A newsletter of the Pulmonary Hypertension Association | Spring 2012 | Volume 21 No. 2

PATHLIGHT

Conference 2012 Preview on pp. 44-48, 50-51

PERSISTENT VOICES INSIDE!

HIGHLIGHTS

PHenomenal Lives 3
A Breath of Fresh Air 4
PH Plus 6

Health Matters 12
Ask a PH Specialist 12
"Helpful Hints" 18
Research Corner 19

Advancing the Cause 20
Advocacy in Action 29
Support Groups 30
Special Events 34

Persistent Voices 38

Community Classroom 44
Conference Preview 44

PHenomenal Youth 49
Family PHocus 51

From a Kitchen Table to Congress: *Join the Conference Advocacy Challenge!*

Never doubt how important your voices are … Some Members of Congress won't sign onto a bill until they've heard from someone in their state or district. They want to know that the bill is something that is important to their constituents.

– Sara Mabry, Legislative Aide,
Sen. Robert Casey (D-PA)

Be one of more than 1,000 people who will contact their senators and representative before PHA's 10th International PH Conference to request co-sponsorship of the *Tom Lantos Pulmonary Hypertension Research and Education Act*. Join the Conference Advocacy Challenge!

Making Progress with PH Legislation

The *PH Research and Education Act* is the only PH-specific legislation in Congress. Building co-sponsorship, and eventually passing the bill, will mean more money for PH research and more education on PH for medical professionals and awareness among our fellow citizens.

In the past, the PH community's advocacy has motivated Congress and government agencies to:

- Fund new PH research centers;
- Contribute nearly three-quarters of a million dollars to PH education and awareness programs;
- Invest more than **$200 million** in PH research in the last three years.

The Challenge

The Conference Advocacy Challenge is a new way to keep PH at the top of your elected officials' agendas. Whether you email, call, write or visit, PHA will tally every time you and others contact Members of Congress. We'll announce the results live at Conference on June 24, online and in *Pathlight*.

STORY CONTINUED ON PAGE 48

PHA Pulmonary Hypertension Association
Empowered by hope

MESSAGE FROM PHA'S BOARD CHAIR

Laura Hoyt D'Anna, DrPH

On Feb. 11, my family and I celebrated what would have been my lovely sister Rachel's 42nd birthday had we not lost her to pulmonary hypertension. Every year on this date, my mom and I visit a serene place in nature and read a book of Rachel's poems, and this year we reflected on all that has changed in the past 17 years.

For those of us who loved Rachel, our lives changed in inexpressible ways. During the first year after her death, I could not find relief for the feelings of deep loss and guilt associated with not being able to change her outcome. I read nearly every book about loss published at that time. I tried counseling and medication, and I received invaluable support through the Compassionate Friends.

These efforts were undoubtedly integral to my healing process, but ultimately, I think two things motivated me to action: 1) Our friend Gabrielle was still living with PH and wanted my help to raise money for research, and 2) I kept hearing my sister say to me, "Really? Is this all you got? After I fought so hard, are you just going to lie there when there is so much to do?!"

So, motivated by Rachel's fighting spirit and Gabrielle's vision that even a small group of friends could make a difference, we began writing letters to our family and friends asking them to support our efforts to fund PH research. Within five years, through Gabrielle's leadership, we raised $50,000 and were able to support two research grants, including one through PHA after folding our tiny foundation into PHA the year after Gabrielle lost her battle with PH.

The extraordinary thing about this campaign is that it has not ended! A few years ago, Gabrielle's sister-in-law, Lisa Miyara, and I wanted to commemorate the 10-year anniversary of Gabrielle's passing. We agreed that it would be fitting to do another letter-writing campaign, and this time we could employ the web and email to get our letters out and solicit donations online. We were blown away and deeply touched by the outpouring of support received from those who contributed to funding PH research in memory of Gabrielle and Rachel all these years later.

As a result, we are so pleased that our Web of Friends campaign and the PH community have made it possible to fund another grant in their honor: ***The Gabrielle Miyara and Rachel Hoyt Proof of Concept Grant***. PHA's Proof of Concept Grant Program supports new research projects that are in early exploratory and developmental stages and have the potential to lead to advances in the scientific understanding of PH. We are equally pleased that 100% of what we raised will go to research: No funds were expended in generating this support. All that it required was the time to write the initial letter, send out the emails, and respond with a personalized thank you, also by email!

It is so gratifying to log onto our fundraising website and see the messages of love and support that have been left by so many. Although there is still so much work to do, I believe that my sister would be proud that I got up and did something! I also know Gabrielle would be thrilled that our efforts to raise research funds have continued in her name.

Although this feels like a small achievement compared to what has been accomplished by many of you, this is in fact the point — even a small effort can make a big difference. And, the motivation and energy derived from all this are unexpected gifts that have contributed immensely to my healing process. I would have done absolutely anything to avoid losing my sister, but given that was not meant to be, I am very grateful to be allowed a space in which to honor her life and in so doing, hopefully support others.

In gratitude and partnership,
and with unending love for Rachel and Gabrielle,

Laura Hoyt D'Anna

Please join me on the path to a cure for PH at: ***www.firstgiving.com/HoytD'AnnaMiyara****. To learn how to launch your own* Web of Friends *campaign, contact EllenL@PHAssociation.org.*

PATHLIGHT: A USER'S GUIDE

PHenomenal Lives

Health Matters

Advancing the Cause

Community Classroom

PHenomenal Youth

Family PHocus

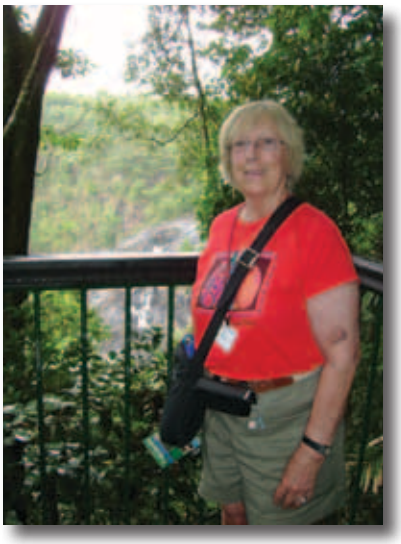
Look for this icon to direct you to important information for healthcare providers.

Look for this icon throughout *Pathlight* to read news from around the world.

Traveling Down Under — With PH as a Companion

This past December, I had the pleasure of summering in Australia, New Zealand and Fiji for three weeks. Summering? Well, they're in the southern hemisphere, so the seasons are the opposite of our U.S. seasons. I'm not going to give you a day-to-day account of my trip, but I want to share how I dealt with PH during this three-week, multi-country vacation.

I'm not bragging, complaining or in any way trying to compare myself to how any other PH patient would fare on this same trip. What I would like to do is share some tips for how a trip like this can be possible for someone with PH.



PH patient Ann Arnott

The PH Planning

My primary PH medication is IV Remodulin™, which means I need to mix a new "batch" every other day. Even though each mixing kit is relatively small and light, three weeks of supplies adds up. Plus, my specialty pharmacy nurse insisted that I carry even more than I would actually need, including pump and dressing change kits. I occasionally had to remind her, "I'm going on vacation. If more supplies can't reach me by the time I run out of all this, it probably means the whole group is in deep trouble somewhere."

Another important part of my planning involved PHA. PHA put me in touch with PH leaders in countries I would be visiting, just as it had done when I vacationed in Europe three years before. These leaders acted as my emergency contacts — what I call my "umbrella." Being prepared means you probably won't need the backup.

Australia

Our first stop was Cairns (pronounced "cans") on the northeast and tropical side of Australia, bounded by the Great Barrier Reef. The glass-bottom boat experience was thrilling; the incredible diversity of living, waving coral, schools of brightly colored fish and huge tortoises was mesmerizing. Because of my catheter, I couldn't go snorkeling, and in any event I was in a restricted area due to shark sightings! The weather, however, was another story. It was in the 90s, with equal humidity and a heat index of about 100 degrees. Everyone was wilting, but it was harder on me due to the PH and a related PH problem, neuropathy of the feet. I'll admit that I was getting weary pretty quickly and looking for every opportunity to sit down — more for the "tired, achy feet" than from overexertion. Fortunately, periods of sitting coincided with one of my first memorable experiences: a long gondola ride up, over and in the massive rain forest.

From there, I went on to Sydney, Australia's biggest city, where the weather was much kinder to all of us. The walking, however, was something else. Our tour guide kept saying, "It's just a wee walk…." Eventually, I said, "Please define 'wee' a little more specifically." The group laughed and, indeed, many of the walks were more than "wee," but I kept up; or at least I didn't hold anyone up. When I visited museums on my own, I could go at my own pace.

New Zealand

I loved New Zealand with its diverse topography of lush valleys and glens, steep and abundant grazing lands for sheep and cattle and snow-capped mountains. The climate was better, and either the activities were less strenuous or my body or medication levels had adjusted (probably both). I had no trouble keeping pace with the group. I did, however, claim a fear of "heart stoppage" to avoid the optional activity of bungee jumping from the spot where this sport originated.

A highlight of New Zealand included meeting with the New Zealand support group leader, Allan Edmondson, and his wife, Sandy. Sandy is a PH patient and Allan "runs" the New Zealand support group. They drove me to their home in Auckland where we talked a lot about PH. Allan stepped in to help when their support group leader became ill, and he ended up as the leader. It sounds like he and Sandy are doing a good job having regular meetings, but they face challenges finding speakers, getting names of newly diagnosed patients and generally meeting the diverse needs and interests of their group. Sounded familiar!

The trip ended with a few days in Fiji, and then the real adventure with my PH started. Three experiences on my

STORY CONTINUED ON PAGE 11

PH, Professionalism and the Digital Age

When I was first diagnosed with PH, I was teaching part-time in a public school. I was met with sympathy and promises of support from the school community. Within months, however, my teaching assignment changed: my hours were cut, my commute extended, and a student was placed on my caseload who required both physical restraints for violence and running after because he tended to bolt. When I tried to have my assignment adjusted, I was shown the door … or I quit … or I was kind of fired. Whatever you call it, I was out of a job, and the correlation between my diagnosis and the change in job assignment was just too convenient to ignore.

Could I have sued? Yes, probably. But I was immersed in this totally terrifying world of being a newly diagnosed PH patient. Like so many, I didn't know if I was going to live more than a few years. I simply did not have the energy or internal strength to take on another fight.

I moved on from that job and began teaching online college classes, something I still do today. A little over a year ago, I also started my own company teaching sign language to kids, caregivers and educators.

Both jobs are independent contractor-based. I have to consistently earn the right to do the work based on job performance. There is no guarantee of work and no net to catch me if it goes badly. But it is work and work I enjoy.

Because of my experience with the public schools, I have guarded the secret of my PH from anyone I have contact with on a professional level. However, in my private life, I am involved daily in advocacy and awareness raising. My activities have become public knowledge and widely chronicled online in my blog, Facebook, newspapers, radio interviews, and through work with PHA. In short, if you Google my name, it's connected with PH.

This has presented a huge professional dilemma. I have worried constantly that word would get out and I would again find myself without employment because someone jumped to conclusions about what PH means as far as my ability to meet professional expectations.

Two semesters ago, this worry started to materialize. A college student did indeed do a Google search on me. Then he wrote me about what he found in regard to PH. It's safe to say he did not understand what he was reading, but I was shaken.

I talked to my friends in Generation Hope about these concerns. Should I just come forward and tell my employers? Their advice was good. In short, it was better to come forward and be in charge of what information got out, and how it got out, than to be blindsided by information someone found online and misconstrued.

Still, I dragged my feet for a while. I was comfortable just doing my job and being trusted as a professional based on the merit of my work. I did not relish the idea of having these good relationships tainted by something like PH, and I had little reason to trust things would go well since they had gone so badly in the past.

But finally, I got sick of it all. I got sick of worrying and hiding and screening friend requests on Facebook. PH is such a big part of my life; I didn't want to hide it anymore. I started with the sign language company I do some independent work for. I called my national director, took a deep breath and told her the story. She's a wonderful lady, and her response was warm and supportive. Since that call, I've been hired to do even more work for them.

The college was harder. It's a more high-pressure job, it's most of my income, and if I lose it, my family and I are going to be in a very difficult financial situation. Finally though, I just had enough of the tiptoeing around, not to mention I had my parents (who also work for the college) under gag order not to talk about my PH. That was difficult for them since they couldn't do any awareness work in the college community.

I sat down and wrote a long letter to my supervisors. I told them my story, and why I had hidden it for so long. I emphasized that I remain, as always, dedicated to my students. The response has been supportive, as has follow-up communication.

I'm slowly relaxing and getting comfortable with the word being out there, trusting that when the hiring season next comes around, my evaluations and work ethic will be what they look to once again.

Conventional wisdom says you should keep your professional and personal life separate, and to a point, I agree. Certainly I've seen the dark side to why that is. However, in the digital age, this is becoming more difficult. There is something to be said for being in control of the situation and managing how and what gets out about your medical condition. There's not much you can do about how PH is going to affect your life sometimes. But there's a lot you can do about how you react to and handle it, and how you use those times to educate others. The professional arena is just one more place to make those considerations … and sometimes a leap of faith. ◆

By Colleen Brunetti, MEd, PH Patient, Member of Generation Hope

A PH Patient Fights Back through Blogging

In September 2008, I was diagnosed with pulmonary hypertension. I had just given birth to my first child, and by the summer I was out of breath with very minimal exertion. Being a new mom, I figured I was just tired and out of shape. A couple weeks later I couldn't push my son's stroller or walk up a slight incline without being winded. In August, when I couldn't dance through a song at a friend's wedding, I thought I must have asthma. But when I couldn't walk up the flight of stairs to our apartment without collapsing at the top, I knew something was really wrong.

I was in a dark, little, cell block of a room at the hospital when the doctors told me I had PH. Having never heard of it, I said, "Ok, but I'm not going to die from it, right?" And the whole room went quiet. A doctor I had never met before said, "Well, everybody dies...." I freaked out. I was a new mother, an athlete, I'd never smoked or done drugs, so how could I have a lung disease? Two to three years was what they gave me. Two to three years?! My son was 6 months old!

It wasn't until I met my wonderful pulmonologist and my PH specialist that I heard any good news. The truth of the matter was, they had no idea when I'd be gone. The problem was, despite the fact that my PH drugs allowed me to feel almost normal most days, two to three years was still in my head. When September 2011 rolled around, I thought I'd feel like, "Well, they were wrong. I'm not dead. I can do anything!" But it actually felt more like, "Well, that's it, three years. I could go at anytime." And that feeling was unacceptable. I wasn't ready. How could I leave my child without a mother?

Having been an actress and a writer pre-baby, I decided to write a book of letters to my son. I wanted to fill it with advice and guidance so, if I did have to leave his life early, he would still have a version of me to help navigate his way through life. Then some media savvy friends convinced me to take that book idea and turn it into a blog. It would still allow me to share my feelings and advice, but on a larger scale. I had little familiarity with the blogosphere, but I liked the idea of making my writing public. It made me accountable. For getting it done. For doing it right. And publishing it every week made it real. I also liked the idea of having something to show for my efforts. And, if I could create a built in audience for a future book, then all the better.

Since I wasn't currently a blogger, nor did I read blogs, I had no idea where to start. I took an

Leigh (pictured right) with her husband and son. Photo courtesy Razi Wilson Photography

'Introduction to Blogging' course online with the *New York Times*. It was a three-week course with two live feed tutorials. It laid down the basics and helped me navigate the world of the web. I spent hours on WordPress.com — a common blogging site — picking the best "look" for my blog, and I wrote. I wrote as much as I could. I learned to hone my "voice" and figure out what I wanted to say. What was my tone? My message? My point? I decided I would post once a week. Enough that I was accountable for working on a new post but not so much that people got tired of me. It was helpful to have some posts "banked" because once I launched, I found that some posts were better for some weeks than others. Being able to pick and choose which came next was better than scrambling to get something up. Some of my earliest stuff never saw the light of day.

The response to **www.incaseimgone.com** has been unbelievable. Not only has it given me a purpose beyond my day-to-day existence as a mother, wife and PHer, it's allowed me to connect with so many others with similar emotions, struggles and realizations. I feel lifted by the process. I feel proactive in my battle with this disease and that I am doing something tangible for my son.

Please feel free to check out the blog. If blogging is something that appeals to you, my advice would be to do your research. Know what it is you want to say and how you want to say it. Be honest and truthful about who you are and how you feel, and people will respond. Finally, proofread. Nothing turns off people quicker than typos. ◆

By Leigh McGowan

PH Patient

Anna Bower: Living and Thriving with Multiple Diseases

Being diagnosed with any chronic illness is difficult to handle. Being diagnosed with multiple chronic illnesses is even worse. You have to balance your life with your limitations. You visit doctors frequently. Your nurses know you by name, and you are sure your insurance company rolls its eyes when receiving a claim for you. You take so many medications you really have to watch supplements and over-the-counter medications for counter-indications. One day you may be ailing from one disease and the next day it is another. It is a lot for anyone to deal with. I have been diagnosed with systemic lupus, PH, hypothyroidism, mixed connective tissue disease, Raynaud's, fibromyalgia, migraines, hypoglycemia, anemia, depression and gluten intolerance. I grew up with the hypothyroid, Raynaud's, migraines and hypoglycemia. The additional diseases came after I finished high school.

Anna Bower (right) with her mother Joyce Davis

I was diagnosed with lupus in 2004 at the age of 20. I have always been a very independent and active person, and the diagnosis changed everything. I was living on my own, going to college and doing the "college thing." With this diagnosis, I was no longer able to continue college or support myself, so I moved back home. No more hiking, rafting or soccer. My hands hurt too much to write, and my feet and knees hurt too much to walk far. Depression had now become a part of my life. My lupus became more than lupus; it became what I call "Lupus+" — my doctor calls it mixed connective tissue disease and fibromyalgia. I had the diagnosis of SLE (lupus), but I also presented with symptoms of scleroderma and polymyositis, like PH. Anemia just kind of comes with the package. In January 2010, I was diagnosed with PH. I think my body just wanted to make life a little more interesting and added the gluten sensitivity.

I had to quit working. I could hardly exist, let alone work. Naps became a regular habit, and I could only go out for an hour or two. I had to give up my dog, my rabbit and my fish. Okay, I didn't really have to give up my fish, but there was no way I could take care of a husky!

I had to avoid the sun because it could cause my lupus to flare up. Since hiking and rafting were out of the question, there went my desire to do photography. I loved to play the clarinet, but my fingers could no longer move fast enough for long enough, not to mention the lack of lung capacity! My life, in its current form, was no longer possible, and I became withdrawn.

At some point after my first year, I realized I couldn't let my diseases define me. I began to figure out what I could do, instead of what I couldn't do. After PH, oxygen became a permanent part of my life. I learned that I could go out in the sun if I remembered sunscreen, long sleeves and hats. I could go hike if I made sure to do an easy trail. I could walk if I found good shoes. Photography became a passion again! It is so wonderful to capture something that others take for granted. Knitting and crocheting are great exercise for my hands.

Then I returned to college and began taking classes again. I enjoyed spending time with other young people and exercising my brain. My college, Colorado Mesa University, offers support for students with needs. They supply carbon paper if I can't take my own notes; some teachers allow tape recorders. Most classes have the PowerPoint slides on the school network. Each semester I meet with my teachers to discuss my situation. I offer to get documentation for them if needed and supply them with a list of days I will miss because of doctors' visits or treatment. Financial aid is also plentiful for students in my position; all you have to do is talk to the office!

