PH Awareness Month 2010: 
Climbing Toward a Cure

As PH-treating medical professionals Dr. Ray Benza, Dr. Robert Frantz and Jessica Lazar, PA, climbed Mount Kilimanjaro, they faced shortness of breath, altitude sickness, syncope and exhaustion. They also found beauty along the way and received lots of support from fellow climbers and the PH community who organized Unity Walks in support of the climb. When they reached the summit, they knew they’d accomplished something worthwhile, including increasing worldwide awareness of pulmonary hypertension.

When it comes to raising awareness about PH, Kilimanjaro isn’t the only mountain to climb. Sixteen years ago PH was one of more than 7,000 rare diseases for which there were no treatments. Today, there are 400 FDA-approved treatments for 200 rare diseases. Thanks to the work of PH community members like you, seven of them are for PH. We’ve climbed a long way, but we have further to go. PH patients often see multiple physicians before finally receiving a correct diagnosis.

Every PH patient and caregiver has a mountain climbing story to tell — from their diagnosis journey to insurance challenges, from travel with oxygen to living with difficult side effects. When you’re alone, the climb can feel impossible but it gets easier with the support of the PH community.

STORY CONTINUED ON PAGE 22

See Highlights from Conference 2010!

PHA’s 9th International PH Conference and Scientific Sessions was the largest gathering of PH patients, caregivers and medical professionals ever. Read all about it starting on p.45 or visit www.PHAssociation.org/Conference
More and more I have come to admire resilience. Not the simple resistance of a pillow, whose foam returns over and over to the same shape, but the sinuous tenacity of a tree: finding the light newly blocked on one side, it turns in another….

From “Optimism” by Jane Hirshfield

I appreciate this opportunity to share my sister’s journey with you as the content for my first letter as Board Chair. Losing her to pulmonary hypertension is what brought me to this cherished community, but the tenacity of her spirit is what keeps me here.

On February 11, 1970, I became a big sister to my only sibling Rachel Suzanne Hoyt. Born prematurely, she relied on tubes and machines to sustain her tiny life. My parents were told that it was unlikely she would survive her first night. However, her strength and will to live emerged then and persevered through the remainder of her life. At age 10 she was diagnosed with portal hypertension following a massive esophageal hemorrhage. After fighting these battles, my insightful, intelligent, beautiful and compassionate sister was finally ready to begin her life — we were unaware that portal hypertension could lead to another, even more serious condition.

For years Rachel had experienced shortness of breath upon exertion, but she was repeatedly told by several physicians that she was out of shape and simply needed to exercise regularly. In August of 1993, a routine physical revealed a heart murmur and a “precautionary” EKG was scheduled. At age 23, my sister was sassy, full of life and unafraid. Thus, she went to her follow-up appointment alone where she learned that although further tests were needed, she likely had something she had never heard of, and that she should plan to make the most of the rest of her life — approximately six months.

Although her journey was extremely difficult, Rachel accepted her diagnosis with grace coupled with a fierce fighting mentality. I share this portion of Rachel’s journey as a tribute to her strength, but also to encourage those living with PH to take advantage of the support that exists through PHA to avoid the lonely battle my sister fought years ago. I learned firsthand that patients living with PH and their caregivers must become highly knowledgeable about their disease and function as their own advocates when needed. For example, I was ignorant about PH-appropriate emergency procedures, and was therefore unable to successfully advocate for my sister when she was admitted to a medical facility whose providers knew nothing about PH. With the resources currently available through PHA, this journey need not be repeated.

Like the tree that resourcefully obtains what it needs for sustenance, Rachel embodied the qualities of optimism and resilience that allowed her to navigate life’s twists and turns up until the moment she took her last breath on January 19, 1995. Her final words were, “I want my sister.” I have uttered the same words countless hundreds of times since, and I guess somewhere along the way uninvited resilience was again born — the resilience which creates a knowledge that, “Something positive can come from this tragedy and … I will make it.”

You do not have to look far to see examples of this same optimism and resilience in your own lives. It is these qualities that will propel us forward to the cure — both in what we do as individuals and in how we touch others.

In loving memory of Rachel Suzanne Hoyt and in celebration of the resiliency that surrounds us,
PH Diagnosis Spurs Sisters to Get Connected and Use Their Talents

At first, Colleen Brunetti thought she was out of shape after the birth of her son, Aidan. Then she developed pleurisy, a painful inflammation of the membrane surrounding the lungs. When doctors x-rayed her to look for signs of pneumonia, they found an enlarged heart instead.

On January 2, 2008, two weeks after her initial visit to the emergency room, Colleen was diagnosed with PH.

Colleen’s younger sister, Caitlin Downs, heard the news three days after she moved away from home to start a new job at a camp. The words “pulmonary hypertension” meant little to her, but the rest of the diagnosis — “high blood pressure in the lungs that could lead to heart failure” — left Caitlin not knowing what to think. How could this be happening to her sister? What could she do about it?

The first six months after Colleen’s diagnosis were the hardest. Misinformation about PH was all over the Internet, and Google searches led to frightening and inaccurate results. Colleen wondered how she could raise her son and if doing so would even be possible.

Fortunately, Colleen soon discovered PHA’s online discussion boards, which provided answers to her questions. Although few PH patients lived near Colleen, she found a friend through PHA and uses the Internet to keep in touch with her.

Just as importantly, Colleen and Caitlin began to find ways to fight back.

For Colleen, fighting back meant getting involved with PHA. A year ago she joined Generation Hope, PHA’s virtual support group for young adults with PH, in order to connect with others in her demographic. She’s now part of Generation Hope’s advisory board, along with Lindsay Nicol, Brittany Riggins and Sean Wyman. The group manages Generation Hope’s discussion boards and comes up with activities for young adults with PH to support and enjoy.

Last November, Colleen started a blog for PH Awareness Month. The response she received encouraged her to keep it up. Blogging is both cathartic and exhausting for Colleen, who hopes she can use her experiences to raise awareness and help people with the same issues.

Caitlin also wanted to help. Despite their 10-year age difference, she and her sister had always been close growing up. PH drew them even closer together. Caitlin started driving four hours every month from New Hampshire to Connecticut to visit Colleen and help with Aidan. She wanted Colleen to know that she would always be there to talk to her.

But Caitlin wanted to do something more, so this summer she started Amharc Photography. Through Amharc, she combines hobby and mission by selling her photographs and donating the proceeds to PHA. The idea, she says, came out of the blue.

“[Amharc] was a total shock to me,” Colleen says, but adds that she’s proud of her sister for putting her gifts to use.

Amharc gives Caitlin a stress-free opportunity to pursue her photography interests. She takes and sells photographs of landscapes, animals and people (including little Aidan), among other subjects. The word “amharc” is Irish for “vision,” reflecting Caitlin and Colleen’s Irish heritage.

Caitlin’s tip for awareness-raising is simply this: “Use something you’re passionate about.”

“I never thought [photography] would be more than a hobby,” Caitlin says. “I’m excited to see where it will go.”

More than two years have passed since the initial shock of Colleen’s diagnosis, and Colleen can say, “I’m feeling much, much better than I probably should.”

Not only that, she and Caitlin have found ways to make a difference through their talents — for each other and for the PH community.

Visit www.AmharcPhotography.org to view Caitlin’s photo gallery and purchase her prints. Follow Colleen’s blog at www.seaglass79.wordpress.com or read her story in Our Journeys: www.PHAssociation.org/Journeys/Colleen

By Amanda Martin
Former PHA Publications Intern

PATHLIGHT FALL 2010  Patient-to-Patient Support Line: 1-800-748-7274 3
Mother Works to Get Insurance Companies, Hospitals on Same Page

My daughter Kendra was diagnosed with pulmonary hypertension in the summer of 2006 right after her seventh birthday. Earlier this year, Kendra’s pulmonary hypertension specialist at Seattle Children’s Hospital told us that her PH was getting worse; she wanted Kendra to be evaluated for a lung transplant. Seattle Children’s Hospital does not do lung transplants, and we were referred to Stanford in Palo Alto, Calif.

I had no idea how to get this approved through Blue Cross and Medicaid. Seattle Children’s Hospital and Accredo Therapeutics had always been great at dealing with the insurance companies and taking care of any problems we had.

Immediately, I got on the phone and called Medicaid, Kendra’s secondary insurance, to get things started. They told me nothing could be done until the appointment was scheduled at Stanford. After much negotiating, I scheduled some appointments at Stanford during Kendra and her younger sister, Skyler’s, spring break. I didn’t want Kendra to miss any window of opportunity to receive a transplant, in case the doctors wanted to list her for a transplant right away.

I kept in touch with both Stanford and the insurance companies to make sure everything was going smoothly. When I started running into problems, a representative at Stanford Hospital said the insurance company needed to handle it. I tried multiple times to help by talking to Medicaid myself, but I was repeatedly told that there was nothing I could do; the hospital needed to take care of things. Medicaid even said I “wasn’t privy to that information,” even though it was about my own daughter.

I grew more and more frustrated, especially when I received a letter from Medicaid denying coverage. The letter said I needed to get a second, third and fourth opinion from doctors here in Washington and in California explaining why Kendra needed an evaluation for a lung transplant. Additionally, Medicaid wanted to know if a closer hospital could do it, even though anyone can look online and see that Stanford is the closest facility to us for pediatric lung transplants.

I started emailing and calling everyone I could think of without much luck. I kept asking myself, “Are we the only family in the United States that has traveled out of state for medical care?” I knew that we weren’t, but it sure felt that way. My boyfriend, Paul, suggested we contact our state representative, Kevin VanDeWege, and ask him to help.

While on the phone with a woman at Representative VanDeWege’s office, the fire alarm went off in the office and the woman had to get off the phone. I thought, “Could this be a sign from God that we aren’t meant to go to Stanford?” I soon put that thought out of my head.

When I received a call from Stanford saying we would have to reschedule the appointment if they didn’t get an approval from Medicaid very soon, my mother bear instinct really kicked into high gear. I called Paul and asked who was higher up than the state representative’s office. He told me the governor’s office, but he said I wouldn’t be able to get through to them in time. I said, “Please give me that number.”

I called Governor Christine Gregoire’s office, and when the receptionist said she could take my name and number and have an aide call me in a few days, I said, “First, listen to my problem.” I told her about the situation, and she got an aide to come to the phone immediately. Within a short time, I had someone very high up calling me from Medicaid, saying everything had been approved and wishing Kendra good luck.

I didn’t rest until I received word that Stanford had received the necessary papers. I still don’t know for sure if it was the governor’s office, the state representative’s office, Seattle Children’s Hospital or something else that made the difference, but it was approved and we went to Stanford for spring break.

The journey to this point was extremely stressful. Fortunately, we discovered at the consultation that, although Kendra’s lungs are in very bad shape, her heart still has good function. This means we can hold off on a transplant for the time being.

My advice to others who run into problems with insurance companies is to remember that “no” doesn’t really mean “no.” It really means that that person doesn’t “know.” When you know in your heart that something is not being handled correctly, never give up.

Read more success stories and find insurance resources at www.PHAssociation.org/Patients/Insurance

By Pamela Sullivan, Mother and Caregiver of Kendra Sullivan
Service Dog Helps Patient, Raises Awareness

He may only weigh six pounds, but he’s made a huge difference in one patient’s life.

When Leroy, a Chi-Weenie (Chihuahua/Dachshund mix), was born in August 2009 to her dog Roo, PH patient Gail Lucero noticed right away that he was a compassionate animal. So when the family that was supposed to adopt him didn’t come through, Gail decided to keep him and train him to be her service dog. They’ve been very attached ever since.

Gail asked her PH clinic at University of California at San Francisco to help her get Leroy licensed as a service dog. All the clinic had to do was write a letter that addressed Gail’s disabilities and how a service dog could help her.

Ever since Leroy became her constant companion, Gail says her life has been happier. She meets more people because dogs make great ice breakers, especially a little “Chi-Weenie” wearing a vest! Besides that, Leroy provides Gail the opportunity to talk about PH — so he’s not only a service dog, but an awareness-raising dog!

Gail has already trained Leroy to alert others if she’s not feeling well or if she passes out. And because she can’t bend down, he picks things up for her. Beyond that, he helps keep her calm and lowers her blood pressure. Says Gail, “When you have something to care for and someone that loves you, they’re your support, your caregiver.”

She plans to train Leroy to bark if she has a serious problem and also hopes to train him to use a medic alert system. He’s learning very well, she says. “When he puts his vest on, he knows he’s working.”

Requirements for service dogs vary from state to state, so Gail recommends that people who are interested should look into their own state rules. To access general information about service dogs, visit www.servicedogcentral.org

The state of California doesn’t require certification, but Leroy has a tag and license that identify him as a service dog. By law he can go everywhere with Gail, “he just has to behave.” Gail says that while most people think of larger breeds in this role, you just have to have “the right dog with the right personality.” It seems that in Leroy she has found both.

By Adrienne Dern
PHA Senior Vice President

PH Patient Christie Breault Shares Her Story on the Today Show

On August 30, Christie Breault unexpectedly found herself in a car headed to the airport with her husband and her good friend Becky Walker. A few months before, Becky sent a letter to the Today Show asking them to spotlight Christie for an “Everyone Has a Story” segment.

Christie was diagnosed with pulmonary hypertension 15 years ago and was a support group leader in Kansas for 10 years. In the Today Show segment Becky spoke about Christie’s decision to give up her dream of teaching full time, but says that Christie never lost her spirit or her drive to be a “life teacher to everyone who knows her.” Becky says, “You would never know that Christie is facing a life-threatening illness simply because she always has a spirit that is shining and her smile just softens your heart. Christie is inspiring beyond comprehensible words. … Instead of focusing on what she can’t do because of her illness, she engages in those things she can do.”

Christie continues to inspire and teach those in her community by raising awareness about pulmonary hypertension. One week after her segment on the Today Show, she reports, “I have 68 new Facebook friend requests/emails regarding PAH and PHA!” Christie has already pitched her story to her local newspaper and is working on sharing it with area TV stations.

Watch Christie’s appearance on the Today Show at http://today.msnbc.msn.com/id/26184891/vp/38973106#38973106
The thought of planning ahead for college can overwhelm most teenagers. For a young person with pulmonary hypertension, the college application process can include the added stress of health considerations, the logistics of moving away from family and a local doctor, and the thought of adding additional expense to a family budget that may already be over-extended due to medical bills. But don’t panic! If you prepare for the medical, social and financial challenges of college life, you can confidently get the most out of your higher education.

If you know you’ll need assistance paying for college, complete the Federal Application for Federal Student Aid (FAFSA) in a timely manner. The FAFSA is required to qualify for federal loans and grants, as well as the funding programs at many universities and private foundations. PH patients can also take advantage of resources available online to make college more affordable for students living with a chronic illness.

Also be sure to talk to your current insurance provider. If you’re on a parent’s insurance plan, your insurance company is now required to continue your coverage until you turn 26, even if you no longer live with your parents, are not a dependent on your parent’s tax return, or are no longer a student. The extension of coverage until the age of 26 is a recent change that is required for plans or policy years that begin on or after September 23, 2010. Check with your insurance provider before you head off to school to make sure your plan has updated its policy.

As you consider different colleges, do your research. Most campuses offer some sort of Disability Support Services (DSS) to help you arrange for services that can make your life easier as you adjust to life on campus. If you’re already enrolled at a university, search your school’s website or campus directory for “disability services” to find the person to speak with about accommodating your PH-related needs.

Most schools can help you address your special dietary restrictions at the dining hall and help arrange for notifications to professors about the need for note-taking help or extensions on exams and papers in the event you miss classes for medical visits. You can also request centrally located housing, handicapped parking, or transportation around campus.

If you and your parents have determined with your doctor that your health is stable enough for you to go away from home, work with your doctor to create a medical plan for the school year. Talk to your doctor about your concerns and decide how you’ll handle severe symptoms or medical emergencies while you’re away.

You can schedule appointments with your doctor in advance so they fall during your semester breaks. It is also a good idea to find a PH specialist near your school in the event of an emergency. Finally, make sure you have copies of all your important medical records with you at school, including extra copies of all your prescriptions.

Although time management skills are essential for all successful college students, planning ahead is indispensable for PH patients who want to stay on top of a heavy workload. Strike a balance between work, play and rest. Through trial, error and common sense, you’ll find the schedule that works best for you.

If you anticipate problems completing certain assignments on time due to multiple deadlines or medical appointments, talk to your professors in advance. According to Sean, a college student living with PH, “If you personally go to them and let them know about your condition, they tend to be more willing to work with you if, say, you have a doctor’s appointment that you can’t reschedule.”

Likewise, learn to say no to class-related and extracurricular activities you don’t have the energy for. Some PH patients choose to take only one or two classes at a time to make sure they have the energy and concentration to devote to their studies. As Sean says, “College is supposed to be a learning experience. Focus on your classes, and don’t party too hard.”

College is a time for meeting new people, trying new things and enjoying new experiences. You get to decide who you spend time with, who you confide in and what you do. You are in control of your life. You can choose who you tell about your PH and how you tell them. You can decide whether one night of sleep deprivation is worth the lag in energy the next day. The decisions you make during this time will arm you with the experience and self-awareness to help you manage a balanced, fulfilling life with PH in your 20s and beyond.

Read the extended version of this article at www.PHAssociation.org/Patients/YoungAdults/College

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

When you are diagnosed with a life-changing disease, it can be difficult to talk about it with others. In a way, telling people makes it real. Explaining your illness to children is particularly challenging. Chronic illness can be a difficult concept for them to understand. When average, healthy children get sick, they get better. While they may not be able to run around the block today, in a week they’ll have their strength back. Children are smart and they can understand amazing things, but they are often very literal. If you tell them that nothing is wrong, they will expect that to be true. While some of us are understandably inclined to hide illness from children, I knew I wanted to explain my disease honestly so my young family members would know what to expect.

