The daily challenges of living with pulmonary hypertension sometimes may feel as draining to patients and their families as pedaling a bike from coast to coast without stopping. In tribute to the perseverance of those touched by PH, six amateur cyclists, including a PH physician, will compete in a grueling biking contest, Race Across America (RAAM), in June 2014 to benefit PHA.

Throughout this year leading up to the race, our PH community will support the team, dubbed Team PHenomenal Hope, through an accompanying awareness and fundraising campaign, Race of our Lives, with opportunities for events in communities nationwide. Working together, the cycling team, PH families and PH professionals will highlight the physical and mental demands of PH while raising money for research and a cure.

The RAAM course, roughly 30 percent longer than the famous Tour de France, crosses 12 states and ascends to more than 170,000 vertical feet of elevation. Unlike the Tour de France, this race continues round the clock until competitors cross the finish line in a maximum of nine days, about half the time of the French event.

RAAM is also known for its cycling teams supporting their favorite charities. For instance, PHA’s logo and colors will be seen on Team PHenomenal Hope’s cycling jerseys and support vehicles as the competitors generate news coverage along the course.

Meet Team PHenomenal Hope

The six women cyclists from Pittsburgh who make up Team...
Welcome to the summer 2013 issue of Pathlight. Within these pages, you will find stories of great courage and inspiration, tales of progress and exciting new ideas, and remembrances of two amazing individuals in our community.

It is with both appreciation and a sense of loss that we dedicate this issue of Pathlight to the memories of two pioneers in our PH history — Dorothy Olson, one of PHA’s four founders, and Robyn Barst, MD, a hero in the PH medical community. Words cannot express how grateful we are for all they brought to our community and for the legacy they leave behind. Dorothy is the reason PHA exists, and Dr. Barst was my valued colleague and a groundbreaking PH researcher and medical professional. Please read tributes to them on the adjacent page.

Dorothy and Dr. Barst laid a foundation for us to continue to build on. One way we are doing that is by introducing you to spreading the word about Team PHenomenal Hope. As you saw on the cover of this issue, we are excited to raise awareness throughout the United States as Team PHenomenal Hope participates in the Race Across America (RAAM) cycling competition in 2014. Join us on this journey! If you are interested in organizing an event in your area to show support for RAAM, contact Leslie Mahaney, PHA’s special events senior manager, at 301-565-3004 x742. Be sure to check out the Team PHenomenal Hope website at www.TeamPHenomenalHope.org.

In this issue of Pathlight, we are also continuing to progress in our critical new fundraising ventures — we are halfway through our first year of chapter development in the Midwest, New York City and San Francisco. With the arrival of summer, our chapter staff members are busy in their communities, hosting events, spreading PH awareness and fundraising to support the PH cause. You can read more about their activities on page 16 in this issue.

Finally, as we continue to make PHA more financially sound for the future, you will notice a change toward the back of this issue. For the first time in Pathlight’s history, we are opening its pages to paid advertising (see page 41). Pathlight has always been made possible by the generous donations of readers like you, and for that, we thank you. As we move into the future, we broaden our fundraising reach to individuals, organizations, corporations and more to continue to make Pathlight and all of PHA’s services available. While the ads will be new, the look, feel and content of Pathlight will remain the same, offering you the quality you have come to expect from each issue.

I hope you enjoy this issue of Pathlight. Have a wonderful and safe summer, and thank you for all that you do to further our shared PH mission.

Vallerie McLaughlin, MD  
PHA Board Chair
**Pulmonary Hypertension Trailblazers: Remembering and Celebrating the Lives of Dorothy Olson and Robyn Barst, MD**

“Having been diagnosed with PH 12 years ago and still managing to do pretty well, I hope to offer encouragement to others. … Many things have happened in my life to make me a firm believer that all things happen for a reason. I feel the reason I am here is to be accessible to others with problems like my own.”

— Dorothy Olson, published in her column “Alphabet Soup: Sound Advice from Dorothy Olson” in the first Pathlight, Volume One, Number One, May 1990

Dorothy Olson, one of PHA’s founders, passed away on May 18 at age 88. Our community thrived on her lifelong leadership, and we are grateful for all she did to fight PH. The following two pieces are excerpts from remembrances given at her memorial service in May.

**Remembrances from Rino Aldrighetti, PHA President**

If Dorothy Olson’s life could be described in two words, they would be: Dorothy’s Victory.

When Dorothy Olson was diagnosed with pulmonary hypertension in 1978, it was 18 years before the first PH treatment was developed. It was seven years before completion of research at the National Institutes of Health (NIH) would show that, without treatment, only half of all PH patients would survive to 2.8 years beyond diagnosis. And it was 13 years before Dorothy sat around a kitchen table in Indian Spring, Fla., with Pat Paton, Judy Simpson and Teresa Knazik to found what would become the Pulmonary Hypertension Association.

Dorothy beat the odds, surviving for 35 years after her diagnosis. The difference she made will affect patients for many generations. It is her legacy.

This is her story: according to an early history of PHA written by Gail Boyer Hayes, when Dorothy was running through an airport to catch a flight in 1978, she was stopped by two stewardesses who saw that she was ready to collapse. They convinced her to delay her flight until she felt better. Several weeks later, she was admiring a bunting bird through her

“Words cannot express my family’s gratitude to Robyn for her dedication to the pediatric pulmonary hypertension population and to each and every patient she treated, including our daughter.”

— Linda Carr, parent of PH patient Hannah Lahmeyer (age 27, diagnosed at age 5)

A pioneer in the field of PH medicine, Robyn Barst, MD, passed away on April 19 following a long illness. Dr. Barst touched the lives of patients, families and medical professionals alike. She left a lasting mark on our community through her medical care, groundbreaking research and numerous scientific contributions, and she played an instrumental role in the leadership and history of this organization. Her legacy will be felt for generations.

According to Judy and Ed Simpson, two of PHA’s founders, “Robyn came onboard to support the United Patients Association for Pulmonary Hypertension, now PHA, early in our existence. She presented at the first International Pulmonary Hypertension Conference at Stone Mountain, Ga., in 1994. She offered her expertise and guidance as our association grew and held a special place in the hearts of many as she worked with PH children and their families.”

Dr. Barst was one of a handful of doctors who was interested in PH in the 1970s and ‘80s, each working separately on this rare and little-understood disease. These physicians met and began collaborating on PH research for the first time in the 1980s when the National Heart, Lung, and Blood Institute united them to develop the first PH registry in the U.S.

In the years since, this group of doctors — including Drs. Greg Elliott, Michael McGoone, Bruce Brundage, Harold Palevsky, John Newman, Lewis Rubin and Stuart Rich — has made lasting progress in understanding the causes and treatments of PH. Their work has expanded scientific
Dorothy had her diagnosis, and she had her mission. She began a lonely and years-long search for other patients. She and Pat Paton, Judy Simpson and Teresa Knazik met around Pat’s kitchen table in 1991.

The organization Dorothy co-founded grew over the years, and she remained active, both on its Board and on its telephone Patient-to-Patient Support Line. As Dorothy’s vision declined, she told leaders, “I may not be able to see anymore, but I can still dial a phone. Use me.”

Today this association is recognized around the world and includes two medical organizations. To the pulmonary hypertension community, Dorothy Olson is a hero who will not be forgotten. She lives on in our love and our gratitude.

Remembrances from Pat Paton, a PHA Founder

Let me tell you some of the things I remember about Dorothy. She was very beautiful. The first time I met her, she and her husband Harry had come to our home for the first meeting of the Pulmonary Hypertension Association on January 12, 1991. Her hair looked as if it had just been done. Her outfit, shoes and jewelry were perfectly matched. I thought she had really gotten dressed up for our meeting, done. Her outfit, shoes and jewelry were perfectly matched. I thought she had really gotten dressed up for our meeting, but I was wrong. In the next 22 years, every time I saw Dorothy she looked exactly that same way.

I remember Dorothy’s intelligence. She could always offer a solution to any problem we could come up with, and we came up with a lot of them. Her experience as an office manager came into play many times as we were struggling to get our organization off the ground.

Dorothy was thoughtful. This was often displayed through her ability to talk to our patients on our 800 support line. She would not only answer their questions but talk to a patient for over an hour until she was sure that person understood what she was trying to convey. She was always concerned about how everyone else was doing, and she watched over the PHA office staff.

Most of all, Dorothy was my friend. The three patients who started this organization — Dorothy, Theresa Knazik and I — had many things in common, and we stuck together. We made each other stronger. Theresa and Dorothy are gone now, but the work they did to get this association started will never be forgotten.

Dorothy continued her lifelong giving to the PH community by including PHA in her will.

Dr. Barst’s family has requested that donations in her memory be made to the Robyn Barst Pediatric PH Research and Mentoring Fund. “Robyn would have wanted people not to mourn her but continue her fight against PH. That’s why supporting PHA’s research and education to end this terrible disease is so important,” says Sam Barst, MD, Robyn’s husband. You can make a gift using the remittance envelope in the center of this issue of Pathlight or by visiting www.PHAssociation.org/BarstFund.
In March, Hall Skåra, PH patient and president of PHA Norway, came with his immediate family to visit family and friends in the United States. Their main stop was in northern Virginia, and since PHA’s headquarters is close by in Maryland, Hall, his wife, his two sons and his brother- and sister-in-law were able to come by to meet PHA staff and talk about PHA Norway.

During his talk, Hall explained how the medical system works in Norway and shared some advantages of being part of a larger European structure. For example, Hall was able to go to an exercise rehabilitation center in Germany as part of a trial for PH, and he brought what he learned there back to Norway.

Hall also told PHA staff about the Ironman Initiative supported by PHA Europe and constituent associations, including PHA Norway. Ironman is an extreme race where athletes swim in the open sea, bicycle for more than 100 miles and then run a marathon. Local PH associations and representatives from PHA Europe will be present at six of the Ironman and half-Ironman events in Europe to raise awareness. This is the first time Ironman has partnered with a charity in Europe.

“We have a disease that breaks down any boundaries or borders,” says Joni. “I think the exchange of ideas was very productive. This is a good example of the international cooperation that has been discussed in so many forums including at the PHA USA Conference and the PHA Europe Conference.”

Association leaders are not the only ones who have taken advantage of travel to meet others in the PH community. In the spring 2012 issue of Pathlight, we reported on Ann Arnott’s travels from the U.S. to Australia, New Zealand and Fiji and her PH connections along the way. To revisit that story, go to www.PHAssociation.org/PHTravelsDownUnder.

For information and tips on traveling with PH, go to www.PHAssociation.org/TravelingWithPH.

With such a strong and well-connected international pulmonary hypertension community, it is no surprise that traveling with PH sometimes includes travel for PH, working together for a common cause even on our trips to visit family, friends or new places. Have you connected with other PHers on your international travels? We want to hear about it! Email Julia Friederich, PHA’s international program associate, at JuliaF@PHAssociation.org.
Whether you are dating, engaged or newly married, having your significant other transition into a caregiving role can be difficult and overwhelming. You may feel guilty for placing a “burden” on your significant other. You may even feel unsure about how to initiate the conversation about PH. You can tell your significant other has a lot of questions, too. We spoke to PH patients who have been through this challenging time, and now we share their advice with you.

**Build your relationship.** Especially if you are in a new relationship, you may feel reluctant to reveal the realities of living with PH, and that’s okay. Diagnosed at age 5, Hannah spent her dating years with PH and says she “never made a big deal about [her] disease.” Instead, she notes it is important to get to know each other first. Regardless of your disease state, all relationships are based on mutual trust, care and respect. Once your relationship has a solid foundation, feel free to share as much or as little as you want about your life with PH.

**Be honest.** When you do decide to talk to your significant other about taking on a caregiving role, it is important to be honest. You want to make sure he or she is prepared for living a life with PH. Consider these tips when preparing to talk to your significant other about PH:

1. Encourage your partner to visit [www.PHAssociation.org/AboutPH](http://www.PHAssociation.org/AboutPH) to learn more about PH.
2. Take your significant other to a doctor appointment with you. Give your significant other a chance to ask the doctor or nurses any questions.
3. Do not hide or exaggerate any part of your diagnosis or medical needs.

You and your significant other may also want to discuss finances, especially if you are engaged or considering marriage. As you already know, treating PH can be very expensive, and your loved one may be unaware of the full costs. Talk openly and honestly about budget and health insurance concerns. If the two of you have a tight budget, meet with a financial advisor or visit [www.PHAssociation.org/FinancialAssistance](http://www.PHAssociation.org/FinancialAssistance) to find ways to cut drug costs and other expenses.

**Split up responsibilities.** As Kevin, a newly diagnosed patient, says, “Daily chores can be doubled, as the caregiver is doing for themselves as well as for us.” Still, you can help ease the workload of your significant other. If it is difficult for you to go grocery shopping, consider creating the grocery list and planning meals for the week instead. If he or she provides the income for both of you, make the budget and find ways to cut costs. On good days, try to wash clothes or straighten up around the house. Even if you cannot do as much as you’d like, your significant other will appreciate your efforts.

**Care for your significant other.** Kevin reminds us that your significant other chooses to live with PH and care for you. Don’t forget your significant other has needs and feelings, too!

Jen was diagnosed in 2005, and her husband did not hesitate to take on a caregiving role. She admits she feels her husband “gets the bad end of the deal” from the ups and downs of PH and works very hard to take care of her. However, Jen does what she can to stay connected with her husband and ensure he remains healthy.

