Persistent Voices

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The race to cure pulmonary hypertension depends on the dedicated, talented researchers we are so fortunate to have in our community. It also depends on us. No matter who you are, the PH community needs your unique contribution to raising PH awareness this November during Pulmonary Hypertension Awareness Month 2013.

Mary’s theme, “Racing Toward a Cure” was selected for PH Awareness Month 2013 and PHA’s International PH Conference and Scientific Sessions in 2014. The theme honors Team PHenomenal Hope — five women who will bike across the U.S. in a nonstop relay during next year’s Race Across America (RAAM) to raise money for PHA — and looks ahead to our 2014 Conference in Indianapolis, a city synonymous with another famous race — the Indy 500.

Whether you are biking across America as a member of Team PHenomenal Hope, organizing a Unity Miles fundraising event (see page 16) or staying active by emailing Members of Congress and sharing your story with the local media, the PHA staff is your pit crew. Let us help you turn your talents and interests into awareness-raising successes this November.

Look for awareness-raising activities from the PH community throughout this issue of Pathlight, or check out our staff picks for ways to get involved on page 18.

“Every time I hear of another PHriend who has been diagnosed … I feel the urgency that a racing theme suggests — Please, researchers, we need you! Hurry, hurry, hurry!”

—Mary Svikhart

#12097

Federal employees and the military can support the PH cause!
TO SHARING YOUR EXPERIENCE

Living PAH is a free resource offering information and tools to help you take a more active role in your care. It is a community where individuals, groups and programs unite in the idea that far more is possible when we work together.

Launching in November, the new LivingPAH.com will feature a tips section that collects the experiences of patients, caregivers and family members dealing with PAH. You can learn from others or share some advice of your own. Your experience may be just what someone else needs to hear.

ENROLL TODAY AT LIVINGPAH.COM
Fall is a time of opportunity and hope for our community, and you can read all about it in this issue of Pathlight. We are gearing up for Awareness Month in November, and as you saw on the front cover, our theme this year is “Racing Toward a Cure.” This theme highlights our drive to find a cure for PH and celebrates the steps we are taking along the way. Find out how you can get involved on page 18.

This fall also marks the conclusion of our first year of PHA chapter growth. We started this venture as a way to ensure that PHA remains financially strong. After all, as PHA President Rino Aldrighetti reminds us, “It is no less expensive to fix a rare disease than a common one.” Our three chapters in New York, the Midwest and San Francisco have been incredibly active this year, laying the groundwork for strong growth into the future. You can read more about the chapter highlights and our plans for the future on page 15.

As we wrap up this year and look ahead to 2014, we have some exciting activities on the horizon — including cheering on Patty George, MD, and the Team PHenomenal Hope cycling team as they Race Across America in June 2014. Dr. George is our “Meet the Doctor” spotlight on page 11 in this issue.

You can also show your support for Team PHenomenal Hope and raise PH awareness and funds through the Race of Our Lives campaign. Host a Unity Miles event in your hometown or spread the word about Team PHenomenal Hope through social media (see page 16).

The individual stories within our community make us strong, and this issue is full of personal narratives, sharing strength and hope in the face of adversity. In the PHenomenal Lives section, we share the story of PH patient Kathy Morton, who cycled across Iowa this summer to achieve a personal victory. In the Persistent Voices section, Barbara Linser shares her PH story and her artwork, while Marcia Brown explores what it’s like to be a patient dealing with both PH and scleroderma. In the PHenomenal Youth section, you will meet Madison Wegener, a very wise 8-year-old PH patient who says, “My friends are still my friends. I am still Madison. I just have PH.”

As you will see in the pages of this Pathlight, our community is full of life. We have exciting plans to wrap up 2013 and look ahead to 2014, and we’re thrilled to have you join us on the journey. ♦

Valleric McLaughlin, MD
PHA Board Chair

PATHLIGHT: A USER’S GUIDE

PHenomenal Lives
Health Matters
Advancing the Cause
Community Classroom
PHenomenal Youth
Family PHocus

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

Look for this icon throughout Pathlight to read news from around the world.
Kathy Morton has endured ups and downs living with PH, but that hasn’t kept her from taking on some tough challenges. “Sometimes what appear to be really big hills don’t turn out to be that bad. Other times, hills that appeared small turned into the biggest obstacles,” she says.

Kathy is talking about the Des Moines Register’s Annual Great Bicycle Ride Across Iowa (RAGBRAI), a weeklong bike ride she completed this July. RAGBRAI is the oldest, largest and longest bicycle touring event in the world.

The whole journey was 406.6 miles, with overnight stops in designated towns across the state. Kathy averaged just under 60 miles a day, braving steep inclines, headwinds and the summer heat. Cycling friends Arek Wdowiak and Michelle Eggert joined her on the journey, and Kathy’s husband Joel Morton and friend Rebecca Bidleman followed along in an RV. “I can’t begin to list all the people who are involved with RAGBRAI, from the planning stage, to the towns, to family members and co-workers,” Kathy says. “With PH we also have teams of healthcare workers, family and friends among others who help us.”

Kathy was diagnosed with pulmonary hypertension in June 2005, only a few months after she started experiencing symptoms. She had been taking a tae kwon do class with her children since the previous year. By the spring of 2005, she started feeling breathless and dizzy during workouts. “It seemed odd that I was more out of shape after several months than I was when I started,” she says.

After undergoing a series of tests with her primary care doctor and cardiologist, she was diagnosed with PH and now sees a PH specialist in Chicago. She had mainly been taking subcutaneous treprostinil until January 2012, when she joined a study that is still ongoing to test an implantable pump.

She attributes her quality of life to early diagnosis and treatment. “I work full time as a high school teacher, exercise regularly, and experience a virtually symptom-free life,” Kathy says. “Early diagnosis has allowed me to call the shots in my life, rather than PH.”

During RAGBRAI, she made sure to pace herself and drink a lot of water. If it got too hot, she would stop to cool down. Kathy, along with many other riders, chose to walk, rather than bike, up some of the particularly steep hills.

“If you need to stop and catch your breath, it’s OK,” Kathy says. “You don’t have to prove anything to the world. All that matters is that you know you are doing your best.”

RAGBRAI is a statewide tradition among Iowans. The bike route changes from year to year, allowing eight towns to act as “host” communities where the riders stay overnight. The cyclists ride anytime between 6 a.m. and 6 p.m. through each day of the event and are met with evening entertainment in each host town.

Many Iowans show their hospitality to the RAGBRAI participants — Kathy observed people letting the riders use the bathrooms in their homes, while other families sold or gave away water, Gatorade and snacks from their driveways. One family allowed riders to jump in their swimming pool as they passed by.

Kathy, who now lives in Peoria, Ill., is proud to call herself an Iowan, having grown up in the Hawkeye State. As a child, the RAGBRAI route stopped in her hometown of Ames several times, and she got to see the riders in person — it’s an experience that always meant a lot to Kathy.

Now that this great bike ride is over, she is already contemplating the next adventure, be it a trip to Japan or biking through wineries in Spain. “There is hope,” Kathy says. “PH doesn’t mean the end of your life.”

You can read Kathy’s diagnosis story at: www.SometimesItsPH.org/KathyMorton

Learn more about RAGBRAI: www.ragbrai.com

By Ellie Falaris Ganelin, PHA Design & Publications Manager
I’m 31 years old, from Bogotá, Colombia, and I have lived in the city of Cali for 14 years. When I was 7 years old, I started to have symptoms like breathlessness and cyanosis, especially when I would participate in physical activities at school. My parents, worried about the situation, took me to a specialist in cardiology who thought it would be a good idea to do a cardiac catheterization and take a lung biopsy to get precise data for a diagnosis. The results showed that I had pulmonary hypertension as a result of congenital heart disease.

The doctor suggested a surgery to correct the defect, but due to the high level of risk involved, as well as a series of complications that I had during my biopsy, my parents decided not to authorize it. Since then my treatment has always been pharmacological and controlled by specialists in cardiology and pulmonology. There have been adjustments along the way, but fortunately, thanks to effective treatment, and especially to a central motivation to live, I have been able to keep my health stable.

To understand the impact of an illness like pulmonary hypertension is not easy at any stage of life; it arrives without warning and forces you to change your thoughts and habits. In my case I understood that it didn’t come to me as an obstacle, but rather a motivation and an opportunity to set challenges and overcome them. In my childhood and adolescence, I would often think of the limitations that I had in participating in many of the normal activities for my age, but I always managed to transform these thoughts into objectives for my new life.

For example, for five years I belonged to the Andean Music Group at my school. I played wind instruments like the quena (a type of Andean recorder) and the zampoña (the Andean panflute), which one would think would be counterproductive for me. However, incredibly, I discovered that I could play well, and the happiness of my achievements, in my opinion, was what motivated me to continue in spite of my adversities.

While playing in the band, I also trained with the gymnastics team. Although I was no great gymnast, I showed myself that I could do it. I also organized sports, musical and intellectual events for the school and at the intercollegiate level; I always gave myself challenges in different areas. All of these demonstrated a need to prove that I was capable of doing a lot of things.

My good academic performance, my organization of all those activities, and my motivation to always move forward landed me a scholarship to a university. Today, I am an industrial engineer, and I have my postgraduate degree in administration, which has allowed me to work in large companies with great results.

My worries in relation to this illness continued, however; and my desire to know other patients made me reach out to the Pulmonary Hypertension Association in the U.S. in 2010. PHA staff invited me to attend the biennial International PH Conference and Scientific Sessions in Garden Grove, Calif. There, besides learning more about symptoms and treatments, I had the opportunity to get to know patients, patients’ families, leaders of associations in other countries, and members of the Sociedad Latina de Hipertensión Pulmonar (SLHP, or the Latin PH Society), which is working to give hope to the Latin PH community through support, education and awareness.

From that moment I started my work in support of patients in Colombia and continued my participation in PHA’s 2012 International PH Conference in Orlando, Fla., and an international gathering in San José, Costa Rica, in 2012. Today I am a support group leader in Colombia, and my goal is to share experiences and do awareness-raising activities with other patients, family members and health professionals in the PH community.

Written by Diego Fernando Gil Cardozo, PH Patient, and translated by Julia Friederich, PHA International Program Associate
People cope with challenging situations differently. For PH patients and caregivers, pets are an important part of coping with illness. This summer PHA asked the PH community to share pet stories with us online, and here is some of what we found.

Statistics show pets are natural stress relievers and mood enhancers. Just watching a fish or a dog can make a person feel less anxious and stressed. The body actually goes through physiological changes. WebMD states that “the level of cortisol, a hormone associated with stress, is lowered. And the production of the chemical associated with well-being is increased.”

Alan Beck, PhD, director of the Center for the Human-Animal Bond at the Purdue University School of Veterinary Medicine, says that for people with chronic illness, pets provide a source of humor, a distraction from discomfort and an opportunity for interaction with other people. While with their animals, patients aren’t thinking about PH, but about their pets.

David Grady, who has PH, says his dog Samantha’s wonderful disposition brings a smile to his face whenever he comes home: “I don’t have time to think of [my] PH because of the wonderful time we spend together.”

Many patients find that their pets help them fight depression. Geal Goldbeck says her dog Gizmo “has been my rock when I was tipping over to a dark side and is always there to lick up my tears when I am feeling down.” Dr. Beck, the Perdue vet, says, “Dogs are sensitive when a member of the pack is not doing well, so when you’re having a bad day, they lie quietly on your bed and are supportive in their own way.”

PH patient Nicole Hedgepeth notices this in her bulldog Tank. She says, “He can sense when I’m not feeling well and then will never leave my side. He’s my ‘fur child,’ my shoulder to cry on and listens without judgment or giving his opinion. He is my biggest cheerleader and trusted friend.”

Pets are also great for patients because they need our companionship as much as we need theirs. Lynn Bastian, who has two cats — Phinehas and Sophia — says, “My cats offer me not only physical comfort (purring and cuddling), but mental comfort as well. Sophia sleeps with me and likes to sleep on or next to my pump sometimes. I think she thinks it is purring at her. Pets offer unconditional love. They don’t judge me when I’m having a bad day. People sometimes think they need to fix you. Cats just love you!”

Many pets, such as dogs or horses, help their owners get exercise. PH patient Mary Ann Cheng says her dog Skippy “takes me on walks of at least one or two miles daily. In cold weather (below 18 degrees), we climb 10 flights of stairs indoors. My six-minute walk test distance gets longer with each test. At my last appointment, my PH doctor told me, ‘Definitely keep the dog!’”

Pets also help support families and caregivers. When Teresa Brown’s mother passed away, Teresa found that having her dog Buddy helped her move forward. Teresa says, “After being my mother’s caregiver for six and a half years, I would be lost without someone, or in this case something, depending on me.”

You can find a pet that fits your lifestyle. Or if you can’t adopt your own pet, you can volunteer at a local shelter. Visit the Humane Society of the United States (www.humanesociety.org/community/volunteers) or contact a local shelter to find volunteer opportunities near you. To read all of the coping stories about pets our community has shared this summer, visit our Pinterest page (www.pinterest.com/phassociation/pets-of-ph).