I have three nieces, two in Alaska and one who lives near me in Colorado. I have had lupus since before they were born, and they have grown up with me being sick. Now that I’ve been diagnosed with PH as well, they accept that there are things I cannot do. They know that they need to be gentle, that I cannot run and that I need naps. At five years old, my oldest niece is an intelligent, matter-of-fact young lady, and as a result she has a lot of questions and expectations. During a recent conversation with her mother, she started asking questions. Why couldn’t I visit her in Alaska? Can I visit when I get better? And then the stumper: why won’t I get better?

The challenge in answering my niece’s questions lies in finding a balance between honesty about my health and my hope for the future. I don’t want to deny my niece of either. I try to live by the saying, “Prepare for the worst, but hope for the best.” When I talk to adults about PH, I start with the tough part, that there is no cure for PH and that it’s a life-threatening illness. Then I give them the hope, that there is medicine to treat the symptoms and that most patients have happy and productive lives. If you hide the negative, friends and family lack the understanding needed to be supportive. A lot of healing comes from strength and hope, and it is for my own benefit that I always add the positive. I use these same ideas when talking with children about PH, but I just simplify it all.

My response to my niece’s questions was straightforward and honest — there are some things doctors just can’t cure yet. She handled that well. After thinking on it a few minutes, she asked her mom if that meant I was going to die. Her mother’s response to that was simple as well – we all die at some point. At that, the conversation turned to talk of death, and she said something very sweet, “Mom, when you die, I will dream about you.”

When I talk to children, I tell the truth. With my niece, I know that if I said I would get better some day, she would expect that. How would she feel if I got worse? She would feel let down, less secure about her world. However, telling her that doctors don’t know how to make me better right now means that if things get worse, no promises are broken, no trust shattered. It also leaves room for improvement, room for hope.

Every day I remember there is no cure for PH. Every day I hope that we will find one. Every day I smile because I am still here. I try to instill this same insight, hope and knowledge into everyone I talk to about PH — both children and adults.

By Anna Bower
PH Patient

Hot off the press!

Order the newly revised edition of Pulmonary Hypertension: A Patient’s Survival Guide. Originally written by a PH patient and now kept up-to-date by a team of patients and medical professionals, this resource book serves as a soup-to-nuts guide for patients living with PH. For more information or to order your copy today, visit www.PHAssociation.org/SurvivalGuide

Chapters updated in this Summer 2010 reprint include:

- PH: The Other High Blood Pressure
- Who Gets PH?
- PH Treatments: The Basics
- PH Drugs
- Resources
Frequently Asked Questions for Family and Friends of PH Patients

My loved one was diagnosed with pulmonary hypertension. What do I do now?

Take a deep breath. PHA is made up of a community of patients, caregivers and medical professionals who can provide information and support as you begin your journey. We know more today about the disease than even five years ago; a number of treatment options are available to reduce symptoms, and clinical research is currently being conducted to improve treatments and find a cure.

Educate yourself. There is a great deal of information available about PH. To avoid misinformation, start your research with trusted sources: your PH specialist, PHA’s website (www.PHAssociation.org) or PHA’s Pulmonary Hypertension: A Patient’s Survival Guide (available at www.PHAssociation.org/Store or by calling 301-565-3004 x0). You can also use PHA’s website to request an Envelope of Hope: a free informational packet specifically designed to help new patients. Learn about available therapies, how they work, and possible side effects. Ask your loved one’s PH specialist about treatment goals and how they will be measured. Read up on your insurance plan to determine if you have prescription coverage, if your loved one needs referrals and prior authorizations and if you require a co-pay for physician visits and testing.

Talk to your loved one about how to best provide support on this journey. Don’t assert yourself too aggressively or try to take control. Instead ask, “How can I help?” Don’t take the lead on activities your loved one can still do independently, but be sensitive to limitations as they become apparent. PH patients have good days and bad days. Be prepared to adapt your level of involvement to the ebb and flow of your loved one’s energy levels.

Be your loved one’s advocate. As the people closest to PH patients, family and friends can see how patients are affected by their illness on a daily basis. If possible, attend doctors’ visits to help record and retain medical information and discuss symptoms the patient hasn’t noticed. PH patients may not always look ill, so it is important that caregivers understand their limitations and make others aware of them as well. Speak up to help relatives and friends recognize the challenges your loved one faces.

Encourage compliance so your PH patient takes medications as prescribed. Contact your loved one’s medical team if you have questions about treatment or if he or she experiences side effects. Family members can also help patients track vital signs between appointments by encouraging their loved ones to weigh themselves and measure blood pressure, heart rate and temperature every day.

What questions should I be asking my loved one’s medical team?

- How do I contact my loved one’s PH doctors?
- What symptoms should I monitor and who should I contact if they change?
- What constitutes an emergency and who should I contact in the event of one?
- What medications are you prescribing and why?
- What testing will you routinely perform and why?
- How often will we be seeing you? Who do I contact to make an appointment?

What sorts of symptoms should I contact the doctor about?

- Chest pain. Is it new, more frequent, or lasting longer? Has the sensation changed (i.e. sharp now vs. dull before)? Is it accompanied by nausea or does it travel from one body part to another?
- Fainting
- Bleeding
- Not eating or decrease in appetite
- Shortness of breath when doing activities he or she used to be able to do
- Increasing fatigue

STORY CONTINUED ON NEXT PAGE
What is the best way to help when my loved one is feeling depressed?

Many individuals who suffer from chronic disease will also suffer from periods of depression. Talk with the patient’s physician if you feel the depression is escalating or negatively impacting your loved one’s ability to cope or manage daily activities. Encourage your loved one to participate in individual therapy or to join a PH support group. When possible, take trips or leave the house to do activities you both enjoy. Be attentive to your own mental wellbeing as well. When your loved one has less energy or you’re feeling overwhelmed, journaling can provide a safe outlet for you and your loved one to express and process your feelings.

Conferece Marks Transition in Board of Trustees' Leadership

PHA’s 9th International Pulmonary Hypertension Conference and Scientific Sessions ended with a change in leadership. Board Chair Carl Hicks, who served from 2008 to 2010, passed the gavel to Laura D’Anna, DrPH, welcoming her as the new Board Chair and Vallerie McLaughlin, MD, as the new Chair-Elect.

During his time as Chair, Carl inspired the PH community with the story of his daughter Meaghan and their family’s fight with PH. In addition to being an empowering leader, Carl is known for his approachability and determination. A long-time pilot, he flies his own Cessna airplane to attend support group meetings in remote areas. “[His] commitment has moved others to become engaged in this fight, and many have thrown their monetary and intellectual contributions into the ring as a result,” says new Board Chair, Laura D’Anna. Carl is currently the CEO and President of WhoCanHelp.com and will continue to serve on PHA’s Board of Trustees.

New Board Chair Laura D’Anna, DrPH, is a Senior Research Fellow and Associate Director of the NIH-funded California State University, Long Beach Center for Health Disparities Research. Dr. D’Anna has extensive experience in the development, administration and evaluation of public and community health agencies and programs, which she uses in her fight against PH. She also works as a private consultant for various nonprofits committed to improving health among underserved communities. After her sister Rachel was diagnosed with PH, Dr. D’Anna served as a board member for the Primary Pulmonary Hypertension Research Foundation, a small nonprofit founded by PH patient Gabrielle Miyara, which ultimately merged with PHA. Unfortunately, she lost Rachel to the disease in 1995 (see Chair letter, p. 2) as well as her dear friend Gabrielle in 1999. She first joined PHA’s Board of Trustees in 2000 and has served as the Board’s Strategic Planning Committee Chair since 2006.

Vallerie McLaughlin, MD, has transitioned into the role of Chair-Elect of the Board of Trustees. Dr. McLaughlin has many years of research experience focusing on pulmonary arterial hypertension and is currently the Director of the Pulmonary Hypertension Program in the Division of Cardiovascular Medicine at the University of Michigan, where she is a Professor of Medicine. She is the 2010 recipient of the PHA Award of Excellence in PAH Care, the Immediate Past-Chair of PHA’s Scientific Leadership Council and a past editor of PHA’s medical journal, Advances in Pulmonary Hypertension.
Transitions on the PHA Board Bring New Faces and Fond Farewells

Every biennial International PH Conference brings transition in PHA’s leadership. We thank our departing Board members, and welcome our newest Trustees. Visit www.PHAssociation.org/BoardOfTrustees to meet all of PHA’s Board members.

Farewells: Thank you for your service!

Dr. David Badesch, a Professor of Medicine at the University of Colorado, is a former Chair of PHA’s Scientific Leadership Council. He has a long history with PH and has been instrumental in the field of PH research. Dr. Badesch has also helped connect ground-breaking pulmonary specialists to PHA. He is leaving the Board after six years of service.

Arlene Schiro, NP, is the Immediate Past Chair of the PH Resource Network. During her tenure as Chair, she helped the PH Resource Network significantly increase in membership and helped create a strong Executive Committee within the PH Resource Network. She continues her work with PH patients at Brigham and Women’s Hospital in Boston. She has been on the Board since 2006.

Betty Lou Wojciechowski, a Board member since 1996, has lost three family members to PH. Despite tremendous personal loss, she continues to be deeply involved with the PH community as a current special event planner and former support group leader. Her annual event, Swing 4 the Cure — Wojo PH Golf Classic, raised nearly $36,000 for PH research in 2010. She recently retired as a teacher at La Madera Elementary School, Calif.

Welcome to our New Board Members

Dr. Richard Channick joins the Board in his new position as Chair-Elect of the Scientific Leadership Council. Dr. Channick is the Director of the Pulmonary Hypertension Program and the Pulmonary Thromboendarterectomy Program at Massachusetts General Hospital. Dr. Channick is also the Editor-in-Chief of PHA’s medical journal, Advances in Pulmonary Hypertension.

Dr. Dunbar Ivy joins PHA’s Board as the second pediatrician to ever serve as a Trustee. He is a Professor of Pediatrics and the Director of the Pulmonary Hypertension Program at the University of Colorado. Dr. Ivy is also a member of PHA’s Scientific Leadership Council.

Dr. Robyn Barst, a renowned pediatric cardiologist and the past Director of the Pulmonary Hypertension Center at New York-Presbyterian Hospital, joins PHA’s Board for a second time. She first served on the Board from 2002–2008. Dr. Barst has also served as a past Chair of the Scientific Leadership Council, and she is the 2008 recipient of the PHA Award of Excellence in PAH Care.

Email Mentor Program Launches for Patients and Family Members

One-on-one support is now just an email away! PHA mentors are caring and knowledgeable patients and family members who are trained to listen, locate useful PH resources and help acclimate new patients and caregivers to the PHA community. Mentors are available to answer non-medical questions or for ongoing email relationships up to three months in length.

People interested in communicating with a mentor can find photos and information about these trained volunteers on PHA’s website (free web log-in required). Patient mentors are searchable by gender, age and related condition. Caregiver mentors are also available for family and friends of children and adults.

Visit www.PHAssociation.org/Mentors to connect with a PHA mentor.

Patients without an Internet connection can reach a patient trained to provide information and support by calling PHA’s Patient-to-Patient Support line: 800-748-7274.

PHA’s mentor program is made possible through an unrestricted educational grant from Gilead Sciences, Inc.
International Faces of PH: Meet Shira Dinur

My journey with PH began in Los Angeles, Calif., when I was born with a heart defect which was misdiagnosed for two and a half years. At six months when I wasn’t growing, I had a right heart catheterization which seemed to indicate that I had a PDA (Patent Ductus Arteriosus). During the surgery, they discovered that I didn’t have a PDA but that I did have pulmonary pressures of 100. My parents were informed that I had PPH and that there was no cure at this time. The doctor said I would most likely die before my teen years.

My parents wouldn’t settle for that prognosis as there were still indications that I had a heart condition. They continued consulting with other cardiologists. By the time I was two and a half, I was finally given the definitive diagnosis of AP window (Aortic-Pulmonary Window) and was rushed into surgery. I had a 50 percent chance of survival. Miraculously, the surgery was successful (thank G-d) and my pulmonary pressures went down to 55. My parents hoped it would continue to drop although there were indications of some irreversible lung damage.

At the age of six, my family and I moved to Israel. I lived a normal active life, not even knowing much about PH. I went to a cardiologist every six months and took low dose aspirin to prevent clotting. The only “problem” I would experience was shortness of breath when I walked up high hills or ran too fast.

When I was 22, I found it a little harder to breathe. After a visit with my cardiologist, we saw that my pressures had gone up to 75 and he decided to start me on Revatio™, which made me feel much better.

By the time I was 24, I was living on my own, working full time at a high-tech company, and going out almost every night. I was living a full, exciting “young adult” life when all of a sudden I started to notice that I got short of breath just by walking or going up stairs.

After having an echocardiogram, we learned that my pressures were now approaching 85 and felt it was time to add an additional oral medication. My pulmonologist decided that I should participate in a stage three research study for the pill Seraphin®. In order to receive an additional treatment in Israel, a right heart cath is required. After a bad experience with the cath (which led to an infected hematoma and a horrible fainting episode), my doctors decided that I needed to start inhalations with Ventavis™. After about a month, I was back at work part time and living with my parents.

Soon after, I started feeling very tired, dizzy and shaky, so my doctors decided to switch my medication to IV Remodulin™. I have now been on this medication for over a year. I am still pretty much at home and trying to slowly get back on my feet. I’m not yet at my right dose of medication and my doctors are considering adding a third medication. I am positive that soon I will start feeling better once we get my medications under control. I do try to walk when I’m feeling good, take chi-kung and get shiatsu treatments which help me relax for a bit. I am very fortunate to have great friends and family who help me and stand by me no matter how I feel!

I was also introduced to a wonderful PH organization here in Israel. Although I’m not well enough to take an active role in it, my parents have joined, and hopefully the organization will continue to raise awareness, get the newer meds approved and get more people involved.

I was also happy to join PHA’s Generation Hope online email group for young adults with PH. I have learned a lot from everyone, made new friends and am happy to finally find people my age with whom I can share stories, ask questions and get feedback. Finally, I don’t feel so alone anymore.

As for the future, I hope to continue to stay positive, and I hope that my pressures will go down, so I can be more active and share my experience of PH with others!

By Shira Dinur
PH Patient

To learn more about PH Israel and pulmonary hypertension in that country, visit PHIsrael.org.il. To get involved online with other young adults with PH, join Generation Hope at PHAgenerationhope@googlegroups.com

Shira is a PH patient living in Israel (see map).
What are the positives and negatives of pulmonary rehabilitation? Should everyone with PH participate in pulmonary rehabilitation?

To understand why those with PH should participate in pulmonary rehabilitation (PR), let’s look at the definition of PR: “Pulmonary rehabilitation is an evidence-based, multi-disciplinary, and comprehensive intervention for patients with chronic respiratory disease who are symptomatic and often have decreased daily life activities. Integrated into the individualized treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status, increase participation and reduce healthcare costs through stabilizing or reversing systemic manifestations of the disease.” American Thoracic Society/ European Respiratory Society definition, 2006

Consider these questions:
1. Do you have a chronic respiratory disease and have symptoms?
2. Do you have decreased activities of daily living?
3. Are you fearful about exercise with your PH diagnosis?
4. Are you using oxygen?

If you answered YES to any of the above, talk to your doctor because you may benefit from pulmonary rehabilitation. PR is an adjunct therapy for the PH patient in collaboration with the PH clinic you get your care from. This strong partnership between the referring doctor, your PH clinic and the pulmonary rehabilitation program will ensure you get the best treatment possible from the PR team. All it takes is a physician referral to PR to get started.

Positives of participating in pulmonary rehabilitation:
• You gain a better understanding of how PH affects your lungs, the oxygen in your body and exercise.
• You improve cardiovascular endurance through a safe and supervised exercise program.
• You increase exercise performance that translates into improvements in activities of daily living.
• You improve your quality of life through education and therapeutic exercise.
• You understand your lung symptoms and decrease your shortness of breath through breathing retraining and ensuring adequate oxygenation at rest and with activity.
• You exercise in a facility where you feel secure and safe because of the skills of the pulmonary rehabilitation therapist working with you.
• Your PR team communicates with your referring doctor and your PH clinic on your progress in PR.

Negatives of participating in pulmonary rehabilitation:
• You have to commit to attending a comprehensive PR program for at least two to three days a week for eight to 12 weeks.
• The PR program may not be easily accessible to where you live.

Should everyone with PH participate in pulmonary rehabilitation?

No, BUT, if you answered YES to the questions at the start of this article, you could benefit from pulmonary rehabilitation.

Is pulmonary rehabilitation covered by my insurance?

There is no simple answer, but typical insurances that cover PR for specific diagnoses are Medicare, Medicaid and some private insurance. The PR program you are referred to should be able to help you with the coverage question. We also encourage each individual to contact their private insurance company and ask, “Is pulmonary rehabilitation a covered benefit under my policy?” If not, you can work with your provider to request an exemption.

To find a PR program in your state go to the American Association of Cardiovascular and Pulmonary Rehabilitation (www.aacvpr.org/Resources/SearchableCertifiedProgramDirectory/tabid/113/Default.aspx) or the American Association of Respiratory Care (www.yourlunghealth.org/finding_care/qrc/pulm_care/index.cfm).

Answer provided by Gerilynn Connors, RRT, BS, FAACVPR, Clinical Manager, Pulmonary Rehabilitation, Inova Fairfax Hospital, Falls Church, Va.
Welcome, Meghan Finney, Patient Education Program Associate!

As Patient Education Program Associate, Meghan is responsible for continuing to develop educational resources that provide patients and caregivers with information about pulmonary hypertension and its management. Meghan works to create patient-oriented brochures, website content, webinars and chats. She continues to assess educational needs within the PH community and assists in the planning of PHA events such as the PHA on the Road program. Meghan graduated from American University in May 2010 with a Bachelor’s degree in Psychology and Philosophy and a focus in Pre-Health. Meghan can be reached at MeghanF@PHAssociation.org or 301-565-3004 x744.