I just finished a six-month treatment of chemo for my lupus, which has been successful so far. This last December I finished my associate's degree, and I am just about to start my next semester of classes on my way toward a bachelor's degree in history. Napping is still a hobby, and my kitten and I enjoy them greatly! My boyfriend has been a huge pillar for me, keeping me motivated while remaining understanding, and my mom is always there for me.

It is okay that my life has changed. With my mind set and the support and love of those I keep around me, I am able to accept and enjoy what I have. Things have definitely changed, but that change doesn't have to be bad. People ask me if I wish it were different. On one hand, of course! But on the other, this life has made me who I am and given me what I have. Why would I want to change that?

By Anna Bower, PH Patient

International Faces of PH: Todor Mangarov

Todor Mangarov is a PH patient from Bulgaria.

My name is Todor Mangarov, and for 13 years, I was an officer in the Bulgarian army. During this time, I was very physically active and often went scuba diving and skydiving. I played football for two hours at a time, but by late 2005, I started feeling short of breath. I didn't think too much about my breathing problem; at the time, I smoked about 40 cigarettes a day and thought that the cigarettes were causing my health problems. In the summer of 2006, I stopped smoking, but my symptoms did not improve. My office was on the fifth floor, but I could no longer climb the stairs all at once.

It was at that moment that I understood something was wrong, and I went to the doctor on Sept. 20, 2006. I was also admitted to the hospital with another problem — an abnormal heartbeat. The doctors could not find a cause, so I met with a cardiologist in Pleven, Dr. Tsvetemira Chorbadzhiyska, and after only three days, she diagnosed me with pulmonary hypertension. I went to the best military hospital in my country, the Military Medical Academy Sofia, where they confirmed on Oct. 10, 2006, that I had chronic thromboembolic PH (CTEPH).

The Bulgarian Health Act stipulates that medications for patients with rare diseases are free, but at the time of my diagnosis, the Bulgarian Ministry of Health did not provide free medications for patients with PAH. The average salary in Bulgaria is about $357 per month, and the treatment of patients with PAH costs from $1,000 to $3,570 per month. By 2010, patients with PAH were still not treated because they could not afford their medication.

For an entire year, I wrote letters to the Bulgarian Ministry of Health about providing free drugs for the treatment of PAH. The Ministry did not respond positively, and in 2008, I began a lawsuit against the Minister of Health because of the discrimination against PH patients in Bulgaria. In January 2011 I won the case, and from March 2011 onward, all patients with PAH are being treated with free drugs, which include Revatio™, Iloprost, Tracleer™ and Volibris™.

I also created the Pulmonary Hypertension Association of Bulgaria (APH Bulgaria) in 2009. APH Bulgaria helps patients with PH obtain more information about their disease and get medical attention at the nearest PH center. In 2010, our group helped to establish criteria for PAH and identify four PH centers in Bulgaria.

Unfortunately, Bulgaria does not offer financial help to patient associations because these associations represent errors and gaps in healthcare. APH Bulgaria is supported only with funds from donations, but the global financial crisis strongly affected our country. In 2010 and 2011 we had very few donations, and Bulgaria is the poorest EU country. APH Bulgaria does not have an office or office associates. My friend, Vanya Toteva, helps APH Bulgaria free of charge. Although we don't have much money for projects, we do what we can for PH patients.

Currently, there are about 40 diagnosed PH patients in Bulgaria, and we are connected to 37 of them. According to statistics in Bulgaria, there should be about 150 patients diagnosed with PH at this time. The fact that there are only 40 diagnosed patients indicates that PH is not well known here. In 2012, our goal will be to focus on specialists — cardiologists and pulmonologists — and educate them about PH.

From diagnosis to now, I have been treated with Revatio™. In July 2011, I had a successful operation to remove my blood clots in Vienna in the clinic of Prof. Walter Klepetko. The surgery is known as a pulmonary thromboendarterectomy (PTE). In October 2011, APH Bulgaria helped a second patient with CTEPH to undergo a successful operation in the same clinic. We will continue to help others with this disease. ◆

By Todor Mangarov (Тодор Мангъров)
PH Patient

For more stories from around the world, please visit:
www.PHAssociation.org/PHInternational/Faces

Patient Mentor Spotlight: Lindsay Nichol

PH 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. Meet Lindsay, one of those mentors.

What is your PH story?

I was in my last year of college when I started having trouble breathing while walking to classes. I was rapidly gaining weight, and I thought that was what was causing my shortness of breath. Allergy tests, antibiotics and hundreds of blood tests later, my doctor said I had asthma. Soon I couldn't even make it 15 feet without being out of breath. I compared my blood tests and noticed that my carbon dioxide, hemoglobin, and blood cell counts were all out of the normal range. While looking up my results on a medical website, I noticed that "Pulmonary Hypertension" kept popping up as a possible illness. I researched PH and the symptoms sounded exactly like mine.

I told my doctor, but he said I was way too young to have PH. I demanded an EKG and found my answer: I was in complete heart failure. I was sent to UCLA Medical for a heart right catheterization where I was diagnosed with having WHO Class IV PPH. After two weeks in ICU, 37 days in the hospital and a new IV line, I was able to walk again without being out of breath. Ten years later, I am no longer in right heart failure, my pressures have dropped significantly, I work more than 60 hours a week, and most days it doesn't even feel like I have PH. I travel all over the world for work and pleasure, I have pushed the boundaries of living life with an IV line by snorkeling and snowboarding, and I never let PH hold me back.

What advice would you give to other young people living with PH?

My advice is to never give up. After 37 days in the hospital, losing 80 pounds of water weight, starting on Flolan™ and then transitioning to IV Remodulin™, I was back to work in two weeks. I needed the medical insurance. I napped at lunch, and I was exhausted every day. My doctor told me that my body needed to "recondition" and to push myself through it. There were days I wanted to give up, to just stay at home and sleep, but I knew that wasn't going to help me "recondition" myself to living with PH. After I was able to get my life to my new "normal," I decided that it was time to get back on the dating scene. I was always afraid that guys would not be able to look past my PH and the IV line, but I was wrong. I met the love of my life last year, and I couldn't have imagined a more caring, understanding and loving man. If I hadn't followed my own advice, I might have never met the man of my dreams and been planning my fairytale wedding. I am now living my dream: a normal life again.

What does being a PH Email Mentor mean to you?

I think being a PH email mentor is about giving hope to those seeking it. We are here to give you advice and support when you need it. I wish I had had another PH patient to ask questions, such as how to deal with side effects, how to take a shower with an IV line, how to work and take diuretics and how to tell someone you are dating that you have a serious disease. After having PH for 10 years, being an Advisory Board Member of Generation Hope, leading patient panels at PHA conferences, speaking at support groups and writing articles for *Pathlight* and the Generation Hope Blog, I have learned more about PH than I would have ever expected. Going through numerous line infections early in my treatment, dealing with college, finding a job, finding a significant other, learning to balance having a career on top of PH, and trying to have enough energy just to make it to the end of the work week, I learned numerous techniques to help me live a "normal" life. By being an email mentor, I can help motivate others to not give up on their dreams. If I can just help one other person get to their new "normal," my goal of being a PH email mentor has been accomplished.

Why should someone contact a PH Email Mentor?

The best part about emailing a mentor is that you get advice from the point of view of a patient, caregiver, etc. It isn't your doctor, a nurse, or a pharmacy, but a person who is in the same position in life as you. We are all extremely friendly, and if we can't give you an answer to a question, we will help you find it. ◆

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

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

Hand Holding: Vital to Both Patients and Caregivers

"No act of kindness, no matter how small, is ever wasted." ~ Aesop

Before I ever knew what it meant to be a caregiver, before I ever heard of an illness called pulmonary hypertension, I read a *Reader's Digest* article about a hospital volunteer position called hand holding. A hand holder sits with a patient, before or during surgical procedures, offering the physical comfort of his or her presence through the simple but profoundly human act of holding hands. I remember thinking, "I'd like to do this someday." And now I do.

As full-time caregiver to my mom, who was officially diagnosed with PH in December of 2008 after a year of clear symptoms and baffled doctors, I offer her the comfort of knowing that my hand — and by extension my love and care — is always within her reach. Sometimes it's all we caregivers can do, but often it is enough. My mom's recent hospitalization at Yale-New Haven Hospital showed me how important it is for caregivers, and not just patients, to have a hand to hold onto.

My mom had been relatively stable, with the usual PH ups and downs, for three years after her diagnosis. But this past fall, a routine blood test showed that she had severe iron deficiency anemia, which caused a rapid spiral into pulmonary edema and a heart arrhythmia called atrial flutter. I took my mom to Yale, where doctors were confident I had gotten her there in time to prevent a PH disaster and she would be just fine. But that's not quite how it worked out.

On her second night in the hospital, my cousin Shannon and her daughter Blaze visited and, afterward, offered me a ride home to shower and return; I never leave my mom alone overnight when she is hospitalized. At home while I was toweling off, Shannon burst into the bathroom holding the telephone out to me, wide-eyed: "It's your mom's nurse." Mike, whose sweet, easygoing, and innocently flirty personality had put my mom's mind at ease, did the same for me as he explained that after I'd left, my mom had had some anxiety and he'd sat with her. Suddenly, her oxygen saturation dipped dangerously low and he was unable to bring it up, so he had transferred her to the ICU. I thanked him for calling, told him I was glad he'd been there with her, and then collapsed crying in my cousin's arms. I had no idea what awaited me when I returned to the hospital.

My mom was in respiratory distress, a term I'd heard but never really understood until that awful night.

Nancy Leaman (left) with her mother Linda

I walked into the darkness of her new room to find her alone, unconscious, and hooked up to what looked like a ventilator. I later discovered it was a high-flow oxygen and air device. I watched, sickened and heartbroken, as each effort to take a breath bent my beautiful mother's body in two. Her shoulders hunched and her stomach heaved with each gasping intake.

On my mom's floor that first night was Dr. Dieffenbach. Young and affable, he chuckled when I told him I'd never remember his name in my state of mind. But I do, and I also remember his kindness and patience as he explained in depth my mom's condition, the treatment plan and the possible outcomes. And, in an even more compassionate gesture, Dr. Dieffenbach peeked his head in the room during my mom's second night in the ICU and said, "I'm not on this floor tonight, but if you need to talk about anything, just ask for me and I'll come." The right bedside manner in a medical professional is a kind of hand holding too.

Hand holding need not take place in person, either. I used Facebook to keep family and friends updated about my mom's condition, and my online friends' messages brought me comfort and happy tears. Often on Facebook, you become connected with people you barely know. Such was the case with Matt, a friend of my cousin's, who had seen my Facebook posts about my mom, gotten my cell phone number from my profile, and texted me: "Hi Nancy. This is Jeff's friend, Matt. How are you doing?" I was in agony, and I told him so. "I'm here for you," he said and meant it. During my mom's two-plus-week hospital stay, every time I sent a text to Matt

STORY CONTINUED ON NEXT PAGE

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saying: "I'm scared," he replied: "I'm here." His hand was a welcome surprise that lifted me, supported me and has led to friendship.

After the awful night when I'd gone home and received the phone call that my mom had been downgraded to critical condition, I was emotionally unable to leave the hospital. I stayed for two days, in the same clothes, by her bedside. On her second night in the ICU, she was agitated and unable to get comfortable. I spent the night on my knees by the bed, holding her head on my shoulder — the only position in which she could sleep. In the morning, a new doctor came during rounds. "I'm Dr. Hajizadeh," she said warmly. "I'll be taking care of your mom."

> **"... as caregivers, we often forget one crucial thing: we need to hold our own hands too."**

"I'm sorry," I said, feeling uneasy, "but I'm going to need Dr. Trow." Dr. Trow is the PH specialist who diagnosed and has cared for my mom over the past four years, and I wanted his familiar face and caring presence. Luckily, Dr. Hajizadeh understood my anxiety and didn't take offense. She explained her place on Dr. Trow's team and his continuing involvement in all things related to my mom's care. Dr. Hajizadeh proved to be brilliant, and I grew to admire and even idolize her as she took control of my mom's care and took me under her wing. Sensing my need to understand and participate in my mother's treatment, she encouraged me to conference with the team of critical care doctors, to view and discuss my mom's computerized test results, and to recognize my importance as a member of my mom's healthcare team.

Like Dr. Hajizadeh, the rest of the Yale staff also took notice of my fragile emotional state and intervened. My mom's next RN was the amazing Michelle, whose no-nonsense but congenial personality told me she would hold my hand but also give me the push I needed to think of my own health. "You look like you're going to drop!" she exclaimed. "You need to go home and sleep in your own bed, not in one of these hospital chairs. You have to get your rest because when your mother gets better, she is going to need you even more. You need to trust us, trust that we know what we're doing and go take care of yourself." It was the hardest thing anyone had yet asked me to do, because as caregivers, we often forget one crucial thing: we need to hold our own hands too.

I balked at Michelle's suggestion, and my mom's respiratory therapist, Peggy, asked me to take a walk with her; she had something to share with me: Yale's Smilow Cancer Center's Healing Garden, a magical rooftop maze of trees and plants, oversized rocks, a babbling brook, benches, a gazebo and a wind chime. While there, she shared with me her story of caregiving for her own mom and then left me to be alone and quiet for a time. In that garden, I allowed myself the comfort I always give to others without remembering to reserve a bit for myself.

Reminding me to keep this newfound balance was the Yale ICU social worker, Donna Palmer, who offered tremendous comfort in two lengthy talk therapy sessions. I learned that it's okay to give myself a little space, to acknowledge I can't do it all, to ask for help. And I started immediately taking care of myself through a request for help that allowed me find the inner peace I needed to be able to leave my mom and go home and sleep. I created a buffer between myself and any possibility of another devastating phone call from the hospital. I did so by turning to my rock, my Uncle Mike: "Can I ask you to put something on your shoulders for me? Will you be the emergency contact for Yale instead of me? Because I can't bear the thought of being alone and getting a call saying my mom is worse or gone." He agreed, and we made an arrangement that he would text me with any good or neutral news, but that if the news was bad, he would deliver it in person, so I'd have his hand to hold.

Thankfully, my Uncle Mike never had to come to my door, and as I write this, my mom is home with me, still recovering and working on getting her strength back, but closer to her old self every day. My gratitude to the Yale medical team that saved her life, and my sanity, is boundless. The doctors, nurses and staff who reached out to me left me with a newfound awareness of my own strength, resourcefulness and resilience. Because my Yale hand holders and my friends and family enveloped me in their caring, I was able to hold on to my mom's hand without letting go even in the darkest moments and lead us both back on to the path toward light. ◆

By Nancy Leaman

Caregiver to her mother Linda

Caregiver Shout-Out!

Amy Hundorf honors her caregiver and daughter, Joy Anna.

I am thankful for my caregiver, my 13-year-old daughter Joy Anna. She may be young and small, but boy, does she have a big heart of gold (now what mother wouldn't say that about her own daughter)! She takes good care of me by spreading the word about PH through our small town. She has gotten teachers and the local ambulance crew so aware that they helped with some fundraisers in December 2011. She takes care of me so well that when I am in the hospital for long periods of time, she will stay with me at least one day of the weekend. Joy is always willing to learn, and she stays on top of my PH. She encourages me to do things that I think I can't do. She makes sure that I take my medications.

It is just so special to have a daughter who cares so much for her mother and the world around her. ◆

Amy Hundorf (right) with her daughter and caregiver Joy Anna

For a chance to express gratitude to a loved one in Pathlight*, submit your own Shout-Out at* **www.PHAssociation.org/Shout-Out** *or mail to Michal Rachlin, 801 Roeder Road, Suite 1000, Silver Spring, MD 20910.*

STORY CONTINUED FROM PAGE 3

return trip sum up the unexpected that can happen with PH:

1. **The lights go out!** On the flight from Fiji to Los Angeles, I had carefully planned my schedule to prepare my next two-day supply of Remodulin™ during our long wait between check-in and boarding time at the airport, but I planned to make the switch well after we were airborne. All went fine but just as I reached for the prepared pump, all the lights went off! I only really needed a light to confirm that my pump was successfully switched on and blinking "2 d." What to do? My new iPad to the rescue! The backlight from the iPad was sufficient for the task. Do you suppose I should inform Apple that "there's an app for that"?

2. **A light goes on.** On my continuing flight from L.A. to Kansas City, my seatmate was a lovely third-year resident at an Osteopathic College in Des Moines. When I said, "I'm going to educate you on something," he was interested to learn that I have PH because "I've never met one of you before." By the time we deplaned, I'll bet he was better informed than any of his classmates.

3. **The nurse's revenge.** So, I'd made it to three countries on two continents, luggage intact, PH medication problem-free, but although I arrived home, my luggage didn't. But, no worries! I not only had my usual complete backup kit, I had my excess Remodulin™ and enough supplies for six more days in my carry-on. The extra precautions were justified!

Ann (pictured right) with Sandy and Allan Edmondson, New Zealand PH support group leaders

Looking back on my trip, no one in my group of 32 (except for a nurse who, I think, quietly filled in a few others) was at all familiar with PAH. I continually tried to find the line between being an advocate and being a bore. I hope I succeeded. ◆

By Ann Arnott, PH Patient

ASK A PH SPECIALIST

Q: As a PH patient, how can I safely treat my allergy symptoms?

A: Allergy season is upon us! Unfortunately, having a diagnosis of pulmonary hypertension doesn't protect you from more run-of-the-mill ailments like seasonal allergies.

Though PH is generally a rare disease, seasonal allergies (or allergic rhinitis) are thought to affect up to 30 percent of all adults. Typical symptoms of allergic rhinitis include nasal congestion, facial pressure, post-nasal drip, itchy and/or watery eyes, swelling around the eyes and sneezing. For some people, seasonal allergies only become troublesome at certain times of the year depending on the environmental allergen that triggers the symptoms (e.g., pollen in the spring). However, a large percentage of patients with allergic rhinitis have some symptoms throughout the entire year. In these cases, an indoor allergen may be responsible. In addition, patients with allergic rhinitis often have a predisposition to other related conditions, such as asthma and/or sinusitis.

As with any medical problem, establishing the correct diagnosis is key to determining proper treatment. It is important to remember that certain medications used to treat PH are associated with nasal congestion as a side effect. These include the endothelin receptor antagonists (bosentan and ambrisentan) as well as phosphodiesterase-5 inhibitors (sildenafil and tadalafil). If nasal congestion occurs after starting a new PH medicine, for example, and there are no other symptoms to suggest allergy (such as itchy eyes or a clear trigger), then it may be that your new PH medicine is responsible for the symptoms. If you suspect this, don't stop the medicine — rather, consult with your PH doctor first. As mentioned above, having allergic rhinitis may predispose to bouts of sinusitis, an infection of the sinus cavities within the head. Bacterial sinus infections may cause fevers, intense facial pressure, yellow or green drainage from one side of the nose, or upper tooth pain. If you notice these sorts of symptoms, you should call your physician immediately as other treatments may be required.

