The first U.S. registry of pulmonary arterial hypertension (PAH) patients was created by the National Institutes of Health in the early 1980s, with 187 patients enrolled. For years, much of what we've known about PAH has been linked to the information gleaned from that registry, but as research in the field expands, our knowledge continues to grow.

The Registry to Evaluate Early and Long Term PAH Disease Management (REVEAL) is a long-term observational study designed to update the PAH knowledge base by examining current clinical decision-making and following patients for at least five years. The Registry recently completed patient enrollment of more than 3,500 patients and is moving into the final, follow-up phase. “The goals of the REVEAL Registry are to achieve a broader view of the demographics and clinical presentation of PAH; determine how different variables of PAH (such as the presence of scleroderma, liver disease, treatment choices, and severity of pulmonary arterial hypertension) affect patient outcomes; identify why different patients have different disease progressions; identify short and long term clinical predictors;”

McGoon, Chair of the REVEAL Steering Committee and Professor of Medicine at the Mayo Clinic in Rochester, Minn.

“As compared to the NIH Registry that followed only untreated idiopathic and inherited PAH patients, the REVEAL Registry should provide additional information because of the large number of patients studied and the five-year follow-up of treated patients,” explains Dr. Carol Vreim, former Project Officer for the NIH Registry and current Advisor to the Medical Services Department at PHA.

According to Dr. McGoon, “The Registry is designed to: achieve a broader view of the demographics and clinical presentation of PAH; determine how different variables of PAH (such as the presence of scleroderma, liver disease, treatment choices, and severity of pulmonary arterial hypertension) affect patient outcomes; identify why different patients have different disease progressions; identify short and long term clinical predictors;”

STORY CONTINUED ON PAGE 18
Most people would probably call me pretty tough. After all, I was a U.S. Army Airborne Ranger and served in some fairly difficult places. I knew not only how to marshal my soldiers, but contain my emotions. I had to be tough — that was my job.

Then pulmonary hypertension came into my life. Anyone who has been reading Pathlight for a while or heard me speak at a PHA event, knows the story of my beautiful daughter Meaghan’s battle with — and ultimate loss to — PH. I’m not too tough to tell you that I have cried a million tears for her and for all she went through, never giving up. And not only for Meaghan, because my involvement with PHA has brought so many magnificent people into my life. Many of whom are still with us fighting the fight for their lives, and others who no longer are. Their loss caused much sadness, but I remember them for their grace and courage under fire.

But sadness isn’t the only emotion I feel. I also feel deep gratitude. My life has been enriched in ways large and small by being a part of the small, but mighty, PH community. This year we saw three medical professionals scale great heights, reaching the top of Mt. Kilimanjaro. And many members of our community joined them in spirit by taking part in Unity Walks across the country. It was with deep gratitude that I watched the Path to a Cure campaign unfold, knowing how many community members exceeded their own expectations, whether it was climbing 19,341 feet to the top of Africa, walking in solidarity at a Unity Walk or toiling through a six-minute walk test as the climbers made their ascent.

You may not know that I pilot a plane, but my little Cessna Skywagon has allowed me to get to know many wonderful patients and caregivers. When I can, I steer my way to support group meetings and special events. Talk about deep gratitude! Support group leaders do so much to end the isolation and increase the knowledge of support group participants. And those participants are something else, too. They share their deepest fears and feelings and help each other in ways too numerous to count.

And special events ... There’s a reason we call them special. Our patients and their family members work so hard to create fun and meaningful events, raise funds for PHA and spread the word about this disease we wish no one ever had to know about. My deepest gratitude to those who plan these miraculous events.

There are so many others who give their heart, soul and time to making our community what it is by serving on our Board of Trustees, writing for Pathlight, helping out before and during our International Conference, talking to the media and legislators, and supporting the work of PHA in myriad other ways. A deep bow to each and every one of you.

Although this is the last letter I’ll be writing as Chair of PHA, you haven’t heard the last of me. The range of emotions that brought me to PHA and spurred my involvement remain and always will. I will be with you every step of the way.

Carl Hicks

www.PHAssociation.org

PATHLIGHT SUMMER 2010

PATHLIGHT: A USER’S GUIDE

PHomomenal Lives
Health Matters
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Community Classroom
PHomomenal 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.
Uncle Draws Inspiration from Nieces Who “Lived a Little Harder”

“Ms. Dern, these were good kids.” These words have stayed with me since I first heard from Tony Chroussis in February about the loss to PH of his two beloved nieces, Sara and Monica. Tony’s brother Paul and his wife Karen were the parents of these two young women who were diagnosed in the spring of 2005 and who passed away much too soon; Sara at age 22 in late 2007, and Monica at age 25 in late 2008.

As a child, Monica already knew what she wanted to be: a doctor or a veterinarian. She applied to medical school after her diagnosis and was accepted, but had to drop out because of her condition. That didn’t stop her though, and she had nearly earned her Master’s degree in education and was engaged to be married when she died.

Sara was different. As a child she said she wanted to be a butterfly, and Tony says he still has the butterfly pin her boyfriend made out of pasta for everyone who came to her memorial service. Her boyfriend intended to propose to her over the New Year’s holiday, but she died on New Year’s Eve.

Tony continues to draw inspiration from these two lovely young women. “They were diagnosed, and instead of stopping, they lived a little harder. … I can’t begin to tell you how much inspiration I draw from their unwillingness to let this condition cripple them,” he says.

But Tony wasn’t writing only to share this very sad story. He wrote because he wanted to honor his nieces’ memories in tangible ways.

A few months after Sara and Monica were diagnosed, a disc in Tony’s back herniated and he’s had several surgeries since that time. But, he told me, following their example, he “refused to allow that injury to define who I am, and how I will live my life.” Tony, a former Marine with dreams of running a marathon, ran in the Marine Corps Historic Half in mid-May “with my purple PH shirt, my purple wristband and a heavy heart.” And he says, “there’s a marathon in my future. For Monica, for Sara and for everyone else who can’t run because of PH.”

On race day — May 16 — Tony didn’t have “the personal belief that my leg and/or physical conditioning would allow me to complete this journey.” But a number of coincidences that day — including hearing a song that reminded him of Monica as he arrived at the start line and seeing butterflies as he ran along the Rappahannock River to remind him of Sara — led Tony to believe that he would run the whole way or they would “carry me off on a stretcher.” No need for a stretcher, Tony completed the race.

This was, he says, an “epic moment” in his life. “I wasn’t there to win or set any records or to work miracles. I will use the next race to raise some cash. I’m on a mission.”

In that spirit, Tony has begun to put the steps into place to organize one or more PHA Fun Runs in memory of Sara and Monica. Tony and his brother and sister-in-law know how important it is to help make others aware of pulmonary hypertension, and with his nieces as his inspiration, we know that Tony will do that and more.

By Adrienne Dern
PHA Senior Vice President
Doctors recommend that pulmonary hypertension patients avoid becoming pregnant due to the risks it poses to mother and child. One recently married patient calls the knowledge that she can’t have a child “the hardest thing about PH.” Family planning can become a source of stress for young women with PH, surrounded by pregnant friends and well-meaning family members who don’t fully understand the health risks of pregnancy with this condition. Many find ways of coping with the loss, turning to family, friends and humor to help them embrace a new take on family life. Some patients in stable health consider alternatives to pregnancy, including foster parenting and adoption. Below, Family Services professional Venessa Nunn and PH patient Hannah Lahmeyer share some of their experiences with the adoption process. The perspectives offered here are not meant as a substitute for a discussion between a PH patient and her medical team about this intensely personal decision.

The Adoption Process: Some First Steps
By Venessa Nunn, PH Caregiver

As an adoption and foster care worker for the Cabinet for Health and Family Services in the state of Kentucky, I receive calls on a daily basis from people who are looking to complete their family. Many of the calls I receive are from couples who cannot conceive for medical reasons. Many people with chronic illness worry that they will be denied the opportunity to be an adoptive parent solely based on their diagnosis. The truth is, chronic illness makes the adoption process more difficult but not impossible.

When a pulmonary hypertension patient is considering adoption, there are many health-related factors to consider. First, you must think about the implications of your illness during different stages in a child’s life. Will you be physically able to lift an infant or toddler? Will you be able to keep pace with a child learning to crawl or walk? Will you have the energy to keep up with an older child and get involved in their activities and school functions? These questions are difficult but worth discussing in a candid conversation with your partner and PH specialist.

Once you’ve determined that adoption is right for your family, the adoption process requires that you present proof that you’re in stable health to begin the process. A physical exam from your doctor is required, and PH patients usually require a special letter from their PH doctor confirming that you are physically capable of raising a child.

Next you must determine the type of adoption that is right for your family. Depending on where you live, state adoptions can offer the benefit of financial assistance. In Kentucky, the state agency pays adoptive families $1,000 to cover attorney fees, along with a monthly subsidy and a Medicaid card for the child’s healthcare costs until he or she turns 18. College assistance is also available for children adopted through the state agency. Financial assistance varies from state to state.

Other options include adoption through a private child care agency, independent adoption, relative adoption and international adoption. Most of these adoptions require fees for attorneys and agency services. Again, these options vary from state to state, so the best place to begin is by calling your state’s public adoption agency. The National Foster Care & Adoption Directory (www.childwelfare.gov/nfcad) is a searchable database of adoption and foster care resources by region.

Choosing adoption is not an easy decision or an easy process. However, if this is something that you feel strongly about, seek out resources that can help you make this decision.

Venessa Nunn is the spouse and caregiver to a PH patient. She has been employed as an adoption and foster care worker by the Cabinet for Health and Family Services since 1996.

My Adoption Success Story
By Hannah Lahmeyer, PH Patient

At 1:30 p.m. on our first Christmas as a married couple, my husband Joe and I received a phone call. Our daughter was about to enter the world. After getting the okay from her birth mother, we drove to the hospital. A short 30 minutes after we heard her birth mother was in labor, I found myself in the operating room, watching my daughter’s birth via C-section. I am pleased to say that I am now the proud mother of a 6-month-old baby girl. We named her Annalise Andrea, which means “favored warrior.”

Not Giving Up on Parenthood: Adoption as an Option

STORY CONTINUED ON NEXT PAGE
While Christmas day was a whirlwind, our adoption story began much earlier than that afternoon in December 2009. I was diagnosed with pulmonary hypertension as a child, and because women with PH are advised against pregnancy, I grew up knowing I would never give birth to a child of my own. Soon after our wedding, Joe and I decided we wanted to become foster parents. Five months into the process, we met a woman through church who runs a crisis pregnancy center. The woman told us of a client at the pregnancy center who was looking for someone to adopt her baby. She also told us that the pregnancy was very high risk, as the mother was involved in drugs and prostitution. We decided that if the child made it through the pregnancy, we would adopt. We had our foster care paperwork transferred to an adoption agency.

Fortunately, in my case my pulmonary hypertension did not negatively affect this process. The only additional step that I was required to take was a letter from my PH doctor stating that I would be physically capable of taking care of a child. The drawbacks of adoption are the expense and the length of the process, which can take two years or more.

Despite these stumbling blocks, I strongly recommend young PHers consider adoption as one option for starting a family. Although she looks nothing like me or Joe, there’s no doubt in our minds that Annalise is our daughter.

PH Community Collaboration Yields New Edition of A Patient’s Survival Guide

PHA is pleased to unveil an updated version of our flagship publication, Pulmonary Hypertension: A Patient’s Survival Guide. This book serves as a soup-to-nuts guide for patients, offering information on diagnosis and treatment and the wisdom on how to live with PH. The newly revised Survival Guide includes updates to the chapters on the diagnosis and classification of PH, medications and patient resources.

The Survival Guide was first written in 1998 by Gail Boyer Hayes, a PH patient and advocate. This go-to text for patients and families is now regularly updated by a team of medical professionals and patient volunteers, with support and leadership from Medical Editor Dr. Ron Oudiz.

For the Survival Guide’s Third Edition, summer 2010 revision, a well-deserved “thank you” goes to:

- **Gail Boyer Hayes**, for her wisdom, guidance and assistance during every Survival Guide update;
- **Ron Oudiz, MD**, Liu Center for Pulmonary Hypertension at Harbor-UCLA Medical Center, for his role as Medical Editor;
- **Michael McGoone, MD**, Mayo Clinic, and **Greg Elliott, MD**, Intermountain Medical Center, both members of PHA’s Board of Trustees and Scientific Leadership Council, for assisting in the medical review of various text updates;
- **Lian Latham, BA, RN**, for updating portions of Chapter 2 – PH: The Other High Blood Pressure;
- **Lisa Wheeler, MT**, Study Coordinator, PAH Genetics Study at Vanderbilt University, for updating portions of Chapter 3 – Who Gets PH?
- **Martha Kingman, FNP-C**, Pulmonary Services, University of Texas SW Medical Center, for updating portions of Chapter 4 – PH Treatments: The Basics;
- **Juliana Liu, RN, MSN, ANP**, Vera M. Wall Center for Pulmonary Vascular Disease at Stanford, for updating Chapter 5 – PH Drugs, including the medications chart;
- **Paula Patty**, PH patient, for reviewing sections of Chapter 14 – Resources;
- **Carol Morrison**, PH patient, for confirming the accuracy of web addresses in Chapter 14 – Resources.

To order a copy of the latest revision of the Survival Guide, call 301-565-3004 or visit www.PHAssociation.org/SurvivalGuide.
During the weekend of February 19-20, 2010, it was my privilege and honor to participate in a ballet called HEART, Function vs. Emotion. And yes, I said participate in a ballet. Dr. Dennis McNamara, Director of the Heart Failure Transplant Program at the University of Pittsburgh Medical Center, approached Maria Caruso, Artistic Director of Bodiography Contemporary Ballet, about doing a ballet about a health issue. They decided to perform a ballet about heart transplant patients and pulmonary arterial hypertension (PAH) patients, and they met with several patients to discuss the possibility of having a ballet in February — heart month.

The first planning meeting for the ballet was in September at the ballet studio. ... The intent of those meetings was to see how we as transplant patients and PAH patients felt, what we had gone through and what we are going through now. ... After that first meeting, preparations really got underway. The dancers practiced; we, the patients, met at a café. The dancers practiced more frequently; we met at the café. Eventually, we met for our first rehearsal together.

We, the patients, watched as the dancers danced and Maria counted out the beats. ... Their movements were graceful, emotional and filled with passion. A lump grew in my throat and tears welled in my eyes as I saw what Maria’s vision had created. ...

