If you didn’t get a chance to attend PHA’s 10th International PH Conference and Scientific Sessions in June — or even if you did and just want to learn more — you’re in luck! PHA is heading to two new cities this year with PHA on the Road: PH Patients and Families Education Forums! PHA on the Road is a FREE, full-day regional education forum that provides patients and families with opportunities to further their pulmonary hypertension education and network with other PH community members in their area.

In fall 2012, PHA will be stopping in New Brunswick, N.J., (Sept. 8) and the Chicago, Ill., area (Oct. 13). We will be bringing together experienced PH medical experts from the local areas to present on a variety of PH-related topics and interact with attendees.

The PHA on the Road forums will feature interactive presentations, general sessions and exhibits regarding the symptoms, diagnosis and treatment of pulmonary hypertension. Sessions will also cover the practical challenges of living and coping with the disease and lifestyle issues such as eating better and exercising.

Attendees of PHA on the Road will have the unique opportunity to network with others in their local regions from patients and caregivers to medical professionals. Each forum will provide pre-forum support group sessions for attendees to learn from each other. Groups will be held for newly diagnosed patients, veteran patients, caregivers and parents of children with pulmonary hypertension.

Participation in PHA on the Road

STORY CONTINUED ON PAGE 42
Dear Friends,

My two-year term is complete and this will be my last letter to you as Chair of the Board of Trustees of this amazing organization that is a lifeline for so many of us. As is PHA’s tradition, our incoming Chair, Dr. Vallerie McLaughlin, assumed leadership of our Board at the end of our 10th International PH Conference and Scientific Sessions in June. As a cardiologist, PH expert, and former Scientific Leadership Council (SLC) Chair, Val has a long history of contributions to PHA and the PH community in general, and PHA will benefit greatly from her service in this role!

Time passes so quickly! Over the past two years, there have been many accomplishments by our PHA staff, Board, SLC and PH community — increases in the number of physicians and allied healthcare professionals involved in furthering PHA’s mission; diversity in the venues at which medical education is delivered; enhancements in the programs available to patients, families and caregivers tailored to unique needs; increased involvement within the international PH community; increased funding for PH-related research with a spotlight on pediatric research; and improved awareness of PH. However, as I look to the future, there is one PHA-driven initiative that stands out among those that have the greatest potential to alter the course of this disease — our Early Diagnosis Campaign.

As all of you are painfully aware, PH can result from more than 30 known causes. It is little-known among general practitioners and is characterized by unspecified symptoms, is often misdiagnosed, and most certainly is underdiagnosed. Even for the form of PH for which significant advances in understanding the etiology have been achieved (pulmonary arterial hypertension [PAH]), the time from onset of symptoms to recognition of the disease has not improved over the past two decades, according to a recent study conducted by Dr. Lynette M. Brown and others (2011).

Upon being presented with this information during our October 2011 Board meeting, our Trustees unanimously agreed that this is simply “unacceptable” and that PHA must take the lead in attempting to improve this statistic. Thus, the Early Diagnosis Campaign emerged. The slogan for this effort is, “In the medical world, doctors are taught: ‘When you hear hoof beats, think horses, not zebras.’ But sometimes it is a zebra, and sometimes it is PH.”

The Board has made this campaign a central focus of PHA’s activities, and PHA staff have hit the ground running with its implementation! Stay tuned for more information on this campaign in future issues of Pathlight and be sure to check out www.SometimesItsPH.org.

Without a doubt, being selected by my peers to serve in this role has been among the greatest honors of my life — second only to being mom to my two beautiful children and big sister to Rachel, who lost her battle to PH at the age of 24. To my friends and colleagues who serve by my side on the Board, I am forever grateful for this opportunity — thank you. I am convinced that there is not a finer, more generous and dedicated group of people amassed for any cause than those who work on our volunteer Board. I cherish your friendship and the knowledge I have gained from each of you.

To our accomplished President/CEO, Rino, and our wonderful PHA staff — you never cease to amaze me! Your dedication and creativity go above and beyond, and you consistently prove that anything is possible. To our talented and expert SLC, PH Professional Network and PH Clinicians and Researchers — thank you for leading the science and for providing models for excellence in patient care. And, to our lovely patients and their families — you inspire us to push harder, reach higher, and achieve our vision of life free from PH.

In loving memory of Rachel and with hope for what the future will bring,

Laura Hoyt D’Anna, DrPH

www.PHAssociation.org      PATHLIGHT SUMMER 2012
Caregiver Mentor Spotlight: Jim Wilson

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. Jim Wilson is one of those mentors, and he shares a little about himself now.

How long has your family been living with PH?

Our involvement with PH started when my wife Debbie was diagnosed in late 1997. Like many who have received this diagnosis, we didn’t know anything about PH. Debbie had taken Fen-Phen diet pills in 1995 but discontinued them when she started feeling run down. She was misdiagnosed for several years until a cardiologist gave us the definitive diagnosis of primary pulmonary hypertension in November 1997. We both remember the physician telling us, “I can’t treat what you have, but what I can tell you is survivability is less than 18 months.” We were referred to a pulmonology group in December 1997. They ran some additional tests and told us to come back after the holidays. We went back with high hopes that they would have answers. This pulmonology group told us that they didn’t know enough about PH to treat her and referred us to a hospital that did lung transplants. The transplant team started my wife on a program designed for PH to see if she could qualify for a transplant.

The transplant physician had done a fellowship with Dr. David Badesch, and he told us that Debbie might be able to take this relatively new drug called Flolan® that was considered a bridge to transplant. Flolan® stabilized Debbie and she’s still around today. In the meantime, we started learning everything we could about PH. We have now been fighting this battle for 14 years, and Debbie has recently transitioned to Veletri®.

My 26-year career as a hospital administrator in the Air Force helped us immensely in navigating the maze of hospitals, insurance issues and physician-speak that can overwhelm anyone diagnosed with a chronic, incurable disease. The other great resource that has helped us is PHA. Our first PHA International PH Conference was in 1998 in Grapevine, Texas. This past Conference in Orlando was our seventh. We always learn something new and come away with a renewed sense of hope that a cure is within reach.

At the first Conference we attended, I went to the scientific sessions and the sessions for male caregivers to help me understand this disease and my role as a caregiver. I got involved in fundraising by organizing several golf tournaments in the Dallas area and eventually drafted the first guidelines for PHA fundraising events. I served a term on PHA’s Board of Trustees and am currently a member of PHA’s Investment Committee.

As my wife and I grew with this disease, our focus changed from the types of Conference sessions we attended to the sessions we led or co-chaired. I was fortunate to co-chair the male caregiver session at the 2006 Houston Conference and the experience only furthered my desire to help others cope with the difficulties of living with this disease. I’ve also had the pleasure of being on panels that discussed traveling with PH, talking with your physician and fundraising.

What advice do you have for other caregivers?

Communicate. Never forget, there are good days and bad days. Be flexible in how you treat each new day. You have to be sensitive to how the patient approaches the disease. Are they going to be upset and angry, or are they going to say, “I’m going to do what I want to do”? My wife stays as active as her health will let her. As her caregiver, I know when she has done too much and I will encourage her to slow down.

Take care of yourself. You both have the disease. There’s stress 24 hours a day in this caregiver role, so you have to have time to de-stress — and not just when you’re sleeping. It’s important to have “me time.” It makes it much more enjoyable if the patient insists on it, too, and they see the value in it for you.

What does being a PH Email Mentor mean to you?

I have to fight this disease. Mentoring is another way I can say, “I am fighting this thing.” I became a mentor because I want to help people who are going through what I’ve gone through. I want people to start living with a sense of hope, not a sense of dread. My goal is to help caregivers who may be feeling forlorn and overwhelmed to develop a sense of hope.

Email Jim at Jim@PHAMentors.org or connect with another PH Email Mentor by gender, age, associated disease or other topic of interest at PHA’s website: www.PHAssociation.org/Mentors
HAVING TO QUIT MY JOB WOULD BE THE WORST THING THAT COULD HAPPEN TO ME,” I THOUGHT AS I LAY ON THE TABLE, AN ALLERGIST PRICKING ME WITH ROWS OF POTENTIAL IRRITANTS.

At 22, I was working 70 hours a week as a pastry chef when I began experiencing difficulty breathing. I was tested for what I thought were allergies to flour and eggs, but I later learned that it was something much more complex. At that time, I couldn’t imagine that nine months later I would be so sick that I would pass out and turn blue only three minutes into a stress echo test, which finally enabled my doctor to diagnose me with severe pulmonary hypertension. A PH specialist sat me down and told me that if I wanted to live more than a couple of months, IV Flolan® was my only option. The funny part was that through each test and all the uncertainty, my career remained my highest priority.

The hardest part about being diagnosed with pulmonary hypertension is that people tell you that you can live a “normal life,” but it’s never the normal life that you had before being diagnosed. After diagnosis, I tried to keep working in kitchens, restaurants, anything that was slightly related to my career. It was what I loved, and honestly, I didn’t have experience doing anything else. Finally, after yet another hospital stay, I realized what I was doing wasn’t helping my health and I needed to make a change. I felt that without my career, I had nothing.

With no other foreseeable options, I went to a temp agency to see about some office work. I had never worked an office job in my life, but I needed income because the medical bills were piling up and COBRA insurance isn’t cheap. Back then we didn’t have the protection of pre-existing conditions, which means if my insurance lapsed, I would be uninsurable, so a lapse in insurance wasn’t an option. The office environment was very different from my pastry background — conference calls, button-up shirts, lunch breaks. The whole thing was a strange experience, but my health was improving. I was placed as a receptionist with a small engineering firm that agreed to hire me. I had insurance! Things were finally looking up.

Less than a year after I was hired at the engineering firm, I was off the phones and given the opportunity to do design work; this was thanks to a co-worker who took the time to teach me drafting techniques. Now I manage the majority of the projects in the office, attend meetings and even travel. If you had asked me seven years ago if this is where I would end up, I would’ve laughed at you, but if I had stayed where I was, it would’ve literally killed me.

There’s a delicate balance to managing PH and working that has to happen on a daily basis. I try not to work too much overtime, and when I travel, I rest up afterwards. My office lets me take off whenever I need for doctor’s appointments. They understand that I am not able to do things like lift heavy items or climb rickety ladders up two stories to the roof tops. My co-workers know about my PH, but my clients don’t.

I chose not to tell my company about my PH until I started Ventavis®. The job I had been working at when I was diagnosed had “let me go” for using two sick days when I was in the hospital to start Flolan®. Ventavis® requires me to administer daily treatments, and we work in such a small office that I had no privacy, so I had to explain to my co-workers what was going on. I am fortunate that everyone in my office is so understanding (even though there are lots of jokes), and I know other patients aren’t so lucky. In another setting, I probably would not disclose details about my PH with the full office. Remember, our employment rights are covered by the Americans with Disabilities Act, so if you do feel you are being discriminated against, you can file a complaint with the Equal Employment Opportunity Commission.

In my experience, it’s not easy to work with PH and not all of us are healthy enough to do it. We don’t always have an option of whether we work either. What’s important is managing your energy and time and having a job that’s realistic about how healthy you are. It’s about finding that “new normal” and making the best of it.

By Brittany Riggins
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.PHASociation.org/Patients/YoungAdults

www.PHAssociation.org
My name is Ingrid Rivera, and I was born on August 13, 1979. I am 32 years old and was diagnosed with PPH in 2003. I live in Tegucigalpa, the capital of Honduras. As many of you know, PH doesn’t have many visible symptoms. Since I can remember, I have always loved sports; in school I was on the women’s football team, volleyball team and cheerleading squad.

In 2003, the year I was graduating from college, I would wake up every morning and run. One day when I started running, I immediately felt my legs go numb and I was out of breath. I figured I probably had not stretched right, so I tried again. This time, besides the numbness and breathlessness, I felt dizzy and almost passed out. I visited the doctor because every step I took to the second floor of my parents’ house would trigger my symptoms.

At my first visit, the doctor said it was just stress since I was in the middle of presenting my college thesis. A week went by, and I went running again and experienced all the same symptoms. I went back to the doctor, and he sent me for an echocardiogram. He later said, “You have a very rare disease called primary pulmonary hypertension.” After many lab exams he concluded my PH was primary because he could not find what caused it.

This was all so new to me, and my family could not believe it. We did research, and everything I read was very scary. I visited many doctors after that, who all said it was hopeless, until I went to Duke University Hospital.

From that day on, my life changed completely. We took everything step by step and I experienced several relapses. In 2004 I underwent surgery for an internal hemorrhage caused by the warfarin I was taking. One day after the surgery, a blood clot went into my lungs.

You might ask, how have I made it this far? First of all, God takes care of me. I take my medicine daily, and I changed my life habits one day at a time. I eat healthier now. I try to get eight hours of sleep, and I try to take everything easy. I don’t let anger defeat me, I exercise every day and I never stop giving thanks for each day. I cherish life and everything that surrounds it. I love the family I have, and I have become more sensitive to people’s health problems and issues. I always say if you suffer from any type of fatal disease, there is HOPE! Never surrender and never give up because we have the best doctors looking for a cure.

I’ve been married for four years now to the greatest and most supportive husband one can have. I love my life, my parents, my brother, my sister and the 13 dogs my family has. I also find comfort in religion. It is all a matter of attitude. I currently take calcium channel blockers (diltiazem), Viagra® (sildenafil) and Coumadin® (warfarin). I take the first two medications four times a day and Coumadin® just once a day. I have regular checkups and live an almost normal life. It’s not 100 percent normal but at least I feel like it is, and that is what matters.

Take it from me, live your life to the fullest and remember that a cure is just around the corner. Good fortune to all of you out there! You have a friend in me. ♦

By Ingrid Rivera, PH Patient

Welcome, Danielle Clifford, Administrative Assistant!

As PHA’s Administrative Assistant, Danielle is the first point of contact for PHA members, families, caregivers and medical professionals. In addition to various administrative functions, Danielle supports the work of the Volunteer Services Department, the Meetings & Conference Planning Department and the Office of the President. She can be reached by email at DanielleC@PHAssociation.org or by phone at 301-565-3004 x746. ♦
My husband Allan and I consider ourselves very responsible adults and have often been accused of being overprotective. The term “caregiver” always felt right and natural. Family is the most important element in our lives, and we care deeply for each and every family member. Nowhere was this more obvious than in our dedication to protecting our children, grandchildren, nieces and nephews and their children from the problems associated with hereditary hemorrhagic telangiectasia (HHT). HHT is a genetic disease that can cause death or other tragic outcomes if not diagnosed and treated.

Although we were aware of the genetic disease in my husband’s family, we did not know about DNA testing, the need to screen for organ involvement, or the connection between HHT and PH. What we knew about were nosebleeds, possible blood transfusions and the need to get “checked out” before becoming pregnant. Ever-vigilant, we made sure our daughter had a pulmonary evaluation before her wedding date.

When we learned about DNA testing, my husband, our children and grandchildren were all tested. We learned who did and did not have HHT. We read everything we could find on the HHT Foundation’s website. We became committed to increasing awareness of this “silent killer.” We urged our nieces and nephews to get tested, mostly because they were starting their own families. They refused. It became a rather uncomfortable topic at family get-togethers. My oldest son wrote a letter to his cousins, citing some tragic cases of children dying or having strokes or other complications due to not knowing about HHT until it was too late. I thought it was a bold and courageous move on his part to risk alienating his cousins but one that was necessary.

In November 2008, shortly after he sent his letter to three cousins, we got a call that one of them, our niece in Florida, was very ill. We had assumed she had HHT because she had frequent severe nosebleeds, but recently she had been having some breathing problems and was diagnosed with exercise-induced asthma. Unaware of the possible connection between HHT and “breathing problems,” we were shocked to learn that a pulmonologist had just diagnosed her with PH; she could be dying.

Everyone moved into “crisis-caretaker” mode, making calls to a specialist who treated HHT and PH, getting our niece quickly transported 500 miles to the Augusta, Ga., HHT Center of Excellence where she was diagnosed with Class 4 PH, right heart failure, and water retention at a critical level. She spent weeks in the hospital being stabilized. While there, she tested positive for HHT. There was no need to continue talking about HHT testing. The cousins all got tested, and no one else was positive.

We couldn’t be with our niece, who lives 1,200 miles away. We called her every day, and she sounded so weak when she said, “I don’t want to die; my little girl needs her mother.” We didn’t know what to do beyond providing a long-distance shoulder to lean on, but we figured out what we could do locally so no one would ever have to go through this again.

We started a support group in Philadelphia. We spread awareness on the Internet, on Facebook groups, to doctors and to the media; we talked about the potential consequences of not being diagnosed. We talked about our niece and how untreated HHT and subsequent PH had changed so many lives. We talked about how her parents and husband shared caregiving roles as they adjusted to changes: trips to the hospital, daily preparation of Flolan®, preparing a PH-friendly diet. All this as our niece faced challenges like showering with a Hickman catheter, taking medical leave from work and trying to spend meaningful time with her husband and daughter.

Three years have passed. Our niece is doing well. The current medications are keeping her PH symptoms under control, but the HHT-related nosebleeds are still a problem, in part because some of the necessary PH meds affect bleeding. We increased our involvement with the HHT Foundation, reaching out to give care and support to people all over the world. We feel that we are making a difference, and you can, too.

For more information about PH and HHT, visit www.PHAssociation.org/Patients/HHT. For more information about HHT, visit www.hht.org.

By Gwen Olitsky, MS
PH and HHT Caregiver
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)


NEW! Coping with Pulmonary Hypertension Guides – Find resources to help patients and family members understand the non-medical impacts of PH and learn coping mechanisms. [www.PHAssociation.org/Coping](http://www.PHAssociation.org/Coping)

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)

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

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

Stay in the loop.

PHANews – This free biweekly email newsletter brings the latest news about PH and PHA 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)

PHA 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.

