am so excited to be a part of the planning for the historic 10th International PH Conference and Scientific Sessions taking place June 22–24, 2012, in Orlando, Florida. This will be the fourth time I’ve attended one of these phenomenal Conferences and I’m especially excited about welcoming each of you to this special anniversary gathering in the state where PHA began. We’re coming home!

My name is Liz Brigham and I’m a PH patient who was diagnosed in June of 2004. I am also one of the co-chairs of the Conference Committee planning the 10th International PH Conference.

The Power of One: From a Kitchen Table to Around the World is the theme of this homecoming Conference. Thank you to patients Marilyn Mears of Canton, N.C., and Stephanie Layer of Maplewood, Minn., for coming up with this most appropriate theme. There might not be a Pulmonary Hypertension Association had four motivated, concerned women not gathered around a kitchen table in Florida back in 1990. These four courageous women came together and generated ideas for connecting with other patients and learning all they could about this illness. That meeting sparked what is now an international group of many thousands of people dedicated to connecting to one another, fighting for patients, encouraging the development of treatments, and finding a cure for this deadly disease.

Three of these inspiring women plan to be at this homecoming Conference. I have had the privilege of working with them over the years, as well as in the planning for this
Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.

~ Albert Einstein

For many of us, the beginning of another New Year marks a tradition of reflecting on the past year and visualizing where we’d like to be in the present year.

In this past year, I have had opportunities to observe the most brilliant medical professionals in this field strategize approaches to furthering PH science and assisting patients to live productive and fulfilling lives.

I have watched exceptionally talented professionals gear their seemingly endless energy toward making their work as PHA staff members a creative expression of their caring for the people they support.

Finally, I have attended special events delivered as labors of love by dedicated patients and their families to increase awareness for PH and to raise support to find a cure. Each of these experiences has been an inspiring testament to the Power of One, and together they provide many reasons to find hope for tomorrow.

Fortunately, another opportunity to continue the journey of learning, living, hoping and questioning is poised for the not-too-distant future! On June 22–24, 2012, PHA will host its 10th International PH Conference and Scientific Sessions in Orlando, Fla. This is the largest meeting of PH patients and PH-treating medical professionals in the world, and it provides unique possibilities for education, networking, support and fun! There is nothing like being a part of this experience in person, and we hope that you will be able to join us!

Included with this issue of Pathlight, you received a Conference brochure detailing information about Conference offerings, registration, and scholarship opportunities available to patients. Additional information can also be found at www.PHAssociation.org/Conference

I look forward to seeing you all at Conference. And, I wish you a New Year full of learning, living and hope.

In partnership,
Patient Mentor Spotlight: Merle R.

Email Mentors are patients and caregivers from all over the world, standing by to help patients, caregivers and parents through one-on-one, email-based support. Merle R. is one of those mentors, and she shares a little about herself now.

What’s your PH story?

It took me one-and-a-half to two years to be properly diagnosed. I wasn’t feeling well, but my father had recently died and 9/11 had happened, so I thought it was stress. One of my daughter’s friends, who works for a doctor, said to me, “You look like you need to see a doctor.” So I did, and he ran all kinds of tests. The tests showed that the left side of my heart was strong, and I didn’t have asthma, so he decided it was stress. Then my daughter begged me to see a cardiologist. The cardiologist had just come back from a seminar where he had learned about pulmonary hypertension. He sent me to a PH center where I went through all the tests again, and I was diagnosed with PH.

I was put on an oral medication, but it didn’t work for me. I participated in several clinical trials, but nothing was working and my PH progressed quickly. One of my PH nurses suggested I try Flolan™, the only other treatment available at that time. I’ve now been living with PH for 10 years and have been on PAH medications for more than nine years.

Why should someone email a PH Mentor?

Communication. To be able to vent if you need to, to be able to share your feelings, to ask questions about how you cope with PH. When I was new to the PH world, it was very scary. Support is so necessary, and being able to share or vent is so very important — and doing it with someone who totally understands what you’re going through is better yet.

What’s your best advice for others living with PH?

Learn how to smile; smiles are contagious. Having a positive attitude is also very important. Remember, even healthy people have “bad” days. You have to learn how to do things you enjoy, whether it’s reading a book, watching a special TV program or movie, going for a walk if you can, knitting, having a hobby — something just for you.

Although PH is a very scary disease, it is a very doable disease with the proper treatment. And we must always remember that there is hope.

What does being a PH Email Mentor mean to you?

I am a person who needs people and needs to help other people. Since I can’t always get out, the computer is my lifeline to the world. Being able to be a part of it, and hopefully being able to help someone along the way, is a plus for me.

Interview conducted by Michal Rachlin, Kerry Bardorf Family Support Program Associate

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

NEW! Ask a Question, Reach a Mentor!

Support is just an email away! Our team of PH Email Mentors is standing by for patients, caregivers and parents looking for one-on-one support.

PH Email Mentors are caring and knowledgeable members of the PH community, available to share what they’ve learned in their own journeys with pulmonary hypertension, point you in the direction of information and resources of value, and work with you to develop strategies for coping with PH in your own life.

Have a quick question or no time to search through mentor profiles? Contact a PH Email Mentor through our new “Ask-a-Question” form!

www.PHAssociation.org/AskAMentor

The PH Email Mentor program is funded through an unrestricted educational grant from Gilead Sciences.
Generation Hope: Members Use Social Networking to Raise Awareness

The value of raising awareness and advocating for pulmonary hypertension is something that has recently become very important to me. Thirteen years ago, when the only FDA-approved treatment for PH was Flolan™, I was given just six months to live.

Things are different now: through research, advocacy and awareness, we now have nine FDA-approved medications. But while medication is extending the lives of those of us living with PH, I want to find a cure for myself and all of my PHriends. That’s why I got involved with Generation Hope in Action (GHA), a subgroup of Generation Hope. GHA strives to raise awareness, advocate for the cause and increase education for young adults living with PH.

GHA is currently working on two projects: a letter-writing campaign to build awareness with elected officials and a video project to show our friends, family and the general population what life is like for a young adult living with PH.

Our videos will be aimed at gaining support for the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011 and educating those outside the PH community by creating a “day in the life of a young adult” series which will address topics such as dating, working, insurance and family life. We intend to share our videos through various social networking channels, including Facebook and Twitter.

Our letter-writing campaign to Congress is also designed to garner support for the Lantos bill and will focus specifically on the challenges faced by young adult PHers. We want everyone, including elected officials, to understand that the normal stages of life — including going to college, starting a career, and having a family — are much harder for those of us living with PH.

You can enhance our effectiveness by joining forces with us! The best part about these projects is that they can be done in the comfort of your home. If you’re not ready to get in front of the video camera, your calls and letters to elected officials can make a real difference. We are building a community of active, engaged young adults and we hope you will join us.

To be honest I’ve just recently gotten involved in advocacy and awareness-raising, but now that I have, I know that it’s easy and gratifying. It’s a great feeling knowing that we really can make a difference, and I’m honored to take on the role of helping to moderate GHA.

If we don’t get involved and do this for ourselves, who will? As PHA staff member Elisabeth Williams put it, “It’s a proactive way to battle PH and build awareness to save lives.”

By Melanie Kozak
PH Patient

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

For more articles from Generation Hope, check out the Generation Hope blog.

Recent blog entries include:
Finding Your Voice
Who Would I Be Without Illness?

www.PHAssociation.org/GenerationHope/Blog
my name is Denneys Niemandt, and I am a 52-year-old male from the beautiful city of Cape Town, South Africa. My journey with pulmonary hypertension began on a sunny Saturday in September 2006 when my wife, Sonja, and I went looking for a new family car. At the car dealership, I started feeling out of breath and experiencing tightness in my chest and pain in my right arm. I asked my wife twice why they were switching the lights on and off in the showroom, not realizing that I was having a blackout.

My wife took me to the N1 City Hospital where the doctors performed tests and my ECG showed abnormalities. They told my wife that I had had a heart attack and needed to see the cardiologist on duty. Fortunately, the cardiologist on duty was Dr. JP Smedema, who had experience dealing with PH in his home country, the Netherlands. PH is not well-known in South Africa and is often misdiagnosed.

Dr. Smedema did some intensive tests and told me that I had pulmonary hypertension and my right heart chamber was enlarged. At that stage, telling me I had PH meant as much to me as telling me I had a virus or minor illness. However, when he explained that PH is a very serious and terminal disease, it felt as if my world fell apart. My daughter was 15 years old and my son was 13, and I thought, “I will never see them become young, beautiful teenagers!”

I told Dr. Smedema that I had been in and out of the hospital over the last 20 years with pleuritis, pneumonia and cardiac arrhythmias. At one point, a specialist even told me it was all in my mind. This specialist told me to exercise more and to stop “thinking myself sick.” At the age of 14, I was diagnosed with hereditary spherocytosis and a splenectomy was performed. Five years later, I had to have a cholecystectomy. Dr. Smedema wrote an article titled “Pulmonary Arterial Hypertension After Splenectomy for Hereditary Spherocytosis” in the Cardiovascular Journal of South Africa in which he concluded that my PH was brought on 32 years after my splenectomy. Apparently, microscopic emboli had formed in my lungs and that was the beginning of my PH.

That is how my life started at the age of 47 with PH hanging over my head. My wife and I Googled PH and, as you all know, it is only doom and gloom if you read about PH on the Internet. Luckily, Sonja works with the medical faculty of the University of Stellenbosch and she helped me do proper research about PH and make changes to my lifestyle. I also made contact with PH organizations in the United States and United Kingdom, where I connected with patients who had the same “dreaded disease.”

It is not always easy for me, and the biggest challenge is that I used to be very active and now I get tired all the time. My youngest, Denneys, was 13 years old when I was diagnosed and is very active in sports. We used to play golf and ball games, but I had to explain to him that I could not do it anymore even if I wanted to, which frustrated me a lot. I got depressed thinking about my physical limitations and I had a difficult time controlling my emotions. The idea of taking so many medications was also overwhelming.

However, I eventually got more involved with other patients and with PHA and I decided there must be something positive to be gained from my disease. I am the current Chairman of PH South Africa (PHSA) and I am proud to say PHSA became a nonprofit organization in 2010.

My biggest dream for PH in South Africa is for it to become as well-known as it is overseas and to raise awareness of PH among the general public, medical professionals, the government and pharmaceutical companies. I also want to begin support groups in South Africa that can bring comfort and information to all PH patients. My message to other PH patients is to never ever give up, accept your condition and don’t fight it. Be thankful for family; they sometimes suffer more than you!

Thanks — and remember — PHenomenal Hope!

By Denneys Niemandt
PH Patient

For more stories from around the world, please visit www.PHAssociation.org/PHInternational/Faces
The PH Caregiver’s Health Checklist:
Tips for Taking Care of Yourself While You Take Care of Others

Many PH caregivers find themselves putting the patients’ health needs ahead of their own. But as one PH caregiver put it, “You can’t provide care and support if you aren’t well yourself.” When you take care of yourself, you improve your health as well as the level of care you are able to provide. Use this checklist to figure out what you can do for you.

√ Get enough sleep. Take naps if necessary! Visit http://sleepyt ime.to calculate what time you should set your alarm to avoid interrupting a sleep cycle. This will help you feel rested and alert for the rest of the day.

√ Schedule regular check-ups with your doctor, dentist and optician.

√ Get a flu shot. Visit www.flu.gov to find a vaccination center near you.

√ Eat nutritious meals every day. Plan and shop for your meals a week at a time so you don’t find yourself falling back on ready-made meals, which are often high in calories and salt.

√ Exercise regularly. Even if you don’t have time to go to the gym, reserve at least 20 minutes a day to take a walk or hit the yoga mat.

√ Turn bad habits into good habits. Using outlets like smoking, drinking and overworking can cause long-term damage to your health. Kick a bad habit for good by finding a new way to relax or recharge. Watch a favorite TV program, take a bath or call a friend.

√ Be kind to yourself. Taking a holistic approach and looking after your emotional, spiritual and social needs as well as your physical health will help keep you from becoming overwhelmed and getting sick yourself. Keep a list of activities that help you relieve stress and make a point of doing something on that list every day.

This checklist was adapted from “Chapter 9: Caregiving” in the 4th edition of Pulmonary Hypertension: A Patient’s Survival Guide. Read the chapter in its entirety by ordering a Survival Guide at www.PHAssociation.org/Store or by calling 301-565-3004 x0.

Caregiver Shout-Out!

Caroline Clemens honors her caregiver Ryan Roberts.

Ryan, my boyfriend of five years, has been through it all with me. He accepted me when I told him I had scleroderma, supported me when I was diagnosed with PH, comforted me through my Remodulin™ clinical trial, helped me when I was put on Flolan™, sat with me when I lost my kidneys, learned with me when we went through dialysis, prayed for me when I had my stroke, and pushed me when I struggled through rehab.

It’s hard to put into words how he has loved me. His actions sure show it. He is my friend, caregiver and, most importantly, my honey bear.

For a chance to express gratitude to your loved one in Pathlight, submit your own Shout-Out at www.PHAssociation.org/Shout-Out
When Melanie Kozak called her friend Tara Suplicki about a PH event happening in a city 345 miles away, Tara didn’t hesitate to say, “Let’s do it!” Together, they drove the six hours from their homes in New Jersey to Pittsburgh for PHA on the Road: PH Patients and Families Education Forum. Melanie and Tara are road warriors in the PH community. Both are PH patients, leaders in our Generation Hope group and good friends, so it’s no surprise that in October, the two would jump in Tara’s car again and hit the road to head some 244 miles south to participate in PHA’s open house and Board meeting in Silver Spring, Md.

After the Board meeting, PHA contacted Tara to find out about their trip. Here’s what she told us:

**PHA’s Board meetings are open to the PH community.**

**Why were you interested in attending?**

We heard from some local patients that there would be an open house at the PHA office. Then we heard about the Board meeting and made a weekend trip out of it. I have been very interested in how PHA’s Board works, as well as learning the inner-workings of the Pulmonary Hypertension Association.

**Was it what you expected?**

It was everything and more. It was so amazing to see how PHA works with its Board. I was just blown away to meet everyone on the Board. It was so well done, so orderly. There were two dozen people there and everyone got a chance to speak. Everything was very well organized.

**Did you learn anything new?**

I learned that PHA does a lot of work for us behind-the-scenes. I knew PHA did this, but I didn’t know to what great lengths PHA goes to do things for us. I didn’t know a lot about the REVEAL Registry.

**Editor’s Notes:** The REVEAL Registry is a multicenter, observational research study of PAH patients. More than 3,500 patients are enrolled in the U.S.-based registry, making it the largest PAH study in the world.

**PHA’s Board of Trustees is all-volunteer.** Board members are all involved in the PH community and affected by the disease in one way or another — patients, caregivers, researchers and medical professionals. You got to meet many of the members of our Board when you observed the meeting. Who are some of the people you met?

Rev. Steve White, who lost his daughter to PH, was inspiring to me, as was Dr. Greg Elliott, who works in genetic PH research. I really enjoyed meeting them both. Rev. White is going to speak at my support group in New Jersey sometime next year. Dr. Elliott came up to me right away and talked to me; he asked about my PH story and he just “got me.”

Jack Stibbs, whose daughter has PH, just makes me laugh; he’s a typical Texan — it makes you feel good to be around him.

The open house was really wonderful, and I got to meet PHA founder Pat Paton and her husband Jerry. And we had the chance to meet the other founders, Judy Simpson and her husband Ed. They were all approachable and down-to-earth.

**What was a highlight of the weekend for you?**

Everything! It was great to just be there. If I had to pick out one thing, I would pick the session where we broke into discussion groups on Saturday. We were discussing different ideas about early diagnosis, and it was great to see the minds work and the thought processes involved in the brainstorming. You can really tell that the members of the Board of Trustees and the entire PHA staff embrace new ideas and the process of really thinking through campaigns.