I made fliers for the event and distributed them before opening weekend. ... On Friday, February 19, we met at the Byham Theater at 1 p.m. ... The dancers were stretching out in the main lobby. Watching them wore me out, and we hadn’t even started. ...

When the curtain opened, we were in a tableaux arrangement; the music began, and the dancers danced. As the program explains, “Act I – Function: The first portion of Heart is an abstract rendering and representation of the organic function of the heart. It begins with the introduction of our collaboration and the visualization of the connection between each patient and their heart.”

Each of us either had a dancer or a few dancers to express our heart’s function. My dancers were Nicole and Maggie, who did an excellent presentation of the struggle PAH patients go through, and I explained my struggle.

Act II, titled “Emotion,” depicted “the physical preparation prior to heart transplantation as well as the operation itself.” As transplant surgeon Dr. Robert Kormos visually demonstrated open heart surgery, a dancer mimicked the struggle a heart would have prior to and during the surgery. The doctor then led the dancer off stage, representing the removal of the old heart, and led a new dancer dressed in white on stage, representing the new heart prior to blood being added.

When it came time to show the patients’ emotions, each patient sat at the edge of the stage while their dancers showed the struggle some of us have gone through (transplant patients) and some are still going through (PAH patients). It truly was emotional. My dancers, Nicole and Maggie, showed the pressure that I have felt in my chest when Maggie stood on top of Nicole. Then for the closing of that segment, Nicole dragged Maggie around, showing the weight of my oxygen tank and all the other just-in-case stuff I have such as my Flolan™, my mixed meds and my just-in-case meds. ...

After each performance, the audience had the opportunity to ask questions. Each of us had a chance to share our feelings; it truly was an emotional time. Tears flowed as we shared our appreciation for the accomplishment and the awareness that was presented over the weekend. ...

At the end of the show that first night, we exited stage right. I gathered up my coat and used oxygen tanks and headed for the lobby to meet my family. I saw a young man and asked if he would pull my cart of oxygen and other supplies up to the lobby. He said he would and was surprised with the weight of the cart even though it was on wheels — another awareness raising moment.

This was a phenomenal event, a time in my life I will cherish forever. I thank all those who made it possible.
A Pianist’s Story by Minju Choi

Since my PAH diagnosis two years ago, it’s been an incredible journey both emotionally and physically. I am a classical pianist and have played the piano since I was four years old. When I was first diagnosed, the doctor told me that I needed to cancel all my concert engagements and piano competitions in order to relieve my stress. I was so discouraged by this news. I was also told to visit PHA’s website in order to be better informed. As I was reading all the information on the website, I froze in my chair. ... I felt the whole world shutting down on me. The website explained in clear words everything I had mysteriously experienced for the past seven years.

I was not prepared for my career to end in five minutes at a doctor’s office. However, canceling these concerts did relieve me of stressful responsibilities. Physically, I wasn’t able to practice for hours the way I used to be able to only a few years before. Until the day I was diagnosed, I blamed it on my work ethic; I must have lost my passion. I kept asking myself, “What the heck is wrong with me?” I was depressed. ... It was like losing my identity. I didn’t know who I was anymore.

January 2009 brought many drastic changes to my life. First, I started seeing Dr. Erika Berman Rosenzweig at the Columbia Hospital. After having lived in New York City for more than 10 years, I moved back to my hometown, Indianapolis, to be near my family. I needed a certain kind of support system that I could only get in my hometown. Life in the city was too tough for a PAH patient.

Thanks to the amazing care I have received at Columbia and to the constant love and support I receive at home, I have been feeling like a new person. At the hospital, I am now known as the patient who asked if I could run my six-minute walk test. Every time I go in to do the walk test, I now have to hear, “This is a WALK test, you hear? you can’t run!” ...”

Emotionally, it’s been quite a journey as well. When I was first diagnosed, I was scared. Fear ate me up for months. I was also angry. I questioned many things. As a pianist, I have learned to live on stress my whole life. Musicians thrive on stress and on pushing themselves to the extreme limits physically and emotionally. But once I accepted PAH as part of my life, I decided to put it to good use. I have discovered PAH to be, in a way, a blessing in disguise. I started having a better relationship with my mom, and I am no longer afraid of her. The disease relieved me of her constant pressure in my music career. You see, the disease changed her as well. It changed my whole family. It freed me from the impossible self-pressure and gave me a reason to be more kind and patient with myself.

PAH has also made me become more honest. Honest with myself and others. I have become more confident in expressing my thoughts and feelings to others. It has brought me closer to my friends — those who take the time to remember the disease’s name and not just say “some weird heart thing.” It has also ended relationships for the better. I have met friends of friends who have come up to me to say they have been praying for me daily. Praying has been the source of peace and strength in my journey, which others may find in meditating, yoga or in praying themselves.

Most importantly, having PAH has pushed me to actually reach for my dreams and make them come true. Since moving to Indianapolis, I fulfilled a lifelong dream of creating a music program for inner-city school children. It’s called Aspire Music Program. I teach piano privately for free as part of an afterschool program at a local inner-city school. I also have talented high school pianists who volunteer to teach the students. It adds another dimension of meaning to my career as a musician.

Having PAH has forced me to ask many questions that I normally would not if I were just a regular young single woman. This disease has made me strong and brave enough to get out there and try to fulfill my dreams like creating Aspire. I have nothing to lose. I have also started performing regularly again. ... The passion is back. I am so hungry to share my music with others. I have noticed that experiencing this journey has added a new depth in my piano playing. ...

I see myself as a strong young woman, a sister, a daughter, a friend, a teacher and a performer. I don’t see myself as a “sick person.” Yes, I do have to take my medications every four hours. But I am a person before I am a patient. It does not mean I am not fragile or that I don’t worry about the disease. I am so grateful for having a sense of true contentment. Anything is possible when one feels great physically and emotionally.
PHA At Your Fingertips

Got questions? Get answers.

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

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

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

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

- **Visit the Pharmaceutical Company List** for links to medication websites: [www.PHAssociation.org/PharmaceuticalCompanies](http://www.PHAssociation.org/PharmaceuticalCompanies)

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

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

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

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

Stay in the loop.

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

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

Looking to help? We’re looking for you.

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

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

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

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Connect from home

**PHA Helpline:** 800-748-7274

The PHA Helpline is answered by a group of trained patient volunteers who are there for anyone who needs someone to talk to about PH.

Call 800-748-7274 to reach a friendly voice who can help provide information and support.

**Online Communities**

Our discussion boards, email groups and chats help you instantly connect with other patients and family members. [www.PHAssociation.org/ConnectOnline](http://www.PHAssociation.org/ConnectOnline)

PHA also holds frequent e-Learning Events. Take part in these monthly webinar presentations, conference call discussions and online Q&A chats at [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

Connect face-to-face

**Support Groups**

Join one of our 215+ support groups nationwide to connect with people who understand what it’s like to live with PH. Find support groups in your area at [www.PHAssociation.org/LocalSupportGroups](http://www.PHAssociation.org/LocalSupportGroups)

**Conference and Patient Education Programs**

PHA’s International Conference brings together more than 1,000 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and coping with PH. Visit [www.PHAssociation.org/Conference](http://www.PHAssociation.org/Conference) to learn more.

PHA also hosts regional patient education conferences throughout the year. Learn more at [www.PHAssociation.org/OntheRoad](http://www.PHAssociation.org/OntheRoad)

**Special Events and More!**

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

Join our community of hope

Become a member to receive Pathlight, a discount on *A Patient’s Survival Guide* and much more. Visit [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join)
In April, PH caregiver Pam Adams posted a call for help on PHA’s online Discussion Board: “I am having a lot of difficulty lately with my stress level being too high. ... What I need are some suggestions for things that could be put into practice in a busy person’s life. A lot of things I read seem to assume you have hours to spend on yourself, which I don’t. In addition, having three children and one sick, I have trained myself to take care of everyone else first. So I almost don’t know where to start.”

Online community members rallied together to support Pam and offered dozens of ideas for reducing stress without falling behind. Here are a few favorites:

» I visit the chiropractor often and make sure I keep all my regular hair and doctor’s appointments. I try not to over-schedule my day. This might sound silly, but I schedule only one or two tasks per day. With all that goes on during the week, I try not to schedule anything for the weekends. ~ Nessie

» I stop for 10 minutes at a park or other beauty spot, turn on soothing music or listen to a book on my mp3 player. ~ Alice

» Following a healthy diet helps. Lots of veggies and fruits. Not too much processed stuff. Whenever you can, if you’re a bath person, try to take enough time to take a quiet, uninterrupted bath. Also, power naps can be a good thing. ~ Kristie

» Make appointments for “me time.” Go do things that you want to do, and schedule them, the same way you’d schedule a doctor’s appointment, something that cannot be changed. You make yourself the priority.

   Make a list of the things you cannot give up and what you can give up (like household chores, overtime at work, etc). Then decide how much time you will devote to each task. Make sure the top of your list includes eight hours of sleep each night. And that’s sleep, not paying bills in bed.

   Most high schools and colleges require students to perform service projects as a graduation requirement. You can be a service learning project. Find out who is in charge of the service learning projects in your neighborhood and make four or five or ten CONCRETE tasks that students can perform for you over a six-week period. ~ Ellen

As Nessie in Kentucky writes, “It’s very easy for someone to say ‘take care of yourself,’ but if they don’t live it, they don’t understand.” That’s why some of the best stress-busting tips come from fellow caregivers (and the PH patients who love them!). Email your ideas for Pam and over-booked caregivers in the same boat to Outreach@PHAssociation.org. We’ll continue to spread the word that rest and rejuvenation are not only possible but necessary in every PH caregiver’s daily life.

Looking for answers to a question of your own? Visit www.PHAssociation.org/DiscussionBoards to tap into the collective wisdom of PHA community members, or visit www.PHAssociation.org/EmailGroups/#Caregiver to join the PHA Caregiver email group.

By Emma Bonanomi
PHA Patient Outreach and Services Manager

Welcome, Anastasia Raftopoulos, Kerry Bardorf Family Support Program Associate!

Anastasia joined PHA in June as the Kerry Bardorf Family Support Program Associate. She graduated from the University of Maryland, Baltimore, in May with a Master’s degree in Social Work with a concentration in Nonprofit Management and Community Organization. With recent experience managing program initiatives at Public Allies, an AmeriCorps program that facilitates youth leadership development, and planning family support and education programs at St. Joseph Medical Center in Towson, Md., Anastasia comes to this new position with experience and enthusiasm. At PHA, Anastasia will be working with caregivers of children and adults to expand and enhance current support and education offerings for families of PH patients. To learn more or to get involved with the Kerry Bardorf Family Support Program, contact Anastasia at Anastasia@PHAssociation.org or 301-565-3004 x800.
It’s amazing how much our lives parallel a row of dominoes. Every aspect of our lives — who we are, what we want to accomplish, our strengths and weaknesses, our priorities — are all set up perfectly. Suddenly, an outside force knocks over that first domino and sets a ripple effect in motion, no tile is left untouched. A PH diagnosis bulldozes that first tile and just keeps on going, squashing dreams, shattering emotions, reshaping the very core of our being. All we can do is pick up the pieces and make a new pattern. We get to start over, emerging with new-found strength and a fighting spirit we never knew we had in us.

Change isn’t always bad. I used to be the quiet girl who would never say two words in class, voluntarily. This past April, I shared my entire PH journey with a room full of soon-to-graduate Physician Assistant students at Marywood University. Pam Rotella, a Cardio-Pulmonary Nurse Specialist, got things started with an in-depth explanation of pulmonary hypertension, its statistics, symptoms and treatment options. Then she turned the spotlight over to me. Through laughter and tears, I relived the three-year roller coaster leading up to my diagnosis and shared what my life has been like since being labeled “handicapped” — the good times and the bad. I was open, honest and just poured my heart out to them with no real idea of what I wanted to say. But, once I got started, I just couldn’t stop. It turned out to be one of the most rewarding experiences I’ve ever had.

I chronicled all the misdiagnoses, the escalation of symptoms and all the confusion, fear and frustration that come as a result. When I was finally diagnosed in September 2006, I was actually just beginning sophomore year at Marywood University. So, since I knew the area well, I would ask my student audience questions like, “How long does it take you to walk from, say, building A to building B?” A few of them chimed in, “Five minutes, ten minutes…” I shook my head and laughed. “It would take me at least 45 minutes — I had to stop every couple feet; I just could not breathe.” A few gasps echoed around the room.

When I got into the most painful, lowest moments, I actually started crying so hard I had to stop and let Pam take over for a few minutes while I pulled myself back together. One of the students walked up and handed me a box of tissues. It was at that point that I realized I had hit home. I was their age. I went to their school. I lived their life. This could’ve happened to any one of them.

It wasn’t all tears, though. I showed off my home-made pump case like a model on a runway, walking from one side of the room to the other to a chorus of “ooohs and ahhhs” from the girls. When I talked about gaining a new-found sense of confidence from having my central line moved from the center of my chest to the side, how exciting it was to buy v-neck shirts again, every pair of hands in that room applauded my success. A little crack about being a girl on Viagra™ helped to lighten the mood and get some laughs too.

Afterwards, in the inevitable line for the ladies room, all the girls said, “Thank you.” “It was so brave of you to tell us your story.” “This was absolutely the best presentation we’ve seen all year. We read about stuff all the time but hearing firsthand from someone who lives with a chronic, life-threatening illness puts it in a whole new light.” It was an incredible feeling.

I’ve talked to high school biology classes, nursing students and art therapy majors since I first began speaking out a year and a half ago. My first audience was made up of high school juniors and seniors. When I pulled my shirt down a little to show them my catheter site, I cried. A huge part of me still felt like a freak with a tube coming out of my chest and the CADD Legacy® brick attached to me. I was afraid to look up and see their reaction, but when I finally did, my gaze was met with ones of sympathy, acceptance and curiosity — not the shameful reflection in my own eyes. I consider that to be a very important step in my own acceptance process.

Getting up in front of a room full of strangers and delving into the most intimate part of our lives is not easy. But we have a wonderfully unique story to tell, one of strength, perseverance and incredible courage. One thing I’ve learned is that you don’t need a bachelor’s degree to be an educator. By sharing a piece of ourselves, we teach everyone around us. Our paths in life are as unique as our fingerprints.