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

PHA offers monthly Telephone Support Groups for both patients and caregivers. Learn more at [www.PHAssociation.org/TelephoneSupport](http://www.PHAssociation.org/TelephoneSupport)

Online
Our discussion boards, 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 email mentor at [www.PHAssociation.org/Mentors](http://www.PHAssociation.org/Mentors)

Connect face-to-face.

Support Groups
Join one of our 240+ 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)

Education Programs
PHA hosts regional patient and family education conferences throughout the year.

**Coming this fall!** PHA will visit:
- **New Brunswick, N.J. (Sept. 8)**
- **Chicago, Ill., area (Oct. 13)**

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)
As a caregiver, it can be easy to fall into the trap of feeling like you need to do it all. After all, your loved one is looking to you to help them manage a chronic disease and, depending on the severity of your loved one’s health challenges, their care may involve significant time and activity. Caregivers may become completely focused on being caregivers, and rarely or never on being caregetters.

Finding and accepting support can be difficult. You may feel uncomfortable trusting another person to be responsible for your loved one’s care, feel obligated or expected to be available 24/7, or simply be used to being the go-to person. But help can take some of the weight off your shoulders, give you some time to refresh your mental, emotional and physical reserves, and ultimately enhance your relationships with both yourself and your loved one.

We spoke to caregivers in a variety of situations to hear their thoughts on finding caregiving support. Here is what we learned:

People want to help, but they might not know how. Cynthia shares, “I learned about a website called www.lotsahelpinghands.com. It’s a calendar where people can sign up to provide help for patients and caregivers dealing with a chronic illness. Since my partner was diagnosed, a lot of people have asked what they can do to help. I ask them to sign up on the site. It allows me to have options for different types of help, but I can choose from people I know.” If you don’t have Internet access, you can make a list of tasks that would be helpful and ask a friend or relative to coordinate volunteers.

Accept help — from your loved one. Remember that before PH, your loved one was probably used to giving as well as receiving support. The loss of this role can be difficult for patients — and sometimes unnecessary. One patient told us, “Sometimes I think my wife believes PH has affected my brain … actually, my brain is the healthiest part of me now, and I really want to be asked to use it.” While you may not be comfortable talking to your loved one about the frustrations you may feel about your role as a caregiver, don’t forget that they still want to be there for you in any capacity they are able to.

Additionally, it’s important that your loved one be prepared if the unexpected happens. “I have created a complete step-by-step direction pamphlet that I leave in my husband’s medication supply kit. He also has a card in his wallet that lists all his medications in case he is ever alone and has an emergency and needs help from the EMTs,” Diane told us. “I can give him the gift of caregiving, but I also want him to be able to take care of himself.”

Make a space for yourself. “I’ve been seeing a therapist since my partner got diagnosed, to help me cope with our ‘new normal,’” says Cynthia. “I feel that talking to a therapist is a way of standing up for myself. It helps me to cope with my partner’s expectations and to work on also taking care of myself.”

The small stuff counts. Sometimes, just having someone acknowledge your efforts as a caregiver can help. “Personally, I love it when someone comes in the house and just asks me how I am,” says Diane. Nancy agrees, “It means the world to me to have someone actually ask me ‘how are you doing?’ To know that someone is concerned for you is huge.” You can reinforce this by thanking the people who take the time to ask how you are. If you’re feeling forgotten, call a friend or family member who you’re close to and let them know that you need someone to lean on or talk to for half an hour from time to time. Don’t be ashamed to ask for support.

Prioritize. “Rethink your family budget in terms of how much you ‘spend’ when doing chores. If your time is more valuable (per hour) than what you’d pay someone to clean your house, grocery shop, do yardwork or other chores, try to find room in your monthly budget to pay them and free up your time for things you cannot pay someone else to do,” suggested a male caregiver who participated in PHA’s Family and Friends survey.

Joe, another male caregiver, adds, “We now pay two ladies who clean our house, but they are the only people who I pay. It’s also good therapy for my wife to talk to them, and they have become another support system.”

If needed, provide training. Look for others who can help you with medical tasks such as mixing medications. “I would like to know if there could be training for in-home care. It’s very scary to know that I am the only one who knows how to handle my mom’s condition,” says Nancy. Many specialty pharmacies will send a nurse out to train caregivers at home; if you have friends or family willing to help you with your loved one’s medication, see if you can schedule a “training date” for them. Similarly, if you have a local support group, see if a specialty pharmacy nurse can run a training session for the group and bring your “caregiver volunteers” to the session so they can learn with you.

STORY CONTINUED ON NEXT PAGE
Reach out if you don’t have local support. Cynthia told us, “Initially, the isolation, I think, was the hardest thing. Then my partner and I found a support group in the Boston area.” Cynthia advises, “Keep your social connections open; just because someone in your life has a chronic illness doesn’t mean you have to close off your social life.”

Long-distance support counts, too. “My out-of-town family sends me gift cards to restaurants to help me with meals,” says Joe. “Other members of my family bought Dream Dinners services for me. You order your meals and they send them to you with an instruction card. When the meals arrived, my family got together like a party and put the meals together.”

The benefits of caregiving support are as many and varied as the types of support. Getting help with something as basic as household chores can contribute to your emotional well-being and sense of communal support. “I’m lucky because my family volunteered; their help freed up my time to do other things,” shares Joe. “It gave me time to go fishing and take time for myself. Because of them, I never feel alone or like I’m stuck.”

Have other tips or questions? Join the conversation on PHA’s Caregiver email group: www.PHAssociation.org/EmailGroups

By Michal Rachlin, PHA Kerry Bardorf Family Support Program Associate

Special thanks to each caregiver who contributed to this story. Thanks as well to Alyson Rupp, LCSW, of the Vera Moulton Wall Center for Pulmonary Vascular Disease at Stanford Hospital and Clinics, for input on support opportunities. For more tips, visit www.PHAssociation.org/Caregivers/Coping

“Help: A Collection of Essays by Those Who Care”

This thin, yet inspirational and powerful book is made up of stories by caregivers who belong to and blog about their experiences on www.caregiving.com. The caregivers who have contributed to this book face a variety of circumstances. They include Laura, whose husband is paralyzed after a road rage motorcycle accident; Bette, who is married with three children and cares for her mother who has dementia; Trish, who cares for her epileptic brother; and several more, including my own piece about the first year of my daughter’s diagnosis with PAH.

These caregivers may care for parents, grandparents, spouses, siblings or children, but no matter who we care for, we have the same struggles. Each caregiver in this book offers their experience, insight and advice for other caregivers seeking help with their caregiving role.

This book makes a great gift for anybody who is a caregiver or somebody who knows a caregiver and wants a glimpse into their world. I would also recommend that caregivers join www.caregiving.com and participate in the online events that entertain, encourage and support.

All the proceeds go to www.caregiving.com’s Caregifters program, which provides $500 for a caregiver in need. I have been one of the recipients of this award, which has allowed me to go through an online school to get a pharmacy technician degree in hopes that I will be able to use this knowledge to help my daughter. If you would like to purchase the book, visit www.lulu.com

By Jane Northrop, PH Caregiver

Caregiver Shout-Out!

This Shout-Out from PH patient Jen Cueva goes to her husband and caregiver Manny.

Manny is my rock; we have been married for almost 20 years now. I would have never thought that I would be the sick one. I was a nurse prior to getting PH.

Since getting this PH diagnosis, and during the time trying to get a true diagnosis, Manny has stood by my side. He has always offered me unconditional love. As he says, our vows say, “in sickness and in health.” Since 2005 he has had to take on a whole lot more around the house. He works full time but also has to do house chores and cook and take care of me.

I know PH has changed our lives greatly, but he never gives up on me and always stands beside me when everyone else leaves. I do not think I would ever have made it this far without him. I love him and want him to know how much I truly appreciate all that he does. I know it is not easy dealing with the ups and downs of PH! I am blessed to have such a wonderful, loving man! ♥

For a chance to express gratitude to a loved one in Pathlight, submit your own Shout-Out at www.PHAssociation.org/Shout-Out
Read All About It: *Survival Guide* Fifth Edition Now Available

The brand new fifth edition of *Pulmonary Hypertension: A Patient’s Survival Guide* is hot off the presses! Called the *Survival Guide* for short, this book serves as a soup-to-nuts resource covering many of the questions patients and their loved ones might have about living with pulmonary hypertension.

The new edition includes updates to these chapters:

- “PH Drugs”
- “Children and PH: Babies, Kids, Teens and Family Planning”
- “What to Eat When You Have PH”
- “Dealing with Emergencies, Doctors, Colds and Flu”
- “You’re Not the Only One with the Blues”
- “The Active Life: Working, Exercising, Traveling and Living”
- “Insurance and Legal Matters”
- “Resources”

The “PH Drugs” chapter has been revamped and separated into three, easier-to-swallow chapters: “PH Drugs: Prostanoids” and “other PH Drugs” provide details about current drugs that treat PAH, while “More on PH Drugs” covers related topics like participation in clinical trials, combination therapies and new treatment options on the horizon.

The book also covers weighty topics like life expectancy, the risks of different treatments, and how PH can sometimes be inherited. There is a dedicated chapter for caregivers, as well as an ever-useful glossary of PH terms.

Gail Boyer Hayes, the original creator and author of the *Survival Guide*, wanted to have a resource fellow PH patients could easily grasp. First published in 1998, it was the first book of its kind on PH, a comprehensive and easy-to-understand resource amidst the complicated medical texts that were available at the time.

Updates to the *Survival Guide* happen annually under the guidance of medical editor Dr. Ron Oudiz, as well as by the many medical professionals and patient volunteers.


Thank you to all the patients and medical professionals who assisted with the publication of the fifth edition of the *Survival Guide*!

*By Ellie Falaris Ganelin*
*Design & Publications Associate*

Resources for families of pediatric PHers

Pediatric Resources for Family and Friends

This FREE information packet is designed for parents of pediatric patients. Learn about the services PHA offers to help you plan your next steps, find important resources and connect with other parents.

PH Handbook for Families

This new FREE information packet that parents can request for their kids and teens offers booklets on pediatric PH and how younger family members can get involved in raising awareness along with PH-related word and picture games.

Request yours at [www.PHAssociation.org/ParentResources](http://www.PHAssociation.org/ParentResources)
Insurance issues can be really frustrating for pulmonary hypertension patients, but as I have learned, when it comes to getting the answers you need, don’t accept no for an answer from someone who doesn’t have the authority to say yes.

Four years ago I started on pulmonary rehabilitation for pulmonary hypertension, and I have been going ever since. It is important that the rehab was specifically for PH. At the time, I was on COBRA and my insurance covered the initial rehab. I don’t recall the standard number of “Phase II” visits that were allowed, but at the end of the initial period, I was told by the rehab staff that insurance did not cover Phase III. I requested they submit the claim as a courtesy and they did. My insurance covered it with no questions asked.

Then there was a change in the COBRA carrier. With the new insurance, I again requested they submit the claim, and pulmonary rehab Phase III was again covered with no questions asked.

When I became covered by Medicare through a Medicare Advantage plan, I was told by everybody — rehab staff, customer service, billing and insurance departments with the provider — that Medicare plans do not cover Phase III pulmonary rehab. I had to fight to get them even to submit the claims. Eventually they did. The claims were denied because of lack of required codes. Instead of supplying the codes, the provider chose to bill me in violation of their agreement with the insurance carrier. Eventually, they did supply the codes, and my carrier covered Phase III pulmonary rehab.

Since then, I have had a change in my Medicare Advantage Plan. I had to go through the whole process and arguments again, but eventually the provider submitted the claims. And again, the claims lacked the proper codes. After many calls on my part, all the required information was submitted, and again, the carrier covered Phase III pulmonary rehab.

Next, to my dismay, the provider instituted a policy of changing account numbers every four to six months, and it looked like I was going to have to go through the whole process two to three times a year. For 2011, I started trying to get claims submitted properly in March. Finally, in January 2012, I wrote to the president of the hospital and told him very clearly the issues I was facing and asked if he felt it was appropriate that they had not been resolved in 10 months.

The president forwarded my letter to the director of patient financial services, who told his personal assistant to take care of the problem. She called me, verified that she understood the issues, and I provided her with some additional information in the form of EOBs (Explanation of Benefits). She took care of the billing problems for me. She also told me that it is true that Medicare plans do not cover Phase III pulmonary rehab for conditions such as COPD. However, she said that many of them do cover Phase III pulmonary rehab for pulmonary hypertension. Pulmonary hypertension is so rare that most rehab programs don’t see even one patient.

With my previous coverage, I did not have to pay anything out of pocket for pulmonary rehab. It wasn’t until the first couple of months this year that I had to pay co-insurance until my maximum out-of-pocket expenses were met.

Bills from providers are one of my pet peeves because I think they are intentionally misleading and vague. The providers are betting on people getting their bills and thinking the amount must be right without verifying what they are paying for. My bills for pulmonary rehab provide the first date of service and no others, even though they cover three to six months of service.

One deputy director told me my claims were denied on a particular date (based on entries in their database). I asked him to send me a copy, which he promised to do. He called back to apologize because on the date in question, they had not even submitted a claim.

I figure I’m not so special. If this has happened to me, then it has happened to others too. How many PH patients are missing out on the proven benefits of pulmonary rehab because their providers tell them it isn’t covered by insurance and they have to pay $60 – 70 a month?

If you have to fight for insurance rights, don’t give up. Sometimes it is hard. Representatives from the provider told me several times that my insurance denied payment, but I kept fighting, and I kept calling, and I finally got the situation worked out.

By Doug Taylor

PH Patient
Aug 2008 was a great month. I was running nearly 40 miles a week. Next marathon on the notch was to be Gasparilla in Tampa, Fla., my home city, for the second time. Over the next month of training, my running got much slower, and I had to stop for frequent walk breaks. I could tell there was something wrong with my breathing but didn’t think anything of it.

In October, I couldn’t even run to the end of my street without stopping. I finally called the doctor. After a brief visit with my primary care provider, I asked for a referral to the pulmonologist. I picked a name out of a hat. I had no idea who to see; all I knew was that I wanted to be seen fast so that my running could get back on track. After calling around, I found one who could see me the very next week. He said that my symptoms sounded like exercise-induced asthma, so he prescribed two inhalers and we made a follow-up appointment in two weeks.

After the first week I felt no relief, so I called the doctor and he recommended I inhale more often while running. That did not help, which I informed him at the second visit. He told me to get a chest x-ray and referred me to his cardiologist friend down the street. My follow-up appointment with the pulmonologist was the day before Thanksgiving. I had an echocardiogram done by the cardiologist. We needed to get out of there fast because my entire family would be arriving in just 12 short hours. I brought my husband and 6-year-old daughter. Why did I bring them? Thinking back, I have no idea what initially made me want to bring them. Remember, I thought I only had exercise-induced asthma.

The doctor came into the room and told me I had pulmonary hypertension. I had no idea what that was and just sat there. I may have even started laughing at that point. To tell you the truth, everything went numb as soon as he said, “Marla, this is serious business. Your life expectancy is three to five years, and you need a lung transplant.”

All I heard was that was it for me. I was a 37-year-old woman with a husband and 6-year-old daughter. Who would take care of my daughter? Who would drive her to school? Who would buy her clothes and watch her get married? We left. What else was there to do at that point? Of course, we called our families and told them the news. Everybody was shocked and in deep sorrow. Imagine how our Thanksgiving was.

On Thanksgiving Day, my father told me about a pulmonologist who specialized in PH. My cousin Scott recommended him to us. Without that recommendation, who knows what kind of care I would have received. He gave my number to Dr. James Gossage at the Medical College of Georgia in the Georgia Health Sciences University. Three weeks later, in the middle of December, we were in Augusta, Ga. The initial diagnosis was confirmed, but there was no life expectancy given this time. I was started on sildenafil at 20mg, three times per day.

After a couple months, I was passing out while walking at work, so I needed something stronger. I had also gained 25 pounds. My cardiologist in Tampa never said a word about it and told me to stop eating so much. When I got back to Georgia in February 2009, I was in right-heart failure and in critical need. My pulmonary pressures were in the 100s and Dr. Gossage immediately admitted me into the hospital and started epoprostenol within 24 hours. At that time I also started bosentan. After two weeks in the hospital, I was finally ready to go home and be a mommy again. Oh yeah, and did I mention I work full time as a speech language pathologist? The truth was, it was tough. I was crying every day because I was afraid I was going to die. It’s
just hard to get past that.

I started seeing a therapist and walking for exercise. I started attending support groups through PHA. I attended two groups, one in Sarasota and one in Lakeland, Fla. I went back to work. My mood started to get better and was becoming somewhat normal again. In September 2009 after seven months on epoprostenol, I had a right heart catheterization. My pulmonary pressures had gone back to normal. Me? Normal? “Maybe only from the neck down,” Dr. Gossage would say.

In October, my doctor and I began weaning me off the pump. In December, I started on treprostinil, an inhaled medication. Since February 2010, I have been on the inhaled medication ambrisentan and sildenafil. I feel great. I exercise five times a week; I take my daughter to amusement parks, the beach, roller skating and bowling, and I work full time.

I also attended PHA’s International PH Conference and Scientific Sessions in California in 2010, where I got the nerve to start running again. It is a very slow process, but I feel awesome. I attribute my mental and medical success to my very supportive family, the support of the PH support groups, and my awesome pulmonologist Dr. James Gossage. I couldn’t have gotten to where I am today without their help.

If you live in the Tampa Bay area in Florida, please attend our newly started support group. We would love to have you. (www.PHAssociation.org/FindASupportGroup)

Haley Lynn, Amarillo, Texas

At 17 years old, I had had enough of not being able to breathe. I could never keep up at school with friends or even my parents. Walking up the stairs was impossible and just walking anywhere caused me to completely lose my breath. This had been going on since I was 11 years old. And it seemed like no one was listening. “I can’t breathe” was just something commonly ignored when it came out of my mouth. I had quit competitive dancing, and I had never participated in any sport at school.

