therapy or worsening WHO FC. In patients where tadalafil was added to bosentan, there was no difference in clinical worsening.

The 40 mg dose also improved quality of life measures; 6/8 domains of the Medical Outcomes Study (MS-36) improved (p<0.01) and all sections of the EuroQol-5D improved (p<0.02). A subset of 93 patients had right heart catheterizations at baseline and at 16 weeks. Both the 20 and 40 mg doses decreased mean PA pressure and pulmonary vascular resistance (PVR), but only the 40 mg dose increased cardiac index (the amount of blood the heart can pump in one minute corrected for body size). There was a trend toward better hemodynamics in treatment naïve patients but the small number of patients did not allow for statistical testing for differences.

All doses of tadalafil were generally well tolerated. Adverse events (side effects) were mostly mild to moderate; the most frequently reported being headache, muscle pain, flushing, nausea, and diarrhea. Adverse events were not significantly different between doses or between the treatment naïve and background bosentan groups. There were no clinically significant changes in laboratory values.

The long term extension trial enrolled 357 patients; 213 patients were on tadalafil for at least 10 months. The mean change in six-minute walk distance at 16 weeks was 37 meters, and at 44 weeks, this was maintained at 38 meters. This suggests that there is long-term benefit beyond the short duration of the placebo controlled trial.

The results of this trial led the investigators to raise several questions. Why did the patients on background therapy with bosentan appear to have less of an effect than tadalafil? Is there a ceiling effect when a second
PAH medication is added? Many PH investigators are now considering other clinical endpoints or biomarkers instead of or in addition to the six-minute walk partly for this reason. With a limited number of PH patients, it is harder to find “treatment naïve” patients for new medication trials. Given the pharmacokinetic interaction between bosentan and tadalafil (via the cytochrome P450 3A4 mediated pathway), would a higher dose of tadalafil be more effective in patients receiving bosentan?

In conclusion, the ability to exercise as measured by the six-minute walk increased in patients receiving tadalafil, and this effect was maintained for at least 10 months. This increase was consistent with the increase seen in other pivotal studies of other PAH medications that are now approved. The optimal dose appears to be 40 mg daily. Quality of life improved even for patients on background therapy with bosentan. The safety profile of tadalafil and its combination with endothelin receptor antagonists and prostanoids should be studied further. The addition of the long-acting, once-a-day PDE-5 inhibitor, tadalafil, to currently approved PAH treatment options is an important clinical advance.

Where to find this article:

Reviewed by Shelley Shapiro, MD, PhD, FACC, Greater Los Angeles VA Healthcare System, David Geffen School of Medicine at UCLA, and Glenna Traiger, RN, MSN, Pulmonary and Critical Care, David Geffen School of Medicine at UCLA

FDA Approves New Intravenous Treatment for PH

In November 2009, the U.S. Food and Drug Administration approved an intravenous form of Revatio™ (sildenafil) for the treatment of pulmonary hypertension. Revatio™ is indicated for the treatment of WHO group I adult pulmonary arterial hypertension patients to improve exercise ability and delay clinical worsening. This is the only treatment for pulmonary hypertension that is available in both oral and intravenous formulations.

Intravenous Revatio™ is administered through a single-use vial with a recommended injection dose of 10 mg (corresponding to 12.5 ml) three times a day. Revatio™ is also available as a 20 mg tablet taken three times a day. The injection is for the continued treatment of patients with pulmonary arterial hypertension who are currently prescribed Revatio™ tablets but who are temporarily unable to take oral medication.

Manufactured by Pfizer Inc., Revatio™ contains the same active ingredient (sildenafil) as Viagra™, which is used to treat erectile dysfunction. Originally released as an oral medication in 2005, Revatio™ is designed to help pulmonary hypertension patients maintain good blood flow between the heart and lungs. For more information visit www.revatio.com.
PH and HHT: What’s the Connection?

As isolating and scary as it can be to have a rare disease like pulmonary hypertension (PH), imagine having a second rare disease with its own set of challenges. That’s exactly what some individuals with pulmonary hypertension and hereditary hemorrhagic telangiectasia (HHT) face.

What is HHT?

**HHT is a blood vessel disorder in which blood vessel abnormalities develop throughout the body that increase with age.** When the large blood vessels are affected, patients develop arterio-venous malformations (AVMs), which typically develop in the lung, liver or brain and can cause bleeding and strokes and induce heart failure. Meanwhile, affected small vessels, or telangiectasias, are commonly found on the skin, nose or gastrointestinal tract and can be quite annoying as well as cause chronic bleeding, leading to iron deficiency anemia.

What causes HHT and how are genes involved?

**HHT is a genetic disorder, meaning it is caused by abnormalities in genes or chromosomes.** Mutations in at least three genes are known to cause HHT: Endoglin 1, ALK-1 and SMAD-4. It is suspected that two other genes on chromosomes 5 and 7 may cause HHT, but this has not been scientifically proven.

Genetic testing plays a large role in diagnosing HHT, and because many HHT patients are not yet experiencing symptoms (90 percent of affected individuals in the U.S. are oblivious to their condition), genetic testing is often used to screen asymptomatic family members. HHT can also be diagnosed on clinical grounds, if any three of four criteria are met: 1) family history consistent with HHT, 2) spontaneous and recurrent nosebleeds, 3) telangiectasias of the skin or oral cavity and 4) internal AVMs.

When do PH and HHT occur together and how are individuals affected?

**PH in HHT is not the same in everyone, and the disease presents in two forms.** In either case, patients may present with shortness of breath and fatigue, but for different reasons. Most commonly, PH in HHT results from excessive blood flow through the lung. This occurs when the pulmonary pressures are modestly elevated (systolic pressure 40–60), cardiac output (amount of blood pumped through the circulatory system each minute) is high and the net relationship between pressure and flow, known as pulmonary vascular resistance or PVR, is normal or low. Over time this can cause the heart to “overheat” and lead to a form of heart failure known as high-output failure, which in turn worsens pulmonary hypertension.

Less commonly, PAH occurs in HHT and is similar to idiopathic pulmonary hypertension (IPAH) or heritable PAH, in which the small arteries of the lung progressively narrow or close off. This causes severely elevated pressure in the lung, decreased cardiac output over time and a high PVR. The incidence of HHT-associated PAH, a WHO Group I diagnosis, is unknown, but non-invasive echocardiography suggests that about 20 percent of HHT patients develop PH during their lifetime. HHT-associated PAH appears to be rare and primarily involving families with ALK-1 mutations.

How is PH-associated HHT treated?

Before treatment begins, it is essential to determine what type of PH exists. This requires a right heart catheterization, which calculates the pulmonary vascular resistance. It is also important to look for excessive blood return to the heart via the liver, which is the usual mechanism for the high-output variety of pulmonary hypertension.

If PH and a high-flow state are confirmed and the PVR is low, then PAH is not the primary issue and does not need specific treatment. PAH medications in this situation may actually make things worse by further increasing the high flow state. Instead, factors contributing to the high-flow state need to be addressed as well as possible (i.e., correcting anemia or possibly liver transplantation). Alternatively, if PH occurs in combination with a low or normal measure of blood-flow and an elevated PVR, patients should be considered for PAH-specific treatments. For these patients, many of the approved PAH-specific treatments have been used sporadically. While these therapies have been successful in individual cases, significant unique adverse effects can occur in HHT patients. Therefore, it is essential that only appropriate HHT patients receive therapies by a specialist.

**STORY CONTINUED ON NEXT PAGE**
If I have PH and HHT, where can I go for help?

Currently, there are 12 specialized ‘HHT Centers of Excellence’ throughout North America. (For a complete list of centers, see http://hht.org) These centers are led by a director and a network of specialists qualified to address the many complex aspects of HHT. At three of these 12 locations, Dr. James Gossage (Medical College of Georgia), Dr. Murali Chakinala (Washington University in St. Louis) and Dr. Karen Swanson (Mayo Clinic in Rochester, Minn.) direct their HHT centers and are also actively involved in the fight against pulmonary hypertension, which provides them with unique insights about these two conditions. If you or someone you know has or may have PH possibly in the setting of HHT, you should seek treatment by a specialist.

Answers provided by Murali Chakinala, MD, Washington University in St. Louis; James Gossage, MD, Medical College of Georgia; and Karen Swanson, DO, Mayo Clinic Rochester

For more information on PHA resources for patients managing multiple illnesses or to join the “PH Plus” email group, refer to the article on p.3 or contact Emma Bonanomni, PHA Patient Outreach and Services Manager, at Emma@PHAssociation.org or 301-565-3004 x777.

Living with PH and HHT, a Patient’s Experience

My name is Christine, and I have pulmonary arterial hypertension (PAH) and hereditary hemorrhagic telangiectasia (HHT). My PAH was diagnosed in November 2006. I knew months before that there was something wrong; I could not physically keep up with co-workers, family or friends. I just assumed that my age (49) and weight (well beyond pleasingly plump) had finally caught up with me. I currently take sildenafil (Revatio™), bosentan (Tracleer™), and as of October 21, 2009, I began taking treprostinil (Tyvaso™) which replaced my iloprost (Ventavis™) and seems to be really working well for me.

HHT is something that has always been a part of my life. Ever since I can remember, my father has had nosebleeds; it was just a part of my family members’ lives. I have had AVMs (arterio-venous malformations) coiled in my lungs and have had to have nasal cautery to help manage my nosebleeds. My father and one of my sisters have been diagnosed with HHT; three of my four other siblings have been screened and do not have HHT. We also suspect that my four-year-old niece has it since she has an unusual amount of nosebleeds for such a young child, and we plan to have her screened when she is a little older.