By Katie Tobias, PH Patient

www.PHAssociation.org

PATHLIGHT SUMMER 2010
Nothing could have prepared my husband and me for the devastating news we received back in September 2003. That is when our pediatrician told us that the mysterious illness plaguing our then five-year-old son Braden was a devastating disease with no known cure called pulmonary hypertension. Like most people, we had never heard of this illness before receiving the diagnosis.

Braden had been suffering from unexplained symptoms for about a year prior to diagnosis. What we first thought to be asthma, we now understood to be a life-threatening illness, and we were scared for our son’s life. When Braden was diagnosed, he began treatment with sildenafil. We started making trips from our home in New Brunswick, Canada, to Sick Children’s Hospital in Toronto, Ontario, at least twice a year (this is about 18 hours from our home) so that he could be followed by the only pediatric PH specialist in Eastern Canada, Dr. Tilman Humpl. Braden did very well on sildenafil for the first two years following diagnosis.

In October 2006, his health took a turn for the worse, and we found ourselves back in Toronto for another cardiac catheterization. At that time, we decided to add Tracleer™ to his treatment. Lung transplant was also discussed; however, once on Tracleer™, Braden again made progress and his health improved. He was able to continue with these oral therapies until January 2008 when we had no other choice but to begin Flolan™ therapy. Braden again stabilized, and just as he had in the past, he accepted this challenge and learned to cope with life on Flolan™. Once again, his health improved.

That all changed in May 2009 when Braden developed a serious case of pneumonia. We had been noticing a slight decline in his health, but this was the last straw. We were very frightened as he spent two weeks in the hospital in Saint John, and we knew that once he was strong enough, it was time to go back to Toronto and discuss our final option — lung transplant.

In July 2009 we packed our three boys in the van (Braden’s younger brothers are 10-year-old twins Jarrett and Rylan) and made the 18-hour drive to Toronto for a week-long battery of tests that would determine whether or not Braden was a candidate for lung transplant and whether or not we were psychologically prepared for all that a transplant entailed.

When we found out he qualified, we quickly made preparations to move our family to Toronto. So much uncertainty now faced us. We did not know whether we were leaving home for six months, a year or more. The wait time for pediatric lung transplant is uncertain, and we prepared the boys to expect to be gone at least a year.

We settled just outside of Toronto. On August 27, Braden was officially placed on the transplant list, and we began what we thought would be a very long waiting process. We enrolled all three boys in school and started to settle into our new home as best as we could.

We were shocked when, just a few weeks after we arrived, we received the call for transplant on September 22. It felt completely surreal, and we were all in a state of shock as we headed to the hospital and waited for word as to whether or not the transplant was a “go.” Many times there are “false alarms” and the organs are not suitable for transplant. As we waited at the hospital, we continued to question whether or not we were making the right decision. Part of me wanted to scoop Braden up and run out of the hospital and take my chances with this horrible disease. At least we knew what we were facing right now even if we didn’t know for how long.

Braden, on the other hand, was confident in his decision and, after the initial shock, he kept reassuring me that he was ready and this was right. At 3 a.m on September 23, he was wheeled into surgery. He kept the brave face right up until they began to wheel him away. Tears welled up in his eyes as he told the nurse, “Take care of my parents — they are probably going to cry a lot!” and then he was gone.

As the doors closed, my husband and I both broke down, wondering if this would be the last time we would see our son. The next 10 hours were agonizing. Finally, at 1 p.m., the surgeons emerged to tell us the surgery was a success. The lungs were a good match, the surgery had gone off without complications and we would see Braden soon. Just a few hours later, we were seated by our son in
Meet Dr. John Newman: A Pioneer in the PH Field

Dr. John Newman is the Elsa S. Hanigan Professor of Pulmonary Medicine at Vanderbilt University in Nashville, Tenn. He has been working in the field of pulmonary hypertension (PH) for more than 30 years and continues to make strides in PH research. Dr. Newman has a longstanding interest in the physiology and genetics of pulmonary hypertension, and he is an active member of PHA. Dr. Newman assumed the position of Chair of PHA’s Scientific Leadership Council at PHA’s 9th International PH Conference and Scientific Sessions, and he recently took the time to talk about his involvement in the fight against PH.

You have worked in various settings throughout your medical career. How did you become interested in pulmonary hypertension?

I became interested in PH when I was a medical resident in 1972 and had a patient with PPH, as it was called then. The disease was so rare and poorly understood that everyone spoke about it in hushed tones, especially because there was no treatment. She was a typical patient, young, otherwise healthy, with no other disease features. When I went to Denver, Colorado, for my Pulmonary Fellowship, I became interested in high altitude pulmonary hypertension and started working on the pulmonary circulation in the laboratory. I also have worked on other problems in the pulmonary circulation such as oxygen toxicity and exercise.

What advances in PH treatment have you seen since you first started practicing?

When I started there was no effective treatment at all. Then calcium channel blockers were discovered, and Ivan McMurtry showed they reversed hypoxic pulmonary vasoconstriction. They were then tried in PPH and shown to work in some patients. This was in 1980. Since then, all the important discoveries have been made, so I predated effective disease treatment and have witnessed all the advances we now have.

What is the most important advice you give PH patients?

I try not to give advice. I do want people to live as normally as is possible. Hope is the most important feature of living with pulmonary hypertension or any life-threatening disease.

How did you become involved with PHA?

I came to the first PHA International PH Conference in 1994 at Stone Mountain Park in Ga. at the request of one of my patients and because my colleague, Jim Loyd, and I wanted to get involved. We were so impressed with the families and the organization. Also, we had been in the National Institutes of Health (NIH) Registry and all the doctors in the Registry were very excited about the organization. That was the first time we drew blood with Greg Elliott for genetic studies — the beginning of what would become the Research Room at PHA’s Conferences.

You have just stepped into the role of Chair of PHA’s Scientific Leadership Council (SLC). What are your plans and goals in this position?

As Chair of the SLC, my goal is to continue to provide service for PAH patients and families, help promote research, give expertise for advocacy. I would like to expand the research portfolio, to work with NIH on translational PH programs and work more with the pediatric pulmonary hypertension community.

You are a professor of Pulmonary Medicine at Vanderbilt University. What advice do you have for new practitioners entering the field of PH?

Work hard, take your work, but not yourself, seriously.

Thank you for speaking with us. Any parting thoughts?

So much good has been done by the PHA and by the health workers interested in the problem. I really think we will see a breakthrough in treatment in the next several years that will convert PAH to a chronic disease that allows patients to lead a normal life. That is my hope and expectation.

Interview conducted by Priscilla Davis
PHA Medical Services Program Associate
Q: Since I was diagnosed with PH, my hair has been thinning. I’ve heard that some PH medications can cause hair loss as a side effect. Is this true?

A: Hair loss, or alopecia, can affect individuals of all ages and can be related to a large number of medical conditions. Although hair loss can be considered a “cosmetic” problem, hair loss can also signal an underlying medical condition that needs to be addressed. Potential causes include an inherited tendency towards hair loss, hair loss related to a stressful event, and medical conditions such as infection, inflammatory skin conditions, connective tissue diseases, thyroid disorders, anemia or a nutritional deficiency.

Certain medications can also contribute to hair loss, and I am sometimes asked whether a specific PAH medication could be causing hair loss. Hair loss is not a frequent side effect of medications other than chemotherapeutic medications, but it is occasionally reported with many commonly used medications, including antihypertensives, anticoagulants, cholesterol lowering medications and others.

Hair loss has not been reported for any of the currently approved PAH medications, including prostacyclins (epoprostenol, treprostinil, iloprost), endothelin antagonists (ambrisentan, bosentan, sitaxsentan) and phosphodiesterase-type-5 inhibitors (sildenafil, tadalafil). However, this does not mean that in any given individual that these medications could not be the cause of hair loss.

Unfortunately, there is no reliable test available to determine whether a medication is causing hair loss. Recommendations are often to consider stopping the medication, if possible, to see if the hair loss resolves. This is usually impossible with PAH, as any type of treatment disruption could lead to clinical worsening.

Because hair loss has not previously been reported with PAH medications and because other causes of hair loss are common, an evaluation for other causes of hair loss should be considered before any thought is given to changing PAH therapy. This might include a limited work-up involving tests for thyroid problems or anemia, consideration of one of the common causes of hair loss listed below and evaluation for any specific conditions suggested by the medical history. In addition to these medical conditions, mechanical traction, chemical hair treatments and “trichotillomania (nervous, self-induced hair pulling)” can also contribute to hair loss and should be considered.

The most common cause of hair loss in the overall population is “androgenetic alopecia,” also known as male pattern baldness. This inherited tendency towards hair loss is caused by an increased sensitivity to androgens, and it can affect both men and women. Women with this hereditary condition tend to develop hair thinning that is more diffuse than men, and they do not usually develop complete baldness. Onset is gradual, with progression typically noticed over a period of years. There are no curative therapies, but medications exist (topical minoxidil and oral finasteride) that can lead to some improvement in hair growth, at least for some patients. Of note, finasteride is only approved in men, and both finasteride and minoxidil are antihypertensives (blood pressure medications) that may not be appropriate for use in some PAH patients.

Another condition that should be considered in patients who have recently been ill or under stress is a “telogen effluvium.” A telogen effluvium is a temporary hair loss
that can occur after any major stressor, such as pregnancy, weight loss, major illness, surgery or a traumatic psychological event. Hair loss typically peaks at three to four months after the stressful event. When uncertainty exists, this can be tested for by “pulling” on two to three dozen hairs with a firm tug. Under normal circumstances, fewer than five hairs will be pulled out by their root (broken hairs don’t count). In contrast, during a telogen effluvium many more hairs will be released. This type of hair loss occurs when the hair growth/rest cycle is disrupted after a stressful event. Hair normally grows for a period of two to three years, followed by a three to four month resting phase known as “telogen.” At the end of telogen, the hair falls out and another hair grows to take its place. A serious stressor can trigger many hair follicles to move into the telogen phase early. This leads to hair loss several months later when the hair follicle begins producing a new hair. There are no specific therapies for this condition, but it is usually reversible with time.

In summary, hair loss is a common condition that is likely to affect many individuals with PAH. In some cases no specific intervention is required, but in other cases a more thorough evaluation is needed, and this should be discussed in more detail with a physician.

Answered by Kelly M. Chin, MD, Associate Director, Pulmonary Hypertension Program, UT Southwestern Medical Center, Dallas, Texas.

BRADEN’S STORY CONTINUED FROM PAGE 11

the Critical Care Unit. Over the next few days, he began an absolutely amazing recovery! Slowly, the many tubes and IVs that covered his body began to be removed, and on the second day, when they removed the breathing tube, Braden opened his eyes and uttered his first words, “I told you I could do it!”

We are now almost eight months post transplant, and Braden is doing things he only dreamed of in the past. In January, he put on skates and played ice hockey for the first time in his life! He is able to run and play with his brothers and enjoy the things in life that so many of us take for granted every day. In April, we returned to our home in New Brunswick, and Braden was treated to a hero’s welcome with his entire school lining the street to welcome him back. Every time I look at him, I know that no matter how long we have, this was the best decision we could have made and each and every day we have is an absolute gift. We are forever grateful to the family who gave so selflessly in order to give our son a second chance at life and change our family’s life forever.

To learn more about Braden’s Journey, you may visit his “Caring Bridge” page at www.caringbridge.org/visit/bradengendron for stories and updates.

By Jennifer Gendron
Mother and Caregiver of Braden Gendron

Demystify “PH-Speak” with Our New Acronym Decoder!

Acronyms and shorthand are commonly used by members of the pulmonary hypertension community, but no one is born knowing the difference between your PAP and your PCP! Newcomers and old-timers alike can use this alphabetical list of PH-related abbreviations, adapted from a resource created by PHA Australia, to brush up on the “PH-speak” you run across in our online communities, at support group meetings and at the doctor’s office.

www.PHAssociation.org/Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>6MWT</td>
<td>six-minute walk test</td>
</tr>
<tr>
<td>ABG</td>
<td>arterial blood gas</td>
</tr>
<tr>
<td>ACHD</td>
<td>adult congenital heart disease</td>
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<tr>
<td>AF</td>
<td>atrial fibrillation</td>
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And more online...
Welcome, Meghan Tammaro, Executive Programs Coordinator!

As the Executive Programs Coordinator, Meghan helps support the work of PHA’s President. Meghan serves as the primary support for PHA’s Board of Trustees. She also maintains PHA’s historical archives and works with the President, coordinating logistics and various projects. Meghan is a May 2010 graduate of Lehigh University where she earned a Bachelor’s degree in International Relations. You can reach Meghan by email at MeghanT@PHAssociation.org or by phone at 301-565-3004 x801.

One Patient’s Perspective:
A Second Opinion May Be Just What the Doctor Ordered

The chair is stiff but conforms to my body; the air has a musty, masculine smell to it, as though a man with lots of cologne just walked right by you. I look at my mom and smile a little. Then I look around the rest of the room. Patients of all ages file in: the woman in a wheelchair on oxygen, the gentleman with a fanny pack around his waist and me — the 20-year-old with nothing noticeably wrong. But a secret lies wrapped around my calf, a CADD Legacy® pump surrounded by Coban™ to hold it in place. As I sit there next to my mom, I wait for the nurse to call us back like I have done most of my life (or at least it seems like I have). I think about the PH community and the patients and dedicated doctors who pledge their lives to treatment of their patient population.

All of a sudden an odd phrase pops in my head. “What if?” I ask myself. “What if I was treated by another doctor? Would he or she have a different perspective on my health? Would I still have to take so many pills? Could I be on a smaller pump? Would they have me on oxygen 24 hours a day, seven days a week?” My head suddenly fills with these questions. I become overwhelmed by the possibilities of what could happen if I got a second opinion. I quickly turn to my mom; I want to ask her all the questions formulating in my head. As I take a breath to speak, a nurse calls out my name from a door leading into the doctor’s office.

When pulmonary hypertension was in its infancy, patients were told to go home and enjoy what time they had left with their families. Today, many doctors around the world know about pulmonary hypertension and treat it based on what they know and what they think is best for their patients. However, could another doctor have a different opinion or a different approach to both your medical health and your quality of life? This is just one question that we, as patients, may need to ask ourselves. Receiving a second opinion might answer this question and many others.

Over the years of living with PH, I have noticed that patients’ quality of life has increased as medicine has progressed. With this in mind, I feel that in later years, patients have put our quality of life on hold or on the “back burner” for fear of losing the fight with PH. Well, now that modern science and medical miracles are happening, we no longer have to do this. I believe we must all ask questions and work with our medical professionals to receive the best treatment possible.