Assuming you have typical seasonal allergies, common approaches to treatment are aimed at reducing inflammation in the nasal cavities. Trying to identify the trigger for the symptoms is very important, as this can help you know what to avoid, which might help improve the symptoms. Sometimes, allergy testing can help you figure out what your trigger might be. Assuming you have minimized exposure to any known allergens, nasal corticosteroids are first-line medicines used to treat allergic rhinitis. These act topically to reduce inflammation and congestion. In general, these medicines are safe for use in patients with PH (a tip for use: point the nozzle away from the middle part of the nose, as it can become easily irritated). Second, because the chemical histamine is involved in the allergic process, antihistamine medicines are also commonly used to treat seasonal allergies. Like nasal corticosteroids, we generally feel these are safe for most PH patients; however, they can cause drowsiness. Though less commonly used, some types of rhinitis also may respond to a nasal spray called ipratropium bromide, also believed to be relatively safe in PH.

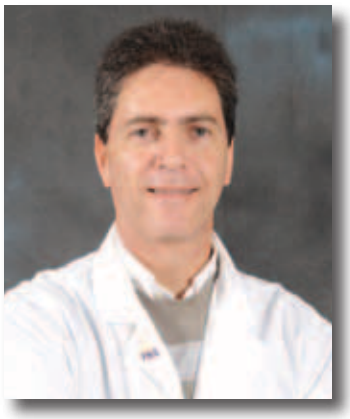
Types of medicines that are considered potentially unsafe in PH are those that act by constricting blood vessels. These are commonly referred to in a generic fashion as "decongestants," but more specifically include the over-the-counter drugs pseudoephedrine (Sudafed®), phenylephrine and the nasal spray oxymetazoline (Afrin®). The first two drugs are often found in common brand-name "cold and flu" or "sinus" preparations (e.g., Tylenol® Sinus or Cold); there are also generic equivalents boxed as drugstore brands. It is important that you always read the list of ingredients when buying a combination product. Some of these types of medicines have been shown in studies to further increase the pressure within the pulmonary vessels as well as put a strain on the right heart. On a case-by-case basis, these medicines may be permissible for short-term use, but you should always consult with your PH doctor first before taking any medications in this category.

Finally, remember that seasonal allergies alone should not cause shortness of breath. If you are noticing worsening breathing difficulty, especially if accompanied by worsening fluid retention (edema) and/or lightheadedness, these may be signs that your PH is worsening. If there is ever any question, you should always contact your PH doctor for guidance. ◆

Answer provided by Jason S. Fritz, MD, Assistant Professor of Clinical Medicine, Perelman School of Medicine at the University of Pennsylvania, Pulmonary, Allergy and Critical Care Division

EACH ISSUE *Pathlight* features a question from our PH community and its answer from a PH specialist. Send us your questions, keeping in mind doctors can only address general topics that are not specific to individuals. Send submissions to **AskADoc@PHAssociation.org** or call 301-565-3004 x770.

Meet Dr. Ronald J. Oudiz: *An Advocate for PH Patients*



Dr. Ronald J. Oudiz is a professor of medicine at the David Geffen School of Medicine at UCLA and director of the Pulmonary Hypertension Center. He also serves as a faculty cardiologist at the Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center in Southern California. His research focus has been to describe the physiologic abnormalities that are caused by PH using measurements of lung gas exchange during exercise and to study exercise rehabilitation as a treatment modality for patients with PH.

In 2011 Dr. Oudiz, a member of PHA's Scientific Leadership Council, received the Pulmonary Hypertension Association Award of Excellence in PAH Care. He is a past editor-in-chief of PHA's medical journal *Advances in Pulmonary Hypertension*, and he is the current editor of *Pulmonary Hypertension: A Patient's Survival Guide*.

You specialize in cardiology. What sparked your interest in pulmonary hypertension? Bruce Brundage, a pioneer in the PH field, was the chief of cardiology at Harbor-UCLA and he was the main reason I went to train there. This was back when epoprostenol was still being studied for FDA approval, and Bruce and the Harbor-UCLA PH nurse coordinator, Joy Beckmann, were in the process of teaching other doctors how to use it. I first started doing echocardiograms on the patients who came to see Bruce in the clinic; then I dove into the database in an effort to show the rest of the world what epoprostenol could do for PH patients. Right after that, Bruce put me in charge of a clinical trial; a year later he semi-retired, and the rest is history.

What advances have you seen in the treatment of PH patients since you started practicing? Epoprostenol was not even approved when I started. Having been a part of all of the studies of newer medications for PH, including bosentan, treprostinil, iloprost, sildenafil, ambrisentan and tadalafil, it has truly been amazing to see the field evolve. So many more patients are being treated now, and so many more patients, caregivers, scientists and clinicians are fighting the fight — the progress has been phenomenal.

What do you find to be the most encouraging advances currently taking place in the PH field? We are hoping that as scientists discover new molecules and companies put these discoveries to the test, there will be breakthroughs that, looking back, will make the current therapies seem like small potatoes. We are also hoping that scientists discover new pathways to target, not just new molecules. In particular, the sequencing of the human genome has fostered discoveries in many areas, but we have not realized the true power of these discoveries for PH. If scientists can "unlock" more of the secret "code" that makes PH what it is, it will be a tremendous aid to helping us get closer to a cure. I have to say I am also excited about the concept of exercise as a way to improve and empower PH patients' lives. We'd like to prove that exercise in fact is a safe and effective way to manage PH patients.

What are some of the rewarding "behind the scenes" projects you're working on to advocate for patients? PHA has been leading the activities in PH advocacy; I am only helping things move along. I am the chair of one of the newest PHA committees called the "Insurance Advocacy Committee." This committee supports PHA in its mission to educate the PH community about insurance while increasing payer awareness about PH treatment and diagnosis best practices. We want to assure that both public and private payers create and adhere to medically sound policies in the best interest of PH patients.

How did you become involved with PHA? My first PHA International Conference was in Chicago in 2000. Soon after I arrived at the Conference hotel, I met so many luminaries in the field all in one place, and all were so welcoming and down to earth. I was really touched. Then, seeing all of the patients and families and caregivers and all of the volunteerism and the camaraderie, I couldn't wait to come back to Harbor and tell all of our patients what they were missing.

What is the most important piece of advice you give your PH patients? They will likely know more about PH than almost anyone they are going to meet, so they are their own best advocates.

Do you have any advice for new practitioners in the PH field? The PH medical community is a tightly knit group that takes pride in providing patients with all we can. These medical professionals are a wonderful bunch of welcoming and nurturing individuals who, despite their passion for PH, would love to be out of work when a cure is found. ◆

Interview conducted by Rebecca Kurikeshu, PHA Medical Outreach Program Associate

Finding Answers to Questions about Lung Transplantation for PH: *Part One in a Two-Part Series*

From the development of epoprostenol in the early 1980s to the discovery of oral and inhaled therapies over the next decades, expansion of medical treatment of pulmonary arterial hypertension (PAH) has improved survival and quality of life over the past 30 years. While research into new medical treatments is ongoing, to date there is no cure.

The first heart-lung transplant was performed at Stanford in 1981 for a patient with primary pulmonary hypertension, and over the next decade, single and double lung transplantation evolved. As surgical techniques and postoperative management have improved, the number of lung transplants has risen every year, reaching more than 3,000 lung transplants in 2009. With improvements in surgical treatments and pre- and post-operative management, lung transplant continues to be a viable treatment for qualified candidates whose disease is progressing despite maximal medical therapy.

When considering lung transplantation, you may ask yourself one or all of the following questions. Part one in this series focuses on general questions about the transplant process.

What types of patients receive lung transplantation for PH? Lung transplantation is a surgical treatment for patients with PAH due to a variety of causes. Patients with idiopathic pulmonary arterial hypertension (IPAH) account for approximately 5 percent of all double lung transplants; however lung transplant is commonly performed for patients with PAH associated with chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis (IPF), connective tissue diseases and other lung diseases.

Although we have made considerable progress in the medical management of PAH, not all patients respond equally well to medications. Therefore, lung transplantation is considered in patients who do not respond to medical therapy. Close and frequent follow up after starting PH medications is essential, in case patients worsen and require additional medical therapies or listing for transplant.

What determines if a patient receives a single, double lung, or heart-lung transplant? By and large, the procedure of choice for patients with PAH is double lung transplant. Although transplantation for PAH began with heart-lung transplant, we have found that in most cases PAH can be effectively treated through double lung transplantation alone. With the immediate changes in pulmonary artery pressures after surgery, the right ventricle is quite remarkable in its ability to heal in the months after transplant. It is important to note that there are cases in which heart-lung transplantation may be required, such as in patients who have poor heart function or irreparable structural problems that they have had since birth.

What are special concerns regarding patients with PAH considering transplantation? In patients who are progressing with PAH, lung transplantation can provide a promise for a chance at a better quality of life. It is important to emphasize that transplantation requires a lot of maintenance and that in essence, when undergoing transplant, a recipient trades their current medical disease for another medical condition that has a better prognosis. In all recipients post lung transplantation, overall survival at one year and five years are 79 percent and 55 percent, respectively. However, supporting a patient with PAH through transplantation is a complicated procedure, reflected in the 76 percent three-month survival in IPAH patients. When patients with IPAH survive through the first year, their overall long-term survival is significantly higher (median survival 9.5 years) compared to patients with other diagnoses (median survival 6.8 years and 6.9 years in patients with COPD and IPF, respectively). Given the technical challenges early after transplantation for IPAH, it is recommended to be cared for at a center with experience in the PAH patient population.

While pulmonary hypertension medications are no longer needed, the transplant patient must take a combination of medications to help their body accept the lungs, as well as prevent infections. Careful medical follow up at the transplant center is also essential to success, as transplant recipients are at risk for complications, such as rejection, infection, side effects from medications. Quality of life can be tremendously improved when things go well, but given the regimen that goes into maintaining a

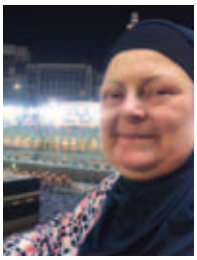
STORY CONTINUED ON PAGE 16

ATTENTION PH COMMUNITY: The United Network for Organ Sharing (UNOS) is currently reviewing the criteria used to generate the lung allocation score (LAS), which is a number from 0 to 100 that determines where a patient is ranked on the transplant list with respect to others. These changes are currently open for public vote and would significantly benefit PH patients awaiting transplant. Vote now: **www.PHAssociation.org/LAS/Vote** Learn more about the LAS: **www.PHAssociation.org/LAS**

Meet PHA's Transplant Email Group Committee

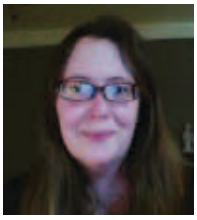
Many PH patients will consider or have questions about transplant during their PH journey. PHA's Transplant email group is a place where patients, family members and transplant recipients can ask their transplant-related questions and connect with people who have received transplants. The email group is organized by the Transplant Committee, consisting of three transplant recipients and one transplant social worker. Read on to meet each committee member and learn about their unique connections to transplant and PH. ◆

Angie Eldam



"I was diagnosed with primary PH in 1990 and had three small children depending on me. I was on Flolan™ therapy, and as my health progressively worsened, I was listed for transplant. On Oct. 6, 1995, I received a double lung transplant at St. Luke's Hospital in Houston, Texas. I currently volunteer with our local organ procurement organization, LifeGift, to promote organ donation awareness. My children are now in their 20s, and I have had many experiences and hit a few speed bumps in my transplant journey, and I would like to use my experience to benefit others. I think this group is important to open the door for PH patients to ask questions regarding transplant and also for transplant recipients to support each other like our PHamily has always done."

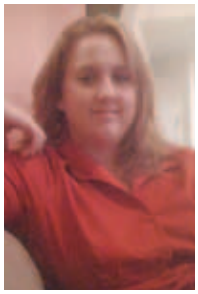
BreAnn McFarland



"I was diagnosed with PPH in 1994, and I was told I probably would not live long enough to celebrate my next birthday. At that time, I didn't know where to find support or information. I couldn't even find anyone who knew what PH was, so I was ecstatic to later learn about PHA. With the help of my pulmonary doctor and PHA, I found the hope I needed to fight for my life. I started Flolan™ in 1995, but unfortunately, it did not lower my pressures. I had been on Flolan™ for two years when I finally admitted to myself that I was not getting any better, and on my eighteenth birthday I was put on the waiting list for a double lung transplant.

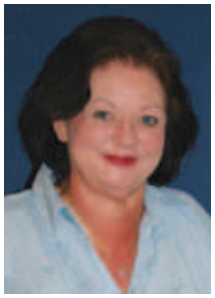
Five years later, on Dec. 8, 2002, I received the gift of life. I remember the fear I felt and the questions I had when I was listed. As a member of the Transplant Committee, I now have the chance to help others with those same fears and questions. One of the most important philosophies that I have lived by is to take one day at a time, both with PPH and transplant. Otherwise, you will become so overwhelmed that you'll drown in worry and fear. I am a survivor."

Sheri Lusk



"My name is Sheri Lusk, and I am a licensed master social worker. I have been a medical social worker for more than 10 years and began working with people who have PAH in June 2011. I have already worked with a number of people who have gone through the transplant process. It can be a scary and overwhelming time. I feel like groups like this email group are extremely valuable to help people navigate the process before and after transplant together. And the fact that it is specific to PH makes people's journeys even more similar, although everyone's journey is unique. I enjoy being a part of the committee that is working to grow and improve this group and to be able to tell the people I work with about it."

Shirley Craig



"Twenty-one years ago, I was diagnosed with pulmonary hypertension secondary to congenital heart defects. The doctors told me I needed a heart/lung transplant. Eighteen years later, I was transplanted at The Methodist Transplant Center in Houston, Texas. Now, I am on a different journey. Now, I have the strength and energy to go places and do things I couldn't even consider before. The best thing ... no more PH!"

Editor's Note: *Shirley Craig served as* Pathlight *editor from 2000 – 2006.*

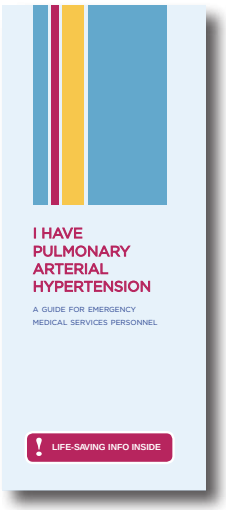
Did you know that April is Organ Donor Awareness Month? To learn more about organ donation and transplant, join PHA's Transplant Group.

www.PHAssociation.org/TransplantGroup

Questions? Email Transplant@PHAssociation.org

New EMS Brochure to Educate Emergency Medical Technicians

PHA and the PH Professional Network (PHPN) Education Committee are pleased to announce the creation of the Emergency Medical Services (EMS) brochure. This brochure provides critical and potentially lifesaving information for Emergency Medical Technicians (EMTs) who may be called in cases of PH-related medical emergencies. It explains how to best provide emergency care for PH patients based on the individual's current treatment regimens. This resource is especially useful for patients using an IV pump to administer treatment, as it provides explicit instructions on emergency pump care.



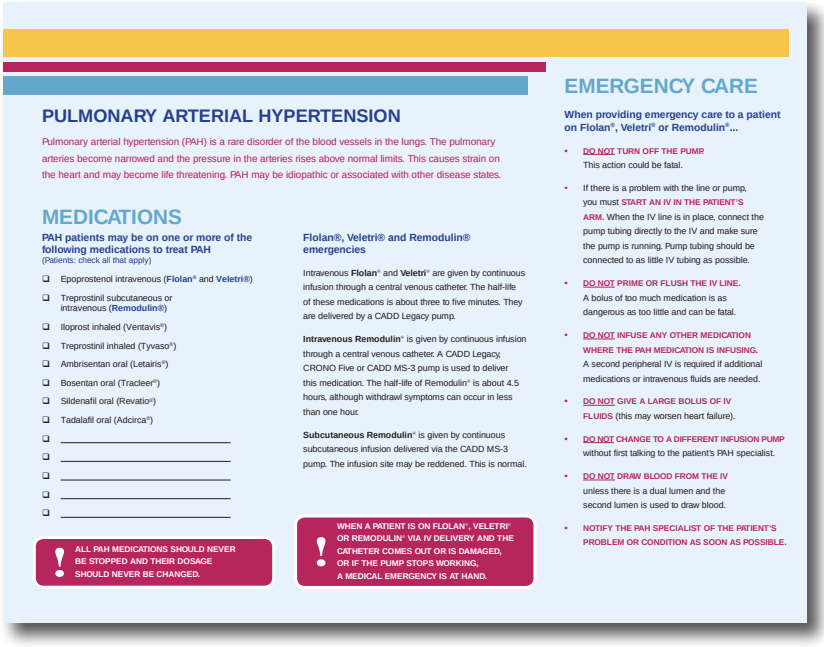
How to use the EMS brochure:

- On the "Patient Profile" panel, fill out your personal information (see below);
- On the "Medications" panel, check the PH-related medication(s) you are currently on. Use the additional space to write in any non-PH related medications you may be taking (see below).
- Place the brochure on your refrigerator (it has a magnet on the back) or in another location where you keep your medicine and/or vital health information. EMTs are trained to look for vital health information on refrigerators.
- If your course of treatment changes, request another brochure from PHA at any time.

To request your copy of the EMS brochure, visit **www.PHAssociation.org/EMSBrochure**

Patient Profile

"Medication" panel and emergency care instructions



TRANSPLANT STORY CONTINUED FROM PAGE 14

lung transplant, as well as complications that may occur, life frequently is not entirely "normal." This is discussed further in part two of this series.

Check out the summer issue of Pathlight *for questions about transplant evaluation and follow up. Also be sure to visit* **www.unos.org** *or* ***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.

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PH Community Members: *Find Free PH Education Online*

Whether you are a patient, family member or medical professional, PHA's online education resources can provide you with up-to-date information on important PH topics. All you need is an Internet connection to get the latest in PH education through *PHA Classroom* or *PHA Online University* — both programs of PHA's Medical Education Fund.

For patients and caregivers: *PHA Classroom*
www.PHAssociation.org/Classroom

In this vibrant e-learning center, patients and their families can learn about PH through live e-learning events or through one of the more than 120 recordings, including those from PHA's 9th International PH Conference and Scientific Sessions. Live e-learning events are scheduled regularly, but if you can't make the event, don't worry! Recordings are posted a few days after each webinar.

Highlighted Recordings

- Newly Diagnosed? What You Need to Know
- Maintaining Relationships with Friends and Family after Diagnosis
- Spring into Action: Planning Your Spring Special Event

For medical professionals: *PHA Online University*
www.PHAOnlineUniv.org

PHA's source for education for all medical professionals, *PHA Online University* provides free CME-accredited education as well as recordings from past conferences and symposia. Recordings from the 2011 PH Professional Network Symposium, "Inspiring Hope: New Directions in PAH," are now available. These sessions focus on a variety of issues, including:

- **Team Hope: A Multidisciplinary Approach to PAH Care**, *Mae Centeno, DNP, RN, CCRN, CCNS, ACNS-BC, Heather Langlois, MSW, LICSW, and Peggy Kirkwood, RN, MSN, ACNPC, AACC*
- **Asking the Right Questions: The Lost Art of Patient Interviewing**, *Janet M. Pinson, NP, Arlene G. Schiro, MA, ACNP-BC and Beth A. Coleman, RN, MSN, CPNP-PC*
- **Portopulmonary Hypertension: Double Trouble**, *Louise A. Durst, RN, and Michael J. Krowka, MD*

These recordings and more can be found online at **www.PHAOnlineUniv.org** in the Library under "Abstracts and Presentations." Check them out now!