Living with these two diseases is a challenge. I am still employed full time. I enjoy my job very much though it has evolved in the past three years to accommodate my PAH and HHT. At times my fatigue, which I believe is a combination of anemia from the HHT and just a part of PAH, can set me back. I’m still learning to accept my ‘bad days’ and to enjoy my ‘good days.’ ‘Bad days’ are the days when I can’t seem to muster the energy to get out of bed to go to work or when just getting ready to go to work is so tiring that I consider my 45-minute commute a chance to rest! ‘Bad days’ are also the days when I have the opportunity to babysit my nieces and nephews and have to decline because I just do not have the energy. ‘Good days’ are those days when I feel like my ‘old’ self. I can do normal, simple things like grocery shopping, house cleaning and putting in a good day of work without exhausting myself. With the love of my family, all my days are truly blessed.

By Christine Fini
PH and HHT Patient
What Have We Learned About PAH from Genetics?

Ten years ago we knew very little about the underlying causes of pulmonary arterial hypertension (PAH). We knew that certain conditions were associated with PAH, such as congenital heart disease or connective tissue disease, but in the absence of these associated conditions, the cause of idiopathic PAH remained a mystery. It had been known for many years that severe PAH could occur in families. The NIH registry in the 1980s established that approximately 10 percent of patients with PAH have at least one other affected family member. Study of family pedigrees of patients with PAH established that males and females could both be affected and that the disease could skip generations. This latter finding was very important. It means that a family member can carry the disease gene without actually developing PAH and the disease could then manifest in their children or grandchildren. If a parent carries the disease gene then the chances of passing the gene on to each child would be 50:50. Because the disease gene does not inevitably cause PAH, the risk of a child developing PAH if he or she inherits the disease gene is usually less than 50 percent. And if a child inherits a normal copy of the gene their risk of developing PAH is the same as the rest of the population, in other words, about a million to one.

So what is this disease gene? In 2000, two groups of researchers independently identified mutations in a particular gene in families with PAH. A mutation is a mistake in the DNA genetic code. Since the genetic code is used to make a whole range of proteins in the body, if a mutation occurs, the protein may not work properly. In familial PAH, mutations were identified in the gene responsible for making a protein called the bone morphogenetic protein type 2 receptor, or BMPR2 for short. At least 70 percent of families with PAH have these mutations. This important receptor is usually found on the surface of cells, which make up the tissues and organs of the body. Like other receptors it transmits signals from the outside to the inside of cells to instruct them to divide or die, or change from one type of cell to another. As its name suggests, BMPR2 belongs to a family of receptors that were originally identified as playing a role in the formation of bone and cartilage. However, we now know that BMPR2 and related receptors have a much wider role in embryonic development and formation of many organs, including the heart and lungs. The sort of mutations found in BMPR2 in families with PAH lead to reduced function of the protein. Without the power of genetic studies such as these it would have taken years and years, or a lucky accident, to discover that BMPR2 was involved in PAH. Here, suddenly, we were presented with the most important part of the puzzle to understanding the underlying cause of familial PAH. Indeed, having identified mutations in BMPR2 in the rare familial form of PAH, studies have now shown that abnormal BMPR2 function is also a feature of other forms of PAH, for example in idiopathic PAH.

It is now nearly 10 years since the discovery of mutations in the BMPR2 gene in familial PAH. We have made much progress in understanding what happens when the BMPR2 gene is mutated. There are still many questions to answer. For example, why does a mutation in such an important gene cause a disease confined to the blood vessels of the lung? And what additional triggers are required to cause PAH in an individual carrying the mutant BMPR2? Ultimately, knowing the answers to these questions may allow us to prevent or treat the disease.

When should patients or relatives consider being tested for the BMPR2 mutation? In general if you have a family history of PAH, that is if there are at least two members of your family with PAH, it is highly likely that a BMPR2 mutation is the cause. At present we do not have any specific way of preventing the disease in someone carrying the disease gene so knowing you have the mutation will not alter the chances of developing it. At the same time, if you don’t have PAH and you are found not to have a mutation, this may be reassuring. If you are found to have a BMPR2 mutation, this may have consequences for life insurance and, of course, for your children. Whether or not to get tested and what to do with this information is a complex area that varies with individual circumstances. Your pulmonary hypertension physician may be able to give further advice on this and would likely recommend speaking with a clinical geneticist to discuss the implications of genetic testing.

For further information see: [www.PHAssociation.org/AboutPH/Genetics](http://www.PHAssociation.org/AboutPH/Genetics)

By Nick Morrell, MD, Professor of Cardiopulmonary Medicine, University of Cambridge, United Kingdom
Putting the Personal in Personal Fundraising Pages

How often have your friends or family members asked, “How can I help?” when learning that someone they care about is living with pulmonary hypertension? Pretty often we would guess.

We know that answering that question can be hard, but PHA’s Web of Friends offers a solution. By using Web of Friends to invite your friends and family to support you, you can raise awareness about PH and raise funds for PHA services and/or research. PHA has harnessed the power of the Internet to help you take your story across the country — or around the world — in just minutes.

As you read the stories below, you’ll see how easy Web of Friends campaigns can be, with each fundraiser adding his or her own personal twist to the program.

Steve White, a PHA board member, was looking for a way to mark his 60th birthday and recognize what would have been his daughter Christen’s 30th birthday. Christen passed away from PH in 2002, and Steve saw an opportunity to honor her memory. “At the beginning of 2009, I became painfully aware of my upcoming 60th birthday,” Steve says. “I wanted to channel my friends’ and family’s desire to celebrate the milestone into something that would provide a lasting benefit outside of presents.” And thus, the “60/30 Virtual Birthday Party” (www.firstgiving.com/stephenwhite) was born. “The fundraising page was a great opportunity to tell Christen’s story, raise awareness about PH and allow my friends and family to get involved with very little effort,” Steve says. “It was actually kind of fun!”

Doreen Lucadamo, a PHA staff member and daughter of PH patient Roberta Granai, had her interest piqued when she saw Steve White’s personal fundraising page. In the weeks leading up to her birthday in 2009, Doreen sent her own Web of Friends page out to friends and family. “A personal fundraising page seemed like such an easy way to engage my loved ones in an organization that was important to me,” Doreen says. Doreen had particular success promoting her fundraising page on her Facebook page. A few times a day Doreen would update her status encouraging her Facebook friends to donate to her cause. Everyone from her real estate agent to a childhood camp friend got involved. “People donated five, 10, 15 dollars or more, and it really made a difference,” Doreen says.

Larry Fox was looking for a way to get involved during PH Awareness Month in November 2009. His wife Judy was diagnosed with PH in 1998, and they have been involved with PHA ever since. After finding Web of Friends on PHA’s website, Larry thought that this was a “no brainer” way to get involved, he says. “We can’t find a cure without the dollars,” Larry says. “I wanted to do something that would further the cause.” As an incentive to help encourage friends and family to donate, the Foxes decided to do a drawing for a new iPod® to those who gave at least $10 to their fundraising page. “I wanted to spur on donations,” Larry says. “But I also wanted to give something back to those who were helping out.”

Since PHA’s first year using personal fundraising pages, members have raised more than $200,000 online and generated much more offline! Every donation makes a difference.

Whether you’re still deciding to do a Web of Friends campaign or you’re ready to get started, PHA is here to help! We can assist you at every point in this process, and we have a few tricks up our sleeve that we’d like to share to help you with your campaign. Contact Giving@PHAssociation.org or call Jillian at 301-565-3004 x767.

By Jillian McCabe
PHA Associate Director of Development

Steve White’s daughter, Christen

Doreen (right) with her mother

Larry and Judy Fox at PHA’s Rochester, Minn., Gala

By Jillian McCabe
Sustainers Circle Donors Celebrate 5 Years of Giving

Pulmonary hypertension never takes a break. That’s why PHA fights day-in and day-out in our search for a cure and why we maintain a host of programs that make a difference in the lives of patients, their family members and the medical professionals who treat them.

In 2005, PHA began the Sustainers Circle, a program that invites donors to make easy, secure donations to PHA each month on their credit cards. The Sustainers Circle currently has more than 90 donors making automatic monthly gifts, and eight donors will celebrate their 5th anniversary with the Sustainers Circle in 2010.

Gary D. Stacy donates to PHA for a very personal reason: he has chronic thromboembolic pulmonary hypertension, also known as CTEP. “I support PHA so I can help educate patients who are like me,” he says. “I like that PHA reaches out not only to patients, but also to the general public to raise awareness of PH.”

Amanda DaSilva wrote a winter 2007 Pathlight article about her sister, Melanie, and the ease of giving back to PHA each month through a Sustainers Circle donation. “When Melanie was diagnosed in 1998, there seemed to be little or no information available,” she says. “I remember finding PHA and being so thankful that this resource existed.” When Amanda found the Sustainers Circle, she signed up right away. “What a great way to contribute every month,” she says, “and you don’t even have to remember to send that check!”

Freda Scott does remember to send that check — and has been sending one each month for the last five years. Freda, who is a PPH patient, feels more comfortable giving by check, and PHA is very grateful for her monthly support. “There are a few organizations I give to each month,” she says, “and as a patient I especially appreciate what PHA does for us and our caregivers.”

Lilian Leung makes her monthly gift in honor of her son, Terrance, a 10-year-old PH patient. Lilian is active on the PHA discussion boards and enjoys the camaraderie with other PHers. “It’s so easy to give each month on my credit card,” she says. “I don’t have to remember to make a donation that does so much for so many.”