By Camille Frede, PH Patient, Age 20

Template Letters Galore: Help Create New Resources for the PH Community

Help us expand our template letter collection by sending us letters you have used to successfully appeal an insurance decision, gain prior authorization or help a patient access their treatment. For more information or to submit a letter, contact Margaret at Insurance@PHAssociation.org or 301-565-3004 x773 or visit: www.PHAssociation.org/Patients/Insurance/FileClaim/Templates
Climbing for a Cure: Meet Jessica Lazar, PA

On February 26, 2010, Jessica Lazar, PA, summited Mt. Kilimanjaro with Dr. Ray Benza and Dr. Robert Frantz, marking the culmination of PHA’s Path to a Cure campaign (see spring 2010 Pathlight, p. 10). All three medical professionals spoke about their experiences during the keynote address at PHA’s 9th International PH Conference in June. Recently, Jessica Lazar talked with us about her work with patients and her time on the mountain.

What initially sparked your interest in PH? Eleven years ago I began working on the Cardiology Inpatient floors at Allegheny General Hospital in Pittsburgh, where I met Dr. Srinivas Murali. Heart failure and PH patients were my favorite population to work with; I fell in love with these patients. They had such a tremendous challenge to overcome with their conditions, but they were always so positive. Getting to know them and building a personal connection with them — such positive, resilient individuals — was inspiring to me.

Have you had any PH cases that stand out? One patient who stands out to me is a woman who was on advanced PH therapy for eight years, and because of her diagnosis of breast cancer, she was not eligible for a lung transplant. She began combination therapy and was also treated successfully for her cancer. After she was cancer-free for five years, she became eligible for a lung transplant. Now, she is four years out of transplant and doing great. She is a nurse by trade and has been active in her community raising awareness about PH. She is a remarkable advocate for this disease.

What advancements in the field of PH are most exciting to you? It is remarkably exciting to have gone from one complicated advanced therapy to entirely new classifications of medications — oral, inhaled and subcutaneous — which open the door to so many options for patients.

How did you become involved in climbing Mt. Kilimanjaro? This was Dr. Ray Benza’s brainchild. Two years ago he climbed the Grand Tetons into the high altitude and temporarily gave himself PH. He did this to raise awareness of PH after losing a young patient. When Ray told me about his idea to climb Mt. Kilimanjaro, I was awestruck at the idea of raising awareness and temporarily experiencing the symptoms of PH that my patients deal with every day.

How has the climb impacted your PH practice? The climb has made me appreciate what my patients live with on a daily basis. I understood it conceptually before the climb, but it’s a whole different thing when you experience it yourself. It gave me a whole new appreciation for the power of one’s mind; my mountain experience brought that home to me. On my way up the mountain, I became so sick that the guides planned to evacuate me off the mountain. Fortunately, I bounced back, but if I let any negative thoughts go through my head, I couldn’t take another step. I made the decision to think only positive thoughts. That, along with my positive team members, made a big difference in helping me to succeed. The power of positive thinking is something that my patients demonstrate to me every day — they inspire me. Never underestimate the power of positive thinking. Patients who, despite everything else, find something to believe in have a better quality of life. What I experienced on Mt. Kilimanjaro reinforced that for me.

Anything else you’d like to share with Pathlight readers? Prior to climbing Mt. Kilimanjaro, I knew I would temporarily develop PH. I knew I would be short of breath even tying my shoes. I expected that, but I became much sicker than I expected. My oxygen saturation was at 70 percent, which I was able to monitor using the pulse oximeter donated by one of my patient’s families. Having the network of fellow climbers made a huge difference in keeping me positive, which I needed to keep going. On summit night I started passing out, with the mountain guide by my side. I got behind and was separated from the doctors. At that moment I knew if I thought negatively, I couldn’t keep going. I started thinking positive thoughts, singing Bob Marley in my head and saying, “I know I can, I know I can.” I could see people at the top of the mountain, and I also saw people lying on the ground right below the summit, moaning in pain. That negativity was contagious, as a group of climbers gave up. It would have been so easy to give up at that moment, but I thought to myself, “I’ve got to get up there; I won’t let Dr. Benza and Dr. Franz take that picture without me.” I did make it to the top, despite being so sick. Having hope, a goal and a purpose can make a remarkable difference in your journey, as it did for me.

Interview conducted by Rachel Wheat, PHA Medical Membership Program Associate

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PATHLIGHT SUMMER 2010
1. Remember that chronic illness interferes with your ability to tolerate heat. The body cools down by increasing heart rate, breathing rate and sweating. Medications can alter the body’s response to heat and ability to cool down.

2. Talk to your doctor before summer to make sure your health condition is at its best. Monitor your symptoms and call your doctor if you have weight loss or increased lightheadedness, headaches or nausea. Water pills and fluid intake may need to be adjusted if you are in the heat and producing more sweat.

3. Pay attention to weather reports. Plan outside activities around the forecasted temperatures and heat index.

4. Move your outdoor exercise activities inside to a location with air conditioning. Run errands early in the day or late in the afternoon. Be sure to avoid peak temperatures. Never sit or rest in a parked car or enclosure where temperatures can soar.

5. Take a cool bath or shower. Lounge in a pool. Dip your feet in a tub of cool water.

6. Carry an umbrella or floppy hat for instant shade.

7. Wear cotton, loose-fitting clothing. Wear lightweight socks and shoes or switch to sandals.

8. Cool off with a fan — even outdoors.

9. Place ice on your wrist at the pulse site or a damp washcloth on your forehead or neck. Cool your skin with a mister or damp washcloth.

10. Use air conditioning and keep your blinds closed during the day. Even at higher temperatures, air conditioning takes the humidity out of the air, making it easier to breathe. If you don’t have air conditioning, go to a mall or library or friend’s home.

By Traci Stewart, RN, MSN
University of Iowa Hospital and Clinics

“10 Things to Do to Stay Cool on Hot and Humid Days” is one in a series of “10 Things to Do” created by the PH Resource Network Education Committee to serve as a resource for PH patients. This series was inspired by the original “10 Things to Do When You, Your Child or Someone You Love is Diagnosed with Pulmonary Hypertension,” written in 2007 by Traci Housten-Harris, RN, MS, of the PH Resource Network Education Committee.

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

Welcome, Priscilla Davis, Medical Services Program Associate!

As Medical Services Program Associate, Priscilla is responsible for continuing to build PHA’s relationship with members of the healthcare community through the enhancement of the programs and services we offer. Priscilla works to increase the value of member benefits for PH Clinicians and Researchers and PH Resource Network constituents. Priscilla also focuses on coordinating the Building Medical Education in PH program as well as PHA’s Research Program and research partnerships. Priscilla earned her Bachelor’s degree in School and Community Health Education from Towson University in 2009. She can be reached by email at Priscilla@PHAssociation.org or by phone at 301-565-3004 x776.
and refine the medical community’s ability to treat patients with PAH.” Dr. McGoon also points out that “the Registry is unique because it has the capability to capture information about how physicians are diagnosing PAH; specifically, whether decision-making is based on robust clinical information.”

For people currently living with PAH, this study has the potential to be incredibly helpful. A large amount of valuable data about clinical markers, treatment options and demographic information will be available to patients and their doctors when the study is completed, making treatment and management much more evidence-based. Additionally, registry studies like this are different from typical clinical studies because there is no specific treatment being tested, no placebo, and they are not designed to test a specific hypothesis. Rather, a registry like REVEAL is designed to enable formulation of new hypotheses about the disease and its treatment. This means that researchers are able to observe PAH in the real world, as opposed to the sometimes contrived double-blind clinical trial study environment.

Patients in REVEAL were enrolled in the Registry based on clinical criteria, as defined by the World Health Organization. Upon enrollment, the more than 3,500 patients in the registry were interviewed about their medical history and a review of their medical record was conducted. Fifty-four academic and community centers participate in the Registry.

Early findings indicate several interesting and useful results. First, there remains a long time period between symptom presentation to a confirmed diagnosis and referral to a treatment center. Second, the study’s early results detected an apparently increasing predominance in the U.S. of females with PAH. Third, the study shows a high prevalence of recreational drug use and co-morbidities associated with PAH. Each of these findings has important consequences for clinical management of the disease, future research efforts and patient and provider education.

Furthermore, the study is exploring whether even a minor elevation in pulmonary capillary wedge pressure (PCWP) may have significant effects on a person’s health and should be considered when prescribing treatment. Differences between pediatric and adult patients were also found and should be studied further so a better understanding can be achieved.

The eventual goal of REVEAL is to better understand the clinical course of PAH, determine which treatments produce the best outcomes for patients with different forms of the disease, and facilitate early symptom recognition and referral to treatment centers familiar with PAH. Hopefully, this new knowledge base will provide information that will help inform the decisions of clinicians who treat individuals with PAH and lead to better outcomes for all PAH patients.

Funding for the REVEAL Registry is provided by Actelion Pharmaceuticals US, Inc.

References:
Welcome, Suzanne Flood, Marketing & Communications Associate!

As PHA’s Marketing & Communications Associate, Suzanne oversees marketing and promotional efforts for a number of PHA events including the PH Resource Network Symposium, PHA on the Road and the biennial International PH Conference and Scientific Sessions. Before joining PHA, Suzanne volunteered as the public relations director of Teen Scene Magazine and worked as a medical documentation assistant at HomeCare Concepts, Inc., in New York. She graduated from York College of Pennsylvania with a B.A. in Public Relations and Mass Communications. Suzanne can be reached by email at Suzanne@PHAssociation.org or by phone at 301-565-3004 x768.

PHA Establishes Robyn Barst Pediatric Research Fund

PHA recently announced the establishment of the Robyn Barst Pediatric Research Fund, following a $215,000 donation from Dr. Robyn Barst. PHA’s hope is to establish an endowed research fund for pediatric PH research, and Dr. Barst’s generous donation is one step toward achieving that goal. In the coming months, PHA will consider recommendations from our Scientific Leadership Council, working with Dr. Barst, on how best to support researchers who are actively working to improve patient outcomes and quality of life for children with pulmonary hypertension.

Dr. Barst, a pioneer in the field of pediatric PH research and clinical care, has served on PHA’s Board of Trustees and is a past Chair of the Scientific Leadership Council. In 2008, she received the PHA Award of Excellence in PAH Care. She served as Director of the Pulmonary Hypertension Center at Columbia University in New York, N.Y., from 1982-2008 and is Professor Emeritus of Pediatrics at Columbia University.

PHA Continues Expanding Education for Medical Professionals

As the field of PH expands, so too does the need for education for those members of the medical community on the front-lines, who are charged with making accurate and early diagnoses and providing the best care possible to their patients facing the challenges of living with PH. PHA is meeting that need by expanding our medical educational programming in 2010 through the Medical Education Fund, as well as our latest medical education initiative called PHA Medical Education On-Demand.

Planning for the Medical Education Fund programs is well under way for 2010. With the 30-City Medical Education Program, PHA visits cities remote from larger pulmonary hypertension centers across the United States, presenting information on the diagnosis and management of PAH to health professionals who do not have regular access to comprehensive sessions on pulmonary hypertension.

The PHA Preceptorship Program facilitates direct education and training of medical professionals. Led by experienced pulmonary hypertension specialists in clinical settings, this program instructs front-line clinicians in the highest quality of care for PAH patients.

Through PHA Medical Education On-Demand, medical professionals can partner with PHA to design a continuing medical education activity that meets their medical community’s educational needs concerning pulmonary arterial hypertension. The program committee has identified five topics, four program formats and more than 50 PH experts to participate as faculty for these programs. Medical professionals wishing to request a program can log on to PHA’s website and choose their preferred topic, speaker, format, date and location, and PHA will bring the education to them.

Programs of the PHA Medical Education Fund are supported by unrestricted educational grants from Platinum-level sponsors Actelion Pharmaceuticals and Gilead Sciences and Silver-level sponsors Pfizer and United Therapeutics. The PHA Medical Education On-Demand program is supported by an unrestricted educational grant from Actelion.

Medical professionals can learn more about each of these programs, view up-to-date schedules or register for an upcoming event by visiting www.PHAssociation.org/MedicalEducationFund and www.PHAssociation.org/OnDemand.

By Christa Donald, PHA Associate Director of Medical Services
Researching for a Cure:  
Dr. Revathi Rajkumar Examines the Causes of PH

Each year, PHA’s research program embarks upon exciting new ventures with a fresh crop of researchers. Dr. Revathi Rajkumar at the University of Pittsburgh is one of those researchers. As a 2009 recipient of the PHA/American Heart Association Post-Doctoral Fellowship Award, Dr. Rajkumar has been working toward a better understanding of the cause of pulmonary hypertension and ways to improve treatment.

“The severity and complexity of this disease, along with our poor understanding of its underlying cause, piqued my curiosity and prompted me to find answers to unknown genetic etiologies involving pulmonary hypertension,” Dr. Rajkumar says. “A better understanding of the genetic mechanisms of pulmonary hypertension will afford the opportunity to stratify patients for more specific therapy and uncover new targets for treatment for pulmonary hypertension.”

Her research project, titled “Genetic Mechanisms of Pulmonary Arterial Hypertension,” was designed as a two-stage study to understand the pathogenesis of pulmonary arterial hypertension (PAH). “Our DNA codes for 30,000 genes. In stage one, we measured the expression of all these genes in the lungs of patients with PAH, patients with pulmonary hypertension associated with another lung disease (idiopathic pulmonary fibrosis), and normal volunteers. We found many genes with abnormal expression in patients with PAH,” explains Dr. Rajkumar.

The project is now in stage two, in which Dr. Rajkumar and her team study four genes identified in stage one that may be central to the development of PAH. Through her research, she is working to determine whether changing the expression of these genes in normal cells causes them to behave like abnormal cells from the lungs of patients with PAH. “If we see changes in the behavior of normal cells so that they look like PAH cells, we will conclude that the genes we are manipulating are important in the development of PAH. In the future, we may be able to develop new drugs to prevent these genes from causing PAH,” says Dr. Rajkumar.

With the knowledge gained so far, Dr. Rajkumar and her team are planning to either inhibit or stimulate the expression of selected candidate genes in different normal cells that make up the blood vessels of lungs, pulmonary artery smooth muscle cells (PASMCs), endothelial cells (PAECs) and fibroblast cells, and look for development of PAH-like characteristics such as cellular proliferation, alterations in signaling pathways and concordant downstream gene expression changes.