Jen recommends making sure your significant other has time for self-care. Encourage him or her to take a few hours or a day to spend time with friends and other family members. Look for a fun class such as art or fitness for your loved one to take. If your finances allow it, surprise your significant other with a massage or spa day. Also, your significant other may want to connect with a PHA Caregiver Mentor or join a PHA support group.

**Story continued on next page**
It is also important to pay attention to your significant other’s mental, physical and emotional health. Try to make a daily habit of asking your significant other about his or her day and how he or she is feeling. Encourage honest answers. Pay attention to symptoms of caregiver burnout, which include changes in weight, changes in sleep patterns and feelings of sadness and irritability. If your significant other demonstrates any of those symptoms, consider talking to him or her about seeking help from a doctor or counselor.

Most importantly, don’t let caregiving get in the way of your romantic relationship. Go out for dates, or plan one at home. Compliment each other. Laugh, love and most of all have fun. ♦

Special thanks to Jen, Hannah and Kevin for their contributions to this article.

By Imani Marks
Former PHA Patient & Caregiver Services Intern

Contact a Patient or Caregiver
PH Email Mentor Today!

“Without a mentor, I would not have been able to get through my PH diagnosis. I want to help others who have been diagnosed with PH the way my mentor helped me. I understand what you’re going through. There’s hope. You can be happy. Your life is not over.”

— Wendy Bond, PH Patient and PH Email Mentor

Visit www.PHAssociation.org/Mentors to connect with Wendy or any of our email mentors.

Celebrating 20 Issues: A Message from Megan Mallory, Pathlight Editor

Each issue of Pathlight has its own rhythm. Creating an issue is a three-month process where PHA staff members discuss story ideas, write and prepare material, and then pass material to me to put each Pathlight page together. As I started off on this familiar process for the issue you currently hold in your hands, I realized something special: the summer 2013 issue is my twentieth issue as Pathlight editor, marking five years of collaborating to bring PH news, information and personal stories to the community. It has been a true honor, and I’m taking a moment in this issue to thank you for reading, for sharing your stories, and for making my role in Pathlight’s creation feel so meaningful. Keep sharing your stories! You inspire everything we do at PHA, and I look forward to the next phase of the journey. ♦

Michael McGoon, MD, Receives the 2013 PAR Distinguished Achievement Award

Michael McGoon, MD, professor of medicine at the Mayo Clinic in Rochester, Minn., and a dynamic figure within the PHA community, has been chosen as the recipient of the ATS Public Advisory Roundtable (PAR) 2013 William J. Martin II Distinguished Achievement Award. This award is an honor given to a person who embodies the many characteristics of its namesake: passion for patients, impressive history in public service, innovative spirit and outstanding leadership skills — to name just a few.

Dr. McGoon represents all these characteristics. A dedicated medical professional, Dr. McGoon is an active member and former chair of both the PHA Scientific Leadership Council and PHA Board of Trustees. He and his wife Bonnie play a leading role on the planning committee for the biennial Reach for the Stars Gala to raise funds and awareness to fight PH. He is also a medical editor for Pathlight, reviewing each issue before it reaches your mailbox.

Dr. McGoon was recognized during the ATS PAR Symposium in May at the ATS International Conference. Congratulations, Dr. McGoon, and thanks for all you do for the PH community! ♦
In August 2010, Jenny Klick of Winter Springs, Fla., found herself out of breath — she couldn’t even walk to the bathroom. She attributed her symptoms to her smoking habit and her limited airway disease. However, since she wasn’t quite sure what was going on with her body, she decided to go to the doctor just in case. Her doctor ruled out upper GI problems and sent her to a pulmonologist who concluded she just wasn’t taking her Advair® correctly. Still out of breath, Jenny went to a cardiologist. He performed an echocardiogram where he determined Jenny might have pulmonary hypertension. Like too many patients, Jenny was already in respiratory failure and immediately went to the emergency room.

In order to confirm pulmonary hypertension, the cardiologist performed a right heart catheterization, but her cardiologist could not complete the procedure because her pressure was too high. Eventually, following additional testing, Jenny finally had a diagnosis — Class IV PAH due to lupus, a disease that had never really caused her many problems before.

Though the diagnosing cardiologist explained that PH is a terminal disease, this news did not faze Jenny. Having several other chronic illnesses, including lupus, fibromyalgia and Sjogren’s syndrome, Jenny understood she could not be cured but knew she could continue life with the positive outlook she’s always had. Once Jenny was placed on sildenafil and bosentan, she was released from the hospital, began to feel much better and got back to her life.

A few weeks later, Jenny made an appointment with James Tarver, MD, a well-known PH specialist in Orlando. Bosentan was beginning to affect her liver, so Dr. Tarver transitioned Jenny to treprostinil. She continued to improve, and as she describes, living with PH became her “new normal.”

It wasn’t until Jenny came across an issue of Pathlight that she realized just how devastating the disease could be. She attended her first support group where she met other patients and caregivers. The support group was just what she needed, and several months later she became the support group co-leader. She is in charge of scheduling guest speakers for the group. Jenny loves her role and says “everyone in the PH world is eager to lend a hand and tell their story.”

Jenny’s involvement in the PH community extends to her participation in PHA’s 10th International PH Conference and Scientific Sessions last summer. There she met more supportive individuals who directed her to “PH Family,” a Facebook page created by PH patients. Jenny is now active in the PH community through various online outlets, and she is a peer mentor with one of the PH pharmaceutical companies.

Though Jenny feels she has been fortunate throughout her journey with PH, in January of this year she was hospitalized for a week with a serious respiratory infection. Since then, she says she feels like “a typical PH patient” because simple tasks like climbing stairs are now very difficult for her.

Jenny stresses that she has a strong faith in God and has kept a positive outlook throughout the last couple of years. Though she lives with other serious chronic illnesses, she admits PH has been another beast altogether and is thankful for the support she has received from her family and friends. Her husband especially has been a great caregiver to Jenny and has worked to learn as much as he can about PH. He even called family and friends to talk to them about her new diagnosis so she wouldn’t have to. Jenny knows she is “very blessed to have support and understanding” from those who care about her. She is also thankful for PHA and wishes for a day when she can receive the same great support for her other illnesses.

This article is based on an interview with Jenny Klick and first appeared on the PH Plus blog. To read more articles by and about patients dealing with multiple conditions, visit the PH Plus blog at www.PHAssociation.org/PHPPlusBlog.
Gina Tackett, Little Rock, Ark.

I’m Gina Tackett, and I have primary pulmonary hypertension (PPH). I live in Little Rock, Ark., and I was diagnosed in July 1993. I was in perfect health and became pregnant with my second child at the age of 26. I struggled through the pregnancy, and during my final month, my blood pressure became dangerously high. The doctor recommended inducing delivery and said this would resolve the problem. We induced and my daughter was born on Feb. 9, 1993; however, I suffered severe bleeding and elevated blood pressure. Finally, four days later, I was discharged with my new baby.

Once home, my condition became worse. I suffered extreme shortness of breath, and my blood pressure continued to be elevated. My doctor started me on blood pressure medications; however, the shortness of breath continued. I thought I was simply out of shape. It continued to the point that on July 3, 1993, my infant woke up at 2 a.m. for a feeding, and I passed out and stopped breathing when I went to get her. My husband called 911, and I was transported to the local hospital. Over the next three days, they conducted every test under the sun and came to the conclusion that I had PPH. They told me that this was a rare disease for which there was no treatment or cure. They told me my only hope was to seek a lung transplant as soon as possible. I probably had about six months to live. I went home and cried a lot. The thought of never seeing my child grow up was the most devastating thing I could imagine. After many dark days of depression, I decided to start making calls to major transplant institutions. The statistics were horrible. Then, in August 1993 I received a call from Stuart Rich, MD, with Rush University in Chicago, Ill. He was given my name by the transplant coordinator. He urged me to come to Chicago to see him for an evaluation before I considered transplant. He had been treating PH for many years and had one of the largest programs in the country for treating PH patients. I was very skeptical since I had seen four doctors who all said I would die without a transplant. He urged me to come and told me he had options other doctors could not offer. After struggling to breathe daily, I decided it was worth a shot.

Dr. Rich conducted all the usual tests. While in the catheterization lab, he gave me calcium channel blockers, and I actually responded. Flolan® was not available in 1993. He started me on medication, and I returned home and continued to see improvement. I was feeling better, breathing better and had a new lease on life. In 2001 my disease had progressed and the calcium channel blockers were no longer working. Dr. Rich told me about Flolan®, and I told him I would rather die than be connected to a 24-hour intravenous medication. He said I was out of options, and I would die without it. Finally, I decided it was a sacrifice I would have to make if I wanted to be here for my daughter. I once again traveled to Chicago. They called in the special procedure team to insert a peripherally inserted central catheter (PICC) line. As they were inserting the PICC line, things took a turn for the worse. I fully coded. I woke up in the ICU an hour later. They successfully brought me back and got the drug started.

I spent 14 days in the hospital, fighting side effects, learning the mixing technique and learning to take care of myself. I was terrified of the mixing process, but I returned to Arkansas and began my new life with this new drug. It took time, but I have been on it for 11 years.

I am so thankful to Dr. Rich. I have been stable for years and can do most anything I want except climb stairs. We added additional medications in 2004, and I returned to Chicago in December 2011 and did more than 15 minutes on the treadmill. Dr. Rich said he could not ask for better results.

I live one day at a time and am thankful for every day. I am considered a long-term survivor and that is a miracle. I continue to see Dr. Rich. He saved my life, and I feel thankful for each day. Mixing has become second nature. My daughter is 19 now, and I am so thankful to see her grow up. In 1993 they told me that would never happen; well, never say never. ✭

Our Journeys are stories that bring the PH community together and shine as beacons of hope for those who feel isolated and alone with this disease. Read more stories or watch Video Journeys by visiting www.PHAssociation.org/OurJourneys.
This piece was originally written in November 2011.

It has been a year since my diagnosis at age 25, and I finally feel like I’m ready to write the first chapter in my journey with PH.

My journey began in 2007 while on vacation with my family in Colorado. I ran up some stairs into an ice cream shop and fainted. Assuring my family I was fine, I made an appointment with a general practitioner the week I returned. He ran a few tests and told me I was fine.

I had symptoms here and there. I couldn’t climb stairs without getting winded. Three years later, another fainting spell brought me back to the same doctor. He did the same tests, but due to my persistence, he also sent me to a cardiologist.

The next two months were filled with tests. We found that the right side of my heart was enlarged. After my last test, I was given the same “I’ll have the results in about a week” speech from the cardiologist.

That night he called to tell me I needed to admit myself to the hospital in San Francisco. I asked if I could do it the next weekend, but he said that it was very serious. So, armed with gossip magazines and movies, I went to the hospital with my parents in tow. I walked into my room and was met by three doctors.

They told me I had pulmonary hypertension and that I would need to drop out of school and go on disability. I was in shock! Disability? I worked out five times a week, and now they were telling me I couldn’t work!

I had a cardiac catheterization that showed my pressures were only 29, and I reacted well to the nitric oxide gas. I spent a few more days in the hospital and was released with instructions not to look up PH on the Internet. Well, I wanted to learn everything about the monster I was now faced with, so I started researching. Bad idea! I live every day determined to not let this diagnosis define who I am — if I do, then PH wins. I have been able to get through this by putting my time and energy into making a difference, spreading awareness about PH and trying to be a good example that you can get through anything.

This disease is a blessing in disguise for me. It has made me so grateful for everyone and everything I have in my life. It is true that “those whose hearts struggle to beat love more fully, laugh more wholly and live like they have nothing to lose.” I live every day determined to not let this diagnosis define who I am — if I do, then PH wins. I have been able to get through this by putting my time and energy into making a difference, spreading awareness about PH and trying to be a good example that you can get through anything.

There will be lots of ups and downs, but just believe that God has a plan and make the best of what is being given to you. Believe me, I know exactly what you are feeling, but you are not alone — there is a wonderful community of people with big hearts (literally!) that can help you to get through it.

This is not the end of my journey. It’s just the beginning, so stay tuned for updates! I’m planning a wedding, and after that you can bet there will be the pitter patter of little feet. Don’t lose hope! Together, we can beat this and have a little fun, too! ✨

Summer 2013 Update: It’s been two and a half years since I was diagnosed, and there have been ups and downs along the way. A year after being diagnosed I got a bad echo result that led to a cardiac cath. Another oral medication was added to my pharmaceutical cocktail that has yielded great results so far. The down made its way back up and was followed by the greatest day of my life, my wedding day. My special day was made even more memorable by our guest of honor, my PH specialist Gehan Devendra, MD. He truly made our day possible. Now my future is bright and filled with possibilities from starting a family to changing my career. PH is a part of me; it always will be. However, it does not define who I am or what I am capable of — that is up to me!
What is exercise-induced pulmonary hypertension?

Exercise-induced pulmonary hypertension (EiPH) is a condition that is now attracting attention. EiPH is defined as raised pulmonary pressures >30mmHg in the setting of normal pulmonary pressures (<20mmHg) at rest.

What happens in EiPH?

Normal pulmonary pressures do not rise beyond 30mmHg during exercise. However, in certain instances, there can be a rise in pulmonary pressures beyond 30mmHg during exercise, which occurs due to an increase in pulmonary vascular resistance. Even though this abnormal response is seen during exercise, resting pulmonary pressures are within the normal limits. Those with EiPH may not notice any symptoms at rest and may complain of only fatigue. Nevertheless, in the presence of EiPH, exercise capacity is grossly reduced when compared to that in individuals without EiPH.

Why is it important?