Jane P. Cooper was diagnosed with PH in 1998. While the prognosis for patients in 1998 was not positive, Jane has remained upbeat and involved in a variety of PHA programs. In addition to being a Sustainers Circle donor, Jane is also a Helpline volunteer, and she and her husband Harold are members of the Legacy of Hope Society. “I feel it is important to give back to causes you are passionate about,” Jane says. “It puts everything in your life in perspective.”

Gale L. Perkins, who is a PH patient, started giving through the Sustainers Circle because her local United Way would not designate her payroll donations to PHA. Gale has directly benefited from many PHA programs and services, especially when she was very sick with severe PH in 1998. “My gift may not be huge,” she says, “but I have to be part of finding a cure and educating others, and giving through the Sustainers Circle allows me to do that.”

Janice Persson was featured in a winter 2009 Pathlight article on the Sustainers Circle. Janice makes her monthly donations in memory of her husband, Lawrence, who passed away in 2004 after battling PH for more than 10 years. “It’s still a cause I hold near and dear,” she says, “and I look forward to seeing progress be made, to improve the lives of current patients and to one day find a cure. Being connected to PHA keeps me updated about research and progress.”

Lisa Wheeler, MT, was featured in a winter 2008 Pathlight article about her connection to familial PH patients. Lisa coordinates a study at Vanderbilt University Medical Center on familial PH and for the past five years has made her monthly Sustainers Circle donation in the honor or memory of some of the patients in the study. “I give through the Sustainers Circle because it is the easiest way for me to support an organization that provides so much for so many with PH,” Lisa says.

Sustainers Circle donors give for a variety of reasons. They realize the power their monthly donations have in providing hope and support to patients, raising awareness, funding research for a cure and advancing our legislative priorities. All so that one day, there will be no such thing as PH and, until then, every patient has access to essential information, resources and support.

Interested in learning more about the Sustainers Circle? Contact Jennifer by calling 301-565-3004 x756 or emailing JenniferK@PHAssociation.org.
Empowered by giving

We’ve just come through the time of year when people experience the pleasures that come with generosity. If you’ve already supported PHA’s 2009 end-of-year campaign, thank you! But if you haven’t yet — and are feeling the urge to be generous — there’s still time to do so. And there are several good reasons why you should:

* You’ll help ensure that PHA meets Pfizer’s matching gift challenge. For the first $22,500 raised from the campaign, Pfizer will provide PHA with a dollar-for-dollar match.

* You’ll receive our inspiring and hope-filled 2010 calendar. This is not a generic calendar, but a beautiful representation of the specific ways our community is empowered — through Community (January), Courage (April), Advocacy (November) and in nine other ways. Curious about the other months? Send your donation today to PHA’s end-of-year campaign and receive your calendar before it’s time to turn the page to February.

* You’ll be making so much possible for so many. Our ability to provide programs and services depends in large part on those who benefit from them. As you read the pages of this Pathlight, think about all the ways your money is put to work — from support groups to advocacy to new patient services — and how important it is to keep our offerings available for everyone who needs them.

Giving doesn’t just feel good — it’s easy to do! You can:

1. Donate online at [www.PHAssociation.org/donate/eoy](http://www.PHAssociation.org/donate/eoy)
2. Note EOY on the inside of the envelope attached to this Pathlight and return it with your check or credit card information.
3. Call 301-565-3004 x756 or x767 to make a donation over the phone.

INCLUDE 100,000 FRIENDS IN YOUR WILL.

A legacy gift to the Pulmonary Hypertension Association will not only expand our fight to defeat this condition, it will be your ongoing expression of support to the people and families bonded together in their struggle against this disease.

Your legacy gift can be established in a number of ways — each designed to maximize various financial and tax benefits, according to individual needs. Your personal financial consultant should be involved with your estate decision.

Personal contributions represent a major source of funding for PHA as we advocate for new PH research, raise awareness within the medical community and provide patient support. Your legacy donation will be the gift that keeps on fighting.

Contact us to find out about the ways that PHA can be included in your estate plans. Call us at 301-565-3004 x767 or email at Giving@PHAssociation.org. Visit our website for more information.

[www.PHAssociation.org/Give](http://www.PHAssociation.org/Give)
Friend Climbs for a Cause and a Cure

Iain Hess, age 9, and Matt Moniz, age 11, have known each other for as long as they can remember. “Since we were born,” Matt says. These old neighbors became fast friends from an early age and that friendship now continues into their adolescence.

While their young friendship mirrors others of similar ages, there is one big difference. Iain Hess has been living with pulmonary hypertension since the age of 5. “Iain experiences shortness of breath, fatigue, dizziness and many other symptoms,” John Hess, Iain’s father, says. “It’s hard for others to understand what he experiences on a daily basis.”

To help raise awareness about PH and support for Iain’s expensive treatments, Matt Moniz decided to walk in Iain’s shoes. Beginning July 10, 2009, Matt and a core team of five climbers (including Iain’s dad John, sister Olivia and Matt’s father Mike) climbed fourteen of Colorado’s famed 14,000-foot peaks, commonly known as the “14ers,” in a short fourteen days. This breathtaking endeavor gave each of the climbers a first-hand sense of the breathlessness that a patient with PH experiences every day.

With 71 miles and 41,201 vertical feet to cover, wake-up calls starting as early as 2:30 a.m., and challenging weather conditions to navigate, the team climbed each day with purpose. “Each day we would meet other people on our climb,” Matt says. “Each meeting was an opportunity to educate people about PH.”

Fellow climbers weren’t the only ones to sit up and take notice of this expedition. After a local newspaper featured their climb, eight other media outlets picked up the story including a national spot on the CBS Early Show. This national attention allowed Matt to reach out to those who did not know about PH as well as those who did. “I got many emails from PH patients who had seen the story,” Matt says. “They thanked me for all I was doing and were excited about using high altitude conditions as a metaphor for the symptoms of living with PH.”

Since his climb, Matt has continued to raise awareness for PH even working to have a congressional resolution entered into record to recognize the team’s efforts in the fight against PH. “Next year we have to find something that is just as powerful as the 14ers climb,” Matt concludes. “We want to keep helping Iain and other PH patients.”

By Jillian McCabe
PHA Associate Director of Development
Behind the Scenes: Meet Our Insurance Volunteer

Carol Morrison, Terryville, Conn.

What is your connection to PH?

I was diagnosed with primary pulmonary hypertension in 2002 when I found myself in an emergency room due to shortness of breath. Six days later I was told I had pulmonary hypertension.

What type of insurance industry experience do you have?

I worked for 15 years for a large insurance company in Connecticut before I became ill with PH. I held many positions within the company over the past 15 years, from claim payment to medical review. My last job was manager of an advocacy department handling executive office and Department of Insurance complaints.

How did you get involved with PHA’s Insurance Advocacy and Education Program?

Once I was feeling better, my daughter and I started going to PH conferences. I learned so much about my illness, treatments, and things I can do to have the best quality of life possible. At all the conferences we went to, I would hear people asking questions about insurance coverage for medication or other treatments they needed in order to manage their PH. My daughter would always say to me, “Mom, you should tell them about your insurance experience. I think you could help people with insurance problems.” I finally took my daughter’s advice and contacted PHA in August 2009.

What types of projects are you working on at PHA?

I have been working with PHA’s Insurance Advocacy and Education Program, helping to monitor the chats/boards for any questions or concerns regarding insurance coverage. I have also been developing educational material on how to file a Department of Insurance complaint. The material includes tips on what information to include when you file a complaint as well as a template letter.

Can you tell us some more about yourself?

I believe we will stay healthy if we have a good attitude, keep busy, volunteer where and when we can, and praise God for each day He gives us. I did not think I would be here one year after my diagnosis, so to be here seven years later is just unbelievable and wonderful. My doctor always tells me, “Carol, you are doing so well.” I always have hope and I shoot for the stars when it comes to finding a cure.

Have Insurance Experience? Want to Help Other PH Patients with their Insurance Problems?

We are looking for experienced volunteers to be part of our Insurance Advocacy and Education Program.

If you have experience working for or with private insurance companies, Medicare, Medicaid, Social Security Administration or other types of insurance organizations, put your knowledge to use at PHA.

Contact Margaret at 301-565-3004 x773 or Margaret@PHAssociation.org for more information on how you can get involved.
PH Advocates Make Lobbying a Year-Round Phenomenon

I am so glad I went that day to Capitol Hill, I learned a lot from my colleagues on how to present and be a part of the action. I look forward to going again!

~ First-time Advocacy Day participant
Sherry Duveneck, BSN, RN

A few years ago, PHA began the District Visit Campaign to provide resources and support to advocates who wanted to visit in person with their Members of Congress during the Congressional recess in August.

The District Visit Campaign is still going strong, but now PH patients, family members and medical professionals are connecting face-to-face with their Members of Congress year-round and building support for the Tom Lantos PH Research and Education Act as they go. Many of these individuals are members of PHA’s 435 Campaign, which engages PH advocates in building relationships with their senators and representative.

Here’s how they advocate:

Support Group Meetings

Rep. Virgil Goode sent his district representative Judy Mattox [to our support group meeting]. She reported on the status of the PH Research and Education Act and the Ending the Medicare Waiting Period Act, then listened while group members educated her about living with PH.

~ Susan Temple, PH patient and 435 Campaign Member

Participating in Town Hall Meetings

I have attended several town hall meetings, and I always have an advocacy folder (which PHA provides) to pass on to the Congressperson or Senator ...

