Lil Long and Nicky Roberts were best friends who met at the height of their careers as marketing executives. Both would joke that instead of being joined at the hip, they were “joined at the ear” – at their first meeting, Lil had an earache in her right ear and Nicky in her left. As their friendship grew, Lil and Nicky saw each other through life’s highs and lows, including 40th birthday celebrations and a cancer diagnosis. However, says Lil, “It all ended when [Nicky] was diagnosed with PH.”

Lil was there when her best friend lost her battle to PH in 2007 and, shortly thereafter, Lil began experiencing her own health issues. In June 2009, Lil heard the words “pulmonary hypertension” again, but this time it was in reference to her own PH diagnosis. Drawing strength and inspiration from Nicky’s legacy, Lil, a native of Duncan, Miss., began to fight back. As part of a healthy lifestyle, Lil began swimming regularly that same summer. Lil’s husband, Henry Earl, was so impressed with her efforts he began bragging to friends that Lil would be able to take on the Mississippi River by the next year.

Lil proved her husband right by swimming the width of the Mississippi River on September 11, 2010 – eight days after the third anniversary of Nicky’s passing – in an event she dubbed the Long Battle for Nicky. Lil’s personal triumph that day was preceded by a host of regional media attention surrounding her swim. Lil also organized the Long Battle for Nicky gala, which raised more than $40,000 for PH.
From caring comes courage.
~ Lao Tzu

PHA’s mission is “To find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness.” Caregivers are integral to assuring this mission is accomplished. As one attempt to provide support and connection to caregivers within the PH community, PHA has developed a new feature entitled, “Conversations in Caregiving,” which debuts on page 6 in this edition of Pathlight.

It is impossible to overestimate the essential role that caregivers play in enhancing well-being and bringing hope to those who are living with PH. If living with PH can be compared to a very complex puzzle, the caregiver is the piece that ties all the other pieces together.

Although the intricacies of the relationship between patient and caregiver may vary, the value the caregiver adds in instilling courage is universal and timeless. The caregiver — a parent, spouse, partner, sibling, child, other family member or friend — mixes meds, assists with daily living tasks, facilitates and provides accompaniment to doctors’ appointments, rubs the malleable pains away, bestows hugs and a listening ear, and helps sustain the courage needed to live life to its fullest despite the severe obstacles PH can deliver.

Here it seems fitting to share one of many pictures of courage that I witnessed during PHA’s 9th International PH Conference last June. As I entered the “Meet and Greet” event on Friday evening, I noticed a woman sitting alone at a poolside table. She wore at least one visible life-sustaining apparatus, and I approached her, mistakenly thinking she was a patient member of our PH community. I quickly learned that although she was stricken with a life-threatening disease, she did not have PH. Instead, she had traveled half way across the country to obtain information and hope for her mother, who was recently diagnosed with PH and was too ill to travel herself.

This is one of many telling illustrations of the potential for deep caring and love that rests within the human spirit. It also exemplifies the reciprocal nature of the courage that caring breeds. Undoubtedly, the caregiver is the rock on which a patient leans. We as caregivers would trade places and give our life for the patient at a moment’s notice. However, the patient who battles this disease daily also creates within us a desire to emulate in our lives the courage and strength our loved one exhibits in theirs. I know this to be true because I was a caregiver who benefitted daily from the courage of the patient in my life.

In deep admiration for the caring and courage displayed within our community daily by wonderful caregivers and their beloved patients,
In 1980, I was 15. I remember the sports teacher beginning his lesson: “Today we will run two miles.” In response, I thought, “Oh no, please let it be through the forest, not the track.” “Through the forest” would mean a chance to find a short cut. I was average in sports and all short distances with a good “B” or an “A,” but long distances... a disastrous “E.” It was the same with my private sports activity. Wild water canoe slalom — I had good technique; fast sprints were fine, but during the second half of races, despite hard training, I could not improve my endurance. Later, during my university years, I played badminton, and it was the same. One day I played against a 55-year-old cardiologist. I was fighting to play — puffy and short of breath. Maybe he should have said, “Come to my practice and we’ll check why a young strong man can’t keep up with a 55-year-old.” But I still felt strong and healthy.

I started my career as an electronics development engineer; it was a pretty stressful but satisfying and exciting job. I married and moved with my wife to another city. A few years later I played a badminton match, and this time I was short of breath within a minute; I had to stop. “OK, maybe I have become too fat,” I thought. During the next year, I felt more and more tired in the evenings after work, and I began to sweat extensively after minimal effort. I went to my local doctor and got a sick leave, and I felt better after two days of relaxation. I went back to work, but I repeated this same routine every four-to-six weeks. Around this time, in 1995, a local internist checked me and said it wasn’t my weight but my heart. That was the beginning of my PH journey.

A cardiologist and then a three-week hospitalization followed, finally leading to my diagnosis. Before the doctors told me the diagnosis, some said things like, “you really chose a bad disease,” “maybe two-to-three years,” “maybe a transplant could help,” and “no sports.”

The doctors were hoping to find it secondary to something else, but everything was excluded. I read that I had a 10 percent chance to survive the next five years, and I told the doctor that I would beat those odds.

Once I was diagnosed, I began some treatments and my wife encouraged me to slow down, get out of my stressful job and care for the house, garden and our little girl. In those first years, I became anxious when I researched information about PH. I found only those statistics on 2.8 years average survival and no patient organization website in sight — for me at least. And what’s more, there were no drugs for PH in Germany except first experiments with epoprostenol.

Two years later, I had my second right heart catheterization, and I was finally sent to a real PH center to be checked for a lung transplant. At the MH Hannover, I met Professor Hoeper, MD, (a young PH doctor back then). He was enrolling patients for a trial with inhaled iloprost. Around 2000 I transferred to the University of Gießen PH-ambulance Centre, the biggest in Germany, and I finally found and joined the German PH association, PHev, founded by Bruno Kopp. Over time I lost my anxiety because I was still alive (time and milestones are the best medicine against anxiety, in my eyes). Meanwhile, great PH boards and chats were emerging online worldwide. I met wonderful people online and became friends. Drugs were invented or under development. What a wonderful new PH world — at least compared to the earlier years!

Now I want to learn as much as possible for myself and to support “newbies” with PH worldwide. This has become a kind of mission for me: learning, sharing knowledge and transferring news over the Atlantic as news moderator for several PH forums. Maybe the most important part of my activity is to give hope and to help people regain a positive attitude. I believe optimism is a key factor for successfully living with a disease like PH. Besides my personal advocacy for PH, I help Bruno Kopp from time to time with presentations or running booths. We also conducted a patient survey.

I know that I have been blessed to survive so long and that not all patients are so lucky. My list of drugs has added up to a good dozen over time. I am optimistic that great scientists and the pharmaceutical industry, with our help as “test pilots” in clinical trials, will bring us better drugs in the near future.

In January 2010, after positive encouragement from Prof. Grünig and my doctor, I started supervised exercising. Yes, sports — but carefully and with supervision! ♦

By Ralf S., PH Patient

International Faces of PH: Ralf S. from Germany
Progression Happens with PH

Disease progression is a fear we all have — one we try very hard to keep buried deep in the catacombs of our minds. We are told on day one that PH is a progressive disease. The symptoms are treatable but there is no cure. All of us, in our own way and on our own time, reach some level of acceptance. We get back to living our life despite the dim prognosis. Then one day it happens. The disease takes that first step beyond the control of our medications. Suddenly, each breath becomes more precious than ever; our lungs struggle to function once again.

One day you’re fine and the next you are gasping for air. Your mind races against the clock, constantly searching for an answer. The familiar hyper-vigilance of symptoms returns. All the while, you are wishing and praying that relief comes before you take that final breath; never knowing if this next inhalation is your last. Anxiety skyrocketed, emotions rage like the ocean surface in the midst of a hurricane. You are thrust back into the survival mode you thought you conquered early on — when the white coats said, “You’re knocking on death’s door.” But guess what?!? This is all normal.

My downhill slide began in July 2010, after nearly four years of improvement and eventual stability. With no apparent rhyme or reason, my heart would begin beating with so much force, that it felt like my chest wall would collapse at any second. Breathing became more difficult. The IV Remodulin™ dose was increased twice, yielding only temporary side effects but no relief. By September, I couldn’t walk the 20 feet from the couch to the bathroom without gasping for air. Two “near-syncopal episodes” (meaning I was unresponsive, but still conscious) later, I was on continuous oxygen and scheduled for a right heart catheterization.

I never thought the day would come where hearing that “PH is doing what it’s supposed to” would be welcome news. In that case, there would be a plan of action. We would not be groping blindly in the dark for an answer, an explanation. Instead, my frustrations were met with a chorus of “We don’t know what is wrong with you.” The cath results were the same as they were back in April 2010, when I felt better than ever. I thought once this rare disease was finally diagnosed, everything else would be a piece of cake.

As the days slowly passed, my couch and I got reacquainted. There were times when I was short of breath just watching a movie, on 3L of continuous room-concentrated oxygen. It felt like someone entered my lungs and flipped an “on/off” switch. My chest would rise and fall, air would be pulled in … but nothing happened. It felt like all I needed to do was take a deep breath and I’d be fine, but that breath would never come. Then, just as suddenly, the “switch” was flipped back on. At first, these “episodes” occurred a few times a week and lasted maybe an hour or two. But now, as I write this in early November, the “down time” has increased in frequency, lasting entire days at a time.

After a series of pulmonary function tests, CT and VQ scans, blood work, echocardiograms with bubble studies, a Transesophageal echo and the standard six-minute walk test (where, for the first time, I seriously debated sinking into the chairs lining the wall halfway through), we decided to switch to Flolan™, the theory being that the PH has progressed in ways the current tests cannot prove.

The very annoying, but very true disclaimer, “Everyone’s different,” has been repeated umpteen times but I have found that talking to other PHers has been of more help than all the calculations in the world. For the longest time, I was fixated on the numbers, the test results. I needed cold, hard evidence of where I stood with this disease, of how bad I “really” was. That obsession has gone by the wayside. When science’s multitude of advancements falls short and cannot explain your deteriorating health, it is a VERY difficult pill to swallow. But, as it turns out, sharing our trials, as well as our triumphs, can be more powerful than the most potent drug on the market.

At this moment, disease progression is inevitable. But this moment is all we have, so make the most of it. Allow yourself to feel the emotions but also know that no matter what life’s path has in store for you, there is ALWAYS a ray of hope illuminating your every step. Armed with IV pumps, oxygen tanks and your own private pharmacy, you kicked down death’s door once, crushing the grim reaper waiting for you on the other side, and you can do it again!

By Katie Tobias, PH Patient, Age 23

“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 late teens, 20s and 30s, visit www.PHAssociation.org/Patients/YoungAdults
Got questions? Get answers.

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

- **Find a PH Specialist** – Look here for a list of PH-treating physicians from around the world. [www.PHAssociation.org/Patients/FindaDoctor](http://www.PHAssociation.org/Patients/FindaDoctor)

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

- **Tips for Emergencies** – [www.PHAssociation.org/Patients/EmergencySituations](http://www.PHAssociation.org/Patients/EmergencySituations)

- **PHA Classroom** – A place to participate in live e-learning events or watch recordings on your own time. [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

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

- **PHA’s Patient Resources List** – A handy guide to organizations that can offer you legal assistance, financial help, and targeted information. Visit [www.PHAssociation.org/Patients/Resources](http://www.PHAssociation.org/Patients/Resources)

- **Visit PHA’s caregiver resources** at [www.PHAssociation.org/Caregivers](http://www.PHAssociation.org/Caregivers)

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

**Stay in the loop.**

- **PHANews** – This biweekly email newsletter brings the latest news about PH and PHA straight to your inbox. [www.PHAssociation.org/PHANews](http://www.PHAssociation.org/PHANews)

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

Looking to help? We’re looking for you.

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

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

- **PHAware Campaign** – Contact your local media outlets to spread the word about PH! PHA provides a step-by-step Media Guide, press kits and an email group to help you connect with other media advocates. [www.PHAssociation.org/PHAware](http://www.PHAssociation.org/PHAware)
Caregiver: Take Care!

Generally speaking, caregiving is not a role we choose, but one that chooses us. A loved one falls ill and needs our help and there’s no question: we do what we need to do. And while caregivers often experience satisfaction from the loving and attentive care they provide, the “job” comes with its own stresses and strains that need to be paid attention to.

One of the first things that a caregiver may give up is their own self-care. But caregivers need to pay attention to their own health and find outlets for reducing stress for their own good as well as for the good of their loved one.

Caregivers of PH patients know what it means to be busy. In addition to all the responsibilities you had before PH entered your life, you now have to lend a hand with medical care, take on extra chores and help the patient in many other ways. It’s no wonder that most caregivers often fail to make time for themselves and let their own care fall by the wayside. But according to the Family Caregiver Alliance (FCA), this lack of self-care can impair caregivers’ own health and well-being.

According to the FCA, caregiving can impair a caregiver’s mental and physical health. But it also rightly notes that caring for a family member “demonstrates love and commitment and can be a very rewarding personal experience” as long as caregivers also take care of themselves. To do that, FCA offers eight tools for caregiver self-care:

#1 — Reduce your personal stress. It’s important to recognize the early warning signs of stress so you make changes before you become overwhelmed. Some steps for managing stress include identifying the source of your stress; recognizing and accepting the things you can change from those you can’t; and taking action, such as going for a walk, meditating, or spending time with a friend.

#2 — Set goals. Your goals can include taking a break from caregiving, getting help with your caregiving tasks and doing things that promote your own good health. Once you’ve set a goal, create an action step to help you achieve it.