**Interview conducted by Debbie Castro, PHA Director of Volunteer Services**

Tara was diagnosed with PH in June 2008 and leads the Morristown Memorial PH Support Group in New Jersey.
This is a story of a young man, Matthew, with aspiring potential, who sees his future lead to dread and tragedy, and then to one of hope. Matthew graduated high school with honors and was accepted to three University of California schools. As a result of unexpected circumstances, he enrolled in the honors program at a local community college. Unbeknownst to me, Matthew disliked the community college, and he got involved with drugs. An arrest in March 2008 led him to drop out of college and enter drug rehabilitation while out on bail. In June 2009, Matthew and his attorney accepted a plea arrangement for 32 months in the state prison.

Meanwhile, although Matthew started to experience shortness of breath, he delayed seeing the doctor. In May 2009, his primary care doctor said he was probably feeling anxious about his upcoming court appearances and prescribed him antianxiety medication. It wasn’t until November 2009 that Matthew was diagnosed with idiopathic PH and interstitial lung disease.

As Matthew awaited his incarceration, his PH doctor, who has gone above and beyond the call of duty, wrote two letters about Matthew’s PH. Although Matthew’s attorney presented these letters to the judge and I spoke directly to the head district attorney, Matthew was taken into custody on Nov. 30, 2010. Before Matthew was cuffed, the bailiff let me give him a hug — our last hug for the next 15 weeks.

One of many things that the PHA website taught me as a PH caregiver is to always be prepared. I gave his attorney a list of Matthew’s five medications and their dosages and he inserted it in Matthew’s court file. Nonetheless, within 36 hours, I received a frantic call from a nurse at the infirmary about Matthew’s PH and his high uric acid levels. He and the doctor didn’t understand PH at all. The next day I dropped off a 10-day supply of Matthew’s PH medications and followed the same procedure 10 days later.

Matthew was then transferred to the Los Angeles County Prison. I drove 75 miles to bring a 30-day supply of his medications to the pharmacist there.

I was let through the front gate, only to face five big, armed guards at the visitor center. They told me, “You don’t understand! This isn’t jail; this is prison! Nobody brings medication here!” Medication transfers from the “outside – in” had never been done before. They reluctantly called the pharmacist who sent her assistant to the visitor center to accept the drugs.

Thirty days later, I followed the same routine. The prison was able to get Matthew’s sildenafil rather quickly and the pharmacist began the process to have the California Department of Corrections and Rehabilitation pay for his ambrisentan.

Matthew was soon transferred to California Men’s Colony (CMC) State Prison in San Luis Obispo (SLO). While there, he contracted viral bronchitis, which left him in a wheelchair and on oxygen.

I stayed in contact with PHA all this time, and when I told them about Matthew’s situation, they sent a letter to the prison on Matthew’s behalf, stating that Matthew should be seen by a PH specialist. The letter made its way up to the chief medical officer, and within four weeks Matthew was seen by the local PH specialist, Dr. Michael Ryan, in SLO. Unfortunately, Matthew’s right heart pressures were still high and his heart’s capacity had been significantly compromised. Dr. Ryan said that treprostinil was now the obvious medication for him.

Matthew decided to start on inhaled treprostinil. This required close cooperation by Dr. Ryan, his primary care physician, Dr. Thomas Amoto, and the CMC medical social worker, Chelsea Emerson. They worked together to get it approved and then advocated for special clearance for the inhaled treprostinil specialist to come and train Matthew and the nurses.

I’m not going to give up advocating for Matthew. I am also not going to give up advocating for others afflicted with PH. Through this whole experience, I have felt a positive sense of humanity. All those who come in contact with PH become part of a family — a family of support, resourcefulness and hope. The PH family is helping keep my son alive today. I thank PHA and all those I have referenced above who have supported Matthew and me.

By Craig Courtney, PH Caregiver

Due to space limitations, this is only a short excerpt. Read Craig’s full journey, including his caregiver trials and triumphs, at www.PHASassociation.org/Journeys/CraigCourtney

www.PHASassociation.org
From California to Michigan to Washington, D.C.: Steve Van Wormer Rides the Awareness Month Wave

As reflected in the theme for PH Awareness Month in November 2011 — The Power of One — everyone in the PH community has the power to do something to increase awareness about this disease. Separately, individuals and their stories are powerful, but when we end isolation and share our stories and ideas with each other, our power multiplies. Steven Van Wormer’s story is just one example of the snowball effect many of this year’s PH Awareness Month initiatives created.

Steve’s son Lucas has PH, and Steve, a PHA Board member, continually finds new ways to contribute to the PH community. This past November was no exception. Steve’s Awareness Month story begins with Doug Taylor’s challenge to everyone in the PH community to request a proclamation recognizing PH Awareness Month. This challenge had a domino effect.

Perry Mamigonian, a PH patient in California, responded to the challenge by organizing a proclamation effort in his home state, which also happens to be Steve’s. Perry sent an email to all of the California PH support group leaders and asked them to sign onto a letter requesting that the governor of California proclaim November PH Awareness Month. Steve was one of the 26 leaders who received the email, and he immediately agreed to sign on.

While Perry continued to work on the proclamation request from the governor of California, Steve was inspired to implement a similar statewide proclamation effort in the state of Michigan, where he still has family. Just as in California, all of the support group leaders in Michigan signed onto Steve’s letter, which he promptly sent to the governor’s office.

While Steve waited for a reply, he thought about how to turn the proclamation challenge and statewide proclamation efforts into a multipronged advocacy approach. As a result, Steve and his father came to Washington, D.C., and met with his Members of Congress from California and his dad’s Members of Congress from Michigan to ask them to co-sponsor the only PH-specific bill in Congress, the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011.

Recognizing that coming to Washington, D.C., to visit your Members of Congress isn’t feasible for everyone in the PH community, Steve encourages you to do whatever it is you can to raise awareness about pulmonary hypertension. “If you’re able to spend a lot of time on the computer, then that’s great! Send a letter to your Members of Congress or try to get a proclamation from your local government,” Steve says. “If you’re able to meet with your Members of Congress, then go that step further and create that connection to awareness. Do anything and everything you can do to help the momentum and the wave.”

Steve is not the only one making waves. Read more about PH Awareness Month proclamation successes throughout the entire PH community on p. 28.

Awareness Month may be over, but reaching out to your Members of Congress is always a great idea! Find out how you can carry the momentum forward by visiting www.PHAssociation.org/AdvocacyActionCenter or by contacting PHA’s Grassroots Campaigns Associate, Elisabeth Williams, at ElisabethW@PHAssociation.org or 301-565-3004 x753.

By Elisabeth Williams, PHA Grassroots Campaigns Associate
When you are a little 8-year-old girl, you have big dreams. Dreams of being a ballerina, a princess or a teacher. You don’t think about going to bed and never waking up again. You don’t think about leaving your family, friends and your favorite Cabbage Patch Kid doll. I did. I was diagnosed with primary pulmonary hypertension in 1988 as a scared little girl who instantly had to grow up. I cried for my mom to sleep with me in case I didn’t wake up. I took all the attention from my little sister who didn’t know what was wrong with her big sister and best friend. My parents divorced and everyone looked at me with those pity eyes. “That poor girl, she’s so young.”

I began calcium channel blockers to control my PH during my teens. I felt like an outcast all throughout school. I couldn’t participate in gym classes, sports or sometimes even slumber parties. I gained weight and used oxygen when I slept. I only had a couple friends who stood by me and cared. I never thought I fit in anywhere because thoughts of dying and not having a future were never far from my mind. Even though I went through a bad year or so of rebelling against my doctors and parents by smoking and not taking care of myself, I graduated high school with good grades and my PH was stable.

I became pregnant at age 20 and although that was not good for my PH, I decided to have my beautiful daughter against my doctor’s advice. My PH doctor at the University of Michigan told me I would die if I continued with the pregnancy. I knew God had everything under control and I had a perfect pregnancy and delivery. I had a right heart catheterization in place during the caesarian section delivery.

Things were great PH-wise until a year after Brianna was born. I couldn’t carry my daughter, walk to the bathroom or do anything without gasping and occasionally passing out. I was told to get my priorities straight because my health was failing. I was put on epoprostenol in 2003 and that changed my life. The man of my dreams asked me to marry him. He knew about my PH and the possibility that I might not have a long future, but he promised to make that future the greatest time of our lives. So far, he has kept that promise. My daughter is now 10 years old and she is the greatest gift God has ever given me. She is sweet and caring and she loves to take care of me even when I tell her that I am the mom and I need to take care of her. She learned to mix my epoprostenol and she helps me with house work. I love her and my husband so much. I am truly blessed.

I am no longer that scared, frightened little girl. I am a strong confident young woman with dreams and goals for my future. I won the United States Bowling Congress (USBC) Women’s City Bowling Tournament in Muskegon, Mich., in 2009. I took home six trophies the night of our banquet, but above all I took home the greatest feeling anyone with PH can have and that is “accomplishment.”

The following year, 2010, I won first place at the USBC Michigan State Woman’s Tournament for handicap Singles Third division. I even got featured in the Michigan Ten Pin flyer and was able to bring PH and organ donation to light. Just because we have PH doesn’t mean we are destined to die. We are destined to LIVE!! If you would have asked me years ago where I would be right now, I would have said, “Dead.” Not today. Now I can say with confidence that my future is full. I am a wonderful mother to a beautiful, PH-free daughter. I am a great wife to the most loving, amazing and generous man I have ever met. I am the daughter to the greatest caregiver, friend and giving mother anyone could have. I am a wife, mother, daughter, bowler, knitter, scrapbooker and friend. I am not PH!

I know my future is not guaranteed, but neither is anyone else’s. I have good days, I have bad days and I have days that I think, “This is the end.” But I never give up being me. Believing in my future and striving for more life is what keeps me going.

P.S. — A little Viagra helps, too, right!? ♥
Sarah Mary Peek’s Journey as told by her parents, Michelle and Dave: An Indomitable Spirit Until the End

From the moment she was born, we knew Sarah would change our lives forever. At birth Sarah survived a severe brain bleed and rash of seizures, from which we were told she’d die or face severe mental retardation. This left her with mild cerebral palsy, eventually requiring her to wear specially fitted braces to walk. In addition, a detached retina caused her to lose vision in her right eye.

The first two years of her life were booked with appointments to specialists and visits from therapists. These early years left us feeling very protective of Sarah. Sarah, on the other hand, was already easing our worries. It amazed us that she showed no sign of mental delay whatsoever. Quite the opposite, really! She adapted to the vision loss well and lovingly called her ankle-foot orthotic (AFO) braces her “walking boots.”

We finally began to relax and enjoy our little girl as we watched her personality and determination completely overshadow any of her disabilities. Soon we felt comfortable enough to handle a new addition to our family, and when she was 2, Sarah got a little brother.

But before long, we had new nagging feelings that something else was wrong. Sarah was very pale compared to her new baby brother. Her feet, lips and fingers occasionally turned a bluish color.

Just before her third birthday, at a routine appointment, I brought in some pictures of her blue feet. I recapped her medical history with the doctor. I wanted Sarah to be sent to a cardiologist.

I was assured her heart was fine and my fear was unwarranted. But two days later she collapsed in our front yard.

The day after Sarah collapsed we were at the cardiologist’s office where they performed an echocardiogram followed by an EKG and then delivered a diagnosis of pulmonary hypertension. We were told that Sarah was already in the end stages of the disease, and they gave her six months at the most. This began our frantic search to find some kind of hope! And we quickly found that hope through PHA. Through PHA’s resources, we were able to get in contact with Dr. Erika Rosenzweig at N.Y. Columbia Presbyterian. But Sarah’s PH treatment would be another big life change.

We wanted to shut Sarah in a big plastic bubble and keep her safe from anything that could cause her to get sick or threaten her pump and central line.

My husband Dave and I were trying to make sense of why things had to keep happening to our poor little girl. But not Sarah. She accepted everything thrown at her with such grace and strength that it humbled us. So I have a tube coming out of my chest? So I need to wear a pump? Have dressing changes? I can’t swim anymore? Wear a cannula at night? No biggie!

She just wanted to live every moment to its fullest, but we had a hard time letting her. One of the first things that was hard was going to the N.Y. State Fair for the first time. It’s only 10 minutes from us, and Sarah and her brother Nathan really wanted to go. Sarah had just turned 5. We hadn’t done much for two years after diagnosis. We stayed close to home. We had all her emergency supplies in a luggage bag on wheels we took everywhere we went.

At the fair, we took the kids through exhibits to see animals, butter sculptures and trains. It was going pretty well until we came upon the kiddie rides. She wanted to ride them with Nathan. Would she have an arrhythmia? What if her pump started to alarm while she was on?

Her life became fairly boring after PH entered our lives. Mostly staying home playing with her brother and getting visits from various therapists for her cerebral palsy. Excitement was our five-hour road trip twice a year to her PH doctor.

We looked at each other and then Sarah. She had already been through so much in her short life. Didn’t we want however much time she had left to be happy and fun? That was the beginning of our letting go. We agreed that her life may be shorter than the rest of ours, but it was going to be full!

We watched as she climbed in the kiddie rollercoaster with her brother, smiling the biggest smile! She knew to alert us if she heard her pump alarming. We held our breath as they took off. The joy and elation on
her face each time they made a pass was wonderful!

Next was ballet. She could go without her AFO braces here and there, and she wanted to be in a dance recital ever since she was 2 and saw her young Aunt Emily on stage. I found a place that was more laid back and all about the kids just having fun. I wanted to be in the room watching. (What if she fell? Her line could get pulled, the kids could pick on her, she may get too tired!)

No, I’ll be right outside if needed. The kids were given an explanation of her illness and pump; she needs to feel some sense of independence. Ugh, this is hard!

As I sat in the waiting area with the other mothers, clutching her emergency bag, I watched her scamper off to class so excited. When she emerged from class beaming with happiness, my anxiety started to melt away. And she fulfilled her wish to be on stage twice!

That year we were trying to figure out our next big step: kindergarten! She wanted to go to school more than anything and ride a school bus. This was more difficult than we ever thought. My husband, my mom and I were the only people in Syracuse who could mix her medicine, change her line and dressing and know what to do in a PH emergency. The journey to find her a nurse would take us another year. We needed someone we trusted, someone who would be like another member of our family.

We found that in Tina. She started training to learn about PH and all that comes with it. We spent a lot of time together before school started, and right after Sarah turned 6, the day finally came. I thought Sarah would jump out of her skin that morning she was so excited. I thought I would upchuck or be sick with worry all day. But the utter joy on her face as she climbed the stairs of the bus and turned to wave goodbye took it all away.

Sarah made a ton of friends and they all wanted to learn about her pump and backpack. The teacher made a big stop sign to put on the back of it to remind kids not to touch it. Sarah thought that was so cool!

Her friends all wore purple on a special day in November to help with PH awareness month; Sarah felt so special. She also won the heart of one of our local news anchors. He did two awareness news stories with her, and she loved to be on TV!

When she started first grade, she was even more excited than the year before! Now she and her brother Nathan would ride the bus together. She would get sick a few times that fall, and all she cared about was feeling better and going back to school.

At the end of November 2009, her central line broke. It was the first time in four years that happened. We were off to N.Y. Presbyterian for a new one. All her friends sent her get well cards and she loved it!

She got another bad bug in February 2010. When March 1 came around, she finally didn’t have a fever and said she wanted to go to school. She still seemed weak but begged me to go back. She had missed two weeks and was miserable about it.

She pushed through those first two days but started to have little nose bleeds. We were only weeks away from going for her annual heart catheterization, and the doctor and I were talking about moving that up.

March 3 was Wacky Waffle Wednesday at school. Her nurse Tina called me a couple times from school about her nose bleeds. They were heading to gym class (one of Sarah’s favorites), and Tina had told her she couldn’t join in today. Sarah had given her the lip and Tina made a deal with her. She could join in, but one more nose bleed and she would call me back to come pick them up.