At some town hall meetings you are required to sign in if you want to ask a question. At that point I hand the Congressperson or Senator the folder, say one sentence about the importance of the bill and ask that they co-sponsor H.R. 1030.

~ Merle Reeseman, PH patient and 435 Campaign Member

Visiting Local Congressional Offices

I first got involved with advocacy when my support group leader asked me to go with her and a few other group members to meet Senator Burr.

I was really nervous sitting there. I was intimidated by his desk and all his pictures with the president and so on. Then, I looked down — he had no socks on! In my head I laughed. Then I relaxed and realized he was human. Yes, he has a position of authority and can help us, but he wasn’t wearing socks!

~ Diane Ramirez, PH Patient and 435 Campaign Member

On Capitol Hill

Stake-outs aren’t just for the movies! Though it’s always a better idea to plan in-person legislative visits in advance, on a recent trip to D.C., my wife Marina, my son Lucas and I made an impromptu stop at our senator’s office. We patiently waited in the lobby until one of her health advisers gave us the opportunity to advocate for the PH community.

~ Steve Van Wormer, PH Parent and 435 Campaign Member

Each of the events described above resulted in new support for the PH community and the Tom Lantos Pulmonary Hypertension Research and Education Act, but there is more to be done! For information about connecting with your senators and representative in any of these ways, contact Katie at 301-565-3004 x749 or Katherine@PHAssociation.org.

By Katie Kroner
PHA Director of Advocacy and Awareness

www.PHAssociation.org
November is an exciting time in the PH community. All across the country, PH patients are busy raising money for research, telling their stories to local media, getting proclamations and doing many other activities that spread the word about PH during Awareness Month. We did amazing things together last November, and we’re sure to continue building on our success in 2010!

The following are the reflections of four PHers who dedicate themselves to raising awareness of PH. Together, the time they commit to our cause makes a tremendous impact in our work toward a cure:

I raise awareness of PH because it gives my life purpose. If I can provide hope to only one person and their family who may be experiencing the helplessness I felt until I was correctly diagnosed with PH, then the efforts have all been worthwhile. I do it because of the continual misdiagnosis or non-diagnosis of the disease; people are dying unnecessarily. I know it is only through awareness and education that we will see a change and, hopefully, a cure in my lifetime.

~ Carol Lindstrom, leader of the Nebraska/West Iowa PH Support Group

Carol got proclamations declaring November PH Awareness Month from the Mayor of Bellevue, Neb., and the Governor of Nebraska. Her efforts were highlighted in a story in her local newspaper, the Bellevue Leader.

What did we learn? We learned that people want to help and support causes that touch those they know and love. We learned people will help, donate, and share their experience and expertise if you just ask! We learned that hard work yields terrific results.

~ Trish Duque and Amy Moseley (pictured above, L to R), organizers of the annual Spur A Cure for PH special event in Arizona

When we meet with our Congress members face to face, they learn about us personally and remember PH, its symptoms and how drastically it will change your life when you are diagnosed. Meeting face to face helps get the process moving. When anybody asks about our meetings and if they should try, I say go for it. The worst that can happen is that you won’t get a meeting, but you will still be able to talk to someone about PH and still spread awareness.

~ Diane Ramirez, member of the 435 Campaign and Advocacy Chair of the Piedmont PH Support Group in North Carolina

By Nathan Barker
PHA Advocacy and Awareness Associate

A Community Empowered by Hope Moves to Action During Awareness Month

PHAware Campaign members raise awareness through the media in many ways. Some tell their stories and others publicize their support groups and special events. Now, with new PHAware Campaign tools, PHA can help you share information about PH and even promote your event on the radio!

Order the free PHAware Campaign Public Service Announcement Toolkit to start raising awareness on the radio in your area. The toolkit includes:

- A PSA Media Guide with step-by-step instructions for contacting radio stations and submitting or writing a public service announcement (PSA).
- PHA Press Kits with information on PH to leave with members of the media.
- A CD with four pre-recorded PSAs for playing on the air or just for inspiration.

Contact PHA at 301-565-3004 x753 or email Awareness@PHAssociation.org to get started.
Young PHers Raise Awareness and Share their Lives with StoryCorps®

Members of the PH community show phenomenal creativity and dedication for raising awareness of pulmonary hypertension. Sixteen-year-old Rachel Mumby and twenty-year-old Camille Frede — both PH patients — remind us that all generations of PHers share an equal commitment to building community and persevering over pulmonary hypertension. Camille writes emails to young, newly diagnosed patients and both girls raise awareness online through Facebook and MySpace. Last October, Rachel and Camille got a once-in-a-lifetime chance to share their PH stories with StoryCorps®, the nonprofit organization that travels the country recording and archiving the stories of everyday Americans.

Like so many others in the PH community, Rachel and Camille were brought together by PH. An Accredo nurse introduced them, and they have been friends ever since. When StoryCorps® contacted Camille’s mother Nancy asking for Camille to share her PH story, Camille teamed up with Rachel to make sure they had the greatest impact together.

On October 12, 2009, Rachel and Camille visited the traveling StoryCorps® studio — a converted Airstream trailer — to record their stories. They shared their journeys through diagnosis, provided information on PH and offered suggestions to other PHers on how to live fulfilling lives with this disease. “Doing StoryCorps® was an amazing experience and opportunity,” says Rachel. “I’m glad that Camille and I were able to share our stories. I hope that we’ve helped people by doing it.”

Raising awareness of pulmonary hypertension is just one element of the often complicated lives of PH patients, but for Rachel and Camille, raising awareness is an important one. “We know that other kids can hear our stories and not feel alone,” says Camille. “And it helps for us to know that others deal with PH just like we do.” Rachel adds, “The PH community must stick together to get the word out, and hopefully one day we’ll find a cure.”

Visit www.PHAssociation.org/OurJourneys to listen to clips of Rachel and Camille’s StoryCorps® interview. Rachel and Camille’s interview will be archived in the American Folklife Center and the Library of Congress in Washington, D.C. Their stories are also eligible for broadcast on National Public Radio. For more information on StoryCorps®, visit www.StoryCorps.org.

By Nathan Barker
PHA Advocacy and Awareness Associate

Empowered by hope — a PHA diary

New from PHA’s President,
Rino Aldrighetti
— looking at the PH community from a unique perspective

http://pharino.blogspot.com/
Two brothers from New York will donate proceeds from their new children’s book to PHA — and the environmentalist authors aren’t even out of middle school yet. Abhinav and Ankoor Talwar, sixth- and seventh-grade students respectively, recently wrote The Children’s Garden, a story about how nature and innocence can stop destruction motivated by greed.

Selfishness certainly doesn’t seem to be a motivator for Ankoor and Abhinav, who plan to split the profit from the book’s sale between their school garden and PHA. The boys were inspired to support PHA by their father, Dr. Arunbah Talwar, who treats PH patients and leads the New Hyde Park (NY) Support Group.

Ankoor and Abhinav’s father was also the inspiration behind the project itself. The Children’s Garden began as a bedtime story that Dr. Talwar often told his sons. Together, Ankoor and Abhinav decided to turn their father’s bedtime story into a book that other children could appreciate.

The story shows how humans’ greed harms nature. When a farmer notices how much the neighborhood children enjoy playing in his garden, he decides to profit by charging admission. Because the kids can’t afford entry, they stop visiting the farm and the garden’s beauty fades. When the farmer accidentally leaves the gates open one day, the children slip inside and revive the garden.

Writing The Children’s Garden was the latest of several projects Ankoor and Abhinav have undertaken to foster environmentalism among youth. The boys have also supported a public garden at a nearby school. By tending the garden as a community, students can learn about natural science and caring for the environment.

Ankoor and Abhinav, who plan to be doctors when they grow up, have already begun work on their second story. They chronicle their academic and community service projects on their website www.globalprojecthope.com where you can also find information on how to obtain a copy of the book.

By April Grimsley
PHA Web Assistant

Let’s CLIMB the Path to a Cure!

As you’re reading this article, two PH specialists and PHA Scientific Leadership Council members, Drs. Ray Benza (Allegheny General Hospital) and Robert Frantz (Mayo Clinic), as well as Jessica Lazar, PA, (Allegheny General Hospital) are training for the ultimate challenge — climbing Mount Kilimanjaro, Africa’s highest mountain!

Their goals are universal — raise global PH awareness and demonstrate to others what it means to be truly breathless. In addition to their goal to reach the mountain’s 19,330-ft summit on February 26, the medical professionals also set a fundraising goal of $100,000 to support PHA’s research programs and patient and family services.

But they can’t do it without your help! Here’s how to become an informed and important part of the trek:

• Visit www.PHAssociation.org/PathToACure and learn the back-story to Drs. Benza’s and Frantz’s efforts. Connect to their blog, which contains training updates and thoughtful reflections.
• Visit www.firstgiving.com/pathtoacure and donate to their cause. The Actelion Path to a Cure Matching Fund will match the first $50,000 in donations.

Attend or volunteer at a Unity Walk near you. Help build local PH awareness and financial support. As we go to press, the following groups have signed up to host Unity Walks. For a more up-to-date listing, visit www.PHAssociation.org/PathToACure

- Piedmont PH Support Group (Piedmont area, N.C.)
- South Orange County PH Support Group (Orange County, Calif.)
- Pittsburgh PH Support Group with support from the Allegheny General Hospital Cardiovascular Institute (Pittsburgh, Penn.)

“No, we don’t have the cure yet, but … we just have to push hard enough, be dedicated enough, climb over every obstacle, and keep pushing just when we feel like sitting down. Kind of like climbing a mountain. And kind of like living with PAH.”