By Allison Siebenberg, former PHA intern, Web Services and Patient & Caregiver Services departments

Look for more questions from PHA online, and join the conversation at www.PHAssociation.org/ConnectOnline.
Art from the Heart: PHers of All Ages Show Their Colors

PHA’s Art from the Heart contest offered members of the PH community a way to use their artwork to help in the fight against pulmonary hypertension. The winning artwork will be used to produce “thank you” bookmarks that raise awareness and thank donors who support PHA’s work for a cure. This year’s Art From the Heart contest was held in memory of Christen White, who lost her battle with PH in 2002.

Read on to meet our four winners and learn more about the inspiration behind their artwork.

MURIEL SLATER, AGE 62

“I was diagnosed with pulmonary arterial hypertension one year ago and have slept with nighttime oxygen ever since. … Beyond being compliant with my medications and testing, I work at keeping a positive attitude and a positive outlook.

As a lifetime bird lover, I chose to draw a bird to represent myself with my oxygen therapy. The bird is wearing a cross that represents my faith. The rainbow and the cross represent hope. The colorful design also represents hope and expresses a positive outlook for a cure.”

NICOLE NORTHRUP, AGE 18

“I wear oxygen all the time, and I have to be in a wheelchair if I go somewhere with a lot of walking. I have to deal with the stares that others give me when I’m out.

There is a cure somewhere. We just have to find it, and we will have to get through a bunch of obstacles to get to it.

My character Alfie sees the cure and knows she has to obtain it to give to all of the PH patients. She will have to find a way around the obstacles. They might be challenging, but she knows that it will all be worth it in the end.”

VICTORIA CHAVEZ, AGE 25

“My mother was diagnosed with PH last year, and it has changed our entire family’s life. … In my life my mother has the role of mom, dad, advisor, best friend. She is the person I turn to, the one who is always there without fail. There is so much more I want to experience with her. For me, my mother is the reason finding a cure is imperative.

To me, having PH is like not being able to breathe underwater. Finding a cure would be as though you are free above the water, able to breathe easily again. I also drew the ocean because my mother loves the ocean. She can’t swim anymore because of PH, but we hope that one day she will again.”

ROSEMARY HUGGINS, AGE 47

“Finding a cure would mean getting my life back — the life I wanted, not the one thrust upon me by pulmonary hypertension.

My picture shows many hands reaching for a cure. The cure won’t be found by one person — it will take many people working together.”

By Michal Rachlin
PHA Kerry Bardorf Family Support Program Coordinator

Interested in receiving one of these bookmarks?

One monetary donation can make a world of difference to the PH community, and we will thank you with one of these colorful bookmarks. Visit www.PHAssociation.org/ArtFromTheHeart or contact Maggie Bahrmasel at 301-565-3004 x756 to make your donation today.
Working Around PH: Find the Right Work-Life Balance to Remain an Active Member of the Workforce

If you or your loved one has been diagnosed with pulmonary hypertension, maintaining the typical 9-to-5 work routine can be tough.

Caregivers: Know that you’re not alone — according to a 2009 Metlife survey, 7 out of 10 caregivers work full or part-time. These caregivers make up 15 percent of the U.S. workforce, and this number is expected to grow in coming years as people live longer and retire later.

PH patients: According to the Partnership to Fight Chronic Diseases, at least half of Americans are living with a chronic disease, forcing them to make decisions about whether they can continue to work. In fact, pulmonary conditions are one of the most common chronic diseases among Americans.

Each family will need to find the right approach for their own situation, but it’s important to know that there are options besides all-or-nothing when it comes to work.

Flextime Scheduling. Flextime scheduling means different things at different companies. It may mean that you are allowed to choose your own schedule but need to be consistent (i.e., you could choose to work 7 a.m.–3:30 p.m. vs. 9 a.m.–5:30 p.m.), or it may mean that you can choose your specific hours day-to-day as long as you put in the required total work hours.

The Four-Day Work Week. The four-day work week typically involves longer business hours, balanced by a three-day weekend. In some cases, employers keep normal business hours but are open four days a week. Research has shown that the four-day work week is beneficial for employees and employers alike, giving employees more time to recover and reenergize before Monday rolls around and encouraging employees to use their time more productively.

Work From Home. While you may not be able to or want to negotiate a shorter work week, you may be able to negotiate to complete a certain percentage of your hours telecommuting from home. Many employers can arrange for you to access your files from a home computer and to participate in meetings via phone, Skype or a webinar system.

Respite Care from Insurance, State and Other Sources. Long-term care insurance policies, Social Security, veterans’ benefit plans, local and state agencies all may have programs to help cover the costs of someone coming to your home or for you or your loved one to go out to a respite care program for patients or caregivers. In some cases, these programs may even pay caregivers a small “salary” for their caregiver role.

Do your research; these programs may have very specific guidelines for how you use the “respite time” they cover.

Know Your Rights. Various state and federal laws protect the workplace rights of people living with serious medical conditions and their caregivers. The Family and Medical Leave Act (FMLA) and Americans with Disabilities Act (ADA) are two of the most important laws for you to know about as a working PH patient or caregiver.

» The Family and Medical Leave Act (FMLA). FMLA allows eligible employees to take up to 12 weeks of unpaid, job- and health benefits–protected leave each year for serious health conditions, whether their own or an immediate family member’s. If this leave is for medically necessary care, FMLA allows caregivers and patients to take those 12 weeks intermittently (i.e., one day a week). For more information, call the Department of Labor’s FMLA information number at 1-800-959-FMLA or visit www.dol.gov/whd/fmla.

» Americans with Disabilities Act (ADA). ADA not only covers people with disabilities — it protects their caregivers from workplace discrimination, too. Workplace discrimination is, essentially, differential treatment of one group of employees over another. If your place of employment allows mothers to take time off to care for their sick kids, then legally they can’t deny you the same right to take time off to care for your sick spouse or parent. ADA also entitles individuals to reasonable accommodations. If you need to leave the office on your lunch breaks to mix medication or take your loved one to a doctor’s appointment, a policy that bars employees from leaving the office at lunchtime could be in violation of “reasonable accommodations” under ADA. For more information, call 800-514-0301 or visit www.ADA.gov.

Whatever work-life balance you and your loved one choose, know that hundreds of other PH patients and caregivers are facing similar choices at the same time. If you’re looking for others to share ideas with, try our telephone, in-person or online support groups. Get connected at www.PHASassociation.org/Community.

By Michal Rachlin
PHA Kerry Bardorf Family Support Program Coordinator

www.PHAssociation.org
Our Summer Interns Explain the Value of Working at PHA

PHA is able to provide programs and services to the PH community thanks to the teamwork of staff, donors, community members and — throughout the various seasons of the year — the hard work of our interns. Read on to meet the interns who have been an integral part of PHA this past summer.

Savannah Chaisson, Medical Services Intern, Elon University, Elon, N.C.

“My summer internship at PHA has been an incredible experience that has encouraged me to pursue future opportunities in public health. The medical services team at PHA has helped me gain a great perspective on patient education and working in a nonprofit environment. I have no doubt that what I have learned at PHA will continue to benefit me in my endeavors finishing school and beyond.”

Laura Johns, Patient & Caregiver Services Intern, Ohio University, Athens, Ohio

“I enjoyed my time working at PHA this summer in the Patient & Caregiver Services department. I gained a lot of valuable experience through this internship. This summer, I wrote blog posts for PH Plus and Generation Hope, helped create PHA’s 2013 Caregiver Survey (to be launched in November 2013), developed a resource about homeschooling and more. Many of the projects I worked on allowed me to interact with people in the PH community. Everyone I got a chance to interact with was friendly, encouraging and helpful. I want to thank PHA and the pulmonary hypertension community for providing me with such a great opportunity.”


“I am grateful for this wonderful opportunity to be a part of the work at PHA. I have witnessed and admired PHA as truly patient-centered, powered by care for patients and fueled by its growing and strong network of patient support groups. During my internship, I actively learned about the PH community, talked to inspiring support group leaders, researched leader discussions and the 2012 leader census, and used that research to make edits to the Support Group Leader Manual. I love how PHA mobilizes patients to become informed owners of their disease and leaders in their communities, so I am thankful to be a part of this movement!”

Rachel Parker, Development Intern, Catholic University of America, Washington, D.C.

“I have learned so much from this internship — from how to work with every type of printer to basic communication skills. My favorite part of the internship was definitely working in such an inspiring atmosphere. Everyone here at PHA is so dedicated to advancing PHA’s mission to raise awareness and funds for PH.”

Haley Payne, Advocacy & Awareness Intern, Indiana University, Bloomington, Ind.

“I learned so much at PHA this summer. I gained a wealth of experience working in a professional environment and developed several marketable skills. I would recommend this internship because this is not what you would consider the stereotypical internship — I have worked on a variety of projects that have contributed to the larger goals of PHA, and I have definitely enjoyed my time here!”

Allisson Siebenberg, Social Media & e-Marketing Intern, University of Maryland, College Park, Md.

“Working as an intern at PHA this summer has been a great experience. I was able to come to work with a smile on my face every day because of how much I loved working here. I always had something to do, and I feel as if my work made a difference. One of my favorite experiences at PHA was when I attended a support group meeting. The people were some of the most inspirational and welcoming people I have ever met.”

Interested in Interning at PHA?

Help change the future of this disease. Become a PHA intern, and make a real difference. To learn more about PHA’s internship program or to apply, visit www.PHAssociation.org/Internships or email Internships@PHAssociation.org. While on our website, check out video testimonials from past interns.
Q: How does the clinical trials process work for bringing new PH medications to market?

A: All therapies, including those developed for pulmonary arterial hypertension (PAH), must first be studied in laboratory animals to determine any potential for toxicity before being evaluated in humans. If the therapy has an acceptable safety profile in animal studies, clinical trials (also known as clinical studies) can proceed.

In Phase 1 trials, researchers test single (and on occasion, limited repeated-dose) administrations of the experimental drug and compare the resulting effects with those resulting from placebo treatment. These early studies usually involve 20–80 healthy volunteers and evaluate side effects and drug concentrations in the blood across different dose ranges. These investigations are relatively short in duration and can involve both healthy individuals as well as patients for whom the drug is finally intended. Any participation of a healthy individual or a patient in any clinical trial is voluntary, and no study-related procedure can occur without written informed consent. Participants in a clinical trial can withdraw at any time without prejudice to their future medical care.

Once possible dosing regimens and acute safety issues are better defined, a Phase 2 trial can begin. In Phase 2 trials, the experimental treatment is given to a larger group of patients, typically for a longer period of time than in Phase 1. The purpose of a Phase 2 trial is to evaluate what doses of the drug might be effective, to evaluate the best measures of determining effectiveness and to further evaluate safety. Because some patients may improve spontaneously over a brief period of time even without a drug, these trials often have a control group not receiving the experimental drug for comparison. With Phase 2 PAH trials, participating patients usually enter a study evaluating the new therapy as an addition to their existing therapy. As a result, the “placebo group” is not a “no-treatment group” but a group receiving placebo in addition to each participant’s existing background therapy. Historically, Phase 2 trials in PAH have been three to six months in duration, with the availability of extension studies for patients who are believed to be receiving benefit from the therapy.

In Phase 3 trials, the treatment is given to even larger groups of patients to confirm the effectiveness observed in Phase 2, to further evaluate side effects, to compare the treatment being studied to commonly used treatments (when appropriate) and to collect additional information that will allow the determination of its risk-benefit profile.

When all the data are collected, the company or governmental agency that sponsors the clinical trials collates and summarizes the information and submits it to regulatory agencies (e.g., the U.S. Food and Drug Administration) for consideration of approval for sale and availability to patients. The latter process of regulatory review usually takes 10–12 months and often involves submission of the regulatory data to multiple jurisdictions simultaneously (e.g., the European Union, the U.S., etc.).

The degree of evidence that determines whether a drug is safe and effective enough to be approved depends to a large degree on the seriousness of the disease it is intended to treat. With PAH, the seriousness of the disease has resulted in regulators encouraging the development of new drugs and showing significant receptivity to development programs that are streamlined, requiring fewer and smaller trials with less drug exposure than in non-serious diseases and providing shorter regulatory review periods.

After approval, Phase 4 trials (often called post-marketing studies) may evaluate a drug or therapy in different but related doses, durations, outcome measures or conditions slightly different from its approved indication.

The process of drug development is usually costly and lengthy, and the pipeline for PAH drug development remains an area of strong interest with novel therapies being continually investigated. You can often access information on clinical trials as they occur. With PAH, a general description of a recruiting Phase 2 and 3 clinical study (including general eligibility criteria to participate) is usually listed at [http://clinicaltrials.gov](http://clinicaltrials.gov).

Answer provided by Mark Robert Nicolls, MD, Chief, Division of Pulmonary and Critical Care Medicine, Associate Professor of Medicine, Stanford University School of Medicine, Stanford, Calif.
Meet Dr. Patricia George: Racing Across America to Raise Support for the PH Community

Next summer Patricia George, MD, will don her Team PHenomenal Hope jersey as a member of the cycling team racing nonstop across America to raise pulmonary hypertension awareness and funds for PH research and patient services. Before that exciting race, we contacted Dr. George to learn more about her involvement with the team and her experience as a PH practitioner.

Dr. George is an assistant professor of medicine at the University of Pittsburgh/UPMC, and she serves as the pulmonary transplant liaison for the Cardiology/Pulmonary Comprehensive Pulmonary Hypertension Clinic at UPMC. Her clinical focus since 2007 has been lung transplantation and PH.