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:

Thomas L. Petty Aspen Lung Conference
June 6 – 9, 2012
University of Colorado, Denver – Aspen, Colo.
Visit **www.aspenlungconference.org** for more information

6th Annual Pulmonary Hypertension Symposium
June 7, 2012
Yale University — Norwalk, Conn.
Visit **http://cme.yale.edu** for more information

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

PHA Pulmonary Hypertension Association
Empowered by hope

Medical Professionals: To partner with PHA in *Building Medical Education in PH* for your upcoming CME event, please contact Kimberly Demirhan at BME@PHAssociation.org or 301-565-3004 x763.

To learn more about this partnership, visit **www.PHAssociation.org/BME**

Sleep Well — Feel Better

We haven't done a clinical trial yet about an apple a day keeping the doctor away, but we know that a little sleep can go along way. Everyone benefits from a good night's sleep, but it's essential for those with PH. Check out the tips below to help you get your Zzzzs.

Maintain good sleep hygiene (which means habits).

- Stick to a regular schedule during the day. Try to wake up and go to bed at the same time each day.
- Resist the urge to sleep in even if you didn't sleep well the night before.
- Don't exercise within three hours of going to bed.
- Try not to nap. If you're really sleepy, only take one nap and do it before 3:00 p.m.
- Create a bedtime routine you can go through for about 30 minutes before going to bed, such as reading, listening to music, etc.
- Don't drink caffeine within six hours of going to bed. Try to take caffeine out of your diet completely; remember that it is a stimulant and will likely increase your heart rate.
- Don't use nicotine (as in tobacco products). This is also a stimulant. If you do smoke or chew, make an effort to stop; it will prolong and improve your quality of life.
- Don't eat a large meal before you go to bed; a light snack is preferred for those who are diabetic or those who can't go through the night on an empty stomach.
- Don't drink alcohol within six hours of going to bed. It is preferred that PAH patients avoid alcohol in any event since it can affect your liver, which is already being challenged by chronic heart failure. It can also interact with several medications that you may be taking, especially anything you may take for sleep.
- Limit any intake of fluid at least two hours prior to going to bed so that you don't have to get up and urinate at night, which then makes it harder to go back to sleep. For those on diuretics (water pills), remember not to take them later than 5 p.m. or you may also be up several times in the night.
- Make your bedroom a room for sleep. Move distractions, like a computer or a television, out of your bedroom. Make your sleeping environment as comfortable as possible.
- If you have a diagnosis of sleep apnea, work with your sleep team to get a comfortable fitting mask, a quiet device and, most importantly, be compliant. If you use oxygen, move the concentrator into another room so it will be quieter in your bedroom.
- If you can't get to sleep within 15 minutes of lying down, get up and do a quiet activity in another room until you feel sleepy and then lie down again.

Here's to many restful, rejuvenating nights ahead of you! ◆

By Natalie Kitterman, BSN, RN, CCRP, Intermountain Medical Center, Murray, Utah

DISCLAIMER

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

Find More Useful Tips in PHA's *Pulmonary Hypertension: A Patient's Survival Guide*

The *Survival Guide* serves as a soup-to-nuts guide for patients and their loved ones covering topics like the mechanics of PH, the latest treatments, patient care and lifestyle issues. You can purchase your copy from the online PHA Store or call PHA at 301-565-3004 to order. The book is $15 for PHA members and $25 for non-members. Visit **www.PHAssociation.org/OrderSurvivalGuide**

High Levels of Hyaluronan in Idiopathic Pulmonary Arterial Hypertension

While different cell types have long been known to contribute to the development of pulmonary hypertension, it is not very clear if the supportive material found between the cells (known as the matrix) is abnormal in this disease. We decided to find out whether hyaluronan, which is one of the components of the matrix, has a role in the idiopathic form of PAH.

Past studies: It is known that the matrix plays important roles in division and movement of cells. One of the major components of the matrix is hyaluronan, which is a large molecule produced by enzymes termed hyaluronan synthases and degraded by enzymes called hyaluronidases. Thus, hyaluronan has an important role in the lung response to injury and other disease processes implicated in idiopathic PAH, including new blood vessel formation, change in lung structure (or remodeling) and increased cell division and movement. However, the role of hyaluronan in idiopathic PAH has not been studied previously. High hyaluronan levels in idiopathic PAH have recently been recognized based on our work, and this was independently confirmed by another group studying humans and more recently in an animal model of idiopathic PAH.

This study: The study included 22 patients with idiopathic PAH and nine healthy control volunteers. Hyaluronan levels in the blood were markedly elevated in the idiopathic PAH patients compared to the control volunteers. When the lung cells were isolated and studied in the laboratory, one particular cell type, the smooth muscles cell, produced high levels of hyaluronan. Hyaluronan can be detected in tissues by staining with markers of different colors. Staining of these cells showed that they make more strands (known as cables) as compared to controls. This increased hyaluronan is shown to be important for various biologic functions like binding to cells that mediate inflammation (swelling of the tissues). We were able to demonstrate that this cell binding is specific to hyaluronan because the binding was diminished by the addition of hyaluronidase (an enzyme that destroys hyaluronan). Staining of lung tissues also showed that there is more intense hyaluronan production around the pulmonary arteries in idiopathic PAH as compared to controls. The most intense staining was seen in areas where the lung disease was so severe (plexigenic lesions) to the point where the structure of the lung was changing (remodeling) and new blood vessels were forming. We believe our findings suggest that hyaluronan may be a good way to monitor changes in lung structure in PH; something that is not easy to test for by the currently available methods.

Hyaluronan comes in different sizes and each size may have very different physiological functions. Big-size hyaluronan is thought of more as a structural component important for wound healing, and remodeling small-size hyaluronan has properties that promote inflammation (tissue swelling). We have demonstrated that the most hyaluronan in idiopathic PAH are big in size. Interestingly, however, we also found some small size hyaluronan produced by pulmonary arterial smooth muscle cells when they are grown in the laboratory.

The key findings of this study are that patients with idiopathic PAH have significantly higher levels of hyaluronan in their blood compared to controls. Furthermore, pulmonary arterial smooth muscle cells from idiopathic PAH patients produce hyaluronan cables (strands) spontaneously (without needing to be stimulated) and that these strands are capable of binding cells that promote inflammation. These findings suggest an improtant role for hyaluronan in the development and progression of idiopathic PAH and a possible role for monitoring changes in the structure of the lungs in patients.

Who may benefit from these findings: These findings are particularly important in view of the fact that the future progress in idiopathic PAH treatment depends on our ability to monitor and treat changes in the structure of the blood vessels in the lungs of patients with PH.

The bottom line: The study showed high levels of hyaluronan (a component of the lung matrix) in patients with idiopathic PAH, which can have an important role in understanding the cause of the disease and could serve as a novel blood test of the changes in the lung structure. However, we still need to determine exactly how and why these changes in hyaluronan develop in the pulmonary hypertension lungs.

Where to find this article: American Journal of Physiology — Lung Cellular and Molecular Physiology. 2008 Nov; 295 (5): L789-99.

Study authors: Metin Aytekin, Suzy A. A. Comhair, Carol de la Motte, Sudip K. Bandyopadhyay, Carol F. Farver, Vincent C. Hascall, Serpil C. Erzurum and Raed A. Dweik. ◆

By Metin Aytekin, PhD, and Raed A. Dweik, MD, Cleveland Clinic, Cleveland, Ohio

"We Need to Hear from You!"
Legislative Aide Discusses the Importance of Patient Advocacy

Sara Mabry, the Legislative Aide to Senator Robert Casey (D-PA), has witnessed firsthand what can happen when one person shares a story with their Member of Congress. In 2009, PH patient Colleen Connor and her family met with staff in Sen. Casey's office and requested co-sponsorship of the *Tom Lantos PH Research and Education Act*. Sara's boss was so moved by Colleen's experience with PH that Sen. Casey introduced the Act on the senate floor within 48 hours. "That never happens," says Sara. "It shows the power of one person speaking up and sharing their story."

Colleen Connor (left) at PHA's Congressional Luncheon in 2009

The *Tom Lantos Pulmonary Hypertension Research and Education Act of 2011* is the only bill in Congress with the sole aim of improving the lives of PH patients. Recently, Sara offered some advice, based on years of experience in Sen. Casey's office, to help the PH community move the *PH Research and Education Act* closer to becoming law.

On the basics of being a good PH advocate…

"Make sure you know the bill number and whether or not your Members of Congress have already co-sponsored. You don't want to make a passionate plea for him or her to sign on, only to find out that it's already happened."

On how to get the attention of your Members of Congress…

"We get a lot of form letters. It still makes a difference because it means we heard from a lot of people about an issue, but it's very different when someone writes to say, 'This is why this is important to me.'

"Members pay attention when their names end up in the press! Write an opinion piece or a letter to the editor in your newspaper and explain why the *PH Research and Education Act* is important."

On why contacting congressional staff is so important…

"The role of educating staff is very important because we have to be a mile wide and an inch deep. I don't always have the information I need.

"Sometimes the reason a Member of Congress hasn't signed onto a bill is simply that no one has ever asked. There are literally tens of thousands of bills introduced each Congress. The easiest way to figure out which ones we need to pay attention to is by looking at the mail we're getting and the requests constituents make. If someone took the time to write or visit about a bill, then that means it's important to them."

On the power of your voice…

"Never doubt how important your voices are. We need to hear from you, and our bosses need to hear about what is important to you. In fact, some members won't sign onto a bill until they've heard from someone in their state or district. They want to know that the bill is something that is important to their constituents."

Members of Congress need to hear from everyone who is affected by PH about the need for more PH research and education and the importance of the *Tom Lantos PH Research and Education Act*. For more information about how to help move the bill forward, contact Elisabeth Williams at 301-565-3004 x753 or ElisabethW@PHAssociation.org or visit **www.PHAssociation.org/Advocacy** ◆

PHA National Call-In Day: Pledge to Call Congress and End Misdiagnosis on April 26!

Your Members of Congress walk thousands of steps each day to cast their vote on legislation. Before treatment, the average pulmonary hypertension patient gets winded after just a few steps. Pledge to call your Members of Congress during PHA's National Call-In Day on April 26 and help end misdiagnosis by asking your Members of Congress to co-sponsor the *Tom Lantos PH Research and Education Act*. Contact Elisabeth Williams at 301-565-3004 or ElisabethW@PHAssociation.org or visit **www.PHAssociation.org/PHANationalCallInDay** for more information.

Cindy Pickles Finds Many Ways to Give Back to the Cause

Not only is Cindy Pickles a PH patient and active member of PHA's Board of Trustees, she also leads a support group in North Carolina, is a monthly *Sustainers Circle* donor and runs an annual golf tournament that, along with her other special events, has raised more than $97,000. Her latest way to contribute to PHA is by becoming a member of the *Legacy of Hope Society*. We took this opportunity to ask her about her PH diagnosis and why she is compelled to do so much for the PH community.

Cindy and John Pickles

Like many PH patients, your road to diagnosis was a long one. How were you finally diagnosed?

I started feeling terrible toward the end of 2002. When we were shopping for Thanksgiving dinner, I looked down and all of my fingers were blue. In early December after a project meeting with my boss, I said to her, "I have no idea what is wrong. I am just so tired all the time." After Christmas, things escalated to the point where my husband, John, told me he needed to take me to the emergency room. After what seemed like a zillion tests to rule out pneumonia, pulmonary emboli and other stuff, they sent me home thinking I had bronchitis. Soon after, I was put on oxygen.

Tests after tests followed: multiple chest CTs, echocardiograms, blood gases, chest x-rays, bronchoscope, heart cath, open lung biopsy and shunt studies. I was dizzy if I raised my arm to dry my hair or bent down to get a pan out of the cupboard. I would take a shower and have to rest before getting dressed, and I literally crawled up the steps.

I was desperate for answers and began to search the Internet. It brought me to the PHA website. I ordered a copy of *Pulmonary Hypertension: A Patient's Survival Guide* and read each page carefully. I eventually found a doctor at our local medical center who had an interest in pulmonary hypertension and had trained at San Diego. An exercise echocardiogram he performed showed PAP at 100 with exertion. I finally knew the enemy: I had pulmonary hypertension. Far from being upset, after two and a half years, I was happy to finally have the correct diagnosis. By this time, I was finished with the grieving process.

How did you become involved with PHA?

After my diagnosis, I wanted to attend a PH support group, but the closest one was 40 miles away. I thought since I could not travel that far, I would just start my own. An Accredo advocate told me that if I found the speaker and location, she would supply the food. Thus, our group was born in January 2006. I did not want to see another patient go on the rollercoaster ride I did to get the correct diagnosis. And if you are helping someone else, you don't have time for a pity party.

Our support group has held five golf tournaments and two small run/walks. My husband, John, is my rock. He, along with my son, Tim, and daughter, LeeAnn, help in the organization of these special events: moving boxes, folding and stamping forms, driving the beverage cart. They truly are family events, working toward a common goal: a PH cure.

In 2009 I was asked to serve on the Board of Trustees. What an amazing experience that has been, working behind the scenes to help make things better for the patients and their families!

You recently became a member of PHA's *Legacy of Hope Society*. Why did you decide to do this?

Before becoming a Board member, I would see the ads in *Pathlight* asking readers to consider becoming a *Legacy of Hope* contributor. I would skim over them, thinking they didn't apply to me. But with some planning, there are many innovative ways to approach giving when you are no longer here. You can designate a portion in your will or life insurance policy, stocks, things of value. John and I decided to designate a portion of my life insurance payout to PHA when I pass away. All we had to do was contact our insurance agent to obtain and sign the appropriate forms.

We feel that becoming part of the *Legacy of Hope Society* is so very important as a way of giving back to the organization that has done so much for us. We like being givers and not just takers. We want PHA to carry on its good work and remain alive and solvent for those patients coming behind us. ◆

To learn more about PHA's Legacy of Hope Society, *turn to p. 23 or visit* ***www.PHAssociation.org/Give****.*

Sustainers Circle Donors Honor Loved Ones

PH never takes a break. And neither does PHA. Our monthly giving club, the Sustainers Circle*, invites donors to join us in this fight by making easy, secure donations to PHA each month. Each donor has a unique story and gives for a variety of reasons. We'd like to share two of those stories with you now.*

Christina Buchanan

Christina Buchanan donates to PHA's *Sustainers Circle* in honor of her daughter Riley. Riley is 4 years old, and when she was born, she was diagnosed with persistent pulmonary hypertension of the newborn.

Riley's nurses say she is "spicy." She is full of jokes, loves to help cook, go on shopping trips and listen to music. She is on oxygen 24/7 and knows how to untangle the tubing if it gets caught on something.

On Dec. 27, 2011, Riley became actively listed for transplant at Children's Hospital of Philadelphia.

Riley is a "very happy girl. She doesn't let any of this slow her down," Christina says. When Riley was 2, she saw the flame on the PHA T-shirt and asked what it was. Her grandmother said it was hope. From that moment on, whenever Riley sees that flame, she points to it and says, "That's Riley's hope."

At night, when Riley says her prayers, she "prays for all her PH friends. She's very sweet," Christina says.

When Riley was diagnosed, Christina found PHA's website and became active in the online PH community. "The other parents have been the biggest help in all of this," she says. It helps "when you have people who understand."

In December 2011, in an effort to do more, Christina joined PHA's *Sustainers Circle*. As she explains, "Now seems like the perfect time to give because of the advances in pediatric research, including the Robin Barst Pediatric Research Fund." Her donations help her know that she's "making a difference in helping even if the cure comes after Riley's transplant."

Christina is the second person in her family to donate to the *Sustainers Circle* in honor of Riley. Christina's father and Riley's grandfather, Thomas Myers, has been donating since August 2009. Giving is important to Christina and her family because, as she explains, "You don't know the need until you've lived it." ◆

Lauren Murawski

My name is Lauren Murawski (pictured right), and my friend Colleen Connor has PH. I am hard-pressed to remember exactly when I first met Colleen because I feel like I have known her forever. She has that effect on many people because she is one of the most warm-hearted women I know.

Each time I see her, she has learned something new about PH and is happy to share what she has learned with others. She amazes me with her knowledge and understanding of PH to the point that I wonder when she went to medical school! She is determined to find answers, and she is a true example of a fighter. She is going to make a difference for PH — so be ready!

I decided to join PHA's *Sustainers Circle* because I have a "Vision of Hope" for my friend and others with PH. When we are teenagers, we feel like we are invincible and that nothing could ever happen to us. I am fortunate to be a healthy adult, and subconsciously, I think I carry that same teenage sentiment with me. But when someone like Colleen gets a diagnosis like PH, I am reminded that I am not invincible and this could happen to me just as easily as it happened to her. No one has a crystal ball. But, I am truly hoping my small contribution can make a difference in the research and understanding of PH. I am proud to let others know that I support PHA.

A small monthly donation could make a huge impact on the research and development of a cure for PH. I think all too often that we don't realize that every dollar counts. It is very easy to join the *Sustainers Circle,* and the response from PHA is amazing! I am honored to be a part of such an amazing group fighting for such an important cause! One by One, I truly feel we can make a difference. ◆

Sustainers Circle *donors realize the power their monthly donations have in providing hope and support to patients, raising awareness, funding research for a cure and advancing our legislative priorities. All so that one day, there will be no such thing as PH and, until then, every patient has access to essential information, resources and support. Interested in learning more about the* Sustainers Circle*? Email Giving@PHAssociation.org or call Ellen Leoni at 301-565-3004 x756.*

Let Me Breathe: One Man's Tribute to the PH Community

Canadian composer J. Paul Adams learned about pulmonary hypertension from his niece, PH patient Emily Dolan. Emily started having symptoms when she was 9 years old but was not diagnosed until age 27. As her health problems increased, she left advanced university studies in Halifax, Nova Scotia, to move back in with her family in Toronto. During this tough time, Emily and her family found the PHA Canada Toronto Chapter where they received support and answers.

J. Paul Adams sings during the "Let Me Breathe" video.

Emily's uncle was so moved by the support group meeting he attended that he composed and performed "Let Me Breathe," a tribute to the PH community, to raise awareness of PH. Paul continued his work with friends and colleagues in the music industry to capture the heart and soul of the PH community through film. In November 2011, he posted the "Let Me Breathe" music video, sung with a choir of PH patients, on YouTube, and as we go to print, it has received more than 2,200 views.

The music video "premiered" at the Annual Vegas PH fundraiser hosted by the PHA Canada Toronto Chapter on November 5, 2011. During the 2011 National PH Awareness Month Campaign, "Let Me Breathe" was also featured at an awareness event on Parliament Hill, the legislative heart of Canada.

Paul's song continues to raise awareness and bring hope to the PH community in Canada and abroad.

Please join Paul, Emily and other members of the PH community in sharing this video worldwide. Share it with your friends, family, supporters and anyone who will listen. Do your part to raise pulmonary hypertension awareness now! ◆

*To view the video, visit **www.YouTube.com** and search "Let Me Breathe PH" or visit **www.phacanada.ca**.*

By Meghan Tammaro
PHA International Services Manager

A THREE-MONTH PROGNOSIS FOR THEIR DAUGHTER SENT JACK AND MARCIA STIBBS LOOKING FOR HOPE. THEY FOUND IT AT PHA.