~ Dr. Frantz
More than 52 pulmonary hypertension support groups met during PH Awareness Month. That meant that almost every day in November a patient somewhere in the country experienced that moment of relief that comes from meeting another patient for the first time and finally finding someone who understands what it’s like to live with PH. Patients came together in support group meetings to get and offer advice, to support others, and to learn from medical professionals and other experts about PH and living with the disease.

You are not alone! More than 216 groups meet frequently across the country and even more groups meet around the world. Here is a sampling of the topics, speakers and activities that occurred during Awareness Month support group meetings this past November:

**Topics:**
- Parents and Families of PH Patients (Boston, Mass.)
- Understanding the Right Heart’s Role in PH (Hershey/ Harrisburg, Penn.)
- A Look at PH from a Pulmonary View (Morristown, N.J.)
- Oxygen Therapies and Exercise (Santa Barbara, Calif.)
- Living Wills and Advanced Directives (Charlotte, N.C.)
- Social Security Disability Programs, Work Incentives: How will work affect my benefits? (Houston, Texas)
- Insurance (Mobile, Ala.)
- Meet a PH Specialist (Bryan-College Station, Texas)
- “I’ve been told I have PH. What can I expect?” (Green Bay, Wis.; Anchorage, Alaska)
- Scleroderma with PH (Toledo & Northwest Ohio)
- Chair Yoga (Upstate, S.C.)

**Activities:**
- PH Jeopardy! (Pittsburgh, Penn.)
- 10 Year Anniversary Holiday Party! (West L.A., Calif.)
- PH Bingo and Prizes (Treasure Valley, Idaho)
- Awareness Tables (South Orange County, Calif.)
- Medical Professionals Appreciation (Long Island, N.Y.)

At least 17 groups offered medical education with healthcare professionals speaking about PH at meetings. Thanks to the advocacy efforts of our groups, dozens of local, county and state proclamations were issued to officially designate November as PH Awareness Month. This includes a South Carolina coalition of support group leaders who worked to secure 12 proclamations. Support groups organized fun walks, galas and other fundraisers, and many more set up educational tables and exhibits in hospitals, medical centers, malls and public spaces to raise awareness and educate about PH. Many leaders and their members worked to raise awareness by telling their stories to the media.

We can’t thank our support groups and their leaders enough for these activities promoting education, support, advocacy and awareness!

By Debbie Castro
PHA Director of Volunteer Services

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We Salute a Retiring Support Group Leader!

One of our veteran support group leaders is stepping down after 17 years co-leading the Houston PH Support Group. Angie Eldam is a transplant survivor who wants a PH patient, directly affected by the disease, to be involved in the leadership of the group. We salute Angie for her years of dedication and leadership in the PH Community!

Angie tells us, “I feel I need to concentrate more on my transplant and diabetes. I will NEVER forget my PHamily!”
Building a Movement, One Support Group Meeting at a Time

A patient originally from Puerto Rico but now living in Texas attended PHA’s 8th International PH Conference in Houston and noticed that there was no support group or organization for residents of Puerto Rico. Although Evelyn Crespo lives in Texas, she travels frequently to Puerto Rico and contacted PHA almost immediately after Conference to determine what steps she should take to organize a group there.

Since that time, two groups have formed for Puerto Rico. One is headed by patient leader Mineliz Colon and her doctor, Dr. Héctor Stella-Estevez. This group — known as the Caparra Wellness Center PAH Support Group — has already held two meetings for patients in the area. A second group for patients is led by Evelyn along with patient Luz Batista-Santiago, Luz’s caregiver and husband Ricardo, and their PH-treating doctor, Dr. Alvaro Aranda, from the region’s Auxilio Mutuo Hospital. Thanks to the people fueling this new pulmonary hypertension community, Puerto Rico now has its first PH Center for the comprehensive treatment of patients, scheduled to open in January 2010.

Not only does the Puerto Rican PH community work together to organize patient meetings, but it is already raising awareness, advocating for PH inclusion in Puerto Rico’s healthcare insurance, and securing official government proclamations declaring November as PH Awareness Month.

One of the largest efforts during Awareness Month was a rally and exhibit at the Plaza Las Americas, the biggest shopping center in the Caribbean. For 12 hours on October 31 and six hours on November 1, the support group led by Evelyn, Ricardo and others set up a booth to draw attention to the disease for the approximately 60,000 people who walk through the Plaza daily. Ricardo and Luz prepared special shirts, brochures and banners to draw even more attention in this high traffic shopping area.

This group also uses Facebook to organize its patients, and as we go to press, this online group boasts 161 members with postings and photos listed frequently. Group co-leader Luz was selected as the Blue Lip Idol for PHA-UK’s global “Pucker Up for PH” campaign, which has generated attention for her story and the growing movement of patients in Puerto Rico.

PHA boasts a network of more than 216 support groups, but we still need to expand into areas that don’t have groups and in areas where patients must travel a distance to find other patients. What does it take to go from Evelyn’s observation that “there are no groups here” to this now vibrant and growing network? For ideas and support, contact PHA’s Director of Volunteer Services, Debbie Castro, at 301-565-3004 x755 or Debbie@PHAssociation.org — it can be done and we can help you!

By Debbie Castro
PHA Director of Volunteer Services

The support group in Puerto Rico led by Evelyn, Ricardo and others.
Patient Drives 300 Miles Round Trip for Support Group Meetings

Patient Keith Lisonbee and his wife and caregiver Judy live in Green River, Wyo., and three times in 2009 the couple made the 300-mile, round-trip drive to Riverton, Wyo., to attend the meetings of their nearest support group.

According to support group leader Nancy Stearns, “Their loyalty to the group humbles me and keeps me motivated.” She and co-leader Cricket Mitchell work hard to make each meeting educational, informative and supportive, and the quality of the meetings motivates Keith to continue to make his 300-mile journey. “The speaker — or the individual giving the presentation — is giving me good insight in terms of how PH affects me or how it can possibly affect me,” he says. Speakers for the group have included Dr. David Badesch from the University of Colorado Hospital and Dr. Kishore Yalamanchili from Amarillo, Texas.

Our goal at PHA is to ensure that no patient has to drive more than three hours to attend a support group meeting. For some parts of the country like Alaska, Wyoming and South Dakota, organizing patients is challenging. With no PH clinic and smaller, spread out populations in general, one support group typically serves patients sprinkled throughout a large area. In these situations, leaders do their best to bring great programming and speakers so that patients like Keith who drive the distance get the most out of their trip!

All Ages Turn Out for First Meeting of the Pee Dee Region Support Group

The Pee Dee Region South Carolina PH Support Group held its inaugural meeting Saturday, September 19, at Carolinas Hospital System in Florence. We had an outstanding turnout of approximately 20 people, including PH patients, friends and family members.

The first meeting was a “Meet and Greet,” and most were new to the support group experience. Everyone had the opportunity to introduce themselves and share their connection to the PH community. It was amazing to see the wide range of situations, ranging from those newly diagnosed to some who had been living with PH for eight years or more. There was also a wide age-range, from teenagers to seniors.

After an overview of how other PH support groups in South Carolina function, everyone shared their ideas for future meeting topics. We discussed PHA and distributed PH literature. We looked through *Pulmonary Hypertension: A Patient’s Survival Guide* and created a lending system to share this awesome resource.

We discussed PH Awareness Month, and Midlands Support Group Leader Doug Taylor outlined a challenge to all of us to have local governments proclaim November as PH Awareness Month in each county in South Carolina.

We covered a range of topics, and overall, the first meeting went very well. The turnout was PHenomenal. We hope that future meetings will be even more informative and helpful as we discover the needs of our local PH community and look for ways to meet those needs.

Article submitted by Heather Settlemyre
Pee Dee Region South Carolina PH Support Group
April graduated from George Mason University in May 2009 with a B.A. in communication. Her concentration was journalism, but she realized during her senior year that she’d rather put her writing, editing and web skills to work in the nonprofit sector. As she says, “I’m having a great time at PHA!” During her time as an intern, April assisted with the website redesign, wrote articles for PHANews and Pathlight, and published and distributed PHANews to the PH community. When her internship ended in December, April joined PHA’s staff as Web Assistant to carry on her work with the website redesign. She will continue in this position through February.

Laura Gil González, International & Marketing Intern

As a Spanish journalist currently living in the D.C. area, Laura joined PHA’s International and Marketing departments to help with outreach to the Spanish-speaking population within the PH community, both within and outside the United States. Laura has been involved in translating a variety of materials, assisting with the redesign of the En Español section of the website, and performing research on the unmet needs of Spanish-speaking constituents. This experience has provided her with valuable knowledge on the impact that language barriers can have on the emotional support of the Hispanic PH community in the U.S. She hopes this project enables her to further her professional goals in the U.S., which merge health communication and Hispanic outreach.

Zahra Haleem, Medical Services Intern

Zahra graduated from the University of Maryland in May 2009 with a B.S. in Neurophysiology. During her time at PHA, she was responsible for reaching out to past and present research grant award winners and tracking their progress and future plans in research. She attended a number of events including the PH Resource Network Symposium and Congressional Luncheon. Of her internship, Zahra says, “My time at PHA has been a more rewarding experience than I could have ever imagined. Not only did I learn a lot about PH and meet with numerous PH patients, I was able to work with a group of people who truly support the cause.” In the spring, Zahra plans to attend George Mason University to pursue a Masters in Public Health with a concentration in Health Administration.

Welcome, Patti Lalley, Special Projects Assistant!