Sarah was elated and ran to join her friends. They were playing games and having a blast when Sarah slowly dropped to her knees and fell over. I was called immediately and raced to the school. She looked very peaceful lying in her principal’s arms. She slipped away as I walked with her to get in the ambulance.

In the days that followed, I beat myself up for what I should or shouldn’t have done. Cursed myself for letting her do too much. She would be fine if she had just stayed home. Nonsense!

I look back at pictures of her doing the things that had been worrisome to us. In every single one, she isn’t just smiling a rehearsed smile but is in a moment of pure joy. Losing her was the most devastating thing in the world. But looking back and not having to regret holding her back because of her illness gives us happiness.

Now we think back to some of the dreams that she had: dancing on stage, going to school and riding the bus ... She did them all, and that puts a smile on our faces and peace in our hearts.

To read the full version of Sarah’s story, visit www.PHAssociation.org/OurJourneys/SarahMaryPeek
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)

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

**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.

**PHA News** – 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)

Connect from home

**Patient-to-Patient Support Line:** 800-748-7274
The Support Line is answered by trained volunteer patients who are there for anyone who needs to talk about pulmonary hypertension.

**Online**
Our discussion board, email groups and chats help you instantly connect with other patients and family members. [www.PHAssociation.org/ConnectOnline](http://www.PHAssociation.org/ConnectOnline)
Find a patient or caregiver mentor at [www.PHAssociation.org/Mentors](http://www.PHAssociation.org/Mentors)

**Connect face-to-face**

**Support Groups**
Join one of our 235+ support groups nationwide to connect with people who understand what it’s like to live with PH. Find support groups in your area at [www.PHAssociation.org/LocalSupportGroups](http://www.PHAssociation.org/LocalSupportGroups)

**Conference and Patient Education Programs**
PHA’s International PH Conference brings together more than 1,000 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and coping with PH. To learn more, visit [www.PHAssociation.org/Conference](http://www.PHAssociation.org/Conference)
PHA also hosts regional patient education conferences throughout the year. Learn more at [www.PHAssociation.org/OntheRoad](http://www.PHAssociation.org/OntheRoad)

**Special Events and More!**
Attend an event near you to meet patients and support PHA: [www.PHAssociation.org/Events](http://www.PHAssociation.org/Events)

Join our community of hope

Become a member to receive Pathlight, a discount on *Pulmonary Hypertension: A Patient’s Survival Guide* and much more. Visit [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join)
Q: What are the special considerations I should be aware of as a PH patient when I get a cold?

A: This is a good and important question. As much as we all hope to avoid colds, this is simply not always possible and adults in the United States can expect to have two to three colds per year. Therefore, having a plan in place for what you will do when the sniffles inevitably set in will help you to be prepared. When we talk about colds, we are generally referring to an “upper respiratory illness” that may include sneezing, sore throat, cough, runny nose, headache, low-grade fevers and generally feeling poorly, so called “malaise.” Colds are almost always caused by a virus. I’m happy to provide questions I get asked most frequently about colds in my clinic and provide my answers below.

When should I call the doctor if I think I have a cold?

Most colds cause symptoms in the nose, mouth and chest and most have passed by 7-10 days. So if the symptoms are outside of those locations or time frame, it would be unusual. Some illnesses seem like colds but might be other, more serious conditions, such as influenza. If you have high fevers (>102°F), aching muscles and it is the winter or early spring, it would be useful to call your doctor’s office to determine if influenza might be the culprit and require treatment. If vomiting or diarrhea accompany your nasal symptoms and persist for more than a day or you are getting dizzy, you should contact your doctor’s office. If your symptoms last for more than a week, you should contact the doctor’s office and decide if a course of antibiotics might be useful in case bronchitis or sinusitis may have developed.

Because PH patients have special considerations, if you can’t take your PH medications because of a cough or weakness, you should contact your doctor. Or if you have a worsening of your PH symptoms aside from mild increase in shortness of breath from your cough, e.g. if you have more leg swelling or begin passing out, you should call your doctor.

What can I do or take to feel better when I have a cold?

Colds are usually caused by viruses and, unfortunately, there isn’t any medication that will kill the virus. So our treatments are aimed at making people feel better while we are waiting for the virus to pass. Old-fashioned home remedies are still useful, and we recommend rest, adequate hydration and continued use of your PH and other medications, unless directed otherwise. Sometimes patients believe that drinking more liquids such as hot tea or water will help the virus to pass, but this is not true and may lead to too much fluid in the body of PH patients. So, try to drink when you are thirsty and stick to your physician’s recommendations of how much fluid to drink in a day. Along these lines, continue to avoid salty foods, especially canned soup that can be a land mine of salt and worsen breathing and swelling.

Sometimes symptoms are uncomfortable enough that patients would like to try over-the-counter medications. For fever, body aches and sore throat, acetaminophen or Tylenol™ at the recommended doses are fine. Patients taking blood thinners such as warfarin should be careful with other non-steroidal anti-inflammatories such as ibuprofen and consult with their doctors before taking them.

For management of coughing and nasal congestion, we have generally recommended that patients avoid decongestants containing pseudoephedrine and phenylephrine as these medications have the potential to interact with PH medications and even increase pressure in the lungs. These medications frequently are marketed with the suffix “-d”. Good alternatives include diphenhydramine (Benadryl™) or guaifenisin (Robitussin™ or Mucinex™) without any pseudoephedrine or phenylephrine added into the preparation. Generic drugs are often more affordable for patients and just as effective, so I recommend their use. Just check the ingredient list closely to avoid the two drugs above.

There is some data that zinc lozenges may shorten duration of symptoms, and these are safe for PH patients to take, though the nasal spray preparations should be avoided.

There are no data that vitamin C or other vitamins will prevent colds or make them pass faster and we generally don’t recommend these. Physicians may be able to...
Meet Dr. Virginia Steen: A Dedicated Partner in the PH Field

Virginia D. Steen, MD, is Professor of Medicine at Georgetown University Medical Center where she also serves as the fellowship director in the rheumatology division and as a consultant in rheumatology in the arthritis division of the NIH. Recently, Dr. Steen spoke with PHA about her work with scleroderma and PH patients.

You specialize in rheumatology. What sparked your interest in PH? I have been interested in PH in scleroderma for more than 25 years. My research interest is the epidemiology of scleroderma, particularly with regard to the scleroderma database out of the University of Pittsburgh, which I helped establish. I was involved with a study that followed a group of scleroderma patients with PH. It was the 1980s and there was no treatment for PH. As treatments became available, I knew it was extremely important to identify scleroderma patients with PH as soon as they were diagnosed. After all, we had a population of patients who we knew was at risk. I continued my research to identify which patients were at greatest risk for PH and found that those with limited cutaneous scleroderma with long-standing Raynaud’s disease, an anti-centromere antibody, and those with a very low DLCO (a valuable test of lung function) were at greatest risk.

What advances have you seen in the treatment of PH patients? It has been really wonderful NOT to have to tell patients they are going to die in two years and we have nothing to treat them with. True, PH is still a serious complication in scleroderma but it is definitely treatable. It’s exciting to see the number and variety of treatments grow.

Can you tell us about your experience treating scleroderma patients who have PH? For many reasons, treating PH in scleroderma is more difficult than treating idiopathic PAH (IPAH). Patients are often older, have complicating medical problems, and perhaps other conditions. Additionally, the PH in scleroderma is often not pure PAH; our patients often have some component of interstitial lung, myocardial fibrosis, and even veno-occlusive disease in addition to pulmonary arterial disease. For all these reasons, the disease is not as responsive to treatment as it is in IPAH. Scleroderma patients are not complainers, they adapt to their disability, and far too often they don’t get diagnosed until they are already functional class III with right heart failure. It is critical that we identify these patients sooner and get them treated as early as possible.

From your time working in the PH field, do any cases really stand out to you? The first PH patient I treated with an endothelin receptor antagonist was a 72-year-old woman who kept insisting she wasn’t short of breath. She had significant PH, and even though she denied shortness of breath, I treated her anyway. She came back three months later and almost ran into my office hugging me and telling me she never realized how short of breath she was. She was now able to go to church (to climb the stairs to get to the church), which she hadn’t been able to do for three years. I had another 72-year-old scleroderma patient who for three years had been doing very well on oral agents but kept requiring more and more oxygen. At that point she was ready to give up because she didn’t want to have to deal with the more invasive medication. However, after several long discussions, she decided to try intravenous therapy, and now two years later, she rarely needs oxygen and just returned from seeing her new grandchild.

How did you become involved with PHA? I was asked to speak at one of the early PHA programs for physicians and patients and was so impressed with PHA’s extraordinary efforts and success at PH education. In scleroderma, we really need the education to teach the physicians how to identify, screen, diagnose and get the patients treated. Through PHA Online University and other educational programs, we are making more educational opportunities possible. In the future, I look forward to educating even more rheumatologists.

What’s the most important piece of advice you give your PH patients? I encourage all of my PH patients to participate in a cardiopulmonary exercise program to improve their function and to stay as active as they can. As for other scleroderma patients with PH, I would encourage them to work very closely with both the PH doctor as well as their rheumatologist. The scleroderma patient has additional problems besides PH that should not get neglected, and there are scleroderma problems that mimic side effects of medication, so it is important to have a team of doctors who work together to optimize care.

Interview conducted by Rebecca Kurikeshu, PHA Medical Outreach Program Associate
Healthy Ways to Lose Weight in the New Year

Many people use the start of a new year as a time to reflect on the past and resolve to make positive changes. For many, reaching a healthy weight and/or improving physical fitness is on their list of resolutions for 2012. Here are some tips to achieving your goal, while taking care of your PH at the same time.

**Know where you are going:**

The first step in planning any goal is to know where you want to go. Begin by calculating your BMI (Body Mass Index). Use the calculation:

\[
\text{Weight (lbs)} / (\text{Height (in)} \times \text{Height (in)}) \times 703
\]

Or use this calculator online: [www.nhlbisupport.com/bmi](http://www.nhlbisupport.com/bmi)

A BMI less than 18.5 is underweight, a BMI of 18.5-24.9 is healthy, 25-29.9 is overweight, and greater than 30 is obese.

While the BMI is not perfect, aiming for a number in the healthy range is generally considered a sensible target. The good news is, even modest weight loss (around 5-10 percent) can have significant health benefits. Work with your PAH provider to develop appropriate and realistic weight loss goals for you.

**So how do I get there?**

It is important to learn how many calories per day you usually consume. Try keeping a daily food diary for a week to give you an idea of your average daily calorie intake. There are several online calorie counters or you can purchase a calorie counting book at your local bookstore.

You need to be in a deficit of 3,500 calories to lose one pound. You can do this by either eating 3,500 fewer calories or burning 3,500 calories more than usual. Try eating 500-1000 fewer calories each day. By the week’s end, you will have cut 3,500-7,000 from your diet, giving you a weight loss of approximately 1-2 lbs.

**Sorry, but there are no shortcuts**

Losing weight can be tough, and it is natural to want instant results. However, generally people who lose weight gradually (1-2 lbs. per week) are more successful at keeping the weight off than those who lose it quickly. Try to focus on lifestyle changes rather than going on a diet.

There are many advertisements promising fast or effortless weight loss. These claims are generally false, exaggerated or even dangerous, especially for PAH patients. For example, some diet products contain stimulants, which can worsen PAH.

Diets that eliminate certain types of foods (carbs, fats, etc.) are not generally sustainable and have not been shown to have long-term weight loss results. PAH patients need to be especially mindful of their nutritional, electrolyte and fluid intake, particularly if they are on coumadin, diuretics or potassium supplements.

Currently popular are diets promising fast weight loss by using hormones combined with an extremely low-calorie diet. These have not been studied sufficiently, and we do not know their long-term effects, particularly in people with PAH. Remember, if it sounds too good to be true, it probably is.

**What about activity?**

For PAH patients, physical fitness can be challenging. Patients often worry about the safety of exercise or feel too fatigued or short of breath to be active. Your body was designed to move. However, you will need to exercise within the recommendations of your PAH provider. A great place to start is by participating in a cardiopulmonary rehabilitation program at your PAH center or local hospital. This is a monitored exercise program designed for people with activity limitations from heart and/or lung disease. Physical therapists who are knowledgeable about PAH will teach you about safe exercise and better breathing.

Walking is generally safe, but you will need to walk at your own pace. Increased shortness of breath, chest pain, heart palpitations or dizziness are signs that you may need to slow down and rest.

Patients with less severe PAH may be capable of more intense exercise, but it is important to get clearance from your PAH provider.

**What now?**

Keep in mind that your needs are unique, even from other PAH patients. It is extremely important before deciding to embark on a diet/exercise program or before considering starting additional supplements/medications that you discuss your plan with your PAH provider. He or she can help you decide on a healthy plan to meet your goals. Remember, they are there to help! And, as always, visit [www.PHAssociation.org](http://www.PHAssociation.org) for lots of helpful tips.

By Lisa L. Roessel, FNP-BC, Pulmonary Hypertension Program Coordinator, Division of Pulmonary & Critical Care Medicine, Legacy Clinic Northwest, Portland, Ore.

References:

www.PHAssociation.org

PATHLIGHT WINTER 2012
Top pulmonary hypertension medical professionals from around the world recently produced a white paper titled “Recommendations for Improving Patient Outcomes” which found that the time between onset of symptoms and diagnosis is still much too long for a majority of PH patients.

The paper reviews the important advancements that have been made over the past 20 years in diagnosis and treatment of PH and focuses on the continuing barriers to patient care.

Among the paper’s findings are that in the United States, the average age at diagnosis is currently 50 years old, and women are four times more likely to be diagnosed with PH than men.

Additionally, despite the discovery of effective treatments, PAH remains difficult to diagnose. Currently, the average time from symptom onset to diagnosis is 2.8 years, just as it was 20 years ago. As this paper reports, most patients see three different physicians over a three-year period before being diagnosed with PAH. Patients most likely to experience delays are young people (under 36 years old) and people with a history of respiratory illnesses. Because of the significant delays in diagnosis, nearly 75 percent of patients are in the late stages of the disease and experience significant limitations in physical activity by the time they are diagnosed.

The paper also issues a “call to action” through recommendations on how to enhance patient care. One of the recommendations highlights the importance of rapid and accurate diagnosis: “With earlier diagnosis and treatment — preferably while patients are still Functional Class I or II — disease progression can be delayed, impacting both survival and quality of life.”

To achieve this goal, the paper notes the importance of increasing PH awareness among the general public and all types of medical professionals. Because patients generally present with symptoms to a non-PH specialist first, the white paper stresses the importance of educating these physicians about PH and its symptoms. Additionally, the authors believe that it is important to inform the general public about PH and how closely it mimics other, more common, diseases.

The paper also focuses on the importance of the PH specialist, noting that the advent of oral therapies has made it easier for community physicians to treat PH patients. However, it notes, PH specialists have expertise in the disease and more advanced treatments as well as access to clinical trials and registries.

“Due to the complexity of treating this life-threatening disease, the ongoing care of patients with PAH should be nothing short of a collaborative team effort between the patients’ primary care physician and a PH specialty center,” the paper states.

Based in part on these recommendations, PHA is launching an Early Diagnosis Campaign to increase awareness of PH. Through this campaign, PHA will reach out to different groups — including the general public, patients with other commonly associated conditions and medical professionals — to decrease delays in diagnosis and help patients receive effective treatments sooner.

*By Meghan Finney, PHA Patient Education Manager

To read the entire paper, go to the Library section of www.PHAOnlineUniv.org and click on Guidelines and Recommendations.

**ASK A PH SPECIALIST** CONTINUED FROM PAGE 14

recommend other prescription medications if symptoms are particularly severe or prolonged. Finally, cigarette smokers who quit will decrease the duration of their future colds.