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

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

PHA

Like Jack and Marcia Stibbs, you can strike a blow against PH by designating PHA as a legacy beneficiary. Your contribution will help shape a brighter future for all those affected by PH. For details, call us at 301-565-3004 x756, or email Giving@PHAssociation.org. Visit our website for more information at PHAssociation.org/Give.

PHA Unveils Phineas, a New PHriend for the PH Community

Meet the creative community members behind PHA's new PHriend, Phineas: artist Leslie Polss and the winners of the naming contest, 5-year-old Parker Romney and 9-year-old William Reilly.

Leslie Polss

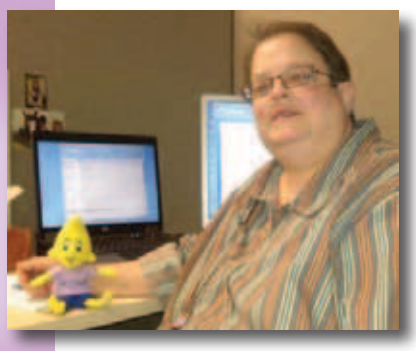
Leslie is the original creator of Phineas. He made his debut as a cartoon drawing during Awareness Month 2007. Leslie has made several theme-specific versions of him for PHA throughout the years.

PHA: What is your connection to PH?

Leslie: I'm a PH patient, diagnosed in 2003.

PHA: How has your artwork helped you on your PH journey?

Leslie: It was sort of a natural place for me to turn when there were experiences to be expressed and dealt with. I find that a lot of times when I'm going through something, with PH in particular, I'm actually thinking about the cartoon that I'm going to do out of the experience. It sort of gives me a lighter outlook on stuff that's happening. It's instinctive; it's my way of dealing with the world.



PHA: What inspired you to create the "flame guy" image?

Leslie: The flame sort of lent itself to a character. The first one came on ice skates, and after that, it became kind of a challenge to dress him up in some other way. They got more and more detailed as time went on. For the one that was climbing the mountain, I actually looked up mountain climbing gear to make it as authentic as possible.

PHA: Where are you keeping your new PHriend?

Leslie: I had to hide him to keep my little niece from taking him home with her! She really, really wants one. She's 6 and a half. I sort of wanted to keep [Phineas] for myself, so I promised her I would get her another one.

Parker Romney

Parker is a happy, active PH patient. PHA spoke with his mother, Jennifer, about Parker and how he came up with the name Phineas.

PHA: What's Parker's connection to PH?

Jennifer: He was diagnosed with PH when he was 10 months old, and he's now 5 years old.

PHA: How did Parker think of the name?

Jennifer: He's a big fan of *Phineas and Ferb*, the Disney show. Of course, he didn't really think of the "PH," but I said, that would be good because it would be "PH" for "pulmonary hypertension."

PHA: Could you share any stories about how Parker has been playing with his new PHriend?

Jennifer: It was a big hit! He played with Phineas all morning; he's been taking Phineas everywhere with him and sleeping with him. Parker just thinks he's the greatest thing, and he's had a lot of fun with Phineas so far.

William Reilly

William lost his grandmother, whom he called Nana, to PH in November 2011. We spoke with him and his mother Amy about Phineas and their connection to PH.

PHA: Tell us about William and his grandmother.

Amy R: William has autism, and he had a really great bond with his Nana, so he was really excited to name [the plush] Phineas.

William: She was really sweet. You know the game Ghost Hunters? Me and Nana would play it a lot.

PHA: How did you think of the name?

Wiliiam : I told everyone I know about the contest. We were trying to think of something that has PH in it.

PHA: What have you been doing with your new PHriend?

William: I've been taking him with me everywhere. I've even taken him with me when I go to sleep. ◆

Interview conducted by April Grimsley, PHA Administrative Assistant

You can get a PHriend of your own by visiting ***www.PHAssociation.org/Store*** *or calling 301-565-3004.*

An Awareness Idea Becomes Reality through a Lantos Award

Like all of us touched by this disease, my greatest wish is for a cure. But as time has gone on, I have also realized that if I am going to have the right to hope for a cure, then I have to take some active part in pursuing it as well. I'm no doctor; ideas for research and better treatments aren't going to come from me. But I am by nature very much a "people person." And as a stay-at-home mom who is self-employed, I'm also a social networking addict.

Last year, the call for applicants went out for the *Tom Lantos Innovation in Community Service Awards*. I thought, "Oh, that's nice." And really, I had no intention of applying. Already involved in several PHA outlets, I didn't have time for another project!

But then I started thinking about how the email group part of Generation Hope, PHA's community for patients in their late teens, 20s and 30s, was such a lifeline for me, and I knew PHA had these groups for people in other demographics too. I also thought about how allied health professionals see patients every day, and they are the ones who are going to ask a patient, "How are you coping with all this?" They need to know about the powerful tools they can offer patients through PHA. I could help get that word out.

So, less than 48 hours before the deadline, I applied for an award. And, much to my surprise, I got it.

I was able to locate *Design Is Love*, an organization that seeks to link up creative types with non-profit organizations. As luck would have it, I started contacting artists on this website and landed on the founders themselves. Co:Lab in Hartford, Conn., worked with me to bring what was initially a very simple vision right through to a reality.

In addition to the design team, patients Melanie Kozak, Raye Bohn and Carol Morrison and caregiver Misty Lewis agreed to participate in the video. My friend Adam Blau, a composer in Hollywood, donated his talents for music, and PH Dad and PHA Board member

L to R: PSA video participants Melanie Kozak, Carol Morrison, Misty Lewis and Colleen Brunetti

Steve Van Wormer provided the professional voiceover.

The end result was so much more than I originally dreamed up, a result of a group of dedicated individuals all coming together. Sure, it was my idea, but that idea was further shaped by the Lantos awards committee and the project participants, and it really came to life through the many talents of everyone involved.

The video has now gone out to thousands of people across the country via DVD and digital distribution. My sincere hope is people will view it and when sitting across from a patient who is overwhelmed with PH or, like me, wanting to reach out and make a difference, they can then say, "Hey, I know of these great groups you can join where you can find other patients just like you." And, because the PH community always comes full circle, people will continue to find the support they need and offer support in return.

We make a difference when united together. Someday I believe that collective effort is what will ultimately drive us to the cure. ◆

By Colleen Brunetti, PH Patient

Visit **www.PHAssociation.org/LantosAwards** to learn more about *Tom Lantos Innovation in Community Service Awards*. To view Colleen's video, go to **www.PHAssociation.org/PHAEmailGroupsVideo**

Welcome, Ellen Leoni, Development Associate!

As Development Associate, Ellen works to implement programs that generate support for PHA, its programs, services and research agenda. Ellen coordinates *Our Workplace Has a Heart*, featuring PHA's myriad workplace giving programs; *In Honor of Our Lives*, PHA's program to include PH awareness and fundraising in celebration of personal milestones; and *Web of Friends*, PHA's program where participants create personal fundraising pages online. Ellen is also the contact for the *Sustainers Circle*, PHA's monthly giving program. In conjunction with the entire development team, Ellen answers donor and membership inquiries. Ellen can be reached at 301-565-3004 x756 or EllenL@PHAssociation.org. ◆

International Highlights:
What's Going on Around the World?

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

- ***In Canada…*** The British Columbia PH Society (BCPHS) held its 11th Annual PH Symposium on February 17-18, 2012, in Vancouver, Canada. The event started with a Meet and Greet for PH patients on Friday evening followed by the PH Symposium on Saturday.
- ***In Europe…*** PHA Europe published and distributed the winter 2012 edition of its quarterly newsletter, *MariposaNews*. To learn about the work of PH associations in Europe and read past issues of *MariposaNews*, visit **www.PHAEurope.org**.
- ***In Israel…*** The Israel PH Association is working to create a teleconference for PH associations around the world. The goal is to discuss issues important to the global PH community and work together to advance the field. The event will be held in conjunction with World PH Day (read the "In Spain…" item for more information).
- ***In Latin America…*** Migdalia Denis, leader of the Sociedad Latina de Hipertensión Pulmonar (SLHP), had the opportunity to be interviewed on CNN's Notimujer, a program broadcast in Spanish. She talked about her PH experience and PH awareness. Her video can be viewed online at **www.PHAssociation.org/MigdaliaCNNenEspanol**.
- ***In Spain…*** The Asociación Nacional de Hipertensión Pulmonar (ANHP) is creating and organizing the first worldwide day of PH awareness on May 5, 2012. World PH Day will involve PH associations and partner organizations from all over the world in an effort to promote awareness of PH. The main event will be held in Madrid, Spain.

The news featured in this issue's roundup is only the beginning! For more news from around the world, visit **www.PHAssociation.org/PHInternational** ◆

By Meghan Tammaro

PHA International Services Manager

Experiential Learning Opportunities at PHA!

Are you — or someone you know — looking to enhance your academic experience beyond classroom walls?

PHA offers a variety of internships year-round. From International Services to Marketing & Communications to Patient Outreach, there is something to meet your educational and professional goals.

For more information, visit **www.PHAssociation.org/Internships** or contact Internships@PHAssociation.org.

Help change the future of this disease: apply for a PHA internship.

www.PHAsociation.org/PHADailyBeat

With all that's going on in the PH community, it may seem difficult to keep up with everything. The *PHA Daily Beat* makes it easy by giving you one place to go to stay in-the-know. You'll find:

- The latest news about PH and research
- Stories from PHers about their journey with PH and victories for the cause
- Details about upcoming events
- Links to educational materials and recorded presentations
- Information about ways to get involved
- And more!

Check out the *PHA Daily Beat* online or subscribe to receive stories as soon as they're posted.

Insurance Finds: *Your 2012 Healthcare Reform Rundown*

When the *Patient Protection and Affordable Care Act* (ACA) was enacted into law in 2010, the legislation laid out an eight-year timeline for implementing a series of changes to the health insurance industry.

While you shouldn't expect any additional benefits to be implemented in 2012 (such as the elimination of preexisting condition clauses for adults — that's coming later), this year could still prove very meaningful for you and your coverage.

Keep an eye out for the following developments:

- **Uniform Explanation of Coverage.** Starting September 2012, insurers will be required to provide their plan participants with an explanation of benefits and coverage written in plain language.

  This summary must include information such as clear definitions of standard insurance terms (e.g., copayment, deductible), your expected out-of-pocket contribution, and a website where you can obtain a full-length copy of the plan.

  Your employer must provide you with the summary before you enroll, re-enroll, or receive your certificate of coverage.

- **Quality of Care Reporting:** The Department of Health and Human Services (HHS) is developing quality of care standards that insurance plans must adhere to. By March 23, insurance plans must begin submitting annual reports to both HHS and the plan's enrollees on whether the plans fulfill these standards. Penalties for noncompliance and/or failing to meet these standards are currently being set.

- **Defining Essential Health Benefits:** HHS is currently working to define "essential health benefits." Once they're defined, essential health benefits will set the minimum requirements for affordable health insurance plans offered to individuals and businesses as a result of the ACA.

  Recent discussion indicates these benefits will consist of core items and services, such as emergency and maternity care. States will have some flexibility in defining additional required items.

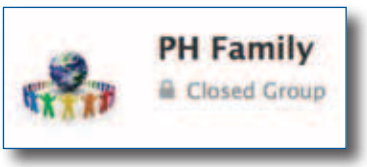
- **Supreme Court Challenges:** In 2012, the U.S. Supreme Court will rule on the constitutionality of the ACA. However, it is too early to tell what action the court will take and how its decision will affect the implementation of the ACA.

PHA will continue to update you on any developments. We will also continue to advocate for policies that are important to the PH community.

Find more information about healthcare reform at **www.PHAssociation.org/Insurance/HealthcareReform**. Or, email Insurance@PHAssociation.org or call 301-565-3004 x773. ◆

Have You Heard About PH Family?

PH Family, a pulmonary hypertension group on Facebook, was started in November 2010 by PH patients Lawana Timberlake and Kimberlee Ford. The purpose of the group is to connect in real time with others by asking questions, sharing personal experiences and offering support, helpful resources, and upcoming event information from around the globe.



"This group is all about hope in the face of adversity. When I have my PH days, I can come here and share what I am going through, and people understand and support me in times of trial," explains James, a PH Family group member since 2010.

PH Family originally started with four members and has grown to more than 700 PH patients, caregivers and others friends in the PH community. The group is closed/private, which means information will only be shared with other group members.

To find out more about this group or to join, visit us on Facebook by searching "PH Family." This group should not be used as a substitute for speaking with a medical professional. ◆

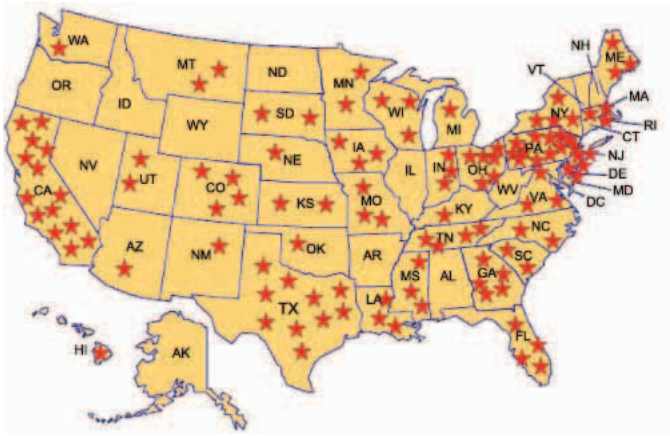
By Kimberlee Ford and Lawana Timberlake
PH Patients

50 State Media Challengers Raise Awareness Throughout the U.S.

In 2011, PHers appeared in online publications, local and national newspapers and TV news programs 144 times in 37 states across the country! Many of them were driven by a desire to ensure that their neighbors could put a face to pulmonary hypertension. PH patient Linda McDonald told a reporter at a newspaper in Texas, "I never took a sick day and hardly ever took an aspirin. Then all of a sudden I would have to stop and catch my breath for a good 10 minutes."

Others sought out the media to raise awareness about PH to help those who remain undiagnosed. "I am terrified of sitting in front of a camera and being interviewed, but I am so passionate about PH awareness and getting the message out that I am willing to 'put myself out there' so others may not have to go as long as I did before finally being diagnosed," said Patty Kaiser after being filmed for a St Louis segment that aired Nov. 1, 2011.

Get inspired by a couple of the media victories from your PHriends and then consider how you could share your story to raise PH awareness in your area!



Joan Stevenson, Allentown, Pa.

PH patient and PH support group leader Joan Stevenson was featured in an article about overcoming several obstacles and becoming an advocate for PH after her diagnosis. "I won't take 'It can't be done' as an answer," says Joan.

Joan Stevenson

Delia Rivera, Corpus Christi, Texas

Delia Rivera, who is living with PH, and her husband Michael were featured in a lengthy story in their local paper. The Riveras' story includes the loss of Delia's sister to PH because she wasn't properly diagnosed, the Riveras' PH support group, and Delia's own journey with this illness.

Delia Rivera (left) and her husband Michael

To read all of the PH news stories from 2011 and learn more about the PHers who inspired them, visit **www.PHAssociation.org/50StateChallenge/MediaSuccesses**. Then find out how you can join PHA's Media Hall of Fame! Details below.

New Educational Tool About PH Available!

Would you like to help someone in your life better understand PH? Whether your goal is to educate a reporter, a Member of Congress or your mother-in-law, PHA has a resource for you. Our new DVD, *Understanding Pulmonary Hypertension: Empowered by Hope*, answers questions about what PH is, who it impacts and how it is treated.

Order a free copy online at **www.PHAssociation.org/Store** or by calling 301-565-3004.

Join PHA's Media Hall of Fame

In 2012, PHA's Media Hall of Fame will highlight the names and faces of those who receive media coverage throughout the year. Visit **www.PHAssociation.org/MediaHallofFame** to see the media successes of your fellow PH community members. Then, make your mark on PH awareness by sharing your story with reporters!

Get started today! Visit PHA's website at **www.PHAssociation.org/PHAware** or contact Elisabeth Williams, PHA's Grassroots Campaigns Associate, at ElisabethW@PHAssociation.org or 301-565-3004 x753.

PH Bill Gains New Co-Sponsors

Since the beginning of the year, the following U.S. representatives have become co-sponsors of the *Tom Lantos Pulmonary Hypertension Research and Education Act*: Elijah Cummings (MD-7); Steven LaTourette (OH-14); Todd Platts (PA-19); David Price (NC-4); Tim Ryan (OH-17) and Louise Slaughter (NY-28).

Jeannette Morrill speaks at PHA's Congressional Luncheon in November 2011.

Five more representatives have expressed interest in co-sponsoring and are waiting for their names to be added to the bill: Jason Altmire (PA-4); Jesse Jackson Jr. (IL-2); Gregory Meeks (NY-6); Michael Michaud (ME-2) and Chris Murphy (CT-5).

Each new Member who adds his or her name to the PH bill represents a PH patient, caregiver or medical professional who contacted that Member and shared a story. Six Members signed on after receiving visits during PHA's Congressional Luncheon in November, but some signed on after a simple phone call or email from a constituent.

"I met a patient from Vermont who had never connected with another patient. She had been isolated from the time of her diagnosis, about two years ago. These situations clearly show why the Tom Lantos bill is so important to the pulmonary hypertension community," said PH patient Jeanette Morrill during a presentation to Members of Congress and their staff. Jeanette's representative, Michael Michaud, had co-sponsored PH legislation on multiple occasions thanks to Jeanette's efforts to keep him connected to the PH community.

The *Tom Lantos PH Research and Education Act* is the only bill in Congress that is solely focused on improving the lives of PH patients. To learn more about keeping your Member of Congress aware of the PH community, contact Elisabeth Williams at 301-565-3004 x753 or ElisabethW@PHAssociation.org. ◆

PHers Stand Up for a Common Cause: Fighting Rare Diseases

Invite Your Members of Congress to the Rare Disease Caucus

The Rare Disease Congressional Caucus is a forum for members of Congress to voice constituent concerns, share ideas, and build support for legislation that will improve the lives of people with rare diseases. If you're looking for a new way to connect with your Members of Congress about PH, check on their membership in the Rare Disease Caucus. If they don't belong to the caucus, encourage them to join. If they do belong, but haven't yet co-sponsored the *Tom Lantos PH Research and Education Act*, ask why.

Members of Congress can join the Rare Disease Caucus by contacting the offices of co-chairs Rep. Joseph Crowley (NY-7) or Rep. Leonard Lance (NJ-7). Learn more and see a list of current caucus members at **www.rarediseases.org/advocacy/initiatives-updates/caucus** ◆

Rare Disease Day Touched Lives around the World

Thirty million Americans live with one of 7,000 rare diseases, and these conditions touch the lives of millions more worldwide. Everyone who has been impacted by a rare disease has a unique story to tell. Rare Disease Day (RDD), on Feb. 29, brought those voices together to raise global awareness of the importance of rare disease research and education.

PHA promoted Rare Disease Day opportunities on our website and Facebook wall and PHers added their voices to the cause. In fact, the day included a unique Capitol Hill briefing that brought Members of Congress and their staffs together with PH patients and medical professionals to learn more about pulmonary hypertension and pulmonary fibrosis. Other RDD successes included state and local proclamations, dozens of events, and media coverage across the country and around the world. Learn more at **www.rarediseaseday.us** ◆

The Persuasive Case for Support Groups: Leaders Share Benefits When Recruiting Newcomers

Attending support group meetings for the first time may be easy for some people, but for others, being a newcomer to a support group can be intimidating. Patients and their loved ones may need some time to mentally prepare themselves for talking about PH with others in a support group environment, according to Tina Silks, leader of the San Luis Obispo, Calif., group.