As Special Projects Assistant, Patti will work in the Office of the President on special projects related to the PHA Board of Trustees and Corporate Committee. Prior to joining PHA’s staff, Patti completed two internships with PHA. She served as the Nonprofit Management Intern in fall 2009 and Special Events Intern in spring 2009. Of her experiences at PHA, Patti says, “I have truly learned so much, grown my professional skills and experience, and have enjoyed the camaraderie I feel from the PHA staff. I am proud to be a part of an association that not only funds research, but also educates our community to learn more about this terrible disease.” Patti can be reached at 301-565-3004 x774 or by email at Patti@PHAssociation.org.

PHA wishes to thank our fall 2009 interns. These individuals eagerly joined our team and, through their commitment and determination, have made a real impact on the programs and services PHA is able to provide. To learn more about PHA’s internship program, visit www.PHAssociation.org/Internships.
On November 7, the St. Louis, Mo., Support Group hosted its inaugural St. Louis Support Group/Wine Tasting Fundraiser. Held in a modest venue on the outskirts of the city, the event made its mark on the regional community with nearly 180 participants and keynote presentations by Carl Hicks, PHA’s Board Chair, and Dr. Murali Chakinala of Washington University. The event raised approximately $8,000 for PH research and patient and family services.

Amanda McKee, St. Louis Support Group leader and primary event organizer, emphasized that the fundraiser was a “true group effort.” This teamwork resulted in a tasty buffet-style dinner, keynote presentations to raise PH awareness, a wine tasting provided by a local family-owned winery, a silent auction boasting nearly 50 items, a swing band and dancing, and plenty of fellowship.

With the dinner and wine tasting, the support group was able to meet its three primary goals, which they collectively set when event planning began in January of 2009: awareness raising, education and fundraising. While guests represented the full spectrum of the PH community — support group members, friends and family of patients, those newly diagnosed, coworkers, PH-treating physicians, pharmaceutical representatives, and nurses and research coordinators from local PH clinics — Amanda emphasized that Carl’s and Dr. Chakinala’s messages resonated with each guest, breaking down barriers while raising awareness and providing the latest on advances in the field of PH.

“In the end, everyone walked away with a good feeling,” Amanda says. “It was due to the combination of all three components. People were saying to one another, ‘Come meet my friends and family!’ It was a great opportunity to see and relate to everyone outside the scope of support group meetings.”

Inspiration for planning the fundraiser came from a young boy named Gage, the support group’s first pediatric PH patient member, and his family. “[Their] joining the group sparked a lot of energy and enthusiasm that wasn’t there before,” says Amanda. Gage’s family proposed the idea of the fundraiser and offered the services of their family winery. “They gave us the opportunity to go for it, and it was too good to pass up!”

With the support group on board, the focus switched to forming a planning committee. Group members each had unique skills to offer, and they “matched people to tasks and gave people the space to go out and accomplish them,” Amanda says. This sort of group empowerment increased focus and commitment to success.

While the entire group was responsible for ticket sales, individual members headed up planning elements such as print materials, public relations and media outreach, and organizing the silent auction. All group members contributed items for the auction.

“The fundraiser gave us a chance to prove ourselves to the community and create a greater local presence,” says Amanda. She believes fundraisers that heighten PH awareness also keep the door open for continued community involvement. As a direct result of the evening, several newly diagnosed patients and others previously unconnected with the PH cause were exposed to local patient community support, making the effort more than worthwhile.

Special thanks to Bob and Gwen Zamberlan, Alicia House, Shirley Green, Bill and Christy Victor, the Bardenheier family, Carson Smith, Chris Fini, Pat Fischer and the St. Louis PH Support Group.

By Jessica McKearin
PHA Special Events Manager

In her own words... 
Amanda shares tips with fellow organizers and those interested in future event planning:

- PHA holds many local events each year. Ask them to connect you with a mentor who has hosted similar events, and you can benefit from their past experiences.
- Organize your planning committee and your day-of volunteers early in the planning process. Assign responsibilities to trustworthy individuals and match tasks to strengths.
Fall was a busy time for special events. Check out the photos on this page and the next to see what’s been going on.

**Cure PH Casino Night** — An evening of success was “in the cards” for the “Cure PH Casino Night” in Phoenix, Ariz., on November 7. The event raised more than $21,000 for PH research and services. Participants each received a stack of chips to try their hand at craps, roulette and blackjack — and friendly competition ensued!

**Race Against PH** — A few members of Team Hernandez pose in their “Flolan Man” T-shirts, a crowd favorite at the “9th Annual Race Against PH” in Palo Alto, Calif., on November 1. On race day, patient Dennis Hernandez received the 1st PH Impact Award for his dedication and support of fellow patients. The event had over 1,500 in attendance and raised more than $75,000, which will directly support PHA, the Vera Moulton Wall Center patient programs and the Ewing Family Fund for PH Research at Stanford.

**Baltimore Fun Walk** — A crowd of 125 enjoyed the early November sunshine at the “Baltimore PH Walk for Hope” at Camden Yards on November 7. In addition to patient, family and caregiver representation, PH Centers at Johns Hopkins and the University of Maryland, support groups (pictured: the Capitol Breathers support group walk team) and PHA staff participated in the event.

**Through Tears Comes Laughter** — Dr. Terry Fortin (Duke University Pulmonary and Respiratory Medicine) presents at the inaugural “Through Tears Comes Laughter” event in Charlotte, N.C., on October 24, in honor of PH patient Scott Chippendale. Friends and family shared laughs at a variety show with featured performances by comics Michele Balan and Kurt Green.
SPECIAL EVENTS

NY Fun Walk for a Cure — Patient Sarah Peek and PHA President Rino Aldrighetti appear here at the “5th Annual New York Fun Walk” in East Meadow on October 3, which raised more than $62,000 for PH research. About 375 people attended. Many attendees were part of large walk teams that set fundraising and awareness-raising goals.

Georgia Fun Walk — PH patient and event organizer Sally Maddox (top row, fourth from left) gathers with her friends and family at the “6th Annual Georgia Fun Walk” registration area on October 10. Over the years, this event has raised more than $60,000.

CurePH Texas Legacy Golf Tournament — On Oct. 2, Jim Wilson, tournament director and husband of PH patient Debbie Wilson (both pictured left), hosted 63 golfers at the Bridlewood Golf Club in Flower Mound, Texas. In addition to golf, festivities included auctions, raffles and a buffet dinner of Texas barbecue. Sponsors included United Therapeutics, Actelion, Pfizer, Accredo Therapeutics, TEVA Pharmaceuticals, CuraScript, Gilead and Caring Voice Coalition. Local companies fielding teams and lending their support included the Fred Allen Group, Encore Bank and Trust, University of Texas-Southwestern Medical Center, Johnson Medical Associates and Gardere Wynne Sewell.

Thank You, Awareness Month Sponsors!

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www.PHAssociation.org PATHLIGHT WINTER 2010
Sat., January 23, 2010
3rd Annual A Cure for Five Pennies
WHERE: Schaumburg, Ill.
DETAILS: Denise DeGuzman at 847-967-2934 or www.freewebs.com/cureforfivepennies

Fri., February 19 — Fri., February 26, 2010
Path to a Cure: Drs. Benza and Frantz and Jessica Lazar, PA, Climb Mount Kilimanjaro
WHERE: Tanzania, Africa; Unity Walks across U.S.
DETAILS: Call 301-565-3004 x758; visit www.PHAssociation.org/PathToACure; email pathtoacure@PHAssociation.org

Sat., March 27, 2010
The Woodlands Crawfish Festival
WHERE: The Woodlands, Texas
DETAILS: msaul@stibbsco.com or 281-367-2222

Sat., April 17, 2010
2nd Annual Scramble for a Cure
WHERE: Las Vegas, Nevada
DETAILS: www.scramble4acure.com or Jack Nino at 702-250-2214

Sat., April 24, 2010
4th Annual Spur a Cure for PH
WHERE: Phoenix, Ariz.
DETAILS: www.cureph.com or Amy Moseley at 602-885-191 or Trish Duque at 602-369-4376

Mon., June 28, 2010
2010 Swing 4 the Cure — Wojo PH Golf Classic
WHERE: Dana Point, Calif.
DETAILS: www.swing4thecure.us or Betty Lou Wojciechowski at 949-215-1573

Sat., October 23, 2010
2nd Annual “Through Tears Comes Laughter: An Evening of Comedy and Music to Benefit PHA”
WHERE: Charlotte, N.C.
DETAILS: Glenn Johnson at gajohnson1214@yahoo.com

Sun., November 7, 2010
10th Annual Race Against PH
WHERE: Stanford, Calif.
DETAILS: Email vjoven@stanford.edu or visit http://wallcenter.stanford.edu/community/ph.html

Sat., November 13, 2010
2nd Annual Arizona Cure PH Casino Night
WHERE: Phoenix, Ariz.
DETAILS: Contact Wendy Bockhorst at 480-219-4327 or wbockhorst@cox.net

For more special events coverage, visit www.PHAssociation.org/SpecialEvents

To view a complete and up-to-date listing of PH events, visit www.PHAssociation.org/EVENTS

Add these events to your calendar now and be prepared for PH events all year long!
What I’m Looking Forward to at the 2010 Conference:

- Nearly 60 education sessions for patients and caregivers led by medical professionals, patients and caregivers.
- More networking opportunities, including pre-conference meet-up sessions and the Thursday evening Patient & Caregiver Meet-and-Greet.
- New support group meetings including groups for young adults, teens, families and those with associated conditions such as scleroderma.
- Streamlined registration process for participation in the Research Room.
- More educational opportunities for our healthcare professionals, especially the new nurse coordinator session.

and learn new nuggets of information on PH parenting in the pediatric support group, I also found hope in the most unlikely of places — the hotel pool.