Leadership Changes in PHA's Medical Communities

PHA’s International PH Conference in June brought with it leadership transitions within PHA’s Scientific Leadership Council (SLC), and September 2010 saw changes in PHA’s PH Resource Network. The SLC, composed of 28 global leaders in the field of pulmonary hypertension, coordinates the medical arm of PHA, providing medical and scientific leadership and guidance for the mission of the Pulmonary Hypertension Association and overseeing the development of the wide array of all PHA’s medical programming. The PH Resource Network is a membership community of PH-treating allied health professionals dedicated to enhancing communication, professional development, research and education about pulmonary hypertension. PHA thanks the leaders of the SLC and PH Resource Network for their dedicated service over the past two years and welcomes the new leaders who will serve from 2010 to 2012.

Scientific Leadership Council (SLC)
CURRENT CHAIR: John H. Newman, MD (pictured)
CHAIR-ELECT: Richard Channick, MD
IMMEDIATE PAST CHAIR: Vallerie V. McLaughlin, MD

Thank you to Dr. Vallerie McLaughlin for working hard to advance the SLC during her time as Chair, from 2008-2010, and to Dr. David Badesch for his service as Immediate Past Chair, from 2008-2010. To learn more about the SLC, visit www.PHAssociation.org/SLC

PH Resource Network
CURRENT CHAIR: Louise Durst, RN (pictured left)
CHAIR-ELECT: Traci Stewart, RN, MSN
IMMEDIATE PAST CHAIR: Arlene Schiro, NP, MA, ACNP

Thank you to Arlene Schiro for her dedication during her time as Chair, from 2008-2010, to Joy Beckmann for her service as Immediate Past Chair, from 2008-2010, and to Marilyn Schmidt for her service as Education Committee Chair from 2008-2010. To learn more about the PH Resource Network, visit www.PHAssociation.org/PHResourceNetwork

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

For PH patients diagnosed with an additional medical condition that requires general surgery, balancing PH therapy with surgical needs can be challenging. A good first step to meet this challenge, according to Dr. Teresa De Marco, Director of the University of California, San Francisco Heart Failure and PH Program, is to find a multidisciplinary medical team that is experienced in the management of patients with PH. This team should include an anesthesiologist, PH specialist and surgeon.

Once the team is assembled, patients and their medical team should discuss what types of medications the patient is taking and develop a plan for managing any complications that may arise due to these drugs. Dr. Brian Hanna, Director of PH Cardiology at the Children’s Hospital of Philadelphia, explains, “If you need a root canal, or if you need a sudden (or not so sudden) appendectomy or have kidney stones, you should know ahead of time what you need to talk about with new (or familiar) dentists and doctors. These situations are not uncommon and similar questions should be asked for each.”

Hanna outlines what patients and doctors should know about the three major classes of PH drugs. Phosphodiesterase inhibitors, such as Cialis™, Adcirca™, Revatio™ (sildenafil) and Viagra™, can sometimes impact hearing, vision and blood pressure. Because these adverse events are often due to preventable drug-drug interactions, patients should always tell their physicians all the drugs (PH-specific and general) that they are taking. Thelin™, Tracleer™ and Letairis® are common names for endothelin receptor antagonists, the second major class of PH medications. These drugs are metabolized in the liver, so patients with liver issues like hepatitis or liver dysfunction can have very different responses. It is, therefore, very important for patients to be compliant with liver enzyme testing prior to starting surgery. Finally, prostacyclins, including Flolan™ and Remodulin™, can cause dangerously lowered blood pressures, platelet dysfunction (bleeding issues) and rashes.

Beyond knowing what drugs you are taking and talking about what types of adverse events are possible, patients and their medical team should talk about PH drug administration before, during and after surgery. Specifically, Hanna says, you should discuss fluid and blood pressure issues that could arise if anesthesia becomes delayed or extended. This discussion should center on which drugs the patient can tolerate prior to and after surgery, and should lead to a plan for administering alternate drugs if need arises. For example, for a patient on prostacyclins, it may be appropriate to hydrate oneself on an IV while waiting for surgery and to decide on alternatives to oral or inhaled drug administration in case you are unconscious after surgery.

To prepare for emergencies, in which in-person discussions with a medical team may be impossible, Hanna suggests wearing a medical identification band. “These are indispensable to alert physicians to what drugs you are taking, and what things are wrong with you. This can allow you to avoid serious issues and complications,” he says.

PH patient Raye Bohn’s recent experience with general surgery shows how vital it is to have these pre-surgery planning sessions. Raye learned about Flolan™ and its ability to cause hemATOMA — a collection of blood outside of a blood vessel — first-hand when she underwent thyroid removal surgery in 2009. She had a multidisciplinary team of doctors, and her procedure took place in a research hospital with appropriate specialists and staffs. Upon checking-in for her surgery, she was “pleasantly surprised that the nurses all seemed to know what Flolan™ was.”

While the surgery itself proceeded smoothly, Raye woke up the next day with bruises from her chin to her chest. She recalls, “In came the PH specialist doctor and his staff to check me out and he was so surprised to see what had happened.” This surprise came despite the fact that her specialist was versed in potential Flolan™ side effects and informed her that it was the likely cause of her hematoma. Raye underwent two additional surgeries to “fix the bleeder,” began taking blood-clotting medication, and slowly regained her PH-normal health over the course of the next month. She remembers thinking, “I did not know that Flolan™ could do this.”

While the experience of her physicians helped Raye to effectively recover from these complications, the lack of pre-surgery discussion about them may have caused additional anxiety in the post-surgery environment and a longer recovery time. Whether a surgery takes place under anticipated or emergency circumstances, having a plan put into place of who to call, what treatment factors to discuss, and what to do if something goes wrong can reduce surgical stress and promote healthy recovery.
Meet Dr. Pham: Engaging His Patients in Their PH Care

Dr. David Pham is the founder and medical director of Allianz Medical and Research Center in Fountain Valley, Calif. He has been working in the field of pulmonary hypertension for more than 10 years and constantly looks for ways to engage his patients. Dr. Pham is an active member of PHA and served as the sub-committee chair for the 2009 PHA on the Road forum in Southern California. He is also a member of the Clean Air Regional Board, helping the American Lung Association in California and the Committee on Government to promote Clean Air Bill SB375. He recently took the time to talk to us about his involvement with the PH community and his dedication to the fight against PH.

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

Growth and understanding of this disease state are occurring in leaps and bounds. Scientists from all over the world are making strides in managing this disease. We have therapies available that have impacted the lives of many PAH patients. We should educate those around us with PAH and support those who have difficulty in handling this disease. We will one day gain the upper hand against this disease.

You’re a big proponent of patient interaction and lend your office space for support group meetings. Why do you think patient interaction is so important for PH patients?

Patient interaction gives them strength and understanding that they are not alone in this disease. PAH is a disease with a “big heart” of people from patients, caregivers, medical providers and scientists standing side by side to find a cure and provide support.

How did you get involved with PHA?

I wanted to maintain scientific contact with my peers and contribute my time to help advance the care of PAH. I saw a need to bring PAH care and awareness to Orange County, Calif., and I also realized that PHA helps bring awareness of this disease to the community.

What advice do you have for new practitioners entering the field of PH?

I would say, “PAH is a challenging disorder. Significant scientific and therapeutic growth in the field have occurred over the last decade. These changes need the support of new physicians to aid in the battle against this disease. Patients really appreciate every effort the new physician is providing in care, awareness and support!”

Interview conducted by Priscilla Davis
Former PHA Medical Services Program Associate
Meet the Nurse: Deb McCollister

Deborah McCollister, RN, BSN, is an active member of PHA and the PH community. She is the recipient of the 2010 Outstanding Medical Professional Award, presented at PHA’s 9th International PH Conference and Scientific Sessions in Garden Grove, Calif. Deb has served on the PH Resource Network Executive Committee and helped to plan both the 2007 and 2009 PH Resource Network Symposia. This past year, she conducted a study on depression and PAH and co-authored an article in Advances in Pulmonary Hypertension on her findings. Deb recently spoke with us about her involvement in the PH community.

What initially sparked your interest in PH?
I started my career as an oncology nurse, first in the hospital setting for two years and then in research for about 10 years. I’ve always been interested in being on the cutting edge of treatment development, so being a research nurse coordinator has always suited me perfectly. I took a break for a while when I had kids, and when I decided to go back to work, I saw an ad for a pulmonary hypertension nurse coordinator in the newspaper. I didn’t know anything about PH at the time, but I thought the position sounded really interesting. When I started this position in 2003, there were very few FDA approved drugs and only a handful of ongoing research studies. I became very interested in the PH population, and I found many similarities between the challenges PH patients face and oncology patients face: an uncertain prognosis, an incurable disease with few treatments and psychological struggles.

What excites you most about the progress you have seen in the PH field?
I have been in this position for seven years and have seen the number of PH drugs approved by the FDA nearly triple, but we still don’t have a cure for the disease. Current therapies center on modulating the symptoms of PH and slowing the progression of the disease, which is important, but I think it’s time to focus on potential cures.

This is not to say that current medications are not helpful to patients, because they certainly are. I have seen them help patients live many, many years. One of my patients, who participated in a research study, is now raising her great-grandson. This wouldn’t have been possible without the current medications.

What PH cases stand out in your mind?
I had a patient who was a train engineer. He was a tough-as-nails kind of guy; swearing was part of his vocabulary. He had a past diagnosis of cancer but was cancer free when he became my patient. He participated in one of my research studies, and I got to know him and his family very well. As his disease progressed, he became less able to do simple things, and he taught me what it really means to live with PH. I remember one time when he said to me, with intense emotion, “I have a real hard time watching my wife mow the lawn.” This helped me see what it was like to be him. There are many losses that go along with having PH, but it’s how you deal with these losses that will determine whether you will be content or unhappy with your life.

Can you tell us about your current research project?
My colleagues and I at the University of Colorado completed a two-center study looking at the prevalence of depressive symptoms in patients with PH. We found 55 percent of patients had depressive symptoms. We’re hoping to build on that study and look at how depressive symptoms affect quality of life and functional status in PH patients. In our clinic, we are trying to be more proactive in looking for depressive symptoms in our patient population, and we have implemented a strategy to assess all our patients for depression so that patients are more likely to be diagnosed and treated.

You co-chaired PH Resource Network Symposia in 2007 and 2009. How did you decide to take on this role?
I’m a “big project” person. I had attended the 2005 Symposium, and it was the first time I felt like, “WOW, there are all these other nurses and allied health professionals doing exactly what I’m doing.” I felt such a sense of belonging after that Symposium. The Symposia are professionally very satisfying to do; education is key to improving the quality of care.

Interview conducted by Rachel Wheat
PHA Medical Membership Program Associate
What’s in Your Medicine Cabinet?

**Tips to Avoid Possible Interactions with Existing Medications**

Nearly all pulmonary hypertension patients take at least one drug specifically used to treat their PH. In addition, patients may also receive one or more general therapies given to supplement the PH medication. The combination of all these therapies places the patient at an increased risk for drug-drug interactions, and therefore, these therapies are carefully monitored by a patient’s physicians, nurses and pharmacists. For example, anticoagulants, such as warfarin (Coumadin®), help prevent clotting complications sometimes seen with PAH. With this therapy, patients are required to have routine lab work to monitor and maintain adequate blood clotting time.

In addition to prescribed treatments, some patients may choose to obtain other products such as herbal supplements, vitamins and other over-the-counter (OTC) products used for cough/cold and pain. Because these products are available in health food stores and pharmacies without the need of a prescription, many patients are unaware of the potential risks and interactions associated with these products. Vitamin supplements have the potential to interact with prescribed medications and could decrease the medications’ effectiveness or increase the side effects.

Here are some important points regarding the use of OTC medications, vitamins and herbal products as they relate to pulmonary hypertension:

- Although often considered harmless, no product available without a prescription should be taken BEFORE consulting with your physician, nurse or pharmacist.
- Dosages listed on the OTC container should not be exceeded without consent or discussion with your physician.
- The following popular herbal products have documented interactions:
  - Ginkgo biloba, often used to improve memory and brain function, is associated with increased bleeding episodes and, therefore, interferes with anticoagulant therapies.
  - Flaxseed, often used as a laxative and to lower cholesterol levels, has been known to interact with cardiac medications, increasing their levels in the bloodstream and increasing effects and side effects.
  - Feverfew, commonly used for migraine headaches, interferes in the blood clotting process and, therefore, interferes with anticoagulant therapies.
  - Ginger, often used to diminish nausea and decrease stomach upset, again interferes with platelet activity and should be avoided with anticoagulants.
  - St John’s wort, used for depression, may increase skin sensitivity to the sun and has been shown to interact with other anti-depressant medications.

- The following vitamins have noted interactions:
  - The fat soluble vitamins — vitamins A, E and K — can all interfere with platelet activity and blood clotting properties and, therefore, create an interaction with anticoagulants.
  - The use of Niacin (a vitamin B complex) with statin medications for cholesterol may increase the side effects of the statins.
  - Diuretics such as furosemide and bumetanide (Lasix® and Bumex®) may increase elimination of calcium, thereby decreasing the effects of calcium supplements.

- Some foods within the diet can interfere with other medications:
  - Salt substitutes containing potassium may interfere with diuretic use and heart medications by increasing the amount of potassium in the bloodstream.
  - Grapefruit and grapefruit juice decrease the effectiveness of various medications.
  - Green leafy vegetables contain vitamin K and may interfere with anticoagulants.
  - Wine and cheese may interact with some anti-depressants.

To summarize, most OTC preparations, vitamins and herbals can be taken safely and without effect. However, before purchasing these products, it is important to consult with your physician, nurse or pharmacist and provide them with a complete list of all current medications. After a careful review, your healthcare professional can best advise you on the appropriate medications to take to prevent any unwanted interactions or therapy complications.

*By Kari Ehringer, PharmD, Cardiopulmonary Account Manager, Accredo Health Group, Southern California*
Research has long been the key to unlocking PH mysteries, and each year new discoveries occur that move us further along in our understanding and treatment of PH. Dr. Yinzhong Zhang of the Feinstein Institute for Medical Research is doing his part to propel PH research forward. Dr. Zhang was a 2008 recipient of the PHA/American Heart Association Post-Doctoral Fellowship Award for his research project entitled “Role of Macrophage Migration Inhibiting Factor (MIF) in Hypoxia-Induced Pulmonary Vascular Remodeling.”

As Dr. Zhang explains, “Hypoxia can induce pulmonary vascular remodeling, which is an important mechanism in PH formation and processing; it remains unclear how the hypoxia causes pulmonary vascular remodeling. Since PH patients have increased MIF and MIF increase cell growth, hypoxia can drive cells to produce more MIF, and since the lungs are a major source of MIF, we hypothesize that MIF may be an important mediator between hypoxia and PH. In my study, I have used an hypoxic mice model and an hypoxic cell proliferation model to study the role of MIF in hypoxic cell proliferation and finally PH formation.”

Through this study, Dr. Zhang hopes to discover a new therapeutic target to help end this devastating disease. “So far I have found that hypoxia can induce both MIF expression and cell proliferation. A blockade on MIF by an inhibitor can dose dependently inhibit hypoxia-induced cell proliferation. If the cells are genetically deficient in MIF gene, they do not show hypoxic cell proliferation. However, these cells can regain the hypoxic cell proliferation by the supplement of MIF, which was achieved by giving the condition medium from non-deficient cells,” Dr. Zhang says. “In addition, MIF inhibitor significantly alleviates hypoxia-induced PH in our animal model. This data clearly shows that MIF is an important mediator between hypoxia and pulmonary hypertension and has a potential of being a new therapeutic target for PH.”

Dr. Zhang’s current research builds upon the work of other researchers. Before Dr. Zhang joined Dr. Edmund J. Miller’s lab at the Feinstein Institute for Medical Research as a Postdoctoral Fellow in 2007, this lab “had collaborated with Dr. Talwar, a pulmonary physician specializing in PH,” Dr. Zhang says. “Our lab’s previous data showed that PH patients have increased levels of MIF. Based on this data, I was very interested in whether MIF plays a role in hypoxia-induced pulmonary vascular remodeling. The idea finally formed into a Fellowship application, and I was fortunate enough to be funded by PHA.”

Dr. Zhang’s interest in PH began when he was working at Peking Union Medical College Hospital (PUMCH), which is one of the top hospitals in China. While working as an anesthesiologist at PUMCH from 2003–2006, he encountered many patients who required anesthesia, but their cases were complicated by the presence of PH. During this time, he also joined a group of medical professionals performing surgical therapy for a special kind of PH, chronic thromboembolic pulmonary hypertension (CTEPH), and he assisted with the anesthesia for eight CTEPH surgeries. Dr. Zhang published a paper on the anesthesia management for CTEPH surgeries and gave a presentation on the topic to his department. In order to prepare for the surgeries, the paper and the presentation, Dr. Zhang not only researched but also connected with PH patients. “Through my contact with PH patients, I came to understand their suffering. I think these experiences initially sparked my interest in PH,” he says.

In addition to his research, Dr. Zhang participates in PHA events, including PHA’s 9th International PH Conference and Scientific Sessions in Garden Grove, Calif., this past June. “I was deeply touched by the PH patients,” he says. “I think the highlight was the fashion show put on by the patients. Their love of life drives me to work hard on my research, and I hope my results can really help them in the future.”

PHA is proud to support the work of Dr. Zhang and all the researchers who work each and every day to advance the treatment of PH. PHA’s research program has committed more than $9 million for PH research through partnerships with the National Heart, Lung and Blood Institute, the American Thoracic Society and the American Heart Association. PHA has supported 44 outstanding researchers through three independently reviewed cutting-edge research programs to date.

Visit www.PHAssociation.org/Research to learn more about PHA’s research program and research grant recipients.
Robert Converse has a big advocacy goal this year: to get his three Members of Congress to co-sponsor the Tom Lantos Pulmonary Hypertension Research and Education Act. To get started, he has already reached out to his senators and representative to set up meetings. As Robert says, “We’ve got to get the word out to our Members of Congress. I can do this — I’ve got nothing to lose!”

Robert is a member of PHA’s 435 Campaign, a group of grassroots volunteers who actively engage their Members of Congress year round, while also inspiring their fellow Campaign members. Robert’s story demonstrates how a little inspiration and support can motivate you to overcome your fears, find your voice and reach out in support of a cause.