For those who are hesitant, Tina offers gentle encouragement, asking people first to consider just visiting the group. "I tell them to come, try it, just sit and listen. You don't have to speak. It doesn't have to be scary." Whether these people attend or not, Tina calls them whenever a meeting is coming up so they know they are always welcome.

Continuously reaching out to new people is important to keeping PH support groups vibrant. To help our PH community bring in new members who may be wavering, PHA asked support group leaders and co-leaders from around the country about ways they have benefited from the group. Their thoughts may help you bring new members to your local group.

Here's what you had to say.

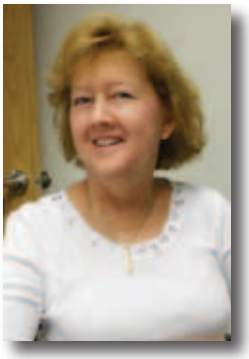
Nicole Cooper, Charm City Exhalers of Baltimore, values being with and learning from other patients.

"Being with other PH patients who have had PH longer than I have and who have gone through different scenarios has been the most beneficial part of my support group experience. It was refreshing to discover that I was not alone and that I was going to have a future. I have family and friends who want to help me, but I can't talk to them about why I can't breathe, not the way I can with others with PH."

Katherine (Joy) Morgan, PH Support Group, Central Florida, mentioned developing and promoting self-advocacy skills and making close friends.

"My involvement has helped me become my own advocate in fighting PH, and I encourage others to be their own advocate as well, to learn more about PH beyond what our doctors are telling us. I am more passionate in my involvement now more than ever. Also, before each meeting, I most look forward to seeing my group members. They are like family to me, and we actually have fun together."

Marla Shaffer (Hawaii) noted the caring bond between group members.



"There's a certain level of understanding and compassion with our Hawaii support group. I'm sure this is true for other areas of the country as well. This is a huge benefit that has been there from the very beginning. The level of friendship and support just continues to grow as we take this PH journey together."

Elsa Dasigo, PH Support Group, Hawaii, cherishes the strength and coping skills she has gained.

"Through being in a support group, I have become more aware of how to deal with my PH. I know that I don't need to face the fears of this rare and incurable disease on my own. I feel that everyone's involvement in sharing our knowledge and symptoms with each other helps make each of us a little bit stronger. It's even more valuable to know that we make a difference in each other's lives."

Learn more about PHA support groups. Visit **www.PHAssociation.org/LocalSupportGroups**.

Your Prescription for Well-Being: Attend a Support Group

Support groups offer attendees so many benefits, both physically and emotionally. According to the Mayo Clinic, patients experience a number of health benefits when they attend support groups, including reduced distress, depression and anxiety as well as improved skills for coping and a greater sense of control over their own health. How do support groups do this? Read on to find out!

Finding Medical Answers

It's not unusual to have a lot of questions regarding your PH diagnosis and your treatment. Is nausea a normal side effect? Is it all right for me to take allergy medication? Sometimes you won't remember all the questions that you have or even have time to bring them up during your appointments with your PH specialist. Your PH support group may offer another outlet to discuss health-related questions.

Support groups often feature pulmonologists, cardiologists, nurses or respiratory therapists as speakers. And the majority of the time the speaker saves time for patient questions. If you have a pressing question, don't be afraid to ask, take notes and bring back what you learned to your next medical appointment.

Medical professionals are an invaluable part of support group education. Not only do they provide education and support, leaders often find that more people attend their meetings when a doctor is speaking. Cindy Green, support group leader of the Piedmont, N.C., Support Group, says, "We are an older group of PHers and we're trying to make our presence known. We have as many as 30 members when I can get a doctor to speak." Cindy explains that some of the new members who have joined the group first came to learn more about the disease, but have since grown close to others and return often.

Gaining Strength through Purpose

Even when your support group meeting does not feature a medical speaker, it still has the potential to positively affect your health. Support groups can provide a sense of purpose and control over your disease. Some support groups even hold special meetings focused on these ideas. Every year Charlotte McCabe, support group leader in Puyallup, Wash., plans a meeting about "Being Your Own Advocate" where she speaks about what pulmonary hypertension patients can do to get the most out of their medical appointments. Patients who arrive at appointments well-prepared, with a list of questions and notes on any health changes, will be able to get the most out of their time with a PH specialist.

Healing through Sharing

Hearing stories of others' experiences with the disease can help you troubleshoot day-to-day issues regarding your own situation. Hearing what others have to say about their experience can also put you at ease about difficult parts of living with PH. Mary Svikhart, a support group leader for the Hershey and Harrisburg, Pa., Support Group, found her first right-heart catheterization very distressing. Leading up to her second catheterization, she asked other patients about their experiences. Mary was surprised with the how calmly they reflected on the same procedure. In the end, the second catheterization was much easier. "They were right," she recounts. "That's the kind of cath I was supposed to have." Feedback from other PH patients can change your outlook and help make you more willing to go forward with your treatment.

Support groups also provide health benefits by by allowing everyone to share achievements with each other. The St. Louis, Mo., Support Group celebrated the end of 2011 by making a list of some of the health successes members of the group had over the course of the year, from an improved six-minute walk to a successful lung transplant. The benefits of witnessing the triumphs of others cannot be downplayed. At diagnosis, no one really knows what's in store for them and getting to know others with pulmonary hypertension may help. For the newly diagnosed patient, seeing someone who has lived with the disease for many years or getting to know someone who no longer needs to use oxygen can entirely change that person's expectations of the coming years. These are just a few of the many good reasons why support groups are good for your well-being. ◆

What benefits do support groups bring to your well-being? Let us know! Email SophieK@PHAssociation.org.

By Sophie Klein
PHA Volunteer Services Associate

The PHA Support Group "Scoop"

Winter's cold, rain and snow didn't stop our PH support groups all across the country from bringing members together and hosting meetings.

1. **Giving and Receiving!** Winter is a time for holiday parties and gatherings for our support groups. Patients and caregivers had fun with "white elephant" gift exchanges at group meetings in Phoenix, Orlando and Puyallup, Wash. We love that the Eastern Panhandle, W.Va., group called it a "Yankee Gift Exchange" during its holiday brunch. The West Los Angeles group not only hosted a gift exchange, but raised nearly $500 in a silent auction at its annual holiday party.

2. **You better watch out!** The Fresno PH support group hosted its holiday party at the Old Spaghetti Factory and co-leader, Josh Daniels, dressed up as Santa Claus. The Twin-Cities, Minn., group also had a Santa at its holiday gathering in January.

3. **Steppin' Out.** Our groups like to dress up and have special meetings outside of their usual community rooms. The San Luis Obispo group hosted a dinner meeting at a cozy, home-style restaurant based out of Apple Farm, a well-known winery in the region. The Southwest Virginia group continued its tradition of hosting an annual holiday gathering at the historic Hotel Roanoke.

   The St. Louis PH support group hosted an end-of-year party at Maggiano's, and the North Texas group hosted its holiday party and gift exchange at Dave & Busters.

   The Carbondale-Southern Illinois, Tampa Bay, Central Florida, Penn Presbyterian, Midlands South Carolina, St. Luke's-NYC and Del Val, Pa., patient support groups had a great time celebrating the holidays, too.

   The Hampton Roads, Va., group gave its annual holiday party the inspiring title, "Attitude of Gratitude and Sharing."

   Last but not least, the Newport Beach, Calif., support group holiday party always makes us want to relocate to the West Coast. Members celebrated at the 103rd Annual Newport Beach Christmas Boat Parade. The parade draws an audience of more than a million people and features richly decorated yachts sailing along the harbor.

4. **Eat Right and Exercise.** PH patients must take careful steps to ensure their activities are truly beneficial and safe. Our PH support groups are helping patients learn how they can integrate physical activity and healthy foods into their daily lifestyles.

   The PH support group in York, Penn., brought in a speaker to discuss physical therapy.

   Our Chicago group featured a speaker from Edward Hospital discussing pulmonary rehabilitation — a popular activity among PH patients. The Greater Kansas City group hosted a talk on exercise as well.

   Our Fort Worth, Texas, group hosted a well-known nurse practitioner, Martha Kingman, giving a cooking demonstration and talking about low-sodium diets.

   Our Cleveland, Ohio, group brought in Dr. Robert Chliz who discussed "Staying in the Groove," which is code for exercise!

5. **Cameo Appearances from Famous and Exciting Speakers!** PH nurses and doctors may not be movie stars, but to the PH community, they're well-loved and respected for their work in the field. Many groups had medical professionals speak during the last few months.

   Doctors may give you a prescription, but sometimes laughter is the best medicine! The Upstate South Carolina group featured a Certified Laugh Instructor who had the group in stitches. Thankfully, not *those* kinds of stitches.

   You have the right to remain informed! A corporal with the Forsyth County Sherriff's Department spoke to members of the Piedmont Area Support Group in North Carolina about keeping safe during the holidays.

   Speaking of safety, both the Minn-la-KOTA group in South Dakota and the Treasure Valley group in Idaho had a speaker discuss emergency preparedness.

   The Valley of the Sun group brought the president of the Caring Voice Coalition, Pam Harris, to Phoenix to talk about financial assistance and other patient support services from their organization.

   A representative from the office of Congressman Adam Smith (D-WA) was the special guest speaker at the Des Moines, Seattle (WA) Support Group. Patients and caregivers shared their experiences about how the disease affects their lives and the group discussed the *Tom Lantos PH Research and Education Act*. ◆

Check Out These Support Group Happenings from Coast to Coast

The Corpus Christi, Texas, PH Support Group met in December around a couple of tables at a Starbucks Café. They heard from a nurse educator who explained the basics of pulmonary hypertension.

The Port Charlotte, Fla., Support Group hosted a "Spaghetti & Meatball Dinner and Dance" — the group's first fundraiser for PHA! According to Linda Milo, the group leader, "It was a huge success. I made the sauce and my husband made the meatballs. Everyone enjoyed the dinner, so they say!" The support group raised more than $500 for the cause.

The Fresno, Calif., Support Group brought 33 patients and caregivers together for a talk on clinical trials by nurse educator and group co-leader Josh Daniels.

The D.C. Capital Breathers hosted a large holiday gathering at a restaurant inside historic Union Station in Washington, D.C. Patients brought their sisters, brothers, parents, children and friends to this party. "It felt like one big happy PHamily," says support group member and patient, Alex Flipse.

Support Group Co-leader Mary McCarthy reads the Support Group Member Agreement and Confidentiality Statement at the Valley of the Sun PH Support Group in Phoenix, Ariz.

Want to find a support group near you?
Connect with a local group by visiting
www.PHAssociation.org/LocalSupportGroups

Celebrating the New York Fun Walk:
A Day of Awareness, Fundraising, Community and Remembrance

Left: The Lugo Team walks arm in arm.
Above: Framed photos at the candle lighting memorial

On Saturday, Dec. 10, 2011, a crowd of more than 350 people gathered at Nassau Coliseum in Uniondale, N.Y., for the 7th Annual New York Fun Walk. This year's event, held indoors for the first time, allowed attendees the opportunity to attend the New York Islanders hockey game following the walk, at which PHA was the "Charity of the Game." Spearheaded by Long Island PH Support Group co-leaders, Joanne Sperando-Schmidt and Mary Bartlett, the annual New York Fun Walk has become a staple event in the lives of PH patients, families and friends in the New York metro area.

While the New York Fun Walk celebrated its seventh anniversary this year, Joanne, Mary and members of the Long Island Support Group have been coming together to raise PH awareness and funds for research for more than 10 years, starting with garage sales and luncheons. Then in 2004, after hearing Jack Stibbs talk about his fundraising efforts at PHA's International PH Conference, Joanne knew her group could do more.

In November 2005, to correspond with PH Awareness Month, the group used their talents and ideas to host the first New York Fun Walk. The Fun Walk drew a crowd of about 100 people and raised $18,670. Since then, the walk has grown significantly, drawing a yearly crowd of 300-400 people and raising more than $340,000 since its inception. Joanne attributes this success to various factors. The first is getting everyone involved. Joanne encourages all members of her support group to reach out to their networks to spread the word about PH, encourage event attendance and/or raffle donations. As a result, each year attendance, the number of patient and family teams, and the number of raffle prizes has increased. Support group member Linda Sullivan and her family managed this year's raffle of more than 70 items and raised more than $4,000.

Raising PH awareness is also an important element of event success as it connects the crowd to the cause. Guest speakers — including this year's honored guest, PHA President and CEO Rino Aldrighetti — educate the crowd about PH and share their stories and current advances in the field. This year the New York Fun Walk also paid tribute to PH doctors. All PH treating physicians in the New York metro area were invited and honored and acknowledged with a plaque during the ceremony.

Aside from raising PH awareness and funds for research, the New York Fun Walk has allowed patients, those who have lost a loved one to PH, medical professionals, friends and families to "stand together." In 2007, Joanne went one step further in strengthening this community of support by incorporating an "Angel Board" and Memorial Balloon Release into the walk as a way to honor the lives of those lost and to remind everyone that these patients and their families will always remain a part of our community. The "Angel Board" hosts photos and messages, and prior to the walk start, Joanne reads each name, followed by "We remember you." Family members and the community would stand together and release the balloons simultaneously in remembrance.

This year, in lieu of a balloon release, a candle lighting ceremony was held. Framed photos of loved ones and candles adorned a table by the stage. As Joanne read the names, families came forward and lit the candle in front of their loved one. The candles remained lit throughout the event, symbolizing the ongoing presence of these angels and a reminder to keep striving for a cure.

Although they are very tired at the end of each walk, Joanne and all members of the planning committee remain committed to creating an event that truly captures the essence of a PHA special event — raising PH awareness and funds for continued research in the field, while nurturing a sense of community and remembrance among PH patients, families and friends. The New York Fun Walk is truly an event created by the community for the community. ◆

By Leslie Mahaney, PHA Special Events Associate

Special Events: What Could $600,000 Do?

Special event fundraisers play a vital role in the PH community for a variety of reasons — primarily because they raise significant funds for cutting-edge PH research and programs, information and resources designed to improve the daily lives of those directly affected by PH. In 2011, hundreds of volunteers worked together to host 50 events which collectively raised more than $600,000 directly benefitting PHA's Research Program and programs for patients, families and caregivers.

What can $600,000 do, you ask? It equates to significant progress in our ongoing mission to find ways to prevent and cure pulmonary hypertension while offering a hearty helping of hope. Take a look! ◆

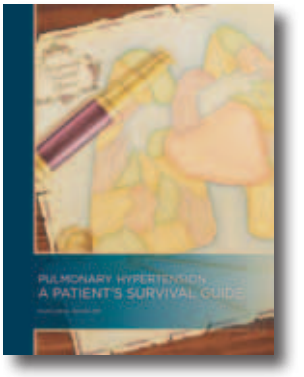
Theoretically speaking, $600,000 could:

Help fund nine different PH research studies for one full year

Send 600 patients in need to PHA's 10th International PH Conference and Scientific Sessions on a full scholarship

Keep PHA's comprehensive website running for the next 1,200 weeks (just over 23 years)

Give 40,000 PHA memberships to community members who cannot afford it



Provide each of the next 24,000 diagnosed individuals with a copy of *Pulmonary Hypertension: A Patient's Survival Guide*

PHA in Top 1 Percent of Rated Charities!

CHARITY NAVIGATOR
★★★★
Four Star Charity

PHA's done it again! For the 9th consecutive year, PHA has received a four star rating from Charity Navigator, the premier evaluator of charities in the United States. According to Ken Berger, Charity Navigator President and CEO, only 1 percent of charities rated have received the highest rating for nine consecutive years, indicating that the Pulmonary Hypertension Association "outperforms most other charities in America." To learn more, go to **www.PHAssociation.org/CharityNavigatorRating** ◆

Helpful Hints from Event Organizers to Raise Awareness, Funds and Fun!

Connect with your local elected officials: State Rep. Jim Waldman (left) attended the 4th Annual South Florida Fun Walk in Pompano Beach, Fla., welcoming the crowd and presenting PH patient Al Abram with a Proclamation.

Get Creative: Colleen Brunetti (center), PHA Board Member, turned her love of Zumba into a special event — hosting PHA's first "Zumbathon for PH" in Canton, Conn., during PH Awareness Month.

Invite Guest Speakers: Dr. Murali Chakinala (far left), Assistant Professor of Pulmonary and Critical Care Medicine at Washington University School of Medicine, and Laura D'Anna (not pictured), PHA Board Chair, shared their personal stories and connection to PH as guest speakers at the Greater St. Louis, Mo., Dinner and Wine Tasting.

Hold Wraparound Fundraisers: Event organizers held a Happy Hour months before their event to kick off fundraising for the 2nd Annual Walk 2 Cure PH: Ellie Godina Memorial Walk, which is scheduled for April 28, 2012, in Euclid, Ohio.

DID YOU KNOW WE HAD 18 DIFFERENT VOLUNTEER-ORGANIZED FUN WALKS OR FUN RUNS IN 2011?

2012 can be a record-breaking year for the PH community! With a brand new logo for our Fun Walks for a Cure, new banners for your event, and updated awareness-raising materials, we are ready to support your efforts. Contact Events@PHAssociation.org or 301-565-3004 x765 for more information. In addition to Fun Walks, we offer the Six Minute Marathon, a smaller-scale fundraising event. Learn more at **www.PHAssociation.org/6MM**.

PHA FUN WALKS & RUNS
ONE STEP CLOSER TO A CURE

Thursday, April 19, 2012

Our second special events webinar of 2012! Learn about "Peer-to-Peer Fundraising 2.0"
All are welcome!
Register: **www.PHAssociation.org/Classroom**

Saturday, April 28, 2012

4th Annual Scramble for a Cure
WHERE: Angel Park Golf Club, Las Vegas, Nev.
DETAILS: Jack Nino at Jack.Nino@igt.com or 702-250-2214

Saturday, April 28, 2012

N.C. Cure PH Golf Tournament
WHERE: Pudding Ridge Golf Club, Mocksville, N.C.
DETAILS: Cindy Pickles at cpickles50@gmail.com or 336-978-1668

Saturday, April 28, 2012

2nd Annual Walk 2 Cure PH: Ellie Godina Memorial Walk
WHERE: Lakefront Community Center, Euclid, Ohio
DETAILS: Missy Godina at melissagodina@sbcglobal.net

Saturday, May 5, 2012

2nd Annual Rolling PHor a Cure Bunco Tournament
WHERE: Prince of Peace Catholic Church, Ormond Beach, Fla.
DETAILS: Amy Piazza at cureph@hotmail.com or 386-235-0884

Sunday, May 6, 2012

Stride to the Cure PHA 5K Run/Walk
WHERE: Chicago Botanic Garden, Chicago, Ill.
DETAILS: Jessica McKearin at 301-565-3004 x765 or Events@PHAssociation.org

Saturday, May 12, 2012

DeWitt Take a Breath for PH & Get Moving for MS
WHERE: DeWitt, Mich.
DETAILS: Melinda Grubich at grubich@msu.edu or 517-281-6197

Saturday, May 19, 2012

Southwest Virginia Night Out for PH
WHERE: Radford, Va.
DETAILS: Jonette Robinson at 540-818-2813 or jlrobinson1@peoplepc.com

Sunday, May 27, 2012

PH Sweet Walk of Life
WHERE: Santa Fe Springs, Calif.
DETAILS: Monica Penaranda at villagesweetswhittier@yahoo.com

Saturday, June 2, 2012

3rd Annual Race 2 Cure PH: Taylor Caffrey Memorial 5K
WHERE: Anaheim Hills, Calif.
DETAILS: Shari Caffrey at shari@TaylorsWish.org or 714-200-8322 or **www.TaylorsWish.org**

Sunday, June 3, 2012

2nd Annual Power for PH: New Jersey's PHun Walk
WHERE: Roosevelt Park, Edison, N.J.
DETAILS: Christina Lapatka or Christina Rodrigues at powerforph@gmail.com

Friday, June 22, 2012

Attending PHA's 10th International PH Conference in Orlando, Fla.? Make plans to participate in a skill-building workshop! We're hosting "Put the Special in Special Events" from 5:15 – 6:15 p.m.