**What can I do to avoid getting a cold?**

Colds happen to everyone at some point, so they can’t be completely avoided. However, good hand hygiene and avoiding close contact with friends and family who have fevers, runny nose or other cold symptoms is reasonable as colds are usually passed from hand-to-hand or hand-to-face contact. Alcohol-based hand gels or washes may be useful for use in public places before eating when hand washing is not feasible. Although it won’t prevent colds, annual influenza vaccination is critical for PH patients and worth mentioning.

Just remember, the cold will pass eventually. Patience and taking care of yourself will make it as tolerable as possible.

*Answer provided by Anna R. Hemnes, MD, Vanderbilt University Medical Center, Nashville, Tenn.*
Education and Collaboration Abound at Symposium 2011

The 2011 PH Professional Network (PHPN) Symposium, “Inspiring Hope: New Directions In PAH,” was a phenomenal three-day education and networking event. From Sept. 22-24, allied health professionals convened in Arlington, Va., to discuss advances in PH treatment and care.

This was the first biannual Symposium since PHPN changed its name from PH Resource Network (PHRN) to better represent the multidisciplinary diversity within the PH field. With 59 expert speakers and 14 hours of education, Symposium provided allied health professionals with the chance to learn about innovations in PH treatment and care from top medical professionals in the field.

In addition to being a fantastic educational opportunity, the 2011 Symposium was a chance for health professionals from all across the country to build coalitions across specialties and disciplines to advance PH treatment. Bringing together nurses, pharmacists, respiratory therapists, social workers, nurse practitioners, physician assistants, doctors and more, this year’s Symposium had a record-breaking 426 participants.

Advocacy Day on Thursday, Sept. 22, was the perfect kick-off to the 2011 Symposium, providing allied health professionals with the chance to raise awareness about PH. More than 70 allied health professionals traveled to Capitol Hill to meet with their senators to promote sponsorship of the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011. Read more about Advocacy Day on the facing page.

The energy generated during the day carried into the opening dinner Thursday evening, where keynote speaker, Jessica Lazar, PA, shared her story of climbing Mount Kilimanjaro with Drs. Ray Benza and Robert Frantz. Her moving address, “Inspiring Hope: One Medical Professional’s Climb to a Cure,” discussed the joys and trials of her seven days spent on the mountain, the highest point in Africa, in order to raise awareness about PH around the world.

The educational component of Symposium began on Friday morning, as Dr. Richard Channick, and Arlene Schiro, NP, presented “Hope in 2011: Top 10 Clinical Advances in PH.” Their presentation helped all of us to reflect on how far we have come in the treatment and management of PH.

Participants took all the positive energy generated from this presentation into the Exhibit Hall where they mingled with PHPN Committee Members at the PHPN Committee Meet Up. This Meet Up provided participants with the chance to talk with members of the Membership, Symposium, Publications, Education, and Practice committees and learn more about getting involved with PHPN. The PHPN Mentors were also on hand to talk about their experiences with mentorship and encourage other members to take advantage of this great opportunity to learn from one another.

Later that day, participants headed to the Poster Hall to view the 40 abstracts on display. Doubled in size from the last Symposium, the Poster Hall contained abstracts authored by PHPN members from across the country addressing an array of PH issues. This was a great way for participants to learn about what their colleagues have been working on in their institutions and hospitals and take some of these best practices back home.

The concluding presentation at Symposium 2011 was “Team Hope, A Multidisciplinary Approach to PAH Care.” Mae Centeno, NP, Heather Langlois, LI-CSW, and Peggy Kirkwood, NP, talked about how to work across the various allied health professions together to provide the best patient treatment and care. It was the perfect end to our three-day celebration of building coalitions across all health professions working with PH. With so much engagement and collaboration from Symposium 2011, I can only imagine the stellar programming and networking we have to look forward to at Symposium 2013!

By Gerilynn L. Connors, BS, RRT, MFAACVPR, FAARC, Clinical Manager, Outpatient Services, Respiratory Care, Pulmonary Diagnostics & Pulmonary Rehabilitation, Inova Fairfax Hospital, Falls Church, Va.
In late September, more than 70 PH Professional Network members from 29 states visited over 60 Senate offices to educate Members of Congress about the urgent need for PH awareness, early diagnosis and treatment, and to request co-sponsorship of the Tom Lantos PH Research and Education Act of 2011. In this article, Fran Rogers, MSN, CRNP, and Sue Huseman, RN, reflect on their Advocacy Day experience.

Fran Rogers, MSN, CRNP

Attending Advocacy Day 2011 was a unique and rewarding experience. It isn’t every day that we can take our PH knowledge as healthcare professionals directly to our lawmakers! We share it every day with our patients and their families, but for me, spreading that knowledge on Capitol Hill was “taking the next step.”

The informative prep session before leaving for “The Hill” gave us the tools we needed to make every minute count as we navigated from the House to the Senate. One of the highlights of Advocacy Day for me was hearing from Congresswoman Lois Capps (D-CA), a registered nurse, who sponsored the Tom Lantos Pulmonary Hypertension Research and Education Act of 2011 with Congressman Kevin Brady (R-TX), an early and passionate supporter. She took time out of her busy schedule to thank us for coming to help spread the word about how this bill can save lives by making more research possible sooner and increasing public and professional awareness of PH. It was obvious that the passage of this bill is as important to her as it is to us!

Armed with Congresswoman Capps’ inspiration and our determination, we set out to meet with our legislators. Whether we met with them or their legislative assistants, we were able to effectively explain why co-sponsorship and eventual passage of this bill is so important to their constituents — PH patients, families, caregivers and healthcare providers. At a time when our elected officials are faced with monumental issues, I think our presence and message on Capitol Hill did not go unnoticed or unheard. We will go back again and again, if need be.

If you haven’t attended Advocacy Day during a PHPN Symposium, please consider it in 2013. There truly is strength in numbers. It will offer you another way to “care” for our PH patients — one you won’t soon forget!

Sue Huseman, RN

Have you ever wanted to do something important to support a cause you are passionate about? Do you have a great story about a PH patient who benefited from your intervention? PHA’s PH Professional Network Advocacy Day was a way for me to share my stories. My first year (2009) I really had no idea what to expect but just the experience of walking into the halls of Capital Hill was pretty awesome. To actually speak to people in the offices about PH was even more empowering. I was a little intimidated at first, but PHA staff explained it all before we got started. As the PH stories and disease explanations started flowing, conversation was easy.

I had a purpose. We were asking Members of Congress to co-sponsor the Tom Lantos PH Research and Education Act, a much-needed bill to support PH education and funding for research. It is important to our community and on Advocacy Day I actively chose to help move it along. You have to agree that’s pretty awesome!

In September 2011, when I attended my second Advocacy Day, I knew what to expect! I was no longer intimidated by being on Capitol Hill. I had a story to tell — sometimes more than one — and I needed my senators’ support. I was also honored to have a patient in our group this time who had a personal story to share.

If you have passion about PH and are willing to share your knowledge, experience and stories, then attending Advocacy Day is for you. Take the opportunity to walk the halls of Congress and speak to the people you help to elect. You have a duty as a responsible, concerned professional who represents a population of individuals living with a devastating disease. Speak out. I encourage you to take some action. Hope to see you next time, because this is an event I don’t plan to miss.
How Social Workers Can Help You in Your PH Journey

“I don’t need a social worker.”

Have you ever said that? If so, you aren’t alone. Social workers are an important but often underutilized part of the multidisciplinary care team. Personal experience tells me that this is likely due to confusion and misconceptions about the role of medical social workers. Anyone who’s watched televised medical dramas would no doubt believe that social workers are only called in to deal with troubled families and serve little purpose in the hospital outside child protection.

But the truth of the matter is that social workers wear many hats: supporter, educator, advocate, cheerleader and guide — to name just a few. The services they provide are often intangible. Social workers may not cure PH, but they focus on the patient and family, identify areas of need, and work to restore balance. Where most medical professions are disease-focused, social workers approach each patient with a broad lens, evaluating all the factors that influence the patient’s well-being, beyond their diagnosis.

So, what can a social worker do for you?

Support: Social work is, first and foremost, a helping profession. By nature of their training, social workers are well-equipped to provide emotional support when you need it — at the time of initial PH diagnosis, during hospitalizations or clinic visits, or when facing other life stressors. Crisis intervention and adjustment to illness are critical aspects of their work. They recognize that sometimes simply listening is what is needed most. Don’t be afraid to use your social worker for support. They are neutral, nonjudgmental and, trust me, nothing you say will shock them! Living with PH brings unique challenges. Your social worker can be a wonderful resource for support and encouragement as you learn more about PH and incorporate your diagnosis into your life.

Educate: Sometimes dealing with the healthcare system or community resources is like visiting another country complete with unfamiliar languages and foreign customs. Especially at the time of initial PH diagnosis, social workers play a central role in helping patients navigate unfamiliar systems, manage medical needs, and find balance. From identifying who’s who on the medical team to learning how to organize your personal medical record, social workers have information that can help you get the most out of your medical care while also ensuring that you have a life outside of your diagnosis. Not sure what your insurance will cover? Unclear if PH qualifies you for state or federal resources? Worried about what accommodations you might need in school or for travel? Your social worker can answer your questions and give you the knowledge you need to move forward.

Advocate: Doctors, nurses, and other medical professionals are focused on your care, but like everyone, they can have strong opinions. Patients need a voice in their care. Social workers can help you express your wants and needs constructively, allowing you to be better heard by your PH team. Because of their understanding of your physical, social and psychological conditions, social workers also play a critical role in helping the medical team understand how to interact with you most effectively.

Connect: Living with PH can be isolating and overwhelming at times. It may feel as though no one really understands what you are experiencing or that you lack the resources to meet your needs. However, social workers are an excellent source for connecting you with other PH patients or caregivers and alternative supportive resources. Because of their work within the hospital system and the wider community, they are familiar with other individuals, support networks and community resources, such as PHA’s support communities, that may be helpful for you. A thriving support and educational community exists for PH patients and families — you just have to know where to look! Social workers can assess what your needs are and then make appropriate connections to those missing resources.

Empower: A patient or caregiver’s capacity to cope can be significantly diminished when confronted with a diagnosis of PH, a change in baseline function, or other life stressor. Social workers, through education, support and advocacy, provide a bridge for individuals back to stability and control. By helping you identify your own strengths and supports, they work with you to regain control of your life and improve your ability to cope.

Social workers can be your best ally in living (and thriving) with pulmonary hypertension. If your PH program doesn’t include a social worker, contact the social work department at your primary hospital and ask about resources. Better yet, request that your PH program add a social worker to the team and everyone will benefit!

By Heather Langlois, LICSW, C-SWHC, Children’s National Heart Institute, Children’s National Medical Center
PH Specialist Advocates for Improved Organ Allocation for PH Patients in Need of Transplant

Dr. Raymond Benza from the West Penn Allegheny Healthcare System in Pittsburgh, Penn., working with the United Network of Organ Sharing (UNOS), recently spearheaded an initiative to “even the playing field” for PH patients seeking lung transplants. This initiative, which was highly supported by the thoracic committee of UNOS, will dramatically improve the organ allocation for PH patients in need of transplant.

UNOS is responsible for helping to allocate organs to those who need them most through a carefully designed structure that makes the limited supply of transplant organs available to patients based on medical need and anticipated prognosis.

Dr. Benza and other PH specialists recognized a longstanding issue with Lung Allocation Scores (LAS) for PH patients in need of transplant. The LAS estimates the risk of death while waiting for a transplant and weighs it against the projected survival of any individual patient after transplant. Those who have the highest risk of death while waiting and the best possible survival post transplant get the highest LAS and, therefore, get transplanted first. The idea is that this will make the best use of scarce organs and will yield the highest transplant success.

However, the LAS significantly underestimates a PH patient’s risk of death, largely because the LAS was designed to predict death from “lung disease.” Although PH occurs in the lungs, PH patients die from heart failure, not lung disease. In many of these cases, patients in other disease states were being chosen for transplant before deserving PH patients because the criteria did not represent some of the crucial cardiac implications related to necessary transplant.

Dr. Benza and others recognized this inequality, and by using data from the 3,000+-patient REVEAL Registry, proposed alternative factors that could be incorporated into the LAS to account for significant cardiac dysfunction. He and other REVEAL investigators authored a paper about the topic and petitioned UNOS to consider their assessment. UNOS was extremely receptive and invited Dr. Benza and Dave Miller from REVEAL to present their findings to the thoracic council. The information was well-received and confirmatory analyses were ordered through the scientific registry for transplant recipients (SRTR).

Dr. Benza spent the next three years as a member of the thoracic board and, working with UNOS, confirmed these data. The resultant work is leading to important policy changes at UNOS. Importantly, it was confirmed that PH patients were at high risk for death while waiting for transplant. This confirmation allowed the subsequent confirmation of the importance of hemodynamic elements depicting right heart failure as an important marker for death. These elements will now be added to the LAS, if approved via public comment and the UNOS board of directors. This vote is expected to happen in March.

This change and recognition of how the LAS for PH patients should be evaluated differently is a huge victory for PH. Dr. Benza referred to it as “one of the proudest accomplishments of my career.” He echoed that “the dedication and openness of the Thoracic Advisory Board at UNOS was instrumental in allowing this to evolve. The system worked!”

By Micaela Cohen, PHA Director of Medical Services

To learn more about transplant, join PHA’s Transplant email group: www.PHAssociation.org/PHATransplantGroup

Get PH community updates delivered straight to your Inbox!

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

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.
Pulmonary Hypertension: Linkage to Blood Cell Abnormalities

Pulmonary arterial hypertension is associated with increased pressures in the arteries of the lungs and thickening of the blood vessels due to abnormal and excessive growth of the cells in the blood vessel wall. Interestingly, patients with pulmonary arterial hypertension are known to have a tendency to develop abnormalities in the blood-forming cells in the bone marrow (myeloid diseases). Likewise, some patients with bone marrow diseases, such as primary myelofibrosis and leukemia, develop pulmonary hypertension, and the treatment of the bone marrow disease is associated with regression of pulmonary hypertension.

Recent studies have shown that certain cells from the bone marrow capable of forming white blood cells, red blood cells or platelets known as progenitor cells are also important in the formation and growth of new blood vessels. A hallmark of pulmonary arterial hypertension is the appearance of growth on the pulmonary blood vessel walls known as plexiform lesions. The association of bone marrow diseases and pulmonary hypertension, as well as the role of bone marrow progenitor cells in blood vessel growth, has caused a great deal of thought regarding the link between blood cell abnormalities and pulmonary hypertension.

In our recent study, we wanted to further investigate the linkage between these two diseases. Patients with pulmonary hypertension (13 familial, 24 idiopathic and 15 associated) and 62 healthy volunteers were enrolled in the study. We obtained blood and bone marrow samples from patients with pulmonary hypertension and healthy volunteers to evaluate differences in the progenitor cells in the bone marrow and those circulating in the blood. Strikingly, we found increased numbers of progenitor cells in the bone marrow and in the circulation of pulmonary hypertension patients. The lung tissue from patients with pulmonary hypertension (obtained at the time of transplant) compared to normal lung tissue also showed increased numbers of progenitor cells. These findings suggested a potential link between the bone marrow and the lungs in pulmonary arterial hypertension patients.

We focused on these progenitor cells to better understand the link between the lungs and the bone marrow by identifying the factors that might be controlling these progenitor cells. We looked at molecules in the blood of patients that are known to control these blood cells. Some of these molecules are hypoxia-inducible factors, protein groups that decide the body’s response to low oxygen levels and help heal damaged tissue. We found elevated levels of certain types of these proteins, such as erythropoietin (helps other cells make red blood cells) and hepatocyte growth factor (assists cells to divide, grow and heal) in pulmonary hypertension patients.