You are part of Team PHenomenal Hope, preparing to support the PH cause through the Race Across America (RAAM) in 2014. How did this goal come about? I have been inspired by the incredible resilience of people who live with PH but do not let it defeat them. I have ridden and raced bikes and had this nagging notion about someday racing in RAAM, claimed by many to be the most difficult bike race in the world. It was one of those ideas that settles in the back of your mind and surfaces from time to time. At the 2010 PHA International PH Conference, like many, I was inspired by PH providers Ray Benza, Robert Franz and Jessica Lazar, who climbed Mount Kilimanjaro to raise PH awareness. I saw how people who accomplish extraordinary feats can inspire others. Suddenly, this nagging notion grew into a gut feeling, as I realized we could utilize our passion for cycling to do something positive for the PH community.

What do you and your team want to accomplish by participating in the race? Our mission is to dedicate our training and racing to the PH community, raise PH awareness and generate funds to find a cure. RAAM provides a tremendous platform to raise awareness in our own communities and nationwide. We hope to raise a significant amount of money to positively impact research for a cure and patient services and, finally, to inspire people living with PH to participate in this effort — whether by raising awareness through hosting their own events, sharing their stories, or spreading the word to friends in person or on social media.

We believe Team PHenomenal Hope is not just our group of cyclists and crew members but the team of the PH community. We want everyone to be a part of this effort. Team PHenomenal Hope is a team of cyclists, supporters, patients, caregivers, healthcare professionals, researchers and many more.

From your work, do any cases or patients really stand out to you? I think every doctor has certain patients who have taught them something — whether it is a unique manifestation of their disease or just the strength of how patients live with their disease.

In the PH clinic, in addition to helping evaluate and care for patients, I help patients on maximal medical therapy through transplant evaluations. Throughout this I’ve developed close relationships with patients, and it has been rewarding to see those who thrive after transplant. On the other hand, I have struggled with complicated patients who were referred too late in their disease, and I have seen people miss the window of opportunity for transplant. This is something that stays with me, not only inspiring me to raise awareness about early diagnosis and treatment, but also early referral for lung transplantation. Transplant evaluation takes time and requires much testing. We would rather see people too early than too late.

What’s the most important piece of advice you give to your patients? To patients I’d say, “Be your own advocate.” Ask questions and seek answers. Learn about PH from your physicians, and communicate with them so they can best help you get your healthiest. You are not in this alone. There is an incredible community out there that can help support you in living with PH.

Do you have any parting words? Looking back 10 years, I don’t think I envisioned just how amazing my life would be right now. I am grateful and privileged to work with wonderful colleagues and patients in my “day job” as a clinician and researcher, and I truly enjoy riding my bike for a cause very personal to me. My goal is to honor those with PH by working hard as a physician, pursuing further understanding of the disease through my research, and training as a member of Team PHenomenal Hope.

Interview by Briana Rivas-Morello, PHA Patient Education Associate
Meet the New Members of the PHPN Executive Committee

This September, three new members joined the PH Professional Network (PHPN) Executive Committee for two-year terms. Michelle Cash joins as Vice-Chair of the Symposium Committee, Avery McKee as Chair of the Practice Committee and Lisa Wheeler as Chair of the Membership Committee.

Michelle Cash, MSN, RN, APRN, Cincinnati Children’s Hospital Medical Center, Cincinnati, Ohio

How did you begin working in the field of PH? While looking for a nurse practitioner position, I interviewed for this job that was exclusive to caring for PH patients. After researching the disease state on PHA’s website (true story, I promise), I decided that advocating and caring for chronically ill patients and their families through a significant portion of their lifespan would come with great satisfaction.

What is your area of expertise? I care for pediatric patients with PH, including from birth through young adulthood.

How are you involved with PHA? I joined PHA at the time I started my position six years ago. I immediately became involved utilizing the Mentor Program as I grew into my practice. Since then, I have attended every PHPN and PHA conference. As a PHPN member, I have had the honor of serving on the PHPN Publications Committee, PHPN Symposium Planning Committee and PHA Pediatric Ad Hoc Resource Committee, and I have presented at conferences and on PHA Online University.

Avery P. McKee, BSN, RN, RRT, Ochsner Medical Center, New Orleans, La.

How did you begin working in the field of PH? I first started in PH in April 2008 as a PRN nurse (a per diem nurse). I was working full time in the intensive care unit (ICU) and was asked if I could help in the section because the RN just left. In three months I became a full-time PH coordinator.

What is your area of expertise? I was a registered respiratory therapist for 13 years before attending nursing school. My respiratory experience was mainly in the neonatal intensive care unit and then management of the respiratory department. When I graduated from nursing school, I started at Ochsner Adult ICU and at the same time was clinical director of the Delgado Respiratory Program. I then transferred to Critical Care Educator for the Adult ICU.

Since starting this position, both my respiratory and nursing experience have come together. I have needed to train several nurses, so I developed an orientation manual for PAH, standing orders for admitting PAH patients, and forms developed to guide each step of the process from right heart catheterization to line insertion.

How are you involved with PHA? My activities with PHA mainly include working with our local support group leader and attending conferences. Last year I was on a panel to discuss PAH therapies, and this year at the PHPN Symposium, I spoke about one of my favorite topics, high-flow oxygen. It is a recent therapy and presents a challenge to many healthcare providers.

Lisa Wheeler, MT (ASCP), Vanderbilt University Medical Center, Nashville, Tenn.

How did you begin working in the field of PH? I was hired by James Lloyd, MD, in 1994 as his research coordinator. I had no experience so he took a leap of faith! But I must have done OK because I am still at it.

What is your area of expertise? My training is in medical technology. For those unaware, a medical technologist is a person who works in the clinical laboratory, usually at a hospital. We run tests on samples (blood, urine, etc.) that your doctor requests to help him make a diagnosis or monitor your health. I worked for six years in a molecular biology research lab prior to my career in the PH world.

How are you involved with PHA? Dr. Lloyd and I have worked closely with what was then UPAPH (now PHA) since 1994. Dr. Lloyd attended the first PHA International PH Conference and Scientific Sessions; I was hired about two months after, so I missed that one. I have attended every Conference and two or three PHPN Symposia from 1996 to the present. Early in the history of PHPN, then PHRN, I was chair of the Research and Publications Committee (now Practice Committee). I have been involved as a member or chair of various PHPN committees for several years.

Visit www.PHAssociation.org/PHPN to learn more about the PH Professional Network.
The ABCs for Better Breathing: The Medical Team at North Shore University Hospital Offers PAH Advice

Pulmonary arterial hypertension (PAH) can cause uncertainty and trepidation for those living with it. As a medical team, we’ve tried to come up with a few suggestions to help improve your overall well-being.

- **Always be positive!** — Each day is a new day, and you can make an effort to improve your breathing.
- **Breathe** — Your breathing can be improved with a little work and exercise. Follow the guidance of your physician and rehabilitation counselors.
- **Concentrate** — Hone in on the process of breathing so you can gain a better understanding of it and how to control it.
- **Diary** — Keep a diary of things that make breathing worse or techniques you use to make it better.
- **Exhale** — During any activity in which you have to exert yourself, don’t forget to exhale. Exhaling as much as you can will help make your breathing more efficient.
- **Follow** — Your doctor’s recommendations may be the key to your breathing success. Be sure to take all the medications and follow your doctor’s instructions.
- **Grow** — Advanced lung disease is a chronic condition. You will have to grow with it and learn to control it — not let it control you.
- **Help** — Don’t be afraid to ask for help when a task is difficult or overwhelming. Seek help in understanding your illness or aspects of your care.
- **Inhale** — Make sure to inhale when you are involved in active motion. This allows for the maximum amount of oxygen to enter your blood.
- **Jump to action!** If you notice any changes in your breathing, alert your physician immediately.
- **Keep calm** — When you feel anxiety or an episode of shortness of breath coming on, stay calm and focus on your breathing. Remember the breathing exercises that your physician or respiratory therapist taught you.
- **Live each day to its fullest!** Just because you have a chronic illness does not mean you should stop enjoying your life and the things you like to do — although some activities may need to be done in moderation.
- **Manage your medications.** Keep a log of your medications, who prescribed them and why.
- **Never leave the house without your inhalers and a list of all your medications.** This could be vital information in case of emergency.

- **Oxygenate** — If your breathing is becoming a handicap, talk to your physician about oxygen therapy.
- **Pace yourself.** Complete all tasks at your own pace to prevent shortness of breath and other complications.
- **Quit smoking** — If you smoke and currently have a breathing problem, quit smoking. Your breathing starts improving as soon as you put out your last cigarette.
- **Remember your support system.** Your support system includes your family, caregivers, physicians, respiratory therapist and anyone else who is involved in your care. If you need any help with your health, remember to contact the appropriate individual without delay.
- **Support groups** — A support group exists for virtually all pulmonary diseases. You can find your local PH support group at www.PHAssociation.org/SupportGroups.
- **Take** — It’s important to take all your medications as your doctor has prescribed. Take advice; your healthcare providers are there to help. Do NOT stop any medication without consulting a healthcare provider.
- **Understand your disease and be proactive.** Taking an active approach to your health is the best way you can help your breathing. Educating yourself on your own medical condition will help you understand the causes of your breathing problems and help you manage it.
- **Ventilation** — It’s important to keep the air in your house well ventilated and in constant circulation. Dust, pets and other irritants may worsen your breathing. Ask your physician about proper ventilation methods.
- **Watch for breathing pitfalls.** Breathing pitfalls are situations when you spend lots of extra energy. For example, forgetting something on the first floor when you go upstairs requires you to make an extra trip.
- **eXercise** — Slow but steady physical and strength-training exercises can help you better your breathing efficiency. It may be difficult at first, but it will eventually help your breathing.
- **Yesterday is gone!** Focus on what you can do today to improve your health and well-being.
- **Zest** — Incorporate some activities in your life that make you happy. Being in a better mood can increase your overall health and help improve your breathing and outlook on life.

By Sonu Sahni, MD; Sameer Verma, MD; Sophy Dedopulos, NP; Arunabh Talwar, MD; Advanced Lung Disease Center, North Shore – Long Island Jewish Health System, New Hyde Park, NY
Targeting the Right Ventricle in Pulmonary Arterial Hypertension: The Role of β-Blockers

Pulmonary arterial hypertension is characterized by pathological remodeling of the pulmonary vasculature leading to a progressive increase in pulmonary vascular resistance and pressure with subsequent development of right heart failure. Right ventricular dysfunction is an independent predictor of negative outcome in pulmonary arterial hypertension\(^2\), \(^4\). As such, there has been increasing interest in better understanding the role of the right ventricle in the pathophysiology of pulmonary arterial hypertension and in developing therapies to target the right ventricle\(^5\). Here we will review novel therapeutic approaches to target the right ventricle in pulmonary arterial hypertension.

As in left heart failure, the sympathetic nervous system is upregulated in right heart failure. Studies have shown elevated plasma norepinephrine\(^6, \(^7\), reduced cardiac uptake of metaiodobenzylguanidine\(^8\), increased postganglionic muscle sympathetic nerve activity\(^9\), downregulation of the β1-adrenergic receptors in the right ventricle\(^10\), and reduced heart rate variability\(^11\). Treatments targeting these pathways are approved for left heart failure, whereas little evidence is available for their use in right heart failure.

β-blockers are considered relatively contraindicated in pulmonary arterial hypertension, due to concerns for the possible negative effect on these patients’ hemodynamics and exercise capacity. This is based on a study involving 10 patients with portopulmonary hypertension, in whom withdrawal of propranolol was associated with improved exercise tolerance\(^12\). A case report described a patient with portopulmonary hypertension who suffered acute cardiovascular decompensation after receiving a β-blocker for supraventricular tachycardia\(^13\). In another study, patients with severe mitral stenosis and pulmonary hypertension undergoing valvuloplasty had increased pulmonary vascular resistance and decreased cardiac output when given atenolol, a β-blocker\(^14\).

On the other hand, β-blockers have been shown to improve right ventricular function and prevent remodeling in the heart muscle in animal models of pulmonary hypertension\(^15, \(^16\). In humans, So et al. showed in a prospective study that there are no increased adverse clinical or hemodynamic consequences associated with the administration of those drugs\(^17\). This study involved 94 patients with pulmonary arterial hypertension, among whom 28 percent were prescribed a variety of β-blocker. The study had limitations in that it was non-randomized, and there were differences in pulmonary arterial hypertension subtypes, exercise capacity, and accompanying diseases between groups treated with and without β-blockers. As such, the role of β-blockers in pulmonary arterial hypertension remains uncertain.

In summary, the right ventricle plays a central role in pulmonary arterial hypertension, and the management of right ventricular dysfunction and failure remains a challenge. Recent work has advanced our understanding of the mechanisms leading to RV failure and remodeling. Targeting these pathways should guide the development of RV-specific therapies. Studies are needed to further look into whether β-blockers benefit the right heart in patients with pulmonary arterial hypertension.

By E.C. Roach and J. Sharp, Department of Pathobiology, Lerner Research Institute, and Respiratory Institute, Cleveland Clinic, Cleveland, Ohio

References

As we wrap up 2013 and our first year of PHA chapter development, we take a look back at how the year went and look forward to the exciting developments to come in 2014.

“The PH community is very active but not large. As PHA has been asked to take on more programs and activities to support patients, families and the medical community, we are determined not to be limited by either our size or income,” says Rino Aldrighetti, PHA President. “The chapters were approved by our Board of Trustees as the best path to sustain PHA’s vision and our future.”