According to Dr. Rajkumar, “These results will suggest that this gene is a primary mediator of PAH, rather than a secondary effect of disease.”

So far, the outcomes of Dr. Rajkumar’s extensive research have confirmed that at least one gene replicates the findings of their stage one microarray study and leads to features such as excessive proliferation in normal pulmonary artery smooth muscle cells (PASMCs). “We are currently manipulating the expression of these genes in other cell types such as pulmonary artery endothelial cells and lung fibroblast cells to understand more fully its role and the development of PAH,” she explains.

Looking toward the future of pulmonary hypertension research, Dr. Rajkumar says, “I feel very optimistic that with continued funding we will achieve our long-term goal — better diagnosis and treatment for this complex disease. I am grateful to PHA and all of its sponsors for the PHA postdoctoral award that will not only prepare me to work as an independent researcher but will also give me the freedom to carry out research that I am passionate about.”

PHA is proud to support the exceptional work of researchers such as Dr. Rajkumar. In just a little under a decade, PHA’s Research Program has committed more than $9 million for PH research by leveraging partnerships with the National Heart, Lung and Blood Institute (NHLBI), American Thoracic Society (ATS) and the American Heart Association (AHA). PHA has already supported 44 promising researchers through three independently reviewed cutting-edge research programs.

To learn more about PHA’s research program and research grant recipients, go to www.PHAssociation.org/Research

By Priscilla Davis  
PHA Medical Services Program Associate
Young Son Inspires Legacy Gift to PHA

Since Daniel Torres’ birth, he has had to overcome obstacles that most young boys have not had to face. When his mother, Martha Gonzalez, was four months pregnant, she knew her son would be born with a heart defect. Two days after he was born on December 3, 2005, Daniel underwent open heart surgery at Columbia Presbyterian Hospital, and his heart was successfully repaired.

However, a few days later, he was diagnosed with the rare incurable disease “Biliary Atresia,” a form of liver cirrhosis in infants. Daniel had a liver transplant when he was six months old at the Children’s Hospital of Philadelphia. “After Daniel’s recovery, our family was finally beginning to get back to normal,” Martha says. “We went back to school, back to our jobs and thought that the worst was behind us.”

But at a routine scheduled checkup with his cardiologist, Martha and her family heard the diagnosis that would change their lives: Daniel had pulmonary hypertension. “As a mother I was devastated to hear again the word ‘incurable,’” Martha says. “It didn’t seem possible that after all we had been through, our son would have to face another challenge.” Daniel was just one year old.

After the diagnosis Daniel’s doctor connected the Torres-Gonzalez family with PHA. “Becoming a member of PHA was the best thing that has happened to us,” Martha says. “We were able to have access to information on treatments, and we were able to hear the stories of others who were living with this disease. It gave us hope.”

Now four years old, Daniel is responding well to treatment, and Martha, along with the rest of the family (Daniel’s father Carlos, brother Sergio and sister Mia), has continued to stay active with PHA. To honor their commitment to an organization that helped them in their time of need, the Torres-Gonzalez family joined PHA’s Legacy of Hope Society and included PHA as a beneficiary of their life insurance. “We are dreamers, so we hope and pray for a cure for Daniel,” Martha says. “But we are realistic too. We need to make change happen and that is why we support PHA.”

You can help secure a better future for the community of hope by including PHA in your estate plans. In addition to leaving a legacy for PH patients in the future, you can create income streams and realize tax benefits during your lifetime through creative estate planning. For more information about planned giving and PHA’s Legacy of Hope Society, email Giving@PHAssociation.org or call Jillian at 301-565-3004 x767.

By Jillian McCabe
PHA Associate Director of Development
Patient’s Mom Raises Funds for PH (And Has Fun, Too!)

Before she worked with family and friends to coordinate five Blue Jeans for PH events at schools in the Lower Dauphin School District in Pennsylvania, Jane Corsnitz had never done anything like this before. When Jane first contacted PHA about hosting the events, she said, “This is my first fundraiser ever, so I need lots of help!”

Jane’s daughter, Ursula Hummel, was diagnosed with pulmonary hypertension in March 2009, and Jane immediately knew she wanted to get involved with PHA. “As a Mom, you always try to take away the pain or the hurt, but this time I can’t,” she says. “So what better way to help than to raise money for awareness and research?”

Jane and her family decided to hold Blue Jeans for PH fundraising events, which encourage employees to wear blue jeans to work in return for a $5 or more donation to PHA. Jane learned about the blue jeans event when she contacted PHA and requested a free Our Workplace Has a Heart toolkit, which details the steps involved in hosting a variety of workplace fundraising events. “I decided to do a jeans day,” Jane says, “because it is the easiest way for the teachers and staff to participate — they really like to dress down!”

After receiving approval from the district’s superintendent, as well as the principal of each participating school, Jane’s Blue Jeans for PH events were held in five different schools on select days in March, April and May 2010. Faculty, staff and classroom aides were able to wear blue jeans to school in return for donations to PHA. In total, these events raised $1,528 for PHA programs and services.

After the success of the blue jeans events, one of the schools — East Hanover Elementary, where Jane works as a custodian — decided to name PHA as the recipient of its annual Penny War. Over the course of one week, students throughout the school brought in pennies and the classroom that collected the most pennies was rewarded with a pizza party. This fun, student-centered event helped raise an additional $2,360 for PHA.

And Jane isn’t resting on her fundraising success: she and her husband are now in the process of planning a bowling fundraiser for late summer. “PHA is very close to my heart, and I’m glad I can help in my small way,” she says. “Fundraising is really fun!”

To learn more about Blue Jeans for PH, Our Workplace Has a Heart, and other ways you can fundraise for PH at work, please visit our website at www.PHAssociation.org/Fundraise/AtWork or contact Jennifer at 301-565-3004 x756.

By Jennifer Kaminski
PHA Development Associate
Awards Highlight Ingenuity of PH Community

The selection of the four recipients of the Tom Lantos Innovation in Community Service awards reveals a lot about our PH community: the creativity, the diverse needs to be met, the geographic reach and the commitment to serve.

The awards program was established in memory of Tom Lantos, an extraordinary advocate for the PH cause, to recognize and make possible significant contributions by members of the PH community.

Members like …

» Carol Lindstrom, from Bellevue, Neb., whose “Angel Project” will bring support group services to underserved patients in Nebraska and western Iowa by starting “mini groups” in those areas and providing recordings of speakers from larger meetings;

» Donna Caterini, from Harrisburg, Penn., whose “Huff and Puff” poster, featuring the Big Bad Wolf, will be provided to support group leaders across the country to help raise awareness of pulmonary hypertension and make their communities aware of their local group;

» Elzarie Devenish, from Bloemfontein, South Africa, who will organize and host a PH Retreat in South Africa, to bring together patients and PH-treating specialists for a weekend of education and to serve as a launch pad for establishing a support group for patients;

» Kathy Dee Groebner, from Clayton, Calif., whose “Bears with Back Packs” are designed to teach others what life is like with a pump by bringing adorable stuffed bears wearing packs to events, and providing children with colorful and fun backpacks for their pumps.

We are delighted to congratulate each of these winners and to thank Gilead Sciences for its support of this program. Look for more news on each of these wonderful programs in future issues of Pathlight as well as for the opportunity to apply for a 2011 award!

The Fight to Defeat PH Depends on the Few Who Know It Exists

For those who have it, PH is not a rare disease. Yet, not enough people know about the devastation this disease brings to families every day. All the more reason for those affected to take PH personally.

A legacy gift to the Pulmonary Hypertension Association will not only expand our fight to defeat this condition, it will be your ongoing expression of support to the people and families bonded together in their struggle against this disease.

Your legacy gift can be established in a number of ways — each designed to maximize various financial and tax benefits, according to individual needs. Your personal financial consultant should be involved with your estate decision.

Contact us to find out about the ways that PHA can be included in your estate plans. Call us at 301-565-3004 x767 or email at Giving@PHAssociation.org. Visit our website for more information at www.PHAssociation.org/Give.

MAKE IT YOUR PERSONAL LEGACY TO KNOCK OUT PH.
Big Steps for Swiss Group

It must be true that good things come in both small packages and to those who wait. It certainly is for Bruno Bosshard, who began the Swiss PH Support Group 10 years ago. We’re excited to share that this year the support group has grown into the first official PH association in Switzerland, the Schweizer PH-Association (SPHV). Switzerland, a country less than twice the size of New Jersey, boasts four official languages, making patient organizing and education a unique challenge. They have been actively hosting meetings and raising awareness of PH, working closely with PHA Europe. Learn more at www.lungenhochdruck.ch

Patient’s Survival Guide Reaches Iran

PHA’s Pulmonary Hypertension: A Patient’s Survival Guide has been fully translated into Spanish, Chinese, Japanese, Korean and, now, Farsi! The Iranian version of the guide will be available for purchase in August. Contact Christine at International@PHAssociation.org for more information.

Can’t-Miss Resources from Across the Pond

Looking for more information about issues of intimacy or clinical trials? PHA-UK has released two impressive guides. For more information, contact office@phassociation.uk.com — and if you haven’t listened to “EmPHAsis On Air,” the radio show for PHers, tune in online! Visit www.phassociation.uk.com

Medical Education Gets a Hand from Leaders Abroad

Well over 1,000 copies of Advances in Pulmonary Hypertension were hand-delivered this year to PH-treating physicians outside the U.S., thanks to the partnership of 20 PH groups and sponsorship from Lilly, Inc. to support PHA’s international distribution program. This is the second opportunity PHA has received to get the journal out to those medical professionals who need it most, and we are pleased to play a part in such crucial education.

Pucker Up 4 PH Awareness

It’s time to break out the blue lipstick one more time in an effort to raise awareness of PH and break the Guinness World Record! PHA-UK launched the second iteration of the popular PuckerUp4PH campaign in May, and PHers here in the U.S. got the ball rolling at PHA’s 9th International PH Conference! The energizing awareness campaign calls attention to cyanosis, or blue lips — a common symptom of PH, and galvanized thousands of PH supporters all over the world last year (visit www.PuckerUp4PH.com to view the photo gallery and learn more).

Check out www.PHAssociation.org/Conference to see photos from the kissing booth at the event, and contact Christine at International@PHAssociation.org to get YOUR PuckerUp on! The PuckerUp4PH campaign runs through Awareness Month this November. How many lips can you collect by then?
ERIC ROTER, MD, a Board-Certified emergency room physician and Juilliard-trained cellist has combined his two passions — medicine and music — to create the Bach to Health initiative to help support “outstanding health-care charities and organizations,” including the Pulmonary Hypertension Association.

While Dr. Roter doesn’t have a personal connection to all of the 36 diseases represented in his project, he does have one to PH: his mother-in-law, who passed away several years ago, developed pulmonary hypertension in association with scleroderma.

While a music student in NYC, Dr. Roter occasionally performed as a “street musician.” He says that he never forgot the generosity of the thousands of passersby who threw donations into an open instrument case.

After becoming a physician, Dr. Roter realized he could help far more people by combining his unique talents in medicine and music. He recreated his street-playing experiences by merging his recently recorded videos of J.S. Bach’s masterpiece “Cello Suites” with his own videos of Manhattan. For PHA, he selected Suite No. 5 in C minor: The Sarabande. To enjoy Dr. Roter’s rendition of this beautiful piece of music, go to www.BachtoHealth.org.

By Adrienne Dern
PHA Senior Vice President

PHERS RAISE AWARENESS THROUGH A VARIETY OF MEDIA OUTLETS

You may not think of yourself as a hero, but chances are your local news outlets will. Whether you want to educate your community, advertise your PH fundraiser, build support for PH research or help undiagnosed patients find the care they need, your story is newsworthy. Here are just a few examples of the way PHers have been utilizing news coverage.

Orena Alsip received newspaper and television coverage when she introduced the 2010 PuckerUp4PH Campaign in the U.S. in memory of her daughter, Amber Newby, who passed away in January. PuckerUp4PH is a global attempt to set a Guinness World Record for the largest number of blue lip prints. PuckerUp4PH originated in the United Kingdom and is coordinated by PHA-UK. The campaign officially launched in May. To learn more about PuckerUp4PH, visit www.puckerup4ph.com.

PH patients Linda Miles and Brenda McCallum appeared on HealthWise, a program of WTVI. To watch the segment, visit http://wtvi.org/healthwisepd.cfm and scroll down to the March 7 episode on pulmonary hypertension.

After requesting a media toolkit from PHA and reaching out to area media outlets, Pat Harrington (pictured above, right) was invited to submit a public service announcement about the Arizona Spur A Cure fundraiser to Clear Channel KOY1230.

Learn more about raising PH awareness through the media, visit www.PHAssociation.org/Awareness/ThroughTheMedia

Pat Harrington (second from right) with the Spur A Cure planning committee
Changing Policy One Meeting at a Time

*PHA Advocates to Make Social Security Disability More Accessible to Those Who Qualify*

For PH patients, applying for Social Security Disability (SSD) can be challenging. While 30 percent of disability applicants get approved in their initial filing, PH patients may be at a disadvantage because the language in the Social Security Administration’s (SSA) List of Impairments doesn’t properly include pulmonary hypertension. However, change is on the horizon.

The SSA is currently in the process of updating both their cardiovascular and pulmonary listings, and revising language about PH has been on its radar from the beginning.

Recently, the SSA invited the Scientific Leadership Council (SLC) — PHA’s committee of leading medical experts in the PH field — to present at a meeting to determine how PH should be properly integrated into the Cardiovascular List of Impairments.

Dr. Ron Oudiz, who presented at the April 7 meeting along with Drs. Robyn Barst and Harrison Farber, says that he was delighted when he heard that PHA had been given an opportunity to provide input on this extremely important issue.

“During the actual meeting, both the SSA members and the members of the Institute of Medicine (who are the ones making the disability recommendations to SSA) were extremely receptive to our input,” says Dr. Oudiz. “We first gave an overview of what PH is and why it is important to understand the nuances of disability in PH patients. The attendees were very appreciative of this educational effort. Next, we described the issues specific to disability in PH patients, which seemed to hit home. We believe that by the time the SSA disability guidelines are updated, limitations unique to PH patients will be formally recognized and will help the SSA better determine the need for disability in our patients.”