Prior to his PH diagnosis, Robert worked as a pilot for a commercial airline. He frequently rode his bicycle as much as two hours a day, jumped horses and played basketball in his spare time. One day while shooting hoops at his local YMCA, Robert noticed that he was having trouble breathing. After a blood pressure reading of 80/60, Robert spent the next few months working with doctors to figure out how an active pilot, who had just received a good bill of health in his annual physical a few months earlier, was now struggling to catch his breath. Robert was diagnosed with PH in 2004.

Robert’s advocacy interests started small. After his diagnosis, he began sending letters to his Members of Congress, asking them to take action on health insurance protection and the PH Research and Education Act. Although his friend Carl Hicks, fellow flight enthusiast and former Chair of PHA’s Board of Trustees, encouraged him to take his advocacy to the next level and join the 435 Campaign, Robert waited. He waited for six years, and finally, this year he received that extra bit of encouragement.

While attending PHA’s 9th International PH Conference and Scientific Sessions, Robert found himself drawn to an advocacy session. The session, led by 435 Campaigners Charlotte McCabe and Doug Taylor, gave attendees an introductory lesson in how to build relationships with and advocate to their Members of Congress.

“Something just clicked and I figured I had nothing to lose. This is something I can do, I can talk,” Robert says of the session. Quoting Charlotte McCabe, he says, “If there is a fear there, it’s your own fear” because Members of Congress want to hear from their constituents.

Robert is finding this concept true as he becomes more involved in the Campaign. He says, “There are millions of people in the United States and only 435 Representatives representing us. We’ve got to get the word out!”

Since Conference, Robert has jumped into the 435 Campaign and now urges everyone else to get involved in advocacy to make a difference in the lives of PH patients. He encourages, “Just jump in and do it!” As he has found, sending letters through PHA’s Advocacy Action Center is an easy way to begin advocating and cultivating a relationship with your Member of Congress. Robert says, “I don’t have to think about what to write because the language is already so great. I don’t have to reinvent the wheel!” Visit www.PHAssociation.org/AdvocacyActionCenter to access these letters.

As PH Awareness Month approaches this November, Robert is gearing up to secure additional sponsorships for the Tom Lantos PH Research and Education Act and raise awareness of PH on Capitol Hill. To find out how you can join Robert in the 435 Campaign or connect with your senators and representative, visit www.PHAssociation.org/Advocacy/435Campaign or contact Elisabeth Williams at 301-565-3004 x753 or Elisabeth@PHAssociation.org.

By Elisabeth Williams

PHA Grassroots Campaigns Associate
Linda Gates Educates Her Community Through Media Outreach

Like many other pulmonary hypertension patients, Linda Gates knew very little about this disease and its symptoms before she was diagnosed. Linda, who worked as a secretary until her diagnosis in 2001, thought her shortness of breath could be explained by her age, weight or lifestyle. And the trouble she had catching her breath at Yosemite National Park was easily explained by the high altitude. However, Linda’s general practitioner looked at the results from a routine stress test and knew something wasn’t quite right. After a series of tests over several months, Linda was diagnosed with PH.

Linda, who has been a leader of the New Orleans Support Group since 2005, is well aware that other PH patients aren’t so lucky in their diagnoses. That’s why Linda decided to become more active in raising PH awareness in her own community through the PH Aware Campaign, PHA’s grassroots media campaign. “People are still having diagnosis problems,” Linda says.

She thinks back to her own journey right after her PH diagnosis and remembers how important a successful PH media story can be. At that time, Linda saw an interview with Dr. Bennett de Boisblanc about pulmonary hypertension on her local TV station and decided to contact him for more information.

Now Linda is going to do her own awareness raising. She is new to the PH Aware Campaign, but she’s already thinking about the best way to pitch PH stories to the news organizations in her community. Her immediate goals are to build relationships with the reporters at her local paper and news stations. That way, she knows the best people to talk to about each of her story ideas. She has also started thinking about how to get the members of her support group involved in pitching their stories, and she wants to advertise her support group meetings in the paper. “It may take time to establish these relationships,” Linda says, “but you just have to make up your mind that it’s something you want to do.”

To find out more information about the PH Aware Campaign and how you can connect with media in your community, visit www.PHAssociation.org/Awareness/PHAwareCampaign or contact Elisabeth at 301-565-3004 x753 or Elisabeth@PHAssociation.org.

By Elisabeth Williams
PHA Grassroots Campaigns Associate

Thank You to Our Silent Auction Donors and Winners!

This June at PHA’s 9th International PH Conference in Garden Grove, Calif., PHA offered fun and fantastic bidding opportunities on items donated from our PH community. Proceeds from the auction support our mission to find a cure for PH through research and to enhance patient wellbeing through support, education, advocacy and awareness.

PHA would like to extend a special thank you to the individuals who generously donated the items up for bid and a hearty thank you to all the bidders who were ready to reach deep into their pockets to benefit PHA’s programs and services.

“Bay Breeses” was created and generously donated by Kathy Levitt, PH patient. Stu Berwick was the bidding winner.

“City by the Sea” was also created and donated by Kathy Levitt, PH patient. Karen Lindemann placed the highest bid.

“Rush Hour” was donated by Susan Terry, grandmother of PH patient Katy Doak. Dr. Karen Fagan got to take this quilt home based on her winning bid.
A three-month prognosis for their daughter sent Jack and Marcia Stibbs looking for hope. They found it at PHA.

Even if you don’t consider yourself a grant writer — and not too many people do — you can receive funding for your pet project through the Tom Lantos Innovation in Community Service Awards program.

Named for one of the true heroes of the PH community, and sponsored by Gilead, these awards support members of the PH community who are making a significant impact in the following ways:

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

You truly have an opportunity to win an award with as many as 10 projects receiving funding of up to $5,000 in 2011. And PHA is here to help you submit the best application possible. Look for upcoming announcements of opportunities for training on our website and in PHANews.

For a little inspiration, turn to page 28 to learn about one of our 2010 award winners.

The application process opens October 8. Applications are due January 3, 2011, and winners will be announced in April 2011.

For more information and to apply online, go to www.PHAssociation.org/LantosAwards or contact Adrienne Dern at Adrienne@PHAssociation.org.

Have an Innovative Idea? Get It Funded!
Apply for a Tom Lantos Innovation in Community Service Award

Even if you don’t consider yourself a grant writer — and not too many people do — you can receive funding for your pet project through the Tom Lantos Innovation in Community Service Awards program.

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Above: A 2010 project funded by a Service Award.
Right: Tom Lantos

Jack and Marcia remember the moment when they knew something was not right with their five-year old daughter, Emily. It was at a Fourth of July parade, and Emily was having trouble keeping up with the other children on her bike. Initially, her pediatrician thought Emily was just out of shape. But when Jack and Marcia noticed Emily’s blue lips and fingernails, they pushed for an appointment at Texas Children’s Hospital. They received the diagnosis that left them in shock and disbelief.

To read how the Stibbs family rallied around Emily, and didn’t accept her first prognosis, visit PHAssociation.org/Give/Stibbs.

Like Jack and Marcia Stibbs, you can strike a blow against PH by designating PHA as a legacy beneficiary. Your contribution will help shape a brighter future for all those affected by PH. For details, call us at 301-565-3004 x767, or email giving@PHAssociation.org. Visit our website for more information at PHAssociation.org/Give.
Sometimes, educating others about PH is the inspiration we need to keep us putting one foot in front of another. As Theresa Stahl, PH patient from Defiance, Ohio, says, “To me, that’s the crowning glory of persistence, right? If I can even help just one more person, that’s all I hope for.”

What PH mountains have you summited? During PH Awareness Month this November, join PHers all over the world in sharing your story and raising awareness about PH in your local community. You’ll find ideas for getting involved throughout this issue of Pathlight and at www.PHAssociation.org/AwarenessMonth2010

Together, we’ll climb further than ever before on the path to a cure.

By Katie Kroner
PHA Director of Advocacy and Awareness

PH 2.0: Using the Web to Fight Against PH

The Internet can be powerful in the fight against PH. Online tools make it easy for you to raise awareness and funds from the comfort of your computer chair. Here are some ways to get involved during Awareness Month and all year long.

**Advocacy Action Alerts:** Email your senators and representative in support of federal funding for PH research and education through PHA’s e-advocacy tool. www.PHAssociation.org/Advocacy/Alerts

**Web of Friends Personal Fundraising Pages:** Setting up a personal fundraising page is free and easy. Personalize your page with your PH story, and then invite your friends and family to support you by sending the link across the country — or the world — in just minutes. www.PHAssociation.org/Fundraise/Online

**Facebook:** Become a fan of PHA’s Facebook page, and then share our posts with your network of friends. See p. 24 for more information.

**Twitter:** Follow PHA’s Twitter feed and retweet our tweets to your followers. See p. 24 for more information.

**Blogging & Other Social Networking Sites:** Subscribe to our What’s New in Pulmonary Hypertension RSS feed and share the information with your friends on other social networking sites or write about it on your personal blog. www.PHAssociation.org/WhatsNew

During Awareness Month 2009:

» Colleen Connor of Pennsylvania shared her PH story with Senator Bob Casey. Less than an hour after they were first introduced, Senator Casey agreed to sponsor the PH Research and Education Act of 2009. Pictured left: Colleen Connor (foreground) hearing the news about Sen. Casey. Learn more about advocacy opportunities: www.PHAssociation.org/AdvocacyActionCenter

» Pat Hellyer’s 3rd Annual South Florida PH Fun Walk brought her community together in support of PH research and PHA programs. Her state representative kicked off the event and her U.S. representative donated a flag that had flown over the Capitol. Learn more about fundraising for a cure: www.PHAssociation.org/SpecialEvents

» Diane Ramirez (pictured right) was sitting in a doctor’s office, flipping through a handy magazine when she got her Awareness Month inspiration. She made a call and offered her story to a reporter at the magazine, and it was published. The magazine distributed 22,000 copies to 100 locations in Davidson County, N.C., including hospitals, doctors’ offices and physical therapy centers. Learn more about connecting with the media: www.PHAssociation.org/Awareness/ThroughTheMedia

» Annette Markin and Carol Lindstrom shared their PH stories with their local elected officials. Not only did their local governments issue PH Awareness Month proclamations, but they received coverage in their local papers. Learn more about requesting a proclamation: www.PHAssociation.org/Awareness/Proclamations
U.S. Representative Pledges to Co–Sponsor
PH Research and Education Act After District Visit

As we go to press, advocates across the country are contacting their Members of Congress as a part of PHA’s District Visit Campaign. One of those advocates, Merle Reeseman, scored a victory for PH when Representative Jason Altmire [PA-D 4th] visited her Pittsburgh Pulmonary Hypertension Support Group. During his hour-long visit, Altmire spoke about pulmonary hypertension and healthcare legislation in Congress, and he answered questions from some of the 40 support group members in attendance. Altmire even had Merle jumping out of her seat when he surprised the support group by announcing he would co-sponsor the Tom Lantos PH Research and Education Act.

“When I get back to Washington, D.C., in September, I will do everything I can to get my colleagues to co-sponsor this bill,” Representative Altmire announced. “It passed in the House before; we can get it to pass again.”

His announcement was the culmination of five months of work. Merle knew how quickly a Member of Congress’s calendar can fill up, so she contacted his district office in March to schedule a district visit. “Just because they are Congressmen doesn’t mean they know everything about this bill. It’s important for us to let them know about it,” Merle says.

Congratulations to Merle and to everyone reaching out to their Members of Congress during this year’s District Visit Campaign!

Will your Member of Congress be the next to co-sponsor the Tom Lantos PH Research and Education Act? PHA can help you work with your Member of Congress to fight PH through legislative advocacy. Contact Elisabeth, PHA’s Grassroots Campaigns Associate, at 301-565-3004 x753 or Elisabeth@PHAssociation.org to find out if your Member of Congress is a co-sponsor and to learn more about getting involved with legislative advocacy.

 Invite Your Members of Congress to PHA’s Congressional Luncheon!

We always think that one person can’t make a difference, but I think we’ve proved today that they can.

~ PH Lobby Day participant, 2009

Help us bring at least one Member of Congress from every state to this year’s Congressional Luncheon where they’ll learn more about PH and how they can support funding for PH research.

Visit www.PHAssociation.org/GetInvolved/ CongressionalLuncheon or call Katie at 301-565-3004 x749 to:

» See current event details
» Find a sample script for inviting your Member of Congress
» RSVP to attend this free Luncheon

Representative Jason Altmire [PA-D 4th] speaks to the Pittsburgh Support Group. “I walked up to him after he pledged his support and put both the PHA ribbon pin and the Hope for a Cure pin on his lapel!” Merle says.

Jeanette Morrill during PHA’s 2009 Lobby Day
Thanks to the widespread popularity of social media websites like Facebook and Twitter, there are all sorts of quick and easy ways for you to make a difference this Awareness Month. Social media sites are websites designed to help people share and discuss information they care about. Friend-to-friend connections on these sites help you make awareness-raising messages personal. If you’re already using one of these sites, then you know the potential for brief, compelling posts to be shared many times over. If you’re new to social networking, signing up is easy and free. Just visit www.facebook.com or www.twitter.com to start your account. Then read on for some ideas to make the most of your account as you spread the word about PH this Awareness Month. The following ideas are designed for Facebook but can easily be adjusted for tweeting on Twitter as well.

10 Ideas for Spreading PH Awareness on Facebook

1. Follow PHA on Facebook at www.facebook.com/PulmonaryHypertensionAssociation and invite your friends and family to do the same.

2. Join the conversation on PHA’s Facebook wall. Share, post and comment about the things that matter most to you.

3. Join PHA Online Messengers to begin receiving weekly emails with stories and stats to share with your network. Sign up at http://groups.google.com/group/PHAonlinemessengers (membership requires a free Google account).

4. Write a Facebook note about how PH affects your life. Tag 10 friends and ask them to share your story with 10 of their friends.

5. Change your Facebook photo to the PH Awareness Flame Guy. You can easily download this image from PHA’s website: www.PHAssociation.org/PHAImages

6. Mention pulmonary hypertension in the “About Me” section of your profile. Include a link to PHA’s website so your friends know where they can go to learn more.

7. Start a video blog about your life with PH. Share your videos on Facebook.

8. Share a PH fact or statistic in your Facebook status at least once a week. Use one of your own, or try one of these:
   - 1. Unwrap a drinking straw.
   - 2. Hold your nose.
   - 3. Breathe through the straw for one minute. Still with me? Pulmonary hypertension is an under-diagnosed lung disease that can make breathing this difficult 1,440 minutes a day. Learn more: www.PHAssociation.org
   - In the U.S., about 1,000 new cases of pulmonary hypertension are diagnosed each year.
    - Breathlessness isn’t always asthma. Sometimes it’s pulmonary hypertension. Spread the word.

9. When you come across interesting articles about pulmonary hypertension or PH patients, share the links on your Facebook wall. Include your thoughts, or ask a question to get your friends talking.

10. Write a Facebook message to your friends and family and ask them to become a part of PHA’s Awareness Month activities, on and offline! Send them to www.PHAssociation.org/Awareness to get involved.

Follow PHA on Facebook and Twitter!

www.facebook.com/PulmonaryHypertensionAssociation

www.twitter.com/short_of_breath
Just over two weeks before his 51st birthday, Stuart Berwick received a message from Facebook Causes:

“Your birthday is coming up. Why not celebrate by asking your friends and family to support a cause that’s important to you and create a Facebook Birthday Wish?” Within minutes Stu had set up his Facebook Birthday Wish, set a fundraising goal, and sent his first (of many) messages to family and friends about this fun and unique way to say “Happy Birthday!”

Facebook Causes is an application that helps individuals leverage their social network to effect positive change. Any Facebook user can create a cause, recruit their friends to that cause, keep everyone who supports the cause up-to-date on issues and, last but not least, raise money directly through the cause to support a registered U.S. 501(c)(3) nonprofit or Canadian registered charity.

Stu became an active participant in PHA’s Facebook Cause in January 2010. Up until then, he had primarily used Facebook for fun, games and limited socializing. “I realized I had wasted a year,” Stu says, and from that moment forward he pledged to himself to find every single PH patient on Facebook.

As Stu made more contacts on Facebook, he built his network of PH Facebook friends, which in turn helped him find more and more PHers all across the world. “My ultimate goal,” Stu says, “is to become the clearing-house for PH information on Facebook.” At this point, Stu is so well-known in the PH Facebook community that he no longer has to seek out patients — they find him through his many PH-related activities on Facebook, such as his Facebook Causes activities.

Stu originally set a modest $250 goal for his Facebook Birthday Wish. And, thanks to generous donations from family, friends and his many online PH friends, Stu exceeded his original goal in just a week. But Stu didn’t stop there. He continued to send messages to everyone he knew — those who used Facebook and those who didn’t — asking them to make a donation to PHA in honor of his birthday. By the close of his Facebook Birthday Wish, Stu had raised $410 for PHA from 12 donors. “There is nothing anyone could buy me that equals their making a gift to PHA,” Stu says. “Not even close.”

Stu’s campaign wasn’t without its challenges. For 10 days during his Birthday Wish, he experienced technology problems at home and was without internet access. “I’m going to do so much better next time,” Stu says. “My Internet issues have been resolved, and now my Facebook network is so much larger. Who knows how much I’ll be able to raise!”

Facebook isn’t the only way you can ask friends and family to support a cause so important to you. PHA has two programs that are similar to Facebook Birthday Wishes: Web of Friends, which gives you a personal fundraising page where you can share your PH story and ask others for donations to PHA, and In Honor of Our Lives, a special program for incorporating PH fundraising in personal milestone celebrations.

To learn more about Facebook Birthday Wishes, Web of Friends, In Honor of Our Lives or the many other ways you can help raise funds for PH research and patient and family services, contact Jennifer Kaminski at Jennifer@PHAssociation.org or call 301-565-3004 x756.

By Jennifer Kaminski
PHA Development Associate

Stay Informed! Get the latest news about developments in the field of PH and PHA activities. You can sign up to receive alerts via email or RSS feeds.

www.PHAssociation.org/News
Kissing for a Cure? PuckerUp4PH this Fall!