#3 — Seek solutions. Identify the problem or problems you’re facing and list their possible solutions. Try a solution, but if it doesn’t work — try another one. If nothing seems to work, accept that the problem may not be solvable at the moment and revisit it later.

#4 — Communicate constructively. Here’s advice that works well in any situation: Use “I” messages to express your feelings; respect others’ feelings; be clear and specific about what you need; and listen well.

#5 — Ask for and accept help. People really do want to help you, but they need to know how. The following guidelines should lead to success:

- Consider the other person’s abilities, interests and availability;
- Don’t ask the same person for help repeatedly;
- Prepare a list of things that need to be done and let the other person choose what suits them best;
- Be prepared for a “no,” or even hesitation. Accept it, but if the person gives you an opening, ask another time; and
- Don’t weaken your request — be clear about what you need, including how important it is to you and the amount of time that help would be needed.

#6 — Talk to the physician. As someone who is part of your loved one’s healthcare team, it is important that you build a relationship with their physician as well. The physician and his or her staff need to understand any needs you may have for training on the complex therapies used to treat PH, but also any impact you feel that caregiving is having on your own health and well-being.

#7 — Exercise. We all know that exercise is good for us, but when someone becomes a caregiver, it may be one of the first things to go. If you don’t already exercise or if you’ve given up your routine, FCA recommends walking because, in addition to its physical benefits, it can reduce tension.

#8 — Learn from your emotions. Our emotions are great teachers, but some, like anger, guilt and depression, can be very uncomfortable. It can be helpful to see such emotions as a sign that you need to make a change in your caregiving situation, that your stress level has increased or that you need to ask for more help.

PH patient Jeannette Morrill with her husband and caregiver, David.
Words of wisdom from one of our community’s caregivers

The Family Caregiver Alliance provides invaluable information about caregiving, but within our own community we have veteran caregivers who share their experiences from their heart. Our caregivers email group (phacaregiver@googlegroups.com) continues to grow and meet the very real needs for information and support among our community’s caregivers.

Diane Creed of Arizona is one such caregiver. Her husband Chuck was diagnosed with PH and lymphoma in 2007, just one year after the couple was married. Her advice to caregivers in the email group is full of love and hard-won wisdom:

"It is a job! You will want to take the weight off your loved one by doing as much as you can to give him/her a break to save energy. It is very tiring and overwhelming at times but the payoff is when your loved one feels better, stronger and then you can both enjoy life again. Get as much help as you can so you have a break. Find a housekeeper, ask friends or family for help with just anything. I found that friends or family wanted to help but didn’t know what to do! I had a neighbor take the garbage cans down to the road and return them. I was very grateful for that little help. I asked neighbors to pick up whatever I needed at the grocery store (you have to plan ahead a bit) but it is worth it and saves you time away. I have asked family to come by and visit my loved one so I could run out for awhile. Asking was the hardest to do, but also the best thing. If friends or family ask to bring over a meal, take them up on it! Freeze food for later if you can’t use it that day.

In subsequent correspondence, Diane added another important element to her role as a caregiver — the search for knowledge. Here’s how she explains it:

While my husband had no energy to do the search, he did appreciate my search and the more I learned about PH, the more I felt we were in control, knew what the docs were talking about, and, of course, the PHA website has been absolutely a life saver. Even though my husband is doing better now, I still spend hours checking out new topics, etc. I guess that is the teacher in me, too, but it is such a positive way to spend time, to know what you are dealing with, see new treatments from all over the world and to cheer others on who are doing better as a result.

So, caregiver, remember that providing care includes self-care. As Diane wisely advises, “find an hour a day to sit and read or listen to music, anything to get off your feet.” That will be good for you — and good for your loved one.

For more words of wisdom from our community, turn to p.9 of the Summer 2010 issue of Pathlight.

**Give a Shout-out to Your Caregiver!**

Pathlight’s new “Caregiver Shout-out” feature honors the family members and friends in the PH community who provide patients with daily encouragement and support. For a chance to express gratitude to a loved one in Pathlight, tell us about a family member or friend whose support has made a difference in your life. Please include both of your names, your relationship, a paragraph about why you’re thankful for your caregiver and, if you can, send us a photo of the two of you together. Email submissions to Caregiver@PHAssociation.org

Here’s an excerpt from a shout-out by PH patient Alex Flipse:

Debbie is my younger sister by seven years. Debbie has helped me through the worst times of my life: right before diagnosis when I was passing out, the period of time when I was starting Flolan™, and during my divorce. For two years, she opened up her heart, her home and her life to my two daughters and me.

Debbie has helped me see myself in a different light — a survivor instead of a victim. She has taught me to stand up for my rights, as she stands up for the rights of so many others, including her family, friends and the PH community. I love my sister. She means the world to me!

**Check Out PHA’s Resources for Caregivers**

In addition to our caregiver email group, PHA’s website is full of useful information for caregivers. Go to www.PHAssociation.org/Caregivers where you can:

- Read caregiver FAQs
- Watch our webinar — My Loved One Has PH: A Caregiver’s Toolbox
- Learn about PH
- Learn how to care for your loved one and yourself
- Find a comprehensive list of caregiver resources

PHA also has a group of experienced caregivers ready and willing to mentor you in your caregiving role. Go to www.PHAssociation.org/Mentors
Empowering the Patient with Associated PH

As a patient with congenital heart disease (CHD) and pulmonary arterial hypertension (PAH), I know how hard it is to juggle two diseases. It was hard enough having one major disease growing up, but acquiring PAH in my early thirties was a whole new ballgame! I’ve gone through life with doctors saying things like, “We just don’t know how your body will respond,” and “We haven’t had any patients like you.” With PH and all the fancy medicines that comes with it, I hear things like this even more often than before!

That is why it is important for people like me, who have PH with an associated disease, to stay on their toes. Patients with associated diseases have to be proactive with their health management so they can help all the specialists they see coordinate with each other. Our doctors need to consider everything that’s going on in our bodies and how our various diseases and symptoms interact. Here are some things you can do to become your own health advocate and help your doctors give you proper treatment:

1. Educate yourself and your medical professionals
   Stay educated about your diseases. I use the PHA website, the Adult Congenital Heart Association website and the websites of the specialty pharmacies. I ask lots of questions of my doctors, nurses and pharmacists. Read what you can, pay attention to the news and talk to other patients. Use the forums on the websites, connect with local support groups and go to conferences. The key is to use your common sense because if there is one thing I’ve learned, it’s that I’m not in the textbooks. Run new information you come across by your PH specialist as it may not apply to you.
   Armed with what you’ve learned, be sure all your doctors understand your primary and associated illnesses. Many doctors aren’t familiar with PH and how to treat it, or how associated diseases affect PH. It often falls to the PH patient to educate their non-PH specialists.

2. Get your doctors talking
   Communication between patient and doctor is key. You can ask why a medication or procedure has been recommended and what it will entail. It’s part of your doctor’s job to answer these questions and listen to what you need. This holds true in the hospital too. If a doctor other than your own prescribes a medication you weren’t expecting, it is your right to ask who ordered it and get verification from your doctor or ask the doctor on call to come talk to you.

   It is also important that your doctors communicate with each other because PH poses different risks and challenges in association with other diseases. Try to find doctors who are willing to work together. It helps to have a good primary care physician who understands your needs and is willing to work with your other doctors. It’s also important that your associated disease specialists are willing to consult with your PH doctor.

   Between consultations, it’s up to you to take responsibility for communicating information among all of the doctors treating you. Keep up-to-date on your medicines and stay informed about side effects and interactions with other medications and foods. Be as thorough as possible when relaying your medical history and medications to new doctors or when having a procedure.

3. Listen to yourself
   Having grown up with chronic illnesses, I was taught at an early age by my doctors to take cues from my body. While I always keep in mind that I’m not the expert, sometimes I have information from other doctors, from past experiences or from the way I’m feeling that is helpful in guiding my care. And remember you don’t have to do it alone — look to your family members, friends and other doctors to back you up when you need support and encouragement to stand up for yourself.

   As you can see, there are lots of things to consider, and honestly, my healthcare coordination truly is my second job. However, my hard work usually pays off. We, as patients, need to use all our resources and fight for what we need.

By Melinda Schissel
PH Patient

“PH Plus” is devoted to patients with PH and associated illnesses. To learn more visit www.PHAssociation.org/PHPlus
PHA’s Scientific Leadership Council Welcomes New Members

If you’ve ever attended an education session at a PHA conference or gathered new medical information from PHA’s website, you’ve interacted with PHA’s Scientific Leadership Council (SLC). The SLC is a group of world-renowned PH medical professionals who work together to guide PHA’s clinical and research activities. In 2011, the SLC welcomes seven new members: Murali Chakinala, MD; Roham Zamanian, MD; Duncan Stewart, MD; Marc Humbert, MD; Dinesh Khanna, MD; Tomas Pulido, MD; and Virginia Steen, MD.

Members of the SLC are clinicians and research scientists in medical centers recognized for performing outstanding research and providing excellent care for PH patients. Medical professionals are invited to join the SLC as a result of their demonstrated dedication to the advancement of PH education and treatment. In the SLC’s 18 year history, every physician who has been asked to join this body has accepted the invitation.

The SLC is crucial to PHA’s ability to provide comprehensive education to both medical professionals and patients. Its members are involved in aspects of every educational initiative that PHA pioneers, from orchestrating the educational components of PHA on the Road: PH Patients and Families Education Forum to developing content for PHA’s professional medical education programs such as PHA Online University (www.PHAOnlineUniv.org), PHA 30-City Medical Education Program and PHA Preceptorship Program. Learn more about these programs by visiting www.PHAssociation.org/MedicalEducationFund.

The SLC was born out of the PHA philosophy that patients and medical professionals can achieve more working together. SLC members show their care for the patient population in many ways, including developing educational materials to help patients understand the symptoms of PH, coordinating and speaking at PHA on the Road and PHA International PH Conferences, and attending support group meetings to talk to patients.

It is with great pleasure that we welcome the new members of the SLC. The names of all SLC members are listed on the last page of each issue of Pathlight (see p.51 of this issue). To learn more about the SLC, visit www.PHAssociation.org/SLC.

Welcome, Micaela Cohen, MPH, LICSW, Associate Director of Medical Services!

As Associate Director of Medical Services, Micaela works with PHA’s professional membership groups to ensure that they have access to all of the resources they need to make progress in the fight against PH. She also coordinates the various educational programs that comprise PHA’s medical education initiative, and assists in coordinating PHA’s research grant opportunities. Micaela can be reached by phone at 301-565-3004 x770 or by email at Micaela@PHAssociation.org.

Welcome, John Krizel, Medical Outreach Program Associate!

As Medical Outreach Program Associate, John is responsible for promoting membership in PH Clinicians and Researchers (PHCR) and helping to develop the group’s knowledge and other resources in ways that will benefit the entire PH community. He works closely with PHCR and the Scientific Leadership Council (SLC) to help these groups develop organizationally to meet their goals. He also provides assistance and support for PHA Online University and maintains the Find a Doctor directory on PHA’s website. John can be reached by email at John@PHAssociation.org or by phone at 301-565-3004 x776.
As members of a rare disease community, it’s important for PH patients and their loved ones to reach out to one another and build connections. The Our Journeys program empowers PHers to share their stories with the world and learn about how others live with pulmonary hypertension.

Read more stories, submit your own, or watch Video Journeys by visiting www.PHAssociation.org/OurJourneys

Perry Mamigonian, Fresno, Calif.

It was March 2009 when I was finally diagnosed with Idiopathic Pulmonary Arterial Hypertension (IPAH). For several years prior to this, I had struggled with shortness of breath and fatigue, but blamed myself for being out of shape, overweight and just getting older. By late 2008, I began to feel much worse. I was catching frequent colds and was left feeling achy and weak, as if I had the flu. I also developed a frequent cough with spells so bad that I would become dizzy.

On March 11 of the following year, I had a coughing spell so severe that I blacked out and crashed as I was driving to work. Fortunately no one else was hurt, but while I was recovering in the hospital the doctors began running tests to determine why I had passed out. After about a week the verdict was in: I had Class III/Severe IPAH, which was something I had never heard of. On March 18, I began my Remodulin™ therapy and was declared unable to return to work in the printing industry I had been in for 25 years.

Like so many of us diagnosed with PH, the shock of having my life turned upside down was too much to take. I was filled with anger and self-pity, with no desire to get out of the house. It was only when I received a phone call from Kelli Danner, the Accredo Community Advocate in Northern California, that I began to see the light in dealing with my condition. Kelli gave me encouragement and showed me compassion when I was feeling completely alone and isolated.

I urged me to attend the Pulmonary Hypertension Association’s International Conference and Scientific Sessions in Southern California in June 2010 and even arranged a scholarship so that I could afford to go. It was here that I had the opportunity to meet other pulmonary hypertension patients for the first time. There were so many kind people who reached out to me with advice and reassurance. It was also the first time that I experienced first-hand the hard work of PHA. The first thing I did when I returned home was send in my membership check.

At this time, I also met Joanne Sanders from United Therapeutics and signed up for their Remodulin™ Therapy Assistance Program. She has become a good friend and helps me feel like a normal person, not just a patient.

Since then I have met many other “PHriends” in my hometown and online. Their stories have been heartbreaking and encouraging — all have been inspiring. If there is anything positive about having PH, it is in learning — from my doctors, pulmonary therapists, family, friends and fellow patients — how kind and generous people can be. You never realize how good people can be until you need help.