This isn’t the first time PHA has worked with the Social Security Administration. In 2008, PHA met with the SSA shortly after Alan Harder — former SSA employee and caregiver to his wife and PH patient, Marsha — shared with PHA that outdated listings regarding PH were leading to unnecessary application denials. Based on a script created by PHA’s Scientific Leadership (lead author, Adaani Frost, MD), the SSA then produced a training video, available at [www.PHAssociation.org/SSAVideo](http://www.PHAssociation.org/SSAVideo), to educate adjudicators about PH-related listings.

The SSA is still only in the early process of making the revisions in their cardiovascular and pulmonary listings, as any changes to federal regulations have to go through a multi-step process involving public comment periods and even more revisions. However, with the continued involvement of the SLC and the PH community, the updated listings should make receiving disability assistance less of a hurdle for PH patients.

*By Margaret Beardsworth*

*PHA Insurance Program Manager*

A special thank you to all who have volunteered their time and expertise on this initiative, including Drs. Robyn Barst, Charles Burger, Greg Elliott, Harrison Farber, Adaani Frost, Nicholas Hill, Michael McGoon, Vallerie McLaughlin, Ron Oudiz, Erika Berman Rosenzweig and Carol Vreim as well as Alan Harder, Gavin Lindberg and Jennifer Jaff.

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The SSA uses a five-step process to decide if you are disabled:

1. Are you working?
2. Is your medical condition “severe”?
3. Is your medical condition on the List of Impairments?
   
   *This is the first step where disability can potentially be determined. The SSA uses its List of Impairments that describes medical conditions considered so severe that they automatically mean you are disabled.*

   *If the severity of your medical condition meets or equals that of a listed impairment, you qualify as disabled. If it does not, the SSA goes on to the next step.*

4. Can you do the work you did before?
5. Can you do any other type of work?
Healthcare Highlights: A Brief Look at the New Law

The Patient Protection and Affordable Care Act (PPACA) was signed into law on March 23, 2010, and healthcare in the United States is on the brink of change. Although the bill does not fully address all the concerns of the PH community, many of the provisions align with our own, long-standing advocacy initiatives to improve the quality of care for PH patients.

According to the Congressional Budget Office, the legislation will provide coverage to 32 million currently uninsured Americans — a leap toward the vision that every PH patient will have healthcare that is universal, continuous (portable), affordable, sustainable and accessible.

Only months after enactment...

PPACA requires the establishment of high-risk pools for people with pre-existing conditions who have been uninsured for at least six months and prohibits insurers from rescinding policies once a beneficiary becomes sick. Additionally, it will:

+ Require insurers to allow young adults to stay on their parents’ policy until age 26;
+ Begin to phase out the Medicare Part D doughnut hole (to be completely phased out by 2020);
+ Prohibit insurers from imposing lifetime benefit caps — another cornerstone in PHA’s advocacy efforts;
+ Prohibit insurers from denying coverage to children (up to age 19) who have a pre-existing condition.

Because of the complexity of some of the undertakings required to implement these changes, many of the requirements will not take effect until 2014.

Starting 2014...

The legislation will require guaranteed issue and renewability of coverage and allow rating variation based only on age, rating area, family composition and tobacco use. Since most individuals will be required to obtain health insurance coverage, states will also be required to establish health insurance exchanges — or marketplaces — where insurance companies can offer plans for individuals and small businesses. In addition, the law will:

+ Eliminate pre-existing coverage exclusions for adults;
+ Establish subsidies for low income families to purchase coverage through the exchanges;
+ Prohibit annual benefit caps; and
+ Prohibit waiting periods of greater than 90 days for coverage to begin.

As reform efforts begin to shift toward implementation, PHA will continue to advocate for policy and regulations that mirror our Statement of Principles on Healthcare reform and increase access to healthcare for PH patients.

To find out how you can get involved or to view the entire statement on healthcare reform, visit www.PHAssociation.org/Advocacy/Alerts

By Margaret Beardsworth
PHA Insurance Program Manager

Insurance Finds: New Sections Added to Online Insurance Guide

PHA’s Online Insurance Guide includes Financial Assistance and Medicare sections. Look for information on Patient Assistance Programs and general support programs under the Financial Assistance section. Or find helpful resources, charts and diagrams to help you understand your Medicare coverage in the Understanding & Choosing Your Insurance: Medicare section.

Let us know what you think! Contact Margaret at Insurance@PHAssociation.org or 301-565-3004 x773 for more information or to offer suggestions or comments about the guide.

Visit www.PHAssociation.org/Patients/Insurance to view our Online Insurance Guide.
As Grassroots Campaigns Associate, Elisabeth works to build the 435 and PHAware Campaigns and support current Campaign members. The 435 Campaign, PHA’s grassroots legislative network, is comprised of volunteers who communicate with their Members of Congress and engage them in critical pulmonary hypertension legislative issues. The volunteers who make up the PHAware Campaign work with local media to share the stories of how pulmonary hypertension has affected their lives. Elisabeth is available to provide resources, advice, and support to anyone interested in PH advocacy or media awareness. She graduated with a B.A. in Political Science from the University of Nevada, Reno, and just received a Masters in Education Policy from the University of Maryland, College Park. Elisabeth can be reached at Elisabeth@PHAssociation.org or 301-565-3004 x753.

Welcome, Elisabeth Williams, Grassroots Campaigns Associate!

In August, Members of Congress leave Washington, D.C., and work from offices in their home states. Chances are, your senators and representative have an office near you.

Join the District Visit Campaign and schedule a visit with your senator or a staff member in his or her local office.

Get started today by contacting Elisabeth at Elisabeth@PHAssociation.org or 301-565-3004 x753 or by using the resources on PHA’s website: www.PHAssociation.org/Advocacy/ConnectLocally

Patient Outreach Leads to 2nd Senate Co-Sponsor for PH Bill

“...doesn’t agree to co-sponsor during the first meeting is to follow up. You plant the seed and when you follow up, you’re watering it. Hopefully, it will grow into co-sponsorship.”

Those words of wisdom are from PH patient and 435 Campaign member Diane Ramirez whose senator, Kay Hagan (D-NC), became the second Senate co-sponsor of the Tom Lantos PH Research and Education Act of 2009.

With the help and support of PH patients Cindy Pickles and Janet Cecil, Diane began reaching out to Hagan shortly after she was elected in November 2008. She spent almost a year corresponding with staff in Hagan’s district office, but they had trouble fitting her in to the Senator’s busy schedule.

Finally, Janet, Cindy and Diane decided that if Hagan wouldn’t come to them, they would go to her. In October 2009, they drove to Washington D.C., and met face-to-face with Hagan during her weekly constituent coffee.

Over the next few months, Diane followed up with the Senator’s office through phone and email. In February, Hagan became the second Senate co-sponsor of the Tom Lantos PH Research and Education Act of 2009.

In August, Members of Congress leave Washington, D.C., and work from offices in their home states. Chances are, your senators and representative have an office near you.

Join the District Visit Campaign and schedule a visit with your senator or a staff member in his or her local office.

Get started today by contacting Elisabeth at Elisabeth@PHAssociation.org or 301-565-3004 x753 or by using the resources on PHA’s website: www.PHAssociation.org/Advocacy/ConnectLocally
PHA is grateful to our spring 2010 interns, who enthusiastically joined our team and supported our mission. They have made a real impact on the programs and services PHA is able to provide. To learn more about PHA’s internship program, visit www.PHAssociation.org/Internships.

Nick Petropoulos, Volunteer Services Department
Nick received his Bachelor of Arts degree in May 2010 from The Catholic University of America. During his internship at PHA, he worked with PHA’s more than 215 support groups and was able to collaborate with new and interested leaders to boost the current number of support groups to 225. “Reaching out to the PH community and leaders has opened my eyes to the daily life and struggles of PH patients and the joy they get out of the support group program,” Nick says. “It really is an excellent program!” At the end of his internship, Nick joined PHA’s staff as the Volunteer Services Program Associate, and he will remain in this role until he returns to school in the fall. Thank you, Nick, and welcome! Nick can be reached by email at Nick@PHAssociation.org or by phone at 301-565-3004 x758.

Sona Chaudhry, International Services Department
Sona Chaudhry, a recent graduate of the University of Maryland, joined us this spring as the International Services Intern. Sona worked to update the Worldwide Therapies listing, coordinated our Translations program, and began work on an initiative to increase international membership in PH Clinicians and Researchers. Her science background and pre-med interests, as well as her international travel and healthcare experiences, made her a valuable asset to the department. Sona went on to complete a medical mission in Ethiopia this summer and will be attending medical school in the fall.

Warren Bell, Advocacy and Awareness Department
Warren Bell, a graduate student from The Catholic University of America, came to PHA to explore his interest in advocacy. Warren has a B.S.W. from Bowie State University and is a veteran of the United States Navy. As an intern at PHA, Warren supported the 435 PHAware Campaigns by writing action alerts, communicating with special events coordinators about their advocacy efforts, and tracking news hits as well as legislative contacts. He worked to improve PHA’s video tracking and editing system and use of PHA’s YouTube channel. “Working at PHA provided excellent firsthand experience. I was able to learn and develop skills that will allow me to be more effective in my social work career,” he says. Warren graduated in May 2010 with a Masters in Social Work and plans to pursue a career as an advocate for veterans of the U.S. Armed Forces.

PHA DOES IT AGAIN! RECEIVES CHARITY NAVIGATOR’S 4-STAR RATING FOR SEVENTH YEAR

For the seventh consecutive year, PHA has received Charity Navigator’s 4-star rating, the highest recognition conferred by the leading charity evaluator in America. PHA is one of only 2 percent of all charities that have received this designation over this period of time.

According to Charity Navigator President & CEO Ken Berger, this evaluation indicates that PHA “consistently executes its mission in a fiscally responsible way, and outperforms most other charities in America. He goes on to say that “This ‘exceptional’ designation differentiates the Pulmonary Hypertension Association from its peers and demonstrates to the public it is worthy of their trust.”

In the subject category in which PHA is rated — Health: Diseases, Disorders, Disciplines — fewer than 25 percent of charities in this category currently have a 4-star rating. For more information and to read PHA’s profile, go to www.PHAssociation.org/CharityNavigatorRating.
4th Annual Support Group Leader Training: 
Southern California Support Group Leaders Join Together in Collaboration

Leaders are not born — they are made. Practice, trial and error, training and mentoring are key tools in the development of a good leader. PHA Support Group leaders are busy people with families, jobs and the challenges of life managing pulmonary hypertension. We at PHA help our busy leaders develop the skills they need through our Support Group Leadership Institute, a series of monthly phone trainings and annual in-person regional trainings.

In March, 12 leaders who manage nine support groups came together in Garden Grove, Calif., for PHA’s fourth annual Support Group Leadership Institute Regional Training. As one leader explains, “I enjoyed networking with other group leaders. Hearing about how they hold the groups together and raise funds was very helpful.”

This training occurred in conjunction with our PHA Board Meeting in Garden Grove, Calif. Patient and caregiver leaders discussed ideas for meeting topics, speakers, expanding their membership and much more.

“As a new leader, my biggest problem is finding speakers and approaching them,” explains a second attendee. “This was my first meeting and it was very well organized; it had a little of everything and, at the same time, was not overwhelming. Being able to meet others who are working toward the same goal was inspiring!”

The Southern California regional training and all of the trainings provided by the Support Group Leadership Institute are made possible by an endowment from United Therapeutics.

By Debbie Castro
PHA Director of Volunteer Services

The Pros and Cons of Attending Support Group Meetings
From a Patient’s Point of View

This past spring PHA moved into a new office, and in the moving and cleaning process, we rediscovered treasures from our past. The following is an article published in the 1993 spring edition of Pathlight. It was written by Pat Paton, one of PHA’s founders, and its message is as true today as it was 17 years ago.

Are you fearful of finding other patients in a deteriorating state of disease? Perhaps the site of the meeting may require some travel. Or maybe you are afraid to get involved with “sick” people. These are the cons, or the reasons that may prevent you from attending a meeting. You are not alone. You see, most of us have had these reservations at one time or another.

Now consider the pros. You have the opportunity to meet other patients with the same fears, experiences and feelings that you have. You have a chance to share information and ideas with each other. You will probably establish friendships that can be continued through letters and phone calls between meeting dates.

Meetings offer opportunities for family members to meet each other and share their concerns. You will find encouragement in seeing firsthand how well others are doing. You may learn more about your disorder, or you may learn ways to ease the day to day tasks that you must do. Once you attend a meeting, you will come away with the satisfaction of knowing that you can help others through some difficult times. Most of all, you will know that you are not alone.
Inland NW Support Group Honors Supportive Employers

While a pulmonary hypertension diagnosis often prevents patients from holding a job, some patients continue to work, balancing the challenges of both PH and their work life. An understanding employer can make this balance much easier, and the Inland NW PAH Support Group has decided to recognize this employer commitment.

Each year during PH Awareness Month in November, this support group holds a fundraising luncheon to garner support and raise awareness in the fight against PH. In 2005, to add a fresh element to the event, the group began recognizing individuals with awards such as Patient of the Year, Caregiver of the Year, Physician/Medical Professional of the Year and — when they find a deserving candidate — Employer of the Year.

“I love recognizing people publicly for their good works,” says Linda Pall, coordinator of the awards and one of the support group leaders. “It honors the individual who has contributed, and (here’s the selfish part) it casts reflected glory on those who have made the award.”

The group chooses recipients for the Employer of the Year award based on the employer’s ability to recognize the impact PH has on an employee’s life and to respond sympathetically and creatively to the needs of the employee.

“Just doing the minimum does not qualify,” Linda says. “A very important piece of the puzzle is having and showing respect for the individual, the image they have of themselves and the hopes and dreams they have for their career and work, despite the disease.”

To find deserving employer award candidates, Linda begins requesting nominations at support group meetings during the summer and early fall. She also creates a press release for general distribution. “If we do not have nominees who are really worthy, we don’t present the award,” Linda says. “I have wanted to keep this as a genuine honor for people of real distinction and significant contribution.”

The first Employer of the Year award went to Linda’s employer Dr. Robert Greenburg at Washington State University. “His response to hearing that one of his professors had a terminal disease was really phenomenal,” Linda remembers. “He was immediately anxious to rearrange schedules, rooms, other conditions — whatever I needed, I would get. He assured me that I should not worry about the security of my teaching position.”