When we looked at lung tissues from pulmonary hypertension patients, we found that the cells that line the inside of the blood vessels in the lungs produced increased levels of these factors, mainly hepatocyte growth factor and another factor, stromal cell derived factor alpha, which plays an important role in the formation of new vessels. Because these factors also regulate bone marrow progenitor cells, this suggests that there may be an abnormal signaling between the blood cells and lung blood vessel cells causing abnormal behavior.

Interestingly, there was some degree of myelofibrosis (internal scarring of the bone marrow) in all patients with pulmonary hypertension studied and in many of the healthy family members of patients with familial pulmonary hypertension. This suggests that the bone marrow abnormalities might be happening at the same time as the pulmonary hypertension and the bone marrow changes may be involved in the changes in the blood vessels of the lungs.

The findings have significance for development of new treatments, which might target the bone marrow disease in PH to block the changes that occur in the lung blood vessels. Further research will help provide a better understanding of the level of cross-influence between these two conditions in order to improve current treatments and potentially identify new treatment strategies and ultimately improve disease survival.

Research article: Hypoxia Inducible Factors in Human Pulmonary Arterial Hypertension: A Link to the Intrinsic Myeloid Abnormalities, Samar Farha, Kewal Asosingh, Weiling Xu, Jacqueline Sharp, Deepa George, Suzy Comhair, Margaret Park, W. H. Wilson Tang, James E. Loyd, Karl Theil, Raymond Tubbs, Eric Hsi, Alan Lichtin, Serpil C. Erzurum

By Samar Farha, MD, Pulmonologist, Cleveland Clinic, Cleveland, Ohio
An experienced special event coordinator will tell you that every successful special event requires lots of preparation, which is why working with the media may seem like a daunting task to add to an already miles long to-do list. However, working with reporters is a great way to multiply your special event’s impact. A story in a community newspaper or on the local news can bring your event to the attention of community members who are unfamiliar with pulmonary hypertension.

So what’s a busy special event coordinator to do? Why not designate a PHriend to help you with public relations for your event like Nicole Cooper did!

Nicole’s Vision of Hope Gala, which occurred on Nov. 12 in Baltimore, Md., took over a year to plan and was action-packed. The event featured several speakers, a fashion show, a raffle and a silent auction. Nicole wanted to reach out to reporters, but she was concerned about the amount of time she could devote to that effort. “I knew I wouldn’t be able to take on that responsibility in addition to everything else that was going on with the Gala, so giving someone the media responsibilities was critical,” she says.

Nicole relied on her PHriends Alex Flipse and Melanie Kozak to help her reach out to the media. Both were eager to help Nicole raise awareness and volunteered their time to send emails, make calls and follow up with reporters. “Nicole and I had spoken long before the preparations for the Gala began. I had offered to help anyway I could,” Alex says. “At that time, I was living in California, so there wasn’t much I could do to help Nicole aside from activities I could do online. That’s when she said it would be helpful if I got in touch with newspapers and television reporters.”

In the months leading up to the Gala, Melanie and Alex worked together to send the Gala press release to reporters all over the Baltimore area. Meanwhile, Nicole complemented their efforts by reaching out specifically to local TV news anchors to urge them to cover the Gala. “We asked most of the major newspapers in Baltimore and the surrounding cities to put information about the Gala on their online calendar of events. Everyone we asked agreed to post the information on their website!” says Alex.

“The key to any successful event is marketing. Working with the media to get your event in the news is important and it’s free! People I would never have been able to reach contacted me after the calendar post online,” Nicole explains. “I think those announcements got a lot of people who wouldn’t otherwise have attended to click on the Gala announcement and get more information about the disease and how to help the cause.”

The buzz created by the Vision of Hope team’s media and marketing plan paid off. The gala drew more than 200 attendees, many of whom were not fully aware of the impact PH has on an individual. Increasing public understanding of PH, one of Nicole’s main goals for the event, was accomplished through informative and emotionally impactful presentations by Dr. Myung Park (University of Maryland School of Medicine) and southern California PH advocate and former caregiver Betty Lou Wojciechowski. Presentations were complemented by fun and entertaining dance performances and a PH-themed fashion show. This balance of the light-hearted and serious left attendees already asking about the next Baltimore event! The Vision of Hope Gala raised more than $23,600 which will directly benefit pulmonary hypertension research.

For tips and resources to help you connect with the media in your community, contact Elisabeth, PHA’s Grassroots Campaigns Associate, by phone at 301-565-3004 x753 or email at ElisabethW@PHAssociation.org. Visit www.PHAssociation.org/PHAwareCampaign.

To learn more about all of November’s special events, turn to the special events section on pp. 33–36.

By Elisabeth Williams, PHA Grassroots Campaigns Associate
Winner of 2011 Tom Lantos Innovation in Community Service Award Inspired by Daughter

The Tom Lantos Innovation in Community Service Awards are named for the late Rep. Tom Lantos, a long-time advocate in the fight against PH. Lantos Awards are given to members of the PH community to help them implement innovative awareness-raising initiatives, grow PH community service programs or duplicate existing programs in another area. These awards are supported by Gilead Sciences.

I submitted an application for the 2011 Tom Lantos Innovation in Community Service Awards program to be able to make Kari Bags. My daughter, Andrea, and I had come up with the idea for Kari Bags in honor and memory of my youngest daughter, Kari Beth Lain (9/9/1982 – 5/27/2003). Kari had PH secondary to lupus.

The primary goal of Kari Bags is to provide an outlet for children diagnosed with pulmonary hypertension. The bags provide educational material about PH and are filled with age-appropriate toys, games and stress reliever items. The idea was that Kari Bags would allow kids to have stuff to play with when they are required to be in the hospital for procedures and tests or admitted for infections or line problems.

When Andrea and I were notified that we had received a grant to make the bags, we started working with an artist to design the outside of the bag. PHA sent information about its programs for us to put in the bags. We decided on three age groups: ages 3 to 6, ages 7 to 11, and ages 12 and up. We had the bags printed, and through extensive research and searching through catalogues, along with Andrea’s knowledge from her work with summer day camps and after school programs, we were able to include 10 items in each bag for each age group.

It was a very exciting day when we invited family and friends to come together with us to fill 750 bags, 250 for each age group. Everyone was very enthusiastic and thought it was a great legacy and a fun way to honor Kari’s memory.

Then we started marketing the bags so we could get them into the hands of children with PH. We sent a letter to the clinic coordinator for each PH center and to the support group leaders for the pediatric support groups. The bags were also featured at the PH Professional Network Symposium at the end of September. To date, we have received orders from five PH centers and have shipped out 150 bags. We are very grateful to have been given this award and hope to fill more orders very soon.

I am very thrilled to have been able to put together the Kari Bags. We would not have been able to carry out this idea without the 2011 Tom Lantos Innovation in Community Service Awards program. It is very exciting to be able to provide these bags to pediatric patients in Kari’s memory. Kari was very passionate about hospitals and care, and I believe she would be pleased that because of this project, kids are getting some joy and fun while undergoing medical procedures. To be able to see the Kari Bags filled and shipped is priceless to me and a wonderful legacy to such a special person.

By Donna Lain
Creator of Kari Bags
First PH Patient Meeting in Norway Takes Place

In September 2011, the Norwegian PH organization ran its first patient meeting which brought together 14 PH patients and eight caregivers. “It was great to meet some of the other PH patients,” one of the participants expressed. “I have had PH for many years, and I have never met another person with the same disease. It is wonderful to meet and talk to other people that understand me and my situation!”

The Norwegian PH Association developed a comprehensive two-day program with several prominent speakers. However, the greatest benefit of the conference was the opportunity to meet with other PH patients and caregivers. Valuable friendships were formed and lots of information was exchanged.

A leading Norwegian PH specialist gave a presentation about the disease and the treatments available in Norway. Patients in Norway are fortunate that they do not have any restrictions as to which medications are available. Moreover, the medications are free of charge due to the centralized public healthcare system. One method of PH treatment that received particular attention was the implanted pump. One of the attendees had this pump installed and demonstrated it in front of the group. The implanted pump is working very well for this patient, and it has enabled her to continue her work as a full-time nurse at a clinic for people with lung and heart diseases.

In addition to the lecture by the PH specialist, leaders of a rehabilitation clinic discussed their rehabilitation program. Although patients with other heart and lung diseases primarily attend the program, they also have experience in helping PH patients. In spring 2012, they will run a rehabilitation program consisting only of PH patients.

Other presentations included the psychological challenges of living with a chronic illness, a patient’s private survival guide, PH medications of today and the future, and resources for newly diagnosed patients and their caregivers.

Another goal for this first patient meeting was to increase awareness of PH since it is estimated that there are many people living with the disease in Norway who have not been diagnosed. Current media successes have included an article about PH that was featured in a local newspaper which has 36,000 subscribers. The leader of the Norwegian organization and the leading PH specialist were also recently interviewed in a radio program that was aired nationwide.

The patient meeting was a great success and will be repeated next year. The meeting was made possible through a contribution from Actelion Pharmaceuticals US, Inc. and a Tom Lantos Innovation in Community Service Award supported by Gilead Sciences.

By Hall Skåra
PH Patient and Founder of the Norwegian PH organization

Welcome, Mollie Katz, Vice President, Community Engagement!

As Vice President, Community Engagement, Mollie’s role is to more closely tie together three departments which all address aspects of PHA’s grassroots and public communication — Web Services, Advocacy and Awareness, and Volunteer Services — to enhance the way PHA engages patients and caregivers, as well as medical professionals, in the volunteer spirit upon which the organization was born and built. Mollie also helps these departments strengthen PHA’s impact in reaching key audiences with effective messages about PH and the needs of the PH community. Mollie can be reached at 301-565-3004 x774 or MollieK@PHAssociation.org.
International Highlights: What’s Going on Around the World?

With more than 55 PH associations worldwide, there have been some exciting developments in the global PH community. These highlights are a testament to the hard work of PH community members everywhere!

• **In Canada…** PHA Canada has begun a nationwide “BLuES” campaign for PH awareness, which stands for Bluish hands, feet and lips; Lightheadedness; Unable to breathe; Edema; and Syncope. The campaign started in four cities in Canada and ended with a visit to Parliament Hill, Ontario. On Sept. 16-18, 2011, PHA Canada held the second National PHA Canada Pulmonary Hypertension Conference. Read more on p. 40.

• **In the Dominican Republic…** The first PH patient support group was founded in the Dominican Republic with the help and support of the Universidad Católica Santo Domingo.

• **In Europe…** PHA Europe held its Annual General Meeting in Castelldefels, Spain, from Sept. 8–11, 2011. The meeting brought together 46 patient leaders and representatives from 22 countries. PHA Europe also launched its “Time Matters” campaign in an effort to increase global awareness of the disease and reduce the delay in PH diagnosis for many patients. Visit the website to learn more and share your story: www.phtimematters.org

• **In Latin America…** The Sociedad Latina de Hipertensión Pulmonar (SLHP) celebrated the first “Latin Day of PH” on Nov. 28, 2011, which focused on PH awareness and education for the Spanish-speaking PH community.

• **In Panama…** The new PH patient association, la Fundación de Pacientes con Hipertensión Pulmonar de Panamá, recently held its first patient meeting.

• **In Uruguay…** The Grupo de Apoyo para Pacientes con Hipertensión Pulmonar en Uruguay is the first PH patient support group to form in Uruguay. This group will bring much-needed support to patients in this country.

• **In South Africa…** In August 2011, PHA South Africa (PHSA) received an International Seed Grant award from PHA to promote awareness of PH and develop brochures and resources for PH patients in South Africa. PHSA used part of its award to host an educational event for medical professionals on Nov. 12, 2011.

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

*By Meghan Tammaro*
*PHA International Services Manager*

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**It’s Not Too Late!**

Even though 2012 has begun, it’s not too late to make your impact on PHA’s “End of Year” appeal. Your gift will help us realize the full $25,000 matching gift challenge from Actelion Pharmaceuticals and will ensure that PHA is able to continue serving our community through support, education, advocacy, awareness and so much more.

Make your gift today at www.PHAssociation.org/E0Y2011

If you’ve already given, please accept our gratitude and know that your gift is working hard to make life better for the entire PH family.
Insurance Finds: Tips for Applying for Social Security Disability (SSD)

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

- A patient starter-kit with successful PH-based SSD applications to reference;
- An inside look at how the SSA views PH, including an educational video;
- A detailed outline of the disability process;
- An Ask-an-Expert tool to get personalized answers to your SSD questions.

www.PHAssociation.org/Patients/Insurance/Disability

Experiential Learning Opportunities at PHA!

Are you — or someone you know — looking to enhance your academic experience beyond classroom walls for the spring semester or summer?

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

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

Be part of the team that is changing the future of this disease: Apply for a PHA internship!

In 2006, Martha Gonzalez heard news that changed her life. She responded by changing the lives of 30,000 others.

Two days after Martha’s son Daniel Torres was born in 2005, he underwent open heart surgery to repair a life-threatening defect. Just six months later, he was diagnosed with a rare liver disease, and ultimately received a liver transplant. Then—just when Martha let herself believe they could start getting back to normal—came the most devastating news of all.

To read how Martha and her family responded to his PH diagnosis, please visit PHAssociation.org/Give/TorresGonzalez

Like the Torres-Gonzales family, 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, x756 or email Giving@PHAssociation.org. Visit our website for more information at PHAssociation.org/Give.
PH Community Proclaims November ‘PH Awareness Month’

States, cities, counties and local governments are much more aware of pulmonary hypertension thanks to proclamation requests from veteran advocates and Awareness Month first-timers.

Requests for local governments to recognize November as PH Awareness Month got a boost this year thanks to Doug Taylor’s proclamation challenge. Doug created a Facebook page and asked everyone in the PH community to request proclamations. The PH community responded in a big way! As we go to press, PHers have been presented with 44 proclamations. That is already 14 more than the PH community received in 2010!

Michelle Holden is one advocate who accepted the challenge and ran with it. She received seven proclamations from city councils throughout Florida. Joan Stevenson, who worked with her Lehigh Poconos PH Support Group in Pennsylvania to get four proclamations, said afterwards, “This is the most we have reached out in any year!”

Congratulations to everyone who received a proclamation from their city, county or state recognizing PH Awareness Month! Did you receive a proclamation for Awareness Month? Share your success with PHA by contacting Elisabeth, PHA’s Grassroots Campaigns Associate, at ElisabethW@PHAssociation.org or 301-565-3004 x753.

State & Local Proclamations (alphabetical by state):

State of Arizona
State of California
Diamond Bar, Calif.
Fresno, Calif.
Cocoa, Fla.
Jacksonville, Fla.
Melbourne, Fla.
Miami, Fla.
Orlando, Fla.
Palm Bay, Fla.
Vero Beach, Fla.
Council Bluffs, Iowa
State of Maryland
Montgomery County, Md.
Takoma Park, Md.
State of Minnesota
State of Nebraska
Bellevue, Nebr.
Omaha, Nebr.
Papillion, Nebr.
State of New Jersey
Clifton, N.J.
Passaic County, N.J.
Secaucus, N.J.
Thomasville, N.C.
State of Pennsylvania
Allentown, Penn.
Lehigh County, Penn.
Northampton County, Penn.
Pike County, Penn.
State of South Carolina
Easley, S.C.
Greenville, S.C.
Spartenburg, S.C.
Spartenburg County, S.C.
State of Tennessee
Bartlett, Tenn.
Memphis, Tenn.
Shelby County, Tenn.
State of Texas
Corpus Christi, Texas

Congressional Proclamations and Citations:
Congresswoman Ann Marie Buerkle (N.Y.)
Congressman Charles Dent (Penn.)
State Sen. John A. DeFrancisco (N.Y.) (citation)
I found out that I am one of only a few 30-plus-year survivors of PH … I have been to the very rock bottom with this disease and I know the despair, sorrow and destruction associated with everything patients deal with trying to live with PH. I have been fortunate enough to know the other side as well, the side that gives hope to continue the battle against PH.