Every doctor I went to was at a loss for words and would simply say, “It’s asthma.” Being a senior in high school, I was finished with this game. My father began to see how serious I was when I couldn’t walk from the parking lot of Wal-Mart into the store without passing out. Finally, two months after my high school graduation, I had an appointment with a cardiologist.

Electrocardiograms, oxygen saturation tests and tons of questions later, my doctor finally entered my room. He shook his head and said, “Something is very wrong with you.” All I could do was smile. That sounds weird, but I was so ready to know what was wrong with my body. After listening to my heart, my doctor diagnosed me with atrial septal defect (ASD). I was scheduled to have a right-heart catheterization to look at the hole that they thought was in my heart. In surgery, they found no hole and instead my diagnosis was pulmonary hypertension.

It’s a little over a year later and I have made a great recovery thanks to my pulmonologist, cardiologist and specialist. I was put on two vasodilators and Coumadin®. I couldn’t have been more excited to be diagnosed; even though I will be dealing with this disease my whole life, I can truly say I am content. The hospitals, needles, medicines and doctors get old sometimes, but I am blessed to finally have the knowledge that I am not a normal 19-year-old, nor do I have to try to keep up like one either. I am simply PHenomenal.
As a PH patient, what can I do to make traveling easier for myself?

Traveling can be a stressful time for anyone. However, travel for people with pulmonary hypertension may be especially stressful with extra planning needed before a trip. Issues to consider include medication, blood clots, emergency contact information, overexertion, need for oxygen and eating on the road. For many patients who use supplemental oxygen or who have borderline low oxygen levels, method of travel will play a major role.

**Oxygen:** Travel to higher altitudes may present a specific challenge due to lower oxygen levels in the air. When traveling on the road by car, train or bus at higher elevations, increased levels of supplemental oxygen may be necessary, especially when above 4,000 – 5,000 ft. Symptoms to look for include fatigue, more shortness of breath at rest or with activity, rapid breathing, lightheadedness, rapid heartbeats and headaches. On the road, the change in elevation may be gradual and not noticeable until you get out and move around. However, the change occurs rapidly if traveling by plane. Fortunately, passenger airplanes pump compressed air into their cabins when traveling above 10,000 ft. But oxygen levels are 25 percent lower in pressurized cabins compared to sea level.

People who use oxygen only at night or one to two liters with activity typically do well without the need for oxygen during the flight. However, people who use two liters at rest or three to four liters with activity will likely need oxygen during air travel.

In some medical clinics, one can perform an “altitude test” using a special pressurized chamber to test oxygen levels at different altitudes to determine whether oxygen will be needed. The test, however, is not routinely needed prior to travel. Certain portable oxygen concentrators (POC) can be used in-flight but must be approved by the airline ahead of time. Empty oxygen tanks and POC can also be checked as luggage.

**Recommendations for traveling with oxygen:**

1. Ask your doctor if you need oxygen while traveling. Ask for a “medical certificate” that states why you need oxygen (i.e., why it is medically necessary) and the “flow rate per minute” that you need (allowable range = 0.5-6 liters/minute). The certificate must also state the oxygen user is physically and cognitively able to use it and respond to warnings/alarms.
2. When booking your ticket, let the airline know that you need oxygen in-flight.
3. Federal law requires that oxygen be dispensed only by the airline. Each airline works with an oxygen provider. Charges vary. (American Airlines, for instance, charges $100 per segment for oxygen service. This fee may or may not be covered by insurance.)
4. Contact the oxygen vendor at your final destination to arrange for oxygen once you arrive. This is done separately through a health agency and not through the airline.
5. If using a POC, check with the airline to ensure it is approved. Bring enough batteries for 150 percent of the expected flight duration in case of delays.

**Medications/Pumps/Etc.:** Certain medications like epoprostenol (e.g., Flolan®) require pumps, cooled storage and extra supplies. Carry extra tubing, needles, backup pump and extra medication. Be prepared in case of delays by having extra medication packed in your carry-on luggage. If your medication requires being kept cool, bring six to eight ice packs and a premixed dose. Anticipate how you could handle flight delays or cancellations.

**Blood Clots:** Long periods of inactivity during travel may raise the risk of developing a blood clot. With air travel, get up and be active. Consider support stockings for your legs if you have had a blood clot in the past. If traveling by ground, stop frequently (at least every two hours) and walk for a couple of minutes.

**Eating on the Road:** We eat differently when we travel. Be aware of eating foods that are high in salt as extra fluid will be retained. Try to eat lightly with lots of fruits and vegetables and limit the temptation to eat fast food (high in salt).

**Pre-travel Physical:** Talk to your doctor ahead of time and come up with a plan in case you develop symptoms such as...
Targeted Pediatric Research in PH Needed

“It is believed that in the United States, pulmonary arterial hypertension (PAH) will affect 40 – 50 pediatric patients per million children at some point in their lives.” While research has come incredibly far in the last 15 years or so, with nine approved PH therapies and many more in the pipeline, none of these therapies is approved for use in children.

You may think this is not a problem. We can just treat children like “small adults,” with smaller medication doses, right?

Unfortunately, the answer is no. Children are not just “small adults.” I sat down with two leading pediatric PH specialists to find out more. Thanks to Robyn Barst, MD, and Dunbar Ivy, MD, for their contributions to this article.

Why is it important to consider pediatric patients separately from the adult PH population? In short, Dr. Ivy says that the disease is often different. While there are some idiopathic PH patients in the pediatric population, there are also many who have conditions not so commonly found in adults, such as lung disease of prematurity and congenital heart disease.

In addition, the metabolism of children is vastly different from that of adults. And while it stands to reason that the dosing is therefore different, it doesn’t necessarily mean just giving an arbitrary “less.” Sometimes children metabolize drugs more rapidly and need higher doses, while other times their liver is not well developed and they should receive less medication. If the metabolic pathway is not maturely developed, some medications may have serious consequences. Further, a child’s metabolism can change throughout childhood, and even for children who have “normal” metabolism for their age, metabolism changes from toddlers to adolescents. Therefore, dosing based on weight can also be affected by age.

Dr. Barst says that when it comes to a treatment like Flolan®, for instance, it has been found that a higher dose per body weight is actually more effective than in adult patients. It took a long time for practitioners to realize this, but when they tried to cut back on high doses, kids actually got worse.

While it is true that pediatric patients likely metabolize medication more quickly (and thus may require more frequent dosing), in very young infants the metabolism of medication may in fact be much slower and too much medication too often can cause organ dysfunction in tiny bodies.

These dosing questions should not be trial and error, and clinical trials and pediatric guidelines would help with more targeted dosing recommendations.

Dr. Barst says pediatric practitioners are now seeing that there may be an optimal window of development, a time when more aggressive treatment may in fact have a higher impact on outcome, largely due to the growth and change in the body during childhood. More research on what that window of development is, and how to best capitalize on it, is also needed.

What personal traits do kids bring to the table that makes them different to treat? When it comes to the basics of administering and tracking treatments, kids bring their own set of challenges, often in the following areas:

Medication: Often, the delivery of the dose can be problematic. As of this publication, four PH medications come in pill form and two are inhaled. Both may be challenging for small children. As Dr. Ivy explains, a medication that can be delivered in liquid suspension and easily swallowed is often important, even ideal, and some PH medications do not translate well into that form. Three medications are delivered continuously via IV 24 hours a day, and this can be very tricky for an active child of any age. Likewise, keeping oxygen on a child on the move can be very difficult.

Outcomes: While an adult PH patient with advanced disease is likely very symptomatic, the same does not necessarily hold true for the pediatric patient unless they are very sick. A six-minute walk, the standard evaluation for PH function and class in adults, does not work as well with a pediatric patient. It can, in fact, be invalid because even children with advanced PH may still have good heart function. Since the six-minute walk is also a primary endpoint in clinical trials and is often used to gauge how effective a course of treatment is, different standards need
Finding Answers to Questions about Lung Transplantation for PH: 
Part Two in a Two-Part Series

Part two in our series examines questions about the transplant evaluation, the process of being listed for transplant and what to expect after a transplant.

**What is involved in transplant evaluation?** After a patient decides to undergo transplant evaluation, the patient’s physician contacts a transplant center to arrange the outpatient evaluation week. This involves several days of outpatient testing and visits with various doctors and consultants. While some testing is performed by the patient’s primary care physician (routine cancer screening and vaccinations, for example), other testing may be done during the transplant week (lab testing, radiologic studies, catheterizations and other cardiac testing). After this is complete, the center’s committee reviews the data and makes a recommendation on whether or not the patient is a candidate. If the patient is not yet sick enough for transplant, the committee may decide that they could be a candidate in the future but would not list the patient at this time. Instead, the center will follow them closely every three to six months and list when their condition worsens.

The decision of when to list a patient for transplant is complicated, and we often refer to the “transplant window.” Listing too soon may potentially shorten a patient’s life due to the risk of lung transplant itself. Waiting too long may mean a patient’s heart may not recover fully with double lung transplant alone, and they may require heart-lung transplant or even be unable to be transplanted. Therefore, routine follow-up at the transplant center, even prior to listing, is essential to determining when a patient is within the window for listing.

**What is involved in listing for transplantation?**

When patients meet criteria for transplant, the decision is made by the transplant team and patient to list the patient for transplant. Data from their evaluation week (e.g., age, diagnosis, functional status, oxygen requirement, pulmonary function testing, right heart catheterization data, carbon dioxide levels, six-minute walk distance, serum creatinine) are used to register them with the United Network for Organ Sharing (UNOS). This generates a lung allocation score (LAS), which is a number from 0 to 100 that determines where a patient is ranked on the list with respect to others. A sicker patient will have higher LAS, and thus have a higher priority in obtaining lungs when they become available.

It is known that the formula for calculating the LAS, which is used in all diagnoses (COPD, IPF, IPAH, etc.) places IPAH patients at a disadvantage. To address this, UNOS currently employs an expedited appeals process so that patients who meet certain criteria will be moved to the ninetieth percentile on the list. To meet these criteria, patients must be deteriorating on optimal medical therapy and have a right atrial pressure greater than 15 mmHg or a cardiac index less than 1.8 L/min/m2. These factors are reflective of the stability of the right ventricle, which is ultimately tied to prognosis in all PAH patients. Due to the potential for these appeals, it is important for patients to follow up routinely pre-transplant.

In addition, recent data from the REVEAL study showed that additional factors, if incorporated into the LAS calculation, would more accurately predict survival and thereby better reflect organ prioritization in patients with IPAH. These additional factors include estimates of right ventricular function, which as stated earlier, are key to determining survival in IPAH. The LAS in its current construct, more heavily weighs factors reflective of “pure lung dysfunction,” like FEV1 (a measure of airway capacity) since these predict survival better for patients with “lung diseases” like COPD. Although IPAH does occur in the lung and is hence considered a “lung disease,” these parameters are not useful in predicting survival in IPAH. This is why it was imperative to have these new “heart-related” parameters added to the LAS. This is currently under review by UNOS, and a revised formula incorporating these changes is now under consideration.

**What is life like after transplant?** Lung transplantation involves a complete lifestyle change, and while patients no longer require PH medications, they now require a new set of medications that allows their body to accept the lungs as well as prevents infections. Careful medical follow-up is crucial to success. Lung transplantation is an active medical condition that involves routine labs, pulmonary function testing, and frequent visits to the transplant center for the rest of a patient’s life. The transplant medications often have side effects, and patients frequently require additional medications to treat new conditions such as high blood pressure, cholesterol or diabetes. Although transplant involves active maintenance by each patient, it offers the possibility of helping patients with severe IPAH live longer and improve their quality of life. When all goes well and with close medical follow up, lung transplantation provides patients the opportunity to physically do activities they have not been able to do in years.

STORY CONTINUED ON PAGE 20
Meet Dr. Roxana Sulica: A Voice of Support for PH Patients

Dr. Roxana Sulica received her medical degree from the Carol Davila University of Medicine and Pharmacy in Bucharest, Romania, and completed her fellowship in pulmonary critical care and a dedicated clinical and research fellowship in pulmonary hypertension at Mount Sinai School of Medicine in New York, New York.

Dr. Sulica has served on the editorial board of the journal Advances in Pulmonary Hypertension, as well as a reviewer for numerous scientific journals, including Chest, Critical Care Medicine, Respiratory Medicine and Mount Sinai Journal of Medicine. She currently serves as principal investigator in several international, multicenter trials examining novel treatments for PH.

You specialize in internal medicine. What sparked your interest in pulmonary hypertension? I am a pulmonary critical care physician working in the PH field for the past 12 years, and I devote 85-90 percent of my time to PH. My interest has been sparked by the challenge, the unknown, the dynamism, the complexity of the field and, most importantly, by the utmost inner beauty of my patients.

What advances have you seen in the treatment of PH patients since you started practicing? I started when Flolan® was the only therapeutic option for PH patients, and I’ve witnessed and actively participated in the development of the entire pharmacopeia that we currently have available.

What do you find to be the most encouraging advances currently taking place in the PH field? I have always been impressed with the medical community’s enthusiasm and interest in raising the bar at each turn and to keep fighting for a cure for PH. We’ve come a long way, and we’re gladly following the same path to the end.

You’ve been working in the field of PH for a long time. Do any cases or patients really stand out to you and why? This question is hard to answer because even now, after years of experience, each patient still teaches me a new lesson, and they continue to surprise me with the intricacies of their disease. Most recently, after using goal-directed therapy like most experts in the field do, I started to believe that we are probably using the parenteral prostacyclins a bit too late, at least in some PH patients.

How did you become involved with PHA? PHA has always been a wonderful help and mentor to me. I have been on the editorial board of Advances in Pulmonary Hypertension, PHA’s medical journal. I have directed CME symposia sponsored by PHA, and I try not to miss any of the international meetings. PHA has great impact on our activity, and I am profoundly grateful to the work and enthusiasm of the organization.

You are active with local support groups, particularly the NYC Beth Israel group. What do you find rewarding about this involvement? I use these meetings to shed light on medical aspects of the disease, to provide psychological support and to generally educate patients about their disease, such as organizing cooking classes targeted to their pathology or inviting other healthcare professionals to talk, such as psychologists and rehabilitation technicians. It is extremely rewarding to be able to take care of the entire human being.

You are involved with the 2012 PHA on the Road: PH Patients and Families Education Forums as committee co-chair of the New Jersey program. What do you envision for this program, and what do you hope attendees will gain from it? We hope to gain awareness and to help to demystify this field. We also hope to improve relationships with front-line physicians and facilitate the care of these patients since I believe this is still an underserved population.

What is the most important piece of advice you give your PH patients? My most important advice for the patients is to seek care in a specialized PH center. We are all thrilled to work in conjunction with the local and referring physician, but this is not a common cardiac or pulmonary disease to be taken lightly. It requires experience, dedication, expertise — none of these being built overnight. At a PH center, we are endowed with multiple resources to facilitate patient care. I’d like to mention the team that is working with me because I would not be here without them: Nakia Mitchell, my coordinator of 12 years, and Rebecca Fenton, my clinical nurse coordinator, both of whom are devoted to the program to the highest extent possible.

Do you have any advice for new practitioners in the PH field? You are welcome on board, but there are dues to be paid: your time, your knowledge and your commitment. PH has to be treated with deep knowledge, respect and involvement.

Interview conducted by Rebecca Kurikeshu, PHA Medical Outreach Program Associate
In addition to their work in clinics and research labs, many allied health professionals participate in patient support groups. We spoke with a few of them to hear why they choose to be involved in support groups and what they get from these experiences.

**Sandra Lombardi, RN, Leader of the San Diego Support Group**

When I joined the San Diego support group 13 years ago, PH was an isolating disease and patients felt very alone, not knowing how to live their lives with the disease. The support group was an important opportunity for patients to connect with each other and end the isolation. I wanted to be a part of the group to help in any way that I could to improve the quality of life for our patients.

When I am involved in the support group, I really feel like I am making a difference. It is so rewarding to help even just one patient. If I can talk to a patient at a support group and help that patient to get the resources he or she needs to improve his or her life, it makes me feel a real sense of accomplishment.

**Fran Rogers, CRNP, Co-leader of the University of Pennsylvania Health System PH Support Group**

I wanted to be able to help our patients and their caregivers outside of a strictly clinical setting. To be able to sit across the table from them and enjoy a light lunch provides a different setting for education as well as information sharing. Our support group attendees share coping mechanisms and cheer each other on. The group is an integral part of helping patients live with PH.

I feel recharged after leaving a meeting. It is moving to see the way patients and their family members comfort and encourage each other. Support groups remind me why we, as healthcare professionals, need to continue to help provide hope in any way we can. My greatest satisfaction is watching one patient support another through a difficult situation, such as getting used to supplemental oxygen, coping with fatigue, facing fears, etc.

**Amy Kimber, APNP, Leader of the Wisconsin-Southeast PH Support Group**

When I began working in PH, I made it my priority to start a support group. I felt the group would be an integral part of each patient’s care plan. I believe it is important to provide patients and caregivers with a forum for sharing ideas and concerns about living with PH. My approach to patient care is to make sure my patients have the tools they need to understand and manage their own healthcare needs. I truly enjoy helping patients realize that they are not alone in their journey.

**Chris Archer-Chicko, MSN, CRNP, Co-leader of the University of Pennsylvania Health System PH Support Group**

I started the UPHS Pulmonary Hypertension Support Group in 2008 because I wanted another setting to educate patients and their families about PH and how to live with this difficult disease. I felt it would be helpful to have PH patients meet other PH patients.

Very simply, my involvement in our PH support group brings me a sense of joy. My typical days are stressful with numerous phone calls and emails, coordinating procedures, completing tedious paperwork and trying to get multiple tasks done in a timely manner. I enjoy interacting with the patients in a more social and relaxed setting. In our meetings, we invite patients to share their experiences, offer comments and ask questions. I often learn from the patients themselves. My greatest satisfaction is watching one patient support another through a difficult situation, such as getting used to supplemental oxygen, coping with fatigue, facing fears, etc.