The presence of EiPH brings to light a sub-type of patients with pulmonary hypertension. It is important that those at risk of PH (i.e., hereditary PAH, systemic sclerosis, etc.) be assessed for EiPH. This may be an early finding and may have a role in altering the treatment and prognosis of the patient.

How can EiPH be diagnosed?

The basis for EiPH is still not very clear. Many controversies exist as to the cause for EiPH. It is not confirmed whether it is an early form of PH or a stable form. Diagnosis of EiPH requires exercise echocardiography or invasive cardiopulmonary exercise testing. Both of these tests require expertise and qualified testing facilities. Your treating physician will have information on these methods and will be able to help you if there is a need for these tests to be performed.

Does EiPH require treatment?

Research in this field is in its very early stages. A recent small trial among those with systemic sclerosis was carried out by Rajeev Saggar, MD, and colleagues at the Heart & Lung Institute, St. Joseph’s Hospital and Medical Center, Phoenix, Ariz. They used ambrisentan (5mg or 10mg) daily for 24 weeks and found a decrease in pulmonary pressure and pulmonary vascular resistance during exercise along with improvements in cardiac output, six-minute walk distance and quality of life. Thus, it would seem that there may be a role for drugs in EiPH. However, more studies are required.

Answer provided by Abraham Samuel Babu, FCR, MPT, FPVRI, (PhD), Assistant Professor, Department of Physiotherapy, Manipal College of Allied Health Sciences, Manipal University, Manipal - 576104, Karnataka, India
2013 PH Professional Network Symposium
The Power of Teamwork: 10 Years of Professional Collaboration in PAH

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

SYMPOSIUM HIGHLIGHTS
This Symposium will feature an extraordinary line-up of speakers and topics highlighting the latest advances and research in pulmonary hypertension.

- **Nearly 30 educational sessions** led by multidisciplinary panels of speakers.
- **Opportunity to earn CEUs** — up to 10.25 hours
- **Networking opportunities** with other PH-treating colleagues from across the country.
- **Opportunity to advocate** for PH patients on Capitol Hill.

REGISTRATION STILL AVAILABLE
PHA is offering a reduced registration fee of $100 for the first 250* PH-treating healthcare professionals who register!

Register online at www.PHAssociation.org/PHPN/Symposium

*In order to receive the reduced registration fee, attendee must have an active PH Professional Network membership.

Questions? Contact 301-565-3004 x761 or Symposium@PHAssociation.org

Get Pumped for Symposium with *PHA Online University!*

While you’re waiting for PHA’s 2013 PH Professional Network Symposium this September, take advantage of sessions from the 2011 Symposium, which are now available on *PHA Online University.*

Whether you missed a session or want to recap your favorite, now is your chance. Take a look back at great past sessions, including sessions on research and clinical advances in the field of pulmonary hypertension, and get excited for new sessions this fall at the 2013 Symposium.

While you’re at it, check out *PHA Online University* to find the latest in pulmonary hypertension education, including courses, the latest issue of the medical journal *Advances in Pulmonary Hypertension* and abstracts from past events including the 2011 PH Professional Network Symposium.

All this and more is available at: www.PHAOnlineUniv.org/2011Symposium

Highlighted Recordings:

- A New Dimension of Hope: Virtual Catheterization Lab
- Hope in 2011: Top 10 Clinical Advances
- Team Hope: A Multidisciplinary Approach to PAH Care
- Complex Cases: Are You Up for the Challenge?
Natural disasters are frightening, especially for those coping with PH, but good preparation can allay some of the fear. This information can help you be ready for the worst when it comes to your safety and your health.

Hurricanes, Tornadoes and Floods

These natural disasters can destroy homes and lives. Preparing for such events starts with knowing when hurricane season starts on each coast. For example, according to the Federal Emergency Management Agency, the Atlantic hurricane season lasts from June to November. Tornado season commonly occurs from March through August, but tornadoes can occur at any time in any state.

The majority of the time, floods occur as a result of a hurricane. Of course, just as with any other natural disaster, developing an emergency plan is important. Make sure gutters, ditches and drains are kept clear, and reinforce the home by using sand bags or flood bags. Also, elevate furniture and electronics to avoid damage and prevent harm to patients and family members.

Emergency Supplies

Stock water, food, first aid kits, flashlights, batteries, and any other bare necessities. PH patients on intravenous or subcutaneous infusions should prepare an in-case-of-emergency bag. This bag should include any medications and supplies needed to change the cassette or syringe and an extra infusion pump in case there is a need to evacuate your home. Patients with oxygen should make sure to have enough full oxygen tanks to avoid running short. Here are additional helpful tips:

- Keep a list of your medications with you at all times. For intravenous and subcutaneous infusion patients, specify on the list that your medication should NEVER be interrupted or shut off. Also include the phone number to your specialty pharmacy.
- Create a supply checklist for your in-case-of emergency bag. This will help you remember any supplies you may need during stressful events.
- Keep a list of your doctors’ names and phone numbers with you.
- Keep a copy of your electrocardiogram (EKG) with you. This can help doctors compare EKGs in case you have to take a trip to the local ER.
- Keep a list of emergency contacts and their phone numbers, including home phone and cell, with you.

Power Outages and Infusions

Natural disasters can lead to power outages, resulting in the added worry of how to maintain intravenous infusions. A power outage poses a problem because refrigeration is needed to keep epoprostenol cold to maintain its potency for 24-hour mixes and to keep extra cassettes cold. If a power outage does occur, patients should fill a cooler with plenty of ice and use it to store ice packs and, if they want, a maximum of 48 hours’ worth of reconstituted cassettes. For safety purposes, patients should always inspect their cassettes for residue and discoloration prior to administering. If possible, go to a family member’s home to utilize their energy and refrigeration.

Oxygen Issues

A power outage for a patient on supplemental oxygen can be dangerous. In this situation, you should:

- Contact your electric/power company to ask what kind of services they offer to oxygen-dependent patients. Ask how long the power outage will be and if a generator can be provided.
- Call your oxygen company to ask if extra oxygen tanks can be delivered immediately.
- Contact your local fire department/EMS to let them know you are oxygen-dependent. Ask to use them as a backup power source.
- Contact your support system of family and friends to ask for a helping hand during this stressful time.

Natural disasters should be taken seriously. Learn about your community’s emergency plans, warning signals, evacuation routes and emergency shelter locations. Find out more about emergency preparedness at www.PHAssociation.org/Patients/EmergencySituations.

By Donneea Edwards-Moore, RN, MSN, PH Nurse Coordinator, Pulmonary Hypertension Program, University of Chicago Medicine, Chicago, Ill.

Disclaimer

We encourage readers to discuss their healthcare with their doctors. This newsletter is intended only to provide information on PH/PAH and not to provide medical advice on personal health matters, which should be obtained directly from a physician. PHA will not be responsible for readers’ actions taken as a result of their interpretation of information contained in this newsletter.
Meet Dr. Gabriel Fernando Díaz Góngora: Exploring the Effects of PH in Children at Moderate Altitude

One of the main topics of research for Gabriel Fernando Díaz Góngora, MD, is PH in children at moderate altitude, and we spoke with him about this research and his PH practice. He has written two textbooks in collaboration with international experts: *Cardiología Pediátrica* (Pediatric Cardiology) and *Hipertensión Pulmonar en Niños* (Pulmonary Hypertension in Children). *Hipertensión Pulmonar en Niños* is the first globally published book on pediatric PH in children. Dr. Díaz Góngora is a pediatric cardiologist at the Hospital Universitario Pediátrico La Misericordia y Fundación Santafé in Bogotá, Colombia, and a professor of pediatric cardiology in the pediatric department at the Universidad Nacional de Colombia (National University of Colombia).

You specialize in cardiology. What exactly sparked your interest in PH and, more specifically, pediatric PH? When I started working with PH, what had initially sparked my interest was realizing that there was very little known about the disease, and it was simply considered that “nothing could be done about it.” Since then, many advances have been made in terms of the improvement of quality of life as well as the increase in life expectancy for patients. Nonetheless, I am convinced that the key therapeutic approach and focus should be early detection to prevent advancement of pulmonary vascular disease. That is what sparked my interest in the importance of detecting the disease early in childhood and improving the lives of pediatric PH patients.

You are conducting a study of pediatric PH patients at moderate altitude. Why did you decide to begin this study? I chose to conduct this study because there are no studies of PH patients at moderate altitude (Bogotá is 2,640 meters or 8,662 feet above sea level) and because PH and pulmonary vascular diseases are manifested differently in pediatric and adult patients. We cannot extrapolate results from PH studies on adults to apply to PH pediatric patients, and we cannot extrapolate results from studies on patients living at sea level, which are the majority, to apply to PH patients at higher altitude. Every patient is different, and pulmonary vascular reactivity must be considered individually for each patient.

How can different levels of elevation above sea level affect PH patients? At higher altitude the barometric pressure is lower, the partial oxygen pressure is lower and patients can suffer the effects of hypobaric hypoxia (decreased oxygen supply to body tissues due to low atmospheric pressures, which can have an important effect on the dynamic of the pulmonary vascular structure). For example, at high altitude pulmonary hypertension and pulmonary vascular hyperreactivity are more frequent. Thus, this research is important for PH patients living in high elevations because it demonstrates the importance of hypobaric hypoxia, the importance of oxygen and, therefore, the benefit of living at low altitude as an important part of treatment for these patients.

You’ve been working in the field of PH for a long time. Do any cases or patients stand out to you? Why? The average life expectancy for PH patients without proper treatment after the diagnosis is 2.8 years for an adult and 10 months for a child (Widlitz and Barst 2003). Among my pediatric patients with severe PH, there are three interesting cases: two are now at 28 months of follow-up. The third child, who had an initial pulmonary pressure of 153 mm Hg, was cast aside and informed that there was no possibility of treatment. I am happy to say that with treatment and living at low altitude, this child is now 12 years old and is currently asymptomatic. The most gratifying and enjoyable part of working with this community has been seeing excellent results in children and improving quality of life for patients and their families.

Do you have any advice for PH patients or new PH practitioners? The most important piece of advice I give to patients inhabiting moderate and high altitudes is how essential it is for their health to move to lower elevations after a discussion with their PH-treating doctor. I always emphasize the importance of early diagnosis and detection despite the basic problem that PH is initially a “silent” disease to medical professionals. It is crucial to avoid advanced pulmonary vascular disease. The earlier the disease is detected, the better the patients respond to treatment and the better the overall prognosis is.
**PHA at Your Fingertips**

The *Pulmonary Hypertension Association Quick Resource Guide*

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**Be prepared.**

- **Find a PH Doctor.** View for a list of PH-treating physicians from around the world. [www.PHAssociation.org/FindaDoctor](http://www.PHAssociation.org/FindaDoctor)

- **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)

- **Empowered Patient Online Toolkit.** Templates, checklists and tips to help you manage your healthcare. [www.PHAssociation.org/OnlineToolkit](http://www.PHAssociation.org/OnlineToolkit)

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

**Expand your knowledge.**

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

- **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)

- **Living with PH.** Tips for emergency situations, living and working with PH, traveling with oxygen and more. [www.PHAssociation.org/Patients/LivingwithPH](http://www.PHAssociation.org/Patients/LivingwithPH)

- **PHA Classroom: e-Learning. Anytime. Anyplace.** Learn about diagnosis of PH, treatments on the horizon, and other popular topics at: [www.PHAssociation.org/Classroom](http://www.PHAssociation.org/Classroom)

**Stay in the loop.**

- **PHANews** and **PHA Daily Beat.** Get the latest news about research, our community and PHA offerings sent straight to your Inbox or RSS feed. [www.PHAssociation.org/News](http://www.PHAssociation.org/News)

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

**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 make it easy to do. [www.PHAssociation.org/PHAWARE](http://www.PHAssociation.org/PHAWARE)

**Join our community of hope.**

- **Become a member.** Receive *Pathlight*, a discount on *A Patient's Survival Guide* and much more. [www.PHAssociation.org/Join](http://www.PHAssociation.org/Join)

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**Connect!**

**Patient-to-Patient Support Line:**

**800-748-7274**

This toll-free line is answered by friendly volunteer patients who are there for anyone who needs someone to talk to about PH.

**Support Groups.** Join one of our 240+ support groups nationwide to connect with people who understand what it’s like to live with PH. To find support groups in your area, visit: [www.PHAssociation.org/SupportGroups](http://www.PHAssociation.org/SupportGroups)

Learn about our telephone support groups: [www.PHAssociation.org/TelephoneSupport](http://www.PHAssociation.org/TelephoneSupport)

**Online Opportunities.** Our discussion boards, email groups and chats help you instantly connect with other patients and family members. With special groups for young adults, patients with associated illnesses, caregivers and parents, you’re bound to find a group that’s just right for you. Visit: [www.PHAssociation.org/Community](http://www.PHAssociation.org/Community)

Email a patient or caregiver mentor for one-on-one support. [www.PHAssociation.org/Mentors](http://www.PHAssociation.org/Mentors)

**Caregiver Resources.** Find support and information for family and friends of PH patients. [www.PHAssociation.org/Caregivers/Support](http://www.PHAssociation.org/Caregivers/Support)

**Go places.**

**PHA’s International Conferences** bring together more than 1,500 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and coping with PH. Our 2014 Conference takes place June 20–22 in Indianapolis, Ind. Learn more at [www.PHAssociation.org/Conference](http://www.PHAssociation.org/Conference)

**PHA on the Road.** Connect with fellow patients and families at this FREE educational event in select cities around the country. [www.PHAssociation.org/OnTheRoad](http://www.PHAssociation.org/OnTheRoad)
PHA Chapters on the Move: PH Events, Fundraising and Awareness Are Taking Place from Coast to Coast

This summer marks six months since PHA’s three chapters began operating in the N.Y. Tri-State area, the Midwest and the San Francisco Bay area. Our events, fundraising and awareness raising are in full swing. Read on to find out what the chapters are up to.