~ Jeannette Morrill shared her story at PHA’s Congressional Luncheon

Each November, PHA hosts a luncheon in Washington, D.C., that brings PH patients, their families and their medical professionals together with Members of Congress and legislative staff. The goal: to help our elected officials understand pulmonary hypertension and keep the PH community in mind when they make policy decisions.

PHers from across the country worked to make this year’s event a success by participating directly or inviting their Members of Congress to attend. Thanks to your calls and emails, nearly 100 people, representing more than 25 congressional offices, attended the luncheon.

Powerful presentations from PH patient Jeannette Morrill, PH-treating physician Dr. John Berger, Congresswoman Lois Capps, Congressman Kevin Brady and Sara Mabry from Sen. Bob Casey’s office, inspired many in the audience to get involved in the fight against PH. After lunch, PH community members reinforced the message by visiting their representatives’ offices. Within a week, four congressional offices had contacted PHA to let us know that they plan to co-sponsor the Tom Lantos PH Research and Education Act.

Keep Up the Momentum!

Members of Congress and staff from these legislative offices participated in PHA’s Congressional Luncheon and Advocacy Day. If your senators and representative are on the list, thank them. If they’re not, follow up and let them know you’re sorry they couldn’t attend. Either way, ask them to co-sponsor the Tom Lantos PH Research and Education Act.

For more information or to find out if your Member of Congress has already become a co-sponsor, contact Elisabeth, PHA’s Grassroots Campaigns Associate, at 301-565-3004 x753 or ElisabethW@PHAssociation.org

Keep Up the Momentum!

- Rick Crawford (AR)
- Lois Capps (CA)*
- Richard Blumenthal (CT)
- Joe Courtney (CT)
- Jim Himes (CT)
- John B. Larson (CT)
- Joe Lieberman (CT)
- Christopher Murphy (CT)
- Eleanor Holmes Norton (DC)
- John Carney, Jr. (DE)
- Corrine Brown (FL)
- C.W. Bill Young (FL)
- John Lewis (GA)
- Hank Johnson (GA)
- Daniel Inouye (HI)
- Dave Loebshack (IA)
- Jesse Jackson Jr. (IL)
- John Sarbanes (MD)*
- Todd Platts (MD)
- Elijah Cummings (MD)
- Michael Michaud (ME)
- Charles Rangel (NY)
- Gregory Meeks (NY)
- Louise Slaughter (NY)
- Nita Lowey (NY)
- Bob Casey (PA)*
- Joe Pitts (PA)
- Todd Platts (PA)
- Richard Burr (SC)
- Mick Mulvaney (SC)
- Joe Wilson (SC)
- Kevin Brady (TX)*
- Sheila Jackson Lee (TX)
- Gerald Connolly (VA)
- Randy Forbes (VA)
- Jay Inslee (WA)
- Nick Rahall II (WV)

*Current bill co-sponsor

Offices Represented at the Luncheon or Visited During Advocacy Day

By Katie Kroner, Director of Advocacy and Awareness

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Jeannette Morrill’s Congressman, Mike Michaud (D-ME), agreed to co-sponsor the Tom Lantos PH Research and Education Act after Jeannette and her lobby group met with him during PHA’s Congressional Luncheon and Advocacy Day.
Support Groups

The PHA Support Group “Scoop”

When you think of a “Support Group,” do you ever think “laughter yoga” or “game night”? Well, that’s what we’ve got! We’re not trying to brag or anything, but PHA’s support groups are AWESOME! Don’t believe us? Check out what some of our more than 235 support groups have been up to this fall.

1. What the heck is “therapeutic laughter yoga”? The dozens of patients and members of the Minn-la-Kota PH support group in Sioux Falls, S.D., weren’t sure, but they left the meeting with tears of laughter running down their faces! The support group leader, Jan Howd, looked up “yoga” in the Yellow Pages and found this particular type of yoga intriguing. A couple of phone calls later she found someone to give a free talk and demonstration to the group!

2. What would it be like to have had PH in the 1980s? PHA founding member Dorothy Olson knows that firsthand. She shared her story of courage, hope and success as a long-term survivor (diagnosed 1978) with the Tampa Bay Area group.

3. November is not only PH Awareness Month, but it is also Caregiver Appreciation Month.
   - The UPHS Penn Presbyterian, East Central Florida and DC Capital Breathers PH support groups celebrated their caregivers by offering resources, information and recognition for their dedication.
   - The Puyallup, Wash., group had a twist on thanking caregivers: they thanked their patient leader for all of her support. Charlotte McCabe cares for her group as if it were her own family. Co-leader Ric Franzen presented her with a certificate of appreciation and a gift on behalf of the group!

4. Want more time with your PH specialist or medical professional? Many of them take time to provide medical education at support group meetings.
   - The Southwest Virginia group brought Dr. Steven Nathan to discuss transplant and PH.
   - The Tri-State PH group in Cincinnati brought Peter Engel, MD, FACC, to discuss right-heart catheterization.
   - The Charleston, W.V., group featured the clinical director of the PH Clinic at Mayo, Dr. Robert Frantz, who discussed “Long-term PAH Management.”
   - The PH support group of Piedmont, N.C., tackled PH and over-the-counter drugs.

5. Not only can you find medical information and support, PHA’s support groups also provide practical resources and education on issues like insurance and government disability benefits.
   - The Orlando and Brevard County groups brought representatives of SHINE (Sharing Health Insurance Needs of the Elderly) from their state’s Department of Elder Affairs.
   - The Lehigh, Penn., group invited a public affairs specialist to talk about Social Security Disability.
   - The South Carolina Midlands group revealed the “mysteries” of Medicare open enrollment and medical insurance.
   - The group in Sarasota featured a Caring Voice Coalition leader speaking about financial assistance and insurance.

6. Our groups often meet for fun and support!
   - Central Florida, Oklahoma City and New Hampshire PH groups organized luncheons.
   - New Haven and Syracuse groups held “Meet and Greets” for members to get to know each other.
   - Treasure Valley, Idaho and Inland Empire Southern California groups were among the many groups to organize potlucks where patients could showcase their recipes and culinary talents.
   - The Salt Lake City support group had an ice cream social while learning more about advocacy and the Tom Lantos PH Research and Education Act.
   - The York, Penn., group hosted a game night.
   - Several groups hosted first meetings, including the Richland, Ore., and New York Grupo en Español.

7. Even if you’ve had PH for awhile, there are always new things to learn and ways to improve your life.
   - The Niagara Falls group tackled tips for coping with a chronic illness.
   - The North Central Florida group hosted a respiratory nurse to discuss traveling with oxygen.
   - The Santa Barbara group brought in local PH authors from the community.
   - Exercise physiologists and other experts spoke at both the Michigan Metro Detroit and Puyallup group meetings.
Check Out What Support Groups Across the Country Are Doing

The Valley of the Sun PH Support Group in Phoenix, Ariz., held a 2011 Holiday Hoe Down at Rustler’s Rooste, a local restaurant in Phoenix. Forty-three attendees enjoyed a western-style cowpoke cookout and a live country western band.

“"We have some new patients crying for answers. We talk a lot, answer questions, share feelings, laugh, eat … My PH doctor stepped in too and answered questions … and at the end of the day, there is more happiness and that is priceless.”

~ Mineliz Colon, Puerto Rico Support Group

On a warm day at the end of August, the Leigh-Poconos Support Group brought patients and supporters together for a fundraiser and outdoor entertainment at a baseball game in Allentown, Penn. Support Group Leader Joan Stevenson is pictured waving at the camera.

Every year the Sacramento PH Support Group hosts a picnic event. “We ate very well — a catered BBQ. We had a huge raffle and the weather was perfect. It had been in the 90s but cooled off for our picnic to the mid 80s,” says Support Group Co-Leader Marilyn Clements.

Talk about LOVE! The Dallas Support Group took this picture to wish Kim Ford, the support group leader of the D.C. and Silver Spring Capital Breathers, a happy birthday. Kim founded the PH Family Facebook group, a special group for patients to connect with one another regardless of where they live.

Corpus Christi, Texas, Support Group Leader Michael Rivera (pictured left) worked hard to have his city issue a proclamation officially recognizing November as Pulmonary Hypertension Awareness Month.
**Support Groups**

**Why Not? PHA Leaders Dispels Support Group Myths**

Do you think support group meetings are not for you? Think again! Some patients who are new to living with pulmonary hypertension are hesitant to come to meetings because of fear and confusion. Others may have trouble making it to nearby meetings. Read on as support group leaders and PHA staff members dispel some of the misconceptions that may keep you away from meetings. Find out what you can do to make meetings better for you! To find a support group, visit [www.PHAssociation.org/LocalSupportGroups](http://www.PHAssociation.org/LocalSupportGroups).

"I am scared, to be honest. I'm scared to see someone with the same disease as me but much worse off."

**A Support Group Leader Responds:**

"We are all scared but knowledge calms the scare. It gives you power over the disease when you learn."

~ Stuart Benwick, Dallas, Texas, PH Support Group Leader

**PHA Says:**

"Not to speak in cliché, but knowledge truly is power. The more you know, the easier it is to fight your disease. In addition to attending a support group, you can also email a mentor with a question. Visit [www.PHAssociation.org/Mentors](http://www.PHAssociation.org/Mentors)."

~ Chanda Causer, PHA’s Patient Outreach and Services Manager

"There is no support group around where I live. What should I do?"

**A Support Group Leader Responds:**

“I lived where there was no support group. So I started a group. That’s right! I started a group and found others who wanted and needed to meet as well.”

~ Mack McCarthy, Valley of the Sun PH Support Group Leader, Phoenix, Ariz.

**PHA Says:**

“Consider becoming a support group leader, or even just being listed as a point of contact in your area. Contact SupportGroups@PHAssociation.org for more information. Not ready to lead a group, but still looking for support? Learn more about our telephone support groups at [www.PHAssociation.org/TelephoneSupport](http://www.PHAssociation.org/TelephoneSupport).”

~ Debbie Castro, PHA’s Director of Volunteer Services

“I have not been able to get around like I used to. I stay in touch with people I have connected with by email and telephone. Isn’t that enough?"

**A Support Group Leader Responds:**

 “[Online chat] is indeed awesome, but it lacks something that support groups give, and that is seeing a smile, holding someone who is confused and scared, having someone give me a hug.”

~ Joy Gore, Bullhead City, Ariz., Support Group Leader

**PHA Says:**

“If it’s hard to get around due to your health, consider attending your meeting every once in a while. It can boost your spirits to see those in your group even if you can’t make it regularly. Is transportation the issue? Contact your support group leader and see if they can help you find someone to carpool with.”

~ Sophie Klein, PHA’s Volunteer Services Associate
Rochester PH Gala: 10 Years Raising PH Awareness, Funds and Fun!

The Rochester PH Gala was first held in 2001. The inspiration for its initiation can be traced back to the PHA International PH Conference in Chicago in 2000. At that Conference, a real sense emerged that we had seen genuine progress in the treatment of PH and yet there remained much to be done.

We (nurses, physicians and non-medical spouses) returned to Rochester, Minn., thinking there was a vibrant atmosphere of accomplishment, hope and need. Informal discussions led to the idea of a gala to spark community awareness and (we hoped) generosity. Before we knew it, plans solidified for a formal dinner and dance with a lottery (for a classic Corvette donated by a generous patient) and a silent auction.

The first gala was a wonderful success and it initiated a series of biennial events which have continued to evolve. Each subsequent gala has capitalized on the successful aspects of the galas that came before. We went from a formal affair to themed events, such as recreating an atmosphere of the 1940s, and fun entertainment, like magic shows and karaoke contests. The lottery of motor vehicles continues, and we’ve had raffles of jewelry from a local business. Our auctions include items such as private airplane excursions piloted by Carl Hicks, former chair of PHA’s Board of Trustees.

Through the gala, we realized that pulmonary hypertension was becoming a well-recognized cause behind which the community could rally — awareness was palpably increased with each passing year. In order to focus on this aspect, we recruited the participation of the editor of Rochester Magazine, Steve Lange, as our honorary chairman in 2009. He generously publicized the events in 2009 and 2011.

The gala has fostered awareness and contributed resources to the mission of PHA, and it has become a communal activity where medical professionals, patients, medical companies and community members all make essential contributions. The challenge now is to continue to live up to the high expectations that have been established — a challenge that we look forward to meeting at each succeeding event.

By Michael McGoon, MD, and Bonnie McGoon, Organizers of the Rochester PH Gala

Race Against PH Raises Awareness, Kicks Off Six-Minute Marathon

On Sunday, Nov. 6, 2011, nearly 1,200 walkers and runners, plus hundreds of volunteers, joined together to participate in the 11th Annual Race Against PH on the Stanford University Campus in Palo Alto, Calif. This event served as an important way to raise PH awareness on the West Coast, and this year, PHA partnered with the Race Against PH to debut our newest awareness-raising campaign, the Six-Minute Marathon (6MM).

Based on the six-minute walk test, a common metric used to evaluate the well-being of PH patients, the 6MM acts as an easy-to-understand activity to raise public awareness of PH. By running or walking the Race Against PH course, each race participant also completed his or her own timed 6MM within the longer 5K route. The Race Against PH organizers opted to make their 6MM 400 meters in length, one possible distance that a PH patient might cover during a six-minute walk test.

After the race, participants visited PHA’s tent to receive a commemorative 6MM T-shirt (supported by Actelion Pharmaceuticals US, Inc.) and race certificate, and to stock up on PH awareness materials. Patient and caregiver volunteers at PHA’s tent generously gave their time in order to educate others about what it is like to be affected by PH.

Thanks to the Race Against PH, PHA was able to launch our newest national campaign on the right foot! In 2012, let’s grow the 6MM — these simple events can be hosted coast-to-coast in a variety of settings such as schools, hospital grounds, community centers and local outdoor tracks. You can even incorporate a 6MM into an existing special event, like Race Against PH did. For more information about creating a 6MM event, visit www.PHAassociation.org/6MM.
Awareness Month Special Events Make November Event-ful

PH Awareness month was truly event-ful with 14 special events taking place across the country this past November. Fun walks, 5Ks, galas, pubcrawls, dinners, brunches, chili and Zumba drew crowds together in a joint effort to fight back against this underdiagnosed illness.

**Event:** 5th Annual North Texas Fun Walk  
**Location:** Grand Prairie, Texas  
**Attendance:** Approximately 125 adults and 20 children  
**Guest Speakers:** Dr. Kelly Chin (UT Southwestern) and Debbie Castro (PHA’s Director of Volunteer Services)  
**Fun Fact:** This year’s walk included a 5k fun run in addition to the traditional one-mile walk.

**Event:** 2nd Annual J. Patrick Garcia Breathe Easy 2011  
**Location:** Albuquerque, N.M.  
**Attendance:** Approximately 120 participants  
**Guest Speakers:** Members of the Garcia family  
**Fun Fact:** Event organizer, Jason Garcia, successfully used local sports media outlets to promote the event and raise PH awareness, including an hourlong interview on the “Steve Davis Show” on the ProView Networks.

**Event:** Vision of Hope Gala  
**Location:** Baltimore, Md.  
**Attendance:** Approximately 200 people  
**Guest Speakers:** Dr. Myung Park (University of Md.), Betty Lou Wojciechowski (former PHA Board Member), Regina O’Neal (PH patient), Vern Gore (PH caregiver) and Nicole Cooper (PH patient and event organizer)  
**Fun Fact:** Aside from the inspirational guest speakers, attendees were treated to a fashion show and dance performances by the “Waxter Dancers” (pictured above).