**Antonia Heininger, BA, Contributor and Presenter for the Rochester, N.Y., Support Group**

In our work lives as healthcare professionals, we see the patient as someone with a disease who needs healthcare. We churn out prior authorizations, schedule tests, etc. At the support group meetings, we see the person and how they interact with their family, how dedicated and hardworking their caregivers are and how the disease affects them beyond the clinical setting. We get to see their latest art project and pictures of their grandchildren and hear their stories. These things are a real motivating factor for me when I am swamped with work; it helps me remember why I choose to work with people with this disease.

I find inspiration from our support group. They remind me every day not to take life for granted, to live life to the fullest, and embrace challenges. If our patients can face each new day and each new set of challenges with a smile, then I can too.
When Should You Call Your PH Center?

It can be difficult to know when you should call your PH center. Sometimes you shouldn’t wait for your next scheduled appointment or phone call. Here are some good reasons to pick up the phone.

• **Worsening shortness of breath or exercise tolerance:** PH is a disease that can change over time. Other things, like adding new medications, can also change how you feel. Try to set a benchmark for something you do every day, like walking to the mailbox. Know how you feel when you do this task. Do you have to stop once on your way to the mailbox? Twice? If this changes, let your PH center know.

• **Increased oxygen needs:** If you feel you need more oxygen or you note lower saturations, call your PH center.

• **Weight gain:** Weigh yourself every day and write your weight down. If your weight goes up two pounds in one day or five pounds in one week, give your PH center a call. Rapid weight gain can often be a sign of fluid buildup.

• **Swelling in your legs or abdomen:** This can be a symptom of PH and/or a side effect of some medications. Let your PH center know if this happens.

• **Constant or worsening dizziness or fainting:** This can be a symptom of PH and can also be a side effect of medications. Let your PH center help sort this out.

• **New medications, including over-the-counter medication:** If any doctor (like your family doctor or dentist) prescribes new medication, call your PH center and let them know. Your PH center can make sure that your new medication does not interact with any of your current medications.

• **If you are having side effects and recently began a new PH medication:** PH medications can have unusual side effects. If you note new or worsening side effects and you have just started a new medication, give your PH center a call.

• **Prior authorizations:** Insurance companies often require special permission to be on PH medications. Often those permissions need to be renewed at least annually. You will most likely hear from your insurance company about this before your PH center is notified. You should call your PH center and notify them.

• **If you notice you do not have any more refills of your medication:** Call your PH center 10 days prior to running out of your medication. This way there is not a scramble when you are down to just a couple of pills.

• **If you have a planned surgical procedure:** Such as a colonoscopy, wisdom teeth removal or joint replacements, let your PH center know so your medical team can best plan to keep you safe.

• **If your specialty pharmacy or family doctor encourages you to call your PH center:** Trust their instincts and call your PH center if instructed to do so, because sometimes your specialty pharmacy or family doctor notices issues you may not see.

• **Any questions that you have related to your PH:** Of course, if you have any questions about PH and its treatment, or your specific treatment plan, you should call your PH center.

• **If you are going to the emergency room for any reason:** Call and notify your PH Center. When in doubt, contact your PH center. The doctors, nurses and respiratory therapists who work there are on the phone frequently. Sometimes when you call your PH center, you may get their voicemail. Be sure to leave a message so they know you called.

*By Crystal Weber, RN, PH Nurse Clinician, Pulmonary Vascular Disease Center, Duke University, Durham, N.C.*
to be developed for pediatric patients.

**Social Factors:** Most people don’t really like to be different, but in kids this can be even more true. Dr. Ivy explains that it is a challenge to convince a small child to carry a backpack or wear oxygen all the time when it makes them feel like they stand out and are different from their friends. Developmentally, children rely on social interactions and understanding from their peers a great deal, and we must take steps to support this process in a way that both allows them to grow socially and addresses their medical needs.

In closing, both doctors envision a world where they can treat pediatric patients with more effective medications: medications that are easy to administer, have minimal side effects, and are dosed or even created especially for children. As Dr. Barst stresses, this will only come with increased collaboration between researchers, doctors, pharmaceutical companies and the regulators (FDA). And we cannot forget about safety — both long-term and short-term. Most of the drugs we would treat children with will continue to be used for years, if not an entire lifetime. Knowing the effects of drugs long-term, especially in children who are continuing to grow and develop, is critical.

To that end, the Robyn Barst Pediatric Research and Mentoring Fund for Pulmonary Hypertension has been established to raise funding and establish mentoring programs for promising pediatric researchers and practitioners. To learn more about this fund, visit [www.PHAssociation.org/BarstFund](http://www.PHAssociation.org/BarstFund).

*By Colleen Brunetti, PH Patient*

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

as swelling in the legs, worsening shortness of breath, fatigue or other symptoms. Get your medical certificate at the visit. Carry your PH center contact numbers with you. Ask your PH doctor who they would recommend you contact in the area you are traveling if you need medical attention.

**The Quick Checklist:**

1. Plan ahead and anticipate problems.
2. Keep emergency contact numbers for your PH nurses and physicians with you.
3. Ask your PH doctor for a letter describing why you need to carry your medications, pump and/or oxygen with you. If carrying oxygen, you will need a medical certificate from your doctor that describes why you need oxygen and the flow rate per minute.
4. Contact the airline prior to booking a flight to determine the policies on in-flight oxygen or POCs.
5. Allow extra time to maneuver through the ticketing area and security checkpoints and to reach the gate.
6. Use transport assistance whenever possible to and from the gates. Most airlines can arrange to have a wheelchair available at each connection point if given notice.
7. Carry a “reserve” of medications with you (in carry-on luggage) in case your luggage does not make it to your final destination in a timely manner.
8. Be active every one to two hours to prevent blood clots. Stop frequently or get up and move around.
9. Have fun and enjoy your trip!

*Answer provided by Eric R. Fenstad, MD, Cardiovascular Fellow, Mayo Clinic Division of Cardiovascular Diseases and Internal Medicine, Rochester, Minn.*

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**TRANSPLANT ARTICLE CONTINUED FROM PAGE 16**

In summary, for many patients with PAH, lung transplantation remains a viable treatment option, and if a patient’s disease is severe or worsening, transplant evaluation should be considered. It is better to be evaluated too soon, when a patient is “too well” so that the center can follow along and transplant can remain an option down the road should the patient’s condition worsen. While lung transplant requires a lot of medications and maintenance, it does provide the chance to improve survival and quality of life.

*For more information about transplants, be sure to visit [www.unos.org](http://www.unos.org) or [www.ustransplant.org](http://www.ustransplant.org)*

*By M. Patricia George, MD, University of Pittsburgh School of Medicine, and Raymond Benza, MD, West Penn Allegheny Health System, Temple University, School of Medicine, Pittsburgh, Pa.*

**References:**


Pulm Circ. 2011 Apr; 1(2):182-91. Lung transplantation for pulmonary hypertension. George, MP; Champion, HC; Pilewski JM.

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Frost, A; Barst, RJ; Krichman, AM; McGoon, MD. Pulm Circ. 2011 Apr; 1(2):182-91. Lung transplantation for pulmonary hypertension. George, MP; Champion, HC; Pilewski JM. Transplantation. 2010 Aug 15; 90(3):298-305. Analysis of the lung allocation score estimation of risk of death in patients with pulmonary arterial hypertension using data from the REVEAL Registry. Benza, RL; Miller, DP; Frost, A; Barst, RJ; Krichman, AM; McGoon, MD.
17-Beta Estradiol Attenuates Hypoxic Pulmonary Hypertension via Estrogen Receptor-Mediated Effects

The question: How does 17β-estradiol (E2) exert its protective effects in hypoxia-induced pulmonary hypertension? Does E2 work indirectly by being converted to certain metabolites or directly by activating the estrogen receptor?

Why is this important? Even though women are more frequently affected by pulmonary arterial hypertension (PAH), they exhibit better right ventricular function and higher survival rates than men. Women also appear to be protected from hypoxia-induced pulmonary hypertension (HPH), a type of PH that is distinct from PAH and is associated with prolonged exposure to low oxygen concentrations from chronic lung disease, sleep-disordered breathing or residence at high altitude. A better understanding of the effects of sex hormones on the pulmonary vasculature and right ventricle is therefore needed, since this 1) may help explain the reason for the observed gender differences in PH and 2) may facilitate the development of novel, hormone-derived therapies for PAH and/or HPH.

Past studies: Several investigators have demonstrated protective effects of E2 in animal studies of HPH or other types of PH. It has also been demonstrated that the phase of the menstrual cycle affects the ability of pulmonary arteries to contract: pulmonary arteries from female rats with high endogenous E2 levels contract less than arteries from female rats with lower E2 levels or than arteries from male rats. However, while these studies revealed mechanisms of how E2 affects modulators of pulmonary artery contraction, it remains unknown how E2 affects the uncontrolled growth of cells of the pulmonary artery wall that contributes to the narrowing of the pulmonary vasculature. In addition, it remains unknown how E2 improves the function of the right ventricle (a critical determinant of survival in all forms of PH). Lastly, since E2 may work indirectly by being converted to certain metabolites or directly by activating the estrogen receptor, it is important to decipher which of these pathways mediates E2 protection in HPH. This pathway may then be targeted therapeutically.

This study: Male rats with HPH were treated with E2 and co-treated with either inhibitors of the E2 conversion process or with an agent that blocks the estrogen receptor. While the conversion inhibitors did not affect E2-mediated protection, blockade of the estrogen receptor significantly attenuated E2’s protective effects. This indicates that E2-metabolite conversion is not necessary for E2 protection in HPH. Rather, it is E2’s effect on the estrogen receptor that mediates its protection.

Further experiments revealed that both of the two estrogen receptor subtypes (estrogen receptor-α and –β) mediate E2’s actions. E2 exerted beneficial receptor-mediated effects on both the pulmonary vasculature and right ventricle, which were associated with inhibition of signaling pathways that drive cellular growth and with augmentation of pathways that inhibit cell growth. In isolated pulmonary artery endothelial cells (cells that make up the lining of lung blood vessels), E2 again inhibited cell growth. However, this effect was only seen in cells exposed to low oxygen concentrations, suggesting that E2 exerts specific protective effects when oxygen levels are low. Taken together, these results suggest that E2 exerts hypoxia-specific and receptor-mediated inhibitory effects on the growth of cells of the pulmonary vasculature and right ventricle.

Who may benefit from these findings: Patients with HPH or PAH, healthcare providers and researchers.

The bottom line: While it is premature to make recommendations on the use of estrogens for HPH, this study indicates that in an environment characterized by low oxygen concentrations, E2 may exert beneficial effects on the pulmonary artery and right ventricle. Further exploration of the pathways affected by E2 may, therefore, allow for the development of targeted, non-hormonal therapies for both men and women with HPH. This is of importance since no specific pharmacologic therapy for HPH exists. In fact, the drugs that are used for PAH may worsen symptoms in HPH since they may decrease patients’ oxygen saturations. While we cannot extrapolate the current results to patients with PAH, this study, viewed in the context of previous investigations, raises the possibility that protective estrogen receptor signaling may be distorted in PAH, thereby making women more prone to the development of the disease.


Funding: This article was funded in part by an American Thoracic Society/Pulmonary Hypertension Association/Pfizer Fellowship in Pulmonary Arterial Hypertension Research to Tim Lahm. Please see the article for a complete list of the investigators’ research support.

Article provided for Pathlight by Tim Lahm, MD, Division of Pulmonary, Allergy, Critical Care, Occupational and Sleep Medicine, Richard L. Roudebush VA Medical Center; Department of Medicine, Indiana University School of Medicine, Indianapolis, Ind.
A Father and Son Team Up to Raise PH Awareness One PSA at a Time

Steve Van Wormer, a PHA Board member, has four very important things to communicate about PH, and none of them takes more than a minute. That’s because he has built these messages into four dynamic video public service announcements (PSAs) the length of most commercials.

With funding from a Tom Lantos Innovation in Community Service Award, Steve, who works in Hollywood’s television industry, wrote the scripts, assembled photos and worked with a professional designer to create additional images in PHA’s signature colors to make these messages fresh and distinctive.

Boosted by social media and public relations, these PSAs have been shared widely by Steve, by PHA and by others in the PH community. Through them, we have conveyed widely:

- The need for more research into treatments of pediatric PH (voiced by Steve’s 10-year-old son Lucas, who has PH);
- The importance of the Tom Lantos PH Research and Education Act in Congress;
- An explanation of PH;
- An introduction to PHA.

The project has been not only creative, but has gained wonderful exposure in diverse media. For instance, one or more of the PSAs have appeared:

- On YouTube;
- On the PHA website;
- On PHA’s Facebook page;
- In email messages to our volunteer advocates to support National Call-In Day for the Tom Lantos Act in Congress;
- On a satellite feed delivering all four messages to hundreds of local television stations, courtesy of West Glen Communications’ Nonprofit Give-Back program, offering free satellite time for selected PSAs;
- In print and online news outlets around Los Angeles, boosted by a UCLA Health Sciences press release on Lucas, a UCLA patient, and his experience narrating the pediatric PSA. News organizations that told the story and featured the video included CenturyCityPatch.com and The Burbank Times newspaper;
- Embedded in two personal experience stories written by Marina Van Wormer, Steve’s wife and Lucas’s mom. These were posted on two websites for parents, Babycenter.com and SpanglishBaby.com;
- In social media messages sent by PHA Board members and others to their own contacts.

In addition, Lucas’s performance and the publicity around it led to a job offer to do more voice-over work in radio and television like his father. To view all four PSAs, visit www.PHAssociation.org/MediaGuide/PSA/Samples

Opportunity in the Lantos Awards

This awareness-raising project is an example of how the Tom Lantos Awards can create opportunities for children and adults, patients and caregivers who have been touched by PH. The awards, funded by Gilead Sciences, provide monetary grants of up to $5,000 each for projects that benefit the PH community through approaches such as awareness-raising, advocacy and enhanced patient services. Recipients of these awards have done projects such as producing posters, holding educational retreats and preparing bags of small toys for children with PH.

The Lantos Awards selection process begins in the fall, when PHA begins calling for applications involving a written description of the project, its goal and its budget. A committee of PH community members reviews the applications during the winter and announces award recipients in the spring.

Is there something you’d like to do to advance the PH cause? If so, plan to apply for a 2013 Lantos Award. For more information, contact Mollie Katz, MollieK@PHAssociation.org or 301-565-3004, x774.

By Mollie Katz, PHA Vice President, Community Engagement
A Family Fights Back Against PH

By April of senior year, most high school students are thinking about prom, graduation and heading off to college. High school may be coming to an end, yet their lives are really just beginning. They will begin to learn a lot about who they are and who they want to be.

Two years ago, my little brother Jake was on this very path; he would be graduating in a couple months and starting his first semester at Temple University in the fall. He was just as carefree and optimistic as any other 18 year old — until he went in for a routine checkup for his ulcerative colitis and left in an ambulance.

While the doctor was performing a CAT scan, he saw that the right side of Jake’s heart was dangerously enlarged and had him immediately rushed to Children’s Hospital of Philadelphia (CHoP). After spending five days in an intensive care unit and undergoing an extensive battery of tests, a diagnosis of pulmonary hypertension was confirmed. From that moment on, Jake would no longer be that carefree 18 year old whom he very much deserved to be. He found out earlier than most who he was. He was now a person who had PH, and I think I could safely say that he would have rather been anyone else.

Our whole family spent the next few months digesting this diagnosis and helping Jake get accustomed not only to his first year of college, but also living his life with this chronic disease. We were very lucky that CHoP had accepted him as a new patient, even though he was already 18, and even luckier that Dr. Brian Hanna, a PH specialist, was interested in taking on Jake’s case. Dr. Hanna knew that we would be searching for more information on the disease, and he actually forbid us to look at any website other than PHA’s. With the help of Dr. Hanna, Jake was able to adjust to his new medical regimen and to integrate his disease into his life. Jake appeared to be living successfully with PH.

Unfortunately, his good fortune only lasted about nine months. When Jake went to CHOP for his annual heart catheterization the following summer, we were informed that the medicine was not effectively controlling his PH and that he would have to be put on a pump that would deliver medicine into his body 24 hours a day. Jake made a valiant effort to return to school in the fall, but he quickly realized that his body simply could not handle it. It was at this time that Jake knew he would no longer be able to pursue his dream of becoming an athletic trainer, and he withdrew from college for medical reasons.

Perhaps that first year after his diagnosis blinded us all to the reality of his disease. Maybe we were just too scared or delusional to imagine the possibility that all the negative things we read about PH would actually become Jake’s reality. One thing was for certain, we could no longer ignore it. We needed to get involved, to fight back.

I decided to create a fundraising page through the PHA website to tell people about my little brother and raise awareness of PH. I wanted to show him just how many people believed that his life was worth fighting for. The response I got was absolutely overwhelming. We were able to raise more than $5,000 in just two weeks. It goes to show that people really can surprise you if you just give them the chance.

Our mom contributed with fundraising efforts of her own as her office began a new program in which they would raise money for a different cause every other month. Many of her co-workers and friends had lived this journey with her from the very beginning, so they were more than happy to have PH be their first cause. My family and I have experienced great success in our initial fundraising efforts and plan to continue to tell Jake’s story and raise awareness of PH any way that we can.

Jake loves to make people laugh. He is undoubtedly one of the funniest guys I know, and I guarantee most of the people who know him would agree with me. Jake is smart in that natural, witty kind of way that everyone always wishes they could be. Jake dreams big, he has plans for himself that most would consider impossible given his condition. He is loyal and kind. Most importantly, my little brother is brave. In the two years since his diagnosis I have never heard him complain, not even once. I know Jake struggles with his disease every day, but he chooses to suffer in silence. Life has dealt him a less than ideal hand, yet he continues to joke his way through the pain; Jake may be a person who has pulmonary hypertension, but he has not, and never will, let his diagnosis define him. ♦

By Brooke Gunter, Sister to PH Patient Jake, and Their Mother Ellice
Grab a Piece of the Fundraising Pie!
**Join the Fight Against PH by Planning a Fundraiser**

Do you want to get more involved in the fight against PH? Consider hosting a fundraiser! Aside from raising money to fight PH, fundraisers are great ways to raise PH awareness and educate your friends, family and co-workers about PH.