If there is anything positive about having PH, it is in learning — from my doctors, pulmonary therapists, family, friends and fellow patients — how kind and generous people can be. You never realize how good people can be until you need help. I have been fortunate to show much improvement in the last 14 months, and while nobody knows what the future holds, I do know that there will always be a lot to live for and a lot worth fighting for. ♦
My name is Jhenna, I am 22 years old and was diagnosed with pulmonary hypertension in March 2010. It was back in October 2009 when I first started noticing that I was having difficulty getting around. I got out of breath very easily, and I had this miserable cough that wouldn’t go away. I went to an urgent care facility in November of 2009 and was told that I had bronchitis and was given antibiotics. I also noticed that day that my pulse rate was 115 and my blood pressure was high, which is very unusual for me.

After about two weeks, I returned to the same facility because I was not feeling any better. I told my doctor that I was having difficulty breathing and I noticed my blood pressure and pulse rate were still off. The doctor said that I didn’t have bronchitis: it was just a cold and I should take cold medicine for a week. So I continued my normal routine, working 40+ hours a week as the manager of a pet store, lifting hundreds of pounds of dog and cat food.

A week before Christmas, I felt so much worse. I couldn’t even climb up the stairs without feeling like I was going to pass out, so I decided to try a different urgent care facility. They took my blood pressure that night and, sure enough, my blood pressure and pulse rate were still unusually high. The doctor also ordered a chest X-ray because I still had that bad cough. However, she didn’t seem too worried because she gave me more antibiotics and told me she would call me with my chest X-ray results.

Three weeks went by and I had not heard anything from the doctor, so I decided to just give up — I thought I must just be out of shape. Thankfully, my mom did not feel the same way and she decided to call to get my results. At first, the nurse told us that the chest X-ray was normal but then 10 minutes later I got a phone call from the doctor telling me my heart looked enlarged and that I should go to a primary physician to get a referral to see a cardiologist because of my high blood pressure. I couldn’t believe what I was hearing. I possibly had an enlarged heart and this doctor waited three weeks to tell me!

I then went to my primary care doctor and she referred me to a cardiologist who performed an echo. The echo showed that I have severe Idiopathic Pulmonary Arterial Hypertension (IPAH) and I needed to go for a right heart catheterization as soon as possible. I was so scared, I actually started crying. The doctor then suggested that I go see a pulmonary specialist. On March 16, 2010, my pulmonary specialist did a left and right heart catheterization to make sure I had no other complications. The devastating results confirmed that I had severe IPAH.

My pulmonary specialist told me that he usually admits people into the hospital with the results I had, but for some reason I was a lot stronger for someone with these pressures. He told me my best treatment option would be to start IV medication in combination with other medications. I definitely had my ups and downs with the medication but I am happy to report today that I feel great! I can now climb up stairs and I don’t feel like I am going to pass out anymore. I am also going for a consultation for a lung transplant because my specialist wants to make sure I have back-up options just in case my PH worsens.

During this time, I have been very lucky to have the support of my family and fiancé. I don’t know how I would have gotten through this without them. I love them with all my heart! I hope to help raise as much PH awareness as I can in the future, to make sure no person has to go through what I went through.

Jhenna Pacelli, New Haven, Conn.

I hope to raise as much PH awareness as I can in the future, to make sure no person has to go through what I went through.
ASK A PH SPECIALIST

Q: I’ve noticed that I feel more “down” and have less energy than usual during the fall and winter months. Is there anything that PH patients can do to avoid feeling blue or depressed around the holiday season?

A: These feelings may be associated with any severe illness like PH. I would advise that you first discuss these feelings with your PH physician to ensure that there is not a physiological explanation such as low oxygen or side effects of a medication. In addition, you want to make sure your feelings are not representative of a more severe condition such as clinical depression that may require treatment. Indeed, we are learning from the REVEAL registry that a significant number of patients require treatment for depression. Once you have addressed any treatable issues, you can begin to take advantage of available resources to help combat these feelings. Pulmonary Hypertension: A Patient’s Survival Guide has a chapter on coping with PH, and your local support group offers networking opportunities with other patients who may be experiencing similar issues. It’s also important to be open with your friends and family so that they can be supportive.

Answer provided by Charles Burger, MD, Chair, Pulmonary and Critical Care Medicine, Mayo Clinic Florida, Division of Pulmonary and Critical Care

A: It is not uncommon to experience an increase in depressive symptoms during the fall and winter months. This phenomenon — sometimes called “winter depression” or the “winter blues” — is often referred to by physicians as “Seasonal Affective Disorder.” Seasonal affective disorder is not considered a psychiatric condition itself, but rather describes the seasonal fluctuation in symptoms that can accompany mood disorders. Studies of this disorder indicate that it is quite common, occurring in up to 10 percent of the general population. It appears to be more prevalent among those living at higher northern latitudes. Like PH, seasonal affective disorder affects women more commonly, and data suggest that the risk decreases with age.

Many patients with PH report symptoms of depression. Symptoms of depression include: feeling down, loss of energy, diminished interest or pleasure in activities, feelings of guilt or hopelessness, inability to concentrate and changes in sleep or appetite. Although most people can relate to feeling this way at some point in their life, such symptoms are considered abnormal if they are severe, persist beyond two weeks or are accompanied by the desire to harm yourself. If any of these apply to you, then you should seek medical attention immediately.

The exact cause of seasonal affective disorder is not known. One predominant theory is that decreasing daylight during the fall and winter months alters the level of certain neurotransmitters in the brain that are associated with depression. For that reason, bright light therapy is often recommended for individuals suffering from this disorder. Studies on the efficacy of light therapy are variable, but most seem to suggest that it reduces the severity of symptoms. Light therapy involves staring at a special light box that emits a particular intensity of light. Use of conventional lighting fixtures in your home is not recommended, as the small point source can cause retinal damage. Several manufacturers sell light boxes online. In some cases, your insurance may partially help cover costs if prescribed by a physician.

For those with mild symptoms, simpler interventions may also be effective. Examples include: scheduling a daily walk outside, increasing the number and brightness of lights inside your home/office and setting a “dawn simulator” or “artificial sunrise” device to gradually increase the light in your bedroom approximately one hour before waking. Of course, maintaining a healthy diet, regular meals, staying active during the day, avoiding caffeine during the evening and getting to bed on time are also important in helping your body adjust to the change in seasons.

Answer provided by Hubert Chen, MD, MPH, Assistant Professor of Medicine, University of California San Francisco, Division of Pulmonary & Critical Care Medicine

Online Resource: Dr. Stephen Mathai led a webinar about keeping the PH blues away. To view the recording, visit www.PHAssociation.org/PHBluesAway

EACH ISSUE, Pathlight features a question from our PH community and its answer from a PH specialist. Send us your questions, keeping in mind doctors can only address general topics that are not specific to individuals. Send submissions to askadoc@PHAssociation.org or call 301-565-3004 x770.
Because pulmonary hypertension is such a complex disease, providing education for patients, caregivers and medical professionals is a vital part of PHA’s mission. That’s why PHA goes “on the road” each year, bringing patients, families and local PH experts together through PHA on the Road: PH Patients and Families Education Forums. Dr. Charles Burger, a PH expert and chair in 2009 and 2010 of the PHA on the Road committee, is integral to this education initiative. Dr. Burger has a rich history in the field of PH, and he recently shared some of his experiences with us.

Dr. Burger works in the Division of Pulmonary and Critical Care Medicine at the Mayo Clinic Florida in Jacksonville, Fla. During his 20 years working with pulmonary hypertension, the field’s understanding of PH has advanced exponentially. Formerly a disease with no approved treatments and only a handful of diagnosed patients, the field of PH now has eight PH treatments with more in the pipeline and more than 20,000 diagnosed patients. Of all the advances Dr. Burger has witnessed, he believes the most exciting and encouraging has been, without question, “the ever expanding availability of FDA-approved therapies to improve patient’s quality of life.”

Dr. Burger has seen firsthand how medical advancements can help PH patients. He recalls one woman who was referred to him after her physician saw a reference to Flolan™ and to Dr. Burger’s knowledge about the drug in the hospital newsletter. She had severe pulmonary hypertension and required three and a half years of infusion therapy with Flolan™. Amazingly, her disease reversed to such a degree that she is currently doing quite well on oral calcium channel blockers. Now that she “got her life back,” Dr. Burger says, she is a tremendous advocate for pulmonary hypertension patients.

Dr. Burger became involved with PHA when some colleagues advised him to attend the PHA International PH Conference and Scientific Sessions in 2004. He took their advice, and while attending Conference, Dr. Burger was “impressed by the incredible commitment of the patients and their providers in search of a cure for this disease.” After witnessing this commitment, he immediately felt like part of the PHA family and decided to become more involved.

In January 2010, Dr. Burger was welcomed as a member of PHA’s Scientific Leadership Council, a group of 28 global leaders in the field of pulmonary hypertension who oversee the development of PHA’s medical programming and coordinate the medical arm of PHA (see p.9). He has also chaired the PHA on the Road committee since the introduction of that program two years ago. Under his leadership, six forums have taken place with four more planned for this spring (see p.34).

While serving as chair of the committee, Dr. Burger says he enjoyed attending these forums because of the unique opportunity for local PH experts and local PH patients to learn together, side-by-side, in a formal educational venue. For Dr. Burger, the program is like “an extension of the support groups that have worked so hard to provide patient education at the local level.” As he explains, attendees can receive “up-to-date and practical information on living with PH” from local physicians and patients while “networking with other patients and providers” and contributing to the general PH community.

As a physician, Dr. Burger stresses the importance of maintaining a positive attitude and commitment to his patients. He emphasizes that patients must “stay positive and give your providers a chance to make you better by strictly following their advice. There are no shortcuts, but this is a battle that can be won!” A true representative of PHA’s mission, Dr. Burger believes that everyone and anyone connected to PH can play their part in working towards a cure: “It will take the collective wisdom and efforts of all involved, including patients, families, healthcare providers, researchers, PHA and others, to reach our ultimate goal of a cure. Let’s all commit to working together!”

By Meghan Finney, PHA Patient Education Program Associate
Traci Stewart: Supporting Patients, Caregivers and Fellow Colleagues

Traci Stewart, RN, MSN, engages the PH community through her involvement in various activities, including leading a patient support group and facilitating education for patients and her fellow nurses. In 2010, she was voted chair-elect of the PH Resource Network and joined PHA’s Board of Trustees. Recently, Traci took time to talk about her involvement in the PH community and how it has impacted her life.

What motivated you to pursue a career in PH? I started my nursing career on an inpatient cardiac step-down unit at the University of Iowa in 1992. In 1995, shortly after Flolan™ was approved by the FDA, some of the nurses in the hospital where I worked were afraid to take care of patients admitted on Flolan™. In response, two of us volunteered to become the “floor experts” for these patients. About 13 years ago, I transferred to my current position as a heart failure nurse clinician specialist in the Cardiomyopathy Treatment Program at the University of Iowa. Because of my interest in PH, I was asked and honored to take on the role as primary PH nurse coordinator.

What’s the most satisfying thing about working with the PH population? People diagnosed with PH are looking for answers. Often times, newly diagnosed patients are grieving after being misdiagnosed or being told there are no treatments for PH. It has been very satisfying to help people understand this disease state and the therapies available to them. Helping someone with PH make lifestyle changes and learn to cope with the illness instead of letting the illness control their life is very rewarding.

How has your work with PH patients impacted you both professionally and personally? My work in the field of PH has helped me grow as a nurse leader. Along with my physician mentors, I have been involved in clinical and research program development. Educating patients and providers at conferences and in the community has helped me understand patient, nurse, and community physician perspectives. Knowledge is powerful; we need to continually look for ways to improve how we deliver information in busy clinic settings.

On a personal level, caring for this patient population has helped me learn to problem-solve and listen. I try to provide information that is realistic, compassionate and specific to each person’s needs. We are all in this together and a team approach can provide creative, individualized solutions for the challenges people with PH face every day.

How has your connection to PHA and the PH Resource Network helped you along the way? PHA and the PH Resource Network are absolutely fantastic resources — but you have to get involved to get the full benefit. One of the great benefits of the PH Resource Network for those who are new to PH is the connection with more experienced medical professionals and the ability to ask questions to see if others have encountered similar challenges. We are all working to provide excellent patient care and chances are someone has already confronted a tough situation and figured out a solution.

Similarly, through PHA, newly diagnosed patients can talk to others with the same symptoms and seek solutions to daily challenges. There is an opportunity to network and share knowledge on so many levels.

What do you hope to accomplish during your term as Chair-Elect of the PH Resource Network? Any time we can improve outcomes for people with PH, we are succeeding. My focus remains on education as one way to improve patient outcomes. By educating nurses, we can ensure quality care to our patients; by educating the community, we can identify PH earlier and start treatments earlier; and by educating patients, they learn to cope and adapt to life with PH. All these areas of education are essential ways to improve outcomes for individuals diagnosed with PH.

What’s the most important piece of advice you give your PH patients? My prayer is that I say what my patients need to hear when they need to hear it. We often talk in our support group about coping and strategies to conserve energy to prevent “running out of steam” early in the day. I really advocate for people to be as active as they can, yet to ask for help when needed. I want to help improve their quality of life by identifying challenges so we can work toward solutions.

Interview conducted by Rachel Wheat
PHA Allied Health Program Associate
Tips for Staying Healthy in Cold Weather

1. Continue with daily exercise but limit your time outside in the cold weather. Try walking inside a mall or use a treadmill or stationary bicycle in your home. It is recommended that you exercise with someone or have another person close by, should any problems arise.