**Event:** “Sarah Smiles” Inaugural Fun Walk for PH  
**Location:** Camillus, N.Y.  
**Attendance:** More than 130 people  
**Guest Speakers:** Michelle and David Peek, Sarah’s parents and the walk’s organizers. Sarah lost her battle with PH in 2010. *Read Sarah’s story as told by her parents on p. 11 of this issue of Pathlight.*  
**Fun Fact:** The walk received both a citation from New York State Senator John DeFrancisco and a proclamation from U.S. Congresswoman Ann Marie Buerkle recognizing November as Pulmonary Hypertension Awareness Month!
Spring into Special Events

By the time you read this, PH Awareness Month in November will have wrapped up, and PHA’s 10th International PH Conference and Scientific Sessions in Orlando, Fla., will be just a few short months away. The coldest winter months are here, and while we do our best to stay warm and cope with day-to-day living with PH, planning a spring special event is one great way to keep the awareness-raising momentum alive and to demonstrate why the PH cause is personally important to those around you.

Last spring, PHA had a record-breaking spring events season (April/May/June) with 16 fundraising events. Not only did these events take place from coast to coast, but they were unusually diverse in the types of events held and the volunteers who hosted them! Parents hosted community PH fun walks honoring their children, a newly diagnosed patient had a bunco tournament to celebrate life, and a new PH advocate coordinated art and performance reflective of her sister’s legacy — to highlight just a few. What’s more is that eight of those 16 successful events were hosted by first-time event organizers! Our goal is to be your biggest cheerleader as you create and plan a PHA special event, everything from choosing the date to coaching you on how to get participants to come to your event and everything in between.

Because planning a special event takes people power, fundraising power and, most of all, plenty of time — winter is the best time to “spring” into action. Let’s add many new events to the spring calendar in an effort to bring us all one event closer to a cure!

Here’s some added encouragement and inspiration from a few of our spring 2011 first-time special event organizers:

**Amy Piazza**

Amy blazed trails by hosting PHA’s first bunco tournament in Florida last June. Bunco is an easy-to-learn (and supposedly addictive!) dice game. “The event was marking a milestone for me. I made it through my first year with PH with a smile on my face. It hasn’t been the easiest year, but I am doing very well and I am extremely grateful for that. It is important to me to spread the word about PH and to raise money for PHA. No other organization does so much and offers so much hope to the PH community,” Amy says.

**Bernie Gore**

Bernie hosted a California walk last June, honoring her father’s memory. “The outpouring of love, generosity and encouragement that surrounded me — from embarking on the early planning stages to event completion — was profound,” Bernie says. “Our event made a difference in the lives of patients suffering from PH along with their caregivers, and with each step we take, we get closer to finding a cure for this devastating disease. It’s really beautiful that as my father battled every day … through losing his fight he has given life and breath to a movement much larger than us all.”

The success of Bernie’s spring fundraiser led to an additional event in December 2011. Eighth-grade students, led by their teacher, Mrs. Sue Sweetman, of St. Dorothy School in Glendora, Calif., honored the memory of Bernie’s father, through a Christmas tree and wreath sale to raise funds to find a cure for PH (pictured below).

**Alice Matiz**

Alice, inspired by her sister Maritza’s talent and legacy, planned an art expo in New Jersey last June with enthusiasm. “I can’t bring her back, but I can help other people who might be suffering from this disease … I feel very blessed. I’m so moved at the willingness of others to help.” Alice Matiz (quote courtesy of *My Latino Voice*, “Pulmonary Hypertension and Celebrating a Sister’s Love,” by Robert Waddell, June 2011). One of the artwork pieces from the show is featured to the right.

To learn more about PHA’s Special Events program, contact Events@PHAssociation.org, call 301-565-3004 x765 or visit www.PHAssociation.org/SpecialEvents
**January 2012 — Happy New Year!**
What better way to kick off 2012 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 at Events@PHAssociation.org

**February 2012 — Attention Spring Event Organizers!**
Time to finalize your event date/time/location and begin securing sponsors! MORE INFORMATION: [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook)

**Saturday, Feb. 18, 2012**
Strut Your Stuff Against PH
WHERE: Wilkes-Barre, Penn.
CONTACT: Lisa Granahan at clgran@ptd.net or Katie Tobias at kaytee.tobias@gmail.com

**March 2012 — Event-ful Times!**
Look for the first Special Events e-newsletter of 2012 in your inbox. Make sure you’re on the list! CONTACT: Leslie Mahaney at Eventful@PHAssociation.org

**March 2012 — Attention Spring Event Organizers!**
Get the word out about your fundraiser and begin your media outreach! MORE INFORMATION: [www.PHAssociation.org/SpecialEvents/Publicize](http://www.PHAssociation.org/SpecialEvents/Publicize)

**Saturday, March 24, 2012**
The Woodlands CrawPhish Festival
WHERE: The Woodlands, Texas
CONTACT: Matacha Saul at 281-367-2222 or msaul@stibbsco.com

**Saturday, March 31, 2012**
San Antonio PHun Walk 4 Hope
WHERE: San Antonio, Texas
CONTACT: Sarah Rios at hanna84.sr@gmail.com or 210-548-6174

**Thursday, April 19, 2012 — A free PHA Classroom webinar!**
*Peer to Peer Fundraising: Using Your Personal Networks to Increase Attendance and Funds for Your Event*
REGISTER: [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)
QUESTIONS: Jessica McKearin at Events@PHAssociation.org

**Saturday, April 28, 2012**
4th Annual Scramble for a Cure
WHERE: Las Vegas, Nev.
CONTACT: Jack Nino at Jack.Nino@igt.com or 702-250-2214

**Saturday, April 28, 2012**
N.C. Cure PH Golf Tournament
WHERE: Mocksville, N.C.
CONTACT: Cindy Pickles at 336-978-1668 or cpickles50@gmail.com

**Saturday, April 28, 2012**
2nd Annual Walk 2 Cure PH:
Ellie Godina Memorial 5K Walk/Run
WHERE: Euclid, Ohio
CONTACT: Melissa Godina at 216-261-0334 or melissagodina@sbcglobal.net

**May 2012 — Attention Spring Event Organizers!**
Your big day is almost here! Confirm last-minute details and coordinate day-of volunteers and tasks. Thank you for your efforts and have a fun and successful event! MORE INFORMATION: [www.PHAssociation.org/SpecialEvents/EventVolunteers](http://www.PHAssociation.org/SpecialEvents/EventVolunteers)

**Sunday, May 6, 2012**
Chicago Fun Walk for PH
WHERE: Chicago, Ill.
CONTACT: Heather Scherzer at heatherscherzer@yahoo.com

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**Signature Special Event Gets a New Look!**
Check out our new “Funwalk for a Cure” logo, chosen by you, the PH community! The new logo reflects the growth in popularity of PH fun walks, fun runs and even community 5Ks in recent years. For more “Funwalk for a Cure” information, including a free how-to kit, contact Events@PHAssociation.org or 301-565-3004 x765. Or scan the QR code with your smartphone.
Conference, and they are remarkable. Rumor has it that the original kitchen table, around which the initial ideas for the Pulmonary Hypertension Association were generated, will actually be at the 2012 Conference!

I’m so excited to be part of this historic gathering! I’m excited to meet those of you who have not been to Conference before and to reconnect with those of you I have met at various meetings and Conferences over the years. I can hardly wait to set foot in the lobby on the opening day of Conference. I know it will be buzzing with bundles of warm, excited energy, lots of hugs and all sorts of folks helping each other find their way around.

My Story

Just after my diagnosis was confirmed in 2004, one of the nurses on my healthcare team suggested I attend the International PH Conference taking place in Miami in two weeks. I thought this nurse was crazy! I remember thinking, “Why would poor ol’ sick me want to travel so far to attend some boring Conference?” Of course, I didn’t go in 2004 (my loss), but in 2006 I was asked by this same nurse to be a volunteer for the Conference in Minneapolis. I lived in Wisconsin at that time and Conference was going to take place right there in my backyard, so I decided to attend. What an amazing experience!

At the 2006 Conference, I found myself surrounded by hundreds of other PH patients and healthcare professionals from around the world who are associated with PH research and treatment. I loved Conference. I loved getting to know other patients from all over the world. I loved hearing about everything that was new and what was on the horizon in the field of PH. I loved joining with other patients in Support Groups and Patient/Family Led Sessions. I loved visiting the exhibit booths, trying out new devices and gathering PH-related product information. I loved the meals and talks that took place with the larger community, and I especially loved the Fashion Show that highlighted the many ways patients with intravenous medications could dress up or dress down! I learned that I was NOT alone anymore. There was an entire community dedicated to the fight against this illness. I have attended every International PH Conference since my first amazing Conference in Minneapolis.

My adult daughter had the opportunity to attend the 2010 Conference with me. She came away amazed at what she didn’t know about PH and the new treatments on the horizon. On our way home she asked if she could come with me to the 2012 Conference. Now, that speaks volumes about the power of the International PH Conference.

The Power of One. Come to PHA’s 10th International PH Conference and Scientific Sessions and learn all the beautiful ways in which each and every one of us has the power within to inspire those around us, just as those four women did around the kitchen table in 1990. I hope to see you June 22–24, 2012, at the Renaissance Orlando at SeaWorld® in Florida.

By Liz Brigham, PH Patient

10th International PH Conference Scholarship Program

Scholarships are designed to help patients who, without financial support, would not have the opportunity to benefit from all that Conference has to offer. Applications for patients in need are available online by visiting www.PHAssociation.org/Conference/Scholarships. To request a paper application, please call 301-565-3004 x764 or email Scholarships@PHAssociation.org.

You are eligible to apply for a Conference Scholarship if:

• You are a PH patient or caregiver to a child PH patient.
• You are a PHA member.
• You did not attend the 2010 Conference on a full scholarship.
• You are currently a support group leader and/or Support Line volunteer. (You are eligible even if you attended the 2010 Conference on a full scholarship.)
• You are a confirmed speaker or panel discussion leader at the 2012 Conference. (You are eligible even if you attended the 2010 Conference on a full scholarship.)

Questions regarding Conference Scholarships can be directed to Carsten Hailey at 301-565-3004 x764 or Scholarships@PHAssociation.org.

PHA thanks the generous supporters of the Patient Scholarship Fund. To see a list of supporters, please visit www.PHAssociation.org/Conference/Scholarships/Contributors. To donate to the Patient Scholarship Fund, please visit www.PHAssociation.org/Conference/Scholarships/Donate.

Availability of scholarships is dependent on funds raised solely for this purpose. The Conference Scholarship Committee regrets that it may not be able to fund all worthy requests.
Did you know?... Conference History Highlights

Over the years, PHA’s International PH Conference has grown significantly in all areas from the number of registrants to the amount of educational sessions we provide for our attendees. Each Conference marks a special time in the lives of our attendees and provides the education and networking opportunities they value so highly. Take a look back at some of the highlights of Conferences past. Be a part of history!

1st International PH Conference (1994)
The first Research Room was set up at this Conference and three research teams participated in the opportunity to draw blood samples from Conference attendees. Blood samples taken from this Conference — the largest single blood draw from PH patients to that date — helped to identify the PH familial gene (BMPR2).

2nd International PH Conference (1996)
Attendees at this Conference were a talented group and many participated in a PH Talent Show. Patients, family members and even medical professionals participated in everything from singing to acrobatic dances and even poetry reading. The talent at this Conference was astounding!

3rd International PH Conference (1998)
The third Conference was the first hosted by the Pulmonary Hypertension Association (PHA) under its new name. The two previous Conferences were hosted by the group under its original name: United Patients’ Association for Pulmonary Hypertension (UPAPH).

4th International PH Conference (2000)
PH Resource Network (now PH Professional Network) met for the first time at this Conference. The group started with 80 PH-treating allied health professionals and has grown to close to 1,000 members today!

5th International PH Conference (2002)
PHA awarded five Grant Awards at this Conference to medical professionals who were conducting research in pulmonary hypertension to improve the lives of all patients. These awards continue today and help fund more research, which is needed in the field.

The first Scientific Sessions program was added to Conference, bringing together clinicians and researchers from around the world to discuss pulmonary hypertension. This opened the door for continuing PH education for medical professionals at each Conference and through other PHA programs thereafter.

7th International PH Conference (2006)
This Conference boasted more than 100 medical professional presenters who volunteered to educate PH patients and family members on all aspects of pulmonary hypertension. This number continues to grow each year as more medical professionals get involved in treating this disease.

8th International PH Conference (2008)
More than 1,150 people registered to attend Conference in 2008, making it the largest PH meeting in the world! The number of registrants for the International PH Conference grows each time as more people learn about PH and the community expands.

9th International PH Conference (2010)
The 9th International PH Conference hosted the First International Leaders’ Summit, bringing together 23 leaders from international PH associations. At this Conference, approximately 100 international guests representing 20 countries were in attendance!

10th International PH Conference (2012)
What will the hallmark of the 10th International PH Conference be? Will YOU be a part of the history?

The Power of One: From a Kitchen Table to Around the World

June 22–24, 2012 • Orlando, Florida, U.S.A. Renaissance Orlando at SeaWorld®

Registration Opens January 11, 2012
www.PHAssociation.org/Conference
Submit Nominations for PHA Outstanding Member Awards!

At every International PH Conference and Scientific Sessions, PHA recognizes the unique contributions of certain individuals in the pulmonary hypertension community through the PHA Outstanding Member Awards. The 2012 winners will be chosen by committees comprised of past award winners.

Outstanding PH Citizen
This award goes to a PH patient who exemplifies dedication to the PH community through any combination of the following: raising awareness, advocating for PH patients, participating in fundraising efforts, service to the PH community, and helping to provide the public with a voice and face of the PH community. 2010 Winner: Merle Reeseman

Outstanding Young PH Citizen
This award goes to a PH patient, less than 30 years of age, who exemplifies dedication to the PH community through any combination of the following: raising awareness, advocating for PH patients, participating in fundraising efforts, service to the PH community, and helping to provide the public with a voice and face of the PH community. 2010 Winner: Lauren Johnson

Outstanding Caregiver
This award goes to a non-patient caregiver whose efforts are focused on the needs of a loved one with PH and who does what it takes to ensure the patient has the best quality of life possible. 2010 Winner: Jason Janjanin

Outstanding PHA Support Group Leader
This award goes to a support group leader who provides a welcoming environment for patients, families and friends of PH patients; champions and serves the PH community by leading local efforts to raise awareness; leads and participates in advocacy efforts; and acts as a PH ambassador to the general public. 2010 Winner: Barbara Nickels

Outstanding Physician
This award goes to an outstanding physician who has been most notable in his or her service to the PH community and in promoting excellent clinical care, research, education and advocacy on behalf of PAH patients. 2011 Winner: Ronald Oudiz, MD

Outstanding Allied Health Professional
This award goes to a PH-treating allied health professional for contributions to the PH community through any combination of the following: participation in advocacy and awareness efforts, service to the PH community, and providing kind and compassionate care to PH patients. 2010 Winner: Deb McCollister, RN, BSN

Julie Hendry Memorial Scholarship Award
Julie Paton Hendry, daughter of PHA founding members Pat and Jerry Paton, was the first full-time, non-patient PHA volunteer. Every two years, she looked forward to the PHA Conference as an opportunity to meet the PH patients and families she talked with by telephone and email. Sadly, Julie passed away in 1998. Her family established the Julie Hendry Memorial Scholarship Award in her memory to help a non-patient volunteer attend Conference. 2010 Winner: Matacha Saul

By Jennifer Kaminski
PHA Manager, Finance & Human Resources

Nominate an Outstanding Individual!
Visit www.PHAssociation.org/Conference/Awards to submit a nomination (please limit yourself to one nominee per category).

For more information, or to request a paper nomination form, please contact Jennifer Kaminski at Awards@PHAssociation.org or call 301-565-3004 x747.