What do teenage boys in California share in common with seniors in Canada and moms in Florida? They’ve all lent their lips to save lives! This fall, PHA United Kingdom is again spearheading the international PuckerUp4PH campaign and you can be a part of raising PH awareness and setting a Guinness World Record! More than 400 PHers kicked things off for the U.S. effort at our 9th International PH Conference in June, and groups around the world are lending their lips to save lives as well. If you’re looking to spice up your next support group meeting, special event or to get your community to recognize the symptoms of PH (including cyanosis, or blue lips), contact PHA and request a complete PuckerUp4PH Kit — we’ll send official postcards, blue lipstick, stickers, fliers and more. Lending your lips will give you the edge as you plan your Awareness Month activities, and will help PHriends in nearly 30 countries as we race toward a record. To learn more about the campaign, visit www.PuckerUp4PH.com. Ready to get involved? Contact Christine@PHAssociation.org to request your free kits today!

By Christine Dickler
PHA Associate Director of International Services

PH Understanding Goes Global

If you haven’t picked up your copy of the newly revised Pulmonary Hypertension: A Patient’s Survival Guide, what are you waiting for? This book is the most comprehensive patient-friendly resource you could find... on every continent! This fall, the first Farsi translation is available in Iran. Bardia Farzamfar, PharmD, PhD, translated the guide after his young daughter was diagnosed with PH. His work produced the sixth complete translation of the Survival Guide; patients and doctors in China, Japan, Taiwan, Korea and the Spanish-speaking world are also reading this PH-bestseller. Visit www.PHAssociation.org/PHInternational/Languages for more information about translations, or www.PHAssociation.org/Store to order your copy of the English guide.

PHA is proud to support the global recognition of lung diseases through the American Thoracic and Forum of International Respiratory Societies’ 2010 campaign: The Year of the Lung.

www.YearOfTheLung.org | www.PHAssociation.org
A Look at Healthcare Reform in 2010

Since the passage of the Patient Protection and Affordable Care Act (PPACA) in March, the U.S. healthcare system has been a hot topic in the news. In fact, PPACA is expected to bring so many changes that some of the components of the law will not take full effect until 2020 because of the amount of work it will take to construct and implement the new regulations effectively.

With the full impact of the law yet to be seen, it’s hard to predict exactly what the healthcare insurance system will look like in 2020. Still, PHA is working to keep you updated with reliable information about healthcare reform changes. Here’s a recap of some milestones we’ve seen this year:

» **March 2010**: President Obama signs PPACA into law.
» **June 2010**: Medicare Part D beneficiaries who have reached the donut hole receive a $250 rebate, part of the eventual phase-down of the Medicare Part D coverage gap.
» **July 2010**: High risk insurance pools begin, available to individuals who have been uninsured for at least six months because of pre-existing conditions. The plan is a temporary solution until 2014 when all discrimination against pre-existing conditions will be prohibited.
» **July 2010**: The Department of Health and Human Services outlines standards for preventative care benefits; all new insurance plans administered after September 23, 2010, will be required to cover these benefits without charging a copayment, coinsurance or deductible.
» **September 2010**: Plans must allow young adults to stay on their parents’ plan until they turn 26 years old.
» **September 2010**: Insurance plans are no longer allowed to impose lifetime caps on essential benefits or deny coverage to children under the age of 19 with a pre-existing condition. Companies are also prohibited from rescinding coverage.
» **September 2010**: Consumers have the right to appeal denials directly to their insurers and then, if necessary, to external review boards, even if the patient is covered by a self-insured company.

Visit [www.healthcare.gov](http://www.healthcare.gov) for more details. Don’t forget to let us know how healthcare reform has affected you. Contact Margaret with your feedback and questions at 301-565-3004 x773 or send an email to Insurance@PHAssociation.org.

By Margaret Beardsworth

PHA Insurance Program Manager

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**Insurance Finds:**

**Tips for Applying for Social Security Disability (SSD)**

Did you know that 30 percent of SSD applicants get approved on their initial application? Visit the new SSD section on our Online Insurance Guide to learn how you can be in that 30 percent. Find more tips and resources, including:

- A patient starter-kit with successful PH-based SSD applications to reference.
- An inside look at how the SSA views PH, including an educational video.
- A detailed outline of the disability process.

www.PHAssociation.org/Patients/Insurance/Disability

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**Call for Template Letters! Help Expand PHA’s Insurance Letter Library**

PHA currently offers several insurance-related template letters to help you negotiate challenges with insurance companies. Our insurance letter library is off to a good start, and we are continuing to expand it to provide additional tools for patients and medical professionals.

If you have letters you’ve used to successfully appeal to insurance companies — with topics ranging from home oxygen approval to flying with medical equipment — now is your chance to share them with the PH community. Check out our current template collection or submit a new letter at www.PHAssociation.org/Patients/Insurance/FileClaim/Templates.

Questions and letter submissions can also be directed to InsuranceLetters@PHAssociation.org or 301-565-3004.
Lantos Award Turned My Dream into Reality

Editor’s Note: The Lantos awards program (see p.21) helped turn one support group leader’s inspiration into an engaging and unique PH awareness-raising tool. Here’s how it happened.

One day while visiting my sisters, our dogs began panting with anticipation of the mailman’s imminent arrival. My sister said, “They’re huffing and puffing. That must be what the Big Bad Wolf was doing.” The thought then hit me that I huff and puff all the time because of my pulmonary hypertension. Being a professional communicator, I realized I had just struck gold. Why not use the Big Bad Wolf’s image on a poster to spread the word about this disease? I knew the Wolf’s likeness would draw the attention of passersby.

So I gave the wolf a canister of portable oxygen and a bedraggled look to show how PH had sapped his energy. The Three Little Pigs appeared carefree because they knew the wolf could not harm them anymore.

The members of my support group — which serves the Hershey/Harrisburg area of Pennsylvania — not only liked the idea of the poster as a November Awareness Month project, but suggested that the poster could be put to good use to promote PHA support groups. So I included space at the bottom of the poster for a support group’s name and contact number, and the poster became one that could be used nationwide.

Once I learned about the Lantos awards program, it became very easy to turn the idea of the poster into reality. After just a couple hours of my time completing the application and calling printers for estimates, my request for funding was ready and in the hands of PHA’s Lantos Grants review board. I worried that the committee would have questions or wouldn’t accept my application because some vital piece of information was missing. But I was assured by PHA’s Senior Vice President Adrienne Dem that the committee was working with applicants to understand their requests fully and wouldn’t simply reject an application because it “wasn’t done right.”

Imagine my excitement when I learned that not only had I been selected to receive the grant, but that PHA and the grant committee loved the suggestion to make quantities of the poster available to PHA’s more than 230 support groups. And I was pleased that PHA wanted the poster available in time for distribution to support group leaders at PHA’s International Conference in June.

My portion of the work was done on a volunteer basis, but the grant allowed me to provide a small stipend to the graphic artist who turned my idea into the colorful and attractive poster you see here, and sufficient funds to produce 5,000 copies. PHA is so excited about the poster, it’s making them available as a free item in its online store for anyone who wants to spread the word about PH in their community. Visit www.PHAssociation.org/Store to request copies.

Finally, I was thrilled to hear from PHA’s Director of Volunteer Services Debbie Castro that the posters were being enthusiastically snatched up at PHA’s Conference. Now let’s hope the posters do their trick of telling the story of PH and its symptoms, and of providing information about PHA and its local support groups, so that more people can be diagnosed early and live happily ever after!

By Donna Caterini
Hershey and Harrisburg (Penn.) Support Group Leader

Welcome, Sophie Klein, Volunteer Services Associate!

As PHA’s Volunteer Services Associate, Sophie manages the Support Group Central Fund, providing support groups with funds they can use to enhance social aspects of meetings, including offering food. She also manages the mailings of support group meeting reminder cards to PHA’s members. Sophie is originally from Minnesota, and she graduated this past May with a Bachelor’s Degree in English from Grinnell College in Grinnell, Iowa. Sophie can be reached by email at Sophie@PHAssociation.org or by phone at 301-565-3004 x758.
Leaders Empower Each Other During Conference Training

PHA’s 9th International PH Conference in June was the largest gathering of the PH community in history. So it’s no surprise that it was also the largest gathering of our PHA support group leaders. During Conference, PHA hosted a special Support Group Leader Networking Luncheon and Training for 130 leaders.

What happens when you bring these leaders together under one roof? Idea sharing, support, mentoring and inspiration. New leaders benefited from the advice of seasoned leaders, and long-time leaders gained fresh perspectives, new ideas and a jolt of excitement from the new leaders.

Betty Lou Wojciechowski, former support group leader in Orange County, Calif., and Carl Hicks, former PHA Board Chair, spoke about their involvement as Board Members working closely with support groups. Carl also spoke about the future of support groups and how excited he is to help get members of the Board more involved with our groups and leaders.

During the luncheon, PHA also introduced new resources to help all leaders run their groups and raise PH awareness. We premiered a new awareness poster designed by Support Group Leader Donna Caterini and based on the “Huff and Puff” theme from the “Three Little Pigs” children’s story.

At PHA, we know that running a support group is fun but challenging. It involves running a meeting, facilitating conversation, inviting speakers, advertising, reaching out to new patients and more. Through training opportunities like this luncheon, we try to give leaders the encouragement and support they need to make their groups as strong as possible.

By Debbie Castro
PHA Director of Volunteer Services

PHA’s Patient-to-Patient Support Line: New Name, Same Great Service

Have you ever spoken with another PH patient? If so, you know how amazing that connection can be. Finally, someone who understands! you can have that same experience again — or for the first time — right now from the comfort of your home.

PHA’s Patient-to-Patient Support Line (formerly known as the Patient-to-Patient Helpline) is staffed by friendly, long-term patient survivors. They can answer patients’ and loved ones’ PH questions, lend a sympathetic ear or help solve problems or issues relating to living with PH.

A patient is always there to hear your story, give you feedback and tips, connect you with a service or organization, find a local doctor, or see if there’s a support group near you.

This line is not answered by PHA staff members or medical professionals; it’s more personal than that. It’s a unique service that immediately connects a patient or their caregiver with another patient for direct support. And it’s not just for newly diagnosed patients. Whether you are newly diagnosed or a long-term survivor, you can call this line for information and support.

Call the Patient-to-Patient Support Line to:
1. Talk to another patient right away
2. Ask questions and get tips about living with PH
3. Find a local doctor
4. Vent!
5. Find a local support group
6. Get feedback from a long-term survivor
7. Learn more about PHA
8. Learn how you can get involved with PHA

Call 911 for emergencies, and for anything else, call on us (daytime only, please!)
As she stepped into the role of leading the Cincinnati, Ohio/Northern Kentucky Support Group and began planning the calendar of events, Pam Carner’s mind was racing. She was not completely sure of what meeting topics and events would be good for the group, so she turned to one of the many resources that PHA provides support group leaders: the Yahoo! Groups Leaders Forum.

Yahoo! Groups allow support group leaders from across the country to connect with one another, network and provide support. Pam took the first step and introduced herself to the forum as a new leader, and she immediately received warm welcomes and ideas from many in the network of more than 230 leaders. One of the welcomes she received came from Carl Hicks, who was PHA’s Chair of the Board of Trustees at the time. Although Carl lives in the Northwest, he has family in Ohio and told Pam he would love to attend one of her support group meetings. Pam jumped at his offer, and they set a date for the event.

As Pam explains, “Carl was just a friendly and outgoing guy. I could not believe he would be willing to travel across the country for my meeting.”

Pam started planning for this event several months in advance and was able to find co-sponsorship from United Therapeutics and LungRx. Together, they secured the private dining space at McCormick and Schmick’s Seafood Restaurant in Cincinnati. “I was so excited for this event,” Pam says. “I wanted it to be a hit with the community!”

Pam started marketing to her support group and the other PH support groups in the area. She also contacted the local newspaper and private-access TV channels to help reach out to a larger and more diverse population.

Pam believes that “the best type of marketing is word of mouth; that’s how you get the best [turnout].” Word of mouth — with the assistance of the resources that PHA provides — helped Pam fill the private room to capacity for this exciting event.

When the night of the event came, Pam was thrilled that her months of planning were about to pay off. The room at McCormick & Schmick’s quickly filled in anticipation of Carl’s speech. “The energy in that room was vibrant,” Pam says. “[You] could feel the energy from the attendees!”

Once Carl arrived, he started his talk, welcoming everyone and giving a brief history of who he was and how he came to be involved in the PH community. He recounted the story of his daughter Meaghan, her struggle with PH, and his own desire to continue the fight in Meaghan’s memory and in honor of everyone who continues to fight.

“It was captivating; he has always been a captivating speaker,” Pam says. “Carl talked and you could have heard a pin drop with the attention the attendees gave him.” Pam explains that in addition to his talk, Carl really wanted to touch base with every single person in the room. “It was more important to Carl to talk with each patient and caregiver in the room than to eat the fantastic meal! Now that’s dedication!”

By the end of the evening, Carl had given hope to everyone in the room. And Pam was well on her way as a support group leader.

The PHA Board of Trustees is a group of individuals who have close ties to the PH community and value the opportunity to attend support group meetings and events. As Pam says, “They are accessible!” If you want to learn more about the members of the Board of Trustees, visit www.PHAssociation.org/BoardofTrustees. One of them might be able to come to your next support group meeting!
Support Groups Make an Impact at PHA's 9th International Conference

The Wojo South Orange County Support Group hosted the official Welcome Table at PHA's 9th International PH Conference in June. The leaders organized shifts for members to staff the table throughout the event. Members of the local group provided warm smiles and information to all attendees.

Support Group leaders were a huge part of our volunteer crew. Here, Atlanta, Ga., Support Group Leader and Board Member Sally Maddox (left) and her mother, Mary Felkel, pose wearing their volunteer shirts. Sally helped with registration and as a room host while Mary worked the PHA store for 90 percent of the entire Conference!

Three support group leaders lend their perspective and expertise at a patient-led session "When People Just Don’t Understand PH" at PHA’s 9th International PH Conference. L to R: St. Louis Support Group Leader Amanda McKee; Southside, Va., Leader Sheree Rickman; and Dallas Support Group Leader Marcia Beverly.

Washington, D.C., and Silver Spring, M.D., Capital Breathers Support Group Leader Alex Flipse (right) speaks at the "Creative Connection" skill building session at PHA's 9th International Conference. She is joined by long-time PH advocate and former Wojo Support Group Leader Betty Lou Wociejchowski (center) and PHA Volunteer Services Director Debbie Castro (left).
Thank you, Interns!

PHA greatly appreciates our summer 2010 interns, whose enthusiastic support and commitment 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.

Amanda Martin, Publications Intern
Amanda Martin, a senior from Grove City College, Penn., joined us this summer as the Publications Intern. During her time at PHA, she worked on Pathlight, attending planning meetings, conducting interviews and writing and editing articles. She also assisted the Office of the President in designing and preparing print materials for PHA’s International PH Conference, and started work on a redesign of Pulmonary Hypertension: A Patient’s Survival Guide. She enjoyed her opportunity to get involved in so many different printing processes. She returned to Grove City College in the fall, where she will receive her B.A. in English in spring 2011.

Amy Butler, Meetings Department Intern/Office of the President Intern
Amy Butler currently attends the University of Maryland, College Park, where she studies Organizational Sociology. She started her internship with PHA in January, and spent many months helping to prepare for PHA’s International Conference, with a particular focus on setting up the Kids’ Room and arranging fieldtrips. “I [was] very appreciative — and lucky — to get to go to Conference,” Amy says. Post-Conference, Amy worked with the Office of the President to organize PHA’s archives and historical documents. After her graduation in 2011, Amy plans to study NonProfit Management in grad school, with the goal of someday running her own nonprofit.

Ellen Leoni, Advocacy and Awareness Intern
Ellen Leoni joined PHA as our Advocacy and Awareness Intern after a conversation with PHA staff at an internship fair piqued her interest. As an intern at PHA, she helped to coordinate Advocacy and Awareness programs, starting with the August District Visits. She also collected feedback on PHA’s Action Kits in preparation for Awareness Month and helped to organize the Congressional Luncheon, among other projects. She says she enjoyed her internship because of the insights it gave her into the human component of awareness raising. Ellen will graduate from American University in December with a B.A. in American Studies and Psychology.

Naeha Gupta, Medical Services Intern
A senior at the University of Maryland, College Park, Naeha Gupta came to PHA as the Medical Services intern. Her responsibilities included putting together PHA membership packets for medical professionals and sending them to new members. She also helped collect information and identify an effective format for an emergency medical services flipbook, which will help medical workers assist PH patients experiencing emergencies. “I’m usually in a hospital wearing scrubs,” Naeha says, “so it’s good to see the other side of things.” She will graduate from the University of Maryland in 2011 and plans to apply to medical school.

Janelle Winters joined PHA as a temporary staff member for summer 2010, working with the Medical Services department. She has a Bachelors degree in Zoology and the History of Science, Medicine and Technology from the University of Wisconsin-Madison, and received her Masters degree in Epidemiology and Public Health from Yale in spring 2010. Her interests in nonprofits and international health led her to PHA. Throughout the summer, she worked with PHA’s Online University, improving the evaluation system to enhance the quality of the courses offered. Janelle left PHA at the end of the summer to teach biology. Thank you, Janelle!
Race 2 Cure PH: Taylor Caffrey Memorial 5K Run/Walk

On June 5, the inaugural Race 2 Cure PH: Taylor Caffrey Memorial 5K Run/Walk took place in Anaheim Hills, Calif. Honoring the life of 4-year-old Taylor, who lost her battle with PH in September 2009, the race brought an entire community together, netted nearly $30,000 for PHA’s Research Program and helped a family cope with the grief of an all-too-soon loss of a very special young girl.

Taylor’s mother, Shari Caffrey, who organized the event with her husband Michael and a committee of dedicated family and friends, explains, “Tay’s passing was such a shock. When something like that happens, you begin running through the ‘If only’s’ — if only she had been diagnosed sooner, if only we had more knowledge of PH.”