2. Avoid decongestants or cough suppressing medications that contain dextromethorphan (DM), which causes shallow breathing and the heart rate to increase.

3. Get your seasonal flu shot and pneumonia vaccine every five years.

4. Use a humidifier in your home to relieve dry throats and to prevent coughs from the dry cold air.

5. Drink warm liquids to maintain hydration while also keeping warm. Keep a thermos of warm fluids with you in your home or during travel.

By Janette T. Reyes, RN, BScN, NP-Peds, The Labatt Family Heart Centre, The Hospital for Sick Children, Toronto, Ontario, Canada

Cold Weather Tips from the PH Community

The following cold weather tips come from YOU, the PH community. PHers constantly share tips and advice on PHA’s message boards and email groups (www.PHAAssociation.org/ConnectOnline). Check out these tips and be sure to join the conversation online.

- Look into WinterSilks® (www.wintersilks.com or 800-718-3687). They make three weights of silk underwear and offer many other products.
- Get a pair of “Cuddl Duds.” They are lightweight and warm under your clothes all year long. (www.cuddlids.com)
- Always wear or carry layers appropriate to the season and be sure your sweaters, jackets, etc. have sufficient pockets to help warm your hands.
- Drink something hot — sometimes even just hot water if you are avoiding caffeine, sugar and artificial sweeteners or flavors.
- Eat hot, nourishing cereals in the morning and hot, nourishing soups the rest of the day.
- A Towel Spa® (www.towelspa.com) is very useful to warm up hats, gloves, under garments, pants — whatever fits!
- Keep fleece blankets handy.

For more information and resources for handling the changing seasons, visit www.PHAAssociation.org/Patients/ClimateAndPH

DISCLAIMER

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

Adiponectin is a fat cell-derived protein hormone that regulates the metabolism of lipids and glucose. Adiponectin is known to influence the body’s response to insulin and have anti-inflammatory effects on the cells lining the walls of blood vessels. It is also suspected of playing a vital role in suppressing processes such as cell proliferation and production. More generally, adiponectin plays an important preventative or protective role in several diseases such as insulin resistance, diabetes, obesity, obstructive sleep apnea-hyponemia syndrome and, possibly, pulmonary vascular disease.

In adults, levels of adiponectin are inversely related to body fat percentage; patients who are lean and healthy have high levels of circulating adiponectin, while patients who are obese or have increased body mass index have low levels of circulating adiponectin. The low levels of adiponectin in obese patients are suspected of being a result of feedback mechanisms.

Past Research

Previous work on adiponectin recognizes the protein primarily as an insulin influencer. Specifically, adiponectin is suspected of playing an important role in the prevention of insulin resistance in diabetic patients. Insulin resistance occurs when the body stops responding to high levels of insulin in the blood, therefore decreasing the body’s ability to use insulin effectively to decrease blood sugar levels. As a result, blood sugar levels, as well as circulating triglyceride levels, remain high. If untreated, this form of insulin resistance can lead to type II diabetes. To protect against insulin resistance, adiponectin activates the production of triglyceride-combusting molecules, and therefore decreases the amount of triglycerides in the muscles and liver.

Current Research

While adiponectin is most widely known to influence insulin levels, recent studies suggest its important role in controlling inflammation, cell production, and homeostasis. Recent studies reveal possible relationships between adiponectin levels and pulmonary hypertension. As a result, low levels of adiponectin are associated with increased inflammation of the lungs and airways, and increased vascular remodeling (or thickening of the vascular walls and subsequent narrowing of the vascular lumen). Currently, studies show that inflammation is a significant stimulus for the development of pulmonary hypertension. This increased inflammation and thickening of the lung blood vessel wall leads to increased resistance within the blood vessels and consequentially increases blood pressure in the lungs. This can be likened to sticking your thumb over the top of a water hose. When your thumb blocks part of the opening, the same amount of water is forced to flow out of a smaller hole, increasing the pressure of the water coming out of the hose. When the walls thicken in your blood vessels in the lungs, the same amount of blood is being forced through a smaller opening, causing increased blood pressure throughout your lung blood vessels. The stress on your vessels caused by increased blood pressure causes decreased elasticity and further thickening, requiring even more work by the right side of the heart to adequately pump blood through the lungs and its surrounding vessels. This increased workload on the heart causes hypertrophy, or muscle thickening, of the right ventricle, making it more difficult to pump blood effectively.

Studies show that high levels of adiponectin may decrease inflammation and inhibit uncontrolled cell proliferation, preventing high pressure build up and stress to the blood vessels and heart. These anti-inflammatory and anti-atherogenic (build up of plaque along blood vessels) properties protect against diseases like pulmonary hypertension.

Application

The recent studies provide further insight on the influence of obesity and other indicators of metabolic syndrome on the development of pulmonary hypertension due to the depletion of anti-inflammatory molecules such as adiponectin. More research is needed to better establish adiponectin’s role in the development of obesity, diabetes and pulmonary hypertension. Currently, researchers are investigating treatment options to enhance adiponectin levels to protect against pulmonary vascular disease, such as pulmonary arterial hypertension.

By Amy Zeifman, BS, and Jason X.-J. Yuan, MD, PhD, Department of Medicine, University of Illinois at Chicago, Chicago, Ill.
Miles for Monica

Since taking up running several years ago, motivation has rarely been a problem for Ellen Robinson. The 23-year-old Johnstown, N.Y., native developed a passion for pounding out the miles, whether for her own wellbeing or that of others. Ellen helped raise money by participating in the Arthritis Foundation’s Jingle Bell Run/Walk for Arthritis in December 2009 in Syracuse, N.Y., but a family tragedy fueled Ellen’s greatest running triumph.

In July 2010, my daughter, and Ellen’s two-year-old cousin, Monica Grace Allen, passed away after a lifelong battle with pulmonary hypertension. “From the day she was born and the first moment I held her, I felt a special bond with Monica,” Ellen told me. “After we lost her, I felt powerless. I wanted so badly to do something for her.”

That something, Ellen decided, would be to finish the Adirondack Marathon Distance Festival, a 26.2-mile race held September 26, 2010, in Schroon Lake, N.Y. In dedicating her first marathon to her cousin, Ellen determined that it was an excellent opportunity to raise money for the Pulmonary Hypertension Association. Ellen contacted PHA Development Associate Jennifer Kaminski, who steered Ellen to FirstGiving, a resource PHA uses to make it easy to raise money online through its Web of Friends campaign.

FirstGiving became the perfect vehicle for Ellen’s quest. Finding a name for that quest was the next challenge. “It came to me while I was running one day,” she said. “I thought, ‘I should just start dedicating these miles for Monica.’” And so, “Miles for Monica” was born. A short time later, Ellen’s beautiful tribute to Monica graced her FirstGiving webpage.

With the marathon only a couple of months away, Ellen figured she should set her fundraising goal relatively low. She thought $1,000 was optimistic. However, as Ellen spread the word to family, friends and co-workers, donations began streaming in. “I had to bump up the goal,” she said, “to $2,000, then $3,000, and $4,000.” Even that wasn’t high enough. As of late October, “Miles for Monica” had raised $5,500 for PHA (the website is active until February 2011).

Seeing the tally grow gave Ellen even more motivation to prepare. But it wasn’t easy. In August, Ellen started a new job in western Connecticut. While adjusting to the move from her parents’ home to apartment life, Ellen also spent a month commuting to Manhattan for a client project at her employer’s corporate headquarters. She got up at 4:30 a.m. every day to complete her training. As summer turned to fall and mornings became colder and darker, memories of Monica kept Ellen moving: “She was with me on all my runs. Her sweet little smile and happiness were great motivations to keep on running.”

On the day of the race, clad in “Miles for Monica” T-shirts, Ellen’s cheering squad included her mother, father, boyfriend and my wife, Megan Allen, and me.

As the race began, Ellen quickly disappeared into the pack. “Even when I was tired,” Ellen said, “I kept thinking about Monica and it kept me going. At one point I was struggling up a steep slope when I saw the sunlight glowing on the orange and yellow leaves. (Yellow was Monica’s favorite color.) Then a milkweed seed floated in the air toward me. I caught it and held it for a while. It was like holding Monica with me.”

Three hours and 47 minutes after dashing from the starting line, Ellen completed the marathon. Ellen finished seventy-third overall and seventh among female competitors. She finished third in her age group.

“It was really important that I finish,” she said. “PH is a disease that I had never heard of before Monica was diagnosed, but it affects so many families. Hopefully, ‘Miles for Monica’ will motivate more people to donate and give those families more strength to keep going until a cure is found.”

By Andy Marino, Ellen’s uncle and Monica’s father

Since PHA first started using personal fundraising pages, members have raised more than $200,000 online, and generated much more offline! Every donation makes a difference. Whether you’re still deciding to do a Web of Friends campaign or ready to get started, PHA is here to help! We can assist you at every point in this process — and we have a few tricks up our sleeve that we’d like to share. Contact Giving@PHAssociation.org or call Jennifer at 301-565-3004 x756.
Fundraising at Celebrations: It’s Not a Party Until It’s a PHA Party!

Are you planning a celebration? Make it even more meaningful by including a cause that’s important to you: pulmonary hypertension.

PHA’s In Honor of Our Lives program gives you the opportunity to include fundraising and awareness-raising in your special celebrations. In Honor of Our Lives is also a special way to honor or remember the courage of PH patients in the fight against this terrible disease.

Whether you’re planning a birthday, wedding, retirement or anniversary, make your special day extra special by inviting PHA to the party. You can ask your party guests to make donations to PHA in lieu of presents, or you can make a donation in honor of your guests in lieu of party favors. By including fundraising and awareness-raising at your party, you can use your celebration to help beat PH.

Ready to get your party started? Contact Jennifer at 301-565-3004 x756 to learn more about the program, and how PHA can help provide informational materials for your event. ♦

By Jennifer Kaminski, PHA Development Associate

Jay and Jasmine’s Wedding Celebration

When Jay Hamm and Jasmine Gonzalvo began planning their wedding celebration, they knew they wanted to incorporate PH awareness-raising in their special day. Instead of having favors at the reception, Jay and Jasmine made a gift to PHA in memory of Rexanna Hamm, Jay’s mom. They received a number of compliments during and after the reception about their special gift, and they feel it was a nice way to have Rexanna’s spirit with them throughout the day.

To learn more about In Honor of Our Lives, visit www.PHAssociation.org/Fundraise/AtCelebrations

CHRISTEN WHITE TOLD HER FAMILY SHE WANTED TO LEARN MORE ABOUT PH. TODAY, THEY WANT THE WHOLE WORLD TO KNOW MORE.

Stephen White remembers the phone call he got from his 22-year-old daughter, Christen, just a few months before she succumbed to PH in 2002. She had applied for a scholarship for the Pulmonary Hypertension Association’s 5th International PH Conference. When she got it, she called her dad to ask him to accompany her on this journey.

To read how the White Family rallied to meet the challenge of PH, visit PHAssociation.org/Give/White

Like Stephen and Andrea White, 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.
With support from a Tom Lantos Award for Innovation in Community Service grant, PHA South Africa proudly hosted its first PH Retreat on October 30-31, 2010. “It was an historic moment for persons living with pulmonary hypertension,” says Elzarie Devenish, grant winner and retreat planner. Twenty-nine medical staff, PH patients and family members attended the retreat, the first of its kind in South Africa.

The retreat aimed to reduce patient isolation, discuss advances in PH and the medical situation in South Africa, launch the work of PHA South Africa and its support group, raise media awareness, and create an opportunity to monitor and evaluate needs. The program was comprised of PH patient stories and speakers from the PH medical field. The energy and enthusiasm of all the attendees was electric.

Denneys Niemandt, Chairperson of PHA South Africa, wrote before the retreat, “Now I know how Neil Armstrong and his team felt the day they landed on the moon: I cannot wait.” Dr. Paul Williams, guest speaker, acknowledged the value of the meeting, thanking the organizers for getting it right by involving the medical community with PH patients, a unique situation that has never happened before in South Africa. Dr. Freek Bester added that the energy created was wonderful.

Mrs. Devenish gave a presentation on “The Road to the Retreat,” describing how PHA South Africa links internationally and what the group needs to do. Promotion and awareness-raising were key elements of the retreat. The local newspaper, Volksblad, ran two articles on the retreat, reaching more than 20,000 readers. SABC Radio interviewed Mrs. Devenish in Afrikaans and English about the outcomes of the retreat and broadcast the piece nationally. Mrs. Nicoline Muller launched the PuckerUp4PH awareness raising campaign in South Africa and the group painted their lips blue for PH, an activity that all joined in — from medical professionals to PH patients and their families.

The value of this retreat cannot be described in words; it gave individuals living with PH, their families and the medical community hope, direction and a way forward in South Africa. “Hope,” says Mrs. Theresa van der Walt, mother of 9-year-old PH patient Leonique, “that is what this retreat taught me. It meant so much sharing with people who understand what is going on, and lasting friendships were formed.”

This model can be replicated in any third world country for extending the reach of promotion and awareness of pulmonary hypertension. However, we would not be at this point without our Tom Lantos Innovation in Community Service Award, PHA and the international network of associations, and Gilead, sponsor of the Lantos Awards program. As Mr. Nico Muller explains, “It was one of the best experiences in my life, thank you.”

Compiled by Elzarie Devenish, South Africa
PH Newsletters Around the World

In 2010, PHA celebrated the twentieth anniversary of the very first edition of Pathlight, which began as a volunteer endeavor in 1990 and has grown to become a full-color quarterly newsletter reaching approximately 10,000 readers. Then, as now, Pathlight performed a hugely important function in both connecting and educating PH patients, families and medical professionals. But Pathlight is by no means the only PH newsletter out there.