Our chapters were tasked with raising PH awareness and funds for a cure in three areas of the country — New York, the Midwest and San Francisco. “Each of our current chapters is a true start-up company. You do everything on a shoestring and bust your chops, working long hours and trying to make the dream work,” says Carl Hicks, PHA Executive Vice President. “I am very proud of them and have complete confidence in their prospects for continued success in the future.”

**New York Tri-State Area Chapter**

In its first year, the New York Tri-State Area Chapter has focused on building a solid foundation for future growth. “Thanks to the support of the PH community in the New York Tri-State area, we have held several successful special events and have begun bringing new people and corporations into the organization for future years,” says Gina Parziale, executive director of the chapter. “Overall, we are quite happy with the progress we have made and are grateful to all who have supported us.”

As chapter staff round out 2013, they are excited to host the 1st Annual O2 breathe Gala in November to honor the legacy of Robyn Barst, MD, a pioneer in the field of PH (see page 36 for event details). Moving into 2014, they look forward to developing the relationships they have built this year and bringing more people and businesses into the fight against PH.

**Midwest Chapter**

The Midwest Chapter has seen extensive growth in 2013, evolving from covering the greater Chicago area to now encompassing five states (Illinois, Indiana, Michigan, Wisconsin and Missouri) and surrounding areas.

“The first year has been an exciting adventure with a very steep learning curve, encouraging an immediate ‘call to action,’” says Lisa Beth Gansberg, executive director of the chapter. “We have further developed our knowledge of the disease from our patients, vendors and medical communities, and we have learned how to best serve our constituencies by listening to their needs and responding to them.”

As the chapter heads into year two, staff looks forward to further awareness raising and forging new partnerships. In 2014 staff will host fundraising events such as the Six-Minute Marathon (6MM), and be on the lookout for a major blue lips campaign to raise awareness in the general public.

**San Francisco Bay Area Chapter**

For the San Francisco Bay Area Chapter, the first year has been a whirlwind of planning, scheduling, event management and community outreach and learning. Chapter staff has participated in many ventures this year, including creating a partnership with SteadyMed Therapeutics, forging relationships with local support groups, participating in PHA on the Road: PH Patients and Families Education Forum, securing major gifts and cultivating relationships with major area donors, and more.

“Looking forward to 2014, our determination to ‘think outside the box’ in what has proven to be a far more fluid and rapidly transforming fundraising environment is perhaps the greatest lesson we’ve learned,” says Bette Perez, executive director of the chapter. “As we embark on our second year, our chapter is looking to strengthen our existing partnerships with Bay Area support groups, community organizations, businesses, and our PHA corporate partners to populate our event calendar with a series of well-designed and exciting fundraising activities, and engage in unrelenting efforts to spread PH awareness across the region.”

**What’s next?** PHA is excited to announce the opening in 2014 of our fourth chapter in Houston, Texas. Stay tuned for more details on this chapter in the coming year.

**How can you help?** You are the best storytellers of your experiences, and we need you to raise your voice, share your stories and help us fundraise for a cure. If you live in the areas they serve, reach out to our chapters and find out how you can get involved. Visit [www.NY-PHA.org](http://www.NY-PHA.org) (NY Tri-State Area Chapter), [www.Midwest-PHA.org](http://www.Midwest-PHA.org) (Midwest Chapter) and [www.SF-PHA.org](http://www.SF-PHA.org) (San Francisco Bay Area Chapter).
Leaving home with PH means preparing in advance for any possible circumstance. Team PHenomenal Hope — the cycling team that will represent PHA next summer in the high-endurance Race Across America (RAAM) — understands how important such planning is in patients’ daily lives. Much of the team’s success in the race will hinge on the same kind of detailed preparation.

Greta Daniels and Kate Bennett, the team’s crew chiefs, are responsible for proper preparation. They act as the team’s chief executive officers, using the crew to support the racers physically, logistically and emotionally. The chiefs’ many roles include driver, navigator, race strategist, logistics expert, coach and friend.

Greta and Kate will lead a 12-person crew including medics, bike mechanics and errand-runners. The crew will travel in three vehicles — two vans to hold their gear and an RV that gives racers a place to eat, sleep and regroup.

The racers — Dr. Patty George, a PH-treating physician from UPMC; Anne-Marie Alderson; Ryanne Palermo; Stacie Truszkowski and Sara Harper — and their crew are planning for many aspects of their journey. You may find yourself making parallel plans for your own journeys with PH. Considerations include:

**Equipment.** Team members are already riding high-tech bikes provided by a sponsor, Big Bang Bicycles, and outfitted with electronic gear shifts. The crew will also transport an extra bike pre-adjusted for climbing to high elevations. Other equipment will include helmets and lights for the bikes and support vehicles at night.

**Physical training.** During the summer, Team P Phenomenal Hope members each rode in a variety of events to develop a base level of fitness. After some rest in December, more rigorous training will start in January with the team all following one regimen with a trainer.

**Winning strategy.** In the race, groups of two women will alternate taking eight-hour biking shifts, with constant 30-minute intervals on and off the bike. These intervals allow each cyclist to race at peak performance for short periods but also allow hours of recovery time.

**Nutrition.** The team members favor a low carb, high protein, high fat diet based on foods that are not highly processed. They love food they can eat while pedaling, like bananas slathered with peanut butter. They often favor healthy recipes from The Feed Zone and The Feed Zone Portables cookbooks written for athletes.

**Sleep.** Sleep deprivation is an unavoidable part of RAAM. The team must be ready to work around it. Learning to take a short nap whenever and wherever possible is a skill Greta says she may need to practice.

**Mental strength.** Every team member relishes the adventure of this extreme sporting challenge. Yet all have experienced low points in long competitions. So far, each racer is finding her best methods for coping, such as meditating and learning to endure boredom by working out on a stationary bike for three hours at a low speed. They don’t ask whether they will meet RAAM’s challenges, only how they will meet them. “If it is all about hard work, we can do that,” Greta says.

By Mollie Katz
PHA Vice President, Community Engagement

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Like Life with PH, Intense Bike Race Requires Solid Planning

**Team P Phenomenal Hope**

**Join the Race of Our Lives**

**Plan a Unity Miles Event**

Team P Phenomenal Hope’s veteran bike racers have described RAAM as the hardest race of their lives. To show support for the team, PH patients, families and professionals around the country are participating in PHA’s Race of Our Lives campaign by organizing fundraisers and awareness activities in their own communities. They are holding Unity Miles walks, raising funds online and advancing awareness through news and social media.

Interested in hosting your own Unity Miles event? Find out more and get involved at www.PHASassociation.org/RaceOfOurLives
In November 2007, the Skuldt family of Arlington Heights, Ill. — parents Dean and Juliet and daughters Lucia and Cordelia — stopped at the grocery store on the way home from a party. Cordelia, age 4, cried, “Mommy, I don’t feel good.” She had turned white and had started shaking as she clutched her chest.

Juliet knew immediately something was wrong. Terrified, she rushed her young daughter to the hospital. Cordelia spent nearly the next two months in the hospital before she was diagnosed with pulmonary hypertension.

Dean and Juliet began to research PH online to find answers to their many questions. “The initial image was grim,” Juliet says. “PHA’s website was great to get up to speed. It was just a wealth of information on PH.”

Later, after Cordelia stabilized, PHA’s resources for families became very helpful for the Skulds. The family also has a strong support system of family and friends who have helped them to adjust to their “new normal.”

Juliet describes PH as a “shaping force” for both her daughters. She says, “Both girls have taken on more adult concerns than kids their own age who haven’t experienced these events.”

Fighting PH: A Family Affair

More than 300 miles away in Rochester, Minn., Cordelia’s grandparents, Eric and Jan, began fighting back against PH. Eric, a retired IBM engineer, and Jan, a retired school teacher, stay actively involved in their local community through volunteering and working part-time teaching adults with disabilities.

Last year, Jan connected with Michael McGoon, MD, at the Mayo Clinic about ways to get more involved. Dr. McGoon and his wife, Bonnie, are part of the planning committee for the annual Reach for the Stars Gala. For the gala’s seventh year, Eric and Jan decided they wanted to do something more than just participate. Eric and Jan have pledged to fund three grants for PHA’s Robyn Barst Pediatric PH Research and Mentoring Program, the first pediatric PH research program in the world, in loving honor of their granddaughter.

Jan comments on their generous research contributions, “This feels really good. We are so happy that we are able to take advantage of this opportunity to help.” Eric and Jan are acting on the extended charitable IRA legislation, which allows individuals more than 70.5 years old to make charitable gifts now using funds from individual retirement accounts (IRAs) without undesirable tax effects. “This is the time to do it,” urges Eric.

For Dean and Juliet, Eric and Jan’s generosity is inspiring. Juliet says, “We all have more within our means and more ways to extend ourselves. It’s not just this hugely significant grant, but Eric and Jan are amazing in other aspects of their lives, too.”

Both generations of Skulds are inspired to get involved by the support they’ve received from Cordelia’s doctors and the growth they see in Cordelia, PH research and PHA. This year, Dean, Juliet and their two daughters got involved in local fundraising events.

Looking Toward the Future

In December 2007, shortly after Cordelia was diagnosed, the Skulds traveled to New York to see Robyn Barst, MD, a leading pediatric PH specialist who passed this spring. Cordelia was put on an aggressive therapy schedule, giving the family renewed hope for their future. “Our whole perspective changed. Life is full of challenges and now PH, but we have to move forward with hope and positivity.”

The Skuldt family, both in Illinois and Minnesota, is making a huge difference in the fight against PH just by getting involved and asking, “What can we do to help?” The strength of the PHA community and the momentum of our fight against PH is fueled by individuals all over the country like Eric, Jan, Dean and Juliet, discovering how they can contribute to this important battle.

The Skuldt family has taken advantage of a relatively new naming opportunity. Their grants will be named in honor of their granddaughter Cordelia. To learn how you can help, visit www.PHAssociation.org/GetInvolved. To learn more about how to make tax-free gifts from your IRA, visit www.PHAssociation.org/IRACharitableRollover.
On Your Mark, Get Set: Four Easy Awareness-Raising Opportunities

November and PH Awareness Month are racing toward us, but there is still time to get involved. Below are a few activities that will bring the PH community closer to a cure. Whether you get involved in one of them or think of your own creative way to raise awareness, don’t forget to share your activity with the PH community! Post updates and photos on PHA’s Facebook, Twitter, Instagram or Pinterest pages or visit www.PHAssociation.org/AwarenessMonth/News. For more information, contact Elisabeth at 301-565-3004 x753 or Advocacy@PHAssociation.org.

1. Spread Online Awareness.

“We should all share information about PH online to help others understand what PH is. It brings the community closer together when we share the things we’re all going through, and it helps families and friends understand what we are dealing with.”

– Alex Flipse

Online Awareness Day is Nov. 1; however, PHA’s social networks will offer ways to keep your texting thumbs and mouse-clicking fingers busy all month! Share our sample messages on Facebook and Twitter, and pin your Awareness Month photos to PHA’s Pinterest page to educate your social networks about PH: www.PHAssociation.org/AwarenessMonth/Online

2. Educate Congress.

“There were no treatments, support groups or PH centers when I was first diagnosed. My brother was the first person I met with PAH. My life is better with treatment, and I have the freedom to do what I never thought I would do. We need to continue to spread awareness. We need to educate each other, and the Pulmonary Hypertension Research and Diagnosis Act allows us to do this.”

– Diane Ramirez

On Tuesday, Nov. 12, the PH community will visit Congress to ask Members to co-sponsor critical PH legislation. You can participate from anywhere! Here’s how:

1. Invite your Members of Congress to attend PHA’s Congressional Luncheon on Tuesday, November 12.

2. Advocate for our bill from your home state:
   • Schedule a meeting with staff in your Member of Congress’ local office: www.PHAssociation.org/ConnectLocallyWithCongress
   • Call or email your Member of Congress: www.PHAssociation.org/TakeAction

3. Support Team PHenomenal Hope.

“Dr. George is a phenomenal woman. She cares so much for her patients that she’s willing to do a grueling Race Across America to raise funds for research and awareness. I feel honored to be a special part of it.”

– Merle Reeseman

Join other PHers around the country who are raising PH awareness by hosting Unity Miles events in solidarity with Team PHenomenal Hope as they prepare for the high-endurance cycling event, Race Across America. Find a Unity Miles event near you: www.PHAssociation.org/RaceOfOurLives/UnityMilesEvents. Create your own Unity Miles fundraising page: www.PHAssociation.org/RaceOfOurLives/VirtualPages

4. Talk to the Media.

“Even though I am terrified of sitting in front of a camera and being interviewed, I am so passionate about PH awareness and getting the message out that I am willing to ‘put myself out there’ so others may not have to go as long as I did before finally being diagnosed.”

– Patty Kaiser

Educate your entire community about PH by sharing your PH story with news reporters. PHA has two Awareness Month template media pitches you can easily adapt and send to reporters at local newspapers, radio and television stations or online media outlets. We also have fact sheets, videos, public service announcements and more to send with your media pitch: www.PHAssociation.org/OnlineMediaGuide/BasicSteps.
How Patients and Families are Advancing Early Diagnosis

Shortening the time it takes to diagnose a PH patient is the goal of PHA’s Sometimes it’s PH campaign (learn more at www.SometimesitsPH.org). While the campaign is pursuing ways to educate doctors, nurses, pharmacists and others through respected organizations in the medical community, patients, families and support groups are also highlighting the importance of early diagnosis.