The N.Y. Tri-State Area Chapter, under the leadership of executive director Gina Parziale, has been reaching out to the community by hosting a launch party, attending support groups and visiting local medical centers.

The chapter kicked off signature O₂ breathe walks in June to bring the community together and empower all participants to fight back. “The more funds we raise, the more services and support we can provide and research we can fund to find a cure,” says Gina. “PHA has come so far as an organization, and by raising funds and awareness, O₂ breathe participants will be an important part of taking the fight against PH to the next level.”

In addition to various outreach efforts, the chapter looks forward to an O₂ breathe gala in the fall to honor the legacy of Robyn Barst, MD. See page 18 for more information.

“We are grateful for the warm reception and support we have received from New York City and are honored to be a part of the team fighting against PH,” says Gina.

Midwest — www.Midwest-PHA.org

The Midwest Chapter, under the leadership of executive director Lisa Beth Gansberg, has been engaging the community from many angles, developing an Industry (Pharmaceutical) Commerce Committee, Medical Support Team, Flames of Light Young Advisory Board and Chapter Board. These various groups help create unique cause-related events, increase awareness of PH, and develop relationships with communities outside the chapter’s immediate reach.

The Midwest Chapter has started hosting several events, including signature O₂ breathe walks and a Flames of Light Young Professionals Soiree with musician Sting. As the year continues, be on the lookout for a concert in the park “Under the Stars Lounge: Beach Ball with Brian Wilson & P_friends” this July, a 100-hole golf challenge and even a parade.

“We welcome volunteers, corporate partners, patients and their families, caregivers and all others in our goal to increase funding to find a cure for PH,” says Lisa Beth. “If you want to join the PHun, please sign up on our website or call us direct, toll free at 855-ZEBRA55.”

San Francisco Bay Area — www.SF-PHA.org

Over the past six months, the San Francisco Bay Area Chapter has participated in a number of events to connect with the surrounding community, including reaching out to patients and families, corporate partners and medical professionals in the area. Under the leadership of executive director Bette Perez, one of the first major successes for the chapter came in early May when staff participated in the Human Race, a community fundraising event in the North Bay, finishing first in money raised among 190 competing charities.

Additional highlights include cultivating major donors, expanding the chapter’s reach beyond the traditional limits of the San Francisco Peninsula, and furthering connections with local support groups, including two emerging ones in Petaluma and San Luis Obispo. Be sure to read the support group article by Michael Ehret, director of development for the chapter, on page 27 in the support group section of this Pathlight.

“If our reception is any indication, the community is ready, willing and able to go to battle with pulmonary hypertension,” says Bette. “While PHA has always performed an incredible service to PH patients, caregivers and family members in terms of outreach, education, advocacy and awareness, and while our support groups have been successful, it is our chapters which have been entrusted with securing the financial future of the organization. Bumps in the road aside, the future appears as promising as we had hoped it would be. Please join us!”

Help us continue this phenomenal progress! Check out each chapter’s individual website or their collective website at www.02breathe.org, and be sure to follow all of our chapters on Facebook and Twitter. Just search for the chapter name.
Reaching New Heights:
Best Friend Climbs Mt. Kilimanjaro and Raises $14,000

A long friendship, an ambitious climb and a boost from social media added up to fundraising success for PHA by two young women in Minnesota.

“It’s incredible to see the outpouring of support, and it feels great to have gone beyond our goal of $5,000,” says Kathleen Gildea of Shorewood, Minn., about the fundraiser she and her mom, Lois Gildea, organized in January and February 2013 in honor of her best friend, Anna Jeter.

Kathleen and Anna have been best friends for 10 years and recently graduated high school together. Anna has been living with pulmonary hypertension since she was 4 years old. Together, the two friends helped raise more than $14,000 in just a few months.

In late January 2013, Kathleen and her family traveled to Tanzania to visit her older brother, Jimmy, on his semester abroad and to climb Mt. Kilimanjaro. Kathleen and her mom Lois dedicated their epic climb to Anna by supporting PHA. “Anna’s been such a good friend, and this was just a good opportunity to raise awareness and money for research,” Kathleen says.

Lois sent an email to friends and family, making note of the similarities between the strenuous climb and the symptoms of PH, “Everyday of [Anna’s] life is like climbing a mountain.” The email’s direct link to the PHA website made it easy for email recipients to make a donation.

Meanwhile, Kathleen and Anna reached out to their friends to get involved, too. They created a Facebook event to sell PH awareness bracelets, which were donated by Anna’s mother. Kathleen and Anna said sales really took off when friends started wearing the bracelets at school and tweeting about the sales on social media. They sold more than 250 bracelets.

Anna says, “It’s a joy seeing everyone at school wearing the bracelets and supporting the PH cause.”

Both girls are proud to have made such a great impact and recommend fundraising to others who are thinking of getting involved in the fight against PH.

Kathleen says climbing Mt. Kilimanjaro was the hardest thing she’s ever done, but thinking of Anna and her battle with PH kept her motivated to reach the summit.

To learn more about fundraising for PHA, visit www.PHAssociation.org/Fundraise.

Act now to create an estate plan that benefits your family and offers hope to thousands of others touched by PH.

Learn more about giving options at: www.PHAssociation.org/Give or 301-565-3004 x756
Put Your 9-to-5 to Work to Advance the PH Cause: Check Out Our Guide to Workplace Giving

PHA is supported by many different kinds of donations from community members. Did you know that PHA supporters give nearly $100,000 for the fight against PH through workplace giving programs? Read on to see how you can easily get involved with workplace giving.

Pledge to PHA!

Did you know many companies have charitable fund drives in the fall? This is a great way to support PHA. Company fund drives may allow payroll deduction designations — tax-deductible contributions that support all of PHA’s work to fight pulmonary hypertension.

Contact your HR department to find out if you have a company fund drive and if PHA is eligible to receive company donations.

This fall, pledge to PHA. Every dollar counts and moves us closer to our ultimate goal: a cure. Don’t forget to ask your co-workers and families to pledge to PHA as well.

Visit www.PHAssociation.org/GetInvolved/WorkplaceGiving or contact PHA at Giving@PHAssociation.org or 301-565-3004 x756 to learn more about how you can promote PHA during your workplace fund drive.

Double Your Impact!

Many companies match charitable gifts. You may be able to turn a $50 donation into a $100 contribution just by contacting your HR department to see if your gift is eligible to be doubled!

Requesting a charitable match is easy. First, you contact your HR department and provide information about your gift to PHA. Second, your employer will contact PHA to confirm that we have received your donation. Third, your employer sends an equal donation to PHA.

Every matching gift program differs slightly, so ask your HR department for details. And if you have any questions along the way, we can help. Contact PHA at Giving@PHAssociation.org or call 301-565-3004 x756.

Imagine if every gift was doubled? With your help, PHA can continue to make tremendous progress in our fight to find a cure for pulmonary hypertension.

Hey, event organizers and fundraisers!

Maximize your event’s success by encouraging your supporters to see if their employers will match their contributions.

PHA participates in the Combined Federal Campaign (CFC)! Designate PHA, #12097, this fall and ask your coworkers to designate PHA, too!

Save the Date!

The Pulmonary Hypertension Association New York Tri-State Area Chapter’s First Annual New York City Gala

O₂ breathe

Empowering Hope to Cure Pulmonary Hypertension

An elegant evening honoring the legacy of Robyn Barst, MD, and raising funds and awareness to fight pulmonary hypertension.

Thursday, Nov. 7, 2013

The Lighthouse at Chelsea Pier, New York, N.Y.

Sponsorship, ad and ticket information available at: www.02breathe.org or 646-568-2068
Opinion Research Informs Campaign’s Approach to Professionals

PHA’s Sometimes it’s PH: Early Diagnosis Campaign has set the long-term goal of educating and informing medical professionals about the need to understand PH, to diagnose it promptly and correctly and to work with PH specialists for the best patient care. What will it take to meet these critical objectives?

PHA’s plan for effective campaign approaches includes involving organizations respected by medical professionals, providing continuing education, presenting speakers at conferences, publishing in peer-reviewed journals and the news media, and telling patient stories. The importance of these techniques to those we aim to reach has now been confirmed through opinion research commissioned by PHA.

In this first year of the five-year Sometimes it’s PH initiative, we are focusing most on reaching primary care professionals, including family physicians, internists, nurse practitioners and physician assistants. In most cases, patients with symptoms of PH first seek medical advice from their primary care providers. Yet PHA has seldom worked with the primary care community. To understand this population better, we gathered information from primary care providers about their needs, interests and limitations.

A public opinion polling firm, Heath & Co., experienced in assessing the views of medical professionals for health nonprofits, conducted our research. The firm’s principal, Angela Heath, drew on lessons from others’ past campaigns and sought feedback from medical professionals on our ideas for this campaign. Angela’s firm conducted three studies:

• An environmental scan, in this case a review of past health campaigns directed at medical professionals. The research team identified more than 50 campaigns, then summarized 16 of them using Internet information and brief telephone interviews.

• Thought leader interviews, or 30-minute phone interviews with representatives of health organizations including the American Academy of Family Physicians, the American Association for Medical Assistants and the American Medical Women’s Association.

• An online focus group with about 30 professionals. Participants posted their responses on a special website, engaging in discussion with the moderator and with each other.

Overall, the research strengthened our knowledge of the value of partnerships, education and information in bringing PH to the fore in healthcare. Interviewees named specific organizations, journals, meetings and media they trust and urged us to keep all our material for professionals concise, clinical and focused on diagnosis and treatment. They pointed out the importance of electronic resources professionals use when diagnosing a patient. They also welcomed patient stories to help deliver the campaign message. The research findings will allow us to sharpen our focus and pursue options we believe will have the strongest impact.

These lessons reinforce our campaign plans to work through committees on strategic partnerships, professional education and communication. We will be rallying each of our committees around these approaches as we now deepen the level of campaign activity. We will build that future on a track record of early successes, including:

• Placing an article on diagnosing PH in primary care in the American College of Physicians in its monthly magazine, ACP Internist, reaching 130,000 physicians nationwide.

• Contributing an article by Gerilynn Connors, a respiratory therapist and leader in the Pulmonary Hypertension Professional Network (PHPN), to the online news publication ADVANCE for Respiratory Care and Sleep Medicine.

• Accumulating endorsements for the campaign from organizations in the U.S., complementing the 18 international endorsements from PHA’s global counterparts. They are listed at www.SometimesItsPH/Endorsements.

• Inviting Diane Ramirez, PHA Board member and Piedmont Area, S.C., Support Group Advocacy Chair, to lead patient, family and caregiver participation in the campaign.

Visit www.SometimesItsPH.org for background on the campaign. You may direct questions to Mollie Katz at MollieK@PHAssociation.org or 301-565-3004 x774.

By Mollie Katz, PHA Vice President, Community Engagement
New PH Legislation Seeks to Improve Diagnosis and Treatment

In May, Reps. Kevin Brady (R-TX) and Lois Capps (D-CA) introduced the Pulmonary Hypertension Research and Diagnosis Act of 2013 (H.R.2073) in the House of Representatives.

This is a completely new bill for the PH community. It calls for the creation of a committee within the federal government focused on improving health outcomes for individuals living with PH. The committee would include leaders from the National Institutes of Health (NIH), Food and Drug Administration and other agencies as well as a PH patient and caregiver.

The group would develop a strategic plan for how these agencies should best work together to:

- Advance the full spectrum of PH research from basic science to clinical trials
- Increase early and accurate diagnosis of PH
- Educate medical professionals and the public

The new bill is different from the old one in a few key ways. Most importantly, it is budget neutral — it does not ask Congress for any money. Second, since Members of Congress don’t like to tell the NIH and other agencies how to do their jobs, our new bill requires that agencies find ways to improve the lives of PHers, but allows them to make their own choices about how to do that.

The PH community is already taking action to get legislators signed on as co-sponsors of our new bill. Read on for highlights of our progress so far and to learn how you can get involved.

National PH Call-In Day Gets PH Bill off to a Strong Start

Thanks to your phone calls during National PH Call-In Day, Reps. Timothy Bishop (D-NY), Jim Costa (D-CA), Peter King (R-NY), Devin Nunes (R-CA) and Peter Roskam (R-IL) and Del. Eleanor Holmes Norton (D-DC) became co-sponsors of the PH Research and Diagnosis Act. “As a patient, being active in PHA’s National Call-In Day and advocacy gives me another way to fight PH besides the physical fight. We all have the right to be heard by our elected representatives, so there’s nothing to fear. Educate yourself, be prepared and just do it!” says Perry Mamigonian, Call-In Day participant.

Keep Up Our Momentum

Make PH a hot topic for your senators and representative this summer by meeting with them and requesting their co-sponsorship of the PH bill. You can visit them in their local office or invite them to your support group meeting.

For more information on scheduling a legislative visit, or on other ways to build Congressional support for PH legislation, contact Elisabeth Williams at Advocacy@PHAssociation.org or 301-565-3004 x753 or check out PHA’s new online advocacy tools at www.PHAssociation.org/Advocacy/Alerts.