The best part about fundraising is that there are so many ways to do it. Anyone can be a fundraiser — patients, family members, friends and medical professionals. There’s a fundraiser to fit every lifestyle! At PHA, we break fundraisers into four types — fundraising online, at work, at celebrations or with a special event. Every fundraiser is unique and completely what you, the organizer, make it.

**A personal fundraising page**

**is quick and easy to set up!**

You can use it to promote workplace and celebration fundraisers, too!

**At Work**

Educate your co-workers about PH and get them involved with the fight against PH. Host a Blue Jeans for PH day or a bake sale — the options for workplace fundraisers are endless!

[www.PHAssociation.org/Fundraise/AtWork](http://www.PHAssociation.org/Fundraise/AtWork)

**Online**

Join the fight against PH and make a difference without leaving your home! Tell your PH story on your own personal fundraising page and then share the link with your friends and family.

[www.PHAssociation.org/Fundraise/Online](http://www.PHAssociation.org/Fundraise/Online)

**At a Celebration**

Take your special life milestones to the next level and raise awareness and funds for PH. Ask friends and family to make a gift in your honor for your birthday, wedding, Bar or Bat Mitzvah or retirement party. Or, give a gift to PHA in your guests’ honor!

[www.PHAssociation.org/Fundraise/AtCelebrations](http://www.PHAssociation.org/Fundraise/AtCelebrations)

**With a Special Event**

Ready to roll up your sleeves and engage your entire community? Plan a special event! Get creative! Special events can be anything from Fun Walks to galas to Periwinkle Parties to pub crawls!

[www.PHAssociation.org/SpecialEvents](http://www.PHAssociation.org/SpecialEvents)

Get started! Not sure where to start? Ask us! We have a dedicated team of staff members here to support you every step of the way. We have everything you need to make your fundraiser a success!

**Meet the team!** Ready to launch your personal fundraising page, host your workplace fundraiser or fundraise at your celebration? Contact Ellen Leoni at Giving@PHAssociation.org or 301-565-3004 x756. Jessica McKearin and Leslie Mahaney are here to help you with brainstorming, questions and everything special events-related. Just email Events@PHAssociation.org or call 301-565-3004 x765.
Insurance Finds:  
Financial Assistance  
Pop Quiz!

Your prescription copayments cost more each month than your rent! Which organization can you contact for financial assistance to help cover your larger-than-life insurance costs?

A. Social Security Administration  
B. Goodwill  
C. Caring Voice Coalition  
D. Medicare

If you answered Caring Voice Coalition (CVC), you know your resources! CVC provides financial assistance to eligible PH patients, in the form of monetary grants, to help remove the barriers to starting or remaining on PH therapy.

Learn more about financial assistance resources at [www.PHAssociation.org/FinancialAssistance](http://www.PHAssociation.org/FinancialAssistance) or contact 301-565-3004 x773.

Pin on Your PH Pride with a PHA Logo Pin!

PHA Member Special: Don’t miss out on this limited-time offer!

40% OFF!  
(NOW ONLY $3)

Only PHA Members are eligible for this special, limited-time offer. Order now through Oct. 2 at the PHA Online Store, [www.PHAssociation.org/Store](http://www.PHAssociation.org/Store) or give us a call.

Not a member?

Visit [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join) to become a member of PHA today!

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

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

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

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

Like Stephen and Andrea White, you can strike a blow against PH by designating PHA as a legacy beneficiary. Your contribution will help shape a brighter future for all those affected by PH. For details, call us at 301-565-3004 x756 or email Giving@PHAssociation.org. Visit our website for more information at PHAssociation.org/Give.
PHA National Call-In Day 2012: Congressional Staffers Inundated with Phone Calls for a Cure

PH community members called their Members of Congress during PHA National Call-In Day on April 26 to urge them to co-sponsor the Tom Lantos PH Research and Education Act of 2011. Thanks to everyone who called and made the day a resounding success!

After PHA National Call-In Day, Rep. Devin Nunes (R-CA) and Rep. Richard Neal (D-MA) agreed to co-sponsor our bill, the only PH-specific bill in Congress.

Help PHA Turn Your Phone Calls for a Cure Into More Co-sponsors!

PHA has been following up with the Congressional offices you called during PHA National Call-In Day to ask them to co-sponsor the Tom Lantos PH Research and Education Act. Several members of the PH community have decided to follow up with their Members of Congress individually to continue to advocate for a cure. Here are just a few of their ideas:

- “I will be following up with printed materials about the Lantos bill and probably a DVD we made about my mom,” says Erica Huntzinger of California.

- “Just wanted to let you know that both my mom and I called our representative and senators in South Carolina. I am going to drop off personal letters from my support group members asking the representative and senators to co-sponsor the Tom Lantos PH Research and Education Act,” reports Doug Taylor of South Carolina.

- “I left word with the health legislative assistants for Senators Cornyn and Hutchinson and Representative Canseco. Since I am on a roll, I’m going to try to set up some meetings so that I can meet face-to-face and talk about our needs,” explains Sylvia Creach of Texas.

If you’re interested in starting or continuing to advocate to your Members of Congress, PHA has resources to help. Contact Elisabeth Williams at 301-565-3004 x753 or Advocacy@PHAssociation.org to learn more about the steps you can take to help get us closer to a cure!

By Elisabeth Williams
PHA Grassroots Campaigns Manager

PHA’s Conference Advocacy Challenge: Increasing PH Awareness in Congress One Contact at a Time

Since January, we’ve been counting all emails, phone calls, letters and Congressional visits from PH community members. Our goal was to inundate Congress with more than 1,100 requests for co-sponsorship of the Tom Lantos PH Research and Education Act by the end of PHA’s 10th International PH Conference and Scientific Sessions in June 2012.

PH community members gathered from all over the world at PHA’s Conference and many of them shared their stories in letters they wrote to their senators and representatives.

How many messages did the PH community collectively send? As we go to print, our count stands at more than 575 — and that doesn’t even include the letters from Conference! Stay tuned for the fall issue of Pathlight for an official count and a full wrap-up of PHA’s Conference Advocacy Challenge or visit www.PHAssociation.org/Advocacy/Victories!

PHA’s Conference Advocacy Challenge is over, but it’s never too late to advocate for the PH community. Contact Elisabeth Williams, PHA’s Grassroots Campaigns Manager, at ElisabethW@PHAssociation.org or 301-565-3004 x753 to find out how to talk with your Members of Congress about research and education that will save PH patients’ lives.
PHA Board Chair Laura D’Anna Spreads PH Awareness to Congress

In April, PHA Board Chair Laura D’Anna came to Washington, D.C., to raise PH awareness and ask her senators and representative to co-sponsor the Tom Lantos PH Research and Education Act of 2011. We asked Laura a few questions about her experience on Capitol Hill.

What was the best part of your day on the Hill? We were received warmly in each office, and I appreciated the opportunity to connect the importance of our bill to my personal story of losing my sister to PH and the stories of countless others who remain undiagnosed. I also really valued the opportunity to conduct these visits with my two children. It was their first time on the Hill, and sharing with them the importance of being an advocate for causes in which they believe was a truly memorable experience for me.

What tips do you have for PH advocates? The most important thing is for advocates to tell their stories in their own words. Elected officials and staffers hear thousands of requests from their constituents annually, so in the few minutes we are with them, it is important to highlight why our request is critical. Our story is a compelling one given the complexity and severity of PH, the need for additional research, the requirements for specialized knowledge among medical providers, the fights to obtain an accurate diagnosis and appropriate care, all that has been accomplished through PHA, and the support we have at the National Institutes of Health (NIH) and Centers for Disease Control and Prevention (CDC).

And PHA makes it easy to do with a wealth of information and resources at www.PHAssociation.org/Advocacy/Toolbox. The staff is also on hand to assist with in-person visits and letter-writing campaigns.

You’ve followed up with each of the offices since your visits. What was the response? I visited staff from the offices of Sen. Barbara Boxer (D-CA), Rep. Laura Richardson (D-CA) and Rep. Dana Rohrabacher (R-CA). We were not able to meet with staff from Sen. Dianne Feinstein’s office (D-CA), but we did leave a personalized letter and a stack of letters from PH community members. Since my visits, I sent follow-up notes to all of the staff with whom we met. I’ve already received confirmation from Rep. Richardson’s office that she will co-sponsor the bill, which was very exciting news. For me, it really demonstrated the importance of doing these visits! I’m continuing to follow up with Rep. Rohrabacher, Sen. Feinstein and Sen. Boxer by email. I’ve also sent them additional letters from their constituents so they know this issue is important to many PH community members in their respective districts.

Why do you think the PH community should advocate for the PH Research and Education Act? This legislation will allow us to continue to receive critical support from the NIH to fund PH-specific research, and it will assure additional CDC-driven support for education for medical professionals and the public. Beyond the specifics contained in the bill, if passed, this legislation would significantly raise the awareness of PH within Congress and would then facilitate additional requests in the future.

In some ways, this process is a numbers game, and those who have the greatest number of constituents advocating for any particular issue typically gain the support of their legislator. Because PH affects relatively few Americans compared to other diseases, it is even more important that we have a good proportion of our community talking to their Congressional representatives.

Anything else you’d like to add? We can move this legislation through, but we need your help! If you have already reached out to your Members of Congress, please do so again. I don’t think they can hear from us too often. Numbers matter and we are counting on you! PHA has several resources available to help you:

• If this is your first time contacting your Members of Congress, please log on to www.PHAssociation.org/TomLantosPHResearchAct/Senate and fill out a letter to your Members of Congress today. All you need to do is add your contact information and share your story!
• Visit www.PHAssociation.org/Advocacy for specific tips on how to create an email request to set up an in-person visit with your senators or representative.
• Contact Elisabeth Williams at 301-565-3004 x753 or ElisabethW@PHAssociation.org to get more involved in educating your Members of Congress about the only PH-specific bill in Congress.

Interview conducted by Elisabeth Williams, PHA Grassroots Campaigns Manager
Have you ever listened to a news report and wondered why editors chose the stories they did? Understanding what makes a story attractive to journalists makes a big difference in successfully getting a PH-related story into the media.

To explain what wins a journalist’s attention, PHA turned to Robert McCartney of the Washington Post. McCartney, a local columnist and former top metro editor at the Post, has often evaluated and selected stories offered by advocacy organizations like PHA. He says that to be effective, story ideas should contain as many of the following elements as possible:

- **Timeliness.** A journalist’s job is to tell the news — what is happening now. To gain attention, McCartney recommends contacting the media with something that’s just happened, recently happened or is just about to happen. Connecting your story to a trend also provides a helpful context for your idea within a larger scope. For instance, the trend of more children surviving to young adulthood with PH can be the backdrop for the personal story of a patient under age 30.

- **Relevance to the audience.** Will your idea or event have the most impact in a suburb or part of a city? McCartney says suburban or neighborhood media, including highly localized online news sites, may be the best route. If pitching a story in a larger city, look for a local angle that’s meaningful to a wider population, he says. Then you’ll stand out more from the many other worthy organizations also competing for coverage.

- **Human interest.** Stories about overcoming adversity, spurring community involvement and overcoming the odds are good attention-getters, McCartney says. Personal experience stories about living with PH are rich in these themes.

- **Visual material.** Print, television and online media need to look good as well as sound good, so the opportunity to use photos or video appeals to editors. McCartney emphasizes that visuals should help tell the story. Images of people doing activities are one strong approach. Other ways to provide good visuals might be staging a balloon launch, showing a crowd expressing its spirit, or presenting medical equipment for PH patients with an explanation of how it is used.

- **An expert.** Especially with a disease as little-known and complex as PH, a doctor, nurse practitioner or other allied health provider brings the depth of knowledge often needed to answer journalists’ questions.

- **A one-page fact sheet.** Putting the key information at a journalist’s fingertips is important, McCartney notes. Always include dates, times, places and contact information for special events. For stories of PH patient experiences, write a very brief summary of the patient’s story, highlighting what makes it interesting or inspiring. Add basic information about PH — the condition, symptoms and treatment — or enclose PHA materials as background.

**Who to Contact**

McCartney also recommends that those contacting the media approach a variety of staff at a single news organization simultaneously. For instance, a story about a PH special event might be pitched to a local editor, a local reporter, a health editor, a health reporter and someone who covers nonprofits and philanthropy. The more people you try, the more likely you are to find your idea accepted.

He says the fastest way to get the right names is to call the newsroom and ask. When pitching your idea, however, be sure to tailor your message — showcase the health angles to the health journalists, for instance.

Any single news organization is not likely to cover PH-related stories often, McCartney says, so volunteers may want to put news organizations or journalists in priority order. He suggests saving the very most compelling stories for the news outlets most important to your effort, while sharing the lesser ones with a wider range of newsrooms.

PHA’s Advocacy & Awareness department always welcomes new volunteers interested in seeking coverage through our PHAware Campaign. We are also available throughout the year to help you solve media relations challenges. Visit [www.PHAssociation.org/Awareness](http://www.PHAssociation.org/Awareness) to learn more, or contact Elisabeth Williams at 301-565-3004 x753 or ElisabethW@PHAssociation.org.

*By Mollie Katz*

*PHA Vice President, Community Engagement*
Advocate for PH This August (Without Leaving Your Home State!)

This August, as Congress goes into recess, Members will return to their states to meet face-to-face with their constituents about the issues that matter to them. Take this golden opportunity to meet with your Members of Congress and urge them to co-sponsor the only PH-specific bill in Congress, the Tom Lantos Pulmonary Hypertension Research and Education Act.

To get you started, here’s advice from three advocates who have found Congressional meetings effective and rewarding.

What was your first district visit like?

**Dick Tunstall:** At first, I had trouble getting a meeting with my Members of Congress, so I decided to set up appointments toward the end of the summer. Around August, it’s easier to set up appointments with Congressional Members because they have more time and are more relaxed. That’s how I got my first visit with then Rep. Chris Shays in his district office in Connecticut.

Rep. Shays didn’t make a commitment after that first visit, but I made a second visit and that meeting was a slam dunk. He was familiar with the bill and pulmonary hypertension and agreed to co-sponsor almost immediately.

What is your advice for PH community members who want to visit their Members of Congress this August?

**Dick Tunstall:** Be persistent, keep focused, know your facts and be professional. Before that first visit, I practiced, practiced, practiced what I was going to say. I also had a one-page sheet that served as my 30-second elevator pitch with quick answers to questions about the disease and the bill. I spend the first few minutes of every visit walking staffers or Members of Congress through that information sheet.

**Diane Ramirez:** Get someone else to go with you. Remember, you don’t have to be a patient to advocate for this bill! Caregivers and loved ones also have been touched by PH. Their experiences are valuable to share.

**Joan Stevenson:** I have three pieces of advice:

1. Be prepared with facts and props to show what it’s like to have PH. It could be a medication list with the costs of each drug or simply showing your oxygen tank, pump or other medications.
2. If you don’t know the answer to a question, say you will look it up and get back in touch with the congressional office.
3. Don’t forget to smile!

Share a memorable experience that happened during one of your visits.

**Dick Tunstall:** Rep. Jim Himes was a newly elected member and rather new to his office in Stamford, Conn., when my group met with him. One of the PH patients, a resident of Stamford, pointed out a landmark outside the window. Jim admitted he wasn’t sure whether he was looking west or north because he’d never really looked out the window before. We kidded him about showing him around to become more familiar with his district, but the lesson there is sometimes these Members of Congress don’t know everything. It’s our responsibility to teach them about the need for more PH research and education.

**Diane Ramirez:** After meeting with Elizabeth Dole, the former Senator from North Carolina, my group and I stood up for a photo with her. As we stood there, one of the patients unhooked her Remodulin® pouch and placed it around Sen. Dole’s waist. She was shocked by the weight. She gave each of us a big hug and whispered “thank you” in my ear. It was a day when the joy and tears and all the hard work made sense!

Why do you think meeting with your Members of Congress is important?

**Joan Stevenson:** It is important because PH is life-threatening, but it isn’t common. The more we visit our elected legislators, the more they will be aware of PH.

**Diane Ramirez:** When I stand up and share about my life with PAH and talk about the help we need for research and a cure, I have become an integral part of the solution. I feel like I am actively making a difference for myself, my friends, my family and the PH community. It’s an incredible feeling, and I want everyone to feel this at least once in their PH journey.

Visit [www.PHAssociation.org/Advocacy/DistrictVisit](http://www.PHAssociation.org/Advocacy/DistrictVisit) or contact Elisabeth Williams at 301-565-3004 x753 for more advice and resources to help you with your district visits in August.

By Elisabeth Williams
PHA Grassroots Campaigns Manager
Advocacy has always been a central component of our work at PHA. We advocate on Capitol Hill for the Tom Lantos PH Research and Education Act, we join with other groups in calling for adequate funding of research at the National Institutes of Health, and we make the case for certain specific disability policy changes at the Social Security Administration.

But did you know that the Food & Drug Administration (FDA) offers opportunities for patients with serious or life-threatening diseases to represent their disease communities when new products are being reviewed?

The FDA, which approves the safety of drugs and medical devices, has woven patients’ concerns into its approval process since the 1990s, when the HIV community sought to express its voice as treatments for HIV were first becoming available.

How the Program Works

The Patient Representative Program allows patients, caregivers, medical professionals and advocates of those affected by a rare or life-threatening disease to play a direct role in the decision and policy-making process at the FDA. Patient representatives attend biannual meetings, provide disease-specific perspectives and vote on issues pertinent to their disease communities when a product or therapy (drug, biologic or medical device) related to their illnesses is under review. Patient representatives have worked with the FDA on illnesses such as cardiovascular disease, lung transplantation, lupus, sickle cell disease and obesity.