Special Events

Some in the PH community have created opportunities to talk about early diagnosis at special events which have showcased the zebra, a medical symbol of unexpected diagnosis. For example, working together, support groups in Dallas and Fort Worth made the zebra the theme of their sixth annual Zebra PHriends 5K and 1M PHun Walk in 2012.

Susan Kennedy, one of the organizers, says a whimsical zebra in purple tennis shoes became the logo used on posters and flyers around the community. She wrote press releases with the headline “Zebras in the Park,” which generated newspaper and television coverage that explained the need for early diagnosis. The zebra is being used again this fall. In fact, the web page for the October walk, www.cureph5kandphunwalk.com, includes a section labeled “Why the Zebra?” and PHA’s one-minute video on early diagnosis.

The first zebra walk included a contest for best zebra clothing and accessories, zebra stripe face painting for children, and zebra stripes on event signs. According to Susan, the fun of the zebra theme lent a light mood to the event. “This campaign gave us something to be hopeful about,” she says.

Advocacy

Diane Ramirez, a PH patient and PHA Board of Trustees member, is passionate about advocating for PH and for early diagnosis and advises patients who want to speak out on these related issues. “I’ve used Sometimes it’s PH in advocacy with patients all over the country, including in California, Texas, Ohio, Florida and Connecticut,” she says. The message can be carried to Members of Congress and other elected officials through visits, letters, emails and calls.

Diane urges advocates to explain the matter this way: Our PH bill will help improve research and awareness, which will in turn make it easier to diagnose PH earlier, an area where we’ve had no progress in the past 20 years despite available treatment. We want that to change, and we are asking Congress to help us with that.

News Media

PHA has always encouraged patients and families to seek coverage of their PH experiences in the news media. Sometimes it’s PH provides background information on the frequency of misdiagnosis and the reasons medical professionals often mistake PH for other illnesses. Last November, Support Group Leader Karen Crow of DeSoto, Ill., invited a reporter from her local newspaper, The Southern Illinoisan, to attend the group and write about PH. Karen and her husband were quoted about Karen’s delayed diagnosis. Their comments included a reference to the importance of looking for zebras, or uncommon diagnoses, even with symptoms that could signal more common diseases.

Campaign Leadership

Occasionally, a physician who also has PH gets involved with PHA, bringing the perspectives of both doctor and patient. Bonnie Hudak, MD, a pediatric pulmonologist at Nemours Children’s Clinic in Jacksonville, Fla., treats children with cystic fibrosis and asthma but not PH. After reading about Sometimes it’s PH, she joined the campaign’s Education Committee to help influence other health professionals.

Before her PH diagnosis, even though she was being treated for scleroderma by a physician she respected, Dr. Hudak was told that her test results were fine. However, more detailed testing at a PH specialty center later confirmed she had PH. She has since used oral medication and has continued her active life as a doctor and parent.

Become Involved Yourself

The Sometimes it’s PH campaign consistently offers opportunities to take action, speak out and share with others the importance of early diagnosis. To get involved, contact Diane Ramirez at 336-313-5430 or diramirez87@yahoo.com.

By Mollie Katz, PHA Vice President, Community Engagement
Work With the Media to Ensure Your Special Event Draws People and Publicity

PHA patient and family volunteers organize more than 60 events per year. That’s more than five per month and more than one per week. That’s a great effort for a community of our size, and more volunteers are jumping in every year. Media coverage is an important part of these events’ success.

If you are planning a special event, media coverage is a great way to raise PH awareness beyond your friends and family, a step that truly strengthens our cause. News headlines highlighting your special event can bring new volunteers, increase attendance and even increase donations to PHA. Recently, Trudy Seidel of Vinton, Iowa, and Nicole Stafford of Vienna, Ohio, held successful special events, and both credit much of the outcome to local news coverage.

More than 1,000 people came to Trudy Seidel’s fundraiser Pray PHor a Cure, which raised $12,000. She told three of her local news stations the story behind her event, and all three decided to cover it. One news station visited her home to interview her for ‘Someone You Should Know,’ a segment that features community members who make a difference in eastern Iowa.

When asked if she thought reaching out to the media helped boost attendance, Trudy says, “Absolutely!” A few weeks after the event Trudy found out that four children in her community were raising money for PHA by selling lemonade. “Until May 4, they never knew that PH existed,” she says.

Nicole Stafford hosted a golf tournament in July that attracted 108 golfers and raised $25,000. Her local newspaper published her diagnosis story and advertised her upcoming event. More than 40 people showed up the day of the event to volunteer. “There were more volunteers than things that needed to be done!” Nicole says. Friends and family shared the article all over Facebook. Weeks after the event was over, Nicole continued to receive donations from people who could not attend.

Are you planning an event for PH Awareness Month in November? Don’t forget to reach out to the media. It isn’t as complicated as you might think! Visit www.PHAssociation.org/MediaAtPHevents or call 301-565-3004 x753 for some helpful tips to get you started. If you’d like to talk about organizing your event, contact Leslie Mahaney at 301-565-3004 x742 or LeslieM@PHAssociation.org.

We love seeing the results of your hard work and letting others in the PH community know of your successes, so share your media victories with PHA! Contact Elisabeth Williams at 301-565-3004 x753 or PHAware@PHAssociation.org.

By Elisabeth Williams, PHA Grassroots Campaigns Manager

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

With more than 60 PH associations worldwide, there is always something phenomenal happening in the global PH community. These international highlights are a testament to the hard work of PH community members everywhere!

- **In Bulgaria…** Todor Mangarov of PHA Bulgaria biked from Sofia, Bulgaria, to University Hospital in Vienna, Austria, to raise awareness of and access to pulmonary thromboendarterectomy (PTE) surgery for Bulgarian chronic thromboembolic pulmonary hypertension (CTEPH) patients. At the end of Todor’s 1200 km journey, he met with Dr. Walter Klepetko, who was Todor’s own doctor during his successful CTEPH treatments.

**Meanwhile…** The Bulgarian Society of Patients with PH (BSPPH) is hosting two Awareness Month events: The First Meeting of Balkan Women with PH with Zonta International and a “Faculty of Support” to provide patients and family members with training and support. BSPPH also published its website in August, www.bspph.net.

- **In Canada…** The 3rd National PH Conference was held Sept. 20–22 in Ottawa.

- **In Chile…** HAPCHI, the new Chilean association, is working with the Sociedad Latina de Hipertensión Pulmonar to hold the Día Latino de Hipertensión Pulmonar (Latin PH Day) event in Santiago, Chile, Nov. 22–23, 2013.

- **In China and Colombia…** Two new patient news bulletins (pictured below) have been created to spread information and hope to PH patients across the two countries. In China, the publication is Blue Lips (蓝嘴唇); the Colombian publication is called Pulmonary Hypertension Colombia (Hipertensión Pulmonar Colombia).

- **In Europe…** Ironman competitions in Austria, France, Germany, Norway, Spain and Switzerland included athletes running on behalf of PHA Europe and local PH associations; banners and activities advertising PH along the Ironman courses; and booths about pulmonary hypertension. PHA Europe also got some press time and had the opportunity to network with a few royals who showed their support for the PH community (Princess Alexia of Greece and Denmark and Prince Al Khalifa of Bahrain). Lastly, athlete Mark Martinez raced for PH in Spain and won his age category, which means he wore the PHA Europe and Asociación Nacional de HP (Spanish PH Association) logos for audiences at the finals in Hawaii Oct. 12.

PHA Europe had its general annual meeting in Barcelona in early September, when the group also celebrated its 10th anniversary as an association. Congratulations to PHA Europe!

- **In France…** HTAPFrance hosted the Second Patients’ Congress in French in Lyon, France, Oct. 5–6. The Congress was for PH patients and their families to learn about PH and how to manage it, as well as to share how patients and families deal with different PH-related problems in their daily lives.

- **In Japan…** PHA Japan is hosting several exciting events this fall: the Annual Congress of the Japanese PH Society Oct. 14 in Tokyo, which used the theme “Sometimes it’s PH,” the 7th National PH Conference Oct. 20 in Osaka and a Six-Minute Run for PH Awareness in November in Kyushu.

- **In Singapore…** The Singapore Support Group will use the “Blue Lips” campaign to spread knowledge of PH across Singapore this Awareness Month.

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By Julia Friederich
PHA International Services Associate
PH Bill Now Introduced in House and Senate: Help Us Move It Toward Passage!

Sen. Bob Casey (D-PA) has introduced the Pulmonary Hypertension Research and Diagnosis Act of 2013 in the Senate. In a press release about his leadership on the bill, Sen. Casey said, “I’m proud to introduce this legislation to improve our understanding of PH and promote earlier diagnosis of this devastating disease … I’m hopeful this legislation will lead to better outcomes for individuals with PH and their families.”

The PH bill in the Senate is nearly identical to the one introduced by Reps. Kevin Brady (R-TX) and Lois Capps (D-CA) in the House of Representatives in May. It calls for the creation of a committee within the federal government focused on giving people living with PH longer, better lives. The group would 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.

What’s the next step?

PHA needs advocates like you to encourage your senators and representatives to co-sponsor. You can make your request through an email, phone call or even a face-to-face visit. Getting started with an email has never been simpler thanks to this prepared message: www.PHAssociation.org/TakeAction/PHAct2013

As always, you can personalize your message with your PH experience to help Congress understand the need for more treatments and early diagnosis. You don’t even have to have PH to advocate for the PH community! Forward the prepared email to your friends and family and ask them to take action and widen our impact in Congress. Our elected representatives have an obligation to listen to all their constituents.

To take your advocacy a step further, you can schedule visits with your Members of Congress at their offices near you. Contact Elisabeth at 301-565-3004 x753 or Advocacy@PHAssociation.org for help.

Invite Your Members of Congress to PHA’s Congressional Luncheon

Sitting down to lunch with someone is a great way to find out what’s on their mind. That makes PHA’s Congressional Luncheon a valuable opportunity to let your senators and representative know what matters to the PH community and secure their co-sponsorship of the Pulmonary Hypertension Research and Diagnosis Act of 2013.

How do senators and representatives learn about the luncheon? You invite them!

SAVE THE DATE! TUESDAY, NOV. 12

Call Katie at 301-565-3004 x749 or visit www.PHAssociation.org/GetInvolved/CongressionalLuncheon to:

» See current event details
» Find a sample script for inviting your Member of Congress
» RSVP to attend this free luncheon

Ryan Greenstein (left) and PHA staff member Julia Friederich (right) visited with a legislative staff member from the Georgia delegation during PHA’s Congressional Luncheon in 2012.
Success! Rep. Jim Costa (D-CA) Co-sponsors PH Research and Diagnosis Act

Earlier this year, when the Pulmonary Hypertension Research and Diagnosis Act of 2013 (H.R. 2073, S. 1453) was introduced in the House of Representatives, legislative advocate Perry Mamigonian wasted no time contacting his representative’s office and asking him to co-sponsor the bill. After just a brief conversation, a staff member from Rep. Jim Costa’s office told Perry that Rep. Costa (D-CA) would co-sponsor. What’s Perry’s secret to advocacy success? Persistence. Over the last couple of years, Perry took every opportunity to email, call and visit with his Member of Congress to talk about PH and related legislation. The relationship he built over time has helped Perry’s advocacy efforts. “Persistence is key,” says Perry. “You may have to contact the Member of Congress many times before you are able to consistently connect with one person; however, the benefits of a lasting relationship are immeasurable.”


PHers Bring National Advocacy Home

Every August, Members of Congress return to their home states to meet with voters like you and your neighbors. This year, several PH community members took advantage of this and set up meetings to educate their senators and representative about PH and ask them to co-sponsor the Pulmonary Hypertension Research and Diagnosis Act of 2013. Kudos to all who visited these legislators’ offices:

- Colleen Connor — Sen. Patrick Toomey (R-PA)
- Noel Holly — Rep. Dana Rohrabacher (R-CA)
- Perry Mamigonian — Rep. Jeff Denham (R-CA) and Rep. David Valadeo (R-CA)
- Amanda McKee — Sen. Claire McCaskill (D-MO)
- John Scandurra — Sen. Al Franken (D-MN)

August isn’t the only time you can meet with your Members of Congress. You can call and ask for a meeting time in the fall or even invite your Members of Congress and their staff to attend your support group meeting where they will likely meet other voters who can influence them on PH issues. Meeting with a health legislative assistant can be just as effective as speaking with the senator or representative personally, as these staffers are the eyes and ears for your elected official in the community.

“I NEVER would have thought that I could do something like this, but I did!” says Noel Holly after her first visit with her Member of Congress.

Visit www.PHAssociation.org/DistrictVisits to learn more about district visits or contact Elisabeth Williams at Advocacy@PHAssociation.org or 301-565-3004 x753.

NEW TOOL GIVES PH COMMUNITY A MORE POWERFUL VOICE IN CONGRESS

You already know that keeping your address up to date with PHA gets you connected to Pathlight. Now it also helps PHA represent the entire PH community on Capitol Hill!

Earlier this year, PHA added congressional districts to our database. Now, we can easily tell Members of Congress the number of people affected by PH in their district. The PH community may be small compared to other diseases, but we’re making sure every voice counts in the halls of Congress.