PHA and ATS Build Support for Lung Disease Research

Katie Kroner, PHA’s Director of Advocacy and Awareness, joined members of the American Thoracic Society (ATS) — including PH-treating physician, Roberto Machado, MD — on Capitol Hill in April. The group advocated for increased lung-disease research and treatment programs through the National Institutes of Health, Centers for Disease Control and Veterans Affairs. Katie also shared copies of the new PH bill with the legislative staff she visited.

L to R: Katie Kroner (PHA); Roberto Machado, MD; Robert Primus (Office of Rep. Capuano); Augustine Choi, MD; and Nuala Moore (ATS)
FDA Pilot Project to Focus on PAH

The Food and Drug Administration (FDA) recently selected 20 disease communities to work with over the next three years as part of their patient-centered drug development initiative — the PAH community is one of them! Several diseases associated with PAH are also among the 20 selected, including sickle cell, HIV and idiopathic pulmonary fibrosis.

The goal of this initiative is to engage those living with a variety of diseases in giving input to the FDA about how the drug and device approval processes can be adapted to better meet patients’ needs. For example, the FDA will seek input on the way they assess risk versus benefit during the approval process for new drugs and devices.

The FDA received hundreds of requests from disease communities interested in being selected for this initiative. Patient and PHA Board Member Colleen Brunetti represented the PH community before the FDA last fall. Based on her testimony and comments submitted by PHA’s president, Rino Aldrighetti, the PH community was selected.

PHA plans to use this opportunity to build a long-term, collaborative relationship with the FDA that will benefit the entire PH community well beyond the term of the initial project.

Changes to Benefit PHers Waiting for Transplant

The United Network for Organ Sharing, the nonprofit organization hired by the Department of Health and Human Services to coordinate the nation’s organ transplant system, has approved the changes to the lung allocation score (LAS) for which the PH community advocated last spring. Though the changes aren’t yet in effect, ultimately we expect them to significantly benefit PH patients awaiting lung transplantation.

The LAS is a system used to allocate donated lungs to those on the transplant waiting list based on a patient’s medical need and anticipated prognosis. When it came to PH, the existing system did not account for a PH patient’s risk of heart failure. It only addressed lung diseases and, therefore, significantly underestimated the urgency of PH patients’ need for lungs. The goal of the proposed changes was to address the severity of PH by incorporating factors that account for both lung disease and heart failure.

Despite Sequestration, PHA Advocates for Federal Health Funding in 2014

In our last issue of Pathlight, we wrote that PH advocates were contacting their Members of Congress about the importance of coming to a budget agreement and stopping the automatic funding cuts known as sequestration. Unfortunately, Congress was unable to come to an agreement, and several federal programs critical to the PH community have been affected, including:

- **National Institutes of Health (NIH):** Medical research funding was cut by 5.1 percent. This means the NIH will fund 700 fewer research grants than in 2012.

- **Centers for Medicare and Medicaid Services (CMS):**

  Physician reimbursement was cut by 2 percent, meaning that physicians will get reimbursed less for services to Medicare and Medicaid patients. Some physicians may choose to stop seeing these patients.

- **Food and Drug Administration (FDA):** Funding for innovative treatment review and monitoring was cut by 9.3 percent, making it harder for new drugs to get approved and to patients.

Congress is now debating budget proposals for 2014. PHA and other health organizations are speaking out in favor of proposals that will keep U.S. investment in health research and health services strong by providing the NIH and related agencies with funding increases.

Researchers studying PH causes and treatments have a new opportunity to get money to support their work — grants from the Department of Defense (DOD). In 2013, pulmonary hypertension became one of fewer than 30 diseases eligible for study through the DOD’s Peer Review Medical Research Program, which gives grants to scientists researching diseases that impact military personnel and their families.
Timing is Important! Give Yourself (and Reporters) Enough Time to Ensure That Your Media Story Makes Headlines

Scoring a media success is easier once you realize that reporters need ample time to produce a quality story. That’s why it’s a good idea to start your media efforts six to eight weeks in advance.

For example, if you’re a parent and you want a reporter to cover a story about educating your child’s school about PH-related emergencies, it would be a good idea to plan for that story to run in papers or on TV stations around the start of the school year. In that case, you should start prepping and gathering materials approximately eight weeks ahead of time. Here are some ways to pace yourself on the project:

- **8 Weeks Ahead — Choose Your Theme and Gather Information:** What do you want the focus of the article to be? Perhaps the story you’d like to see in headlines is one highlighting your upcoming fundraiser or support group meeting. Or maybe you just want to share your personal journey with PH. You could also try piggy-backing your story to a seasonal event, such as sharing your experience as a mother living with PH around Mother’s Day.

  Whatever theme you choose, make sure to make your pitch irresistible to reporters by doing some of the work for them. Visit www.PHAssociation.org/Press to gather fact sheets, informational video clips and other resources you could share with reporters. Now is also a good time to ask your PH specialist if he or she would be willing to talk to a reporter about the clinical side of pulmonary hypertension.

- **7 Weeks Ahead — Research Media:** Don’t just make a random call to an editor. Look your local newspaper over or watch your local news station and think about how your story can fit into what they’re already doing. Are you a local citizen to be featured in a neighborhood news section? Are you part of an unfolding science-research story? Are you a senior citizen? Many papers have specific features, beats or sections devoted to these niches. Identify the reporters who cover similar stories and create a list with their emails and phone numbers.

- **5 Weeks Ahead — Write a Pitch:** If you’re writing your own pitch (as opposed to using a template pitch from PHA), make sure to keep your pitch to half a page. Include relevant information about your story, special event or support group, and highlight the information materials you gathered earlier in the process. Have someone less familiar with the story you are trying to share review your pitch. Is it interesting to them? Do they want to know more? Finally, spend a few minutes thinking of a brief subject line for your email pitch that will grab a reporter’s attention.

- **3 Weeks Ahead — Contact Journalists:** Email your pitch to the list of reporters that you created earlier. Within a few days, call the reporters on your list, and ask if they’re interested in covering your story. When you follow up with reporters, try to offer something new each time — an additional fact, new source, related article or a website.

- **After Securing Media Coverage — Enjoy Your Success!** Congratulations! You got your story in the news! We’d love to hear about your victory, so share your media coverage with PHA on our Facebook page www.facebook.com/PulmonaryHypertensionAssociation or by contacting Elisabeth Williams at PHAware@PHAssociation.org or 301-565-3004 x753.

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By Elisabeth Williams, PHA Grassroots Campaigns Manager

Be a PH Superhero
Share Your Story!

Each time you share your story with your Members of Congress and reporters in your area, you’re flexing your PH awareness-raising muscle!

PHA, your trusty sidekick, is here to help you get started. Contact Elisabeth Williams at 301-565-3004 x753 or Advocacy@PHAssociation.org to learn more.
World PH Day on May 5: A Driving Force for Awareness and Support Around the World

World PH Day 2013, held May 5, brought associations around the globe together to raise awareness and show support for pulmonary hypertension patients. The Asociación Nacional de Hipertensión Pulmonar in Madrid, Spain, held the first World PH Day last year with the hope that the day would truly become a world day with events around the globe. From a handful of events last year (a symposium in Madrid and some satellite events in China and Argentina) to more than 60 events this year, this dream has truly become a reality.

Almost every PH patient association in the world did something special for World PH Day, including groups of people in Chile and Costa Rica, where patients and families are trying to start associations. In Chile several people held a protest for insurance rights, and in Costa Rica patients and families celebrated a “healthy living” day. This year many groups around the world took to the streets to raise awareness by handing out flyers or holding flash mobs, a sudden gathering of a group of people in a public place.

The day was also used as a way to reveal new programming or materials, like a Patient’s Guide in Argentina and a new website design in South Africa. PHA Europe’s “Get Breathless” sporting events included everything from bicycling to Six-Minute Marathons to boxing and dancing activities. Even Pope Francis acknowledged World PH Day by mentioning patients and their families in his address on May 5.

In the U.S., PHA held a “Flames of Hope” fundraiser and hosted a PHA Online University webinar on schistosomiasis, a disease caused by a parasite that can lead to the development of PH, with Dr. Ghazwan Butrous of the Pulmonary Vascular Research Institute. Photos from the World PH Day activities can be viewed at www.WorldPHDay.org, a site developed for the world PH community by PHA.

For those who could not join an event in person, the World PH Day website provided opportunities for participation. The website has had more than 11,000 page views from 83 countries around the world! The World PH Day Facebook group had a reach of more than 3,000 people on World PH Day alone. Additionally, 149 people submitted photos and messages to the Worldwide Photo Mosaic (www.WorldPHDay.org/WorldwidePhotoMosaic), and many more posted pictures on other social media sites like Facebook and Weibo, the main Chinese social networking site.

We believe that the momentum of this year’s World PH Day will only mean a bigger and better May 5 next year, with the worldwide coordination of events and resources making the PH community’s shout for awareness that much louder! *

By Julia Friederich, PHA International Program Associate

*International News

Olga Scalone (left) and her daughter Marlucy Scalone in Jaboatão dos Guararapes, participating in RESPIRAR support group’s Blue Hands and Lips online awareness event.

World PH Day celebrations (photos from left to right): Athletes compete in the Ironman Lanzarote in Spain on behalf of PHA Europe and the Asociación Nacional de Hipertensión Pulmonar (Spain). Members of Associazione Malati Ipertensione Polmonare (AMIP) pose in St. Peter’s Square as Pope Frances expresses concern for PH patients and their families in his address; their sign says: “Pope Frances, our heart is next to yours.” Patients, family and friends march for those who are sick without guaranteed health plan access in Santiago, Chile.
Yoga, Paintings and Ice Cream: 
2013 Lantos Grants Support Many Paths to Awareness

PHA’s history is the story of inspired people with the drive to turn ideas into reality. For the fourth consecutive year, Gilead Sciences is funding the Tom Lantos Innovation in Community Service Awards to keep that spirit thriving. Lantos grants provide individuals with funding of up to $5,000 each to act on original ideas to advance the PH cause. The following projects will be funded in 2013.

Restorative Yoga DVD by Patricia Fantuz, Detroit, Mich. Patricia Fantuz, pulmonary hypertension nurse coordinator at Henry Ford Hospital in Detroit, will provide PH patients access to medically sound, low-impact yoga exercises they can do conveniently at home. Working with physicians and other professionals at the hospital, she will produce a DVD demonstrating exercises that improve balance, endurance, muscle strength and flexibility.

Beats Per Mimi by Britt McNiff, Arlington, Mass. Britt, mother of 5-year-old Mimi, a PH patient, will use zebra artwork to increase awareness of pediatric PH among pediatricians and parents in Boston and western Massachusetts. The project will produce zebra-themed paintings to be hung on the walls of pediatricians’ offices. Each painting will come with an information card about PH.

The Scoop on PH by Jayna Wall, Burlington, N.C. Jayna’s project will promote the Sometimes it’s PH early diagnosis campaign by partnering with a local ice cream shop to sell a special purple ice cream flavor dedicated to PH. At one event, the PH message will also be communicated on souvenir bowls and ice cream scoops imprinted with “The Scoop on PH.” At a second event, the zebra emblem of Sometimes it’s PH will appear on magnets, temporary tattoos and coloring sheets.

Just Breathe Tees and Phenomenal Hope Posters by Haley Lynn, Amarillo, Texas. Having struggled to get through high school, even gym class, with her PH, Haley, a young adult and Generation Hope member, will raise awareness about teen PH among high school students and their school administrators while encouraging youth activism on PH. She will speak in high school classrooms, hang PH posters in school hallways and recognize young people who get involved in fighting PH with “Just Breathe” T-shirts she has designed and printed. She is pictured left, wearing her T-shirt.

Hipertensión Pulmonar Aquí (HPAquí) — Sin Fronteras/Ipertensão Pulmonar Aquí (HPAquí) — Sem Fronteiras by Martha Gonzalez, North Bergen, N.J. As a native of Ecuador and the mother of a child with PH, Martha saw a need for more extensive information for Spanish- and Portuguese-speaking PH patients in their native languages in the U.S. and abroad. She will develop a website whose name translates to Pulmonary Hypertension Here — Without Borders. It will connect patients to other patients and direct them to the PH organizations in their countries and to content in their languages, including on PHA’s website.

Faculty of Pulmonary Hypertension by Natalia Maeva, Bulgaria. This project promotes PH education among newly diagnosed patients, encouraging them to take responsibility for adhering to their treatment plans. Working with groups of Bulgarian health professionals and the Bulgarian Society of Patients with PH, this project will hold seminars for patients in four cities.

Climbing for PH by Huang Huan, Beijing, China. This project, implemented on World PH Day May 4–5, used a celebrity endorsement and an activity popular with Chinese office workers — a stair climbing contest — to increase awareness of PH in China. More than 30 workers wearing PH T-shirts climbed 14 floors in the competition. Also, a news conference drew 200 people and resulted in 10 stories in the Chinese media.

Digital PSAs, International Versions by Steve Van Wormer, Burbank, Calif. Steve, a member of PHA’s Board of Trustees, is creating foreign language versions of the popular 60-second public service announcement (PSA), or “zebra video,” about the Sometimes it’s PH campaign, which was created through an earlier Lantos grant. The PSAs will be given to international PH patient organizations. See the PSAs: www.PHAssociation.org/GlobalPSAs

Hope Hot Holders by Bonnie Patricelli and Ryan Juntii, Clementon, N.J. Extending the reach of their Lantos project from 2012, Bonnie and her adult son Ryan, who has PH, will again imprint a PH awareness message on “hot holders,” the sleeves that prevent coffee cups from burning fingers. This year they will distribute them to healthcare professionals in cafeterias in medical teaching hospitals and universities.