The Caffreys took these “If only’s” and changed them into a “Let’s do something about it” mentality. Toward the end of 2009, Shari and Michael began exchanging ideas and pulling together a planning committee of friends and family to brainstorm awareness-raising ideas. Eventually, they settled on a fun run. “From the beginning, we knew we wanted it to be a family-friendly event,” Shari says.

The Caffreys and the Race 2 Cure PH committee stayed true to this vision. Taylor’s personality was woven into nearly every aspect of the day — from the blue balloons (Taylor’s favorite color) to pictures of Taylor on each mile marker, to Rice Krispies treats and glow-in-the-dark bracelet giveaways for children. “We found inexpensive ways to make kids happy,” she says.

Nearly 600 registered walkers and runners came out to support the cause, including athletes, community groups, extended families, schools and companies — many who put together their own walk teams. “[The day] felt almost like a wedding!” Shari exclaims. “People not only showed up, but they cared. Our mission was to get the word out about PH. I think that’s the reason we haven’t found a cure — not that people don’t care, but there’s not enough information available to the general public. That information has the power to move people to action. The most amazing thing to me was that everyone was moved to action that day.”

So what’s in store for the 2nd Annual Race 2 Cure PH scheduled for June 4, 2011? In addition to maintaining a strong emphasis on PH education, the Caffrey family has plans to “go bigger, better, louder, with more exposure!” Shari explains. A 1K fun run will be added for the very young, and additional vendors will be there so the planning committee can truly promote the event as a “family fun day” for the entire community.

And of course, Taylor’s legacy will continue to live on through each future race. “I’d like to think Tay is an inspiration to the PH community. She was 4 ½ and had her whole life to live,” says Shari. “There’s always hope; it’s what wakes you up every day.”

For more coverage of the Inaugural Race 2 Cure PH, visit PHA’s featured special event stories at www.PHAssociation.org/SpecialEvents/FeatureStories

For more information about Race 2 Cure PH and related events, visit www.TaylorsWish.org

Turning Grief to Hope: Shari Caffrey in her own words

Last September, we lost our 4-year-old daughter Taylor to PH. We were devastated, and we began our journey through the stages of grief: shock/denial, pain/guilt, and anger. That is when I decided that I was going to do something about it.

I sought help from PHA. The staff encouraged me when I got depressed or doubted my ability to do Taylor’s memory justice. Happily, I got to talk about Taylor, which was very therapeutic. My grief started turning. I began working through my feelings of loss.

Although emotionally difficult at times, it was quite cathartic. I have not completely accepted Tay’s passing yet. But, I do have hope for our future and for the future of PH research.
What Does It Take to Plan a Special Event?
Fundraising through a special event: The second in a four-part series.

Hosting a special event gives you and your community the chance to contribute to PH research, patient services and education. Deciding to host a special event is a big step, but there’s no reason to get overwhelmed as you begin planning — not even over money matters!

Your event can generate funds through two sources: sponsors and donors, and participants. Your task is to develop a strategy that integrates both to the best extent.

**FUNDRAISE THROUGH SPONSORS AND DONORS**

Your creativity in finding and soliciting sponsors, as well as making the most of their donations, will make a huge impact on your event. Even if sponsors decline to give money, don’t rule them out! Their donated goods and services can drastically reduce your expenses.

**Make a contact list.** Family and friends’ workplaces, local businesses and even specialty pharmacies may all be interested in supporting your event.

**Face-to-face time is key!** Contact potential sponsors in person, bringing them news of your event, with details included in a letter or packet. Promise to honor their donation with recognition at the event — for example, including company information in participants’ goody bags. Businesses are attracted by the opportunity to advertise at your event! **Tailor your requests to fit your needs and a sponsor’s ability to meet them.** Some businesses may support the event by donating items or gift cards for use in a raffle or silent auction. Grocery stores and restaurants may provide food. Printers may provide special rates for fliers and signs.

**FUNDRAISE THROUGH PARTICIPANTS**

As you coordinate your event, decide whether you want to ask participants for a registration fee, set a personal fundraising goal or some combination of both.

If you decide to charge a registration fee, keep your own costs in mind, as well as what participants will get from attending the event. Event coordinators generally ask for $15-$35 for fun walks/runs, $50-$150 for galas and $75 or more for golf tournaments.

You can reasonably increase your fee if you are providing other goods or services (including donated goods or services) to participants. You can encourage involvement by offering discounts — for example, creating family/group registration rates or discounts for children 12 and under.

If asking participants to set a personal fundraising goal, encourage them to raise the money in advance by finding their own sponsors. These participants then present the money before or at the event in order to take part. PHA offers easy-to-use online fundraising tools for special events, making personal fundraising goals easy to reach! For more information, contact Jessica McKearin, PHA’s Special Events Manager, at Events@PHAssociation.org or 301-565-3004 x765.

**DON’T JUST TAKE OUR WORD FOR IT!**

Here’s a real-life example of a mother-daughter duo from the PH community who took a creative idea and ran with it. And the awareness-raising and fundraising results followed! For the past two years, teenage PH patient Lauren Johnson has pulled off the successful fundraiser, *Painting a Stroke of Phenomenal Hope*. Inspired by a cake decorating fundraiser, she and her mother, Melissa Johnson, turned Lauren’s love of art into an event. Lauren asked friends at an art studio to paint a picture in only an hour and a half, and then contribute their work to a silent auction. Participants paid for games and food, which were supplied by donors such as local restaurants and Lauren’s church. Lauren was able to provide a carnival for the children as well. “It’s amazing to see how it goes from nothing to huge,” Lauren says.

Lauren recommends that event planners really try to give themselves enough time — don’t rush! The first time she put on the fundraiser, she only had two months, which was very stressful. The second time, she gave herself six months to plan everything, contact the media and hand out fliers.

When it comes to planning a fundraiser, be ready to incorporate anything people are willing to give you. “It’s a matter of asking and not being afraid,” Lauren says.

For more information about writing letters to sponsors or planning special events in general, visit the Special Events section of PHA’s website at [www.PHAssociation.org/SpecialEvents](http://www.PHAssociation.org/SpecialEvents) or contact Jessica, PHA’s Special Events Manager, at JessicaM@PHAssociation.org or 301-565-3004 x765. *Look for the next part in our series, “What Does it Take to Plan a Special Event?” in the next issue of Pathlight.*
Participants battle it out in the putting contest that kicked off the 3rd Annual Swing 4 the Cure — Wojo PH Golf Classic. The event took place in Tustin, Calif., and raised more than $35K for PH research.

This group poses for a picture at the 2010 JFK Tower Golf Tournament in White Plains, N.Y. The long-standing fundraiser is held annually in honor of Rachel Abraham.

Lil “Battle” Long takes the stage during the Long Battle for Nicky Fundraiser in Cleveland, Miss. Long held the event in July in memory of her best friend Nicky Roberts and continued to honor Nicky and spread PH awareness by swimming the Mississippi River in September.

A place setting is displayed at one of the PHood PHight Against PH house parties in Emeryville, Calif. Organizer Denise Bradby hosted several of these dinner events.

The Minnesota PH Support Group — along with family, friends and medical professionals — gathered together at the 10th Annual Picnic in August. The group had its biggest attendance yet and enjoyed a sunny day filled with food and fellowship!
## PHA Upcoming Events

<table>
<thead>
<tr>
<th>Date</th>
<th>Event Name</th>
<th>WHERE</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sat., Oct. 16, 2010</td>
<td>PHA Benefit Concert</td>
<td>Austin, Texas</td>
<td>Whit Harrington at <a href="mailto:whitharrington@hotmail.com">whitharrington@hotmail.com</a> or 512-804-1565; or Al Shire at <a href="mailto:alshire1@gmail.com">alshire1@gmail.com</a></td>
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<tr>
<td>Sat., Oct. 23, 2010</td>
<td>2nd Annual “Through Tears Comes Laughter: An Afternoon of Comedy to Benefit PHA”</td>
<td>Cornelius, N.C.</td>
<td>Glenn Johnson at <a href="mailto:gajohnson1214@yahoo.com">gajohnson1214@yahoo.com</a></td>
</tr>
<tr>
<td>Fri., Nov. 5, 2010</td>
<td>8th Annual Inland NW PAH Support Group Luncheon</td>
<td>Spokane, Wash.</td>
<td>Linda Pall at <a href="mailto:lpall@wsu.edu">lpall@wsu.edu</a> or 509-335-3080</td>
</tr>
<tr>
<td>Sat., Nov. 6, 2010</td>
<td>3rd Annual Baltimore PH Walk for Hope</td>
<td>Baltimore, Md.</td>
<td>Janice Frederick at <a href="mailto:jfrederi@medicine.umaryland.edu">jfrederi@medicine.umaryland.edu</a> or 410-328-7260</td>
</tr>
<tr>
<td>Sat., Nov. 6, 2010</td>
<td>Phenomenal Hope for a Cure</td>
<td>Omaha, Neb.</td>
<td>Cindy Klein at 402-699-0733 or <a href="mailto:klein1058@aol.com">klein1058@aol.com</a></td>
</tr>
<tr>
<td>Sat. &amp; Sun., Nov. 6-7, 2010</td>
<td>J. Patrick Garcia 5K Fun Walk/Run &amp; Benefit Lunch</td>
<td>Albuquerque, N.M.</td>
<td>Jason Garcia at 505-506-3211 or <a href="mailto:jpatrick20@gmail.com">jpatrick20@gmail.com</a></td>
</tr>
<tr>
<td>Sun., Nov. 7, 2010</td>
<td>10th Annual Race Against PH</td>
<td>Stanford University Pac-10 Plaza, Stanford, Calif.</td>
<td><a href="http://raceagainstph.org">raceagainstph.org</a> or contact Lori Barth or Victoria Rodriges at <a href="mailto:wallcenter@stanford.edu">wallcenter@stanford.edu</a> or 800-640-9255</td>
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<tr>
<td>Sat., Nov. 13, 2010</td>
<td>3rd Annual South Florida PH Fun Walk</td>
<td>Pompano Beach, Fla.</td>
<td>Pat Hellyer at 561-628-5597 or <a href="mailto:phellyer@wxel.org">phellyer@wxel.org</a></td>
</tr>
<tr>
<td>Sat. &amp; Sun., Nov. 6-7, 2010</td>
<td>2nd Annual Pulmonary Pints: PubCrawl for PH</td>
<td>Baltimore, Md.</td>
<td>Ashley Boehk at 703-607-4360 or <a href="mailto:ashley.boehk@gmail.com">ashley.boehk@gmail.com</a></td>
</tr>
<tr>
<td>Sun., Nov. 7, 2010</td>
<td>Evening of Awareness</td>
<td>Salt Lake City, Utah</td>
<td>Christina Doak at 801-572-1609 or <a href="mailto:jcdoak@comcast.net">jcdoak@comcast.net</a></td>
</tr>
<tr>
<td>Sat., Nov. 13, 2010</td>
<td>North Texas Fun Walk for a Cure</td>
<td>Grand Prairie, Texas</td>
<td>Sheila Williams at 817-938-9639 or <a href="mailto:sheilamw67@yahoo.com">sheilamw67@yahoo.com</a></td>
</tr>
<tr>
<td>Sun., Nov. 14, 2010</td>
<td>PHA Coffeehouse/variety Show</td>
<td>Littlestown, Penn.</td>
<td>Mary Hack Svikhart at <a href="mailto:merrycee@pa.net">merrycee@pa.net</a> or 717-359-9092</td>
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**For more special events coverage visit**
[www.PHAssociation.org/SpecialEvents](http://www.PHAssociation.org/SpecialEvents)

**To view a complete, up-to-date listing visit**
[www.PHAssociation.org/Events](http://www.PHAssociation.org/Events)

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**Spring into 2011 with a Special Event!**

Now’s the perfect time to start planning your spring fundraising event! With PHA’s resources and support, you too can help bring us one event closer to a cure. To help get the ball rolling check out PHA’s Special Events Planning Guidebook at [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook)

Want to stay connected to the Special Events community and get planning ideas and inspiration along the way? Subscribe to our quarterly e-newsletter, Event-ful Times, by visiting [www.PHAssociation.org/SpecialEvents/Newsletter](http://www.PHAssociation.org/SpecialEvents/Newsletter)

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[www.PHAssociation.org](http://www.PHAssociation.org)
Anna won't let her illnesses stand in the way of accomplishing her goals and continuing to grow as a person. Her attitude is admirable as she reminds us that every "down" has an "up."

— Joanne

My Persistent Life by Anna Bower, Grand Junction, Colo.

While reading stories told by patients with PAH, I have noticed a prominent message. Don't give up, and don't let your disease define you. I would like to think I have followed those guidelines pretty well. My life has changed, but only in ways I have allowed. I mean, we all have had to make adjustments: using supplemental oxygen and medications, visiting the doctor’s office more often, and reaching for support — just to name a few. I think the main question to ask yourself is this, have you continued to grow as your own individual person? Do you continue with a sense of purpose? As a child I was taught that each person has something to bring to or teach the world. I was told that everything happens for a reason, even if we don’t learn what that reason is in this life.

I have always been an active person. I loved camping, fishing, swimming, hiking, bike riding and almost every other outdoor activity as a child. I began playing soccer in grade school, and in high school I began coaching. In middle school I got to play on an international American soccer team in England. In middle school I also began to play music. It started with the clarinet, and I added saxophone, bass clarinet and bassoon, as well as percussion. In my spare time (between work, school, band and soccer, there wasn’t a lot of it!), I would go white water rafting. The year after graduation, I rafted the Grand Canyon! Eighteen days of sun, sand, cuts, bruises, scorpions, bugs, heat (did After a little while, and a few talks with my nurse, I realized why I was on this medication: to LIVE."

For the cure,
Joanne Sperando-Schmidt, Persistent Voices Editor
I mention sun?) and water! I always had loving parents and stepparents who encouraged and inspired me.

I was diagnosed in 2004 with SLE (systemic lupus). It caused intense joint pain in my hands and feet to the point I couldn’t use my hands, and I was unable to walk. With that diagnosis, my life ended, or so I thought. I became depressed, and in essence I grieved for my life. I wanted to be a landscape architect, or maybe a high school history teacher, or maybe a psychologist. But how could I go to school if I couldn’t take notes or walk through campus? And sometimes couldn’t attend classes? I ended up dropping out of school entirely. I buried myself in a mountain of debt and, in general, attempted to escape life. At some point, I decided I had to live again. I had moved away to go to college, so I moved home for support. I lived with my parents, got a job, and even attempted school again.

My lupus seemed to come under control. I was able to walk regularly, open doors, and occasionally open jars. I decided to move away again to try to start my young adult life again, and it seemed to be going well. While I was not attending classes, I was holding a steady job and living on my own. My friends knew about my lupus and helped when I needed it. My family was close as well.

After a year or so, my lupus seemed to be active again. I started having more joint pain, rashes and, in general, felt awful. This roller coaster ride — my life with lupus — continued. I would heal and get better only to return to the pain. But after a few years of ups and downs with my health, things seemed pretty steady. I was “in control” of my life.

That is when I started having issues with my heart. I was told I had pericarditis, which means the pericardium is swollen. My heart literally hurt. I had a feeling things were going to get bad for me, so I decided against renewing my lease and moved home. For a few months things were fine, and I thought I had just been scared. Then it hit me fast and hard. Over the course of a week or two, I began having trouble breathing while lying down. It got to the point where the day after Christmas, I went to my on-call doctor. And thus began the diagnosis for pulmonary arterial hypertension, and yet another course of my life. I was lucky; it only took a few weeks to be diagnosed and then another month to get in to see a specialist. A month after that, I was on IV Remodulin™.

Again, my life as I knew it was over. They said I was likely to have less than two years without medication, and with medication, no one knew. At the end, I could look forward to a lung transplant if I was lucky. I closed myself off. My doctor wouldn’t let me return to work, and I started getting disability. After a little while, and a few talks with my nurse, I realized why I was on this medication: to LIVE.

I began to live again. I grabbed old friends and brought them back into my life; I picked up my camera and started taking pictures again. It was great! I may not be able to go out in the sun without sunscreen, hats and long sleeves, but I can go out. I may not be able to run with my nieces, but I can go to the park with them. I may not be able to do marathon shopping at the mall, but I can enjoy an afternoon out shopping. One of the reasons I am doing so well is my persistence and optimism. I look back fondly at what I have done without regret, and I do what I can, how I can. I started taking classes again this fall, even one is a start! Maybe someday I can move out on my own again. I still have my ups and downs, but I know that with every down, there comes an up.
Tom Albertson, Lima, Ohio

When I was first diagnosed with pulmonary hypertension back in 2004, the patient community didn’t know about babies suffering from PH or exactly why and how most of us developed PH. I was fortunate to have a cardiologist who read my echo-cardiogram and told me I needed an urgent appointment in Cleveland because my calculated pulmonary arterial pressure was over 50mmHg. At the time, I had no idea what she was talking about, but I knew at 50, I could no longer mow my lawn or even stay awake at work during a treatment team meeting, and I was the treatment team leader!

My experience in Cleveland was awesome. After months of testing, referrals to other departments, some suggestion that I might need a new heart and lungs and much worrying about the outcome, my pulmonologist told me that I was too sick to be included in any drug trials and too sick to be considered for transplant surgery since my liver disease precluded any anti-rejection medications. All along I had been researching this new disease called PH, and I was comforted that there was finally something that explained some of my symptoms.

My cardiologist in my hometown had been treating me with calcium channel blockers, but my right heart failure had precluded the continued use of these drugs. At this point I had right ventricular myopathy and some leaking valves. It was interesting to look at previous echo-cardiograms to check the calculated pulmonary arterial pressures and see numbers above 40 as far back as 1996.

My first medical treatment was in 1962 at the age of 10 when I was diagnosed with Raynaud’s disease. At 10 years old, I was started on a vasodilator called dibenzyline. I later learned that this diagnosis was the beginning of mixed connective tissue disease (MCTD), and today it is the connective tissue disease that caused my PH. No wonder I was suffering from congestive heart failure, autoimmune hepatitis, interstitial lung disease, insulin dependent diabetes, chronic kidney failure and GERD.