Nominations must be received by PHA no later than Friday, March 30, 2012.
Canada Comes Together: Uniting the PH Community from Coast to Coast

The weekend of Sept. 16–18, 2011, marked the second National PHA Canada Pulmonary Hypertension Conference, where 250 patients, caregivers, family members and medical professionals from across Canada (as well as a few special guests from the U.S.) gathered in Toronto for an incredible weekend of learning, celebrating and sharing. The theme of this year’s conference was “Uniting the Community from Coast to Coast” and this spirit was truly present as attendees arrived from as far away as British Columbia and Prince Edward Island.

Conference weekend kicked off on Friday evening with a special “Meet & Greet” where attendees mingled while enjoying entertainment by special guest performer, Paul Adams. He sang “Let Me Breathe,” a song he composed as a tribute to those living with PH.

The rest of the weekend included a lineup of educational and support group breakout sessions on topics such as an interactive PH and Yoga workshop. The Saturday keynote dinner included the presentation of awards to outstanding members of the PH community followed by a presentation by the speaker, Mark Black, a heart and double-lung transplant recipient turned four-time marathon runner, best-selling author, life coach and motivational speaker. Mark captured the hearts of all who heard him speak and received a standing ovation.

The weekend continued on Sunday morning with a very inspirational speech given by PHA Board member and Immediate Past-Chair of the PHA Board of Trustees, Carl Hicks. Carl motivated everyone to get involved in the fight against PH with his speech “The Power of One.”

A common thread throughout the weekend was the idea that no one does it alone; friends, family and the support network around us give us strength and make a huge positive impact on our lives. This could be seen in all the new friendships created throughout the weekend when people from all parts of the country met and shared their stories and words of support. It could be seen on the “Wall of Hope” where attendees left messages of hope for others as well as in the video interviews many attendees gave to our camera crew. These messages were used in PHA Canada’s “Lend a Hand for PH” awareness campaign.

PHA Canada’s new Board of Directors was elected during the weekend. While we were sad to say goodbye to a few Board members who decided not to run for re-election, we are excited to add some new faces to the Board. PHA Canada’s president since 2008, Darren Bell, decided to step down, and we are pleased to welcome our new president, Frank Poon.

Conference weekend was a huge success and we hope attendees met new friends, found strength in others fighting the same battle, and were inspired to take action to help fellow PHfriends in their community. We look forward to hosting many more attendees at the 3rd National PH Conference in 2013!

By Jennifer Gendron, PHA Canada Regional Coordinator, and Angie Knott, PHA Canada National Manager

Welcome, Paul Ravenscroft, Director of Finance and HR!

As PHA’s Director of Finance and HR, Paul is responsible for the monthly and annual production of financial statements. Working closely with the president and each department within PHA, he coordinates the budgeting process for the organization. He also acts as the liaison with the outside auditors. Paul can be reached by phone at 301-565-3004 x751 or by email at PaulR@PHAssociation.org.
Building Medical Education in PH

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

PHA extends its thanks to our 2011 Building Medical Education in PH partners:

- Cleveland Clinic, Cleveland, Ohio
- Duke University, Durham, N.C.
- Greater Kansas Support Group, Lansing, Kans.
- Grover Conference, Sedalia, Colo.
- Kansas Heath Care Association, Topeka, Kans.
- Kansas University Medical Center, Kansas City, Kans.
- Mayo Clinic, Jacksonville, Fla.
- Tufts Medical Center, Boston, Mass.
- Tufts University School of Medicine, Boston, Mass.
- University of California – San Francisco, San Francisco, Calif.
- The University of North Carolina at Chapel Hill, Chapel Hill, N.C.
- Washington University, St. Louis, Mo.
- Yale University School of Medicine, Hartford, Conn.

Find Free Pulmonary Hypertension Education Online

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

PHA Classroom

PHA Classroom (www.PHAssociation.org/Classroom), a program of PHA’s Medical Education Fund, is a vibrant e-learning center where patients and their families can participate in live events or watch recordings on their own schedule. Choose from more than 120 recordings of live e-learning events and PHA’s 9th International PH Conference and Scientific Sessions or participate in any of the regularly scheduled live e-learning events.

Highlighted Recordings

- Improving Patient Outcomes and Early Diagnosis: An Examination of the REVEAL Registry
- Telling Your Story: Explaining PH to Friends, Family and Co-workers
- Creative Expression for Well-being

PHA Online University

PHA Online University (www.PHAOnlineUniv.org) is a source of free, up-to-date, CME-accredited education and other resources about PH for medical professionals from all disciplines. Learn about PH by taking courses authored by the foremost experts in the field.

Highlighted Courses and Webinars

Course: PH Specific Intravenous Therapy
Faculty: Dunbar Ivy, MD, University of Colorado School of Medicine, Denver, Colo.
This course reviews intravenous therapies specific to PH including epoprostenol, subcutaneous and intravenous treprostinil as well as combination therapy.

Webinar: New Quality Indicator Set for Systemic Sclerosis
Faculty: Daniel Furst, MD, University of California in Los Angeles, Los Angeles, Calif.
*Recordings of webinars can be found in the PHA Online University Library under “Abstracts and Presentations.”
**INTERVIEW WITH PH PATIENT**

**TARA MASTERS**


How old are you?
I am 12 years old, and I’m turning 13 next March.

When were you diagnosed?
I was diagnosed in 2000, when I was one-and-a-half years old. I was literally on the operating table to have heart surgery to fix the heart defects I was born with when the surgeon discovered my high pulmonary pressures.

When did you first start having symptoms of PH?
I first started having symptoms early in 2000.

What were your symptoms?
My symptoms were blue lips and declining oxygen, which the doctors thought were caused by my heart defects.

What activities do you like to do?
I love dancing, playing netball and swimming. It’s hot and humid where I live, and I have a pool that I can swim in that the Make A Wish Foundation gave me when I was 8.

Have you ever felt unable to do something because of PH?
I am unable to go running because I get puffed and out of breath, but I really wish I could run in my school carnival.

How has your life changed since your PH diagnosis?
Since I’ve had PH from a very young age, I don’t really know what life without PH would be like. Sometimes I get annoyed because of all my medications, doctors’ visits and tests that interfere with what I want to do. I know I need all my medication, but sometimes I wish my doctor would let me stop taking some of the medication.

What is a message you’d like to pass on to other kids with pulmonary hypertension?
Enjoy the things that you can do and don’t worry about what you can’t do. Stay strong and brave and as active as you can.

**Interview conducted by Mira Kruger**
PHA Pathlight Volunteer
Hi, my name is Emily Broadhurst, and I’m 13 years old. I live in Methuen, Mass. In fourth grade (2008), when I was 10 years old, I was diagnosed with pulmonary hypertension. When I was diagnosed, I was getting my treatment through a central line, and I was using the CADD pump.

Even though I was feeling much better and it was a lot easier for me to breathe, I thought I would not be able to play softball and go to dance classes. These were my favorite activities, so I was upset. Thankfully, I was soon proven wrong.

Within a year I went back to softball. My mom and I went to Eastern Mountain Sports to find a bag to put my pump in. We found an awesome little backpack used to hold water (it’s called a Camelpack).

Although I returned to softball, I didn’t return to dance because in class we had to wear leotards. In the leotard, I felt self-conscious because you could see the outline of my central line.

I finished out the softball season and had a lot of fun. Soon, I realized that I missed dance and I wanted to go back.

In the fall I returned to dance, still self-conscious, and realized that no one cared if I had a central line or not! Everyone was just happy that I had returned!

I couldn’t believe that I had talked myself into not doing what I loved! As my dad always says, “You can see the glass as half full or half empty depending on how you look at it.” I realized that with something like this, you should look at the glass as half full.

I’m happy to say that I’ve been doing very well since then, and am now using the Crono 5 pump. For me, this pump is better.

I’m also happy to say that I will be starting my second year of dance classes since I got diagnosed. Also I’m playing on an AAU/Tournament softball team. I can’t wait for my first softball practice and dance class this season! Along with these two activities, I have also been learning how to ski! This is a lot of fun and it’s the only reason I can’t wait for snow to be on the ground!

I couldn’t be happier with my achievements, and every day I’m feeling healthier and stronger and I’m putting my best foot forward in everything I do.

*By Emily Broadhurst, PH Patient*

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**Only two of the concentrators are exactly the same! Can you find them?**

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

Drawing by Nicole Northrop, PH Patient, age 16

Answer: C and E
Co-Parenting a Child with PH: Enjoying the Highs, Embracing the Lows

Parenting a child who has PH can feel like riding a roller coaster that you can’t get off, enjoying some exhilarating highs while also fearing the long, unexpected drops. It can offer gifts: growing inner strength and wisdom, gaining perspective that directs our attention to the “big things,” and the closeness that comes from friends and family. It also offers many challenges, including fear for the future, unexpected hospitalizations, disrupted schedules, and expenses that are financially burdensome. These challenges can lead to conflict between you and your partner, even within the strongest of relationships.

It is common for two partners to have different parenting and coping styles. In families with a chronically ill child, these differences can lead to unspoken tensions and assumptions about acceptance of illness and sharing of responsibilities on both sides. One parent may be primarily focused on the day-to-day needs of their child, while another may focus attention on tangible tasks during difficult times, such as maintaining a job to keep the medical insurance. While all are necessary to sustain stability of the family, the different approaches can lead to conflict.

Similarly, one parent may reach out to family and friends for support, while the other may need time alone to process their feelings and reactions. It is important to know and accept that everyone copes in different ways.

As your child grows, you and your partner will experience new challenges and needs in relation to his/her PH. Though every family and relationship has its own way of dealing with chronic illness, communication is critical and there are ways to lay a positive foundation when you have these discussions.

• **Try to have “the conversation” when there is NOT a crisis.** You and your partner can think more clearly when you are not reacting to an immediate concern or need.

• **Remember, you (as well as your child) are the expert!** Even though you know what you need and what to do, and can probably do “it” by yourself, it is often helpful and comforting to have someone else go through events with you. Tell your significant other your reason for including him/her, and what is most important that he or she take away from your conversation. Your knowledge is bound to instill confidence and respect, and honesty is so often rewarded with the support one needs.

• **Recognize that while you have come to adapt and excel at dealing with the situation, elements of shock, fear, reluctance, grief and distress may still arise in your partner.** You likely had some of the same emotions (and maybe even still do) and needed to take time to process them. Your partner may be at a different stage in processing, accepting and coping with your child’s diagnosis, particularly if new health concerns develop.

• **Trust your instincts.** If the conversation is not going well — stop. Don’t put yourself through the process of being vulnerable without the respect and time it deserves. Return to the discussion when you feel you can, when your partner seems interested (or, better yet, initiates it).

• **Decide what your roles can and should be.** Are there strengths that you each bring that may be perfectly aligned with your child’s (and your) needs? Are there areas where you struggle, but your significant other is a “natural” and may be willing to take on some tasks?

• **Be honest.** Talk about what the future may hold: for you, your relationship and, obviously, your child.

• **Assure your significant other that there will be time to share together.** Your child likely will not always require complete, undivided attention (and, face it, kids will WANT some autonomy), and your relationship(s) with others are critical to your resiliency and coping. Your partner knows that already, but it helps to hear you say it. Discuss a standing “date night” or alone time and how it will affect your own life and your family life. You need this time, too.

• **Give your partner some examples of how you do what you do.** Focus on YOUR strengths. Give him or her a chance to do the same thing. Remind each other that the qualities that drew you together were likely based on values, priorities and characteristics that can help you manage your child’s PH.

• **Educate your significant other.** You both want to know all that you can to help and nurture your child. Help keep you and your partner on the same page with your knowledge of PH and your child’s needs.

STORY CONTINUED ON NEXT PAGE
• **Be sure that your partner knows what to do in a crisis or when he or she may have important questions.** Have your partner come to clinic visits, support groups and related appointments. Attend teacher conferences and sporting events together to demonstrate how all of these functions can co-exist. Familiarize your partner with the basics of medications, where to call for help when needed, and what symptoms to look out for and respond to.

• **Be yourself.** Be the advocate you are for your child, and that will transcend the boundaries of other relationships in ways that are positive and build respect. It may be a challenging series of discussions, but the benefits that result will be invaluable. You and your child will add another “expert” to your base of supporters. You will have a renewed sense of mastery as a parent, a partner and a caregiver.

While there is no guarantee of what the future holds, you do what you can to normalize, champion and survive the impacts of PH with each person in your family. Your ability to sustain yourself through the ups and downs, and balance the routine stressors of life, is admirable and an inspiration to your children and the PH community.

*By Allyson Rupp, LCSW, & Darci Albrecht, LCSW, Vera Moulton Wall Center for Pulmonary Vascular Disease, Stanford, Stanford, Calif.*

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**Check Out This Book:** *Walk on Water* by Michael Ruhlman

Some books pull you in from the opening pages, grabbing your attention before you even know you’re hooked. Others build your interest over time, weaving fact and narrative into an engrossing tapestry that subtly wraps you in their grasp. A few books do both.

*Walk on Water: The Miracle of Saving Children’s Lives*, by Michael Ruhlman, is one of those books.

A riveting history of pediatric cardiovascular surgery told mostly through the groundbreaking work of New Zealander Roger Mee at the Cleveland Clinic in the 1990s, *Walk on Water* manages to be compelling and detailed without becoming maudlin or too “inside baseball.”

For the lay reader, the book is a 332-page snapshot of an intimidating, sometimes inscrutable world that’s as overwhelming as it is awesome, as terrifying as it is promising.

But for the parents of “heart babies” — whose memories of invasive procedures, relentlessly beeping monitors, sleepless nights in the ICU, and knee-weakening odds are wide, deep and ever-present — it’s testimony.

That’s how the book felt to me, at least.

After the birth of our fourth child, Elie, in November 2007, my husband and I received a crash course in pediatric cardiovascular surgery and all the innovations and unknowns that go with it.

Fortunate to live near Children’s National Medical Center in Washington, D.C., and its rock-star cardiac surgeon, the Aussie Richard Jonas (who gets several mentions in the book), we were lucky that Elie benefited from the most up-to-date — and highly successful — treatments available to kids born with complex heart defects.

It wasn’t until reading *Walk on Water*, though, that I realized just how much luck had to do with it. If our youngest daughter’s truncus arteriosus and PH — treated today with a host of drugs and a series of aggressive angioplasties — had occurred in our oldest daughter (born in 1991), the outcome could’ve been very different.

That’s because, as the book chronicles, the field of pediatric cardiovascular surgery was, up until relatively recently, quite short on triumphs. Long-term successes were rare.

But thanks to pioneers like Mee, Jonas, Ed Bove and Frank Hanley, not to mention the countless unnamed nurses, physicians’ assistants, nurse practitioners, respiratory therapists, and others working behind the scenes to heal children’s broken hearts, such successes are no longer the exception. They’re the rule.

Although I highly recommend *Walk on Water* to “heart parents” who’ve already been in the trenches, so to speak, I especially encourage those parents’ families and friends to read this incredible book. As gut-wrenching and downright sad as it can be, it’s equally hopeful and life-affirming. In other words, just like the world of pediatric cardiovascular surgery itself.

*By Holly Smith, caregiver to her 4-year-old daughter Elie, who has truncus arteriosus, unilateral PH, VCFS and a contagious smile.*

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Holly and her daughter Elie
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 x747 or Passages@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

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

DONATIONS LISTED WERE RECEIVED BETWEEN SEPTEMBER 1 AND NOVEMBER 30, 2011.
PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

IN MEMORY OF

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

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PASTLIGHT WINTER 2012
PATHLIGHT WINTER 2012

PATHLIGHT and Persistent Voices Submissions

The Spring issue deadline is February 3, 2012.

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

“Newsletter Submission” or “Newsletter Submission”
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Print@PHAssociation.org
Pulmonary Hypertension Association
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Silver Spring, MD 20910

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

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

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PATHLIGHT Winter 2012
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