By Mollie Katz, PHA Vice President, Community Engagement
PHA sends a heartfelt thanks to our spring 2013 interns. They have been an integral part of PHA for the past few months and have made a real difference in the programs and services we are able to provide. Read on to meet our spring interns and to find out what they did while they were with us. To learn more about PHA’s internship program, visit www.PHAssociation.org/Internships.

Imani Marks, Patient and Caregiver Services

While at PHA, Imani worked to improve outreach and resources for the PH community. She researched social media best practices, and her findings led to the creation of PHA’s Social Media Advisory Board. Imani prepared a literature review for best practices in PHA’s online Support Group Chats. She also helped assess the PH Email Mentors program and develop surveys to determine accessibility, expectations and successes of the program. Imani helped design the curriculum for The Newly Diagnosed Self-Study: PH Ready, an educational series for newly diagnosed patients and their caregivers, and she created a guide for incorporating empathy in online communication. She also wrote two articles for this Pathlight.

Having spent an entire school year with PHA, Imani is thankful for the experience and support the organization has provided to her. Imani is a rising junior at George Washington University, majoring in public health with a minor in biology. In addition to interning with PHA, she works as an online hotline staffer for the Rape, Abuse and Incest National Network (RAINN) and serves as a campus coordinator for Health Leads D.C. She hopes to become a physician assistant and work with vulnerable populations in underserved communities.

Theresa Krawiec, Medical Services

In PHA’s Medical Services department, Theresa worked on a number of projects throughout the semester. She helped with editing and updating PH Treatment Fact Sheets for PHA’s Scientific Leadership Council Education Committee. She also helped select images for the PHA Online University Image Gallery, a project for the PH Professional Network Practice Committee. Additionally, she worked with our other spring intern, Imani, to review PHA’s School Resource Guide, a project for the PH Professional Network Education Committee. Her largest project this spring was organizing a database containing information regarding grants awarded by PHA’s Research Program.

This fall Theresa is entering her senior year at the Catholic University of America, majoring in biology. After graduation, she hopes to obtain her master’s in public health and attend medical school. “Interning at PHA this past semester has inspired me,” she says. “I never thought that I would be able to work with such wonderful people dedicated to helping those with PH.”

Come join the PHA intern team!

Are you — or someone you know — looking to enhance your academic experience beyond classroom walls? Come intern with PHA!

PHA offers a variety of internships year-round, including:

- Grassroots Advocacy
- Patient & Caregiver Services
- Social Media & e-Marketing
- And more!

For more information, visit www.PHAssociation.org/Internships or contact Internships@PHAssociation.org.
Support Groups Focus on Mindfulness and Well-being

When you’re diagnosed with pulmonary hypertension, you learn quickly about the things you CAN’T do — things you no longer have the energy to do. PHA’s support groups are here to show you the things you CAN do. Support groups are meeting every month and focusing on the “glass-half-full” perspective, empowering you and your family with knowledge, tips for better living, a positive outlook and hope.

Members of the Midlands South Carolina Palmetto PHriends support group hosted a two-part series on breathing with one meeting focused on breathing and the second on exercise and toning. The speaker was from a neighboring yoga and wellness center and introduced techniques and exercises that were appropriate for all patients, including those with limited mobility.

Have you heard of “Qi Gong” (pronounced CHEE-Kung)? Well, if you’re a member of the Fort Worth, Texas, PH Support Group or the Tri-Cities PH Support Group in Richland, Wash., you learned all about the stress-reducing and balance-improving techniques from this ancient Chinese healing art.

The Birmingham, Ala., PH Support Group plans to bring a clown to its summer meeting for a “Laughter is the Best Medicine” theme. Other groups have done similar meetings with uproarious results!

The Minnesota “Twin Cities” PH Support Group hosted a “therapeutic journaling” meeting, where members were guided through a writing exercise as a form of healing.

The Fresno PH Support Group leader is organizing an art class designed to encourage patients to unlock emotions and ideas through creativity.

In one month of this year alone, support group leaders have organized meetings on transcendental meditation, chair yoga, breathing and relaxation. The Delaware Valley PH Support Group in Pennsylvania hosted a “Show and Tell” style meeting where members brought their favorite hobbies to talk about and demonstrate at the meeting. The Charlotte PH Support Group in North Carolina hosted an interactive session presenting “mindfulness, personal effectiveness and meditation tips for times of physical and emotional stress.” The speaker was a specially certified life coach who provided positive tips for daily life and dealing with a chronic condition.

Is your support group getting creative and promoting wellness in positive ways? Let us know! Contact SupportGroups@PHAssociation.org.

By Debbie Castro, PHA Senior Director, Volunteer Services

Back in the Saddle: Group Overcomes Challenges of PH to Return to a Treasured Hobby

My name is Diane Johnson-Jaeckel. I live in Rochester, N.Y., and I wanted to meet in a small group of patients on a monthly basis. I found others in my area who felt the same way, and we started a small support group.

During our first meeting, we agreed that while getting to know each other, we wanted to find out our past and current hobbies or passions. When it became apparent that we all had ridden or owned horses in the past, we just felt we had to look into the possibility of riding again as a group.

I remembered a place that used to give trail rides in our area. I arranged it, after the patient on supplemental oxygen checked to be sure it was okay to ride at that stable, and off we went on our appointed ride.

As I sank into the saddle again, I realized it was just like sinking into my favorite easy chair. To me, there is nothing better than seeing the world from atop a horse!

We agreed to ride together again soon and to explore other shared activities going forward. We’ve all suffered many setbacks and limitations with our PAH struggles. Supporting each other to do this ride unshackled us, for a time, from the “have to be carefuls” outlook of our illness. We were careful, and we did it!
A Beautiful Collaboration: Northern California Support Groups and PHA’s San Francisco Bay Area Chapter

In Northern California, the San Francisco Bay Area Chapter has been blessed to discover a vast and vibrant honeycomb of support groups. They stretch from the San Francisco Peninsula itself to as far away as the state capital in Sacramento and the City of Fresno in California’s extended Central Valley. My name is Michael Ehret, Development Director of the San Francisco Bay Area Chapter, and I’d like to tell you a little about these amazing groups.

Whether longstanding groups based out of the Centers for Excellence at the University of California, San Francisco (UCSF) and Stanford or homegrown groups meeting regularly in the densely populated Silicon Valley of the South Bay, the growing network of support groups is opening doors to PH patients, caregivers and family members at every turn. We’ve even got groups 60 miles inland in the more rural farm community of Modesto.

The good news becomes even better when word spreads of revitalizing support groups in both the wine country north of the Golden Gate Bridge and as far south as San Luis Obispo along California’s Central Coast. A Spanish-speaking support group at Stanford is also on the horizon, attesting to the remarkable breadth and scope of PHA’s expanding community outreach.

My wife, Karen Lindemann, and I regularly attended support groups at both Stanford and in San Jose throughout Karen’s decade-long battle with PH. We are thankful for the education and support we received in those meetings, which helped Karen advocate for and subsequently receive a series of life-extending therapies concluding with a successful double-lung transplant in 2009. Karen now serves the San Francisco Bay Area Chapter as an unofficial “Ambassador of Hope,” inspiring others to never give up their own fight.

If you live in California or plan to visit soon, be sure to check out our amazing network of support groups here, and stop in and say hi to the San Francisco Bay Area Chapter staff.

By Michael Ehret
PHA Development Director, San Francisco Bay Area Chapter
Hope for a Cure: Patient Hosts Gala to Fulfill Dream and Share Her Story with Her Community

On April 27, PH patient Colleen Connor, backed by support from her network of family, friends and colleagues, hosted the inaugural Philadelphia’s Hope for a Cure Gala at the Springfield Country Club in Springfield, Pa. As the Philly-area community enjoyed a night of dinner, dancing and bidding on auction items, Colleen achieved a significant milestone for PHA — hosting one of the most successful fundraisers in the history of the organization. At press time, the gala has raised well over $200,000 toward PH research and patient- and family-serving programs.

With the family’s permission, we’d like to share an excerpt from Colleen’s keynote speech that evening:

Tonight, my PH friends, please consider my family and friends yours. I know they will take very good care of you.

I need to take a minute to tell you how this event started. This evening came about as a result of a book club party at Lisa Scottoline’s home. Lisa is a local writer and New York Times bestselling author. She invites her readers to her home each fall for a big book club party. As we debriefed, a friend shared with me the sad news of her mother’s passing from pulmonary fibrosis. We compared these terrible lung diseases and went on to discussing bucket lists. I mentioned that my bucket list really only contained one wish that I would regret not trying to fulfill. My wish was a fundraiser and awareness campaign for my disease, pulmonary hypertension.

My family and friends have been waiting for me to be ready to commit to this effort, because for several years I was too sick to act on it. They were excited to know I was ready to move forward now that I am stable. As background, I was declared “off the brink,” so to speak, at the beginning of last summer by my doctors and the director of the lung transplant team at the University of Pennsylvania. So the pressure to list for a double-lung transplant is on hold. My disease is progressive, however, with my prognosis unknown.

And tonight, with you all joining us, my dream has become a reality.

One of my goals is to create awareness for PH, and I want to explain why that is important. After I had my daughter Keira, I noticed I was slowing down. I thought I was out of shape from the pregnancy. I tried to exercise or play games like kickball in the backyard with my son Ryan, and I could not breathe. I could not walk up a flight of steps without being breathless for a good 10 minutes. I could not walk and talk at the same time. I asked my doctor about it, and he assumed I had asthma. As time went on, we experimented and escalated the asthma medications, but none of the ones we tried worked for me.

I went to see a local pulmonologist. I was really embarrassed when he told me that my “symptoms are greatly exaggerated” for the degree of asthma that I had. He ran a series of tests, and they all came back negative. As it turns out, I don’t have asthma.

I went to see a cardiologist, but to be honest, even I could not believe there could possibly be any issue with my heart or lungs because I was an athlete growing up, and I had just had two healthy children. Surely we would have realized there was an issue somewhere along the line. It didn’t help that I still pretty much believed I was invincible.

The cardiologist stayed to read the echo, and he told me he was sorry. The pressures on the right side of my heart were 500 percent above normal, and he thought I had a rare lung disease called pulmonary hypertension.

Internet sources reported prognosis as 1.8–2.5 years from diagnosis. It was the first of many sleepless nights for us.

The diagnosis changed everything. It was determined that I needed oxygen, which I was mortified to administer.

The adoption of oxygen forced me to confront the fact that I was not invincible.

Colleen Connor with her husband Shawn and children Keira and Ryan at the Hope for a Cure Gala
by. I could not believe I’d have to wear this disease on my sleeve, and everyone would know.

The PH diagnosis was like having the brakes slammed on our lives. ... [It] is a progressive disease, and I’ve certainly experienced that firsthand.

Eventually, my doctors told me it was time to try the IV medication. It’s a scary thing having an IV put into your chest. Not so much having it done; it’s the living with it. I can remember waking up when my line was placed and being shocked by everything going on down there. I thought there would be just a tube, but there are connectors, a clamp, lots of iodine and bandages. I thought it looked a little like a science experiment.

This IV medication needs to be made every day, and I am dependent on it. I have become my own pharmacist, mixing medications, and my own nurse, taking care of the central line in my chest.

After the IV medication, we hoped I’d be able to do more, but instead my health declined to the point that I needed a scooter to go even short distances.

Everyone thought it was time to list for new lungs. Lung transplant is an option, but it comes with a whole new set of medical issues. We did ride out that scary time, and now I am once again stable. We know how temperamental my health is.

I want to leave you with a few thoughts. There have been several advancements in the medications available to help PH patients live a better life — but this is NOT a cure. PH patients are considered long-term survivors after living with the disease for eight years. We need more medical advancements so we can live longer and see our children grow up.

Before diagnosis, many of my family and friends can attest that I had incredible endurance — now I have incredible fatigue.

I watch life from the sidelines and depending on what we are doing, my participation is significantly reduced, or I’m altogether absent.

Regardless, we really are positive, hopeful and grateful for all the blessings we have received. ♦

Planning an inaugural event? Apply to PHA for start-up funding

If you’re interested in hosting a special event fundraiser for pulmonary hypertension in your city or town and are looking for ways to get the ball rolling, look no further! PHA provides a limited number of seed grants annually to inaugural event fundraisers to assist in the planning and implementation of your special event.

If you are a PHA member and you plan to host an annual event where the funds will benefit PHA, you are eligible to apply for up to $1,000 in grant funding.

To receive a grant, your event must be a PHA-recognized fundraiser, so contact PHA at 301-565-3004 x752 or email Events@PHAssociation.org to learn more about this process.

Help us get one step closer to a cure today! ♦
Race to Cure PH: Taylor Caffrey Memorial 5K
Location: Anaheim Hills, Calif.
Details: More than 1,200 people gathered for this event. Organizer Shari Caffrey, her husband Michael and daughter Brooke welcomed the crowd at this annual race held in memory of Taylor Caffrey, who lost her battle with PH when she was 4 ½ years old.

Father-Daughter Benefit Dance
Location: West Chester, Pa.
Details: Girls from kindergarten through 8th grade enjoyed a magical evening with their fathers at the “Father-Daughter Charity Dance” in Pennsylvania. Attendees danced the night away with refreshments, a live DJ and fun for all. All proceeds from this event benefitted the Robyn J. Barst Pediatric Research and Mentoring Fund.