Linda encourages all support groups to consider recognizing employers in this way. “I think it is hugely important for PH patients, who continue with their work, to have their cooperative employers recognized and be able to bring that person or persons to the support group to ‘show them off!’” Linda says. “I also think that every time we award deserving employers, we give the rest of the business world good examples to emulate. PH is a terrible disease, but it is a challenge that does not have to end life when the diagnosis is confirmed. Continuing productive work helps keep one’s life meaningful.”

The Inland NW PAH Support Group has bestowed two Employer of the Year awards so far and hopes to find a third deserving candidate this November.

By Megan Mallory
PHA Publications Manager

Linda Pall shares her ideas about what work can mean to a PH patient:

Many patients find real meaning in being an integral part of life. We want to be in the thick of it. We want people to pay attention to our ideas, our plans, our strategies and schemes. People with PH want to be part of their world, continuing with their lives and not being defined by their disease. Work (whether it is professional work outside the home or the work of keeping a home and family) is central to our identity and gives our lives meaning. We want to be able to continue with the important activities that framed our lives the day before we heard those dreadful words, “Dr. Pall, you have pulmonary hypertension.”
Crawfish, Zydeco and Alligator? Oh My!
The Woodlands Crawfish Festival Continues a Long Legacy of Impacting PH Research

The Woodlands Crawfish Festival, held on March 27 in The Woodlands, Texas, brought raising PH awareness and funds for research to a whole new level. With 2,000+ people in attendance from the PH and general communities, this year’s “bug boil” was the largest in its three-year history. Hosted by PHA Board of Trustees member Jack Stibbs, his wife Marcia and their CurePH fundraising committee, this exciting New Orleans-themed event was so popular that it sold out!

The CurePH legacy has quite the backstory: the Stibbs’ first event for PH research was a golf tournament in 1999. Year after year it drew larger and larger crowds of golfers, establishing itself as a go-to community event. Then in 2008, the Stibbs family decided to make the switch from swinging golf clubs to eating “bugs” for a cure — and the annual CurePH Crawfish (“Bug”) Boil was born. Lively zydeco music, steaming plates of crawfish (or “bugs”) and plenty of activities for the kids helped these Texans party New Orleans style each spring to benefit a great cause.

CurePH event committee member Matacha Saul sums up this year’s bug boil, which was the result of a partnership with The Woodlands, Texas, Chamber of Commerce and re-named The Woodlands Crawfish Festival: “It was a great success, gorgeous day and fun had by all. … We had approximately 2,000 in attendance, ate 6,000 pounds of crawfish, 160 pounds of alligator and 2,000 pieces of chicken.”

We asked both Jack and Matacha to talk about the evolution of their fundraising efforts, and here’s what they had to say:

**Can you describe the concept behind your bug boils?**
We’d describe them as simple and relatively low-cost family events with lots of opportunity for awareness and education of pulmonary hypertension.

**How was this year’s Crawfish Festival different from previous years?**
This year was really different only in scale — feeding and entertaining 2,000 plus people required more logistical planning.

**What was the most challenging aspect of expanding the CurePH bug boils?**
Believe it or not, making sure we controlled attendance so as not to get too big too fast.

**What was the most rewarding aspect of expanding the CurePH bug boils?**
The most rewarding aspect of expanding the event this year was the opportunity for increased awareness of pulmonary hypertension.

**How did you conduct outreach for your event?**
Advertising through the local Chamber of Commerce and media outlets. [The CurePH Committee partnered with the Young Professional’s Network from their local Chamber of Commerce to promote The Woodlands Crawfish Festival.]

**You had more than 2,000 attendees at the festival. What sort of impact do you think this had on local PH awareness-raising?**
High! We had a few PH patients come from out of state, such as Colorado. We also learned that a local vendor of our event is a PH patient.

**Have you seen any long-lasting impact on the community as a result of The Woodlands Crawfish Festival?**
We believe we have started something that will grow and flourish for many years to come.

**Is there anything new in the works for the 2011 Woodlands Crawfish Festival?**
In 2011, we are going to make the event even bigger and better, and we will be designing a new event logo emphasizing PH.

**Any advice for someone who is thinking about planning a PHA fundraiser?**
Start with a small committee of volunteers who will help you plan — and keep it simple!

*Interview conducted by Jessica McKearin
PHA Special Events Manager*
Event planners get creative across the country. Check out these spring special events!

**Dancers don their best cowboy boots as they “pony up” for a cure at the 4th Annual Spur A Cure for PH.** This Phoenix-based western-themed dinner and auction raised more than $20,000 for PH research and services.

**It’s raining … golf balls?** With an assist from a helicopter, the 2nd Annual Scramble for a Cure golf tournament in Las Vegas, Nev., completes the “ball drop,” a fun 50/50 raffle concept in which the owner of the ball landing closest to the hole wins.

**The Southwest Virginia PH Support Group, family and friends take time out to pose at their Inaugural Radford Fun Walk for a Cure.** The rain couldn’t keep this dedicated group away from the fun and fellowship, which included a luncheon, raffle and DJ! Over $2,500 was raised towards research and patient/family services.

**More than 150 people from all walks of life rocked out for a cure at “Rock Your Heart Out for Pulmonary Hypertension,” a benefit concert in Atlanta hosted by PH patient and PHA Generation Hope member Brittany Riggins (pictured right). Performances from three bands and exciting raffle opportunities generated more than $4,000 for PHA.**
What Does It Take to Plan a Special Event?  
*The first in a four-part series.*

If you’ve ever considered planning a PHA special event in your neighborhood — or if you just need a Fundraising 101 refresher course — PHA is here to help! By hosting a special event, you, your friends and family have the chance to directly impact PH research, essential patient services and medical education.

Read on to learn the five key ingredients for planning a successful event and visit [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook) for even more nitty-gritty details.

**Choose a date, time and location:** The date you choose will impact the turnout and overall success of your event. Weekend events tend to get the best attendance, but you might also want to consider connecting your event with PH Awareness Month in November or a birthday, anniversary or other special day in your life. Choose a location that fits the event. For instance, a park would be a perfect place for a summer fun walk in Maine, but that same park might be a little chilly in December.

**Make a timeline:** Each event is different, but all events need a certain amount of planning beforehand. Once you choose your event, work backwards to determine what you need to do each month leading up to the big day. Visit [www.PHAssociation.org/SpecialEvents/PlanningTimeline](http://www.PHAssociation.org/SpecialEvents/PlanningTimeline) to view a sample planning timeline.

**Remember fundraising:** Before you begin to organize your special event, remember there are various ways an event can raise funds. Both sponsors and event participants can get involved to provide financial support. More to come on this topic as our article series continues!

**Recruit Volunteers:** Volunteers will be a HUGE help to you, both before and during your event. Make sure to recruit volunteers early and assign tasks so that all responsibilities are covered. Contact your local support group for help, enlist family and friends, invite neighborhood and school groups to get involved or find volunteers online. If you have time, talk to volunteers individually to find out what their interests are, what skills and experiences they can bring to the event and if they have any useful business or community contacts. Create a list of all tasks that need to be completed by volunteers before the event, as well as the day of the event, and match tasks to volunteer skills.

**Publicize your event:** Spread the word about your event online, offline and through the media. You will attract attendees, volunteers and donors and — most importantly — you will raise awareness about PH. More to come on this topic as our article series continues!

And remember, PHA is here to support you throughout the planning process. For more information about planning a special event, visit PHA’s website at [www.PHASpecialEvents.org](http://www.PHASpecialEvents.org) or contact Jessica, PHA’s Special Events Manager, at JessicaM@PHAssociation.org or 301-565-3004 x765. Look for more special events tips in the next issue of *Pathlight*.

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**Make November “Event-ful”**

Whether you choose to walk, sing or dine for a cure, now’s the perfect time to grab your family and friends and begin planning your PH Awareness Month Special Event fundraiser. With PHA’s resources designed especially for volunteer event planners, making your November “event-ful” has never been easier!

For more information, visit PHA’s online Special Event Planning Guidebook at [www.PHAssociation.org/SpecialEvents/Guidebook](http://www.PHAssociation.org/SpecialEvents/Guidebook)

Kick off your planning process by contacting Jessica, PHA’s Special Events Manager, at JessicaM@PHAssociation.org or 301-565-3004 x765.

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**Walking Options**

*Walk*  
*Run*  
*Climb*

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**Event Options**

*One Event Closer to a Cure.*  
*Swing*  
*Dinner*  
*Concert*  
*Gala*
Welcome, Jenna Roe, Special Events Program Associate!

As PHA’s Special Events Program Associate, Jenna is responsible for working with PHA’s veteran volunteer event planners, providing them with the tools they need to host successful fundraisers for PHA’s research program and patient services. Jenna also works to revitalize and refine the resources PHA’s Special Events program provides to its volunteers, including the launch of “Event-ful Times,” a bi-monthly e-newsletter geared toward planners. Jenna earned her Bachelor’s degree in Public Affairs from Indiana University-Bloomington in 2009 and recently completed a year-long placement with AmeriCorps *VISTA. She can be reached by email at Jenna@PHAssociation.org or by phone at 301-565-3004 x742.
Thank You, Conference Volunteers, Speakers, Attendees and Supporters

On June 25-27, PHA hosted our 9th International PH Conference and Scientific Sessions in Garden Grove, Calif. Conference was a huge success because of the tireless efforts of our volunteers and the enthusiastic spirit of our attendees. Our volunteers and community members, as well as those who serve each year on our Conference Planning Committee, spent many hours planning each detail of Conference to make it a special experience for our patients and family members. We’d especially like to thank those who stepped up to share their experiences in the Patient/Family Led Sessions and the Support Group Sessions. We appreciate how difficult it may be to share the emotions and stories of life with PH.

PHA would also like to extend a big “thank you” to every patient, caregiver, family member, medical professional and supporter who attended this year’s Conference. This biennial event would be nothing without the spirit, energy and thirst for knowledge you’ve shown. YOU make Conference the life-changing experience that it is!

What’s Next After Conference? Stay Tuned at www.PHAssociation.org/Conference

What’s next? Lots! In the fall issue of Pathlight we will share some additional highlights, stories and photos from our International PH Conference. We want to hear from you! Please submit your Conference stories and feedback to Conference@PHAssociation.org. Also, we invite you to visit our website (www.PHAssociation.org/Conference) in the coming months to view Conference photos, video footage, Journeys stories and downloadable PDF documents of session handouts.

But wait, there’s more! If you were in attendance at Conference, you may have noticed that PHA was recording a number of Medically Led and Patient/Family Led breakout educational sessions. This was to allow us to create an extensive video online library that will be available on PHA’s website in the coming months. Select sessions will be posted online, allowing presenters to share their Conference presentations and expert knowledge with the whole PHA community. If you were unable to attend Conference, or just unable to attend a particular session, you will be able to learn online with PHA! We hope these videotaped sessions will bring a small part of the Conference experience to all of our PHA members.

Thank You, Conference Sponsors!
PHA thanks our corporate sponsors for helping to make our 9th International PH Conference a huge success.

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

Gold Sponsor
Bayer HealthCare • GlaxoSmithKline • Novartis Pharmaceuticals • United Therapeutics Corporation

Silver Sponsor
LungRx

Bronze Sponsors
Lilly USA, LLC • Teva Health Systems • Accredo Health Group, Inc.

Additional Sponsors
CVS Caremark • WWMR, a division of IntrinsiQ • CuraScript

Save the Date!
PHA’s 10th International Pulmonary Hypertension Conference and Scientific Sessions June 22 – 24, 2012 Renaissance Orlando at SeaWorld Orlando, Fla.
www.PHAssociation.org/Conference
**PHA's e-Newsletters Get a Makeover!**

Not only do we have a brand new website design, our e-newsletters have a vibrant new look too. When PHANews arrives in your Inbox, you will see exciting new colors (pictured right) and each issue will be jam-packed with new content and features about the latest news in the PH community. Just as Pathlight has regular features like “Ask the PH Specialist” and “Meet the Doctor,” the new PHANews includes sections such as “Get Smart” with information on medical education, “Living Better with PH” with tips for patients and caregivers, “PH Community Scoop” with updates from the community such as support group news and special events, and much more.

Also be on the lookout for new styles on our other e-newsletters, including Advances in PH, Advocacy Action Alerts, D.C. Metro Volunteers and Media Action Alerts. To subscribe to PHANews or any of our other e-newsletters, visit [www.PHAssociation.org/EmailSubscriptions](http://www.PHAssociation.org/EmailSubscriptions)

**RSS Feeds Make Debut on PHA’s New Site**

Do you prefer to get your news via RSS (real simple syndication) feeds? We have them! RSS feeds come to you instantly, and the Google Reader is simple and free.

To sign up for our RSS feeds, visit [www.PHAssociation.org/RSSFeeds](http://www.PHAssociation.org/RSSFeeds)

**Monthly e-Learning Events**

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

Attend PH educational events from the comfort of your own home or office.

Q&A chats, conference call discussions and webinar presentations

**Upcoming Events**

- July  My Loved One Has PH: A Caregiver’s Toolbox
- July  Lobby Locally! Visit Your Members of Congress without Leaving Your State
- July  Put the Special in Special Events: PHA Local Event Planning & Fundraising 101
- August  Working with PH
- August  Special Events and the PHAware Campaign: Making Media Outreach Work for You *(sponsored by the Centers for Disease Control and Prevention)*
- September  Side Effects of PH Medications
- October  Speak Out! Getting Involved During PH Awareness Month

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

PHA’s monthly e-Learning Event series is made possible through an unrestricted educational grant from Pfizer, Inc.
An Invitation from Dr. Charles Burger to Attend

*PHA on the Road: PH Patients and Families Education Forums*

I would like to personally invite you to attend one of the upcoming *PHA on the Road: PH Patients and Families Education Forums* in the Baltimore/Washington, D.C. area on Sept. 25 and Dallas, Texas, on Oct. 2. The Forums, a program of the PHA Medical Education Fund, are part of a broad-based medical education effort by PHA to bring updated clinical information to patients, their families and caregivers. It is self-evident that continued education for our patients and families coping with PH is key to improving overall health and disease management.

The inaugural *PHA on the Road Forums* — four one-day Forums held across the U.S. from Costa Mesa, Calif., to Buena Vista, Fla.; Dearborn, Mich., to Providence, R.I. — were held last year and greatly exceeded our expectations. A couple of representative comments by the attendees signify the success of our educational effort:

“All of the sessions were informative and helpful. … I plan to use the techniques I learned in my daily life!”