To kick off the next decade of Pathlight, we decided to turn the spotlight on those associations worldwide that are also producing newsletters. Here are just a few examples of the many varied print resources produced across the PH international community.

One of the youngest PH newsletters is Hap En Noticias, pictured below and produced by the Latin PH Society. Production first began on this Spanish-language newsletter in November 2009 and, already, they are working on their fifth edition. Typically, it covers PH events, scientific articles, and stories from patients. Each issue contains an article written by Dr. Jaime Morales called “Progress in Latin America.” As the only newsletter of its type in Latin America, it fulfills a vital educational function for its readership. PH patient Migdalia Denis, who produces the bulletin with Dr. Morales and her sister Denis Lourdes, notes that for her the best part “is the great human content of our newsletter, and that all stories are written and submitted to us by the patients.”

Mariposa News is another new addition to the long list of international newsletters. Produced three times a year since early 2010 by PHA Europe, it includes news from PH patient associations in Europe and around the world. The newsletter also closely monitors European Union and NGO (non-governmental organization) activity in the fields of rare diseases and orphan drugs, organ donation and transplantation and other PH-related issues. Production is overseen by Pisana Ferrari, the first vice president of the Board of PHA Europe. With PHA Europe’s ongoing membership expansion (eighteen countries are now members), and a readership already in the thousands, it is likely that Mariposa News will continue to grow.

The British Columbia Pulmonary Hypertension Society (BCPHS) newsletter, ph way, began with the vision of one woman working on her personal laptop. As Liz McCall says herself, “We thought it was a good way to connect the PH Community in BC, Canada and internationally. I started it on my home computer and had never done such a thing before. It was a ‘do and learn project’ — still is at times!” In any edition you might find the life stories of people with PH, memorials to those who lost their battle with PH, events organized by BCPHS, fundraisers, PHA conferences and other PH group conferences.

Another Canadian publication is Connections. First launched in 2010 by PHA Canada, it followed on the heels of a very successful first PH Canada Conference the previous year. Each article is printed in both English and French and, like all PH newsletters, it aims to share patient stories, “inspiring one another … giving each other hope and … working to make a difference in the lives of those with this disease.”

Emphasis is the long-running quarterly publication of PHA-UK. It enjoys an international circulation of more than 2,000 readers, and anyone can download a pdf copy online. One of PHA-UK’s biggest success stories has been the PuckerUp4PH campaign, so it is no wonder that this has featured prominently in Emphasis since the campaign’s inception in 2008. One recent news feature highlighted a campaign to allow PH patients easier access to airline supplemental oxygen.

And there are more newsletters to come! PH South Africa, officially launched as an association at their PH Retreat in Bloemfontein in October 2010 (see p.19), plans to begin work on a newsletter in the near future. SSPH (Sdruzeni Pacientu Plicni Hypertenzii), the PH association of the Czech Republic, recently began work on its first Bulletin. Articles will cover plans for 2011, people who work in the association and the socio-legal issues associated with PH.

Want to keep up with what’s going on around the world? Contact International@PHAssociation.org

By Sylvia Earley
PHA Nonprofit Communications & Development Coordinator
Legislative Victory: Obama Signs Improving Access to Clinical Trials Act into Law

In late 2010, President Barack Obama signed the Improving Access to Clinical Trials Act of 2009 into law. This new law will enable patients with rare diseases to enroll in compensated clinical trials without that compensation counting against their Social Security Disability or Medicaid eligibility income caps. This will allow more PH patients to participate in clinical trials, an important step toward new and improved PH treatments and — ultimately — a cure for pulmonary hypertension.

A legislative victory like this could not happen without you. Thank you to everyone who called or emailed their Members of Congress about this legislation!

Help us score our next legislative victory. Contact Elisabeth, PHA’s Grassroots Campaigns Associate, at 301-565-3004 x753 or Elisabeth@PHAssociation.org to get involved in advocacy.

Advocates Across the Country Proclaim November PH Awareness Month!

Last November, Lexington, S.C., Support Group Leader Doug Taylor issued a challenge to every support group leader: Get at least one proclamation in your city, county or state officially recognizing Pulmonary Hypertension Awareness Month in November 2010. Doug’s friendly challenge spurred a domino effect. Support group leaders, members and their families and friends across the country requested PH Awareness Month proclamations from their local officials.

As we go to press, PHA members have received nearly 30 proclamations. South Carolina is setting the bar high with 11 proclamations, and PHA members from all over have taken up the proclamation challenge. Governors in Connecticut, Maryland, Minnesota, South Carolina, Tennessee and Puerto Rico have signed proclamations recognizing November as PH Awareness Month. Pam Carner from Ohio secured a proclamation from Rep. Jean Schmidt (R-OH) from the U.S. House of Representatives.

PH patient Nicole Cooper, who requested and received a proclamation from Maryland Governor Martin O’Malley, echoes sentiments from other proclamation seekers, “It is really easy. Follow-up is the key to getting it done.”

PH Awareness Month may be over, but every month is a good month to raise awareness. To learn more about getting involved with awareness-raising, contact Elisabeth at 301-565-3004 x753 or Elisabeth@PHAssociation.org or visit www.PHAssociation.org/Advocacy.

Congressional Luncheon Moves Hearts and Minds

PHA’s 2010 Congressional Luncheon included more than a few tears and multiple standing ovations. Kimberly Thompson Ellis, representing Rep. Kevin Brady (R-TX); Dr. John Berger, Director of the Pulmonary Hypertension Program at the Children’s National Medical Center; Kimberlee Ford, a PH patient and support group leader; and Carl Hicks, who lost his daughter Meaghan to PH, shared compelling stories that helped legislative staff and others understand both how PH impacts the body and how it impacts individual lives. All were in agreement — we’ve come a long way but there is much further to go, and support for the Tom Lantos PH Research and Education Act will help get us there.

After lunch, PH patients, family members and medical professionals visited the offices of Members of Congress who had been unable to attend. It wasn’t unusual, on these visits, to see legislative staff members’ mouths drop open when they learned about the expenses and complications of living with PH. These moments were a sure sign that the PH community is getting our message across and will have new support in the 112th Congress.
PuckerUp4PH Recap: Sean Wyman vs. Tara Suplicki

PHA-UK got PH communities around the world lending their lips to save lives and compete for a Guinness World Record in 2010. While we’ve still got visions of blue lips dancing in our heads, we thought we’d take a look at some of what went down here in the U.S. Meet our West Coast PuckerUp-er, Sean, and our East Coast PuckerUp-er, Tara!

PH patient Sean Wyman, 27, lives in Southern California, where he is studying medicine. He saw his 30,000+ student campus as the perfect place to launch an awareness campaign. Tara Suplicki is a 32-year-old patient in Hopatcong, N.J. We asked them about their experiences:

**PHA: What surprised you about doing the Campaign?**

**Sean:** How easy it is to increase awareness. When people see the blue lipstick, they are a bit turned off, confused, and then interested, so they ask questions. Once they find out about it, they are receptive to learning more about the disease. They are even more shocked to see me and hear how ambitious I am. I think I have had to tell my story three dozen times now!

**Tara:** What most surprised me about doing this campaign was how willing everyone was to help me with it. I had people from all over my community reach out to offer their help in collecting kisses. Every Girl Scout Troop in town, every Boy Scout Troop in town — they all collected kisses for me. At events, I would meet people who would offer to take Pucker Up with them back to their jobs to get people to Pucker up there. I really saw things come full circle when a woman came up to me one day and said, “I believe that I just Puckered up for you at work today.” She recognized me from the picture that my friend’s mom had blown up of me and had pasted on the board at her work where she was collecting kisses. I was really touched at how people pulled together to help us make this goal!

**PHA: What was your favorite thing about organizing PuckerUp events?**

**Sean:** That people are receptive to actually participating, especially future health care students. I have been fortunate to get health care clubs and organizations at UC Riverside to pucker up. My mom (Evan White), Alex Flipse and I also went out to an elementary school, where we collected 134 puckers from children and parents!

**Tara:** My favorite thing about organizing the events was just setting up and rallying my team! My fiancé Michael, my sister Jenna, my brother Bob and his friend Erin were my team. They were all at most of my events. The two biggest events that I did were the Warriors PuckerUp4PH and Battle of the Bands for PH. Each of those events garnered more than 300 kisses each! I had one lady take a clipboard and a pen and start recruiting people to come over to my booth. Before we knew it, we had a huge line. We could barely keep up, but everyone was patient and we made it through. I had a ton of mini events. Basically, I carried my Pucker Up supplies with me everywhere and turned every situation into an opportunity to get people to PuckerUp4PH! One woman I work with became enthralled with my campaign and spoke with her neighbor, who happened to work for Bayer. They had a PuckerUp4PH Day held in my honor. It was really awesome the way it all worked out.

**PHA: Sean, who is your MVP?**

**Sean:** I don’t have an MVP; I have an MVT — Most Valuable Team! My mom, Evan White, has helped get tons of puckers from local PH support groups and collect kisses at the Medical Scholars Program, Jocelyn Cavendar collected kisses in Kabul, Afghanistan, in my name and for the sake of PuckerUp4PH, and the girls of ΣΠΑ.

**PHA: Tara, how many kisses do you think you collected?**

**Tara:** I estimate that I collected 1,023 kisses for PuckerUp4PH! That is 1/40th of the goal! I took this as a personal challenge. The funny thing was when I first got started, I thought that a great goal would be 300 kisses. I collected that many by September. Then I decided that 600 would be a good goal, and I made that and more with my second event. So I decided that 1,000 would be my goal, and I achieved it. Yes, I was physically exhausted at times, and for a couple of days, I lost my voice, but I feel like it was all worth it! I think of all the lives I have touched with this campaign. I have only ever had two people turn me down. Things like that surprise me about events like this — the people who you least think will help you, turn out to be your biggest advocates.
As a part-time Office Assistant, Tracey helps process shipments and general mailings, puts materials together for various meetings, acts as back-up receptionist and provides general administrative support to the staff. Tracey can be reached by email at Tracey@PHAssociation.org or by phone at 301-565-3004 x769.
Ric Franzen: Puyallup Support Group’s Media Guru

Ric Franzen’s foray into working with the media for his support group began after a short exchange with Puyallup Support Group Leader Charlotte McCabe. Ric asked Charlotte whether the details for the next support group meeting had been posted in the local newspaper. Charlotte laughed and said, “Nope, but you can do that. Looks like you’re our support group’s new media chair!”

Ric felt compelled to truly embrace this media role because the Puyallup Support Group is a great resource for him and his wife, something their lives lacked until April 2009. In 2004, Ric was diagnosed with idiopathic pulmonary fibrosis (IPF), but there were no IPF support groups in the area, so he and his wife coped with his disease to the best of their ability. In early 2009, when Ric was diagnosed with pulmonary hypertension, he was pleasantly surprised to find out that Puyallup had a PH support group. He and his wife immediately became involved.

After Ric was dubbed the media chair for the group, he started reaching out to local newspapers, but he grew frustrated after a few months because the reporters he spoke to did not seem interested in running his story. Ric kept trying, however, and one day he got a call from a reporter who interviewed him and Charlotte about pulmonary hypertension and their involvement in the Puyallup Support Group. Ric was delighted when the Puyallup Herald ran the story on September 8, right before the group’s next meeting.

After this news article appeared in the Puyallup Herald, five new people (four patients and the relative of a current member) showed up for the Puyallup Support Group meeting in September. “I wish the ads my business runs always got such good results,” Ric jokes.

Ric believes that working with the media to publicize his support group’s meetings is the best way to get the word out to PH patients and caregivers in the area about the value of the group. Media coverage also raises PH awareness throughout his community. As media chair, Ric’s main goal is “to make this resource known to the patients. Support groups are key because they give PH patients access to education, group support and advocacy and awareness.”

For those fellow PH Aware Campaigners working to get news coverage in their communities, Ric says, “Don’t give up. I appreciate your frustration!”

Ric has found the benefits in persistently pursuing media coverage and keeping in touch with reporters. As he says, “Our persistence has paid off and our media frustration abated a bit. We have a foothold now but can’t let up. Charlotte and I putting ourselves out there will encourage the rest of the choir to raise their voices.”

By Elisabeth Williams
PHA Grassroots Campaigns Associate

112th Congress Begins — Do your Members of Congress know about the Tom Lantos PH Research and Education Act?

Your stories are the reason we will ultimately pass your legislation. This is a democracy; share your stories!

~ Rep. Lois Capps, sponsor of the Tom Lantos Pulmonary Hypertension Research and Education Act of 2009

The new congressional session has officially begun and your Members of Congress have settled in. Have you shared your story with them?

PHA will let you know as soon as the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011 is introduced, but it’s never too soon to start a conversation with your Members of Congress.

Ready to get started? Find contact information for your Members of Congress at www.PHAssociation.org/Advocacy/MemberContactInfo.

To learn more about how you and your community can get involved with legislative advocacy, contact Elisabeth at 301-565-3004 x753 or Elisabeth@PHAssociation.org

PH patients Meg Horne (right) and Katherine Shipherd pose with former Representative Bob Inglis (R-SC)
If you’ve been following our insurance updates carefully, you might already know that PHA has been on a three-year journey to update the Social Security Administration’s (SSA) Listing of Impairments. Just two Pathlight issues ago, we reported on an exciting development when the Scientific Leadership Council (SLC) — the group that provides oversight of PHA’s medical program — was invited to present to the Institute of Medicine (IOM) committee charged with updating the Cardiovascular Listing of Impairments.