The goal of this program is to help the FDA understand the unique objectives and needs of those affected by rare and life-threatening disease. Most FDA policymakers are scientists and physicians looking at new products from a technical perspective. Patient representatives, on the other hand, bring knowledge and insight into how people actually use drugs and medical devices. Often they note circumstances that others with decision-making power might have overlooked.

The Patient Representative Program allows people without advanced degrees to play a significant role in the decisions made by the FDA. The FDA regards these representatives as spokespersons for the community of others with the same disease. While there is no formal education requirement, detailed knowledge of your specific disease and a strong advocacy background is preferred. Before each meeting, patient representatives are given approximately 10 hours of scientific reading.

The FDA’s Office of Special Health Issues provides orientation on an individual basis for patient representatives. The orientation includes basic information about the mission and structure of the FDA, the function and structure of advisory committees, the role and responsibilities of the patient representative, and conflict-of-interest information pertinent to being designated a special government employee and receiving compensation for relevant service, travel and lodging. New patient representatives may also be able to observe an advisory committee meeting before they begin serving in order to better understand the deliberation process. The FDA encourages these representatives to be in touch with others who have filled this role to learn from their experiences.

Take Action Now

Are you interested in applying to represent the PH community to FDA? An application can be found on the FDA’s website, www.fda.gov, along with detailed instructions on pursuing the opportunity. You may also contact Mollie Katz at PHA to discuss your interest at MollieK@PHAssociation.org or 301-565-3004 x774.

By Emily Dreckshage
Former PHA Advocacy & Awareness Intern

Welcome, Erin Wiegert, Executive Program Associate!

As PHA’s Executive Program Associate, Erin is part of the team that supports the work of PHA’s president. Erin serves as the primary liaison to PHA’s Board of Trustees, maintains PHA’s historical archives, assists with PHA’s corporate programs and assists with other projects that are of priority for the president and the organization. Erin graduated with a B.S. in Journalism from Boston University. She can be reached at ErinW@PHAssociation.org or 301-565-3004 x762.
Thank you, Interns!

PHA extends its heartfelt thanks to our spring 2012 interns. They have made a real difference in the programs and services PHA provides. To learn more about PHA’s internship program, visit [www.PHAssociation.org/Internships](http://www.PHAssociation.org/Internships).

**Emily Dreckshage, Advocacy and Awareness**

While at PHA, Emily sought to increase the patient’s role in PHA’s advocacy and awareness campaigns. By updating special events packets and media kits as well as directly reaching out to PH community members, she helped demystify this often-intimidating process. Emily helped raise awareness for PHA’s second annual National Call-In Day and encouraged constituents to reach out to their Members of Congress. She also worked on the Early Diagnosis Campaign and wrote an article for this issue of Pathlight (see p. 30). “My favorite part of this internship was speaking with patients and support group leaders. Their passion was contagious and provided me with limitless inspiration for this underrepresented cause,” says Emily. This fall Emily will begin her senior year at the University of Maryland, where she is majoring in Public & Community Health, with a minor in Spanish. She eventually hopes to pursue a career in nonprofit management.

**Ashley Kallarakal, International Services**

During her internship, Ashley helped prepare for the International Leaders’ Summit at PHA’s 10th International Conference. She also helped increase international membership in PH Clinicians and Researchers (PHCR), PHA’s medical membership network for physicians and researchers. She worked to raise awareness of World PH Day, and helped maintain communication with international PH organizations. Ashley graduated from Boston College in May 2011, and she is currently working on her master’s degree in Public Health at George Washington University, concentrating on Global Health Communications. She works part time for Dhoonya, a Bollywood/fusion dance fitness studio, and she says, “It’s funny how health has managed to take over my life between my MPH, working with PHA, and teaching and dance classes for Dhoonya. I love it!”

**Ashlynn Profit, Marketing and Communications**

Ashlynn’s main task was to assist the Meetings & Conference Planning Department with PHA’s 10th International PH Conference. She wrote and designed Table Talk Tidbits, a pre-Conference newsletter highlighting what to expect at Conference. She developed a Conference flier for families, researched and secured a Conference photographer, assisted with adding information into the Conference mobile application, and helped edit the Conference Program/Handout book. Ashlynn also wrote for PHANews, PHA’s biweekly e-newsletter, and helped plan Table Talk, the Conference on-site daily newsletter. Ashlynn says, “My favorite part about working at PHA was learning so many new things from a great department and feeling like everything I did actually meant something to someone in the amazing community PHA serves.” She is a junior at George Washington University, majoring in Communication and minoring in Journalism.

**Danica Sun, Volunteer Services**

Danica Sun is a recent graduate of Florida State University. She has a special connection to PH: her aunt, Joy Morgan, has had PH for more than seven years and is the Central Florida Support Group Leader. During her internship, Danica interviewed many support group leaders and Patient-to-Patient Support Line volunteers to promote new programs and resources for the community. In addition, she worked closely by phone and email with new leaders, helping them to start patient support groups. This fall Danica will enter her first year at Ave Maria School of Law in Naples, Fla. In her spare time, she will help coordinate a 5K/PHun Walk fundraiser with her aunt. “Interning at PHA, and especially being a part of the Volunteer Services team, has been an absolute privilege and an asset to my future career goals,” Danica says. “Most of all, I’ve enjoyed working with the most wonderful individuals on the planet, our support group leaders and Support Line volunteers!”
On March 4 the iSeek PH Cultural Center, a Chinese non-governmental PH organization, held an awareness activity named “Seeking Blue Lips and Focusing on Pulmonary Hypertension.” This was one of the first times that a Chinese NGO spread PH awareness to the general public. More than 1,000 people witnessed the activities at the iSeek booth, which spurred strong responses from websites, TV, newspapers, and the like.

Professor Chen Jingyu, an expert in lung transplantation and a representative of the National People’s Congress, educated the public about PH patients and their symptoms, such as blue lips. He also advocated for equality among healthy individuals and PH patients; currently, treatment costs are high and the medical system for rare-disease patients in China is poor. Dr. Xu Xiqi, who is a PH specialist at No. 361 Hospital, also talked about the origin of PH and treatments.

Many PH patients enthusiastically participated in the day’s activities. One attendee sang her song, “Stubbornness,” which helped all of us understand the strong spirit of PH patients. Chang Xinyue, a girl from Shanxi, spoke of her difficult journey with PH, which moved everyone in the audience. Yong Mei, a famous actress as well as the spokeswoman for the Rare Disease Office of the China Charity Federation, cheerfully sang along with PH patients.

These activities also provided a platform to share medical information. Several doctors gave free consultations, PH patients shared their experiences with newly diagnosed patients, and patients and their families spoke with one another about transplantation and medicine.

More than 99 percent of the visitors had never heard of pulmonary hypertension, but they were quite willing to join the activities and leave their blue lip prints. We have collected more than 100 blue lip prints and will keep on collecting from this day on to promote PH awareness. The activities also promoted Rare Disease Day and the “PuckerUp4PH” campaign in China. The collection of blue lip prints will be undertaken by iSeek among universities and residences in Beijing.

It is important to raise awareness of PH in China because PH patients are not entitled to financial assistance for their medications; all of their treatments are self-paid. Although a few of the PH pharmaceutical enterprises have charitable programs, more than 80 percent of PH patients cannot afford treatments, which leads to unnecessary deaths every month. iSeek tries its best to provide information to patients about medical care, education, employment and traveling. iSeek also is working to achieve early diagnosis, early treatment, and treatment coverage.

The event ended with iSeek’s connection to three new PH patients. We are now seeking appropriate medical support for those individuals.

By Ziye Li, Executive Director, iSeek PH Cultural Center, Beijing
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 international highlights are a testament to the hard work on the part of PH community members everywhere!

- **In Argentina**… Each month, HIPuA (Hipertensión Pulmonar Argentina) hosts meetings for patients and caregivers called “Learning to Live with PH.” They consist of an education program led by hematologists, nutritionists, emergency medical technicians, doctors and alternative therapy practitioners. The program also brings in psychologists to help PH patients deal with the emotional toll of living with the illness.

- **In Europe and the U.S.**… The National Organization of Rare Disorders (NoRD) in the U.S. has teamed up with the European Organization for Rare Diseases (EURODIS) to create communities for rare-disease patients around the world. The goal is to help patients who speak different languages connect with one another. For more information, visit www.rareconnect.org/en/community/pulmonary-hypertension

- **In Indonesia**… The first Indonesian PH Support Group was held in March 2012. Six patients attended from Jakarta, including a pediatric PH patient. The “Indonesian PH Family” has connected with 15 PH patients in that country.

- **In Israel**… The second annual Yarid Shira, in memory of PH patient Shira Dinur, was held on May 28, 2012. The evening consisted of music, entertainment, a raffle and buffet. All proceeds went to the Israeli Pulmonary Hypertension Association.

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

By Meghan Tammaro, PHA International Services Manager

Communities Across the Globe Celebrate World PH Day

The Asociación Nacional de Hipertensión Pulmonar (ANHP) created World Pulmonary Hypertension Day, May 5, to raise awareness of PH on a global scale. The event consisted of a Scientific Symposium on May 4 for PH physicians, followed by the main World PH Day events, a cocktail gala and the ANHP General Assembly in Madrid, Spain, on May 5.

World PH Day was truly an international event. Not only did patients’ organizations, rare-disease associations, international organizations and scientific societies endorse May 5 as World PH Day, but many patient organizations also held events in their own countries to celebrate it. Though the main celebration was in Madrid, satellite celebrations took place in New Zealand, Argentina, Israel and the U.S. In total, 40 PH and related disease organizations endorsed the event.

World PH Day is the day of the disease. While patients can participate and take pride in the event, so too can clinicians, researchers, pharmaceutical company representatives and health professionals. Nurses, too, played a crucial role in World PH Day because they are so closely linked to patients and they can claim World PH Day as their own. ANHP is very proud to belong to the PH community. We don’t feel the need to create a worldwide organization, but we strongly believe in the power of raising our individual voices for one common interest, the PH patient, regardless of where they live and what organization they belong to.

We believe that we are small because prevalence of PH is not high, but we are wrong; World PH Day taught all of us we are not alone. It is a privilege to know that a patient in Madagascar or a civil servant in New Zealand can say, “I own World PH Day.” And other owners will answer, “Yes, you do. Take care of it and make it grow.”

By Juan Fuertes Guillén
Coordinator, Asociación Nacional de Hipertensión Pulmonar
Spotlight on a Patient-to-Patient Support Line Volunteer: Rita Orth

For years, I thought my difficulty breathing was because I was overweight and needed to exercise more. However, in 1999, I was diagnosed with PH. I was overwhelmed and fearful, so I began looking into resources at PHA. During the first few months of being diagnosed, calling the Patient-to-Patient Support Line helped me through my toughest times. My outlook on my diagnosis changed, and I felt a new hope.

About six years ago, I decided I wanted to become a Support Line volunteer because I was very passionate about helping patients and giving them the same support I was given years ago. I’ve been living with PH for more than 13 years. Prior to that, I was a nurse. My role as a Support Line volunteer has allowed me to continue to help others.

As a Support Line volunteer, the calls I receive deal with a multitude of issues and a variety of emotions. Sometimes I’m crying with the patient; other times there is a lot of laughter and gratitude. I believe my role as a Support Line volunteer is to alleviate the fears and anxiety of patients.

PHA asked me about my experiences as a Patient-to-Patient Support Line volunteer, and here’s what I said:

**Why should someone call the Support Line?**

There are many reasons a patient should call the Support Line. If you feel you need more information about PH, need a shoulder to lean on, can’t seem to find anyone else to relate to, want fears to be taken away, need support, or encouragement … you should call! Maybe you are a family member who doesn’t understand PH or why your loved one looks normal, but is actually very sick … Call in!

**Have you ever had a memorable experience on the Support Line?**

One time I was on the phone with an individual who was a bishop of a Mormon church. He was a very nice man but was having a hard time adjusting to getting help, as he had just been diagnosed with PH. It became clear how overwhelmed and depressed he was. After he was on the phone with me for a few hours, his entire demeanor changed. Being a Support Line volunteer, you hear many times how grateful someone is, but hearing it from this man saying, “You don’t know how grateful I am” was one of my most memorable experiences.

**Did you ever have a caller who affected you emotionally or brought you to tears?**

One time I had a caller who was a woman in her early 30s. She just had a child and lived near me. The woman was just diagnosed with PH and was absolutely devastated. I tried to lift her spirits on the call, as well as speaking to her husband who was also upset. I invited them to my support group meeting, and after attending the meeting, they told me, “You’ve given us hope; thank you.”

**Do you ever feel like you saved someone’s life?**

I’ve told individuals that back when I was diagnosed with PH, there was only one therapy. Now there are nine. I tell them PH is not a death sentence. I also suggest they see a medical professional who has had patients with PH in the past. I stress that it’s important to find a doctor who knows how to treat PH. I tell them to ask the current doctor, “Do you treat anyone with PH?” After giving one individual this advice, he switched to a new doctor the same week we spoke on the phone!

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

There is hope. I believe the cure is around the corner. Additionally, PHA has so many resources to offer to help you as you live with PH. Join a support group!

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*By Rita Orth, PH Patient, and Danica Sun, former PHA Volunteer Services Intern*

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**Patient-to-Patient Support Line: 800-748-7274**
The PHA Support Group “Scoop”

What do planting herbs, guided relaxation and identity theft have in common? All were recent topics of PH support group meetings! Many believe support groups are “doom and gloom,” but it’s not true — they provide outlets to relax, useful tips for living better and more.

Little-known fact: yoga can be done on a chair. It’s true! The Dallas PH Support Group received a demonstration of “chair yoga.” Members learned breathing and stretching techniques to help them improve their health. Central Florida Support Group members learned a little bit of yoga as well. The Inland Empire PH Support Group which meets in Riverside, Calif., experienced “Guided Relaxation” and learned other ways to reduce stress.

Put your feet up and let us help you with your chores — your local support group might just be able to help you find help around the house! The Southwest Florida PH Support Group and the group in Mercer, Pa., brought special relationship managers and administrators to teach members how to make their homes safer and make housework easier to manage. You never know what you’ll learn at a PH support group!

Do you know where your driver’s license is? The Midlands/Palmetto, S.C., PH Support Group featured a speaker from the local government’s Department of Consumer Affairs to talk about identity theft!

Put your coffee mug down and read this: members of the Brevard County, Fla., PH Support Group received tips from a sleep disorder specialist about how they can eat their way to a good night’s sleep. The Kentuckiana/Louisville and Portland, Ore., PH Support Groups featured speakers discussing ways to maintain an anti-inflammatory, heart-healthy diet. Patients in Newark, N.J., dished about “food makeovers” — or how they can make their favorite foods tasty with less salt and fat. Long Island — Nassau, N.Y., PH Support Group members met at Whole Foods and had a cooking demonstration and tour of healthy food options (see photo on p. 37).

Imagine if a storm cut off your electricity or running water; for a PH patient, advance preparation can make a world of difference in managing health in an emergency. Fortunately for patients in Port Charlotte, Fla., the local EMS came to a meeting and spoke on hurricane preparedness.

Ever heard of art for the heart? Crafting, drawing and painting can be a good way to relax and de-stress.

The Cleveland, Ohio, PH Support Group hosted a special meeting about bonding and self-expression through art.

The Philadelphia, University of PA Health System PH Support Group is digging in the dirt! Members learned about gardening during a recent meeting.

The Valley of the Sun (Phoenix, Ariz.) and Dallas PHriends PH Support Groups brought medical experts to discuss pain management.

I’ll take “Pulmonary Hypertension Trivia” for 500, Alex! PH support groups took “Jeopardy” to a personal level: several group leaders used game show-style trivia with PH facts to educate and spice up their meetings.

Patients tested their PH knowledge at recent meetings in Mid-Hudson Valley, N.Y., North Central Florida, Jacksonville and Santa Barbara.

PHA welcomes first meetings of new groups: South Jersey; Shreveport, La.; Springdale, Ark.; Binghamton, N.Y.; Corpus Christi, Texas, and Flint/Saginaw, Mich.

PH groups in South Dakota have the distinction of operating in one of the few states to have no PH clinics. Their April meeting was the largest in their history; 30 came together, including five who were new to the group. This turnout represents three times their regular attendance. Cindy Schulz, the new support group co-leader, attributes it to the interest in guest speaker Dr. Kevin Vaska.

Dr. Deborah Levine spoke at the Eastern Panhandle, W.Va., PH Support Group on improving patient and medical professional relationships for better healthcare.

Ft. Myers, Fla., PH Support Group Leader Bob Hertz worked hard to set up his largest meeting to date, bringing an international PH leader: Gerald Fischer, PHA-Europe President. Patients around the region traveled to this meeting, including the South Florida Latino PH Support Group, which rented a shuttle to bring patients to the meeting.

The Ft. Wayne, Ind., PH Support Group, was very pleased to host Dr. Vallerie McLaughlin as its special guest speaker. According to one patient, “Dr. McLaughlin is the most awesome woman ever! If not for her, I’d have died. She saved my life twice! She is always at the forefront of new technology, medicines and techniques for keeping us healthier longer.”

By Debbie Castro
PHA Director, Volunteer Services

PATHLIGHT SUMMER 2012 Patient-to-Patient Support Line: 1-800-748-7274
Generation Hope Members Gather for First Meet-up

The first meet-up of Generation Hope members took place on May 12 and was a smashing success. After years of communicating online through PHA’s Generation Hope email group, a group for patients in their late teens, 20s and 30s, members met in person for the first time on Broadway in New York City.

Eleven patients and three caregivers traveled from near and far to participate, including Connecticut, New York, New Jersey, Maryland and Nebraska.