~ PH Patient, Southern California *PHA on the Road*

“There was hope in the air, and I learned where I can get help.”

~ Dorothy Breisch (Madison, Wis.)

“I appreciated the chance to meet one of the doctors from my area.”

~ PH Patient, Central Florida *PHA on the Road*

An array of topics will be addressed during these free one-day events. Some of the favorite topics from last year’s events — exercise, travel and healthy eating — will be included across the board in these upcoming *PHA on the Road Forums*. *PHA on the Road* is an outstanding opportunity to learn more about pulmonary hypertension and to meet others dealing with this disease right in your own backyard. The sharing of these personal experiences provides perspective and helpful hints for coping and daily living.

I look forward to seeing you there!

Charles Burger, MD
Committee Chair
*PHA on the Road: PH Patients and Families Education Forums*
Mayo Clinic, Jacksonville, Fla.

Learn more at [www.PHAssociation.org/OnTheRoad](http://www.PHAssociation.org/OnTheRoad)
PH Patients and Families Education Forum

A program of the Pulmonary Hypertension Association Medical Education Fund

Baltimore/Washington, D.C. Area
Saturday, September 25, 2010
Sheraton Baltimore North Hotel
Towson, Md.
8:30 a.m. – 4:30 p.m.

Speakers include:
Stephen Mathai, MD
Johns Hopkins University
Baltimore, Md.

Paul Fairman, MD
Medical College of Virginia
Richmond, Va.

Myung Park, MD
University of Maryland
College Park, Md.

Traci Housten, RN, MS
Johns Hopkins University
Baltimore, Md.

Virginia Steen, MD
Georgetown University
Washington, D.C.

Steven Nathan, MD
INOVA Fairfax Hospital
Falls Church, Va.

Gerilynn Connors, RRT, BS, FAACVPR
INOVA Fairfax Hospital
Falls Church, Va.


Dallas, Texas
Saturday, October 2, 2010
Westin Park Central
8:30 a.m. – 4:30 p.m.

Speakers include:
Adaani Frost, MD
Baylor College of Medicine
Houston, Texas

Zeenat Safdar, MD
Baylor College of Medicine
Houston, Texas

Scarlett Harden, ACNP
UT Southwestern Medical Center
Dallas, Texas

Alexander Duarte, MD
University of Texas Medical Branch
Galveston, Texas

Helena Purl, RN, BSN, CCRC
Baylor College of Medicine
Houston, Texas

Deborah Levine, MD
UT Health Science Center
Houston, Texas

Fernando Torres, MD
UT Southwestern Medical Center
Dallas, Texas

Martha Kingman, RN, FNP-C
UT Southwestern Medical Center
Dallas, Texas

Topics Include:
Overview of PH (For Newly Diagnosed Patients) * Life After Being Diagnosed with PH (For Veteran Patients) *
Living With PH (For Caregivers) * How is PAH Diagnosed? * What Are the Current Treatments for PAH? *
Eating Better * Exercise and Yoga * Traveling with PH * Emergency Situations * Understanding Transplant Options *
PH and Connective Tissue Disease * What Is on the Horizon for PH?

This is a FREE patient education event. Space is limited and we encourage early registration to better accommodate all those who wish to attend. Register online now by visiting www.PHAssociation.org/OnTheRoad
For more information about PHA on the Road visit: www.PHAssociation.org/OnTheRoad,
email OnTheRoad@PHAssociation.org or call 301-565-3004 x764.
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Enhance the impact of your Center’s medical education program. Partner with PHA!

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

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

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

To learn more about partnering with PHA through Building Medical Education in PH for your next CME event, please contact Priscilla Davis, Medical Education Program Associate, at 301-565-3004 x776 or BME@PHAssociation.org

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

Welcome, April Grimsley, Administrative Assistant!

As PHA’s Administrative Assistant, April is the first point of contact for members of the PH community. In addition to general office administration, April supports both the Finance and Development departments with processing donations and letters of acknowledgement. She also assists staff with various Web and IT projects. Prior to joining PHA’s staff as the Administrative Assistant, April served as the Web Reporter Intern in fall 2009, and she helped with PHA’s website redesign in the position of Web Assistant through winter 2009. April can be reached at April@PHAssociation.org or 301-565-3004 x746.
Congratulations, Hannah Albert, Winner of the Kids’ Mascot Naming Contest for PHA’s International PH Conference!

Hannah Albert submitted the winning mascot name — Hang Ten Harry — for PHA’s International PH Conference kids’ mascot. Hannah’s mother is a PH patient, and recently, PHA spoke with Hannah about how she chose the mascot’s name and how she helps her mother deal with PH.

Where do you live?
I live in Cedar Bluff, Mississippi.

How old are you?
I am 11 years old.

How did you come up with the name Hang Ten Harry for the kids’ mascot at Conference?
I used to watch a lot of surfing shows when I was little.

Did you attend PHA’s Conference in June?
Yes, my whole family went. I had never been to California before.

What were you looking forward to the most about Conference?
I was looking forward to going on an airplane ride, going to Disneyland and going on the kids’ field trip.

When was your mom diagnosed with PH?
She was diagnosed when I was born.

What are your favorite things to do with your mom?
We go on vacations like to SeaWorld®.

What do you like to do to help your mom out with her PH?
I like to take naps with her and do chores around the house.

What message do you have for other kids whose parents have PH?
Just to help out their parents as much as they can if they see their mom or dad is having any difficulties.
INTERVIEW WITH PH PATIENTS AND BROTHERS, ERIC AND ISAAC HUTCHINSON

Where do you live?

Eric & Isaac: We live in Georgia.

How old are you?

Isaac: I turned 14 on May 26.
Eric: I am 9, but I will be 10 on September 22.

When were you diagnosed?

Isaac: I was actually diagnosed on my mom’s birthday, August 12, 2005.
Eric: I was diagnosed on January 2, 2009.

When did you first start having PH symptoms?

Isaac: When I was around 2 years old.
Eric: A long time ago, when I was around 5 years old.

What were your symptoms?

Isaac: I would get tired easily, and I was short of breath and dizzy. I had chest pains, and I passed out multiple times.
Eric: My chest would hurt when I played too hard, and it would be hard to breathe. Sometimes it felt like I couldn’t get enough breath and I would get dizzy. I almost passed out twice.

What activities do you like to do?

Isaac: I like playing football, and I am hoping to get to play next school year, but my mom doesn’t really want me to.
Eric: I love to play video games.

How has your life changed since your PH diagnosis?

Isaac: Now I am always at the doctor’s office for something, and my mom is always asking me questions about how I’m feeling.
Eric: I have to go to the doctor’s a lot now, and I have to get blood work done every month, which I hate! I also sometimes get special treatment from the teachers at my school, and when I’m not feeling well, my mom will also give me special attention.

What is it like having a brother who also has PH?

Isaac: It can be kind of scary because I know how PH makes me feel, and I don’t want anyone else to have to feel that way. And now my sister might also have PH. We have to wait for the heart catheterization to confirm.
Eric: It’s okay. It wasn’t as scary for me when I got diagnosed because we already knew a lot about PH from Isaac.

What message would you like to pass on to other kids with PH?

Isaac: There are people out there who know how you feel. It is not a death sentence, and with medicine you can feel better and live a pretty normal life.
Eric: You are not alone, and you can still have fun, especially if you like video games.
dragonfly Heart Camp was founded in 2006 to serve children with complex cardio-pulmonary conditions. Specifically, the camp reserves about half of its enrollment for children with pulmonary hypertension; the other spots are reserved for children who have undergone heart or lung transplant.

The camp’s director, Rhonda Cataldo, had the idea for the camp when her daughter received a heart transplant on her eighth birthday. During the seven months Rhonda spent at the Children’s Hospital of Philadelphia, she found support in the community of parents she met there. The Dragonfly Heart Camp, a 501(c)(3) nonprofit, grew out of their shared interest in giving their children some feeling of normalcy and independence after leaving the hospital.

According to Rhonda, the camp’s strong medical presence, which also includes an onsite doctor and a team of nurses available 24/7, is part of the camp’s appeal to parents. Another is the price tag: free to qualified children, thanks to the fundraising of Rhonda and her team throughout the year. Dragonfly Heart Camp runs for one week each summer at the Echo Hill Outdoor School in Wharton, Maryland. In 2010 the camp expects to host 30 campers, who will enjoy many of the perks of a classic sleep-away summer camp, including a campfire, talent show and zip line. Under the supervision of the camp’s medical director, Dr. Brian Hanna, all children, including those on intravenous medication, will be given the opportunity to swim, many of them for the first time.

The camp hosts children ages 8-18 and accepts applications on a first-come, first-serve basis. Visit www.dragonflyheartcamp.org to learn more.

By Emma Bonanomi
PHA Patient Outreach and Services Manager

Parents: For more information about camps for children with PH, visit www.PHAssociation.org/Parents/Camps

New Look for PHA’s Generation Hope
Generation Hope, PHA’s virtual support group for young adults with PH, now sports a new logo designed by volunteer Susanne Back of Backview Graphics and Fine Arts.

Wear Your Hope on Your Sleeve
Visit http://shops.cafepress.com/GenerationHope1 to check out T-shirts, hoodies, mugs and more — all featuring Generation Hope’s new logo. The Generation Hope Café Press shop will donate 10 percent of each purchase to PHA.

CONGRATULATIONS,
CLASS OF 2010!

THREE CHEERS FOR THE 2010 GRADUATES!
No more pencils, no more books! All that studying has finally paid off and PHA couldn’t be happier for all of the PHers who graduated this year. Let us know what you’re up to next! Happy summer and best of luck as you embark on your next journey!

TALK BACK! This is your space.
Send your cartoons, drawings, poems, questions, comments on articles or ideas for future articles to Camille Frede, Pathlight’s Youth Editor, at ponyforme@comcast.net. Or contact Megan at Megan@PHAssociation.org, 301-565-3004 x754.
Frequently Asked Questions for Parents of Children with PH

1. What causes pulmonary hypertension in children?

The causes of pulmonary hypertension in children are essentially the same as in adults; in some cases it is associated with another medical condition such as congenital heart disease or other lung disease; and in other cases we simply don’t know the cause (idiopathic PH). A small percentage of patients have familial pulmonary arterial hypertension, which is an inherited condition.

2. I’ve read about pulmonary hypertension, but most of what I read is about adults with PH. What are the primary differences between PH in adults and PH in children?

The primary difference between PH in adults and PH in children is in the treatment. Until recently, there have been very few clinical trials that study treatments specifically for children. Because of this, while the medications used for children are the same as adults, there aren’t specified pediatric doses, which makes going to a pediatric pulmonary hypertension specialist critical. Weight is a very big consideration in determining an appropriate dose for children as opposed to adults where there is standard dosing.

3. What kinds of treatment are available for children with PH?

There are many medications that are currently used for the treatment of PH in children. They are given in different ways: by mouth, by inhalation, by continuous intravenous infusion (directly into the vein) and continuous subcutaneous infusion (beneath the skin).

Medications such as bosentan (Tracleer™) and ambrisentan (Letairis®) are oral therapies that work on reversing effects of endothelin, a substance that PH patients tend to have too much of in their bodies. Sildenafil (Revatio™) and tadalafil (Adcirca™) are oral medications that help to produce more of the body’s natural vasodilators (nitric oxide).

There are several medications that work by mimicking prostaglandins, which PH patients tend to have very little of in their bodies. These include epoprostenol (Flolan™), which is administered intravenously; treprostinil (Remodulin™ and Tyvaso™), which can be administered intravenously, subcutaneously or by inhalation; and iloprost (Ventavis™), which is an inhalation therapy. It is also possible that your child will be prescribed anticoagulation therapy such as warfarin (Coumadin™) to help prevent blood clots, diuretics to reduce fluid retention, and oxygen.

4. What kinds of side effects will my child experience as a result of PH medications?

The most common side effects for all PH medications include headache, nasal congestion, nausea, hypotension (low blood pressure), dizziness and flushing (feeling of warmth).

Tracleer™ and Letairis® could adversely affect the liver (although this is rare), so monthly blood tests are required to monitor liver function.

Inhaled therapies (Tyvaso™ and Ventavis™) could also cause cough and throat irritation.

Side effects of Flolan™ and Remodulin™ also include diarrhea and jaw pain and infusion site pain (subcutaneous administration only).

You should discuss all side effects with your medical team even if they seem unusual or are not listed here.
5. What type of doctor should my son or daughter be seeing for PH?

It is important that your child be treated by a pediatric pulmonary hypertension specialist. This is usually a pediatric cardiologist or pulmonologist who has extensive training in PH and treats many children with PH.

For a listing of pediatric PH specialists, visit www.PHAssociation.org/Pediatricians

6. How often should we see our PH specialist?

This will vary depending on your specialist, but be prepared to see your doctor every three to six months to monitor symptoms and treatment.

7. How will PH affect my child’s growth and development?

Most children with idiopathic pulmonary hypertension have normal growth and development; however, when it is associated with another medical condition, there could be developmental issues that may need to be addressed. For example, if breathing takes significantly more effort, their weight gain may not be normal since they use calories to breathe.

8. Will the PH get worse as my child gets older?

There is no known cure for pulmonary hypertension, but fortunately there are many treatments available that help prevent disease progression and support improvement in PH symptoms. Response to treatment varies from patient to patient, so communicating with your medical team will be important in determining the right treatment for your child. New research is being conducted all the time that will hopefully result in additional treatment options.

9. Can my child play with other kids? What about sports?

Your child can absolutely play with other children. Just be aware that your child may have to rest more frequently than other children depending on the activity and should avoid playing with children who might have the flu or upper respiratory infection, etc. What sports your child can play will depend on the type of treatment your child is on and the severity of their disease. Your medical team will be able to assist you in these kinds of decisions.

10. What kinds of questions should I be asking my child’s medical team?

It’s important to understand why certain tests are being done, what treatment options are available for your child, medication side effects, symptoms that warrant a call to the doctor, and what activities your child can and can’t do. You should ask how often you should see them and what to expect at each visit. It’s also important to find out how to reach your medical team after normal business hours. Keep a list of all your questions between appointments and remember that there are no silly questions, so don’t be afraid to ask!

Answers provided by Daniela Brady, RN, Pulmonary Hypertension Center at the Columbia University Medical Center

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Now Only $3 ($5 after October 1)
Passages is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x762 or Amanda@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

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PATHLIGHT SUMMER 2010

The Fall Issue deadline is August 2, 2010.

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

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

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