Thank goodness for PHA and its bulletin boards. I signed in as Joe Camel. Almost every patient I talked to back then is no longer with us and what a trauma that has been for me. I have met other patients, and through networking, I learned of other possible places I could go for treatment. I went north to Ann Arbor and saw one of the pioneers of PH research. I was given a workup and then referred to other departments for treatment of my other diseases. I was too sick to take any PH medications and was referred to an outpatient clinic to treat my “severe uncontrolled hypertension” and my “interstitial alveolitis.” The high blood pressure, which had developed and was first diagnosed at age 30, was still uncontrolled and the alveolitis was not treated because I could not take steroids. I was sent home to be put on “comfort care” to die.

Lucky for me, my pulmonologist thought that at age 53, I was too young to die, and
he decided to go for the necessary training to allow him to prescribe PH medications. I was first put on Tracleer™. I was so pleased that it did not cause any further damage to my liver. The Tracleer™ helped, but my physician wanted to prescribe a prostacyclin such as Flolan™ or Remodulin™. We decided to implant a catheter into my chest wall so that I could receive IV Remodulin™. Unfortunately, I developed enough side effects that the Remodulin™ had to be stopped. I was then trained on Ventavis™, but I couldn’t tolerate the treatments because of the pain associated with the lung disease and the inhalation necessary for the Ventavis™. Finally, Tyvaso™ was approved by the FDA, and I was so excited to start this new drug.

I found out about Tyvaso™ in May 2009. By September, it was approved by the FDA, but we were still waiting for Congress to make the decision about Medicare. Would it be billed as Part B or Part D? I was so impatient! My pulmonary arterial pressure means were rising, and I was now at over 70mmhg. I knew that 16mmhg is a normal pressure, and by my increased fatigue and shortness of breath, I knew that without further treatment, I would not live much longer. I knew I couldn’t wait for anyone else to get the job done, so I called one of my senators in Washington, D.C., and explained the situation. It wasn’t just me, but hundreds, maybe thousands, of patients wanted so desperately to try this new Tyvaso™, and time was so critical. Early in December 2009, I got a call from my senator’s office and was told that Medicare could now process the claims for Tyvaso™. I immediately called PHA and spoke to several friends. I called my specialty pharmacy and told the insurance people who were very excited.

I have now been on Tyvaso™ since December 2009 and recently had my PAP measured and got a wonderful result of 65mmhg. If nothing else, the escalation has stopped and my numbers have rolled back slightly. Life is still difficult, but I am still so grateful for each and every day! My secret: learn to be your own best advocate and NEVER GIVE UP! Say a prayer each day and thank your God for the blessing of life you have been given. ♦

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We’ve often heard, “It’s not what happens to you, but how you deal with it.” This eternal truth comes through in Grace’s story as she shares what she’s learned and how she keeps moving forward with her life.

— Joanne

Grace Finkle, PhD, Cary, N.C.

As a psychologist, I know it is important to have a positive attitude — in general, toward oneself, toward others, toward adversity. As a patient with PAH, scleroderma, Sjogrens disease, Raynaud’s disease, fibromyalgia and other medical conditions, I know that keeping a positive attitude can be challenging. I know we can’t control what comes our way in life, although we can try to avoid risky situations and use our best
judgment. The important thing is to approach what we are dealt with the best we can. Sometimes this involves taking a stand, getting a second opinion, fighting to stay strong. At other times, it involves acceptance, prayer, support of loved ones, and the right specialists. And it involves having a “persistent voice” in our care and with ourselves and others, making our best way in life with what we have. I truly believe that everyone ends up having to deal with at least some type of adversity or loss. There are the “necessary losses” that Judith Viorst discusses in her book of that title, such as those of aging and losing loved ones with time. There are also the unusual ones, the “unnecessary” ones, such as PAH. How we deal with this defines us, versus the other way around.

I am 57 and have worked for 24 years as a clinical psychologist at a state university’s counseling center, helping college students deal with personal, academic and career issues. I feel very fortunate to (“knock on wood”) still be able to work in a field where I can give to others in need. It is a daily effort to get up when I ache and am tired. I am lucky that, once I am there, my work is not physical, and I can still do it well. I feel that whatever we go through in life can enable us to help others. Since the PAH and scleroderma support groups help me, I thought that I would start a Wellness Support Group for students living with chronic illnesses. This has worked well. Although the students have different illnesses, they share and understand each others’ experiences. Like the students helping each other, we all do this in innumerable ways when we give to others by kindness and understanding in our daily lives.

Looking back, I probably had PAH since I was 24, when I came down with autoimmune disease symptoms. I couldn’t raise my arms or legs very much and couldn’t go up steps or inclines without feeling pain, stopping all the time, and breathing heavily. I also developed Raynaud’s disease, which causes painful symptoms like frostbite in fingers and toes due to the constriction of blood vessels. I wasn’t referred to a rheumatologist or a pulmonary doctor. My primary care physician said I had a virus. About five years later, I was finally referred to a specialist and received the diagnosis “undifferentiated connective tissue disease” and pulmonary fibrosis. It wasn’t until I started seeing a rheumatologist at Duke University Medical Center in 2000 that I was diagnosed with scleroderma. Scleroderma is the cause of my PAH, which wasn’t diagnosed until 2002, when I got a pericardial effusion. I now take Revatio™ and Ventavis™. I manage my Ventavis™ treatments every two hours around my work schedule, which has been a challenge. I am so lucky that my long-term boyfriend Jack recommended Duke and has taken me to all of my appointments since then (and has stuck with me in his caring way).

I know that PAH is progressive (although I absolutely HATE it when anyone says this to me). But then again, so is life. There are things that we may have to give up, and there is help that we need to accept. Right now, I am fortunate to be working. For 10 years, I loved my hobby of singing in the chorus of an opera company. However, I had to stop because it became too demanding physically. I can still sing at home.

We have to live the song that we’re given, which may have words that we don’t like, but we can change how we approach the singing of it. ✪
Marilyn’s story is one you won’t soon forget. She bravely shares her battle with drug addiction and her journey with PH and the challenges that come with it.

— Joanne

Marilyn Clements, Woodland, Calif.

My journey started in 1996 when I started feeling short of breath while walking a short distance. I went to my primary care doctor and told him I had been smoking methamphetamine for about six years. He heard a distinct heart murmur and referred me to cardiology. That doctor ordered a heart catheterization, and during the procedure, they decided to check the right side of my heart. As I sat in my room, awaiting the results, a lady doctor came swooping in and jammed an oxygen hose up my nose and told me I had pulmonary hypertension with two to five years to live. Then they sent me home. Little did I realize that I was lucky to be diagnosed right away.

When I left the hospital, I got on the Internet and began to cry when I saw the information that was available at the time. At my follow-up appointment with the pulmonologist, I waited about an hour in the exam room for the doctor. When she arrived, she apologized for taking so long, but she said she was reading a book about PH since she had never dealt with it before. She told me that I would have to quit doing drugs so I could start the business of getting a double-lung or heart-lung transplant. I was so far in denial that I just kept doing my drugs every day. The doctor put me on calcium channel blockers and saw me about every three months. She would always ask me if I had quit yet, and I would say no. She also told me about FlolanTM and how it worked, but I didn’t like that either.

About a year later, I saw a new pulmonologist. He asked me if I was still doing drugs, and I told him yes. He said if I would quit, he would refer me to the University of California Davis Medical Center (UCD) in Sacramento, and after I had been clean for six months, they would put me on Flolan™. I told him I didn’t think that was going to happen. Then he said, “You need to go home and start reading the Bible, Romans in particular.” That was it! That was the moment that made me face reality. When I saw him next, I had been clean for two months and was ready to do what I had to do.

Four months later, I met Dr. Allen at UCD in September 2000; I was stage four. He put me in the hospital right away and started me on Flolan™. For the next six years, my symptoms lessened and I felt better. I even started going to support group meetings in Sacramento where I met Debbie Baugh and her co-leader, Karen Alcauter. They were both on Flolan™, and we became good friends. Karen was very sick, but before she passed away in 2003, she made me promise to take her place as co-leader of the group. So, that’s what I do. We have an awesome group of people, and we meet every other month and have a great picnic every September.

But with Flolan™ comes problems; about once a year I would get a major line infection and spend a week or more in the hospital receiving IV antibiotics and getting a new line in my chest. I wanted to go on the “new” Tracleer™, but Dr Allen was...
reluctant to do so because the Flolan™ was working so well for me. Finally, after another major infection, he started weaning me off Flolan™, and I started taking Tracleer™. Everything was fine for 18 months until my liver enzymes started to rise. I had to stop taking Tracleer™, and Dr. Allen told me about a clinical trial that was going on for oral Remodulin™. It required that I go 30 days without any treatment; then I would either get the real drug or the placebo for 12 weeks.

That sounded kind of scary, but I had been going to Weight Watchers, lost 60 pounds and was feeling pretty good as long as I didn’t exert myself. I agreed to do the trial. As it turned out, I was on the placebo for the first 12 weeks. I firmly believe that if I had not lost the weight, I may not have made it through four months with no treatment. Finally, in January 2008, I started taking the real drug. I knew it was real right away because I had headaches and nausea every day for a while. Now, I only get occasional headaches and flushing, and I feel great. In fact, I feel better than I have in 40 years, and I’m looking forward to being around many more years.

I have never told my full story for PHA or anywhere else because I was ashamed of my drug use being the cause of my disease. Most people don’t talk about it for a number of reasons, but I really feel that telling the truth is a big part of my therapy and recovery process. Of course, the doctors say I have idiopathic PH, and they can never be sure of the cause. But when you read the information about PH, you learn that methamphetamine use is sometimes associated with the development of PH. I do not have any other disease, and I believe I am luckier than most because I have responded to treatment so well.

Now, if I could just get myself to exercise more, everything would be perfect!

Simply put, this is a family love story. A son’s admiration for how his mom battled PH, cancer, tumors and two lung transplants. What an extraordinary woman, lovingly remembered by her son.

— Joanne

Pittsburgh, Penn., Support Group Leader Sharren Yamron Will Continue to Be an Inspiration Beyond Her Passing
As told by her son Sam Yamron

When my mom, Sharren Yamron, was first diagnosed with primary pulmonary hypertension in 1993, being the social person she was, she sought out other patients with the same disease in the Pittsburgh area. Upon finding that there was no network or group in the Pittsburgh area, Mom decided to start a local support group — this was no surprise to anyone who knew her. What would eventually become the Pittsburgh chapter of PHA started off as only three patients around a kitchen table.

Mom passed away on June 23, 2010, after fighting PH, breast cancer, brain tumors, and having gone through two lung transplants. She loved being a support group
leader and often times referred to it as her baby. She was so proud that
at recent meetings, there had been more than 60 patients along with their
families, doctors, nurses and other medical support staff attending. She
loved bringing people together and providing any help that she could offer,
especially in the form of providing her insight and thoughts with patients
when she would take calls on the Patient-to-Patient Support Line (formerly
the Patient-to-Patient Helpline). Anyone who knew Mom knew she was an
advocate and a friend who was devoted to giving her time and help to others
so that she might encourage them to fight for survival and enjoy life the way
she did.

The most notable quality and often repeated statement about Mom’s
character was that of her courage, determination and fight. She fought 17
years with illness, having two lung transplants in 1995 and 2001, being
diagnosed with breast cancer in 2005, having countless hospital stays and
all the other complications that entailed. Throughout those 17 years, she
stubbornly refused to let her illnesses prevent her from enjoying life. Her
doctors told her that her story was often told as an example of what one
could accomplish with such limited physical capacity. Her story would inspire
others to enjoy life and live it to its fullest.

I know that Mom inspired many people during her short time, but
most of all, she inspired her family. She always made it known that her
proudest job was being a mother to my brother and me. She was tireless
in her devotion to us. Every conversation or phone call always included the
question of what we were eating and if we were keeping well fed. She loved
us with all her heart and anyone who knew her, knew this to be true.

One notable thing about Mom was that she enjoyed fashion and, in
particular, very bright and colorful clothes. She would always get dressed
up in brightly colored clothes when she would go out for her weekly
chemotherapy treatments. In fact, she always wore a skirt and would get
dressed up no matter where she would go. When she would enter a room,
she would immediately brighten it up with her appearance, and if you
spoke to her, she would brighten your day with her cheerful demeanor and
optimism. She lived life with enormous passion, and it was love of life that
kept her going.

One thing Mom never did much care for and was a bit embarrassed
about was being referred to as brave. She said she didn’t keep on fighting to
live simply for the sake of fighting. She loved life and didn’t want to miss one
bit, whether it be a big event — such as my graduations from high school,
college and law school — or the daily events of having dinner with her family
or eating chocolate. Mom’s enormous appreciation of all that she had and
that was around her will continue to inspire me, and it is my hope that her
passion for living can inspire those who read this as well. *
Surfs Up: Conference Through the Eyes of the Theme Contest Winner

If you “rode the wave” at PHA’s 9th International PH Conference and Scientific Sessions, then you have Melinda Schissel to thank for that! Melinda was the winner of the Conference theme contest with the theme “Riding the Wave to a Cure,” and with the conclusion of Conference, Melinda now looks back fondly on her three days in Garden Grove, Calif.

“When I got to the Conference, the impact of seeing [my theme] everywhere was really wild. It was really fun to see!” Melinda says. She enjoyed seeing the wave concept carried out on everything from the program books and the Daily Wave newsletter to the signs and her Hyatt Regency hotel room key.

To get to Conference, Melinda spent nine hours in a car traveling from her home in Berkeley, Calif., but she says it was all worth it. “I got a lot out of it and I really liked it,” she says. “I think it’s really great to see all the people there — even seeing all the other people with oxygen and taking the different medicines.”

Melinda was a first-time Conference attendee, having received a complimentary registration for her winning Conference theme, and was looking forward to networking with other associated-condition patients. Melinda, who was diagnosed with pulmonary hypertension in 1998, was born with congenital heart disease and had never met another PH patient with this condition. She had the opportunity to attend the “Congenital Heart Disease & PH” session where she finally saw other PH patients with congenital heart disease. For Melinda, Conference provided lots of time for networking, allowing her to meet medical professionals, patients and others. She even had the opportunity to reconnect with the nurse who trained her on Remodulin™.

During Conference, Melinda helped facilitate support group meetings for “PTE Patients and Other Conditions Associated with PH” and “PHers Transitioning from One Medication to Another,” which also allowed her to forge new connections.

Having attended a number of large-scale events previously, such as the California PH Forum in June 2009, Melinda noticed the thought that went into all the details at PHA’s Conference. One aspect she liked was the availability of wheelchairs for patient use. “It just seemed like everything was full circle,” she says. “Everybody was really trying to make it a good event, make it easy, and everybody really understood.”

Melinda also enjoyed the Climbing for a Cure: Conference Opening and Keynote Address presented by the Path to a Cure climbing team, Dr. Raymond Benza, Dr. Robert Frantz and Jessica Lazar, MPA, PA-C. She especially appreciated seeing images of the team’s pulse oximeter readings at the high altitudes on Mt. Kilimanjaro. For Melinda and other PH patients, similar readings are a daily occurrence. “I thought that was really great,” she says. “It was amazing what they did, and I think they really did get a feel for what it’s like on a day-to-day basis for a PH patient.”

For those planning to attend the Conference in 2012, Melinda has some advice based on what she learned at this year’s Conference. “Look through the program book ahead of time and really ‘plan your attack,’” she says. Melinda admits that in the excitement of everything going on, it’s easy to forget all the different activities you want to do. She suggests using your program book to plan out what sessions you want to attend and to find the people you are hoping to meet.

Will Melinda be attending PHA’s 2012 Conference? She says, “You know, I would love to.” PHA’s 10th International Pulmonary Hypertension Conference and Scientific Sessions will be held June 22-24, 2012, in Orlando, Fla. We hope to see everybody, including Melinda, there! *

By Suzanne Flood
PHA Marketing and Communications Associate

Conference 2010 by the Numbers — 1264 Registrants made this the largest PH meeting in the world!

Patients: 335  Physicians/Researchers: 169  International Attendees: 102  Volunteers: 113
Caregivers: 259  Allied Health Professionals: 155  Countries represented: 20  Unclassified: 64
Children: 42  Medical Students/Residents: 25
In Your Own Words: Experiencing Conference through Blogging

This year at PHA’s International PH Conference, PHA hosted the BlogosPHere internet Station, which allowed attendees to write about their personal Conference experiences and share those comments on their social networking websites or personal blogs. Select blog stories were also featured on the PHA Conference Blog (www.PHAssociation.org/Conference/Blog). Read on to find blog quotes from Conference attendees:

» “I thought the Conference was very informative, and I’ve learned so many things I didn’t know before. I’ve met a lot of interesting people who share the same disease as I have, and I now know that I am not alone.”
  ~ Elsa Dasigo, PH patient; Honolulu, Hawaii

» “One of the most exciting things for me is seeing all my chat room friends in person. I feel like I am dreaming when I see them. How could I know these people? I never knew them before PH. We are now like one big family.”
  ~ Jas James, PH Patient; Vancouver Island, BC, Canada

» “I have met so many people just genuinely passionate about PH and making a difference in the world. Meeting with PHers with the illness >20 plus years gives me much hope for my daughter’s future.”
  ~ Patty Slattery, PH Caregiver, Green Bay, Wis.

» “Thanks to this Conference I now know that when someone asks my kids, ‘What is wrong with your mom?’ they will be able to tell them about all the people from different places and different ages that they met at Conference and hopefully raise the awareness that this disease does not discriminate.”
  ~ Dana Osburn Albert, PH patient; Cedar Bluff, Miss.

» “I had a great time at the Conference and was only able to attend due to a scholarship from the Pulmonary Hypertension Association, as I am currently on disability. I would like to thank all the doctors, nurses, and volunteers — you made the Conference so special for me!”
  ~ Christina Waldman, PH Patient; Orlando, Fla.

Thank You, International PH Conference Plenary Speakers

PHA’s International PH Conference featured remarkable speakers and presenters during the plenary sessions throughout the weekend. Whether they were emceeing, giving a presentation or participating on a panel, all our speakers deserve a round of applause.