7th Annual Spur a Cure for PH
Location: Phoenix, Ariz.
Details: More than 140 people kicked up their heels for PH at this year’s Spur a Cure for PH. This photo features some members of the planning committee: (L to R) Debra Luteyn, Jim Perry, Trish Duque, Kaye Perry, Dr. Jeremy Feldman and Deborah Taylor.

Woodlands CrawPHish Festival
Location: The Woodlands, Texas
Details: Prior to this year’s Woodlands CrawPHish Festival, planning committee members gathered at “Painting with a Twist” for a team-building activity. They also judged submitted artwork with the winning design featured on the festival T-shirt.

2013 N.C. Cure PH Golf Tournament
Location: Mocksville, N.C.
Details: Ninety-two golfers played in this year’s N.C. Cure PH Golf Tournament held in memory of Donna Wesley. Featured above is Team Wesley. L to R: Don Haake, Bob McDowell, Marc Press, Bill Wesley (Donna’s husband) and Lanie Bemis (Donna’s daughter).

Pray PHor a Cure for Pulmonary Hypertension
Location: Vinton, Iowa
Details: Hundreds gathered at the Benton County Fairgrounds for this community-driven bake sale, craft sale, plant sale, garage sale, silent auction and raffle spearheaded by PH patient Trudy Seidel (second from right). Carl Hicks, PHA’s executive vice president, made a special appearance (second from left).
### Monday, July 29, 2013
6th Annual Swing 4 the Cure: Wojo PH Golf Classic  
DETAILS: Betty Lou Wojciechowski at 949-215-1573 or bettylouwojo@hotmail.com

### Friday, Sept. 27, 2013
O₂ breathe 100 Hole Challenge ♦  
WHERE: Countryside Golf Course, 20800 W. Hawley St., Mundelein, IL 60060  
DETAILS: PHA Midwest Chapter at 1-855-ZEBRA-55

### AUGUST
Now is the perfect time to start planning your November PH Awareness Month fundraising event! Host a PHA Periwinkle Party, Fun Walk or Six-Minute Marathon! Email Eventful@PHAssociation.org or call 301-565-3004 x742.

### Sunday, Aug. 11, 2013
2nd Annual Walking PHor a Cure  
WHERE: Pittsburgh, Pa.  
DETAILS: Merle Reeseman at 724-458-5573 or opha.pher@yahoo.com

### Saturday, Aug. 17, 2013
2nd Annual Santa Barbara PH Fun Walk for a Cure  
WHERE: Chase Palm Park, Santa Barbara, Calif.  
DETAILS: info@santabarbarafunwalk.org

### Sunday, Sept. 15, 2013
Colorado Pulmonary Hypertension Run for PHun 2013  
WHERE: City Park, Denver, Colo.  
DETAILS: Deb McCollister at Deb.McCollister@ucdenver.edu or Beth Coleman at Beth.Coleman@childrenscolorado.org

### Monday, Sept. 16, 2013
O₂ breathe Golf Tournament — Armonk, N.Y. ♦  
DETAILS: PHA New York Tri-State Area Chapter at 646-568-2068

### Saturday, Sept. 21, 2013
O₂ breathe Walk — Chicago/Northwest ♦  
WHERE: Twin Lakes Recreation Area, Palatine, Ill.  
DETAILS: PHA Midwest Chapter at 1-855-ZEBRA-55

### Saturday, Oct. 5, 2013
New England PH Forum | Swinging for a Cure Golf Tournament  
WHERE: Falmouth Country Club, Falmouth, Maine  
DETAILS: Jeannette Morrill at 207-695-3042 or jeannettem@myfairpoint.net

### Sunday, Oct. 6, 2013
Baltimore Walk for Hope  
WHERE: Inner Harbor, Md.  
DETAILS: Danielle Clifford at DanielleC@PHAssociation.org

### Saturday, Oct. 12, 2013
9th Annual PHun Walk ♦  
WHERE: Firemen’s Memorial Park, Lindenhurst, N.Y.  
DETAILS: Juliette Pelletier at 646-568-2068 or JuliettePelletier@NY-PHA.org

### Saturday, Oct. 12, 2013
7th Annual North Texas Zebra PHriends 5K and 1M PHun Walk  
WHERE: Fort Worth, Texas  
DETAILS: Susan Kennedy at 972-322-2443 or skanddwd@hotmail.com

### Saturday, Oct. 19, 2013
10th Annual GA FUN Walk for a Cure  
WHERE: East Cobb Park, Marietta, Ga.  
DETAILS: Sally Maddox at skshmaddox@yahoo.com

♦ PHA Chapter Events — In late 2012, PHA launched three fundraising chapter offices: Midwest; NY Tri-State Area; San Francisco Bay Area.

For more Special Events listings, visit www.PHAssociation.org/Events
Announcing the Conference 2014 Theme: Racing Toward a Cure

PHA is pleased to announce the theme for the 2014 International PH Conference and Scientific Sessions taking place in Indianapolis, Ind., on June 20–22. While we had an overwhelming list of great suggestions from the PH community, Mary Svikhart’s theme, Racing Toward a Cure, inspired by the urgency to find a cure for PH, ultimately won.

Mary, a patient from Littlestown, Pa., was “utterly delighted” and surprised to find out she won, “I don’t usually win contests that depend on any level of creativity.”

She thought the idea of “racing” was a clear choice, particularly when it comes to supporting research for a cure. “It seemed like an obvious choice to me, with us headed for Indianapolis in 2014. But I must admit I didn’t ‘dig deeper’ for another idea because every time I hear of another PHriend who has been diagnosed (particularly our youngest fellow patients), I feel the urgency that a racing theme suggests. ‘Please, researchers, we need you! Hurry, hurry, hurry!”’

Being a patient, Mary knows all too well the need to find a cure. Mary was diagnosed with IPAH in August of 2008 after nearly three years of worsening symptoms and a false diagnosis from her doctor. “My general practitioner [was] telling me I was just old and fat and needed to exercise,” Mary says. “Guess I showed her, huh?”

While she was thrilled finally to have an explanation for what she was going through, Mary says the sense of comfort didn’t last long. “On the one hand, I was relieved to know what I was dealing with. On the other hand, the ‘no cure’ part threw me for a loop. I did not see that coming!”

Like many patients, Mary credits PHA with helping her cope early on in her diagnosis. “I have been so impressed with PHA since my earliest days of diagnosis when I went out on the web looking for answers. I was scared, and the PHA website had so much information, as well as ways to connect with other patients, which was just about as comforting. It was incredibly helpful knowing I had found a place where I could trust what I was reading.”

PHA seeks to bring this online experience to life in our biannual Conference. PHA’s Conference is the largest gathering for PH patients, family members and medical professionals in the world. Attendees have the unique opportunity to come together for three days of networking and education.

Over the years, PHA’s Conference has grown significantly in all areas, from the number of registrants to the number of educational sessions provided. Each Conference marks a special time in the lives of our attendees.

PHA has brought Conference to cities all over the United States, and in 2014 we are delighted to be heading to Indianapolis. While many factors go into choosing a Conference city, the central location of Indianapolis means that even more patients, family members and medical professionals will be able to attend. Labeled the Crossroads of America, Indianapolis is within a day’s drive from many surrounding cities.

In 2010 Mary experienced first-hand the impact of attending a Conference. “I was so excited finally to be among people who understood exactly what I was dealing with,” she says. “It’s hard to express how empowering that was.”

While the opportunity to network with others in the PH community is unrivaled, the educational sessions offered at Conference are also a huge draw for attendees. Mary notes, “The seminars were so helpful; it seemed I wanted to know something about every topic. For some sessions, it was a struggle to decide which one to attend.”

Mary is already counting down the days to the 2014 Conference. “I’m excited to meet more online PHriends, to hug the ones who have become more than cyber PHriends, to attend more super-helpful seminars, and to give blood (or whatever) to every researcher who wants it in the Research Room,” she says.

For submitting the winning theme, Mary will receive a complimentary registration for Conference 2014.

We hope to see you in Indianapolis in June 2014!

By Rebecca Gifford, PHA Meeting Planning Associate
Building Medical Education in PH
A Partnership Initiative to Advance Medical Understanding of Pulmonary Hypertension

Building Medical Education in PH (BME) events are designed to foster partnerships between PHA, PH Centers and medical professionals. The program supports continued education in the PH field through CEU/CME educational events. Participating in PHA’s BME program can benefit your educational event by providing one-time use of PHA’s medical professionals mailing list, advertising support, educational materials for distribution to attendees and more.

To partner with PHA in Building Medical Education in PH for your upcoming CME event, please contact 301-565-3004 x776 or BME@PHAssociation.org.

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

Upcoming BME events:

5th Annual North Carolina Research Triangle PH Symposium
Nov. 8, 2013
Duke University and UNC Chapel Hill
Durham, N.C.
Register at: www.dcri.org

Cleveland Clinic PH Summit
Nov. 15, 2013
Cleveland Clinic
Cleveland, Ohio

* Both meetings include offerings for patients *

To view a full list of educational opportunities for medical professionals, visit: www.PHAOnlineUniv.org/Calendar
PHenomenal Hope are training hard to be ready to cycle from Oceanside, Calif., to Annapolis, Md., in the race next summer. As a relay team with one cyclist always on the road, they will race roughly 375 miles per day, aiming for a maximum of eight nonstop days. This high-endurance ride will culminate during PHA’s 2014 International PH Conference and Scientific Sessions in Indianapolis, June 20–22, the world’s largest gathering of the PH community.

Patty George, MD, the manager of the cycling team, is an assistant professor of medicine and a PH researcher at the University of Pittsburgh Medical Center (UPMC), where she cares for patients who have received heart and lung transplants. Her teammates are:

- **Stacie Truszkowski**, an administrative assistant at UPMC in pulmonary, allergy and critical care medicine. Patty and Stacie have competed in other endurance cycling races, and Stacie was the 2011 Pennsylvania women’s category 4 state champion in cyclocross, another kind of bike race over demanding terrain.

- **Anne-Marie Alderson**, an engineer at Cook Myosite, Inc. She is a triathlete certified to coach other triathletes, and she has won local bike races including one climbing Pittsburgh’s steepest hills.

- **Ryanne Palermo**, a graduate student in pharmacy and an endurance mountain bike racer. Among her biking victories are a six-hour road bike race and a 13-hour mountain bike challenge.

- **Kate Bennett**, an administrative coordinator at Carnegie Mellon University and one of two crew chiefs essential to the bike team’s performance. Her experience includes road racing, cyclocross and mountain biking. She was a champion in the Appalachian Bicycle Racing Series.

- **Greta Daniels**, crew chief and an alternate racer. Greta is the alumni relations director at Sewickley Academy, who with Kate took fifth place in the 2013 nine-hour Cranky Monkey mountain bike race. She also was victorious in the Appalachian Bicycle Racing Series.

Team PHenomenal Hope has been drawn to RAAM by the intense physical challenge, the opportunity to help PHA, and the same spirit shown by other PH professionals who climbed Mt. Kilimanjaro in 2010 for PH awareness. Ray Benza, MD, and physician assistant Jessica Lazar, both of Allegheny General Hospital in Pittsburgh, scaled Mt. Kilimanjaro with Robert Frantz, MD, of Mayo Clinic in 2010. The PH community responded with its own local Unity Walk fundraisers and press coverage to educate the public about PH.

“The Kilimanjaro climb spurred a lot of excitement in our PH community,” says Rino Aldrighetti, PHA’s president. “RAAM 2014 is another excellent mirror of the extreme demands that PH can put on a patient and family. I know our PH families and Team PHenomenal Hope are going to be inspired by one another’s determination and strength.”

The cyclists have already been touched by the PH patients and family members they have met at PHA’s 2012 International PH Conference and elsewhere. Between this summer and next, they look forward to sharing the excitement with many more members of the PH community through special events, social media, PHA publications, media coverage, video and more. While training and racing, “we’ll be thinking about our friends and patients who are living with this disease and who have a race to ride that is much longer than the one we have,” Dr. George says.

You may get acquainted with the team and the race by visiting Team PHenomenal Hope’s website at [www.TeamPHenomenalHope.org](http://www.TeamPHenomenalHope.org). You can also like them on Facebook and follow them on Twitter (@TeamPHenomHope). Keep your eyes on PHA as well for ways you can participate in the 12-month Race of Our Lives campaign.

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By Mollie Katz, PHA Vice President, Community Engagement
In June, PHA on the Road: PH Patients and Families Education Forums brought PH educational sessions and networking opportunities to patients and family members in four new parts of the country — Denver, Colo.; Boston, Mass.; Durham, N.C. and San Francisco, Calif. PHA extends a special thank you to:

- **All those who attended** the forums — traveling from far and wide!
- **More than 70 local medical professional speakers and presenters** who volunteered their time to lead sessions and help plan the forum programming.
- **Our PHA on the Road National Committee Chair** — Dr. Zeenat Safdar, MD, FCCP, FACP, FPVRI — for her leadership in planning the forums.

For more information about PHA on the Road, visit [www.PHAssociation.org/OnTheRoad](http://www.PHAssociation.org/OnTheRoad).

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Stay Informed Throughout the Year

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

Subscribe to:

- **PHA Daily Beat** via email or RSS
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I enjoy your webinars as they help to provide greater insight and different perspectives on my condition.

— PHA Classroom webinar attendee
The 2013 revision of *Pulmonary Hypertension: A Patient's Survival Guide* is now available as an e-book. You can read this soup-to-nuts resource on your Kindle, iPad, smartphone or other mobile device, making it even easier to keep background information on treatments, emergency planning, lifestyle topics and more at your fingertips. For those who prefer to read a printed book, you can still get it as a paperback as well.