Since the SLC’s presentation, the IOM committee has released its final report to the Social Security Administration, outlining how they think the SSA can most effectively revise the Cardiovascular Listing. They included many of the SLC’s recommendations almost word for word.

The recommendations haven’t made it into the Listing just yet. The SSA still has to internalize the IOM’s report and then allow the public to comment on any proposed changes to the existing Listing. Nonetheless, this is a victory for the PH community.

Our goal is to make it as easy as possible for qualified PH patients to get approved for SSD, and if the SSA adopts the IOM’s report, the PH community will be well on the way to reaching this goal. Meanwhile, PHA continues with our advocacy efforts, making our presence known within the SSA.

For more information on the disability process or PHA’s work with the SSA, visit www.PHAssociation.org/Patients/Insurance/Disability or call Margaret at 301-565-3004 x773.

By Margaret Beardsworth
PHA Insurance Program Manager

Insur ance Finds: How is Healthcare Reform Affecting You? Speak Up Through PHA’s Online Insurance Guide!

Changes to healthcare industry are well under way as a result of the Affordable Care Act of 2010. PHA will continue to advocate for health policies that benefit the entire PH community and align with our Statement of Principles on Healthcare Reform, but we need your feedback to do so.

Let us know how healthcare reform is affecting you and check out what other PH patients are saying at PHA’s newest Online Insurance Guide section on Healthcare Reform. Visit www.PHAssociation.org/Patients/Insurance/HealthcareReform for updates on the latest developments in healthcare reform policy, new resources and patient-to-patient dialogue.

For print information, contact Margaret, PHA’s Insurance Manager, at 301-565-3004 x773.

By Margaret Beardsworth
PHA Insurance Program Manager

Welcome, Sylvia Earley, Nonprofit Communications & Development Coordinator!

As Nonprofit Communications & Development Coordinator, Sylvia works with Print Services, Patient Outreach and Services and International Services to help produce PHA’s print and online publications. Sylvia moved from Ireland to work with PHA through a program which allows professionals with a degree and five years+ experience to work in the U.S. Sylvia is a PH patient who has undergone successful PTE surgery and has also volunteered for PHA for three years. She has a Degree in English and History and a Masters in History from Trinity College, Dublin. Immediately prior to joining PHA, she worked both as a communications coordinator for a multi-national educational company and as a freelance editor. Sylvia can be reached by email at Sylvia@PHAssociation.org or by phone at 301-565-3004 x802.
Insurance Letters Help PH Clinic Take on Local Insurance Company

At the University of Rochester Pulmonary Hypertension Program in Rochester, N.Y., we not only treat patients with pulmonary hypertension, but also help patients fight for medical insurance coverage. One of our biggest challenges began five years ago when a local insurer refused to cover our patients. It took a collaborative effort — starting with writing letters — to finally get our patients approved.

The local insurer denied coverage for PAH medications, especially combination therapies, because of a lack of supportive research. At the time, we were dealing with patients who had been on medications for a long time but were not getting reapproved because their employer had switched to this insurance company.

A doctor in our program wrote compelling letters describing the clinical trials that lead to individual drug approval. Additionally, we submitted evidence to show that these patients had failed on mono therapy but had improved when we added one or two drugs to the regime. We had to submit letters like this for all patients starting on a newly approved medication because the company wouldn’t approve new drugs for at least six months.

Patients and their family members also wrote letters expressing dissatisfaction with the company’s practices. Patients wrote to their local congresspersons to ask for help in regulating the behavior of this company. In some cases we wrote letters to the New York State Insurance Department to have cases externally reviewed. We sent copies of each letter to the insurance company as well.

Additionally, we reached out to other stakeholders — the large employers who had switched to this plan, newspapers and hospital administration. We had to work collaboratively with these influential groups to make the insurance company understand the disservice they were doing to patients with pulmonary hypertension.

After our letter-writing campaign, we finally secured a meeting with senior leadership at the insurance company to discuss our concerns. We highlighted the problems with their PAH policies and helped them understand the disease. Since the meeting, we have not had a problem with the company. If there are questions or concerns about medications or if they are going to deny a medication, they call our office to ask questions, get clarification and see if there is anything they missed before rendering a final decision.

This campaign lasted for nearly five years, but we can now say that we achieved great success. What started as a dysfunctional system that denied patients treatment and caused psychological hardship is now a system that is efficient, patient- and doctor-friendly and gets patients the drugs they need in a very timely fashion.

After we were successful, we also submitted our letters to PHA in case other patients were going through a similar situation. PHA then posted the letters as templates for other medical professionals and patients to use when communicating with their insurance company.

If you are having insurance challenges and want to send your own letter, check out PHA’s collection of successful insurance letters by visiting www.PHAssociation.org/Patients/Insurance/Letters.

Resolve your own insurance challenges!

Step 1: Identify the insurance problem
Step 2: Browse insurance letters on PHA’s website: www.PHAssociation.org/Patients/Insurance/Letters
Step 3: Write and send letters to your insurance company
Step 4: Achieve success!
Step 5: Share with other patients and medical professionals through PHA. Submit your letters to InsuranceLetters@PHAssociation.org

By Toni M. Heininger, Project Coordinator, University of Rochester Pulmonary Hypertension Program

IT’S NOT TOO LATE! Although it’s past the “end of the year,” it’s not too late to donate to PHA’s “End of Year” campaign!

When you do, you’ll …

• Help ensure that we achieve the full $25,000 matching gift challenge from Actelion, and
• Receive our 2011 Calendar, Express Yourself, where you’ll see the unique ways that members of PHA’s community of hope express themselves.
Support Groups Get Creative in 2010

When was the last time you went to the zoo, played a harmonica, or tried your hand at gardening? For a number of PH patients, the answer would be at a support group meeting. In 2010, leaders across the country got really creative in planning their meetings, giving these get-togethers a fresh and lively spirit.

Popular topics at meetings in 2010 included medical presentations on pulmonary hypertension, information on PH and exercise, and tips for traveling with PH. Many educational topics stem from patient desire for particular information. For instance, as health insurance policies continue to evolve, many patients are unsure how these changes apply to them. Support groups all over the country brought insurance experts to their meetings to talk about how these changes relate to pulmonary hypertension.

Some support group leaders tried unique approaches to common topics like healthy eating. Understanding the importance of a low-sodium diet for PH patients, but also realizing that reducing salt content can lead to bland food, the Fox River Valley Support Group in Wisconsin had a meeting on growing and cooking with 10 popular herbs that add flavor to meals. Several other groups spiced up their meetings on nutrition and low-sodium diets by turning them into outings to local grocery stores for tours and cooking demonstrations.

Similarly, some support group leaders jazzed up their meetings by planning interactive presentations and activities to keep everyone engaged. In Riverton, Wyo., support group members participated in an educational meeting on pulmonary rehabilitation called “Breathing Retraining: Harmonicas & Breathing.” In the July meeting of the Kansas City Support Group, serving Kansas City, Mo., and Kansas City, Kans., attendees tried out some new moves when a physical therapist presented and demonstrated helpful exercises for those with PH.

For some well-established groups, support group meetings became the ideal time to organize efforts to promote PH awareness. Since support groups bring together many patients, each with their own story of living with PH, meetings became an ideal time for patients to share their stories with area politicians and ensure that lawmakers keep the needs of those with PH in mind. As part of their advocacy efforts, the York, Penn., Support Group invited Pennsylvania State Representative Keith Gillespie (R-PA) to a meeting so he could meet patients and form a personal connection with those with the disease. Merle Reeseman invited Representative Jason Altmire (D-PA) to her monthly support group meeting in Pittsburgh, Penn., during PHA’s District Visit Campaign in August 2010.

The Louisville PH Support Group turned its October meeting into a workshop to create Awareness Month displays to put up around the city. Around the country and in Puerto Rico, groups took time during their meetings to participate in the PuckerUp4PH Campaign, collecting blue lip prints to help PHA break a Guinness Book World Record. See our support groups puckering up on p.29 and read about one group’s success in getting media attention on p.24.

Finally, some groups got creative with meeting locations, leaving behind churches, community centers and hospital conference rooms for different and informal settings that gave their meetings a change of scenery. For an exceptionally novel and lighthearted gathering, the Santa Barbara, Calif., Support Group utilized PHA’s Support Group Central Fund to host an after-hours dinner at the zoo. The Maine PH Support Group took its gathering off land and enjoyed a sunset cruise with views of their beautiful rocky coastline.

Patients, you never know what’s in store for you when you attend a support group meeting. Drop in on the next one and see what your leader has planned for you! To find a support group in your area, visit www.PHAssociation.org/LocalSupportGroups

By Sophie Klein
PHA Volunteer Services Associate
Support Groups Celebrate the Holidays with Style

All year long, and all across the United States, PHA’s support groups bring patients together for education, support and ways to get involved. Support group leaders plan meetings, medical professionals volunteer their time to give presentations, and patients and caregivers try to take in all the information they can about PH. After all this hard work, everyone has plenty to celebrate! At the end of 2010 and beginning of 2011, holiday celebrations took place across the country, giving support groups a chance to relax and come together in celebration.

From gift exchanges to festive food options, new and veteran groups created holiday traditions of their own during this time of celebration. For instance, several support groups held White Elephant gift exchanges where members brought an inexpensive gift to give to someone else during the party. In the case of the Inland Empire, Calif., Support Group, group members brought ornaments to exchange instead of gifts.

Other favorite holiday celebrations this year included a Thanksgiving-themed potluck and a slideshow with pictures of the group at all their meetings and events throughout the year. As a way of combining festivities and fundraising, the SW Florida Support Group continued a tradition of having a holiday raffle.

In some cases, PH support groups find that a holiday party may be the best time to educate patients. The distance from nearby clinics makes it difficult for the rural Southwest Virginia Support Group to find speakers for their meetings. Since their annual holiday gathering attracts more attendees than their regular meetings, the group uses that meeting to bring in a notable speaker by collaborating with the Duke University Hospital in North Carolina.

In order to make holiday meetings special and enjoyable, many groups decided to forego their usual locations in favor of a new venue or restaurant. PHA’s Support Group Central Fund sponsored many of these meeting and made it possible for patients and caregivers to come together for a festive affair. As many as 30 support groups worked with PHA’s Central Fund to plan special holiday meetings.

To learn more about PHA’s Support Group Central Fund, contact Sophie Klein, PHA’s Volunteer Services Associate, at Sophie@PHAssociation.org or 301-565-3004 x758. To learn more about support group activities in your area, visit www.PHAssociation.org/LocalSupportGroups.

By Sophie Klein
PHA Volunteer Services Associate

Patient-to-Patient Support Line Beats the Winter Blues

When it’s chilly, snowy, blistered or downright miserable outside, sometimes it’s hard to get out of bed — let alone the house. If you live in the colder northern states, your local PH Support Group may have suspended meetings during the winter due to frosty and unsafe weather conditions. Even if you don’t live in the colder states, the winter may still be too cold to leave the house.

Your pulmonary hypertension “PHriends” and “PHamily” are still here for you — and you don’t even have to leave the comfort of your bed. Pick up the phone and call our Patient-to-Patient Support Line (1-800-748-7274). You’ll reach a friendly, longterm patient survivor who can talk with you about your life, your PH or anything else. The Support Line is not just a place to call with questions, it’s a place for stories, for venting, or just for conversation. PHA’s “SUPPORT” line is here to support you through sickness, health, cold days, warm days, sunny days or cold, wintery nights (not too late though — the line dials directly into a patient’s home!).

Photo provided by Leslie Polss, Del Val, Penn., PHA Support Group Leader and PH cartoonist
Support Groups Join the PuckerUp4PH Campaign

Support groups everywhere got into the act, collecting blue lips prints as part of PHA UK’s campaign to raise PH awareness and break a Guinness Book World Record.

The Mid South Tennessee Support Group collected blue lips during meetings such as in this picture, and even had the audience of The Loretta McNary Show, a local talk show, wear blue lips when the leader was interviewed about PH.

The Minneapolis/Twin Cities Support Group in Minnesota collected blue lips prints at its local hospital. Members set up a booth and asked everyone to stop by and PuckerUp4PH.

Luz Batista Santiago (pictured center), winner of the 2009 Blue Lips contest, was thanked on the PHA UK Campaign’s website, www.PuckerUp4PH.com: “Her group alone will have generated a quarter of the lip prints needed to break the world record.” Her support group is pictured above, sporting their blue lips.

The Wojo South Orange County Support Group in California has organized multiple outreach activities for PuckerUp4PH. This photo is from their efforts at their local hospital, Mission Hospital.

PH patient Linda Milo (pictured front row with lips puckered) hosted a Blue Lip Tea Party at her home in Port Charlotte, Fla., for the Port Charlotte Support Group.

Members of ABRAF, the PH association in Brazil, collected blue lip prints at ABRAF’s third annual patient conference in November. Paula Menzes, pictured on the right, lost her mother to PH. She founded ABRAF four years ago.
LIL LONG’S STORY CONTINUED FROM PAGE 1

research and PHA patient and family services.

Following Lil’s swim, PHA caught up with her to reflect on the experience. The following is an excerpt from our interview with Lil. To read a full transcript of the interview and learn more about Lil’s experience, visit www.PHAssociation.org/Swim

PHA: As a PH patient, what made you decide to tackle this challenge of swimming the Mississippi River?