The Path to a Cure climbing team — Dr. Ray Benza, Dr. Robert Frantz and Jessica Lazar, PA — shared their experience summiting Mt. Kilimanjaro during Conference’s Opening Keynote address. Their journey on the mountain allowed them to experience many of the same symptoms that PH patients experience every day. Visit http://phamultimedia.org/UnityWalks/ to view the video that introduced the climbers at Conference.

Drs. Vallerie McLaughlin and Victor Tapson informed and entertained the audience Friday night during the Unraveling the Mysteries of PH dinner. Their presentation even included a closing limerick!

The Journeys Luncheon on Saturday provided insight on the close relationships that develop between PH specialists and their patients as patients and their doctors shared their PH experiences with Conference attendees.

The Founders’ Dinner — A Seat at the Kitchen Table — on Saturday night would not have been complete without a keynote speech from Carl Hicks, Jr., PHA’s former Chair of the Board of Trustees.

Sunday’s Next Generation of PHA Leaders Breakfast introduced attendees to a panel of PH community members who are pursuing exciting initiatives to promote the PH cause and further PHA’s mission.

PHA extends a special “thank you” to every speaker and presenter at this year’s Conference. These speeches and presentations — and the individuals who give them — keep hope alive in the PH community.
Volunteers: PHA Conference Heroes!

Who were those people at PHA’s International PH Conference wearing the bright aqua blue T-shirts? Patients, caregivers, medical professionals and industry staff took time out of their busy Conference schedules to give back and help out with all types of jobs.

Room Host volunteers introduced breakout sessions, kept track of time and helped speakers with audio-visual needs. Registration volunteers welcomed all attendees and helped answer many questions for those getting acclimated to this dynamic event. Volunteers helped manage games and field trips for the Kids’ Room, worked backstage at the Fashion Show, and helped monitor doors during the Scientific Sessions. We couldn’t do it without our volunteers!

While we only needed 113 volunteers, more than 190 Conference registrants stepped up and offered to volunteer, and we thank you. Our volunteers gave up their own time to help us and, therefore, help others take full advantage of Conference! A special thanks goes out to the volunteers who went above and beyond and dedicated most of their time at Conference to volunteering: Bill Bockhorst, Jack Nino, Mary Felkel, Deborah Kersman, Ruth Walegir, Perry Mamigonian and so many more. We couldn’t have done it without your time and energy!

Volunteers by the Numbers:
- 509 volunteer shifts
- 113 volunteers (not including 217 volunteer speakers)
- 14 types of volunteer support
- 1 GREAT TIME!

"I had a great time, and I look forward to another opportunity to put on a volunteer 'T' and go to work. I got to meet some interesting people and to hear some wonderful stories/words of wisdom. Sign me up for Florida!"

~ Volunteer Paul Fairman, MD, FACP, FCCP, Virginia Commonwealth University

PHA's International Conference Makes the News!

Viewers of Garden Grove, California’s Channel 3 caught the Wave to a Cure during PHA’s 9th International PH Conference. The station aired a news segment that highlighted the stories of PHA Board Member Carl Hicks, patients Evette Britton and Diane Ramirez and the Path to a Cure team, Dr. Ray Benza, Dr. Robert Franz and Jessica Lazar, PA. You can view the news clip at www.youtube.com/gardengrovetv3#p/a/f/0/5jD871Jn3Hw

In addition, Dr. Val McLaughlin and PHA President Rino Aldrighetti conducted 15 interviews on PH as part of a three-hour radio tour before Conference. They reached 2.5 million listeners live and as many as 4 million through recorded interviews.

Learn more about PHA’s media awareness campaign at www.PHAssociation.org/Awareness/ThroughTheMedia or by contacting Elisabeth: 301-565-3005 x759 or Elisabeth@PHAssociation.org
First International Leaders’ Summit Marks High Tide in Education and Relationship-Building

PHA was honored and delighted to welcome 23 leaders of international PH associations to our First International Leaders’ Summit on June 24. The day was packed with presentations on developing patient education programs (Hall Skåra of Norway and Ümit Atli of Turkey), engaging volunteers and grassroots players (Paula Menezes of Brazil and PHA’s Debbie Castro), developing medical education (Vallerie McLaughlin, MD), fundraising (Gerry Fischer of Austria and PHA President Rino Aldrighetti) and raising awareness of PH through social networking (PHA’s Emma Bonanomi). The day was brimming with relevant, excited and engaged conversation. Representatives of Australia, Canada, Iran, Ireland, Israel, Japan, Mexico and Venezuela contributed ideas and experiences.

Guests described the Summit as “truly inspirational,” saying that the event “recharged [their] batteries.” Perhaps even more impressive than the skills and ideas that leaders are returning home with, hugs and handshakes abounded, reaffirming to us all what true partners we have in this fight.

Since PHA committed to supporting the growth and development of international PH communities in 2002, at least 50 PH associations have formed worldwide. The leaders of these groups are patients, parents, family members and medical professionals — just like PHA’s own founders. These groups are responsible for lobbying for medication approval and research funding, writing and creating translations of critical PH information to serve their countries, and boosting the spirit of their own communities and each others’ work.

Nearly 100 international guests attended the 9th international PH Conference and Scientific Sessions, representing 20 countries (seven of which had never before been represented at Conference!).

By Christine Dickler, PHA Associate Director, International Services
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

2nd Annual UNC-Duke Research Triangle Pulmonary Hypertension Symposium
October 22, 2010
The Friday Center
Chapel Hill, N.C.
Email: Jennifer_Mayfield@med.unc.edu
Call: 919-962-7399

8th Annual Update in Pulmonary Hypertension: Tufts University and Medical Center
December 3, 2010
Hyatt Regency Cambridge
Cambridge, Mass.
www.ganesco.com

Medical professionals interested in learning more about partnering with PHA through Building Medical Education in PH for your next CME event, please contact Suzanne Flood, Marketing and Communications Associate, at 301-565-3004 x768 or BME@PHAssociation.org

Building Medical Education in PH events are designed to foster partnerships between PHA and PH Centers to promote continuing education in the field of pulmonary hypertension through CME educational events. More information on upcoming BME events can be found on the calendar listing at PHA Online University: www.PHAOnlineUniv.org/Calendar

Thank You, Scholarship Fund Sponsors!
Thanks to the generosity of a number of industry, group and individual donors, more than 180 PH patients and family members were able to participate in the 2010 Conference through PHA’s Conference Scholarship Program.

Actelion Community of Hope Fund * Actelion Fellows Fund *
Gilead Community of Hope Fund * Pfizer Community of Hope Fund *
Rochester, Minn., PHA Gala Community of Hope Fund *
Barbara L. Smith Scholarship Endowment Fund *
Mason Hoffman Scholarship Fund * Christen White Cranford Memorial Scholarships * Dean and Tammy Hazen Tribute Scholarships *
Michelle Carr Memorial Scholarships * Wendy Bockhorst Memorial Scholarships * Heather Massey Memorial Scholarships *
PHA Staff Scholarship * Harbor-UCLA PH Awareness Scholarship

And thank you to many others who generously added to the 2010 Scholarship Fund!

Thank You, Conference Sponsors!
On behalf of the entire PH community, PHA sends a heartfelt “thank you” to our many Conference Sponsors.


Gold Level: Bayer Healthcare * GlaxoSmithKline * Novartis Pharmaceuticals * United Therapeutics Corporation

Silver Level: Lung Rx

Bronze Level: Lilly USA, LLC * Teva Health Systems * Accredo Health Group, Inc.

General Sponsors: CVS Caremark * WWMR, a division of IntrinsiQ * CuraScript, Inc.
This fall, PHA on the Road: PH Patients and Families Education Forum traveled to the Baltimore/Washington, D.C., area and Dallas, Texas, to bring together patients, family members, caregivers and medical professionals. The regional forums provided many exciting educational sessions, covering a variety of essential PH topics.

PHA would like to thank all those who attended and participated in the two PHA on the Road forums. Without your participation and desire to gain more education in the area of PH, these forums would not be a success. Attendees traveled from as far away as Stamford, Conn., to attend PHA on the Road in the Baltimore/Washington, D.C., area and as far away as Broken Bow, Okla., to attend the forum in Dallas, Texas.

PHA also thanks all of our forum speakers as well as the members of our PHA on the Road planning committee. Thanks to your participation, we brought attendees information on a variety of topics, including Living with PH, Traveling with PH and — new this year — Caring for a Child with PH.

Stay tuned for our full recap of the 2010 PHA on the Road forums in the winter issue of Pathlight. Also, keep checking PHA’s website for future PHA on the Road locations (www.PHAssociation.org/OnTheRoad). You never know, we may be visiting your region soon!

By Suzanne Flood
PHA Marketing and Communications Associate

Patient Coordinates Scleroderma/PH Day of Education

On June 19, 2010, Jerri Sue (“Sam”) DeTray, support group leader in Toledo, Ohio, hosted Toledo Educational Day, an educational event for patients in her area. The event brought together 45 people — medical professionals, patients and caregivers — to learn more about PH and scleroderma. “Every year I try to do an educational meeting for those who cannot make the national conferences for scleroderma or PH,” Sam explains.

Sam was diagnosed with scleroderma in 1996 and started a scleroderma support group in 2003 because she did not know anyone with scleroderma. Later, when she was diagnosed with PH secondary to scleroderma in 2006, her group transformed into a support group for scleroderma and PH patients. The Toledo Educational Day is the third such event she has hosted since 2005.

Sam brought together several doctors to speak on a variety of relevant topics, ranging from surgery to mental health. Dr. Ragheb Assaly, a pulmonologist at the University of Toledo Medical Center (UTMC), spoke about the effects scleroderma has on the lungs and the connection to PH.

Dr. Samer Khouri, a cardiologist at UTMC, spoke about how scleroderma affects the heart.

Dr. Bashar Kahaleh, a scleroderma specialist at UTMC, discussed genetics and the impact of the environment on scleroderma. He also spoke about new developments in scleroderma research.

Dr. Wael Yousef, also from UTMC, discussed how scleroderma affects the gastrointestinal tract.

Dr. Bruce Heck, an orthopedic doctor from Northwest General Orthopedics and Sport Medicine, Inc., discussed how scleroderma affects the musculoskeletal system.

Dr. Heather Heck, who specializes in chiropractic medicine and nutritional wellness at Northwest General Orthopedics and Sport Medicine, Inc., spoke about clinical nutrition for scleroderma patients.

Finally, two therapists, Andy Lesniewicz and Kirt Stuckey from the Fulton County Health Center, discussed the acceptance process patients go through when they have a chronic illness. They also offered suggestions on what to do to limit stressful days.

“It was a long day, full of great information, and I am already starting to work on the next educational day in the fall of 2011,” Sam says.
Save the Date!

2011 PH Resource Network Symposium
Inspiring Hope: New Directions in PAH
September 22-24, 2011
Hyatt Regency Crystal City – Arlington, Va.

The PH Resource Network, PHA’s membership community for nurses and other allied health professionals, is thrilled to present its 5th PH Resource Network Symposium "Inspiring Hope: New Directions in PAH." This program is for PH-treating allied health professionals of varied experience and interests. Breakout sessions will provide health professionals the chance to choose individual sessions based on their level of experience. A complete agenda, including speakers and topic descriptions for the sessions, will be available at www.PHAssociation.org/PHRN/Symposium in the coming months.

Registration for this unique event will open March 2011!

*** Pass this on to your nurses and other allied health professionals!

PHA Classroom Live e-Learning Events
www.PHAssociation.org/Classroom
Webinar Presentations, Online Q&A Chats, and Conference Call Discussions

Upcoming Live Events
October  Speak Out! Getting Involved during PH Awareness Month
October  Keeping the PH Blues Away
November Tips for Talking about Being a PH Patient
November  Medicare Part D and Enrollment: Choosing a Plan that Works for You
December The Empowered Patient: Nurturing Partnerships with your Medical Professionals to Get the Best Care Possible
January  Newly Diagnosed? What You Need to Know
January  PH Treatments: What’s on the Horizon
February  Special Events 101: Planting the Seeds for a Successful Spring Fundraiser
February  State of PHA — An Annual Update from PHA President Rino Aldrighetti

Newly Posted Recordings
Put the Special in Special Events: PHA Local Event Planning & Fundraising 101 • Media Matters! Working Media into your Special Event • Working with PH • Side Effects of PH Medications

Send feedback or suggestions for topics to PHA’s webmaster Diane at Web@PHAssociation.org or 301-565-3004 x759.
**INTERVIEW WITH PH PATIENT IAINE HESS**

Where do you live?
I live in Boulder, Colorado.

How old are you?
I am 10 years old and will be turning 11 in October.

When did you first start having symptoms?
My mom and dad first noticed symptoms at my fifth year birthday party. I was playing indoor soccer with my friends, and I was really tired and short of breath. When I had my annual checkup when I was 5, my doctor heard a loud heart sound. She sent us to Children’s Hospital in Denver.

How did your friends and family react to your diagnosis?
My family and friends did many nice things for me. My best friend Matt climbed 14 mountain peaks in Colorado to raise money for pulmonary hypertension. My Uncle Don takes me down to go fishing every year in Florida. I love to fish. My friends and family have been very supportive and understanding.

How has your life at school been affected by having PH?
I used to have to take medicine and change ice packs at school, but not any more. I don’t do some things at PE, but I do everything else.

Are there any activities that you feel like PH has stopped you from doing?
Yes. Some of the activities I can’t do are soccer, mountain climbing and skiing. I can’t go up to high altitudes for long. I also can’t travel as much as I would like to.

What are some of your favorite activities that PH hasn’t stopped you from doing?
I love to play baseball (pitching and first base) and go rock climbing. I also ride my bike and go on walks with my family.

Is there anything you wish more people understood about having PH or about kids who have PH?
I wish that the school nurses understood PH better. I once went to the school nurse with a leaking broviac and she told me it would be all right and sent me back to class. **See Editor’s Note**

What message would you like to pass on to other kids with PH?
I want to wish all of my friends with PH well and to hope for a cure for them. I really look forward to seeing them again at the next PHA Conference.

**Editor’s Note for Parents: PHA’s School Resource Handbook can help educate teachers and other school personnel about PH. Go to www.PHAssociation.org/Parents/School/ResourceGuide to access the Handbook.**

Interview conducted by Isaac Kruger
PHA Pathlight Volunteer
Are you the parent of a young PHer? Connect with other families!

PHA now offers a monthly telephone support group for parents of children with PH! Families of young PH patients can be few and far between, making it hard to connect at traditional PH support group meetings. The monthly telephone support group was created to give parents of PH kids across the country a forum to connect with one another and share information about pediatric PH. Parents can also look forward to education from periodic guest speakers. Calls take place on the third Thursday of every month.

**Upcoming Call Schedule:**
8:30 p.m. ET/5:30 p.m. PT
October 21, 2010
November 18, 2010
December 16, 2010

**Instructions to call in:**
Dial toll-free from the U.S. or Canada: 1-866-740-1260. When prompted, enter access code: 5653004.

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PHA Receives Awards of Excellence

APEX 2010, the twenty-second annual awards program recognizing excellence in publications, presented PHA with two Awards of Publication Excellence:

- Most Improved Newsletters – Pathlight
- Most Improved Web & Intranet Sites – www.PHAssociation.org

These awards recognize the changing face of both Pathlight and PHA’s website over the years as the Pulmonary Hypertension Association has continued to grow. According to the awards committee, “APEX Awards are based on excellence in graphic design, editorial content and the ability to achieve overall communications excellence. … With more than 3,700 entries, competition was exceptionally intense.” PHA is proud to accept these awards as recognition of our efforts to share engaging, informative and empowering information with the PH community in accessible and visually appealing ways.
Passages is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

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

IN MEMORY OF

Donations Listed Were Received Between June 1, 2010, And August 31, 2010.
PHA is Deeply Grateful to the PH Community for its Extraordinary Support.

Take a Look! Sustainers Circle Members Recognized
PHA recognizes members of our Sustainers Circle in the donations lists. Look for a @ symbol to see who has made a sustained commitment to donate to PHA on a monthly basis. If you are not a member of our Sustainers Circle but are interested in joining, visit www.PHAssociation.org/Donate/SustainersCircle or call Jennifer at 301-565-3004 x756. You may also use the remittance envelope enclosed in this issue of Pathlight.
Miss Sara Robinson
Ron and Pat Robinson
Mr. Dan Robinson
Ms. Gail L. Robinson
Miss Ellen N. Robinson
Ms. Dona J. Robinson
Lester Y. Rosenzweig and Thomas J. Walling
Ms. Madalene Salamack
Ms. Jessica Scheckton
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PATHLIGHT & PERSISTENT VOICES SUBMISSIONS

The Winter issue deadline is November 5, 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:

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

Work submitted will be printed as space permits. Please let us know if you would like anything returned. PHA cannot be held responsible for any materials lost.
When is the perfect time to support PHA at work? Right now!

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

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

   When you request a copy of the kit, you’ll receive a colorful, easy-to-use binder filled with everything you need to plan a fun and successful event.

   Contents include ideas and step-by-step instructions for easy fundraising events (including a recipe for “Cha-ching chocolate chip cookies” for your bake sale); a CD-ROM full of templates for you to customize and use for promoting your event; advice on how to attract media attention and spread PH awareness to your entire community; and everything you need to plan PHA’s signature workplace event, *Blue Jeans for PH*.

» **Give to PHA at work**
   Many employers host charitable fund drives in the fall, and you may be able to designate PHA as the recipient of your pledge. Check to see if your employer participates in the United Way, or if it holds its own fund drive, and encourage your coworkers to pledge to a charity that means so much to you. One of the country’s biggest fund drives is the Combined Federal Campaign (CFC) for employees of the federal government, postal service, and members of the military. PHA is #12097.

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

**Ready to get started?** Workplace events are great any time of year, but November is the perfect time to hold a workplace fundraiser because it’s PH Awareness Month! Contact Jennifer at 301-565-3004 x756 or Jennifer@PHAssociation.org to request PHA’s free *Our Workplace Has a Heart* kit or for more information.