“The weekend allowed me to more easily humanize an amazing set of cyber-friends … to make real and lasting connections with many who share similar hopes and dreams and fears and struggles,” says Joshua Griffis, PH patient and Generation Hope Advisory Board member. “It was a weekend to be real, to be raw, to be beautiful — a weekend to be forever remembered. My only regret was that not everyone could attend.”

The group was a powerhouse of leaders and diverse patient populations: two male patients, two male caregivers, six support group leaders, one Board member and one celebrity patient (Kirsten Larson, who raised PH awareness on Mystery Diagnosis, The Montel Show and Who’s Wedding Is It Anyway?).

“For me, it was seeing everyone come together, the excitement in their voices as they met for the first time or saw each other after a long time had passed,” says Colleen Brunetti, PH patient and PHA Board member. “It was listening to the chatter around me and hearing people connect not just about PH, but life in general. It made all the work on Generation Hope the past few years come alive and feel so worth it!”

The group had a late lunch at Ellen’s Stardust Diner, spent time at a flea market in Times Square and finished the night at a cafe. The conversation flowed freely and occasionally included PH, with members discussing birth control, pregnancy, exercise, diet and healthy sleep habits. The group also discussed how to find support when your family is in denial.

“I liked everything about the meeting. It was great to get to meet PHers who were my age. I always feel like I’m the youngest at my support group meetings, but here everyone was just like me. It was so cool!” says Kiara Tatum, PH patient and Generation Hope member. “I loved singing along with the wait staff at Ellen’s Stardust Diner, shopping with Alex Flipse, laughing and having a fun time with everyone. It felt so good just to be there and get to know everyone.”

To learn more about Generation Hope or to connect with the Generation Hope email group, visit www.PHAssociation.org/GenerationHope

By Debbie Castro
PHA Director, Volunteer Services

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

www.PHAssociation.org/GenerationHopeBlog

Find a Meeting Near You!
Check out the new support groups calendar! PHA created a sortable, easy-to-use calendar that can help you find support group meetings in your state and across the country. Now it’s easier than ever to connect with others living with PH. Visit www.PHAssociation.org/SupportGroupCalendars/AllStates
Support Groups Make Connections Across the Country

Who doesn’t love to eat and talk about food at the same time? This past spring, the Nassau, N.Y., PH Support Group met at Whole Foods in Jericho, N.Y., for a nutritional luncheon and seminar. They got to enjoy some delicious food while learning how to prepare healthy recipes!

Are PH support groups fun? BINGO! The Charleston, W.Va., PH Support Group created a twist on traditional games like Bingo and Scrabble — they used PH words and terminology for their party. Members also enjoyed a picnic at this social meeting.

Our PH doctors are hardworking, but they know how to have fun and are very much a part of the PHamily! Dr. Christopher Fiak (left) from Queen’s Medical Center in Honolulu is “hanging loose” with Barbara Gamer, Hawaii’s former support group leader, at a typical group meeting.

The Springdale, Ark., Support Group met for the first time in April. Through tears, one of the group members told Deloris Peacy, the support group leader, “You really did help me. I feel so much better after coming to this meeting.” The group is small but powerful and PHA salutes it in its work!

Let’s not forget about PH nurses! Susan Tointon, RN, Mayo Clinic in Rochester, Minn., really loves her local support group! She donated this banner to the Twin Cities, Minn., Support Group. Stephanie Layer, the support group leader, says, “We really appreciate her kindness, and we will use this at every event. Thank you, Susan!”
North Texas Fun Walk: Going Strong Since 2007

Diane Dauwalder of Ft. Worth, Texas, and Marcia Beverly of Dallas are proving that combining forces for a common cause can lead to spectacular results. Not only are they PH patients and support group leaders in their respective communities, but they have co-chaired a PHA Special Event, the North Texas 5K Run and PHun Walk, now in its sixth year. We asked them to tell us more about the event, which takes place Nov. 3 this year. To read the full interview, visit www.PHAssociation.org/SpecialEvents/NorthTexasWalk.

What made you decide to host a PHA Special Event?

Diane: Like everyone else, it took forever for me to be diagnosed: [I went to doctors in] three different states and nobody knew what PH was. We needed to get the word out about PH so others would get diagnosed earlier.

Marcia: I am co-leader for the Dallas Support Group and we work together with the Ft. Worth group a few times a year. We wanted to do a fundraiser and this seemed the easiest way. Our first PHun Walk was in 2007.

How has the event grown over the years?

Diane: The first few years we had only patients and their families. And there were not a lot of us in North Texas. Also, not all of us were able to participate due to illness. But we still had fun. We did a $1 raffle of donated items and everyone was able to go home with a prize. Last year we had about 150 in attendance and this year we are looking at close to 500 people. We’ve gone from raising $3,000 our first year to $9,000, and this year we hope to double that. This year we are at our third park. We have patients who live in that community, and that helps to get sponsors. Local businesses don’t want to be left out if other businesses are participating.

Marcia: We started with just the two combined groups of Dallas and Ft. Worth. When we are combined, we call ourselves the North Texas PH Support Group. In the beginning, it was just patients and families, plus the medical staff at our clinic. We had about 60 people. The raffle was mostly garage sale-type items. We had a minimal amount of food and asked people to bring a dish.

The next year we had about 100 people and had some friends of patients join us. It has continued to grow each year. At our fifth event, we wanted to expand, so we added a 5K PHun Run. We didn’t have much help, so we just did the best we could. We had only 10 runners, but that was 10 more than the year before. This year we have a committee, with two members who are runners and are not sick, so we are already off to a major start. We had our first runner sign up in April.

What has been the greatest key to the event’s success?

Diane: For the 5K race, because we are obviously not runners and never organized a race, we had no clue what we were doing. We hit a lot of dead ends and found out it costs money for timing racers and tags. We learned a lot. This year is very different and the big key to our success will be the efforts of two healthy people; one is a mom to a PH patient in our support group and the other lost her dad to PH. These two people are helping us take our event not just to the next level, but many levels up! We had our first runner sign up in April!

Marcia: The growth is due to word of mouth and Firstgiving. It is so easy to set up your own web page on Firstgiving.com and let your friends and family know about the event. Having this wonderful committee with people knowledgeable about 5K runs and sponsorship to help us and using a professional group for the 5K run has taken this event to a whole new level. In fact, I think we skipped a few levels and are greatly expanding.

What has been the most difficult obstacle to overcome?

Diane: Getting sponsors and media attention. Previously we have done it all ourselves with help from family and friends. We sent out news releases and emails to media but received no attention.

Marcia: For me, personally, it has been the media challenge. Local media has been zilch but that will change this year. I have worked for six years to get anything on TV or newspaper and met with no success. I suppose I could have tried harder but it has been intimidating. I think this year, with all the things we have going on and our...
**The Woodlands CrawPHish Festival**

*Location:* The Woodlands, Tex.

*Fun Fact:* The annual Woodlands, Tex., CrawPHish Festival is by far PHA’s largest special event, drawing thousands. 2012’s festival had the most attendance yet, making it the single largest special event in PHA’s history to date.

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**N.C. Cure PH Golf Tournament**

*Location:* Mocksville, N.C.

*Fun Fact:* Dr. Derek Williams (pictured left with event organizer Cindy Pickles), Pediatric Cardiologist at Wake Forest University Baptist Medical Center, spoke about the significance of supporting PH research through events such as this golf tournament. Attendees also enjoyed the new PHA Public Service Announcements. Read more about these PSAs on p. 22.

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**4th Annual Scramble for a Cure**

*Location:* Las Vegas, Nev.

*Fun Fact:* This year’s crowd was the largest to date with 63 golfers and 85 participants at the luncheon! The event included a helicopter ball drop. The winner is pictured here with event organizer Jack Nino (second from left). PHA Board Chair Laura D’Anna spoke during the luncheon.

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**2nd Annual Walk 2 Cure PH: The Ellie Godina Memorial Walk**

*Location:* Euclid, Ohio

*Fun Fact:* More than 300 people gathered for this event, which raised nearly $5,000 for PH research and programs on the day of the event alone through donations and a raffle featuring more than 40 gift baskets.

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**6th Annual Spur a Cure for PH**

*Location:* Phoenix, Ariz.

*Fun Fact:* This year’s event featured guest speaker, Dr. Jeremy Feldman, Director of the Pulmonary Hypertension Program at Arizona Pulmonary Specialists, as well as a special guest performance by Nashville recording artist Sheylyn Jaymes.

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**Stride to the Cure PHA 5K Run/Walk for a Cure**

*Location:* Chicago, Ill.

*Fun Fact:* This first-year event had more than 200 participants representing 14 walk teams, and together they raised more than $18,000 online alone!
**Saturday, Aug. 4, 2012**
CAPHS 6th Annual Walk and Roll
WHERE: Wadsworth Shelter at Sandrun Metro Park, Akron, Ohio
DETAILS: Merle Reeseman at 724-458-5573 or ohpa.pher@yahoo.com

**Friday, Aug. 10, 2012**
Messages of Hope — An Evening with Psychic Medium Josephine Ghiringhelli
WHERE: Selden, N.Y.
DETAILS: Linda Sullivan at PH.Hope.81012@gmail.com

**Saturday, Aug. 18, 2012**
Central Coast PHun Walk for a Cure
WHERE: Chase Palm Park, Santa Barbara, Calif.
DETAILS: Kelley Skumautz at theskumikians@sbcglobal.net or Dana Sager at danasager@gmail.com

**Thursday, Aug. 30, 2012**
PHA Night at Iron Pigs Stadium
WHERE: Allentown, Pa.
DETAILS: Joan Stevenson at jsteve@ptd.net or Gloria Hamm at glohamm@aol.com

**Saturday, Sept. 1, 2012**
Central Florida PHun Walk & 5K
WHERE: Lakeland, Fla.
DETAILS: Joy Morgan at kjcmorgan@yahoo.com or 863-646-4937

**Friday, Sept. 14, and Saturday, Sept. 15, 2012**
New England PH Forum & Swinging for a Cure Golf Tournament
WHERE: Falmouth Country Club, Falmouth, Maine
DETAILS: Jeannette Morrill at 207-695-3042 or jeannette@myfairpoint.net

**Sunday, Sept. 16, 2012**
Colorado Pulmonary Hypertension Run for PHun 2012
WHERE: City Park, Denver, Colo.
DETAILS: Deb McCollister at Deb.Mccollister@ucdenver.edu or Beth Coleman at Coleman.Beth@tchden.org

**Saturday, Oct. 6, 2012**
9th Annual GA Fun Walk for a Cure
WHERE: East Cobb Park, Marietta, Ga.
DETAILS: Sally Maddox at skshmaddox@yahoo.com

**Saturday, Oct. 6, 2012**
8th Annual New York Fun Walk
WHERE: Fireman’s Memorial Park, Lindenhurst, N.Y.
DETAILS: Joanne Schmidt at 631-427-4586 or joanne64@optonline.net

**Saturday, Oct. 6, 2012**
Baltimore PH Walk for HOPE 2012
WHERE: M & T Bank Stadium, Baltimore, Md.
DETAILS: Janice Frederick at 410-328-7260 or jfrederi@medicine.umaryland.edu

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**For more Special Events listings, visit www.PHAssociation.org/Calendar**

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**Walk to Cure PH Story Continued from Page 38**

Great committee, we will succeed in getting some media attention. We have done this ourselves, and last year was too much work for patients to do ourselves. In order to grow we knew we needed more help, and now we have it.

**Your event is support-group driven. How does that work?**

**Diane:** Everyone pitches in. We ask all to be part of the event committee, but not everyone is able to. We just hope they all come to the event. We try to share responsibilities so it is not too much for any one person.

**Marcia:** The support groups are the main participants and they bring their family members. Some create their own FirstGiving page and raise money in that way, and some sell raffle tickets. We haven’t had any outside resources — except for our drug reps — until this year.

**What advice would you give to other event organizers?**

**Diane:** Don’t get discouraged when starting out. Don’t burn yourself out, either. Keep on talking, passing out fliers everywhere: doctor offices, grocery stores, etc., and people will begin to ask and inquire. If you only get one person to learn about PH, you are a success.

**Marcia:** Start small with just your own group and make it fun. It will grow every year. Use Firstgiving and Facebook to your advantage.

*Interview conducted by Edward Freundl, PH Patient*
On June 22-24, PHA hosted our 10th International PH Conference and Scientific Sessions in Orlando, Fla. Our Conference was a huge success and we would like to thank everyone who worked tirelessly to make it happen. From our Conference Planning Committee, which spent many hours planning the fine details of the Conference, to our on-site volunteers who helped carry out a variety of tasks — we thank you! Your efforts made Conference such a special experience for those in the PH community who attended.

PHA would also like to thank the many speakers and presenters who helped educate many new — and veteran — community members about pulmonary hypertension. Your knowledge and personal experiences added educational value to the many sessions that took place.

Last, but certainly not least, PHA thanks every patient, family member, medical professional and friend who attended this year’s Conference. Your enthusiastic spirit and energy was an integral part of the success of Conference. We hope to see you all in Indianapolis in 2014!

Don’t forget to look for the full recap of PHA’s 10th International PH Conference and Scientific Sessions in the fall 2012 issue of Pathlight.

Save the Date!
PHA’s 11th International PH Conference and Scientific Sessions
June 20 – 22, 2014
JW Marriott Indianapolis
Indianapolis, Ind.
www.PHAssociation.org/Conference

Conference Recordings Available Later this Year!
Missed PHA’s 10th International PH Conference and Scientific Sessions? Enjoyed a session at Conference and want to share it with a friend or family member who wasn’t able to attend?

For Patients and Caregivers:
Medically Led and Patient/Family Led Sessions will be available on PHA Classroom.
www.PHAssociation.org/Classroom

For Medical Professionals:
PH Fundamentals and Scientific Sessions will be available on PHA Online University. Additionally, a selection of the recordings will be offered for CME/CEU credits.
www.PHAOnlineUniv.org

Stay tuned for more information!

PHA Extends a Huge Thank You to Our Conference Sponsors!
PHA thanks our corporate sponsors for helping to make our 10th International PH Conference a huge success.

Diamond Sponsors
Actelion Pharmaceuticals US, Inc. • Pfizer, Inc. • Gilead Sciences, Inc.

Gold Sponsor
Bayer HealthCare • United Therapeutics Corporation • Novartis Pharmaceuticals

Silver Sponsor
Lung LLC

Bronze Sponsors
Accredo Health Group, Inc.

General Sponsors
Curascript • CVS Caremark
PH Patients and Families Education Forums

A program of the Pulmonary Hypertension Association Medical Education Fund

PHA on the Road recognizes that YOU, the patient, are the heart of a larger PH community that makes support, connection, information and education available to anyone who needs it. These free patient-focused educational forums will feature interactive presentations, general sessions, time to meet other patients and caregivers, and exhibits. Forum speakers are leading PH medical professionals from the local area.

Join us “on the road” as we visit:

New Brunswick, N.J.
Saturday, Sept. 8, 2012
8:30 a.m. – 4:30 p.m.
Hyatt Regency New Brunswick
New Brunswick, N.J.

Regional Chairs:
Harold Palevsky, MD
Penn Presbyterian Medical Center, Philadelphia, Penn. (Co-Chair)
Sean Studer, MD
Newark Beth Israel Medical Center, Newark, N.J. (Co-Chair)
Roxana Sulica, MD
Beth Israel Medical Center, New York, N.Y. (Co-Chair)

Chicago, Ill., Area
Saturday, Oct. 13, 2012
8:30 a.m. – 4:30 p.m.
The Stonegate Conference & Banquet Centre
Hoffman Estates, Ill.

Regional Chairs:
Mardi Gomberg-Maitland, MD, MSc
University of Chicago Medical Center, Chicago, Ill. (Co-Chair)
Roberto Machado, MD
University of Illinois–Chicago, Chicago, Ill. (Co-Chair)

Session Topics to Include:

How is PAH Diagnosed? • Initial PAH Treatments • Long-term PAH Management • What is on the Horizon for PAH (Clinical Trials) • Eating Better • Pediatric PH – for Patients • Exercise and Yoga • PH and Connective Tissue Disease • Understanding Transplant Options • Traveling with PH • Emergency Situations

Visit www.PHAssociation.org/OnTheRoad for more information and to register.

This is a FREE patient education event and registration is required. Space is limited so early registration is strongly encouraged. Questions? Contact OnTheRoad@PHAssociation.org or 301-565-3004 x768.

By Suzanne Flood
PHA Marketing & Communications Manager
PH Community Members: Find Free PH Education Online

As a patient, family member or medical professional, you can access up-to-date information on important PH topics. All you need is an Internet connection and you can get the latest in PH education through these programs of PHA’s Medical Education Fund.

PHA Classroom

PHA Classroom is PHA’s vibrant e-learning center where patients and families can learn about PH through live e-learning events and through one of the more than 140 recordings, including recordings from PHA’s 9th International PH Conference and Scientific Sessions. Live e-learning events are scheduled regularly, but don’t worry if you can’t make an event! Event recordings are posted to PHA Classroom shortly after each webinar.

Highlighted Recordings

- Life After Diagnosis: Staying Active with PH
- PH Treatments: What’s On the Horizon
- Peer-to-Peer Fundraising: Using Your Personal Network to Increase Attendance and Funds for Your Event

PHA Online University

PHA Online University is PHA’s premier resource for medical professionals who want to learn about screening, diagnosis and treatment of pulmonary hypertension, including FREE CME/CEU accredited courses, issues of Advances in Pulmonary Hypertension, PHA’s quarterly medical journal, and regular webinars.

Highlighted Courses:

- Sarcoidosis-Associated Pulmonary Hypertension (SAPH), Vivek N. Iyer, MD, MPH, Mayo Clinic, Rochester, Minn.
- Congenital Heart Disease in PAH, Usha Krishnan, MD, Columbia University, New York, N.Y.

Building Medical Education in PH

A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

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.