Monday, July 9, 2012

2011 Swing 4 the Cure: Wojo PH Golf Classic (5th Annual)
WHERE: Aliso Viejo Country Club and Conference Center, Aliso Viejo, Calif.
DETAILS: Betty Lou Wojciechowski at 949-215-1573 or bettylouwojo@hotmail.com or **www.swing4thecure.us**

Saturday, July 28, 2012

Country Happenings PHun Walk
WHERE: Brant, Mich.
DETAILS: Victoria Turner at 989-717-1499

July 2012 *(Date TDB)*

Central Florida PHun Walk and 5K
WHERE: Lakeland, Fla.
DETAILS: Darren Sun at djs11d@my.fsu.edu or Joy Morgan at kjcmorgan@yahoo.com or 863-646-4937

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

EDITOR'S CORNER

Hello, PH community, and welcome to Persistent Voices*. In this edition, you'll read about four strong women and their journeys with pulmonary hypertension. They generously share their experiences and their philosophies on coping and living with illness. Thank you all for telling your stories. We learn from each other!*

For the cure,
Joanne Sperando-Schmidt, Persistent Voices *Editor*

Dale's story is an inspiring snapshot of her PH journey. She sets a wonderful example of how to advocate for yourself, set goals and KEEP dreaming — no matter what the circumstances — and make things happen.

— Joanne

Dale Rankin-Mack, Rochester Mills, Mich.

It was Super Bowl Sunday 2006, late in the afternoon. I was tired, horridly tired. In the past months, my breathing was more and more labored; the colder it got, the worse it got. All I really wanted was a hot bath. My thought was that it would help my breathing and open up what my doctors had been treating as asthma, maybe allergies.

All I remember is falling to the ground and I couldn't breathe. I'd been in the tub; the water was nice and warm. The perfect bubble bath. Then I tried to get out, but the bath had made my breathing worse. My husband helped me up.

The next morning, my son drove me to our family doctor, and with my oxygen level down to 40, I was rushed to the local hospital. After three days of every test imaginable, things were no better.

It's funny when I look at it now, but I had just talked two nurses into helping me wash my hair right there in my bed. A solemn doctor I'd not met before came into my room. He introduced himself as the director of the pulmonary department. I remember him saying, "You're going to die, maybe six hours. I've no medicines to give you." In my head, I was saying, "Right, you must be kidding. I just washed my hair. You're wrong; I'm not going to die!"

According to my husband, the next few hours were frantic, although I didn't know all that went on until much later. It seems this doctor had picked up the business card of a physician who had spoken at a conference about a very rare, very difficult to diagnose lung disease. The real problem was he had no number for her. After trying everything he could think of to reach her, they finally succeeded and saved my life. Her name is Dr. Vallerie McLaughlin.

From that moment on, my life changed forever. I had primary pulmonary hypertension.

I spent more than three months in the ICU at the University of Michigan. I found out later that there were six other patients in the ICU at the same time, all with PH. All of us were very sick, and all six of them died in that ICU. Why did they die? Why was I alive?

I was at level four. I was terrified of the medications and what was happening to me. Still, I believe something in my heart stirred in those three months. I really wanted to live. And (chuckle) I

wasn't going to let anyone stop me.

Since most of you have spent a few (and I use this almost jokingly) days, weeks, months, etc. in the hospital, you all know how hard it can be to get real information, stand up for yourself, even keep yourself sane.

In fact, you have much more control than you know. Being your own advocate is a very important piece of healing. I've got so many stories I'd like to share with all of you. This journey has been, of all things, a wonderful experience. I know, that's hard to believe. I have truly been blessed.

My father, William Kales Rankin, died just a few months before I was diagnosed. He was a wonderful, active gregarious 83-year-old until he had a closed head injury and a series of brain bleeds. Weather permitting, he came over each Sunday for dinner. One Sunday, a few weeks before he died, he pulled me down in the sofa seat next to him. Sometimes when he spoke to me, he seemed very confused. Today he looked right through me and said, "The boys will still go to Scotland, and you too."

Dale with her son Sean at Edinburgh Castle

My father's family is from Scotland, and for as long as I could remember, he had wanted me to take my sons to Scotland to see where their ancestors were from. For nearly five years after I was diagnosed with PH, I truly believed that could never happen. I was on disability. I had a pump connected to my body, I took 17 pills, and I was almost always tired. One day, holding on to a cart in Walmart, I made a very conscious decision. Every day I would walk; I would walk until I could walk one mile without holding on to anything.

Some days were horrid, but it did get better little by little. I was no longer on oxygen during the day. I did better and better on my six-minute hall walks. Finally, Dr. Mel Rubenfire (the other doctor who saved my life) gave me a surprising piece of news. He said, "Do you understand what's happening? Your heart pressures are amazing, and your hall walk is now faster than 95 percent of the healthy women your age."

I think I must have looked stunned because I asked him to say it again. Only a few years ago, I couldn't get out of my bed. Now he was saying I even had stamina.

Each little step you take, you are learning how to walk again. A short walk in a store with a cart to lean on, even taking time to plant a few flowers — each step makes all the difference in the world.

In May of 2010, an extraordinary event took place in my life when I took my sons, Sean and Chris, to Edinburgh, Scotland. That promise my Dad had me make came true. We also went to Paris and London. We carried all the medications, pills, etc. everywhere. Not once did we have any issues with our travel, pump and all.

If you are reading this, and you have PH, you are among the strongest people in the world. You will have setbacks — like my three other "long" visits to the ICU. But each day, you have it in you to be stronger. Not everyone around you, not even your family, may understand. Unless their bodies have gone through a "terminal" disease, they may never really know what you are going though. But you are great. You have so much power in you to complete anything your heart can imagine. ◆

To read Dale's full story, visit ***www.PHAssociation.org/OurJourneys/DaleRankinMack***

Mary lost her son Michael in 2009. She tells us to stay positive and strong and reminds our caregivers to remember to take care of themselves as well as their loved one. She also reminds us that the families of our PH angels will always be a part of the PH family. Mary, you honor us and we thank you for continuing to give us love and support.

— Joanne

A Pulmonary Hypertension Challenge by Mary White, Anderson, Ind.

This challenge comes from the bottom of my heart in memory of my son, Michael L. White Jr. He lost his battle with pulmonary hypertension at the age of 37 on June 10, 2009.

When Mike was born, God gave him the breath of life and the strength for his little body to grow with the heart defect he was born with (transposition of great vessels).

The ugly signs of PH appeared as Mike grew to be a young man. His dream was to be an EMT and to care for others. He accomplished these things and worked as an EMT for a few years. After that, he worked as a critical care technician at our local hospital for 10 years. Eventually, PH took its toll and he could no longer carry out his duties at work.

As Mike fought PH, he fought with all his might to keep PH from taking over his life. He tried to live and love each day to its fullest.

As PH progressed, the struggle to breathe became harder. All of the many meds just would not let his body function any longer. God took him out of his misery, and now he is breathing easy. He soars with the eagles now.

I, as a caregiver and parent, want to challenge and encourage all of you patients and caregivers to be strong! Be positive! Live and love each day to its fullest! Most of all, take care of yourselves and love yourselves!

Caregivers, you are the only advocates your patient/loved one may have. You also have to stay strong and positive. This is not easy to do in those most difficult times. Take care of yourselves.

PH patients and caregivers are some of the strongest people I know. Keep on with your hopes and dreams. I believe there is a cure for PH in the future. It's coming! Be strong, and hang in there!

You are all important in this journey to find a cure, and I feel that I always will be connected to and feel love for PH patients and caregivers. ◆

Mary's son Michael

Julienne shares her PH story of diagnosis and surgery (a thromboendarterectomy to remove blood clots from her lungs) and her philosophy of living life fully and moving forward no matter what! She sent this submission to Persistent Voices *shorltly after reading about other patients' experiences in the fall 2011 issue of* Pathlight.

— Joanne

Julienne Brock, Totowa, N.J.

Dear PHriends,

I just finished reading *Pathlight*. Every article interested me because I too have PH and have had it for many years. I too have gone through the stages described by the wonderful PHriends who have thoughtfully written in the pages. I can't help feeling as though I should be contributing somehow to all the great efforts that others are making for a cure, so I'll send my story hoping that it will help in some way.

I was strong and eager when I was in my 20s and 30s. At some point, I hurt my back because I didn't know the proper way to lift. After several back surgeries and lots of pain, I trudged on. I can't even count all the tests, x-rays and medicine I went through — yet I still have back pain. I wasn't able to do heavy nursing work any more, but I did do all that I possibly could in other areas. I was activities director in a home for the elderly and also managed to direct the arts and crafts department and was the volunteer director. Now I work at the reception desk.

I can't remember when I first noticed the symptoms of PH because of all the difficulty in dealing with the back pain, but I did feel terrible at times and I suppose it was coming on. I had cardiac symptoms — breathlessness and chest pain, headaches and tiredness. Sometimes I felt as if I was being smothered. I again underwent a gamut of tests, even occasional trips to the ER, but nothing showed up. The cardiologist was sure there was "something" wrong, but he couldn't pinpoint it. This was around 1990.

Then in 1996 I traveled by plane from Albany, N.Y., to Cleveland, Ohio, to visit my elderly mother, and on the way I could barely walk from one terminal to the other. I knew that there was something seriously wrong, but I wasn't going to let my mother know. I planned to call my doctor when I returned home to Albany, but that wasn't going to happen because I coughed up blood while I was in the bathroom in her apartment.

I had to tell her then because I was afraid something would happen when we went visiting or shopping or to church. You can imagine the look on my brother's face when he arrived with pizza, expecting to have a little party with us and hearing that we needed him to take me to the ER at the nearby hospital!

By the time I got there, I was fine and looking very well. (I always look good!) In a way I was glad because I didn't want anything to go wrong now. I told Dr. Ellen Cory that I coughed up blood and immediately she suspected a blood clot in my lungs. After much discussion, she convinced a pulmonary doctor to test me. He ordered an angiogram and the results were alarming. I had multiple blood clots in both lungs. I was put on Coumadin™ after having a filter placed in a main vein going to my heart. When I was discharged, I returned to Albany to die.

STORY CONTINUED ON NEXT PAGE

STORY CONTINUED FROM PREVIOUS PAGE

I soon called Albany Med and made an appointment to see a pulmonary specialist there. Fortunately, it was Dr. Anthony Malanga. As soon as he saw me walk in the door, he said, “San Diego.” I said, “California?” He said, “Yes, and the sooner, the better.” Everything happened so fast after that!

I soon found myself on a plane with an oxygen tank heading for San Diego. I stayed with my sisters in San Pedro, and they were kind enough to see that I got back and forth to San Diego where I underwent a pulmonary thromboendarterectomy. They actually went in and removed the clots in my lungs. It is a very dangerous operation, but I went through it without a hitch. I’m convinced that it was thanks to all the prayers that were said for me, and the doctors agreed.

Among other things, they told me that my pressures went down immediately during the surgery, so I presumed that all my problems were solved. As time went by, I did feel much better. I kept working, and I moved from Albany to Enfield, Conn., and now to Paterson, N.J. — all the time continuing the Coumadin™, which is no big deal, considering. (Although I don’t like the frequent blood tests.) The diagnosis of PH was kept on my records, and I presumed it was because I once had it.

Gradually, 10 years later in 2007, I recognized the symptoms. I was short of breath and sighing a lot, so I told my doctor who referred me to a cardiologist who specializes in PH. No blood clots this time. He was very compassionate and honestly explained the diagnosis. After all that I had been through, I wasn’t surprised and accepted it calmly. I suppose he thought I didn’t understand, but I did — perfectly.

Then after a right-heart angiogram, he told me that the “numbers were high.” That didn’t surprise me either. He put me on Tracleer™, and I immediately felt better. I continue to live as I mentioned in the beginning. I don’t need oxygen nor do I have a caregiver. In fact, nobody even knows that I’m sick. Who can tell when you breathe differently? I “live with it” and go on as long as I can. I love my life! I have plans for the next year, yet I am conscious of the fact that anything can happen anytime.

PH is “life threatening and incurable.” But who knows how long it takes? I sometimes wonder what the future will bring, and then I leave it all in God’s hands and trust Him to take care of me as He has for the past 73 years. I do pray for those who work so hard for a cure. I love their confident spirit and perseverance. I have benefited from their efforts already by taking my medication, and I pray that soon our hopes will be realized. I say thank you with all my heart. God bless you! ◆

Sincerely,
Julienne Brock

“ I do pray for those who work so hard for a cure. I love their confident spirit and perseverance. I have benefited from their efforts already by taking my medication, and I pray that soon our hopes will be realized.”

The first word that came to mind after reading Regina's poem was 'Fierce!' Her poem is so inspiring as she talks to PH and promises 'as long as there's breath in my body,' she'll be fighting for herself and patients everywhere.

— Joanne

Regina O'Neal, Odenton, Md.

Dear PH,

There is one thing that I know for sure. I am a PH patient, and I really need a cure. Things happen in life and I may not have a choice, but I will not be silenced. I will exercise my voice. PH is my enemy; it is not my friend, but I'm not afraid of it because I know I'm going to win.

Before I met you, I had a great life, but I realized — when I opened my eyes — to accept my blessing and stop second-guessing about what my life could have been. I will not live my life looking in the rearview mirror. I'll keep fighting so my vision is clearer.

There are days when you try to wear me down, and I forget to smile. Instead I wear an ugly frown, but today I came to let you know your time is limited and I can't wait for you to go.

On days when my body is tired and I want to rest, you become the reality that you are my biggest test. You have me feeling inadequate, unable to fight, but that's when God steps in and shows me the light. The light is a reminder and it lets me know we have a lot of work to do. So let's go.

PH, you look at me and say, "Now how do you think your going to win this race, when you walk at such a slow pace?" Oh, but that is where you are wrong. I have a lot of PH friends, and together we are strong. We are motivated, dedicated and focused on you, and we'll keep fighting until you are through.

Before I go to bed each night, I pray for all the PH Angels who inspire me to fight. In my prayers I ask for a breakthrough to finding the cure for me and for you. So on this day I declare and I decree as long as there is breath in my body, there will be a winner in me. ◆

Your story is going to touch the heart of someone who reads it, so don't think it isn't worth telling.

— Jerry Wojciechowski

The purpose of *Persistent Voices* is to allow patients and their families and friends to share their personal experiences and coping strategies with one another. It is not to provide medical advice on personal health matters, which should be obtained directly from a physician. *Persistent Voices* assumes no responsibility for readers' actions taken as a result of their interpretation of information contained in the publication. Please submit your stories, with contact information and appropriate photograph, to: **Megan Mallory, "Persistent Voices," Pulmonary Hypertension Association, 801 Roeder Rd., Suite 1000, Silver Spring, MD 20910** or as an attachment (.pdf, .doc or .rtf) to **Print@PHAssociation.org**. (Submissions may be edited for length and clarity.)

Come Join Us for PHA's 10th International PH Conference!

Every two years, the pulmonary hypertension community gathers at PHA's International PH Conference and Scientific Sessions for the largest meeting of PH patients, family members and medical professionals in the world. The 10th International PH Conference, *The Power of One: From a Kitchen Table to Around the World*, takes place June 22-24, 2012, at the Renaissance Orlando at SeaWorld® in Orlando, Fla.

The Conference will provide attendees with a unique opportunity — three days of educational sessions covering the latest advances in PH research and treatment and the chance to connect with others in the PH community. Want to know more about what education and networking opportunities are in store? Read on for the highlights of what you can expect at this year's International PH Conference. See you in Orlando!

*Visit **www.PHAssociation.org/Conference** for the most up-to-date information, or to register. You may also call PHA at 301-565-3004 x768 to request a paper registration form.*

Find an Abundance of Educational Opportunities

For patients and family members attending the 10th International PH Conference and Scientific Sessions, a great deal of education awaits! Attendees will have the opportunity to attend Medically Led Sessions and Patient/Family Led Sessions covering a wide variety of topics. We have learning opportunities for everyone at Conference.

The Medically Led Sessions are concurrent educational sessions for patients and family members led by panels of medical professionals and, for the first time, patient panelists on select sessions. This year, we look forward to bringing together more than 100 medical professionals to present in 40 sessions on a variety of PH-related topics over the course of two days.

Medical topics new to Conference this year include:

- Heart Failure — Salt, Water and Diuretics: Am I Drinking Too Much or Not Enough? Managing Fluids and Water Weight Gain in PH
- Surgery and Anesthesia in Patients with PH: What You Should Know
- Breathing Better – Oxygen Supplementation and Pulmonary Rehabilitation
- Education for the PH Caregiver

We will also offer past Conference favorites covering the topics of General PH Information, Living with PH/Alternative Approaches, Treatment Information, Future of PH/Research and Pediatrics. Some sessions will also be available in Spanish. For the most up-to-date information, visit **www.PHAssociation.org/Conference/MedicallyLedSessions**.

The Patient/Family Led Sessions provide peer-to-peer learning opportunities for patients and family members. These sessions are led by fellow patients, parents and caregivers. This year we will bring together more than 40 community leaders to share opinions and advice on 16 different topics.

Exciting new sessions include:

- Making PH Sexy — Navigating dating and relationship matters
- 9 to 5 with PH — Ways to continue working while maintaining your health
- PH Goes to College — College students and recent graduates discuss how they juggle PH, academic goals and career planning.

We will also feature Conference favorites such as: Spiritualty, Traveling with PH, and Coping as a Caregiver. Parent-focused sessions and Spanish-language sessions will also take place. Visit **www.PHAssociation.org/Conference/PatientFamilyLedSessions** for an up-to-date listing of session topics, descriptions and speakers. ◆

Mix and Mingle in Orlando, Fla.

The 10th International Pulmonary Hypertension Conference and Scientific Sessions not only offers plenty of educational opportunities, but networking experiences too! This is a great chance to mix and mingle with other PH patients, family members and medical professionals from around the world. Check out these opportunities to connect during the weekend.

Patient and Family Meet-and-Greet

This year, everyone gets to be king and queen for a night at our Homecoming-inspired Patient and Family Meet-and-Greet taking place on Thursday, June 21, from 6 – 8 p.m. Throughout the evening, enjoy light hors d'oeuvres, refreshments, music, raffles and activities for the whole family. Come out to celebrate with PHA as we "come home" to our Florida roots!