Lil: I was upset from the beginning of Nicky’s illness. I went online and couldn’t find anything much about this disease that was suddenly taking my best friend away from me. And then, in a blink, she was gone. Nicky was a very flamboyant person and a great event planner, and one night she came to me in a dream, telling me to get out of my chair and fight this illness that she couldn’t. That’s when I built my pool and started swimming, three minutes the first time to 60 minutes in a month. One day while I was in my pool, my husband brought a friend over and told him I was swimming so far that he thought I could swim the Mississippi River. And from there, the idea hatched — the biggest undertaking I could imagine in honor of Nicky. I could finally give her her due.

PHA: Your swim from one shore to the other took 27 minutes. What were the most memorable moments?

Lil: I will never forget … seeing all the guys with T-shirts that said, “GO, LIL, GO!” [PHA Board member] Steve White giving me communion and sharing a tearful prayer together (he lost a 22-year-old daughter to PH); the calm that came over me as I eased into the water; the trouble breathing on the last eighth mile; [being about to] give up and my son yelling, “You’ve got it now, Mama;” hearing the screams and shouts of joy.

PHA: What was the first thought that came into your mind when you successfully completed your swim, arriving on the Arkansas shore of the Mississippi River?

Lil: That I had finally accomplished something I had trained a year for; that Nicky was jumping up and down screaming, “Good job!!” Many thoughts ran through my head at once.

PHA: As with any challenge in life, it’s hard to tackle a difficult task like your swim all by yourself. How were you supported throughout the process?

Lil: My friends never let me quit! They all knew if they did, it would be the end of me. Then my husband, after finally deciding I was serious, got behind me 100 percent. He really is my hero through all of this. PHA kept in touch, guiding me through a lot of difficult moments. … They became extended family. And speaking of family, my children were a real driving force. My son thought I was crazy but wouldn’t let me down, and my daughter reassured me that my son wasn’t really mad at all, just worried. She told me from the very beginning to go for it. She understands me.

PHA: Do you have any future awareness-raising plans on the horizon?

Lil: I did invite PHA to go along with me down my bucket list! Next year’s pick is to go to the triple Crown races. Maybe I’ll wear the greatest hat and get media attention and tell the world about PH. Who knows what’s on the horizon? I DO know that wherever I go and whatever I do, it will be in the name of PH.

PHA: What message do you have for the PH community?

Lil: I’m not always upbeat about this card I’ve been dealt. Believe me, I understand frustration, depression and fears, but if you have the courage to get out of bed every morning, you’re more than halfway there. I say if I can just keep putting one foot in front of the other, I can keep going. Do even small things that you think you can’t and then take the time to celebrate those moments. And, for heaven’s sake, throw away the guilt! You’re sick. It’s not like you chose to be. I was on one of those awful carts in the grocery store the other day and some woman looked at me and said, “Now that’s what I need.” And I said, “Honey, just be thankful that you don’t.”

Lil Long’s swim has been captured on video! Visit www.PHAssociation.org/Swim to view this inspiring footage, and share it with your friends and family.
Special Events: Spreading PH Awareness in November 2010!

With 15 fundraisers in 11 states, PH Awareness Month in November was a busy time for PHA Special Events! Signature events like fun walks, races and luncheons took place across the country. Awareness Month was also marked by a creative flare as several distinctive fundraisers took place, including a masquerade ball, pubcrawl and casino night. View our scrapbook of all November events at www.PHAssociation.org/SpecialEvents/FeatureStories

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**Event:** Baltimore PH Walk for HOPE  
**Location:** Baltimore, Md.  
**History:** Third Annual  
**2010 Attendance:** Approximately 130 participants  
**Guest Speakers/Attendees:** Nicole Cooper, PH patient and Support Group Leader; Dr. Myung Park, University of Maryland Medical Center; Dr. Paul Hassoun, Johns Hopkins University School of Medicine; Rino Aldrighetti, President, PHA  
**Fun Fact:** The walk was held at Camden Yards, the ballpark of the Baltimore Orioles professional baseball team.

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**Event:** Abby’s Road PHun Walk  
**Location:** Albuquerque, N.M.  
**History:** Inaugural Event  
**2010 Attendance:** Approximately 90 walkers  
**Guests of Honor:** The Blair Family, who lost two daughters to PH and have a third daughter who is a nine-year double lung and heart transplant survivor.  
**Fun Fact:** The walk wove in creative PH awareness stations along the walk route — one included breathing through a straw to mimic PH symptoms.

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**Event:** Inaugural J. Patrick Garcia Memorial “Breathe Easy” Run, Walk and Luncheon  
**Location:** Albuquerque, N.M.  
**History:** Inaugural Event  
**2010 Attendance:** Approximately 75 walkers/runners and 130 luncheon attendees  
**Guest Speakers/Attendees:** Dr. Franz Rischard, University of Arizona, Tucson; Jerry Ortiz y Pino, New Mexico State Senate  
**Fun Fact:** Senator Jerry Ortiz y Pino presented a proclamation at the event designating November as PH Awareness Month.

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**Event:** PHenomenal Hope for a Cure Luncheon  
**Location:** Omaha, Neb.  
**History:** Fifth Annual  
**2010 Attendance:** Approximately 160 attendees  
**Guest Speakers/Attendees:** Betty Lou Wojciechowski, former PHA Board Member; Sally Ganem, Nebraska’s First Lady served as Honorary Chair  
**Fun Fact:** Event organizers, PH patient Carol Lindstrom and her daughter Cindy Klein, appeared on an Omaha-area morning news show the day before the event to talk about PH, Awareness Month and the luncheon.
What Does It Take to Plan a Special Event?
Part three in a four-part series: Marketing & advertising

All PHA special events share the common goal of fundraising, and because of that, every event requires ample marketing and advertising to build enthusiasm and generate participation. While individual factors such as event size, location, history and type will impact specific efforts, here are some “tips of the trade” that can be applied to all special events.

Local Marketing: Create the Buzz Around Town

Brand your event. Branding is one of the most important components of marketing and is typically the first step when it comes to event promotion. Establishing an identity through branding allows those outside your immediate circle to connect with the event and its purpose. A brand’s complexity can run from a memorable phrase/slogan to a professionally created logo. Most importantly, it should speak specifically to your event and become the starting point for all other promotional pieces.

Create and distribute materials. The next step is to compile all the logistical information into a single document for distribution. Whether it’s a flyer, brochure or postcard, it’s essential for any event to have a physical handout to solicit donations, registrations, sponsorships and/or volunteers. You can create these materials in basic computer programs such as Microsoft Word or Publisher, and PHA Special Events staff can help with revisions as needed and provide example handouts from past events to help generate ideas. PHA can also print these items in color and distribute them via specific mailing lists drawn from our database.

You can also choose to hire a print vendor, which can generate a very professional end product. The tradeoff is that print vendors can be expensive and may take up to several weeks to finalize. Oftentimes, vendors will work for a discounted price if they are doing business with a 501(c)(3) non-profit. Nonetheless, it’s important to get the bottom-line quote up front — this number should include any potential “hidden” fees such as setup charges, art charges, proofs and delivery. If time allows, shopping around, including on the Internet, for the best price can save hundreds!

Tap into local connections. It’s up to you and your committee members to take advantage of your personal and professional networks to further spread the word!

Are there local businesses where you can post flyers and handouts? What clubs and organizations are you already involved with that can distribute materials? It may be worth Designating someone within your committee to focus solely on the marketing and promotion of the event.

Consider all the opportunities for free advertising that are available in your hometown. Community calendar listings, church bulletins, exhibit booths and promotion at fairs and other announcement boards can really help get the word out. And don’t be afraid to go out on a limb! Approaching a complete stranger or a new business can often yield surprising positive results.

Mass Marketing: PHA’s Network is Your Network

Web resources are here. One of the first steps that PHA will assist with is getting your event up on the web. PHA’s Events Calendar Listing is the launching pad for all things related to special events.

Online registration and fundraising is a major component of most events, and it’s another thing PHA can help with. While some events develop a web presence independent of PHA’s assistance, many planners take advantage of the ability for PHA Special Events staff to create an event webpage that allows for online registrations and donations by credit card.

As your event nears, PHA can use our database to send an email announcement to several hundred people in a specific area. Social networking is another major resource for special events. PHA’s Facebook and Twitter pages are great avenues for quickly reaching a large audience.

Connection within the community. Often the biggest support for special events comes from those within the PHA community — and the community is bigger than you may realize! PHA can help connect you with local PH support groups, local or regional PH centers and the medical community to help get the word out.

For all things related to special events, visit the Special Events section of PHA’s website at www.PHAssociation.org/SpecialEvents or contact Jessica McKearin, PHA’s Associate Director of Special Events, at JessicaM@PHAssociation.org or 301-565-3004 x765. Look for the final installment of our series, “What Does it Take to Plan a Special Event?” in the next issue of Pathlight.
### January 2011

Happy New Year! What better way to kick off 2011 than to plan a springtime special event fundraiser!

**GET STARTED:** [www.PHAssociation.org/SpecialEvents/OrganizeAnEvent](http://www.PHAssociation.org/SpecialEvents/OrganizeAnEvent)

**THEN, NOTIFY US OF YOUR PLANS:** Jessica McKearin (PHA) at Events@PHAssociation.org

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### February 2011

Spring event organizers: Time to finalize your event date/time/location and begin securing sponsors!

**MORE INFORMATION:** [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook)

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**Thursday, Feb. 3, 2011**

*Special Events 101: Planting the Seeds for a Successful Spring Fundraiser*

A free PHA Classroom webinar!

**REGISTER:** [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

**QUESTIONS:** Jessica McKearin (PHA) at Events@PHAssociation.org

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### March 2011

First *Event-ful Times* e-newsletter of the new year!

Make sure you’re on the list to receive this PHA Special Events publication!

Sign up at [www.PHAssociation.org/SpecialEvents/OrganizeAnEvent](http://www.PHAssociation.org/SpecialEvents/OrganizeAnEvent)

**QUESTIONS:** Jenna Roe (PHA) at Eventful@PHAssociation.org

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### April 2011

Spring event organizers: Monitor registration, coordinate on-site fundraising (for example: a silent auction!)

**DETAILS AND QUESTIONS:** Jessica McKearin (PHA) at Events@PHAssociation.org

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**Sat., April 9, 2011**

*Race 2 Cure PH: Ellie Godina Memorial 5K Walk/Run*

WHERE: Sparky DiBiasio Stadium, Euclid, Ohio

**DETAILS:** Melissa Godina at 216-261-0334 or melissagodina@sbcglobal.net

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**Sat., April 9, 2011**

*Spur a Cure for PH*

WHERE: Rustler’s Rooste, Phoenix, Ariz.

**DETAILS:** Trish Duque at trish.duque@gmail.com

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**Sat., April 16, 2011**

*3rd Annual Scramble for a Cure Golf Tournament*

WHERE: Angel Park Golf Club, Las Vegas, Nevada

**DETAILS:** Jack Nino at 702-250-2214 or Jack.Nino@igt.com

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**Sat., April 30, 2011**

*The Grape Escape 2011*

WHERE: St. Stephen’s Hall & Picnic Grounds, Richwoods, Mo.

**DETAILS:** Jenny Bardenheier at jennbardenheier@yahoo.com

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### May 2011

Spring event organizers: Your big day is almost here! Confirm last minute details and coordinate day-of volunteers and tasks. Thank you for your efforts and have a fun and successful event!

**MORE INFORMATION:** [www.PHAssociation.org/SpecialEvents/EventVolunteers](http://www.PHAssociation.org/SpecialEvents/EventVolunteers)

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**Sat., May 14, 2011**

*N.C. Cure PH Golf Tournament*

WHERE: Salem Glen Golf & Country Club, Clemmons, N.C.

**DETAILS:** Cindy Pickles at 336-978-1668 or cpickles50@gmail.com

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For more special events coverage, visit [www.PHAssociation.org/SpecialEvents](http://www.PHAssociation.org/SpecialEvents)
PHA on the Road: Two Years Strong and Counting

This past fall marked the second year of PHA on the Road: PH Patients and Families Education Forums. In 2010, PHA on the Road visited two new cities — Baltimore/Washington, D.C., on September 25 and Dallas, Texas, on October 2. With almost 500 people participating in the 2010 forums, we wrapped up a strong, successful second year and now look ahead with tremendous hope to our third year in 2011.

Like PHA on the Road in 2009, each forum in 2010 consisted of a free full-day of patient education. The forums began with pre-forum networking sessions, which allowed attendees to meet other patients, caregivers and family members face-to-face. The pre-forum sessions were geared toward unique populations within the PH community, including newly diagnosed patients, veteran patients, caregivers and parents of children with PH.

The breakout sessions for each of the forums included the topics Eating Better, Exercise and Yoga, Traveling with PH, and Women’s Issues. Popular topics from the program’s first year, Eating Better and Traveling with PH, were presented in both the morning and afternoon breakout sessions to ensure that all who wished to attend had the opportunity.

General sessions for the day covered a range of PH topics, including how PAH is diagnosed, current treatments and understanding transplant options. Emergency Situations, a favorite sessions for 2010 attendees, helped patients and caregivers understand how to prepare for, prevent and cope with medical emergencies.

New in 2010, PHA on the Road included family programming, which incorporated a session geared toward parents of children with PH as well as a Kids’ Room for children who accompanied their parents to the forum.

After two successful years of the PHA on the Road program, PHA is going back “on the road” in Spring 2011. Visit www.PHAssociation.org/OnTheRoad to find out where we’ll be in 2011!