One night, while winding down in the pool after a full day of sessions, I witnessed a small, yet remarkable, moment that still moves me to this day. I watched a young boy with a pump swim laps in his custom made “drysuit.”

I eyed a young girl, who also used a pump, as she watched him swim in wild wonder. I was amazed at her excitement when that boy let her take a dip in his “drysuit” — something she had never had the opportunity to do up until that moment. To me, moments of connection like that are what Conference is all about.

Shortly after that last Conference, I was asked to serve on PHA’s Board of Trustees. I am humbled and honored to be part of this PHA community. I have since put a majority of my efforts into Conference planning for 2010. Together with the dedicated efforts of the PHA staff and the dozens of devoted volunteers, we are working to create a weekend of memorable moments that will add up to an unforgettable experience for all in attendance. I look forward to meeting everyone in California as we ride the wave to a cure together!

By Steve Van Wormer, PH Caregiver, 2008 Recipient of a Julie Hendry Memorial Scholarship Award, 2010 International PH Conference Communications Subcommittee Chair, PHA Board Member
10 Reasons to Attend PHA’s 9th International PH Conference and Scientific Sessions Riding the Wave to a Cure

1. **You will be a part of the largest PH gathering in the world!** PHA expects more than 1,300 people from 20 nations made up of patients, caregivers, families, doctors, researchers, nurses and allied health professionals.

2. **You will catch a highly contagious case of the “Me toos!”** You have had that happen to you? ME TOO! People say that to you? ME TOO! With special programs for newly diagnosed patients, families of children with PH, young adults, caregivers, and people with associated illnesses, Conference is your chance to meet people who understand just what you’re going through.

3. **You will learn, learn, LEARN!** The Conference will provide educationally rich programming designed by renowned medical professionals, experienced patients and caregivers to teach you everything and anything about living and working with PH.

4. **You will teach, teach, TEACH!** At Conference, everyone has something to share; we are each other’s best teachers and mentors. By attending the patient and family led breakout sessions and the support group meetings, you can share your experiences with PHers just like you!

5. **You will make friends!** Many Conference attendees have never been to a meeting like this before. PHA’s Conference Buddy System can pair you with another patient, caregiver or family member so you have someone to catch up with during breaks and meals.

6. **You can contribute to research for the PH cure!** You can participate in the Research Room at Conference by helping PH researchers collect valuable information, and you can participate in a number of PH-specific studies and registries. This information is vital to researchers to help find a cure for PH.

7. **You will smile!** PHA offers many exciting programs along with educational sessions, including the highly popular PH Fashion Show, the “Journeys” Luncheon, children’s room and field trips for kids and young adults.

8. **You will clap until your hands hurt!** PHA recognizes outstanding members of the PH community at Conference. These highly deserving individuals — including outstanding volunteers, medical professionals, patients and caregivers — are honored for their many contributions to the PH community.

9. **You will be in California!** Many Conference attendees will travel to Conference this year. With a little planning and coordination with your medical professionals, travel is possible even with PH. PH will not hold you back from enjoying sunny California!

10. **You will testify!** There are many ways to tell others about Conference — why you are attending, why others should attend too, and what you’ve learned. You can participate in our “Journeys to Conference” program, post photos and comments to Facebook, tweet on Twitter, post videos to YouTube and much more.

Visit the Phenomenal Youth section on page 47 to participate in the 9th International PH Conference Kids Mascot Naming Contest.
Inspiration comes in many forms: a friendly welcome from a stranger, a new life lesson learned from a son, the open arms and ears of a friend, the unconditional love of a brother. Inspiration comes in many forms and according to those who knew him, Mason Hoffman embodied them all.

Mason was 21 at the time of his death from pulmonary hypertension this past June. Despite his young age, Mason was a source of support and knowledge for other PH patients. Friends describe Mason as a young man who simply looked life straight in the eye and never blinked. It was this attitude that made him an integral part of the support system within the PH community. Dr. Thomas Mahrer, one of Mason’s physicians, describes him as always optimistic: “He was bright, he was intelligent and he was emotionally and psychologically strong despite [his physical] deterioration.”

As an active participant in PHA’s online community, Mason provided friendship and insight to PH patients — both newly diagnosed and long-term survivors. When another patient was in need of encouragement, Mason was there with, what some refer to as, his “Masonisms.” Mason’s commitment to assisting other PH patients was so innate that even as he struggled during the last few days of his life, he took the time to respond to emails from other patients seeking his advice.

One of Mason’s strongest messages was to make each day count. Mason completed high school at the age of 16 and went on to attend community college. He was an accomplished athlete, including water sports, skiing, golf and motocross racing. Mason also completed enough in-flight hours to qualify for a pilot’s license. When Mason’s health kept him indoors, he channeled his seemingly limitless energy into family Monopoly® tournaments.

In 2008, Mason saw PHA’s 8th International PH Conference in Houston, Texas, as an opportunity to meet many of his online friends in person, and he applied for financial assistance through the Conference Scholarship Program. According to his father, Dale Hoffman, Mason was excited when he received a scholarship to attend because it offered him the opportunity to continue to make a positive impact in the community. While at Conference, Mason called his father each day happily sharing news of old and new friends. When Mason arrived back home to Arizona, he was elated; Dale recalls, “It was truly a great experience for him.” Those people who had the opportunity to meet Mason at Conference in 2008 say they count themselves lucky to have known him.

After Mason’s passing in June, his family and friends discussed ways to honor Mason’s memory. Dale credits his son for being a strong influence in his own life, “From the time Mason was very young, I learned many things from him. It was quite amazing … to be inspired by a young lad just starting to grow up.” In that spirit, with funds from Mason’s life insurance policy, Dale Hoffman generously established the Mason Hoffman Memorial Scholarship Fund, which will enable two young adult PH patients (ages 18-30) to attend the 2010 International PH Conference without financial burden. The fund will support additional young adults at future conferences.

Laura Hoffman, Mason’s older sister, describes her brother as a special person who became an extraordinary person when illness struck. Mason was brave, strong and caring. He has been called wise beyond his years, determined, optimistic, gracious, humorous, handsome and a true gentleman. He was an inspiration to family, friends, doctors and strangers alike. Through the Mason Hoffman Conference Scholarship Fund, Mason’s strong spirit will be passed on to two young adult recipients who will have the opportunity to attend PHA’s 2010 International PH Conference. It is the Hoffman family’s hope that these recipients will see firsthand the generosity and fearlessness Mason inspired within the PH community, and that others will follow in Mason’s compassionate footsteps.

For more information about the Mason Hoffman Conference Scholarship Fund, contact Jennie Carman at Jennifer@PHAssociation.org or 301-565-3004 x743.

By Jennie Carman  
PHA Conference Scholarship Coordinator
associations make a crucial difference in the lives of PH patients, families and medical professionals. More than 50 associations worldwide work daily to lobby their governments for change, promote and fund research, raise public awareness, and offer emotional and informational support to those touched by PH — just as PHA does here in the U.S.

This June, we’re inviting the leaders of those associations to California for a day-long International Leaders’ Summit, which will create opportunities to develop relationships, enhance skills, and identify and strategize priorities in the global fight against PH. This event will take place on June 24, one day prior to the official start of PHA’s 9th International PH Conference and Scientific Sessions in Garden Grove, Calif. If you’re thinking of coming to Conference, this year’s event will be the perfect chance to meet PHriends from abroad and learn about the PH community in other parts of the world! For more Conference information, see p.1.

It’s just one more way to ensure that no one needs to face PH alone. To learn more, call Christine at 301-565-3004 x760, email Christine@PHAssociation.org or visit www.PHAssociation.org/Conference.

By Christine Dickler
PHA Associate Director of International Services

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**Monthly e-Learning Events**

**www.PHAssociation.org/Classroom**

**Attend PH Educational Events from the Comfort of Your Own Home or Office**

Online Q&A Chats, Conference Call Discussions, and Webinar Presentations

**Upcoming Events**

**January**  PHA’s 2010 International PH Conference: What to Expect
February  Tour PHA’s New Website with Webmaster Diane:
  **Finding All Your Old Favorites & Learning What’s New**
February  State of PHA — an Annual Update from PHA President Rino Aldrighetti
March  Traveling to PHA’s 2010 International PH Conference
April  PH Treatments & What’s on the Horizon

**Newly Posted Archive Recordings**

Healthy Eating: Tips for the Holiday Season
Staying Positive with PH: Maximizing Your Quality of Life
Starting the Year off Right: Exercise Tips for Staying Healthy

Send feedback or suggestions for topics to PHA’s webmaster Diane at Web@PHAssociation.org or 301-565-3004 x759.

PHA’s monthly e-Learning Events series is made possible through unrestricted educational grants from Pfizer Inc.

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In 2008, 14 countries were represented at PHA’s International PH Conference.
PHA’s Redesigned Website Debuts in January 2010

It’s here! PHA’s website has undergone a major overhaul from the design to the navigational structure, and we are happy to announce it’s live online for you to visit. We’d like to thank the hundreds of PHers who filled out our community survey about changes they wanted to see, our website guru volunteer John Hess and the numerous volunteers from the community who helped us test the site before launch. Given the importance of PHA’s website in providing you, the PH community, with education and informational resources, community connection and ways to get involved, this was a labor of love. Enjoy!

When you visit www.PHAssociation.org, you will see...
As you click around, you will find...