Help PHA keep its database up to date. If you move or need to change your address for any reason, you can do so by visiting www.PHAssociation.org/UpdateYourProfile. (You will be asked to sign in.)

Interested in joining PHA’s grassroots advocacy network? Contact Elisabeth at 301-565-3004 x753 or Advocacy@PHAssociation.org.
Meetings Nurture PHA’s Relationships with Key Research Organizations in Washington

I had a unique opportunity this summer to be part of a group strengthening PHA’s important relationships with three research-funding agencies established by the federal government. Decisions made by these organizations are vital to PHA because federal funding is one of the largest sources of financial support for medical research. It underwrites the study of the causes of pulmonary hypertension and provides the basic science that fuels industry to invest its own dollars in new treatments and a cure.

Here’s an overview of the meetings I attended with Bob Schilz, MD, and members of the PHA staff.

A New Player — PCORI

The Patient Centered Outcomes Research Institute (PCORI) is a young organization created through federal law to focus on an emerging form of research — findings that give patients a better understanding of the prevention, treatment and care options available to them and the science behind those options. Dr. Schilz explained PH to Susan Hildebrandt and Gregory Martin from PCORI’s stakeholder engagement office, and Murali Chakinala, MD, who joined in by phone, explained PHA’s new PH Care Center (PHCC) initiative. PHCCs aim to improve patient outcomes by identifying best practices and the most highly specialized PH treatment centers. A lively discussion followed on common goals of PCORI and PHA, including developing patient-centered research projects on rare diseases.

An Agency We Know Well — NHLBI

Our second meeting put us in front of scientific leaders who know PH very well — officials at the National Heart, Lung, and Blood Institute (NHLBI), funder of more PH research than any other federal agency. Gary Gibbons, MD, the new director of NHLBI; Jim Kiley, MD, director of NHLBI’s division of lung diseases; and Tim Moore, MD, director of the lung cell and vascular biology program, were all present. I spoke about the success of PHA-funded research programs. This included the partnership between NHLBI and PHA in providing supplements to federal grants for mentored career development for junior physician-researchers. We reported that all the researchers who have received this grant to get started in the PH field have continued to work on PH in academic medicine — a great piece of news. Drs. Gibbons, Kiley, and Moore expressed excitement about continuing our partnership.

Accelerators of Progress — ORDR and NCATS

The National Center for Advancing Translational Science (NCATS) is an office of the National Institutes of Health (NIH) that helps laboratory findings be more quickly used to develop treatments for diseases. Allying with patient advocacy groups like PHA is an essential part of this process for NCATS and for the NIH Office of Rare Disease Research (ORDR), which is housed at NCATS.

Steve Groft, MD, director of ORDR, who helped connect PHA’s founders in the 1980s, attended our meeting along with seven other NCATS staffers. Our PHA team shared ideas for continuing to advance PH research and how PHA can be a model for younger rare disease organizations. The meeting was also an opportunity for PHA to learn more about the work of NCATS.

Though these behind-the-scenes meetings involved small numbers of people, they are an example of the important work being done every day by PHA’s Advocacy and Awareness Department to assure that our community maximizes opportunities to advance our cause among influential people in the legislative and executive branches of American government.

To learn about the role you can play in PHA’s grassroots advocacy, visit PHA’s Advocacy Action Center at www.PHAssociation.org/TakeAction.

By Karen Fagan, MD, Chair Elect, Scientific Leadership Council
ObamaCare and the Health Insurance Marketplace:
What Does It Mean for Me?

As a result of the Affordable Care Act (also called ObamaCare), beginning in 2014 every person in the U.S. will be required to have basic health insurance coverage. One way you will be able to obtain this coverage is through the Health Insurance Marketplace. Here are some brief answers to common questions about this new system.

What is the Marketplace?
The Marketplace is a one-stop shop where you can view private insurance options in direct comparison with one another. This will be primarily available online; however, if you do not have access to the Internet, you can also get assistance in person (more information below).

How will I know if I need to enroll?
If you currently have health insurance coverage, you are all set. If you do not have coverage or if you do not have enough coverage, you will need to enroll or risk paying a fine.

What will I find at the Marketplace?
You will be able to compare the premiums and out-of-pocket costs of the plans available to you as well as find out if you are eligible for financial assistance. You will also be able to see if you qualify for Medicaid or the Children’s Health Insurance Program (CHIP).

When and how do I enroll?
Open enrollment began on Oct. 1, 2013, with coverage beginning as soon as Jan. 1, 2014. You will need to complete the application most appropriate to your situation. There is one for families, one for individuals who are seeking financial assistance and one for individuals who are not seeking financial assistance.

How does the application process work?
Once you submit your application, it will be verified, and you will be determined eligible for either the private insurance Marketplace or for Medicaid/CHIP.

Where can I fill out my application?
Since Oct. 1, 2013, the application has been available online at www.Healthcare.gov/Marketplace. You may also apply by phone, mail or in person with a Patient Navigator in your community.

What exactly is a Patient Navigator?
A Navigator is someone who has been trained and certified to provide information about the Marketplace and to help people enroll. Navigators may be associated with a wide variety of groups including but not limited to nonprofit organizations, chambers of commerce, unions and insurance brokerage firms. Many schools and public libraries will have Navigators available as well.

As a PH patient, how will the Marketplace benefit me?
For starters, insurance companies will no longer be able to refuse coverage or raise costs on those who have a pre-existing condition. In addition, all plans offered in the Marketplace must meet a certain standard of care and be labeled as a Qualified Health Plan (QHP). They must, at minimum, offer the following services: ambulatory, emergency, hospitalization, maternity, prescription coverage, rehabilitation, laboratory, preventative healthcare, chronic disease management, mental health and substance abuse and pediatrics, including oral and vision care.

The Marketplace will also offer catastrophic plans. These plans have high deductibles, so they are considered emergency plans in case you are faced with a worst-case scenario. Catastrophic plans are offered to those who are less than 30 years of age or those who have limited incomes. These plans will have lower monthly premiums and cover three primary care visits per year.

What happens if I don’t apply?
The aim of the Affordable Care Act is to make sure everyone has a standard level of insurance. Applying to the Marketplace is not mandatory. However, if you don’t have a minimum level of health insurance coverage by 2014, you may have to pay a fee with your tax return.

By Haley Payne, Former PHA Advocacy & Awareness Intern

I need more assistance!
• Marketplace phone help line: 1-800-318-2596
• Live online chat: www.Healthcare.gov/Chat
• Quick survey for fast answers: www.Healthcare.gov/Quick-Answers
• Sign up for email and text updates: www.Healthcare.gov/Subscribe
• More information:
  » www.PHAssociation.org/Insurance/CoverageConnection
PHA on the Road: Arkansas? 
One Patient's Journey to Make Connections in Her Small Town

Over the years, we have taken our PHA on the Road: PH Patients and Families Education Forums to cities like Baltimore, Seattle, Pittsburgh and San Francisco — major cities across the country. These programs introduce patients to other patients facing similar challenges. But what does it take to bring patients and families together in places like Springdale, Ark.? 

Our PHA support groups are one of the best ways to get support, information and hope for the future. When a group doesn’t exist, we depend upon patients in the area to start a group. Here’s the story of one patient who drove eight hours to her nearest group before slowly building a vibrant group in her small Arkansas town.

Long Miles to Support Groups

Deloris Peacy, whose PH diagnosis took four years, began learning about PH and taking medication right after discovering she had this disease. She then reached out to other patients, but there were no patient support groups to be found in 2004 in her hometown of Springdale, Ark.

Deloris learned of a group meeting in Little Rock — some 200 miles away from her town. But the Little Rock support group meetings stopped abruptly, which sometimes happens when a leader moves or steps down for health reasons. Deloris still wanted to participate, learn and help, so she went to the Nashville, Tenn., support group meetings. These meetings were more than 500 miles away, about an eight-hour drive.

Remaking the Founder’s Table

It soon became difficult for Deloris and her husband to make the drive, so they made fewer trips. Things began to change when the leader of the Nashville group told Deloris about another patient making the eight-hour drive from Arkansas — someone who lived very near to her and who was struggling with the diagnosis.

“Anne [name changed for privacy] was my first call; she had lots going on at the time,” Deloris says. “She called me many times, at all times of the day, in tears, and still thanks me for helping her.” 

Deloris’s first call to Anne was a difficult one — Anne could not stop crying. She was still in shock over the diagnosis. After several calls, Deloris made a personal visit to Anne in the hospital. They later had dinner together, and Deloris supported Anne through the scary diagnosis period.

Deloris learned what a huge difference one person could make in helping another keep fighting against PH. This experience encouraged Deloris to start her own support group in her hometown.

At the first Springdale support group meeting, four women came together at a table, mirroring PHA’s own founding by a few patients and a caregiver at a kitchen table. Patients came from all over western Arkansas and Oklahoma, and one patient even came from Joplin, Mo. Soon, this group sparked two patients in Tulsa, Okla., to start their own group.

After a year of organizing meetings, the Springdale group had grown to 16 members and thrived with the support of caregivers, including Deloris’s husband.

Deloris’s message to patients is, “Don’t give up the fight.” We are very glad that she didn’t give up and that now patients in Arkansas have a strong source of support.

By Eunah Lee
Former PHA Volunteer Services Intern

Interested in starting a group? Contact Debbie Castro at DebbieC@PHAssociation.org or 301-565-3004 x755 or visit www.PHAssociation.org/LocalSupportGroups/StartGroup.
Taking Chicago by Storm: From Patient-Led Support Groups to Professional Fundraising, We’ve Got You Covered!

PHA’s Midwest Chapter, based in Chicago, is spearheading vibrant fundraising campaigns to support the mission of the Pulmonary Hypertension Association. While the chapter’s main focus is philanthropy, our dedicated staff doesn’t stop there. From involving existing local support groups in fundraising efforts to inspiring the formation of new groups, chapter staff members are continuously engaging the greater PH community while creating a thriving, local PHA presence.

One of the many ways our mission is fulfilled is through forming and nurturing patient-led support groups. We’re excited to share that we have more than 50 groups in the Midwestern United States.

The Midwest Chapter staff has had the opportunity to meet with the families of pediatric PH patients as well as a physician who works extensively with underserved populations. With chapter help, plans to establish both a Spanish-speaking and a pediatric PH support group in the Chicago area are moving ahead.

In an effort to strengthen the PHA presence in the Midwest, the chapter has also assisted in developing special events such as the O₂ breathe™ Walk, the O₂ breathe™ Golf Challenge, a gala and even a concert with the musician Sting.

Special event fundraising is not always easy. A dynamic team is required — including patients and professionals, caregivers and community members — working hand-in-hand toward our common goal to prevent and cure pulmonary hypertension. If you or your support group would like to join with PHA’s Midwest Chapter, contact the chapter staff directly at GetInvolved@Midwest-PHA.org. Also be sure to check out the list of Chicago-area support groups below. Contact them next time you’re in the area!

By Joshua Griffis
PHA National Support Group Coordinator

FOCUS ON SUPPORT GROUPS: THE CHICAGO AREA

CHICAGO SOUTH SIDE
Sandra Coslet – Co-Leader
Dale Rankin Mack – Co-Leader
www.PHAssociation.org/
ChicagoSouthSide
IL-ChicagoSouthSide@PHASupportGroups.org

DOWNTOWN CHICAGO (U OF IL)
Kami Sneed – Leader
www.PHAssociation.org/
DowntownChicagoUIC
IL-ChicagoUIC@PHASupportGroups.org

ELMHurst
Benita Kosiara – Co-Leader
Dianne Reed – Co-Leader
www.PHAssociation.org/Elmhurst
IL-Elmhurst@PHASupportGroups.org

NAPERVILLE-EDWARD HOSPITAL
Donna Serlin – Leader
www.PHAssociation.org/Naperville
IL-Naperville@PHASupportGroups.org

NORTHERN ILLINOIS
Rosanne Huber – Leader
www.PHAssociation.org/NorthernILGroup
IL-Northshore@PHASupportGroups.org

Our first meeting had five attendees, and in our second meeting, we grew to nearly 30! I was so proud of everyone. This is so awesome!

— Dale Rankin-Mack, Support Group Leader, Chicago South Side

If you want to find a support group, PHA wants to help! Visit www.PHAssociation.org/SupportGroups to locate the group nearest you.
At Lakewood Regional High School in Wanaque, N.J., Shelley Lisbona — a pulmonary hypertension patient — formed strong friendships through her extracurricular activities — color guard, chorale and marching band. That made the high school a fitting place for two of her close friends to bring their community together to commemorate and remember her with a new special event this past summer, the PHun Walk for Shelley.

Shelley’s friends Vicky Nelson and Kate Bryan, who had met her through these after-school activities, created the fundraising walk to celebrate and honor Shelley, who lost her battle with PH in 2010, only six months after her diagnosis. Vicky shares, “Kate and I met Shelley at separate times and in separate ways, but we both knew we were making a great friend.” Shelley, according to her friends, fought hard against PH with a daily smile and positive attitude, which has inspired Vicky and Kate to take action.

This pair is not new to special event fundraising and awareness-raising for PH — they helped organize a smaller fundraiser at their high school while Shelley was battling PH. But, the idea for the PHun Walk for Shelley came after Vicky and Kate attended the Power for PH Fun Walk in Edison, N.J., last year. Kate says, “A lot of people from our community and from our high school wanted to go, but they didn’t want to drive so far for the event.”