By Suzanne Flood
PHA Marketing & Communications Associate

“I liked the fact that this regional conference was held. I was able to see people that I had met at the International Conference in June and also to meet some people from my area that I did not know already. Thanks so much for giving all of us the opportunity to get together!”

~ Gayle Barnard, PH Patient, Smithfield, Va.

“Thank you so much for having this mini conference. I was able to go to California for the larger conference, but my mom missed out on it. This allowed her to be able to connect with other caregivers and gather information.”

~ Honey Kennedy, PH Patient, Lake Dallas, Texas
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Enhance the impact of your center’s medical education program by partnering with PHA!

Credibility
PHA is an internationally recognized and respected organization within the PH medical community including our distinguished Scientific Leadership Council, PH Clinicians and Researchers and the PH Resource Network. As part of the Building Medical Education in PH program, a PHA promotional package is at your disposal including PHA logo, PHA program language and usage guidelines for all promotional material from signage to registration brochures and online outlets.

Contacts
PHA will supplement your medical center’s marketing with our own targeted lists of medical professionals, offering new opportunities for maximum outreach and success.

Continuing Education
PHA provides the opportunity for post-event discussion, follow-up events and a venue for sharing session content through our primary website and the PHA Online University, www.PHAOnlineUniv.org

To learn more about partnering with PHA through Building Medical Education in PH for your next CME event, contact Micaela Cohen, Associate Director of Medical Services, at 301-565-3004 x770 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

Save the Date!

2011 PH Resource Network Symposium
Inspiring Hope: New Directions in PAH

September 22 – 24, 2011
Hyatt Regency Crystal City — Arlington, Va.

Registration for this event opens March 2011!

- Up to 11 credit hours CE/CME will be available to nurses, pharmacists, physician assistants and respiratory therapists
- Participate in Advocacy Day on Capitol Hill on September 22
- Attend Symposium educational sessions on September 23-24

For more information, visit www.PHAssociation.org/PHRN/Symposium
PHA Classroom Offers e-Learning for Patients and Caregivers

PHA’s website now includes a robust e-learning center for patients and caregivers. PHA Classroom, a program of PHA’s Medical Education Fund, provides a space for you to participate in live events or watch recordings at your leisure. Classes cover topics ranging from information about pulmonary hypertension to tips on living with PH and ways to fight back.

PHA Classroom is the new home for PHA’s popular monthly live e-learning events. All you need is an Internet connection and a phone line to participate. See the list of upcoming events below. For dates as they become available, and recordings posted after the live events take place, visit www.PHAssociation.org/Classroom.

This new e-learning center complements PHA’s patient and caregiver education events, such as our biennial International PH Conference and PHA on the Road. More than 50 session recordings from PHA’s 2010 International PH Conference will be posted by the end of February 2011, bringing the PHA Classroom catalogue to more than 80 offerings.

For more information or to suggest educational topics, contact Meghan Finney at Classroom@PHAssociation.org or 301-565-3004 x744.

Welcome, Caitlin Flewellen, Online Education Associate!

As PHA’s Online Education Associate, Caitlin develops the PHA Online University as an educational resource for physicians and allied health professionals looking to expand their knowledge about diagnosing PH and caring for their PH patients. She manages both the course creation process and the website homepage. Together with some of the foremost experts in PH around the world, Caitlin strives to make the PHA Online University an engaging and active community for providers that will increase awareness of PH. Caitlin can be reached at Caitlin@PHAssociation.org or 301-565-3004 x771.

PHA Classroom News Feed

Receive alerts about scheduled live e-learning events and newly posted recordings.

www.PHAssociation.org/Classroom/NewsFeed

Upcoming Live e-Learning Events

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<tr>
<th>Month</th>
<th>Event Title</th>
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<td>January</td>
<td>How to Start a Support Group</td>
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<td>January</td>
<td>The Empowered Patient: Nurturing Partnerships with Your Medical Professionals to Get the Best Care Possible</td>
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<td>January</td>
<td>Newly Diagnosed? What You Need to Know</td>
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<td>February</td>
<td>PH Treatments: What’s on the Horizon</td>
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<td>February</td>
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<td>February</td>
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<td>March</td>
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<td>PHA on the Road: Roadmap to the Forum</td>
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<tr>
<td>April</td>
<td>Telling Your Story: Explaining Your PH to Friends, Family and Co-workers</td>
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INTERVIEW WITH PH PATIENT
ISAIAH GALLEGOS

Where do you live? Coeur d' Alene, Idaho

How old are you? I'm 8 years old.

When were you diagnosed?
I was diagnosed two months after my fourth birthday.

When did you first start having symptoms of PH?
I started having symptoms right after I turned 3.

What were your symptoms?
I would start screaming sometimes and then I would pass out. After I turned 4, I would tell my mom that it felt like my heart was running away and that my chest really hurt.

What activities do you like to do?
I really like swimming and diving, riding my bike, playing soccer and baseball and hanging out with my friends.

Have you ever felt unable to do something because of PH?
No, not really. When I was 4 years old, I would have to wear a backpack with a small tank of oxygen in it, but I could still play with all my friends during recess and ride my bike. I would tell them that I used the backpack to practice being an astronaut. My mom would put my pills in my juice and call it my “super juice.” All my friends thought I was really cool because I had super powers. Also, back then I really liked Power Rangers, and my mom would tell me that the tests were to check the strength of my super powers.

How has your life changed since your PH diagnosis?
My family moved to a different state so I wouldn’t have to use oxygen anymore. I don’t get to see my grandma and grandpa or all my cousins very often, but we like where we live now.

What is a message you’d like to pass on to other kids with pulmonary hypertension?
You can do almost anything that you want even when you have oxygen attached to your nose.

Interview conducted by Mira Kruger
PHA Pathlight Volunteer

PH Teens Get Social Online!

PHA Teens is a new social network for kids ages 13–18 living with PH.

Once they’ve been approved by PHA for membership in the network, teens can:

- Meet other teenagers living with PH
- Create profiles (visible only to other members)
- Chat, post and blog in a safe and secure online environment
- Share PHA-approved photos and videos

Help your teen get social at www.PHATeens.ning.com

Parents, email Kids@PHAssociation.org to learn more.
Speaking of PH ... with Teachers

I was diagnosed with pulmonary hypertension when I was 6 (I’m now almost 25). My parents really wanted to make sure I lived life as normally as possible, so they were in charge of explaining my PH to teachers until I was in high school. When the school year started, my mom always provided my teachers and the school nurse with a packet of information that included an explanation of PH and its symptoms, my list of medications, my doctors’ phone numbers and our other emergency contacts.

I was very lucky and throughout most of my school years, my PH was very stable. I had to leave every day to take my medicine, but other than that, I was a pretty normal kid. If I was experiencing any problems, I tried to be as specific as possible about my symptoms (“I am having chest pain” or “I am short of breath”) and then asked to go to the nurse’s office and dealt with the issue there. Teachers have so much on their plate that I felt most comfortable sharing most of the details of my experience with the nurse rather than many different teachers.

Still, most of my teachers were very helpful when I needed them. I always made sure they were aware of my condition in case I had a fainting spell in class. In high school I was out sick for several weeks, but during that time, I stayed in close email contact with my teachers. They were very helpful in getting assignments to me so that I could stay on top of my school work.

One of the toughest things to do was get out of gym class. In school so many kids try and get out of gym because they just don’t want to be there, and my teachers looked at me like just another defiant teenager who didn’t want to be in gym. Little did they know I would have given anything to run around and play. My mom and I went to the counselor, but she didn’t understand at first either. We had to get a special doctor’s note explaining pulmonary hypertension.

To all the other kids out there growing up with PH, try to be straightforward and confident when talking to your teachers. Stand up for yourself, and don’t take no for an answer. You know your limits, and don’t let anyone tell you any differently. Most teachers are very understanding and supportive; if you do have to miss school because of your PH, make sure you keep in contact with your teachers. It shows them you care about your studies and would love to be sitting in class rather than at home or in the hospital because of PH. And if you’re having trouble, don’t worry. It’ll get easier. As I got older and started to understand better what it was I had, I knew what symptoms to look for and when to take my teacher aside and talk about things. You’ll get there, too.

By Nicole Turner
PH Patient

Welcome, Michal Rachlin, Kerry Bardorf Family Support Program Associate!

As the Kerry Bardorf Family Support Program Associate, Michal develops and maintains support and educational opportunities for caregivers of adult PH patients and families of children with PH. Before joining PHA, Michal worked with education and community outreach at history and science museums. She is always looking for ideas for new programs and ways to enhance support for caregivers, and she would love to hear from you! To learn more or to get involved with the Kerry Bardorf Family Support Program, contact Michal by email at Michal@PHAssociation.org or by phone at 301-565-3004 x800.
Transitioning a Child from Pediatric to Adult PH Care

As difficult as it is for any parent to deal with having a child with PH, often one of the more trying periods is when an adolescent transitions to becoming an adult with PH. The move from a pediatric PH clinic to a new, adult-focused one can be difficult at first for many patients. Additionally, some patients have trouble accepting ownership of their disease as an adult while parents worry about the newfound independence available to the patient.

So how can parents ensure that the move from child to adult care is a smooth one? Whether a formal transition program exists in your child’s pediatric clinic or you are helping your child to make that transition yourself, there are many ways to deal with this change effectively.

**Start early.** The earlier you start preparing your child for life as an adult PH patient, the better. This process can begin by the age of 15 and should include ensuring that your child fully understands PH and its symptoms and limitations. Explain medications to your child, so your child knows what each one does. Encourage them to mix their medications or fill their pill boxes occasionally — you might even want to offer a reward system for doing so. Your child should also have a list of all pertinent contact details for medical offices and emergency contacts and know exactly when it is necessary to call.

**Learn to let go.** You have been the primary caregiver to your child for many years and, no doubt, you know more about PH than they do. However, as your child reaches adulthood, it is vital that they learn to take responsibility for their own health. While you might be the one who has, up to now, asked the questions during doctors’ appointments, encourage your child to speak up and take the lead. Once a patient reaches eighteen, they will be treated as an independent adult by medical professionals. Encourage them to speak on their own behalf now so they’re prepared when that time comes.

**Practical matters.** Before your child turns 18, look at their insurance policy and ensure they have all the coverage they need. Discuss whether they will be applying for Supplemental Security Income (SSI). Complete medical records should be sent from the pediatric specialist to the adult PH physician to ensure continuity of care. Likewise, if changing primary care physicians, ensure this is done well in advance of seeing a new adult PH specialist.

**Going to college.** Going to college, moving away from home and/or starting a new job will all bring a new set of challenges for the young PH patient. Work in partnership with your young adult to investigate such issues as: will a move necessitate transferring to a new clinic/hospital; university disability programs; living arrangements; and a new primary caregiver, if necessary. Many colleges also offer services such as transportation between classes and handicapped parking, and it is worthwhile to look into options sooner rather than later.

**Sex, drugs and rock ‘n’ roll.** Being a young adult is difficult enough even without the stresses of dealing with a chronic condition. With independence comes new temptations and young patients should be educated on the risks involved with their new lifestyle. They need to be made aware of the effect of alcohol and social drug use on their health. Women need to know about birth control and risks. Talk to your doctor, nurse or social worker about the best ways of dealing with these issues. Don’t forget to also emphasize the good things about independence!

**Communication.** For many PH patients, adulthood brings the full realization that this disease is something that they will have to deal with for life. Learning to cope with this is not something that can be done overnight and every patient deals with it in their own way. The key to success is to keep the lines of communication open. Encourage open discussion with their medical support team, such as a nurse or social worker. Emphasize that you are also always there to talk; parents remain the vital source of love and support. Professional therapy might also be an option for patients as they learn to accept dealing with a chronic illness, and another helpful resource is PHA’s Generation Hope. This is a group for patients in their late teens, 20s and 30s. These young adults have been through this before and can offer perspective and support: www.PHAssociation.org/GenerationHope

*This article was adapted from the Ask a Pediatrician session at PHA’s 9th International PH Conference. To view the full session, visit www.PHAssociation.org/Classroom/AskAPedTransitions*

By Sylvia Earley

PHA Nonprofit Communications & Development Coordinator
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.

The following names have been added to the Sustainers Circle for a minimum donation of $100 per month. PHA now recognizes members of our Sustainers Circle in the donations lists. Look for a symbol next to a name to see who has made a sustained commitment to donate to PHA on a monthly basis.

DONATIONS LISTED WERE RECEIVED BETWEEN SEPTEMBER 1 AND NOVEMBER 30, 2010. PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

IN MEMORY OF

Mr. Cary Kingdom
Miss Ashlee Keogh
Ms. Lindsay Kenton
Ms. Eleanor P. Keehan
Mr. Scott M. Jeffers
Mr. and Mrs. Tony Javarone
Mr. Brian F. Hunte
Mrs. Lynn Hunte
Miss Kathryn J. Holland
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Mr. Brian F. Hunte
Mr. and Mrs. Tony Javarone
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Arlene Gabbert
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Rebecca Adams
Monica E. Gregory
Suzanne Keyhani
Anna Langley
Frances Martin
Joyce Matzen
Gisella Meridith
Freda M. Scott

Amy Caroline Stamp
Natalie Sternstein
Shirley Sullivan
Merlen Teer
Mary Etta Thompson
Melissa Ann Weymouth

In memory

Rebecca Adams
Jean Anderson
Joan Marie DeVore Cole
Franklin Crockford
Arlene Gabbert
J. Patrick Garcia

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PATHLIGHT WINTER 2011

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“Newsletter Submission” or “Newsletter Submission”
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Pulmonary Hypertension Association
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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.

Pathlight & Persistent Voices

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