Eight out of the 17 chapters, plus the glossary and appendices, were updated for this latest version of the book. Of note, the chapter “Tell Me Doc, How Long Do I Have?” is refreshed with all new charts, as well as stats from the REVEAL Registry.

The *Survival Guide* includes a discussion of PH drugs, diagnostic tests, diet, traveling, depression, insurance and other topics.

Gail Boyer Hayes, the original author of the *Survival Guide*, wrote this book in a way that fellow PH patients could easily understand. First published in 1998, it was the first resource of its kind on PH amidst all the complicated medical texts that were available at the time.

PHA updates the *Survival Guide* every year under the guidance of medical editor Ron Oudiz, MD, with assistance from a host of medical professionals and patients who volunteer their time to ensure the book is medically accurate and easy to understand.

To order your copy, call 301- 565-3004 or visit www.PHAssociation.org/OrderSurvivalGuide.

Thank you to all the volunteer editors who assisted with the publication of the Fifth Edition, 2013 Revision of the *Survival Guide*!

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By Ellie Falaris Ganelin

PHA Design & Publications Manager

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**PHA thanks the sponsors of the 2013 Sometimes it’s PH: Early Diagnosis Campaign!**

Visit the campaign website at www.SometimesItsPH.org and read more about it on page 19.
late in April, PHA President Rino Aldrighetti and Julia Friederich, PHA’s international program associate, boarded a plane to Jeddah, Saudi Arabia, for the Saudi Association of Pulmonary Hypertension’s 6th Annual PH Meeting and the 3rd Pulmonary Hypertension in the Young Assembly. Doctors and researchers came from all over the Gulf Region, as well as from Brazil, Germany, Spain, Sudan, Switzerland and the U.K. An important reason for PHA’s attendance at the meeting was a leadership discussion on how PHA could assist the Saudi Association for Pulmonary Hypertension (SAPH) in the development of a patient structure.

The two days of SAPH meetings highlighted problems treating PH in different Middle Eastern countries. An emerging theme throughout the discussions was the need for better medical training and coordination in remote areas and improved patient support and education.

The meetings covered a wide scope of problems and updates from the clinical, academic and scientific research perspectives. Most of the presentations also managed to approach treatment from a well-integrated clinical and social approach. Many doctors pointed out that it was important to remember to treat the patient, not the catheterization numbers. A presentation on medical ethics included the perspective of Islamic ethics, which promote the pursuit of knowledge and scientific progress, “do no harm,” and the concept of putting what is best for your patients first and foremost beyond all other norms and rules.

The pediatric assembly began with a moment of silence in memory of the late Robyn Barst, MD, who helped develop the Saudi Guidelines for the Diagnosis and Treatment of PH. As it has throughout the world, PHA plans to continue Dr. Barst’s legacy of cooperation between our two countries as we move forward with translations of patient materials and as we continue to share ideas for both medical and patient support and education.

To this end, PHA recently signed a Memorandum of Understanding (MOU) with SAPH. An MOU is an agreement between PHA and a partner PH organization in which both organizations commit to share information and best practices to accelerate the growth of the PH movement.

“It was a wonderful experience,” Rino says, reflecting on the meetings and sharing of ideas. “We thank our hosts at SAPH and look forward to rapidly evolving this partnership.”

To learn more about SAPH, visit its website at saph.med.sa.

By Julia Friederich, PHA International Program Associate

What does the international community mean to you?

“I feel united to my friends across the world by the same language — the language of being a patient and knowing that not everyone has equal opportunity to access medical treatments. As PH is [better] known in the world, more pathways will open up [for] drugs where there are none. Through the union of the international community, we feel heard and supported.”

— Adriana Posada, Mexico

“For me the PH community means: PH patients, caregivers, health professionals, organizations and friends who promote PH awareness and develop activities to give us hope and improve our well-being.”

— Diego Gil, Colombia

“We feel very proud that we are a part of the big international PH community. No person can choose when or what disease to suffer from. Some people have rare diseases hidden inside of them, but that does not mean they do not have the right to live [life] to the fullest. On the contrary, they fight twice as hard as others to achieve their aims. ... We all have the same dream to find a cure for PH. Together, we can do more!”

— Natalia Maeva, Bulgaria
Interview with PH Patient
Evelyn Keltgen

Where do you live?
I live in Mankato, Minnesota.

How old are you?
I am 6 years old.

When were you diagnosed with PH?
When I was a baby. I couldn’t breathe when I was born.

How do you explain PH to your classmates if they ask?
I say, “Sometimes I can’t run for very long.” They ask, “Why?” and I say, “I have PH.” Then they ask, “What is PH?” and I say, “I can’t explain it. It is too hard to explain.”

What do you like to do for fun?
I like to swing, slide, and sled in the winter. I like gymnastics.

If you were a superhero, what kind would you be?
If I was a superhero, my name would be wolverine. I would help people. I would fight mean robots. (Pictured left: Evelyn’s drawing of herself as wolverine)

How is your family fighting back against PH?
They put me on oxygen when I’m sick, and I also do breathing treatments. We go and see Dr. Ivy, and we see Dr. Driscoll.

What message do you want to pass on to other kids who have PH?
Sometimes you might not feel good about it. But sometimes it helps me, I think. I like other kids with PH, including you. My best friend with PH is Katie Grace.

Meet other kids living with PH at www.PHAssociation.org/PHKids.
The PH community is full of heroes of all different ages doing amazing things for the PH community and the world at large. Read on to learn about two teens who have recently been honored for their acts of selflessness.

**Meera Salamah**

Meera was diagnosed with PH at age 8. Unable to play soccer, she joined her school’s environmental club. The club fostered her love of nature. When Meera had the opportunity to take a Make-a-Wish trip, she knew what she wanted: to plant a tree in the Maui rainforest, “So that others can breathe easier.”

About a year ago, Meera was contacted by Rachelle Sparks. Rachelle was writing a book about Make-A-Wish trips. The Make-a-Wish Foundation recommended Meera’s story, “because Make-A-Wish found my wish to be unique and selfless,” says Meera.

The book is called *Once Upon A Wish: True Inspirational Stories of Make-A-Wish Children* by Rachelle Sparks (Mar 5, 2013), and since its release, Meera, along with her friends and family, has been using the book to help raise awareness of PH through book signings and at local events.

**Trey Scott**

Trey was diagnosed with PH at age 3. At age 18, he was waiting for a double lung transplant. When Cardiac Kids, a local support group for families and kids born with heart defects, asked Trey if there was anything special he wanted, he told them he wanted to hold a blood drive with the American Red Cross.

Trey’s family, friends and Cardiac Kids put together a blood drive in his honor in February 2012. Right before the blood drive, Trey got the call for transplant. One year post-transplant, Trey was honored by the American Red Cross for his contribution.

“When you give blood, you’re giving more than just your blood,” explains Trey. “You’re giving a person a couple seconds or minutes longer so the doctors can pull out the complication or problem and save them.”

Have you been doing news-worthy activities? Share them with other PH teens in our Facebook group or email us about them! Join other teens with PH by searching for PHA Teens on Facebook, or email PHA at Teens@PHAssociation.org.

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By Michal Rachlin  
PHA Kerry Bardorf Family Support Program Coordinator

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**Attention, teens! We’ve got lots of stuff for YOU!**

**PHA Teens Facebook group:** A space for teens with PH! Join by searching “PHA Teens” on Facebook.

**Teens online:** Check out our articles for teens at www.PHAssociation.org/Teens. Interested in submitting your own? Email Teens@PHAssociation.org.

**Teen Transition Guide:** Are you thinking about transitioning to adult PH care? Check out this how-to with all the facts: www.PHAssociation.org/Teens/Transition.

**PH Email Mentors:** Do you have questions for someone who “gets it”? Shoot an email to one of our young adult email mentors at www.PHAssociation.org/Mentors.
School Days: Keeping Up with Work and Play

Whether your child is just entering kindergarten or is already thinking about graduation, PH can be disruptive to his or her school experience. The first step to ensuring that your child has a safe and positive educational experience is to arrange for the accommodations he or she may need. Read on for a brief introduction to Individualized Education Plans (IEPs) and 504 Plans and some main points to remember when communicating with your child’s school personnel and classmates. For a more detailed overview of all the topics touched on in this article, watch our Preparing for the School Year with PH webinar at www.PHAssociation.org/SchoolWithPH.

IEPs and 504s in 60 Seconds or Less

A 504 plan, which falls under the Americans with Disabilities Act, spells out the accommodations needed for a child with a disability to participate in school activities. Children diagnosed with PH are eligible for a 504 plan because they have a chronic illness. An Individualized Education Plan (IEP), which falls under the Individuals with Disabilities Education Act, is concerned with providing educational services to students who have a learning impairment and require specialized instruction. PH medications may have an effect on a child’s cognitive functioning, making a child eligible for an IEP instead of a 504 plan. Parents should discuss which option is appropriate for their child with school administration.

Communicating with School Staff

“In high school, along with an email explaining my PH and 504 plan, I had a meeting with my teachers. For my teachers who weren’t able to come to the meeting, I stayed after class and quickly talked about my PH and things that might happen because of my PH during the year. I think talking to my other teachers really helped because learning about my PH wasn’t just one of their emails, but an actual person who talked to them about what they needed to know. Throughout the year whenever I needed to go to the nurse, my teachers would always ask if I needed someone to walk with me even if it wasn’t PH-related. I was so happy that they remembered that if it’s PH-related, I need someone to walk with me and they were taking extra precautions.”

— Dani Epstein, age 15

While your child is at school, your child’s teacher is the caregiver. As such, it’s immensely important to keep your child’s teacher in the loop on medication changes, health ups and downs, and how your child is doing generally.

One challenge that many PH patients encounter, regardless of age, is “not looking sick.” Jeanne Kane, an education specialist at the Vera Moulton Wall Center, says, “It’s about educating your school staff.” Jeanne often helps teachers “get it” by comparing PH to their experience when they take cold medicine — you can look okay but still not be at your best. It’s also worth getting to know your school or district nurse. This is the person who should have a health plan ready if your child has an emergency, and this nurse can be an important advocate if you have difficulty communicating your child’s needs to the teachers.

Many parents provide a letter from their child’s doctor or use PHA’s School Resource Guide to help school personnel understand PH and their child’s treatments. The School Resource Guide offers a basic overview of PH, PH treatments and associated side effects, and customizable forms for you to fill out specifying your child’s emergency information. The newest version of the School Resource Guide, which will be released in early August 2013, was revised with input from 30 teachers around the U.S. to make sure it is both an effective and comprehensive resource. The Guide is available at www.PHAssociation.org/Parents/School/ResourceGuide.

Communicating with Classmates

“There’s a lot of research showing that kids who heard from a professional about their classmate’s illness helped support that child coming back to school with a chronic illness. Those peers actually become a really good support system for that child,” shares Jeanne Kane. Jeanne recommends having someone explain PH to a child’s class when he or she is in elementary school. This might be you, your child’s doctor, a specialty pharmacy nurse or other PH healthcare professional. In high school, Jeanne recommends talking just with the teachers. You can also practice answering questions about PH with your child to help him or her feel comfortable responding to classmates and teachers.

THERE’S MORE TO LEARN!
Get informed about your child’s rights, arranging accommodations and helping your child cope in school at www.PHAssociation.org/Parents/School.
CVS Caremark is committed to creating thriving, healthy communities while helping to provide better outcomes for all. Through our integrated offerings across the entire spectrum of pulmonary arterial hypertension care, we are uniquely positioned to engage patients in behaviors that improve their health. Our PAH nurses and specialty pharmacists partner with hospitals and physician practices to help streamline both inpatient and outpatient PAH care.

Learn more about CVS Caremark Specialty Pharmacy and our commitment to PAH service excellence. Please call 877-242-2738 for more information.
PASSAGES is PHA’s way of honoring those who have lost their battle with PH, as it has been since the very first Pathlight was published in May 1990. As we learn of patients’ passing, we inform the PH community. PHA extends sympathy to the families and friends of those who are gone but not forgotten; each Pathlight is dedicated to their memory.

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The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x803 or SarahB@PHAssociation.org to have a recently deceased loved one’s name listed in Passages or to report errors or omissions.

For those for whom it would be helpful, PHA has developed a resource, Mourning a Loved One: A Guide to Grieving, which is available at www.PHAssociation.org/Caregivers/Bereavement. For more information, or to request a print version of this guide, please contact Bereavement@PHAssociation.org or 301-565-3004 x803. We welcome all loved ones to remain a part of our community for as long as it is beneficial.
IN MEMORY OF


TAKE A LOOK! Sustainers Circle Members Recognized

PHA recognizes members of our Sustainers Circle in the donations list. Look for a symbol to see who has made a sustained commitment to donate to PHA on a monthly basis. If you are not a member of our Sustainers Circle but are interested in joining, visit www.PHAssociation.org/Donate/SustainersCircle or call Erin Wiegert at 301-565-3004 x762. You may also use the remittance envelope enclosed in this issue of Pathlight.

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Last call for submissions!

ATTENTION, PH COMMUNITY!
PHA’s Art from the Heart design contest will be closing soon.

We are only accepting artwork until July 31, 2013!

Don’t wait! Get creative for a cure and visit www.PHAssociation.org/ArtFromTheHeart to join the contest.

You can help PHA work to find a cure for PH by drawing a picture that shows a PH story for the PHA Art from the Heart bookmarks design contest.

Winning submissions will be printed on bookmarks that are used to say “thank you” to PHA donors.