Upcoming Events for Medical Professionals:

Pulmonary Vascular Disease and Right Ventricular Dysfunction: Current Concepts and Future Therapies
Sept. 10 – 15, 2012
Keystone Symposia – Monterey, Calif.
Visit www.keystonesymposia.org for more information

10th Annual Update in Pulmonary Hypertension
Nov. 30, 2012
Tufts University School of Medicine and Tufts Medical Center — Boston, Mass.
Visit www.ganesco.com for more information

To view a full list of education opportunities for medical professionals, visit www.PHAOnlineUniv.org/Calendar

Medical Professionals: To partner with PHA in Building Medical Education in PH for your upcoming CME event, please contact Suzanne Flood at BME@PHAssociation.org or 301-565-3004 x768.

To learn more about this partnership, visit www.PHAssociation.org/BME
SAVE THE DATE!

2013 PH Professional Network Symposium
The Power of Teamwork: 10 Years of Professional Collaboration in PAH

September 26 – 28, 2013
Crystal Gateway Marriott — Arlington, Va.


This educational program is designed for PH-treating allied health professionals of varied experience and interests. Breakout sessions will provide attendees the chance to choose individual sessions based on their level of experience and interest.

Registration opens March 2013

For more information and the latest updates visit: www.PHAssociation.org/PHPN/Symposium

Welcome, Rebecca Gifford, Meeting Planning Associate!

As PHA’s Meeting Planning Associate for Patient Programs, Rebecca’s responsibilities include providing logistical support for several of PHA’s events, including PHA’s International PH Conferences and Scientific Sessions, PHA on the Road: PH Patients and Families Education Forums and our Corporate Committee meetings. During Conference years, she serves as the Scholarship Committee staff liaison and helps coordinate all the needs of the scholarship award recipients in order to ensure a safe and successful time at Conference.

Rebecca is a 2010 graduate of York College in Pennsylvania where she received a B.A. in Public Relations and Marketing. Rebecca can be reached by email at RebeccaG@PHAssociation.org or by phone at 301-565-3004 x764.

Stay Informed Throughout the Year

Keep up with the latest PH news with headlines, events, educational information and ways to get involved.

Subscribe to:
- PHA Daily Beat via email or RSS
- PHANews biweekly e-newsletter
- Or lots of other email lists and RSS feeds

www.PHAssociation.org/News
INTERVIEW WITH PH PATIENT
Taryn Petry

Where do you live?
I live in Wisconsin.

How old are you?
I’m 8 years old.

When were you diagnosed?
My mom says I was diagnosed when I was 5 years old.

When did you first start having symptoms of pulmonary hypertension?
I started having symptoms when I was 1 year old, but my mom says that they didn’t recognize my symptoms until after I was diagnosed.

What were your symptoms?
I started having fainting spells when I was 1 year old that were caused by PH. I also got tired really easily whenever I walked, but my parents thought it was because I was little.

What activities do you like to do?
I like to read, play piano and do Irish dancing.

Have you ever felt unable to do something because of PH?
I can’t run very much at the gym or during recess, and I also can’t play basketball anymore.

How has your life changed since you’ve been diagnosed with PH?
I don’t remember not having PH, so I don’t know what would be different if I didn’t have it.

What is a message you’d like to pass on to other kids with PH?
Remember to take your medicine because it makes you feel better. You may not be able to run, but there are a lot of fun things you can still do!
Bully: “A Movie That Kids and Teens Need to See”

Bully, released in theaters March 2012, is a documentary that centers on five kids ranging in age from 11 to 17 who have experienced bullying. As a PH patient familiar with how bullying happens when people see you as different, I thought this movie was important to see and share with others.

In the documentary, one boy suffers every day on the school bus as kids poke and punch him, and even sit on his face. A whole town turns against a young girl and her family when the news comes out that she is gay. Family friends who have known the girl for years refuse to even look at her when she walks down the street. Another girl decides that the only way to protect herself from the bullying she is suffering from is to wave a gun in the bullies’ faces. Although no shots are fired, she is sent to a juvenile detention center. Two families react to their sons’ suicides at ages 17 and 11 by trying to raise awareness of bullying in their schools.

The movie Bully takes a look at the school systems, teachers and administrators who are supposed to keep our children safe but fail to do so. Alex is teased on the school bus every day. When his parents go to meet with the principal, they are told that the kids on that bus are “as good as gold.” Throughout the theater where I watched the movie, the audience scoffed at the principal’s blindness and ignorance of the situation going on at her school. In another town, the parents of one of the boys who committed suicide hold a town hall meeting and invite the police force and school officials. No one from the school comes to hear the concerns the town had for their children. No one from the school comes to help make it right.

The movie ends with pictures and videos from candlelight vigils. The family of Tyler, the 11-year-old who killed himself, started an organization called Stand for the Silent and travels around the country speaking out against bullying and holding candlelight vigils in support of those who suffer from bullying. With bracelets that read “I am Somebody” and shirts that say “I Stand for the Silent,” this organization is helping to raise awareness about the growing epidemic in our society.

On the movie’s website, www.thebullyproject.com, you can check whether this eye-opening movie is playing in a theater near you. (It is not yet playing in all major theaters.) While in some states it is rated PG-13 or “Unrated,” it is a movie that kids and teens need to see. There is some strong language used; however, it helps illustrate just what is going on in our schools.

Living with PH, I know firsthand that you can be bullied because of your illness. People may make comments or tease you because you wear oxygen, have a pump or because you can’t walk up a flight of stairs. But I want to remind you that you are not alone. The whole PH community loves and cares about you. Find your strength from us to deal with whatever is thrown at you. We are here for you.

By Becca Atherton, PH Patient

Meet Becca and other teens who have PH at www.PHATeens.ning.com. PHA Teens is a secure social networking site for teens age 13-18 who have PH.

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PH Word Morphs

A word morph is where you “morph” one word into another!

1. You can change only one letter at a time.
2. Each word you create has to be a real word.

Here’s a sample Word Morph: how do you get from Head to Foot?

HEAD
BEAD
BEAT
BOAT
BOOT
FOOT

Try these two Word Morphs:

Beginner Level: Intermediate Level:
HEART HOPE


BEATS


CARE

Visit www.PHAssociation.org/PHKids for more!
Helping Children with Pulmonary Hypertension Cope

When a child is diagnosed with PH, families face a whole new set of circumstances and challenges. Whether your family has been living with PH for a few weeks or several years, it’s normal to have lots of questions about raising a child with a chronic illness and what you can do to help your child cope. Read on for an excerpt adapted from PHA’s online article, Helping Children with Pulmonary Hypertension Cope.

Appointments and Hospital Visits

Visits to the doctor’s office or hospital, whether routine or not, can be difficult times for children of all ages. They may be afraid of certain tests and procedures, anxious at the thought of interacting with strangers, put off by the clinical atmosphere, or worried about missing school or social activities.

Children have a tendency to feel anxious about the unknown. If possible, prepare your son or daughter for appointments and hospital visits in advance by describing the appointment or procedure, who will be in the room, what devices will be used, and how much your child will feel during any tests or procedures. How much you tell your child and how far in advance will depend on age and developmental stage. One strategy is to wait the equivalent number of days before an appointment as your child’s age in years (four days for a 4-year-old, two weeks for a 14-year-old), but this guideline will vary from child to child. Talk to your PH team for ideas about how to talk to your child about medical tests, as it’s likely they have time-tested strategies for explaining complicated topics to young patients. Some hospitals have pediatric social workers and child life specialists who can help you prepare your child for hospitalizations.

Unplanned visits to the hospital can be frightening for both parent and child. You can reduce your own stress in these situations by having an emergency plan ready and following it when the time comes.

- Pack a bag of essentials to keep near your front door. Include a change of clothing for each family member, books and magazines, comfort objects for your child, nonperishable snacks, $20 in cash for parking, and your child’s medication list.

- Keep a supply of pre-made meals in your freezer and ask two to three neighbors or family members to serve as “on-call babysitters” for your other children or pets if you need to leave the house in a hurry.

- Children have a tendency to take cues from adults in stressful situations. If you’re able to manage your own tension and project a calm demeanor, your child will be more likely to follow suit.

- On the trip to the hospital, pay close attention to your child, responding to any questions with simple and reassuring language. If possible, use distraction techniques like singing or car games to take you child’s mind off any pain or anxiety.

Once at the hospital, stay attentive to your child’s body language for signs of discomfort. Keep in mind that it can be difficult for young people to interact with adults they don’t know. Children are sometimes embarrassed to ask nurses for help. Explain that nurses spend time with other kids with conditions like PH every day. Stay at your child’s side whenever possible, and work with the doctor and nurse to explain what’s happening to put your child at ease. You can actively participate in your child’s care during a hospitalization by staying overnight or helping in tasks such as washing. Honest answers to questions such as “Will this hurt?” help build trust between parent and child and may help to remove the fear of the unknown.

Many parents also try to ease the anxiety their children feel around appointments and procedures by concentrating on the positive. You might focus conversation on how great it will be to feel better after surgery, or all the visitors and games there are to look forward to during a hospital stay.

PH patient Hannah, now in her 20s, fondly remembers her parents’ strategy for relieving her hospital-related stress. After blood draws, IVs, PICC lines and heart caths, she would always receive a small gift. She told us, “I wasn’t spoiled … I never got money for good grades, but that was something simple that my parents did to keep my mind off the pain. To this day I often go get an ice cream after a less-than-fun doctor’s visit.”

Read the full article at: www.PHAssociation.org/Parents/HelpingPHKidsCope

PHA is thankful to Michele Calderbank, Pulmonary Hypertension Coordinator at Children’s Hospital, Colorado, for her input and medical review, and to the parents and children who shared their experiences to make this resource possible.
Dr. Thomas Albertson  Selena Auston  Margaret Mary Bateridge  Raymond Bills  Alexandria Beeson  Barbara Berg  Carol Ann Braden  Stephen Buccol  Dianne Call  Merle Childers  Eugene Francis Clocon  Karen D’Angelo

Victor Gerard DiLeo  Paul-Michel Di Paolo  Theron Dye  Paul Leo “Papa” Fischer  Gerald P. Forest  Amy Frazier  Carolyn Gray  Debbie Paige Cooper Greer  Estelle Guillcatandana  William Hagzan  Erika Hall  Colleen Holbert

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Julia Rich  Jim Robins  Janet Faye Rurup  Mildred Saunders  Lawrence Schmidt  Ann Janet Simpson  Jessica Steckly  Janice Stewart  MaryAnna Struttman  Frances Thuber Talmadge  Sandy Vandiver  Kathy Weaver

PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.


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

The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x800 or Michal@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.

IN MEMORY OF

PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

TAKING A LOOK! Sustainers Circle Members Recognized

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

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IN MEMORY OF


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**PATHLIGHT SUMMER 2012**

**Patient-to-Patient Support Line:** 1-800-748-7274

www.PHAssociation.org

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**Tracey Delaney**
**Micaela Cohen**
**Chanda Causer**
**Debbie Castro**
**Dorothy Bradley**
**Robert F. Browning** and Lee Broadbent
**Rita and Bruce Brundage**
**Jane P.* and Harold P. Cooper**
**James F. Corbett**
**Lauri Hoyt D’Anna, DrPH**
**Charles W. DeVier, III**
**Linda M. Feibel**
**Barbara Gamer**
**Franklin D. Gillespie**
**Tammy* and Dean Hazen**
**Mary Jan and Carl Hicks**
**Jacqueyn Holt**
**Richard L. Horrocks**
**Jessie Kohier**
**Terri L. Kopp**
**Gloria Lang**
**Thomas and Mary Jo Linnen**
**Sally Maddox**

*deceased members

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**Legacy of Hope Society**

To honor those who have included PHA in their estate plans or whose legacies have been realized, PHA created the Legacy of Hope Society. PHA is pleased to recognize the following members.

Sandra Alt Awood
Dauna Leigh Bauer*
Sylvia Marie Becherer*
Gloria G. Blodgett*
Dorothy E. Bradley
Robert F. Browning* and Lee Broadbent
Rita and Bruce Brundage
Jane P.* and Harold P. Cooper
James F. Corbett*
Lauri Hoyt D’Anna, DrPH
Charles W. DeVier, III*
Linda M. Feibel*
Barbara Gamer
Franklin D. Gillespie*
Tammy* and Dean Hazen
Mary Jan and Carl Hicks
Jacqueyn Holt
Richard L. Horrocks
Jessie Kohier
Terri L. Kopp*
Gloria Lang*
Thomas and Mary Jo Linnen
Sally Maddox

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**Mail or fax completed form to:**

Pulmonary Hypertension Association
801 Roeder Road, Ste. 1000
Silver Spring, MD 20910
Fax: 301-565-3994

You may also submit a change of address online at www.PHAssociation.org/ContactUs

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**ARE WE MISSING YOU?**

Please update my mailing list information as follows:
(Please print.)

- Mr.  [ ] Mrs.  [ ] Ms  [ ] Dr.  [ ] Miss

Name: _______________________

Business (if any): __________________________

Address: _____________________________________________

City: ___________________________ State: ______ Zip: ______

Phone: __________________________ Fax: ___________________

Email: __________________________

I am a:

- [ ] Patient  [ ] Caregiver  [ ] Parent of a child with PH
- [ ] Medical professional (title and affiliation):

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**Please update my mailing list information as follows:**

(Please print.)

- Mr.  [ ] Mrs.  [ ] Ms  [ ] Dr.  [ ] Miss

Name: _______________________

Business (if any): __________________________

Address: _____________________________________________

City: __________________________________________ State: ______ Zip: ______

Phone: __________________________ Fax: ___________________

Email: __________________________

I am a:

- [ ] Patient  [ ] Caregiver  [ ] Parent of a child with PH
- [ ] Medical professional (title and affiliation):

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**Mail or fax completed form to:**

Pulmonary Hypertension Association
801 Roeder Road, Ste. 1000
Silver Spring, MD 20910
Fax: 301-565-3994

You may also submit a change of address online at www.PHAssociation.org/ContactUs
### Contact PHA

<table>
<thead>
<tr>
<th>PHONE</th>
<th>301-565-3004</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAX</td>
<td>301-565-3994</td>
</tr>
<tr>
<td>EMAIL</td>
<td><a href="mailto:pha@PHAssociation.org">pha@PHAssociation.org</a></td>
</tr>
</tbody>
</table>

**Envelope of Hope (Free Packet for New Patients)**

- Chanda Causer
- x777, EOH@PHAssociation.org
- Ellen Leoni
- x756, Membership@PHAssociation.org
- New Member Packets, Pins, Brochures and Cards
- x0, store@PHAssociation.org
- Support Groups
  - Debbie Castro
  - x755, Debbie@PHAssociation.org

### PHA Resources and Services

**Patient-to-Patient Support Line (daytime, please)** 1-800-748-7274

**Children with PH/PPH**

- Laurie Jeter, njeterl@aol.com
  - 952-380-4999

**Organization Liaisons**

- National Institutes of Health: Heart, Lung, and Blood Institute
  - Rino Aldighetti, RinoA@PHAssociation.org
  - 301-565-3004

- American Thoracic Society: Public Advisory Roundtable
  - Rino Aldighetti, RinoA@PHAssociation.org
  - 301-565-3004

**Patient-to-Patient Support Line Coordinator**

- Pat Paton, pjpaton@onearrow.net
- 772-597-4962

### Insurance Resources

- Accredo’s Hotline for Flolan for Velextr: 1-866-9FLoLAN
- for Remodulin: 1-888-485-8350
- for Tracleer: 1-877-483-6828
- for Ventavis: 1-877-483-6828
- Caring Voice Coalition: 1-888-267-1440
- Curascript Helpline: 1-866-4PH-TEAM
- CVS Caremark Helpline (Remodulin, Tracleer and Flolan): 1-877-242-2738
- GlaxoSmithKline Patient Assistance Program: www.gskforyou.com
- Letairs: 1-866-664-LEAP
- NeedyMeds: www.needy meds.org
- Partnership for Prescription Assistance: www.ppa trông.com
- Priority Healthcare Remodulin Hotline: 1-877-462-6225
- Tracleer Access Program: 1-866-228-3546

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### PATHLIGHT & PERSISTENT VOICES SUBMISSIONS

The Fall Issue deadline is **July 31, 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”
- Print Services Department
- Print@PHAssociation.org
- Pulmonary Hypertension Association
- 801 Roeder Road, Ste. 1000
- Silver Spring, MD 20910

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

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### PHA Roundtable

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

- **Shirley Craig,** General Review
- **Robert Tash,** Volunteer Services
- **Raye Bohn,** Advocacy and Awareness
- **Jessica Lazar,** PA, Medical Services
NORD Honors PHA for Leadership in the PH Community

The National Organization for Rare Disorders (NORD) awarded PHA the Abbey S. Meyers Leadership Award for outstanding leadership and representation of our members in education and advocacy. Roughly 500 members of the rare disease community came together on May 15, 2012, to recognize outstanding Members of Congress, the NIH, as well as companies and organizations that strive to improve the lives of people with rare diseases. In honoring PHA with this award, NORD highlighted many of PHA’s services, including: PHA on the Road: PH Patients and Families Education Forums, PHA’s International PH Conference, PHA Classroom, PHA Online University, PHA Medical Education On-Demand Programs, Lobby Day visits to Capitol Hill, PHA’s growing research program that has committed more than $11.5 million to cutting-edge PH research, PHA’s Patient-to-Patient Support Line and PHA’s many global connections. PHA has been a member of NORD since 1993.

Resources for Coping with PH

Beyond managing the physical aspects of PH, patients and their families often struggle to cope with the emotional and social aspects of life with a chronic disease. PHA has developed resources to help patients and family members understand the non-medical impacts of PH and learn effective coping mechanisms.

Coping with Pulmonary Hypertension Guides are available for:

- Newly Diagnosed Patients
- Long-term Survivors
- Parents
- Coming soon!  Caregivers
- Coming soon!  A Guide for Teens

Visit www.PHAssociation.org/Coping to learn more and download your free guide(s) today!