Pre-Conference Meet-ups

Looking to meet people before the official start of Conference? Check out the Pre-Conference Meet-ups, taking place on Friday, June 22, from 10:30 – 11:15 a.m. These Meet-ups give you the opportunity to connect with people who have something in common with you.

Parents' Mixer

Remember how nice it was to hire a babysitter and go out with your friends? We didn't think so. As a refresher, join other parents in the Parents' Mixer at Conference and unwind as you enjoy this adult-only event on Friday, June 22, from 6 – 7 p.m.

Generation Hope After Dark

Join your Generation Hope peers (20s and 30s) for conversation and cocktails at the Generation Hope After Dark event. Unwind with the new generation ready to fight PH at this exclusive event taking place on Friday, June 22, at 9 p.m. ◆

Scientific Sessions at Conference 2012: *The Genetics of Pulmonary Hypertension*

This year, the Scientific Sessions committee is hard at work preparing a program that will bring together approximately 400 physicians, researchers and others with an interest in pulmonary vascular disease. This year's topic, *The Genetics of Pulmonary Hypertension*, will feature PH experts sharing their experiences and understanding of heredity in the field. Young investigators and seasoned PH professionals will participate in these sessions together, offering a unique opportunity for mentoring and growth in the field.

The learning begins on Thursday, June 21, with two educational dinner forums, one for members of PH Clinicians and Researchers (PHCR) and one for PH Professional Network (PHPN) members, focusing on important factors in PH care and advancing PH science.

The Scientific Sessions program continues on Friday, June 22, with a day of programming focused on this year's theme. Esteemed speakers will lead sessions on topics ranging from PH and the BMPR2 pathway to the role of microRNAs in PH. The day will also feature a robust presentation of abstract posters, and free-form panel discussions about the top abstracts. Medical professionals with all levels of experience are encouraged to attend the Scientific Sessions and review the posters.

For more information about Scientific Sessions, speakers and topics, please visit **www.PHAssociation.org/Conference/ScientificSessions** ◆

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

New Global Programs and Activities for Conference 2012

PHA's 10th International PH Conference and Scientific Sessions provides an important opportunity for the PH community to look back on the progress that has been made in the PH field, both in the United States and abroad. In 2001, only three PH associations existed worldwide. As the number of PH associations has grown, so have PHA's programs for global guests.

- **International Leaders' Dinner with the PHA Board of Trustees, Wed., June 20*:** A NEW opportunity for PH association leaders to meet each other and the PHA Board of Trustees.
- **International Leaders' Summit, Thurs., June 21*:** The First International Leaders' Summit in 2010 brought together 23 PH association leaders from all over the world to participate in a day of peer-to-peer learning and networking. At the Second International Leaders' Summit, participants will share tips and advice on new topics relevant to the international PH association community, including Patient Resources, Building Relationships in the PH Community, PH Advocacy and Awareness, and Association Management.
- **Regional International Meetings, Fri., June 22*:** These meetings will bring together PH leaders and PH patients from the same region.
- **International Reception, Fri., June 22*:** This reception for global guests will honor an outstanding PH physician through the presentation of the new International Physician Award.
- **International Strategy Meeting, Sat., June 23*:** With more awareness events happening around the world each year, this one-hour meeting provides a venue for the global PH community to discuss how to best leverage the awareness-raising efforts of PH associations around the world.
- **International Exhibit:** Throughout Conference, the International Exhibit will be available for all attendees to see what PH resources are available worldwide and to meet PH leaders from around the world.

For the most up-to-date information about the global programming available at Conference, please visit **www.PHAssociation.org/Conference/International**.

**These programs are by invitation only.*

Programas en español:

Así como ha ido creciendo la comunidad de hipertensión pulmonar hispanohablante, también el programa de español que ofrecerá la Pulmonary Hypertension Association en La Conferencia Internacional de Hipertensión Pulmonar. En el 2012, más programas que antes serán ofrecidos en español:

- **Sesiones Dirigidas por Pacientes, viernes, 22 de junio:**
  - » Hipertensión Pulmonar y Relaciones entre Familiares
  - » Sobreviviendo Hipertensión Pulmonar: Lecciones de Sobrevivientes de Largo Término
- **Sesiones Dirigidas por Profesionales Médicos, sábado, 23 de junio y el domingo, 24 de junio.**
  - » Información Fundamental de Hipertensión Arterial Pulmonar
  - » Diferencias Entre Causas de Hipertensión Pulmonar, a que Grupo Pertenezco?
  - » Como Mejorar mi Estilo de Vida si Padezco de Hipertensión Pulmonar: Dieta, Ejercicio, Oxígeno, etc.
  - » Tratamientos Actuales e Investigacionales en Hipertensión Pulmonar
- **Una Red con un Profesional Médico, sábado, 23 de junio**
- **Reuniones de los Grupos de Apoyo**

Aprenda más: **www.PHAssociation.org/Conferencia/Espanol**.

Honor Those Who've Made a Difference in Your Life

When your life or that of a loved one has been touched by PH many others are affected. The program book for PHA's 10th International PH Conference and Science Sessions provides the opportunity for you to acknowledge those who have helped you on your journey or to remember those who have passed.

For $25/entry (40 word maximum) you can make your appreciation or memories known to the more than 1,300 attendees expected at the Conference. All proceeds will support the Conference Scholarship Fund and help patients fulfill their dream of attending Conference. Notes must be submitted by Tuesday, May 1.

You can complete our online form at **www.PHAssociation.org/ConferenceNotes** or contact Ellen Leoni at EllenL@PHAssociation.org or 301-565-3004 x756 for assistance. ◆

Participate in Research for a Cure

The International PH Conference provides researchers with a rare opportunity to collect information and samples from a large number of patients at one time. Your participation will help provide researchers with a clearer understanding of PH and will help bring them one step closer to finding more effective treatments and a cure.

The new Research Room structure will minimize the wait time for patients interested in participating by allowing you to complete Research Room forms prior to arriving at Conference. Detailed information and forms will be available on the Conference website in May. Pre-registration to participate is not required. Visit **www.PHAssociation.org/Conference**, email ResearchRoom@PHAssocation.org or call Micaela Cohen at 301-565-3004 x770 to learn more. ◆

Find out what's available for kids at Conference! Turn to p. 50!

Conference Volunteers Needed

The International PH Conference is PHA's largest event and we need your help to ensure that everything runs smoothly. Whether you are a local from the Orlando, Fla., area or traveling from outside the country, you can volunteer to assist PHA at the Conference!

As a volunteer, you can help prepare registration bags, serve as a room host or partner with PHA staff to complete necessary tasks as your health and capabilities allow. Here's how to help:

- To volunteer **during** Conference, check the volunteer box on your registration form. You will hear back from PHA with questions regarding your availability.
- For more information, contact Debbie Castro, PHA Director of Volunteer Services, at DebbieC@PHAssociation.org or 301-565-3004 x755.

The "Rockin' Awareness" PH Fashion Show

Do you have a creative way of raising PH awareness? If you have a unique idea that incorporates periwinkle and other PH awareness facts, symbols and logos into every day clothing, sign up to participate in this year's PH Fashion Show. We will also feature casual, business and formal attire on the runway. Here's your chance to showcase your look, inspire others and have some fun! All ages welcome. If interested, contact Jessica McKearin at JessicaM@PHAssociation.org or 301-565-3004 x765 or visit our Conference Fashion Show webpage at **www.PHAssociation.org/Conference/FashionShow** ◆

COVER STORY CONTINUED FROM PAGE 1

Help Us Reach 1,000 Contacts

Stand up and be counted by sharing the story of how PH has impacted your life with your Members of Congress and request co-sponsorship of our bill. Don't forget to involve your family, friends, neighbors … anyone who knows you has been touched by PH. There are lots of ways to get started:

- Call or email Elisabeth Williams, PHA's Grassroots Campaigns Associate, for Member of Congress contact information and talking points about the PH bill. Call 301-565-3004 x753 or email ElisabethW@PHAssociation.org.
- Join the 2nd Annual Legislative PH Call-In Day. Learn more on p. 20.
- Use PHA's advocacy email system: **www.PHAssociation.org/Advocacy/Alerts** ◆

By Katie Kroner,
PHA Director of Advocacy and Awareness

Table Talk: Wired
...the inside scoop on Conference

Never attended a Conference and want to know what it's like? Are you a Conference "veteran" curious about new things this year? Want to stay up-to-date on key Conference announcements and deadlines?

Look no further than our Conference blog, *Table Talk: Wired*, for the inside scoop on Conference!

www.PHAssociation.org/TableTalkWired

You can read stories from PHers about past Conferences, the latest on activities planned for our 10th International PH Conference in June, and key announcements of things you need to know. You can even subscribe to receive new stories in your Inbox or RSS reader when they're posted to stay in-the-know!

Did you know that there is a mobile event application for PHA's 10th International PH Conference and Scientific Sessions?

This app features the latest innovations in mobile technology. With it, you will have instant access to Conference information — all in the palm of your hand!

Use the app to access:

- Conference alerts
- Schedule of events
- Speaker information — as speakers are named!
- Live feeds from PHA's Facebook and Twitter accounts
- Maps of the hotel and Orlando area

For instructions or to view that app, go to:
www.PHAssociation.org/Conference/App

So what are you waiting for? Download the app and get connected today!

Bring Home Our Newest PHriend: Phineas!

Special Member Discount: $2 Off! (Now only $12)*

Only PHA Members are eligible for this special, limited-time offer. Order now through July 1 at the PHA Online Store, **www.PHAssociation.org/Store** or give us a call.

Want a discount on the Phineas PHriend, but not a member? Visit **www.PHAssociation.org/Join** to become a member of PHA today!

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

* *Attendees of PHA's International PH Conference must be PHA members. Become a member today!*

Read more about Phineas on p. 24.

Camille Frede, *Youth Editor*
ponyforme@comcast.net

INTERVIEW WITH PH PATIENT JOSIAH WINDZ

Interview conducted by Mira Kruger
PHA Pathlight *Volunteer*

Where do you live?

I live in Grass Valley, Calif.

How old are you?

I am 14 years old.

When were you diagnosed?

My mom says I was diagnosed as a baby, and I have been on oxygen since birth.

When did you first start having symptoms of PH?

I was symptomatic at birth. My mom says I was a very sick baby. When I was little, I would turn blue even if my mom took off my oxygen just to change my shirt. I am much better now since I am on the medicines Tracleer™ and sildenafil, but I still get short of breath easily and I still wear oxygen all the time. Sometimes I get dizzy, and I run out of energy faster than a lot of my friends.

What activities do you like to do?

I like riding my bike and playing baseball and basketball. I also love to read and I especially like looking at maps.

Have you ever felt unable to do something because of PH?

I do get frustrated when I can't keep up in sports or carry heavy things, and sometimes I get tired of having to wear my oxygen. I can't carry my tank upstairs, and it is hard to walk on uneven ground and carry my oxygen.

How would you describe your life with PH?

I have always had PH, so I don't know any other way of living.

What is a message you'd like to pass on to other kids with PH?

Hang in there. I have a really good life despite my PH, and you can too.

TALK BACK! This is your space. Send your cartoons, poems, drawings, jokes, questions, comments on articles or ideas for future articles to Michal. She can be reached by email at Kids@PHAssociation.org or call 301-565-3004 x800.

What's happening at Conference for kids, tweens and teens?

PHA's 10th International PH Conference and Scientific Sessions is packed with tons of great stuff for kids, tweens and teens. From crafts to movies to field trips, we've got you covered! Read on to see what's going on and to tell PHA what you'd like to do.

1. **Creative expression opportunities.** Jack Larsen, a 14-year-old PH teen, is writing a song about living with PH. Lucas Van Wormer, a fourth-grader, is working on a cartoon about being a PH Kid. This Conference, everyone will have the chance to raise awareness by sharing their story about living with PH. Join us in raising awareness by recording your own message in the Kids' Room, and explore your own creative skills at our new Creative Expression workshop!

2. **Roving Reporter Contest.** PHA is looking for four teen reporters to contribute to the daily newsletter at Conference. The contest winners will each be assigned one activity at Conference to attend and write about for the next morning's newsletter. Visit **www.PHAssociation.org/Conference/RovingReporter** for the details!

3. **Fashion Show.** PHA is bringing back the Fashion Show and you can be part of it! Come strut your stuff and show us what you got! For more details or to sign up, visit our Conference Fashion Show webpage at **www.PHAssociation.org/Conference/FashionShow** or contact Jessica McKearin, Associate Director of Special Events, at JessicaM@PHAssociation.org.

Kendra Sullivan (left) and Lauren Johnson (right) model as part of the fashion show during Conference 2010.

4. **Field Trip.** The field trip is one of the most popular Kids' Room events, and we're planning a visit to another exciting location this year! Stay tuned for details! Remember, the field trip requires pre-registration! Register online at **www.PHAssociation.org/Conference/KidsRoom**.

5. **Movie Night.** Make a night of it with popcorn and a movie in the Kids' Room for all ages to enjoy!

6. **Arts, crafts and fun activities for kids, tweens and teens: You can help us decide!** We're planning lots of fun activities for Conference! The Kids' Room will have lots of things happening all three days of Conference, and we want to choose the best activities for our busy schedule! Which of these three activities would you rather have in the Kids' Room? Email your answer to KidsRoom@PHAssociation.org.

   a. Sports Trivia
   b. Tie-Dye Activity
   c. Let's Make a Deal

Kids Room coloring during Conference 2010

HOW MANY WORDS CAN YOU MAKE FROM THE LETTERS IN CONFERENCE?

Nancy Frede, *Parent Editor,*
ponyforme@comcast.net

A Mother Shares Her Experiences as a Veteran of Four Conferences

PHA's 10th International PH Conference and Scientific Sessions in Orlando will be here before we know it. I'm sure parents are mulling over the decision to attend, but for me it is an easy decision. I will be taking my family to Orlando for my fifth Conference and their fourth. There is no other venue at which a family dealing with pulmonary hypertension can receive the same kind of support, emotional connection and education.

The Doak family (L to R): Mom, Emily, Jim and Katy

My family includes my husband, Jim, and our daughters, Katy, 13 years old, and Emily, 9. Katy was diagnosed with PH in 2003, at the age of 4. In 2004 I went to the Conference by myself. It was a last-minute decision to attend, spurred by feelings of indecision about Katy's medical care. Jim and I were considering putting Katy on IV Flolan™ but had no idea what this life change would mean for our family. At the end of the weekend, I left with feelings of hope, inspiration, optimism and confidence that I could make good decisions for Katy's care. It was such a unique experience that I couldn't wait for 2006 to take my whole family to the next Conference. You ask why?

There are several major reasons, the first being its educational value. I learn so much from the medical professionals. These professionals specialize in PH and are amazingly dedicated to their patients. They commit this weekend to sharing their knowledge with us. PHA gives structure to this education through scheduled topics and sessions, research posters, and the Exhibition Hall.

Everyone is friendly, compassionate and willing to share their experience and knowledge with you. Not only do you learn from the PH medical teams during the Medically Led Sessions, but during meals, in the hallways, and while attending the Patient/Family Led Sessions. You spend the weekend getting all your questions answered, not by one doctor, but by many. And for me, in my fight to help Katy battle PH, knowledge is power.

Another very important reason that I continue to return to PHA's International PH Conference is the emotional support my family and I receive from the PH community. Parents of children with PH often struggle with a sense of isolation. PHA makes an amazing effort to provide opportunities for families to connect. Katy gets to spend the weekend with other kids who have PH, my husband and I get to know parents who share the same challenges and Emily gets to have fun with other siblings and PH patients. There is really nothing I can imagine that is more cathartic.

At Conference, parents get to share with each other how we handle school situations, exercise or sports, social situations, and how we communicate to our families about this awful disease. PHA provides many opportunities for us to share: the pre-conference meet-ups, the Patient/Family Led sessions, the support groups, socializing at the Parents' Mixer (new this year), meals and after-Conference hours in the hotel lounge.

Our kids get to find support through many avenues as well. The Kids' Room includes activities for kids of all ages: crafts, video games, live entertainment and — new this year — a creative expression workshop. A field trip for kids and teens is provided (monitored by a nurse, of course). PHA provides youth learning opportunities and support groups. But mostly, the kids and teens socialize and have fun, both during Conference hours and into the night. And this, I think, is the most healing experience for them.

Finally, I want to share a few of my favorite Conference activities. I don't ever miss the "Journeys" Luncheon in which patients and their doctors share amazing stories of inspiration and hope (bring a tissue). The fashion show is always standing room only. PH patients, including our friends and family, get to show off how they make their medical accessories a fashion statement! And most importantly, the friends I have made over the years continue to draw me back.

So despite being a nine-year veteran parent of a PH patient, I continue to attend PHA's International PH Conference. And every time I learn more, find continued hope and inspiration, and feel renewed to face the challenges of the upcoming two years until the next Conference. ◆

By Christina Doak, PH Parent

PASSAGES

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

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

DONATIONS LISTED WERE RECEIVED BETWEEN DECEMBER 1, 2011, AND FEBRUARY 29, 2012.
PHA IS DEEPLY GRATEFUL TO THE PH COMMUNITY FOR ITS EXTRAORDINARY SUPPORT.

TAKE A LOOK! *Sustainers Circle* Members Recognized ◎

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

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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.

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❑ Medical professional (title and affiliation): _____

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Patient-to-Patient Support Line (daytime, please)	1-800-748-7274
Children with PH/PPH	
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Organization Liaisons	
National Institutes of Health: Heart, Lung, and Blood Institute	
Rino Aldrighetti, RinoA@PHAssociation.org	479-253-0082
American Thoracic Society: Public Advisory Roundtable	
Rino Aldrighetti, 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	1-866-9FLOLAN
for Veletri	1-866-344-4874
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 Assistant Programs	www.gskforyou.com
Letairis	1-866-664-LEAP
NeedyMeds	www.needymeds.org
Partnership for Prescription Assistance www.pparx.com	1-888-477-2669
Priority Healthcare Remodulin Hotline	1-877-462-6225
Tracleer Access Program	1-866-228-3546

PATHLIGHT AND PERSISTENT VOICES SUBMISSIONS

The Summer issue deadline is **May 6, 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"
Print Services Department
Pulmonary Hypertension Association
801 Roeder Road, Ste. 1000
Silver Spring, MD 20910

or

"Newsletter Submission"
Print@PHAssociation.org

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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Conference by the Numbers:
What to Expect at PHA's 10th International PH Conference

If you're planning to attend the 10th International PH Conference and Scientific Sessions, here's what you can expect when you arrive in Orlando!

- **40 Medically Led Sessions** — Bringing together more than 100 experts in the field to educate attendees on a wide variety of PH topics.
- **15 Support Group Meetings** — Allowing you to share tips on living phenomenal lives with PH with patients and family members in the PH community.
- **14 Patient/Family Led Sessions** — Allowing you to learn from and teach each other.
- **7 Skill Building Workshops** — Providing staff and volunteer-led informational seminars designed to help attendees enhance or learn new skills that can be used in the fight for our shared cause.
- **7 Pre-Conference Meet-up Groups** — Giving you the chance to mix and mingle with people who have something important in common with you.
- **1 LIFE-CHANGING EXPERIENCE!**

TURN TO PAGES 44-48, 50-51 TO FIND OUT MORE ABOUT WHAT AWAITS YOU AT CONFERENCE 2012!