Before starting the planning process for the PHun Walk for Shelley, Vicky and Kate asked their close group of friends from high school what they thought of the fundraiser idea. The feedback was positive, and this group of friends became the core volunteers for the PHun Walk for Shelley. Next, they contacted PHA’s Special Events department and asked, “How can we use the PHun Walk for Shelley to best help in the search for a cure?” Both women felt that PHA was helpful when it came to planning details, including organizing refreshments and activities for kids.

In addition to the event logistics, Vicky and Kate added their own special touches to the walk. They bought carnations from a local florist and had participants at the event write messages to Shelley and staple them to the flowers. After the walk, a few of Shelley’s high school friends joined Vicky and Kate to place the flowers at her gravesite.

The PHun Walk for Shelley became a time for the entire community to heal, celebrate and remember. Kate adds, “We were able to use this event as an opportunity to come together, remember Shelley, and show her family our support.” The Lisbona family members, who no longer live nearby, were able to travel back to Wanaque for the walk.

More than 50 people participated, helping Vicky and Kate exceed their goal of raising $3,000 for PHA. These young women were thrilled to be able to help support PH research and PHA resources in whatever way they could. Both say through Shelley’s advocacy during her fight against PH, they came to associate the disease with PHA.

Vicky and Kate agree that the greatest result of this event was simply getting the word out.

Vicky says, “I had never heard of PH before Shelley explained what the disease was. We were able to raise awareness about PH, and now our community knows more than they did before.”

By Rachel Parker
Former PHA Development Intern
This summer PHA was the recipient of proceeds from the 24th Annual Colorado Bluegrass Festival, which hosted more than 4,000 attendees. Pictured above: event organizers Tom Thornburg (left), whose granddaughter has PH, and Damian Rotolo and Colorado State Fair representative Dani Griffin (center) present Dunbar Ivy, MD, (right) and PH patient Kylie Jackson with a check for $10,000 designated to the Robyn Barst Pediatric PH Research and Mentoring Program.

The Santa Barbara PH Support Group celebrated its 2nd Annual Fun Walk this summer, raising more than $10,000 for PH research and patient support services. A speaker presentation including Jeffrey Sager, MD; Rajan Saggar, MD; and Michael and Karen Ehret added to a fun-filled day of PH awareness, community and support.

Pittsburgh Walking PHor A Cure — Unity Miles Kickoff Event: The Pittsburgh PH Support Group gathered the community together to “Walk PHor a Cure” and show its support for Team PHenomenal Hope. This Unity Miles kickoff event raised more than $7,000 for PHA’s Race of Our Lives campaign.

O₂ breathe N.J. Fun Walk: Raymond Telep, who created the team Robyn’s Rebels, was the top fundraiser for the N.J. O₂ breathe Walk and had the honor of cutting the ribbon at the starting line.

On Par to a Cure for PH: The San Francisco Bay Area PH community came together ‘Fore’ the cause at the O₂ breathe Golf Classic this past August.

More than 100 people gathered in St. Francis, Wis., on June 15 for the first ever Southeastern Wisconsin PHA fundraiser. The Steps for Stripes Fun Walk raised more than $8,000 for PHA.
PHANING THE CAUSE

Saturday, Oct. 19, 2013
DRIVING “FORE” A CURE FOR PH GOLF TOURNAMENT
WHERE: Clayton, N.C.
DETAILS: Matt Wall at 919-357-3201 or mattwall67@gmail.com

Saturday, Oct. 19, 2013
10TH ANNUAL GA FUN WALK FOR A CURE
WHERE: Marietta, Ga.
DETAILS: Sally Maddox at 706-331-0938 or skshmaddox@gmail.com

Saturday, Oct. 19, 2013
FRESNO’S SIX-MINUTE MARATHON & BBQ
WHERE: Clovis, Calif.
DETAILS: Perry Mamigonian at 559-251-0032 or pmam2001@yahoo.com

Saturday, Oct. 26, 2013
2ND ANNUAL BULLHEAD CITY 6MM
WHERE: Bullhead City, Ariz.
DETAILS: Joy Gore at 928-704-0053 or gore2r14lif@frontier.com

November 2013
RAAM BIKE CHALLENGE — "AN EVENING OF WHINING"
DETAILS: www.Midwest-PHA.org

Saturday, Nov. 9, 2013
3RD ANNUAL SARAH SMILES PHUN-RAISER FOR A CURE
WHERE: Camillus, N.Y.
DETAILS: Michelle Peek at 315-569-5756 or mpeak@twcny.rr.com

Sunday, Nov. 3, 2013
13TH ANNUAL RACE AGAINST PH AT STANFORD UNIVERSITY & HOSPITAL
WHERE: Stanford, Calif.
DETAILS: Michael Ehret at MichaelEhret@SF-PHA.org or Kristy Kerivan at kerivan@stanford.edu

Thursday, Nov. 7, 2013
O, BREATHE NYC GALA HONORING THE LEGACY OF DR. ROBYN BARST
WHERE: New York, N.Y.
DETAILS: www.o2breathe.org; call 646-568-2068; email NY-Events@PHAssociation.org

Friday, Nov. 8, 2013
SAN FRANCISCO PHA’S FIRST ANNUAL BAY AREA GALA
WHERE: Foster City, Calif.
DETAILS: Lisa Brundage O’Connell at LisaOConnell@SF-PHA.org or www.o2breathe.org/SFBayAreaGala

Saturday, Nov. 9, 2013
7TH BIENNIAL "REACH FOR THE STARS" ROCHESTER PHA GALA
WHERE: Rochester, Minn.
DETAILS: info@rochesterphagala.org or www.rochesterphagala.org

Saturday, Nov. 9, 2013
6TH ANNUAL SOUTH FLORIDA PH FUN WALK
WHERE: Pompano Beach, Fla.
DETAILS: Pat Hellyer at phellyer@wxel.org

Saturday, Nov. 9, 2013
4TH ANNUAL BREATHE EASY 5K
WHERE: Albuquerque, N.M.
DETAILS: Jason Garcia at 505-506-3211 or jpatrick20@gmail.com

Saturday, Nov. 9, 2013
PHKIDS4ACURE HOUSTON 5K AND 1 MILE FUN WALK
WHERE: Houston, Texas
DETAILS: Teresa Meyers 832-552-7124 or phkids4acure@gmail.com

Saturday, Nov. 9, 2013
JUDE’S PHAMILY OF PAILTH PHUN Run
WHERE: Denton, Texas
DETAILS: Jessica Sawyer at 940-594-0158 or missheb98@msn.com

Saturday, Nov. 9, 2013
8TH ANNUAL PHENOMENAL HOPE FOR A CURE
WHERE: Omaha, Neb.
DETAILS: Lori Shaal at 402-890-4624 or Lori.Shaal@nebraska.gov

Friday, Nov. 15, 2013
ANNUAL FRED ASTAIRE GOLF TOURNAMENT, BENEFITTING PHA
WHERE: Kingwood, Texas
DETAILS: Annette Nino at 281-655-0069 or anino5@yahoo.com

Saturday, Nov. 16, 2013
GET SHORT OF BREATH FOR PH ... LET’S KICK SOME ASPHALT
WHERE: Cedar Rapids, Iowa
DETAILS: Ginger Kahler at 319-621-9337 or getshortofbreath5Kcr.ia@gmail.com

Saturday, Nov. 23, 2013
BREATHE PHREE GALA
WHERE: Wilkes-Barre, Pa.
DETAILS: Katie Tobias at BreathePhree@gmail.com

December 2013
MICHIGAN SUPPORT GROUP RAFFLE
DETAILS: www.Midwest-PHA.org

January 2014
RAAM BIKE CHALLENGE — "JAVA & JAM"
DETAILS: www.Midwest-PHA.org

Saturday, Jan. 4, 2014
PHIND A CURE 5K
WHERE: Mobile, Ala.
DETAILS: Donna Head at head_df@bellsouth.net

◆ PHA Chapter Events

To view a complete, up-to-date listing, visit www.PHAssociation.org/Events

www.PHAssociation.org
EDITOR’S CORNER

Hello, PH Community, and welcome to the fall edition of Persistent Voices!

I hope everyone enjoyed the summer. This edition of Persistent Voices introduces you to two women who’ve had very different journeys with pulmonary hypertension but share a positive outlook and attitude about their lives with chronic illness. This theme reinforces the knowledge that while we are all very different, we can still learn from each other and share our life lessons. I promise you’ll enjoy these honest and brave stories.

Joanne Sperando-Schmidt, Persistent Voices Editor

Barbara’s story hits on so many themes we PH patients experience: a too-long wait for a correct diagnosis, the forfeiture of career, and a suggestion that her problem was psychological, not physical. How ironic that it was a psychiatrist who helped her get on the right path to diagnosis and treatment and then helped her deal with all the issues of being diagnosed with PH. Barbara’s artwork is poignant in its symbolism of her journey and something she generously shares to show her gratitude.

— Joanne

Story and Artwork by Barbara Linser, Cincinnati, Ohio

Shortly after my third son was born, I began to experience weakness and extreme fatigue. Since I have a congenital heart defect (pulmonary stenosis), my first thought was to go see my cardiologist. He did a stress test, and my heart rate soared within two minutes. This was in 1993, and it would be 10 long years before a different cardiologist, Dr. Lynn Wagoner, would figure out the real problem.

Many tests, surgeries and medicines were tried by a plethora of doctors. Sometimes the treatments helped, but always I continued to get worse. At some point a cardiologist decided I might have a psychological problem and sent me to a psychiatrist, Dr. Bernard Foster. I went angrily to see him because I knew something was really wrong. Because I worked as a pediatric occupational therapist, some doctors would think I knew too much about medicine and would become judgmental. It was a very painful and confusing time. I was trying to raise my sons and work part time as well.

As it turned out, Dr. Foster helped me figure out how to proceed in finding out what was wrong. He helped me sort through the good and not-so-good doctors; figure out how to keep my children from being traumatized by all that was going on; and face my own feelings of anger, denial, despair and sadness about what was happening to my body. When I was finally diagnosed, he helped me continue to figure out how to spend my limited energy, and he helped me with the...
grief I felt when I had to stop working. Dr. Foster saved my life as much as my amazing team of PAH pulmonologists (Dr. Jean Elwing and Dr. Mark Scott), my cardiologist and my family doctor (Dr. Lisa Larken) did.

I have been physically stable now for 10 years. My three sons have turned into fine young men, and I have four wonderful grandchildren. I could not have gotten through the medical maze without Dr. Foster. When he retired at age 80 last year, I made this artwork (pictured right) as a thank you to him.

I am grateful for all my current doctors, my family and the PAH support group for helping me learn to live with PAH. ✤

I’m always awed by the courage of people I meet who are battling more than one chronic illness. Marcia shares her journey with scleroderma, a diagnosis received at a very tender age, and then later, pulmonary hypertension. Her life was truly derailed after her first diagnosis, but faith, spirit and determination got her back on track. You won’t want to miss her story.

— Joanne

Double Jeopardy by Marcia Brown, Brooklyn, N.Y.

In 1973, at age 16, while living in Jamaica, West Indies, I noticed strange things happening to my body. My athletic, lithe self was slowly becoming tight, stiff and painful, and I was tired all the time. This phenomenon could not be seen by anyone, but I definitely felt it. Over the next few months, my lack of speed was obvious in my track and field competitions and in my basketball practices. The pain and fatigue became overwhelming, and as a result I had to drop out of high school my senior year.

A diagnosis of scleroderma (rare disease #1) was made about a year after my initial symptoms, and the doctor told my parents I had two years to live. This time frame was kept secret from me for about 10 years. I spent four months in the hospital, and my dramatic physical decline, coupled with what I now realize was a deep depression, kept me in a downward spiral to the point where I essentially became an invalid.

During a period about eight to 10 years after my initial diagnosis, for no apparent
reason, I began feeling better. The darkness cleared, and I slowly began to regain my independence. With family support and by the grace of God, I was able to finish high school (at age 26), get my driver’s license (a big deal at the time), graduate from college (at age 34), get my master’s degree (at age 35), travel extensively throughout Europe and the Caribbean, purchase my own house, mentor numerous children, and work in a career as an accountant for 25 years before being hit by PAH in 2009 (rare disease #2).

My house is right around the corner from the bus stop, and one cool March day, as I left my home to run an errand, I heard the familiar diesel engine sound of a bus slowing down. So, like I had so easily done countless times before, I ran to catch the bus. But this time even though I caught the bus, I was completely and almost totally out of breath to the point of near fainting. Luckily, there were available seats on the bus. After a few minutes, the palpitations slowed, and I was able to relax. At my next doctor’s appointment, I mentioned the incident to my rheumatologist who immediately knew that it could probably be pulmonary arterial hypertension and referred me to a PH specialist.

Dr. Roxanna Sulica from Beth Israel Hospital in New York City did a right heart catheterization and determined that I indeed had PAH. Since then my life has taken a different turn. I retired a year after my diagnosis, and after repeated allergic reactions to ambrisentan and bosentan, I am now stable on tadalafil, and I get tremendous benefit from pulmonary rehabilitation, support groups and the educational conferences and forums.

To everyone with PAH and/or scleroderma, realize that there are going to be stages to your life, and you will have to keep making adjustments to your “normal” every time you experience a setback or a disappointment. However, your life can still be rewarding and full even with two rare diseases.