**PATIENTS** | **CAREGIVERS** | **MEDICAL PROFESSIONALS**

We have new site navigation that makes it easier to find what you’re looking for, including clear sections to go to depending on whether you’re a patient, caregiver or medical professional.

**My Account**

You will be able to update your contact information, manage your email subscriptions and check your membership status.

**COMMUNITY**

Our online community section includes new discussion boards, dynamic support group sites, and more special interest email groups to choose from.

**CAREGIVERS**

The new site has much more content for caregivers, including those for parents of children with PH, with more in development.

**RESEARCH**

We have enhanced our research section with a news feed about the latest research developments, ways to get involved and updates from PH specialists about what’s in the pipeline.

**WHAT’S NEW?**

You will be able to quickly see the latest news and information about the PH community, PHA events, new materials online and the latest research towards a cure.

**PATIENTS** | **CAREGIVERS**

Newly Diagnosed
About PH
Find a Doctor
Living with PH
PH Kids
Young Adults with PH
Associated Diseases
Insurance Resources
Education Programs
Research & Clinical Trials
Resources
News & Information

All of our materials about pulmonary hypertension, from diagnosis and treatment to managing your medications and travel, are located in just two sections – **About PH** and **Living with PH**. We have new sections for kids and young adults with PH and patients managing other diseases along with their PH.

**MAKE YOUR VOICE BE HEARD.**

Pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness. Learn More

The site features a fresh, new design using bright colors (which you’ll see online!) and lots of photos and videos to reflect the vibrancy of the PH community.

**EMAIL UPDATES**

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You can easily share information and resources with the click of a mouse via email, Facebook or other social networking services. Sign up for email updates to stay in the know or subscribe to our new RSS feeds on a number of topics, with more in development.
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Pulmonary Arterial Hypertension Symposium
February 27, 2010
University of Miami Hospital
Coral Gables, Fla.

The Alfred P. Fishman Conference: Right Ventricular Structure and Function in Health and Disease
April 9-10, 2010
University of Pennsylvania School of Medicine
Philadelphia, Penn.

4th Annual Pulmonary Hypertension Symposium: Updates on Classification and Therapies
June 3, 2010
Yale School of Medicine
East Haddam, Conn.

Thank you to our 2009 Building Medical Education in PH Partners:

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Questions? Call the PHA Office at 301-565-3004.
Camille Frede, Youth Editor
ponyforme@comcast.net

WE WANT YOUR IDEAS!

This PHA surfer, the mascot for PHA’s 9th International PH Conference and Scientific Sessions, needs a name!

You could win...

A PHA PRIZE PACK!

Just send us...

* Your Name
* Your Age (Must be 15 or younger to enter)
* Your City and State
* How you are connected to PH:
  * I am a patient
  * I have a sibling with PH
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  * Other
* Your name for the mascot

Email your suggestions to
Conference@PHAssociation.org

or write to
PHA Mascot Contest
801 Roeder Road, Suite 400
Silver Spring, MD 20910

Contest winner will be announced at Conference!

PHA would like to thank Leslie Polss, PH patient, for her creative contribution to this year’s International PH Conference by bringing the theme, Riding the Wave to a Cure, to life.

Visit PHA on Facebook!
PHA’s Facebook page is a place for you to make friends, share information, and stay up to date on the latest from PHA. We invite you to join the conversation. Check out our page at www.facebook.com/PulmonaryHypertensionAssociation and click “Become a Fan” to join in.
Interview with PH Patient

Ryan Michaels

Interview conducted by Mira Kruger
PHA Pathlight Volunteer

Where do you live?
I live in Chester Springs, Pennsylvania.

How old are you?
I'm 12 years old.

When were you diagnosed?
I was diagnosed June 29, 2009, when I had a heart catheterization to check on things with my heart.

When did you first start having symptoms of PH?
Luckily, I've never experienced any symptoms of PH. I ended up getting PH as a result from my congenital heart disease.

When were you diagnosed with the congenital heart disease?
I was diagnosed at birth with Tetralogy of Fallot with Pulmonary Atresia.

What activities do you do?
I like to do a lot of things. I ride my bike, wave board, play baseball and basketball, and play video games.

Have you ever felt unable to do things because of having PH?
I don’t really feel like I’ve missed out on anything or been restricted from doing anything because of PH. My heart defect keeps me from doing contact sports and tons of sit ups and pushups, but that’s okay with me. I have a lot of other activities that I can do, so I’m not disappointed with the things I can’t do.

How has your life changed since your PH diagnosis?
Certain things have changed since I’ve been diagnosed with PH. I have to take more medicine and have to go to more doctor’s appointments with more tests. I have a great doctor at the Children’s Hospital of Philadelphia, Dr. Hanna, and a great nurse practitioner, Steve Walker, who really take the time to explain things to me and are doing their best to make sure I can keep on doing everything I love to do.

What is a message you’d like to pass on to other kids with PH?
My message to other kids with PH would be to not let PH take over your life. It can be a scary thing to think about but so is a really hard math test or tryouts for a sports team. It’s not the end of the world. I know that if I continue to go to my doctor’s appointments and take my medicine, then I can look forward to having a long, happy life.

We Want to Talk to You!

If you are a young PH patient and want to be featured in an interview, please contact Megan at Megan@PHAssociation.org or call 301-565-3004 x754.
Navigating the 504 Plan: What Parents of PH Patients Need to Know

Children and teenagers who have pulmonary hypertension face a variety of challenges related to their illness. They often miss school because of doctor’s appointments, symptoms of the disease and side effects due to medications. Frequent absences can cause major disruptions in a child’s learning. In addition, student patients might have physical difficulties negotiating their school environment. Families of children with chronic illnesses can get help through their schools to maximize their child’s education.

Section 504* is a civil rights law that applies to public and private schools that accept federal funding guaranteeing “equal access” to educational programs and activities for students with disabilities. Students who meet the definition of a person with a disability are those who have a physical or mental impairment which substantially limits one or more major life activities; have a record of such an impairment; or are regarded as having such an impairment.

Children diagnosed with PH are eligible because PH is a chronic health condition. Once a student is found to be eligible under Section 504, parents and school staff meet to create a written document (a 504 Plan) detailing the services and accommodations to be provided. Older children with PH might need expanded accommodations that are specific to the demands of middle and high school. These demands often include: changing classes throughout the day, traveling through large buildings, carrying multiple heavy textbooks, etc.

Below is an example list of 504 Plan accommodations created by the family of a teenage PH patient and the school staff serving that student. Accommodations related to field trips and substitute teacher notification might be helpful for younger children with PH as well. Keep in mind that a 504 Plan can be modified at any time during the school year.

**Classroom accommodations in a sample 504 plan for a high school student:**

1. Assignments may need to be shortened or excused due to absences. Extra time may be necessary to prepare for tests and complete assignments. Student or her parents will request these accommodations as needed. In addition, the student may have additional time on in-class and standardized tests when requested.

2. Student may need to access the restroom several times during class, due to medications. Please accommodate her requests.

3. Student may leave class early or arrive to class late.

4. Student is capable of determining what she needs and will communicate those needs to her teachers. All requests related to her illness or side effects are reasonable and should be granted.

5. In situations where student is not feeling well, teachers or staff need to check to make sure she is all right.

6. Substitute teacher lesson plans will include information about student’s condition and needs.

7. The Attendance Secretary will notify her teachers’ substitutes of student’s condition OR contact the nurse, administration or counselor to alert the substitute.

8. At the beginning of each year, all teachers, office staff and support staff will be informed of student’s condition and needs.

9. Prior to each semester, a meeting will be held to review student’s schedule in order to pre-enroll her in classes.

10. Student will have two sets of books, one for school and one set for home.

11. Student is excused from all Physical Education graduation requirements.

12. Coverage on field trips will be arranged between parents and teachers.

In addition to the accommodations that are officially covered in the 504 Plan, other school arrangements include: assigning a locker in a central location; having a classmate in each class selected ahead of time as a designated helper in case there needs to be an escort to the office or check-in in the restroom; having access to teacher email accounts to help efficiently communicate modification needs for assignments/tests and to inform teachers of upcoming planned absences.

*Section 504 information: U.S. Department of Education www.ed.gov/about/offices/list/ocr/504faq.html

Article submitted by the parent of a teen PH patient
PASSAGES is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

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The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x762 or Amanda@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

IN MEMORY OF

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TAKE A LOOK! Sustainers Circle Members Recognized

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

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**PATHLIGHT & PERSISTENT VOICES SUBMISSIONS**

The Spring issue deadline is February 6, 2010.

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

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**PATHLIGHT & PERSISTENT VOICES**

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**PATHLIGHT ROUNDTABLE**

PHA thanks the Pathlight Roundtable volunteers for their guidance and contributions to this issue of Pathlight.

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Ensuring patients have the financial resources necessary to attend PHA’s 9th International PH Conference requires a comprehensive effort from the entire PH community. PHA staff members (pictured below) have done their part by establishing the PHA Staff Scholarship Fund. Through their own personal fundraising efforts, PHA staff members have raised more than $1,900 — enough to support one full patient scholarship and cover the registration fee for three additional patients. Now it’s your turn! Find out how you can help by visiting

www.PHAssociation.org/Conference/Scholarships

PHA Staff Helps Patients Get to Conference

PHA has overhauled our website from the look and feel to the organizational structure of the navigation. Take a tour of the new site with PHA’s webmaster Diane to see where all your old favorites are and to learn about what’s new.

Sign up for the tour at

www.PHAssociation.org/Classroom

TOUR PHA’S NEW WEBSITE – FEBRUARY 2