Somebody once said, “If you choose to sing, you will always find a song,” and I choose to sing.

**A Little More About Me**

I moved from Jamaica to the U.S. in 1983. I retired in 2010 at 55 years old from a 25-year public service career as an accountant with the New York City government. I now volunteer with an organization called New York Cares and support community service projects close to my heart, especially those that benefit the well-being of the disabled and other disadvantaged groups.

My PAH is secondary to scleroderma. I have experienced practically all the manifestations of both diseases. I do not travel out of the country as extensively as I used to, primarily because of the many adjustments needed for air travel with PAH. There are times I cannot get out of bed, but when I can, I make sure I get out of the house. I am determined to keep a song in my heart because it makes me feel better and reinforces my usual positive, hopeful outlook on life. I live in Brooklyn, N.Y., and I have a host of family members and friends close by for support. ♥
2013 PH Professional Network Symposium

The Power of Teamwork: 10 Years of Professional Collaboration in PAH

Thank you, everyone, for making Symposium such a success!

The 2013 PH Professional Network Symposium just wrapped up this September, but we didn’t want to wait to extend a special thank you to all those who made the event a success!

• All those who attended the 2013 Symposium, from all over the country and even internationally!
• The more than 60 medical professional speakers who volunteered their time to lead close to 30 educational sessions covering a wide range of PH-related topics.
• The members of the 2013 Symposium Planning Committee who helped organize and plan the programming for our attendees.
• Our Symposium Committee Chair Melisa Wilson, ARNP, ACNP-BC, and Vice-Chair Frances Rogers, MSN, CRNP, for their leadership throughout the planning.

For more information about the PH Professional Network Symposium, visit www.PHAssociation.org/PHPN/Symposium.

2013 PH Professional Network Symposium

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New Recordings on PHA Online University

PHA is pleased to partner with the University of California, San Francisco (UCSF) for the third year to host recordings on PHA Online University from the 6th Annual International Neonatal and Childhood Pulmonary Vascular Disease Conference. This conference, which took place on June 21–22, brought together global experts to discuss current therapies and ongoing research.

Highlighted sessions include:
- Intravenous Prostanoids in Pediatric Pulmonary Arterial Hypertension, Erika Berman Rosenzweig, MD
- Use of PH-Directed Therapies in Patients with Single Ventricles, Brian D. Hanna, MDCM, PhD
- Pulmonary Arterio-venous Fistulas, Julien I. E. Hoffman, MD

For more information and to view the recordings, visit www.PHAOnlineUniv.org/2013UCSFConference.

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:

2nd Annual PAH Symposium
Nov. 8, 2013 • The Westin Virginia Beach Town Center Virginia Beach, Va.
Register at: www.sentara.com/cardieducation

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

Cleveland Clinic PH Summit 2013*
Nov. 15 - 16, 2013 • InterContinental Hotel • Cleveland, Ohio Register at: www.ccfmed.org/2013PulHyper

11th Annual Update in Pulmonary Hypertension*
Dec. 6, 2013 • Boston Marriott Cambridge Cambridge, Mass. • Register at: www.ganesco.com

*Offers medical and patient components

Check Out These Topics

PHA Classroom, a program of PHA’s Medical Education Fund, provides a space for you to participate in live events or watch recordings at your leisure. Classes cover topics ranging from information about PH to tips on living with PH and ways to fight back. View the recordings or sign up for live events at www.PHAssociation.org/Classroom.

Recently added recordings:
- Newly Diagnosed? What You Need to Know
- Newly Diagnosed Self-Study: PH Ready Wrap-Up Webinar
- Chronic Thromboembolic Pulmonary Hypertension — What You Need to Know
- PH Caregiving 101
- Exercise-Induced Pulmonary Hypertension — What Is It and What Do We Do About It?
- Preparing for the School Year with PH
Coming Soon: Feedback Loop for Your Specialty Pharmacy

PHA has a new initiative dedicated to collecting information about how well specialty pharmacies are serving PH patients. We’ll be using this information to promote improved service through a Specialty Pharmacy Advisory Board.

PHA will collect your input through a feedback form. The form will allow you to share your experiences directly with PHA and (if you wish) the specialty pharmacy that provides your PH medication.

For more information about this program or other initiatives in PHA’s Insurance Advocacy and Education Program, contact 301-565-3004 x749, email Insurance@PHAssociation.org or visit www.PHAssociation.org/Patients/Insurance.

Are you PH Ready?

If you or someone close to you has recently been diagnosed with pulmonary hypertension, you probably have a lot of questions and concerns. Or, you may be feeling so overwhelmed by the diagnosis that you aren’t sure what questions to ask. PHA has created The Newly Diagnosed Self-Study: PH Ready, a series of e-courses, as a roadmap for newly diagnosed PH patients. We also offer PH Ready Caregivers, a companion curriculum for family and friends of PH patients.

Visit www.PHAssociation.org/PHReady to get started now.

Save the Date!

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

O2 breathe
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An elegant evening honoring the legacy of Dr. Robyn Barst and raising funds and awareness to fight pulmonary hypertension

Thursday, November 7, 2013
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Sign up online for Conference Early Alert emails to stay up-to-date on the newest Conference developments!

Conference Scholarship Program
Applications for patients in need will be made available online starting on Nov. 5, 2013. Please visit www.PHAssociation.org/Conference/Scholarships for more information. If you would like a Conference scholarship application mailed to you, please email Scholarships@PHAssociation.org or call 301-565-3004 x763.

www.PHAssociation.org/Conference

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CVS Caremark is committed to creating thriving, healthy communities while helping to provide better outcomes for all.

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For more information, call 877-242-2738 or visit www.CVSCaremarkSpecialtyRx.com.
INTERVIEW WITH PH PATIENT
MADISON WEGENER

When were you diagnosed with PH?
I was diagnosed with PH in January of 2012, when I was in the first grade.

You recently went on a Make-a-Wish trip. Where did you go? Why did you choose that place?
For my Make-a-Wish trip, I chose Alaska because I’ve grown up hearing a lot of cool stories about it from my Aunt Mary Beth, who lives there, and from my mom and dad. I wanted to see my aunt and was excited to see Alaska for myself. My favorite part about the trip was seeing my aunt, and my favorite activities were dogsledding and fishing on the Kenai River.

What is your favorite memory from PHA’s International PH Conference last year?
My favorite memory was meeting other people — adults and kids — who also had to wear oxygen and who also had PH. Conference made me feel better about it. I also got to make a special new friend, Laney.

If you were a superhero, who would you be?
If I were a superhero I’d want to be a doctor superhero who could fix anybody with her superpowers.

What do you say when people ask about PH?
I tell them that one of the parts that runs between my heart and my lungs tightens or closes off when it is not supposed to do so. This makes my heart work harder, and I easily run out of breath when I’m running or playing. God made me in a special way.

What message do you want to pass on to other kids who have PH?
I’d tell them that sometimes you might feel like you are the only ones with PH, but you’re not. There are other people who have PH, too. PH involves lots of trips to the hospital, and it is sometimes scary, but you can make friends with the doctors and nurses there. When I first got PH, I had to wear oxygen all of the time. Soon after that I had a tube placed into my chest so that medicine could be pumped into my heart. This was scary, too, and I felt a bit different than other kids, but now it is more normal for me. My friends are still my friends. I am still Madison. I just have PH.

Madison Wegener is 8 years old and lives in Brighton, Mich.
Facebook Group: A Place for PH Teens to Connect Online

Social media, already popular among teens, can be beneficial in promoting positive friendships and providing social support, and it can also be a way for young people with pulmonary hypertension to find others dealing with this illness. PHA, therefore, has created the PHA Teens Facebook group just for those PHers between the ages of 13 and 18.

This group provides a safe place for PH teens to share their feelings and connect with others going through similar experiences. Here teens are able to get support from the people who best understand what they are going through.

“I think other teens should join because having PH is tough in many ways,” says Lauren Thompson, a member of PHA Teens. “We all have our bad days with PH, and it’s nice to vent about it and get it off our shoulders. We are a family, and we are always there to make each other feel better. I just love being able to talk to other PH teens.”

If you are a teenager living with PH, look into joining the PHA Teens group on Facebook today. You can join by searching “PHA Teens” on Facebook. Other teens are there to support you, answer your questions and cheer you on as you achieve your greatest accomplishments. For additional assistance, contact Teens@PHAssociation.org.

What’s trending on PHA Teens?
- PH and High School
- Accomplishments
- Prom
- PH Medications
- Graduation
- Travel Plans and Tips
- College Plans
- PHA Special Events

By Laura Johns, Former PHA Patient & Caregiver Services Intern

Resource for Families

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

Request your PH Handbook for Families, along with our other free information packets, at: www.PHAssociation.org/Families/InfoPackets

ATTENTION, TEEN WRITERS! We’re looking for teens to contribute articles to Pathlight. Get your creative juices flowing and contact Michal at Teens@PHAssociation.org for more details.
Teachers Offer Their Perspectives on PH

For several hours a day, your child’s teacher is his or her caregiver. Having a strong relationship with teachers can play a significant role in your child’s opportunity to be a happy and successful student.

This past summer, the PH Professional Network (PHPN) Education Committee worked with more than 30 teachers and our Parents Advisory Board to update and improve our School Resource Guide. This Guide offers an overview of PH, PH treatments and related side effects, and it offers forms to organize your child’s specific medical needs. As part of this process, PHA spoke to teachers about the challenges they perceived for both teacher and student when the student has PH. Here is what we heard:

Communication. Every teacher we spoke with emphasized the importance of proactive, ongoing and open communication between parents and teachers. “The communication piece is the most critical part,” shares Katie Dempsey, who teaches seventh and eighth grade in Washington state. “It’s important to know that they are having a bad day physically or mentally, so we can all be on the same page and work together.”

“It’s really important to be proactive before the school year starts,” adds Troy Rood, a fifth and sixth grade physical education teacher in Iowa. “Request meetings with the administrators and teachers. We do modifications for kids all the time; this shouldn’t be any different.”

Hand-in-hand with communication is trust on both sides. “My student with PH trusted that I would modify the activities as best I could, and I trusted that she would tell me when she wasn’t feeling well. Trust is key,” Troy tells us.

Teachers also mentioned that written materials about PH and in-person demonstrations of medical equipment are helpful.

Fitting In. Several teachers watched PH kids struggling to feel normal. “‘Normal’ is a speed on a washing machine,” argues Jayne Tuerff, a second grade teacher in Tennessee. Her student, Sarah, was diagnosed with PH mid-year. “Nobody is ‘normal’ and every child has his or her own set of challenges. Having Sarah in my class reminded me to love each and every child where he or she is. She just wanted to be treated like a regular kid and have regular experiences. I tried to keep perspective that she was the same child as before her diagnosis and deserved to be treated that way.”

Rebecca Flowers, a preschool teacher in New Jersey, agrees: “At first I was concerned about [my student’s] pump. Once I was comfortable with that, it was fine. I treated her like any other kid. It’s hard for a kid when people can’t see past the pump and the PH.”

Keeping Up. Teachers also spoke about the stress for older students who miss school and fall behind on schoolwork. “Staying caught up is definitely a challenge,” Katie says. “At that age [fifth – sixth grade], when a kid misses a lot of school, it can be emotionally stressful.”

Be Persistent. What if you’re in a school that isn’t listening? “Continue to provide information and keep the door open, even if people aren’t as responsive as you want them to be,” recommends Katie, the Washington middle school teacher. “Parents are their child’s best advocates. Education is the pathway to success in the future. Never give up advocating for whatever allows your child success in the educational arena. But if your child is in an environment where you’ve tried and tried and it just doesn’t work, maybe it’s time to make a change — because with a PH kid, as much or more than with other kids, it’s important to be on the same page.”

Jayne from Tennessee adds, “It’s important, as educators, that we understand each individual child. Sometimes it probably feels like it falls on deaf ears, but you have to keep plugging away for your child. Every child deserves the opportunity to be in school and learn in the classroom. I feel, as an educator, that’s my gift — to work with all children. I would have lost out on so much by not having Sarah in my class. She taught me more than I could ever have taught her in a year.”

By Michal Rachlin, PHA Kerry Bardorf Family Support Program Coordinator

[After reading the Guide,] I understand that these students should be very in-tune with how their bodies feel, and they are the best judges of their physical limitations. That being said, if a child shows symptoms of being unwell, I would immediately talk to the child and have a buddy walk with him or her to the nurse for rest or medical attention. I would also call the parent and say that I suspected the child overdid it during that class. If we were outside, I would keep my cell phone with me so that I could call without leaving the other students unsupervised.

— Teacher comment during update and review of School Resource Guide

Download the Guide: www.PHAssociation.org/Parents/School
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To honor those who have included PHA in their estate plans or whose legacies have been realized, PHA created the Legacy of Hope Society. PHA is pleased to recognize the following members. For more information on PHA’s legacy planning program, call Michael Catell at 301-565-3004 x767, email Legacy@PHAssociation.org or visit www.PHAssociation.org/Give.

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The accuracy of this list is very important to us. Please contact the PHA office at 301-565-3004 x746 or ElissaT@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 x746. We welcome all loved ones to remain a part of our community for as long as it is beneficial.

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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?” reports on improved survival rates from the REVEAL Registry, plus all new charts. Other updated topics include insurance coverage, new resources, as well as conventional, drug and surgical treatments.


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